The long-term conditions questionnaire (LTCQ): a patient-reported outcome measure

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Background

• Health and social care policy interest in assessing outcomes in long-term conditions (LTCs)

• Outcomes are to be assessed by patient-reported outcome measures (PROMs) such as EQ-5D

• Focus on LTCs due to increasing prevalence, multi-morbidity and complexity of people’s needs
Routine PROMs data collection in LTCs

• To evaluate the feasibility and acceptability of using PROMs for long-term conditions (asthma, COPD, diabetes, epilepsy, heart failure and stroke) in primary care

• Identified challenges with such data collection including exclusion and participation rates, few significant findings on PROMs data, queries about suitability of the PROMs used and presentation and use of the findings

• Recommendation to develop a generic PROM for LTCs

Development of the Long-Term Conditions Questionnaire (LTCQ)

• To complement EQ-5D
• Broadly relevant (health and social care)
• Short and practical
• Potentially relevant to individual patient care but also population based analysis
• Suitable for single and multiple morbidities
LTCQ development - methods

- Stakeholder consultation
- Literature reviews and reviews of major PROMs
- Qualitative interviews with people with at least one LTC
- Item generation
- Cognitive interviews (round 1)
- Translatability assessment
- Stakeholder consultation and Patient and Public Involvement
- Cognitive interviews (rounds 2 and 3)
- Translatability assessment
- Validation survey
Stakeholder consultation

• Semi-structured qualitative interviews
• 31 participants from across primary care, secondary care, social care, charities, and NHS policy and commissioning, and lay stakeholders
• Broadly supportive of a PROM for LTCs
• Content
  – Traditional PROM items such as physical functioning, mental well-being, social functioning
  – Non-traditional dimensions, frequently assessed by other patient-reported measures e.g. feeling in control, empowerment and experiences of services

Interviews with people with LTCs

• Semi-structured in-depth qualitative interviews
• Recruited through primary care in Thames Valley and London
• At least one LTC diagnosed more than a year ago
  – cancer, chronic obstructive pulmonary disease, depression, diabetes, inflammatory bowel disease, ischaemic heart disease, multiple sclerosis, osteoarthritis, schizophrenia and stroke
Qualitative interviews with people with at least one LTC

• 42 participants recruited through primary care and 6 from a previous study
  – 26 men and 22 women
  – Age range 33-97 (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 (total of 33 different LTCs reported)
  – 7 had experience of social care
Qualitative interviews - results

• Three overarching main themes
  – Impact of LTC(s)
    E.g. Emotional well-being, impact on daily activities, safety, sense of (in)dependence
  – Experience of services and support
    • E.g. burden of services and/or treatments, dignity, involvement in health decisions
  – Self-care
    • E.g. empowerment, knowledge and information
Impact of LTC(s)

‘...I can dress myself except for when it comes to my feet, because I can’t get that far on my back, and my knees don’t move properly... I’ll cook with a microwave, but I can’t prepare vegetables ... I can’t hold hot saucepans ... if it’s just a matter of putting something in a microwave, I can do that. I just look to do the things I can do like I can dust, my husband hoovers, I can’t manage the hoover.... ‘

64-year old woman with COPD, stroke, arthritis, agoraphobia, depression, IHD, gout and stenosis
Experiences of services and support

‘... and it's also planning sort of like work around hospital... I seem to have so many hospital appointments these days ... I get the impression that once they get hold of you they're never going to let you go...’

A 77-year old man with IHD

‘... I get tired ... I’m trying to take it easier, cos I like working hard and doing it all myself [LAUGHS] but I have to let others do stuff for me...’

45 year-old woman with MS
‘... I think a lot of people find it difficult to find out information from social services, about what they’re entitled to... I wouldn’t know, if I was entitled to any help or not, not now but in the future, people don’t know, a lot of people don’t know...’

70-year old man with type 2 diabetes, stroke, IHD, gout and chronic back pain
Cognitive interviews

<table>
<thead>
<tr>
<th>Round 1</th>
<th>Translatability assessment</th>
<th>Round 2</th>
<th>Round 3</th>
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<tbody>
<tr>
<td>Participants</td>
<td>• 7 women, 6 men &lt;br&gt; • 36-88 years &lt;br&gt; • 18 LTCs</td>
<td>• 5 women, 4 men &lt;br&gt; • 45-80 years &lt;br&gt; • 11 LTCs</td>
<td>• 6 women, 4 men &lt;br&gt; • 30-79 years &lt;br&gt; • 18 LTCs</td>
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<tr>
<td>23 items</td>
<td>Minor revisions to 5 items</td>
<td>18 items</td>
<td>20 items</td>
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<tr>
<td>• 5 removed &lt;br&gt; • 18 reworded &lt;br&gt; • 2 week time frame changed to 4 weeks</td>
<td>• 2 added &lt;br&gt; • 2 extensively revised</td>
<td>• Minor revision to 1 item</td>
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NB. A second translatability assessment was carried out on new and extensively revised items, with no further revisions necessary.
Stakeholder consultation

• 13 professional stakeholders and 5 lay advisors commented on early version of LTCQ

• General consensus was that
  – the measure covered items of value and importance to LTCs, with appreciation for the range of issues covered (social, psychological, physical).
  – The measure is relevant to mental health conditions, and social care (and carers, potentially).
LTCQ domains (20 items)

• Impact of LTCs
  – Ability to achieve goals
  – Dependency
  – Suitability of home
  – Impact of LTCs
  – Loneliness
  – Physical activity
  – Safety
  – Social participation
  – Stigma

• Self-care
  – Coping
  – Knowledge about LTCs
  – Self-management
  – Sense of control

• Experience of services and support
  – Feeling supported
  – Impact of treatment and services
Conclusions

• Health and social care policy has a strong interest in collecting PROMs data for LTCs
• Challenges to collect such data
• Development of LTCQ – a measure to assess outcomes across LTCs
• Next steps – validation of LTCQ in two surveys (primary care and social care samples)
• Future challenges - implementation into practice