

**The Conference  
Board of Canada**



# Advancing Patient-Reported Outcomes in Canada

Perspectives From VBHC Canada Roundtable Participants

**Issue briefing** | January 22, 2025



# Value-Based Healthcare Canada

Value-Based Healthcare Canada (VBHC Canada) is a research centre dedicated to building an evidence base for the systematic implementation and integration of value-based healthcare approaches across Canada. Value-based healthcare (VBHC) is an international movement that seeks to achieve the best outcomes for patients at the most reasonable cost by placing self-reported health and quality of life at the centre of healthcare decision-making. It informs a framework for restructuring healthcare systems, with the goal of optimizing value to patients and systems.

We work with key stakeholders from private, public, not-for-profit, healthcare delivery, and academic sectors, to tackle the daunting problem of how to improve patient care and outcomes while containing healthcare costs. VBHC Canada endeavours to be the Canadian champion for the VBHC movement, which means being the driver for applied research and stakeholder connections in support of advancing VBHC approaches and system-level impact across Canada's health systems.

Our Research Centre is funded by multiple members—united in their mission for progress—who support and inform the Centre's research agenda. Funding Members have the opportunity to help shape the future of Canada by ensuring independent, evidence-based research in value-based healthcare is developed and delivered to decision-makers in government, business, and civil society.

We are appreciative of the support from our funding members. Their passion and understanding of the urgent need for progress helps propel us forward and allows us to conduct research that matters into healthcare.

We welcome you to join us.

## Funding Members

### Partners



### Collaborator



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# Key findings

- Patient-reported outcome (PRO) data informs patient care pathways, encourages provider-patient communication, evaluates patient priorities, and can be used for quality improvement and research.
- PRO implementation is most successful when it starts by addressing a focused, specific pain point in healthcare delivery.
- Engagement with a diverse range of patients is essential to PRO development, validation, collection, and interpretation.
- Involving a range of stakeholders in PRO implementation supports the sharing of expertise and mitigates risks (e.g., misaligned incentives) and concerns, such as data privacy.
- Environments primed to uptake PROs are those with integrated learning health teams who share an understanding of the benefits of PROs and a motivation to drive improvements in care.



# Advancing patient-reported outcomes (PROs)

In February 2024, The Conference Board of Canada hosted a virtual Value-Based Healthcare (VBHC) Canada roundtable event titled, *Data and Decision Making to Advance the Application and Use of Patient-Reported Outcomes in Canada*. The objective of the event was to draw on the insights and direction from 10 invited speakers to inform and advance the application and use of patient-reported outcomes across Canada.

# PRO roundtable speakers

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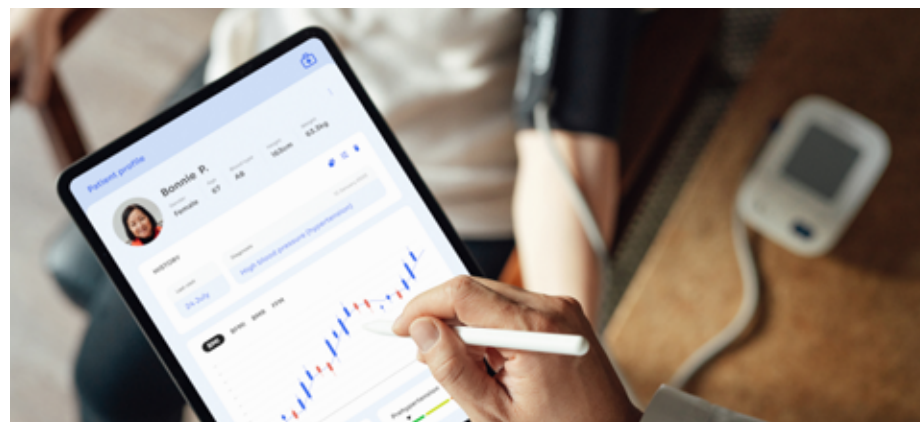
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## Patient-reported outcomes in value-based healthcare transformation

The “value” in value-based healthcare (VBHC) transformation is commonly defined as measured improvements in patient health outcomes for the cost of delivering those outcomes.<sup>1</sup> Measuring clinical outcomes (e.g., disease progression or regression, and functional status) and PROs is an essential element in value-based clinical practice. PRO data measures the impact of illness and treatment from the patient’s perspective. The process of collecting and using PROs promotes proactive communication and positive health behaviours in patients. It also increases clinician awareness of patient symptoms.<sup>2</sup>

PRO data is critical for implementation of VBHC across Canada. Knowing this, the speakers at the 2024 VBHC Canada PRO roundtable event clarified the path forward to improve PRO use and enhance system performance. They provided new perspectives on PRO development, data collection, data management, data analysis, and application and advancement of PROs in healthcare settings. They shared how they are implementing PROs and offered insights on how to expand PRO use across the healthcare system.



### What are patient-reported outcomes?

PROs are outcomes or sets of measures that use patients’ views and opinions to assess patient health, quality of life, or functional status associated with illness, healthcare, or treatment. Patients directly report PRO data through self-reporting instruments without intervention or interpretation by clinicians or anyone else.<sup>3</sup>

In this briefing, we present a synthesis of the key points from the 2024 PRO roundtable in relation to the Teisberg, Wallace, and O’Hara VBHC Transformation Framework and its five key elements for implementing value-based healthcare.<sup>4</sup> Roundtable speakers’ recommendations for advancing PROs are summarized in Table 1.

<sup>1</sup> Porter and Teisberg, *Redefining Health Care*.

<sup>2</sup> Silveira Bianchim and others, “The Implementation, Use and Impact of Patient-Reported Outcome Measures.”

<sup>3</sup> Johnston, Patrick, Devji, and others, “Chapter 18, Patient-reported outcomes.”

<sup>4</sup> Teisberg, Wallace, and O’Hara, “Defining and Implementing Value-Based Health Care.”

**Table 1**

Summary of PRO roundtable speaker recommendations and considerations

Key elements of the VBHC transformation framework	Roundtable speaker recommendations for advancing PROs
1. Understand shared health needs of patients	<ul style="list-style-type: none"> <li>• Design PROs that capture what is meaningful to patients.</li> <li>• Seek input from a diversity of stakeholders.</li> <li>• Engage patients in PRO development, validation, collection, and interpretation.</li> <li>• Build trust with patients and patient advocacy groups by maintaining transparency and ensuring privacy.</li> <li>• Show patients and clinicians how their contributions to PROs enhance patient health and well-being.</li> </ul>
2. Design solutions to improve health outcomes	<ul style="list-style-type: none"> <li>• Start small and focus on a pain point for patients or providers.</li> <li>• Create workflows of current and future states.</li> <li>• Embed PROs in current workflows, while considering their application in future workflows.</li> <li>• Apply user-centric design principles.</li> <li>• Ensure PROs are actionable at the patient and provider level.</li> <li>• Ensure alignment in understanding of PROs across stakeholders.</li> </ul>
3. Measure health outcomes and costs	<ul style="list-style-type: none"> <li>• Embed PROs in care pathways.</li> <li>• Report data back to patients and providers.</li> <li>• Integrate PRO data with clinical outcomes, quality indicators, and cost data.</li> <li>• Leverage standard PRO measurement sets.</li> <li>• Consider resources, training capacity, and goals when selecting PRO measurement instruments and tools.</li> <li>• Make efforts to strengthen data quality.</li> <li>• Note methodological issues when interpreting and applying PROs.</li> <li>• Establish a data governance framework.</li> </ul>
4. Integrate learning teams	<ul style="list-style-type: none"> <li>• Involve a multidisciplinary learning health team in implementing PROs.</li> <li>• Ensure stakeholders have a shared understanding of PROs.</li> <li>• Support capacity building for application of PROs.</li> <li>• Leverage data and analytics to improve care and evolve PRO implementation.</li> <li>• Include the evaluation of PRO initiatives in the implementation process.</li> </ul>
5. Expand partnerships	<ul style="list-style-type: none"> <li>• Receive ongoing input, guidance and advice from a broad coalition of stakeholders.</li> <li>• Identify and acknowledge individuals acting as champions for PRO implementation.</li> <li>• Form networks of organizations and people with mutual interest in PRO implementation.</li> </ul>

PRO, patient-reported outcomes; VBHC, value-based healthcare.

Sources: The Conference Board of Canada; Teisberg, Wallace, and O'Hara, "Defining and Implementing Value-Based Health Care."

## 1. Understand shared health needs of patients

A leading element of VBHC implementation is understanding the health needs of patients.<sup>5</sup> Roundtable speakers emphasized the importance of including all stakeholder voices—patient organizations, those receiving care, and healthcare providers—to better identify and understand patient needs.

Incorporating diverse stakeholder perspectives with respect to regional, gender, and ethnicity differences is crucial for successful system- and organizational-level implementation of PROs. Having diverse representation aids in understanding unique challenges as well as providing necessary information for scaling implementation to different places or populations.

“... diverse stakeholder perspectives [are] important when we’re thinking of [the] patient journey across every disease state, including a focus on diversity, equity, and inclusion....”

**PRO roundtable speaker**

There is evidence of a disconnect between what healthcare providers believe; what patients want, feel, and value; and what patients express.<sup>6</sup> Patient involvement is necessary for the entire lifespan of PRO implementation through development, validation, collection, and interpretation of data. Teams need to build trust with patients when engaging them in PRO utilization, particularly around how patient data is managed and used. This is done by ensuring privacy and providing transparency.

At the roundtable, two speakers highlighted how integrating the measurement and use of PROs enables healthcare providers and planners to identify patient issues from the patient’s own perspective. By leveraging PRO data, care teams can focus efforts on problems that patients are having. In turn, this has greater impact on outcomes and efficiencies.

Furthermore, using PROs in clinical practice at the point of care supports communication among the care team and the patient. Not only does this improve patient experience, but it also ensures continued understanding of patient needs. Patients should experience the real-time benefits of contributing their data—including being empowered to engage informed decision-making about their care.



<sup>5</sup> Teisberg, Wallace, and O'Hara, "Defining and Implementing Value-Based Health Care."

<sup>6</sup> STAT, "In Health Care, It's Time to Get a Second Opinion."



## 2. Design solutions to improve health outcomes

VBHC is about broadly improving healthcare system value. But building value-based solutions through PROs means focusing on their role in improving health outcomes for patients. One speaker shared that VBHC improvement efforts are sometimes focused on system transformation and organization-level changes. However, PROs are tools that benefit patients. They enable healthcare providers to achieve the primary goal of improving care for their patients. For this reason, all levels of the healthcare system should be invested in advancing the collection and use of PROs and ongoing engagement with patients.

Careful and deliberate first steps are required at the start for PRO implementation to improve the health of patients. Once a patient's or patient group's needs are identified, practitioners often also identify complexities that make creating a whole-system solution challenging and, at times, overwhelming. Several PRO roundtable speakers suggest designing PRO-based solutions by identifying and addressing a single actionable pain point for patients or providers. The speakers advised to use this method rather than enacting broad, non-specific systematic PRO implementation.

*“... having done this in over 100 hospitals now ... how we can make a dent in patient outcomes is that we've got to start small and keep building.”*

**PRO roundtable speaker**

As a first step, one roundtable speaker suggested recording workflows of the current state of care delivery before designing a future state. This helps teams identify how PROs can be embedded in current workflows and mitigate the administrative burden. Furthermore, roundtable speakers recommend user-centric

approaches to initially design the collection of PROs to support adoption. Careful consideration is needed, not only for what is measured but also for how data is collected from patients and shared with patients and providers.

Implementation of PROs in Canadian healthcare is often initiated as part of a time-limited research or quality improvement project. Transitioning and sustaining PRO use in clinical practice requires that these approaches be embedded in practice and be actionable at the patient and clinician levels. System- and organization-level supports or changes are often required to enable these transformational actions at the practice-level.

PROs help identify gaps or obstacles undermining patients' health. Roundtable speakers recommend making small, incremental changes with rapid reporting back to stakeholders, so they see the benefits of providing data.

*“We had to look at our processes involved in moving towards value-based care delivery and how these can be optimized to be effective in enhancing experience, engagement and driving positive outcomes.”*

**PRO roundtable speaker**

The PRO roundtable speakers also emphasized that there needs to be a shared understanding of the PROs among all stakeholders. The reason is that it is not perceived only as a research tool, a clinical tool, or an evaluation tool. Instead, it should be recognized as a way to realize a vision of improved patient outcomes and greater value.

### 3. Measure health outcomes and costs

PROs directly engage patients in providing health outcomes data that is meaningful to delivering value for patients from healthcare—the very heart of VBHC.

“PROs are really exciting for us as they allow us to unlock [outcomes] data that’s not normally collected.”

**PRO roundtable speaker**

Evaluating the impact of healthcare change using a value-based approach requires measuring costs and outcomes. Costs serve as the denominator in a value calculation and include the total costs used during a patient’s full cycle of care. This can incorporate clinical, administrative, and social costs.<sup>7</sup> Outcomes include clinical outcomes (e.g., cholesterol or blood pressure) and PROs (e.g., patient-reported pain or ability to conduct daily activities). Outcomes may be measured before, during, and after care.

PRO data informs a patient’s care pathway, encourages provider-patient communication, and evaluates patient priorities. Additionally, when standardized, the data can be used in quality improvement initiatives, benchmarking, and research. However, obtaining correct PRO measurements for these needs is challenging.

Roundtable speakers shared several considerations for PRO measurement:

- Structure measurement around the patient care process. As well, feed data back to the patient, and demonstrate how their data is used directly to inform their care or interactions with the healthcare system.
- Build in measurement approaches that include mechanisms for healthcare providers to have real-time or near-real-time access to PRO data. This will enable providers to use these tools effectively to improve care delivery and efficiency.
- Strive for incorporation of PRO data with other clinical outcome data, quality data, and costing data. Together, these enable value to be assessed at the patient-, unit-, or organization-level, which is a key input for making value-based decisions.
- Determine which set of PROs you will measure. The literature provides some guidance. Organizations, such as the International Consortium for Health Outcomes Measurement and the Canadian Institute of Health Information, provide standard measurement sets for several disease areas.<sup>8</sup>
- Select appropriate PRO measurement instruments, tools, and technologies based on workflows, resource availabilities, and training capacity. Implementation of patient-reported data collection differs from other clinical outcomes and often requires special training and supports to assist patients in completing the measures.

7 EIT Health, *Implementing Value-Based Health Care in Europe*.

8 Canadian Institute of Health Information and Organisation for Economic Co-operation and Development, “OECD Patient-Reported Indicator Surveys (PaRIS) Initiative.”

- Engage patients in validation of PROs. Recognize that language drives interpretation of PROs and the accuracy of the information being reported by patients.
- Be clear on what format is needed for the data. Does the team require raw, aggregated, electronic, or integrated data? Electronically integrated PRO measurement can be efficient, but technology can be a barrier and impede the use and application of PROs without adequate supports. Alternatively, using paper-driven questionnaires can raise questions about the data's reliability.
- Improve data quality by considering consistency in PRO measurement across sites or studies and mitigating biases (e.g., changes in patient responses due to frequency of data collection).
- Note methodological issues when interpreting or applying PROs. The field is still advancing its understanding about:
  - how much normal variation exists for PROs;
  - which case-mix variables are required for adjustment;
  - whether it is appropriate to use PROs for comparing performance of providers;
  - how sensitive PROs are to changes in care.

- Ensure that PRO data is being collected, stored, and used safely and appropriately. A data governance framework can establish goals and targets and provide data guidelines and protection.
- Consider the future goals of PRO measurement. If starting as a research project but wanting to scale up, consider infrastructure requirements, coordination of collection, and standardization.

Value-based measurement models continue to advance, but there is still a sense that we are too often measuring process-based outcomes and not patient-centered outcomes. PROs support transformation toward a value-driven rather than a volume-driven system. It is important to continue to include PROs in measurement models to align measurement with the goals of the system.



## 4. Integrate learning teams

The implementation of PROs benefits from the involvement of a dedicated multidisciplinary learning health team. The team includes clinicians, patient representatives, decision-support specialists, data analysts, information technology specialists, researchers, and others. Having a shared motivation and understanding of the benefit of PROs creates an environment for integrated learning and opportunities for enhancing PRO measurement.

As demonstrated by the examples shared by several roundtable speakers, these teams work to advance the use of PROs. They do this by supporting capacity building, evaluating PRO implementation initiatives, and identifying innovations or opportunities. The lessons learned from structured evaluations can be used to strengthen the learning health team's care program as well as provide insight for others seeking to use PROs.

In the following examples, two speakers demonstrate how leveraging the data and analytics helped them redesign and rethink how care is delivered through integrating learning across their care teams and scale VBHC concepts across their organization:

1. **A roundtable speaker shared how they were able to use the PROs data to tell a compelling story.** They detailed the organization's processes, quality of care, and patient outcomes in relation to the cost of delivering care. This was possible because they implemented tools that enabled the organization to look across the continuum of care and match outcome data with cost data
2. **Another speaker described a predictor tool they developed to flag patients at risk of going to the hospital.** They did this by correlating PRO data with hospital and emergency department visits. This tool supports value-based decision making by helping providers intervene and provide care in lower-cost, more appropriate settings.

Clinicians want to know what the PRO scores mean and what they should do clinically to address them. It is important to remind clinicians that PROs are subjective measures from the patient perspective and are a vehicle for communication between patients and providers. Demonstrating the value of PRO data to clinicians and teaching them how to use and interpret it are important components of supporting PROs in learning health teams.

One roundtable speaker shared how, despite uptake of PROs in pockets, the organization was not meeting its goals of widespread adoption and use across several sites. To understand why implementation was stalled, the research team conducted a qualitative evaluation. They spoke with their multidisciplinary team of people working with PROs in practice, performance measurement, quality improvement, and research. The research team was able to identify areas to address together to enhance the PRO quality and uptake. One of their findings was the need to bolster organizational commitment and support. The need was based on the ongoing efforts required for establishing a shared understanding of the importance of PROs, embedding PROs into a comprehensive outcome measurement framework, and training staff and clinicians on use of PRO data.

[“Let's start talking to the people ... what is it that we need to do to improve and enhance PRO use across the system?”](#)

**PRO roundtable speaker**



## 5. Expanding partnerships

Expanding partnerships supports the increased use and application of PROs. Partnerships build a broad coalition of stakeholders focused on delivering value-based care. The coalition includes:

- patients
- patient advocacy organizations
- physicians
- pharmacists
- therapists
- nurses
- other clinicians
- managers
- clinical leads
- decision-support analysts
- policy analysts
- researchers
- decision-makers

Engaging a broad range of stakeholders throughout the process of implementing PROs helps mitigate downstream risks. These include low adoption resulting from misaligned incentives and a lack of understanding of the purpose of PROs, and concerns with privacy and data handling.

PRO roundtable speakers highlighted that the two most important stakeholders are clinicians and patients. Clinicians are important champions for PRO adoption and provide critical buy-in at the front line. Meanwhile, patients are necessary champions for utilization and increasing the health impact of PROs.

Partnerships may form between stakeholder groups, similar organizations, or organizations from different parts of the system. These partnerships enable sharing of expertise, integrating of PRO measurement across partners, and leveraging PRO assets for wider implementation across care sites.

For example, building partnerships between those who research PRO use and those who provide clinical care can expand adoption. One speaker recommended that when a research program wants to transition PRO implementation to broader adoption in practice, they should partner with an operational organization that makes PRO implementation a priority.

Working with stakeholders and identifying partners enables organizations to leverage these groups who are the experts in the PRO space, learn from what they've already done, and expand the application of PROs.

*“Chances are that you are going to learn different things when you're talking to different stakeholders”*

**PRO roundtable speaker**

## Moving from shared experiences to practical insight

The PRO roundtable provided significant insight into real world examples of the factors needed to implement PROs as part of value-based care in Canada. The 10 speakers shared their experiences implementing PROs from the provider- (micro), organization- or region- (meso), and system- (macro) level.

These insights raised a critical question for VBHC Canada. That is, how can we classify and articulate the implementation of PROs in VBHC where it is being used in Canada?

Addressing this question will include:

- Determining the resources and contextual factors required for successful and sustained implementation of PROs.
- Identifying the implementation stages necessary to incentivize and support clinicians to collect and use PROs.
- Understanding the key factors motivating or impeding patients to report PROs.



## Appendix A

# Methodology

On February 29, 2024, The Conference Board of Canada hosted the Value-Based Healthcare Canada 2024 virtual roundtable event: *Data and Decision Making to Advance the Application and Use of Patient-Reported Outcomes (PROs) in Canada*. Ten speakers were invited to speak on their experience with PRO implementation. The Conference Board of Canada selected these speakers to represent a range of perspectives in geography, health system levels, organizations, and roles.

Each speaker gave a 10-minute presentation. The presentations were followed by a 25-minute facilitated discussion. The event (speaker presentations and facilitated discussion) was recorded and transcribed in Microsoft teams. The transcription was reviewed against the recording for accuracy and uploaded into NVivo. The transcript was 69 pages (22,793 words). A content analysis was performed with one researcher deductively coding the transcript according to the five elements for implementing value-based healthcare. The elements are defined in the Teisberg, Wallace, and O'Hara strategic framework<sup>1</sup>:

1. Understand shared health needs of patients.
2. Design solution to improve health outcomes.
3. Integrate learning teams.
4. Measure health outcomes and costs.
5. Expand partnerships.

The researcher also identified codes and subcodes inductively during the coding process. A second researcher reviewed the coding framework and supported the charting process. The researchers described themes aligned to the five strategic framework elements, along with supporting context and quotations from the roundtable event.

1 Teisberg, Wallace, and O'Hara, "Defining and Implementing Value-Based Health Care."

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