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Validation of the Long-Term Conditions Questionnaire (LTCQ)

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Background

• Long-term chronic conditions (LTCs) are the main challenge of health and social care services today due to their increasing prevalence and complexity, including multi-morbidity.

• Monitoring outcomes is a key focus of UK health care policy. The EQ-5D is the current measure of choice, but it does not capture all issues of importance for people living with LTCs.

• From previous research (Hunter et al. 2015), professional and lay stakeholders support the idea of a new measure for LTCs.

• The aim of this work was to validate the Long-Term Conditions Questionnaire (LTCQ), a short self-report measure for people living with a broad range of LTCs. Conceptual development of items for the LTCQ has been previously reported (Peters et al. 2016).

• 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

1. Random selection of patients with at least one of eleven selected LTCs, identified by fifteen primary care practices across England
2. Concurrent identification of social care recipients with at least one LTC through a local authority in southern England
3. Survey 1 containing the LTCQ, EQ-5D-SL, Lorig self-efficacy scale, an Activities of Daily Living scale, the Bayliss multi-morbidity scale, and ASCOT (social care sample only) were mailed to potential participants
4. Participants returned Survey 1 anonymously OR provided contact details for a follow-up survey approximately two weeks later
5. A sub-sample who provided contact details (N=612) were sent Survey 2, containing the LTCQ and health change/demographic questions only

A diverse sample: health and social care users

<table>
<thead>
<tr>
<th>LTCQ summed scores (mean)</th>
<th>EQ-5D-SL index values (mean)</th>
</tr>
</thead>
<tbody>
<tr>
<td>COMBINED</td>
<td>Health Care</td>
</tr>
<tr>
<td>Health Care</td>
<td>Social Care</td>
</tr>
<tr>
<td>Lorig self-efficacy scores (mean)</td>
<td>Health Care</td>
</tr>
<tr>
<td>Bayliss multi-morbidity (mean)</td>
<td>Health Care</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>COMBINED</th>
<th>Health Care</th>
<th>Social Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>72.08</td>
<td>74.73</td>
<td>79.65</td>
</tr>
<tr>
<td>0.85</td>
<td>0.70</td>
<td>0.16</td>
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<tr>
<td>6.15</td>
<td>6.79</td>
<td>7.12</td>
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<tr>
<td>15.82</td>
<td>14.71</td>
<td>21.73</td>
</tr>
</tbody>
</table>

Participants (N=1,090)

Health care sample (N=917)
- 52% female, 95% white British
- Age range 18 to 101 (mean 66)
- 12% permanently sick or disabled
- 2% completed by proxy
- Number of LTCs (mean): 6

Social care sample (N=173)
- 65% female, 82% white British
- Age range 19 to 102 (mean 70)
- 41% permanently sick or disabled
- 22% completed by proxy
- Number of LTCs (mean): 7

Prevalence of recruiting conditions across the total sample:
- depression / anxiety (39%), chronic back pain / sciatica (37%), diabetes (26%), osteoarthritis (25%), heart disease (23%), colon problems (23%), COPD (15%), cancer in the last 5 years (14%), stroke (14%), bipolar / schizophrenia (7%), multiple sclerosis (5%)

Summary of preliminary findings

• The LTCQ is a new measure for assessing well-being in people living with a wide range of long-term conditions. For preliminary analysis the score was calculated as the sum of all items, with maximum score of 100 and higher scores indicating greater well-being.

• The LTCQ was acceptable to a diverse sample of health and social care users, with low levels of missing data (≤ 2% per item).

• Preliminary analysis indicates excellent internal reliability (α=0.96) and test-retest reliability (ICC = 0.92, 95% CI 0.90 to 0.94)

• Further analysis will be undertaken to refine the scoring system and to clarify the interpretation of scores.

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