

Living with Long-Term Conditions: Validation of the Long-Term Conditions Questionnaire (LTCQ)

A Department of Health and the National Institute for Health Research (NIHR)-funded research project

Background

There are numerous ways to assess quality of life outcomes in long-term conditions (LTCs). Over recent years there has been a shift to patient-centred outcomes. This is because traditional clinical outcomes, such as improvements in physical health, are not as informative to help monitor outcomes in people with LTCs. One useful way to measure patient-centred outcomes is to look at what is important to patients directly. Patient-reported outcome measures (PROMs) were created to assess outcomes from the perspective of patients. These self-report questionnaires are fast, easy to administer and allow us to directly understand what is important to patients.

There are two types of PROMs: generic measures and disease specific measures. Each have strengths and limitations. Generic outcome measures are applicable across populations but do not always capture all outcomes of importance in LTCs. On the other hand, disease-specific measures capture more specific aspects of every disease or condition but the scores cannot be compared across different LTCs populations. There is a need for a questionnaire that directly measures outcomes across different LTCs.

Aims

This project aims to validate the Long-Term Conditions Questionnaire (LTCQ), a 20-item self-report measure, by administering the LTCQ to a large and diverse sample of people with LTCs, including those who receive social services.

The objectives are to:

- Identify the structure of the LTCQ as an outcome measure for LTCs
- Explore whether the number of items in the LTCQ could be reduced
- Assess whether the LTCQ is valid for use in people with LTCs
- Assess whether the LTCQ is a reliable measure

Methods

The project has a planned study phase of 11 months, commencing December 2015. The study will consist of two surveys: the primary care survey and social care survey, as described below. The data collection for each survey will run simultaneously. Ethical and HRA approval was obtained first for the primary care survey (REC reference 15/EM/0414). We have also obtained a favourable opinion from the East Midlands – Derby Research Ethics Committee (REC reference 15/EM/0414) for the social care survey. Research governance approval will be obtained for each participating local authority.

1. The primary care survey

The aim of the primary care survey is to validate the LTCQ in a sample of people with a range of LTCs. The aim is to invite 3000 individuals with either a single LTC or multiple LTCs.

One way to include people with different LTCs is to invite various primary care practices in several geographical areas in England to help identify and recruit the desired sample. Given the difference in prevalence of each selected LTC, the

number of practices needed to recruit the desired sample may vary.

Practices will select people with LTCs with the specified inclusion and exclusion criteria. This will be reviewed by a GP or nurse, and they will remove anyone who is not eligible. Once approved, they will send out the primary care survey, which will include the LTCQ, along with some questions asking about people's health-related quality of life.

Participants are also invited to complete a second, shorter questionnaire only including the LTCQ.

Data collection is currently underway and is due to be completed Summer 2016.

For more information about the primary care survey, please contact Caroline Potter or Louise Geneen: 08001 383 009 or ltprom@dph.ox.ac.uk

2. The social care survey

The aim of the social care survey is to validate the LTCQ in a sample of people with LTCs who receive social services. Taking part will help develop the LTCQ that is intended to be used to monitor various LTCs. We aim to invite a minimum of six local authorities. Participation is voluntary.

Local authorities will be asked to randomly select people with LTCs who receive social services based on a list of inclusion and exclusion criteria. The aim will be to invite 278 individuals with LTCs who receive social care services within each participating local authority. The research team will send all the documentation for potential participants to local authorities. The research team will reimburse postage

costs. Local authorities will be asked to send out the social care survey, which will include the LTCQ, along with some questions asking about people's social care- and health-related quality of life. Recruitment will take place between February and late Summer 2016.

Participants are also invited to complete a second, shorter questionnaire only including the LTCQ.

For more information about the social care survey, please contact Laurie Batchelder: 01227 816 166 or L.Batchelder@kent.ac.uk

Outputs

We plan to report findings through journal articles, reports and conferences. We also plan to report findings through social media, on our project website and the QORU website:

[Project Website](#)

[QORU website](#)

Research Team

The staff conducting the study are: Professor Julien Forder, Dr Karen Jones, Dr Laurie Batchelder and Diane Fox at PSSRU, the University of Kent; Professor Ray Fitzpatrick (Chief Investigator), Dr Michele Peters, Dr Caroline Potter, Dr Laura Kelly, Dr Louise Geneen, Elizabeth Gibbons, Professor Crispin Jenkinson and Dr Angela Coulter at the University of Oxford; and Jennifer Bostock and Matthew Baker from the QORU Public Involvement Implementation Group.

About QORU

The Policy Research Unit in Quality and Outcomes of person-centred care (QORU) is a collaboration involving researchers in health and social care from the Universities of Kent, Oxford and the London School of Economics (LSE) funded by the Department of Health. Our aim is to improve the quality of health and social care for people with long-term conditions through generating high-quality evidence about need, quality and outcomes of person-centred care.

Disclaimer

This is research commissioned and funded by the Policy Research Programme in the Department of Health. The views expressed are not necessarily those of the Department.