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EFORT open reviews

Orthopaedic registries with patient-reported outcome measures

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- Total joint arthroplasty is performed to decreased pain, restore function and productivity and improve quality of life.
- One-year implant survivorship following surgery is nearly 100%; however, self-reported satisfaction is 80% after total knee arthroplasty and 90% after total hip arthroplasty.
- Patient-reported outcomes (PROs) are produced by patients reporting on their own health status directly without interpretation from a surgeon or other medical professional; a PRO measure (PROM) is a tool, often a questionnaire, that measures different aspects of patient-related outcomes.
- Generic PROs are related to a patient's general health and quality of life, whereas a specific PRO is focused on a particular disease, symptom or anatomical region.
- While revision surgery is the traditional endpoint of registries, it is blunt and likely insufficient as a measure of success; PROMs address this shortcoming by expanding beyond survival and measuring outcomes that are relevant to patients – relief of pain, restoration of function and improvement in quality of life.
- PROMs are increasing in use in many national and regional orthopaedic arthroplasty registries.
- PROMs data can provide important information on value-based care, support quality assurance and improvement initiatives, help refine surgical indications and may improve shared decision-making and surgical timing.
- There are several practical considerations that need to be considered when implementing PROMs collection, as the undertaking itself may be expensive, a burden to the patient, as well as being time and labour intensive.

Keywords: patient-reported outcome; patient-reported outcome measure; joint registry; hip arthroplasty; knee arthroplasty

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Introduction

Traditionally, revision surgery was the endpoint reported by joint arthroplasty registries. Since data collection began in 1975 and 1979 in the Swedish Knee and Hip Arthroplasty Registers (SKAR, SHAR), respectively, significant strides have been made in reducing revision rates.[1,2] This improvement was initially related to refinement of implant selection, but as the different types of data being captured expanded, the importance of other factors on early revision risk such as age, sex, fixation strategy and surgical technique became apparent.[1] Total joint arthroplasty is performed to decrease pain, restore function and productivity and improve quality of life (QoL). It is, therefore, logical to measure these same outcomes when assessing the results of surgery. Revision itself as an endpoint is rather straightforward, but it is likely insufficient as a measure of success given the fact that one-year implant survivorship is nearly 100%, while only 80% of total knee arthroplasty (TKA) patients and 90% of total hip arthroplasty (THA) patients are satisfied one year following surgery.[1-4] Therefore, it makes sense to move beyond simply survival and measure outcomes that are relevant to patients – relief of pain, restoration of function and improvement in QoL.

Table 1. Usefulness of patient-reported outcome measures (PROMs) from various perspectives[66]

Stakeholder	Uses of PROMs
Health system policy-makers/system managers	• Compare outcomes at a local regional, provincial and international level as well as over time. • Compare different models of care and clinical pathways (e.g. referral patterns). • Support health service allocation decisions ('value-based care). • Inform quality improvement initiatives.
Healthcare organizations	• Monitor organization and provider performance. • Conduct comparisons with peer organizations. • Inform quality improvement initiatives.
Healthcare providers	• Provide feedback to inform care plan. • Provide evidence on improved or maintained health of patients. • Improve clinician-patient communication. • Facilitate performance comparisons with expected standards. • Facilitate comparative effectiveness research.[67]
Patients	• Provide opportunity to give feedback and input regarding treatment outcomes, care processes and indicate preferences. • Increase awareness of expected outcomes of care. • Enhance communication with providers. • Increase involvement in care planning and decision-making.

When a patient reports on their own health status directly without interpretation from a surgeon or other medical professional, this is known as a patient-reported outcome (PRO).[5] Two broad classifications of PROs exist: generic and specific.[5] Generic PROs are concerned with a patient's general health or health-related QoL (HRQoL), which may include assessment of a patient's physical, mental and social aspects of health.[5-7] Specific PROs are focused on a particular disease, symptom, intervention, treatment, body function or anatomical region i.e. hip or knee.[5-7] Both generic and specific PROs are typically measured using a patient-reported outcome measure (PROM), a tool which usually takes the form of a self-completed questionnaire. PROMs have traditionally been used for research purposes in clinical trials but have relevance as tools for assessing outcomes and care delivery from the perspective of health system policy-makers, health care organizations, providers and patients (Table 1); the most appropriate PROMs for each of these areas may be different.

The collection of PROMs necessitates significant time, resource and financial investment.[5-9] However, the collection of PROMs within joint registries and other domains is becoming increasingly important, as healthcare transitions to patient-centred and value-based care with emphasis on quality improvement.[5,6,8-11]

A concept that is similar but distinct from PROMS (and not the focus of this review), is patient-reported experience measures, which are instruments used to assess the overall experience and satisfaction associated with an instance of received care, such as an acute inpatient hospital admission.[7] These factors, such as hospital cleanliness and attentiveness of nursing staff, "reflect experience of the process rather than the outcome"[13] and are beneficial for improving the process of care delivery, and typically aren't included in registries.[7,12,13]

The purpose of this review is to identify PROMs commonly used in arthroplasty registries, provide an overview of measurement properties and relevant terminology, review collection methods and timing and provide practical recommendations for the implementation of PROMs collection. We also review implementation challenges and the role of PROMs in public reporting, value-based care and comparisons of care delivery. Furthermore, we provide examples of registry experience with PROMS, and examine if the use of PROMs can improve outcomes.

Search methods

To identify registries that report on PROMs, a MEDLINE (Ovid) and PubMed search limited to the English language was performed using the medical subject heading terms "Patient Reported Outcome Measures", "Orthopedics", "Registries", "Arthroplasty, Replacement, Hip" and "Arthroplasty, Replacement, Knee". The search yielded six relevant articles for screening.[5,9,14-17] References from the retrieved papers were reviewed for additional papers not identified in the search. The directory from the International Society of Arthroplasty Registries website was consulted to identify member registries.[18] Review of these arthroplasty registries' publicly available annual reports was performed to confirm which registries were collecting PROMs and if additional registries had started collecting this data in the interim since it was last assessed within the related references. Not all registries were found to have publicly available data. Data extracted from the annual reports included, where available, the year of PROMs implementation, which joints were registered, number of patients included, which generic and specific PROMs were used, the frequency of response obtained, timing of collection and any information regarding how the PROMs data was used. Information obtained from the literature included the specifics of the PROMs tools, measurement properties, PROMs implementation, examples of PROMs use in registries and information related to the individual headings of the manuscript herein.

Table 2. Generic and specific patient-reported outcome measures (PROMs) tools commonly used. Adapted from Rolfson et al[9]*

Name of PROMs tool	Abbreviated name	Year developed	Validation	License requirements	Number of translations	Number of items-questions	Time to complete (mins)
Generic							
EuroQol 5-dimension health outcome survey (3-level)	EQ-5D-3L	1990	Hip, knee	Yes	> 170	6	1 to 2
EuroQol 5-dimension health outcome survey (5-level)	EQ-5D-5L	2011	Unknown	Yes	Unknown	6	2 to 3
Short Form-36 health survey	SF-36	1992	Hip, knee	Yes	> 50	36	5 to 10
Short Form-12 health survey	SF-12	1996	Unknown	Yes	> 40	12	2
Veterans Rand 36-item survey	VR-36	Unknown	Unknown	No	> 3	36	5 to 10
Veterans Rand 12-item survey	VR-12	1997	Unknown	No	> 3	12	2 to 3
Patient-Reported Outcome Measurement Information System Global 10	PROMIS-10 Global	2004	No	No	> 40	10	2 to 3
Specific							
Oxford Knee Score	OKS	1998	Knee	Yes	19	12	3 to 4
Oxford Hip Score	OHS	1996	Hip	Yes	11	12	3 to 4
Knee Injury and Osteoarthritis Outcome score	KOOS	1998	Knee	No	44	42	10 to 15
KOOS short form (joint replacement)	KOOS-JR	2007	Knee	No	Unknown	7	3
Hip Disability and Osteoarthritis Outcome score	HOOS	2003	Hip	No	17	40	10 to 15
HOOS short form (joint replacement)	HOOS-JR	2008	Hip	No	Unknown	6	3
Harris Hip Score	HHS	1969	Hip	No	Many, but not all validated	10	5 to 7
Western Ontario and McMaster Universities Arthritis Index	WOMAC	1982	Hip, knee	Yes	92	24	5 to 10
University of California at Los Angeles Activity Score	UCLA	1984	Hip, knee	No	Unknown	1 (10 levels)	2 to 3
Visual analogue scale for pain	VAS	1920s (first use), 1970s (acceptance)	Yes construct, no criterion	No	Unknown	1	< 1

*Domains covered by surveys: EQ-5D-3L, EQ-5D-5L: mobility, self-care, usual activities, pain/discomfort, anxiety/depression; SF-36, SF-12, VR-36, VR-12: vitality, physical functioning, bodily pain, general health perceptions, physical role functioning, emotional role functioning, social role functioning, mental health; PROMIS-10 Global: general, physical and mental health, pain, fatigue, quality of life, social function, emotional problems; OKS, OHS: joint pain and function; KOOS/HOOS: pain, other symptoms, function in activities of daily living, function in sport and recreation, knee-/hip-related; quality of life; KOOS-JR/HOOS-JR: function in daily living, joint pain, stiffness (KOOS-JR only); HHS: pain, function including gait and activities of daily living, absence of deformity, range of motion;[68] WOMAC: pain, disability and joint stiffness in knee and hip osteoarthritis; UCLA: level of activity; VAS: scale 0 (no pain) to 100 (worst pain imaginable), patient marks along scale; graphic formats (varying degrees of happy to sad face) exist[34]

PROMs used in arthroplasty registries

Generic measures

There are a variety of generic PROMs available for use (Table 2). They differ in terms of the number and type of questions ('items') asked, whether or not a cost or license is required for their use,[5,9] the recommended reading level required to complete the questionnaire,[19] the available language/translations of the PROM itself,[5,9] the time required to complete and the type of subscales or measures produced. The EuroQol 5-dimension health outcome survey (EQ-5D)[20] is the most commonly used generic PROM amongst arthroplasty registers[5] and provides measurement in five dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Another generic PROMs tool used in arthroplasty is the Short Form-36 (SF-36) health survey or a shortened version, the Short Form-12 (SF-12),[5,21-23] whose responses are summarized to provide a physical and mental component score. The SF-36 is a commonly used PROM in clinical trials, but, while utilized, is not the most common among arthroplasty registers.[9,13] A nearly identical tool developed at the Boston University School of Public Health is the Veterans Rand (VR) health survey, which is available in both 36- and 12-question versions.[24] The PROM Information System Global 10 Health Measure (PROMIS-10 Global) is another generic PROM that includes both a physical and mental health component, but that has not yet been validated for arthroplasty.[14,25] Together, the SF and VR are the second most commonly used generic PROMs within arthroplasty registers, however, the PROMIS-10 Global is gaining in popularity and use, particularly in North America.[5,14] As illustrative examples, the EQ-5D is currently used in 61% of the known major national and regional arthroplasty registers that collect PROMs including the Swedish national joint registries (SKAR, SHAR), the English and Welsh National Joint Registry and the New Zealand Joint Registry. Furthermore, the

VR-12 and PROMIS-10 Global are used in the American Joint Replacement Registry (AJRR) and the SF-12 and SF-36 by the regional Geneva Arthroplasty Registry and the Function and Outcomes Research for Comparative Effectiveness in Total Joint Replacement (FORCE-TJR) registry, respectively.[5] According to the International Society of Arthroplasty Registries (ISAR) PROMs Working Group, there is no recommendation of one generic PROMs tool over the other.[5,9,26]

Joint-specific measures

Like generic PROMs tools, there are many different hip and knee joint specific PROMs tools that can be utilized to collect data. Commonly used questionnaires include the Hip Disability and Osteoarthritis Outcome Score (HOOS) and Knee Injury and Osteoarthritis Outcome Score (KOOS).[5,27-29] The full versions of the KOOS/HOOS include many items and can take considerable time to complete, thus they have been broken down into shorter versions that specifically assess physical function and pain,[15,16] as well as an additional item for stiffness in the knee only. The Oxford Knee Score and Oxford Hip Score are also commonly used; each includes 12 questions related to pain and function[30-32] and produces a single score. The Western Ontario and McMaster Universities Arthritis Index (WOMAC) is another commonly used specific PROMs tool used by various joint registries.[5,33] The WOMAC includes 24 questions regarding pain, stiffness and disability, although a modified 12 question version has also been developed.[5,33] The ISAR PROMs Working Group does not recommend one specific PROMs tool over another given the number available and the differential use between various registries.

Single-question measures

When PROMs tools do not provide specific measures of pain, registries may account for this by gathering pain data using a visual analogue scale (VAS) or a numeric rating scale (NRS),[34] such as done at the SHAR.[5] Completion of a pain VAS typically requires the patient to place a mark on a 10-cm line that runs from 0 (no pain) to 100 (worst pain imaginable); it is scored by measuring the location on the line where the patient marks their pain level. Completion of a pain NRS typically involves the patient simply choosing a value between 0 (no pain) and 10 (worst pain). While both methods are valid, collection of pain scores using the VAS can be more resource intensive due to the need to manually measure and input data.

Measurement properties and relevant terminology

The development of a PROM tool is a complex process that requires rigorous assessment of the questionnaire's measurement properties to ensure it is reliable, valid, responsive and acceptable to patients.[5,6,9,13] Reliability is "the consistency between the score of a health outcome measure applied in different circumstances"[6] and includes the principles of "internal consistency" and reproducibility.[5] It can be thought of as the ability of a measurement tool to produce the same value on different occasions when assessing an attribute that remains unchanged. Validity is "the ability of an instrument to measure the intended outcome"[5] and can be demonstrated three ways: content, criterion and construct.[5,6,35] Content validity is the magnitude to which the tool assesses the desired concept.[5,6] Criterion validity is a tool's ability to measure something relative to a known gold-standard benchmark.[5,6] Construct validity is how the instrument performs between different groups and the extent to which it correlates with other tools.[5,6] Responsiveness is "the ability of the PROM tool to detect a change in the patients' clinical condition"[6] and includes recognition of the concepts of minimal clinically important difference (MCID) and minimal detectable change (MDC).[5,6] MCID is the minimum amount of change in a PROMs score that is clinically apparent or consequential to a patient.[6,36] MDC is the necessary amount of change to ensure the change seen is true and outside the measurement error associated with the PROM itself.[5,37] Lastly, the PROM must be acceptable to the patient completing it; including the time required to complete the questionnaire, the number of questions, the language translation and the reading level of the PROM.[5,6,19,38]

The concepts of differential item functioning (DIF) and response shift and how they relate to analysis and interpretation of PROMs data requires further understanding. DIF refers to the "failure of measurement invariance"[39], otherwise known as the absence of bias, and is a component of item response theory.[39,40] DIF occurs when an 'item' (question) in a PROMs tool produces different measures for different groups of patients (age, sex, socioeconomic status, etc.). The concept is important for valid assessment of PROs in health disparity research. Response shift reflects patient adaptation to chronic illness, such as hip and knee osteoarthritis. It involves changes in "internal standards, values, or conceptualization"[42] that one may go through to adjust and live with their illness. For example, Perneger and Lubbeke[41] found that patients' self-evaluation of their health after hip or knee arthroplasty surgery did not change, despite significant improvements in both the physical and mental subscales of the SF-12. This likely represents a change in their "internal standard of measurement"[41] that occurred after surgery. This concept is important to QoL research, and thus PROMs research, as it shows how QoL is affected by changes in health status and aids in the creation of validated measures to assess such changes.[42,43]

Collection methods and timing

PROMs data is typically collected via a patient-completed paper form or electronic-based questionnaire.[7,9,13] Electronic data may be collected by computer, tablet or other handheld computing device, telephone or web-based survey tool.[9] A secure web-based PROMs reporting system has been developed and implemented within the FORCE-TJR registry for patient use with over 80% enrolment and data completion.[44] In-office computer terminals can be effective, but may require staff to be available to support patients if difficulties are encountered with completion to avoid missing data. Paper-based questionnaires can be relatively easy for patients to complete, but issues persist with mail-out, having patients mail them back, following up on missing data, entering data manually and possible data entry errors or duplications. Generally, PROMs should be administered by dedicated staff as surgeons themselves may not have the time in clinic to facilitate their proper completion and collection to avoid missing data, though adherence and completion rates may improve if the surgeon requests the patient to comply specifically.[9] At the SHAR, regional coordinators send lists of patients due for follow-up to local administrators whose job it is to send out forms, enter data and pursue missing data.[1] This centralized method has enabled them to achieve a successful response rate of approximately 90%, whereas other registers may struggle with a much lower response success rate. Preoperatively it is recommended that the questionnaire be completed by the patient who has decided to undergo surgery at least three to four weeks prior to their surgical date.[9] Postoperatively, questionnaires should be completed at six months to one year for patients that have undergone either hip or knee arthroplasty.[9]

Collection recommendations

The ISAR Working Group has previously made recommendations regarding how joint registries should collect PROMs. While there is no recommendation regarding use of a particular generic or specific PROM, they do recommend that when selecting a PROMs tool, it has been "appropriately developed with a relevant patient population"[9] and "has good measurement properties for patients who have arthroplasty".[5,9] Regardless of the implemented tool, it is recommended that registries choose only one specific and generic tool and keep the number of items to the minimum that is required to obtain the essential information about overall pain and function. In addition, they also recommended inclusion of both a single-item pain and satisfaction question with wording in a specific manner. The Group recommends that patients be provided the option of completing paper-based or electronic-based PROMs questionnaires. A response rate of 60% has been accepted in recognition of the difficulties associated with collection of PROMs. Furthermore, they recommend recording the specific primary diagnosis for each joint, age, sex, preoperative health status, education level, Charnley classification and degree of joint pain and functional limitation (pre- and postoperative) to be used in 'case-mix adjustment models' so that outcomes may be compared appropriately between international registries.[5,9] It is also recommended that qualified statisticians or epidemiologists be employed by registries to facilitate proper analysis and reporting of collected data. Despite best intentions, what PROMs data is collected may be based on a pragmatic approach influenced by geographical- and region-specific variations in what is acceptable and practiced nationally.

Other considerations

Implementation challenges

Despite the benefits that collection of PROMs can provide, they have not yet been widely adopted and criticisms remain.[5-7,9,13,45] This is partly due to the fact that initiation of a PROMs programme and collection of this data within a registry is a significant undertaking with respect to time, effort and cost. Establishment is resource heavy, requiring a surgeon or registry-affiliated champion or project lead, buy-in from registry executive or board members, as well as from the orthopaedic surgeons performing the surgeries and contributing data to the registry itself.[9] Additionally, a team of dedicated PROMs researchers may be required in order to administer the questionnaires (paper or electronic), follow-up on their completion to minimize missing data, enter the data into a collection system and minimize transcribing errors or duplications, ensure data is stored properly to prevent inadvertent release of personal health data, send notifications to patients to complete the questionnaires and maintain the employ of a statistician or epidemiologist for proper data analysis.[5-7,9,13] The often-elderly arthroplasty patient population and potential lack of knowledge regarding use of electronic devices and computers may make increased electronic administration reliance difficult.[9,13,46] A 2016 paper by Rana[17] outlines the implementation of a PROMs database for a group of six arthroplasty surgeons in Maine, United States and the unexpected difficulties which were encountered.[17]

Scepticism regarding the use of PROMs may be an issue.[6] For example, a Cochrane review regarding the use of PROMs to improve treatment for adult mental health disorders found that providers felt pressured to use PROMs in practice, leading to scepticism and irritation.[47] Providers felt that patient diversity and differences could not be reasonably represented by the rigid PROMs tools, leading

to significant bias, and that thorough patient assessments, if properly performed, provided enough information to guide appropriate treatment.[47]

Public reporting

Public reporting of PROMs may become reality in the near-future, particularly in the United States where outcomes data is already available for thoracic and cardiac surgery,[48] as well as in the United Kingdom with the NJR.[49-51] A recent publication by Greenhalgh et al[12] examining how outcomes data might stimulate healthcare improvement utilized realist synthesis of 63 papers to identify three main theories underlying the public reporting of PROMs: 1) supporting patient choice; 2) improving accountability; and 3) enabling providers to compare their performance with others. Interestingly, they found that patients and their general practitioners rarely used publicly available data when selecting providers; providers were skeptical of reporting schemes they viewed as "politically led" and not clinician driven, but that meaningful clinician involvement in indicator selection, case mix adjustment and data ownership could drive improved patient care. Other important considerations included the timeliness of data, the ability to link to other data sources to undertake risk adjustment and understand possible reasons for poorer outcomes and the necessity of having a system-wide approach to change within their organization. Overall, it does appear that when done in a thoughtful manner that is supported by clinicians and occurs in an environment that supports change, the public reporting of PROMs holds the potential to improve care delivery.

Value-based care

Value-based care, as described by Porter,[10] is the concept of value being defined by outcomes relative to costs per dollar spent. He advocates that value should be measured by the outcome achieved for the patient rather than the "volume of services delivered" and that a focus on saving money can limit effective care, which alters the goals of delivering care. The concept provides a rationale and means for directing resources to care that provides 'value' to patients: care that successfully meets their needs.[10] It is important to understand what value is from a patient's perspective and should be measured accordingly, a role that PROMs can fulfill. Being able to understand and measure the value provided by different medical therapies or interventions, such as with the use of quality-adjusted life years (QALYs), can provide for a more rational allocation of healthcare resources.[52] A QALY is a generic measure of disease burden that incorporates both measures of generic QoL (such as that measured by the EQ-5D)[20,52] and the quantity of time lived; one QALY equates to one year of perfect health. A study by Jenkins et al[52] confirmed the cost-effectiveness of THA and TKA as measured by the number of and cost per QALYs gained, as well as in overall clinical improvement. They found that QALYs increased by 6.5 years after THA and four years after TKA with a cost per QALY of $1792 (USD) for THA and $2744 for TKA.[52] Comparatively, dialysis for end-stage renal disease typically results in QALY improvement of 2.4 years with cost per QALY of $61 294.[53] Understanding costs and the importance of outcomes can benefit all stakeholders and help to achieve economic sustainability in one's respective healthcare system[10] by directing resources from low-value care to high-value care. The use of PROMs is integral to this process.

Comparisons of PROMs data across registries

Comparison of PROMs data between different registries is an area that deserves further exploration. Comparisons can demonstrate national or regional differences in pre- and postoperative PROMs, as well as improvement in PROMs. These differences have the potential to help illustrate how variations in patient selection (preoperative disease severity, age, sex, comorbidities) and processes of care delivery (for example public *versus* private funding) can affect rates of surgery and surgical outcomes. However, these comparisons need to be done thoughtfully, as confounding factors such as age, sex, body mass index, comorbidities[54] and socioeconomic status[55] among others may make comparisons difficult.[9] The use of different PROMs tools across registries also presents unique challenges, since robust 'cross walk' algorithms will need to be developed to allow for valid comparisons.

Some examples of registry experience with PROMS

Approximately 18 orthopaedic arthroplasty registries, primarily the larger, well-established national registries, collect PROMs on all or a sample of hip and knee arthroplasty patients recorded in their registry and report on their findings on a yearly basis.[9] Some registries are currently in the evaluation phase and determining how the logistics of PROMs collection will work within their registry (Australia and America),[26,56] while the Canadian Joint Replacement Registry is set to begin regular collection in 2018.[57,58] There are a total of 38 full or associate ISAR member registries listed in the ISAR directory and, though a survey was not conducted as done by Rolfson et al[5] in 2014, a thorough search of each registry's website and annual report, when available, determined 18 registries currently collecting PROMs, leaving 20 registries that are not. Table 3 lists the known national and regional registries that collect and report on PROMs, as well as those pending collection, as evidenced by details provided in each registry's respective

Table 3. Characteristics of arthroplasty registries that routinely collect patient-reported outcome measures (PROMs). Adapted from Rolfson et al[9]

Registry type/name	When started collecting PROMs	Joint included		Patients included	Generic PROMs	Specific PROMs	Satisfaction item	Frequency of response (%)		Data collection times	
		Hip	Knee					Preoperative	Postoperative	Preoperative	Postoperative
National											
Swedish Hip Arthroplasty Register	2002	Yes	No	All	EQ-5D	Pain Likert scale	Yes	86 to 89	87 to 92	Yes	1 yr, 6 yrs, 10 yrs
Swedish Knee Arthroplasty Register	2008	No	Yes	Samples	EQ-5D	KOOS, pain VAS	Yes	90	80	Yes	1 yr
National Joint Registry (United Kingdom/National Health Service)	2009			All	EQ-5D	OHS/OKS	Yes	80	80	Yes	6 mths
New Zealand Joint Registry	2002	Yes	Yes	Random samples*	EQ-5D	OHS/OKS	No	-	70 to 75	No	6 mths, 5 yrs
Dutch Arthroplasty Register	2007-	Yes	Yes	All	EQ-5D	OHS/OKS	Yes	48 to 54	50	Yes	3 mths, 6 mths, 1 yr
Norwegian Arthroplasty Register	-	Yes	Yes	Samples	EQ-5D	HOOS/KOOS	No	-	80	No	1 to 2 yrs
Lithuanian Arthroplasty Register	-	Yes	Yes	Samples	EQ-5D	HOOS/KOOS	No	100	60	Yes	6 mths, 1 yrs
Australian Orthopaedic Association National Joint Replacement Registry	2 yrs pilot, started 2018	-	-	-	-	HOOS-12/ KOOS-12	-	-	-	Yes	-
American Joint Replacement Registry	Pilot, started 2016	Yes	Yes	All	VR-12, PROMIS-10 Global†	HOOS-JR/ KOOS-JR	-	1.4 to 31 (combined)‡		Yes	-
Function and Outcomes Research for Comparative Effectiveness in Total Joint Replacement (United States)	2015	Yes	Yes	All	SF-36	HOOS-JR/ KOOS-JR, pain VAS	No	80 to 85	80 to 85	Yes	6 mths, 1 yrs
Canadian Joint Replacement Registry	Pilot, start Spring 2018	Yes	Yes	All	EQ-5D	OHS/OKS	Yes	-	-	Yes	1 yr
Arthroplasty Clinical Outcomes Registry National (Australia)	2012	Yes	Yes	All	EQ-5D	OHS/OKS	Yes	-	89.7	Yes	6 mths
Regional											
California Joint Registry	2011	Yes	Yes	All	VR-12	WOMAC, UCLA	No	30	30	Yes	6 mths, 1 yr, 2 yrs
Michigan Arthroplasty Registry	2015	Yes	Yes	All	PROMIS-10 Global	HOOS-JR/ KOOS-JR	No	25	10	Yes	5 to 13 wks, 5 to 13 mths, 2 yrs, 5 yrs, 10 yrs
Hospital for Special Surgery (United States)	-	Yes	Yes	All	PROMIS-10 Global	HOOS-JR/ KOOS-JR	Yes	80	75	Yes	1 yr
Harris Joint Registry (United States)**	-	Yes	Yes	All	EQ-5D	HHS/ KOOS/ UCLA	Yes	-	-	Yes	1 yr, 3 yrs, 5 yrs, 7 yrs, 10 yrs
Geneva Arthroplasty Registry**	-	Yes	Yes	All	SF-12	WOMAC, UCLA, HHS	Yes	77	77	Yes	1 yr, 5 yrs, 10 yrs, 15 yrs
Italian Progetto Registro Italiano Artro Protesi**	-	Yes	No	Samples	EQ-5D	HOOS	Yes	30	80	Yes	1 yr

*20% sample from each group hip and knee
†PROMIS-10 Global not yet validated for arthroplasty [14]
‡6% to 11% of sites reporting
**Will also collect patient-reported experience measures (PREMs) via Canadian Patient Experiences Reporting System
Data from Rolfson et al[9] (not public)
Hyphen (-): data either missing or unknown/not available.
EQ-5D, EuroQol 5-dimension health outcome survey; KOOS, Knee Injury and Osteoarthritis Outcome score; VAS, visual analogue scale; OHS, Oxford Hip Score; OKS, Oxford Knee Score; HOOS, Hip Disability and Osteoarthritis Outcome score; VR-12, Veterans Rand 12-item survey; PROMIS-10 Global, Patient-Reported Outcome Measurement Information System Global 10; HOOS-JR, HOOS short form (joint replacement); KOOS-JR, KOOS short form (joint replacement); WOMAC, Western Ontario and McMaster Universities Arthritis Index; UCLA, University of California at Los Angeles Activity Score; HHS, Harris Hip Score

annual report and survey work previously performed by the ISAR Working Group.[5,9,13] There is significant variability between what generic and specific PROMs tool is used, the percentage of total patients included i.e. all hip and knee patients or just a representative sample, frequency of response and number lost to follow-up or missing data and pre- and postoperative time-points when data is collected. This leads to one of the common criticisms of PROMs which is the ability to perform comparisons between collected data despite the varied use of PROMs instruments and variable response completion.[5,9] For instance, in the first year of PROMs collection in the AJRR, they had only 6% of reporting sites submitting PRO data, which later improved to 11%.[26] Contrast this with the Swedish hip or knee registers which consistently report near to 90% completion.[1,2]

PRO data collection in the United Kingdom began in 2008 with a voluntary review of mastectomy and breast reconstruction, followed a year later by expansion to mandatorily include common elective surgical procedures such as hip and knee arthroplasty, varicose vein stripping and inguinal hernia repairs.[7,50,51] Included were pre- and postoperative generic and specific PROMs tools and the data collected were analyzed and published on a continual basis, available to providers and all members of the public.[50,51] The data itself has been utilized over the years to facilitate patient-centred care, aid in decisions regarding surgical timing, to evaluate the effectiveness of care provided, compare outcomes between surgeons and facilities within the National Health Service, to identify areas requiring further attention and to foster quality improvement initiatives.[7,50]

Collection of PROMs has already begun to yield results[1] but there is still much work and analysis to be done with the data until significant benefits with respect to patient care, outcomes and quality improvement are seen.[2,12] For example, PROMs data collection processes from the SHAR have been improved upon and streamlined over time, demonstrating an overall positive trend, but this has led to the identification of 'geographic inequality' related to HRQoL and pain levels among different regions within the country.[1] This can then prompt investigation as to why a certain region is performing poorly compared with others and attempts can be made to rectify the situation with various quality improvement measures. As an additional example, they also found there was no difference in PROs at one-year postoperatively when the experience level of the surgeon or group was considered, which provides affirmation and encouragement regarding the country's residency training programme.[1] Furthermore, it has been shown that PROMs can be affected by different aspects of the surgical technique utilized such as THA approach[59] (i.e. posterior better than lateral) and fixation methods.[1,9,60,61] These examples provide hints at the potential insights gained with PROMs data and show that there is still much work and research to be done in this regard.

Does PROMs use in registries improve outcomes?

To date there is limited evidence demonstrating that PROMs collection in arthroplasty registries has effected any significant change or quality improvement initiative, except for the positive trend noted in the SHAR since 2008.[1,12] In the majority of regions in Sweden patients have been reporting, with a convincing positive improvement trend, better overall health, diminished pain and satisfaction levels exceeding expectations.[1]

A Cochrane review about how one's practice and patient outcomes can be affected by audit and feedback showed improvement, albeit small to moderate, in patient outcomes.[62] They identified factors that aid in increasing the effectiveness of feedback such as being provided on multiple occasions in verbal and written form by different individuals; colleagues, supervisors and patients among others.[62] When feedback is combined with practice audit, it becomes obvious how PROMs can lead to practice changes that benefit patients, such as increased adherence to professional standards, more frequent educational meetings and proper utilization of medical interventions and testing.[62]

While PROMs cannot yet be used at the individual patient level to determine a cut point or appropriateness for surgery,[63] their collection in registries does allow for a better understanding of how other related factors such as age, sex, preoperative disease severity, generic QoL and comorbidities broadly affect the outcome of surgery at the population level.[54,64] This can help inform the individual decision-making process as the information can be incorporated into the clinical setting and, when counselling potential arthroplasty patients regarding surgery, reasonable expectations can be discussed based on fact rather than conjecture.[50] The inability to precisely predict appropriateness at the individual patient level using PROMs is related to poor questionnaire reliability at the individual level, the impact that patient demographics, diagnosis, expectations and comorbidities have on outcome and the lack of validation of PROMs for this purpose.[63]

Conclusion

PROMs are increasing in use in orthopaedic arthroplasty registries.[5,9,13,65] Collection of PROMs data has the potential to provide important information on value-based care, ongoing quality assurance and improvement initiatives, refinement of surgical indications, improved shared decision-making and surgical timing and endpoints that patients are invested in such as HRQoL, pain relief and improved function, rather than revision specifically. PROMs may help with understanding of regional variations and lead

to identification and resolution of potential barriers to effective care. With more PROMs data being collected, new areas of research can expand. Work still needs to be done to understand how PROMs can be utilized effectively to improve patient outcomes. Reporting consistency will need to improve among registries collecting PROMs to allow for useful data characterization and comparison. Despite their drawbacks, PROMs, in theory, should allow for value-based comparisons with other medical interventions and for a more rational allocation of healthcare resources. THA and TKA are procedures done to relieve pain, recover function and improve QoL; thus, it makes sense to measure these characteristics themselves and, only through these measurements, can we then begin to understand how best to improve patient care.

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LICENCE

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