# Measuring Quality of Life and Quality-Adjusted Survival

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## Background

Many health conditions affect multiple bodily functions and the ability to perform usual activities. One approach when measuring the full impact of disease is to assess patients' health-related quality of life (HRQoL). Numerous instruments are available, some of which facilitate utility estimation, whereby QoL is measured from 0 (death) to 1 (perfect health) according to individuals' preferences (negative values represent states worse than death). Utilities can be combined with survival data to generate Quality-Adjusted Life-Years (QALYs). QALYs are advocated as outcome measures when assessing the cost-effectiveness of interventions. In England, the National Institute for Health and Care Excellence (NICE) requires cost-effectiveness information with outcomes measured in QALYs, and QoL measured using the Euroqol-5 Dimensions (EQ-5D).

## HERC work assessing HRQoL

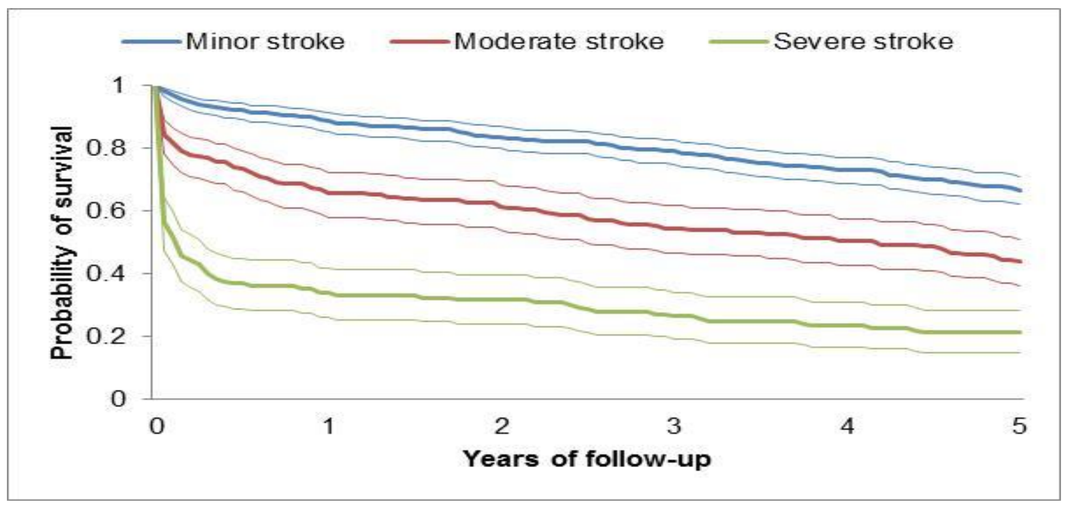
HERC has worked extensively in the measurement of HRQoL and quality-adjusted survival. Three case studies are presented here on:

1) Long-term impact of disease on HRQoL and quality-adjusted survival;
2) Importance of longitudinal data when establishing the true impact of disease complications on HRQoL; and
3) Obtaining preference-based HRQoL estimates from disease specific measures (mapping algorithms)

## Case Study 1: Quality-adjusted survival after stroke

Stroke patients from a UK population-based study (Oxford Vascular Study) were recruited from 2002 to 2007, and followed-up until 2012. QoL was assessed over 5 years using the EQ-5D, with responses converted into utilities using UK population valuations. Utilities for stroke patients were compared to those in matched controls obtained from the 2006 Health Survey for England. 5-year QALYs were estimated by combining utility and survival information.

**Figure 1: Probability of survival by stroke severity**




748 stroke patients were ascertained and included. Utility improved from 0.64 1-month after stroke to 0.70 at 6 months (p=0.006), remaining at around 0.70 thereafter. Matched-controls had considerably higher utility levels than stroke patients (0.85, p<0.001). Event severity was a predictor of diminished utility both in the short- and long-term, with a 1 point NIHSS score rise reducing utility by 0.029 at 1 month and by 0.031 at 5 years. Suffering one or more recurrent strokes was also a predictor of decreased utility, reducing utility by 0.150 at 1 month and 0.068 at 5 years. Of a possible 5 years in perfect health, stroke patients lost 1.71 years due to mortality, and a further 1.08 due to reduced QoL, resulting in 2.21 QALYs. Considerable 5-year quality-adjusted survival differences were observed depending on stroke severity: 2.94 QALYs after minor stroke, 1.65 after moderate stroke and 0.70 for severe stroke.

Reference: Luengo-Fernandez et al. Quality of Life after TIA and stroke: 10-year results of the Oxford Vascular Study. Neurology 2013;81:1588-1595

## Case Study 2: The effect of diabetes complications on HRQoL

People with diabetes are at an increased risk of micro- and macro-vascular complications with pronounced effect on their further morbidity and quality of life. The impact of six diabetes related complications (myocardial infarction, ischemic heart disease, stroke, heart failure, amputation and visual acuity) on quality of life is estimated using six rounds of EQ-5D questionnaires administered between 2002 and 2007 during the UK Prospective Diabetes Post Trial Monitoring Study. The use of cross-sectional data in the literature for such estimates is widespread, being less expensive and easier to collect.

We show, however, that cross-sectional analysis consistently over-estimates the effects of complications on utility, as patients who experience complications tend to have a lower pre-complication quality of life compared to those who do not incur them. Our results highlight the importance of studying quality of life changes over time to distinguish between time invariant determinants of QoL and the effect of specific events such as diabetes complications.

**Table 1: The effect of diabetes-related complications on QoL**

| | Fixed effects estimates (SE) using longitudinal QoL data[1] | OLS estimates (SE) using pooled QoL data[2] | Difference (95% CI) |
|---|---|---|---|
| **QoL effect of disease complication (MI, Ischemic heart disease, stroke, heart failure, amputation, blindness in 1 eye) in diabetes‡** | | | |
| Complication | -0.054 (0.014)** | -0.106 (0.012)** | 0.051 (0.015; 0.087) |
| **QoL effects of the separate disease complications in diabetes‡** | | | |
| MI (within past year) | -0.065 (0.030)* | -0.102 (0.037) ** | 0.047 (-0.056; 0.130) |
| MI (earlier) | 0.008 (0.024) | -0.038 (0.018)* | 0.047 (-0.012; 0.105) |
| Ischemic heart disease | -0.028 (0.022) | -0.073 (0.016) ** | 0.046 (-0.008; 0.099) |
| Stroke | -0.165 (0.035) ** | -0.193 (0.030) ** | 0.027 (-0.063; 0.118) |
| Heart Failure | -0.101 (0.032) ** | -0.166 (0.031) ** | 0.065 (-0.021; 0.152) |
| Amputation | -0.172 (0.045) ** | -0.201 (0.039) ** | 0.029 (-0.088; 0.146) |
| Blindness in 1 eye | 0.033 (0.027) | -0.038 (0.022) ** | 0.070 (0.002; 0.139) |

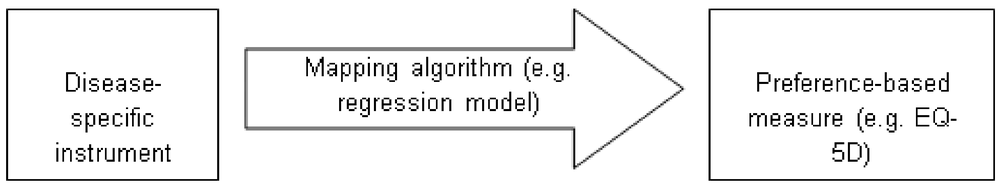
[1]prefered approach; [2] with additional time-invariant covariates: gender, ethnicity, social class and trial centre; ‡further adjusted for age and QoL questionnaire number; ** p<0.01; * p<0.05

Reference: Alva et al. The Effect of Diabetes Complications on Health-Related QoL: The Importance of Longitudinal Data to Address Patient Heterogenity. Health Econ 2013

## Case Study 3: Mapping between QoL instruments

HERC has been leading the way in developing algorithms to "map" between QoL instruments. Algorithms that predict utilities or responses to preference-based questionnaires (e.g. EQ-5D) from patients' responses or scores on one quality of life instrument facilitate economic evaluations based on older studies that included only non-preference-based instruments.

**Figure 2: Applying a mapping algorithm**




To help researchers to identify mapping studies, HERC staff have developed a publically-available database summarising a systematic review of mapping studies, currently including 121 mapping algorithms from 90 studies (www.herc.ox.ac.uk/downloads/mappingdatabase/).

HERC has been developing applied mapping algorithms for more than a decade, including those from the following instruments: SF-12, Oxford Knee Score (OKS), Eight and 39-item Parkinson's Disease Questionnaires (PDQ-8 and PDQ-39), Modified Rankin Scale (mRS), OM8-30 otitis media-specific instrument, MacDQoL macular degeneration quality of life instrument, Measures of visual function, and the Oxford Shoulder Score (OSS).

HERC staff have also been instrumental in developing novel regression methods for mapping: particularly response mapping, in which other instruments are mapped onto patients' responses to the five EQ-5D questions. HERC collaborations have led to several Stata commands which make it easier for other researchers to predict utilities from response mapping algorithms.

Reference: Dakin. Review of studies mapping from quality of life or clinical measures to EQ-5D: an online database. Health Qual Life Outcomes 2013;11:151.

## Future work: QoL in children

ARCHIE

As a component of the ARCHIE (The early use of Antibiotics for at Risk CHildren with InfluEnza in primary care) randomized-controlled trial, researchers at HERC have sought to address the challenges associated with collecting quality of life data from children. There is currently no methodological guidance from NICE in terms of which tool should be used to collect health-related quality of life data from children or at which age it is appropriate for children to self-report their quality of life, in order to obtain health state utility scores. Our aim is to review the available instruments appropriate for use in UK child-based populations and evaluate their use in children (aged 6 months -12 years) and their carers' proxy valuations