

# Extending the QALY: Developing and testing the proposed items for a new generic measure - results from qualitative review and face validity with patients, social care users and carers

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## Background and Aim

Common quality-adjusted life year (QALY) instruments (EQ-5D, SF-6D etc.) used in economic evaluation measure and value changes in *health-related* quality of life. As such they have limited ability to capture the impacts on carers' quality of life, or important outcomes in other sectors such as social care. Sector specific QALY instruments (such as ASCOT for social care, and CarerQoL for carers) offer one approach to this limitation. However, this limits inter-sectoral comparisons and is also problematic when the impacts of an intervention include health and non-health benefits. The Extending the QALY project aims to develop a new measure of quality of life that will capture the benefits of interventions in health and social care for use in economic evaluation.

## Methods

A targeted systematic search was undertaken to identify primary qualitative work used in measure development and qualitative reviews on the impact of health conditions, being an informal carer and social care use on quality of life (QoL). Framework analysis was used to identify domains and sub-domains. Potential items were identified from existing health and wellbeing measures and item banks which were reviewed against a set of item selection criteria. New items were generated where none could be found in the literature.

Our aim was to test the items with potential users of the new measure to ensure appropriate wording of items prior to a large multi-country psychometric survey. Semi-structured qualitative interviews with patients, carers and social care users are completed or on-going in six countries (Argentina, Australia, China, England, Germany and USA; n=20-25 in each country, n=45 in England) to test the proposed items and domains. Translation into Argentinian Spanish, German and Simplified Chinese was undertaken by a single company using independent forward and back translation with input from country investigators. A single interview protocol was developed and refined for use across all the countries.

Figure 1: Domains from literature review

## Item generation

## Face validity

27 sub-domains

### Item generation

- A pool of 458 items were reviewed from existing health, carer and social care quality of life measures. An additional 229 items were reviewed from item banks.
- Application of the item selection criteria resulted in 82 items
- Consultation with the advisory groups resulted in 97 items that were taken forward to face validity including variants in the way questions were asked
- Face validity is expected to result in further modification of tested items

### Key face validity findings

- ✓ Short items can be answered but respondents prefer more information on context
- ✓ Items sometimes work well for one group e.g. carers but not another
- ✓ There is a preference for simpler layouts
- ✓ Preferred response options varies (frequency, severity or difficulty)
- ✓ Respondents often unable to say why they prefer one option over another
- ✓ Instructions including the recall period are often ignored or forgotten
- ✓ Work from different countries often complementary in findings

## Discussion

Targeted extraction and synthesis of the review resulted in seven high level themes/domains (Figure 1) with 27 sub-domains. A large pool of items was identified for face validity although many of the items were not suitable when taking preference-based valuation into account. The face validity stage provided an opportunity to reduce the item pool as well as to refine items. Using different groups was important as some items work better in some groups compared to others.

## Conclusion

The findings from the review have identified themes that go beyond health and that are relevant to patients, informal carers and social care users. The face validity exercise has provided details of which specific questions to include in the next stage of instrument development.

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