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ORIGINAL RESEARCH

The Long-Term Conditions Questionnaire: conceptual framework and item development

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Michele Peters[1]
Caroline M Potter[1]
Laura Kelly[1]
Cheryl Hunter[1]
Elizabeth Gibbons[1]
Crispin Jenkinson[1]
Angela Coulter[1]
Julien Forder[2]
Ann-Marie Towers[2]
Christine A'Court[3,4]
Ray Fitzpatrick[1]

[1]Health Services Research Unit, Nuffield Department of Population Health, University of Oxford, Oxford, [2]Personal Social Services Research Unit, University of Kent, Canterbury, [3]Nuffield Department of Primary Health Care Sciences, University of Oxford, Oxford, [4]Broadshires Health Centre, Carterton, UK

Purpose: To identify the main issues of importance when living with long-term conditions to refine a conceptual framework for informing the item development of a patient-reported outcome measure for long-term conditions.

Materials and methods: Semi-structured qualitative interviews (n=48) were conducted with people living with at least one long-term condition. Participants were recruited through primary care. The interviews were transcribed verbatim and analyzed by thematic analysis. The analysis served to refine the conceptual framework, based on reviews of the literature and stakeholder consultations, for developing candidate items for a new measure for long-term conditions.

Results: Three main organizing concepts were identified: impact of long-term conditions, experience of services and support, and self-care. The findings helped to refine a conceptual framework, leading to the development of 23 items that represent issues of importance in long-term conditions. The 23 candidate items formed the first draft of the measure, currently named the Long-Term Conditions Questionnaire.

Conclusion: The aim of this study was to refine the conceptual framework and develop items for a patient-reported outcome measure for long-term conditions, including single and multiple morbidities and physical and mental health conditions. Qualitative interviews identified the key themes for assessing outcomes in long-term conditions, and these underpinned the development of the initial draft of the measure. These initial items will undergo cognitive testing to refine the items prior to further validation in a survey.

Keywords: long-term conditions, conceptual framework, qualitative interviews, patient-reported outcome measure

Introduction

Patient-reported outcome measures (PROMs) have been proposed as a means to measure what matters to patients to strengthen patient involvement in their care, to enable individualization of care,[1] and to evaluate the performance and quality of care.[2] It is generally agreed that a PROM should have a clear underlying conceptual framework,[3–5] which specifies the specific goal of the measure, its intended use, and the target population.[3,4] Although these criteria have been highlighted in particular for PROMs used in clinical trials, it is equally important that PROMs developed for use in other contexts, such as clinical practice or performance monitoring, are also developed to a high standard. It is recommended that an initial hypothesized conceptual framework be based on a literature review and expert opinion, and that this framework be further refined as domains and items are developed on the basis of in-depth qualitative and cognitive interviews.[5]

Correspondence: Michele Peters
Health Services Research Unit, Nuffield Department of Population Health, University of Oxford, Old Road Campus, Oxford OX3 7LF, UK
Telephone +44 1865 289 428
Email michele.peters@dph.ox.ac.uk

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Table 1 Initial domains in the conceptual framework for the development of the Long-Term Conditions Questionnaire

Literature reviews of key domains	Stakeholder interviews[a]
1. Outcomes included in generic and disease-specific PROMs	1. Empowerment
2. Self-management	2. Quality of life or impact of illness and/or treatment on life
3. Coping	3. Patient-specific or personalized goals
4. Empowerment	4. Functioning (including social, physical, and psychological)
5. Burden of treatment	5. Social participation
6. Stigma	6. Psychological well-being
7. Safety	7. Symptoms or clinical outcomes
8. Involvement in decision making	8. Access to services (includes access to information)
9. Information and health literacy	9. Joined-up nature of services
10. Ability to achieve goals	10. Impact on carers
11. Social participation	
12. Social support	

Notes: [a]Adapted from Hunter C, Fitzpatrick R, Jenkinson C, et al. Perspectives from health, social care and policy stakeholders on the value of a single self-report outcome measure across long-term conditions: a qualitative study. *BMJ Open*. 2015;5(5):e006986.[18]
Abbreviation: PROMs, patient-reported outcome measures.

Long-term chronic conditions are the main challenge facing health and social care services today, due to their increasing prevalence, complexity, and impact on quality of life.[6–10] Multimorbidity adds further to this challenge. Enhancing quality of life for people with long-term conditions (LTCs) by monitoring PROM scores is a key goal of health and social care policy in England and in other countries.[11–14] The use of PROMs has been pilot-tested for six LTCs in primary care.[15] This pilot study highlighted a number of challenges, including the reporting of PROM data (for one generic and six disease-specific PROMs) in a meaningful and concise manner across multiple LTCs.[16] As no PROM exists to capture outcomes across all LTCs, the EuroQol five-dimension questionnaire (EQ-5D) is used in England to assess LTC outcomes, eg, as part of the GP Patient Survey.[17] However, the EQ-5D may not capture all issues of importance to patients and clinicians. Therefore, professional and lay stakeholders support the development of a new measure for LTCs.[18] The intention of this measure would be to capture issues of importance across LTCs and to offer a practical, easily interpretable, and useful method to assess outcomes across a range of health and social care services.

The aim was to develop a short self-completed questionnaire about issues of importance when living with LTCs. The intention was to develop a measure for use by adults with single and multiple morbidities, including both physical and mental health conditions. We intend it to be used for individual care and for population monitoring across all health and social care settings. The domains and items are intended to be complementary to those of the EQ-5D, and to reflect both traditional domains (ie, aspects of quality of life) and less traditional domains of importance in LTCs (eg, empowerment) that can be assessed by patient self-report. Following scoping reviews of the literature covering 12 key domains that can be assessed through patient reports and a stakeholder consultation,[18] an initial conceptual framework was developed (see Table 1 for the initial framework).[3,4] This article describes the refinement of the conceptual framework and the development of the thematic domains and initial items.

Materials and methods

Qualitative interviews

Recruitment

Eight primary care practices in England (four in Oxfordshire and four in London) agreed to recruit people with at least one of ten specified LTCs from their patient database. The ten LTCs were selected by a panel composed of the authors, PROM experts, and lay advisors. The aim was to select maximally diverse LTCs (in terms of symptoms, bodily systems, disease trajectory, prevalence, likelihood of comorbidities, burden of disease and care, and level of self-management). To aid this process, the panel was provided with information on bodily systems, the World Health Organization Global Burden of Disease study,[19] a study on multimorbidity,[7] and the LTCs included in the Quality and Outcomes Framework (http://www.nice.org.uk/aboutnice/qof/qof.jsp). The following LTCs were selected: cancer, chronic obstructive pulmonary disease (COPD), ischemic heart disease (IHD), diabetes, depression, inflammatory bowel disease (IBD), multiple sclerosis (MS), osteoarthritis, schizophrenia, and stroke. Seven of these were selected by over half the panel, and three (IBD, MS, and schizophrenia) were selected by at least one panel member and included to contrast maximally with the other seven LTCs.

Practice staff conducted a search on the database comprised of the electronic patient record of all individuals registered with the practice. Search criteria were followed according to instructions developed and tested by one of the authors (CA). This search produced a list of patients with the relevant LTCs. Practices fed back the number of patients identified per LTC. The researchers used an online randomization tool (www.random.org) to generate random patient numbers per LTC. Practice staff then selected patients according to the randomization numbers from the list, and checked each patient against the inclusion and exclusion criteria. A total of 360 eligible patients were invited into the study. For LTCs with lifelong implications (COPD, diabetes, IBD, IHD, MS, osteoarthritis, and stroke), eligibility was defined as the presence of the LTC. Where full prolonged remission or cure is possible (cancer, depression, and schizophrenia), additional criteria in relation to duration of disease and/or current treatment were determined, similarly to the approach taken by Barnett et al.[7] Additionally, the diagnosis needed to have been confirmed more than 12 months ago, to ensure that patients had time to adjust to their diagnosis and had experienced a range of services and strategies for the management of their LTC(s). Only adult patients were included (ie, 18 years of age and above). There was no upper age limit.

No participants with schizophrenia were recruited through primary care; therefore, the data were supplemented with interviews from a study conducted in 2013–2014 by RF and MP on outcomes valued by people with schizophrenia.[20] Participants had been recruited through an email invitation by Rethink Mental Illness (https://www.rethink.org/about-us) and snowball sampling. The exact number of people receiving the invitation is not known, but 47 people made contact to participate. Of these 47, 13 were excluded due to not reporting a diagnosis of schizophrenia or schizoaffective disorder, five people refused to be interviewed, and seven failed to respond to emails after their initial contact. For the purposes of the study presented here, six transcripts of diverse participants (in terms of age and sex) were selected for secondary analysis.

Data collection

Eligible patients were sent a letter of invitation by the primary care practice and were asked to contact the researchers if they were interested in participating. Following initial contact that included confirmation of eligibility, the researchers arranged an interview time and location according to the preference of the participant; most interviews took place in participants' homes, their workplace, or the University of Oxford. All participants gave written consent. The semi-structured interviews were conducted by CH, LK, and CP. All interviews were digitally audio-recorded.

The topic guide for the primary care participants (Table 2) was informed by our previous scoping literature reviews on PROMs and the key domains (Table 1), health care-policy documents (such as the National Health Service Outcomes Framework and the Social Care Outcomes Framework),[21,22] and the stakeholder interviews.[18] It focused on impacts and outcomes of LTCs, personal self-care strategies, help needed or received in managing LTCs (including experiences of health, social care, or community/voluntary services), and goals or problems regarding LTC management. In later interviews, participants were also invited to comment on emerging themes that were being considered as candidate items for a new PROM for LTCs. The schizophrenia topic guide (Table 2) was developed on the basis of a stakeholder consensus meeting and the literature.

Table 2 Topic guide for interviews

Primary care interviews	Schizophrenia interviews
1. Can you tell me a bit about yourself (eg, living arrangements, day-to-day activities)?	1. Can you tell me a little about yourself?
2. What long-term conditions (physical and mental health) do you have? How long have you had these?	2. Can you tell me a bit about your current diagnosis? How long have you had this diagnosis?/Can you remember when you were first given this diagnosis?
3. What aspects of your day-to-day life are affected by [condition/s]?	3. Have you had any other diagnoses? If yes, can you tell me what they are/were?
4. How has your health been recently?	4. Thinking about your health now, how do you feel that you are doing in general?
5. Has living with [condition/s] changed over time? If so, in what way/s?	5. In what areas of your life do you feel you are doing well/not so well/having difficulties?
6. Is there anything you're able to do to look after yourself and manage your health?	6. Currently, in which areas of your life/health do you feel it would be most important to see improvements? Are you currently receiving any form of treatment? What are your experiences of this treatment? What are the most important benefits or effects of the treatment(s)?
7. What help do you have in order to manage your health?	7. Can you tell me about when you have been unwell? Thinking back to this time period, what do you feel were the most important consequences or outcomes of the treatment you received?
8. What are your main priorities in managing your [condition/s]?	8. Could we now talk about when you started to feel better/more stable? Thinking back to this time, what were the most important consequences or outcomes of the treatment you received?
9. How would you feel about being asked to complete a short questionnaire on your health every now and then, as part of your health care (and social care)?	9. Is there anything that we haven't covered that you feel is particularly important to mention in relation to our discussion?
10. Is there anything else that you would like to mention about the impact of your health on your day-to-day life?	

Data analysis and development of items

The interviews were transcribed verbatim by a professional transcription company. All transcripts were verified and anonymized by the interviewers before analyzing the data in QSR NVivo 10, a qualitative software package. An iterative framework analysis was used.[23] According to this approach, eight interviews were analyzed according to an initial coding framework drawing on the literature review and the stakeholder interviews.[18] After discussion among the authors, the coding framework was expanded to take account of emerging themes, particularly those relating to social care; a further 18 interviews were analyzed using the expanded framework. CH, CP, and LK conducted the analysis, and MP and RF analyzed ten interview transcripts (five each). These ten transcripts were selected to represent a range of LTCs. The analysis framework was then discussed and further refined, before the remaining 22 interview transcripts (including the six schizophrenia transcripts) were analyzed. Once all transcripts had been coded, the framework was reviewed again, with no further changes made. Earlier transcripts were then recoded to incorporate the additional codes from the final framework.

A data-saturation table was created to evaluate if thematic saturation had been achieved. Saturation was defined as "the point in the data collection process when no new concept-relevant information is being elicited from individual interviews or focus groups".[4] The interview data were analyzed systematically and subsequently, and concurrently with data collection, using a constant comparison method moving between the codebook, the saturation table, and full transcripts,[24] to determine if new themes emerged. Data collection was considered complete when no new relevant themes were emerging. As described earlier, the analysis framework was established following a review of the framework based on the analysis of 18 interviews. No further themes were added to the framework during the subsequent analysis.

Individual team members (MP, CH, LK, RF, CJ, and AMT) drafted candidate items based on a number of dimensions. Each dimension represented either one theme or subtheme from the qualitative analysis or two merged themes/subthemes. All the dimensions represented the refined conceptual framework underpinning the new measure. The candidate items were discussed in team meetings to identify and reach consensus on individual candidate items. Criteria for retaining candidate items included that they represented issues identified as important in the interviews (either to all the participants or important subgroups, such as social care users) and that they were deemed clear and easy to understand. Usually, duplicate items or those that significantly overlap (ie, represent similar underlying concepts) would also be removed in this process. However, the first draft of the questionnaire included a small number of items that were duplicates (as they were either worded positively and negatively) or that represented similar concepts. While this meant some items were very similar, it allowed pretesting differently worded items with people with LTCs in cognitive interviews.

Ethical approval

For the primary care participants, ethical approval was obtained through the National Research Ethics Service Committee London – Bromley. Ethical approval for the schizophrenia study had been gained through the East of Scotland Research Ethics Service. All participants signed an informed consent form.

Results

Participants

A total of 48 people with LTCs (42 recruited through primary care and six through the schizophrenia study) were interviewed (Tables 3 and S1 for details on participants). Participants reported a wide range of LTCs, in addition to the index LTC. Information on the use of social care was only available for the participants recruited through primary care, as the schizophrenia study did not directly ask about this.

The overarching concepts and themes

Following the analysis, three overarching organizing concepts were identified to focus thinking about the emerging patterns of data in relation to living with LTCs: impact of LTC(s), experiences of services and support, and self-care. The three overarching concepts contained 22 themes; 16 themes were analyzed at this level only, and six themes contained 17 subthemes (Table 4). Impact of LTC(s) encompassed the largest range of themes with 15 themes, experience of services and support included four themes, and self-care was composed of three themes. The majority of the participants discussed aspects of each of the three overarching concepts.

Impact of LTC(s)

Participants described how their lives had been affected by their LTCs (Table 4). This included such issues as impact on day-to-day activities, emotional or mental well-being, and social participation, mentioned by more than 75% of

Table 3 Characteristics of interview participants

	Primary care recruitment	Schizophrenia study
Number of interviews	42	6
Sex	22 men, 20 women	Four men, two women
Age range (years)	30–97	29–60
Ethnicity	36 white British or Irish. Also one white European, one Egyptian, four South Asian	Four white British, one white European, one black British
LTCs		
Single morbidity (n)	18	3
Multimorbidity (n)	24 (range 2–8 LTCs)	3 (range 2–4 LTCs)
Participants per LTC determining recruitment (n)	COPD (three), diabetes (14), IHD (six), cancer (five), depression (three), schizophrenia (zero), stroke/TIA (five), IBD (four), MS (seven), OA (ten)	A type of schizophrenia (six)
All other LTCs reported	Agoraphobia, asthma, bipolar disorder, borderline personality disorder, chronic kidney disease, chronic back pain/sciatica, chronic renal failure, chronic skin condition, diverticulitis, gout, hearing loss, heart failure, epilepsy, dyslexia, hypertension, hypothyroidism or other thyroid condition, neurofibromatosis type 1, peripheral vascular disease, psoriatic arthritis, psychosis (drug-induced), spinal stenosis, and visual loss	Anxiety, spinal stenosis, depression, breast cancer, and long-term hepatitis C
Social care use	Seven with some form of social care experience	Participants were not asked about use of social care

Abbreviations: LTCs, long-term conditions; COPD, chronic obstructive pulmonary disease; IHD, ischemic heart disease; TIA, transient ischemic attack; IBD, inflammatory bowel disease; MS, multiple sclerosis; OA, osteoarthritis.

Table 4 The three main overarching concepts, with their themes (•) and subthemes (○) identified within the interviews

Impact of the LTC(s)	Experience of services and support	Self-care
• Achieving personal goals • Health status • Impact on day-to-day activities • Impact on emotional or mental well-being • Impact on family or carer • (In)dependence ○ Independence ○ Dependence/sense of being a burden • Loneliness • Physical activity • Roles and responsibilities • Safe environment • Social participation and involvement • Stigma ○ Self-perception ○ Social stigma • Suitability of home • Temporal awareness of LTC(s) • Worry about staying well in the future	• Burden of care ○ Burden of services ○ Burden of treatment • Experiences of services ○ Sense of being (un)supported by services ○ Dignity ○ Level of expertise of services ○ Pressure on services ○ Use of private health care • Involvement in health decisions • Social support	• Coping with LTC(s) ○ Through planning or adjusting to LTC(s) ○ Reprioritization in light of LTC(s) • Empowerment • Self-management in relation to LTC(s) ○ Confidence to self-manage ○ Desire to self-manage ○ Knowledge and/or information to manage LTC(s) ○ Skills to manage LTC(s)

Abbreviation: LTCs, long-term conditions.

participants, to such themes as impact on family or carers and loneliness, discussed by fewer than 35% of participants (Table 5).

A 64-year-old woman with COPD, stroke, arthritis, agoraphobia, depression, IHD, gout, and stenosis of the spine described the impact of her LTC(s) on her physical health and daily activities:

> [...] 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 [...] so I can't do that [...]. I'll cook with a microwave, but I can't prepare vegetables, but I can cook, but I can't hold hot saucepans, and hot things, so 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 [...].

The ability to achieve personal goals was discussed by over half of the participants. Personal goals could relate to anything that participants valued; however, mostly it centered on work and family, but could also focus on the ability to look after pets or keep up with hobbies or physical activity.

Table 5 Themes, subthemes, numbers, and rank of interviews endorsing theme

Theme	Subtheme	Schizophrenia (n=6)	LTC (n=42)	Total (n=48)	Rank
Experiences of services	**Sense of being (un)supported by services**	**6**	**41**	**47**	**1**
Impact on day-to-day activities		**5**	**41**	**46**	**2**
Social support		**6**	**38**	**44**	**3**
Social participation and involvement		**6**	**37**	**43**	**4**
Impact on emotional or mental well-being		**6**	**36**	**42**	**5**
Coping with LTC(s)		**5**	**35**	**40**	**6**
Self-management	**Knowledge and/or information to manage LTC(s)**	**4**	**36**	**40**	**6**
Burden of care	**Treatment burden**	**6**	**32**	**38**	**8**
Achieving personal goals		**6**	**30**	**36**	**9**
Self-management	Skills to manage LTC(s)	3	32	35	10
Empowerment: a sense of control over one's daily life		**5**	**28**	**33**	**11**
Self-management	Desire to self-manage	2	30	32	12
Physical activity		**2**	**28**	**30**	**13**
Self-management	**Confidence to manage LTC(s)**	**3**	**26**	**29**	**14**
Burden of care	**Service burden**	**3**	**25**	**28**	**15**
Stigma	**Social stigma**	**5**	**22**	**27**	**16**
Roles and responsibility		**2**	**25**	**27**	**16**
(In)dependence	Independence	2	25	27	16
Stigma	Self-perception	4	19	23	19
Health-status ratings		2	21	23	19
Experience of services	Level of expertise from services	3	19	22	21
Coping with LTC(s)	Coping through planning or adjusting way of living	3	18	21	22
Worry about staying well in future		2	17	19	23
Experience of services	**Dignity (how you are treated by services)**	**1**	**17**	**18**	**24**
Safe environment		**3**	**15**	**18**	**24**
(In)dependence	**Dependence or being a burden**	**1**	**16**	**17**	**26**
Involvement in health decisions		4	13	17	26
Impact on family or carer		2	13	15	28
Suitability of home		**0**	**15**	**15**	**28**
Self-management (especially relating to LTC[s])		1	13	14	30
Temporal awareness of LTC(s)		1	13	14	30
Loneliness		**0**	**12**	**12**	**32**
Experience of services	Services as pressured – sense of responsibility	2	9	11	33
Experience of services	Using private health care – reasons	0	11	11	33
Coping with LTC(s)	Reprioritization in light of LTC(s)	2	8	10	35

Note: Themes/subthemes in bold were considered for item development.
Abbreviation: LTCs, long-term conditions.

A 58-year-old woman explained how schizophrenia impacted on her work:

> [...] I have a degree in psychology, I am a qualified counselor; I wanted to become an analyst. I mean, my career: every time I had a breakdown, it falls apart [...].

Maintenance of independence or becoming dependent formed a significant part of the impact of LTC(s). A 65-year-old woman with MS explained how a parking permit for disabled drivers helped her keep mobile and independent:

> [...] I have a condition which is incurable, and in general what happens is you just get worse until you end up in a wheelchair, so I mean obviously my priority is keeping mobile, keeping independent, so independence and mobility is what would be my aim [...]. I think I'm independent, but frankly my blue badge is important to me for independence [...].

Experiences of services and support

In this concept, participants described the types of health and/or social care services they had used, their various types of support, and the burden caused by the services and care needed to manage their LTC(s). Support included help given by people or organizations outside health and social services, such as family members, friends or charities. The most frequently discussed themes (by over 75% of participants) were support by either services or others, and burden of treatment (Table 5). A 77-year-old man with IHD explained how hospital appointments could be difficult to manage:

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

In contrast, a 69-year-old man with cancer had found the input by health services helpful:

> [...] impressed with the health service. One of the things that's difficult I personally think is, like most others I suspect, it's difficult to get a GP appointment when you actually want one, but I think once you've been identified as having something they have to treat, or believe that they will be able to help with treatment, I have to say I haven't looked back. The treatment and care and the response I get from even the GP, I was transformed by that [...].

Additionally, as to whether services provide adequate support, participants also talked about how they were treated by health care professionals. A 66-year-old woman with cancer and IBD talked about contrasting experiences when consulting different doctors:

> [...] there was only the two main doctors: the first one [doctor], he seemed very abrupt, very "doctorerfied" if that makes sense, whereas the other one was very casual in his mannerisms, and you felt you could talk to him [...].

However, it is not only health services that provide support. The importance of social support is explained by a 35-year-old male with IBD and chronic renal failure:

> [...] we travel a lot. That's partly because actually my wife forces me to, or has forced me to, and now I do it a lot more, and I enjoy it and I get a lot out of it. One role of the partner I think is potentially quite interesting: you know, I've had some amazing travel experiences over the last 4 years, partly because I'm with somebody I don't worry as much about what might happen if I were ill and I was away, and also she absorbs [...] quite a lot of my angst, so that enables me to do those things [...].

Self-care

Self-care focused on actions or strategies that participants used to look after themselves and their LTC(s) or strategies to cope with their LTC(s). This included both active strategies, such as planning around the LTC(s), or passive strategies, such as acceptance of their limitations and reframing priorities. The most widely discussed theme (by over 75% of participants) was coping with LTC(s). Self-care had the potential to influence positively or negatively the impact of LTC(s). Participants differed in the extent to which they felt able to take positive actions, such as adopting healthier behaviors. There was also a time impact, with participants discussing variations in how well they could self-care during different time periods. When participants struggled with self-care, other problems could occur or the impact of LTC(s) could increase, or worsen the impact of the LTC(s), as explained by a 31-year-old man with depression and medication-induced psychosis:

> [...] I've still got depression, I fight every day, I do fight it every day, but before where I'd let it sort of overtake me [...]. I could sit indoors for 2 weeks. I think there was about a time of 2–3 months where I was going to bed at 12 o'clock in the day and sleeping until 9 o'clock at night and then I'd wake up, and I'd sit the whole night like just watching TV, and all I'd eat was a bowl of Weetabix. I went down to 9 stone, I looked anorexic, and it just spiraled out of control [...].

A certain degree of own judgment and flexibility was often needed to find the best way to deal with the LTC(s). A 68-year-old woman described how she adapted to cope with the dietary changes needed to manage her diabetes:

> [...] Initially I had to reeducate myself diet-wise [...] by nature I have a very bad sweet tooth, so I had to restrict my intake of sweets. But otherwise it wasn't [...] but I'm somebody [that] once I know I have to do something, I condition my mind and just get on with it [...].

Acceptance of LTC(s), and the limitations this might impose, was explained by a 72-year-old man with four different morbidities, including diabetes and arthritis:

> [...] I've had these various problems, starting with polio and asthma when I was very young. I've missed a fair bit of schooling through the polio, you just get sort of used to it,

> and you get one more thing to put up with and you get on with it. There's no point in sitting around: you've got to make the best of things and you know, and fight back basically […].

Item development

As it is the intention to develop a short measure for LTCs, it was not feasible to include items for each theme or subtheme from the interviews, although the three organizing concepts are represented in the items. Twenty themes or subthemes were taken into account in item development. These 20 themes or subthemes mostly ranked highly in terms of the number of interviews in which they were discussed. The lowest level of analysis was used for the ranking, meaning 18 themes and 17 subthemes. The 20 themes/subthemes selected for item development are highlighted in bold in Table 5, and they underpinned 17 dimensions (some themes collapsed for item development, eg, "Impact on day-to-day activities" and "Impact on emotional or mental well-being" were collapsed into "Impact of LTCs") that were used to develop items (Table 6). The dimensions, representing the refined conceptual

Table 6 LTCQ dimensions, qualitative themes, and illustrative quotes

Impact of LTCs		
LTCQ dimensions	**Definition (coding framework)**	**Examples from the qualitative interviews**
Achieving personal goals	Any personal goals (ie, something participants talk about valuing or wishing they could do) and how LTC(s) impact on ability to achieve personal goals or how goals have changed due to the LTC(s)	"[...]. The arthritis, yes, it does, at the moment, with the damp weather and things. I'm waiting for a knee replacement, and my knee is giving me so much [...] restricting my movement quite a bit. I'm in quite a bit of agony and it restricts my movement, which is annoying me, because I'm not someone who can sit for long periods doing nothing, but this is forcing me to do that, which I really am not enjoying at all [...]." [68-year-old woman with diabetes and psoriatic arthritis] "[...]. I want to be able to carry on walking the dogs properly and we have – believe it not – there's a swimming pool out there. I'd like to be able to keep swimming, because that's such good exercise [...]." [54-year-old woman with MS]
Dependence and being a burden	Feelings of being too dependent on others for basic or other needs, eg, feeling like a burden, unhappiness about having to rely on others, future fears of dependence	"[...]. Pretty much I look after myself. I do all my own cooking and stuff, so I manage the diabetes, nobody else gets involved with that. I do all the injections and put all my tablets out, and so I do all that myself [...]." [59-year-old man with diabetes] "[...]. It's just been the same. I don't think anything's really changed, except for the fact that as time goes by I seem to get less and less independent [...]. I've been used to being independent, and losing that independence has been the hardest thing in the world [...]." [64-year-old woman with MS, arthritis, stroke, and problems with vision] "[...]. As long as I live, I want to be fairly healthy for them [family], so I'm not a burden [...]." [76-year-old woman with COPD, asthma, OA, diverticulitis, and depression] "[...] we have done holidays with friends, and you just feel very conscious that if I'm there, I'm restricting what they can all do. It's not just me, it affects everybody else [...] you know we're aware that all the others are thinking that they'd like to go off and see this thing, or do that thing, and you tend to really hold back and try and persuade – 'Just go, don't worry about us going, you do it' – you know, and I feel hard done by, but I don't want to put the extra burden on other people [...]." [55-year-old woman with MS]
Impact of LTC(s)	Impact LTC(s) have on ability to complete day-to-day activities (like cooking, cleaning, work, self-care, looking after family/pets) and impact on emotional health and mental state, including LTCs causing anxiety/worry, feeling depressed as a result of LTCs, difficulties concentrating, etc.	"[...]. [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 IBD (ulcerative colitis)] "[...]. I do arrow words and crosswords just to keep my brain going, because I've got this stupid memory that drives me absolutely silly, and I keep thinking, 'Well, I don't know, as long as do things like that, it'll keep my brain moving', and I do tend to do a lot of those. It makes me relax, to be quite honest, because I used to be really, really fit, really, really busy, you know, I never had time to sit around or anything, but now I'm stuck because I've got all this time and I don't really want it, so I've got to fill it in or else I get depressed [...]." [64-year-old woman with COPD, stroke, arthritis, agoraphobia, depression, IHD, gout, and stenosis of the spine] "[...] perhaps when I was at university, various things where I was convinced that I really wasn't, you know, I was the lowest of the low, and I had absolutely no self-esteem whatsoever and I couldn't believe it if, you know, a bloke chatted me up, I thought he was only after my good-looking friend, or whatever, and times when I've, you know, just been convinced that people have only sort of put up with having me around for one reason or another, rather than actually being genuine friends, and I look back on that and think, 'Well, yeah, that's [...] you were depressed at that point' [...]." [44-year-old woman with depression and OA]

Impact of LTCs

LTCQ dimensions	Definition (coding framework)	Examples from the qualitative interviews
Loneliness	Perceptions of whether social contact is adequate or potential loneliness as a result of LTC(s), worries about loneliness and the impact of LTCs on social contact and loneliness	"[...]. I'm very lucky, I say, in having [neighbor] next door to me. That's because there is nobody else up here that could be the same as him next door, you know, where I can go in, have a little chat, discuss what's in the paper, and that sort of thing, and that, believe me, is a big thing when you're stuck up here all day long [...]." [97-year-old woman with OA, hypertension, hearing loss, chronic back pain, knee replacement, and sciatica] "[...]. It's quite funny, really. And if it wasn't for my son visiting twice a day, and my dog and my cat, there'd be nothing in my life, really, you'd just be sitting here looking out the window or watching the television, and that'd be it [...]." [64-year-old woman with MS, arthritis, stroke, and problems with vision] "[...] I must admit I am quite, um, content with my own company when I'm not doing anything [...]. But I do like company from time to time [...]." [45-year-old man with paranoid schizophrenia, anxiety, depression, and spinal stenosis]
Physical activity	Impact of LTC(s) on physical activity levels; this might overlap with impact on day-to day-activities, as these often require physical activity, but additionally includes exercise as a physical activity undertaken for health or leisure purposes	"[...] I have a friend who lives very high up and there are no lifts. There's 84 steps, and it's just too much for me, I am out of breath at the top of that. Steep hills are a bit of a problem [...]." [76-year-old woman with COPD, asthma, OA, diverticulitis, and depression] "[...] I used to walk miles. I ended up walking with the aid of a stick, but before that I could walk miles. I think it sort of descended on me suddenly, and I don't know why, and I couldn't walk without the aid of a stick or a frame, and that reduced my activity right down [...]." [87-year-old man with cancer and chronic skin condition] "[...] 'cos you feel like you want to do some exercise, just to keep some sort of fitness, but because of the fatigue side of things, it just took over too much of life, because I would do the gym, then come home, be completely wiped out, couldn't do anything [...] so [gym] three times [a week]. I think the MS physio, I think she said she thought that was too much, so I've cut it down now to once a week, and that's only about half an hour, which half of me thinks, 'Is there any point me doing that?', 'cos it's such a tiny thing, I sort of half feel it's not worth doing [...]." [55-year-old woman with MS]
Roles and responsibilities	Impact of LTC(s) on a person's ability to undertake valued social roles and where LTC(s) affects their ability to take on or fulfill responsibilities, eg, parenting, family duties, work, or community responsibilities	"[...] I didn't want to leave work, but since 2007 I've just not been well, one thing after another, and I just had to give up my job, which wasn't great for me, because I loved my job [...]. Loved it, really loved it, but then I started to get sick, this, that, and the other, and in the end it wasn't fair on them and it wasn't fair on me. So my husband's struggling a bit, so I thought, 'No, this has got to stop', so I was of retirement age anyway, well nearly, so, you know, I just had to bite the bullet, as you do [...]." [64-year-old woman with COPD, stroke, arthritis, agoraphobia, depression, IHD, gout, and stenosis of the spine] "[...] I have to take the wife to do the shopping. I can't go in with her because it's too far to walk, you know, so I have to sit in the car, and I can't take the dogs round the park anymore, that upsets me quite a bit [...]." [70-year-old man with diabetes, OA, stroke, angina, hypertension, and cancer]
Safe environment	The extent to which people feel safe or unsafe in relation to inside and outside their home, in particular when this is health-related, eg, falls in the home; from a social services perspective, people may also feel unsafe for other reasons, eg, fear of abuse, crime, etc	"[...] I've slowly but surely got worse over the years, my walking is a joke. I can't [...] I do go out, but I'm very nervous the whole time, because this foot goes out to the side and I've got no muscles to keep it over [...]. I've not got the freedom I used to have, because I'm scared to go out on my own now. I have to go out, thank goodness, because I've got [dog] to walk in the mornings, and my son comes in, takes him out at night for a long run, but I've found I need to keep my head up and look where I want to go, because if I look down or look around, I can get dizzy and lose where I am [...]." [64 year old woman with MS, arthritis, stroke, and problems with vision] "[...] I had had a fall down these three steps, and I couldn't get to my phone. I had to loaf around on the floor all night. I got to the fridge, I got a pint of milk out of there, and I waited for the paperboy to come in the morning [...]." [88-year-old man with diabetes, COPD, OA, and hypertension] "[...]. [It] depends where you live, doesn't it? I feel quite safe round here. I know it's a bad area, but it's what I'm used to. I would feel less safe in somewhere like somewhere posh, because of people's attitudes [...]." [49-year-old woman with diabetes, borderline personality disorder, and sciatica]

(*Continued*)

Table 6 (*Continued*)

Impact of LTCs		
LTCQ dimensions	**Definition (coding framework)**	**Examples from the qualitative interviews**
Social participation	Social activities and any social involvement that people value that are negatively or positively affected by LTC(s), eg, family-related activities, activities with friends, and voluntary activities or work-related activities that are valued for the social aspect	"[...] I guess I could be a bit more sociable sometimes, but half the times I don't know if I can really [...] if I'm really in the mood to do anything [...]." [29-year-old woman with paranoid schizophrenia and depression] "[...] I also meet up with a group of people that have MS. They meet up once a month in the evening, go have dinner [...] [husband] said he'd rather stick his head in the sand, pretend it wasn't happening, whereas I just wanted to just meet other people, and my sister said, 'Trust you to make it a social occasion' [laughs] [...]." [45-year-old woman with MS] "[...]. The people I know and socialize with know that I have a limitation, and they take that into consideration. Sometimes it's forgotten, but I'll do things at my own pace. We go out once a month, a group of lads from the village here, go out on a beer and curry night, into [...] We take in our local pub, then we have a coach take us into [city] [...] there is a bit of walking once the coach has dropped us off. There was one particular evening, where the walk was a bit further and I was struggling. So we got a taxi, it was called a police car [laughs], took me to the curry house. It took a bit of explaining to get it done, but they did get it done, because I can take that lightheartedly, but I would have got there anyway, but it would have taken just another 10–15 minutes for me to get there. I wouldn't have tried to keep up with people, that's the key. If we're out walking, I will do it at my pace, and if I need to rest, I'll rest. Therefore, I won't let it get too uncomfortable. I can feel it coming on, and just slow down, take a rest, as I need to [...]." [59-year-old man with diabetes, arthritis, and circulatory problems]
Stigma	Negative judgments or worries about negative judgments upon a person by virtue of LTCs including internal (people view themselves less positively or negatively) and external stigma (perceived negatively by other people)	"[...]. Everybody started talking about me, saying rumors, and saying I was thick, and, you know, sort of saying I was bent and all that sort of thing; and then I got a complex about myself [...]." [45-year-old man with paranoid schizophrenia, anxiety, depression, and spinal stenosis] "[...] there's things sort of like when you have questionnaires to do with mortgage and whatever, life insurance, and when you're talking to a financial advisor, they go, 'Oh, yeah, we've just got the quick questionnaire to do, and, you know, obviously you've never suffered from this, this, this, and this', and you say, 'Well, actually yeah, I'm on antidepressants 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] "[...] I don't feel that stigma. I think, 'Well, that's your problem if you think you know that I'm different' [...]. Just to give you an anecdote, when I was first diagnosed with MS, I went to [...] announce it to my parents, and when I said, 'I've been diagnosed with MS' and explained what it meant, my father's reaction was, 'Don't you find that very embarrassing?' And I thought, 'No, I don't', and I've never found it embarrassing; I don't feel embarrassed. You know, I'm a man, I have sexual problems: do I find that embarrassing? No, it's just a fact [...]." [67-year-old man with MS]
Suitability of home	Any problems with accommodation from a health-related perspective, including any solutions that helped alleviate the problems, such as walking frames, walk-in showers etc; includes support by social services	"[...] We got an extra banister, a wall banister, going up the stair, and I tend to hold onto both when I'm going up and down. I feel going up and down is quite good for me [...]." [65-year-old woman with MS] "[...] can't go out walking with the dogs because of my legs, and there's several things I can't do, but it's a struggle sometimes to get upstairs. I've had one or two accidents because I couldn't make it upstairs quick enough [laughs]. A bit silly, but you don't really want to know about that do you [...]." [70-year-old man with diabetes, OA, stroke, angina, hypertension, and cancer] "[...] the house, I mean, I don't think it's too bad: it's clean, a bit cluttered, I suppose, with gadgets for the animals. I want to be comfortable, I'm stuck in a lot, I want to be comfortable, and I can't be any more comfortable, I don't think, and this is my cocoon, this house, 'cos I mean there's some days I just don't want to go out of it [...]." [64-year-old woman with COPD, stroke, arthritis, agoraphobia, depression, IHD, gout, and stenosis of the spine]

Experiences of services and support		
LTCQ dimensions	**Definition (coding framework)**	**Examples from the qualitative interviews**
Burden of treatment and services	Burden of treatment is whether treatment(s) creates burden or difficulties, or whether treatment(s) is easy and clear to manage; treatment(s) includes any interventions (eg, dietary, exercise, or social services) or medications Service burden refers to whether services create difficulties (eg, high frequency of consultations, expense, difficulties with access); this is specific to the process of using services, and relates to use of health, social care, and community services	"[...] I'm seen bimonthly by the renal team at [hospital], so I'm in hospital as an outpatient on average once a month because I go in, twice every 2 months, if you see what I mean. I'll go in once to have some blood tests and then back again a week or so later for a clinic, so that's 12 times a year. So I'm in hospital very regularly, go to my GP as needed, very regular blood tests, administration and medication that I can't give myself, I'm on a range of medication that supports both how I feel but also to keep my kidney function as good as possible, so I have to inject myself weekly with a hormone called EPO, which you probably know about, on top of the tablets, then they give me injections of the iron when needed. That's about it really [...]." [35-year-old man with IBD and chronic renal failure] "[...] I don't go to the doctors often, to be honest, but I have appointments up the [hospital] for the diabetes, every 6 months, and I go to the heart clinic once a year. That's not too bad, but it can be annoying when you have to go to the doctors, but it's not too bad [...]." [70-year-old man with diabetes, stroke, IHD, gout, and chronic back pain] "[...] It's just the side effects of it, and it's a bit, it's annoying because I have actually [...] you know, I have asked whether my medication can be changed to something completely different but they're [...] their feeling is that they don't, they think the [um], they don't think that's a very good idea. They don't think the side effects of that are severe enough for me to change [...]." [29-year-old woman with paranoid schizophrenia and depression]
Dignity	Dignity experienced within health and social care; includes how respected and valued people feel when accessing services and whether they feel treated as an individual (or not) by services	"[...] the worst thing for me was after I had my operation – this was another bug bear of mine – I was told beforehand that there were cancerous nodes, and that's why they had to be removed [...] from the day I was diagnosed, the doctor sent to me to the specialist. I was like a hamster on a wheel: I couldn't get off, you know it's going to happen, but you can't stop it [laughs], and after the operation was done, this woman came in and she pulled the curtains round me, and she said, "By the way, you're diagnosed with cancer", and she walked out and she left me with that, and for me it was just a brick that she had hit me with, and I was so angry, I really was. I saw red and afterwards I just cried and cried and cried, and when somebody asked me "Why?" and I tried to tell them, they went "What?" I said "yes". I sincerely hope and trust that they take them to task about it, because that's an awful thing to do to anybody [...]." [70-year-old woman with diabetes and thyroid problems] "[...] there was a time a little while ago when I was starting to feel really quite down by it, and I just had a great chat with my GP about it, and about what to do and you know, and possible therapy options and what we could do if things got worse, which they didn't. Yeah, they're very, very pleasant people working in an imperfect system, but they are excellent in that they understand [...]. I think they understand very well the nature of chronic conditions [...]." [35-year-old man with IBD and chronic renal failure]
Support	Any support people with LTC(s) receive or do not receive, including help by health and social services and support by significant others, such as family, friends, neighbors, work colleagues	"[...] 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] "[...] you come away from somewhere like the doctor or a consultant, and you think, 'What was the flaming point of all that?' He doesn't [...] he's [...] they're only interested in what is physically wrong, they don't want to probe what impact it's had on you [...]." [64-year-old woman with MS, arthritis, stroke, and problems with vision] "[...]. There's some people who know about the chinks in my armor, and that's fine, and strangely enough I was with one yesterday afternoon, who I hadn't seen for a while, because we used to sit next to each other when we worked [together] [...]. She knew, just by my mood, if there was something [...] if my blood sugars were dropping or if there was something wrong and she would say, 'Have you checked your blood sugar?', and I actually said to her yesterday how I miss that so much, but she just knew by how I was what was going on, but, you know, we don't work together anymore, and it was funny, at the time, I kept saying, 'Oh, [name], don't fuss', but I realize I did really appreciate that a lot [...]." [58-year-old woman with diabetes and asthma]

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Table 6 (*Continued*)

Self-care		
LTCQ dimensions	**Definition (coding framework)**	**Examples from the qualitative interviews**
Coping	Any tactics or methods used to cope with LTC(s), such as accepting the LTC(s) or finding different ways of doing things; can include problems or difficulties that lead to people not coping with LTC(s) and emotional responses to LTC(s), eg, feeling overwhelmed or frustrated	"[...] do I regret the things I can't do? No, I just can't do them, so, you know, even if I hadn't had MS, I would never have been able to climb mountains. Do I regret I can't climb mountains? No, I just can't do them, so I apply that to other things, you know, I'm getting older, I've lost all my youth, do I regret losing all of my youth? No, not really. Things just move on, and I cope with what I've got [...]." [33-year-old woman with IBD (ulcerative colitis)] "[...] I stay on these tablets I'm on. They tried me to go back on some others that are not so potent, but every time I take them I get the diarrhea, so I had to stop taking them [...] you do live in a little bit of a fear of you might go to the toilet any time of the day, and I don't wear pads very often now. I chance it and hope for the best, but I do wear them occasionally if I'm going to go on a long journey, like I went on holiday, and yes I wore when, when I was on the plane, well you think, 'I could get stuck on the plane' [...]. I always carry pads and cleaning stuff with me, all the time, because I never know when I might just suddenly go, and I need to clean myself up and I have been caught out when I've been on walks, along the sea coast and things, I've got caught out and had to find a loo, and change my knickers or chuck my knickers away, and put new ones on: catches you out, you know. I live with it. I don't say it's good, but I live with it at the moment [...]." [66-year-old woman with IBD (ulcerative colitis) and cancer]
Empowerment/ sense of control	Feeling empowered and in control and the process of being enabled to be in control of life through support and help by treatments, services, and other people	"[...] I'm in control of everything, completely, not just my life, a lot of the people around me will come to me for advice and steer them [...]." [59-year-old man with type 2 diabetes] "[...] 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, and whether it is for other people, but for me it's 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 IHD]
Information and knowledge	The resources people have or need to understand and manage their LTC(s)	"[...] access to better information. I think that's something the NHS tends to neglect. The GPs tend to have information that they impart, when they want to impart to you when you're, you know, in your 10-minute consultation you get [very little] information during that time. Sometimes, they give you some articles they get off the web, they print out for you, but generally speaking, that sort of level of information is fine, but I tend to want more information [...]." [71-year-old man with diabetes and cancer] "[...] I think a lot of people find it difficult to find out information from social services, about what they're entitled to, rather than what they can get, but what they are 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] "[...] you've got a colitis [society] that you can join. I think it's a booklet they send you, every so often, and you can read about other people, or you can go to meetings and meet people. I'm not saying you do, but you can. There are obviously associations around, where you can go and talk about your problems, or what's going on in your life, and you get these books, and they tell you about it, and the hospital gives you three or four booklets when you come out, that tells you sort of about it, and tries to describe what's it like and what it's not like [...]." [66-year-old woman with IBD (ulcerative colitis) and cancer]
Confidence to manage LTC(s)	Confidence or a lack of confidence (could be anxiety or feeling overwhelmed or confused) to manage LTC(s) and/or any treatments and/or any medications in relation to their LTC(s)	"[...] it's really down to the person at the end of the day. You can be talking to goodness knows how many people about how you're feeling and this, that, and the other, but really and truly if you're not really ready to make a change or you're not well enough to make a change or whatever, nothing [...] it's not going to make no difference [...]" [29-year-old woman with paranoid schizophrenia and depression] "[...] I increased my walking, and sometimes I think, 'Cut down on the sweets', 'Cut down on the sugar', and things like that, you know. But apart from that, some time I find that I need a bit of sugar, my body will ask, and then I say, 'Well, why did I do that?', and then when you do it, then you find that and you know that your level was going low, or whatever. You become a doctor for yourself [...]." [75-year-old man with IHD] "[...] I believe I manage my diabetes 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 [...]." [59-year-old man with diabetes, arthritis, and circulatory problems]

Abbreviations: LTC, long-term condition; LTCQ, Long-Term Conditions Questionnaire; MS, multiple sclerosis; COPD, chronic obstructive pulmonary disease; OA, osteoarthritis; IHD, ischemic heart disease; EPO, erythropoietin; IBD, inflammatory bowel disease; NHS, National Health Service; GP, general practitioner.

framework on which item development was based, are defined in Table 6, together with further illustrative quotes from the interviews. Themes that ranked less highly either significantly overlapped (ie, represented a similar underlying concept) with a more highly ranked theme (such as loneliness overlapping with social participation) or they were considered important for less represented groups in the sample. In line with the aim to develop a short measure, a small number of items (one to three) were developed per dimension to give a total of 23 initial items. These 23 items will undergo cognitive testing in further interviews with people with LTCs.

Discussion

The aim of this study was to develop a measure for LTCs. The aim of this new PROM is to be relevant to adults with single or multiple LTCs (both physical and mental health conditions) and is intended for use at both an individual and a population-based level across all health and social care services. This qualitative study served to refine further the conceptual framework that was initially developed on the basis of literature reviews and stakeholder interviews. The use of in-depth qualitative interviews serves to enhance content validity of a newly developed measure.[25]

The in-depth interviews identified outcomes of importance to people with single and multiple morbidities. Due to the sampling strategies, the ten preselected LTCs were more commonly represented, but 23 additional morbidities were reported by the participants. The ten LTCs were chosen on the basis of their diversity, and together with other reported morbidities, a good spread of LTCs was reported by the 48 participants. The interviews generated rich data on a wide range of issues of importance to outcomes in LTC(s). These themes and subthemes formed three concepts: impact of LTC(s), experiences of services and support, and self-care.

Many of the themes, in particular those coded in "Impact of LTC(s)", resonate with those that are often included in PROMs;[26] however, some themes, such as self-management, empowerment, experiences of services, suitability of housing, or safety, may be explored less frequently as part of a PROM. These latter outcomes represent outcomes of care, rather than the more traditional outcomes of the condition or disease, but they are nonetheless important in LTCs. Also, these are frequently assessed by patient self-report, eg, self-management can be assessed by the Self-Management Ability Scale (SMAS)-30 questionnaire.[27] Empowerment, on the other hand, is still considered ill-defined, and the need for a specific PROM to assess empowerment has been identified.[28] Some would argue that experience of services is a process, not an outcome; however, recently it is becoming more widely recognized that health care and treatment, in particular in multimorbidity, can place a burden on people.[29] Therefore, as the new measure intends to cover a broad range of issues of relevance in potentially very diverse LTCs, these issues have been included in the item development. The majority of themes/subthemes that underpinned item development ranked highly in terms of the number of participants who discussed them. There were some exceptions, eg, loneliness, safety, and suitability of housing, were talked about by fewer participants. However, these are considered important, either due to their impact on LTCs or due to their relevance to specific groups of people with LTCs. For example, such issues as suitability of housing and safety are of high importance for social care recipients, as demonstrated by the fact that such items are included in the Adult Social Care Outcomes Toolkit (ASCOT).[30] Therefore, items based on these themes were also developed for the Long-Term Conditions Questionnaire (LTCQ).

While some PROMs, such as the SMAS-30 or the ASCOT, give scope to assess specific outcomes (self-management and outcomes in social care, respectively) in more depth, the ambition of the new measure is to be short and practical while assessing issues of importance in a wide range of LTCs. If outcomes in LTCs are to be assessed within clinical care or on a routine basis, it would not be practical if multiple different tools needed to be used with the same patient and across health and social care services. The items developed for the measure include less traditional but important outcomes. It is hoped that this approach will result in making the LTCQ a measure that is practical for use in the context of clinical care and routine PROM data collection. The candidate items for the new measure will be pretested in cognitive interviews before a large-scale survey is conducted to test the psychometric properties of the measure.

Some limitations of the study need to be acknowledged. First, although the sample included participants with a wide range of LTCs, there were proportionally fewer participants with mental health problems and few participants with experience of social care. This was not unexpected, as they represent smaller groups of people. In the process of selecting themes and refining the conceptual framework, it was ensured that themes that were valued by participants who were less represented were not excluded on the basis that they were not discussed by the majority of the participants. Also, the mental health sample was supplemented by interviews from a study on outcomes in schizophrenia, as no patient with schizophrenia invited through primary care agreed to participate. Although the method of recruitment and interview-topic guides differed between the two studies, many issues of importance (eg, treatment burden) overlapped with those reported in the primary care sample, as shown in Table 5. Also, plans for future testing will aim to include larger samples of people with mental health conditions and social care experience. A second limitation might be that a single method of data collection was used. Differences may have been found through using focus groups, although the extensive literature searches and stakeholder consultations give confidence that the main issues of importance for LTCs have been covered. A final limitation may be that LTCs were self-reported, even though participants were selected by GP practices on the basis of a formal diagnosis of a specific LTC. Participants may not have reported all their LTC(s), and issues of importance in relation to these would not have been discussed. Nevertheless, a wide range of LTCs has been included, and thematic saturation was achieved in the interviews. This gives confidence that the main issues of LTCs have been included, and that the resulting measure will have wide relevance.

Conclusion

This article describes the development of items for a new PROM for LTCs. On the basis of previously published interviews with stakeholders, literature reviews, and in-depth qualitative interviews, a conceptual framework was developed and refined. This framework served to develop 23 items to form the first draft of the new PROM. These items will be pretested in cognitive interviews to make any necessary amendments to ensure its relevance and validity before the new PROM – the LTCQ – is administered to a larger sample of people with LTCs in a survey to test its psychometric properties.

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Author contributions

RF, MP, CJ, AC, and JF conceived the study. CP, LK, and CH conducted and analyzed the qualitative interviews. CA developed and tested the search strategy for identifying eligible participants. MP led the writing of the manuscript, with the contribution of all other authors. All authors contributed toward data analysis, drafting and critically revising the paper, gave final approval of the version to be published, and agree to be accountable for all aspects of the work.

Disclosure

The authors report no conflicts of interest in this work. The views expressed in this paper are those of the authors, and not necessarily those of the National Health Service, the NIHR, or the Department of Health.

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Supplementary material

Table S1 LTCQ interview participants

Sex	Age, years	Ethnicity	LTCs	Social care
Male	69	White British	Cancer – lymphoma	Did not report using social care
Male	71	White British	Diabetes type 2, cancer – chronic lymphatic leukemia	Did not report using social care
Female	80	White British	OA, hypothyroidism, and hiatus hernia	Uses day center
Male	88	White British	Diabetes, COPD, OA, and hypertension	Did not report using social care
Male	87	White British	Cancer and chronic skin condition	In private care home
Female	54	White British	Multiple sclerosis	Did not report using social care
Male	69	White British	Stroke/TIA and epilepsy	Did not report using social care
Female	70	White Irish	Diabetes and thyroid condition	Did not report using social care
Female	44	White British	Depression and OA	Did not report using social care
Female	97	White British	OA, hypertension, hearing loss, chronic back pain, knee replacement, and sciatica	In private care home
Male	59	White British	Diabetes type 2	Did not report using social care
Female	76	White British	COPD, asthma, OA, and diverticulitis	Did not report using social care
Female	66	White European	MS	Did not report using social care
Male	35	White British	IBD and chronic renal failure	Did not report using social care
Female	33	Egyptian	IBD – ulcerative colitis	Did not report using social care
Female	64	White British	MS (possibly polio secondary effects), arthritis, stroke, and vision problems	Son as carer
Male	75	South Asian	IHD (angina, stent)	Did not report using social care
Female	58	South Asian	Diabetes, heart failure, and chronic kidney disease	Did not report using social care
Male	80	South Asian	Diabetes type 2 and IHD	Did not report using social care
Female	49	White British	Diabetes type 2, borderline personality disorder, and sciatica	Yes, she cares for daughter
Male	51	White British	Crohn's (IBD)	Did not report using social care
Male	61	White British	MS	Did not report using social care
Male	70	White British	Diabetes, OA, stroke, angina, hypertension, and cancer	Did not report using social care
Male	65	White British	Diabetes type 2	Did not report using social care
Female	55	White British	MS	Receives benefits
Male	70	White British	Diabetes type 2, stroke, IHD (angina), gout, and chronic back pain	Did not report using social care
Male	72	White British	Arthritis, asthma, diabetes, and polio-related issues	Did not report using social care
Male	77	White British	IHD (heart attack, angina)	Did not report using social care
Male	67	White British	MS	Did not report using social care
Female	64	White British	COPD, stroke, arthritis, agoraphobia, depression, IHD (atrial fibrillation), gout, and stenosis of spine	Did not report using social care
Female	58	Not confirmed – on phone	Diabetes type 1 and asthma	Did not report using social care
Female	66	White British	IBD (ulcerative colitis) and cancer	Did not report using social care
Male	69	White British	IHD (angina, triple bypass)	Did not report using social care
Female	65	White	MS	Did not report using social care
Female	43	White	Bipolar disorder	Day center
Male	59	White British	Diabetes, arthritis, and circulatory problems	Did not report using social care
Female	68	South Asian	Diabetes type 2 and arthritis – psoriatic	Did not report using social care
Male	59	White British	Neurofibromatosis type 1 and dyslexia	Did not report using social care
Female	45	White British	MS	Did not report using social care
Female	69	White British	MS	Did not report using social care
Male	30	Not confirmed	MS	Did not report using social care
Male	31	White British	Depression and drug-induced psychosis	Did not report using social care

Sex	Age	Ethnicity	LTCs	Social care
Schizophrenia study participants				
Male	45	White British	Paranoid schizophrenia, anxiety, depression, and spinal stenosis	Did not report using social care
Female	29	Black British	Paranoid schizophrenia and depression	Did not report using social care
Female	58	White European	Paranoid schizophrenia, breast cancer, and long-term hepatitis C	Did not report using social care
Male	36	White British	Schizophrenia (paranoid psychosis)	Did not report using social care
Male	60	White British	Paranoid schizophrenia	Did not report using social care
Male	30s	White British	Schizophrenia	Did not report using social care

Abbreviations: LTC, long-term condition; LTCQ, Long-Term Conditions Questionnaire; COPD, chronic obstructive pulmonary disease; TIA, transient ischemic attack; IBD, inflammatory bowel disease; IHD, ischemic heart disease; MS, multiple sclerosis; OA, osteoarthritis.