Ontario

# Q&A on Patient Reported Outcome Measures

## Background /Context

### Q1 **What are Patient Reported Outcome Measures?**

A1. Patient Reported Outcome Measures, or “PROMs”, are measurement instruments (i.e., surveys) that patients complete to provide information on aspects of their health status and quality of life, including symptoms, function, pain and physical and mental health. PROMs also capture patient perspectives on aspects of their health status that are not typically captured by standard diagnostic tools.

PROMs are essential to understanding whether health care services and procedures make a difference to patients’ health status and health care experiences, as they provide insight into the effectiveness of care from the patients’ perspective and complement existing information on care quality and health care delivery.

Additional background information on PROMs is available at www.cihi.ca/proms

### Q2 **Why is the ministry supporting the collection of Patient Reported Outcome Measures?**

A2. To support the delivery of patient-centred, evidence-based care in Ontario, the Ministry of Health (ministry) has implemented the collection of PROMs in hospital settings across the province beginning in 2017.

PROMs complement traditional, clinical, administrative and client-based outcomes data, enabling a more comprehensive understanding of patient outcomes and the effectiveness of treatment options. The systematic collection of PROMs associated with hip and knee replacement surgery will equip Ontario with a valuable mechanism for measuring patients’ views on the benefits of these surgeries and promote more patient-centered and consistent care in hospital settings across the province.

Although evidence shows that the systematic collection and analysis of PROMs data can lead to better communication and decision-making between doctors and patients and improve patient satisfaction with care, the use of PROMs data in clinical practice is intermittent.

Many jurisdictions in Canada and internationally collect PROMs associated with hip and knee replacement surgery; including British Columbia, Alberta, Saskatchewan, and Manitoba in Canada and, internationally, the United Kingdom, United States, Australia, and Sweden. The widespread collection of PROMs associated with hip and knee replacement surgery will thus allow for comparative reporting and benchmarking across Canadian jurisdictions and internationally, which will further benefit Ontario.

Q3. **Has the ministry partnered with any organizations in order to develop and implement the Patient Reported Outcome Measures?**

A3. In order to appropriately test PROMs collection, the ministry has secured the support of Ontario Health (OH) which has a decade of experience in PROMs collection and one of the largest oncology PROMs databases in the world, as well as the Canadian Institute for Health Information (CIHI), which is a leader in PROMs standards and manages the Canadian Joint Replacement Registry.

These organizations will support the project by establishing PROMs data collection standards, a data collection platform, providing support to participating sites, data processing and analytics, reporting, administration, and IT support and services.

To support the successful execution of the PROMs project, the ministry has also convened a PROMs Steering Committee, composed of key stakeholder organizations and PROMs thought leaders, including clinical leaders, from across the province, who will advise on PROMs implementation, site readiness and opportunities for improvement, and ensure alignment between the PROMs project and the bundled hip and knee replacement Quality Based Procedures (QBP) program.

Q4 **What are the guiding principles of the ministry's hip and knee PROMs project?**

A4. The PROMs project will be guided by the following key principles:

- **Patients First:** The project will promote the delivery of high quality, patient-centred care and support improved patient experiences of care, regardless of where the patient is receiving treatment.
- **Evidence-based**: The project will be rooted in best practices and the PROMs collection tools and PROMs touch-points will be determined based on research evidence.
- **Value-driven**: PROMs collection will support improved patient experiences and enable more patient-centred care, but will not represent a significant data / cost burden to participating hospital sites or the broader health system.
- **Support Innovation**: PROMs data will be made available to clinicians and policy makers in order to support quality improvement and inform the allocation of health system resources. Data must also align with and be comparable to the PROMs collected in other regions / jurisdictions.
- **Generalizable:** The PROMs collection model that is developed and tested must be transferrable to other conditions / disease states.

Q5 **Why did the ministry select hip and knee replacement surgery as the area of focus for the PROMs project?**

A5. Hip and knee replacement surgery was selected as the area of focus for the PROMs project for three reasons:

1. Ontario performs nearly 42% of the hip and knee replacement surgeries in Canada, providing significant opportunities for improved patient experiences and outcomes.
2. Ontario's health system spends more than $650 million annually to provide these surgeries.
3. Other provinces and jurisdictions are increasingly measuring hip/knee PROM; implementing similar data collection/analysis methods in Ontario would allow for pan-Canadian and international comparisons of PROMs data.

## PROMs Collection and Reporting

Q6 **At what points will PROMs data be collected from patients?**

A6. To align with national standards, best practices, and the key patient interactions of the bundled hip and knee QBP project, participating sites will be required to collect PROMs data at three key touch points along the patient's journey:

1. Pre-operative assessment (within eight weeks prior to surgery)
2. 3-5 months post-operative assessment (within 90-150 days post-surgery)
3. One-year post-operative assessment (within 9-15 months post-surgery)

While participating sites are encouraged to collect PROMs as often as they deem necessary, only the three mentioned above are mandatory in order to participate in the program and are the only data points that will be used in comparative analyses.

Q7 **What PROMs tools will be utilized and why were those tools chosen?**

A7. Based on the recommendations of CIHI's national Hip and Knee PROMs Working Group and the Canadian Joint Replacement Registry (CJRR) Advisory Committee, the PROMs project will utilize and support the collection of the EQ-5D-5L (generic survey), and the Oxford Hip/Knee Scores (condition-specific).

The PROMs tools were selected in order to align with national standards for PROMs in hip/knee arthroplasty. Considerations included:

- Psychometric properties of instruments (e.g., reliability, validity, responsiveness)
- Clinical acceptance and use across Canada and internationally
- Burden of data collection for patients (e.g. survey length, time to complete) and health systems (e.g. licensing fees and requirements)

If you have any questions about these tool standards, please contact the CIHI team at proms@cihi.ca.

Q8 **How will PROMs data be collected?**

A8. To optimize access to PROMs for patients, and data for providers, hospitals and policy makers, OH developed the Integrated Symptom Assessment and Collection (ISAAC) platform. ISAAC enables PROMs to be launched electronically via kiosks or

mobile devices, such as smartphones and tablets. ISAAC also automatically pulls data from completed PROMs and transmits it to OH, where it is passed through data quality assurance protocols.

ISSAC has been adapted to hip and knee replacement surgery and will help to ensure that all PROMs data is captured and delivered to providers in a clinically meaningful manner. Leveraging ISAAC and OH's expertise in PROMs collection will support the rapid and efficient introduction of electronic collection and reporting of PROMs for hip and knee replacement surgeries across the province. Accommodations will also be made for sites to leverage existing PROMs collection platforms in lieu of implementing the ISAAC system.

Q9 **My organization already has a PROMs reporting system or platform; does it need to use OH's PROMs collection platform?**

A9. No, it is not mandatory for participating sites to utilize the PROMs collection platform that has been developed by OH. However, all participating sites will be required to collect the same patient registration data elements (e.g. Health card number, gender etc.) and surveys that are implemented through ISAAC (i.e., EQ-5D-5L and the Oxford Hip and Knee Scores) and provide the collected data to OH, in a manner dictated by them.

The intent of the PROMs project is not to inhibit or otherwise interfere with the excellent PROMs collection work that has been underway in many of Ontario's hospitals. Rather, it is aimed at enabling robust and standard PROMs collection in *all* of Ontario's orthopedic sites and ensuring consistent and systematic PROMs collection, which will allow for a more comprehensive understanding of patient outcomes and experiences, and enable regional / jurisdictional comparative analyses.

Q10 **What supports (infrastructure, logistics, etc.) will be provided to participating sites to ensure they can meet their reporting requirements?**

A10. The ministry is committed to supporting all participating sites in the implementation and collection of hip and knee replacement surgery PROMs data. The ministry, in partnership with OH and CIHI, will be contacting sites to assess the specific needs of each participating hospital. OH will also provide the following site-specific supports during the project:

- Collaborating with sites to optimize integration of PROMs into clinic workflow
- Providing orientation to site administrators on the use of portals to access data (e.g., ISAAC Administrator Portal)
- Providing ongoing implementation and operational support for sites, including troubleshooting technology and data flow issues
- Conducting site visits to assess clinical workflow and address unique facility challenges

Q11 **What will be done with the PROMs data that is collected at participating sites?**

A11. Patient responses to PROMs will flow directly into the ISAAC database in real-time, and physicians will have immediate access to individual patient responses and physician-level reports via the ISAAC Admin portal (note: real-time data flow is subject to facility internet connectivity).

Physician and facility-level reporting is enabled as raw data, and more sophisticated reporting will need to be explored as part of the project. Automatically generated ISSAC reporting functionalities can help measure PROM uptake in clinics and view patient response trends over time.

OH will provide CIHI with regular data cuts via the ISAAC database, enabling CIHI to provide sites with performance measurement and reporting with both provincial and national comparisons.

Q12 **Does a hospital already have to be submitting patient experience data to CIHI in order to participate in the PROMs project?**

A12. No. The collection of patient experience data is not a prerequisite for participation in the PROMs project.

Q13 **Will participating sites have access to real-time PROMs data?**

A13. Yes. PROMs data that patients enter into a tablet or kiosk that hosts the ISAAC platform will be sent to the ISAAC database in real-time. The clinical care team will have immediate access to all individual patient responses via the ISAAC Administrator portal.

In addition, patient-level PROMs data will be available to sites via summary reports in the ISAAC Administrator portal.

Q14 **Can patients use their home computers or other personal devices to input their PROMs data?**

A14. Yes. Patients who are not seen in clinic during the specified time points can complete PROMs at home through a URL which can be accessed off any internet enabled device. The URL is: https://promsortho.ccohealth.ca

## PROMs and the Bundled Hip and Knee QBP Pilot

Q15 **If my organization is participating in the bundled hip and knee QBP program, is it mandatory to collect Patient Reported Outcome Measures?**

A15. Yes. Sites participating in the bundled hip and knee QBP project will be required to collect PROMs data in order to enable the consistent and systematic collection of valuable data that will inform patient care and potentially improve patient outcomes and experiences.

The ministry, in partnership with OH and CIHI, will ensure sites have the supports and resources they need to successfully collect PROMs and will be reaching out to sites individually to assess their specific needs.

Q16 **Can my organization participate in the PROMs project if it is not participating in the bundled hip and knee QBP program?**

A16. Yes. Participation in the PROMs project is voluntary for non-bundled sites and all interested hospital sites are encouraged to participate.

One of the primary objectives of the pilot is to establish a mechanism for the ongoing collection of PROMs (associated with multiple conditions) across the province and ultimately expand PROMs collection beyond the bundled hip and knee QBP sites.

Q17 **Will there be additional funding associated with hospitals' participating in the PROMs project?**

A17. No. There will not be additional funding provided to sites participating in the PROMs project.

However, the ministry is committed to providing participating sites with the supports (including funding for technological hardware) they need in order to successfully fulfill their reporting requirements and facilitate PROMs collection across the province, which will be facilitated by OH.

The ministry is also committed to working with CIHI to assess any site-specific costs associated with PROMs tool licensing.

Q.18 **Will the collection of Patient Reported Experience Measures (PREMs) be required as part of participation in the bundled hip and knee QBP program?**

A18. Yes. The ministry is currently working on the identification and validation of appropriate PREMs to collect at participating sites. Once finalized, PREMs will be collected in the same manner as PROMs (outlined above). More information on PREMs questions and collection methodology will be shared with sites at a later date.

## Next Steps and Additional Information

Q19 **What are the timelines for the rollout of the PROMs project?**

A19. Sites will be onboarded in a phased approach, based on site readiness, resources, needs, and capacity. Participating sites will be expected to work with OH to ensure the requirements of implementing PROMs are met and enable the necessary data flow to OH.

Q20 **Where do I go for additional information?**

A20. For additional information visit Ontario Health's website:

https://www.ccohealth.ca/en/person-centred-care/orthopedic

If you have any further questions, please contact Leanna Mora (leanna.mora2@ontario.ca)