Item Generation for the Long-Term Conditions Questionnaire (LTCQ): Qualitative Interviews with Patients

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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 PROMs scores is a key focus of UK health care policy, with the EQ-5D the current measure of choice.
- The EQ-5D 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-5D.

Methods

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

...I mean the more dialogue there is about long-term illnesses, I would have thought the better. The more real dialogue, well for me it's important... the importance of as I've said already, of being engaged in it, and feeling that it's under my control, and that I have a big say in what's done to me...'

69-year-old man with ischaemic heart disease

"... [it] made me think "if I don't take my medicines this time, I'm going to have a newborn, and a 5-year-old at home, and I'm going to be in hospital, and there's no one to take care of them", do you know what I mean, so since then, since that one attack during pregnancy, I've been taking my remission medication like it's a religion...'

33-year-old woman with inflammatory bowel disease

Confidence to manage LTC(s) **Empowerment** sense of **Burden of**

control

Dignity

Roles and

responsibilities

treatment and services

Impact of

LTCs

Dependency being a

burden Suitability of home

Safe

environment

Dimensions of the LTCQ

Coping with LTC(s) Knowledge

Feeling supported

Social participation

Loneliness

Physical activity

and

information

Stigma

Achieving

personal

goals

quite well. Hence why I'm not having constant hypos and I'm not having, I try and watch out for it going too high. I don't test myself every 5 minutes, but I've learnt how my body feels, and I can tell when things are not quite right...'

"... I believe I manage my diabetes

59-year-old man with diabetes, arthritis and circulatory problems

'... and you say "Well, actually yeah, I'm on anti-depressants and probably will be for the rest of my life" and you can see this sort of "Oh, you poor thing" and "Oh crumbs, what do I say now?" kind of look on people's faces. But again, I've got less sensitive about that and as years go by, you always think, well, yeah it's just part of me that doesn't quite work properly...'

44-year-old woman with depression and osteoarthritis

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.

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 multimorbidity.
- 17 dimensions underpinned the first 23-item draft of the LTCQ. These dimensions reflect three overarching themes: impact of LTC(s), experience of services and support, and self-care (pink, yellow, and green in figure above).
- The LTCQ will undergo further refinement through cognitive testing and validation through a large-scale survey.

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