

Outcomes of social care for adults: developing a preference-weighted measure

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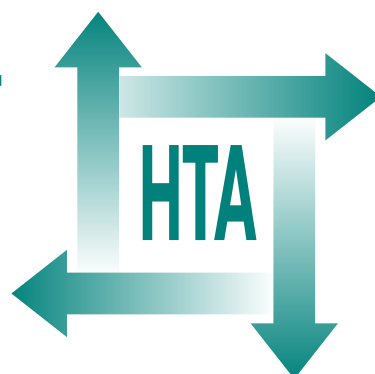


Executive summary

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Executive summary

Background

There is an increasing policy focus on outcomes in the field of health and social care in England. In times of financial stringency, it is particularly important to be able to identify the impact of interventions in order to assess cost-effective alternatives and make the best use of limited resources. In the field of health, the quality-adjusted life year (QALY) is widely accepted as the measure of health outcome used to evaluate the cost-effectiveness of new health interventions. There has been no equivalent for social care, despite its growing importance as the population ages. Lack of such a measure has made it difficult to assess accurately the full impact of interventions intended to address both health and social care, to plan future resource needs for long-term care, and to move to outcome-based commissioning that makes best use of resources.

Objectives

The study was designed to develop an equivalent measure to the QALY in health that would reflect the particular characteristics of social care and could be used in a range of circumstances to reflect the impact and value of social care interventions. The objectives were to:

- develop a measure of social care outcome that captures all relevant domains, has credibility in the social care community, has been cognitively tested and demonstrates good psychometric properties
- test a variety of approaches to establishing preference weights for methodological soundness and practical application with the general population
- investigate how applicable these methods are to a service user population
- conduct a population preference study
- develop a set of weights for calculating social care QALYs (SC-QALYs) and weighting measures of social care output
- explore how the views of service users differ from those of the general population, and establish alternative preference weights, if appropriate
- identify the factors that affect preferences among the general population and service users.

Methods

The project comprised two phases. The first development and feasibility phase covered the first three objectives, and was used to inform the design for the second phase, in which preference weights for the final measure were estimated.

The development of the measure during the first phase included conceptual development, a focused literature review, analysis of data sets that incorporated previous versions of the measure, cognitive testing of items with 30 service users, and a survey of 300 older people using home care. We built on a number of previous studies on outcome measurement in social care, and the project both contributed to, and drew on, parallel work undertaken as part of the Measuring Outcomes for Public Service Users (MOPSU) project, which itself fed into the development of the Adult Social Care Outcome Toolkit (ASCOT). In addition, some refinements were made to the wording of two of the items in the instrument as a result of concerns about the distribution

of these items. These were cognitively tested with 25 service users as part of a study feeding into the development of the national Adult Social Care Survey (ASCS), and the final set of items was included in a pilot postal survey for the ASCS of 1364 people from all service user groups. An important element of the development phase of the work was the involvement of key stakeholders, including service users, local councils and experts in the field, to assist in ensuring the practicality and acceptability of the proposed measure.

The preference elicitation feasibility work involved testing alternative discrete choice approaches through a survey of 300 members of the general population, and cognitively testing these approaches in the interviews with 30 service users about the instrument. In order to explore the feasibility of anchoring the measure to the state of 'being dead', we cognitively tested the use of time trade-off (TTO) techniques with 19 members of the general population. A preference elicitation survey of 1000 members of the general population, undertaken as part of the MOPSU project, was used to test the proposed best-worst scaling (BWS) design, with half of the sample using the provisional social care-related quality-of-life (SCRQoL) domains and levels developed for this study.

The second phase drew on this iterative work and, for the final version of the instrument, involved a main preference study of 500 members of the general population using BWS and a follow-up TTO exercise with a subsample of 126 people. We also conducted a preference study with 458 people who used equipment services to establish service user preferences, and undertook a follow-up study with a subsample of 101 of these people to test further the final version of the instrument.

Results

Development of the Adult Social Care Outcome Toolkit measure

Health outcome measures identify specific aspects of health-related quality of life in order to ensure that they are sensitive to the impact of health-care interventions. In addressing social care we used an equivalent – SCRQoL. Our review and analysis of previous measures of SCRQoL resulted in eight domains that were deemed to be relevant to a greater or lesser degree to all service user groups: *personal cleanliness and comfort, accommodation cleanliness and comfort, food and drink, safety, social participation and involvement, occupation, control over daily life and dignity*. All of these domains had been included in earlier versions of the measure, with the exception of *dignity*, intended to reflect the psychological impact of support and care on a service user's personal sense of significance. A further domain, which identified whether or not the individual was 'living in own home', was tested but rejected for the final measure.

Previous versions had defined three levels of 'need' in each domain ('no', 'low' and 'high'). As a result of our analyses and consultations, we decided that a fourth level should be added to make the measure more sensitive to differences within the 'no needs' option. Here, we aimed to reflect Sen's distinction between 'capabilities' and 'functionings'. The latter concept is based on the principle that society is not prepared for citizens to maintain such a poor level of functioning in any domain that there are health implications if their needs are not met. Once needs are met, it is also essential to identify capabilities: whether or not people are able to achieve their desired situation. Each domain has four levels, aimed to reflect as closely as possible:

- *Ideal* The preferred situation, where needs are met to the desired level.
- *No needs* Where needs are met, but not to the desired level.
- *Some needs* Where there are needs, but these do not have an immediate or longer-term health implication.

- *High needs* Where there are needs that have an immediate or longer-term health implication.

The long-term, compensatory nature of social care makes it particularly challenging to measure outcomes. But the fact that people are usually well aware of – and have often experienced – what their situation would be like in the absence of services does aid the study of social care outcomes, and enabled us to pursue a pragmatic approach to establishing outcomes in this area. Drawing on previous work, we incorporated questions for each domain that identified whether or not services had an impact on this aspect of their lives and, if so, their ‘expected’ situation in the absence of the service. These questions allow the estimation of three SCRQoL measures: *current* or experienced; *expected* in the absence of support and services; and *gain*, which provides an indicator of impact.

Cognitive testing refined the wording and confirmed that the responses to the ‘expected’ items appeared to function as intended across a range of service user groups. The testing of the *dignity* item suggested the inclusion of an additional item (not included in scoring the measure), to allow for the fact that some people have problems coming to terms with needing help at all. The interviews with a larger sample of older home care users showed that response rates were good for both the current and expected items, suggesting that the pragmatic approach to outcome measurement was feasible with this population.

There was good evidence for the validity of the descriptive system for ASCOT: each attribute seemed to capture a different aspect of SCRQoL and had the anticipated relationship with other variables capturing similar and dissimilar concepts. There was also evidence for the validity of the SCRQoL scales reporting the current situation and the service impact. However, the distribution of service users across the different levels of *accommodation* and *food and drink* suggested that we were not reflecting the range of situations very effectively. Subsequent revisions resulted in improved distributions in the ASCS pilot survey and a revised version was taken through to the second phase of the project.

Development of preference elicitation methods

Establishing preference weights for our measure was particularly challenging because of the number of attributes involved. We investigated and compared the results of using a discrete choice experiment design and a BWS approach as alternative preference elicitation techniques, both statistically in a sample of the general population and cognitively with service users. The two techniques yielded similar results, and both were seen to be understandable and acceptable to service users. We decided to use the BWS approach for the second phase of the study, as it had a number of advantages:

- respondents are presented with all domains at the same time
- coefficients are estimated on a common scale
- it poses a smaller cognitive burden on respondents.

After some modification, a computer-aided approach to TTO was found to work well. Respondents found questions acceptable and understandable, and lack of respondent fatigue allowed us to increase the number of scenarios presented in the final main stage design.

Population and service user preferences

A key question for the project was whether there were significant differences between the SCRQoL preferences of the general population and those of service users. The models showed no substantive differences in the preferences of the two samples. The models were consistent, both showing differences in values in the expected directions and, with a few minor exceptions, statistically significant differences between the coefficients for the levels within each domain. The

key domain was *control over daily life*, strongly estimated in both models, with the lowest and highest levels demonstrating the lowest and highest values for any domain. The BWS analysis of general population preferences was able to capitalise on the MOPSU project data collection conducted 1 year earlier, as there was remarkable consistency between models based on that study and models based on the data collected as part of this project. Recent methodological developments have demonstrated the importance of allowing for sample-level variance heterogeneity, which can be seen as variations in the levels of certainty with which different groups express their preferences. Models were used to take account of observable heterogeneity between the two samples and other subgroups, both in generating utility weights and identifying factors associated with preferences. After allowing for these, there were some differences in factors associated with preferences, with service users' preferences more closely associated with aspects of their own SCRQoL.

The mean values for the 64 sample states in the TTO exercise showed a linear association with the BWS estimated values for those states. Some states were estimated as worse than 'being dead', with a TTO score of < 0 .

The Adult Social Care Outcome Toolkit measure

The final BWS weights were estimated based on the combined MOPSU and Outcomes of Social Care for Adults sample of 1000 members of the general population. A formula based on the TTO analysis is provided for converting these to weights that could be used for a SC-QALY. This yields a range of possible scores between -0.171 and 1 , with '0' being equivalent to 'being dead' and '1' being the 'ideal' SCRQoL state.

In order both to familiarise respondents with the domains and to provide context for interpreting the results, all of those who took part in the BWS preference surveys were asked about their current SCRQoL state using ASCOT. This provided us with a useful comparison between the general population and service users. As we might expect, members of the general population reported significantly higher SCRQoL than service users [SC-QALY scores of 0.86 and 0.73 , respectively ($p < 0.001$)]. Moreover, the differences were reflected in the areas expected, with members of the general population more likely to experience the 'ideal' state and service users the 'no needs' or 'mustn't grumble' state. As we would hope, no respondent was currently experiencing a state that would be rated as bad as or worse than 'being dead'.

Conclusions

Resources are always limited, but this is even more the case in the current financial climate. This, together with the policy emphasis on outcomes, makes it all the more important that we have good measures to reflect the value of social care interventions for those who use them. The ASCOT measure now provides the basis for a social care equivalent to the QALY, which can be used in a range of circumstances to reflect the impact and value of social care interventions. The policy emphasis on giving service users greater control is supported by the results, and we have a basis on which to compare the SCRQoL of service users and the general population, potentially providing evidence for an 'outcomes' basis on which to make difficult decisions about resources.

The study was the first to use TTO in a social care context. Anchoring the score to the state of 'being dead' provides the first step in generating evidence on the relative cost-effectiveness of health and social care interventions. In addition, our pragmatic approach to reflecting the impact of services has the potential to provide a basis for measuring the impact or 'value added' of social care.

There has been widespread interest in the measure since June 2010, when ASCOT was first made widely available through www.pssru.ac.uk/ASCOT. The measure is included in annual national ASCSs, and has been proposed as an important element of the Transparency in Social Outcomes Framework, which should enhance its value by providing benchmark data about current SCRQoL states for a range of service user groups and contexts.

In terms of future research, we would recommend:

- extending the approach to include informal carers
- exploring the potential to link ASCOT to the European Quality of Life-5 Dimensions in estimating and comparing QALYs
- developing validated approaches to establishing ASCOT states for service users who have cognitive impairment and communication difficulties and who are living in their own homes
- further work to test the validity, reliability and sensitivity of the current expected and gain measures in a variety of contexts.

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Publication

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The research reported in this issue of the journal was commissioned by the National Coordinating Centre for Research Methodology (NCCRM), and was formally transferred to the HTA programme in April 2007 under the newly established NIHR Methodology Panel. The HTA programme project number is 06/96/01. The contractual start date was in August 2008. The draft report began editorial review in March 2011 and was accepted for publication in August 2011. The commissioning brief was devised by the NCCRM who specified the research question and study design. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The HTA editors and publisher have tried to ensure the accuracy of the authors' report and would like to thank the referees for their constructive comments on the draft document. However, they do not accept liability for damages or losses arising from material published in this report.

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