Validation of the long-term conditions questionnaire (LTCQ)

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Aims: Building on item content developed through previous qualitative interviews with patients and stakeholders, this research sought to validate items of the Long-Term Conditions Questionnaire (LTCQ) through a large-scale survey. The LTCQ is intended to be a short patient-reported outcome measure (PRO) designed to capture the impact of living with long-term physical and/or mental health conditions and to be relevant across health and social care.

Methods: 2615 participants with LTCs were invited into the study through primary care practices in three geographic regions of the UK. Patients were identified on the basis of having one of eleven selected conditions: chronic obstructive pulmonary disease, diabetes, cancer, chronic back pain, ischaemic heart disease, depression, severe mental illness, irritable bowel syndrome, stroke, multiple sclerosis, osteoarthritis. Participants were mailed Survey 1 that included the LTCQ and demographic questions alongside other validated measures for assessment of construct validity: EQ-5D-5L, Self-efficacy for Managing Chronic Disease 6-item scale, Activities of Daily Living questionnaire, and a co-morbidities scale. Participants had the option of returning the questionnaire anonymously or providing their contact details for a follow-up survey to test for reproducibility. A sub-sample of 395 participants was selected for the follow-up study; Survey 2 was also administered by post and included the LTCQ, a question about health status change, and demographic questions.

Results: 806 completed Survey 1 questionnaires were returned (31 % response rate). All eleven recruiting conditions were represented, with more than 80 % of the sample reporting multiple LTCs. Analysis indicates that that vast majority of questionnaires were completed in full, with low levels of missing data (\3 % for each item of the LTCQ). 318 completed Survey 2 questionnaires were returned (80 % response rate), which enabled test–retest reliability to be assessed.

Conclusions: Preliminary analysis suggests that the 20-item LTCQ was acceptable to a large sample of patients living with a diversity of long-term conditions. The LTCQ will now be administered to a further sample of approximately 1700 social care users to assess its relevance for integrated health and social care. Factor analysis on the combined samples will be undertaken in order to refine the LTCQ into its final form.