

# The Role of Patient-Reported Outcomes in Person-Centred Care in Canada



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## Abstract

In Canada, efforts have been made to move healthcare towards patient-centred care (PCC), which promotes the inclusion of patient perspectives in the evaluation of care, recognizing the value their experiences provide in helping to achieve high quality and effective healthcare. Patient-reported outcomes (PROs) allow healthcare providers to evaluate, monitor, and personalize patient care. Although the Canadian healthcare system is moving PCC forward, the use of PROs in clinical care and at system level has been inconsistent. Currently there are no standardized mechanisms in place to integrate, measure and monitor PCC at national level. This report describes the role of PROs in health and healthcare to advancing PCC in Canada.

## Background

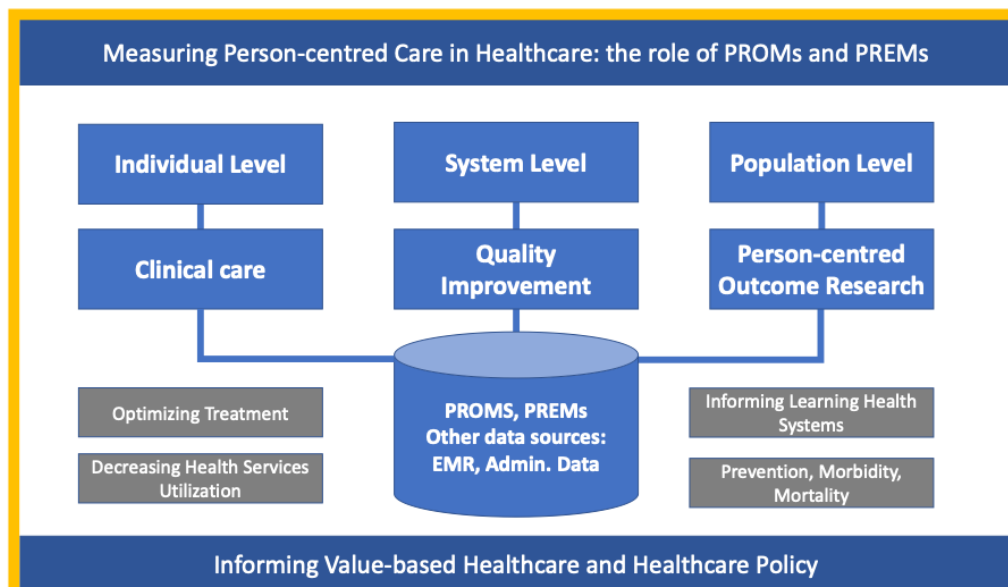
Determining what matters most to patients is essential for healthcare professionals to provide person-centred care (PCC)<sup>1,2</sup>. PCC emphasizes holistic care incorporating the whole individual including the person's well-being, preferences, and beliefs, and refrains from reducing the person to just their symptoms and/or disease<sup>3</sup>. PCC is not only limited to patients, but also involves families, caregivers, as well as health promotion and prevention activities<sup>3</sup>. PCC is a model in which healthcare providers are encouraged to partner with patients and families to co-design and deliver personalized care<sup>3-5</sup>.

In Canada, efforts have been made to move healthcare and research towards PCC by responding to individual patient and family preferences, needs and values<sup>6-9</sup>. This has been done, in part, to address increasing costs and the inappropriate use of resources, while providing high-quality healthcare and improving overall patient outcomes<sup>10,11</sup>.

The implementation and evaluation of PCC is complicated and multifaceted<sup>10,12</sup>. PCC implementation and evaluation requires all healthcare stakeholders, including healthcare organizations, healthcare professionals, patient organizations, and patients and families to become active collaborators in healthcare. The lack of measurement, reporting of results and implementation of PCC in Canada is partly due to disconnect that exists amongst healthcare systems, providers and the people who use the healthcare system.

To this end, patient-reported outcomes (PROs) play a central role in the measurement of PCC. This paper presents a framework illustrated by Canadian examples on the use of PROs in healthcare. PROs are measures collected directly from the patient and are essential to understand if healthcare services are providing quality care, improving patient experiences, and making a difference to patients' health status, outcomes, and quality of life<sup>13-19</sup>.

**Figure 1. Measuring Person-centred care in healthcare: The role of PROMs and PREMs**



Note: Blue boxes depict the role of PROs, while grey boxes highlight impact.

***The objective of this paper is to describe the role of patient-reported outcomes in health and healthcare.*** We discuss how PRO implementation may serve different purposes; from improving patient health outcomes to improving quality of healthcare, informing policy, as well as presenting opportunities to support patient-oriented outcomes research.

## Patient-reported outcomes: What are they and how are they used?

Patient-reported outcomes are measured using validated questionnaires used to collect information directly from patients<sup>13</sup> and allow the patients' values and perspectives to be reported without any interpretation of this response by a healthcare practitioner or anyone else. Patient-reported outcomes include patient-reported outcome measures (PROMs)<sup>13-15,17</sup> and patient-reported experience measures (PREMs)<sup>20,21</sup>. PROMs are concerned with the outcomes of a patient's health condition or disability; including measures of symptom burden that report the frequency, severity, and impact of symptoms<sup>13,22</sup>. A diverse group of measures fall under the PROMs umbrella, including psychological and emotional health indicators, adverse reactions and symptoms, which can either be generic or disease-specific<sup>13</sup>. An example of generic PROMs is the Short-Form 12-Item Survey (SF-12)<sup>23</sup>. while a disease-specific one is the Western Ontario and McMaster Universities Osteoarthritis Index (WOMAC)<sup>24</sup>; an instrument that is routinely used to assess functional impairment associated with osteoarthritis.

PREMs<sup>20,21,25,26</sup> on the other hand, are primarily concerned with a patient's perceived experiences with healthcare delivery. PREMs are essential to PCC, as they assess a range of interactions that patients have with the healthcare system and the extent to which care

delivery responds to individual patient needs and values<sup>20,24,25,27</sup>. Patients typically provide feedback regarding aspects of care including but not limited to involvement in healthcare decision-making, access to and navigation of services, communication and information, supportive care, and care continuity across healthcare providers, in acute care and hospital settings. In the acute care setting, examples of commonly used PREMs include the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) survey<sup>28</sup> and the Canadian Patient Experience Survey – In hospital care (CPES-IC)<sup>29</sup>.

## What are the roles of PROMs and PREMs?

There are several purposes for using PROs. Evidence has shown that when PROMs are integrated in routine clinical care, patient outcomes including survival<sup>30</sup> and quality of life improve<sup>14,16,19</sup>. Furthermore, aggregated PRO data that are linked to other data sources, such as electronic medical records (EMRs), provide opportunities for patient-oriented outcome research<sup>31,32</sup>, quality improvement activities informing policy and healthcare programs<sup>32</sup>. For individuals living with a chronic illness, the integration of PROMs provides vital and often missing information that the healthcare team can use to support patient care while promoting self-management and decision-making<sup>13,14,16,19,27,30,32</sup>. PROMs and PREMs provide opportunities to link both quality and outcomes of care from the patient's point of view and have the potential to play important roles in transforming the health of the Canadian population.

Overall, PROMs and PREMs are essential in evaluating whether healthcare services result in high quality care by improving patient experiences while making a difference to patients' health status and quality of life from their point of view. Moreover, PROMs and PREMs

can be incorporated to assess the value in health services for policymakers. Figure 1 describe the roles of PROMs and PREMs in health care informing: individual clinical care, healthcare system quality improvement, and patient-centred outcome research.

### *Individual level - Clinical care*

Routine use of PROMs in daily clinical practice may have potential benefits for patient management, including facilitating patient– clinician communication, specifically about issues that are important to patients, facilitating communication between health professionals, promoting shared decision making, and monitoring the progression of a patient’s illness and response to treatment plans<sup>13,14,27,32,33</sup>.

Additionally, PROMs can be used as a surveillance system<sup>30,32,34</sup>; patients can report their symptoms and health status periodically, via their home computer or their smartphone<sup>32,34</sup>. These reports could be used to track progress and monitor any changes in a patient’s health leading to adjustments in the frequency of clinic visits depending on these results<sup>30,32,34</sup>. Patients can also report on their health prior to their clinic visit and the information they provide can be instantly graphically summarized and presented to healthcare providers highlighting the patient’s own health concerns<sup>21-23</sup>. For instance, in Canada most cancer centres are integrating PROMs in their routine clinical care developing systems of collection and reporting that aims to support the complex care needed by their patient and family population. Additionally, at national level, we have established the CancerPRO network that involves oncologists, patients, family members, health informatics data organizations and researchers to collaborate across Canada in supporting innovative ways to integrate, use, link, and report PROs in cancer care.

Tremendous efforts have been done to integrate PROMs in routine clinical care. From developing international guidelines based on evidence, to strong research programs [Santana, Sawatzky, Ahmed, Watson] the integration of PROMs in clinical care requires attention to contextual barriers and adaptations to individual clinics and teams are required.

Although the impact of using PREMs at individual level on clinical practice has not been extensively examined nor the combined use of PREMs and PROMs, there is an interest in using PREMs to inform PCC by feeding back information to clinicians about patients' healthcare experiences; and adding this information to the PROMs data to understand the relation between patient experiences and outcomes and the overall impact on their quality of life<sup>35</sup>. A recent example is the initiative led by the Health Quality Council of Alberta (HQCA) to collect PREM data in primary care to inform timely quality improvement.

### *System level*

The ability of healthcare systems to learn what is most important to patients and families receiving care is crucial for the delivery of high-quality PCC. To this end, many health systems regularly collect survey data from patients and their families and are engaged in activities to publicly report the results. At the system level, PROMs and PREMs are key informants of quality improvement programs and value-based healthcare initiatives.

#### *1. Quality Improvement.*

Both PROMs and PREMs data can be stored in the patients' electronic health records (EMR) and integrated with other patient clinical data<sup>30,32,34</sup>. These linkages can facilitate and support multiple tasks, including quality improvement, health services research, and public reporting.



The results can be used for national benchmarking ensuring that quality is consistent across sectors and allows for allocating resources efficiently, while providing appropriate access for given needs where health inequalities might exist<sup>32</sup>.

In Alberta, Alberta Health, Alberta Health Services (AHS) and the Health Quality Council of Alberta (HQCA) have jointly agreed to use and implement the EQ-5D as PROM for healthcare services. The EQ-5D is also being incorporated into the new province-wide Connect Care electronic medical record system in Alberta. EQ-5D implementation demonstrates how PROMs data can be used to better understand individual and system level impacts. [<https://apersu.ca/>]

Despite the interest across the country to standardize the use of PROMs, there is not a national strategy for implementing PROMs in healthcare systems.

Related to PREM initiatives, at national level, the Canadian Institute of Health Information (CIHI) has embarked upon public reporting of inpatient hospital experience across Canada. To date, five jurisdictions (British Columbia, Alberta, Manitoba, Ontario, New Brunswick) are participating in the Canadian Patient Experiences Reporting System<sup>36</sup> (36) – a national repository using the Canadian Patient Experiences Survey – Inpatient Care (CPES-IC) instrument<sup>36</sup>. This however, is based upon voluntary participation from healthcare organizations, and is limited to the inpatient setting. It is presumed that if successful, the program may be expanded to other care settings. Examples of this include the PREMs programs in Alberta and British Columbia.

In Alberta, Alberta Health Services (AHS) collects and reports the overall experience rating of their hospital patients on a quarterly basis<sup>37</sup>. AHS collects PREMs routinely on a random sample of 10% of the Albertans discharged from hospitals across the province. The

PREMs used include the Canadian Patient Experiences Survey– Inpatient Care (CPES-IC)<sup>36</sup>, developed by the Canadian Institute for Health Information (CIHI) for adult inpatient care; and the Alberta Pediatric Inpatient Experiences Survey (APIES)<sup>38,39</sup>, to capture experiences of parents and guardians of hospitalized children. Each year, approximately 25,000 adult, and 2,500 pediatric (child and newborn) inpatient surveys are obtained<sup>39</sup>. Potential respondents are selected randomly and contacted between day 2 and 42 following discharge from hospital. The PREM provincial data is reported and used for quality improvement across hospitals in Alberta<sup>25,38,39</sup>.

Alberta Health Services has conducted patient experience surveys since 2011<sup>38</sup>. Since 2015, our research team has conducted multiple studies using this survey data, both in isolation, and in linkages with other administrative data sources (e.g., inpatient, emergency department visits)<sup>25,26,38,39</sup>. Linkages with these administrative data sets have allowed us to examine patient experiences according to other clinical features (e.g., most responsible diagnosis, procedures performed, number of medical comorbidities). This linked data also allows us to conduct stratified analyses (e.g., based on age, sex, length of stay, etc.), to examine the experiences of pre-defined clinical cohorts (e.g., by diagnosis, surgical procedure, time period), and to examine the potential associations of survey data with other outcomes (e.g., readmissions, emergency department visits, patient safety indicators) in regression analyses. At the time of this article, our team has published over 20 manuscripts from this work, the methods, and products of which, are published in a recent article in the *International Journal of Population Data Science*<sup>40</sup>.

These highlighted examples represent work that is occurring in Canada at the provincial level. Recognizing the need for standardized collection and dissemination of national patient experience survey results, CIHI commenced public reporting of results in 2019 with CPES-IC data housed as part of the Canadian Patient Experiences Reporting System<sup>41</sup>. This however, is limited to the inpatient setting. It is presumed that if successful, the program may be expanded to other care settings.

Another successful program is the British Columbia PREMs Program that has coordinated province-wide surveys<sup>35</sup>. (35) The program has obtained feedback from more than one million healthcare services users across 13 sectors in all age groups<sup>35</sup>. Quantitative and qualitative data have been analyzed and reported. Using a “modular” approach, practical support for the effective use of the data for quality improvement purposes has been provided, in conjunction with public reporting of results.

## II. Value-based Healthcare.

One value-based approach is to measure outcomes of patients receiving health services from their own perspective using both PROMs and PREMs as both measures inform the quadruple aim<sup>42</sup>. Value-based care assesses healthcare that has been done safely and efficiently in a personalized and timely manner<sup>43</sup>.

Thus, in healthcare delivery, value-based approaches allow to shift the focus to the outcomes that matter to people receiving care in relation to the cost of delivering those services, rather than focusing on the total amount of investment<sup>43</sup>. For instance, when the outcomes of people receiving the service improve and costs are lower or unchanged, value increases.

## Research - Patient-centered outcomes research (PCOR)

PCOR provides an opportunity to include information that patients, family members and clinicians need to improve care quality and patient outcomes. In some instances, this information also relates to treatment alternatives, quality of life considerations, and introduces a person-centric approach into research<sup>44</sup>.

In relation to PCOR, our Person-centred Research Team<sup>45</sup> has collaborated with AHS and the HQCA in our PREM program. Since 2015, we have conducted a variety of studies which have explored patient experience survey data, in isolation, and in linkages with routinely captured administrative data sets across Alberta. Via secondary analyses, these studies have shed light upon the drivers of inpatient experience, the specific aspects of care which are most correlated with one's overall experiences, and the association of elements of the patient experience with other measures, such as patient safety indicators and unplanned hospital readmissions<sup>45</sup>.

## Recommendations

Despite many successful discussions and initiatives surrounding the collection and use of PROMs and PREMs in Canada, there has been a slow integration of these measures within healthcare systems. One potential reason for this is the diversity and resulting heterogeneity of these measures<sup>46</sup>. Historically, healthcare organizations and jurisdictions have selected tools to fit their own needs, in isolation from one another. This lack of consensus with respect to instrument selection impedes benchmarking across institutions and provinces<sup>35,46</sup>. (35, 46) In addition, standardized approaches for linking PROMs and PREMs data with EMRs are lacking.

Other potential contributing challenges pertain to the diverse uses of PROMs, including the several considerations which need to be taken into account when selecting which PROM to use including the context and purpose for collecting PROMs data<sup>17</sup>. Second, when completing PROMs, individuals may interpret questions about their health or quality of life differently, or an individual's frame of reference may change in response to a health event or intervention – a phenomenon referred to as “response shift”<sup>44</sup>. These challenges threaten the comparability of scores across individuals or groups and/or scores over time. There is a need for innovative statistical approaches for the analysis of PROMs data to ensure these accurate comparisons, and to minimize patient burden<sup>44</sup>. Third, when PROMs are used in clinical care at individual level, there is a need to develop training programs<sup>22</sup>. These programs should be tailored to specific applications and include healthcare providers, patients, and family members to aid the interpretation of results and guide their use to support self-care management<sup>47</sup>. To advance the use of PROMs in clinical care, further development of reporting systems with total integration into EMRs are needed. One of the challenges to integration is the rigidity of EMR systems. At the moment, the integration is sparse and mostly funded by research projects. There is a need for further work supporting the integration of these measures in healthcare, specifically from healthcare organizations to fully operationalize the use of PROMs and PREMs to individualize clinical care, improve quality of care and facilitate PCOR.

With respect to PREMs, the methods for collecting patient experience have tended to be using sector-specific (e.g., inpatient, emergency department, primary care, mental health) surveys. This had led to challenges in capturing PREM data pertaining to transitions of care, or care across the health continuum. Despite this, there are examples of promising work, including initiatives to publicly communicate PREM results<sup>41</sup>. In conclusion, PROMs and PREMs play a crucial role in the delivery of PCC.

Canada is far from implementing and standardizing PROMs and PREMs in healthcare; new national initiatives are needed as PROMs and PREMs are integral to PCC measurement and should have a central role in Canadian health policy to improve health and healthcare.

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