



PROMs

Patient-Reported Outcome Measures
Data Collection Manual
Hip and Knee Arthroplasty

2019



Canadian Institute
for Health Information

Institut canadien
d'information sur la santé

Production of this document is made possible by financial contributions from Health Canada and provincial and territorial governments. The views expressed herein do not necessarily represent the views of Health Canada or any provincial or territorial government.

All rights reserved.

The contents of this publication may be reproduced unaltered, in whole or in part and by any means, solely for non-commercial purposes, provided that the Canadian Institute for Health Information is properly and fully acknowledged as the copyright owner. Any reproduction or use of this publication or its contents for any commercial purpose requires the prior written authorization of the Canadian Institute for Health Information. Reproduction or use that suggests endorsement by, or affiliation with, the Canadian Institute for Health Information is prohibited.

For permission or information, please contact CIHI:

Canadian Institute for Health Information

495 Richmond Road, Suite 600

Ottawa, Ontario K2A 4H6

Phone: 613-241-7860

Fax: 613-241-8120

cihi.ca

copyright@cihi.ca

© 2019 Canadian Institute for Health Information

Cette publication est aussi disponible en français sous le titre *Manuel de collecte de données sur les mesures des résultats déclarés par les patients : arthroplasties de la hanche et du genou, 2019.*

Table of contents

Acknowledgements	4
Background	5
About CIHI	5
PROMs overview	5
Hip and knee replacement surgeries	6
Development of the PROMs standards	6
Purpose of the PROMs Data Collection Manual	7
Contact information	7
PROMs instruments	8
Types of PROMs instruments	8
Recommended instruments	8
Licences for PROMs instruments	9
Survey administration	10
Administration approach	10
Method of administration (survey mode)	10
Languages	11
Survey time points	12
National standard	12
Minimum data set	13
Data elements	13
Information sources	13
Collection instructions	15
General guidelines	15
OHS and OKS instructions	16
Detailed collection guidelines	17
Appendix A: Standards used in the PROMs MDS	27
References	28

Acknowledgements

The Canadian Institute for Health Information (CIHI) would like to acknowledge the following for their contribution to the development of the *PROMs Data Collection Manual: Hip and Knee Arthroplasty, 2018*:

- Patient-Reported Outcome Measures (PROMs) and Canadian Joint Replacement Registry (CJRR) teams, CIHI
- Strategy, Planning and Architecture team, CIHI
- CJRR Advisory Committee
- CIHI PROMs Hip and Knee Working Group

Background

About CIHI

The Canadian Institute for Health Information (CIHI) is an independent, not-for-profit organization that provides essential information on Canada's health systems and the health of Canadians.

We provide comparable and actionable data and information that are used to accelerate improvements in health care, health system performance and population health across Canada. Our stakeholders use our broad range of health system databases, measurements and standards, together with our evidence-based reports and analyses, in their decision-making processes. We protect the privacy of Canadians by ensuring the confidentiality and integrity of the health care information we provide.

For more information, visit our website at cihi.ca.

PROMs overview

Patient-reported outcome measures (PROMs) are measurement instruments completed by patients to obtain information on aspects of their health status that are relevant to their quality of life, including symptoms, functionality and physical, mental and social health.

PROMs are increasingly recognized as valuable and essential information for achieving health system goals and to support clinical and health system decision-making, as they provide patients' perspectives on their health and outcomes of care. They are essential to understanding whether health care services and procedures make the expected difference to patients' health status and quality of life. PROMs are especially important in elective surgeries and chronic illness management, where the predominant goal is to enhance patients' quality of life.

While there are several independent jurisdictional and regional PROMs initiatives, a coordinated national program to routinely collect and report PROMs does not currently exist in Canada. In response to stakeholder feedback and desire, CIHI established a PROMs program in 2015 and is working with a broad range of stakeholders to advance a common approach to PROMs across Canada, with hip and knee arthroplasty being one of the initial areas of focus.

Additional background information on PROMs is available in the *PROMs Background Document* at cihi.ca/proms.

Hip and knee replacement surgeries

Hip and knee joint replacement surgeries (arthroplasties) are among the most effective ways to reduce joint pain and improve functioning for patients with advanced hip and knee problems, most commonly from osteoarthritis. In Canada, more than 120,000 hip and knee replacement surgeries are performed annually.¹

Hip and knee arthroplasty were identified as initial areas of focus for PROMs because

- PROMs programs currently exist in these areas across Canada and internationally;
- There is strong support from the clinical community;
- Evidence supports expected improvements in pain, function and quality of life; and
- A high number of patients undergo these surgeries, resulting in substantial costs to health systems.

Availability of PROMs data will allow for a systematic method of measuring patients' views on the benefits of hip and knee arthroplasty and support improvements in health care delivery.

Development of the PROMs standards

While several PROMs programs for hip and knee arthroplasty exist in Canada, they have not been implemented in a standardized manner to allow for national and international comparative reporting.

In 2016, CIHI convened the PROMs Hip and Knee Working Group to guide the development of common approaches for PROMs in hip and knee arthroplasty across Canada. Members include provincial government representatives, orthopedic surgeons and senior researchers actively involved in PROMs.

With support from the Canadian Joint Replacement Registry (CJRR) Advisory Committee, CIHI worked with the PROMs Hip and Knee Working Group to develop national standards for PROMs collection. Considerations when developing the PROMs standards included alignment with recommendations, guidelines and best practices from existing programs and registries across Canada and internationally, where feasible, and the ability to minimize the burden of data collection for patients and service providers (e.g., cost, resources, time).

In November 2017, the national PROMs data collection standards for hip and knee arthroplasty were approved by the CJRR Advisory Committee and the PROMs Hip and Knee Working Group. The national PROMs standards include guidelines for survey time points, a minimum data set (MDS) and recommended PROMs instruments.

Purpose of the PROMs Data Collection Manual

The *PROMs Data Collection Manual: Hip and Knee Arthroplasty, 2018* is intended to serve as a resource for organizations interested in collecting standardized PROMs in hip and knee arthroplasty. PROMs data submitted to CIHI must adhere to these standards to be included in national comparative reporting.

This manual outlines CIHI's PROMs data collection standards in hip and knee arthroplasty:

- Guidelines for survey administration, including collection time points and instructions for specific survey modes;
- The PROMs MDS, including detailed descriptions, permissible responses and collection guidelines for each data element; and
- Recommended PROMs instruments for use in hip and knee arthroplasty.

It is recommended that organizations confirm with their respective ministries/departments of health whether jurisdiction-specific collection instructions for PROMs exist.

Contact information

Please email proms@cihi.ca for additional information about CIHI's PROMs Program and standards, including

- Implementing CIHI's national PROMs data collection standards;
- Adopting CIHI's national PROMs data collection standards;
- Obtaining licences to use the recommended PROMs instruments;
- Submitting PROMs data to CIHI; and
- Accessing CIHI's PROMs data submission specifications and technical requirements.

PROMs instruments

Types of PROMs instruments

PROMs instruments are categorized as generic (can be applied across different populations) or condition-specific (used to assess outcomes that are characteristic of or unique to particular diseases or sectors of care). Typically, both types of instruments are administered concurrently, as they provide complementary information and are applied differently to support various information needs.

Recommended instruments

The CJRR Advisory Committee and CIHI’s PROMs Hip and Knee Working Group recommend that the Canadian versions of the following instruments be used concurrently:

Procedure	Condition-specific instrument*	Generic instrument*
Hip arthroplasty	Oxford Hip Score (OHS)	EQ-5D-5L
Knee arthroplasty	Oxford Knee Score (OKS)	EQ-5D-5L

Note

* The Canadian versions of the EQ-5D-5L and OHS/OKS should be used. These are validated tools and should not be modified.

In developing a recommendation for PROMs instruments, CIHI’s PROMs Hip and Knee Working Group examined existing, validated PROMs instruments that could be adopted for use in routine care in hip and knee arthroplasty. Instruments were compared based on psychometric properties (e.g., responsiveness, reliability, validity), domains (e.g., pain, function), use and applications in existing PROMs programs (within Canada and internationally) and documentation in research and literature. Additional considerations included feasibility of implementation, such as respondent burden (e.g., length of survey), licensing requirements and end-user fees, and the availability of validated Canadian versions.

The PROMs landscape in Canada and internationally is evolving and new PROMs assessment tools are being developed; CIHI will continue to monitor the evolving PROMs landscape and, if needed, reassess this recommendation to support national and international alignment.

Licences for PROMs instruments

Licence requirements

The Oxford Hip Score (OHS)/Oxford Knee Score (OKS) and EQ-5D-5L are propriety PROMs instruments owned by [Oxford University Innovation Limited](#) and [EuroQol Group](#), respectively.

To facilitate the adoption and use of the recommended instruments, CIHI has obtained licences to use the OHS/OKS and EQ-5D-5L and is permitted to sub-licence these instruments to Canadian hospitals and providers for use in routine care (i.e., non-commercial purposes).

For information on the collection and use of the PROMs instruments for research purposes, please email proms@cihi.ca.

Terms of use

Use of PROMs materials is governed by the terms and conditions outlined in the Terms of Use on the CIHI PROMs Licence Registration Form.

Users of the EQ-5D-5L, OHS and OKS are required to inform CIHI of their intention to use these PROMs instruments by completing the required registration form and/or emailing proms@cihi.ca. CIHI will confirm authorization to use the PROMs instruments.

Licensing fees

CIHI may charge cost-recovery fees, when applicable, for the administration and use of the licensed PROMs instruments. CIHI will invoice the licensee for these fees.

Electronic versions

Facilities may opt to develop their own electronic versions of the PROMs instruments (e.g., in-house software) or use an electronic version developed by an appropriately licensed vendor.

Facilities that engage a licensed vendor should ensure that the vendor has obtained the required approvals from [Oxford University Innovation Limited](#) and/or the [EuroQol Group](#).

Email proms@cihi.ca for information related to electronic approvals.

Survey administration

Administration approach

Surveys are typically administered using a census-based approach (administered to the entire population) or a sample-based approach (administered to a representative group of a given population).

CIHI recommends that PROMs surveys be administered to **all** hip and knee arthroplasty patients (i.e., a census-based approach). As PROMs have the potential to inform patient care and clinical decision-making, a census-based approach that includes all patients would allow PROMs survey results to be used for these purposes.

Furthermore, in national initiatives focused on health services monitoring and evaluation, PROMs have typically been administered to all recipients of a particular service (e.g., elective surgeries in the United Kingdom, Medicare recipients in the United States). From an implementation perspective, it would be more practical for administrative staff to ask all patients to complete surveys rather than to select respondents based on random sampling. Developing an appropriate random sampling design is complex, and it may be difficult to ensure that a representative sample is obtained (e.g., for lower-volume facilities).

Method of administration (survey mode)

CIHI encourages electronic collection of PROMs surveys. Alternatively, surveys can be collected on paper or via telephone interview.

Electronic

The use of technology, such as web forms and mobile apps, has the potential to reduce data collection burden for staff and patients, resulting in higher response rates, and to improve data quality. For example, electronic collection does not require staff to transcribe responses collected on paper, reducing administrative burden and eliminating potential transcription errors.

Electronic collection of PROMs also supports more timely access to PROMs information and the potential for real-time PROMs reports for use in care and treatment decisions.

Note: All electronic versions of the EQ-5D-5L and OHS/OKS must be approved by the respective licensors. Please refer to [Licences for PROMs instruments](#) for additional information.

Paper

At present, many local PROMs collection efforts continue to rely on paper-based processes. Paper surveys can be completed by the patient during a clinic visit or mailed to patients to be completed at home. Patients are asked to either return completed surveys to the clinic at their next scheduled visit or return the survey by mail.

Email proms@cihi.ca for a sample paper version of the CIHI PROMs survey.

Languages

CIHI PROMs data collection standards for hip and knee are available in English and French.

The EQ-5D-5L, OHS and OKS are available in other languages. Please email proms@cihi.ca if you require these PROMs instruments in additional languages.

Survey time points

National standard

To enable comparative PROMs reporting (e.g., by surgeon; across facilities, regions, nationally or internationally), PROMs surveys need to be collected and analyzed according to standardized time frames. The national standard recommends that PROMs surveys be collected from all hip and knee arthroplasty patients at the following 2 time points:

1. Pre-surgery (within 8 weeks prior to surgery); and
2. At 1 year post-surgery (9 to 15 months post-surgery).

To support the operationalization of these time points, the national standard includes suggested time frames for collection. This standard is endorsed by the PROMs Hip and Knee Working Group and the CJRR Advisory Committee.

In cases where a patient undergoes more than one surgery within a 12-month period (e.g., staged bilateral arthroplasty, revision surgery), the patient should complete a PROMs survey pre-surgery and at 1 year post-surgery for each surgical episode.

Survey administrators can collect PROMs at additional time points (e.g., initial assessment/consultation) to meet local information needs (e.g., regional and provincial programs). PROMs surveys collected at additional time points may also be submitted to CIHI.

Minimum data set

Table 1 provides a summary of data elements included in the CIHI PROMs MDS and potential sources for this information.

Data elements

The CIHI PROMs MDS for hip and knee arthroplasty includes patient-reported surveys (e.g., PROMs instruments) and data elements required to link PROMs surveys to other data sources, such as the Discharge Abstract Database (DAD), National Ambulatory Care Reporting System (NACRS) and CJRR, to allow additional clinical and administrative information to be included in analyses.

The CIHI PROMs MDS will be revisited periodically to ensure alignment with evolving best practices and standards, where feasible, to support national and international comparative reporting. CIHI anticipates that this MDS may be updated due to the evolving PROMs landscape in Canada and internationally.

Information sources

While PROMs surveys must be completed by the patient, other patient information can be provided by the patient or obtained via administrative sources. It is recommended that the survey administrator complete the categories Survey Administration and Clinical/Administrative.

For surveys completed electronically, many data elements could potentially be auto-populated by software (e.g., survey completion date), through an interface with other source systems (e.g., patient information) or with default values (e.g., Facility Identifier).

Table 1 Summary of CIHI PROMs MDS for hip and knee arthroplasty

Data element category	Row	Data element	Information sources
PROMs Surveys Self-report questionnaires that must be completed by the patient	1	General Health	Must be completed by patient
	2	Satisfaction <i>Post-surgery only</i>	
	3a–l	Oxford Hip Score (OHS) 12 questions <i>Hip arthroplasty only</i>	
	4a–l	Oxford Knee Score (OKS) 12 questions <i>Knee arthroplasty only</i>	
	5a–f	EQ-5D-5L 6 questions	
Patient Information Information related to the individual patient that can be used for reporting and that enables linkage of PROMs surveys to other data sources	6	Health Care Number	Can be completed by the patient or obtained via administrative sources (e.g., patient chart)
	7	Authority Issuing Health Care Number	
	8	Birthdate	If PROMs are collected electronically, this information can be auto-populated or obtained via electronic interface with other source systems (e.g., registration system)
	9	Gender Identity	
	10	Sex Assigned at Birth	
	11	Height (cm)	
	12	Weight (kg)	
Survey Administration Information on the PROMs survey that can be used for reporting	13	Survey Completion Date	Should be completed by the survey administrator
	14	Survey Time Point <i>Assessment/consultation, pre-surgery, post-surgery</i>	If PROMs are collected electronically, this information can be auto-populated
	15	Survey Language <i>English, French, other</i>	
	16	Survey Mode <i>Electronic, paper, telephone</i>	
Clinical/Administrative Information on the patient's episode of care that can be used for reporting and that enables linkage of PROMs surveys to other data sources	17	Surgeon Identifier	Should be completed by the survey administrator
	18	Surgery Date <i>Post-surgery only</i>	
	19	Joint Type <i>Hip, knee</i>	Can be obtained from administrative sources (e.g., patient chart)
	20	Joint Side (Location) <i>Unilateral right, unilateral left, bilateral</i>	If PROMs are collected electronically, this information can be auto-populated (e.g., Facility Identifier) or obtained via electronic interfaces with other source systems
	21	Type of Replacement <i>Primary, revision</i>	
	22	Facility Identifier (Source Organization Identifier)	
Not applicable	Please email proms@cihi.ca for details on submitting data to CIHI	Can be completed by survey administrator or data provider (e.g., organization submitting data to CIHI if different from survey administrator)	
Data Submission Information Information required to submit PROMs data to CIHI and to allow unique surveys to be identified			If PROMs are collected electronically, information can be auto-populated

Collection instructions

Survey administrators are expected to adhere to the collection instructions and permissible values outlined in this manual. Detailed data element descriptions, valid values and collection instructions are available in Table 3.

Jurisdictions/regions may have additional requirements and instructions for PROMs collection. It is recommended that organizations confirm with their respective ministries/departments of health whether jurisdiction-specific collection instructions for PROMs exist.

General guidelines

The following bullets highlight key data collection instructions for PROMs in hip and knee arthroplasty:

- All data elements are mandatory to complete, unless otherwise noted.
- Requirements for surveys collected at different time points (i.e., assessment, pre-surgery, post-surgery) may vary slightly and are noted in the collection instructions.
- The Surgeon Identifier is a unique number identifying the provider assigned to the patient. This may be a number assigned by the reporting facility or by the province/territory (e.g., from the relevant college of physicians and surgeons). Organizations should email proms@cihi.ca to confirm the appropriate number to record for this data element.
- Wording for self-report questions (i.e., General Health, Satisfaction, OHS, OKS, EQ-5D-5L) should be used without modification.
- Regardless of the method of survey collection, PROMs surveys should be posed to patients in the following order:
 - Single-item General Health
 - Single-item Satisfaction (post-surgery surveys only)
 - OHS and/or OKS (based on joints being treated/assessed; refer to [OHS and OKS instructions](#))
 - EQ-5D-5L
- Canadian versions of the EQ-5D-5L, OHS and OKS should be used without modification. Survey administrators should follow the instructions in [Licences for PROMs instruments](#) or email proms@cihi.ca to obtain appropriate licences and official versions of these questionnaires prior to administering surveys to patients.

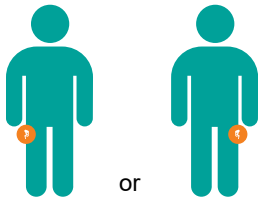

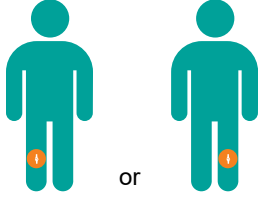

OHS and OKS instructions

Hip patients should complete the OHS and knee patients should complete the OKS for each joint side that is being assessed/treated, per Table 2 below.

When the patient is being assessed/treated for both the hip **and** the knee during the same visit or procedure, the patient should complete the OHS and OKS for each joint side that is being assessed/treated.

When more than one OHS and/or OKS survey is required (e.g., bilateral procedures), the patient is required to complete only the General Health, Satisfaction (post-surgery surveys only) and EQ-5D-5L questions once per survey time point.

Table 2 Instructions for completing the OHS and OKS

Joint	Procedure type	Instructions
Hip	Unilateral 1 procedure occurring on 1 side of the body 	The patient should complete the OHS based on the joint side (right or left) being treated and/or assessed
	Bilateral 1 procedure occurring on both sides of the body 	The patient should complete the OHS twice, once for each joint side (right and left)
Knee	Unilateral 1 procedure occurring on 1 side of the body 	The patient should complete the OKS based on the joint side (right or left) being treated and/or assessed
	Bilateral 1 procedure occurring on both sides of the body 	The patient should complete the OKS twice, once for each joint side (right and left)

Detailed collection guidelines

Table 3 PROMs data element collection guidelines

Row	Data element name and description	Valid values	Applicability	Collection instructions
PROMs Surveys				
1	<p>General Health</p> <p>Single-item question describing the patient's general health</p>	<p>1 (excellent)</p> <p>2 (very good)</p> <p>3 (good)</p> <p>4 (fair)</p> <p>5 (poor)</p> <p>ASKU (asked but unknown)</p>	All	<p>Record the patient's response to the question In general, how would you rate your overall health?</p> <p>ASKU can be recorded only when the survey is administered by paper or telephone. Record ASKU when</p> <ul style="list-style-type: none"> • The patient completes the survey on paper and the response is blank; or • The patient completes the survey via telephone interview and does not want to provide a response.
2	<p>Satisfaction</p> <p>Single-item question describing the patient's level of satisfaction with the joint replacement surgery</p>	<p>1 (very satisfied)</p> <p>2 (satisfied)</p> <p>3 (neutral)</p> <p>4 (dissatisfied)</p> <p>5 (very dissatisfied)</p> <p>ASKU (asked but unknown)</p> <p>NA (not applicable)</p>	Post-surgery surveys only	<p>Record the patient's response to the question How satisfied are you with the results of your right/left hip/knee replacement?</p> <p>Record NA for surveys completed prior to surgery (e.g., pre-surgery).</p> <p>ASKU can be recorded only when the survey is administered by paper or telephone. Record ASKU when</p> <ul style="list-style-type: none"> • The patient completes the survey on paper and the response is blank; or • The patient completes the survey via telephone interview and does not want to provide a response.

Row	Data element name and description	Valid values	Applicability	Collection instructions
3a-I	<p>Oxford Hip Score (OHS) 12 questions</p>	<p>0 to 4 ASKU (asked but unknown)</p> <p>Notes Each question has 5 response options that are assigned a value of 0 to 4, with 0 representing greatest severity and 4 representing fewest or no symptoms.</p> <p>Refer to the paper version of the OHS for response options.</p>	<p>Hip replacements only</p>	<p>Record the patient's responses to the 12 questions in the OHS.</p> <ul style="list-style-type: none"> • For unilateral procedures, provide instructions for the patient to complete the OHS based on the joint side (right or left) being treated and/or assessed. • For bilateral procedures, ask the patient to complete the OHS twice, once for each joint side (right and left). <p>Ensure the Canadian version of the OHS is being used.</p> <p>ASKU can be recorded only when the survey is administered by paper or telephone. Record ASKU when</p> <ul style="list-style-type: none"> • The patient completes the survey on paper and the response is blank; or • The patient completes the survey via telephone interview and does not want to provide a response.
4a-I	<p>Oxford Knee Score (OKS) 12 questions</p>	<p>0 to 4 ASKU (asked but unknown)</p> <p>Notes Each question has 5 response options that are assigned a value of 0 to 4, with 0 representing greatest severity and 4 representing fewest or no symptoms.</p> <p>Refer to the paper version of the OKS for response options.</p>	<p>Knee replacements only</p>	<p>Record the patient's responses to the 12 questions in the OKS.</p> <ul style="list-style-type: none"> • For unilateral procedures, provide instructions for the patient to complete the OKS based on the joint side (right or left) being treated and/or assessed. • For bilateral procedures, ask the patient to complete the OKS twice, once for each joint side (right and left). <p>Ensure the Canadian version of the OKS is being used.</p> <p>ASKU can be recorded only when the survey is administered by paper or telephone. Record ASKU when</p> <ul style="list-style-type: none"> • The patient completes the survey on paper and the response is blank; or • The patient completes the survey via telephone interview and does not want to provide a response.

Row	Data element name and description	Valid values	Applicability	Collection instructions
5a–e	EQ-5D-5L 5 questions	1 to 5 ASKU (asked but unknown) Notes Each question has 5 response options that are assigned a value of 1 to 5, with 1 representing least severity and 5 representing greatest severity. Refer to the paper version of the EQ-5D-5L for response options.	All	Record the patient’s responses to the 5 questions in the EQ-5D-5L. Ensure the Canadian version of the EQ-5D-5L is being used. ASKU can be recorded only when the survey is administered by paper or telephone. Record ASKU when <ul style="list-style-type: none"> • The patient completes the survey on paper and the response is blank; or • The patient completes the survey via telephone interview and does not want to provide a response.
5f	EQ-5D VAS EQ-5D-5L Visual Analog Scale	000 to 100 ASKU (asked but unknown)	All	Record the patient’s response to the Visual Analog Scale in the EQ-5D-5L. Ensure the Canadian version of the EQ-5D-5L is being used. ASKU can be recorded only when the survey is administered by paper or telephone. Record ASKU when <ul style="list-style-type: none"> • The patient completes the survey on paper and the response is blank; or • The patient completes the survey via telephone interview and does not want to provide a response.

Row	Data element name and description	Valid values	Applicability	Collection instructions
Patient Information				
6	<p>Health Care Number</p> <p>The patient's unique health care coverage number as assigned to the patient by the provincial/territorial or federal government</p>	<p>A valid health care number (up to 12 alphanumeric characters)</p> <p>UNK (unknown)</p> <p>NA (not applicable)</p>	All	<p>If the patient is asked to provide this information, record the patient's response to the question What is your health care number?</p> <p>Record the patient's health care number, when available, regardless of the issuer (provincial/territorial or federal government).</p> <p>Record NA when the patient is</p> <ul style="list-style-type: none"> • An out-of-province/-territory resident with an unavailable health care number; • Insured by the federal government with an unavailable health care number; or • An out-of-country resident with no provincial/territorial or federal health care coverage. <p>Record UNK when the patient has provincial/territorial or federal government health care coverage and the health care number is not available (e.g., cannot be obtained from records within the organization).</p> <p>Important note</p> <p>The Health Care Number provided should be consistent with submissions to other CIHI data holdings. For example, jurisdictions that send de-identified Health Care Numbers to CIHI's DAD or NACRS should send Health Care Number for PROMs data using the same de-identification methodology.</p>

Row	Data element name and description	Valid values	Applicability	Collection instructions
7	<p>Authority Issuing Health Care Number</p> <p>The provincial/territorial or federal government that issued the health care number</p>	<p>NL (Newfoundland and Labrador) PE (Prince Edward Island) NS (Nova Scotia) NB (New Brunswick) QC (Quebec) ON (Ontario) MB (Manitoba) SK (Saskatchewan) AB (Alberta) BC (British Columbia) YT (Yukon) NT (Northwest Territories) NU (Nunavut) AA (Indigenous and Northern Affairs Canada) CF (Canadian Armed Forces) CI (Immigration, Refugees and Citizenship Canada) CS (Correctional Service Canada) CA (Canada — other) NA (not applicable)</p>	All	<p>If the patient is asked to provide this information, record the patient’s response to the question Which of the following issued your health card?</p> <p>When the patient is insured by a province/territory, record the provincial/territorial government that provides health care coverage, even when the health care number is unknown.</p> <p>When the patient is insured by the federal government,</p> <ul style="list-style-type: none"> • Record the federal organization that provides health care coverage, even when the health care number is unknown or not assigned. • Record CA when the specific federal organization is not listed (e.g., Royal Canadian Mounted Police, Veterans Affairs Canada). • Record CA when the specific federal organization providing coverage is not known. <p>When the patient does not have provincial/territorial or federal government health care coverage (e.g., out-of-country resident), record NA.</p>

Row	Data element name and description	Valid values	Applicability	Collection instructions
8	<p>Birthdate</p> <p>Date the patient was born</p>	<p>Valid date in numeric format: YYYYMMDD YYYYMM YYYY UNK (unknown)</p> <p>Notes YYYY = year MM = month (01 to 12) DD = day of the month (01 to 31)</p>	All	<p>If the patient is asked to provide this information, record the patient's response to the question What is your birthdate?</p> <p>Record the patient's full date of birth in numeric format. For example, January 6, 1942, would be recorded as 19420106.</p> <p>Record a partial birthdate (i.e., year and month or year alone) when the full birthdate is not available from available sources (e.g., administrative record).</p>
9	<p>Gender Identity</p> <p>The self-identified gender of the patient</p>	<p>M (male) F (female) D (gender diverse) UNK (unknown) NA (not applicable)</p>	All	<p>If the patient is asked to provide this information, record the patient's response to the question What best identifies your current gender identity? (male, female, other identify, prefer not to answer)</p> <p>Record the patient's gender (self-identified), which may be the same as or different from the birth-assigned sex.</p> <p>Record D when the patient identifies as being other than male or female. This includes persons who report being unsure of their gender, being both male and female, or being neither male nor female.</p> <p>Record UNK when this information cannot be obtained from available sources and</p> <ul style="list-style-type: none"> • The patient is asked to identify their gender and does not provide a response; or • The patient is not asked to identify their gender. <p>Record NA when it is inappropriate to ask the question (e.g., children).</p>

Row	Data element name and description	Valid values	Applicability	Collection instructions
10	<p>Sex Assigned at Birth</p> <p>The sex of the patient assigned at birth</p>	<p>M (male) F (female) I (indeterminate) UNK (unknown)</p>	<p>All</p>	<p>If the patient is asked to provide this information, record the patient's response to the question What is your sex assigned at birth? (male, female, not assigned male or female)</p> <p>Record the patient's sex assigned at birth.</p> <p>Record I when the patient was identified as intersex or was not uniquely identified or classified as male or female at birth.</p> <p>Record UNK when the sex assigned at birth is not available (e.g., patient is asked but does not provide a response, information cannot be obtained from administrative records).</p>
11	<p>Height (cm)</p> <p>The patient's height measured in centimetres</p>	<p>000 to 999</p>	<p>All</p>	<p>If the patient is asked to provide this information, record the patient's response to the question What is your height in centimetres?</p> <p>Record the patient's height to the nearest centimetre (cm).</p> <p>When height is recorded in inches, it must be converted to centimetres for submission to CIHI. To convert inches to centimetres, divide the height in inches by 2.54.</p>
12	<p>Weight (kg)</p> <p>The patient's weight measured in kilograms</p>	<p>000 to 999</p>	<p>All</p>	<p>If the patient is asked to provide this information, record the patient's response to the question What is your weight in kilograms?</p> <p>Record the patient's weight to the nearest kilogram (kg).</p> <p>When weight is recorded in pounds, it must be converted to kilograms for submission to CIHI. To convert weight from pounds to kilograms, divide the weight in pounds by 2.2.</p>

Row	Data element name and description	Valid values	Applicability	Collection instructions
Survey Administration				
13	<p>Survey Completion Date</p> <p>Date the survey was completed by the patient</p>	<p>Valid date in the format YYYYMMDD</p> <p>Notes YYYY = year MM = month (01 to 12) DD = day of the month (01 to 31)</p>	All	<p>Record the date the patient completed the survey in numeric format. For example, February 1, 2018, would be recorded as 20180201.</p> <p>Partial dates are not allowed.</p> <p>When a survey is collected electronically, Survey Completion Date can be auto-populated.</p> <p>When a survey is completed on paper, if the survey date is blank or incomplete, record the date the survey was received.</p>
14	<p>Survey Time Point</p> <p>A value indicating when the survey was administered relative to the joint replacement surgery</p>	<p>1 (assessment/consultation prior to surgery) 2 (pre-surgery) 3 (post-surgery)</p>	All	<p>Record 1 when the survey is administered more than 4 weeks prior to surgery (e.g., at initial consultation).</p> <p>Record 2 when the survey is administered up to 4 weeks prior to the joint replacement surgery (e.g., at pre-admission clinic visit).</p> <p>Record 3 when the survey is administered after the joint replacement surgery has been performed (e.g., 90 days post-surgery, 1 year post-surgery).</p> <p>Note Surveys should be collected at pre-surgery and at 1 year post-surgery.</p>
15	<p>Survey Language</p> <p>A value indicating the language in which the patient completed the survey</p>	<p>ENG (English) FRA (French) OTH (other)</p>	All	<p>Record ENG when the survey is administered in English.</p> <p>Record FRA when the survey is administered in French.</p> <p>Record OTH when the survey is administered in a language other than English or French.</p>

Row	Data element name and description	Valid values	Applicability	Collection instructions
16	<p>Survey Mode</p> <p>A value indicating the mode of survey administration used</p>	<p>ELECTRONIC (electronic) MAILWRIT (paper via mail) HANDWRIT (paper in clinic) PHONE (telephone interview)</p>	All	<p>Record ELECTRONIC when the survey is completed electronically, including on a mobile device, tablet, web form, email, computer and kiosk.</p> <p>Record MAILWRIT when the survey is completed on paper and the survey is sent to the patient via courier or postal service.</p> <p>Record HANDWRIT when the survey is completed on paper at the clinic.</p> <p>Record PHONE when the survey is completed via telephone (e.g., with interviewer).</p>
Clinical/Administrative				
17	<p>Surgeon Identifier</p> <p>Identification number associated with the surgeon who performed or will be performing the hip/knee replacement procedure</p>	<p>Up to 15 characters UNK (unknown)</p>	All	<p>The Surgeon Identifier is a unique number that identifies the provider assigned to the patient. This may be a number assigned by the reporting facility or by the province/territory (e.g., from the relevant college of physicians and surgeons). Organizations should email proms@cihi.ca to confirm the appropriate number to record for this data element.</p> <p>Complete Surgeon Identifier as follows:</p> <ul style="list-style-type: none"> ● Assessment/consultation: Record the identification number of the orthopedic surgeon who is assigned to the patient (e.g., who performed the assessment). Record UNK when an orthopedic surgeon was not responsible for the visit (e.g., initial consultation) or has not been assigned to the patient. ● Pre-surgery: Record the identification number of the orthopedic surgeon assigned to perform the surgery on the patient. ● Post-surgery: Record the identification number of the orthopedic surgeon who performed the surgery.

Row	Data element name and description	Valid values	Applicability	Collection instructions
18	Surgery Date Date of joint replacement surgery	Valid date in the format YYYYMMDD Notes YYYY = year MM = month (01 to 12) DD = day of the month (01 to 31)	Post-surgery only	Record the date the joint replacement surgery was performed in numeric format. For example, May 23, 2018, would be recorded as 20180523. When the patient has had more than one surgery in the past 12 months (e.g., staged bilateral), ensure the patient is aware of which surgery he or she is being asked to assess.
19	Joint Type A value indicating the type of joint being assessed or treated	24136001 (hip joint) 49076000 (knee joint)	All	Record the joint type that is being assessed or treated.
20	Joint Side (Location) A value indicating the joint side being assessed or treated	R (unilateral right) L (unilateral left) B (bilateral)	All	Record the joint side that is being assessed or treated.
21	Type of Replacement A value indicating whether the joint replacement is a primary or revision surgery	P (primary) R (revision) A (abandoned after onset) NA (not applicable)	All	Record NA (not applicable) when the patient is not referred to surgery.
22	Facility Identifier (Source Organization Identifier) A unique identifier assigned to a facility by CIHI or the provincial/territorial ministry or department of health that identifies the facility where services are rendered	Up to 10 characters	All	The Facility Identifier is a unique number that identifies the facility where services occurred. This may be a number assigned by CIHI or by the province/territory (e.g., ministry or department of health). Organizations should email proms@cihi.ca to confirm the appropriate number to record for this data element. Record the number assigned to identify the facility collecting the PROMs survey. <ul style="list-style-type: none"> • Assessment/consultation: Record the facility number of the organization where the assessment/consultation occurred. • Pre-surgery and post-surgery: Record the facility number of the organization where the procedure will be/was performed.

Appendix A: Standards used in the PROMs MDS

When available and applicable, the CIHI Reference Data Model was used to develop the valid values and descriptions for data elements in the PROMs MDS and collection guidelines. CIHI also referred to other CIHI databases as well as to pan-Canadian and international data collection sources (e.g., HL7, SNOMED CT).

Table 4 Standards used in the PROMs MDS for hip and knee

Data element	Sources
General Health (single item)	Statistics Canada
Oxford Hip Score (OHS)	Oxford University Innovation Ltd.
Oxford Knee Score (OKS)	Oxford University Innovation Ltd.
EQ-5D-5L	EuroQol Group
Authority Issuing Health Care Number	CIHI Reference Data Model
Gender Identity	CIHI Reference Data Model
Sex Assigned at Birth	CIHI Reference Data Model
Survey Completion Date	CIHI Reference Data Model
Survey Language	CIHI Reference Data Model
Survey Mode	CIHI Reference Data Model
Surgery Date	CIHI Reference Data Model
Joint Type	SNOMED CT
Joint Side (Location)	Canadian Classification of Health Interventions (CCI)
Type of Replacement	CIHI Reference Data Model

References

1. Canadian Institute for Health Information. *Hip and Knee Replacements in Canada: Canadian Joint Replacement Registry 2016–2017 Quick Stats*. 2018.
2. Rolfson O, et al. [Patient-reported outcome measures in arthroplasty registries](#). *Acta Orthopaedica*. May 2016.



CIHI Ottawa

495 Richmond Road
Suite 600
Ottawa, Ont.
K2A 4H6
613-241-7860

CIHI Toronto

4110 Yonge Street
Suite 300
Toronto, Ont.
M2P 2B7
416-481-2002

CIHI Victoria

880 Douglas Street
Suite 600
Victoria, B.C.
V8W 2B7
250-220-4100

CIHI Montréal

1010 Sherbrooke Street West
Suite 602
Montréal, Que.
H3A 2R7
514-842-2226

cihi.ca

20052-0518

