

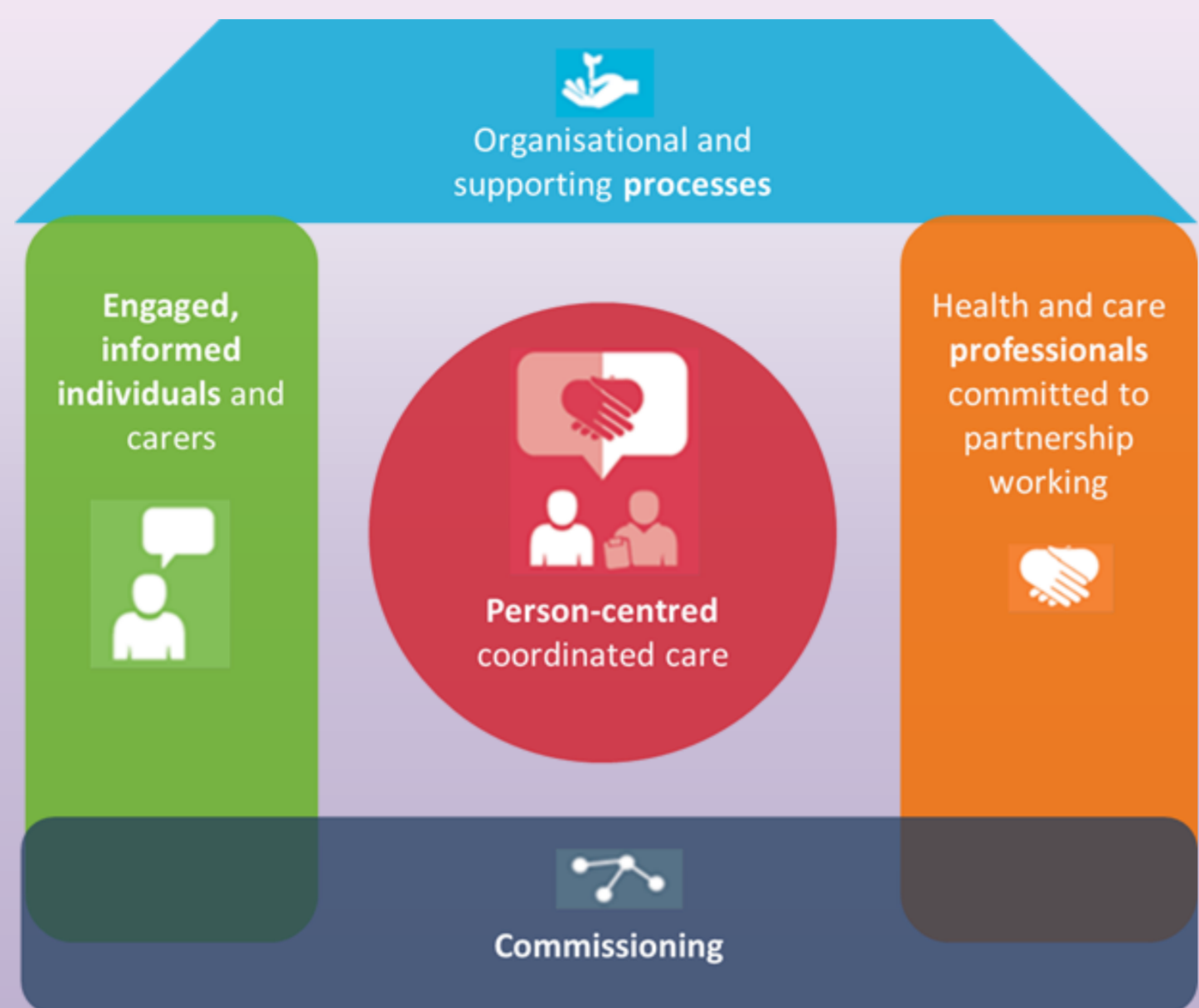
PROs for personalized care: patient perspectives on potential use of the Long-Term Conditions Questionnaire (LTCQ) in clinical practice

Caroline Potter,^{1*} Cheryl Hunter,^{1,4} Laura Kelly,¹ Elizabeth Gibbons,¹
Angela Coulter,¹ Julien Forder,^{2,3} Ray Fitzpatrick,¹ Michele Peters¹

1. Health Services Research Unit, University of Oxford 2. Personal Social Services Research Unit, University of Kent 3. The London School of Economics and Political Science 4. Academic Unit of Primary Care, University of Leeds
*correspondence: caroline.potter@dph.ox.ac.uk

Background

- High burden and increasing complexity of long-term health conditions (LTCs)
- The UK Government and England's National Health Service are committed to outcomes-focused service delivery for LTCs (Domain 2, NHS Outcomes Framework)
- The 'House of Care' model¹ encourages person-centred collaboration within the health system, but it is not clear how the model will be applied to clinical practice.



The House of Care...could PROs open the door?

1. The King's Fund 2013, Delivering better services for people with long-term conditions: Building the House of Care.

Methods

- 1 Patients were randomly selected by eight primary care practices in southern England, on the basis of having one of ten specified LTCs
- 2 Eligibility for the study was checked by the research team when patients made contact to arrange an interview
- 3 Audio-recorded semi-structured interviews were conducted, usually at the participant's home, with 42 people living with diverse LTCs
- 4 Interviews were transcribed and analysed using an iterative coding framework (described in Peters et al. 2016²)
- 5 Data coded under the theme 'value of a long-term conditions questionnaire' were further analysed for sub-themes

2. Peters M, Potter CM, Kelly L et al. 2016, *Patient Related Outcome Measures* 7:109-125.

Encouraging self-management

"I mean it might be a useful thing to know in a broad statistical level, from the point of view of one particular patient, the doctor saying "what do you do?" I suppose *it might be a prompt for the person to think about things they can do, or it could be the start of a conversation about things that they can do maybe*, yeah, so in that way it would be useful, I mean I suppose it's good to flag up that people need to be responsible for their own health, so it's the start of that kind of conversation..."

51-year-old man, living with IBD

Prompting action

"...if I was going to fill it in, is 'how can this help me?' you know, if for example I was incredibly depressed about my condition and perhaps at risk of harm, could a survey expose that? Yes it probably could, but could action be taken off the back of it? *That's the important bit. How does it fit into the pathway?*"

35-year-old man, living with chronic renal failure and Crohn's disease

LTCQ: a door to person-centred care?

Long-Term Conditions Questionnaire (LTCQ)

This questionnaire is aimed at people with at least one long-term health condition, regardless of the level of severity of the condition.

If you have a single long-term health condition, please consider how this condition affects you.

If you have more than one long-term health condition, please consider how all of these conditions affect you.

Please think about your long-term health condition(s) over the past four weeks. How often have you...



Structuring conversation with health professionals

"And it would help the doctors as well, and the health workers, to understand the way other people live their life you know. *It's difficult to say, and I'm not very good at putting things like that into words because of my stroke you know*, sometimes it goes out of my head you know. But *anything that you can write down for helping people, it opens the door a little bit more*, for people to understand how other people live, and the way they live and the things that impact them, you know. Any bit of information is good information."

70-year-old man, living with osteoarthritis, type 2 diabetes, previous stroke, hypertension, non-Hodgkin's lymphoma, deep vein thrombosis

Coordinating services

"Well, it [holistic health review] would help with advice to yourself, I'm sure that could be the case. *So you stop seeing everything in boxes*, you know, this is your diabetes box, this is your CLL box, and never the twain shall meet. In terms of services, hopefully it might help to identify things earlier, which might reduce to the NHS in the long term, perhaps, I don't know... I mean there's an argument to say *the questionnaire you're developing might be the focus for it.*"

71-year-old man, living with diabetes and Chronic Lymphatic Leukaemia (CLL)

Results

Participants indicated that a PRO for LTCs would be most useful to them as a tool for informing individual-level care. They signalled the PRO's value as a 'conversation starter' with health and social care professionals, as a means of prompting and structuring discussion on issues that concerned them. Some participants also indicated its value for capturing changes in their health status over time, potentially opening dialogue with health professionals across multiple services about unmet need.

Conclusions

Patients' perceived value of the LTCQ aligns with aims to extend the use of patient-reported outcome measures beyond population-level monitoring, i.e. for informing individual-level care. As a PRO that taps into broad domains of living well with LTCs, the LTCQ could be used by individual patients to facilitate routine health reviews and communication across multiple services. The LTCQ could thus play a role in operationalizing current policy goals, such as enhancing personalized care planning and encouraging coordination across health and social care.

Acknowledgements: We thank the participants with long-term conditions for taking part in this study. This research was funded by the **Policy Research Programme (PRP) in the Department of Health England**, which supports the Quality and Outcomes of Person-centred Care Policy Research Unit (QORU), and by the **National Institute for Health Research (NIHR)** Collaboration for Leadership in Applied Health Research and Care (CLAHRC) Oxford at Oxford Health NHS Foundation Trust. The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health.