Title Page

Title: 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

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Title: 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

Abstract

Objectives: To explore the views of a range of stakeholders regarding whether patient-reported outcome measures (PROMs) can be developed to measure key attributes of long-term conditions (LTCs) care in England, and the potential value of a single generic measure.

Design: Qualitative semi-structured interview study, analysed using a framework approach

Participants and Setting: Interviews with 31 stakeholders from primary care, secondary care, social care, policy and patient-focused voluntary organisations in England.

Results: There was broad support for a single PROM that could be used to measure outcomes for patients with any LTCs in any health or social care setting. Interviewees identified three desired uses for a PROM: to improve the quality of individual care; to increase people's engagement in their own care; and to monitor the performance of services. Interviewees felt that a PROM for LTCs should incorporate a mixture of traditional and non-traditional domains, such as functioning, empowerment, and social participation, and be co-designed with patients and professional end-users. Stakeholders emphasised the need for a PROM to be feasible for practical implementation at the individual clinical level as a first priority. A number of concerns and potential problems were identified in relation to the application and interpretation of an LTC PROM.

Conclusions: This study has demonstrated support for a single self-report outcome measure that reflects the priorities of people with LTCs, if such a measure can be shown to be meaningful and useful at the individual level. People with LTCs and professional end-users in health and social care should be involved in the development and evaluation of such a measure.

Article Summary

Strengths and Limitations

- This study incorporates a wide range of perspectives on the potential value of a PROM for LTCs from across health, social care and voluntary organisations, and from managerial, policy and front-line levels.
- The findings offer support for the idea of a single measure that can work across LTCs and be used to improve care for people with LTCs.
- Several domains were identified for an LTC PROM, including traditional domains such as quality of life, functioning and social participation, and less traditional domains such as empowerment and support from services.
- A limitation of the study is that it focused on health and social care context in England; however, the issues identified are likely to be applicable across countries.
- To establish an effective and meaningful PROM for LTCs will require further work with end-users to identify key domains and test their applicability within specific health and social care settings.

Introduction

Long-term conditions (LTCs) pose an enormous challenge to healthcare systems because of their prevalence and complexity, exacerbated by an increase in the number of people living with multi-morbidities [1, 2]. It is argued that the scale of this challenge requires major system-level changes [3]. Greater patient engagement, improved self-management support, and individualised care are seen as key elements in policies designed to improve care for LTCs [4-9].

Patient reported outcome measures (PROMs) have been proposed as a technology that may strengthen patient engagement and enable individualisation of care [10]. PROMs were initially developed to enable outcome measurement in clinical trials to take account of people's subjective health status and health-related quality of life [11]. Disease-specific and generic PROMs exist for use with people with LTCs, and these offer different benefits and limitations. For instance, disease-specific PROMs tend to be more sensitive to change, but can only be used in a specific population. In order to compare across LTCs, or capture outcomes for multiple LTCs, a generic PROM would be required but might be less relatable to patients' specific needs and contexts due its broad scope [10]. More recently their use has been promoted and evaluated for other contexts and applications. At the individual level, PROMs have been promoted as a means of improving communication between patients and healthcare professionals; assessing effectiveness of treatments; influencing clinical management; enhancing patient involvement, health behaviours, and satisfaction with services; and improving detection and monitoring of symptoms [11-15]. Results to date have been mixed; whilst patients and practitioners tend to respond positively to the idea of PROMs, the impact of PROMs on clinical practice has been equivocal [16, 17].

An alternative role for PROMs is in providing aggregated evidence of the performance and quality of services [18]. Several healthcare systems worldwide have implemented the routine collection of PROM data, one example being the English National Health Service (NHS) which has collected data before and after elective surgeries since 2009 [19-22]. Studies have demonstrated that collecting PROM data in this way is feasible, and extending the routine collection of PROM data to LTCs has been advocated [21-23]. However, the issue of using PROMs to evaluate service performance in relation to LTCs is challenging [24], and evidence for the impact of PROMs on service improvement is weak [16, 17, 25, 26]. In England, the standardised health status measure EQ-5D has been included in an annual population-based survey of primary care (the GP Patient Survey) and a primary care pilot study to assess feasibility of regular monitoring of health-related quality of life in people with LTCs [23, 27]. Response rates have been low for these surveys [23, 28], and the pilot study raised questions about the suitability of the EQ-5D to detect change in LTCs within the primary care population over time [29]. Studies suggest that further work is needed to determine how to collect PROM data most effectively, and how to ensure implementation of PROM data for service improvement purposes.

A further challenge in relation to PROMs for LTCs is whether PROMs can usefully contribute to the integration of health and social care services. LTCs are most common in the ageing population, where needs often extend beyond the medical [30, 31]. Social care in the UK refers to a range of care activities oriented around providing for people's basic daily needs (such as dressing and feeding), as well as their social and emotional needs [32]. Those with complex needs are most likely to experience fragmentation, poorer quality of services, and poorer health outcomes [33-37]. It is argued that integration can improve the quality of care by reducing fragmentation, facilitating a more patient centred approach to care, and improving access and communication across services [38]. Whether a PROM can inform and contribute to integration is open for debate.

Despite limited evidence of the impact of PROMs either at the individual or aggregate and system level, considerable interest exists in their potential to positively impact on the quality of LTC care [10, 13]. Previous research has highlighted the importance of stakeholder engagement when designing and implementing PROMs, yet no studies to date have examined the views of the range of stakeholders potentially involved in integrated LTC care. We therefore undertook a study of stakeholders from health, social care and community services to determine their views on the likely value of a PROM designed specifically for use with people with LTCs. Below, we have used the

term “patient” to refer to people with an LTC accessing any service, and the term “PROMs” to refer to self-report measures for use by people with LTCs across the health and social care system.

Methods

We conducted semi-structured qualitative interviews with stakeholders in health, social care and community services, including commissioners, policy makers, service providers, health and social care services managers, front-line clinicians and patient-focused voluntary organisations.

The semi-structured topic guide was informed by current literature on PROMs, in particular healthcare and social care policy documents [4-9, 31, 39]. It was co-developed by the authors, who have extensive experience of developing and working with PROMs. Questions focused on the participant’s current role and interests regarding PROMs and LTCs; uses for an LTC PROM; settings for the use of an LTC PROM; users and beneficiaries of PROMs and PROM data; concerns around and issues with the use of an LTC PROM and PROM data; and suggestions of PROM content relevant to LTCs in health and social care. Participants were initially asked an open question about potential PROM content, followed by prompts to consider particular areas.

Participants were recruited through a combination of purposive and snowball sampling. The interviewers (ASD and CH) contacted people who were known to have an interest in LTCs and/or PROMs. Interviewees often referred the interviewers to other relevant stakeholders. Interviews were audio-recorded following informed consent, and transcribed verbatim by a professional transcriber. Data collection continued until saturation of themes relevant to a PROM for LTCs had been reached.

Initial thematic analysis was iteratively carried out during data collection, and was used to develop a thematic framework (see box 1); QSR NVivo 10 was used to manage data and complete the analyses using a framework approach [40]. The analyses were led by CH. ASD, RF and MP analysed a sub-set of transcripts to confirm the main themes (ASD and MP reviewed 5; RF 6 transcripts). Themes were discussed and refined within the research team.

Ethical approval was granted by the Central University Research Ethics Committee (CUREC) at the University of Oxford (Reference Number: MSD-IDREC-C1-2013-206, 2 December 2013).

Results

Sample Characteristics

Twenty-nine interviews were completed, with 31 participants (see table 1). Two interviews were joint interviews, involving two participants. All but two interviews were completed by telephone; these two interviews were conducted face-to-face. Interviews lasted on average 40 minutes (range: 10-79 minutes).

All front-line clinicians had direct experience of working with people with LTCs, but typically had limited experience of using PROMs in practice or in research. Those with a policy or commissioning role had more extensive knowledge of PROMs, in that they tended to be aware of the literature around PROMs and have experience of using and/or reviewing PROMs. The voluntary organisation participants worked with different groups, including people with cancer, mental health problems, multiple LTCs, and social care needs. The level of knowledge and experience of PROMs in this group tended to be quite high, with participants talking about the use of specific PROMs within their organisations, the rationale behind this use, and knowledge of the literature around PROMs. Participants from social care were knowledgeable about PROMs due to their inclusion in annual

social care surveys, but were less used to categorising service users by diagnostic labels, as people are usually identified by need rather than diagnosis in social care practice.

Findings

We report findings under three main themes, as identified through thematic analysis of the transcripts, and utilised in the thematic framework (box 1). The sub-themes highlight the most salient issues and areas of variation across stakeholders.

Theme 1: Uses and Users of an LTC PROM

Participants talked about several uses that they foresaw or desired for an LTC PROM, including using a PROM to: improve care through informing the re-design of services; improve care through influencing the conversation between patient and practitioner; promote patient involvement in their own care; and monitor the outcomes of interventions. Participants debated whether it would be possible to use the same PROM to achieve multiple purposes. Underlying the proposed uses was a consensus that LTC care needs to be re-oriented to prioritise a holistic and patient-driven approach to care, that aims to support people to maintain a desired level of functioning and quality of life and enable people to manage their own LTCs independently (box 2).

1.1 A Tool for Improving Care - through re-designed services

One of the main uses proposed for an LTC PROM was that it could be used to monitor services and align different providers to the same outcomes. The idea underlying this use was that re-designing and incentivising services to achieve the same outcomes would: promote integration by encouraging a sense of shared responsibility across services; reduce duplication and fragmentation of effort; and enable more effective patient-driven care. The content of the LTC PROM would thus represent shared outcomes across services, and PROM data would be used to measure success towards achieving these outcomes.

Multiple users were envisaged for data generated in this manner. Interviewees felt that this could be an important source of data to inform commissioning and service provision decisions, and to hold providers to account for achieving valued outcomes. It was also felt that this use could inform practice at the individual level.

1.2 A Tool for Improving Care - through informing patient-practitioner conversation

Most participants saw a PROM as a tool that could be used at the level of the patient-practitioner interaction. The PROM would be used to open up a conversation about outcomes and needs, and then inform health and/or care decisions. In this use, both patient and practitioner were envisaged as active participants in decision-making and in performing actions arising from the conversation. It was also felt that using an explicit tool such as a PROM to guide the conversation would enhance concordance regarding decisions made.

This was envisaged as an activity that could fit into routine reviews in social care or primary care. This use was felt by some to constitute an intervention, as it would shift the focus of care by virtue of asking holistic questions about LTCs. Interviewees suggested that a PROM would help to capture the patient's perspective quickly and effectively.

1.3 A Means of Involving Patients in their own Care

The use of a PROM to enable the active involvement of patients in their own care was strongly supported by the majority of participants, but some participants were uncertain around how best to achieve this type of involvement.

It was felt that a PROM could facilitate patient empowerment, as it would encourage patients to reflect on their progress and receive information back on how they were doing in comparison to others and with their own previous scores. Feeding information into services about their outcomes could also enable patients to shape and affect service provision. Similar to 1.2, it was argued that this use could be linked to a regular event, like routine reviews, but there was also a contingent who argued that patients might want the flexibility to use an LTC PROM at any desired time.

1.4 Capturing the Outcomes of Interventions

A significant number of participants (n=14) argued that PROM use should be linked to specific services or interventions for patients, so that before-after PROM scores could be captured. This differed from other proposed uses by positioning the PROM as a measurement tool rather than a form of intervention in and of itself.

Whilst some suggested that an LTC PROM could be employed to capture the outcomes of any identifiable intervention or treatment change, most participants who suggested this use specifically recommended linking the PROM to care planning. As care planning explicitly aims to involve patients in their care decisions, a PROM was argued to be a useful complementary tool for enabling involvement (by asking patients to reflect on their conditions), and for tracking the success of care planning (by recording progress in terms of outcomes).

1.5 Using a PROM for multiple purposes

Typically, both front-line clinicians and those with a commissioning and/or policy role wanted a PROM to work on the individual and aggregate level, but front-line clinicians most strongly advocated individual use. Only one regulator (P14) and one public health commissioner (P18) solely advocated PROM use at the aggregate level.

The ideal promoted by most participants was that the PROM should be feasible and useful at the individual level first and foremost, with any aggregate use being an additional benefit. Focusing on the individual level meant that stakeholders prioritised the usability of the PROM for individuals engaged in managing care (patients and practitioners) over its broader applicability. Participants indicated that they would prefer a PROM if it could both inform individual care and help improve services in general.

Theme 2: Concerns around PROM use and implementation

Despite strong support for the notion of an LTC PROM, there were a number of concerns about its feasibility and practical application. The three main concerns are outlined below (see also box 3). These concerns revolved around how to ensure that meaningful PROM data could be collected and shared efficiently (themes 2.1 and 2.2), and how to ensure that PROM data is used in intended and appropriate ways (theme 2.3). These concerns reflected general agreement that an LTC PROM would be valuable if implemented and interpreted carefully.

2.1 PROM implementation: Engaging patients and practitioners

Participants stressed that both patient and practitioner needed to perceive the value of a PROM and feel some ownership over the process of using PROM data. It was felt that an LTC PROM would need to be implemented in the context of a collaborative, person-centred relationship between patient and practitioner, in order to produce useful data for patients, practitioners and services.

Several interviewees (n=12) pointed to cultural barriers in current practices that did not necessarily support working with patients in a person-centred way, for instance, a focus on biomedical indicators in primary care reviews, or a need to financially ration services. Another potential barrier was pre-

existing expectations within the patient-practitioner relationship. Interviewees felt that patients might feel uncomfortable criticising services directly or be concerned about how their answers would influence future access to services. Similarly, concerns were raised that practitioners would find it difficult to modify their practice to treat patients as equal partners in decision-making. However, it was believed that an LTC PROM as a tool could help to promote a more person-centred mode of practice, by bringing in an explicit focus on measuring what matters to the patient and facilitating joint decision-making based on PROM data.

Another challenge participants perceived was balancing the priorities and needs of the different stakeholders when implementing a PROM in practice. They argued that care needed to be more person-centred, and hoped that a PROM would help, but worried about how to resolve differences between what patients prioritised and what practitioners prioritised.

2.2 PROM implementation: Divisions across services

In line with current policy intentions, participants were keen on the idea of a measure that might aid greater integration across all health and social care services. However, they foresaw difficulties related to data sharing across services, where traditional division of responsibilities could create barriers. It was felt that practitioners could be reluctant to work outside the boundaries of their current role, due to pressure around achieving service-specific targets. Interviewees felt that services needed to be shifted towards more integrated modes of working, and that a shared outcome measure could form part of this shift, but that without systemic support, integrated working would struggle.

2.3 PROM use: Interpretability and Usability of PROM data

Related to the issue of engagement, participants talked about the need for a clear set of principles or standards for analysing, interpreting and using PROM data. Interviewees were concerned that PROM data would not influence practice or commissioning decisions if the means to interpret the data were not transparent and agreed upon by stakeholders.

Participants also worried about PROM data being misunderstood, over-interpreted or used inappropriately. They argued that PROM data should be contextualised and carefully interpreted in light of the purpose for collecting the data and the circumstances of collection.

Interviewees made two suggestions on how to ensure the interpretability and usability of PROM data. The first one was to link the PROM to measuring outcomes for a specific intervention; the second to focus on ensuring usability at the clinical level for the patient and practitioner.

Theme 3: Content of an LTC PROM

Participants discussed a number of potential domains or items that should be included if a new PROM were to be developed. Key topic areas endorsed by participants are outlined in boxes 4 and 5 and are described below.

3.1 Shared outcomes across LTCs

Participants suggested a PROM for LTCs that would focus on traditional health-related outcomes, such as quality of life, mental wellbeing and physical functioning, with the inclusion of less traditional outcomes such as empowerment and social participation.

The majority endorsed domains that capture the role of the patient in managing their own LTC(s) and the role of services in enabling or supporting self-management. This was variously described as ‘empowerment’, ‘activation’, ‘supported self-management’, ‘self-control’, ‘self-reliance’, ‘knowledge, skills and confidence to manage’, ‘being a partner in their care’, ‘feeling informed and

in control' and 'control over daily life' (see box 5 for examples). Across health and social care settings, interviewees stressed the importance of supporting people to develop their knowledge, ability, and confidence in managing their own health.

Most participants felt that similarities in the management goals for different LTCs outweighed the differences. Similarly, interviewees tended to agree that a shared measure across health and social care services was viable, if the content was generated in collaboration with patients and practitioners.

3.2 The place of Process/Experience domains

Participants were divided over the extent to which people's experience of using services should be included in an LTC PROM. Some saw experience of services as another form of outcome; others saw it as an important part of the process that could influence outcomes, but as an outcome in its own right. Some participants felt that incorporating experience-related items could lead to the PROM being used to meet performance targets.

What most people agreed on was that there were important experience domains (such as access to services, information, and care coordination) that need to be measured in some way as part of improving commissioning and provision of care. Some participants argued that combining experience and outcome measurement would aid integration into practice and ensure a measure was more meaningful to patients.

In general, it was felt that experience-related domains could be part of an LTC PROM so long as they mattered to patients, and the context of data collection was taken into consideration when designing and implementing the PROM.

3.3 Importance of stakeholder involvement in PROM design

Whilst participants endorsed a number of topic areas as relevant for LTCs, they unanimously agreed that patients and practitioners needed to be involved in determining which domains should be included. Participants also agreed that both patients and practitioners should be involved in decision-making around how to implement and use an LTC PROM.

Interviewees were clear that an LTC PROM should be designed in collaboration with its end-users (especially people with LTCs and frontline practitioners), to ensure that it captures the domains they value, and that it is feasible and acceptable for use.

Discussion

This study incorporates perspectives on the value of an LTC PROM from health, social care and voluntary organisations, and managerial, policy and front-line levels. We found broad support for the idea of a PROM that could be used by people with a wide range of LTCs in various settings. Stakeholders particularly identified three main uses for an LTC PROM: to inform individual care; to encourage patient involvement in their own care; and to monitor and evaluate services based on shared outcomes. Whilst the focus of this study was on the health and social care system in England, the issues discussed are likely to apply to other contexts and countries facing the challenge of improving LTC care [7-9].

Use at the individual level was prioritised over use to inform population-level service monitoring. Most PROMs have been designed to work at an aggregate rather than individual level, and can be of limited value for individual level use [41]. Developing and validating an instrument for use at the individual level will be challenging, as the measure will need to be more precise to capture meaningful change at an individual level [42]. It is worth noting that whilst application at the

individual level was preferred, most interviewees still desired a PROM that would enable comparisons across groups, rather than a completely personalised measure [43].

Stakeholders endorsed a broad range of both traditional and non-traditional domains, such as functioning, quality of life, empowerment, social participation, the experience of services and feeling supported by services. These domains reflected a shared understanding of the direction in which LTC care needs to move, i.e. towards person-centred care, a holistic and integrated approach to patient needs, and greater patient involvement in care decisions and support for self-management. The unanimous insistence that patients and front-line practitioners be involved in designing the content of an LTC PROM also reflected the emphasis on greater patient involvement in LTC care.

Interviewees highlighted concerns and challenges that reiterate findings in previous studies with primary and secondary care clinicians [44-46]. Concerns revolved around the feasibility of implementing a PROM in routine care, particularly in relation to administration, interpretation and application. It was acknowledged that a PROM could not only measure and record outcomes but also be used as a mechanism to change the focus, content, and process of LTC care.

Implementing a PROM in any setting is not simple; it could be more accurately described as a complex intervention [47]. Attempts to implement PROMs in clinical practice have achieved mixed results, with factors at all stages impacting on success [14, 16, 25, 26, 45, 48, 49]. Collecting local or national PROM data is feasible; achieving changes based on these data has been less successful [19, 21]. Two interlinked issues need to be addressed in order to achieve successful implementation and use of an LTC PROM.

First, given the scope of topics suggested for an LTC PROM, further research will be required to design a measure that can succinctly capture key shared outcomes across LTCs. Interviewees stressed the importance of determining PROM content with PROM end-users – this would require engaging patients using health and/or social care, identifying and engaging specific services in which the PROM would be used, and engaging practitioners who may use PROM data. Establishing PROM content and purpose/s for specific contexts would best work in tandem, and would inform practical and methodological decisions around modes of data collection, analysis and feedback [50]. One potential purpose identified in the study was to develop a PROM as a mechanism for engaging patients in self-monitoring outcomes as identified through care planning [51]. The feasibility of engaging patients in using PROMs to guide their own care will need investigation; though patients tend to be positive about PROMs, few studies have explored actively involving patients in interpreting and using PROM data [13].

Second, organisational and cultural barriers will be significant challenges. In order to implement an LTC PROM, organisational support for the process of collecting, analysing, and using these data needs to be established [52]. PROM programmes such as WestChronic in Denmark have achieved success due to the principle behind PROMs being supported at an organisational level, demonstrated through integration of PROMs into the clinical infrastructure. Hjollund et al argue that this is more likely to be achieved if data can be used at both the individual and organisational level [22]. In addition, a significant factor in integrating PROM data into practice is the cultural value attached to the patient-centred approach [22, 52]. A combination of education, engagement, and mutual negotiation with practitioners, alongside organisational support, is likely to be needed in order to demonstrate the value of the patient-centred approach, and the value of PROMs as a patient-centred tool that can complement existing practice [53].

This suggests an approach that incorporates a rigorous development of content involving all the potential end-users of the PROM, including patients [54], with an equally rigorous understanding and evaluation of the contexts for use [55] and the potential mechanisms for change [12, 13]. This is likely to require an iterative process of development and theory-driven implementation, working closely with front-line practitioners and patients, and using mixed methods research to evaluate the context, process and outcomes of PROM use [12, 15, 56-59]. Clearly an essential first step would be to define meaningful outcomes for LTCs with patients, and establish ways in which they would value using and sharing this information.

Conclusion

Stakeholders from a range of backgrounds in health, social care and voluntary organisations were supportive of a PROM that would work across LTCs, and valued the idea of a PROM that could be used to improve care at the individual clinical level. Stakeholders endorsed an LTC PROM that captured both traditional and non-traditional domains, such as functioning, quality of life, empowerment and social participation, and recommended that patients were involved in its design. In order to achieve the goals outlined by stakeholders, designing and implementing an LTC PROM will require engaging the potential end-users of the PROM and the organisations within which the PROM will be used.

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Table 1: Summary of Participants

Job Role		No. Participants With Job Role
NHS Policy and Commissioning		4
Health and Social Care Service Regulator		1
Front-line Clinician	GP	4
	Nurse Practitioner	1
	Psychiatrist	1
	GP Commissioner	3
	Consultant Physician	2
Social Care Services Manager		3
Voluntary Organisation		6
Healthcare Service Provider		3
Clinical Commissioning Group Non-Clinical Members		2
Public Health Commissioning		2
Patient and Public Involvement Representative		1
Total No. Participants Interviewed (NB: Two participants held more than one job role, and are counted twice in the table, but once in the total)		**31**

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