Validation of the Long-Term Conditions Questionnaire (LTCQ) in a diverse sample of health and social care users in England

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Policy context: outcomes-focused, shift to person-centred care

### The House of Care Model for LTCs

#### The NHS Outcomes Framework

<table>
<thead>
<tr>
<th>Domain</th>
<th>Domain Description</th>
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<tbody>
<tr>
<td><strong>Domain 1</strong></td>
<td>Preventing people from dying prematurely</td>
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<td><strong>Domain 2</strong></td>
<td>Enhancing quality of life for people with long-term conditions</td>
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<tr>
<td><strong>Domain 3</strong></td>
<td>Helping people to recover from episodes of ill health or following injury</td>
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<td><strong>Domain 4</strong></td>
<td>Ensuring people have a positive experience of care</td>
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<td><strong>Domain 5</strong></td>
<td>Treating and caring for people in a safe environment and protecting them from avoidable harm</td>
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**Effectiveness**
- Engaged, informed individuals and carers
- Person-centred, coordinated care

**Experience**
- Health and care professionals committed to partnership working

**Safety**
- Commissioning

**But where is the door?**
What does the EQ-5D not tell us?

- Autonomy
- Issues of vulnerability
- Social support
- Enjoyment of life
Aims of the Long-Term Conditions Questionnaire (LTCQ)

- To complement existing PROMs such as EQ-5D and/or to work as a stand-alone measure

- Relevant for
  - health and social care
  - single and multiple morbidities
  - physical and mental health conditions
  - individual and population based levels

- Short and practical
LTCQ development - methods

- Stakeholder consultation (Hunter et al. 2015 BMJ Open)
- Literature reviews and reviews of major PROMs
- Qualitative interviews (Peters et al. 2016 Patient Relat Outcome Meas)
- Item generation
- Cognitive interviews (round 1)
- Translatability assessment
- Stakeholder consultation and Patient and Public Involvement
- Cognitive interviews (rounds 2 and 3)
- Translatability assessment (update) (Kelly et al. 2016 Patient Relat Outcome Meas)
- Validation survey
Recruiting conditions for validation study

- Cancer in the last 5 years
- Chronic back pain
- Chronic obstructive pulmonary disease
- Depression
- Diabetes
- Irritable bowel syndrome
- Ischaemic heart disease
- Multiple sclerosis
- Osteoarthritis
- Severe mental health (e.g. schizophrenia)
- Stroke

OR

- long-term social care support for a physical disability, sensory impairment, or mental health condition as listed on the Short and Long Term Table (SALT) LTS001b (excludes cognitive impairment)
Participant characteristics (N=1,211)

- 917 participants (76%) recruited through primary care, 294 participants (24%) recruited through local authorities
- 54% female, 91% white British, ages 18-102 (mean 67)
- 46% retired from work, 18% permanently sick or disabled, 17% employed / in education
- 54% married or in a civil partnership
- 25% had some kind of help completing the questionnaire, including 6% of questionnaires completed by proxy
LTCQ item responses (N = 1,211)

• Acceptability: low levels of missing data (2% or less) spread evenly across items

• Six items exhibited ceiling effects, (more than 40% of respondents choosing the most positive response options). These items were identified as having particular relevance for social care recipients (safety and suitability of home), or alternatively as capturing themes that were identified as important in qualitative phases of development (burden of treatments and services, support to cope well, confidence to self-manage). No items have been removed at this stage, but these results may suggest a need in future for a full version of the LTCQ to be used in clinical practice and a short form to be used in population-level studies.

• The LTCQ is scored on a scale from 0 to 100, with higher scores representing greater well-being in living with LTCs. No ceiling effect was observed for the measure as a whole.
Reliability and construct validity

- Cronbach’s $\alpha = 0.95$ across the LTCQ’s 20 items. Examination of inter-item correlations suggested no direct repetition between items.

- ICC (type 2: two-way random effects, absolute agreement) for overall LTCQ scores between Survey 1 and Survey 2 was 0.94 (95% CI, 0.93 to 0.95), for those who reported no change in health status over the two-week test-retest period.

- Significant correlations of the LTCQ score with reference measures (EQ-5D-5L, EQ-VAS, Lorig self-efficacy scale, Activities of Daily Living scale, Bayliss burden of morbidity scale, number of LTCs reported) were moderate to strong and in the expected directions. Of note were the strong correlations with both EQ-5D-5L and the Lorig self-efficacy scale, which measure notably different constructs; this suggests that the LTCQ is capturing a broader construct (‘living well with long-term conditions’) than is captured by either of the existing measures.
Distribution of scores
Strengths and limitations of the study

- first psychometric evaluation of the Long-Term Conditions Questionnaire, a new generic PROM
- large survey validation sample of 1,211 health and social care users in England
- highly diverse sample in terms of illness burden and care needs: 93% reporting multi-morbidity and 43% reporting a mental health condition
- low response rate achieved among social care users, although this was consistent with previous studies
- Further validation work among other ethnic groups and in non-English contexts is required since the vast majority of participants were white British
Where next for the LTCQ?

Long-Term Conditions Questionnaire (LTCQ)

This questionnaire is aimed at people with at least one long-term health condition, regardless of the level of severity of the condition.

If you have a single long-term health condition, please consider how this condition affects you.

If you have more than one long-term health condition, please consider how all of these conditions affect you.

Please think about your long-term health condition(s) over the past four weeks. How often have you…
Acknowledgements

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