

Call to action: Addressing the need for patient-reported outcome measures in Canadian healthcare practice

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Patient-reported outcome measures (PROMs) are heading an exciting new era in medicine—an era where patient voices are considered alongside those of the healthcare providers in order to help direct patient care, compare provider and hospital performance, and investigate the efficacy of commonplace medical procedures.^{1,2} Indeed, the addition of novel patient-reported data to the routinely collected, objective clinical data will support decision-making at multiple levels within the healthcare system, ultimately helping minimize patient disability and maximize quality of life.

PROMs are defined as measurement tools or instruments, such as questionnaires that assess a patient's health status across several domains relevant to their quality of life, including pain, day-to-day function, and social, mental, and physical health.^{3,4} Unlike ordinary questionnaires, however, PROMs employ scientifically rigorous psychometric methodology and are thus highly reliable tools for translating subjective aspects of patient health into validated objective data.^{5,6} Depending on the information one hopes to gain, different categories of PROMs can be used. For example, if one hopes to aggregate general aspects of health data from a population of interest, generic PROMs should be used. As their name suggests, generic PROMs measure non-specific components of health and wellbeing, irrespective of any underlying health conditions.⁷ Condition-specific PROMs, on the other hand, should be used if one hopes to measure outcomes relevant to those living with a particular condition.⁷

Although initially developed for research purposes, PROMs quickly spread into the clinical setting as a quality improvement (QI) tool used to assist physicians with patient management and supply data for benchmarking purposes.¹ Since then, a growing number of studies have demonstrated the benefit of QI-oriented PROM initiatives (QI-PROMs) on symptom management, patient survival, and medical intervention cost-effectiveness,⁸⁻¹¹ though further research is needed to more concretely demonstrate their clinical efficacy in other domains.¹² Regardless of promising reports, Canadians appear to be largely behind the curve when it comes to implementing PROMs—especially when compared to leading countries such as England and the United States.¹³ In England, PROMs were introduced in 2009 and continue to be collected on a mandatory basis for elective hip replacement, knee replacement, groin hernia, and varicose vein surgeries,¹⁴ as the primary objective of these procedures is to improve patient quality of life.⁵ The continued collection and public reporting of these data across England have helped evaluate current medical practice, inform policy, compare provider performance, and provide patients with meaningful data to aid their decisions of whether or not to undergo treatment based on predicted outcomes.¹⁵ Similarly, the Affordable Care Act in the United States publicizes patient-reported data as a way of enhancing provider accountability and informing pay-for-performance programs used to reimburse providers.^{13,15}

Although several PROM initiatives exist across Canada, the vast majority are regionally operated and are largely meant to serve independent research projects and patient registries.⁵ For example, the

Patient Experience with Arthroplasty of the Knee (PEAK) Project was a regional initiative in British Columbia that collected both generic and condition-specific PROM data regarding patient satisfaction with surgical outcomes from a prospective cohort of approximately 500 patients who underwent total knee arthroplasty.^{5,16} As a research-oriented project, however, the PEAK study focused primarily on acquiring new knowledge regarding patient experience as opposed to applying this knowledge to patient care. A similar trend is seen with national-level PROMs, where the few ongoing initiatives primarily serve health-surveillance and/or research purposes. However, as demonstrated by current evidence, large-scale PROMs are often preferred to local initiatives for their ability to provide stronger statistical power for national and international comparisons.⁵ One notable example of such an initiative is the Canadian Community Health Survey (CCHS), an annual Canada-wide, cross-sectional survey that collects information on health status, healthcare utilization, and other health determinants of the Canadian population.¹⁷ One strength of the CCHS lies in the flexibility it provides for individual provinces and territories to supplement core questionnaire content with optional modules,¹⁷ thus allowing both regional and national interests to be addressed without compromise. Importantly, the CCHS provides a well-established infrastructure that can be leveraged in the future to greatly reduce the time and resource demands needed to implement and operate any national PROM development. However, regardless of the framework it provides, the CCHS, like most other PROM initiatives in Canada, is of limited direct benefit to patients and providers. Upcoming PROM initiatives should therefore use past projects only as guidelines, as future projects will necessarily require a QI-focus if they hope to bring about change at the clinical level. It is also imperative that stakeholders of all levels, from policy-makers to administrators to clinicians, agree on a common approach in order to ensure that future developments adequately meet the needs of all those involved. Furthermore, stakeholders must ensure that both the selection of PROM instruments (e.g., generic versus condition-specific) and PROM administration mechanisms (e.g., sampling design, method of administration, timing of data collection) align with the purposes of the project.⁵

By collecting and quantifying a patient's perspective, PROMs will undoubtedly help close the gap that exists between healthcare providers and patients. Indeed, considering patient-reported data alongside routinely collected clinical data allows for a more holistic approach to patient care. Ultimately, such an approach will bring us closer to one of the fundamental goals of medicine—to relieve patient pain and suffering. Who could be better at providing this information than the patients themselves?

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