

# AJRR's Patient-Reported Outcome Measures Guide



Part of the AAOS' Registries Portfolio and the Official Registry of AAHKS

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## About the AJRR

Within the American Academy of Orthopaedic Surgeons (AAOS), the American Joint Replacement Registry (AJRR) is the national clinical data registry for data collection and quality improvement initiatives for total hip and knee replacements. AJRR was formed by AAOS in 2009 with support from other subspecialty orthopaedic societies [the American Association of Hip and Knee Surgeons (AAHKS), The Hip Society, The Knee Society], orthopaedic device manufacturers, hospitals, private payers, and public representatives. It is now the cornerstone of the AAOS’ registries portfolio. AAHKS has designated AJRR as its official Registry.

AJRR’s mission focuses on improving care for patients who receive hip and knee replacements. By collecting and reporting data, the AJRR provides actionable information to guide physicians’ and patients’ decision making to improve care. It empowers health care organizations to enhance the patient experience and benchmark performance; orthopaedic surgeons to reduce complications and revision rates; device manufacturers to strengthen quality control through post-market surveillance; and health plans to effectively manage costs.

### **Information provided in this guide**

*AJRR developed this guide to provide information on our patient-reported outcome (PRO) platform and how to utilize it to capture data, while providing some guidance and suggestions on how to start a PRO program at your institution. Each institution is different; therefore, there is no one specific workflow protocol that fits every organization. The guide will describe the types of AJRR participants and the different types of settings that may be involved in the workflow for PRO data capture by giving a broad overview on how to start a PRO program. It is intended to be a very high level document, specific to our platform. Other outcome measurement expert groups have developed far more detailed manuscripts that discuss the types of PROs available and guidance on how to select an appropriate measure/s to meet your requirements (see Appendix A). Each hospital, ambulatory surgery center (ASC), and practice group will need to invest time to define their aims with PRO collection, evaluate the measures they would like to collect, and determine the best process for their institution to use to reach out to its patient population for PRO data collection. Understanding your patient flow from pre-operative to post-operative follow-up will help guide your institution on how to collect patient-reported outcome measures (PROMs) at defined time points.*

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## AJRR's goals for patient-reported outcomes

As part of AJRR's mission to improve care for patients by providing meaningful data to participants, AJRR has developed a patient-reported outcome (PRO) platform for institutions who are interested in capturing patient-based outcome data; specifically, patient-reported outcome measures (PROMs) that assess a patient's health status from the patient's perspective. A PRO is defined as any information on the outcomes of health care obtained directly from patients without modification by clinicians or other health care professionals.<sup>1</sup> A PROM is a survey that captures a patient's self-assessment of his or her health including health status (mental and/or physical), function, symptoms, and health-related quality of life (HRQL). PROMs can "provide a mechanism for evaluating the effectiveness of patient-centered care"<sup>2</sup> including evaluation of surgical or other treatment outcomes.

**"A PRO is defined as any information on the outcomes of health care obtained directly from patients without modification by clinicians or other health care professionals."<sup>1</sup>**

AJRR's goal is to provide a centralized system for its participants to collect, store, and access their orthopaedic data (i.e., clinical information, device data, and PRO data) so that participants have the ability to compare their data to aggregate, national benchmarks. For PROMs, AJRR will only provide national benchmarks for our recommended PROMs (as indicated in Table 1). However, Registry participants may use any of the PROMs that AJRR supports (Table 1) and will be able to pull reports on the PROM data.

## Why include a PRO program at your institution or clinical setting?

Patient-reported outcomes can be valuable tools in guiding physicians and patients on understanding a patient's health status, in the decision-making process regarding patient care – for example, severity of joint disease based on PROM may be a good indicator for surgery, and for evaluating the effectiveness of quality improvement initiatives. *In short, there are three major reasons why providers may be interested in collecting PROs:*

### 1. Expanding the criteria for how to evaluate care by including outcomes based on patient's viewpoint with other clinical measures

As the California Joint Replacement Registry (CJRR), an organization that merged with AJRR, was developing their PRO platform in 2010, they discussed the rationale for capturing PROs in this manner:

*“Longitudinally tracking patient assessment of pain and function can provide insights into the effectiveness of hip and knee arthroplasty across a much broader patient population than the relatively small number of patients that suffer implant failures and require surgery. Perhaps most importantly, PRO data reflect the patient’s perspective on the outcome of the surgery – described as ‘the truest end result of our care as physicians,’ by one orthopedic surgeon.”<sup>3</sup>*

PRO data provide meaningful information in conjunction with other clinical measures, and therefore, provide the opportunity to have a fuller picture of the impact of care and may be used by the clinician during patient encounters. These surveys can be considered an important step toward engaging patients in their own health care and informing medical decision making.

## 2. Federal initiatives

PRO data will be critical as the Centers for Medicare & Medicaid Services (CMS) and other payers move toward defining quality measures to evaluate health care providers’ performance for value-based reimbursement of care. For example, CMS emphasizes the use of PROs by defining PRO requirements within their Medicare reimbursement programs such as the Comprehensive Care for Joint Replacement (CJR) model, which is hospital-based. Eligible professionals have the option to use PROs for the Merit-based Incentive Payment System (MIPS) track of the Medicare Access and CHIP Reauthorization Act of 2015 (MACRA). CMS intends to have 90% of payments tied to quality outcomes by 2018.<sup>4</sup>

For the CJR initiative, hospitals are not *required* to submit PRO data, however PRO data will be linked to the hospital’s reconciliation payment. CMS is using a composite score methodology to link quality outcomes to payment. Specifically, a hospital’s score will be determined in part by performance and improvement on two quality measures: a) the THA/TKA Complications measure (NQF #1550) and b) the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) Survey (NQF #0166) as well as voluntary submission of THA/TKA of PRO and limited risk variable data. Those institutions voluntarily submitting PRO data will have to submit data on  $\geq 50\%$  or  $\geq 50$  eligible procedures. Successful submission of PRO and risk variable data will add two additional points to a participant hospital’s composite quality score. For more information, please view any of the documents posted under the “Additional Information” section of the CJR website at <https://innovation.cms.gov/initiatives/cjr>.

For more information on PROs in the context of MACRA, please see <https://www.medconcert.com/aaos>.

### 3. Comparative benchmarks

AJRR provides institutions with PRO benchmarks to compare their results to the national experience. Knowing how surgeons compare with their peers, as well as against the nation can be very beneficial for practice improvement efforts. Comparative data may facilitate and provide evidence for the need for quality improvement work at both the institution and surgeon level. Additionally, institutions can use that data to publicly report their own results, should they wish. Having the data from a robust National Registry will enable institutions to make informed decisions based on clinical facts and figures.

A national database will be able to analyze and report national total hip and knee arthroplasty measures and offer opportunities for further investigation at both local and national levels. AJRR understands that researchers, institutions, and organizations may want to have opportunities to access the data in the Registry to conduct further analyses to address specific hypotheses, such as replacement outcomes and implant performance, beyond the national benchmarks.

## What type of service does AJRR provide for collecting PROs?

### PRO System

One of AJRR's goals is to provide the orthopaedic community with national comparative PRO data. To assist AJRR institutions in PRO data capture and deliver a service to store and have on-demand access to the data, AJRR developed a PRO platform within our RegistryInsights™ system. The platform has many features for clinical staff to access their patient data while having the ability to manage and assign PRO surveys electronically via a secure application. AJRR's secure application allows patients to access their surveys by means of the Internet at home or in the clinic to complete the surveys in a convenient manner.

*Please note: Currently, AJRR's PRO platform can be accessed using a PC or tablets and only includes English versions of PROMs. In the future, AJRR may offer non-English versions of measures (if participants express the need for other language surveys). If you have specific questions regarding non-English language PROMs, please contact us.*

AJRR's data system also has the capacity to accept PROMs data from participating institutions who are collecting PROMs through another method (e.g., paper collection, PRO collection by their electronic health records (EHR) system, or an orthopaedic charting vendor). For example, Epic and other EHR vendors offer PRO platforms in their systems for those who wish to utilize a platform tailored to their individual needs. AJRR collaborates with a number of these vendors to facilitate seamless transfer of PRO data. *See page 11 for more information on our vendor partners.*

If a participant would like to use the AJRR platform for PROM data collection, the participant will need to subscribe to RegistryInsights. AJRR will provide a Level III PRO platform User Guide and also provide training webinars for new users. The participant will be responsible for managing PRO data collection at their site(s).

## PROM Guidance

Beyond providing a system to capture PRO measures or accessing PRO dashboards, AJRR provides guidance regarding what PROMs your organization may wish to collect, especially for institutions just starting a PRO program. As the National Registry that works closely with the orthopaedic societies and associations, institutions and surgeons are looking to AJRR for guidance regarding PRO collection. AJRR's Data Committee, in collaboration with orthopaedic specialty organizations, identified the specific measures that AJRR recommends for national benchmarks.

The recommendation includes utilization of both an HRQL measure (either VR-12 *or* PROMIS-10 Global Health) and a joint-specific measure (HOOS, JR. and KOOS, JR.). The decision to recommend the instruments was based on AJRR participation in the AAHKS Patient-Reported Outcome Summit for Total Joint Arthroplasty that convened in August 2015. Representatives from orthopaedic organizations (AAHKS, AJRR, American Academy of Orthopaedic Surgeons (AAOS), The Hip Society, and The Knee Society), CMS, Yale-New Haven Health Services Corporation Center for Outcomes Research and Evaluation (YNHHSC/CORE), private payers, and other stakeholders participated in the Summit. The Summit's goal was to obtain a consensus regarding the PRO suitable for total hip and knee arthroplasty performance measures. Our recommendations are also consistent with the CJR Final Rule.

<p>HEALTH-RELATED QUALITY OF LIFE MEASURE: VR-12 OR PROMIS-10 GLOBAL</p> <p>JOINT-SPECIFIC MEASURE: HOOS, JR. AND KOOS, JR.</p>
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Although AJRR has recommended PROMs for national benchmarking, AJRR provides a large list of PROMs (Table 1) for institutions interested in collecting measures other than AJRR's recommendations. AJRR understands institutions may have in place a long-standing PRO data collection process with specific PRO instruments. As these groups may wish to continue utilizing their preferred PROM, AJRR will provide a repository to warehouse all levels of orthopaedic data in a centralized system. Additionally, an institution may prefer to use another measure in order to conduct comprehensive analysis at a more granular level. The AJRR RegistryInsights system will allow for aggregated site-specific reports detailing the patients and summary results for each PROM supported on the AJRR system, even though national benchmarks and dashboards will not be available for these other measures.

## AJRR participants and settings for PROM data collection

Currently, AJRR enrolls mainly hospitals into the Registry because total joint arthroplasties are primarily performed in hospital settings, and therefore data regarding the procedure is collected and warehoused in the hospital's EHR system or other hospital systems (e.g., operating room or

service line). As total joint arthroplasty procedures are increasingly performed in other settings, such as ASCs, the Registry has begun to enroll ASCs. AJRR also enrolls private practice groups, which will provide opportunities to capture pre- and post-op data elements not contained in hospitals' EHRs. AJRR assumes that most PRO data collection will happen at the clinic level, which could be owned by the hospital or a private practice group. **Hence, it will be important for practice groups and hospitals or ASCs to have dialogue regarding this type of initiative and how they may collaborate on this effort.**

This dialogue is critical to successful implementation of the CJR bundled payment initiative as well. All providers (i.e., hospitals, ASCs, and surgeons) who participate in the Registry will have access to their own specific outcome data and de-identified, aggregate national benchmarks.

### AJRR patient-reported outcome measures

The table on the next page lists all PROMs that AJRR will accept and store in the Registry. AJRR participants have the choice to collect the PROMs that best fit their needs, however PRO national benchmarks will only be available for AJRR's recommended PROMs. **Prior to using a new form, please confirm with AJRR that you are utilizing the correct version of the measures.**



As Table 1 shows, AJRR offers HRQL measures and joint-specific measures.

Each type of measure assesses different domains of health from the patient perspective. An HRQL yields a global summary of well-being, which can be further delineated into mental and physical health, but is not limited to these domains. For example, some measures, like the SF-36, can also be scored into more specific domains. Beyond the SF-36's Physical and Mental Summary Component Scores, it has eight subscales (physical functioning, role – physical, bodily pain, general health, vitality, social functioning, role – emotional, and mental health).<sup>5</sup> A disease-specific measure has been designed to address a specific health condition. The majority of disease-specific (or joint-specific) PROMs utilized in orthopaedics were primarily developed for osteoarthritis or rheumatoid arthritis to evaluate treatments for these diseases and to be more sensitive to specific symptoms of these diseases.<sup>6-10</sup> Joint-specific PRO surveys may measure a single domain or multiple domains, such as functional status (ability to perform specific activities), pain, symptoms, or patient experience (i.e., patient satisfaction or patient expectation), summaries of which can be found in Table 2 on page 9. These measures were developed for each domain subscale to be reported as an individual score for the PROM.

**Table 1: Patient-Reported Outcome Measures Accepted by AJRR**

Measure Acronym	Measure	Number of Items	Available as an AJRR Patient Portal Form	National Benchmarks Available via AJRR Dashboard	
<b>Health-Related Quality of Life (HRQL) Measure</b>	VR-12	Veterans RAND 12 Item Health Survey	12	Yes	Yes
	PROMIS-10 Global	Patient Reported Outcome Measure Information System - Global Health Scale	10	Yes	Yes
	SF-12	Medical Outcomes Study 12-Item Short Form Health Survey	12	No, AJRR only accepts final scores	No
	SF-36	Medical Outcomes Study 36-Item Short Form Health Survey	36	Yes	No
	EQ-5D (3L and 5L)	EuroQoL Index and Visual Analog Scale	6	No, AJRR only accepts final scores	No
Measure Acronym	Measure	Number of Items	Available as an AJRR Patient Portal Form	National Benchmarks Available via AJRR Dashboard	
<b>Joint-Specific Measure</b>	HOOS, JR.	Hip Disability and Osteoarthritis Outcome Score (HOOS), JR.	6	Yes	Yes
	KOOS, JR.	Knee Injury and Osteoarthritis Outcome Score (KOOS), JR.	7	Yes	Yes
	HOOS	Hip Disability and Osteoarthritis Outcome Score	40	Yes	No
	KOOS	Knee Injury and Osteoarthritis Outcome Score	42	Yes	No
	Oxford Hip	Oxford Hip Score	12	Yes	No
	Oxford Knee	Oxford Knee Score	12	Yes	No
	KSS (Pre- and Post-Op)	Knee Society Knee Scoring System	44	Yes	No
	Harris Hip Score	Harris Hip Score	8	Yes	No
	WOMAC	Western Ontario and McMaster University Osteoarthritis Index	24	No, AJRR only accepts final scores	No
Measure Acronym	Measure	Number of Items	Available as an AJRR Patient Portal Form	National Benchmarks Available via AJRR Dashboard	
<b>Other Measure</b>	CJR	Comprehensive Joint Replacement (CJR) Patient-Reported Risk Questions	3	Yes	Yes <i>Coming Soon</i>
	CollaboRATE	Blue Shield of California CollaboRATE	3	Yes	No
	UCLA	UCLA Physical Activity Scale	1	Yes	No



	Other Measures		
	CJR	CollaboRATE	UCLA
Back Pain	✓		
Health Literacy	✓		
Pain in Non-Operative Joint	✓		
Physical Activity			✓
Shared Decision Making in the Clinical Encounter		✓	

AJRR’s recommended PROMs were chosen based on the brevity of each instrument, while still meeting the review committees’ standards for valid tools for total hip and knee arthroplasty outcomes.<sup>11</sup> Each recommended PROM is described below (Table 3).

**Table 3: AJRR Recommended PROMs Summary**

Measure	Measure Description	Score(s)	Score Interpretation
<b>VR-12</b>	This instrument is primarily used to measure health-related quality of life, to estimate disease burden, and to evaluate disease-specific benchmarks with other populations. The 12 items in the questionnaire correspond to eight principal physical and mental health domains including general health perceptions; physical functioning; role limitations due to physical and emotional problems; bodily pain; energy – fatigue, social functioning and mental health.	Mental Component Summary (MCS) score  Physical Component Summary (PCS) score	If all 12 items have been answered, then defined weights and the constants can be used to compute PCS and MCS scores from the raw scores of the VR-12. High scores indicate better health. The VR-12 also has an alternate option to address missing items by using a Statistical Analysis System (SAS) algorithm with imputation norms.
<b>PROMIS-10 Global Health</b>	The PROMIS-10 Global Health scale is a 10-item instrument representing multiple domains. The scale assesses health in general (i.e., overall health). Items include global ratings of the five primary PROMIS domains (physical function, fatigue, pain, emotional distress, social health) as well as perceptions of general health that cut across domains.	Global Physical Health (GPH) Component score  Global Mental Health (GMH) Component score	A user converts the simple summed raw scores into T-score values on an individual respondent or group of respondents. In all cases, these conversions only work accurately when all questions on the short form have been answered. T-score distributions are standardized such that a 50 represents the average (mean) for the U.S. general population, and the standard deviation around that mean is 10 points. A high score always represents more of the concept being measured. Thus, a T-score of 60 for both scales is one standard deviation better (more healthy) than the general population. PROMIS also provides an Assessment Center Scoring Service, an online scoring tool that accepts an Excel file and returns a scored file via email.

<b>HOOS, JR.</b>	The HOOS, JR. was developed from the original long version of the Hip Disability and Osteoarthritis Outcome Score (HOOS) survey using Rasch analysis. The HOOS, JR. contains 6 items from the original HOOS survey. The items include domains of pain and function.	HOOS, JR. score	A user sums the raw scores and then converts it to an interval score using a HOOS, JR. Conversion Table. The interval score ranges from 0 to 100, where 0 represents total hip disability and 100 represents perfect hip health. Please note: AJRR can calculate the HOOS, JR. score from the full HOOS.
<b>KOOS, JR.</b>	The KOOS, JR. was developed from the original long version of the Knee Injury and Osteoarthritis Outcome Score (KOOS) survey using Rasch analysis. The KOOS, JR. contains 7 items from the original KOOS survey. The items include domains of stiffness (symptom), pain, and function.	KOOS, JR. score	A user sums the raw scores and then converts it to an interval score using a KOOS, JR. Conversion Table. The interval score ranges from 0 to 100, where 0 represents total knee disability and 100 represents perfect knee health. Please note: AJRR can calculate the KOOS, JR. score from the full KOOS.

### PROM data submission

AJRR has three options for participants to choose from to submit PROMs to the AJRR:

1. If a participant utilizes the AJRR PRO platform to collect PROMs, all PROM data is automatically saved once the patient completes the survey and submits their responses. Each item response and final scores are saved in real time so that clinicians are able to access the data on-demand. Hence, results may be used to facilitate discussion during a patient encounter. The system also provides reports for tracking compliance, completed PRO scores for further analysis, and dashboards for Recommended PROMs. AJRR will provide a Level III PRO platform User Guide and also provide training webinars for new users.
2. If a participant already has an internal system to collect PROMs either electronically or by paper, they can submit PROM scores via a .csv or .xls file to AJRR's SFTP server. A PROM data specification file will be provided to participants so that data meets AJRR standards for submission. If institutions are also subscribing to the AJRR RegistryInsights system, they will have access to the national dashboards and be able to pull PRO reports for further analysis. Additionally, if a subscribing participant is collecting PROMs via paper administration, the system allows for manual data entry of form responses.
3. If a participant employs an orthopaedic charting or other PROMs vendor to capture PROMs data and this vendor has a vendor agreement with AJRR, the vendor is able to submit data directly to AJRR on behalf of a participating institution. AJRR currently has agreements with the following orthopaedic charting vendors:
  - Aver
  - Clarify Health Solutions
  - CODE Technology
  - Consensus Medical Systems, Inc.
  - dataFascia
  - FORCE Therapeutics

- InVivoLink, Inc.
- KareOutcomes
- Kermit
- MedTrak, Inc. (CareSense System)
- [m]pirik
- OM1
- Ortech, Inc.
- OrthoSensor, Inc.
- Q-Centrix
- Ratchet Health
- Surgical Outcomes System (Arthrex)
- Tonic Solutions, Inc.
- URS-Oberd, Inc.
- ValidCare
- VisionTree
- VitalHealth Software
- Vox Telehealth
- Wellbe, Inc.
- Wellpepper, Inc.

## How to start a PRO program at your institution

Developing a PRO program may be an involved process for your institution. It may take months to design and implement, therefore taking time to discuss each category below will hopefully streamline the process and guide you to a successful program.

### Define PRO team

Most likely, within your institution a core group of colleagues (i.e., orthopaedic group, quality department, or hospital administration) has decided that including PROs in your practice of care for total joint arthroplasty may provide important information to improve patient outcomes. Beyond this core group, you may need to bring in other disciplines to help drive this initiative and development. Below is a list of potential key stakeholders who may assist in developing and capturing PROMs for your institution:

- Orthopaedic Department
- Orthopaedic Practice Groups and Clinics (not only physicians and nurses, but front desk staff may need to be involved)
- Quality Department
- Information Technology
- Orthopaedic Service Line
- Research
- Rehabilitation
- Hospital Administration
- Patient Advocate/Patient Representative

“You may consider asking yourselves questions such as:  
Are we launching a research initiative with specific aims?  
Are we seeking comparative benchmarks to our peers?”

- Institutional Review Board (guidance/review)

As you begin to design your protocol for data collection, the appropriate stakeholders will become apparent and engaging these groups will help build collaboration and buy-in on why a PRO program is beneficial and sustainable.

### Define your institution's goals for implementing a PRO program

If you are interested in a PRO program, you and your colleagues will need to determine the reasons you would like to launch a PRO program.



#### You may consider asking yourselves questions such as:

- Are we launching a research initiative with specific aims?
- Are we seeking comparative benchmarks to our peers?
- Are we wanting to quantify our outcomes from our patients' perspective?
  - Do we want to measure if patients have improved function or reduced pain?
    - Are there other areas of self-reported health that are critical to assess?
    - Do we want to screen for referrals for pain management?
  - Do we want to screen for patients at risk for poor outcomes?
- Do we want to measure whether our patients' overall health has improved?
- Are we wanting patient provided data to be utilized during the clinical encounter?
- Do we want to utilize PROs for evaluating quality improvement initiatives?
  - Do we want to allow for analyses to compare procedures or surgical protocols?
- What are the requirements of the payer-specific program for which we are hoping to qualify?

### Determine the appropriate PRO measure

Your reasons for implementing a PRO program will direct your team to a certain instrument(s) that will allow you to meet your objectives. For example, if your institution has decided to collect PROMs for research initiatives, you may choose an instrument that measures multiple domains, like the HOOS and KOOS. These instruments are joint-specific instruments that have five subscales measuring function, pain, hip/knee symptoms, sports and recreation (high level activities of daily living) and quality of life, which would provide a depth of data to address many research hypotheses. However, if you are focused on measuring patients' outcomes as part of your clinical care, a shorter instrument focused on physical function or critical symptoms (e.g., pain) will suffice as long as it is able to detect change.

Other factors to review when assessing PRO instruments are the levels of validity, reliability, and responsiveness of the PROM (Table 4). Each PROM that is available through AJRR's platform has been validated, however it will be up to your institution to determine which instrument(s) meets the standards or needs for your PRO program. You will also need to consider the cost to use a specific PROM. Your institution will be responsible for any PROM licensing cost if you do not use AJRR's PRO platform to collect a PROM that requires a license. However, only three forms (SF-12, EQ-5D, and WOMAC) require licenses.

**Table 4: Key Factors for PRO Validity**

Validity	The extent to which an instrument measures what it is intended to measure and can be useful for its intended purpose <sup>1</sup>
Reliability	The extent to which a scale or measure yields reproducible and consistent results <sup>1</sup>
Responsiveness	The extent to which a scale or measure is able to detect change in health status over time <sup>1,3</sup>

For psychometric and validation data pertaining to each of these measures, please visit the following sites:

#### Health-related quality of life measures

- VR-12: <http://www.bu.edu/sph/research/research-landing-page/vr-36-vr-12-and-vr-6d/>
- PROMIS-10 Global: [www.healthmeasures.net](http://www.healthmeasures.net)
- SF-12: [http://www.rand.org/health/surveys\\_tools/mos/mos\\_core\\_12item.html](http://www.rand.org/health/surveys_tools/mos/mos_core_12item.html)
- SF-36: [http://www.rand.org/health/surveys\\_tools/mos/mos\\_core\\_36item.html](http://www.rand.org/health/surveys_tools/mos/mos_core_36item.html)
- EQ-5D: <http://www.euroqol.org/>

#### Disease-specific measures

- HOOS, JR.: <https://www.hss.edu/hoos-jr-koos-jr-outcomes-surveys.asp>
- KOOS, JR.: <https://www.hss.edu/hoos-jr-koos-jr-outcomes-surveys.asp>
- HOOS: <http://www.koos.nu/>
- KOOS: <http://www.koos.nu/>
- Oxford Hip: <http://isis-innovation.com/outcome-measures/oxford-hip-score-ohs/>
- Oxford Knee: <http://isis-innovation.com/outcome-measures/oxford-knee-score-oks/>
- KSS: <http://www.kneesociety.org/web/outcomes.html>
- Harris Hip Score: <http://www.orthopaedicscore.com/>
- WOMAC: <http://www.womac.org/>

## Other measures

- CollaboRATE: <http://www.collaboratescore.org/>
- CJR Risk Questions: <https://innovation.cms.gov/initiatives/cjr>
- UCLA Physical Activity Scale: no website available

A major factor to address in determining which PROM to utilize is patient and clinician burden. Although longer instruments may provide a more comprehensive or sensitive measure, compliance may be low due to the time it takes a patient to complete the survey (or for a clinician to administer the survey) and may be difficult to analyze if all items are not answered. AJRR, in conjunction with the AAHKS Patient-Reported Outcome Summit, has identified patient burden to complete long instruments as a major barrier in data collection on a national level.<sup>11</sup> AJRR's recommended PROMs are short instruments (12 items or less) that have been validated to detect measurable change over time. Longer instruments may require clinicians or clinic staff taking a more active role in monitoring and checking completion of the forms. With electronic capture, short forms should increase compliance rates and reduce missing data points.



Comparability across populations is another factor to discuss. Instruments that are commonly used and have been developed for across population comparison are useful when comparing diverse communities. AJRR's HRQL measures have been validated for this process.

Also, a cross walk has been developed for the VR-12 and PROMIS-10 Global Health to facilitate linkage between these instruments.<sup>12</sup> In regards to joint-specific measures, outcome measurement groups are in the process of facilitating linkage between these types of instruments as well as among other commonly utilized PROMs.

When considering a PROM, you should take into account your patient population. Age, education, socioeconomic status, and patient literacy (reading, health, and computer) can all be potential barriers for patients to participate with the data collection protocol.<sup>1,13</sup> Language is another consideration – do you need a measure that has been validated and translated into other languages? At this time, AJRR platform only provides English versions of the accepted PROMs. If AJRR participants begin to request non-English versions, AJRR will review and assess whether each PROM has a valid non-English version appropriate for use and analysis. Finally, although total joint PRO surveys may not be considered controversial in content (i.e., they do not ask personal, sensitive questions), they may make a patient feel insecure about their functional capabilities or patients may not be sure how to answer a question if they do not perform a specific activity described in the survey (e.g., they do not engage in vigorous activities).



Evaluating these types of factors will be essential when discussing the type and method to collect PROMs and how you will frame this additional assessment to your patients, especially if your organization plans to share results with patients. For example, including explicit language indicating the purpose of the survey such as: a) we are asking you to complete this survey because we want to know more about how you are doing, b) indicate what the health care team plans on doing with this information (e.g., share only with care team), c) there are no right or wrong answers – some things may be more or less important or relevant to you. Please try to answer all questions.

There are many factors to consider when choosing a PROM to meet your PRO objectives. Again, Appendix A provides additional resources from leading outcome experts that offer more in-depth discussion on the above topics. However, as in each section, below are basic questions to start the discussion.

- What does the measure assess – quality of life or function?
  - Do we want to understand both or just one aspect?
- What is the associated patient burden?
  - What is the length of form? How easy/hard is the form to complete?
- What is the associated staff burden (full-time employee time)? Who will be assisting patients with forms? Whose job is it to follow up with patients?
- What is the cost (licensing fee) to use the form?
- Do we have non-English speakers in our patient population? Will we need translated versions of our preferred PROM(s)?

### Measurement timeline

PROMs guidelines from groups such as the International Consortium for Health Outcome Measurement (ICHOM) have recommended pre-operative (baseline) and one-year follow-up as appropriate time points for data collection to provide meaningful data for comparing outcomes across providers.<sup>14</sup> The CJR Final Rule also advises that post-operative surveys be collected between 270 and 365 days post-surgery.

Each time point will have a window for data collection that follows CMS's accepted time-point intervals. AJRR's platform will allow for other time points (e.g., three-month, six-month, etc.) to be submitted and stored in AJRR's database should you wish. However, national benchmarks will only be reported for pre-operative and one-year outcomes.

Further questions to discuss with your colleagues:

- How often would we like to collect a PROM post-surgery?
- At what time points do our patients consistently come back for a follow-up visit? Is this the

best time to capture the PROMs? (If patient doesn't complete via Internet prior to visit, we have a chance to collect at the clinic visit or provide a reminder to complete it after the visit.)

- For what time point has our chosen PROM been validated to detect change (six months vs. one year)?
- What time frame is needed to address our primary aims for PRO data collection (e.g., data at each clinic visit if used to inform clinical encounter vs. pre-operative and one-year data to meet minimum reporting requirements for payers)?
- How many time points for data collection can be managed by our staff?
- How frequently are patients willing to complete surveys? Should a random subgroup be utilized for more frequent assessment (this may be an option for research driven initiatives)?
- What is our status regarding federal quality initiatives? Are we in one of the CJR geographic areas? Are we in the Bundled Payments for Care Improvements (BPCI) initiative?

### **Develop work flow for data capture**

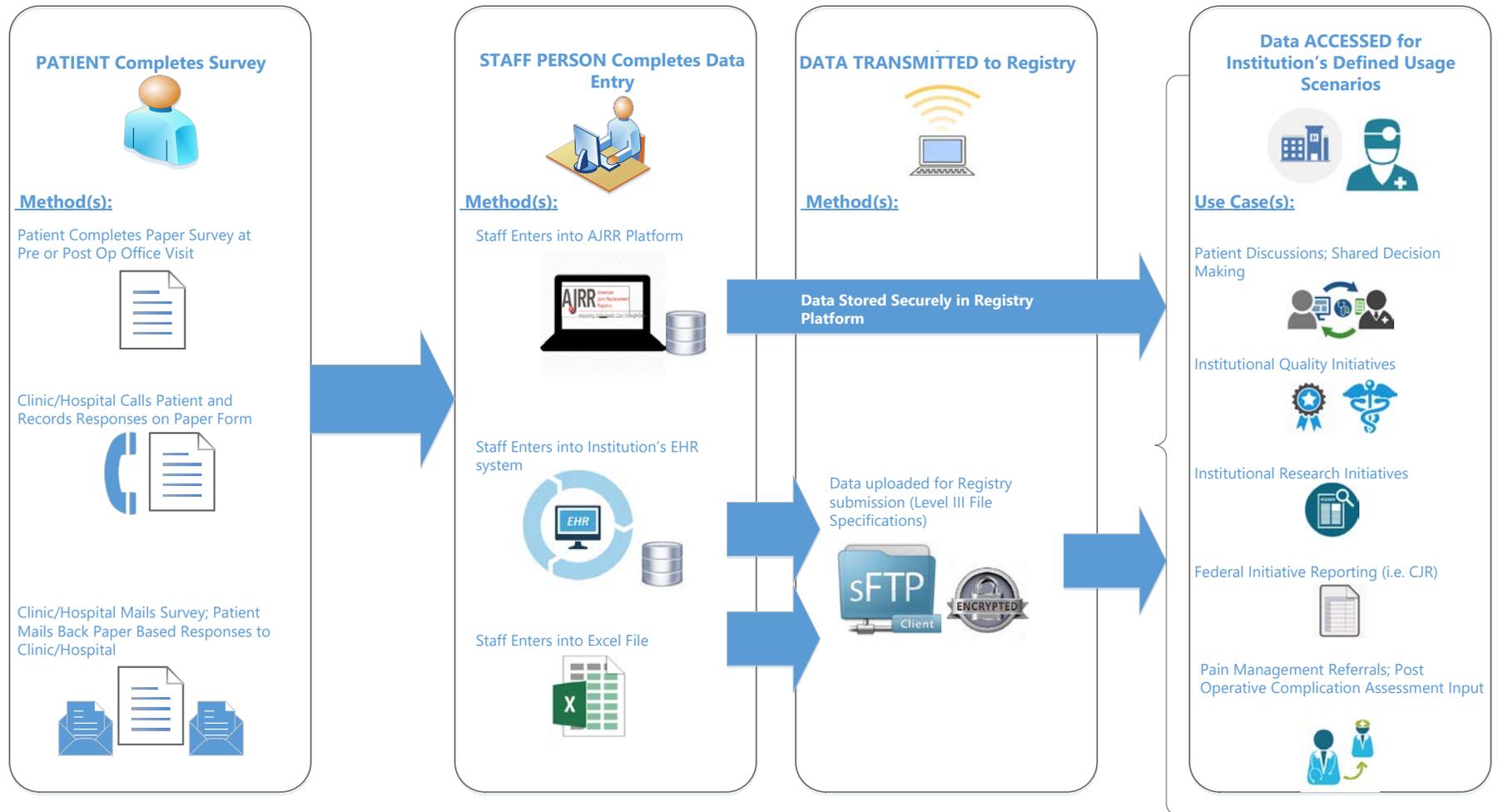
Once you have decided the purpose of PRO data collection, which PROM(s) to collect, and your timeline for data capture, you and your colleagues should develop the protocol for data collection. If electronic data capture is an option for you, then you will need to assess whether the AJRR platform or another system meets your needs. Again, questions to discuss:

- What does our current EHR platform provide? Is the infrastructure sufficient for data capture? *Do our clinics or affiliated practice groups share the same EHR?*
- Do the AJRR tools help us meet those aims?
- What do other orthopaedic charting vendors offer in regards to PROs?
- What are your patient population characteristics? Will they have access to complete the forms electronically?
- Are PROMs in paper form suitable for our aims for data collection? Do we have a process for integrating that information into AJRR?
- What follow-up time points will be the most manageable to capture in clinic? Or do we only want to collect off site via a secure patient portal? Or both?

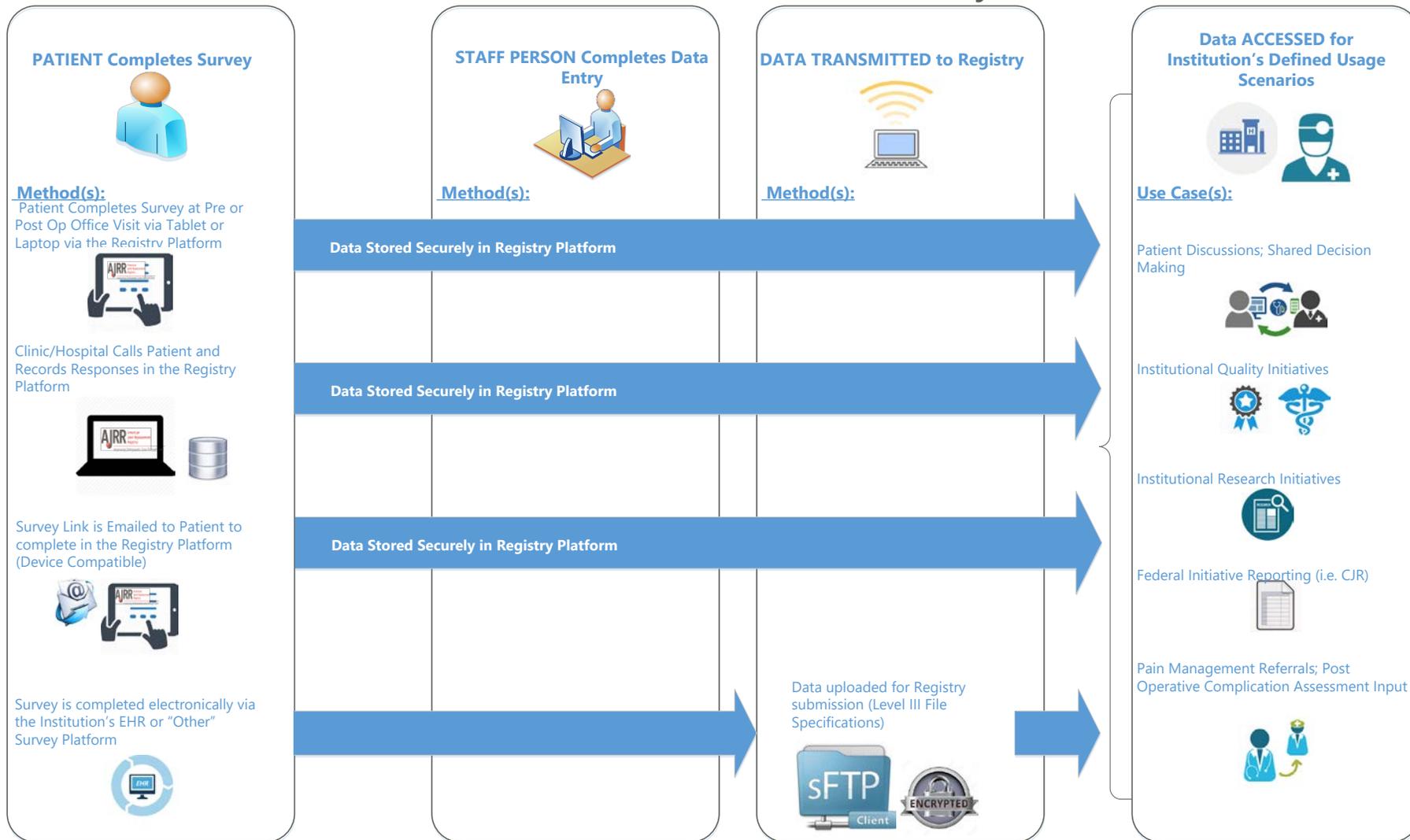
- Will there be adequate time set aside for clinical staff to manage the surveys, track patient enrollment, monitor data completion quality and rates, and follow up on problems?
- How do we train our staff on the data collection processes?
- How do we frame the PRO discussion with patients and when? At time of first visit, after TJR procedure has been scheduled, at the time of the pre-operative TJR class?
- Will the care team want to review the PROM scores with patients at clinic visit?

AJRR has developed two simple workflow diagrams (one for paper format collection and one for electronic capture) to help visualize the whole process from data collection to utilization of data. Although most institutions would prefer to collect PROMs via electronic surveys, this may not be an option for some participants. **Understanding your patient flow from pre-op to post-op follow-up will help guide your institution on how to collect PROMs at defined time points.** As shown by the bold arrows in the following diagrams, the most streamlined method for real time data submission and access is with the use of the AJRR platform.

# Patient Reported Outcome Measures: Collection to Action Workflow for **Paper-Based** Survey Administration



# Patient Reported Outcome Measures: Collection to Action Workflow for **Electronic-Based** Survey Administration



## Interpretation of PRO results

It is important to understand what domain the PROM is measuring and how it is scored in order to be able to utilize it appropriately, especially if your institution will share the results with the patients. Additionally, it is essential to be aware of how clinically significant change in scores between patients or within patients over time is defined and analyzed. Cella and colleagues (2015) state that:

*“Clinically significant change has been defined as ‘changes in patient functioning that are meaningful for individuals who undergo psychosocial or medical interventions.’ Similarly, meaningful change is defined (from patient perspective) as ‘one that results in a meaningful reduction in symptoms or improvement in function ...’ ”*

In PRO data reporting, minimally important differences (MIDs) represent a specific approach to measure clinical significance. They are defined as “the smallest difference in score in the outcome of interest that informed patients or informed proxies perceive as important.”<sup>1</sup> Although this statistical method may be necessary to utilize when reporting scores, it may vary by population and by context and some PROMs may already have known thresholds or meaningful cut points. Further review of these statistical concepts may be necessary by participants as they utilize PRO data. This guide’s goal was to make participants aware of the issues of PRO data collection and usage. As AJRR’s PRO dataset develops, AJRR will be able to provide more insight on how to report and interpret PROM scores.

Therefore, the three main concepts to think about when interpreting PROM results are:

1. Knowing the domain that is being measured and labelling it correctly (e.g., degree pain interferes with physical activity, global physical health)
2. Understanding the score and the meaning of the score (e.g., provide the mean and indicate the reference population, describe the direction of score)
3. In addition to MIDs, there may also be known thresholds or meaningful cut points (e.g., mild/moderate/severe impairment)

## Lessons learned from our participants

Based on focus groups and other discussions with institutions, here are a few helpful hints:

### Planning and starting a PRO program

- Start small – if the hospital or hospital system has multiple clinics, start at one clinic first to implement and evaluate the protocol before moving forward with your PRO program system-wide
- Have all groups involved in the design of the PRO plan (e.g., front desk staff, physician extenders, quality) identify problems and solve potential barriers

- Start looking for a device (e.g., PC/tablet/kiosk) early on as it may take several months to find the right device with enough inventory
- Work with your technical team to set a reasonable due date to have the test device configured and account for this in your timeline so this time doesn't affect the time allotted for testing
- Allow adequate time for Institutional Review Board review of protocol and patient materials

### Implementing a PRO program

- If doing a clinic assessment, have protocol for device (PC/tablet/kiosk) management (e.g., location to secure and charge tablets, process for disinfecting between patients)
- Take advantage of existing clinic wait times
- To promote, educate, and make the patient more comfortable in using a patient portal to complete PROMs (especially, in regards to completing the follow-up surveys via Internet at home), have the patient complete the first form electronically at the clinic so they can ask questions if they need help; patients may be more prone to complete follow-up surveys once they are familiar with the survey process
- Sending email, newsletter, or postcard reminders can be helpful
- Anchoring events may be a challenge as surgical history data may not be easily connected to PRO data – AJRR can address this while other EHR systems may need further configuration



### Scoring

- Complex scoring rules require custom programming – you should allow for time and resources for this if you are not using AJRR's system
- You should allow ample time to test and retest the scoring algorithms in your EHR system (if not using AJRR's system)
- Note that the data security orders to add a survey/PROM into a data system may not be different from adding standard clinical orders

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## Appendix A

If you would like more in-depth information regarding how to select an appropriate PROM, we recommend:

- Patient-Reported Outcomes in Performance Measurement
  - Cella D, Hahn EA, Jensen SE, Butt Z, Nowinski CJ, Rothrock N, Lohr KN (2015). Patient-reported outcomes in performance measurement: RTI Press Publication No. BK-0014-1509. *Research Triangle Park, NC: RTI Press.*
- International Consortium for Health Outcomes Measurement – Standard Set for Hip & Knee Osteoarthritis v2.1
  - <http://www.ichom.org/medical-conditions/hip-knee-osteoarthritis/>
- National Quality Forum – Patient Reported Outcomes (PROs) in Performance Measurement
  - [https://www.qualityforum.org/Publications/2012/12/Patient-Reported\\_Outcomes\\_in\\_Performance\\_Measurement.aspx](https://www.qualityforum.org/Publications/2012/12/Patient-Reported_Outcomes_in_Performance_Measurement.aspx)
- International Society for Quality of Life Research – User’s Guide to Implementing Patient-Reported Outcomes Assessment in Clinical Practice
  - <http://www.isoqol.org/UserFiles/2015UsersGuide-Version2.pdf>
- Bone and Joint Canada – Total Joint Arthroplasty Outcome Measures Toolkit
  - <http://boneandjointcanada.com/tjaom-toolkit-description-for-bone-joint-canada/>
- PROsetta Stone – Linking Patient-Reported Outcome Measures
  - <http://www.prosettastone.org/Pages/default.aspx>

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