PATIENT-REPORTED OUTCOME MEASURES FOR LONG-TERM CONDITIONS: CONCEPTUAL REVIEW AND STAKEHOLDER CONSULTATION

Cheryl Hunter, Michele Peters, Anne-Sophie Darlington, Julien Forder, Angela Coulter, Crispin Jenkinson, Ray Fitzpatrick

Email: cheryl.hunter@dph.ox.ac.uk; ltc-prom@dph.ox.ac.uk

BACKGROUND

- Over 15 million people in England live with at least one long-term condition (LTC).

- It is a central priority of the UK government to assess and improve outcomes in LTCs.

- Patient-reported outcome measures (PROMs) could be a method to aid health and social care services in assessing outcomes in LTCs.

- This research aimed to investigate the uses and potential content for a PROM for LTCs.

METHODS

Conceptual Literature Reviews on:
1) Condition-specific and generic PROMs for LTCs
2) Relevant outcome domains for LTCs
3) Use of PROMs in health and social care

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.

DISCLAIMER AND ACKNOWLEDGEMENTS

RESULTS

Conceptual Literature Review Findings Summary

1. PROMs for LTCs predominantly focus on functioning, with emphasis on physical functioning
2. Social functioning and mental wellbeing are less common, and mental wellbeing is often interpreted as symptoms
3. Domains of potential relevance, but rarely measured, included: empowerment; social participation; control of daily life; activities of daily living; treatment burden; health literacy
4. Uses of PROMs in practice have focused on identifying and monitoring problems, but rarely involved patients in receiving feedback or guiding care decisions

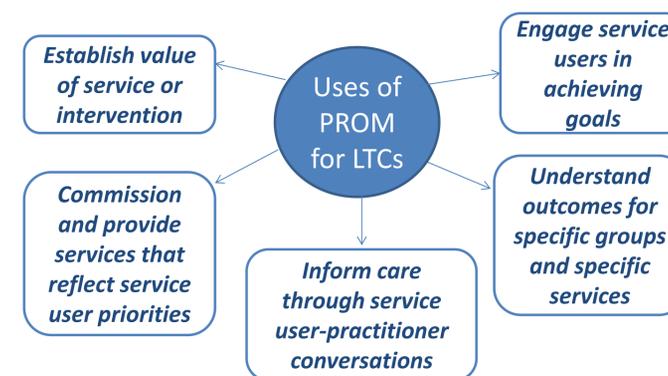### Table 1: Stakeholder Interviewee Characteristics

Job Role		No.
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
Charity/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. People		**31**
(NB: Two participants held more than one job role)		

Stakeholder Interview Themes

Uses of a PROM for LTCs

Stakeholders mentioned a variety of potential uses for PROMs in the context of LTCs

Uses of PROM for LTCs:
- Establish value of service or intervention
- Engage service users in achieving goals
- Commission and provide services that reflect service user priorities
- Understand outcomes for specific groups and specific services
- Inform care through service user-practitioner conversations

Most stakeholders firmly held that a PROM for LTCs should work at the individual level and be meaningful to service users and front-line practitioners first and foremost. Other uses, such as for quality improvement or commissioning, were considered important but secondary to this goal:

> *if it's something that's getting the patient to reflect back on their life, then it becomes something much more useful to me as a clinician if it's being used to open up a conversation and as part of clinical practice (GP)*

> *Its effectiveness and its spread would depend on (…) having a clear kind of frontline validity and purpose and being successfully adopted [in practice] because of that, and then built into local scorecards or dashboards (…) by professionals collaborating together with commissioners (Charity)*

Content of a PROM

Stakeholders espoused a holistic bio-psychosocial concept of LTCs and felt that a PROM should use a broad understanding of functioning (including physical, psychological and social).

> *I think a reported outcome measure covering that totality of the individual's experience is really key (Regulator)*

> *I think you have to have a mixture of social and medical. We absolutely have to get rid of… (…) measuring health or measuring social stuff (Consultant Physician)*

Stakeholders also argued that empowerment, or patient activation, needed to be incorporated as an important domain:

> *we need to build a more nuanced framework that takes into account the personal goals and the empowerment of the individual as well (NHS Policy & Commissioning)*

Capturing the interaction between service users and the service was also valued:

> *[for a PROM] there's something about some symptoms, there's something about how people support you in managing those symptoms and there's something about how you're able to get on with your normal life (Healthcare Provider)*

All stakeholders emphasised the importance of PROM content being driven by service users.

> *I would hope that any PROM development is done (…) including clinicians, but also including the patients who are experts in their own ways (NHS Policy & Commissioning)*

IMPLICATIONS

- A PROM for LTCs which incorporates domains beyond those traditionally included would be valuable to services.
- Stakeholders were keen that the PROM works at the individual management level, and that service users are involved in the development of the PROM.
- The next stage will involve in-depth interviews with a diverse sample of individuals with LTCs to determine potential domains and item content for an LTC PROM.
- The feasibility of combining multiple uses in a single PROM for LTCs will require further research and rigorous testing in practice.