Patient-Reported Outcome Measures

CIHI’s PROMs Program

In 2015, the Canadian Institute for Health Information (CIHI) hosted the pan-Canadian PROMs Forum. (PROMs stands for patient-reported outcome measures.) It launched the PROMs Program to support the development of PROMs data collection standards and reporting in priority areas. CIHI continues to work with a broad range of stakeholders to advance a common approach to collecting and reporting on PROMs across Canada.

**Priority clinical areas and topics**
- Current focus on hip and knee arthroplasty
- Exploring future topics (e.g., mental health, generic tools)

**Standards development**
- Environmental scans, consultations
- National data collection standards for PROMs for hip and knee

**Uses and comparative reporting**
- Measures and comparative reports for PROMs
- PROMs reporting for hip and knee (pilot for OECD’s *Health at a Glance* 2019 report)

**Innovative data collection**
- Promote electronic PROMs collection and submission of data to CIHI

**Stakeholder alignment**
- National PROMs Advisory Committee and working groups
- OECD Patient-Reported Indicators Survey Hip and Knee Replacement Surgery Working Group (co-leading)

**Notes**
- PROMs: Patient-reported outcome measures.
- OECD: Organisation for Economic Co-operation and Development.

**PROMs overview**

PROMs are measurement instruments completed by patients. PROMs obtain information on aspects of and changes in patients’ health status that are relevant to their quality of life, including symptoms, functioning, pain, and physical, mental and social health. PROMs tools are categorized as generic (applied across different populations) or condition-specific (used to assess outcomes that are characteristic of or unique to particular diseases or sectors of care). Patient-reported experience measures (PREMs) and PROMs, when linked to additional CIHI data sources on health care utilization, outcomes and costs, support patient-centred and value-based health care delivery.

**Benefits of PROMs**

PROMs are increasingly recognized as valuable information that is essential for achieving health system goals and supporting a patient-centred approach to care:

- PROMs provide insight on the effectiveness of care from the patient’s perspective. They are required to understand whether health care services and procedures make a difference to patients’ health status and quality of life.
• PROMs can be used to inform clinical practices, health services programming, planning and policies, performance measurements, comparative effectiveness analysis and quality improvement initiatives.
• PROMs can be linked in a privacy-appropriate manner to other data sources — such as clinical and administrative data, and PREMs — to enrich existing information and better inform decisions.

PROMs Program highlights

<table>
<thead>
<tr>
<th>Years</th>
<th>Activities</th>
</tr>
</thead>
</table>
| 2013–2014 to 2015–2016 | • Conducted environmental scan and published PROMs Background Document  
• Hosted pan-Canadian PROMs Forum and published PROMs Forum Proceedings |
| 2015–2016 to 2017–2018 | • Formed National PROMs Advisory Committee  
• Formed PROMs working groups for hip and knee replacement, chronic kidney disease and generic tools  
• Hosted PREMs/PROMs Visioning Day  
• Hosted Patient-Centred Measurement Peer Learning Day  
• Conducted exploratory analysis for demonstration projects using data from the BC Provincial Renal Agency and Winnipeg Regional Health Authority |
| 2017–2018 to 2019–2020 | • Finalized national PROMs data collection standards for hip and knee replacement*  
• Acquired national licences for EQ-5D-5L, OHS and OKS for use in routine care  
• Completed validation project for Canadian versions of OHS and OKS  
• Launched Ontario hip and knee PROMs pilot — co-executed with Cancer Care Ontario — for the Ontario Ministry of Health and Long-Term Care  
• Currently chairing the international Hip and Knee Replacement Surgery Working Group of the Patient-Reported Indicators Survey initiative and co-leading the working group with the OECD  
• Developed and tested common reporting measures across a subset of countries using existing hip and knee replacement PROMs data for health system evaluation for publication in OECD’s Health at a Glance 2019 report |

Notes
* These standards have been endorsed by CIHI’s Canadian Joint Replacement Registry Advisory Committee and PROMs Hip and Knee Replacements Working Group.

PROM: Patient-reported outcome measures.  
PREM: Patient-reported experience measures.  
EQ-5D-5L: The 5-level version of EQ-5D, a measure of health-related quality of life.  
OHS: Oxford Hip Score.  
OKS: Oxford Knee Score.  
OECD: Organisation for Economic Co-operation and Development.

For additional information: proms@cihi.ca or www.cihi.ca/proms

Next steps
• Expand standardized PROMs collection for hip and knee replacements across Canada to enable national comparative reporting.
• Develop and publish international data collection guidelines for hip and knee arthroplasty surgery.
• Explore new areas of expansion and application for generic PROMs tools, such as mental health.