Refining Items in the Long-Term Conditions Questionnaire (LTCQ): Cognitive Interviews, Stakeholder Feedback and Translatability Assessment

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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 patent perspectives of their health and well-being is a key focus of UK health care policy. Professional and lay stakeholders support the development of a new measure for long-term conditions (LTCs).
- This work builds on initial item development for the Long-Term Conditions Questionnaire (LTCQ) [Poster 3037], a short self-report measure for people living with a broad range of LTCs (including physical and mental health).
- The LTCQ is intended to be used across both health and social care services, on its own or as a complement to the EQ-5D.

Methods

- Three rounds of **cognitive interviews** were undertaken with people living with a wide range of LTCs. Participants completed the LTCQ in the presence of the interviewer and then discussed their responses. Interviews were audiorecorded and focused on the content, meaningfulness and usefulness of the LTCQ.
- Professional and lay **stakeholders** were mailed the draft LTCQ and prompted to comment on its content and relevance.
- A translatability assessment was undertaken for seven diverse languages: Arabic, French, Polish, Punjabi, simplified Chinese, Urdu, and the original English.
- Items were reviewed and revised by the authors at the end of each step of the process (four revisions in total).

Cognitive Interviews, round 2

9 participants (5 women, 4

Experience of 11 LTCs

men), age range 45-80 years

Took 1-7 minutes to complete

Two items added and two

items extensively revised

Summary

- The LTCQ has undergone extensive cognitive testing with potential users.
- All 20 refined items were found to be relevant, indicating content validity.
- Stakeholders confirmed the LTCQ's broad relevance for both mental and physical health conditions, and across health and social care services.
- A rigorous translatability assessment raised no fundamental concerns for the LTCQ's use in other languages but prompted further clarification of items.

First draft LTCQ containing 23 items, developed from:

- Literature reviews
- Interviews with professional stakeholders (N=29)
- Interviews with patients (N=42)

February 2015

Five items

removed,

all remaining

items revised,

items re-ordered

March 2015

April 2015

Cognitive Interviews, round 3

May 2015

- 10 participants (6 women, 4 men), age range 30-79 years
- Experience of 18 LTCs
- Average 5 minutes to complete
- All items retained, one item revised, translatability check

Revised LTCQ

- 20 items, relevant across health and social care
- Includes less traditional dimensions such as empowerment, treatment burden, and self-care
- To be validated through a largescale survey of both health and social care users

Cognitive Interviews, round 1

- 13 participants (7 women, 6 men), age range 36-88 years
- Combined experience of 18 LTCs (physical & mental health)
- Took between 3 and 10 minutes to complete the LTCQ

Stakeholder Consultation

- 5 lay responses (draft 1), then 13 professional responses
- The measure covered items of value and importance to LTCs
- Broad relevance across health and social care

Translatability Assessment

- Specialist assessment for potential use of the LTCQ in seven diverse languages
- No fundamental concerns
- Minor revision to five items for greater clarity

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