

# Real World Evidence and the Canadian Institute for Health Information (CIHI)

Drug Pricing Policy Summit: Patients Redefining Health Care

Greg Webster

Director, Acute and Ambulatory Care Information Services

Canadian Institute for Health Information

# Our Vision, Our Mandate and Our Values

## Vision

**Better data.  
Better decisions.  
Healthier Canadians.**

## Mandate

Deliver comparable and actionable information to accelerate improvements in health care, health system performance and population health across the continuum of care.

## Values

Respect • Integrity • Collaboration • Excellence • Innovation

# CIHI's Strategic Plan 2016 to 2021

## Vision

**Better data.  
Better decisions.  
Healthier Canadians.**

## Mandate

**Deliver comparable and actionable information to accelerate improvements in health care, health system performance and population health across the continuum of care**

## Strategic goals



**Be a trusted source of standards and quality data**



**Expand analytical tools to support measurement of health systems**



**Produce actionable analysis and accelerate its adoption**

## Priority themes and populations

### Themes

Patient experience  
Quality and safety  
Outcomes  
Value for money



**Health system performance**

### Populations

Seniors and aging  
Mental health and addictions  
First Nations, Inuit and Métis  
Children and youth



## Foundation



**Our people**



**Stakeholder engagement and partnerships**



**Privacy and security**



**Information technology**

## Values

**Respect • Integrity • Collaboration • Excellence • Innovation**

# Real World Evidence: Data Holdings at CIHI



## Types of Care

- Hospital & Emergency
- Mental Health
- Home Care
- Long-term care
- Rehabilitation
- Pharmaceuticals
- More



## Patient-Reported Data

- Patient-Reported Experience Measures (PREMs)
- Patient-Reported Outcome Measures (PROMs)



## Health Spending

- Patient costing data
- Case Mix & PopGrouper
- Hospital and regional health authority financial accounts
- Physician Billing
- System-wide health expenditures

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CIHI also has a number of databases on the health workforce, e.g. physicians, nurses, allied health professionals.

# Moving Towards Greater Patient Involvement



- CIHI is working to finalize a strategy for more formalized patient engagement to enrich its work, recognizing that this is a journey and there will be opportunities to learn along the way.
- CIHI is working closely with jurisdictions across Canada to understand priorities for measuring patient experience and outcomes across other sectors.
- Analytic work will focus on integrating patient stories and linking experience to outcomes to better inform and drive quality, patient-centered care.

# Understanding Patient Experience and Outcomes is Integral to Improving Patient-Centred Care

*How do our patient experiences and outcomes compare to those in other hospitals?*

*What types of patients have the best care experience and outcomes?*



*Where should our facility focus efforts to improve patient experience and outcomes?*

*Which patient groups should we focus on?*

*Which facility can I look to for best practice sharing?*

# PREMs and PROMs: Complementary Tools and Pillars of CIHI's Patient-Oriented Strategy

## CIHI's Patient-Oriented Strategy

*Including input from family caregivers, residents, clients, and people with lived experience*

### PREMs

Capture the patient's view of what happened during the health care visit

Used to evaluate and monitor service delivery

### PROMs

Capture the impact of an illness or health condition from the patient's perspective

Used to monitor the health condition over time and the effectiveness of treatments and interventions

Measured from the patient's perspective

Used together to support patient-centred care and inform quality of care and services

# CIHI PREMs and PROMs – Leadership Team



- Nicole de Guia, Manager, Joint Replacement Registry & Patient-Reported Outcome & Experiences (JRRPROE)
- Tammy Anderson, Program Lead, JRRPROE
- Ellis Chow, Program Lead, JRRPROE
- Shannon-Weir-Seeley, Program Lead, JRRPROE
- Sunita Karmakar-Hore, Project Lead, JRRPROE
- Greg Webster, Director, Acute and Ambulatory Care Information Services
- Jeanie Lacroix, Manager, Performance Improvement and Capacity Building (PICB)
- Salima Hadibhai, Project Lead, PICB
- Seanna McMartin, Program Lead, PICB
- Doreen McNeil, Program Lead, PICB
- Melanie Josée, Director, Health System Performance
- Natalie Damiano, Director, Specialized Care



# Our Work with Patients



## Patients have contributed in different ways at CIHI:

**Survey development:** Formulating questions for Patient-Reported Experience Measures (PREMs) survey for national use

**Data collection:** Participating on advisory groups (e.g. Canadian Joint Replacement Registry)

**Patient stories:** Providing context and lived experience for key reports (*Dementia in Canada* report)

**Health system capacity building initiatives:** Participating in peer learning day for patient-centred measurement and reporting

**Shared Health Priorities:** Helping us to understand access to home and community care and mental health and addictions services to support improvement in these two areas

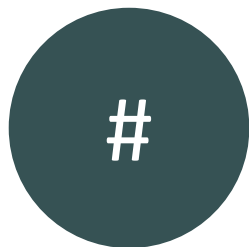
# About Patients, With Patients



CIHI's PREMS and PROMs  
Programs



Standards



Data Collection



Reporting



Building Capacity



Collaboration



## Progress on Patient Reported Experience Measures (PREMs)

# Background



- In 2011, several jurisdictions approached CIHI to lead the development of a pan-Canadian acute care experience survey and data collection system
- CIHI worked with representatives from across Canada to develop a standardized patient experience survey for inpatient care (the [Canadian Patient Experience Survey - Inpatient Care](#) or CPES-IC) and [procedure manual](#). This survey enables patients to provide feedback about the quality of care they experienced during their stay in a Canadian acute care hospital
- CIHI developed the Canadian Patient Experiences Reporting System (CPERS) to serve as Canada's first pan-Canadian reporting system for patient experience data beginning with CPES-IC data in April 2015

# Canadian Patient Experiences Survey — Inpatient Care (CPES-IC)



Standardized pan-  
Canadian survey  
based on HCAHPS



Tailored to the  
Canadian  
context



Endorsed by  
Accreditation  
Canada

- 22 questions from U.S. Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS)
- 19 additional questions developed for Canadian context
- 7 questions for demographic information
- Cognitive and pilot tests completed in 3 provinces, in English and French

# CPES-IC Measurement Themes



- Admission & discharge experience
- Information provided during admission & discharge
- Communication
  - with care providers
  - about medications
- Responsiveness of staff
- Pain control
- Internal coordination
- Involvement in decision-making
- Timeliness of testing
- Emotional support
- Physical environment
- Overall and outcome ratings

# Canadian Patient Experiences Survey – Inpatient Care (2)

## DURING YOUR HOSPITAL STAY

30. Do you feel that there was good communication about your care between doctors, nurses and other hospital staff?

- ☐ Never  
☐ Sometimes  
☐ Usually  
☐ Always

31. How often did doctors, nurses and other hospital staff seem informed and up-to-date about your hospital care?

- ☐ Never  
☐ Sometimes  
☐ Usually  
☐ Always

32. How often were tests and procedures done when you were told they would be done?

- ☐ Never  
☐ Sometimes  
☐ Usually  
☐ Always  
☐ I did not have any tests or procedures

33. During this hospital stay, did you get all the information you needed about your condition and treatment?

- ☐ Never  
☐ Sometimes  
☐ Usually  
☐ Always

34. Did you get the support you needed to help you with any anxieties, fears or worries you had during this hospital stay?

- ☐ Never  
☐ Sometimes  
☐ Usually  
☐ Always  
☐ Not applicable

35. Were you involved as much as you wanted to be in decisions about your care and treatment?

- ☐ Never  
☐ Sometimes  
☐ Usually  
☐ Always

36. Were your family or friends involved as much as you wanted in decisions about your care and treatment?

- ☐ Never  
☐ Sometimes  
☐ Usually  
☐ Always  
☐ I did not want them to be involved  
☐ I did not have family or friends to be involved

## LEAVING THE HOSPITAL

37. Before you left the hospital, did you have a clear understanding about all of your prescribed medications, including those you were taking before your hospital stay?

- ☐ Not at all  
☐ Partly  
☐ Quite a bit  
☐ Completely  
☐ Not applicable

38. Did you receive enough information from hospital staff about what to do if you were worried about your condition or treatment after you left the hospital?

- ☐ Not at all  
☐ Partly  
☐ Quite a bit  
☐ Completely

39. When you left the hospital, did you have a better understanding of your condition than when you entered?

- ☐ Not at all  
☐ Partly  
☐ Quite a bit  
☐ Completely

## YOUR OVERALL RATINGS

40. Overall, do you feel you were helped by your hospital stay? Please answer on a scale where 0 is "not helped at all" and 10 is "helped completely."

Overall . . . (Please circle a number)



41. Overall . . . (Please circle a number)



## ABOUT YOU

42. In general, how would you rate your overall physical health?

- ☐ Excellent  
☐ Very good  
☐ Good  
☐ Fair  
☐ Poor

43. In general, how would you rate your overall mental or emotional health?

- ☐ Excellent  
☐ Very good  
☐ Good  
☐ Fair  
☐ Poor

44. What is the highest grade or level of school that you have completed?

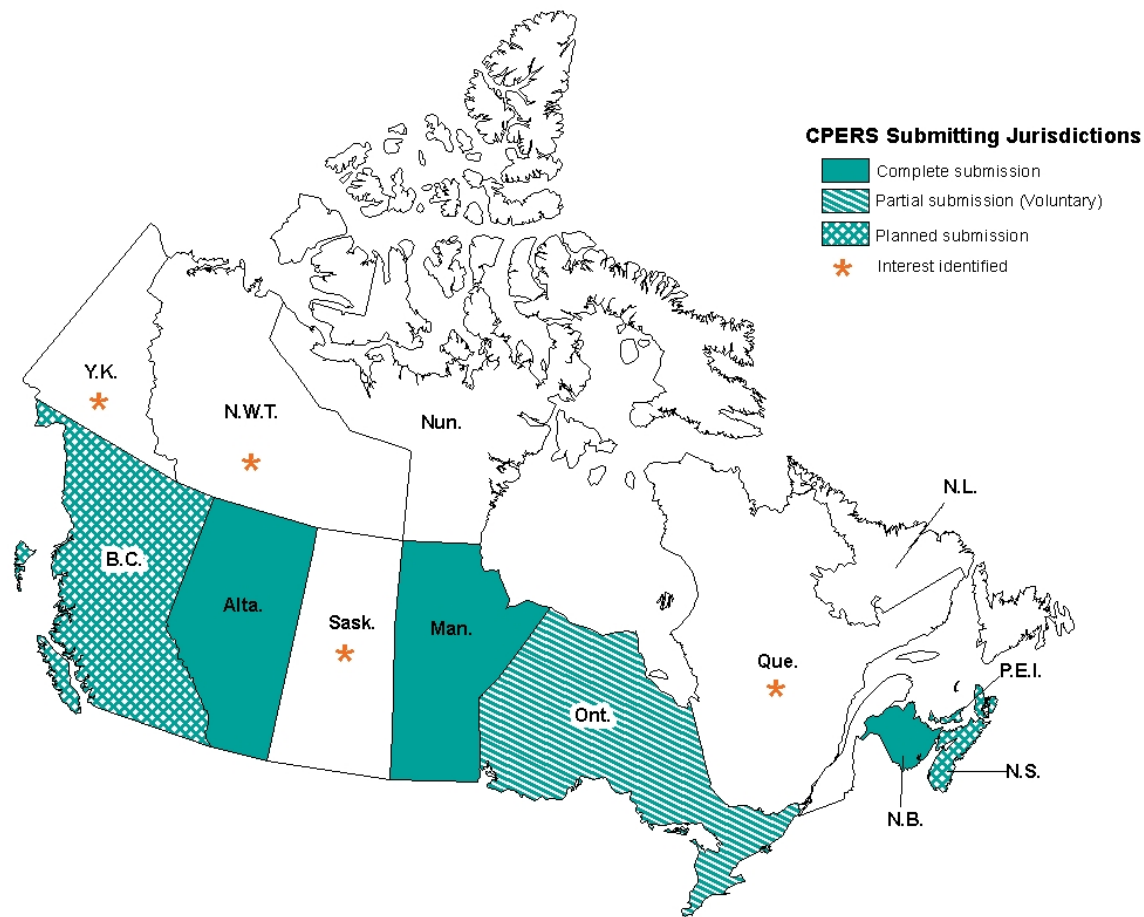
- ☐ 8th grade or less  
☐ Some high school, but did not graduate  
☐ High school or high school equivalency certificate  
☐ College, CEGEP or other non-university certificate or diploma  
☐ Undergraduate degree or some university  
☐ Post-graduate degree or professional designation

45. What is your gender?

- ☐ Male  
☐ Female  
☐ Other

# Canadian Patient Experiences Reporting System (CPERS)

- Canada's first pan-Canadian reporting system for patient experience data
- Since April 2015, CPERS accepting data for inpatient care based on the Canadian Patient Experiences Survey – Inpatient Care (CPES-IC)
- Over 150,000 records to date in CPERS





# CPES: Comparative Results Tool

- Launched: August 2017
- Comparative hospital-level data via secure online tool for participating hospitals
- Comparisons with natural comparators (i.e., peer hospital group, regional/provincial averages)
- Designed to support quality improvement and benchmarking across the country



# CPES: Comparative Results Tool (2)

Access Data and Reports
Submit Data and View Standards
News, Events and Education
About CIHI

## Canadian Patient Experiences Survey: Comparative Results

The Canadian Patient Experiences Survey – Inpatient Care (CPES-IC) contains patient feedback about the quality of care they experienced during their most recent inpatient stay in a Canadian acute care hospital.

Use this tool to assess patient experiences at your hospital and to compare your patients' experiences with those of patients at other acute care hospitals.

### Compare results

Compare your hospital's patient experience measures with those of other hospitals. Compare your results with peer hospital, regional and provincial averages.

Natural comparators, custom comparators and all comparators

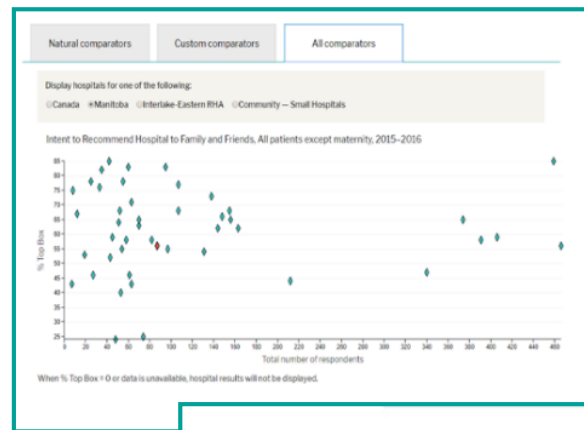
### View results

Explore specific survey questions or view demographic information about survey respondents.

Survey questions    Demographics

### Related content

- [All Data Export Report \(XLSX\)](#)
- [Technical Notes \(PDF\)](#)
- [FAQ](#)
- [Canadian Patient Experiences Reporting System](#)
- [CIHI's work on patient experience](#)



# Approach for Public Reporting



# PREMs in Long-Term Care



- In 2015, CIHI sponsored a study to pilot the interRAI Quality of Life Survey (QoL-LTCF) in 49 long-term care facilities in 5 provinces
- The interRAI QoL-LTCF is the most widely used survey in the Canadian long-term care sector (approx. 500 homes)
- CIHI is preparing a business case related to how CIHI might support implementation and uptake of PREMs in long-term care in the future, including supporting the interRAI QoL-LTCF survey as one Canadian standard



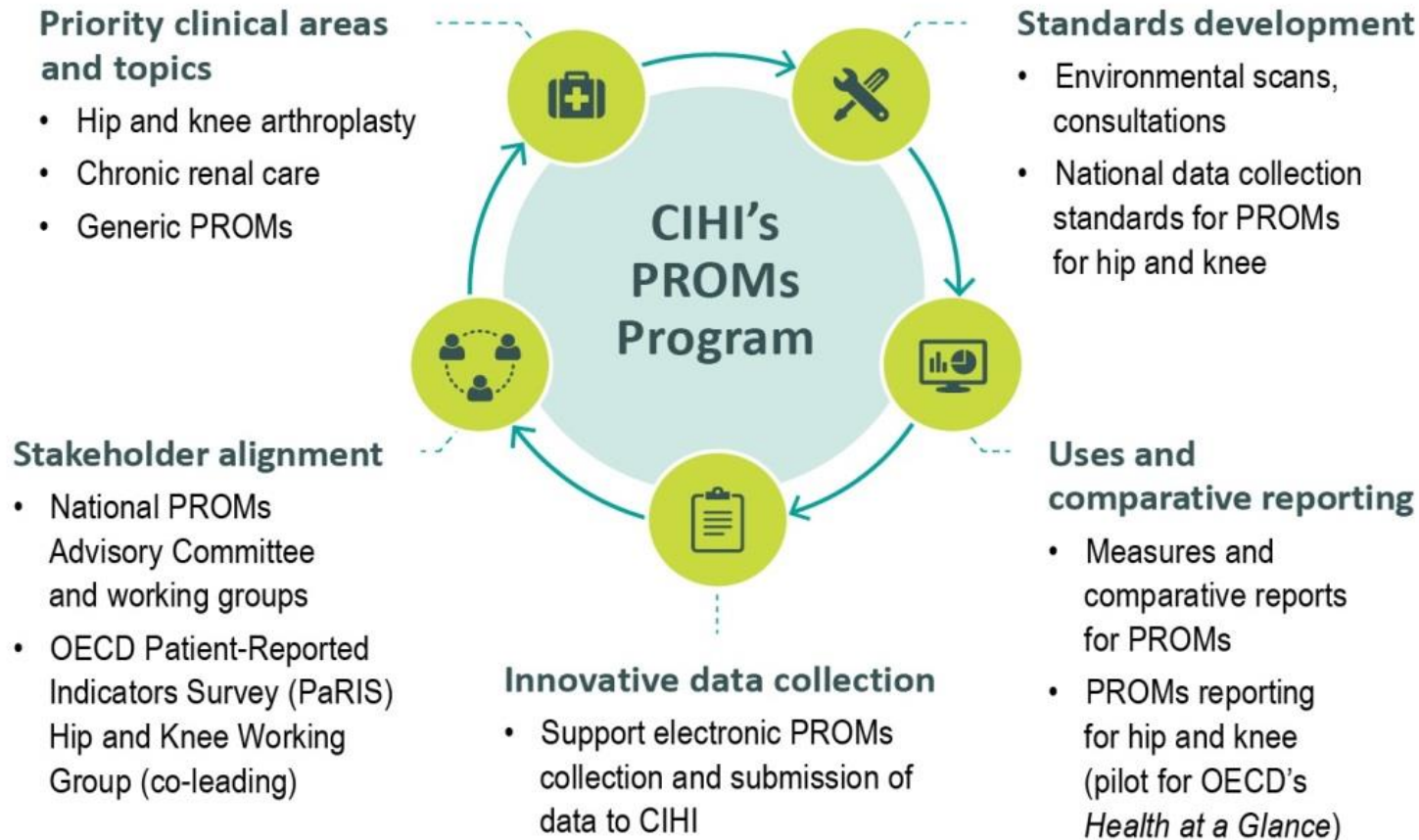
## Progress on Patient-Reported Outcome Measures (PROMs)

# CIHI PROMs Program – Background

- **CIHI program established in 2015 as a result of stakeholder feedback and support**
  - High interest in standardizing PROMs collection and reporting
  - Desire for CIHI to provide leadership in developing common approaches for PROMs in routine care
- **Limited comparability of PROMs data**
  - In Canada, some existing PROMs programs and provincial initiatives (e.g., British Columbia, Alberta); predominantly for independent research projects and patient registries
  - Instruments, collection modes and timing of administration differ within and across clinical areas and conditions



# CIHI's PROMs Program



# CIHI PROMs Hip and Knee Activities



## PROMs Instruments

- Obtained national licenses for EQ-5D-5L, Oxford Hip Score (OHS) and Oxford Knee Score (OKS) in February 2018
- Established a process to sublicense PROMs tools to hospitals

## Minimum Data Set (MDS) Collection Standards

- Finalized data collection standards for hip and knee arthroplasty (e.g. data elements, survey time points)
- Published data collection manual; it can be found at: [www.cihi.ca/proms](http://www.cihi.ca/proms)

## Adoption of National PROMs Standards

- Support adoption of standards in across jurisdictions
- Move towards standardized collection and reporting

## Links to International Work: OECD

- CIHI co-leading international working group on Patient-Reported Indicators for Hip/Knee Replacement Surgery
- Aim to provide comparable reporting using existing PROMs data in OECD *Health at a Glance 2019*



# Generic PROMs: EQ-5D-5L

(Sample UK English version)

Under each heading, please tick the ONE box that best describes your health TODAY.

## MOBILITY

- I have no problems in walking about
- I have slight problems in walking about
- I have moderate problems in walking about
- I have severe problems in walking about
- I am unable to walk about

## SELF-CARE

- I have no problems washing or dressing myself
- I have slight problems washing or dressing myself
- I have moderate problems washing or dressing myself
- I have severe problems washing or dressing myself
- I am unable to wash or dress myself

## USUAL ACTIVITIES (e.g. work, study, housework, family or leisure activities)

- I have no problems doing my usual activities
- I have slight problems doing my usual activities
- I have moderate problems doing my usual activities
- I have severe problems doing my usual activities
- I am unable to do my usual activities

## PAIN / DISCOMFORT

- I have no pain or discomfort
- I have slight pain or discomfort
- I have moderate pain or discomfort
- I have severe pain or discomfort
- I have extreme pain or discomfort

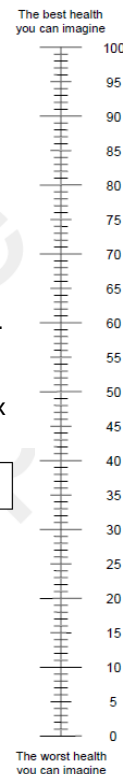
## ANXIETY / DEPRESSION

- I am not anxious or depressed
- I am slightly anxious or depressed
- I am moderately anxious or depressed
- I am severely anxious or depressed
- I am extremely anxious or depressed

## Visual Analog Scale

- This scale is numbered from 0 to 100.
- Mark an X on the scale to indicate how your health is TODAY.
- Now, please write the number you marked on the scale in the box below.

YOUR HEALTH TODAY =



Available under licence through EuroQol <https://euroqol.org/>

# Condition-specific PROMs: Oxford Hip Score

## PROBLEMS WITH YOUR HIP

Tick (✓) one box for every question.

### 1. During the past 4 weeks...

How would you describe the pain you usually have from your hip?

None

☐

Very mild

☐

Mild

☐

Moderate

☐

Severe

☐

### 2. During the past 4 weeks...

Have you had any trouble with washing and drying yourself (all over) because of your hip?

No trouble at all

☐

Very little trouble

☐

Moderate trouble

☐

Extreme difficulty

☐

Impossible to do

☐

### 3. During the past 4 weeks...

Have you had any trouble getting in and out of a car or using public transport because of your hip? (whichever you tend to use)

No trouble at all

☐

Very little trouble

☐

Moderate trouble

☒

Extreme difficulty

☐

Impossible to do

☐

Available under licence through Oxford University Innovation Ltd

# Public Reporting Example: National Joint Registry

## Patient improvement










Patient improvement, featured in this chart, looks at three measures of patient-reported outcomes that are routinely assessed following hip/knee replacement in England. This information is not currently collected in Wales or Northern Ireland and as a result, no data is available to display.

The measures are referred to using their technical names 'Oxford hip/knee score', 'EQ-5D' and 'EQ-VAS' – [click here](#) for a non-technical introduction to these.

## Data for 1 April 2016 - 31 March 2017

Click on the  to find out more about the quality measure and its source data

 HOW TO INTERPRET THIS CHART

Patient Reported Improvement Measure	This Trust	Patient Records Analysed	Trust Avg Health Gain	National Avg Health Gain	Worse than Expected   EXPECTED RANGE   Better than Expected NATIONAL AVERAGE
 Oxford hip Score	 As Expected	166	20.11	21.77	
 EQ-5D	 As Expected	156	0.405	0.444	
 EQ-VAS	 As Expected	155	12.86	13.40	



# Ontario PROMs Project



- To support the delivery of patient-centred, evidence-based care, Ontario is testing the implementation of PROMs in hospitals across Ontario through a three year pilot project
- **The PROMs project (September 2017 to March 2020) has three key objectives:**

## Improved Patient Care

Facilitate the delivery of more patient-centred care through the use of patient-generated data in clinical assessments and patient engagement

## PROMs Collection

Test the collection of PROMs and assess the feasibility of scaling up the collection of hip and knee PROMs to all hospital sites in Ontario

## PROMs Spread

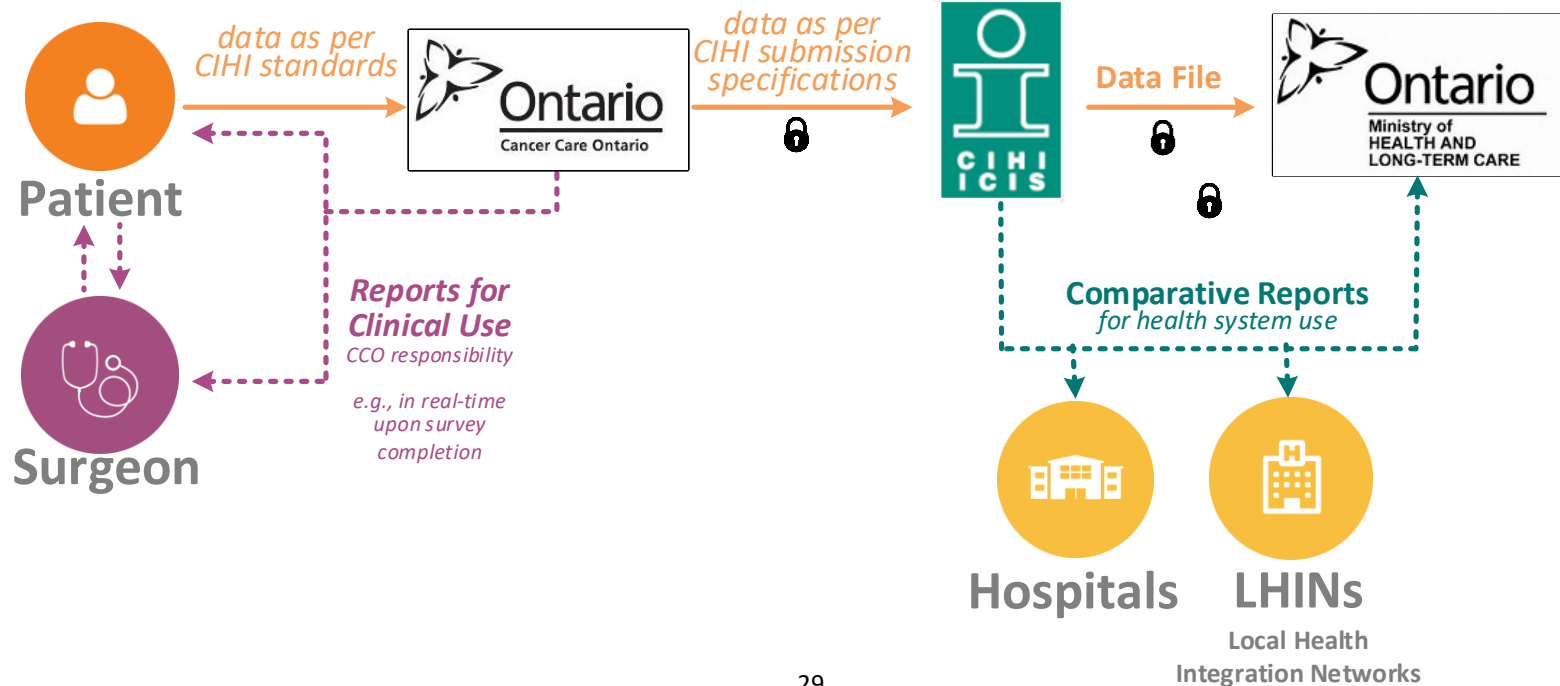
Establish a mechanism for the ongoing collection of PROMs and position Ontario as a world leader in PROMs collection and analysis

- ***Aligning PROMs with the Bundled Hip and Knee Program***

- The Ontario Ministry of Health and Long-Term Care's (MOHLTC) PROMs project is being implemented in alignment with the bundled hip and knee replacement Quality Based Procedures (QBP) program (~ 24 sites across 12 LHINs)
- Collection of PROMs associated with hip and knee replacement surgery is required for all sites participating in the bundled care project

# Ontario PROMs Pilot Project: Roles

- CIHI is leading on **standards** and **health system reporting**
- CCO is leading on **implementation** and **data collection**



# Ontario PROMs Project: Implementation (CCO ISAAC)



Patients use their HCN to complete PROMs electronically using an accessible, touch-screen-based platform (ipad, computer, tablet)



The scores are sent to the CCO ISAAC database in real-time and can be accessed by the patient's care team at point-of-care via the CCO ISAAC Administrator portal



CCO ISAAC has the capability to notify the care team by e-mail when certain scores exceed defined thresholds



Patient-level summary reports help patients and the care team track pain, functional status, and quality of life over time



# OECD PROMs Hip and Knee Replacement Surgery Working Group

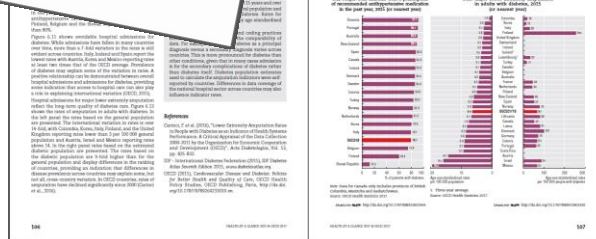
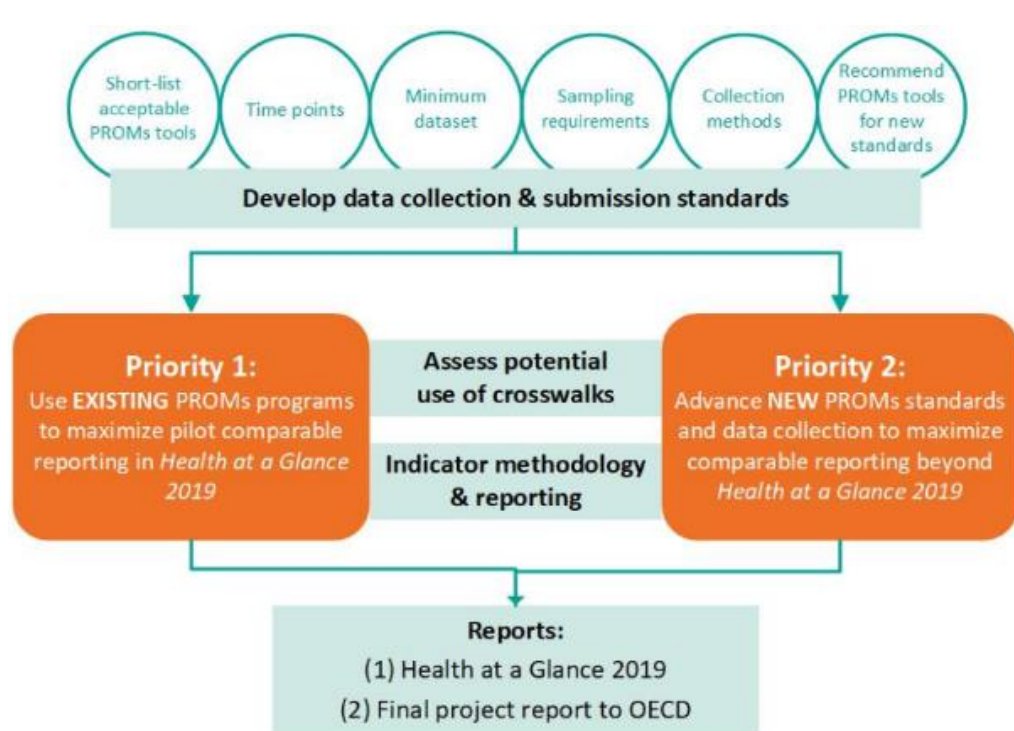


- Chaired by the CIHI in partnership with the OECD
- Representation from:



- Includes members from 13 countries:
  - Australia
  - Belgium
  - Canada
  - Finland
  - France
  - Ireland
  - Italy
  - Netherlands
  - Singapore
  - Slovenia
  - Sweden
  - United Kingdom
  - United States
- Five meetings held since launch in December 2017

# OECD PaRIS Hip & Knee Working Group – priorities & activities





# PROMs: Additional Priority Areas and Topics



## Chronic Kidney Disease

- Demonstration project using data from BC Provincial Renal Agency
- Explore opportunities to develop national data collection standards for PROMs



## Mental Health

- CIHI participating in OECD working group for PROMs in mental health to support development of international standards



## Cancer

- Cancer care (led by Canadian Partnership Against Cancer, participates in OECD breast cancer PROMs group)

# Achieving the Vision for PREMs and PROMs

- In 2016, CIHI brought together a range of stakeholders including patient voice for “PREMs/PROMs Visioning Day”
- Challenges identified include lack of standards across sectors and interpretability of results
- Future priorities
  - Alignment with jurisdictional priorities
  - Expanding standard survey tools
  - Linking PREMs and PROMs together, and with other sources
  - Key partnerships and roles to move the agenda forward



Patient-Centred Measurement  
and Reporting in Canada

Launching the Discussion Toward  
a Future State

# Resources of Interest

## Learn more PROMs at [www.cihi.ca/proms](http://www.cihi.ca/proms)

Resources include:

- 2015 PROMs Forum proceedings
- PROMs background document
- PROMs information sheet
- PROMs Hip and Knee data collection manual

## Learn more about PREMS at [www.cihi.ca/prems](http://www.cihi.ca/prems)

Information and resources include:

- Canadian Patient Experience Survey – Inpatient Care (CPES-IC)
- Canadian Patient Experiences Reporting System (CPERS)
- Information on patient experiences in long-term care
- Patient-Centred Measurement Toolkit from 2016 Peer Learning Day

# Successful Data Partnerships with CIHI

- CIHI welcomes opportunities to collaborate on national projects to advance PREMs and PROMs to improve experiences and outcomes for patients
- Opportunities need to be aligned with CIHI's Strategic Directions, with funding sources
- Given national focus, interest/commitment needed from several jurisdictions





## CIHI Resources

[www.cihi.ca/prems](http://www.cihi.ca/prems)

[www.cihi.ca/proms](http://www.cihi.ca/proms)

## Contacts

[prems@cihi.ca](mailto:prems@cihi.ca)

[proms@cihi.ca](mailto:proms@cihi.ca)

### **Greg Webster**

Director, Acute and Ambulatory Care Information Services  
(AACIS)

[gwebster@cihi.ca](mailto:gwebster@cihi.ca)

416-549-5508





Canadian Institute for Health Information

**Better data. Better decisions. Healthier Canadians.**



@cihi\_icis

prems@cihi.ca or proms@cihi.ca

cihi.ca