OECD Patient-Reported Indicator Surveys (PaRIS) Initiative

Patient-Reported Outcome Measures (PROMs) for Hip and Knee Replacement Surgery

International Data Collection Gui s

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ISBN 978-1-77109-884-7 PDF

How to cite this document:
Canadian Institute for Health Information, Organisation for Economic Co-operation and Development. OECD Patient-Reported Indicator Surveys (PaRIS) Initiative: Patient-Reported Outcome Measures (PROMs) for Hip and Knee Replacement Surgery — International Data Collection Guidelines

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Endorsements

The OECD Patient-Reported Indicator Surveys (PaRIS) Initiative: Patient-Reported Outcome Measures (PROMs) for Hip and Knee Replacement Surgery — International Data Collection Guidelines are endorsed by the following organisations:

Note from the Secretariat

The Organisation for Economic Co-operation and Development (OECD) aims to promote policies that will improve the economic and social well-being of people around the world. The OECD provides a unique forum in which governments can work together to share experiences and seek solutions to common challenges. In January 2017, OECD KHDOWK PLQLVWHUV DVNHG WKH 2(&' 6HFUHWDULDW WR OHDG

The

Acknowledgements

The OECD Patient-Reported Indicator Surveys (PaRIS) Initiative: Patient-Reported Outcome Measures (PROMs) for Hip and Knee Replacement Surgery — International Data Collection Guidelines was developed by the Working Group on Patient-Reported Indicators for Hip and Knee Replacement Surgery, which was co-chaired by the Canadian Institute for Health Information (CIHI) in partnership with the Organisation for Economic Co-operation and Development (OECD).

The Working Group includes participants from 13 member countries and is composed of patient representatives, clinicians, researchers, experts in PROMs and psychometric measurement, national arthroplasty registries and government representatives. Members played a critical role in providing advice on the development, collection and reporting of patient-reported indicators for hip and knee replacement surgery.

CIHI was responsible for conducting research and facilitating discussions to build consensus IRU WKH SUHSDUDWLRQ RI WKHVH JXLGHOLQHV DV ZHOO DV GHY for 2019 pilot reporting with input from the Working Group members. Working Group members also facilitated the provision of data for reporting in Health at a Glance 2019. An expert consultant who provided guidance on the appropriate use of crosswalks made the evaluation of crosswalks for reporting on a single metric possible.

The following individuals contributed to the preparation of these guidelines:

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Patient foreword

“Patient-reported indicator surveys” is a long title that provides a nice abbreviation: PaRIS.

This sounds great. But does it really collect the information that patients need to make an informed choice? Does it provide clues about how health services are performing? And how can we make sure it does both?

Patients seek improvement in quality of life (QoL). They want to know if a particular treatment ZLOO UHDOO\ LPSURYH WKHLU FLUFXPVWDQFHV ZKLFK WKH\ GH less dependence on formal or informal care, and improvement in their ability to do (previous) ZRUN SDLG YROXQWDU\ R ̂FH EDVHG RU VHOI HPSOR\HG ,Q V economic independence, less pain and less reliance on medication?

The importance of the PaRIS initiative is based on increasing the attention given to patients’ feedback on their care. This way, health services and health systems develop the understanding that putting the patient in the centre will improve results, performance and value for all stakeholders — present and future.

In a context where various types of information are available — some very good and some very bad — establishing guidelines on how to collect data directly from patients is a necessity. &UHDWLQJ D XQLIRUP WRRO WR FROOHFW WKLV GDWD LQ GL ‡HU GLVWLQJXLVK WKH GL ‡HUHQFHV LQ WKH ZD\ KHDOWK FDUH LV S respective solutions.

But to enable patients to contribute feedback, it is imperative to approach them in a language adapted to their understanding, i.e., less academic. Involving them from the beginning and in DOO VWDJHV RI UHVHDUFK GHVLJQ DQG LPSOHPHQWDWLRQ ZLG

Background

Introduction to PROMs for hip and knee replacement surgery

Patient-reported outcome measures (PROMs) are measurement instruments completed by patients to obtain information on aspects of their overall quality of life, including symptoms; functional status; and physical, mental and social health. PROMs are essential to delivering patient-centred health care, and when applied routinely they can enhance communication between patients and providers, inform decisions for value-based health system improvements and improve overall patient care experiences and outcomes (Ayers et al., 2013).

PROMs are fundamental to understanding how health care services and procedures make D G L ‡ H U H Q F H W R S D W L H Q W V ¶ K H D O W K D Q G T X D O L W \ R I O L I H S of care from the patient's perspective and complementing existing information on the quality of care and services provided. PROMs are increasingly recognised as contributing valuable information to enable achieving health system goals; thus decision-makers are turning to PROMs to complement other data on health care inputs, outputs and outcomes to evaluate the performance of health services. Table 1 summarises the uses of PROMs E \ G L ‡ H U H Q W V W D N H K R O G H U V

Table 1 Uses of PROMs

Many PROMs instruments have been developed to evaluate the impact of treatments

PROMs are already collected for joint replacement procedures in several countries at the regional or national levels, such as the United Kingdom, Sweden, the Netherlands, Australia, Canada and the United States. Other countries are just beginning to initiate or scale up PROMs collection for joint replacement. Annex 2 provides an environmental scan of PROMs instruments used internationally at the time of this report.

The National Health Service (NHS) (United Kingdom) PROMs Initiative is one of the largest PROMs initiatives worldwide to support continuous quality improvement at the system level for hip and knee replacements. As a result, the NHS reported optimisation of the hip and knee replacement pathway, improvements in surgical treatment and rehabilitation, and patients becoming more involved in the decision-making process (Basser, 2015). The Swedish national hip and knee arthroplasty registries (SHAR and SKAR, respectively) introduced PROMs collection in 2002 for hips and 2008 for knees, with the focus of improving the quality of care for patients. Through annual public reporting,

Development of the guidelines

The widespread international interest in the use of PROMs inspired the need to develop a standardised approach to enable fair comparisons of data internationally. This level of analysis and reporting can help to monitor health system performance across OECD countries and identify variations in quality of care (Figure 1.1). In 2015 the International Consortium for Health Outcome Measurement (ICHOM) published the Hip & Knee Osteoarthritis Reference Guide to facilitate collection of comparable data for global benchmarking and learning for patients with osteoarthritis (ICHOM, 2015). While the objective of the ICHOM guide aligns with that of PaRIS, the patient population includes people managing osteoarthritis, whereas the PaRIS Working Group on Patient-Reported Indicators for Hip and Knee Replacement Surgery (the Working Group) focussed on patients undergoing these procedures. Additionally, in 2016 the International Society of Arthroplasty Registries (ISAR) PROMs Working Group recommended best practices for hip and knee arthroplasty PROMs (Rolfson et al., 2016). Representatives from both ICHOM and ISAR were invited to the Working Group in order to contribute knowledge and experience.

Considerable thought was put into methodologies that would allow for robust collection and comparable reporting of PROMs data for hip and knee arthroplasty patients while also maximising the number of countries able to participate. A literature review, an environmental scan, consultations and discussions were conducted to determine and establish these guidelines. Evaluation of existing PROMs instruments included assessment of psychometric properties (such as reliability, validity and responsiveness), clinical and health system applicability, patient engagement in development, collection burden, translations and validations available, licensing and costs, and use in existing programmes. Mapping algorithms, or crosswalks, that convert scores from various instruments onto one metric for comparison were also researched and evaluated.

The next section provides the international data collection guidelines. They are presented as recommendations W K D W U H À H F W the current context of PROMs collection and the advice of the Working Group. Aligned with the Key Principles of PaRIS, the development of the guidelines was based on the following:

- The guidelines should be grounded in person-centredness — measuring what patients consider important. This is essential to inform quality of care and services.
- The international comparison and benchmarking of indicators based on PROMs and other patient-reported data is not an end in itself, but a means to promote mutual learning and continuous improvements in data collection practices and processes themselves, and health policy and practice.
- International guidelines should complement — not disrupt — existing patient-reported data collection at all levels of participating countries' health systems. As such, they may require

PROMs for Hip and Knee Replacement Surgery — International Data Collection Guidelines

These guidelines provide new and existing hip and knee replacement surgery PROMs programmes with information to support PROMs collection for international reporting for the purposes of monitoring surgical outcomes and system performance. As local needs and resources may vary across OECD countries, consultation with local stakeholders (e.g., patients, clinicians, government bodies) is imperative while planning the implementation or alignment of a PROMs programme.

A high-level summary of the international guidelines presented in this report is provided in the table below. Further information for each of the guidelines is detailed in the sections that follow, including rationale and considerations for local implementation.

Table 3 PROMs for Hip and Knee Replacement Surgery — International Data Collection Guidelines: High-level summary

Elements	Recommendations
Sampling Approach	Census collection of all patients undergoing hip and knee arthroplasty
Survey Time Points	Pre-operatively: Up to 8 weeks Post-operatively: 12 months after surgery (acceptable window is 9 to 18 months)
Collection Methods	Electronic collection (gold standard); paper collection as neededold /SpanMf 9 0e (en-US)/MCID colle

Elements		Recommendations
Single-item questions	General Health	Question: In general, would you say your health is . . . Responses: Excellent; Very Good; Good; Fair; Poor
	Satisfaction	Question: + R Z V D W L V ¿ H G D U H \ R X Z L W K W K H U H V X O W V R I \ R X U [right/left] [hip/knee] replacement? Responses: 9 H U \ ' L V V D W L V ¿ H G ' L V V D W L V ¿ H G 1 H X W U D O 6 D W L V
	Pain For programs not using OHS/OKS	Question: During the past 4 weeks, how would you describe the pain you usually have in your [right/left] [hip/knee]? Responses: None; Very Mild; Mild; Moderate; Severe
	Physical Function For programs not using OHS/OKS	Question: For how long have you been able to walk before pain from your [hip/knee] becomes severe (with or without a cane)? Responses: No pain/more than 30 minutes; 16–30 min; 5–15 min; Around the house only; Not at all/pain severe when walking
Patient Information		• Birthdate • Sex • 8 Q L T X H 3 D W L H Q W , G H Q W L ¿ H U
Survey Administration		• 6 X U Y H \ 5 H F R U G , G H Q W L ¿ H U • Survey Date • Survey Time Point (Pre-Operative, Post-Operative) • Survey Mode • Language
Clinical Information		• Surgery Date • Joint Type (Hip, Knee) • Joint Side (Right, Left, Bilateral) • Extent of Replacement (Total, Partial) • Type of Replacement (Primary, Revision) • Urgency of Surgery (Emergent, Elective) • Principal Diagnosis • 6 X U J H R Q , G H Q W L ¿ H U •) D F L O L W \ , G H Q W L ¿ H U • Body Mass Index • Comorbidity Collection [e.g., individual comorbidity diagnoses, ASA Physical 6 W D W X V & O D V V L ¿ F D W L R Q @

Parameters for data collection

The parameters for data collection include recommendations on sampling approaches, survey time points, collection methods and the patient population for international comparative reporting.

Sampling Approach

PROMs can be administered to the entire patient population or to a sample of patients;

Survey Time Points

PROMs surveys can be collected from patients at multiple time points during the care path; collection time points will vary according to the purpose of collection. The following UHFRPPHQGDWLRQ DOORZV IRU FRPSDUDEOH UHSRUWLQJ RI WK and rehabilitation.

International guideline

- Pre-operatively: Up to 8 weeks
- Post-operatively: 12 months after surgery (acceptable window is 9 to 18 months)

Rationale

- This recommendation aligns with the International Society of Arthroplasty Registries (ISAR) recommendations. Pre-operatively, this allows for a stable assessment of patient pain, function and mobility prior to surgery. Post-operatively, full recovery is generally achieved at 12 months after surgery and is the optimal time to assess outcomes.

Local considerations

Given that osteoarthritis is a chronic condition, a longer pre-operative time frame may be accepted; however, time frames that are too long will not adequately account for changes that could occur between pre-operative survey completion and surgery, which could impact the true assessment of pre–post change.

Some programmes have opted for a 6-month post-op collection instead of 12 months. However, given that patients may still be recovering at 6 months, a 12-month post-op time point collection enables more robust comparisons of health outcomes across programmes of patients at full recovery. For the purpose of international reporting, if 12-month post-operative collection is not available, a 6-month collection time point will be reported.

Survey collection at other time points may be added depending on other programme goals DQG FOLQLFDO ZRUNÀRZ DW WKH ORFDO OHYHO H J PRQLWRU evaluation of wait time impact or long-term outcomes; screening tool for surgical versus non-surgical approaches).

Patient Population

Minimum data set

A minimum data set includes the recommended PROMs instruments, single-item questions, and patient, clinical and survey administration information required for reporting purposes.

PROMs instruments

The general recommendation is that

Among large-scale national-level hip and knee replacement PROMs initiatives underway at WKH WLPH RI ZULWLQJ WKH (4 ' LV WKH PRVW FRPPRQO\ XVHG RI ERWK EHLQJ YHU\ VKRUW DQG EHLQJ DEOH WR SURGXFH 4$/<

Considerations

Annex 1 shows the commonly adopted PROMs instruments that were considered by the Working Group. Both the OHS/OKS and the HOOS/KOOS instruments are valid

International guideline

- Four single-item questions are recommended for collection, in addition to the generic and condition-specific instruments:

Domain	Collection time point(s)	Question	Response options
General Health	Pre-op and post-op	In general, would you say your health is . . .	Excellent; Very Good; Good; Fair; Poor
Satisfaction	Post-op only	,}Á•Ÿ•. Œ Ç}µŒÇ]••Ÿ•. V with the results of your]••Ÿ•. V E µšŒ oV €Œ]PZšlo L•€Z]‰llŸv•.•V sŒÇ^Ÿ•. replacement?	
Pain	Pre-op and post-op, for programmes not already using OHS/OKS	During the past 4 weeks, how would you describe the pain you usually have in Ç}µŒ €Œ]PZšlo L•€Z]‰llv •M	None; Very Mild; Mild; Moderate; Severe
Physical Function	Pre-op and post-op, for programmes not already using OHS/OKS	For how long have you been able to walk before ‰]v (Œ}u Ç}µŒ becomes severe (with or without a cane)?	No pain/more than 30 minutes; 16–30 min; 5–15 min; Around the house only; Not at all/pain severe when walking

Rationale

- These questions represent important domains of patients' health in which improvements are expected after arthroplasty. The pain and satisfaction questions are recommended by ISAR (Rolfson et al., 2011); a question on general health is commonly included in patient-reported health surveys.

Local considerations

In addition to the single-item questions outlined above, programmes may wish to collect other questions that are valuable in understanding variation in results. For example, the two questions Did you complete a supervised exercise program prior to surgery? and Did you complete a supervised rehabilitation program after your surgery? are important JLYHQ WKDW FRQVHUYDWLYH FDUH LV WKH ¿UVW OLQH RI WUHD and may provide context for surgical appropriateness pre-operatively, and given that both pre-operative and post-operative exercise therapy are essential for achieving optimal results after surgery.

International guideline

- Three data elements are recommended for collection within the minimum data set:
  - Birthdate
  - Sex
  - Unique Patient Identifier

Survey Administration

Information on survey administration is ideally populated through automated processes. Survey information is required to distinguish and link multiple surveys completed by unique patients.

International guideline

- Five data elements are recommended for collection within the minimum data set:
  - Survey Record Identifier
  - Survey Date
  - Survey Time Point (Pre-Operative, Post-Operative)
  - Survey Mode
  - Language

Rationale

- Required for reporting and linkage purposes (including interpretation and understanding of the data)

Local considerations

Programmes may wish to collect additional information required for local needs, which may add context to the patient's situation or could be used for risk-adjustment locally (e.g., required assistance to complete survey, use of translator).

International guideline

- These data elements are recommended for collection within the minimum data set:
  - Surgery Date
  - Joint Type (Hip, Knee)
  - Joint Side (Right, Left, Bilateral)
  - Extent of Replacement (Total, Partial)
  - Type of Replacement (Primary, Revision)
  - Urgency of Surgery (Emergent, Elective)
  - Principal Diagnosis
  - Surgeon Identifier
  - [illegible] set:

Anesthesiologists, 2014), which can alternatively be used to adjust for patient's health status. The best choice between these options for collecting or linking to this type of comorbidity

Key considerations include the following:

- Engagement from a broad range of stakeholders throughout PROMs implementation

Purpose of collection

When developing a PROMs initiative, the purpose of the PROMs programme and how the data will be used should be established (see Table 1), as this will inform other critical aspects of collection. For example, the selection of a PROMs instrument includes making decisions about what is to be measured (e.g., which domains and for what purpose) — some instruments DUH EHWWHU VXLWHG WR SURGXFH XWLOLW\ PHDVXUHV IRU FRV WKDW SURGXFH SUR¿OH RU QRUPDWLYH VFRUHV PD\ EH PRUH L DQG KHDOWK VHUYLFHV PRQLWRULQJ 8VHV RI 3520V GDWD ZLO DGPLQLVWUDWLRQ RI WKH 3520V SURJUDP7°{DERXW WK»3 P? À€P

Administration, data collection, resources and infrastructure

Implementing a sustainable PROMs programme requires minimising the impact to clinical
ZRUNÀRZ UHGXFLQJ SDWLHQW DQG SURYLGHU EXUGHQ DQG UH
FROOHFWLRQ ² DOO ZKLOH PD[LPLVLQJ WKH EHQH¿WV RI WKH 3

7R PD[LPLVH WKH EHQH¿WV RI HOHFWURQLF FROOHFWLRQ HQV
access, auto-population of information and linkage to other data sources is key. International standards for health care coding exist and can be used to ensure system interoperability
H J +/)+,5 6WD‡ EXUGHQ LV DOVR DQ LPSRUWDQW FRQVLG
collection is chosen, resources for collection and data entry need to be accounted for.
$GGLWLRQDOO\ VWXGLHV KDYH VKRZQ VLJQL¿FDQW DFTXLHVFH
collection; therefore, patient-coded methods are preferred (Cabitza and Dui, 2019).

Survey time points

While PROMs surveys can be collected from patients at multiple time points during the
FDUH SDWK EXUGHQ WR VWD‡ DQG SDWLHQWV VKRXOG EH FRQ
should be selected carefully. Typically, PROMs for hip and knee replacements are collected both pre- and post-operatively at a time when full recovery is expected (e.g., 12 months
SRVW RSHUDWLYHO\ LQ RUGHU WR DGHTXDWHO\ DVVHVV KHDO
to these time points, programmes may choose to collect PROMs at additional times to meet local information needs. For example, in Sweden, post-surgical data is collected at 1, 6 and 10 years to allow evaluation of long-term outcomes (Rolfson et al., 2011), while some programmes collect sooner or more frequently after surgery to monitor outcomes during recovery in order to identify options to provide more comfortable recovery to patients. Mechanisms need to be in place to trigger the collection and follow-up, especially if patients are not seen in clinic at these time points. Electronic platforms are perhaps the
PRVW FRVW H‡HFWLYH IRU WKLV SXUSRVH DV DXWRPDWHG HPD
LQWR WKH V\VWHP ,I PHDVXULQJ H‡HFWLYHQHVV RI KHDOWK V
WKH 3520V SURJUDPPH H‡HFWLYH IROORZ XS ZLOO EH D NH\ V
good mechanism to ensure adequate follow-up and a high response rate is imperative.

Resources and infrastructure for implementation and ongoing collection

$ FRPPRQ DSSURDFK IRU 3520V FROOHFWLRQ FDQ EH H[FLHQW
GRZQVWUHDP EHQH¿WV ² WKLV UHTXLUHV VXEVWDQWLDO SODQ
deployment. Assessment of existing infrastructure for programme needs is imperative in order to determine where there is need to update or build new infrastructure. Mapping out
WKH FOLQLFDO ZRUNÀRZ DQG H[SHFWHG 3520V GDWD ÀRZ H J
GDWD ÀRZV DFFHVV SRLQWV LV UHFRPPHQGHG GXULQJ WKH S
implementation plans meet the needs of the programme. It is important to consider IT requirements for integration and system interoperability, which account for data collection and reporting needs, and can also reduce patient and provider burden. Accounting for resources for ongoing collection and patient follow-up is also vital for a successful and sustainable programme. Electronic follow-up may be more successful when emails are

Data governance and utilisation

Data storage, management, governance and use are important aspects to consider while planning a PROMs programme. Data governance plays an important role in management, data quality, access and security, and advancement. Strong data governance principles HQVXUH FRQVLVWHQF\ XVDELOLW\ DQG UHXVDELOLW\ PD[LPLV costs; and simplify activities for analysis and reporting (OECD, OECD/LEGAL/0433).

Reporting and benchmarking

PROMs reports may be developed for local use as well as for broader national and international comparisons and benchmarking. For example, aggregate reports may be provided to patients to help set expectations or make decisions on treatment options, or reporting may be used to compare outcomes across the health system (including at the facility, regional and national/international levels) to identify best practices and drive quality improvement. In developing measures and reports, input from stakeholders is imperative to ensure they are relevant and actionable for clinical use and health system evaluation.

The OECD routinely reports internationally comparable indicators to support health system performance. To ensure international comparability of PROMs measures, the PaRIS Working Group for Hip and Knee Replacement Surgery, composed of interested stakeholders from the international community, agreed on indicators for international reporting.

For the OECD's Health at a Glance 2019 publication, the indicators generated from patient-reported measures for hip and knee replacement focussed on the change between SUH DQG SRVW RSHUDWLYH VFRUHV RI JHQHULF DQG VSHFL¿F sex and pre-operative score. Comorbidities were not included in risk-adjustment due to the challenges of collecting this information across programmes at the time; however, use of ASA 3K\VLFDO 6WDWXV &ODVVL¿FDWLRQ RU &KDUOVRQ ,QGH[PD\ EH programmes integrate this into their information systems.

While international comparisons are currently limited to between programmes collecting the same tool, or to those where crosswalks are available, alignment to the international set of common standards has the potential to make international PROMs data more fully comparable and robust.

As PROMs data collection matures and evolves, the implications for these advances could be substantial for local, national and international programmes, particularly for well-established initiatives. The OECD willd etTType 9inal and international programmes, particularl4]TJ

Characteristic	EQ-5D	VR-12	SF-12	PROMIS-10 Global Health
Website	www.euroqol.org	www.bu.edu/sph/research/research-landing-page/vr-36-vr-12-and-vr-6d/		

Table 5 Condition-specific instruments considered by the Working Group

Characteristic	OHS/OKS (international guideline recommendation)	HOOS/KOOS	WOMAC
Description	The Oxford Hip Score (OHS) and Oxford Knee Score (OKS) were developed to assess function and pain after hip and knee replacement surgery. The surveys are owned, managed and supported by Isis Outcomes, an activity within Isis Innovation Ltd., the Technology Transfer Company for the University of Oxford.	The Hip Disability and Osteoarthritis Outcome Score (HOOS) and Knee Injury and Osteoarthritis Outcome Score (KOOS) were developed to assess patient relevant outcomes in patients with hip and knee osteoarthritis: pain, other symptoms, function in daily living, function in sport and recreation, and joint-related quality of life. The Physical Function (HOOS-PS/KOOS-PS) and Joint Replacement (HOOS-JR/KOOS-JR) short forms are also available for use. A 12-item short form (HOOS-12/KOOS-12) has also been made available as of 2019.	The Western Ontario and McMaster Universities Osteoarthritis Index (WOMAC) is a questionnaire developed to assess health status and patient relevant outcomes in function in patients with hip and/or knee osteoarthritis.
Intended use	Hip/knee replacement surgery	Hip disability or osteoarthritis/knee injury or osteoarthritis	Hip/knee osteoarthritis
Length	OHS: 12 items OKS: 12 items	HOOS: 40 items KOOS: 42 items	24 items
Website	innovation.ox.ac.uk/outcome-measures/oxford-hip-score-ohs/ https://innovation.ox.ac.uk/outcome-measures/oxford-knee-score-oks/	www.koos.nu/	www.womac.org/womac/index.htm
Licensing and fee information	Licence required Non-commercial use: free Commercial uses: Fees vary based on project Fee may apply for review of digital versions and support materials	Licence not required Free to use	Licence required Costs depend on project

Annex 2: PROMs instruments used for hip and knee replacement surgeries internationally

		Condition-specific instruments			Generic instruments			
Country	Organisation	OHS/OKS	HOOS/KOOS (available in full, PS short form, JR short form and 12-item short form versions)	WOMAC	EQ-5D (available in 3L and 5L versions)	VR-12	PROMIS-10 Global Health	SF-12 (available in versions 1 and 2)
Australia	Australian Orthopaedic Association National Joint Replacement Registry (AOANJRR)	—	—	—	X (5L)	—	—	—
Canada	Canadian Joint Replacement Registry	X	—	X (Alberta only)	X (5L)	—	—	—
Finland	Coxa Hospital for Joint Replacement	X	—	—	—	—	—	—
Ireland	Irish National Orthopaedic Register (INOR)	X	—	—	X (5L)	—	—	—
Italy	Rizzoli Orthopaedic Institute	—	X (PS short form version)	—	X (3L)	—	—	—
	IRCCS Galeazzi Institute	—	X (full version)	—	—	—	—	X (v1)

Country	Organisation	Condition-specific instruments			Generic instruments			

Resources and infrastructure

Are the resources required to implement a sustainable PROMs programme available (e.g., financial, personnel costs, implementation of electronic platform)?

What IT infrastructures are required to support PROMs collection and access to data (e.g., for patients, clinicians, analysts, decision-makers)?

Are the systems interoperable (e.g., can the systems be linked to existing medical records, patient portals, administrative or registry data)?

What practices are in place to reduce patient and administrator burden?

Privacy and legal

What are the privacy legislations that govern collection, storage, sharing and reporting of patient data, including personal health information, in your jurisdiction/country? Were privacy specialists consulted?

What type of consent is required from patients/providers for collection and sharing of data for specified purposes of PROMs programmes, including within and across countries?

What privacy and security protocols are in place to comply with these policies or potential requests for data?

PROMs instruments

Are the selected instruments available in the languages spoken by the patient population? Have the instruments been validated in appropriate cultural contexts?

Are licences required for the selected instruments? Are the terms of use acceptable? Have you accounted for any associated fees (e.g., review of electronic versions, end-user fees)?

Managing and using data

How will data be managed and governed?

Are practical plans in place for the use of data once collected? How will key learnings be addressed?

How will success be measured?

Annex 4: Text alternatives for figures

Figure 1: Considerations for implementation and data collection

There are interconnected considerations for PROMs implementation and data collection:

- Stakeholder engagement
- Purpose of PROMs data collection
- Resources and infrastructure
- Administration and data collection
- Data governance and utilisation
- Privacy and legal implications

Stakeholder engagement

3DWLHQWV FOLQLFLDQV DGPLQLVWUDWLYH VWD‡ KHDOWK V\V
organisations should be consulted on the purpose of PROMs data collection, resources and infrastructure, administration and data collection, data governance and utilisation, and privacy and legal implications.

3XUSRVH RI 3520V GDWD FROOHFWLRQ

Purpose of PROMs data collection may include health system performance monitoring and quality improvement; programme management, planning and evaluation; clinical decision-making and improved patient–provider communication; and/or comparative- and cost-
H‡HFWLYHQHVV DQDO\VLV

Resources and infrastructure

Resources and infrastructure considerations include implementation and operational costs, IT infrastructure, reduction of patient and administrative burden, system interoperability and data linkage, and mode of administration and follow-up.

Administration and data collection

Administration and data collection considerations include selection of PROMs instruments and associated licensing requirements, sampling approach, collection method and time points, and minimum data set (including survey, clinical and case-mix information).

Data governance and utilisation

Data governance and utilisation considerations include management of data; integration with electronic medical records, patient portals, and administrative and registry data; access to data; and reporting mechanisms and use.

Privacy and legal implications

Privacy and legal considerations include privacy legislation for data collection, storage, sharing and use; patient and provider consent; and privacy and legal considerations for data linkage.

Figure 2: Purpose of collection and collection time points

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