The use of patient and stakeholder opinion to refine items in the development of the Long-Term Conditions Questionnaire (LTCQ)

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Introduction

Incorporating patients' and stakeholders' perspectives when refining candidate questionnaire items for a new patient reported outcome measure (PROM) is often an underreported, yet important step in achieving a valid and meaningful instrument. Using the example of a new PROM for use among people with single or multiple long-term conditions (LTCs), we report how items were refined based on feedback from people living with LTCs and professional stakeholders from across health and social care.

Methods

Draft items were informed through literature reviews, interviews with professional stakeholders (N=29), interviews with patients (N=42) and six interviews from a study on treatment outcomes in schizophrenia. A combination of cognitive interviews (n=32) with people living with LTCs and consultations with professional stakeholders (n=13) and public representatives (n=5) were conducted over several stages to assess the suitability of 23 candidate questionnaire items. Questionnaire items were tested for content and comprehensibility and underwent a translatability assessment to address potential difficulties in future translations into the following languages: Arabic, French, Polish, Punjabi, simplified Chinese, and Urdu.

Results

Four stages of revisions took place following amendments to item structure, improvements to item clarity, removal of duplicate items and consideration of recommendations to improve the accuracy of future translations. Content validity was enhanced through the addition of one item relating to symptoms following patient feedback. Twenty items were confirmed as relevant to living with LTCs and understandable to patients and professional stakeholders. The item order was amended to improve the respondent experience when completing the questionnaire and to reduce completion errors when changing from positively to negatively structured items.

Conclusions

The methods used in this study enabled input from both people living with LTCs and professional stakeholders in the refinement of the new PROM. Employing such methods to refine candidate PROM items can support their content validity while also ensuring that the instrument is useful for professionals in the intended setting.

Acknowledgements

We would like to thank the participants with long-term conditions for taking part in this study, and the lay and professional stakeholders for their comments on the draft LTCQ. This work is funded by the Policy Research Programme (PRP) in the Department of Health England, which supports the Quality and Outcomes of Person-centred Care Policy Research Unit (QORU), and by the National Institute for Health Research (NIHR), which supports the Oxford Collaboration for Leadership in Applied Health Research and Care (CLAHRC). Correspondence author: laura.kelly@dph.ox.ac.uk



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Figure 1: LTCQ refinement using patient and stakeholder opinion and translatability assessment

LTCQ, version 1 (23 items)

Cognitive Interviews (n=13)

7 women, 6 men, 36-88 years Combined experience of 18 LTCs (physical & mental health)

Stakeholder Consultation

Lay consultation (n=5)
Department of Health and NHS
England consultation (n=4)

Action: Revisions to recall period and item order. 12 items revised (to improve clarity) and 6 items deleted (5 duplication and 1 for content)

LTCQ, version 2 (18 items)

Stakeholder Consultation (n=13)

Professionals viewed the items to be of value and importance to people with LTCs with broad relevance across health and social care

Translatability Assessment

Specialist assessment for potential use in seven diverse languages

No fundamental concerns

Action: Instructions revised for clarity, 6 items revised for greater clarity

LTCQ, version 3 (18 items)

Cognitive Interviews (n=9)

5 women, 4 men, 45-80 years Combined experience of 11 LTCs

Action: Five items revised to improve clarity and terminology, additional item added to improve content

LTCQ, version 4 (20 items)

Cognitive Interviews (n=10)

6 women, 4 men, 30-79 years Experience of 18 LTCs

Translatability Assessment

Specialist assessment for potential use of the LTCQ in seven diverse languages

Action: All items retained, one item revised to improve clarity



To be validated through a large-scale survey of both health and social care users