Introduction

- Long-term chronic conditions are the main challenge of health and social care services today due to their increasing prevalence and complexity (including multi-morbidity).
- Monitoring PROMs scores is a key focus of UK health care policy, with the EQ-SD the current measure of choice.
- The EQ-SD does not capture all issues of importance for people living with long-term conditions (LTCs). Professional and lay stakeholders support the idea of a new measure for LTCs.
- The aim of this work was to develop items for the Long Term Conditions Questionnaire (LTCQ), a short self-report measure for people living with a broad range of LTCs.
- The LTCQ is intended to be used across both health and social care services, on its own or as a complement to the EQ-SD.

Methods

1. Random selection of patients with at least one of ten selected LTCs, identified by eight primary care practices in southern England
2. Verbal eligibility check by the research team when patients made contact to arrange an interview
3. Audio-recorded semi-structured interview, usually at patient’s home
4. Interviews transcribed, analysed using an iterative coding framework
5. Data were supplemented by six interviews from a previous study with schizophrenia patients, as none were recruited through primary care

Participants (N=48)

- 42 recruited through primary care, 6 from a previous study
- 26 men, 22 women. Age range 29-97 years (average 60 years)
- 40 white British or Irish, 4 South Asian, 2 white European, 1 black British, 1 Middle Eastern
- 23 single morbidity, 25 multi-morbidity

Representation from selected LTCs: cancer (5 participants), chronic obstructive pulmonary disease (3), depression (3), diabetes (14), inflammatory bowel disease (4), ischaemic heart disease (6), multiple sclerosis (7), osteoarthritis (10), schizophrenia (6), stroke/TIA (5)

Participants experienced 23 co-morbidities in addition to the ten LTCs for which they were recruited into the study.

Dimensions of the LTCQ

- Confidence to manage LTC(s)
- Coping with LTC(s)
- Knowledge and information
- Empowerment / sense of control
- Dignity
- Roles and responsibilities
- Suitability of home
- Burden of treatment and services
- Impact of LTCs
- Dependency / being a burden
- Social participation
- Social support
- Loneliness
- Safe environment
- Physical activity
- Stigma
- Achieving personal goals
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- Social participation
- Loneliness
- Safe environment
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- Achieving personal goals

Summary

- The LTCQ is a new measure for assessing outcomes in people living with long-term conditions.
- Participants in qualitative interviews experienced a wide range of LTCs, including physical and mental health and multi-morbidity.
- 17 dimensions underpinned the first 23-item draft of the LTCQ. These dimensions reflect three overarching themes: impact of LTCs, experience of services and support, and self-care.
- The LTCQ will undergo further refinement through cognitive testing and validation through a large-scale survey.

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