

**PROMs** 

# Data Collection Manual: **Hip and Knee Arthroplasty**

2021



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- 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.<sup>1</sup>

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, 2021 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 <a href="mailto:proms@cihi.ca">proms@cihi.ca</a> 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

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.

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

#### 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 <a href="mailto:proms@cihi.ca">proms@cihi.ca</a>.

#### 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 <a href="mailto:proms@cihi.ca">proms@cihi.ca</a>. 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 <a href="mailto:proms@cihi.ca">proms@cihi.ca</a> 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 <u>Licences for PROMs instruments</u> 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 <a href="mailto:proms@cihi.ca">proms@cihi.ca</a> 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 <a href="mailto:proms@cihi.ca">proms@cihi.ca</a> 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 15-month period (e.g., staged bilateral arthroplasty), the patient should complete a PROMs survey pre-surgery and at 1 year post-surgery for each surgical episode.

If a revision of the primary hip or knee arthroplasty occurs, discontinue survey follow-up for the primary surgery. Aim to collect a PROMs survey pre-surgery and at 1 year post-surgery for the revision surgery.

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

### OHS, OKS and Satisfaction instructions

Hip patients should complete the OHS, knee patients should complete the OKS and all patients should complete the Satisfaction question (post-surgery surveys only) 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, OKS and Satisfaction question (post-surgery surveys only) 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 the General Health and EQ-5D-5L questions only once per survey time point.

Table 2 Instructions for completing the OHS, OKS, and Satisfaction question

Joint	Procedure type	Instructions
Hip	Unilateral 1 procedure occurring on 1 side of the body or	The patient should complete the OHS and Satisfaction question (post-surgery surveys only) 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 and Satisfaction question (post-surgery surveys only) twice, once for each joint side (right and left)
Knee	Unilateral 1 procedure occurring on 1 side of the body or	The patient should complete the OKS and the Satisfaction question (post-surgery surveys only) 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 and Satisfaction question (post-surgery surveys only) 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
PROM	1s Surveys			
1	General Health Single-item question describing the patient's general health	1 (excellent) 2 (very good) 3 (good) 4 (fair) 5 (poor) ASKU (asked but unknown)	All	Record the patient's response to the question In general, how would you rate your overall health?  ASKU can be recorded only when the survey is administered by paper or telephone. Record ASKU when  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.
2a-d	Satisfaction Single-item question describing the patient's level of satisfaction with the joint replacement surgery	1 (very satisfied) 2 (satisfied) 3 (neutral) 4 (dissatisfied) 5 (very dissatisfied) ASKU (asked but unknown) NA (not applicable)	Post-surgery surveys only	Record the patient's response to the question How satisfied are you with the results of your right/left hip/knee replacement?  • For unilateral procedures, provide instructions for the patient to complete the Satisfaction question based on the joint side (right or left) being treated and/or assessed.  • For bilateral procedures, ask the patient to complete the Satisfaction question, once for each joint side (right and left).  Record NA for surveys completed prior to surgery (e.g., pre-surgery).  ASKU can be recorded only when the survey is administered by paper or telephone. Record ASKU when  • 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-l	Oxford Hip Score (OHS)	0 to 4	Hip	Record the patient's responses to the 12 questions in the OHS.
	12 questions	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.  Refer to the paper version of the OHS for response options.	replacements	<ul> <li>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.</li> <li>For bilateral procedures, ask the patient to complete the OHS twice, once for each joint side (right and left).</li> <li>Ensure the Canadian version of the OHS is being used.</li> <li>ASKU can be recorded only when the survey is administered by paper or telephone. Record ASKU when</li> <li>The patient completes the survey on paper and the response is blank; or</li> <li>The patient completes the survey via telephone interview and does not want to provide a response.</li> </ul>
4a-l	Oxford Knee Score	0 to 4	Knee	Record the patient's responses to the 12 questions in the OKS.
	(OKS) 12 questions	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.  Refer to the paper version of the OKS for response options.	replacements only	<ul> <li>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.</li> <li>For bilateral procedures, ask the patient to complete the OKS twice, once for each joint side (right and left).</li> <li>Ensure the Canadian version of the OKS is being used.</li> <li>ASKU can be recorded only when the survey is administered by paper or telephone. Record ASKU when</li> <li>The patient completes the survey on paper and the response is blank; or</li> <li>The patient completes the survey via telephone interview and does not want to provide a response.</li> </ul>

Row	Data element name and description	Valid values	Applicability	Collection instructions
5а-е	EQ-5D-5L	1 to 5	All	Record the patient's responses to the 5 questions in the EQ-5D-5L.
	5 questions	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.		Ensure the Canadian version of the EQ-5D-5L is being used. <b>ASKU</b> can be recorded only when the survey is administered by paper or telephone. Record <b>ASKU</b> when  • 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  • 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
	nt Information	valid values	Applicability	Conection histractions
6	Health Care Number The patient's unique health care coverage number as assigned to the patient by the provincial/territorial or federal government	A valid health care number (up to 12 alphanumeric characters) UNK (unknown) NA (not applicable)	All	If the patient is asked to provide this information, record the patient's response to the question What is your health care number?  Record the patient's health care number, when available, regardless of the issuer (provincial/territorial or federal government).  Record NA when the patient is  • 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.  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).  Important note  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.

Row	Data element name and description	Valid values	Applicability	Collection instructions
7	Authority Issuing Health Care Number The provincial/territorial or federal government that issued the health care number	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 — other) NA (not applicable)	All	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?  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.  When the patient is insured by the federal government,  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.  When the patient does not have provincial/territorial or federal government health care coverage (e.g., out-of-country resident), record NA.

Row	Data element name and description	Valid values	Applicability	Collection instructions
8	Birthdate  Date the patient was born	Valid date in numeric format: YYYYMMDD YYYYMM YYYY UNK (unknown)  Notes YYYY = year MM = month (01 to 12) DD = day of the month (01 to 31)	All	If the patient is asked to provide this information, record the patient's response to the question <b>What is your birthdate?</b> Record the patient's full date of birth in numeric format.  For example, January 6, 1942, would be recorded as 19420106.  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).
9	Gender Identity The self-identified gender of the patient	M (male) F (female) D (gender diverse) UNK (unknown) NA (not applicable)	All	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)  Record the patient's gender (self-identified), which may be the same as or different from the birth-assigned sex.  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.  Record UNK when this information cannot be obtained from available sources and  The patient is asked to identify their gender and does not provide a response; or  The patient is not asked to identify their gender.  Record NA when it is inappropriate to ask the question (e.g., children).

Row	Data element name and description	Valid values	Applicability	Collection instructions
10	Sex Assigned at Birth The sex of the patient assigned at birth	M (male) F (female) I (indeterminate) UNK (unknown)	All	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)  Record the patient's sex assigned at birth.  Record I when the patient was identified as intersex or was not uniquely identified or classified as male or female at birth.  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).
11	Height (cm) The patient's height measured in centimetres	000 to 999	All	If the patient is asked to provide this information, record the patient's response to the question <b>What is your height in centimetres?</b> Record the patient's height to the nearest centimetre (cm).  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.
12	Weight (kg) The patient's weight measured in kilograms	000 to 999	All	If the patient is asked to provide this information, record the patient's response to the question <b>What is your weight in kilograms?</b> Record the patient's weight to the nearest kilogram (kg).  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.

Row	Data element name and description	Valid values	Applicability	Collection instructions
	y Administration	valid values	Applicability	Conection mistractions
13	Survey Completion Date Date the survey was completed by the patient	Valid date in the format YYYYMMDD  Notes YYYY = year MM = month (01 to 12) DD = day of the month (01 to 31)	All	Record the date the patient completed the survey in numeric format. For example, February 1, 2018, would be recorded as 20180201.  Partial dates are not allowed.  When a survey is collected electronically, Survey Completion Date can be auto-populated.  When a survey is completed on paper, if the survey date is blank or incomplete, record the date the survey was received.
14	Survey Time Point A value indicating when the survey was administered relative to the joint replacement surgery	1 (assessment/consultation prior to surgery) 2 (pre-surgery) 3 (post-surgery)	All	Record 1 when the survey is administered more than 8 weeks prior to surgery (e.g., at initial consultation).  Record 2 when the survey is administered up to 8 weeks prior to the joint replacement surgery (e.g., at pre-admission clinic visit).  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).  Note  Surveys should be collected at pre-surgery and at 1 year post-surgery.
15	Survey Language A value indicating the language in which the patient completed the survey	ENG (English) FRA (French) OTH (other)	All	Record <b>ENG</b> when the survey is administered in English.  Record <b>FRA</b> when the survey is administered in French.  Record <b>OTH</b> when the survey is administered in a language other than English or French.

Row	Data element name and description	Valid values	Applicability	Collection instructions
16	Survey Mode A value indicating the mode of survey administration used	ELECTRONIC (electronic) MAILWRIT (paper via mail) HANDWRIT (paper in clinic) PHONE (telephone interview)	All	Record <b>ELECTRONIC</b> when the survey is completed electronically, including on a mobile device, tablet, web form, email, computer and kiosk.  Record <b>MAILWRIT</b> when the survey is completed on paper and the survey is sent to the patient via courier or postal service.  Record <b>HANDWRIT</b> when the survey is completed on paper at the clinic.  Record <b>PHONE</b> when the survey is completed via telephone (e.g., with interviewer).
Clinic	al/Administrative			
17	Surgeon Identifier Identification number associated with the surgeon who performed or will be performing the hip/knee replacement procedure	Up to 15 characters UNK (unknown)	All	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 <a href="mailto:proms@cihi.ca">proms@cihi.ca</a> to confirm the appropriate number to record for this data element.  Complete Surgeon Identifier as follows:  • 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 <b>NA</b> (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 <a href="mailto:proms@cihi.ca">proms@cihi.ca</a> to confirm the appropriate number to record for this data element.  Record the number assigned to identify the facility collecting the PROMs survey.  • 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. <u>Patient-reported outcome measures in arthroplasty registries</u>. *Acta Orthopaedica*. May 2016.



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