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ABSTRACT

Objective. To define a minimum Standard Set of outcome measures and case-mix factors for monitoring, comparing, and improving healthcare for patients with clinically diagnosed hip or knee osteoarthritis (OA) with a focus on defining the outcomes that matter most to patients.

Methods. An international Working Group (WG) of patients, arthroplasty register experts, orthopedic surgeons, primary care physicians, rheumatologists, and physiotherapists representing 10 countries was assembled to review existing literature and practices for assessing outcomes of pharmacological and non-pharmacological OA therapies, including surgery. A series of 8 teleconferences, incorporating a modified Delphi process, were held to reach consensus.

Results. The WG reached consensus on a concise set of outcome measures to evaluate patients’ joint pain, physical functioning, health-related quality of life, work status, mortality, reoperations, readmissions, and overall satisfaction with treatment result. To support analysis of these outcome measures, pertinent baseline characteristics and risk factor metrics were defined. Annual outcome measurement is recommended for all patients.

Conclusion. We have defined a Standard Set of outcome measures for monitoring the care of people with clinically diagnosed hip or knee OA that is appropriate for use across all treatment and care settings. We believe this Standard Set provides meaningful, comparable, and easy to interpret measures ready to implement in clinics and/or registries globally. We view this as an initial step that, when combined with cost data, will facilitate value-based healthcare improvements in the treatment of hip and knee OA.

Key words. Hip osteoarthritis, knee osteoarthritis, patient-reported outcomes, health outcomes, value-based healthcare
SIGNIFICANCE AND INNOVATION

- The work presented here expands upon current regional and national registry efforts from around the globe and represents the first internationally developed core outcome set for the evaluation and comparison of the treatment of hip or knee osteoarthritis in clinical practice across providers, regions, and countries.
- This work also expands upon current registry efforts by providing a single set of outcome measures to evaluate the full continuum of care for hip and knee osteoarthritis, from self-managed and symptomatic treatment to total joint replacement surgery.
INTRODUCTION

Total expenditures on healthcare as a percentage of the gross domestic product continue to rise worldwide (1). Yet, the World Health Organization estimates that 20–40% of healthcare costs are unnecessary (1). Uncertainty about health outcomes combined with increasing costs have driven interest in value-based healthcare, i.e. the idea of competition on value rather than volume in healthcare, where value is defined as the ratio between patient outcomes and the costs necessary to achieve those outcomes. By focusing on the measurement and reporting of outcomes that matter to patients over the full cycle of care, value-based healthcare empowers patients to make informed choices about their care and enables providers to improve outcomes, increase efficiency, streamline care processes, and decrease the costly and inefficient fragmentation of care delivery (2).

Currently, a major challenge in measuring value in healthcare is the lack of universal metrics for defining value. Therefore, in an effort to facilitate the transition to value-based healthcare, the International Consortium for Health Outcomes Measurement (ICHOM) facilitates the transition to value-based healthcare (VBHC) by convening international WGs to develop standardized and concise outcome measure sets for specific medical conditions with a focus on the outcomes that matter most to patients (www.ichom.org).

Hip and knee osteoarthritis (OA) are among the leading causes of global disability, with an aging and increasingly obese population worldwide likely to increase its prevalence (3). The total annual cost of OA per patient has been estimated to be as much as $5,700 in the United States (4).
Pain and impaired joint function are the main limiting symptoms affecting patients with OA. OA typically develops over the course of many years with varying symptom intensity over time (5).

The modern management of symptomatic hip or knee OA involves holistic assessment and selection of therapies from a wide range of options ranging from lifestyle interventions and education to oral medication and joint replacement surgery (6). All patients should be offered basic treatment options such as lifestyle interventions and education (7). Many patients will require options such as physiotherapy, walking aids, oral medication, or intra-articular injections.

If non-surgical treatment alternatives are insufficient to control symptoms, a smaller group of patients may be candidates for joint replacement or other surgical interventions.

The field of orthopedics is a leader in the measurement of outcomes and use of patient-reported outcome measures (PROMs). Joint replacement registries have demonstrated how routine measurement of outcomes can improve clinical practice by eliminating low-value treatments or harmful implant devices (8, 9). However, most joint registries focus on postmarket surveillance of implants rather than patient-reported satisfaction and function. Moreover, joint replacement represents only a fraction of all care associated with hip and knee OA.

Previous efforts at defining universal standards for measuring hip and knee OA outcomes have focused on assessment of physical functioning and metrics for use in clinical trials (10, 11).

However, there is no common definition of key outcome measures for use in clinical care across all treatments for this condition.

The objective of this work was to define a minimum Standard Set of outcome measures and case-mix factors for evaluating, comparing, and improving the clinical care of patients with hip or knee OA with a focus on the outcomes that matter most to patients.
INTERNATIONAL STANDARD SET OF OUTCOME MEASURES FOR HIP AND KNEE OSTEOARTHRITIS

METHODS

Working Group assembly and composition. This work was initiated by ICHOM, a non-profit organization focused on the development and international adoption of standardized outcome measures for major medical conditions. ICHOM convened a WG composed of 2 patient representatives and 21 international experts in various fields of OA care and research. The WG provided balanced representation across geographies, medical specialties, and existing joint replacement registries and international initiatives as shown in the Appendix. The activities of the WG were coordinated by a Project Team consisting of a WG lead (Franklin), 2 project leaders (Maasakkers and Wissig), a research fellow (Rolfson), and the ICHOM Vice President of Research & Development (Stowell).

Work process and decision-making. The Standard Set was developed using a modified Delphi process (12). Between July 2014 and March 2015, 8 teleconferences were held by the WG. Each teleconference had a specific goal such as establishing the scope of the Standard Set, defining the patient population, selecting the appropriate outcomes and case-mix domains, and defining the relevant metrics. For each topic, the Project Team reviewed the existing literature and current practices and gathered input from expert interviews to develop proposals for discussion at the teleconference. Detailed minutes of these discussions were the distributed to WG members, who voted on each item of the Project Team’s proposal via online survey. Each item required a 67% majority vote of survey respondents to be included in the Standard Set. Survey items with less than 67% majority were either excluded from the Standard Set or revised by the Project Team and re-presented for discussion and voting at the next teleconference.
RESULTS

Response rates. Response rates for the 6 post-teleconference surveys were 90%, 85%, 71%, 84%, 85% and 84% respectively. Group size fluctuated slightly due to the late addition of some members and temporary leaves of absence of others.

Scope. The WG first defined the patient population for which outcomes are to be measured. The diagnosis of hip or knee OA is not always straightforward. Patients with radiographic signs of OA may not have any symptoms while others with severe symptoms have no radiographic changes. Therefore, diagnosis is based on an overall assessment of risk factors, symptoms, and clinical examination (13). There are a variety of treatment options available to meet patients’ needs depending on the severity of symptoms and stages of disease. Due to this complexity, it was decided that the Standard Set should target all patients with clinically diagnosed, symptomatic OA of the hip or knee, regardless of treatment. There was unanimous agreement with this scope within the WG.

Outcome domains. Hip and knee pain, hip and knee function, health-related quality of life (HRQoL), and work status formed the core outcomes domains reflecting the main limiting symptoms of hip and knee OA. Table 1 presents all outcome domains and measures included in the Standard Set and the percent of WG members who agreed with their inclusion.

Outcome measures. The selection of measures to capture the outcome domains above was based on an assessment of the domain coverage, psychometric properties, feasibility to implement, and clinical interpretability of available measures. We aimed to balance pragmatism with
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The 24-item Western Ontario and McMaster Universities Arthritis Index (WOMAC) assesses pain, disability, and joint stiffness in patients with hip and knee OA (14) and has proven valid, reliable, and responsive to OA outcomes (14, 15). However, in addition to being lengthy, it requires a licensing fee to use, potentially limiting broad implementation. The 12-item Oxford Knee and Hip Scores (OKS and OHS) assess pain and function and were designed to measure outcomes following joint replacement surgery (16, 17). They are widely used in clinical studies and joint replacement registries but it is unclear how applicable they are to the general OA population and require a license for use. Developed as extensions of the WOMAC, the Knee injury and Osteoarthritis Outcome Score (KOOS) and the Hip disability and Osteoarthritis Outcome Score (HOOS) are non-proprietary comprehensive alternatives (18, 19). However, these questionnaires are long (42 and 40 items respectively), representing a burden to the respondent. Fortunately, short versions (the KOOS-PS and HOOS-PS) have been developed consisting of 7 and 5 questions respectively. Despite their brevity, these instruments exhibit good measurement properties in the domain of physical functioning and are free of charge to use. The KOOS-PS has been translated into 15 languages, including the 4 most widely spoken, and the HOOS-PS has 10 translations. Following careful consideration, the WG agreed to recommend use of the KOOS-PS and HOOS-PS as measures of hip and knee function in the Standard Set (20, 21).

The HOOS-PS and KOOS-PS do not include a measure of pain. It is common to assess pain using visual analogue scales (VAS) or numeric rating scales (NRS). Despite their differences in
granularity, possible modes of collection, and presentation requirements, these instruments provide congruent results (22). Therefore, to facilitate implementation and align with current practices, the WG agreed to recommend assessment of joint pain via either VAS or NRS (11-item version) using a 1-week recall period (18, 19). Given the prevalence of multi-joint OA, it was also agreed that pain would be assessed for all 4 relevant joints (i.e. the right hip, left hip, right knee, and left knee) as well as the lumbar spine.

**HRQoL PROMs.** There are several tools available to measure HRQoL in patients with hip or knee OA. However, existing practices and the volume of supporting research narrow the options to 2 main alternatives: the Short-Form health surveys (www.sf-36.org) and the EuroQol health outcome measures (www.euroqol.org). The Short-Form 36 (SF-36) assesses 8 dimensions of health, which can be summarized into a physical health and mental health composite score (23). Being the most commonly used generic PROMs in clinical trials, the SF-36 has proven to be a psychometrically sound tool for patients with OA (24). However, the shortened version, SF-12, is preferred for routine follow-up in joint replacement registries for practicality of data collection (25).

The EQ-5D is a generic measure of health status developed by the EuroQol Group (26). It consists of questions assessing 5 health outcome domains, which can be summarized into a single score, and a VAS assessing current overall health state (EQ VAS). Although alternative versions exist, the original version with 3 levels of response options (EQ-5D-3L) is by far the most commonly used and best validated in OA patients (27).

Whereas the EuroQol and SF tools require the purchase of a license, an equivalent Veterans SF-12, the VR-12, is freely available for non-commercial use (28). Considering the widespread use
of both EQ-5D and SF-12/VR-12 in existing orthopedic registries and the absence of major advantages of one over the other, the WG agreed to recommend use of either tool for HRQoL evaluation. For comparisons, a cross-walk algorithm is available to convert SF-12 responses into an EQ-5D index score (29).

**Work status.** The standard ICHOM question for evaluating work status was recommended (30). The exact question and response options are presented in Table 1. Comparing responses to this question at baseline and regular follow-up intervals will reveal the impact of OA on a patient’s ability to work over time.

**Satisfaction.** In addition to measuring health status directly, there are other useful patient-reported measures of treatment success such as satisfaction, fulfillment of expectations, and willingness to repeat or to recommend treatment to others. Although such measures are not true PROMs, they are clearly associated with changes in PROM scores and may indicate how well a provider manages to engage the patient in shared decision-making and to set realistic expectations on outcomes (31). As non-surgical and surgical treatments differ in their effectiveness and risk profiles, the WG agreed on overall satisfaction with treatment results as a common outcome domain for evaluating all treatments (32).

**Complications and adverse events.** The WG considered different approaches for measuring complications and adverse events of surgical treatments. In the absence of uniform, internationally applicable definitions for such events, the WG recommended the commonly used all-cause 30-day readmission and all-cause 30-day mortality following surgical intervention (33). In addition, any complication requiring return to theatre for a consecutive surgery (whether major or minor and regardless of when it occurred) was considered a reoperation and must be recorded.
Due to the diversity of non-surgical OA treatments and the lack of specificity of potential complications, it was not considered feasible to measure complications and adverse events associated with non-surgical care in this Standard Set.

**Disease progression measures.** As the natural course of OA is chronic and progressive, the WG felt that it was important to include measures that indicate disease progression and developed two questions to capture this outcome (Table 1). These questions ask which treatments the patient has undergone and which care providers the patient has consulted for their hip or knee problems in the past year. Annual measurement will reveal intensifications of treatment indicating disease progression. The validity and utility of these questions will be evaluated following the collection of pilot data, and necessary changes will be made.

**Case-mix factors.** A number of patient characteristics and risk factors are known to influence the outcomes presented in Table 1. To ensure fair comparisons across providers with diverse patient populations, the WG identified and defined key adjustment measures to include in the Standard Set. We sought internationally valid measures that minimized the burden of data collection on both patients and healthcare providers. As described above for the selection of outcome measures, the WG first agreed on the risk factor domains to be included and then selected definitions for measuring these domains. Selected domains were patient demographics, body habitus, life style factors, joint related factors, and comorbidities. Table 2 presents a complete list of the risk adjustment measures with the percentage of WG members who agreed on their inclusion.

**Demographics, body habitus, and lifestyle factors.** The key demographic factors considered important to include in the Standard Set were patient age, sex, and socioeconomic status (34-36).
Although many different indicators of socioeconomic status have been published in the literature, only education level as defined by the International Standard Classification of Education (ISCED) can be considered consistent across countries and cultures for international use (35, 37). The WG also identified body mass index, smoking status, and living condition as having a potentially important influence on outcomes and relevant for inclusion in the Standard Set (38).

Although physical activity was considered an important factor affecting treatment outcomes, an appropriate and feasible measure could not be identified. Therefore, the WG adapted a question from the Better management of patients with OsteoArthritis (BOA) Registry in Sweden to create the question presented in Table 2. The WG recommends but does not require the use of this newly developed question. The validity of this question will be tested and its formal inclusion in the Standard Set determined in time.

**Joint history.** The diversity of symptoms and clinical presentations of OA as well as its multifactorial etiology suggest that OA is a heterogeneous group of disorders with a common structural endpoint (39). Unfortunately, despite a large body of research, there is no commonly accepted system for classifying OA phenotypes (40). As specific disease history and etiology may influence disease progression and outcome of treatment, in the absence of an existing, robust classification system, the WG developed a simple physician-reported measure of joint history that broadly categorizes OA etiologies (Table 2). A similar physician-reported measure of joint specific previous surgical history was also included in the set. Physicians are asked to report these measures for all 4 joints as multiple joint involvement affects outcomes (41).

**Comorbidity status.** Comorbidities are known to affect outcomes following joint replacement surgery (42). Although there is limited research on the effects of comorbidities on non-surgical
International standard set of outcome measures for hip and knee osteoarthritis

OA treatments, they likely also affect these outcomes and, in some cases, the available treatment options. Therefore, there was strong consensus within the WG on the importance of including a measure of comorbidities regardless of treatment modality.

Although well-established systems for classifying comorbidity status from clinical or administrative data exist, these systems were not considered feasible for inclusion in the Standard Set due to wide variation in how such information is recorded across countries and healthcare systems. A 13-item patient-reported comorbidity “index” has proven feasible and useful for risk stratification in the UK’s National Health Service (NHS) audit for joint replacements (43). It is a simplified version of the Self-Administered Comorbidity Questionnaire developed by Katz et al., which has been shown to have strong correlation with measures derived from administrative data (44, 45). The index used by the NHS was modified for inclusion in the Standard Set to include a measure of spinal disease and inflammatory arthritis (46).

Finally, PROs measured at baseline provide relevant information about patients’ baseline wellbeing and may also be used in risk stratification. For example, the WG recommends using the emotional health components of the SF-12, VR-12, or EQ-5D to adjust for baseline mental health status.

Data collection timeline. The Standard Set includes a recommendation for the timing of data collection, which is presented in Figure 1. Outcomes and case-mix variables were categorized into baseline and annual measures. All patient-reported measures are to be collected at baseline and information about disease etiology and previous surgeries are collected at baseline via physician report or abstraction from clinical records. Annual measures include pain, functional status, HRQoL, and all non-demographic case-mix variables. Data collection may begin at
diagnosis of OA, at referral for surgery, or following other major changes in treatment regime.

Pre-surgery baseline measures may be collected at any time within a 3-month window preceding the date of surgery. Once data collection begins, it continues annually for life or as long as feasible given the constraints of the local healthcare system. In the event that a patient has surgery to treat hip or knee OA after the start of data collection, the data collection timeline is reset by this event.

Importantly, all annual measures are patient-reported. This model has been successfully deployed in recent TJR registry efforts (47-49) and facilitates implementation by enabling data capture outside the context of clinical care, as data collection may not correspond with the timing of patient clinic visits. Physician-reported measures are only required at baseline or prior to surgery, which correspond to clinic visits.

Although annual measures were considered most appropriate for comparing outcomes across providers, the WG also recognized the value of tracking patient-reported outcomes in clinical practice to evaluate the effectiveness of treatments and aid in shared decision-making. Therefore, a smaller set of optional patient-reported measures (pain and functional status) are recommended for use in clinical practice with the timing of data collection for these measures left to the care provider’s discretion.
DISCUSSION

The ICHOM WG on Hip and Knee Osteoarthritis defined a set of patient-centered outcome measures intended for evaluating the treatment of hip and knee OA and facilitating international comparisons, shared learning, and benchmarking on value across healthcare systems. The main outcomes assessed by the Standard Set include joint pain, physical functioning, HRQoL, work status, mortality, reoperations, readmissions, and overall satisfaction with treatment results. In addition, a set of case-mix variables was defined to enable adjusted comparisons across different populations, healthcare providers, or health system. Baseline data collection with annual follow-up is recommended for comparing outcomes across providers. An optional set of measures is recommended but not required for use in clinical practice.

This set of measures focuses patients with hip or knee OA regardless of disease severity, treatment, or type of provider. In doing so, it enables continuous assessment over the entire course of the disease in alignment with the fundamental framework of VBHC delivery (50). Although this approach may currently present an implementation challenge, we hope it stimulates providers from different settings to coordinate their activities around the patient as opposed to conducting isolated interventions, creating consistency over the full continuum of care.

Traditionally, joint replacement registries commonly organize data collection by primary intervention, joint, and laterality (each joint subject to a primary intervention yields a new case). This approach is suitable for implant surveillance and procedure-related outcomes studies, but is inappropriate for evaluating condition- and patient-centered outcomes in patients with more than 1 affected joint. Patients with OA will commonly require symptomatic treatment for more than
one knee and hip so that primary treatment outcomes such as function and work status, are
affected by the total burden of the condition. Therefore, adoption of the condition- and patient-
centered approach to outcomes measurement recommended here may require restructuring of
current databases (47). We believe, however, that registries that invest in these changes will gain
richer data sets for optimizing joint replacement outcomes.

The Standard Set is publically available and was designed to be implemented in a variety of
settings. Individual provider organizations and registries around the world are encouraged to
implement or align with the Standard Set with ICHOM working to facilitate the development of
the infrastructure to share and compare results.

Particularly in countries without a government-run health system or centralized documentation,
patients’ clinical data may be fragmented across several health records due to changes in
providers or insurers or treatment by multiple providers (e.g. physiotherapists, surgeons, and
primary care physicians). The WG was cognizant of this issue when structuring the data
collection. For patients receiving non-surgical treatment, 90% of the measures included in the
Standard Set are patient-reported. Surgery requires the collection of three additional measures.
However, with the exception of adverse events following surgery, all clinical measures are
captured at baseline or pre-surgical assessment when patients are routinely evaluated in the clinic.
Furthermore, all annual follow-up measures are patient-reported. This allows for direct data
collection from patients, alleviating the need to track records across providers. We recommend
that providers and registries begin collecting these measures over as much of the care continuum
as currently feasible with the goal of increasing care coordination and broadening data collection
as the necessary infrastructure evolves.
International standard set of outcome measures for hip and knee osteoarthritis

We aimed to develop a core set of outcome measures appropriate for evaluating care across countries and clinical settings. As such, the WG included representatives from 5 continents, 10 countries, and a range of clinical specialties. A similarly well-balanced steering committee, comprised of 8 members of the original WG, has been established to govern the Standard Set and oversee updates or changes over time.

In conclusion, we believe this Standard Set provides meaningful, comparable, and easy to interpret measures that are ready to implement in clinics and/or registries globally. This single set of case-mix and outcome measures allows comparisons of outcomes across the full continuum of hip and knee OA care, facilitating communication across providers and comparisons across treatment modalities. This knowledge will incentivize and empower providers to improve care, as well as allow patients, providers and payers to make informed decisions about their healthcare spending and treatment options. These are crucial ingredients in a VBHC system that will benefit all involved parties through transparency and well-aligned incentives.

AUTHOR CONTRIBUTIONS

Stowell, Franklin and Maasakkers conceived and designed the study. Literature review was carried out by Rolfson, Wissig and Franklin. At a minimum, all authors participated in 4 of the 8 teleconferences and responded to at least 50% of the surveys. Rolfson and Wissig drafted the article. All authors were involved in revising the article critically for important intellectual content and all authors approved the final version to be submitted for publication.
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International standard set of outcome measures for hip and knee osteoarthritis
International standard set of outcome measures for hip and knee osteoarthritis

<table>
<thead>
<tr>
<th>Category and outcome domain</th>
<th>Outcome definition</th>
<th>Agreement*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient-reported health status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hip and/or knee function</td>
<td>Tracked via the HOOS-PS or KOOS-PS</td>
<td>100%</td>
</tr>
<tr>
<td>Pain in hips, knees, or lower back</td>
<td>Tracked via numeric or visual analog rating scales</td>
<td>88%</td>
</tr>
<tr>
<td>Quality of life</td>
<td>Tracked via either the EQ-5D-3L, SF-12, or VR-12</td>
<td>100%</td>
</tr>
<tr>
<td>Work status</td>
<td>What is your work status? Unable to work due to a condition other than osteoarthritis; Unable to work due to osteoarthritis; Not working by choice (student, retired, homemaker); Seeking employment (I consider myself able to work but cannot find a job); Working part-time; Working full-time</td>
<td>77%</td>
</tr>
<tr>
<td>Satisfaction with results</td>
<td>How satisfied are you with the results of your treatment? Very satisfied; Satisfied; Neither satisfied nor dissatisfied; Unsatisfied; Very unsatisfied</td>
<td>99%</td>
</tr>
<tr>
<td>Surgical outcomes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Death</td>
<td>All cause 30-day mortality</td>
<td>100%</td>
</tr>
<tr>
<td>Admissions</td>
<td>All cause 30-day readmissions</td>
<td>99%</td>
</tr>
<tr>
<td>Reoperation</td>
<td>Any consecutive open surgery performed on the hip or knee. Includes both minor and major reoperations: Minor revision: any reoperation with removal, exchange, and/or addition of minor implant part (e.g. head, liner) Major revision: any reoperation with removal, exchange, and/or addition of major implant part (e.g. cup, femoral component, tibial component)</td>
<td>94%</td>
</tr>
<tr>
<td>Disease progression</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Treatment progression</td>
<td>Which of the following treatments have you undergone in the past year for your osteoarthritis related hip or knee problems? (tick all that apply) Information/advice (ex: patient education, advice on diet, exercise, or other lifestyle alterations); Self-managed care (ex: non-prescription oral pain medication, medications applied to the skin, exercise or diet program); Non-surgical, clinical care (ex: nonsteroidal anti-inflammatory drugs or other prescription drugs, supervised physical or occupational therapy, orthosis or other ambulatory aids, injections directly into the joint); Surgery (ex: osteotomy, resurfacing, partial or total joint replacement)</td>
<td>82%</td>
</tr>
<tr>
<td>Care utilization</td>
<td>In the past year, which of the following health care providers have you seen for treatment of your osteoarthritis related hip or knee problems? (tick all that apply) Health educator/peer support group, dietician, physical therapist, or general practitioner; Rheumatologist; Orthopedic surgeon; Alternative health practitioner</td>
<td>82%</td>
</tr>
</tbody>
</table>

*Percentage agreement among survey respondents
International standard set of outcome measures for hip and knee osteoarthritis

Table 2: Case-mix variable domains and definitions included in the Standard Set

<table>
<thead>
<tr>
<th>Category and case-mix factor domain</th>
<th>Case-mix factor definition</th>
<th>Agreement*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Demographics</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>Date of birth</td>
<td>100%</td>
</tr>
<tr>
<td>Gender</td>
<td>Sex at birth</td>
<td>100%</td>
</tr>
<tr>
<td>Education level</td>
<td>Please indicate the highest level of schooling completed. None; Primary; Secondary; Tertiary (university or equivalent)</td>
<td>88%</td>
</tr>
<tr>
<td>Baseline clinical status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Joint specific history</td>
<td>Please indicate if the patient has a history or findings of any of the following for each hip and knee. None; Trauma or ligamental injury; Congenital or developmental disorders; Other joint disorders including but not limited to osteonecrosis, inflammatory arthritis, gouty arthritis, septic arthritis, and Paget's disease of the bone</td>
<td>84%</td>
</tr>
<tr>
<td>Joint specific surgical history</td>
<td>Please indicate the type of surgery the patient has on each hip and knee. None; Joint replacement; Osteotomy; Osteosynthesis/facture surgery; Ligament reconstruction (knee only); Other arthroscopic procedures</td>
<td>82%</td>
</tr>
<tr>
<td>Other case-mix factors</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Living status</td>
<td>Which statement best describes your living arrangement? I live with partner/spouse/family/friends; I live alone; I live in a nursing home/hospital/other long term care home; Other</td>
<td>100%</td>
</tr>
<tr>
<td>BMI</td>
<td>Calculated from patient-reported height and weight</td>
<td>88%</td>
</tr>
<tr>
<td>Physical Activity</td>
<td>In a typical week, how much time do you spend doing PHYSICAL ACTIVITY? PHYSICAL ACTIVITY is any activity that makes you breathe hard, feel warm, and feel your heart beat faster. Examples of physical activity are walking, bicycling, and dancing and also housecleaning and gardening. None; About 30 minutes; About 1 hour; About 2 hours; More than 2 hours</td>
<td>88%</td>
</tr>
<tr>
<td>Tobacco smoking status</td>
<td>Do you smoke? No; Yes</td>
<td>88%</td>
</tr>
<tr>
<td>Co-morbid conditions</td>
<td>Have you been told by doctor that you have any of the following? (Tick all that apply to you) Heart disease (for example angina, heart attack or heart failure); High blood pressure; Problems caused by a stroke; Leg pain when walking due to poor circulation; Lung disease (for example asthma, chronic bronchitis or emphysema); Diabetes; Kidney disease; Diseases of the nervous system (for example Parkinson’s disease or multiple sclerosis); Liver disease; Cancer (within the last 5 years); Depression; Arthritis in your back or other condition affecting your spine; Rheumatoid arthritis or another kind of arthritis in addition to osteoarthritis</td>
<td>92%</td>
</tr>
</tbody>
</table>

* Percentage agreement among survey respondents
FIGURE LEGENDS

Figure 1: Data collection timeline

Example 1:

Example 2:

The following are example questionnaires to be administered at the indicated time points:
- Baseline Patient Data
- Annual Patient Data
- Baseline Clinical Data
- Optional measures
- Post surgical measures
- Continue annually
International standard set of outcome measures for hip and knee osteoarthritis

APPENDIX

Appendix: Working Group members by country and specialty, including data initiatives represented

<table>
<thead>
<tr>
<th>Country</th>
<th>Specialty</th>
<th>Working Group member</th>
<th>Data initiative</th>
</tr>
</thead>
<tbody>
<tr>
<td>Australia</td>
<td>Patient representative</td>
<td>Noel Smith</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Physiotherapy</td>
<td>Ilana Ackerman</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Rheumatology</td>
<td>Lyn March</td>
<td></td>
</tr>
<tr>
<td>Canada</td>
<td>Rheumatology</td>
<td>Gillian A. Hawker</td>
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</tr>
<tr>
<td>Indonesia</td>
<td>Orthopedics</td>
<td>Nicolaas Budhiparama</td>
<td></td>
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<tr>
<td>Morocco</td>
<td>Orthopedics</td>
<td>Thami Ben zakour</td>
<td></td>
</tr>
<tr>
<td>New Zealand</td>
<td>Physiotherapy</td>
<td>Jennifer Dunn</td>
<td>New Zealand Joint Registry (NZJR)</td>
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<tr>
<td>Saudi Arabia</td>
<td>Orthopedics</td>
<td>Mojib Manzary</td>
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<tr>
<td>Sweden</td>
<td>Orthopedics</td>
<td>Leif Dahlberg</td>
<td>Better management of patients with OsteoArthritis (BOA)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Ola Rolfson</td>
<td>International Society of Arthroplasty Registries (ISAR)</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Swedish Hip Arthroplasty Registry (SHAR)</td>
</tr>
<tr>
<td>The Netherlands</td>
<td>Orthopedics</td>
<td>Rob Nelissen</td>
<td>Dutch Arthroplasty Registry (LROI)</td>
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<tr>
<td>UK</td>
<td>Patient representative</td>
<td>John Pearce</td>
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<tr>
<td></td>
<td>Primary care</td>
<td>Sally Lewis</td>
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<td></td>
<td>Rheumatology</td>
<td>Philip Conaghan</td>
<td>OMERACT</td>
</tr>
<tr>
<td>USA</td>
<td>Orthopedics</td>
<td>David Ayers</td>
<td>Function and Outcomes Research for Comparative Effectiveness in Total Joint Replacement (FORCE-TJR)</td>
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<tr>
<td></td>
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<td>Thomas Barber</td>
<td>Kaiser Permanente Total Joint Replacement Registry (KPTJRR)</td>
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<td>Kevin Bozic</td>
<td>California Joint Replacement Registry</td>
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<td>James Cailouette</td>
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<td>John Grady-Benson</td>
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<td>Henrik Malchau</td>
<td>Harris Joint Registry</td>
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<td>Swedish Hip Arthroplasty Registry (SHAR)</td>
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<td>Nader Nassif</td>
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<tr>
<td></td>
<td>Primary Care</td>
<td>Said A. Ibrahim</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Patricia Franklin</td>
<td>Function and Outcomes Research for Comparative Effectiveness in Total Joint Replacement (FORCE-TJR)</td>
</tr>
</tbody>
</table>
Author/s:
Rolfson, O; Wissig, S; van Maasakkers, L; Stowell, C; Ackerman, I; Ayers, D; Barber, T; Benzakour, T; Bozic, K; Budhiparama, N; Caillouette, J; Conaghan, PG; Dahlberg, L; Dunn, J; Grady-Benson, J; Ibrahim, SA; Lewis, S; Malchau, H; Manzary, M; March, L; Nassif, N; Nelissen, R; Smith, N; Franklin, PD

Title:

Date:
2016-11-01

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