

## INTRODUCTION

Most measures that are used in cost utility analysis focus on a narrow set of health domains, ignoring other important outcomes. This makes it difficult to reflect all outcomes with a single measure and comparison across different interventions with different outcomes is limited<sup>1</sup>. The Extending the Quality Adjusted Life Year (E-QALY) project aims to develop a new generic measure that can be used in economic evaluation across health, social care and public health, based on the views of users and beneficiaries of these services. The project has six stages which are aimed at identifying domains and items, selecting appropriate items, undertaking valuation and testing the new measure.

## METHODS

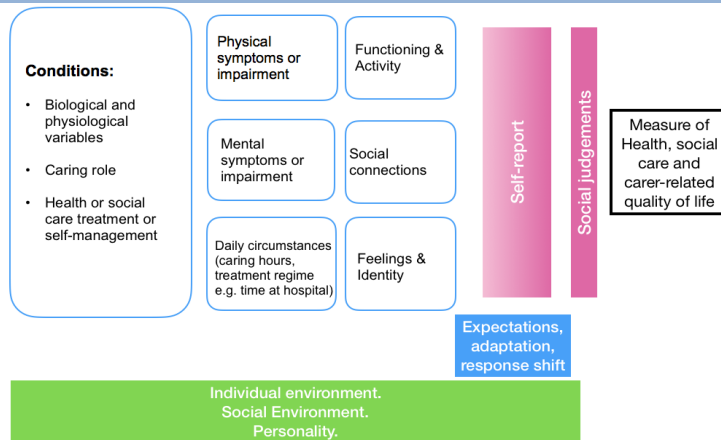
A systematic search was undertaken for four study arms:

1. primary qualitative work used in development of generic measures
2. qualitative reviews on quality of life (QoL) for 17 health conditions. Conditions were identified using the ICD1-0 along with the World Health Organisation Burden of Illness data for the UK to select one or more representative conditions for each Chapter.
3. qualitative reviews on QoL for informal carers as well as primary qualitative work on informal care measures
4. qualitative reviews on QoL for social carer users as well as primary qualitative work on social care measures.

Included studies were in English, based on adults and used qualitative or mixed methods. Countries included: European countries, USA, Canada, Australia, New Zealand.

Framework analysis and synthesis was undertaken based on a conceptual model (Fig 1). Four researchers undertook extraction and initial synthesis. All researchers were involved in the final refinement of themes and sub-themes. Extensive consultation was undertaken with different stakeholders including decision-makers, service users and other academics.

Figure 1: Conceptual Model

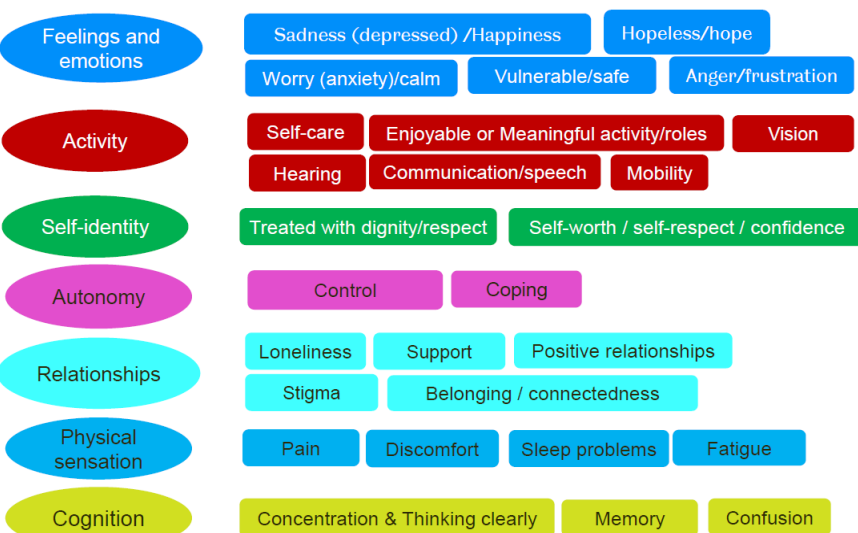


The conceptual model was based on the Wilson and Cleary<sup>2</sup> model which links health to quality of life. We extended it to include other 'conditions' including use of services and the caring role.

## RESULTS

	Generic Measures	Health conditions	Informal care	Social care use
Total no. of papers	27 primary qualitative work	137/6305 qualitative reviews (extraction from 2/3 reviews for each condition)	15/875 qualitative reviews 11/55 primary qualitative work	17/820 qualitative reviews 4/31 primary qualitative work
Details	SF-36, Nottingham Health Profile, Sickness Impact Profile, WHO-QoL, PROMIS29, Dartmouth Primary care Cooperative Information Project (COOP) Charts, EQ-5D, AQoL, Quality of wellbeing scale	Low back pain, chronic headache, hearing loss, diabetes mellitus, asthma, systemic sclerosis, edentulism and severe tooth loss, breast cancer, rheumatoid arthritis, autistic spectrum disorder, Alzheimer's disease and other dementias, vision loss and age related macular degeneration, stroke, prostate cancer, inflammatory bowel disease, mental health	<b>Qualitative reviews:</b> general, dementia, multiple sclerosis (MS) and depression <b>Primary work:</b> Carer Experience Scale, Child's Chronic Disease Questionnaire, Experience of Caregiving Scale	<b>Qualitative reviews:</b> intellectual disabilities, elderly (receiving help at home, nursing home, respite care) and palliative care <b>Primary work:</b> ICECAP-O, ASCOT and End of life Care

Figure 2: E-QALY Proposed domains and sub-domains



## DISCUSSION

The review and subsequent consultation resulted in seven high level domains with 27 sub-domains (Figure 2). Most were relevant across both health and social care, including informal carers.

**Strengths:** Qualitative data drawn from different patients, informal carers and social care users provides a strong evidence base for domains. This was further supported by consultation with different stakeholders who provided views on identified domains.

**Limitations:** Not all conditions were covered but the selection was aimed at identifying the different ways in which the body stops working in order to ensure broad coverage. Extraction was not undertaken for all the identified reviews and primary qualitative work. However, similar themes/sub-themes emerged across the selected reviews.

Future work will undertake item generation, testing and valuation for the new measure.

1 Brazier J, Tsuchiya A. Improving cross-sector comparisons: going beyond the health-related QALY. Applied health economics and health policy. 2015 Dec 1;13(6):557-65

2 Wilson IB, Cleary PD. Linking clinical variables with health-related quality of life: a conceptual model of patient outcomes. Jama. 1995 Jan 4;273(1):59-65.