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Title	Identifying Canadian patient-centered care measurement practices and quality indicators: a survey
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Reviewer 1	Dr. Maryam Kebbe
Institution	University of Alberta, Pediatrics, Edmonton, Alta.
General comments (author response in bold)	<p>The shift from a paternalistic approach to health care to a partnership between healthcare professionals and patients is recognized as key to effective quality of care. As follows, the authors should be applauded for conducting this important and timely research. As they state in their introduction, there is currently no consensus on evaluation measures of PCC, and their study aims to fulfill this gap. The objective was three-fold: (i) to identify whether patient-centered care (PCC) is measured in Canada, (ii) to determine which patient-centered quality indicators (PC-QI) are used, and (iii) to compare measurement practices in Canada with international healthcare systems. They used a structured survey with closed- and open-ended questions to solicit responses from corresponding stakeholders. In relation to their objectives, their data showed that (i) PCC measures inform practice, (ii) PC-QIs used focus on process and outcome (vs structure) components of a particular framework, and (iii) PCC practices in Canada were comparable to international countries. Overall, the study has numerous strengths, including its novelty, broad reach (national and international), and rigour in survey development, including adhering to CHERRIES guidelines. Some additional information/clarifications would be helpful to strengthen and better elucidate the text. Specific comments follow.</p> <p>Major comments:</p> <p>1. Title: To better reflect the objectives, may I suggest an edit to the title. For example: “A Canadian environmental scan identifying patient-centered care measurement practices and quality indicators”.</p> <p>We agree with the reviewer recommendation and have changed the title accordingly.</p> <p>2. Abstract: Nice abstract.</p> <p>Thank you.</p> <p>3. Methods: Page 5: A “Patient-Partner” is mentioned in passing for the first time. Please elaborate or preferably, have a separate section on how, if the case, the study was guided by Patient-Oriented Research.</p> <p>Our Study Patient Partner (Ms. Sandra Zelinsky, included in the acknowledgements), is involved as a Co-Investigator on our research program on developing Patient-Centred Quality Indicators. For this particular study component (environmental scan), she was involved mainly in the review and piloting of the survey, to ensure that the content incorporated the patient perspective. The extent of her participation in this study component was agreed upon by herself and the study authors. Her involvement in other study components was more prominent (assisting in conducting the grey literature review of our scoping review, reviewing tools for qualitative data collection and assisting with synthesis and interpretation of results).</p> <p>Page 5: Please elaborate on how data was captured from telephone calls. Was there a defined approach put in place to document the data?</p> <p>If contact was made through telephone, a script was in place to introduce the study to the potential participants. Following consent to respond to our survey, we would offer them two options: to respond to our survey through an emailed link, or to respond to the survey over the telephone. We added this to the methods for further clarification:</p>

“If contact was made through telephone, a script was in place to introduce the study to the potential participants. Following consent to respond to our survey, participants were asked to complete the survey through an emailed link or over the telephone with the researcher, who guided them through the questions and completed the questionnaire.”

Page 6: Nice strategy to eliminate response bias.

Thank you.

Page 6: A deductive approach was taken to analysis. Please comment on influence on methodological rigour (e.g., steering findings in a pre-defined direction).

Page 6: Content analysis was the method of choice for analysis. Please specify the steps taken based on literature recommendations for added rigor (e.g., did two independent individuals complete the analysis?). Please relate this to ‘item e’ above as well.

To ensure rigour, the authors followed methodology for use of a deductive approached and directed content analysis, as described by Elo et al. (2008) and Hseih & Shannon (2005). The statement was revised to provide clarity on the approach: “Data collected from open-ended responses in the survey were analyzed using directed content analysis methods, and mapped to existing themes identified in the literature, and represented by items in the survey, such as ‘other definitions for PCC,’ ‘plans for developing PC-QIs,’ and ‘other ways data is reported.’ Using this deductive approach, two independent researchers read and analyzed the open-ended responses, to minimize bias, and agree on categorization of data according to pre-set themes.”

Page 6: The Donabedian model is mentioned and you elaborate on the three categories (structure, process, and outcome) previously, however no background to this model is provided (only in abstract), specifically it being a conceptual model rooted in examination and evaluation of health services.

Additional details were provided with regards to the rationale for choosing the Donabedian model, including references for where the model has been applied: “The PC-QIs extracted from the scan were categorized based on the Donabedian model of healthcare systems (24), which has been widely used as a basis for defining and conceptualizing quality of care. “

Page 7: Can inter-rater reliability be calculated for PC-QI classifications done by the research team?

It is not possible to calculate inter-rater reliability, as the PC-QI classification was done as a team, through open discussion. Group discussions offered the greatest flexibility and accuracy, as PC-QIs are broad and some only recently introduced, and require group discussions to fully understand and classify them.

4. Results: Nice results section and use of quotes.

Thank you.

5. Interpretation:

a. PCC is delivered differently in different contexts and with different populations. You mention PC-QI dimensions in the Interpretation section and their influence on variation, and I am wondering why was this not accounted for in the survey. For example, although PC-QIs were linked with a specific sector (e.g. Pediatrics) in Appendix 2, there was no distinction in the questions tailored to pediatric vs adult practices and how PCC is/which PC-QIs are used.

If we understand your comment correctly, we did not tailor the survey to any healthcare sector or specify which healthcare sectors to consider, as we wanted the

participants to respond in an unbiased and comprehensive way. We did not provide specific examples, to encourage participants to answer more broadly. Different healthcare organizations and sectors have variable perspectives on what PC-QIs might look like, and we wanted to capture this variability.

b. Page 11: International countries were chosen because they have comparable health care systems to Canada. Although this was specifically stated as the purpose in Objective #3, to me, this may limit generalizability (e.g., choosing countries with health care systems comparable to Canada may be biased towards having similar PCC practices). Please address this in Limitations section of the Interpretation section.

**We agree with the author, and have added this to the limitations section:
“Although including countries of similar healthcare systems allows for international comparisons, it remains unclear how countries with alternative healthcare systems, such as the United States, measure PCC, reducing the generalizability of the current study”**

6. Appendix 2 and 3:

a. Not sure if it's just my laptop, but most of the links that I tried to visit sent me to an error page. Please update if the case.

The link for the “Project at a Glance” on page 14 have been updated. The links for the other other appendices have been removed, and will be included as supplementary materials.

Minor comments:

1. Abstract (Methods section):

a. Frequencies are assumed to be an inherent component of content analysis. Suggest omitting for brevity.

We omitted “frequency of responses.”

2. Introduction:

a. Please remove the last sentence re: Donabedian model as it belongs (and is) in the Methods section.

We deleted the last sentence, “The PC-QIs identified were categorized according to the Donabedian model of health systems.”

3. Methods:

a. Page 4: Label this section as “Methods” as per journal guidelines.

Labeled as “Methods” rather than “Methods and Analysis.”

b. Page 4: Please indicate who the study collaborators were for contextual information.

Please see clarifications about the study collaborators:

“Our study team, collaborators (those listed in our acknowledgements), and research networks (i.e. International Society for Quality of Life Research and the Canadian Association for Health Services and Policy Research) assisted us in identifying quality improvement leads and PCC measurement experts across Canada, and in England, Sweden, Australia, and New Zealand.”

c. Page 4: Move the paragraph re: follow-up protocol under the ‘Data Collection and Analysis’ subheading.

The paragraph was moved to the first paragraph under “Data Collection and Analysis.”

	<p>d. Page 5: Survey completion rate belongs in the results section (line 55).</p> <p>We relocated the survey completion rate to the first sentence of the results section, under demographics of respondents and healthcare structures.</p> <p>e. Page 5: Please define adaptive questioning for readers who may not be familiar with this method/the CHERRIES checklist.</p> <p>We added an example to help clarify what adaptive questioning is: “The survey used adaptive questioning (e.g. if the participant’s healthcare organization does not practice PCC, the next question is an open-ended question to offer an explanation, rather than asking what kind of PC-QIs they use).”</p> <p>f. Page 6, line 32: Delete mention of the Donabedian framework as it is introduced under ‘Classifying PC-QIs’ on Page 7.</p> <p>Mention of the Donabedian framework was deleted on page 6 line 32.</p> <p>4. Interpretation:</p> <p>a. Page 12: Label this section as “Interpretation” as per journal guidelines.</p> <p>We relabeled the Discussion as “Interpretation.”</p> <p>5. Table 2 and Appendix 2 and 3:</p> <p>a. It may be clearer and less repetitive to reformat the tables by placing each of the unique Province/Jurisdiction/Organization as a merged row heading.</p> <p>Thank you, we have revised the tables as suggested.</p> <p>6. Overall: I encourage a linguistic revision of the text. Some sentence structures/grammar could be improved. Some examples:</p> <p>a. Page 3, first paragraph: “... demonstrated that PCC improves ... decreases in healthcare utilization...”</p> <p>b. Page 4, line 43: Should be “snowball”.</p> <p>c. Page 5, lines 37-38: Repetitive.</p> <p>d. Page 7, line 44: Missing “of” preposition before the word “healthcare”.</p> <p>e. Page 8, line 48: “Alternative” is wrong choice of word. Perhaps “Contrastively”.</p> <p>Thank you for your attention to detail. We have revised these details as suggested.</p>
Reviewer 2	Dr. Sarah Berglas
Institution	Canadian Agency for Drugs and Technologies in Health, Knowledge Mobilization, Ottawa, Ont.
General comments (author response in bold)	<p>This environmental scan is very useful to capture the extent that patient centred care is being measured in Canada and the wide range of measures used. Thank you for undertaking this research. The manuscript is well written without jargon. My comments specific to each section are below and I'm happy to be contacted you'd like me to explain any comment in more detail.</p> <p>Background:</p> <ol style="list-style-type: none"> 1. p 3. Explain why you use the US Institute of Medicine's definition of Patient Centred Care in the research. 2. Perhaps include a few Canadian definitions or conceptualizations of PCC for example from the Association of Ontario Health Centers or Registered Nurses Association of Ontario. <p>We agree with the reviewer that it would be useful to include Canadian definitions or conceptualizations of PCC. However, due to space requirements, we have chosen to</p>

only include the IOM definition of PCC, to be consistent with its use as the operational definition for guiding our program of research on developing Patient-Centred Quality Indicators (PC-QIs).

3. The wider context of the scan is succinctly explained in the methods, so the sentence beginning line 43 is not needed.

We agree with the reviewer, and have deleted the following sentence, but we have alluded to the larger program of research on PC-QIs at the start of the methods: “The study was conducted at the University of Calgary, and it is part of a larger program of research that aims to develop a core set of evidence-based and patient informed PC-QIs that may be used by healthcare systems across the continuum of care to evaluate patient-centred practice and promote quality improvement.”

Methods and Analysis:

4. p 4. Overall, this can be condensed, especially around follow-up and survey platform used. Perhaps reference the checklist of reporting results of internet e-surveys used and include these details in the appendix.

- Great that you've explained why the comparison countries were chosen.

We have cut out some text around follow-up (paragraph two of “Identification and Recruitment of Participants”). The text around the survey platform is required by the CHERRIES checklist and we believe that text provides useful information pertinent to the methods. We have attempted to condense the rest of the methods down.

5. p5. Specify how you used content analysis to synthesis the open-ended responses.

Reviewer 1 suggested a similar comment, and so we have previously addressed it.

6. p6. Explain why you chose the Donabedian framework to classify the PC-QIs. How does use of this framework aid understanding?

Reviewer 1 suggested a similar comment, and so we have previously addressed it.

Results:

7. p 7. The explanation of how results are presented is useful. Add the demographics of international comparisons to the dedicated section at the end for international comparisons. Thank you, we have added the demographics of international comparisons to the referred section.

“100% (11/11) of international organizations served both adults and children, 91% (10/11) served rural, sub-urban and urban populations, and 82% (9/11) provided both community and acute care services. All organizations reported that they practiced PCC, but 36% (4/11) said that they were not currently using PC-QIs. However, 75% (3/4) of those organizations who did not use PC-QIs were currently developing them.”

8. p 7, line 44. Do you mean, "There are 65 Canadian healthcare agencies and authorities (for example LHINs, RHA) and 42 of these agencies responded to the survey." ?

Thank you. We reached out to 67 organizations in Canada, and of those, 47 responded. We altered the sentence to clarify this. However, we did recalculate our response rates, and edited the text accordingly (changes are highlighted). “In Canada, we contacted 67 healthcare agencies and authorities; of these, 47 responded to our survey (70% response rate).”

9. line 51. Does the total of 33 refer the broader provincial organizations (for example Health Quality Ontario, Health Quality Council of Saskatchewan); that are not health authorities?

Yes, this is what we are referring to.

10. Figure 1 isn't required. The comment on the breadth of services covered and that both urban and rural, adult and children patients were captured is suffice.

Thank you for your comment. We have removed Figure 1.

11. p 8. Table 1 has 28 organizations listed. Where does the 43 / 47 come from? If there are other organizations that practice PCC, but do not measure PCC, or use PC-QIs, this would also be worth listing, with an additional column (Use PCC). Explain why there is a total of 47 (not 65 healthcare authorities plus 33 provincial organizations).

Thank you for your comment. We decided against listing all the organizations that did and did not practice PCC, as we did not wish to make it obvious who was not practicing PCC, or those that haven't started measuring PCC yet.

12. p 9, Very useful to see the explanations offered to demonstrate the nuances of not practicing PCC currently.

Thank you.

13. Line 46, move the total number of PC-QI to the next paragraph. With the focus on organizations, move from use of PCC to measurement; then discuss the variety of PC-QIs used.

We moved "In total, we identified 61 PC-QIs" to the following paragraph.

14. p 10, Good to see the section on public reporting of PCC measurement.

Thank you.

15. p 11. I challenge the statement "that the healthcare system in Australia has not yet implement patient-centred care into the health care system". See the Australian College of Nursing, 2014 Position Statement on Person-centred Care at <https://www.acn.edu.au> for example.

The responses from our Australian contacts were described in the paper. These contacts are key leaders in PC-QI development and PCC implementation in nationally-representative organizations. Although they have made many achievements, the participants described that Australia has yet to systematically and nationally implement PCC. We have added this description to our results section for further clarification.

"Our results revealed that the healthcare system in Australia has not yet systematically implemented PCC into the healthcare system at the national level, and has not yet developed PC-QIs."

16. p 11. As there are many small health regions in Sweden, use numbers rather than %; as a sample of 4 regions is interesting, but not representative of the country.

We have changed the percentage to numbers for clarity:

"Of the four sampled regions sampled in Sweden, all of them reported that their healthcare system practiced PCC; three of the four regions are developing PC-QIs, and one region reported using a PC-QI."

Discussion:

17. p 12. Suggest replacing the first paragraph of the discussion by directly responding to the 3 study objectives - is PCC being measured in Canada, what PC-Qis are being used and how does measurement compare to other countries.

We have added to the first paragraph to address these objectives:

	<p>“This environmental scan provides insight into PCC measurement efforts in healthcare organizations across Canada, and compares Canadian measurement efforts to those in England, Sweden, Australia, and New Zealand. Our comprehensive approach in capturing PC-QIs exposed the variation in PCC measurement across Canada. While some healthcare organizations use PC-QIs, others use PCC measures (e.g., surveys), guidelines for PCC, or review PCC practice through patient advisory boards. Many organizations reported that they use a mixture of methods to evaluate PCC, and found value in measuring PCC using a variety of approaches (e.g., use of patient-reported outcomes, feedback from Patient Advisory groups, and self-assessments from healthcare providers). Further, there was inconsistent PC-QI and PCC measurement use within and across organizations in each country. PCC practices and measurement in Canada are comparable to the international countries included in the study. Nationally and internationally, the PC-QIs used focused on measuring healthcare processes and outcomes, with an emphasis on measuring patient experiences with care received and delivered.”</p> <p>18. p 12. The idea that PCC measurement should include various time points is interesting, but where did this idea arise? Did the framework reveal a gap in this area? Was this a theme emerging from the open-ended responses?</p> <p>This concept was identified in the literature. We have clarified this in the sentence: “Further, the literature suggests that PCC measurement include the various time points throughout a patient’s interaction with the healthcare system (i.e., prior to provision of care, during patient care, and outcomes of patient care).”</p> <p>19. Overall, the discussion would be stronger with an explanation of the benefit of measuring PCC using specific indicators and the expected benefit of a Canadian (and/or) international set of standardized indicators for PCC. Was the diversity of PC-QIs used in Canada surprising? Do the indicators reflect the ideas of the IOM definition of PCC?</p> <p>We agree with the reviewer, and we have expanded on the benefits of having a set of standardized indicators for PCC. The following was added to the last paragraph of Interpretation: “The identification and refinement of a list of PC-QIs will provide a standard of quality for PCC, and identify areas of improvement for patient care. If implemented internationally, comparability of PCC across countries will be possible.” We have discussed the diversity of PC-QIs and variety of their definitions on page 12-13, in the second paragraph.</p> <p>20. To respect the word count, the limitation section could just identify the more important limitations. [ED note: Please do not limit the discussion of limitations. You should be able to respect the word count by shortening the Introduction and Interpretation sections and moving illustrative quotes to boxes (where they will not count toward the word count). Also, if necessary, we can allow up to 3000 words]</p> <p>We have cut down on the word count in the limitations to focus on the more important points.</p> <p>Appendices: 21. Good to see the full survey questions and expanded list of indicators. Thank you.</p>
Reviewer 3	Mr. Frank Gavin
Institution	
General comments (author response in bold)	<p>The paper and the project of which it is a part address a real need, but the paper made some assumptions that needed to be questioned and provided little or no detail in places that needed some detail. In addition, the diction was often either vague or opaque.</p> <p>1. There are references to PCC as a "model," but surely there are different models of care</p>

that can be described as "patient-centred," especially in different cultural settings and in different types of healthcare organizations. I also wondered about the declared goal of informing "the development of a standard set of PC-QIs that can be implemented by healthcare organizations ..." Why there needs to be such a "standard set" is never explained? Are they to be used to compare the quality of care in one jurisdiction or in one kind of healthcare organization with the quality in another jurisdiction or organization? Are they be used to used not to compare but to improve the quality of care within the particular organizations that apply them?

The purpose of the scan was to identify which regions and organizations felt they were practicing PCC, and if they measured PCC. While many may report that they practice PCC, developing standardized PC-QIs that measure PCC across the country will ideally help confirm and improve PCC practice. Developing this standardized set of PC-QIs will provide that benchmark of PCC practice, and help organizations and hospitals work towards that goal. This paper will help inform the development of PC-QIs, and demonstrates the irregular practice of PCC and the real need for a way to measure it.

2. We are told that the target response rate was 75% but that only 65% responded. What to make of the 35% non-response rate? Also, the very interesting quoted comments of the two individuals who said their organizations did not practice PCC (p. 9) should have prompted the authors to question whether at least some of the organizations that said they do practice PCC should be taken entirely at their word. This is, after all, the era of "patient-centredness" where every lab, pharmacy, walk-in clinic, and dental practice is proclaiming itself "patient-centred."

The 35% non-response rate will not hinder the interpretation of the results, as the majority of organizations that we reached out to were able to provide us with a survey response (83%). We reached out to many potential contacts within the same organization to ensure sufficient representation in each province. We stated this in the sentence following:

"In Canada, we contacted 67 healthcare agencies and authorities; of these, 47 responded to our survey (70% response rate). We were able to capture information from most provinces and territories with governing organizations direct healthcare quality at the provincial/territorial level, with the exception of Nunavut (30/36, 83%)." The reviewer makes an excellent point regarding those who claim they do not practice PCC. **The purpose of the scan was to identify which regions and organizations felt they were practicing PCC, and if they measured PCC. While many may report that they practice PCC, developing standardized PC-QIs that measure PCC across the country will ideally help confirm and improve PCC practice. Developing this standardized set of PC-QIs will provide that benchmark of PCC practice, and help organizations and hospitals work towards that goal. We hope that we have addressed this lack of clarity in our response to the first comment.**

3. We're told the countries included in the scan were chosen because their health systems are in some way similar to Canada's. That's not sufficient. Why, for instance, Sweden rather than Denmark? And the deliberate decision to omit the U.S. seems like a mistake given the cultural similarities between Canada and the U.S. and given the authors' own acknowledgement that the U.S. "are one of the global leaders in PCC" (p. 13). I was also mystified by the comment that "Australia has not yet implemented PCC into the healthcare system." I recall an Australian physician who accompanied Bev Johnson of the Institute of Patient- and Family-Centered Care to Canada and who told all who heard her of the Australian achievements in this area--and that was 15 years ago.

We purposefully omitted the United States, as they operate using privatized healthcare, whereas Canada provides universal healthcare. Thus, it was inappropriate to compare PC-QI measurement between the two countries in this scan. We clarified this, as stated below:

“These countries were chosen, considering their ongoing efforts measuring PCC, that they have health systems that are comparable to Canada (i.e. universal healthcare systems), and the feasibility of identifying participants through our research networks.”

The responses from our Australian contacts were described in the paper. These contacts are key leaders in PC-QI development and PCC implementation in nationally-representative organizations. Although they have made many achievements, the participants described that Australia has yet to systematically and nationally implement PCC. We have added this description to our results section for further clarification (see response to Reviewer 2, item 15).

“Our results revealed that the healthcare system in Australia has not yet systematically implemented PCC into the healthcare system at the national level, and has not yet developed PC-QIs.”

4. There are also many vague or opaque statements. For instance, we are told that "in recent years, healthcare systems around the world have moved from processes of care to Patient-Centred care" (p. 3)--as if PCC cannot be embedded or is not provided in processes of care. On the same page we read that among the "dimensions of a patient's life" are "the person's context and individual expressions." I have no idea what those last two words mean and I'm not sure how a person's "context" (a very vague term in itself) can be a dimension of his or her life. Later there is reference to the perspectives "of patients, healthcare providers, quality improvement, PCC measurement, and data experts" (p. 5) as if an area of improvement and a type of measurement can have perspectives in the same way that groups of people have perspectives. Also I have no idea what is meant by "treating individuals as unique while valuing patient diversity" (p. 9) I could go on.

To enhance clarity, we have revised the statement on p.3 to read:

“In recent years, healthcare systems around the world have adopted Patient-Centred Care (PCC) as a model to improve quality of care (1).”

We have also removed the description of Person-centred care, including the statements around “dimensions of a patient’s life” and “the personal’s context and individual expressions.” Due to space limitations, we have decided that these descriptions do not add much to the focus of the paper, and have decided to ensure that background focusses on the need for Patient-Centred Quality Indicators.

With regards to the statement around including the perspectives "of patients, healthcare providers, quality improvement, PCC measurement, and data experts" (p. 5), our intent is to ensure that our survey is capturing the right information, that will help us understand how PCC is being measured in Canada. We recognize that as researchers, we may not always use the best (or right) questions or terminology, as those who are collecting this information for system improvements. We may also miss aspects of what is important to measuring PCC, from a patient perspective. Thus, we found it important to develop and pilot this survey with a number of individuals, with various expertise and perspectives.

For the statement on “treating individuals as unique while valuing patient diversity,” this was part of a definition provided by a healthcare organization. We attempted to use similar language as the healthcare organizations, to ensure accuracy in the reporting of our findings.

5. I noted that though 43 Canadian agencies and organizations responded to the survey, a small handful of them (HQO) provided most of the detailed information about QIs. The text should have at least noted this.

The following sentence was added to the second paragraph below “PC-QIs Used to Monitor and Assess PCC” under the results section:

“The majority of the indicators identified were from Health Quality Ontario.”

6. Most of the major problems in the article are evident in one sentence on page 12: "The variety of definitions and PC-QI use across Canada may lead to inconsistent and unstandardized PCC measurement in Canada, suggesting the need for a uniformly

accepted definition of PC-QIs." Is the problem the lack of a definition of patient-centred quality indicators? What does it even mean to define indicators? Do the authors really mean "agree to common indicators"? Or do they really mean to refer here to the variety of definitions of PCC rather than of PC-QIs? And do they mean a widely or universally accepted definition rather than a "uniformly accepted definition" (as if there were such a thing as a uniformly accepted definition of anything)? One also has to ask about the difference between "inconsistent" and "unstandardized" in this context?

In short, I didn't find the paper helpful or illuminating.

Thank you for your comment; this has helped us to look at how we can more clearly communicate the importance of our findings. Modifications to the Interpretation section have been made, to clarify the gap that was identified in measuring PCC. With measuring PCC, it is important to have a common understanding of what PCC is, in order to establish standardized measurement. With our discussion on the role of the Canadian Institute for Health Information, leading the standardization of PCC measurement across Canada, we hope that this sheds some light on how our findings can be leveraged and incorporated into the national PCC measurement initiatives.