Patient-Reported Outcome Measures

CIHI’s PROMs Program

In response to stakeholder interest, the Canadian Institute for Health Information (CIHI) is providing leadership for advancing standardized approaches to PROMs across Canada. In 2015, CIHI launched its 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.

PROMs overview

PROMs are measurement instruments completed by patients to obtain information on aspects of and changes in their health status that are relevant to their quality of life, including symptoms, functioning, pain, and physical, mental and social health.

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 as they

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

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<th>Year</th>
<th>Activities</th>
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<tr>
<td>2013–2014</td>
<td>• Conducted environmental scan and published PROMs Background Document</td>
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<td>2014–2015</td>
<td>• Hosted pan-Canadian PROMs Forum; published PROMs Forum Proceedings</td>
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| 2015–2016   | • 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                                                                                                                                                                      |
| 2016–2017   | • 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   | • Finalized national PROMS data collection standards for hip and knee replacement*  
• Acquired national licences for EQ-5D-5L, Oxford Hip Score (OHS) and Oxford Knee Score (OKS) for use in routine care  
• Completed validation project for Canadian versions of OHS and OKS  
• Launched the Organisation for Economic Co-operation and Development (OECD) Patient-Reported Indicators Survey (PaRIS) Hip and Knee Working Group  
• Launched the Ontario Hip and Knee PROMs project (sponsored by the Ontario Ministry of Health and Long-Term Care, co-executed with Cancer Care Ontario) |

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

Next steps

- Expand standardized PROMs collection for hip and knee replacement across Canada to enable national comparative reporting.
- Develop and pilot common reporting measures across a subset of countries using existing hip and knee replacement PROMs data to address information needs for health system evaluation for publication in OECD Health at a Glance 2019.
- Develop a recommendation for a common generic PROMs instrument for use across conditions and sectors in Canada.
- Develop data collection standards for additional priority clinical areas and sectors, such as chronic kidney disease.
- Explore other priority areas for PROMs standards activities (e.g., cancer, mental health and addictions, home and continuing care).

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