

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.

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

