

## PEER REVIEW HISTORY

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### ARTICLE DETAILS

<b>TITLE (PROVISIONAL)</b>	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
<b>AUTHORS</b>	Hunter, Cheryl; Fitzpatrick, Ray; Jenkinson, Crispin; Darlington, Anne-Sophie; Coulter, Angela; Forder, Julien; Peters, Michele

### VERSION 1 - REVIEW

<b>REVIEWER</b>	Joanne Greenhalgh School of Sociology and Social Policy  Although I have not worked directly with this team, I know a couple of the authors through a shared interest in this field of research.
<b>REVIEW RETURNED</b>	08-Dec-2014

<b>GENERAL COMMENTS</b>	<p>This is an interesting, engaging and highly topical paper. It is clearly written and presented. I have a number of comments that the authors may wish to consider - these are more interesting points of discussion than essential revisions.</p> <p>1. The authors rightly highlight that developing and validating an instrument for use at the individual level will be challenging. It would be helpful to explain why this will be challenging (eg the requirement for the psychometric properties - instruments will need to be much more precise) and also to recognise that very few instruments currently exist for this purpose, most have been developed for group level differences.</p> <p>2. They also appropriately argue that the content of a measure needs to be determined alongside its intended use. I wonder if it might be helpful to explore in a little more detail what this means in practice. For example, there is a difference between using the PROM as a tool to support patient empowerment via patients monitoring their own condition - where you might envisage items focusing on the impact of their condition and its treatment on their functioning and symptoms, compared to monitoring whether they feel their care has been 'patient centred' (which some stakeholders seemed to imply in their answers) in which you would envisage items focusing more on patient experience of (patient centred) care. The challenge will be to decide whether to develop something that can do everything (with the potential risk of the measure being 'jack of all trades and master of none') or to decide that the measure should focus on meeting one of these needs and doing it very well. It is a point for both debate and empirical research which track to take and whether any of the potential risks will materialise.</p>
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<b>REVIEWER</b>	Prof Melanie Calvert
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	University of Birmingham, UK
<b>REVIEW RETURNED</b>	13-Mar-2015

<b>GENERAL COMMENTS</b>	<p>Thank you for inviting me to review this novel and timely piece of research describing stakeholder perspectives on the development of a single PRO for long-term conditions. This is a well-written article and I only have a number of minor comments.</p> <p><b>Abstract</b> The authors describe 31 participants; however there were actually 29 interviews with 29 individuals it just happened that 2 individuals had more than one role. As such I believe it would be more appropriate to say 29 participants.</p> <p><b>Introduction</b> The introduction is clearly written and well-referenced, however the authors may wish to consider adding further information to help readers less familiar with the field - namely: 1. Note the current range of disease specific measures available for LTCs but acknowledge challenges: 1) many measures have been designed for use in trials where data is used at an aggregate rather than individual level and 2) that we cannot compare across LTCs unless we use generic measures (which may lack focus on issues important to service users with LTCs). 2. Describe the role of PREMs as patient experience is discussed later.</p> <p><b>Methods</b> Again very clear although I would like to know which healthcare and social policy documents informed the topic guide – please reference. I would also like to know how many transcripts were analysed as a subset to confirm themes. I was unsure whether participants had been provided with a list of domains to endorse or whether these domains were unsolicited responses. Please clarify.</p> <p><b>Results</b> <b>Sample characteristics</b> As noted earlier the number of interviews/participants confused me initially until I saw the table footnote – please amend to 29 throughout. The authors describe participants as having ‘extensive’ or ‘high’ knowledge but how was this assessed? Please clarify.</p> <p><b>Findings</b> The authors note that the subthemes highlight the most salient issues although I would be interested to know what other issues arose. Is it possible to present additional findings – perhaps as a web-appendix?</p> <p><b>Themes</b> The themes are clear although I would like to see numbers associated with ‘a significant minority’ (page 6-line 1) and ‘several’ (page 6-line 46). It would be helpful if the authors could indicate which participants via their anonymised codes or else provide a total for each of these sections. The authors discuss the incorporation on patient experience into the LTC PROM – I would like to see this discussed further in the broader context of existing PREMs (in the discussion).</p> <p><b>Discussion</b> The authors do not have a strengths and limitations section but this</p>
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	<p>should be included. Limitations include the use of snowballing to recruit study participants – this may have resulted in participation from like-minded individuals and the relatively small samples size (data saturation may not have been reached for subgroups). Although the authors acknowledge the need for service user input into the design of the measure it is a shame that there wasn't greater representation from patients in the study – this again could be acknowledged as a limitation.</p> <p>Finally, given the current interest in PROMIS it would be good if the authors could comment on the benefits (or otherwise) of the LTC PROM in relation to this.</p> <p>Thanks again for inviting me to review this article.</p>
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### VERSION 1 – AUTHOR RESPONSE

Comments from Reviewer 1: Dr Joanne Greenhalgh

1. The authors rightly highlight that developing and validating an instrument for use at the individual level will be challenging. It would be helpful to explain why this will be challenging (eg the requirement for the psychometric properties - instruments will need to be much more precise) and also to recognise that very few instruments currently exist for this purpose, most have been developed for group level differences.

The following was added to the discussion: “Most PROMs have been designed to work at an aggregate rather than individual level, and can be of limited value for individual level use [40]. 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 [41].”

2. They also appropriately argue that the content of a measure needs to be determined alongside its intended use. I wonder if it might be helpful to explore in a little more detail what this means in practice. For example, there is a difference between using the PROM as a tool to support patient empowerment via patients monitoring their own condition - where you might envisage items focusing on the impact of their condition and its treatment on their functioning and symptoms, compared to monitoring whether they feel their care has been 'patient centred' (which some stakeholders seemed to imply in their answers) in which you would envisage items focusing more on patient experience of (patient centred) care. The challenge will be to decide whether to develop something that can do everything (with the potential risk of the measure being 'jack of all trades and master of none') or to decide that the measure should focus on meeting one of these needs and doing it very well. It is a point for both debate and empirical research which track to take and whether any of the potential risks will materialise.

Added in the following to the discussion: “One way to proceed is to adopt a user-focused approach to design: establishing and refining the content of a draft measure in consultation with patients and practitioners, making decisions as to what to include or exclude based on feasibility and the end-users' priorities for use, and finalising the measure's content and format following pilot testing in specific contexts. This process may lead to some uses being prioritised over others.”

Comments from Reviewer 2: Professor Melanie Calvert

1. Abstract

The authors describe 31 participants; however there were actually 29 interviews with 29 individuals it just happened that 2 individuals had more than one role. As such I believe it would be more appropriate to say 29 participants.

There were 29 interviews, two of which were interviews with two people, hence 31 interviewees. The number of participants in table 1 totals 33, as two participants had two distinct job roles that were counted separately. I have added a sentence into the description of method to make this clearer, and explained this in the table.

2. Note the current range of disease specific measures available for LTCs but acknowledge challenges: 1) many measures have been designed for use in trials where data is used at an aggregate rather than individual level and 2) that we cannot compare across LTCs unless we use generic measures (which may lack focus on issues important to service users with LTCs).

The following has been added in: "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]."

3. Describe the role of PREMs as patient experience is discussed later.

The following has been added to the introduction: "Alongside PROMs, there has been a rise in interest in Patient-Reported Experience Measures (PREMs) [39]. Capturing patient experience is also a priority in the UK NHS context, directed at improving the quality of care [40]. PREMs tend to be surveys that aim to capture patient experiences of care in a systematic way, although there are other methods of capturing experience that are more individualised and debates around the best ways to collect and use patient experience data [41]."

#### 4. Methods

Again very clear although I would like to know which healthcare and social policy documents informed the topic guide – please reference.

The key health and social care policy references are added in, although the work was informed by a broader review of the literature than can be indicated here.

5. I would also like to know how many transcripts were analysed as a subset to confirm themes.

The following has been added in: "ASD and MP reviewed 5; RF 6 transcripts"

6. I was unsure whether participants had been provided with a list of domains to endorse or whether these domains were unsolicited responses. Please clarify.

We have added in the following sentence to methods, to give context: "Regarding potential PROM content, participants were initially asked an open question, followed by prompts to consider particular areas, with most participants referring to existing PROMs or PREMs with which they were familiar."

#### 7. Results

##### Sample characteristics

As noted earlier the number of interviews/participants confused me initially until I saw the table footnote – please amend to 29 throughout.

See explanation under abstract (point 1 above).

8. The authors describe participants as having 'extensive' or 'high' knowledge but how was this

assessed? Please clarify.

The following was added to the methods: “Participants were recruited for their experience and expertise around LTCs and PROMs, and were asked to summarise their experience at the beginning of the interviews.”, and the section under findings has been amended to acknowledge that the source of these descriptions is the participants’ self-report of their knowledge and experience.

#### 9. Findings

The authors note that the subthemes highlight the most salient issues although I would be interested to know what other issues arose. Is it possible to present additional findings – perhaps as a web-appendix?

Other sub-themes were mentioned too infrequently to include, or fitted under the broader theme headings, and so are not included in the paper, e.g. two participants talked about “gaming” the system as a concern, but this was discussed more broadly under the “interpretability and usability of PROM data”. We have not included an additional web-appendix for this reason.

#### 10. Themes

The themes are clear although I would like to see numbers associated with ‘a significant minority’ (page 6-line 1) and ‘several’ (page 6-line 46). It would be helpful if the authors could indicate which participants via their anonymised codes or else provide a total for each of these sections.

Totals have been provided within the text as requested.

11. The authors discuss the incorporation on patient experience into the LTC PROM – I would like to see this discussed further in the broader context of existing PREMs (in the discussion).

Added in the following: “The suggestion to include particular experience domains was of note; experiences and outcomes are typically measured separately, or are measured by adding an existing PROM into an experience survey [39]. It would clearly be more efficient for services if all relevant outcomes and experience data could be gathered at the same time, as experience data could inform service quality whilst outcome data helps establish effectiveness [47]. However, outcomes and experience of services have different implications for when, where, and how to collect data, that need to be further explored.”

#### 12. Discussion

The authors do not have a strengths and limitations section but this should be included. Limitations include the use of snowballing to recruit study participants – this may have resulted in participation from like-minded individuals and the relatively small samples size (data saturation may not have been reached for subgroups).

We have added in the following limitations section to answer this point.

##### “Limitations

It is a strength of the study that it incorporated a broad range of perspectives across health and social care, but it should be acknowledged that some sub-groups were under-represented (such as practice nurses or front-line social workers). In addition, as some participants entered the study via snowball sampling technique, this may have led to a bias towards people who share similar ideas taking part. Practitioners who took part had some level of interest in PROMs and LTCs, and so may not be typical of all frontline practitioners.”

The sampling issue is also acknowledged in the strengths and limitations section at the beginning of the paper.

13. Although the authors acknowledge the need for service user input into the design of the measure it is a shame that there wasn't greater representation from patients in the study – this again could be acknowledged as a limitation.

We have added in the following sentence at the end of the limitations section: "Patients' views were not captured in this study, but will be the focus of the next phase of research".

14. Finally, given the current interest in PROMIS it would be good if the authors could comment on the benefits (or otherwise) of the LTC PROM in relation to this.

This paper describes the first exploratory phase of a research programme, and feels too soon to reflect meaningfully on the LTC PROM in relation to PROMIS. We will however keep this comparison in mind to be explored in future work.