



The
University
Of
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Project summary: “Extending the QALY”

The aim of this project is to develop a broad measure of quality of life for use in economic evaluations across health and social care. There are many instruments available that measure quality of life or health-related quality of life, unfortunately, nothing is available that is suitable for evaluations that integrate health and social care.

There are three key distinctions between existing health and quality of life measures and this new instrument:

- Firstly, the new instrument will aim to capture the benefits of interventions in health, social care, and for carers.
- Secondly, the instrument will be made up of aspects of life that patients, social care users and carers think are important to them *and* are impacted by their health condition, the care or treatment they receive or their caring role. This could include how they feel and their happiness.
- Thirdly, because the new instrument is intended to be used in economic evaluations that combine the benefits of extending years of life with improving quality of life, it will need to be valued on a zero to one scale, where zero is equivalent to being dead and one is full quality of life. This is necessary in order to calculate Quality Adjusted Life Years (QALYs).

The project contains six stages:

Stage 1: Establishing the domains for the quality of life instrument

The first step is to identify the broad domains or areas of life that the instrument is going to cover (such as mobility, social relationships or emotional wellbeing). The approach will be to focus on those aspects of life that people think are important - but that are also considered to be relevant for evaluating publicly funded interventions.

Identifying the domains for the instrument will draw from a number of strands of new and existing work. This will include an extensive literature review, and new data analysis on existing datasets. The literature review will gain an overview of research that has looked at the impact of circumstances (e.g. health condition, caring role, social care provision) on quality of life for patients, social care users and carers. The review will have a particular focus

on relevant qualitative work, such as that carried out as part of the development of other quality of life and health instruments. This will result in a list of core domains or areas of life that the new instrument will cover.

These domains will be presented and discussed with advisory and public involvement groups who will give their reflection on the choice of domains. The domains will be modified where appropriate following this consultation and advice from the steering group.

Stage 2: Generate a list of potential items

The next stage is to generate a large list of possible items (or questions) that match the agreed domains (about 35-60 items). The list will be derived from an initial long list generated from a review of existing measures and where necessary creating new items. There will be an initial shortlisting by the research team based on analysis of how well items have performed in the past (i.e. do people seem to be using the item in the way that we would expect) and whether the item is well written (such as avoiding jargon or double negatives).

The decisions will be presented and discussed with the public involvement and advisory groups who will reflect on whether important items are missing, and will help identify any initial problems with any of the items.

Stage 3: Test the face validity of candidate items

The next stage will involve interviews with patients (acute, long term conditions, and mental health service users), social care users, carers and the general public to test whether the items make sense to people, and seem to be capturing quality of life (*their face validity*). About 50 people will be interviewed covering a range of backgrounds.

There will also be a translatability assessment of the items to ensure the items selected can be translated into other languages commonly spoken in the UK, but also the more common languages spoken around the world.

The results of this work will be presented to the public involvement and advisory groups for them to consider the selection of items and exact wording for the item pool. This is expected to result in 30-40 remaining in the pool (at least four items for each domain will be kept).

Stage 4: Psychometric testing of items

A large survey will then be conducted to get data for testing the final item pool from Stage 3 (the 30-40 items). We will survey about 2,000 people in total covering all the groups of interest: social care users, patients (via an on-line panel, through Mental Health Trusts, and through GP practices) and informal carers.

In addition to the 30-40 items from Stage 3 the survey will include commonly used instruments that capture health and quality of life so that we will be able make comparisons between them and the new instrument (this includes EQ-5D, ASCOT and WEMWBS).

The survey will be analysed to identify any items that do not perform well (e.g. responses differ by respondent characteristics when they should not, or they do not distinguish correctly between different response options). The evidence from these analyses, in conjunction with evidence from Stage 3, will be used to select the items and levels for the final measure.

There will be consultation with the public involvement, advisory and steering groups to ensure these judgements are appropriate.

Stage 5: Valuation

The next stage will be to value the instrument - such that it can be scored on the zero to one QALY scale. The aim of the valuation exercise is to find out how important different aspects of quality of life are to people and whether they would consider improvements in one domain (such as emotional wellbeing) as more important than improvements in another domain (such as mobility). It also allows the scoring of the instrument to reflect how people would trade off between increasing lengths of life versus improving quality of life.

The valuation will involve two components. A large choice based valuation exercise (known as time-trade off) with a representative sample of the general public (about 600 people) and a deliberative exercise with members of NICE Citizen's Council.

There will be consultation with the governance groups about the methods used for the valuation exercise. The governance groups will have an opportunity to gain a good understanding of the valuation method and undertake the valuation exercise.

The governance groups will also have opportunity to reflect and discuss the results of the valuation exercise, the accompanying data analysis and recommendations for scoring.

Stage 6: Implementation, dissemination, and impact

The next stage will be disseminating the work. Part of this will involve exploring how it differs to existing instruments and how the decisions of economic evaluations would differ if the new instrument was used rather than existing instruments (such as EQ-5D). This will be done in conjunction with NICE, with support from members of the steering and advisory groups.