



PROMs

OECD Patient-Reported Indicator Surveys (PaRIS) Initiative

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

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## International Data Collection Guidelines

The opinions expressed and arguments employed herein do not necessarily reflect the official views of the OECD member countries.

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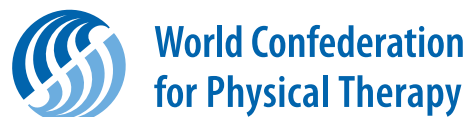
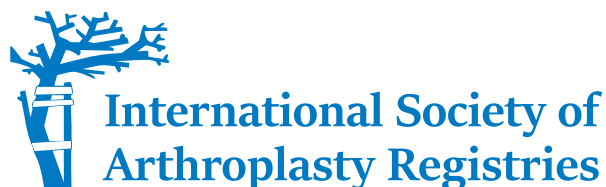
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# Endorsements

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 health ministers asked the OECD Secretariat to lead efforts in establishing comparative measures of patients' experiences and outcomes of medical care. This mandate follows the recommendations of the High-Level Reflection Group on Health Statistics (HLRG), convened by the OECD Health Committee in 2015. The final report of the HLRG in 2017 addressed the need for more information on patient-reported experiences and outcomes of care to better monitor health system performance and drive continuous improvement (OECD, 2017).

The OECD Health Committee, the overarching body of the OECD's health-related activities, is working to fulfill this mandate through the **Patient-Reported Indicator Surveys (PaRIS)** initiative. The goal of this initiative is to address critical information gaps and to develop international benchmarks of health system performance as reported by patients themselves. PaRIS comprises two work streams:

1. To support countries in the adoption and reporting of patient-reported indicators in specific clinical areas: **hip and knee replacement**, breast cancer care and mental health. This work stream is guided by the Health Care Quality and Outcomes (HCQO) Working Party, whose mandate includes the development and reporting of indicators for international comparisons of health care quality; the HCQO Working Party reports to the OECD Health Committee.
2. To develop a new international survey based on the need to understand the outcomes and experiences of patients with complex needs. The survey will be of patients receiving primary health care services who have one or more long-term conditions. The OECD Health Committee oversees this work stream.

To progress the *first work stream*, working groups for each clinical area were established to advise the HCQO Working Party on the development, collection and reporting of patient-reported indicators.

The **Working Group on Patient-Reported Indicators for Hip and Knee Replacement Surgery** mandate included developing indicators based on patient-reported outcome measures (PROMs) data, and promoting a consistent approach to PROMs data collection in order to maximise comparable reporting across OECD countries. Indicators based on pilot data from eight volunteer countries were developed and tested in 2018–2019, and published in *Health at a Glance 2019* (OECD, 2019).

This document is the second deliverable of the Working Group with the aim to provide a set of international guidelines to accelerate and align PROMs data collection in hip and knee replacement procedures in OECD member and partner countries. It intends to serve as a resource for those interested in collecting PROMs both for local needs and for international comparative reporting.

This document is the result of collaboration between the Canadian Institute for Health Information (CIHI), the OECD Health Division and the PaRIS Working Group for Hip and Knee Replacement Surgery.

# 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 for the preparation of these guidelines, as well as developing the data submission specifications 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.

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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 will really improve their circumstances, which they define as a better social and family life, less dependence on formal or informal care, and improvement in their ability to do (previous) work (paid, voluntary, office based or self-employed). In short, did the treatment ensure 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. Creating a uniform tool to collect this data in different countries will allow us all to better distinguish the differences in the way health care is provided, the problems or gaps — and the 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 all stages of research, design and implementation will benefit all stakeholders.

In a constantly changing environment, we need to keep adapting our approach and to keep the information updated and relevant. Only in this way can we achieve the worthwhile goal of improving patients’ health and QoL as they themselves define it.

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# 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 a difference to patients' health and quality of life, providing insight on the effectiveness 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 by different stakeholders.

**Table 1** Uses of PROMs

Stakeholder	Uses
<b>Health system policy-makers/ system managers</b>	<ul style="list-style-type: none"> <li>• Compare outcomes locally, nationally, internationally and over time.</li> <li>• Identify variations in quality of care and leaders in best practice for mutual learning.</li> <li>• Evaluate and drive quality improvement initiatives.</li> <li>• Compare different care models and clinical pathways for outcome analysis.</li> <li>• Support health service allocation decisions informed by the relative cost of achieving desired outcome states (“value-based care”).</li> <li>• Inform health services programming, planning and policies.</li> </ul>
<b>Health care organizations</b>	<ul style="list-style-type: none"> <li>• Monitor organization and provider performance; compare with peer organizations; identify organizations with high outcome scores for engagement and learning opportunities.</li> <li>• Identify and engage providers who would benefit from further support.</li> </ul>
<b>Health care providers</b>	<ul style="list-style-type: none"> <li>• Direct feedback can be used to modify the care path and provide evidence toward improving or maintaining a high level of care.</li> <li>• Support improved clinician–patient communication and raise awareness of problems that would otherwise be unidentified.</li> <li>• Facilitate performance comparisons and quality improvement initiatives.</li> </ul>
<b>Patients</b>	<ul style="list-style-type: none"> <li>• Provide opportunity for patients to provide input from their perspective and to be more aware of expected outcomes and how they compare.</li> <li>• Provide opportunity for patients to provide feedback independent of their provider’s view; potentially identify themselves as having a less-than-satisfactory outcome.</li> <li>• Enhance communication with care providers; improve patient involvement in care planning and decision-making; flag potential issues to providers that may require modification of their treatment plan.</li> </ul>

**Source**

Adapted from Canadian Institute for Health Information. [PROMs Background Document](#). 2015.

Many PROMs instruments have been developed to evaluate the impact of treatments and services. Most of the instruments developed are multidimensional in that they measure various domains of health, including symptoms, functional status, and psychological and social well-being. They are categorised as generic (can be applied across different populations) or condition-specific (used to assess outcomes that are unique to particular health conditions, organs or body regions). Table 2 compares the characteristics of the two types of PROMs instruments widely in use for patients undergoing hip and knee replacement surgery.

**Table 2** Characteristics of PROMs instruments

Generic PROMs	Condition-specific PROMs
<ul style="list-style-type: none"> <li>• Facilitate comparisons across different patient populations and across health sectors</li> <li>• Can be used to compare against general population norms</li> <li>• Some produce utility scores that can be used to calculate quality-adjusted life years (QALYs) for cost-effectiveness analysis</li> <li>• Provide clinicians with a holistic view of the patient, to improve transitions across the continuum of care and flag areas that may require further attention</li> <li>• Examples: EQ-5D, PROMIS-10, SF instruments (see <a href="#">Annex 1</a> for more information on these instruments)</li> </ul>	<ul style="list-style-type: none"> <li>• Designed to assess outcomes that are unique to particular diseases or sectors of care</li> <li>• Tend to be more sensitive in detecting change over time and differences between groups of people who have the same condition</li> <li>• Provide more detailed information that is relevant to the practice of clinicians and patients themselves</li> <li>• Typically do not produce utility scores</li> <li>• Do not readily facilitate the comparison of health outcomes with those of the general population or across different clinical areas</li> <li>• Examples of hip and knee arthroplasty PROMs instruments: HOOS/KOOS, OHS/OKS, WOMAC (see <a href="#">Annex 1</a> for more information on these instruments)</li> </ul>

The OECD identified hip and knee replacement surgery as a clinical area of focus for the PaRIS initiative for the following reasons:

- Hip and knee replacement surgeries are aimed at improving patients' pain, functioning and overall quality of life; thus understanding the patient's perspective is imperative.
- A high number of patients undergo these surgeries, resulting in substantial costs to health systems. Trends in several countries expect an increase (Culliford et al., 2015; Nemes et al., 2015; Inacio et al., 2017); thus they are an ideal target for health system improvement.
- Many countries have data collection infrastructure already in place for this clinical area (Rolfson et al., 2011), and a number of countries have existing PROMs programmes or have expressed interest in PROMs implementation for hip and knee replacement surgery.

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, facilities were able to use comparative reporting and examine resource allocation to optimise results for patients, demonstrating that PROMs data allows for a systematic method of measuring patients' views on the benefits of hip and knee replacement surgery, and supports improvements in health care delivery and value (Prodingler and Taylor, 2018).

While PROMs collection has demonstrated local and regional benefits, the existence of multiple concurrent initiatives using a disparate set of instruments hampers the opportunity for inter-jurisdictional comparison and mutual learning. A limited number of mapping algorithms between tools (or crosswalks) is available, and these algorithms do not cover the broad number of instruments used and add error through estimation of the mapped value. Therefore, consistent with other health information initiatives, taking a common approach to collecting and reporting PROMs data is seen as an efficient and effective way to support local and international comparisons to inform health system performance activities in areas such as quality, funding and patient-centred care.

## 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 for the benefit of mutual learning. 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 that reflect 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 pragmatic trade-offs — or balancing — between robustness and feasibility.
- The OECD should align its international data collection guidelines and processes with those preferred by countries, and make the process as easy as possible. Adherence and participation are strictly voluntary. Information collected and published by the OECD is intended to benefit member and partner countries, not vice versa. The guidelines and processes are intended to promote alignment between clinical, organisational and policy uses of PROMs data.

As the future landscape of PROMs evolves with new approaches, developing technologies and further research, these guidelines will be regularly updated and revised based on the science and practice of PROMs and their adoption in routine care, in order to continue to support international alignment and facilitate (i.e., not to impede) technological and academic progress.

# 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
<b>Sampling Approach</b>	Census collection of all patients undergoing hip and knee arthroplasty
<b>Survey Time Points</b>	<b>Pre-operatively:</b> Up to 8 weeks <b>Post-operatively:</b> 12 months after surgery (acceptable window is 9 to 18 months)
<b>Collection Methods</b>	Electronic collection (gold standard); paper collection as needed
<b>Patient Population</b>	<b>Target population for international reporting is as follows:</b> Total, primary, unilateral, elective hip or knee replacement, with osteoarthritis as the principal diagnosis; excludes patients with subsequent arthroplasty during the follow-up period (e.g., between initial surgery and post-operative survey completion) including revision and staged bilateral procedures
<b>Generic Instruments</b>	<i>No recommendation at this time (pending coordinated consensus among PaRIS clinical groups)</i>
<b>Condition-Specific Instruments</b>	Preferred instruments: Oxford Hip Score (OHS) and Oxford Knee Score (OKS) Alternative instruments: The Hip Disability and Osteoarthritis Outcome Score (HOOS) and Knee Injury and Osteoarthritis Outcome Score (KOOS) may be used if the OHS/OKS cannot be implemented due to local constraints.



Elements		Recommendations
Single-item questions	General Health	<b>Question:</b> In general, would you say your health is . . . <b>Responses:</b> Excellent; Very Good; Good; Fair; Poor
	Satisfaction	<b>Question:</b> How satisfied are you with the results of your [right/left] [hip/knee] replacement? <b>Responses:</b> Very Dissatisfied; Dissatisfied; Neutral; Satisfied; Very Satisfied
	Pain <i>For programs not using OHS/OKS</i>	<b>Question:</b> During the past 4 weeks, how would you describe the pain you usually have in your [right/left] [hip/knee]? <b>Responses:</b> None; Very Mild; Mild; Moderate; Severe
	Physical Function <i>For programs not using OHS/OKS</i>	<b>Question:</b> For how long have you been able to walk before pain from your [hip/knee] becomes severe (with or without a cane)? <b>Responses:</b> 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		<ul style="list-style-type: none"> <li>• Birthdate</li> <li>• Sex</li> <li>• Unique Patient Identifier</li> </ul>
Survey Administration		<ul style="list-style-type: none"> <li>• Survey Record Identifier</li> <li>• Survey Date</li> <li>• Survey Time Point (Pre-Operative, Post-Operative)</li> <li>• Survey Mode</li> <li>• Language</li> </ul>
Clinical Information		<ul style="list-style-type: none"> <li>• Surgery Date</li> <li>• Joint Type (Hip, Knee)</li> <li>• Joint Side (Right, Left, Bilateral)</li> <li>• Extent of Replacement (Total, Partial)</li> <li>• Type of Replacement (Primary, Revision)</li> <li>• Urgency of Surgery (Emergent, Elective)</li> <li>• Principal Diagnosis</li> <li>• Surgeon Identifier</li> <li>• Facility Identifier</li> <li>• Body Mass Index</li> <li>• Comorbidity Collection [e.g., individual comorbidity diagnoses, ASA Physical Status Classification]</li> </ul>

## 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; the method of sampling largely depends on the purposes and resources for data collection.

#### International guideline

- Census collection of all patients undergoing hip and knee arthroplasty

#### Rationale

- A census approach supports patient–provider communication for all patients, as well as patient involvement in decision-making — contributing to improved patient-centred care — and allows for more robust health system performance comparisons (e.g., full coverage/representation).

### Local considerations

While PROMs collected from all patients can be beneficial for clinical decision-making and patient–provider communication, depending on the goals of the programme, some may elect to sample patients in order to decrease costs — in this case, *stratified random sampling* should be used to ensure a representative sample and reduce bias in results. All relevant subgroups (e.g., urban/rural, high-/low-volume settings) and jurisdictions should be adequately represented; consultation with a statistician to determine adequate sample size for statistical inferences is recommended. At the onset, programmes may initiate collection regionally with plans to expand to national participation.

## 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 recommendation allows for comparable reporting of the overall effectiveness of surgery 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 and clinical workflow at the local level (e.g., monitoring during rehabilitation and recovery; evaluation of wait time impact or long-term outcomes; screening tool for surgical versus non-surgical approaches).

## Collection Methods

Possible modes of collection can include paper, telephone and electronic collection; the choice of collection mode will impact implementation, as well as a number of operational factors including burden to patients and administrative staff, timeliness, access and data quality.

### International guideline

- Electronic collection is recommended as the gold standard for PROMs collection. Paper collection should supplement electronic collection, to be used as needed — for example, to meet patient preferences.

### Rationale

- Compared with paper and telephone surveys, collecting PROMs electronically may be more efficient and effective in the long run and provides timelier access to information. Electronic PROMs reduce data collection and follow-up burden for staff and improve data quality; they also have the opportunity to reduce respondent burden (e.g., via computerised adaptive testing).

### Local considerations

While paper collection can contribute to staff burden and increased costs in the long term, it is often faster, easier and more inexpensive to implement; although not the preferred mode of collection, some programmes may choose to start with paper collection for these reasons.

## Patient Population

The patient population targeted for data collection will depend on the goals of the PROMs programme. The following guideline is developed specifically for international comparative reporting.

### International guideline

- Include patients undergoing *total* hip and knee replacement, as an *elective, primary, unilateral* procedure, with osteoarthritis as the principal diagnosis.
- Exclude patients with subsequent arthroplasty during the follow-up period (e.g., between initial surgery and post-operative survey completion) including revision and staged bilateral procedures.

### Rationale

- This is the most common type of surgery and ensures a homogenous group for the international comparisons.

### Local considerations

Consideration should be given to other programme purposes at the local level (e.g., informing clinical care and patient–provider communication; local planning and reporting needs; participation in other research programmes). Therefore, PROMs collection among other groups may be warranted for consideration (e.g., revision surgeries, bilateral surgeries, unicompartamental surgeries, non-osteoarthritis diagnoses). Ease of implementation into the clinical workflow may also be considered (e.g., collecting for all patients versus specific patients).

## 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 **both a generic and a condition-specific PROMs instrument** should be administered concurrently, as they provide complementary information and support different needs (see [Table 2](#)). Varying instruments have already been adopted across the globe. [Annex 1](#) shows the commonly adopted PROMs instruments for hip and knee arthroplasty patients. All instruments have displayed good psychometric properties (e.g., reliability, validity, responsiveness); however, all have also been shown to have some level of floor or ceiling effects, especially for patients who are high-functioning, thus reducing the potential for countries/programmes to document positive change in these patients (Dunbar et al., 2001; Ashby et al., 2008; Bryan et al., 2014; Collins et al., 2016).

There are differences across instruments in the extent to which different domains are represented by each tool's measurement; some instruments have advantages of being relatively short, but this may result in an instrument being less sensitive to the detection of change compared with longer PROMs instruments. Some instruments can produce QALYs so are especially suited for cost-effectiveness analysis. Selection of a PROMs tool must take into consideration the complete set of purposes of the PROMs programme.

## Generic Instruments

### International guideline

- While it is noted that the use of a generic tool is important for data collection and has value for comparisons with other clinical areas and populations, there is currently no recommendation for a specific generic tool. We expect that as the PaRIS initiative progresses, with a coordinated approach across all clinical areas in the selection of a tool, a recommendation will be provided in a future update.

### Rationale

- One of the benefits of generic instruments is that they enable comparisons across different health sectors and patient populations, and can also be used to compare against general population norms. The PaRIS initiative focusses on several clinical areas including hip and knee replacement surgery, breast cancer, mental health and adults living with one or more long-term conditions. A coordinated approach across all clinical areas in the selection of a standard generic tool would be most ideal in order to enable comparisons across groups. Further consideration and time are required in order to reach a consensus for generic instruments across the various PaRIS clinical groups.

### Considerations

It is recognised that there is currently strong momentum and interest across many OECD countries to initiate new PROMs programmes in order to enhance patient-centred care and drive quality improvement. Countries that are ready to implement PROMs collection should consider the current international landscape as well as needs at the local level in selecting the most appropriate generic tool for collection (see [Annex 1](#) and [Annex 2](#)). Consultation with local stakeholders is recommended when selecting a tool.

Among large-scale national-level hip and knee replacement PROMs initiatives underway at the time of writing, the EQ-5D is the most commonly used generic tool, as it has the benefits of both being very short and being able to produce QALYs for cost-effectiveness analysis if desired. It has been translated and validated in a large number of countries and is free for non-commercial use. Two versions of the EQ-5D exist: the 3L with three levels of response choices and the newer 5L with five levels of response choices. Evidence suggests that the 5L is more responsive than the 3L (Janssen et al., 2018); however, valuations for the 5L tool are currently less widely used. The EQ-5D (3L and 5L) has its own shortcomings due to its brevity, and it has also been criticised for its lack of responsiveness and narrow distributions across the spectrum, as it is unable to take a deep dive into specific domains of health (Payakachat et al., 2015). However, combined with the collection of a condition-specific instrument, the benefits of longer generic instruments may be minimised, since questions tend to be repeated between the two types of instruments. The EQ-5D tool requires a licence for its use, and therefore restrictions and burden surrounding the licensing also need to be considered.

While other alternative generic instruments are less widely used, various mapping algorithms (or crosswalks) from SF-12, VR-12 and PROMIS-10 to the EQ-5D have been published in the literature and are currently available (Sullivan et al., 2006; Revicki et al., 2009; Van Hout et al., 2012; Le, 2014; Schalet et al., 2015). However, these algorithms typically offer specific, delimited solutions. For example, they may map to only a particular version of EQ-5D (most map to the 3L measure), and while some map to health states, others map to only specific country valuations (e.g., U.K.-only or U.S.-only value sets). Thus the use of these crosswalks helps establish a common comparison metric but offers a limited solution set for the types of international comparisons that can be made. Crosswalks also compound the error of score estimates, as they incorporate error from the original measure and the resultant measure. For these reasons, alignment on the use of one tool is recommended, with crosswalks to be used only when alignment cannot be achieved. In comparison with other generic instruments in use, the PROMIS-10 and VR-12 have a more limited selection of languages available and (along with the SF-12) cannot directly generate a utility score (e.g., for QALYs); however, these instruments do not require a licence for their use. PROMs instruments are continually evolving; newer instruments such as the PROMIS-Preferences (PROPr) can generate QALYs and provide more depth of information compared with the EQ-5D (Hammer et al., 2018); however, this instrument is much longer in length compared with generic instruments currently in use among this population.



## Condition-Specific Instruments

### International guideline

- The Oxford Hip Score (OHS) and Oxford Knee Score (OKS) are the recommended condition-specific instruments for collection.
- If the OHS/OKS instruments cannot be implemented due to local constraints, the Hip Disability and Osteoarthritis Outcome Score and Knee Injury and Osteoarthritis Outcome Score (HOOS/KOOS) instruments may be used; however, this will limit comparability across countries.
- Consultation with local stakeholders is recommended when selecting a tool.

### Rationale

- The OHS/OKS instruments are the most commonly used condition-specific instruments for routine collection of PROMs in hip and knee arthroplasty in national and regional programmes; these instruments are preferred as they are short and, while still applicable to the continuum of osteoarthritis, are designed specifically for patients with hip and knee arthroplasty. At the time of writing, the Oxford set of instruments requires a licence for use, but they are currently free for non-commercial users (fees for review of electronic versions may apply).
- After the OHS/OKS, the HOOS/KOOS instruments are the next most commonly used; they are non-proprietary, and at the time of writing these instruments do not require a licence for use.

## 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 instruments and have a strong legacy of use within this population. However, for international comparisons, translation of results onto one metric is required — for example, through the use of a crosswalk algorithm — if alignment on one tool cannot be achieved. Currently, no validated crosswalks exist to convert results across condition-specific instruments onto one scale — this prevents international comparisons across different instruments. The PaRIS initiative aspires to stimulate research in this field in order to improve international comparisons, for example, with the development of a crosswalk for these condition-specific instruments. These guidelines may be considered as an interim approach until further research is conducted to improve international comparability and/or alignment initiatives and PROMs tool adoption tilts usage in favour of one specific instrument.

Note that for the HOOS/KOOS instrument, shorter versions such as the HOOS-PS/KOOS-PS (Physical Function), the HOOS-JR/KOOS-JR (Joint Replacement) and the new HOOS-12/KOOS-12 (developed and available as of May 2019), and the Western Ontario and McMaster Universities Osteoarthritis Index (WOMAC) are available; however, these shorter versions are not as widely used. Additionally, the PS version is a physical function assessment and does not include any questions for pain. The full HOOS/KOOS measures 5 health domains; results are not generally summarised into one total or overall score. The shorter HOOS-PS/KOOS-PS, HOOS-JR/KOOS-JR, HOOS-12/KOOS-12 and WOMAC can be scored from the full version of the HOOS/KOOS instrument; however, scores generated from these short versions are not directly comparable with each other. Collecting using the full version of the HOOS/KOOS allows for more flexibility on the metric used for reporting.

Given the selection of countries participating in *Health at a Glance 2019*, the HOOS-PS/KOOS-PS was used for 2019 reporting (in addition to OHS/OKS); however, this could change from year to year depending on programme participation. For example, among programmes that are collecting HOOS-/KOOS-based instruments, if most are collecting the full version of the HOOS/KOOS and a handful are collecting shorter versions, these programmes will be reported using the short version that is collected most widely, allowing for the maximum number of countries to be reported.

## Single-item questions

Single-item questions are informative at the local level, and they additionally allow for wider comparisons across programmes that are unable to align to the preferred tool. All programmes should collect the general health and satisfaction single-item questions. Programmes that are not already using OHS/OKS should also collect the pain and physical function questions.

## 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
<b>General Health</b>	Pre-op and post-op	In general, would you say your health is . . .	Excellent; Very Good; Good; Fair; Poor
<b>Satisfaction</b>	Post-op only	How satisfied are you with the results of your [right/left] [hip/knee] replacement?	Very Dissatisfied; Dissatisfied; Neutral; Satisfied; Very Satisfied
<b>Pain</b>	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 your [right/left] [hip/knee]?	None; Very Mild; Mild; Moderate; Severe
<b>Physical Function</b>	Pre-op and post-op, for programmes not already using OHS/OKS	For how long have you been able to walk before pain from your [hip/knee] 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 given that conservative care is the first line of treatment for hip and knee osteoarthritis 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.

## Patient Information

Patient information (e.g., demographics) can be completed by the patient or, ideally, obtained from administrative sources; if PROMs are collected electronically, considerations to auto-populate these fields can reduce the burden on patients and staff. A unique patient identifier is required to link patients, surgeries and surveys together, and may enable linkage of PROMs data to clinical administrative or registry data, thus allowing information to be captured through other sources. This will depend on maturity of the local information infrastructure, specifically the interoperability of data systems.

### International guideline

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

### Rationale

- Required for reporting purposes (e.g., inclusion/exclusion criteria, case-mix adjustment), as well as to enable linkage across multiple PROMs surveys (per patient) and to other sources of information, including administrative and registry data.

## Local considerations

In addition to the data elements for international use as outlined above, programmes may wish to collect other information required for their own local needs, which may add context to the patient's situation or could be used for risk-adjustment locally (e.g., living with others, socio-economic status).

Note that the OECD will only request aggregate-level data or, in rare circumstances, highly de-identified (non-linkable) record-level data to ensure ease of data sharing.

## 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).

## Clinical Information

Clinical information is ideally obtained through automated processes or data linkage — this may depend on the interoperability of systems.

### 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
  - Facility Identifier
  - Body Mass Index
  - Comorbidities Collection [individual comorbidity diagnoses, ASA Physical Status Classification — see considerations below]

### Rationale

- Required for reporting purposes (e.g., inclusion/exclusion criteria, stratification, case-mix adjustment, interpretation and understanding of the data)

## Considerations

**Comorbidities:** Collection of patient comorbidity information for the purposes of risk-adjustment is very important, particularly for interpretation of results across different providers and jurisdictions. Many programmes collect comorbidity information in the form of individual comorbidity diagnoses (with varying levels of detail), which enable risk-adjustment for individual comorbidities using multivariate analyses or using derived comorbidity information such as the Charlson Index score (Charlson et al., 1987). In the absence of comorbidity information or in addition, many programmes collect the American Society of Anesthesiologists (ASA) Physical Status Classification (American Society of

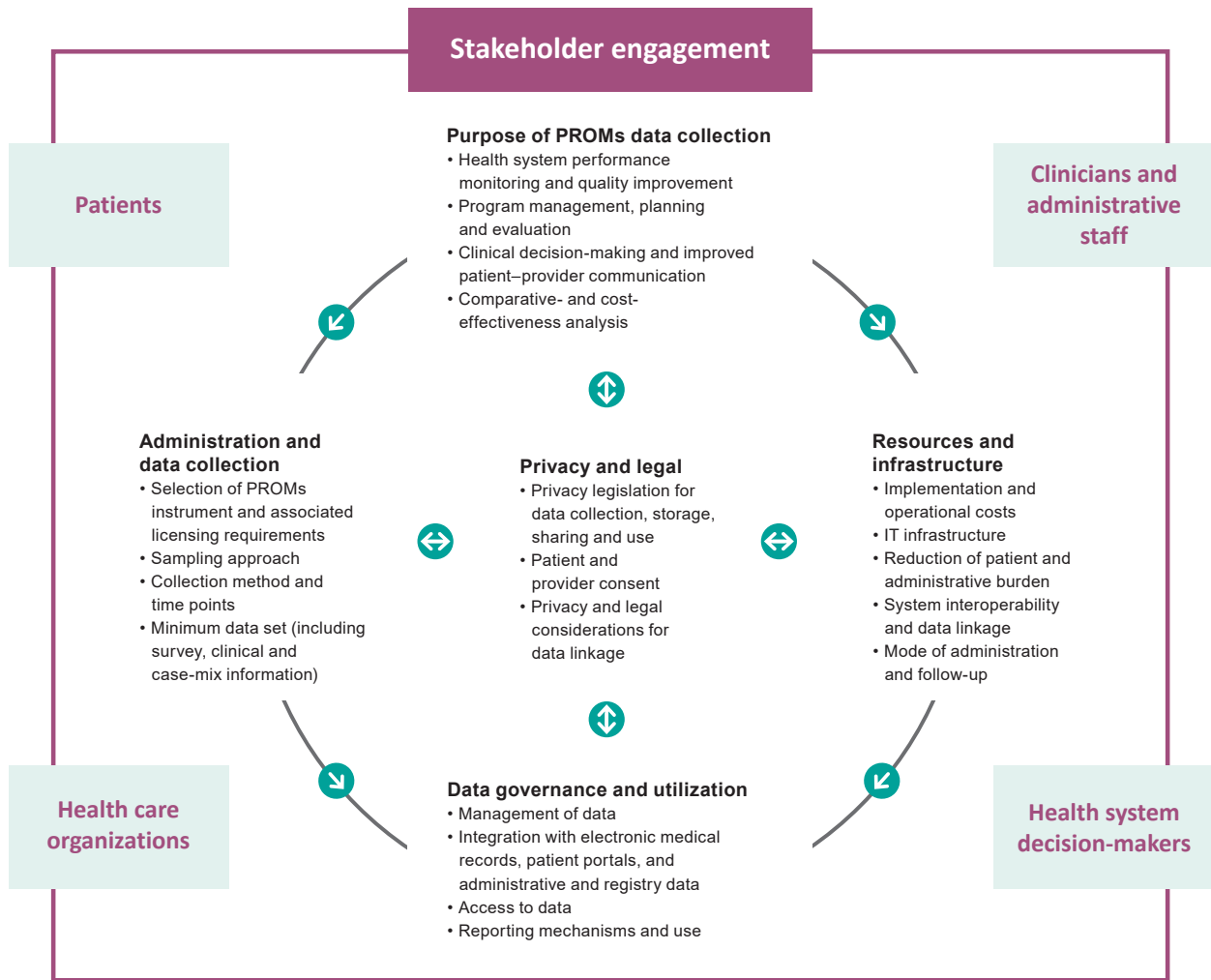
Anesthesiologists, 2014), which can alternatively be used to adjust for patient's health status. The best choice between these options for collecting or linking to this type of comorbidity information is currently unclear, and therefore there is currently no specific international recommendation for international comparable reporting purposes. Further research and development is required to determine the appropriate and feasible measurement of comorbidity for international comparisons.

**Other data elements:** Programmes may wish to also 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., smoking status, socio-economic status). Given the difficulties in collecting this additional information in a standardised way across international jurisdictions, this type of information is not planned for use at the international level.

# Considerations for PROMs implementation and data collection

The successful implementation of PROMs depends on a number of factors, as shown in Figure 1.

**Figure 1** Considerations for implementation and data collection





Key considerations include the following:

- Engagement from a broad range of stakeholders throughout PROMs implementation and data collection, to encourage participation and promote the value of PROMs
- Establishing a clear purpose for PROMs collection and how data will be used
- Administration of PROMs, including infrastructure and resources for collection
- Licensing requirements for the use of PROMs instruments
- Use of a data collection model that minimises data collection burden and maximises response rate, timeliness of data and data quality
- Awareness of privacy and security legislation related to how data can be collected from patients and shared for local and international reporting
- Agreement on common approaches for PROMs collection to enhance efficiencies, reduce overlap and ensure comparability of data for reporting and benchmarking

[Annex 3](#) provides the Implementation Preparedness Checklist outlining considerations for PROMs programme planning that may be used in conjunction with the guidelines presented in this document.

## Stakeholder engagement

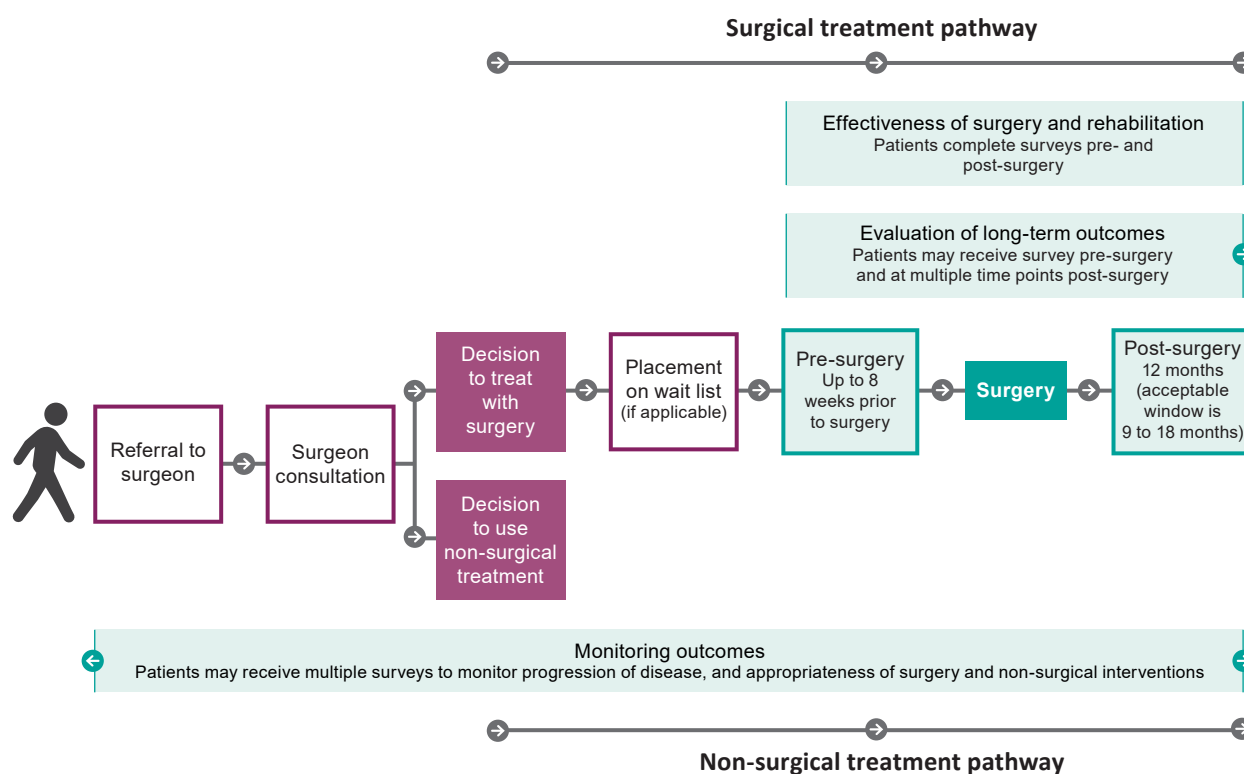
Stakeholder engagement involving support from multiple levels within the health system is critical in ensuring a successful broad-scale PROMs collection initiative, as shown in Figure 1. Successful implementation requires engagement from the clinical community (including administrators, such as nurse coordinators and clinic managers), patients and health system decision-makers. Support from clinical champions helps lead to buy-in from surgeons, the care team and patients, and promotes the value of PROMs in routine care (Chenok et al., 2016).

PROMs collection relies on participation from patients and clinical staff. Ideally, PROMs are integrated into the clinical workflow and viewed by the patient as part of their care process, both pre- and post-operatively. Support from policy-makers is necessary to ensure that the appropriate resources are available and that PROMs collection and use are recognised as a health system priority. It is recommended to engage all levels of stakeholders by helping them understand the added value of collecting PROMs, and to engage patients and clinical staff in developing materials to promote and educate patients, clinicians and health system decision-makers on the collection and use of PROMs information.

## 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 are better suited to produce utility measures for cost-effectiveness analysis, whereas instruments that produce profile or normative scores may be more informative for program evaluation and health services monitoring. Uses of PROMs data will also affect decisions about the administration of the PROMs programme. For example, measuring the effectiveness of surgery will require collection of PROMs information pre- and post-intervention, while screening for surgical appropriateness pre-operatively would require only pre-operative collection. Clinical monitoring during the rehabilitation process may require more frequent post-operative collection compared with measuring overall effectiveness of health system intervention or long-term outcomes. Figure 2 highlights how uses may influence decisions around survey administration.

**Figure 2** Purpose of collection and collection time points



For the purpose of international comparative reporting of surgical effectiveness and health system performance, the international guidelines outlined in the previous section of this document should be followed at a minimum.

## **Administration, data collection, resources and infrastructure**

Implementing a sustainable PROMs programme requires minimising the impact to clinical workflow, reducing patient and provider burden, and reducing resources required for data collection — all while maximising the benefits of the PROMs programme. A collective and coordinated approach across programmes can optimise the benefits.

### **Use of PROMs instruments**

While some instruments are non-proprietary and do not require a licence to use the tool, others do require a licence for their use. Among the latter, some charge a fee depending on the purpose of collection — in some cases, fees are not incurred if the collection is for non-profit use or routine care. Additionally, proprietary instruments may come with restrictions on their use, which should be considered. In cases where licensing and fees apply, it is important to develop a process to ensure smooth implementation and reduce burden to health care providers — for example, having a larger national body coordinate sub-licensing can alleviate burden from smaller regional organisations and health care facilities, and may also reduce end-user fees. See [Annex 1](#) for more information on licensing and costs.

Adoption of electronic platforms to collect the data can also incur additional charges for the review of screenshots for proprietary instruments; however, these fees are typically on a cost-recovery basis and are usually not cost-prohibitive. Language translations and country-specific validations are available in varying degrees for different PROMs instruments; before implementing a particular tool it is prudent to ensure that appropriate translations are available, and that the tool is validated in a suitable cultural context. For example, the wording of questions using English can have different meanings in European versus North American contexts. If suitable translations and validations are not available, programmes may want to consider having this work completed; as a first step, contacting the publishers of the tool will help to identify the translations and validations that have been completed.

### **Collection method**

Electronic collection of PROMs is often the more efficient, effective and advantageous form of survey administration compared with the use of paper or telephone surveys (De Faoite, 2018). The use of technology, such as web forms and mobile apps, has the potential to reduce data collection burden for staff and patients, and this often results in higher response rates, improved data quality and timelier access to data (Chenok et al., 2015). With adequate infrastructure, electronic PROMs can be integrated into a patient's electronic health record, providing access to care providers throughout the patient's continuum of care and allowing the data to be easily integrated with other administrative data sources for analysis. Integration of PROMs into the electronic health record also makes this data readily accessible to patients, improving patient–provider communication and informing medical decisions (Wagle, 2016).

To maximise the benefits of electronic collection, ensuring system interoperability for ease of 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 (e.g., HL7 FHIR). Staff burden is also an important consideration — if paper or telephone collection is chosen, resources for collection and data entry need to be accounted for. Additionally, studies have shown significant acquiescence bias for certain modes of 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 care path, burden to staff and patients should be considered, and therefore time points 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 post-operatively) in order to adequately assess health system effectiveness. In addition 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 most cost-effective for this purpose, as automated email reminders can be programmed into the system. If measuring effectiveness of health system intervention is important to the PROMs programme, effective follow-up will be a key success criterion; therefore, a good mechanism to ensure adequate follow-up and a high response rate is imperative.

## **Resources and infrastructure for implementation and ongoing collection**

A common approach for PROMs collection can be efficient and effective, and can optimise downstream benefits — this requires substantial planning, resources and appropriate 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 the clinical workflow and expected PROMs data flow (e.g., survey collection, data storage, data flows, access points) is recommended during the planning phase, in order to ensure 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

generated from a known entity (e.g., specific health care provider) rather than an unknown source (e.g., generic system email); thus patient education regarding the PROMs process is important. Additionally, considering infrastructure that allows for flexibility in how information is collected (e.g., computerised adaptive testing via electronic collection) has the potential to ease transition and enable changes in the future that are not cost-prohibitive.

## Data linkage

A common unique patient identifier will enable linkage to other data sources to support patient-centred and value-based care delivery; therefore, the infrastructure required for linkage to relevant clinical and administrative data should be considered when planning a PROMs programme. Relevant privacy legislation surrounding data linkage should also be considered. Data linkage serves two important purposes:

- It prevents having to collect additional data for descriptive analytical purposes; and
- It allows for case-mix adjustments based on available administrative data, which are recommended for obtaining meaningful comparisons across jurisdictions and care providers.

Additional information may need to be collected if the information is not available through linkage, as programmes may want to consider additional data elements (e.g., case-mix variables) for collection that may be deemed important for local needs. In order to minimise the burden of data collection on patients and clinicians, collection of additional information should be relevant for providing insight into the patient's health status, care and recovery. A balance is needed to ensure that relevant information is captured while patients do not feel overwhelmed with responding to multiple survey questions.

## Privacy and legal considerations

Privacy and legal considerations apply to any data collection initiative, but more notably for collection involving patient-reported data. Most countries and jurisdictions have established comprehensive privacy laws concerning personal health information. These laws are the primary source of legislative guidance for the collection, use and disclosure of personal health information in the context of PROMs. When implementing PROMs, ensure that local privacy and security requirements are met during collection and sharing of data. In general, sharing of data across international borders for OECD reporting typically requires sharing of aggregate-level data or, in rare circumstances, highly de-identified record-level data. On the whole, it is prudent to seek appropriate counsel (e.g., from the organisations or boards governing local data collection) to ensure requirements are met in the collection and sharing of PROMs data; to the extent possible, this should be done prior to data collection to ensure the potential for sharing upfront in order to make requests for data as smooth as possible.

## 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 ensure consistency, usability and reusability; maximise operational efficiencies; manage 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 pre- and post-operative scores of generic and specific instruments, standardised by age, 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 Physical Status Classification or Charlson Index may be a viable option in the future if more 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.

# PROMs data collection for hip and knee replacement surgery: Current and future states

As with any new data collection initiative — and in particular with patient-reported data — the implementation of a sustainable PROMs programme is complex and resource intensive and requires significant time, effort and funding. Many existing PROMs programmes for hip and knee replacement surgery are invested in the collection of legacy generic and condition-specific PROMs instruments to provide complementary information required to support a broad range of health system decision-making. However, new measurement approaches such as the use of item banks and computerised adaptive testing (CAT) have been developed and are increasingly being implemented in clinical settings, reflecting the dynamic and evolving landscape of PROMs.

Item banks provide opportunities to refine PROMs administration, increasing validity while decreasing patient burden in the number of questions that need to be asked. Questionnaires based on item response theory (IRT) item banks have several advantages over legacy PROMs instruments, including increased score precision, reduced floor and ceiling effects, and the ability to compare results from patients who were administered different short form versions of an item bank-based measure that are all scored on the same IRT scale (Terwee, 2018). Compared with legacy short forms, the use of CAT provides immense practical and measurement advantages.

Nevertheless, item banks are currently less frequently used in clinical practice compared with research settings. This could be because of initial infrastructure costs and implementation burden, technological needs, unfamiliarity with the approach and perceived difficulty of analysis of IRT-based data (Flynn et al., 2008). Continued preference for paper surveys, due to both ease of implementation and preferences among older patients, may continue to be a hindrance for CAT uptake. However, item bank-based measures, with options for fixed forms and CAT administration, are being included in the libraries of an expanding number of readily available electronic platforms (e.g., EPIC, REDCap), which has the potential to dramatically alter measure selection preferences and modes of administration. Given its numerous advantages, CAT assessment may become more prominent in routine care with further research and development in key clinical areas such as hip and knee arthroplasty, and as patients and technologies evolve.

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 will continue to facilitate international alignment to progressively strengthen patient-reported comparisons and support academic and technological progress. Monitoring and reporting on this topic area, as well as a potential transition plan that supports the use of legacy instruments and paper collection, may be the key in moving between the current and future states.

At this time, these guidelines reflect recommendations within the current context of PROMs collection, providing guidance to programmes wishing to align their approach to the current landscape, in order to enable comparisons and benefit from mutual learning. These guidelines aim to accelerate and align PROMs data collection for hip and knee replacement surgeries in a standardised and comparable way to enable robust international comparative reporting of patient-reported data, in order to better monitor health system performance and drive continuous improvement across OECD countries. As the future landscape of PROMs evolves, these guidelines will be reviewed and updated in order to continue to strengthen international alignment and support technological and academic progress.



# Annex 1: PROMs instruments

The tables below provide an overview of the generic and condition-specific PROMs instruments under consideration as part of the PaRIS initiative for hip and knee replacement surgery patients.

**Table 4** Generic instruments considered by the Working Group

Characteristic	EQ-5D	VR-12	SF-12	PROMIS-10 Global Health
<b>Description</b>	The EQ-5D is a widely used generic PROMs instrument developed by the EuroQoL Group. The EQ-5D contains 5 questions to produce a simple descriptive profile and a single index value for health status, as well as a visual analogue scale.  5 dimensions: mobility, self-care, usual activities, pain/discomfort, anxiety/depression  Can produce QALYs for cost-effectiveness analysis.	The Veterans Rand 12-item Health Survey (VR-12) was developed by the Veterans Health Administration. It measure eight domains including physical functioning and mental health. The eight scales can be summarised into separate physical and mental component scores.	The 12-item Short Form Health Survey (SF-12) was developed by the Medical Outcomes Study. It measure eight health domains about functional health and well-being. The survey can be summarised into separate physical and mental component summary scores.	The PROMIS-10 Global Health assessment was made available from the Patient-Reported Outcomes Measurement Information System (PROMIS) in 2004, and measures physical and mental health domains.
<b>Intended use</b>	Measures health-related quality of life	Measures health-related quality of life	Measures health-related quality of life	Measures health-related quality of life
<b>Length</b>	6 items	14 items	12 items	10 items

OECD Patient-Reported Indicator Surveys (PaRIS) Initiative: Patient-Reported Outcome Measures (PROMs)  
for Hip and Knee Replacement Surgery — International Data Collection Guidelines

Characteristic	EQ-5D	VR-12	SF-12	PROMIS-10 Global Health
<b>Website</b>	<a href="http://www.euroqol.org">www.euroqol.org</a>	<a href="http://www.bu.edu/sph/research/research-landing-page/vr-36-vr-12-and-vr-6d/">www.bu.edu/sph/research/research-landing-page/vr-36-vr-12-and-vr-6d/</a>	<a href="http://www.optum.com/solutions/life-sciences/answer-research/patient-insights/sf-health-surveys.html">www.optum.com/solutions/life-sciences/answer-research/patient-insights/sf-health-surveys.html</a>	<a href="http://www.healthmeasures.net/explore-measurement-systems/promis/intro-to-promis">www.healthmeasures.net/explore-measurement-systems/promis/intro-to-promis</a>
<b>Licensing requirements and costs</b>	<p>Licence required</p> <p>Non-commercial use: free</p> <p>Commercial uses: Fees vary based on project</p> <p>Fee may apply for review of digital versions</p>	<p>Licence not required; however, permission for use required</p> <p>Free to use</p>	<p>Licence required</p> <p>Fees vary based on project</p>	<p>Licence not required</p> <p>Non-commercial use: Free</p> <p>Commercial use: Permission required</p> <p>Permission also required to integrate into proprietary technology</p> <p>Fee may apply for digital versions</p>

**Table 5** Condition-specific instruments considered by the Working Group

Characteristic	OHS/OKS (international guideline recommendation)	HOOS/KOOS	WOMAC
<b>Description</b>	<p>The Oxford Hip Score (OHS) and Oxford Knee Score (OKS) are specifically designed and developed to assess function and pain after hip and knee replacement surgery.</p> <p>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.</p>	<p>The Hip Disability and Osteoarthritis Outcome Score (HOOS) and Knee Injury and Osteoarthritis Outcome Score (KOOS) were developed to measure five health domains 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.</p> <p>The Physical Function (HOOS-PS/KOOS-PS) and Joint Replacement (HOOS-JR/KOOS-JR) short forms, which contain five to seven items, are also available for use. A 12-item short form (HOOS-12/KOOS-12) has also been made available as of 2019.</p>	<p>The Western Ontario and McMaster Universities Osteoarthritis Index (WOMAC) is a questionnaire developed to assess pain, stiffness and physical function in patients with hip and/or knee osteoarthritis.</p>
<b>Intended use</b>	Hip/knee replacement surgery	Hip disability or osteoarthritis/knee injury or osteoarthritis	Hip/knee osteoarthritis
<b>Length</b>	OHS: 12 items OKS: 12 items	HOOS: 40 items KOOS: 42 items	24 items
<b>Website</b>	<a href="http://innovation.ox.ac.uk/outcome-measures/oxford-hip-score-ohs/">innovation.ox.ac.uk/outcome-measures/oxford-hip-score-ohs/</a> <a href="https://innovation.ox.ac.uk/outcome-measures/oxford-knee-score-oks/">https://innovation.ox.ac.uk/outcome-measures/oxford-knee-score-oks/</a>	<a href="http://www.koos.nu/">www.koos.nu/</a>	<a href="http://www.womac.org/womac/index.htm">www.womac.org/womac/index.htm</a>
<b>Licensing and fee information</b>	<p>Licence required</p> <p>Non-commercial use: free</p> <p>Commercial uses: Fees vary based on project</p> <p>Fee may apply for review of digital versions and support materials</p>	<p>Licence not required</p> <p>Free to use</p>	<p>Licence required</p> <p>Costs depend on project</p>

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

Country	Organisation	Condition-specific instruments			Generic instruments			
		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)
<b>Australia</b>	Australian Orthopaedic Association National Joint Replacement Registry (AOANJRR)	—	—	—	X (5L)	—	—	—
<b>Canada</b>	Canadian Joint Replacement Registry	X	—	X (Alberta only)	X (5L)	—	—	—
<b>Finland</b>	Coxa Hospital for Joint Replacement	X	—	—	—	—	—	—
<b>Ireland</b>	Irish National Orthopaedic Register (INOR)	X	—	—	X (5L)	—	—	—
<b>Italy</b>	Rizzoli Orthopaedic Institute	—	X (PS short form version)	—	X (3L)	—	—	—
	IRCCS Galeazzi Institute	—	X (full version)	—	—	—	—	X (v1)

OECD Patient-Reported Indicator Surveys (PaRIS) Initiative: Patient-Reported Outcome Measures (PROMs)  
for Hip and Knee Replacement Surgery — International Data Collection Guidelines

Country	Organisation	Condition-specific instruments			Generic instruments			
		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)
Netherlands	The Dutch Arthroplasty Register (LROI)	X	X (PS short form version)	—	X (3L)	—	—	—
New Zealand	New Zealand Joint Registry	X	—	—	—	—	—	—
Norway	Norwegian Arthroplasty Register	—	X (full version)	—	X (5L)	—	—	—
Sweden	Swedish Hip Arthroplasty Register	—	—	—	X (5L)	—	—	—
	Swedish Knee Arthroplasty Register	—	X (full version)	—	X (3L)	—	—	—
Switzerland	Geneva Arthroplasty Registry	—	—	X	—	—	—	X (v2)
United Kingdom	NHS, NJR	X	—	—	X (3L)	—	—	—
United States	CMS, AJRR	—	X (JR short form version)	—	—	X	X	—
	FORCE-TJR	—	X (12-item short form version)	—	—	X	—	—
	Michigan Arthroplasty Register	—	X (JR short form version)	—	—	—	X	—

**Notes**

X: Instrument is used.

— Instrument is not used.

Information is known to be true at time of writing; it is based on an environmental scan and may not be exhaustive.

# Annex 3: Implementation Preparedness Checklist

This checklist complements this full document and should be used in conjunction with the PROMs for Hip and Knee Replacement Surgery — International Data Collection Guidelines.

## Purpose

- Have you established a clear purpose for your PROMs programme? Have you identified the data collection requirements to achieve programme goals (e.g., target population, survey time points, minimum data set)?
- Have you considered both local needs and international guidelines?

## Stakeholder engagement

- Have you identified, contacted and received input from all relevant stakeholders?
- Do you have clinical champions to help promote and advocate for PROMs collection?
- Do you have buy-in from clinicians, patients and staff on the value of PROMs?
- Have you engaged patients and clinical staff in developing materials to promote and educate patients, clinicians and health system decision-makers on the collection and use of PROMs information?

## Administration and collection of data

- Have you determined your target population and optimal sampling approach?
- Have you determined the time points for survey collection? Have you mapped out the clinical workflow to determine how survey collection will be triggered at various time points? Are follow-up procedures in place for patients who do not respond?
- Have you determined the mode of administration (e.g., electronic, paper, telephone)? Do you have the infrastructure and resources to support this (for initial set-up and ongoing collection)?
- Has a minimum data set been established? Can any information be obtained through linkage? Are legal and data infrastructures in place to facilitate linkage?
- How can patients, clinicians and administrative staff share feedback on the process?

### **Resources and infrastructure**

- Are the resources required to implement a sustainable PROMs programme available (e.g., capital and operational costs, including support staff and development/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 the specified purposes of the PROMs programme or potential requests for data, 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**

Patients, clinicians, administrative staff, health system decision-makers and health care 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.

### **Purpose of PROMs data collection**

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-effectiveness analysis.

### **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**

The purpose of PROMs collection may influence decisions around survey time points. The typical patient pathway for a joint replacement candidate consists of referral to surgeon, followed by surgeon consultation, which results in a decision either to treat with surgery or to use non-surgical treatment. If the patient and surgeon agree to move forward with surgery, they may be placed on a wait list. Up to 8 weeks prior to surgery, the patient completes a pre-surgery PROMs survey. The surgery is performed, then 12 months after surgery the patient completes a post-surgery PROMs survey. The acceptable window for this 12-month collection time point is any time between 9 and 18 months. Completion of pre- and post-surgery surveys enables measurement of the effectiveness of surgery and rehabilitation for patients on the surgical treatment pathway and the evaluation of long-term outcomes.

However, patients may receive multiple surveys throughout the continuum of care in order to monitor progression of disease and the appropriateness of surgery or non-surgical interventions. Therefore, PROMs can also be completed by patients on the non-surgical treatment pathway.

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