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Improving the Quality of Person-Centred Healthcare from the Patient Perspective: Development of Person-Centred Quality Indicators

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Transparency statement: The lead author affirms that this manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned (and, if relevant, registered) have been explained.

Data sharing statement: Some materials and documentation may be available to other researchers. Please contact the corresponding author with a detailed request.

Patient and public involvement: In Phase 1 of the study a patient partner (SZ) was recruited to assist the research team. We used a participatory approach to sample diverse patients and caregivers. Focus groups were conducted with the provincial Alberta Health Services Patient and Family Advisory Group, as well as ActionDignity (a Calgary-based NGO). These organizations supported the recruitment, data collection, analysis, and dissemination of findings. Interviews were conducted with 65 patients and caregivers to identify values, preferences, and needs. We also consulted 22 related stakeholders on perceptions of feasibility and prioritization of measuring care. In Phase 2 of the study, we used a consensus process with a panel of 29 people of patients, caregivers, diverse community members, providers, researchers, and quality improvement leads. More than half of the panel were patients, caregivers, and community members. Participants were routinely asked about burdens to participation to ensure appropriate accommodations.

ABSTRACT

Importance: International efforts are being made towards a person-centered care (PCC) model, but there are currently no standardized mechanisms to measure and monitor PCC at a healthcare system level. The use of metrics to measure PCC can help to drive the changes needed to improve the quality of healthcare that is person-centred.

Objective: To develop and validate person-centred care quality indicators (PC-QIs) measuring PCC at a healthcare system level through a synthesis of the evidence and a person-centred consensus approach to ensure the PC-QIs reflect what matters most to people in their care.

Methods: Indicators were first identified through a scoping review of the literature, an international environmental scan, focus groups with diverse patients and caregivers, and interviews with clinicians and experts in quality improvement. The identified indicators were subsequently refined by a modified Delphi consensus process using the RAND/UCLA Appropriateness Method. The international consensus panel consisted of patients, family members, community representatives, clinicians, researchers, and healthcare quality experts.

Results: From an initial 39 unique evidence-based PC-QIs identified and developed, the consensus process yielded 26 final PC-QIs. These included seven related to structure, 16 related to process, two related to outcome and one overall global PC-QI.

Conclusions: The final 26 evidence-based and person-informed PC-QIs can be used to measure and evaluate quality incorporating patient perspectives, empowering jurisdictions to monitor healthcare system performance and evaluate policy and practice related to PCC.

Article Summary

Strengths and limitations
• Using a patient-centred process, we identified 26 indicators to aid in the measurement of person centred care. • These indicators can be used to identify gaps in the delivery of person-centred care. • These indicators may not be applicable in all contexts. • Future work is needed to evaluate the potential for wider implementation and use of the indicators to facilitate improvements in person-centred care.

INTRODUCTION

In 2017, health ministers from OECD countries declared that we need to invest in measuring what matters most to patients[1,2]. Ever since patient-centred care (PCC) was first identified as a foundational component of healthcare quality and patient safety by the Institute of Medicine in 2001[3], it has been recognized as a high priority by healthcare systems globally.[4-8] The use of valid and reliable measures to monitor and evaluate PCC can provide the data needed to identify gaps in the delivery of PCC and target areas for improvement, and thus, drive the changes needed to move towards a true PCC model.

However, there are currently no generally accepted indicators for measuring PCC.[9] Moreover, existing indicators do not tend to incorporate the voices of people involved in healthcare, namely, patients, caregivers, and healthcare providers.[14] This gap means that PCC itself might be measured in ways not relevant to patients, and in ways that do not address practical concerns of healthcare providers for person-centred quality improvement.

Evidence also suggests that the delivery of Person-centred care (PCC) improves healthcare quality, including improvement of patient experiences and outcomes, enhanced involvement of people in their own healthcare decisions, more support for health promotion activities, a decrease in healthcare services utilization and costs, and an improvement in healthcare provider satisfaction.[10-13]

This article presents a new set of Person-Centred Quality Indicators (PC-QIs) developed and validated through a modified Delphi process that featured significant patient involvement. These

PC-QIs are widely-applicable, evidence-based and patient-informed indicators and can be used as tools for healthcare quality improvement by leveraging ongoing initiatives to promote person-centred care. This includes helping to standardize the collection, use, and reporting of patient-reported data (e.g. through Hospital Consumer Assessment of Health Providers and Systems) or incorporation of these indicators into performance measurement frameworks. Importantly, these indicators have the potential to shift our healthcare systems towards a new paradigm for assessing quality by ensuring we measure what matters most to patients.

METHODS

The development of the PC-QIs included two phases (see Figure 1, for a diagram of the overall project). During Phase 1, previously implemented and evaluated PC-QIs were identified and classified using a published PCC framework.[14] In Phase 2, these identified PC-QIs were refined through a modified Delphi consensus process[15] that involved patients, caregivers, and diverse community members, clinicians, quality improvement leaders and decision makers. Ethics approval was granted from the University Health Research Ethics Boards [REB15-2846] at the University of Calgary.

FIGURE 1 HERE

Patient and Public Involvement

A patient partner (SZ) was recruited to as part of the research team at the study's inception, and to ensure the study is guided by the patient perspective. The patient partner has played a critical role in the study design, data collection, review of analyses, interpretation of the data, and the development of this manuscript, in addition to disseminating the findings of this research. Moreover, in Phase 1 of this study, we used a participatory approach to engage 65 diverse patients and caregivers to identify what matters most to them in their healthcare. This would ensure that patient values, needs, and preferences are incorporated into the development of the indicators. These focus groups were conducted with the provincial Alberta Health Services Patient and Family Advisory Group, as well as ActionDignity (a Calgary-based non-profit organization). These organizations supported the development of the focus group discussion tools, recruitment, data collection, analysis, and dissemination of findings. In Phase 2 of the study, we used a consensus process with a panel of 29 people of patients, caregivers, diverse community members, providers, researchers, and quality improvement leads, which is described in this paper. Participants were routinely asked about burdens to participation to ensure appropriate accommodations. Once the article has been published, it will be shared with our patient collaborators and participants.

Phase 1: Preliminary review

This first phase involved preparatory work needed for the consensus process. Consistent with a patient-oriented research approach, and to ensure the patient perspective remains central to the study, a Patient-Partner (SZ) was recruited to work with the research team throughout all phases of the study. In order to identify, categorize, and develop PC-QIs, we developed a conceptual PCC framework[14] based on the Donabedian quality of care model (structure, process and outcome).[16]

This phase also involved a scoping review[17, 18] to identify previously published PC-QIs, their implementation and evaluation in various settings, as well as best practices of PCC monitoring. In parallel, an environmental scan was conducted to identify if healthcare systems in Canada, the United Kingdom, Sweden, Australia and New Zealand were using PC-QIs, which PC-QIs were in use, and how they were implemented.[19] These countries were chosen as they shared many similarities with respect to healthcare delivery and structures.[19] All unique PC-QIs identified through the scoping review and environmental scan were synthesized by the research team.[19]

Using a person-centred approach, consultations with patients and caregivers, as well as key stakeholders (i.e. quality improvement leads, healthcare providers, and PCC researchers) were conducted to inform the development and prioritization of PC-QIs.[20] These consultations were used to guide how existing PC-QIs could be modified or refined, and to identify any PC-QIs still needed for development.[21]

Specifically, drawing on a transformative framework[22] our research team aimed to consult with diverse patients and caregivers through a participatory approach, and employed strategies to attain maximum variation among participants. Focus group discussions were conducted in partnership with the provincial Alberta Health Services Patient and Family Advisory Group, as well as ActionDignity, a community-based organization that works closely with ethno-cultural leaders in Calgary to conduct research and work towards systems and policy change. We identified healthcare values, preferences, and needs from a diverse sample of 65 patients and caregivers. Individual interviews with 22 healthcare providers, quality improvement experts, and PCC researchers from Canada, the USA, and England were conducted to determine perceptions around feasibility and prioritization of measuring specific domains of PCC.

Through a synthesis of the evidence from Phase 1, unique PC-QIs were developed or modified iteratively by the research team, and subsequently classified using the PCC conceptual framework.[14] The details and key results from these sub-studies for Phase 1 have either been published or in the process of publication elsewhere.

Phase 2: Modified Delphi Panel Exercise

Phase 2 included a consensus process, using the RAND/University of California LA Appropriateness Method (RAM).[23] RAM is a reproducible and valid nominal group technique consensus methodology using the modified Delphi technique.[15] RAM is used extensively in health services research.[23] Based on our previous experience, the consensus method (RAM) was considered highly appropriate to facilitate the panel's prioritization and refinement PC-QIs.[24, 25]

Panel Selection

A consensus panel of 29 people was established consisting of patients, caregivers, diverse community members, healthcare providers, PCC researchers, and quality improvement leads. In recognition of the potential power dynamics associated with mixing groups of patients[20] , caregivers, healthcare providers, researchers, and quality improvement experts, we strove to assemble a panel where at least half of the representation was from patients, caregivers, and community members. The community members were representative from the some of the most prominent ethno-cultural communities in Calgary (i.e. Chinese, South Asian, and Filipino). The panelists were identified from their previous participation in the environmental scan, interviews, and focus groups conducted in Phase 1, as well as our collaborators' networks.

The consensus panel comprised:

- 8 patients and 3 caregivers with various experience with the health care system, including primary care, acute care, cancer care, and chronic diseases (e.g. cardiovascular conditions, diabetes, etc.)
- 5 members of diverse ethno-cultural communities who are also patients and/or caregivers
- 2 healthcare providers (an internist and a pediatrician),
- 5 quality improvement experts (representing Canadian Quality Councils and health systems, Cancer Care Ontario, University of Gothenburg Centre for Person-centred Care, Sweden, Picker Institute, and University of Oxford, UK),
- 4 PCC researchers, including: a lead from the Patient-Centered Outcomes Research Institute (PCORI), a Senior Scientist Collaboration for Leadership in Applied Health Research and Care Oxford Unit, professors from Canadian Universities and leaders of the Canadian Strategy for Patient-Oriented Research
- 1 representative of the Canadian Institute for Health Information
- 1 representative from Ministry of Health, British Columbia

Identified individuals were invited via email and provided with a summary of the project and an overview of the consensus process and expectations (e.g., time commitment and activities). A descriptive summary of the panel members can be found in Table 1.

Table 1: Characteristics of the Consensus Panel for Person-Centred Quality Indicators

Panel Characteristics (n= 29)	
Expertise (primary role)	
Patient	8
Caregiver	3
Community Member	5
Person-Centred Care/Measurement Researcher	5
Ministry of Health/ Measurement Lead	1

Quality Improvement Lead	5
Physician	2
Sex (Female)	20
Country	
Canada	25
Sweden	1
United Kingdom	2
United States	1

Rating Process and Materials

Panelists received a package including:

a) a manual that included a monograph of each PC-QI identified, and

b) a rating tool used for panelists to rate the PC-QIs (see: http://bit.do/PC-QI_RatingTool)

The package outlined the PC-QIs that included descriptors such as: type of indicator, proposed data source (including existing patient-reported experience measures already in use), definition, numerator, denominator, benchmark, and risk adjustment. The manual also included definitions to describe what PC-QIs are, and what constitutes a "good" quality indicator. Additionally, the rating tool was derived from the Joint Commission Attributes of Core Performance Measures and Associated Evaluation Criteria.[26] The rating tool asked panelists to rate PC-QIs on each of the following dimensions:

- Was the PC-QI precisely defined?
- Does the PC-QI target important PCC improvements?
- Does it measure what is supposed to measure?
- It is a good global PC-QI for overall evaluation?

The ratings materials also included questions related to implementation including *feasibility* (is data for reporting PC-QI available?) and *usability* (is the PC-QI actionable and interpretable?). Panelists used SurveyMonkey, a web-based survey tool, to remotely rate the PC-QIs in the first, third, and fourth rounds.

Delphi Round 1

The first round involved remote rating by panelists. In each of these remote rating rounds, panelists used the rating material described above and the rating scale, a 9-point scale (1 = strong disagreement, 9 = strong agreement). Overall assessment of the PC-QI scored as: *inappropriate* (1-3), *supplementary* (consider as a PC-QI if more resources available) (4-6) and *appropriate* (7-9). Panelists also had the opportunity to provide written comments and suggest additional PC-QIs.

PC-QIs ratings were summarized using medians and inter-quartile rage (IQR) for the overall rating included in the "globally it is a good PC-QI?" rating scale. Disagreement on the rating for a PC-QI of at least a third of the panel (n=>9) in the median score 1-3 and at least a third (n>=9) of the panel in the median 7-9. PC-QIs with median overall scores of 1-3 were discarded; PC-QIs with median overall score 4-9 were retained for subsequent rounds. Written comments were analyzed using content analysis methods.

Following remote ratings in round 1, the data were analyzed, and suggestions and refinements were made to each PC-QI as appropriate. This revised version was shared via SurveyMonkey prior to the face-to face meeting.

Delphi Round 2

During Round 2, panelists reviewed each PC-QI in a face-to-face meeting. Deliberations were made as a group until final agreement on PC-QI specifications was achieved. The 2-day meeting was co-moderated by our patient-partner (SZ) and a clinician researcher.

Delphi Rounds 3 & 4

Remote ratings in rounds 3 and 4 continued as described in the first remote rating round. Through the remote rounds, revisions of each PC-QI were added to the working document and circulated among panelists for a final rating using paper-based rating tools for final review. Additionally, a working group, created as a response to the discussions held during the face-to-face meeting, studied the development of an indicator that captures outcomes reported directly by the patients.

This working group included five patients, two family members, one physician, two quality improvement leads and two researchers. The group worked on developing the indicator and gathering information to present background knowledge to the rest of panelists. The new indicator and additional information were shared among the rest of the panellists and they rated the new indicator in round 3.

RESULTS

Thirty-nine PC-QIs were identified through Phase 1 and were refined through Phase 2 of the study, where they were summarized into 26 final PC-QIs. These final 26 PC-QIs included seven structure, 16 process, two outcome and one global indicator (see Table 2). During the first round and based on final ratings (see Table 2), 4 indicators were discarded including:

- Timely Unplanned Readmission from ER
- Overall Rating
- Patient-reported Outcome Multi-attribute
- Patient-reported Outcome Mental Health

Based on the decision to discard the last two PC-QIs, the working group proposed a new indicator related to Patient-Reported Outcomes: “Using Patient-Reported Outcome Measures to deliver Patient-Centred Care.” This newly proposed indicator was later rated and accepted in

Round 3. Table 2 summarizes the consensus panel ratings. During Round 2, out of the initial 39 indicators, 11 were merged with other indicators. A summary can be found in Table 3.

Table 2: Summary of Consensus Panel Ratings for Final 26 PC-QIs Developed by the Panel (Median Score on 9-point Scale and (Interquartile Range))

Person-Centred Quality Indicators	Round 1 Remote Panel Rating	Round 2 Face-to-Face Panel Rating	Round 3 Remote Panel Rating
Structure Indicators (n= 7)			
Policy on Person-Centred Care	8 (6, 9)	Keep	8 (7, 8)
Educational Programs on Person-Centred care	8 (7, 9)	Keep	8 (7, 8)
Culturally Competent Care	7 (6, 9)	Keep	8 (7, 8)
Co-designing care in partnership with communities	8 (6, 9)	Keep	8 (7, 8)
Providing an Accommodating and Supportive Person-Centred Care Environment	7 (5, 8)	Keep	7 (6, 8)
Healthcare Information Technology to Support Person-Centred Care	8 (5, 9)	Keep	8 (7,8)
Structures to Report Person-Centred Care Performance	8 (8, 9)	Keep	8 (8, 9)
Process Indicators (n=16)			
Compassionate Care	9 (8, 9)	Keep	8 (8, 9)
Equitable care	8 (7, 9)	Keep	9 (8, 9)
Trusting Relationship with Healthcare Provider	9 (8, 9)	Keep	8 (8, 9)
Timely Access to a Primary Care Provider	8 (7, 9)	Keep	8 (6.5, 9)
Accessing Interpreter Services	8 (7, 9)	Keep	8 (7, 9)
Communication with Healthcare System	8 (7, 9)	Keep	8 (8, 9)
Communication between Patient and Healthcare Provider - Nurse	8 (7.5, 9)	Keep	8 (8, 9)
Communication between Patient and Healthcare Provider - Physician	8 (8, 9)	Keep	9 (8, 9)
Information about Taking Medication	9 (7, 9)	Keep	8 (8, 9)
Communicating Test Results	8 (7, 9)	Keep	8 (8, 9)
Coordination of Care	9 (7, 9)	Keep	8 (8, 9)

Person-Centred Quality Indicators	**Round 1 Remote Panel Rating**	**Round 2 Face-to-Face Panel Rating**	**Round 3 Remote Panel Rating**
Process Indicators (n=16) (cont.)			
Patient and Caregiver Involvement in Decisions about their Care and Treatment	8 (8, 9)	Keep	9 (8, 9)
Engaging Patients in Managing their Own Health	8 (7, 9)	Keep	8 (8, 9)
Patient Preparation for a Care Plan at a Healthcare Facility	8 (7, 9)	Keep	8 (7, 9)
Transition Planning	9 (8, 9)	Keep	9 (8, 9)
Using Patient-reported Outcome Measures (PROMs) to Deliver Patient-Centred Care	Not developed	Newly developed derived from previous 'Patient-reported outcomes'	7 (5, 9)
Outcome Indicators (n=2)			
Cost of Care- Affordability	6.5 (5, 9)	Keep	7 (5,9)
Overall Experience	8 (6, 9)	Keep	9 (7, 9)
Global Indicator (n=1)			
Friends and Family Test	7 (5, 9)	6.5 (2.5, 7)	7 (6, 8)

Table 3: Merged PC-QIs

Original PC-QIs	Final PC-QIs Incorporating Original PC-QIs
Structure	
Supporting a Workshop Committed to PCC	Policy on PCC
Partnership with Communities	
Protocol for integration of structures to support health technology	
Protocol addressing discriminatory care	Educational Programs on PCC
Program/protocol for recruitment and retention of staff of diverse background	
Noise during hospitalization	Providing an Accommodating and Supportive Person-Centred Care Environment
Providing an Environment that Reflects Diversity and Inclusion	
Educational Programs Reflecting Cultural Competency and Humility	Culturally Competent Care
Process	
Post-discharge planning	Transition Planning
Timely follow-up after discharge	
Discharge summaries available after 48 hour of discharge from hospital	

The details of all the modifications can be found in Appendix 1, including a summary of consensus panel ratings for the final 26 PC-QIs developed (Median Score on 9-point Scale and Inter-Quartile Range) through the three rounds and final decisions made in round 4.

Each of these newly developed indicators are evidence-informed and person-centred, some addressing a specific aspect of healthcare quality (e.g. safety versus equity). Additional details and a description of the discussion among panel members will be published elsewhere.

DISCUSSION

As Moira Stewart stated in her 2001 editorial: “The patient should be the judge of patient-centred care.”[27] The overall aim of this research was to ensure that the patient perspective can be used to inform improvements in healthcare quality by developing a core group of person-centred quality indicators (PC-QIs), based on a synthesis of the evidence and, importantly, includes what matters to patients, caregivers, diverse community members, healthcare providers and quality improvement experts, and researchers, when it comes to healthcare.

The strength of this study is the person-centred approach used to develop metrics to evaluate PCC, which ensures that PCC is evaluated from the perspective of those who provide and receive care. To our knowledge, this is the first study to develop PC-QIs using a rigorous evidence-based and person-centred approach. While PC-QIs were identified in the initial scoping review and environmental scan in Phase 1, these were not developed from the patient perspective. Rather, much like most quality indicators that are developed, these PC-QIs were developed based on what healthcare authorities or quality improvement experts deem as most important for their organization to drive quality improvement. Patients and the public are seldom involved in decisions about quality of care despite being the ones who experience and receive care. How can PCC be truly improved if we continue to measure PCC without the patient perspective on what should be measured?

These newly developed indicators present an opportunity to improve healthcare quality in ways that matter most to patients. To drive changes in healthcare policy and practice, there is a need to develop and implement standardized ongoing mechanisms to measure and evaluate quality incorporating the patients' perspectives.[13] These PC-QIs offer a tremendous opportunity to use data already being collected in many healthcare jurisdictions using patient-reported experience measures (PREMs) and patient-reported outcome measures (PROMs), and to promote the actionability of this data. While PREMs and PROMs are often used at the provider level, there is little evidence of use for system-level applications and actionability. These indicators empower jurisdictions to monitor healthcare system performance and evaluate policy and practice related to PCC, while also including the patient's voice. Finally, the routinized use of standardized metrics, such PC-QIs, to evaluate PCC will help to strengthen the evidence-base for the PCC model.[28]

While this method has generated these 26 PC-QIs using a validated consensus method, they may not necessarily be universally applicable in all countries and settings. Different cultural settings in different healthcare regulatory environments may mean that different measures may be more appropriate for certain settings. Further work can be done to tailor and adapt these PC-QIs, recognizing that a consideration of the local context will ensure a more universal relevance.

Future steps for this work include the implementation of these PC-QIs in national and international jurisdictions to promote PCC and an evaluation of the use of these measures for improving healthcare quality of care from the perspectives of the patient.

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References

1 OECD. Health Ministerial Statement - The next generation of health reforms. Published January 17 2017; accessed November 2019. http://www.oecd.org/health/ministerial/ministerial-statement-2017.pdf.

2 Coulter, A. Measuring what matters to patients. *BMJ 2017;356:j816.*

3 Institute of Medicine. Crossing the quality chasm: A new health system for the 21st century. Washington (DC): National Academies Press:2001.

4 Pelzang R. Time to learn: Understanding patient-centred care. *Br J Nurs* 2010;19:912-7.

5 National Department of Health - National Health Service. NHS 2010-2015: From Good to Great. Preventative, People-Centred, Productive. 2009.

6 Davis K, Schoenbaum SC, Audet AM. A 2020 vision of patient-centered primary care. *J Gen Intern Med* 2005;20:953-7.

7 Alberta Health Services. The Patient First Strategy. 2015.

8 Stoelwinder JU. Final report of the National Health and Hospitals Reform Commission: will we get the health care governance reform we need? *Med J Aust* 2009;191:387-8.

9 World Health Organization. Leading and Managing Change towards People-Centred and Integrated Health Services. 2015.

10 Stewart M, Brown JB, Donner A, et al. The impact of patient-centered care on outcomes. *J Fam Pract* 2000;49:796-804.

11 McMillan SS, Kendall E, Sav A, et al. Patient-centered approaches to health care: a systematic review of randomized controlled trials. *Med Care Res Rev* 2013;70:567-96.

12 Mead N, Bower P. Patient-centred consultations and outcomes in primary care: a review of the literature. *Patient Educ Couns* 2002;48:51-61.

13 Berwick DM, Nolan TW, Whittington J. The triple aim: care, health, and cost. *Health Aff* 2008;27:759-69.

14 Santana MJ, Manalili K, Jolley RJ, et al. How to practice person-centred care: A conceptual framework. *Health Expect* 2018;21:429-40.

15 Jones J, Hunter D. Consensus methods for medical and health services research. *Br Med J* 1995;311:376.

16 Donabedian A. Evaluating the quality of medical care. *Milbank Q* 1966;44:166-206.

17 Jolley RJ, Lorenzetti DL, Manalili K, et al. Protocol for a scoping review study to identify and classify patient-centred quality indicators. *BMJ Open* 2017;7:e013632.

18 Santana MJ, Ahmed S, Lorenzetti D, et al. Measuring patient-centred system performance: a scoping review of patient-centred care quality indicators. *BMJ Open* 2019;9:e023596.

19 Doktorchik C, Manalili K, Jolley R, et al. Identifying Canadian patient-centred care measurement practices and quality indicators: a survey. *CMAJ Open* 2018;6:e643.

20 McKenzie E, Potestio ML, Boyd JM, et al. Reconciling patient and provider priorities for improving the care of critically ill patients: a consensus method and qualitative analysis of decision making. *Health Expect* 2017;20:1367-74.

21 Stelfox HT, Straus SE. Measuring quality of care: considering conceptual approaches to quality indicator development and evaluation. *J Clin Epidemiol* 2013;66:1328-37.

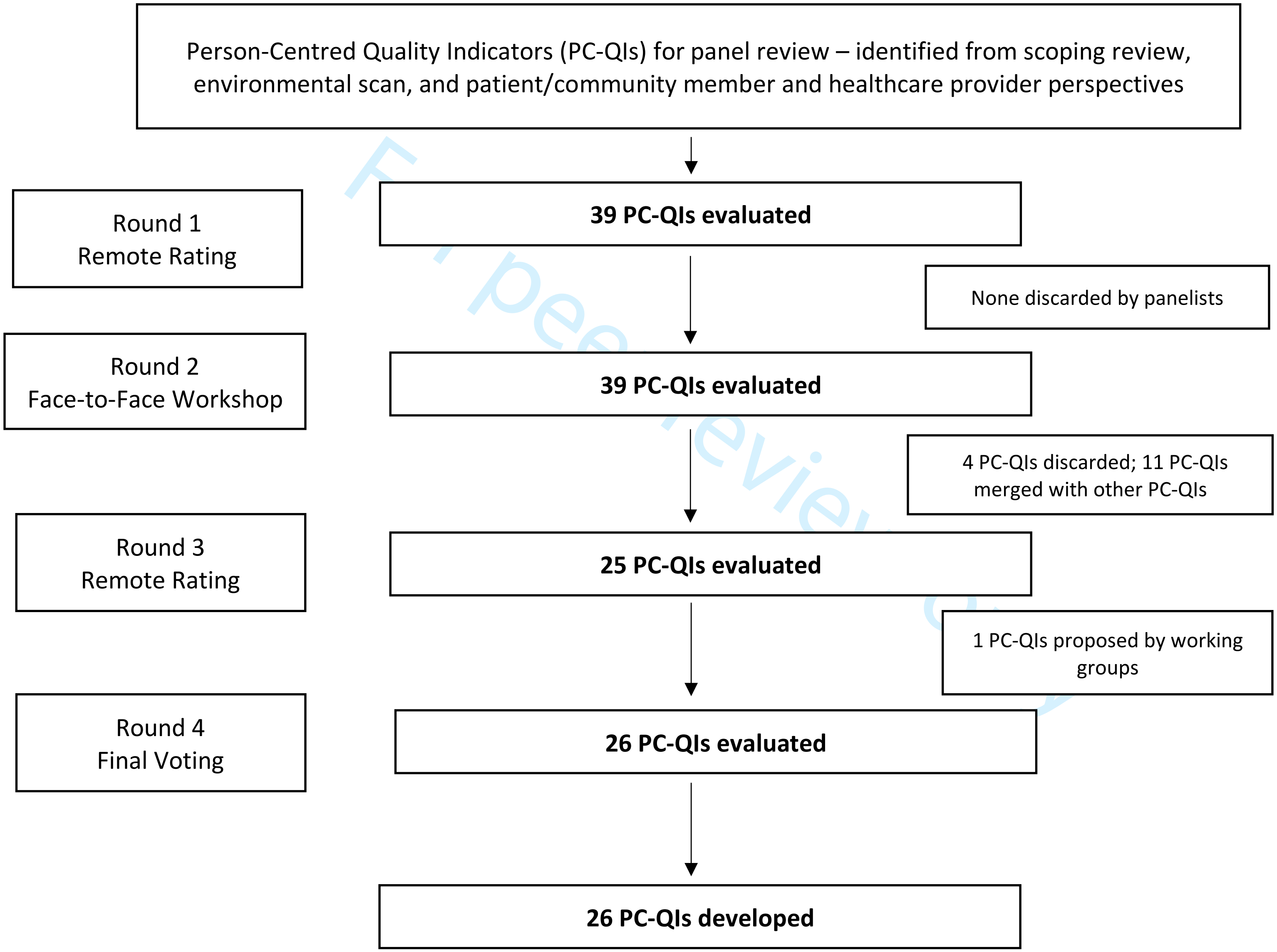
22 Mertens DM, Holmes HM, Harris RL. Transformative research and ethics. In: Mertens DM, Ginsberg, PE eds. The Handbook of Social Research Ethics. Sage Publications: Thousand Oaks, CA. 2009:85-101.

23 Fitch K, Bernstein SJ, Aguilar MD, Burnand B, LaCalle JR. The RAND/UCLA appropriateness method user's manual. RAND CORP: Santa Monica, CA; 2001.

24 Stelfox HT, Khandwala F, Kirkpatrick AW, Santana MJ. Trauma center volume and quality improvement programs. *J Trauma Acute Care Surg* 2012;72:962-8.
25 Santana MJ, Stelfox HT. Development and evaluation of evidence-informed quality indicators for adult injury care. *Ann Surg* 2014;259:186-92.
26 The Joint Commission. Attributes of Core Performance Measures and Asssociated Evaluation Criteria. 2010.
27 Stewart M. Towards a global definition of patient centred care: the patient should be the judge of patient centred care. *BMJ* 2001;322:444-5.
28 Montague T, Gogovor A, Aylen J, et al. Patient-Centred Care in Canada: Key Components and the Path Forward. *Healthc Q* 2017;20:50-6.

Figure 1 Legend: This is a flow chart of the PC-QI Delphi process, describing the timeline for Rounds alongside the numbers of PCQIs surviving each round. There are arrows pointing down from “39 PCQIs evaluated” to each subsequent “*n* PCQIs evaluated” box, until the final “26 PCQIs evaluated” box.

Figure 1: Flow Chart of PC-QI Delphi Process (Ratings and Modifications)



Appendix 1: Summary of Ratings and Modifications for PC-QIs Rated and Revised (PC-QIs = 39)

Initial Person-Centred Quality Indicators	**Round 1 Remote Panel Rating Median Score on 9-point Scale (IQR)**	**Round 2 Face-to-Face Panel Rating Median Score on 9-point Scale (IQR) – as applicable for disagreement** *initially rated as Keep/Discard	**Round 2 Modifications**	**Round 3 Remote Panel Rating Median Score on 9-point Scale (IQR)**	**Round 3 Modifications**	**Round 4 Final Remote Panel Rating – Keep/Discard**
Structure Indicators						
Policy on Person-Centred Care	8 (6, 9)	Keep	Expanded on description	8 (7, 8)	None	Keep
Educational Programs on Person-Centred care	8 (7, 9)	Keep	Expanded on description	8 (7, 8)	Expanded on description	Keep
Protocol addressing Discriminatory Care	7.5 (6, 9)	Keep	Merged with “Educational Programs on Person-Centred Care”	N/A	N/A	N/A
Protocol Addressing Cultural Competence	7 (6, 9)	Keep	Changed wording to “Culturally Competent Care”	8 (7, 8)	Expanded on definition	Keep
Educational Programs reflecting Cultural Competency and Cultural Humility	7 (6, 9)	Keep	Merged with “Culturally Competent Care”	N/A	N/A	N/A

Program/Protocol for recruitment and retention of staff of diverse backgrounds	8 (5.5, 9)	Keep	Merged with “Educational Programs on Person-Centred Care”	N/A	N/A	N/A
Supporting a Workforce Committed to Person-Centred Care	7 (4, 9)	Disagreement	Merged with “Policy on Person-Centred Care”	N/A	N/A	N/A
Providing a Supportive and Accommodating Person-Centred Care Environment	7 (5, 8)	Keep	Clarified language in description	7 (6, 8)	None	Keep
Providing an Environment that Reflects Diversity and Inclusion	8 (5, 9)	Keep	Merged with “Providing a Supportive and Accommodating Person-Centred Care Environment”	N/A	N/A	N/A
Partnership with Communities	8 (6, 9)	Keep	Expanded description; changed wording to “Co-designing care in partnership with communities”	8 (7, 8)	Components merged with “Policy on Person-Centred Care”	Keep
Protocol for the Integration of	8 (5, 9)	Keep	Expanded description;	8 (6, 8)	Components merged with	N/A

Structures to Support Health Information Technology			changed working to "Healthcare Information Technology to Support Person-Centred Care"		"Policy on Person-Centred Care"	
Structures to Report Person-Centred Care Performance	8 (8, 9)	Keep	Changes to description of data source	8 (8, 9)	None	Keep
Process Indicators						
Compassionate Care	9 (8, 9)	Keep	Broadening of definition, providing example measures	8 (8, 9)	None	Keep
Equitable care	8 (7, 9)	Keep	Broadening of definition, providing example measures	9 (8, 9)	Expanded definition	Keep
Trusting Relationship with Healthcare Provider	9 (8, 9)	Keep	Broadening of definition, providing example measures	8 (8, 9)	None	Keep
Accessing Interpreter Services	8 (7, 9)	Keep	Broadening of definition, providing example measures	8 (7, 9)	None	Keep

Communication with Healthcare System	8 (7, 9)	Keep	Broadening of definition, providing example measures	8 (8, 9)	Example items from measure included	Keep
Communication between Patient and Healthcare Provider - Nurse	8 (7.5, 9)	Keep	Broadening of definition	8 (8, 9)	Edits to example measures	Keep
Communication between Patient and Healthcare Provider - Physician	8 (8, 9)	Keep	Broadening of definition	9 (8, 9)	Edits to example measures	Keep
Information about Taking Medication	9 (7, 9)	Keep	Expanded on description	8 (8, 9)	Expanded description	Keep
Communicating Test Results	8 (7, 9)	Keep	Expanded on description; providing example measures	8 (8, 9)	None	Keep
Coordinating Your Care	9 (7, 9)	Keep	Expanded on description; changed wording to “Coordination of Care”	8 (8, 9)	Expanded on definition	Keep
Patient Involvement in Decisions About Their Care and Treatment	8 (8, 9)	Keep	Broadening of definition	9 (8, 9)	Changed wording to “Patient and Caregiver Involvement in Decisions	Keep

					about Their Care and Treatment”	
Engaging Patients in Managing their Own Health	8 (7, 9)	Keep	Clarification of self-management	8 (8, 9)	Expanded on definition	Keep
Timely Access to a Primary Care Provider	8 (7, 9)	Keep	None	8 (6.5, 9)	None	Keep
Patient preparation for a planned admission to hospital	8 (7, 9)	Keep	Broadening of definition and wording changed to “Patient Preparation for a Planned Treatment Program”	8 (7, 9)	None	Keep
Time to Unplanned Admission Through Emergency Department	7.5 (6, 9)	Discard	Discarded by panel	N/A	N/A	N/A
Discharge Planning	9 (8, 9)	Keep	Change focus from discharge to continuum of care; wording changed to “Transition Planning”	9 (8, 9)	Edits to example measures	Keep

Post-Discharge Planning	8 (7, 9)	Keep	Merged with “Transition Planning”	N/A	N/A	N/A
Timely Follow-up with Hospital Discharged Patients	8 (5, 9)	Keep	Merged with “Transition Planning”	N/A	N/A	N/A
Discharge Summaries Available to Community Care Provider Within 48 Hours of Discharge	8 (7, 9)	Keep	Merged with “Transition Planning”	N/A	N/A	N/A
Noise During Hospitalization/Stay	7 (6, 8)	Keep	Merged with “Providing a supportive and accommodating person-centred care environment”	N/A	N/A	N/A
Outcome Indicators						
Overall Rating	7.5 (5, 8.5)	Discard	Discarded by panel	N/A	N/A	N/A
Overall Experience	8 (6, 9)	Keep	None	9 (7, 9)	Expanded description	Keep
Cost of Care-Affordability	6.5 (5, 9)	Keep	None	7 (5, 9)	None	Keep
Patient-Reported Outcomes – General Health	7 (5, 9)	2 (1, 4)	Discarded by panel; agreed to discuss in working group	7 (5, 9)	None	Keep

Patient-reported Outcomes – Multi-attribute	7 (5, 8)	Discard	Discarded by panel	N/A	N/A	N/A
Patient Reported Outcomes- Mental Health	7 (5, 9)	Discard	Discarded by panel	N/A	N/A	N/A
Global Indicator (n=1)						
Friends and Family Test	7 (5, 9)	6.5 (2.5, 7)	None	7 (6, 8)	None	Keep

Improving the Quality of Person-Centred Healthcare from the Patient Perspective: Development of Person-Centred Quality Indicators

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Improving the Quality of Person-Centred Healthcare from the Patient Perspective: Development of Person-Centred Quality Indicators

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Author Contributions:
MJS, KM, SZ, SB, EG, KL, HQ, and RS contributed to the study concept, study design, and acquisition of funding. MJS and KM conducted data analysis and the modifications/refinements to the Person-Centred Quality Indicators that are presented in this manuscript. The manuscript was drafted by MJS, KM, and PF. All authors (MJS, KM, SZ, SB, EG, JK, LF, SW, PF, KL, HQ, and RS) contributed to the data acquisition and interpretation, critical review and revision of the manuscript for intellectual content. All authors also provided their final approval of this publication and agree to be accountable for all aspects of the work to ensure both accuracy and integrity of this research.

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Transparency statement: The lead author affirms that this manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned (and, if relevant, registered) have been explained.

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Data sharing statement: Some materials and documentation may be available to other researchers. Please contact the corresponding author with a detailed request.

ABSTRACT

Importance: International efforts are being made towards a person-centered care (PCC) model, but there are currently no standardized mechanisms to measure and monitor PCC at a healthcare system level. The use of metrics to measure PCC can help to drive the changes needed to improve the quality of healthcare that is person-centred.

Objective: To develop and validate person-centred care quality indicators (PC-QIs) measuring PCC at a healthcare system level through a synthesis of the evidence and a person-centred consensus approach to ensure the PC-QIs reflect what matters most to people in their care.

Methods: Existing indicators were first identified through a scoping review of the literature, and an international environmental scan. Focus group discussions with diverse patients and caregivers, and interviews with clinicians and experts in quality improvement allowed us to identify gaps in current measurement of PCC and inform the development of new PC-QIs. A set of identified and newly developed PC-QIs were subsequently refined by Delphi consensus process using a modified RAND/UCLA Appropriateness Method. The international consensus panel consisted of patients, family members, community representatives, clinicians, researchers, and healthcare quality experts.

Results: From an initial 39 unique evidence-based PC-QIs identified and developed, the consensus process yielded 26 final PC-QIs. These included seven related to structure, 16 related to process, two related to outcome and one overall global PC-QI.

Conclusions: The final 26 evidence-based and person-informed PC-QIs can be used to measure and evaluate quality incorporating patient perspectives, empowering jurisdictions to monitor healthcare system performance and evaluate policy and practice related to PCC.

Article Summary

Strengths and limitations

- The development of the Person-Centred Quality Indicators (PC-QIs) was conducted using a multi-phased rigorous scientific process in collaboration with an international team of experts.
- The development of the indicators followed the National Quality Forum's criteria for "good quality indicators."
- The perspectives of diverse patients, caregivers, and community members were incorporated into the development of the PC-QIs, as well as healthcare providers and quality improvement experts.
- The study did not include an evaluation of PC-QI implementation.

INTRODUCTION

In 2017, health ministers from OECD countries declared that we need to invest in measuring what matters most to patients[1,2]. Ever since patient-centred care (PCC) was first identified as a foundational component of healthcare quality and patient safety by the Institute of Medicine in 2001[3], it has been recognized as a high priority by healthcare systems globally.[4-8] The use of valid and reliable measures to monitor and evaluate PCC can provide the data needed to identify gaps in the delivery of PCC and target areas for improvement, and thus, drive the changes needed to move towards a true PCC model.

However, there are currently no generally accepted indicators for measuring PCC.[9] Moreover, existing indicators do not tend to incorporate the voices of people involved in healthcare, namely, patients, caregivers, and healthcare providers.[10] This gap means that PCC itself might be measured in ways not relevant to patients, and in ways that do not address practical concerns of healthcare providers for person-centred quality improvement.

Evidence also suggests that the delivery of PCC improves healthcare quality, including improvement of patient experiences and outcomes, enhanced involvement of people in their own healthcare decisions, more support for health promotion activities, a decrease in healthcare services utilization and costs, and an improvement in healthcare provider satisfaction.[11-14]

The overall aim of this research was to ensure that the patient perspective can be used to inform improvements in healthcare quality at the system level by developing a core group of person-centred quality indicators (PC-QIs), based on a synthesis of the evidence and, importantly, includes what matters to patients, caregivers, diverse community members, healthcare providers and quality improvement experts, and researchers, when it comes to healthcare. This article presents a new set of evidence-based and person-informed PC-QIs that were developed and validated through a modified Delphi consensus. The use these standardized metrics to measure PCC can help to drive the changes needed to improve the quality of healthcare that is person-centred.

METHODS

This study was part of a multi-phased programme of research to develop, implement, and evaluate PC-QIs for measuring and improving PCC (See *Figure 1 – Study at a glance*). The development of the PC-QIs included two phases. During Phase 1, previously implemented and evaluated PC-QIs were identified and classified using a published PCC framework.[10] In Phase 2, these identified PC-QIs were refined through a modified Delphi consensus process [15] that involved patients, caregivers, and diverse community members, clinicians, quality improvement leaders and decision makers. While this paper provides an overview of the methods used to develop the PC-QIs prior to the consensus process, additional details regarding the first phase of this research (i.e. scoping review of the literature, international environmental scan, focus group discussions, and interviews with stakeholders) will be published elsewhere. Ethics approval was granted from the University Health Research Ethics Boards [REB15-2846] at the University of Calgary.

FIGURE 1 HERE

Patient and Public Involvement

Our research is guided by a transformative framework with the aim of producing knowledge that seeks to improve healthcare for all people, whilst acknowledging that marginalized groups do not tend to be included in the production of knowledge due to existing power and social relationships within society. [16] Thus, consistent with a PCC, we strived to consult with diverse patients and caregivers as active collaborators through a participatory approach – doing research "with" rather than "on" them.

A patient partner (SZ) was recruited to as part of the research team at the study's inception, and to ensure the study is guided by the patient perspective. The patient partner has played a critical role in the study design, data collection, review of analyses, interpretation of the data, and the development of this manuscript, in addition to disseminating the findings of this research. Moreover, in Phase 1 of this study, we used a participatory approach to engage diverse patients and caregivers to identify what matters most to them in their healthcare. This would ensure that patient values, needs, and preferences are incorporated into the development of the indicators. These focus groups were conducted with the provincial Alberta Health Services Patient and Family Advisory Group, as well as ActionDignity (www.actiondignity.org), a community-based organization that works closely with ethno-cultural leaders in Calgary to conduct research and work towards systems and policy change. These organizations supported the development of the focus group discussion tools, recruitment, data collection, analysis, and dissemination of findings. In Phase 2 of the study, we used a consensus process with a panel of 29 people of patients, caregivers, diverse community members, providers, researchers, and quality improvement leads, which is described in this paper. Participants were routinely asked about burdens to participation to ensure appropriate accommodations.

Phase 1: Preliminary review

This first phase involved preparatory work needed for the consensus process. In order to identify, categorize, and develop PC-QIs, we developed a conceptual PCC framework [10] based on the Donabedian quality of care model (Structure, Process and Outcome).[17]

This phase also involved a scoping review [18,19] to identify 29 previously published PC-QIs, their implementation and evaluation in various settings, as well as best practices of PCC monitoring. To be eligible for inclusion, studies/articles had to (1) identify quality indicators for PCC and/or (2) identify PC-QIs in performance measurement (e.g., validation).[18] Indicators were assessed as being person-centred, based on the use of a PCC conceptual framework.[10]

In parallel to the scoping review [19], an environmental scan was conducted to identify if healthcare systems in Canada, the United Kingdom, Sweden, Australia and New Zealand were using PC-QIs, which PC-QIs were in use, and how they were implemented.[20] These countries were chosen as they shared many similarities with respect to healthcare delivery and structures.[20] 61 existing indicators were identified. All unique PC-QIs identified through the scoping review and environmental scan were synthesized by the research team.

Focus group discussions with patients and caregivers, as well interviews as key stakeholders (i.e. quality improvement leads, healthcare providers, and PCC researchers) were conducted to inform the development and prioritization of PC-QIs. With regards to focus group discussions, we employed strategies to attain maximum variation among participants to ensure the patient and caregiver perspectives represent a greater diversity of people, with considerations for age, race, ethnicity, indigeneity, gender and sexual identities, rural/urban, disease conditions, and health care sectors accessed. Focus group discussions were conducted in partnership with the provincial Alberta Health Services Patient and Family Advisory Group and ActionDignity (described previously). These organizations supported the recruitment, data collection, analysis, and dissemination of findings. We identified healthcare values, preferences, and needs from a diverse sample of 65 patients and caregivers. Individual interviews with 22 healthcare providers, quality improvement experts, and PCC researchers from Canada, the USA, and England were conducted to determine perceptions around feasibility and prioritization of measuring specific domains of PCC. The findings from these focus groups and interviews were used to identify the most important PC-QIs from those that were found in the scoping review and environmental scan, as well as to guide how existing PC-QIs could be modified or refined. The focus groups and interviews also allowed us to identify any PC-QIs still needed for development.

Based on the findings from Phase 1 and a review of the literature pertaining to gaps in measurement identified through the focus groups and interviews (i.e. access to an interpreter, cost of care, etc.), 39 unique PC-QIs were developed or modified iteratively by the research team, and subsequently classified using the PCC conceptual framework.[10] The details and key results from these sub-studies for Phase 1 have either been published or in the process of publication elsewhere. [18-20]

Phase 2: Modified Delphi Panel Exercise

Phase 2 included a consensus process, using the RAND/University of California LA Appropriateness Method (RAM).[21] RAM is a reproducible and valid nominal group technique consensus methodology using the modified Delphi technique.[15] This consensus method is used extensively in health services research.[21-23] Based on our previous experience [24, 25], the consensus method was considered highly appropriate to facilitate the panel's prioritization and refinement PC-QIs. The Delphi technique was modified to include additional people as part of the consensus process, to ensure greater representation from patients, caregivers, community members.

Panel Selection

A consensus panel was established consisting of patients, caregivers, diverse community members, healthcare providers, PCC researchers, and quality improvement leads. In recognition of the potential power dynamics associated with mixing groups of patients [22] , caregivers, healthcare providers, researchers, and quality improvement experts, we strove to assemble a panel where at least half of the representation was from patients, caregivers, and community members. The community members were representative from the some of the most prominent ethno-cultural communities in Calgary (i.e. Chinese, South Asian, and Filipino). The panelists were identified from their previous participation in the environmental scan, interviews, and focus groups conducted in Phase 1, as well as our collaborators' networks. Identified individuals were invited via email and provided with a summary of the project and an overview of the consensus process and expectations (e.g., time commitment and activities).

Rating Process and Materials

Panelists received a package including:

a) a manual that included a monograph of each PC-QI identified, and

b) a rating tool used for panelists to rate the PC-QIs (see rating tool here: http://bit.do/PC-QI_RatingTool)

The package outlined the PC-QIs that included descriptors such as: type of indicator, proposed data source (including existing patient-reported experience measures already in use), definition, numerator, denominator, benchmark, and risk adjustment. The manual also included definitions to describe what PC-QIs are, and what constitutes a "good" quality indicator, as outlined by the National Quality Forum, which states the criteria for evaluating a new measure: importance, scientific acceptability, feasibility, and usability.[26] Additionally, the rating tool was derived from the Joint Commission Attributes of Core Performance Measures and Associated Evaluation Criteria.[27] The rating tool asked panelists to rate PC-QIs on each of the following dimensions:

- Was the PC-QI precisely defined?
- Does the PC-QI target important PCC improvements?
- Does it measure what is supposed to measure?
- It is a good global PC-QI for overall evaluation?

These questions were designed to assess *face, as well as construct validity* (i.e. whether the PC-QI measures what it is supposed to measure), and *appropriateness* (whether the PC-QI is an appropriate measure for PCC). The ratings materials also included questions related to implementation including *feasibility* (is data for reporting PC-QI available?) and *usability* (is the PC-QI actionable and interpretable?). Panelists used SurveyMonkey, a web-based survey tool, to remotely rate the PC-QIs in the first, third, and fourth rounds.

Delphi Round 1

The first round involved remote rating by panelists. In each of these remote rating rounds, panelists used the rating material described above and the rating scale, a 9-point scale (1 = strong disagreement, 9 = strong agreement). Overall assessment of the PC-QI scored as: *inappropriate* (1-3), *supplementary* (consider as a PC-QI if more resources available) (4-6) and *appropriate* (7-

9).[21] Panelists also had the opportunity to provide written comments and suggest additional PC-QIs.

PC-QIs ratings were summarized using medians and inter-quartile rage (IQR) for the overall rating included in the “globally it is a good PC-QI?” rating scale. Disagreement on the rating for a PC-QI of at least a third of the panel (n=>9) in the median score 1-3 and at least a third (n>=9) of the panel in the median 7-9. PC-QIs with median overall scores of 1-3 were discarded; PC-QIs with median overall score 4-9 were retained for subsequent rounds. Written comments were analyzed using content analysis methods.

Following remote ratings in round 1, the data were analyzed, and suggestions and refinements were made to each PC-QI as appropriate. This revised version was shared via SurveyMonkey prior to the face-to face meeting.

Delphi Round 2

During Round 2, panelists reviewed each PC-QI in a face-to-face meeting as well as the results from the first round. The 2-day meeting was co-moderated by our patient-partner (SZ) and a clinician researcher. The moderators led the panel through each of the PC-QIs to review the results from the first round and to note areas of disagreement (indicated by the ratings) as they pertained to: perceived importance/necessity and relevancy for person-centred care; scientific acceptability (reliability and validity); feasibility of implementing the PC-QIs given different contexts of care; and usability to make improvements in care. The research team was available to answer clarifying questions about how the PC-QI was identified/developed and the source of the evidence supporting the PC-QIs. Deliberations were made as a group until agreement on PC-

QI specifications was achieved through discussion and subsequent rounds of re-rating. Additionally, a number of indicators were proposed for merging and further refinement, particularly for perceived redundancies and in consideration for decreasing the total number of PC-QIs (for feasibility and concerns around indicator fatigue). Modifications were made to the PC-QIs required subsequent rounds of rating.

Delphi Rounds 3 & 4

Remote ratings in rounds 3 and 4 continued as described in the first remote rating to obtain consensus for the modified/merged PC-QIs. Through the remote rounds, revisions of each PC-QI were added to the working document and circulated among panelists for a final rating using paper-based rating tools for final review. Prior to the third round of rating, a working group that created as a response to the discussions held during the face-to-face meeting, studied the development of an indicator that captures outcomes reported directly by the patients. This working group included five patients, two family members, one physician, two quality improvement leads and two researchers. The group worked on developing the indicator and gathering information to present background knowledge to the rest of panelists. The new indicator and additional information were shared among the rest of the panelists and they rated the new indicator in round 3. Proposed refinements to the PC-QIs during round 3 were agreed on during round 4 of rating, where panelists were also asked specifically about the necessity of each PC-QI, rating either a ‘yes’ or ‘no’ to keeping the indicator.

Appendix 1, displays the ratings as median scores on a 9-point scale and interquartile range, as reported in previous studies [21, 24, 25], as well as details on modifications that were proposed by panelists. A flow chart of the rating process can be found in *Figure 2*.

FIGURE 2 HERE

RESULTS

Panel

A total of 29 people participated on the consensus panel. The consensus panel comprised:

- 8 patients and 3 caregivers (37.9%) with various experience with the health care system, including primary care, acute care, cancer care, and chronic diseases (e.g. cardiovascular conditions, diabetes, etc.)
- 5 members of diverse ethno-cultural communities (17.2%) who are also patients and/or caregivers
- 2 healthcare providers (6.9%; an internist and a pediatrician),
- 5 quality improvement experts (17.2%; representing Canadian Quality Councils and health systems, Cancer Care Ontario, University of Gothenburg Centre for Person-centred Care, Sweden, Picker Institute, and University of Oxford, UK),
- 4 PCC researchers (13.8%), including: a lead from the Patient-Centered Outcomes Research Institute (PCORI), a Senior Scientist Collaboration for Leadership in Applied Health Research and Care Oxford Unit, professors from Canadian Universities and leaders of the Canadian Strategy for Patient-Oriented Research
- 1 representative (3.4%) of the Canadian Institute for Health Information
- 1 representative (3.4%) from Ministry of Health, British Columbia

Of the 29 panelists, for round 2, 27 attended in person, 1 attended via videoconference and 1 was absent (with this panelists comments shared with the panel). For rounds 3 and 4, 27 panelists participated in the consensus, with two panelists not participating in this phase (one caregiver and one clinician-researcher) due to conflicting commitments.

Person-Centred Quality Indicators

Thirty-nine PC-QIs were identified through Phase 1 and were refined through Phase 2 of the study, where they were summarized into 26 final PC-QIs. These final 26 PC-QIs included seven structure, 16 process, two outcome and one global indicator (*see Table 1*). During the first round and based on final ratings (*see Table 1*), 4 indicators were discarded including:

- Timely Unplanned Readmission from ER
- Overall Rating
- Patient-reported Outcome Multi-attribute
- Patient-reported Outcome Mental Health

Based on the decision to discard the last two PC-QIs, the working group proposed a new indicator related to Patient-Reported Outcomes: “Using Patient-Reported Outcome Measures to deliver Patient-Centred Care.” This newly proposed indicator was later rated and accepted in Round 3. *Table 1* summarizes the consensus panel ratings as well as the sources of evidence for each of the indicators. During Round 2, out of the initial 39 indicators, 11 were merged with other indicators (see *Table 2*).

Table 1: Summary of Consensus Panel Ratings for Final 26 PC-QIs Developed by the Panel (Median Score on 9-point Scale and (Interquartile Range)) and Sources for Evidence

Person-Centred Quality Indicators	Round 1 Remote Panel Rating	Round 2 Face-to-Face Panel Rating	Round 3 Remote Panel Rating	Evidence Sources SR = Scoping Review ES = Environmental Scan FGD = Focus Group Discussions I = Interviews
Structure Indicators (n= 7)				
Policy on Person-Centred Care	8 (6, 9)	Keep	8 (7, 8)	SR, ES, FGD, I
Educational Programs on Person-Centred care	8 (7, 9)	Keep	8 (7, 8)	SR, FGD, I
Culturally Competent Care	7 (6, 9)	Keep	8 (7, 8)	SR, FGD
Co-designing care in partnership with communities	8 (6, 9)	Keep	8 (7, 8)	FGD
Providing an Accommodating and Supportive Person-Centred Care Environment	7 (5, 8)	Keep	7 (6, 8)	SR, FGD
Healthcare Information Technology to Support Person-Centred Care	8 (5, 9)	Keep	8 (7,8)	I
Structures to Report Person-Centred Care Performance	8 (8, 9)	Keep	8 (8, 9)	I
Process Indicators (n=16)				
Compassionate Care	9 (8, 9)	Keep	8 (8, 9)	SR, FGD, I
Equitable care	8 (7, 9)	Keep	9 (8, 9)	SR, FGD, I
Trusting Relationship with Healthcare Provider	9 (8, 9)	Keep	8 (8, 9)	SR, FGD, I
Timely Access to a Primary Care Provider	8 (7, 9)	Keep	8 (6.5, 9)	ES, FGD
Accessing Interpreter Services	8 (7, 9)	Keep	8 (7, 9)	SR, FGD

Communication with Healthcare System	8 (7, 9)	Keep	8 (8, 9)	SR, ES, FGD
Communication between Patient and Healthcare Provider - Nurse	8 (7.5, 9)	Keep	8 (8, 9)	SR, ES, FGD, I
Communication between Patient and Healthcare Provider - Physician	8 (8, 9)	Keep	9 (8, 9)	SR, ES, FGD, I
Information about Taking Medication	9 (7, 9)	Keep	8 (8, 9)	SR, ES, FGD
Communicating Test Results	8 (7, 9)	Keep	8 (8, 9)	SR, FGD
Coordination of Care	9 (7, 9)	Keep	8 (8, 9)	SR, ES, FGD
Patient and Caregiver Involvement in Decisions about their Care and Treatment	8 (8, 9)	Keep	9 (8, 9)	SR, ES, FGD, I
Engaging Patients in Managing their Own Health	8 (7, 9)	Keep	8 (8, 9)	SR, ES, FGD, I
Patient Preparation for a Care Plan at a Healthcare Facility	8 (7, 9)	Keep	8 (7, 9)	SR, ES, FGD
Transition Planning	9 (8, 9)	Keep	9 (8, 9)	FGD
Using Patient-reported Outcome Measures (PROMs) to Deliver Patient-Centred Care	Not developed	Newly developed derived from previous 'Patient-reported outcomes'	7 (5, 9)	Consensus
Outcome Indicators (n=2)				
Cost of Care- Affordability	6.5 (5, 9)	Keep	7 (5,9)	FGDs
Overall Experience	8 (6, 9)	Keep	9 (7, 9)	SR, ES
Global Indicator (n=1)				
Friends and Family Test	7 (5, 9)	6.5 (2.5, 7)	7 (6, 8)	ES

Table 2: Merged PC-QIs

Original PC-QIs	Final PC-QIs Incorporating Original PC-QIs
Structure	
Supporting a Workshop Committed to PCC	Policy on PCC
Partnership with Communities	
Protocol for integration of structures to support health technology	
Protocol addressing discriminatory care	Educational Programs on PCC
Program/protocol for recruitment and retention of staff of diverse background	
Noise during hospitalization	Providing an Accommodating and Supportive Person-Centred Care Environment
Providing an Environment that Reflects Diversity and Inclusion	
Educational Programs Reflecting Cultural Competency and Humility	Culturally Competent Care
Process	
Post-discharge planning	Transition Planning
Timely follow-up after discharge	
Discharge summaries available after 48 hour of discharge from hospital	

A complete summary of the final PC-QIs that were developed is available here: https://www.personcentredcareteam.com/s/PC-QIs_Monograph_Santana-et-al-2019.pdf Each of these newly developed indicators are evidence-informed and person-centred, some addressing a specific aspect of healthcare quality (e.g. safety versus equity).

DISCUSSION

As Moira Stewart stated in her 2001 editorial: “The patient should be the judge of patient-centred care.”[28] This article presents a new set of Person-Centred Quality Indicators (PC-QIs) developed and validated through a modified Delphi process that featured the patient perspective on what matters most to them in their care. These PC-QIs are evidence-based and patient-informed, and widely applicable across healthcare sectors and contexts.

The strength of this study is the person-centred approach used to develop metrics to evaluate PCC, which ensures that PCC is evaluated from the perspective of those who provide and receive care. To our knowledge, this is the first study to develop a generic set of PC-QIs using a rigorous evidence-based and person-centred approach, and involving the patient and caregiver throughout the research process – from inception to manuscript development. Using a highly participatory approach and a transformative lens, we sought to ensure the study was guided by the patient perspective, and that diverse and marginalized perspectives were reflected in the development of the PC-QIs. While PC-QIs were identified in the scoping review, first – the vast majority of these were not considered actual indicators in compliance with quality improvement agencies, such as the Agency for Healthcare Research and Quality (presented as units of measurement, such as percentage or proportion); second – many measures were not developed with significant patient input.[29] For instance, previous work conducted by Ouwens et al. in 2010 to develop a person-centred measures for cancer care involved patients in determining what would be important to measure.[30] The patient involvement was limited to semi-structured interviews to obtain the patient perspective on what guideline recommendations could be used for measuring PCC. In another study related to the development of measures for person-centred cancer care, Uphoff et al. 2012 involved patients as part of the consensus panel along with medical professionals.[31] While this work has been instrumental in demonstrating the value of the patient perspective in developing measures for PCC, only three patients were involved, out of fourteen experts on the panel. Issues around potential power imbalances were not accounted for. In our study, we strived to have approximately half of our panelists comprised of patients, caregivers, and community members, to ensure a balance of perspectives. For most quality indicators that are developed, including those we identified in our environmental scan, PC-QIs tend to be developed based on what healthcare authorities, quality improvement experts, or researchers deem as most important for quality improvement. Patients and the public are seldom involved in decisions about quality of care despite being the ones who experience and receive care. How can PCC be truly improved if we continue to measure PCC without the patient perspective on what should be measured? These newly developed indicators present an opportunity to improve healthcare quality in ways that matter most to people. To drive changes in healthcare policy and practice, there is a need to develop and implement standardized ongoing mechanisms to measure and evaluate quality incorporating the patients' perspectives.[14]

These PC-QIs offer a tremendous opportunity leverage ongoing initiatives to improve PCC by using data already being collected in many healthcare jurisdictions and helping to standardize the collection, use, and reporting of this data. This includes patient-reported experience measures (PREMs, such as Hospital Consumer Assessment of Health Providers and Systems) and patient-reported outcome measures (PROMs). Integrating PC-QIs into performance measurement frameworks can promote actionability for improving PCC. While PREMs and PROMs are often used at the provider level, there is little evidence of use for system-level applications and actionability. These indicators empower jurisdictions to monitor healthcare system performance and evaluate policy and practice related to PCC, while also including the patient's voice. Finally, the routinized use of standardized metrics, such PC-QIs, to evaluate PCC will help to strengthen the evidence-base for the PCC model.[32]

A key limitation of this research is that these indicators have yet to be operationalized and evaluated in practice. It is only through empirical testing that the feasibility of data collection can be determined and whether they meet the requirements of “good quality measures” – that are acceptable, reliable, and valid.[33] Moreover, studying the implementation of the PC-QIs can provide important insight into their effectiveness for promoting improvements in PCC as well as patient experiences and outcomes. It is also important to identify any unintended consequences as a result of PC-QI implementation, their use for benchmarking, and other issues, such as workload and cost-effectiveness.[33] Additionally, while this method has generated these 26 PC-QIs using a validated consensus method, they may not necessarily be universally applicable in all countries and settings. Different cultural settings in different healthcare regulatory environments may mean that different measures may be more appropriate for certain settings. Further work can be done to tailor and adapt these PC-QIs, recognizing that a consideration of the local context will ensure a more universal relevance.

Future steps for this work include an assessment of the feasibility of implementing these PC-QIs. Secondly, we plan to pilot the use of the PC-QIs in national and international jurisdictions to promote PCC and to evaluate of the use of these measures for improving healthcare quality of care from the perspectives of the patient.

CONCLUSIONS

In conclusion, the development of these newly developed evidence-based and person-informed PC-QIs represent an important contribution towards efforts to measure and improve person-centred care. While these indicators have yet to be evaluated, the PC-QIs are available tools that healthcare systems can use to monitor and evaluate the delivery of PCC, identify the gaps, and make the changes needed to improve the quality of care. Importantly, these indicators have the potential to shift our healthcare systems towards a new paradigm for assessing quality by ensuring we measure what matters most to patients

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References

1 OECD. Health Ministerial Statement - The next generation of health reforms. Published January 17 2017; accessed November 2019. http://www.oecd.org/health/ministerial/ministerial-statement-2017.pdf.

2 Coulter, A. Measuring what matters to patients. *BMJ 2017;356:j816.*

3 Institute of Medicine. Crossing the quality chasm: A new health system for the 21st century. Washington (DC): National Academies Press:2001.

4 Pelzang R. Time to learn: Understanding patient-centred care. *Br J Nurs* 2010;19:912-7.

5 National Department of Health - National Health Service. NHS 2010-2015: From Good to Great. Preventative, People-Centred, Productive. 2009.

6 Davis K, Schoenbaum SC, Audet AM. A 2020 vision of patient-centered primary care*. J Gen Intern Med* 2005;20:953-7.

7 Alberta Health Services. The Patient First Strategy. 2015.

8 Stoelwinder JU. Final report of the National Health and Hospitals Reform Commission: will we get the health care governance reform we need? *Med J Aust* 2009;191:387-8.

9 World Health Organization. Leading and Managing Change towards People-Centred and Integrated Health Services. 2015.

10 Santana MJ, Manalili K, Jolley RJ, et al. How to practice person-centred care: A conceptual framework. *Health Expect* 2018;21:429-40.

11 Stewart M, Brown JB, Donner A, et al. The impact of patient-centered care on outcomes. *J Fam Pract* 2000;49:796-804.

12 McMillan SS, Kendall E, Sav A, et al. Patient-centered approaches to health care: a systematic review of randomized controlled trials. *Med Care Res Rev* 2013;70:567-96.

13 Mead N, Bower P. Patient-centred consultations and outcomes in primary care: a review of the literature. *Patient Educ Couns* 2002;48:51-61.

14 Berwick DM, Nolan TW, Whittington J. The triple aim: care, health, and cost. *Health Aff* 2008;27:759-69.

15 Jones J, Hunter D. Consensus methods for medical and health services research. *Br Med J* 1995;311:376.

16 Mertens DM, Holmes HM, Harris RL. Transformative research and ethics. In: Mertens DM, Ginsberg, PE eds. The Handbook of Social Research Ethics. Sage Publications: Thousand Oaks, CA. 2009:85-101.

17 Donabedian A. Evaluating the quality of medical care. *Milbank Q* 1966;44:166-206.

18 Jolley RJ, Lorenzetti DL, Manalili K, et al. Protocol for a scoping review study to identify and classify patient-centred quality indicators. *BMJ Open* 2017;7:e013632.

19 Santana MJ, Ahmed S, Lorenzetti D, et al. Measuring patient-centred system performance: a scoping review of patient-centred care quality indicators. *BMJ Open* 2019;9:e023596.

20 Doktorchik C, Manalili K, Jolley R, et al. Identifying Canadian patient-centred care measurement practices and quality indicators: a survey. *CMAJ Open* 2018;6:e643.

21 Fitch K, Bernstein SJ, Aguilar MD, Burnand B, LaCalle JR. The RAND/UCLA appropriateness method user's manual. RAND CORP: Santa Monica, CA; 2001.

22 McKenzie E, Potestio ML, Boyd JM, et al. Reconciling patient and provider priorities for improving the care of critically ill patients: a consensus method and qualitative analysis of decision making. *Health Expect* 2017;20:1367-74.

23 Stelfox HT, Straus SE. Measuring quality of care: considering conceptual approaches to quality indicator development and evaluation. *J Clin Epidemiol* 2013;66:1328-37.

24 Stelfox HT, Khandwala F, Kirkpatrick AW, Santana MJ. Trauma center volume and quality improvement programs. *J Trauma Acute Care Surg* 2012;72:962-8.

25 Santana MJ, Stelfox HT. Development and evaluation of evidence-informed quality indicators for adult injury care. *Ann Surg* 2014;259:186-92.

26 Dimick JB. What makes a "good" quality indicator?: comment on "Quality indicators for evaluating trauma care". Archives of Surgery. 2010 Mar 1;145(3):295.

27 The Joint Commission. Attributes of Core Performance Measures and Asssociated Evaluation Criteria. 2010.

28 Stewart M. Towards a global definition of patient centred care: the patient should be the judge of patient centred care. *BMJ* 2001;322:444-5.

29 Agency for Healthcare Research and Quality. Quality Improvement and monitoring at your fingertips. Secondary Quality Improvement and monitoring at your fingertips. https://www. qualityindicators. ahrq.gov/ (Accessed 01 Oct 2017).

30 Ouwens M, Hermens R, Hulscher M, Vonk-Okhuijsen S, Tjan-Heijnen V, Termeer R, Marres H, Wollersheim H, Grol R. Development of indicators for patient-centred cancer care. *Support Care Cancer*. 2010 Jan 1;18(1):121.

31 Uphoff EP, Wennekes L, Punt CJ, Grol RP, Wollersheim HC, Hermens RP, Ottevanger PB. Development of generic quality indicators for patient-centered cancer care by using a RAND modified Delphi method. *Cancer Nurs*. 2012 Jan 1;35(1):29-37.

32 Montague T, Gogovor A, Aylen J, et al. Patient-Centred Care in Canada: Key Components and the Path Forward. *Healthc Q* 2017;20:50-6.

33 Grol R, Wensing M, Eccles M, Davis D, Editors. Improving patient care: the implementation of change in health care. John Wiley & Sons; 2013.

Figure 1 Legend: Figure 1 shows an overview of the program of research on Developing Person-Centred Quality Indicators (PC-QIs). The program of research includes three phases of research: Identifying and Developing PC-QIs; refinement of the PC-QIs, and feasibility of assessment of the newly developed PC-QIs. This manuscript shows the final results (final set PC-QIs), based on research from the first two phases.

Figure 2 Legend: Figure 2 shows a flow chart of the PC-QI Delphi process, describing the timeline for Rounds alongside the numbers of PCQIs surviving each round. There are arrows pointing down from "39 PCQIs evaluated" to each subsequent "*n* PCQIs evaluated" box, until the final "26 PCQIs evaluated" box.

Figure 1: Study at a Glance

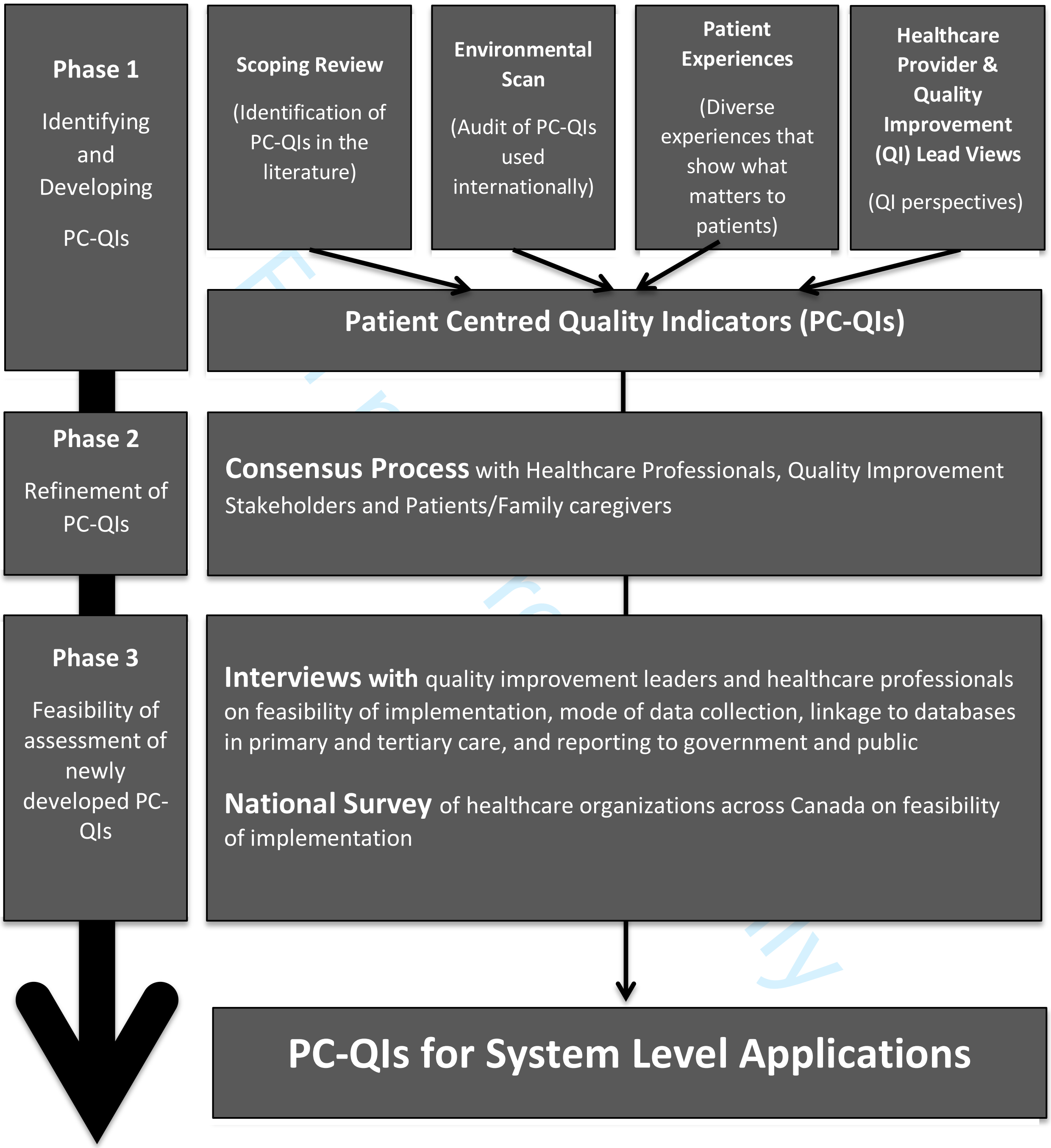

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Figure 2: Flow Chart of PC-QI Delphi Process (Ratings and Modifications)

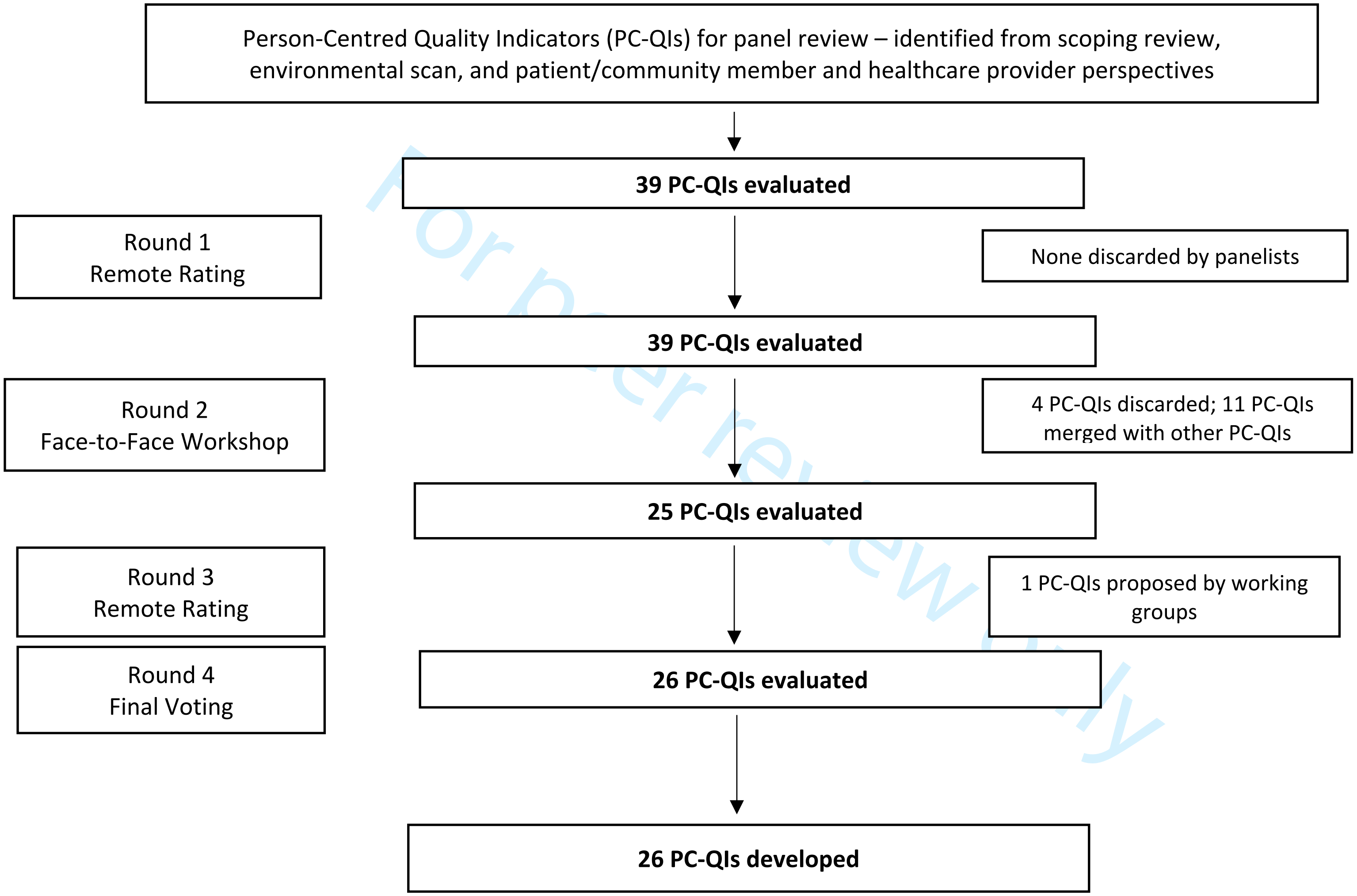

Figure 2 shows a flow chart of the PC-QI Delphi process, describing the timeline for Rounds alongside the numbers of PCQIs surviving each round. There are arrows pointing down from “39 PCQIs evaluated” to each subsequent “*n* PCQIs evaluated” box, until the final “26 PCQIs evaluated” box.

Appendix 1: Summary of Ratings [median score on 9-point scale and interquartile range (IQR)] and Modifications for PC-QIs Rated and Revised (PC-QIs = 39)

Initial Person-Centred Quality Indicators	**Round 1 Remote Panel Rating Median Score on 9-point Scale (IQR)**	**Round 2 Face-to-Face Panel Rating Median Score on 9-point Scale (IQR) – as applicable for disagreement** *initially rated as Keep/Discard	**Round 2 Modifications**	**Round 3 Remote Panel Rating Median Score on 9-point Scale (IQR)**	**Round 3 Modifications**	**Round 4 Final Remote Panel Rating – Keep/Discard**
Structure Indicators						
Policy on Person-Centred Care	8 (6, 9)	Keep	Expanded on description	8 (7, 8)	None	Keep
Educational Programs on Person-Centred care	8 (7, 9)	Keep	Expanded on description	8 (7, 8)	Expanded on description	Keep
Protocol addressing Discriminatory Care	7.5 (6, 9)	Keep	Merged with “Educational Programs on Person-Centred Care”	N/A	N/A	N/A
Protocol Addressing Cultural Competence	7 (6, 9)	Keep	Changed wording to “Culturally Competent Care”	8 (7, 8)	Expanded on definition	Keep
Educational Programs reflecting Cultural Competency and Cultural Humility	7 (6, 9)	Keep	Merged with “Culturally Competent Care”	N/A	N/A	N/A

Program/Protocol for recruitment and retention of staff of diverse backgrounds	8 (5.5, 9)	Keep	Merged with "Educational Programs on Person-Centred Care"	N/A	N/A	N/A
Supporting a Workforce Committed to Person-Centred Care	7 (4, 9)	Disagreement	Merged with "Policy on Person-Centred Care"	N/A	N/A	N/A
Providing a Supportive and Accommodating Person-Centred Care Environment	7 (5, 8)	Keep	Clarified language in description	7 (6, 8)	None	Keep
Providing an Environment that Reflects Diversity and Inclusion	8 (5, 9)	Keep	Merged with "Providing a Supportive and Accommodating Person-Centred Care Environment"	N/A	N/A	N/A
Partnership with Communities	8 (6, 9)	Keep	Expanded description; changed wording to "Co-designing care in partnership with communities"	8 (7, 8)	Components merged with "Policy on Person-Centred Care"	Keep
Protocol for the Integration of	8 (5, 9)	Keep	Expanded description;	8 (6, 8)	Components merged with	N/A

Structures to Support Health Information Technology			changed working to "Healthcare Information Technology to Support Person-Centred Care"		"Policy on Person-Centred Care"	
Structures to Report Person-Centred Care Performance	8 (8, 9)	Keep	Changes to description of data source	8 (8, 9)	None	Keep
Process Indicators						
Compassionate Care	9 (8, 9)	Keep	Broadening of definition, providing example measures	8 (8, 9)	None	Keep
Equitable care	8 (7, 9)	Keep	Broadening of definition, providing example measures	9 (8, 9)	Expanded definition	Keep
Trusting Relationship with Healthcare Provider	9 (8, 9)	Keep	Broadening of definition, providing example measures	8 (8, 9)	None	Keep
Accessing Interpreter Services	8 (7, 9)	Keep	Broadening of definition, providing example measures	8 (7, 9)	None	Keep

Communication with Healthcare System	8 (7, 9)	Keep	Broadening of definition, providing example measures	8 (8, 9)	Example items from measure included	Keep
Communication between Patient and Healthcare Provider - Nurse	8 (7.5, 9)	Keep	Broadening of definition	8 (8, 9)	Edits to example measures	Keep
Communication between Patient and Healthcare Provider - Physician	8 (8, 9)	Keep	Broadening of definition	9 (8, 9)	Edits to example measures	Keep
Information about Taking Medication	9 (7, 9)	Keep	Expanded on description	8 (8, 9)	Expanded description	Keep
Communicating Test Results	8 (7, 9)	Keep	Expanded on description; providing example measures	8 (8, 9)	None	Keep
Coordinating Your Care	9 (7, 9)	Keep	Expanded on description; changed wording to “Coordination of Care”	8 (8, 9)	Expanded on definition	Keep
Patient Involvement in Decisions About Their Care and Treatment	8 (8, 9)	Keep	Broadening of definition	9 (8, 9)	Changed wording to “Patient and Caregiver Involvement in Decisions	Keep

					about Their Care and Treatment”	
Engaging Patients in Managing their Own Health	8 (7, 9)	Keep	Clarification of self-management	8 (8, 9)	Expanded on definition	Keep
Timely Access to a Primary Care Provider	8 (7, 9)	Keep	None	8 (6.5, 9)	None	Keep
Patient preparation for a planned admission to hospital	8 (7, 9)	Keep	Broadening of definition and wording changed to “Patient Preparation for a Planned Treatment Program”	8 (7, 9)	None	Keep
Time to Unplanned Admission Through Emergency Department	7.5 (6, 9)	Discard	Discarded by panel	N/A	N/A	N/A
Discharge Planning	9 (8, 9)	Keep	Change focus from discharge to continuum of care; wording changed to “Transition Planning”	9 (8, 9)	Edits to example measures	Keep

Post-Discharge Planning	8 (7, 9)	Keep	Merged with “Transition Planning”	N/A	N/A	N/A
Timely Follow-up with Hospital Discharged Patients	8 (5, 9)	Keep	Merged with “Transition Planning”	N/A	N/A	N/A
Discharge Summaries Available to Community Care Provider Within 48 Hours of Discharge	8 (7, 9)	Keep	Merged with “Transition Planning”	N/A	N/A	N/A
Noise During Hospitalization/Stay	7 (6, 8)	Keep	Merged with “Providing a supportive and accommodating person-centred care environment”	N/A	N/A	N/A
Outcome Indicators						
Overall Rating	7.5 (5, 8.5)	Discard	Discarded by panel	N/A	N/A	N/A
Overall Experience	8 (6, 9)	Keep	None	9 (7, 9)	Expanded description	Keep
Cost of Care-Affordability	6.5 (5, 9)	Keep	None	7 (5, 9)	None	Keep
Patient-Reported Outcomes – General Health	7 (5, 9)	2 (1, 4)	Discarded by panel; agreed to discuss in working group	7 (5, 9)	None	Keep

Patient-reported Outcomes – Multi-attribute	7 (5, 8)	Discard	Discarded by panel	N/A	N/A	N/A
Patient Reported Outcomes- Mental Health	7 (5, 9)	Discard	Discarded by panel	N/A	N/A	N/A
Global Indicator (n=1)						
Friends and Family Test	7 (5, 9)	6.5 (2.5, 7)	None	7 (6, 8)	None	Keep

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Improving the Quality of Person-Centred Healthcare from the Patient Perspective: Development of Person-Centred Quality Indicators

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Improving the Quality of Person-Centred Healthcare from the Patient Perspective: Development of Person-Centred Quality Indicators

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ABSTRACT

Importance: International efforts are being made towards a person-centered care (PCC) model, but there are currently no standardized mechanisms to measure and monitor PCC at a healthcare system level. The use of metrics to measure PCC can help to drive the changes needed to improve the quality of healthcare that is person-centred.

Objective: To develop and validate person-centred care quality indicators (PC-QIs) measuring PCC at a healthcare system level through a synthesis of the evidence and a person-centred consensus approach to ensure the PC-QIs reflect what matters most to people in their care.

Methods: Existing indicators were first identified through a scoping review of the literature, and an international environmental scan. Focus group discussions with diverse patients and caregivers, and interviews with clinicians and experts in quality improvement allowed us to identify gaps in current measurement of PCC and inform the development of new PC-QIs. A set of identified and newly developed PC-QIs were subsequently refined by Delphi consensus process using a modified RAND/UCLA Appropriateness Method. The international consensus panel consisted of patients, family members, community representatives, clinicians, researchers, and healthcare quality experts.

Results: From an initial 39 unique evidence-based PC-QIs identified and developed, the consensus process yielded 26 final PC-QIs. These included seven related to structure, 16 related to process, two related to outcome and one overall global PC-QI.

Conclusions: The final 26 evidence-based and person-informed PC-QIs can be used to measure and evaluate quality incorporating patient perspectives, empowering jurisdictions to monitor healthcare system performance and evaluate policy and practice related to PCC.

Article Summary

Strengths and limitations
- The development of the Person-Centred Quality Indicators (PC-QIs) was conducted using a multi-phased rigorous scientific process in collaboration with an international team of experts. - The development of the indicators followed the National Quality Forum's criteria for "good quality indicators." - The perspectives of diverse patients, caregivers, and community members were incorporated into the development of the PC-QIs, as well as healthcare providers and quality improvement experts. - The study did not include an evaluation of PC-QI implementation.

INTRODUCTION

In 2017, health ministers from OECD countries declared that we need to invest in measuring what matters most to patients[1,2]. Ever since patient-centred care (PCC) was first identified as a foundational component of healthcare quality and patient safety by the Institute of Medicine in 2001[3], it has been recognized as a high priority by healthcare systems globally.[4-8] The use of valid and reliable measures to monitor and evaluate PCC can provide the data needed to identify gaps in the delivery of PCC and target areas for improvement, and thus, drive the changes needed to move towards a true PCC model.

However, there are currently no generally accepted indicators for measuring PCC.[9] Moreover, existing indicators do not tend to incorporate the voices of people involved in healthcare, namely, patients, caregivers, and healthcare providers.[10] This gap means that PCC itself might be measured in ways not relevant to patients, and in ways that do not address practical concerns of healthcare providers for person-centred quality improvement.

Evidence also suggests that the delivery of PCC improves healthcare quality, including improvement of patient experiences and outcomes, enhanced involvement of people in their own healthcare decisions, more support for health promotion activities, a decrease in healthcare services utilization and costs, and an improvement in healthcare provider satisfaction.[11-14]

The overall aim of this research was to ensure that the patient perspective can be used to inform improvements in healthcare quality at the system level by developing a core group of person-centred quality indicators (PC-QIs), based on a synthesis of the evidence and, importantly, includes what matters to patients, caregivers, diverse community members, healthcare providers and quality improvement experts, and researchers, when it comes to healthcare.

METHODS

This study was part of a multi-phased programme of research to develop, implement, and evaluate PC-QIs for measuring and improving PCC (See *Figure 1 – Study at a glance*). The development of the PC-QIs included two phases. During Phase 1, previously implemented and evaluated PC-QIs were identified and classified using a published PCC framework.[10] In Phase 2, these identified PC-QIs were refined through a modified Delphi consensus process [15] that involved patients, caregivers, and diverse community members, clinicians, quality improvement leaders and decision makers. Phase 3 constitutes future steps of this research and will not be reported in this paper. Phase 3 will involve a feasibility assessment of the newly developed PC-QIs, which will include in-depth interviews with quality improvement leaders and healthcare professionals to obtain their perspectives on the feasibility of implementing the PC-QIs. We will also conduct a survey of health care organizations to obtain a system-level perspective on the feasibility of implementation and to obtain greater generalizability of our findings. While this paper provides an overview of the methods used to develop the PC-QIs prior to the consensus process, additional details regarding the first phase of this research (i.e. scoping review of the literature, international environmental scan, focus group discussions, and interviews with stakeholders) will be published elsewhere. Ethics approval was granted from the University Health Research Ethics Boards [REB15-2846] at the University of Calgary.

FIGURE 1 HERE

Patient and Public Involvement

Our research is guided by a transformative framework with the aim of producing knowledge that seeks to improve healthcare for all people, whilst acknowledging that marginalized groups do not tend to be included in the production of knowledge due to existing power and social relationships within society. [16] Thus, consistent with a PCC, we strived to consult with diverse patients and caregivers as active collaborators through a participatory approach – doing research "with" rather than "on" them.

A patient partner (SZ) was recruited to as part of the research team at the study's inception, and to ensure the study is guided by the patient perspective. The patient partner has played a critical role in the study design, data collection, review of analyses, interpretation of the data, and the development of this manuscript, in addition to disseminating the findings of this research. Moreover, in Phase 1 of this study, we used a participatory approach to engage diverse patients and caregivers to identify what matters most to them in their healthcare. This would ensure that patient values, needs, and preferences are incorporated into the development of the indicators. These focus groups were conducted with the provincial Alberta Health Services Patient and Family Advisory Group, as well as ActionDignity (www.actiondignity.org), a community-based organization that works closely with ethno-cultural leaders in Calgary to conduct research and work towards systems and policy change. These organizations supported the development of the focus group discussion tools, recruitment, data collection, analysis, and dissemination of findings. In Phase 2 of the study, we used a consensus process with a panel of 29 people of patients, caregivers, diverse community members, providers, researchers, and quality improvement leads, which is described in this paper. Participants were routinely asked about burdens to participation to ensure appropriate accommodations.

Phase 1: Preliminary review

This first phase involved preparatory work needed for the consensus process. In order to identify, categorize, and develop PC-QIs, we developed a conceptual PCC framework [10] based on the Donabedian quality of care model (Structure, Process and Outcome).[17]

This phase also involved a scoping review [18,19] to identify 29 previously published PC-QIs, their implementation and evaluation in various settings, as well as best practices of PCC monitoring. To be eligible for inclusion, studies/articles had to (1) identify quality indicators for PCC and/or (2) identify PC-QIs in performance measurement (e.g., validation).[18] Indicators were assessed as being person-centred, based on the use of a PCC conceptual framework.[10]

In parallel to the scoping review [19], an environmental scan was conducted to identify if healthcare systems in Canada, the United Kingdom, Sweden, Australia and New Zealand were using PC-QIs, which PC-QIs were in use, and how they were implemented.[20] These countries were chosen as they shared many similarities with respect to healthcare delivery and structures.[20] 61 existing indicators were identified. All unique PC-QIs identified through the scoping review and environmental scan were synthesized by the research team.

Focus group discussions with patients and caregivers, as well interviews as key stakeholders (i.e. quality improvement leads, healthcare providers, and PCC researchers) were conducted to inform the development and prioritization of PC-QIs. With regards to focus group discussions, we employed strategies to attain maximum variation among participants to ensure the patient and caregiver perspectives represent a greater diversity of people, with considerations for age, race, ethnicity, indigeneity, gender and sexual identities, rural/urban, disease conditions, and health care sectors accessed. Focus group discussions were conducted in partnership with the provincial Alberta Health Services Patient and Family Advisory Group and ActionDignity (described previously). These organizations supported the recruitment, data collection, analysis, and dissemination of findings. We identified healthcare values, preferences, and needs from a diverse sample of 65 patients and caregivers. Individual interviews with 22 healthcare providers, quality improvement experts, and PCC researchers from Canada, the USA, and England were conducted to determine perceptions around feasibility and prioritization of measuring specific domains of PCC. The findings from these focus groups and interviews were used to identify the most important PC-QIs from those that were found in the scoping review and environmental scan, as well as to guide how existing PC-QIs could be modified or refined. The focus groups and interviews also allowed us to identify any PC-QIs still needed for development.

Based on the findings from Phase 1 and a review of the literature pertaining to gaps in measurement identified through the focus groups and interviews (i.e. access to an interpreter, cost of care, etc.), 39 unique PC-QIs were developed or modified iteratively by the research team, and subsequently classified using the PCC conceptual framework.[10] The details and key results from these sub-studies for Phase 1 have either been published or in the process of publication elsewhere. [18-20]

Phase 2: Modified Delphi Panel Exercise

Phase 2 included a consensus process, using the RAND/University of California LA Appropriateness Method (RAM).[21] RAM is a reproducible and valid nominal group technique consensus methodology using the modified Delphi technique.[15] This consensus method is used extensively in health services research.[21-23] Based on our previous experience [24, 25], the consensus method was considered highly appropriate to facilitate the panel's prioritization and refinement PC-QIs. The Delphi technique was modified to include additional people as part of the consensus process, to ensure greater representation from patients, caregivers, community members.

Panel Selection

A consensus panel was established consisting of patients, caregivers, diverse community members, healthcare providers, PCC researchers, and quality improvement leads. In recognition of the potential power dynamics associated with mixing groups of patients [22] , caregivers, healthcare providers, researchers, and quality improvement experts, we strove to assemble a panel where at least half of the representation was from patients, caregivers, and community members. The community members were representative from the some of the most prominent ethno-cultural communities in Calgary (i.e. Chinese, South Asian, and Filipino). The panelists were identified from their previous participation in the environmental scan, interviews, and focus groups conducted in Phase 1, as well as our collaborators' networks. Identified individuals were invited via email and provided with a summary of the project and an overview of the consensus process and expectations (e.g., time commitment and activities).

Rating Process and Materials

Panelists received a package including:

a) a manual that included a monograph of each PC-QI identified, and

b) a rating tool used for panelists to rate the PC-QIs (see rating tool here: http://bit.do/PC-QI_RatingTool)

The package outlined the PC-QIs that included descriptors such as: type of indicator, proposed data source (including existing patient-reported experience measures already in use), definition, numerator, denominator, benchmark, and risk adjustment. The manual also included definitions to describe what PC-QIs are, and what constitutes a "good" quality indicator, as outlined by the National Quality Forum, which states the criteria for evaluating a new measure: importance, scientific acceptability, feasibility, and usability.[26] Additionally, the rating tool was derived from the Joint Commission Attributes of Core Performance Measures and Associated Evaluation Criteria.[27] The rating tool asked panelists to rate PC-QIs on each of the following dimensions:

- Was the PC-QI precisely defined?
- Does the PC-QI target important PCC improvements?
- Does it measure what is supposed to measure?
- It is a good global PC-QI for overall evaluation?

These questions were designed to assess *face, as well as construct validity* (i.e. whether the PC-QI measures what it is supposed to measure), and *appropriateness* (whether the PC-QI is an appropriate measure for PCC). The ratings materials also included questions related to implementation including *feasibility* (is data for reporting PC-QI available?) and *usability* (is the PC-QI actionable and interpretable?). Panelists used SurveyMonkey, a web-based survey tool, to remotely rate the PC-QIs in the first, third, and fourth rounds.

Delphi Round 1

The first round involved remote rating by panelists. In each of these remote rating rounds, panelists used the rating material described above and the rating scale, a 9-point scale (1 = strong disagreement, 9 = strong agreement). Overall assessment of the PC-QI scored as: *inappropriate* (1-3), *supplementary* (consider as a PC-QI if more resources available) (4-6) and *appropriate* (7-9).[21] Panelists also had the opportunity to provide written comments and suggest additional PC-QIs.

PC-QIs ratings were summarized using medians and inter-quartile rage (IQR) for the overall rating included in the "globally it is a good PC-QI?" rating scale. Disagreement on the rating for a PC-QI of at least a third of the panel (n=>9) in the median score 1-3 and at least a third (n>=9) of the panel in the median 7-9. PC-QIs with median overall scores of 1-3 were discarded; PC-QIs with median overall score 4-9 were retained for subsequent rounds. Written comments were analyzed using content analysis methods.

Following remote ratings in round 1, the data were analyzed, and suggestions and refinements were made to each PC-QI as appropriate. This revised version was shared via SurveyMonkey prior to the face-to face meeting.

Delphi Round 2

During Round 2, panelists reviewed each PC-QI in a face-to-face meeting as well as the results from the first round. The 2-day meeting was co-moderated by our patient-partner (SZ) and a clinician researcher. The moderators led the panel through each of the PC-QIs to review the results from the first round and to note areas of disagreement (indicated by the ratings) as they pertained to: perceived importance/necessity and relevancy for person-centred care; scientific acceptability (reliability and validity); feasibility of implementing the PC-QIs given different contexts of care; and usability to make improvements in care. The research team was available to answer clarifying questions about how the PC-QI was identified/developed and the source of the evidence supporting the PC-QIs. Deliberations were made as a group until agreement on PC-QI specifications was achieved through discussion and subsequent rounds of re-rating. Additionally, a number of indicators were proposed for merging and further refinement, particularly for perceived redundancies and in consideration for decreasing the total number of PC-QIs (for feasibility and concerns around indicator fatigue). Modifications were made to the PC-QIs required subsequent rounds of rating.

Delphi Rounds 3 & 4

Remote ratings in rounds 3 and 4 continued as described in the first remote rating to obtain consensus for the modified/merged PC-QIs. Through the remote rounds, revisions of each PC-QI were added to the working document and circulated among panelists for a final rating using paper-based rating tools for final review. Prior to the third round of rating, a working group that created as a response to the discussions held during the face-to-face meeting, studied the development of an indicator that captures outcomes reported directly by the patients. This working group included five patients, two family members, one physician, two quality improvement leads and two researchers. The group worked on developing the indicator and gathering information to present background knowledge to the rest of panelists. The new indicator and additional information were shared among the rest of the panelists and they rated the new indicator in round 3. Proposed refinements to the PC-QIs during round 3 were agreed on during round 4 of rating, where panelists were also asked specifically about the necessity of each PC-QI, rating either a ‘yes’ or ‘no’ to keeping the indicator.

RESULTS

Panel

A total of 29 people participated on the consensus panel. The consensus panel comprised:

- 8 patients and 3 caregivers (37.9%) with various experience with the health care system, including primary care, acute care, cancer care, and chronic diseases (e.g. cardiovascular conditions, diabetes, etc.)
- 5 members of diverse ethno-cultural communities (17.2%) who are also patients and/or caregivers
- 2 healthcare providers (6.9%; an internist and a pediatrician),
- 5 quality improvement experts (17.2%; representing Canadian Quality Councils and health systems, Cancer Care Ontario, University of Gothenburg Centre for Person-centred Care, Sweden, Picker Institute, and University of Oxford, UK),
- 4 PCC researchers (13.8%), including: a lead from the Patient-Centered Outcomes Research Institute (PCORI), a Senior Scientist Collaboration for Leadership in Applied Health Research and Care Oxford Unit, professors from Canadian Universities and leaders of the Canadian Strategy for Patient-Oriented Research
- 1 representative (3.4%) of the Canadian Institute for Health Information

- 1 representative (3.4%) from Ministry of Health, British Columbia

Of the 29 panelists, for round 2, 27 attended in person, 1 attended via videoconference and 1 was absent (with this panelists comments shared with the panel). For rounds 3 and 4, 27 panelists participated in the consensus, with two panelists not participating in this phase (one caregiver and one clinician-researcher) due to conflicting commitments.

Person-Centred Quality Indicators

Thirty-nine PC-QIs were identified through Phase 1 and were refined through Phase 2 of the study, where they were summarized into 26 final PC-QIs. These final 26 PC-QIs included seven structure, 16 process, two outcome and one global indicator (*see Table 1*). During the first round and based on final ratings (*see Table 1*), 4 indicators were discarded including:

- Timely Unplanned Readmission from ER
- Overall Rating
- Patient-reported Outcome Multi-attribute
- Patient-reported Outcome Mental Health

Based on the decision to discard the last two PC-QIs, the working group proposed a new indicator related to Patient-Reported Outcomes: "Using Patient-Reported Outcome Measures to deliver Patient-Centred Care." This newly proposed indicator was later rated and accepted in Round 3. *Table 1* summarizes the consensus panel ratings as median scores on a 9-point scale and interquartile range, as reported in previous studies. [21, 24, 25] The sources of evidence for each of the indicators are also reported in *Table 1*. For additional details on the specific modifications proposed by panelists, please refer to *Appendix 1*. During Round 2, out of the initial 39 indicators, 11 were merged with other indicators (see *Table 2*). *Appendix 1,* displays the ratings as median scores on a 9-point scale and interquartile range, as, as well as details on modifications that were proposed by panelists.

Table 1: Summary of Consensus Panel Ratings for Final 26 PC-QIs Developed by the Panel (Median Score on 9-point Scale and (Interquartile Range)) and Sources for Evidence

Person-Centred Quality Indicators	Round 1 Remote Panel Rating	Round 2 Face-to-Face Panel Rating	Round 3 Remote Panel Rating	Evidence Sources SR = Scoping Review ES = Environmental Scan FGD = Focus Group Discussions I = Interviews
Structure Indicators (n= 7)				
Policy on Person-Centred Care	8 (6, 9)	Keep	8 (7, 8)	SR, ES, FGD, I
Educational Programs on Person-Centred care	8 (7, 9)	Keep	8 (7, 8)	SR, FGD, I
Culturally Competent Care	7 (6, 9)	Keep	8 (7, 8)	SR, FGD
Co-designing care in partnership with communities	8 (6, 9)	Keep	8 (7, 8)	FGD
Providing an Accommodating and Supportive Person-Centred Care Environment	7 (5, 8)	Keep	7 (6, 8)	SR, FGD
Healthcare Information Technology to Support Person-Centred Care	8 (5, 9)	Keep	8 (7,8)	I
Structures to Report Person-Centred Care Performance	8 (8, 9)	Keep	8 (8, 9)	I
Process Indicators (n=16)				
Compassionate Care	9 (8, 9)	Keep	8 (8, 9)	SR, FGD, I
Equitable care	8 (7, 9)	Keep	9 (8, 9)	SR, FGD, I
Trusting Relationship with Healthcare Provider	9 (8, 9)	Keep	8 (8, 9)	SR, FGD, I
Timely Access to a Primary Care Provider	8 (7, 9)	Keep	8 (6.5, 9)	ES, FGD
Accessing Interpreter Services	8 (7, 9)	Keep	8 (7, 9)	SR, FGD

Communication with Healthcare System	8 (7, 9)	Keep	8 (8, 9)	SR, ES, FGD
Communication between Patient and Healthcare Provider - Nurse	8 (7.5, 9)	Keep	8 (8, 9)	SR, ES, FGD, I
Communication between Patient and Healthcare Provider - Physician	8 (8, 9)	Keep	9 (8, 9)	SR, ES, FGD, I
Information about Taking Medication	9 (7, 9)	Keep	8 (8, 9)	SR, ES, FGD
Communicating Test Results	8 (7, 9)	Keep	8 (8, 9)	SR, FGD
Coordination of Care	9 (7, 9)	Keep	8 (8, 9)	SR, ES, FGD
Patient and Caregiver Involvement in Decisions about their Care and Treatment	8 (8, 9)	Keep	9 (8, 9)	SR, ES, FGD, I
Engaging Patients in Managing their Own Health	8 (7, 9)	Keep	8 (8, 9)	SR, ES, FGD, I
Patient Preparation for a Care Plan at a Healthcare Facility	8 (7, 9)	Keep	8 (7, 9)	SR, ES, FGD
Transition Planning	9 (8, 9)	Keep	9 (8, 9)	FGD
Using Patient-reported Outcome Measures (PROMs) to Deliver Patient-Centred Care	Not developed	Newly developed derived from previous 'Patient-reported outcomes'	7 (5, 9)	Consensus
Outcome Indicators (n=2)				
Cost of Care- Affordability	6.5 (5, 9)	Keep	7 (5,9)	FGDs
Overall Experience	8 (6, 9)	Keep	9 (7, 9)	SR, ES
Global Indicator (n=1)				
Friends and Family Test	7 (5, 9)	6.5 (2.5, 7)	7 (6, 8)	ES

Table 2: Merged PC-QIs

Original PC-QIs	Final PC-QIs Incorporating Original PC-QIs
Structure	
Supporting a Workshop Committed to PCC	Policy on PCC
Partnership with Communities	
Protocol for integration of structures to support health technology	
Protocol addressing discriminatory care	Educational Programs on PCC
Program/protocol for recruitment and retention of staff of diverse background	
Noise during hospitalization	Providing an Accommodating and Supportive Person-Centred Care Environment
Providing an Environment that Reflects Diversity and Inclusion	
Educational Programs Reflecting Cultural Competency and Humility	Culturally Competent Care
Process	
Post-discharge planning	Transition Planning
Timely follow-up after discharge	
Discharge summaries available after 48 hour of discharge from hospital	

A flow chart of the rating process can be found in *Figure 2*.

FIGURE 2 HERE

A complete summary of the final PC-QIs that were developed is available here: https://www.personcentredcareteam.com/s/PC-QIs_Monograph_Santana-et-al-2019.pdf Each of these newly developed indicators are evidence-informed and person-centred, some addressing a specific aspect of healthcare quality (e.g. safety versus equity).

DISCUSSION

As Moira Stewart stated in her 2001 editorial: “The patient should be the judge of patient-centred care.”[28] This article presents a new set of Person-Centred Quality Indicators (PC-QIs) developed and validated through a modified Delphi process that featured the patient perspective on what matters most to them in their care. These PC-QIs are evidence-based and patient-informed, and widely applicable across healthcare sectors and contexts. The use of these standardized metrics to measure PCC can help to drive the changes needed to improve the quality of healthcare that is person-centred.

The strength of this study is the person-centred approach used to develop metrics to evaluate PCC, which ensures that PCC is evaluated from the perspective of those who provide and receive care. To our knowledge, this is the first study to develop a generic set of PC-QIs using a rigorous evidence-based and person-centred approach, and involving the patient and caregiver throughout the research process – from inception to manuscript development. Using a highly participatory approach and a transformative lens, we sought to ensure the study was guided by the patient perspective, and that diverse and marginalized perspectives were reflected in the development of the PC-QIs. While PC-QIs were identified in the scoping review, first – the vast majority of these were not considered actual indicators in compliance with quality improvement agencies, such as the Agency for Healthcare Research and Quality (presented as units of measurement, such as percentage or proportion); second – many measures were not developed with significant patient input.[29] For instance, previous work conducted by Ouwens et al. in 2010 to develop a person-centred measures for cancer care involved patients in determining what would be important to measure.[30] The patient involvement was limited to semi-structured interviews to obtain the patient perspective on what guideline recommendations could be used for measuring PCC. In another study related to the development of measures for person-centred cancer care, Uphoff et al. 2012 involved patients as part of the consensus panel along with medical professionals.[31] While this work has been instrumental in demonstrating the value of the patient perspective in developing measures for PCC, only three patients were involved, out of fourteen experts on the panel. Issues around potential power imbalances were not accounted for. In our study, we strived to have approximately half of our panelists comprised of patients, caregivers, and community members, to ensure a balance of perspectives. For most quality indicators that are developed, including those we identified in our environmental scan, PC-QIs tend to be developed based on what healthcare authorities, quality improvement experts, or researchers deem as most important for quality improvement. Patients and the public are seldom involved in decisions about quality of care despite being the ones who experience and receive care. How can PCC be truly improved if we continue to measure PCC without the patient perspective on what should be measured? These newly developed indicators present an opportunity to improve healthcare quality in ways that matter most to people. To drive changes in healthcare policy and practice, there is a need to develop and implement standardized ongoing mechanisms to measure and evaluate quality incorporating the patients' perspectives.[14]

These PC-QIs offer a tremendous opportunity leverage ongoing initiatives to improve PCC by using data already being collected in many healthcare jurisdictions and helping to standardize the collection, use, and reporting of this data. This includes patient-reported experience measures (PREMs, such as Hospital Consumer Assessment of Health Providers and Systems) and patient-reported outcome measures (PROMs). Integrating PC-QIs into performance measurement frameworks can promote actionability for improving PCC. While PREMs and PROMs are often used at the provider level, there is little evidence of use for system-level applications and actionability. These indicators empower jurisdictions to monitor healthcare system performance and evaluate policy and practice related to PCC, while also including the patient's voice. Finally, the routinized use of standardized metrics, such PC-QIs, to evaluate PCC will help to strengthen the evidence-base for the PCC model.[32]

A key limitation of this research is that these indicators have yet to be operationalized and evaluated in practice. It is only through empirical testing that the feasibility of data collection can be determined and whether they meet the requirements of "good quality measures" – that are acceptable, reliable, and valid.[33] Moreover, studying the implementation of the PC-QIs can provide important insight into their effectiveness for promoting improvements in PCC as well as patient experiences and outcomes. It is also important to identify any unintended consequences as a result of PC-QI implementation, their use for benchmarking, and other issues, such as workload and cost-effectiveness.[33] Additionally, while this method has generated these 26 PC-QIs using a validated consensus method, they may not necessarily be universally applicable in all countries and settings. Different cultural settings in different healthcare regulatory environments may mean that different measures may be more appropriate for certain settings. Further work can be done to tailor and adapt these PC-QIs, recognizing that a consideration of the local context will ensure a more universal relevance.

Future steps for this work include an assessment of the feasibility of implementing these PC-QIs (Phase 3, see *Figure 1*). Secondly, we plan to pilot the use of the PC-QIs in national and international jurisdictions to promote PCC and to evaluate of the use of these measures for improving healthcare quality of care from the perspectives of the patient.

CONCLUSIONS

In conclusion, the development of these newly developed evidence-based and person-informed PC-QIs represent an important contribution towards efforts to measure and improve person-centred care. While these indicators have yet to be evaluated, the PC-QIs are available tools that healthcare systems can use to monitor and evaluate the delivery of PCC, identify the gaps, and make the changes needed to improve the quality of care. Importantly, these indicators have the potential to shift our healthcare systems towards a new paradigm for assessing quality by ensuring we measure what matters most to patients

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References

1 OECD. Health Ministerial Statement - The next generation of health reforms. Published January 17 2017; accessed November 2019. http://www.oecd.org/health/ministerial/ministerial-statement-2017.pdf.

2 Coulter, A. Measuring what matters to patients. *BMJ 2017;356:j816.*

3 Institute of Medicine. Crossing the quality chasm: A new health system for the 21st century. Washington (DC): National Academies Press:2001.

4 Pelzang R. Time to learn: Understanding patient-centred care. *Br J Nurs* 2010;19:912-7.

5 National Department of Health - National Health Service. NHS 2010-2015: From Good to Great. Preventative, People-Centred, Productive. 2009.

6 Davis K, Schoenbaum SC, Audet AM. A 2020 vision of patient-centered primary care. *J Gen Intern Med* 2005;20:953-7.

7 Alberta Health Services. The Patient First Strategy. 2015.

8 Stoelwinder JU. Final report of the National Health and Hospitals Reform Commission: will we get the health care governance reform we need? *Med J Aust* 2009;191:387-8.

9 World Health Organization. Leading and Managing Change towards People-Centred and Integrated Health Services. 2015.

10 Santana MJ, Manalili K, Jolley RJ, et al. How to practice person-centred care: A conceptual framework. *Health Expect* 2018;21:429-40.

11 Stewart M, Brown JB, Donner A, et al. The impact of patient-centered care on outcomes. *J Fam Pract* 2000;49:796-804.

12 McMillan SS, Kendall E, Sav A, et al. Patient-centered approaches to health care: a systematic review of randomized controlled trials. *Med Care Res Rev* 2013;70:567-96.

13 Mead N, Bower P. Patient-centred consultations and outcomes in primary care: a review of the literature. *Patient Educ Couns* 2002;48:51-61.

14 Berwick DM, Nolan TW, Whittington J. The triple aim: care, health, and cost. *Health Aff* 2008;27:759-69.

15 Jones J, Hunter D. Consensus methods for medical and health services research. *Br Med J* 1995;311:376.

16 Mertens DM, Holmes HM, Harris RL. Transformative research and ethics. In: Mertens DM, Ginsberg, PE eds. The Handbook of Social Research Ethics. Sage Publications: Thousand Oaks, CA. 2009:85-101.

17 Donabedian A. Evaluating the quality of medical care. *Milbank Q* 1966;44:166-206.

18 Jolley RJ, Lorenzetti DL, Manalili K, et al. Protocol for a scoping review study to identify and classify patient-centred quality indicators. *BMJ Open* 2017;7:e013632.

19 Santana MJ, Ahmed S, Lorenzetti D, et al. Measuring patient-centred system performance: a scoping review of patient-centred care quality indicators. *BMJ Open* 2019;9:e023596.

20 Doktorchik C, Manalili K, Jolley R, et al. Identifying Canadian patient-centred care measurement practices and quality indicators: a survey. *CMAJ Open* 2018;6:e643.

21 Fitch K, Bernstein SJ, Aguilar MD, Burnand B, LaCalle JR. The RAND/UCLA appropriateness method user's manual. RAND CORP: Santa Monica, CA; 2001.

22 McKenzie E, Potestio ML, Boyd JM, et al. Reconciling patient and provider priorities for improving the care of critically ill patients: a consensus method and qualitative analysis of decision making. *Health Expect* 2017;20:1367-74.

23 Stelfox HT, Straus SE. Measuring quality of care: considering conceptual approaches to quality indicator development and evaluation. *J Clin Epidemiol* 2013;66:1328-37.

24 Stelfox HT, Khandwala F, Kirkpatrick AW, Santana MJ. Trauma center volume and quality improvement programs. *J Trauma Acute Care Surg* 2012;72:962-8.
25 Santana MJ, Stelfox HT. Development and evaluation of evidence-informed quality indicators for adult injury care. *Ann Surg* 2014;259:186-92.
26 Dimick JB. What makes a “good” quality indicator?: comment on “Quality indicators for evaluating trauma care”. Archives of Surgery. 2010 Mar 1;145(3):295.
27 The Joint Commission. Attributes of Core Performance Measures and Asssociated Evaluation Criteria. 2010.
28 Stewart M. Towards a global definition of patient centred care: the patient should be the judge of patient centred care. *BMJ* 2001;322:444-5.
29 Agency for Healthcare Research and Quality. Quality Improvement and monitoring at your fingertips. Secondary Quality Improvement and monitoring at your fingertips. https://www. qualityindicators. ahrq.gov/ (Accessed 01 Oct 2017).
30 Ouwens M, Hermens R, Hulscher M, Vonk-Okhuijsen S, Tjan-Heijnen V, Termeer R, Marres H, Wollersheim H, Grol R. Development of indicators for patient-centred cancer care. *Support Care Cancer*. 2010 Jan 1;18(1):121.
31 Uphoff EP, Wennekes L, Punt CJ, Grol RP, Wollersheim HC, Hermens RP, Ottevanger PB. Development of generic quality indicators for patient-centered cancer care by using a RAND modified Delphi method. *Cancer Nurs*. 2012 Jan 1;35(1):29-37.
32 Montague T, Gogovor A, Aylen J, et al. Patient-Centred Care in Canada: Key Components and the Path Forward. *Healthc Q* 2017;20:50-6.
33 Grol R, Wensing M, Eccles M, Davis D, Editors. Improving patient care: the implementation of change in health care. John Wiley & Sons; 2013.

Figure 1 Legend: Figure 1 shows an overview of the program of research on Developing Person-Centred Quality Indicators (PC-QIs). The program of research includes three phases of research: Identifying and Developing PC-QIs; refinement of the PC-QIs, and feasibility of assessment of the newly developed PC-QIs. This manuscript shows the final results (final set PC-QIs), based on research from the first two phases.

Figure 2 Legend: Figure 2 shows a flow chart of the PC-QI Delphi process, describing the timeline for Rounds alongside the numbers of PCQIs surviving each round. There are arrows pointing down from "39 PCQIs evaluated" to each subsequent "*n* PCQIs evaluated" box, until the final "26 PCQIs evaluated" box.

Figure 1: Study at a Glance

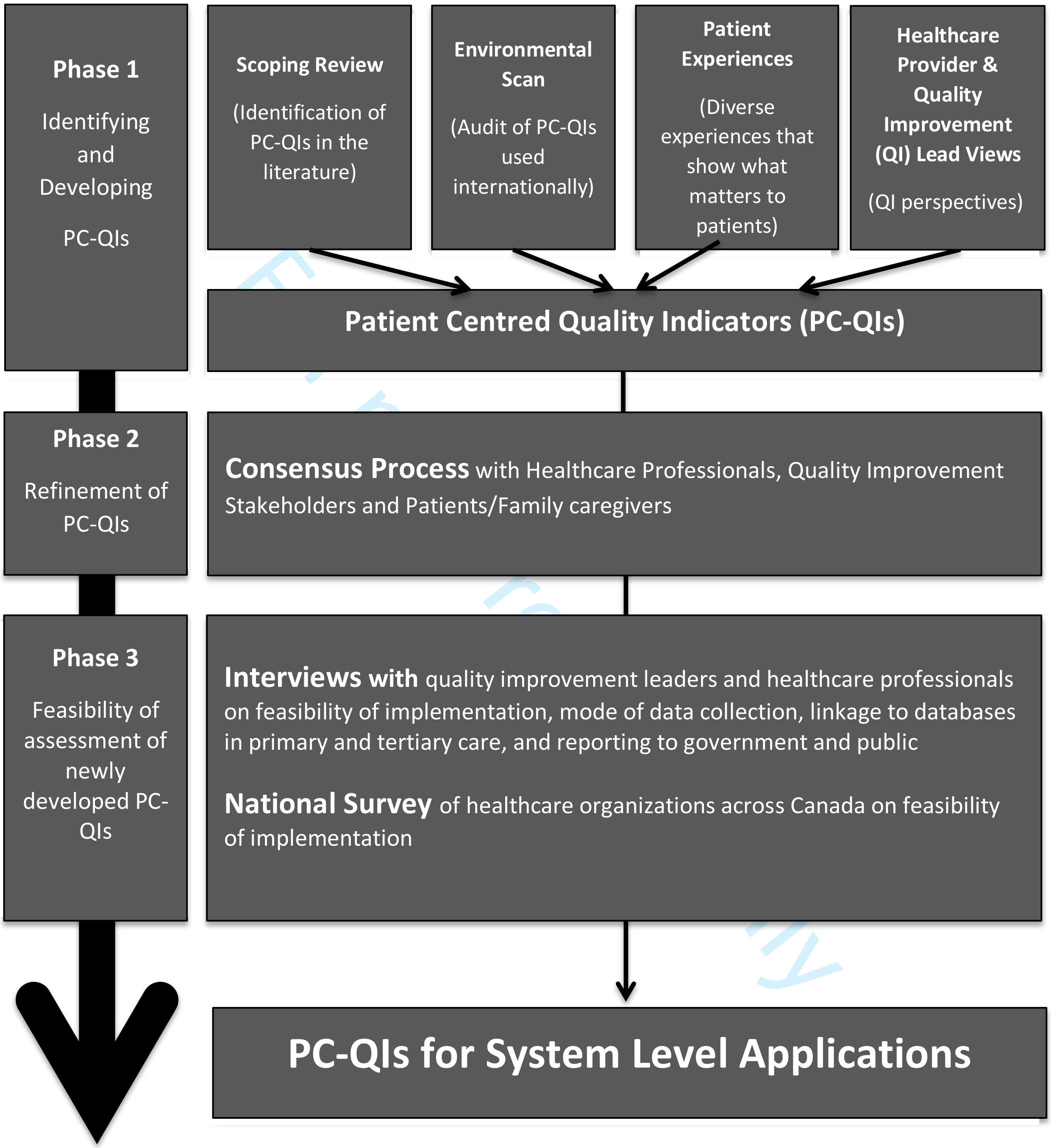

Figure 1 shows an overview of the program of research on *Developing Person-Centred Quality Indicators (PC-QIs)*. The program of research includes three phases of research: Identifying and Developing PC-QIs; refinement of the PC-QIs, and feasibility of assessment of the newly developed PC-QIs. This manuscript shows the final results (final set PC-QIs), based on research from the first two phases.

Figure 2: Flow Chart of PC-QI Delphi Process (Ratings and Modifications)

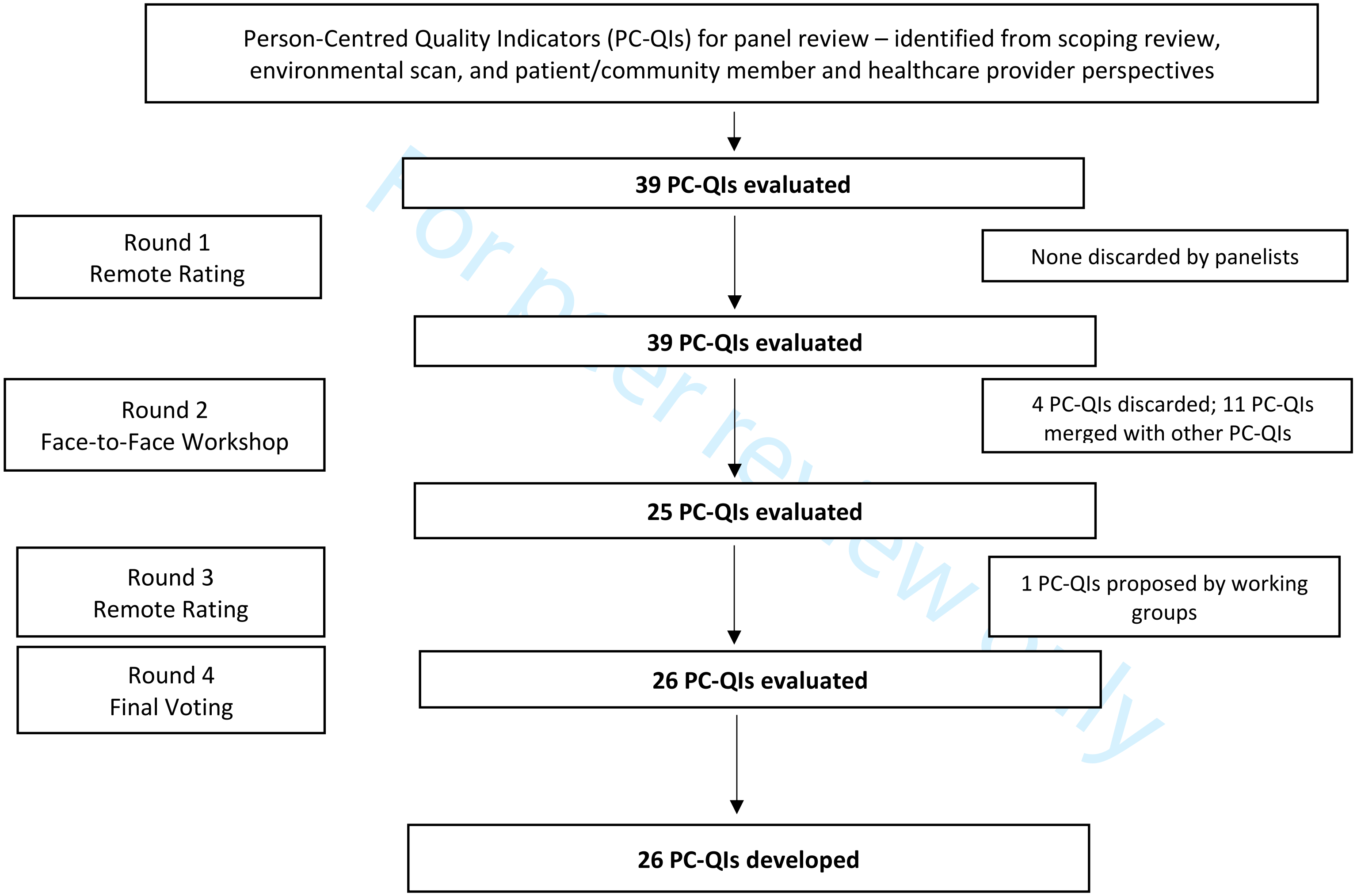

Figure 2 shows a flow chart of the PC-QI Delphi process, describing the timeline for Rounds alongside the numbers of PCQIs surviving each round. There are arrows pointing down from "39 PCQIs evaluated" to each subsequent "*n* PCQIs evaluated" box, until the final "26 PCQIs evaluated" box.

Appendix 1: Summary of Ratings [median score on 9-point scale and interquartile range (IQR)] and Modifications for PC-QIs Rated and Revised (PC-QIs = 39)

Initial Person-Centred Quality Indicators	**Round 1 Remote Panel Rating Median Score on 9-point Scale (IQR)**	**Round 2 Face-to-Face Panel Rating Median Score on 9-point Scale (IQR) – as applicable for disagreement** *initially rated as Keep/Discard	**Round 2 Modifications**	**Round 3 Remote Panel Rating Median Score on 9-point Scale (IQR)**	**Round 3 Modifications**	**Round 4 Final Remote Panel Rating – Keep/Discard**
Structure Indicators						
Policy on Person-Centred Care	8 (6, 9)	Keep	Expanded on description	8 (7, 8)	None	Keep
Educational Programs on Person-Centred care	8 (7, 9)	Keep	Expanded on description	8 (7, 8)	Expanded on description	Keep
Protocol addressing Discriminatory Care	7.5 (6, 9)	Keep	Merged with “Educational Programs on Person-Centred Care”	N/A	N/A	N/A
Protocol Addressing Cultural Competence	7 (6, 9)	Keep	Changed wording to “Culturally Competent Care”	8 (7, 8)	Expanded on definition	Keep
Educational Programs reflecting Cultural Competency and Cultural Humility	7 (6, 9)	Keep	Merged with “Culturally Competent Care”	N/A	N/A	N/A

Program/Protocol for recruitment and retention of staff of diverse backgrounds	8 (5.5, 9)	Keep	Merged with "Educational Programs on Person-Centred Care"	N/A	N/A	N/A
Supporting a Workforce Committed to Person-Centred Care	7 (4, 9)	Disagreement	Merged with "Policy on Person-Centred Care"	N/A	N/A	N/A
Providing a Supportive and Accommodating Person-Centred Care Environment	7 (5, 8)	Keep	Clarified language in description	7 (6, 8)	None	Keep
Providing an Environment that Reflects Diversity and Inclusion	8 (5, 9)	Keep	Merged with "Providing a Supportive and Accommodating Person-Centred Care Environment"	N/A	N/A	N/A
Partnership with Communities	8 (6, 9)	Keep	Expanded description; changed wording to "Co-designing care in partnership with communities"	8 (7, 8)	Components merged with "Policy on Person-Centred Care"	Keep
Protocol for the Integration of	8 (5, 9)	Keep	Expanded description;	8 (6, 8)	Components merged with	N/A

Structures to Support Health Information Technology			changed working to "Healthcare Information Technology to Support Person-Centred Care"		"Policy on Person-Centred Care"	
Structures to Report Person-Centred Care Performance	8 (8, 9)	Keep	Changes to description of data source	8 (8, 9)	None	Keep
Process Indicators						
Compassionate Care	9 (8, 9)	Keep	Broadening of definition, providing example measures	8 (8, 9)	None	Keep
Equitable care	8 (7, 9)	Keep	Broadening of definition, providing example measures	9 (8, 9)	Expanded definition	Keep
Trusting Relationship with Healthcare Provider	9 (8, 9)	Keep	Broadening of definition, providing example measures	8 (8, 9)	None	Keep
Accessing Interpreter Services	8 (7, 9)	Keep	Broadening of definition, providing example measures	8 (7, 9)	None	Keep

Communication with Healthcare System	8 (7, 9)	Keep	Broadening of definition, providing example measures	8 (8, 9)	Example items from measure included	Keep
Communication between Patient and Healthcare Provider - Nurse	8 (7.5, 9)	Keep	Broadening of definition	8 (8, 9)	Edits to example measures	Keep
Communication between Patient and Healthcare Provider - Physician	8 (8, 9)	Keep	Broadening of definition	9 (8, 9)	Edits to example measures	Keep
Information about Taking Medication	9 (7, 9)	Keep	Expanded on description	8 (8, 9)	Expanded description	Keep
Communicating Test Results	8 (7, 9)	Keep	Expanded on description; providing example measures	8 (8, 9)	None	Keep
Coordinating Your Care	9 (7, 9)	Keep	Expanded on description; changed wording to “Coordination of Care”	8 (8, 9)	Expanded on definition	Keep
Patient Involvement in Decisions About Their Care and Treatment	8 (8, 9)	Keep	Broadening of definition	9 (8, 9)	Changed wording to “Patient and Caregiver Involvement in Decisions	Keep

					about Their Care and Treatment”	
Engaging Patients in Managing their Own Health	8 (7, 9)	Keep	Clarification of self-management	8 (8, 9)	Expanded on definition	Keep
Timely Access to a Primary Care Provider	8 (7, 9)	Keep	None	8 (6.5, 9)	None	Keep
Patient preparation for a planned admission to hospital	8 (7, 9)	Keep	Broadening of definition and wording changed to “Patient Preparation for a Planned Treatment Program”	8 (7, 9)	None	Keep
Time to Unplanned Admission Through Emergency Department	7.5 (6, 9)	Discard	Discarded by panel	N/A	N/A	N/A
Discharge Planning	9 (8, 9)	Keep	Change focus from discharge to continuum of care; wording changed to “Transition Planning”	9 (8, 9)	Edits to example measures	Keep

Post-Discharge Planning	8 (7, 9)	Keep	Merged with "Transition Planning"	N/A	N/A	N/A
Timely Follow-up with Hospital Discharged Patients	8 (5, 9)	Keep	Merged with "Transition Planning"	N/A	N/A	N/A
Discharge Summaries Available to Community Care Provider Within 48 Hours of Discharge	8 (7, 9)	Keep	Merged with "Transition Planning"	N/A	N/A	N/A
Noise During Hospitalization/Stay	7 (6, 8)	Keep	Merged with "Providing a supportive and accommodating person-centred care environment"	N/A	N/A	N/A
Outcome Indicators						
Overall Rating	7.5 (5, 8.5)	Discard	Discarded by panel	N/A	N/A	N/A
Overall Experience	8 (6, 9)	Keep	None	9 (7, 9)	Expanded description	Keep
Cost of Care-Affordability	6.5 (5, 9)	Keep	None	7 (5, 9)	None	Keep
Patient-Reported Outcomes – General Health	7 (5, 9)	2 (1, 4)	Discarded by panel; agreed to discuss in working group	7 (5, 9)	None	Keep

Patient-reported Outcomes – Multi-attribute	7 (5, 8)	Discard	Discarded by panel	N/A	N/A	N/A
Patient Reported Outcomes- Mental Health	7 (5, 9)	Discard	Discarded by panel	N/A	N/A	N/A
Global Indicator (n=1)						
Friends and Family Test	7 (5, 9)	6.5 (2.5, 7)	None	7 (6, 8)	None	Keep