

ENABLING AND SUPPORTING PEOPLE TO LIVE WITH LONG-TERM CONDITIONS: QUALITATIVE AND CONCEPTUAL DEVELOPMENT OF A PATIENT-REPORTED OUTCOME MEASURE (PRO)

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BACKGROUND

- Providers of health and social care are keen to improve services to achieve better outcomes for long-term conditions (LTCs).
- A PRO could be an essential tool in the adaptation of services to this end.
- This research aimed to develop a conceptual framework for a PRO that would be valid and acceptable across LTCs, and useful across health and social care.

METHODS

Conceptual Literature Reviews on:

- Condition-specific and generic PROs for LTCs
- Relevant outcome domains for LTCs
- Use of PROs in health and social care settings

Semi-structured interviews with 31 stakeholders in health and social care

Interviews were audio-recorded with consent, transcribed verbatim and analysed using a framework approach in QSR NVivo 10.

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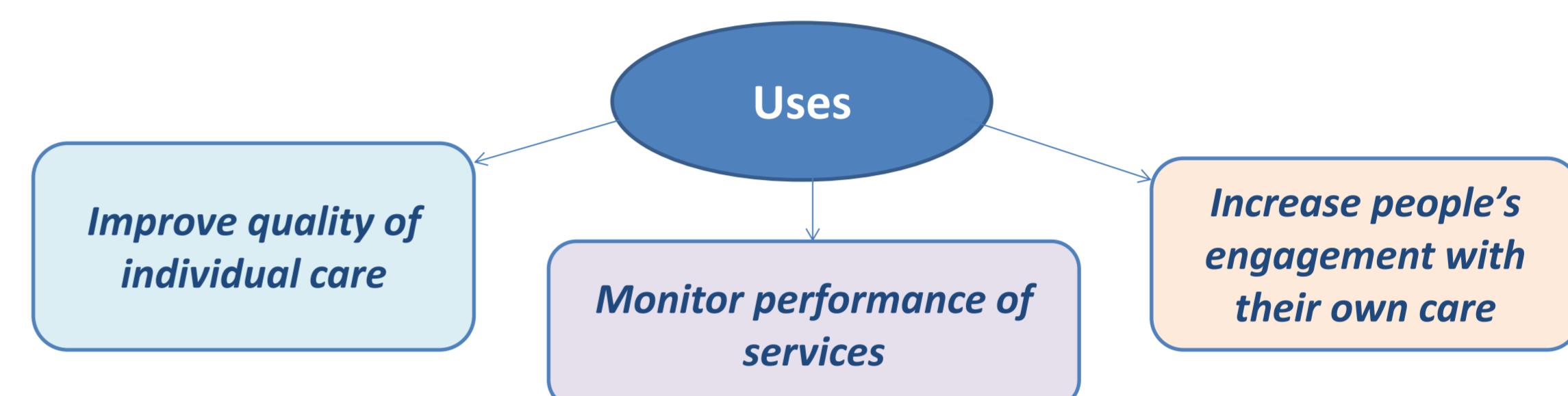
RESULTS

Summary of Literature Reviews	
1.	LTC PROs focus on functioning, with emphasis on physical functioning
2.	Domains of potential relevance, but rarely measured, included: empowerment; social participation; control of daily life; activities of daily living; treatment burden; health literacy
3.	Uses of PROs in practice have focused on identifying and monitoring problems, and rarely involved patients in receiving feedback or guiding care decisions

Stakeholder Interview Themes

USES FOR AN LTC PRO

Stakeholders prioritised three potential uses for an LTC PRO



Stakeholders prioritised the idea of a PRO that works to improve individual care over aggregate-level uses, but most stakeholders desired a measure that could work on both levels.

DOMAINS FOR AN LTC

Key domains endorsed by stakeholders were:

- 1) Empowerment
- 2) Quality of Life
- 3) Patient-specific or personalised goals
- 4) Functioning
- 5) Social Participation
- 6) Psychological wellbeing
- 7) Symptoms
- 8) Experience of services

Shared nature of LTC outcomes

"We think that actually most people with long term conditions have eighty percent of their support needs as being general, not condition specific"
 (Participant from NHS Policy and Commissioning)

Stakeholders suggested a model for a PRO that captured shared outcomes from across the bio-psychosocial spectrum, and that included a way to measure patient empowerment and support for LTCs.

CONCERNs

Feasibility of using a PRO for multiple purposes

"There needs to be a set of principles [for PROs]"
 (Participant working in regulation)

"It's difficult because clinicians will want different information to commissioners and (...) to patients"
 (Participant from NHS Policy and Commissioning)

Ensuring engagement with PRO in practice

"Part of the buy-in is to get the patients to take control of it and feel like it's useful to them first "
 (General Practitioner)

"[Clinicians] need to feel ownership of the measures they use"
 (Participant from Voluntary Organisation)

IMPLICATIONS

- A PRO that is relevant across conditions and reflects a bio-psychosocial approach to LTC management would be considered useful by stakeholders.
- Including people with LTCs in design, use and interpretation of a PRO was desired.
- The next stage will involve in-depth interviews with a diverse sample of people with LTCs to determine potential domains and item content for an LTC PROM.
- The feasibility of combining multiple uses in a single PRO for LTCs will require further research and rigorous testing in practice.