

# Extending the QALY (E-QALY) Project: Stages for developing a new generic measure

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## Background

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.

## Aim

The aim of the E-QALY project is to develop a broad generic measure of quality of life that is valued on the zero to one scale necessary to calculate Quality Adjusted Life Years (QALYs) for use in economic evaluation across health, social care and public health. This will provide a measure that bridges health and social care.

## Methods

The project brings together researchers across different disciplines, clinicians, decision-makers, members of the public and stakeholders in industry in six stages. All the stages involve bringing together different stakeholder views on methods to results in order to develop a measure that is fit for purpose.

### Stage 1

- The instrument domains will be established by drawing on existing qualitative literature to identify what is important based on the views of users and beneficiaries of health and social care services including carers.

### Stage 2

- A long list of potential questions will be generated for each domain and sub-domain that is identified. This will draw on terms identified in the literature review and existing measures based on specified criteria. Modification and development of new questions will also be undertaken.

### Stage 3

- The face validity of the candidate items will be tested using semi-structured face to face or telephone interviews with patients (acute, long term conditions, and mental health service users), social care users, carers and the general public. This will be done in England as well as other countries.

### Stage 4

- Valid items from Stage 3 will be administered in a large survey with social care users, patients and informal carers based on a survey (n=2,000) in order to undertake psychometric testing. Psychometric analysis will be used to inform the choice of items for the final measure and classification system.

### Stage 5

- Valuation will be undertaken using a time trade-off (TTO) survey with a representative sample of the general public and a deliberative exercise with members of NICE Citizens Council to generate an alternative valuation and better understand the results of the TTO.

### Stage 6

- Impact of using the new measure will be assessed against other measures such as EQ-5D. In the short to medium term this will rely on a mapping algorithm between the new measure and existing measures. This will allow analysts to estimate re-weighted utility values from existing data sets and use them to populate cost-effectiveness models.

## Results

**Stage 1 :** Targeted extraction and synthesis from the qualitative literature review resulted in seven high level themes/domains (with sub-themes/domains): **feelings and emotions** (sadness, enjoyment, vulnerability etc.), **cognition, activity** (activities of daily living, communication, mobility, vision, meaningful activity), **self-identity** (self-esteem, dignity/respect), **relationships and social connections** (both positive and negative aspects), **'coping, autonomy and control'** and **physical sensations** (pain, fatigue, discomfort).

**Stage 2:** Item generation identified an initial set of over 100 items for face validation.

**Stage 3** work is on-going and **Stages 4 and 5** are planned for Oct. 2018 to Sept. 2019

## Strengths

- Application of current best practice in instrument development
- Active public involvement
- international steering group and wide & diverse advisory group
- Co-applicants with NICE and other institutions

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