Final Progress Report

Optimizing the Value of PROMs in Improving Care Delivery through Health Information Technology (PROMOTE)

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9/30/2017 - 7/31/2023

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Acknowledgment of Agency Support: Agency for Healthcare Research and Quality

R18 HS025618

Structured Abstract

Purpose: To partner with an orthopedics group to learn what outcomes are most important to patients and whether incorporating PROMs measures in care and performance reports would improve outcomes.

Scope: The aims of this study were: (1) identify additional patient-preferred outcomes (PPOs) and contextual information for patients who are undergoing knee or hip joint replacements or spinal surgery; (2) test the impact on PROM survey response rates from adding other PPOs and patient contextual information (PCI) to these surveys and from using HIT-enhanced patient outreach by texting reminders; and (3) assess changes to PROMS rates based on dissemination and discussion of Quality and Cost Comparison Reports that compared performance by individual surgeons.

Methods: We used a mixed-methods, cross-sectional design, incorporating data on changes over time. This involved interviews and surveys of patients and surgeons, adjustment of PROM rates for confounding factors, a randomized trial of text reminders, and creation of comparative feedback of individual surgeon PROMs scores and costs.

Results: Most patients prefer an outcome individualized to them rather than a multi-item score. Adding a text reminder improved the response rate for PROMs surveys by an overall 5%. PROMS are widely perceived by surgeons as valuable in aggregate both for the department/organization and individual clinicians. Although five quarterly performance comparison reports did not improve outcomes, the department will continue to produce the reports to assess long term impact.

Key Words: Health Information Technology, patient experience, shared decision making, costs, response rates; orthopedics, patient-reported outcome measures, quality improvement.

Purpose (Objectives of the Study)

Systematically collecting patient-reported outcomes measures (PROMs) and using them in both the care of individual patients and as aggregate data for quality improvement of care processes has been a healthcare dream for the past 15 years. However, few organizations make even partial use of such a complete outcomes system and most have low response rates that create credibility concerns. Furthermore, the evidence of impact on those outcomes is limited and the results are mixed. By partnering with operational leaders in a large medical group that has prioritized building a health information technology (HIT)-based PROMs system as well as obtaining input from both clinicians and patients, we proposed to enhance the information collected, improve survey response rates from patients, and facilitate the likelihood of using the information in both the care of individual patients and for quality improvement. The medical group has already begun this initiative, focused initially on patients undergoing knee or hip replacements or spine surgery. We proposed to supplement the initiative and to provide a much more complete and thorough scientific evaluation of its use and impacts than would otherwise be possible.

The specific aims for this demonstration and dissemination project are to:

- 1. Identify additional patient-preferred outcomes and contextual information useful in care planning for patients who are undergoing knee or hip joint replacements or spinal surgery.
- 2. Test the impact on PROM survey response rates from adding other PPOs and PCI to these surveys and from using HIT-enhanced patient outreach before and after knee or hip joint replacement surgery.
- **3.** Assess the change in PROMS rates based on dissemination and discussion of quarterly Quality and Cost Comparison Reports that transparently compare PROM scores and procedure cost performance by individual surgeons.

SCOPE (Background, Context, Settings, Participants, Incidence, Prevalence)

Background. Although patient outcome measures have been a part of both research and patient care for a long time, they were limited to medical measures like mortality and post-surgical complications until the mid-20th century. At that time, health status and quality-of-life measures were developed, although the focus was still on the clinician perspective until about 2000, when the terminology of *patient-reported outcomes* was developed by the Food and Drug Administration.¹ Since then, there has been a large and growing interest by policy-makers, payers, health systems, and researchers in using PROMs as well as patient-centeredness and shared decision-making as ways to emphasize the patient experience and perspective. Nick Black (chair of the UK National Advisory Group for Clinical Audit) believes that using PROMs for both care and performance measurement could help transform healthcare.²

Nevertheless, few care systems or clinics systematically collect any type of patient-oriented outcome measures, and even fewer integrate those measures in their electronic health records (EHRs) or provide their results to individual patients. The evidence thus far from 9 quantitative systematic reviews is that collecting and reporting PROMs in research studies has so far had limited and mixed impact on outcomes, although there is evidence for an impact on patient-clinician communication and satisfaction.³⁻¹¹ However, five of those reviews were limited to patients with cancer or chronic pain, and reviews that reported on the quality of each study considered most to be of poor to fair quality. In order to learn why there was limited impact on outcomes, Boyce et al also conducted a systematic review of qualitative studies of the experiences of professionals trying to use PROMs to improve quality.¹² They attributed the limited impact to a combination of practical problems (workload, workflow disruption, data collection

problems, use of technology), clinician attitudes (openness to feedback and change), interpretability and validity of measures, and useability to guide decisions. Our review of the literature also suggests that the lack of impact on patient outcomes may come from the fact that many studies either did not include timely feedback to doctors and patients or used research staff to provide that feedback. Black has provided the best summary of the challenges of effective widespread implementation of PROMs in practice:²

- 1. Minimizing the time and cost of collection, analysis, and presentation of data
- 2. Achieving high rates of patient participation
- 3. Recognizing all 3 dimensions of quality: safety, effectiveness, and experience
- 4. Attributing outcomes to the quality of care
- 5. Providing appropriate output to different audiences
- 6. Avoiding misuse of PROMs (e.g., to ration care)

To overcome these challenges, Black encouraged combining the use of PROMs for both the care of individual patients and performance measurement, improving collection methods, prioritizing high-value conditions and treatments, and developing value-based care systems in which services are driven by health outcomes per unit cost. Addressing these challenges and testing those recommendations reflect the main intent and focus of this proposal.

To ensure that PROMs for clinical trials were reliable, valid, and feasible in practice, in 2004 the National Institutes of Health (NIH) created PROMIS (Patient-Reported Outcomes Measurement Information System), which currently includes 19 domains.¹³⁻¹⁵ Although these measures are an important resource and are widely used in research, they are nearly all focused on the quantitative measurement of specific symptoms and bodily functions, and there is nothing on the PROMIS website that suggests that patients were involved in identifying these measures. Johnston et al noted in a 2013 review that "many primary studies do not seem to measure aspects of perceived health and quality of life that are important to patients."¹⁶ Camuso et al's systematic review of the literature on "Engaging patients as partners in developing" PROMs outcome measures in cancer found only 13 PROMs tools that had engaged patients in their development.¹⁷ Reeve et al reported on ISOQOL (International Society for Quality of Life Research) member recommendations for minimum standards for PROMs measures without including any mention of patient involvement.¹⁸ Wiering et al published a scoping review of patient involvement in the development of PROMs.¹⁹ Out of 189 studies reporting on the development of 193 PROMs, only 7% involved patients in all aspects of the development, and 26% had no patient involvement in any aspect. The main involvement was in item development and testing for comprehensibility, but they were "never involved in determining which outcome should be measured." Trujold et al proposed a new PROM classification system in 2013 based on the extent to which PROMs incorporate the patient's perspective, but that has not happened yet.²⁰ Pezold et al reported on a research agenda for PROMs in surgery from a Delphi survey of various stakeholders attending the first annual conference on this topic.²¹ They identified 3 important themes for needed PROMs research (PROs in the decision-making process, integrating PROs into the EHR, and measuring quality in surgery with PROs), but Kodalek et al took them to task for doing so without any patient input.²² Finally, in its report on Standards in the Design and Selection of PROMs for use in patient-centered outcomes research, the PCORI Methodology Committee identified 16 exemplar guidance documents, none of which met their standard that "Patient's views and preferences were sought."23

Finally, since most published studies have not measured the impact of integrating PROMs in the clinical care of individual patients, it is not surprising that those studies have not coupled PROMs with the collection of contextual information about those patients that would be important to their use in that setting. Absent information about the values, preferences, and life circumstances of patients, it is hard for a clinician to know what to make of PROMs, much less what changes in the care plan might be desirable and feasible. Therefore, it seems reasonable to expect that building a PROM system that focuses on providing patients and clinicians with both patient-preferred outcomes and relevant contextual

information as well as providing aggregate reports for quality improvement will be much more likely to produce improvements in care and outcomes than simply providing such aggregate PROM reports. Similarly, it seems likely that, if both PROMs scores and care costs were provided in a peer comparison view to surgeons, they would be more likely to modify their care patterns. The Institute of Medicine report, "Best Care at Lower Cost," concludes that "transparency of process, outcomes, price, and cost information has untapped potential to support continuous learning and improvement in patient experience, outcomes, and cost and the delivery of high-value care."²⁴

Context and Setting Participants, Incidence and Prevalence.

PROMOTE (Patient Reported Outcomes Measure Optimization through Technology and Engagement) funded by the Agency for Healthcare Research and Quality, was conducted in the upper Midwest at HealthPartners, an integrated, multi-specialty health system. This research was embedded in the medical group that had already committed to implementing a self-funded PROM system beginning in orthopedics and expanding beyond to HealthPartners Park Nicollet Care Group. HealthPartners has 1,800 multi-specialty physicians, including 58 orthopedic surgeons working in 55 clinic sites and 8 hospitals and provides care for 1.2 million diverse patients across 6 states. While 40% of these patients are insured by its affiliated health plan, another 15% have Medicare, 18% have Medicaid, 5% are uninsured, and the rest have other private insurance plans. The race and ethnicity of all patients are routinely identified, so while Minnesota is less diverse than many states, patient self-report indicates that our patient population includes 25% minorities and 4% Hispanic/Latino.

While the long-term plan is to implement systematic collection and use of PROMs system-wide, the reason for beginning in orthopedics was that 1 of the 3 ortho units in our medical group already had considerable experience with collecting PROMs and using it in aggregate feedback to physicians. Prior to this research, orthopedics spent 8 years collecting validated outcomes measures before and after 8 orthopedics procedures, with preop response rates of about 85% and post-op rates at 1 year of about 60%. These data have been collected through a combination of electronic tablets at visits, emailed links to Web surveys, and mailed paper surveys collected just before surgery and again at intervals over the next 12 months after surgery. However, reports to patients were limited to immediate information about their current PROM score, and reports to clinicians were limited to aggregate scores. In 2013, each of the 3 orthopedics groups began collecting PROMs before and after all total knee replacement cases, with response rates for both pre-op and 1-year post-op of 10%, 15%, and 51% for the 3 groups. They also did this for spinal surgery (both discectomy/laminotomy and fusion procedures), completing both measures in 43% to 61% of patients.

This initiative used a standardized process across all 3 orthopedics groups for collecting validated PROMs for knee replacement (Oxford Knee Score), hip replacement (Oxford Hip Score), and spine surgery (Oswestry & Visual Analogue Scale for Pain), plus the PROMIS 10 general health scale for all 3, with the goal of obtaining data on at least 65% of relevant patients. This process was developed by a design team of frontline staff and managers and consists of an initial email to patients scheduled for any of these operations, with a link to a website to complete an online survey. If these patients have an office visit before surgery (most do) and have not yet completed the online survey, they are asked to complete it on an iPad while in the clinic. Follow-up surveys are handled in the same way at specified intervals up to 1-year post-surgery. The collected data is incorporated in the EHR, both for use during clinical care and as aggregate data for feedback to individual surgeons and overall quality-improvement efforts. The health system plan is in the process of spreading this approach to other specialties.

This research is highly innovative in many ways, but the most important is it was developed and implemented as a close collaboration between with both departmental and senior organizational

leadership along with patient and clinician engagement from conception to implementation, so this project can also serve as a model for others wishing to enhance patient/clinician engagement.

METHODS (Study Design, Data Sources/Collection, Interventions, Measures, Limitations) for each study aim.

To scientifically evaluate this natural experiment by a major medical group to use Health Information Technology to collect and use PROMs and contextual information in clinical care and quality improvement, we used a mixed-methods approach to data collection. This involved interviews and surveys of patients and surgeons, careful analysis, and adjustment of PROM rates for confounding factors, a randomized trial of text reminders to boost survey responses, and creation and comparative feedback of individual surgeon PROMs scores. For each study aim described below, we included the study design, data collection methods, and analytical approach.

Aim 1: Patient Interview

Design: For this first study aim we first interviewed patients to learn what outcomes are important to patients, called Patient Preferred Outcomes (PPOs), as well as what Patient Contextual Information (PCI]) would be helpful to their clinicians in planning care.

Data collection methods: Patients identified and recruited for interviews were care system patients aged 18 and older who would have or have had, total knee or hip replacement, laminotomy, or discectomy in calendar year 2018 at any care system site. We interviewed 65 patients via semi-structured phone interviews. Our contact rate was 93% (proportion of all cases in which an individual was contacted) and our cooperation rate was 82% (proportion of all cases interviewed of all eligible people ever contacted).

The interview guide focused on asking interviewees about the following:

- 1. What are the most important outcomes (PPOs) they hope for from the surgery?
- 2. What is their understanding of the quantitative scores from the PROMIS 10, Oswestry, Oxford Knee Score, or Oxford Hip Score (after an explanation)?
- 3. To what extent would their scores on #2 measures over time be useful to them?
- 4. What information about their personal situation and values (PCI) should their doctors be aware of to provide them with the best patient-centered care?
- 5. What information do they want to receive about outcomes from these procedures and how do they want to receive it?

Analysis: For the patient and physician phone interviews, we used content analysis using an iterative datareduction method. Information was extracted and summarized into categories, themes, and patterns emerging from and grounded in the data, with an a priori focus on identifying contextual information and outcomes that are important to patients. Open coding was used to create the initial coding frame; data was then coded into categories with similar characteristics. Classification schemes and typologies were used to identify and develop themes and concepts emerging from the data. NVivo, a qualitative data-analysis software program, was used in the data analysis.

Aim 1: Patient Survey

<u>Design</u>: The patient survey was designed to obtain quantitative confirmation of what was learned qualitatively in the patient interviews, using a sample of current patients that was representative.

Data collection: For this component of aim 1, study participants were a stratified random sample of adult

orthopedic patients who had scheduled or recently experienced a hip or knee replacement or spinal surgery. Three hundred and fifty pre- and post-op patients completed a patient survey. The survey was completed by 77% of those contacted in mid-January 2019.

<u>Analysis:</u> Individual survey items were summarized with descriptive statistics (frequency, percentage, mean, standard deviation) within the knee and hip replacement patients separately.

Aim 1: Patient Follow up Survey

<u>Design</u>: The purpose of the follow up survey was to determine if patients could identify the same most important outcome from surgery that they did pre-surgery and to determine the extent that patients can report the degree of improvement in pain and other preferred outcomes.

<u>Data Collection</u>: We implemented a follow-up patient survey with a cohort of PROMOTE pre-op (baseline - BL) participants who previously completed the Aim 1: baseline survey and gave us permission to contact them again.

<u>Analysis:</u> Individual survey items were summarized with descriptive statistics (frequency, percentage, mean, standard deviation) within the knee and hip replacement patients separately.

Aim 1: Interviews with Orthopedic Surgeons

<u>Design</u>. A cross-sectional qualitative study was conducted using semi-structured interviews with a purposive sample of orthopedic surgeons and leaders who would have substantial knowledge of and experience with the organization's PROM system, which was embedded in the electronic health record (EHR) and developed for use in clinical care but was not being used.

Data Collection. We included surgeons whose practices consisted of at least 90% patients with osteoarthritis, including surgical and nonsurgical management, and thus their patients would be completing PROMs surveys, or surgeons who were leaders in one of the three orthopedic divisions in the health plan. The senior research manager for orthopedics identified 14 potential participants meeting these criteria, and the final sample consisted of nine orthopedic surgeons and two leaders who are program directors with responsibility for managing and providing leadership within their orthopedic divisions. Participants had a median (range) age of 46 years (36 to 68), 8 of 9 surgeons and 1 of 2 orthopedic leaders were men, and 8 of 9 surgeons specialized in joint replacement and 1 was a sports medicine specialist. Surgeons obtained their medical degrees between 1984 and 2016 and had a median (range) of 13 years (4 to 36) of experience.

The following research questions were addressed by this substudy:

- Why aren't PROM results used in patient care and what might help?
- What aspects of PROMs are seen as useful and how are PPOs viewed?
- What aspects of the care process may be low value (waste)?
- What aspects of the care process are seen as under the control of the surgeons?

<u>Analysis.</u> Interview data were analyzed in NVivo qualitative analysis software (version 12.6.0 for Mac) using a conventional content analysis approach. The analysis team comprised five authors with multidisciplinary experience including qualitative methods, patient care, patient perspectives, and healthcare data.

The team first independently reviewed each transcript, identifying initial codes and emerging patterns, then met regularly to systematically code and structure the data, as well as identify emergent patterns, categories, and themes in the data. Coding issues were discussed until inductive thematic saturation was reached, where no new codes or themes emerged in the analysis. A final coding framework was established, which the lead analyst then applied to all data. The data were considered and discussed from a variety of viewpoints with individual assumptions addressed and personal biases identified and challenged, as well as alternative viewpoints considered. A study codebook was maintained to compile an audit trail, address coding decisions, and to document the data framework to enhance trustworthiness and analytic rigor in the analysis.

Aim 1: Shared Decision Making and Patient Outcomes

<u>Design</u>. Analysis of existing data in PROMs surveys supplemented by added questions about shared decision-making and patient satisfaction in order to learn whether higher scores for shared decision-making were associated with high scores on PROMs and satisfaction.

<u>Data Collection.</u> Questions/purposes (1) Is a measure of SDM before total joint arthroplasty associated with better patient-reported outcome measures (PROMs) 1 year postoperatively? (2) What is the relationship between the measure of SDM and two measures of patient experience (patient rating of the provider and patient likelihood of recommending the provider) at 1 year postoperatively?

In this observational longitudinal survey-based substudy, patients were surveyed after they were scheduled for surgery and again at 12 months after their procedure. The three-item collaboRATE measure of SDM was added to existing patient surveys of PROMs. The surveys also included the Oxford knee or hip score and two validated measures of patient experience (patient rating of the provider and whether a patient would recommend the provider). Of the 2779 eligible primary joint arthroplasties that occurred from April 23, 2018 to May 1, 2019, 48% (1334 procedures; 859 TKAs and 485 THAs) of the patients responded to both the preoperative and 12-month postoperative surveys. Most of the patients who were included in the analytic sample were white (93%; 1255 of 1344), with only 3% (37) using Medicaid benefits at the time of surgery.

<u>Analysis.</u> Patient responses were analyzed in regression models to estimate the association between preoperative collaboRATE scores and the Oxford knee or hip scores, and patient experience measures 12 months postoperatively.

Aim 2: Text Messaging and Impact on PROMS Response Rates

<u>Design</u>. The objective of this substudy was to understand the impact of text message reminders on the likelihood of responding to a PROM survey among those that did not respond to an initial email request and reminders as part of routine care for total hip or knee replacement surgery overall and by subpopulation. This sub-study of text messaging was a two group, parallel arm, patient-randomized controlled trial comparing PROMS survey response rates prior to and following orthopedic surgery in patients provided text message reminders to return a PROMS survey vs. patients not provided text messages.

<u>Data Collection</u>. Initial non-responders were randomized to a text reminder at 7 and 12 days, if needed, after initial email invitation or not. Both groups also received reminder emails at 5 and 10 days after the initial invitation if needed.

<u>Analysis.</u> Improvements in response rates were compared overall and between important subpopulations to understand the impact of text reminders on response and representativeness of data.

Aim 2: Analysis of Newly added questions to the PROMS surveys

<u>Design.</u> New questions had been added to PROMS in the electronic medical record on March 17, 2020 that asked about the most important outcome at baseline and then how well it had been achieved at 3 and 12 months. We analyzed all surveys that had included these questions in order to learn the feasibility and potential value of patient specific questions by adding them to routinely collected PROMs surveys for total knee arthroplasty.

<u>Data Collection/Analysis.</u> A subset of 1,751 completed surveys with the added questions were analyzed. This was all the responses that we had received from the time that the questions were added until we drew the sample. We reviewed responses to questions from surveys completed at baseline: n=643; 3 month: n=438 and 12 months: n=670.

Aim 2: Adjusting for Variation in Patient-Reported Outcome Measures

<u>Design</u>. The overall goal of this sub study was to learn how to adjust PROM scores for potentially confounding variables, using the extensive existing survey data as well as patient and surgeon characteristics from other sources.

<u>Data Collection</u>. Observational study in which preoperative Oxford Knee Score (OKS) and Patient Reported Outcomes Measurement System (PROMIS)-10 measures were prospectively obtained through patient survey from 1,173 of 1,435 possible patients before total knee arthroplasty and from 810 of the 1,173 patients at 12 months postoperatively (response rates =81.7% and 69.0%).

<u>Analysis.</u> Regression analyses identified the relative contribution of patient and surgeon risk factors to OKS change from baseline to 12 months. Adjusted outcomes were used to calculate an observed and expected score for each surgeon.

The Shift from Aim 3 to Combined Aim 3 – 4 or Main Analysis

Significant challenges required our research team to revise our original Aim 3 to develop a combined Aim 3-4 main analysis.

Simply providing PROMs survey results to the surgeon in the EHR during clinical encounters, was found to be nearly completely unused by the surgeons. In fact, when we examined view rates for all orthopedic-associated encounters for patients that had scheduled or completed a total hip or knee replacement surgery between January 2019 and March 2020, among the 2400 TKA surgeries scheduled for 22 individual surgeons, PROMs data during this 15-month time frame was viewed in the EHR system only 156 times with monthly rates of views as a portion of encounters ranging from 0% to 2.8%, averaging views for only 0.9% of all encounters. Because surgeons and care teams were not routinely using PROMS to improve care during individual patient encounters, we quickly realized our initial plan for aim 3 could not possibly have been a useful trial.

In addition, the COVID pandemic posed a significant challenge to our study design. Due to COVID (and especially in the first year of the pandemic), there were frequent periods of significant reductions in outpatient surgery volumes as elective surgeries were put on hold in orthopedics and office visits were more frequently being conducted via telehealth. Because our analyses were focused on elective surgeries

(joint replacements), the reduction in data availability directly impacted our original analysis plan.

We then revised Aim 3 in consultation with our Coordinating Team and shifted to evaluating whether aggregate performance data feedback could be used to improve outcomes. The revised plan (now referred to as our main analysis) involved developing detailed surgeon-level comparative Quality and Cost reports for our orthopedic total joint surgeons. Reports were provided quarterly to total joint surgeons followed by group discussions with them about their understanding of the data and their formatting.

Original Study Aim 3:	• Compare the impact on outcomes and experience (satisfaction and shared decision-making) from making individual PROM/PPO scores available via the EHR during patient care and via mobile devices versus that for other procedures whose scores are available only to physicians in aggregate.
Original Study Aim 4:	• Test the impact on PROM/PPO scores and costs over time from providing surgeons with aggregate information from HIT claims, accounting systems, and the EHR about their own costs and outcomes for hip/knee/spine procedures relative to their peers.
Combined Aim 3 – 4 and as main analysis	• Assess whether providing joint replacement surgeons with quarterly data that compare their outcomes and costs with their colleagues over time leads to improvement in PROMS outcomes.

Table 1: Modification of Study Aims

Main Analysis: Comparative Quality and Cost Reports for Total Joint Surgeons

<u>Design.</u> During 2022, we produced, distributed, and held discussion sessions for each of 5 quarterly comparative surgeon feedback Quality and Cost reports in collaboration with the department. We planned to use an interrupted time series design to assess changes in cost and quality outcomes over time.

<u>Methods.</u> Single group interrupted time series (11 months pre, 7 months post) analyzed with segmented regression analysis in 2236 total knee arthroplasty (TKA) and 1582 total hip arthroplasty (THA) patients assessing pre- to post-exposure to comparative surgeon feedback reports. We tested change in the level and monthly slope of pre-surgery to 3-month patient-reported Oxford Knee/Hip Scores, provider rating, shared decision-making, total implant costs, and procedure time. We also conducted a survey of surgeons to learn their opinions of the data and formatting as well as usability.

Results: (Principal Findings, Outcomes, Discussion, Conclusion, Significance, and Implications)

Principal Findings and Outcomes.

1. Patient Interviews

Overall, we learned that most patients preferred individual outcomes to scores which they perceived as comparing them to others and were not seen as relevant to them. Patients perceived the scores as more useful for the physician than for them. Patients also indicated that personal information about themselves and their life would help their care team better plan for their recovery.

2. Patient Surveys

The most commonly selected outcomes were "pain relief" and "ability to walk without pain/discomfort". "Ability to return to an active lifestyle" was selected as third most important for hip, knee and discectomy/laminotomy while spine fusion patients chose "decreased numbness or weakness in legs" as their third most important outcome. None of the remaining 14 outcomes were selected as the top three most important by more than 30% of patients. "Ability to drive a car," "improved relationships," and "improved mental health" were selected by fewer than 5% of patients. A majority (60%) of patients reported discussing their most important outcomes with their surgeon before surgery, and 69% believed it is important that their surgeon knows the outcomes important to them. Among patients who had already had surgery, 70% considered their surgery to be a success, and patient perceptions of a successful surgery varied widely from 56% for discectomy/laminotomy to 86% for patients with hip replacement. Patients also identified contextual information about their lives that they believed would be important to their post-operative care, with the top issues being dealing with stairs in their house or stairs leading to their house and concerns about pain medications, infections, taking care of pets, and having a house that is not handicapped accessible.

3. Patient Follow-up Survey

Among the 108 patients who completed the survey, 91 participants agreed to be contacted and 47 completed the survey with a 53% response rate. Overall, findings indicated that patients do change their desired outcomes over time from pre to post surgery. Results were used to draft several options for adding questions to the PROMS questionnaires.

4. Orthopedic Surgeon Interviews

The following themes emerged from the analysis:

Theme 1: PROMS scores are not being used in the care of individual patients because of large barriers, both logistical and perceptual.

- *Logistical:* PROMS difficult to access and use in clinical care and E H R is rarely used during the patient visit. There is not enough time in the visit to add conversation about PROMS.
- *Perceptual:* Providers perceive scored PROMs as not useful in clinical care since patients don't understand PROMs scores and there are concerns about PROMs measurement

Theme 2: There are changes in approaches to PROMs systems that can enhance use & reduce barriers in clinical care.

• Subtheme: Facilitate PROMs as a tool for communicating with patients; Change PROM system in E H R to expedite use; Engage patients earlier on PROMs; Encourage use within care teams & facilitate continuity of care needs

Theme 3: PROMS are widely perceived as valuable in aggregate both for the department/organization & individual clinician. Used for standardizing care/evaluation and quality improvement and used for patient engagement at the system level; Aggregate data used for marketing/promotion of the organization and perceived value for individual clinicians for their own practice.

• Theme 4: Individual patient-preferred outcomes are seen as more valuable within patient care than numeric PROMs scores.

• Sub theme: During patient visits the E H R is rarely accessed. Surgeons also reported that they have no desire to expand the use of the E H R during the visit. PROMS might be valuable if available earlier on when patients are making a decision to have surgery. Presenting it to patients needs to be simpler.

5. Shared Decision-Making/Patient Experience

There was a moderate, positive association between preoperative collaboRATE scores and the Oxford scores at 12 months, after adjustment for potential confounders such as patient age and preoperative functional score (b = 0.58; 95% CI 0.14-1.02; p = 0.01). Similarly, patients with preoperative collaboRATE scores had marginally higher patient experience scores at 12 months postoperatively (b = 0.14; 95% CI 0.05-0.24; p = 0.003) and were more likely to recommend their surgeon (OR 1.43; 95% CI 1.11-1.84; p = 0.005). The patient experience measures were also modestly correlated with collaboRATE scores in cross-sectional associations, both preoperatively and at 12 months postoperatively ($0.29 \ \mu r \ \mu 0.54$; p < 0.01).

The association between preoperative collaboRATE scores and Oxford hip or knee scores suggests that SDM could be one tool to encourage better outcomes. Although previous studies have shown that SDM can improve patient experience, the lack of a strong correlation in our study suggests that PROMs and experience measures are separate domains, at least partly. Improving preoperative SDM between the surgeon and patient might help improve surgical outcomes for patients undergoing TKA and THA.

6. Randomized Controlled Trial of Text Messaging to Improve Response Rates of PROMs Surveys

At day seven, when participants were randomized to text or not, the overall response rate was 63%. The overall response rate increased to 81.2% in the text arm and 76.4% in the no text arm by the end of data collection. The effect of the intervention did not vary by subpopulations considered. Text messages improved response rates to PROMs surveys collected as part of clinical care. Improvements were not seen differentially across subpopulations, suggesting that the intervention did not increase any underlying response bias. Compared to interviewer administered data collection, text reminders are an efficient and low cost means to increase overall response rates.

7. Adjusting for Variation in PROMs Scores

Moderate variation was observed in pre-/post-OKS change among the surgeons (n= 16, mean change = 15.56 2.2, range = 12.1-21.1). Forty-five percent of the variance in OKS change was explained by the factors included in our model. Patient preoperative OKS and PROMIS physical score, race, and BMI were markedly associated with change in OKS, but other patient factors, surgeon volume, and years of experience was not. Eight surgeons had observed scores greater than expected after adjustment, providing an opportunity to learn what strategies were associated with better outcomes. Traditional age/sex adjustment of patient mix would have had no effect on mean PROM scores by surgeon.

8. Added Question Analysis

Most patients (over 80%) volunteered a response when asked about their preferred outcome at baseline, 3 and 12 months. At 3 months, 37% of the PPOs that were self-reported had imperfect alignment with preexisting categories. Allowing patients to self-report their individual outcome provides the surgeon with more detailed information about the patient's preferred outcome at baseline and again at each follow up time point; if that outcome has been met and if the patient's goal had changed over time.

9. Interrupted Time Series Analysis of Impact of Quarterly Outcome Performance Reports

There was no consistent evidence that the receipt and discussion of comparative surgeon performance measure feedback by surgeons resulted in improvement on any of the outcomes considered. Oxford Knee Score change from pre-operation to 3 months had a statistically significant and unexpected decrease of - 2.16 in level in the post-exposure period (p=.03). A reduction in THA procedure time by 7.0 minutes in the post-exposure period (p=.009) was the only statistically significant finding. Repeated exposure to written comparative surgeon feedback based on PROMs data and discussion of this information with colleagues was not sufficient to favorably impact the outcomes examined in this brief time series. A longer study or more proactive interventions may be needed.

Following the disseminating of surgeon-specific comparison reports, we administered a brief survey to 23 Total Joint surgeons to obtain their feedback on the use and value of the quality and cost reports. Among the 23 Total Joint Surgeons who were sent the survey, 14 completed it for a 61% return rate. Overall, surgeons reported that they trusted the data they received from these reports, and they found the information helpful individually and overall for the orthopedics department. Surgeons provided constructive feedback on the reports with valuable suggestions for how to make the reports most useful for clinical practice.

Discussion

These results demonstrate the potentially high value of conducting research in partnership with clinical organizations, at least if the research is focused on a vision and goals that originated with the clinical organization. Working in that partnership, we were able to learn and verify that, at least for hip and knee arthroplasty patients, their desired outcomes would not be as well assessed by established multi-item PROMs measures as by simpler tools that used goal-attainment scaling of individualized goals for each patient. We also demonstrated that these patients could identify such goals and their attainment.

What turned out to be a much bigger challenge is how to incorporate surgeon input into such a system in such a way that it would be usable and used by them in the care of these individual patients. Clearly it is not enough to simply provide them with whatever outcome measures one is able to produce in the electronic medical record, especially if, like these surgeons, they do not normally use the EHR during clinical encounters with their patients.

An equally important barrier to use of outcome data for improvement in quality and costs (value) is that surgeons are not accustomed to seeing aggregate individual performance data trended over time and using it to identify improvement opportunities. Even when one can identify the major causes of variation in outcomes and adjust the performance display for those variations, they need training in order to learn how to identify the changeable reasons for performance differences between surgeons. Then they must use the data in that way to change their practices and to determine through repeated measures over time whether the changes have been effective. Simply providing the data had no impact, at least over a 15 month period of time.

The literature on PROMs is extensive, giving the impression that its use is widespread, and its value demonstrated. However, closer examination of that literature reveals that it is incomplete and that even those care systems that collect it have not yet identified or confronted the barriers that remaining, like those identified in this series of studies:

- 1. Collecting patient-reported outcomes that patients and clinicians care about and will use.
- 2. Collecting measures of those outcomes at very high response rates.

- 3. Displaying the measure results in formats that are easily understandable by both patients and clinicians and that do not add time or work to individual patient encounters.
- 4. Understanding and adjusting for that portion of results that are not under the control of the care team so they do not feel unfairly compared with others.
- 5. Given the current payment systems, learning how to collect and display cost data that reliably reflect changeable care decisions made by the care team.
- 6. Providing the kind of infrastructure and training that allow aggregate performance data to be used to identify and monitor potentially correctable quality and cost problems.

Conclusions/Significance

The approach taken by this care system-research partnership has not only provided substantial new information about patient and clinician opinions about the use of PROMs but also has identified important sources of data variation and barriers to using those data in clinical care and for care improvement. One measure of the project's success is that the partner orthopedics department is planning to continue to make use of what has been learned, including reporting performance scores and exploring ways to use the data to improve. They are also desirous of obtaining new research grants that will support those goals and the larger vision.

Limitations

The generalizability of these data lessons is limited by its focus on two major procedures in a single care system, although the identification of challenges for this work and the potential for care system-research partnerships should be relevant for any care problem or opportunity. Our main analysis is also limited by only continuing for 16 months. It is also possible that given a longer period of reports and more active use of the data to identify and change practice could lead to changes in these measures.

Publications

1. Chrenka EA, Solberg LI, Asche SE, Dehmer SP, Ziegenfuss JY, Whitebird RR, Norton CK, Reams M, Johnson PG, Elwyn G. Is shared decision-making associated with better patient-reported outcomes? A longitudinal study of patients undergoing total joint arthroplasty. Clin Orthop Relat Res. 2022;480(1):82-91. Epub 2021/09/09. doi: 10.1097/CORR.00000000001920. PubMed PMID: 34495891; PMCID: PMC8673995.

2. Solberg LI, Chrenka E, Asche SE, Johnson PG, Ziegenfuss JY, Horst PK, Cunningham BP, Reams M, Swiontkowski MF. Adjusting for variation in patient-reported outcome measures is needed to improve care after total knee arthroplasty. J Am Acad Orthop Surg. 2022;30(2):e164-e72. Epub 2021/09/15. doi: 10.5435/JAAOS-D-20-01371. PubMed PMID: 34520430.

3. Whitebird RR, Solberg LI, Norton CK, Ziegenfuss JY, Asche SE, Grossman ES. What outcomes matter to patients after joint or spine surgery? J Patient Cent Res Rev. 2020;7(2):157-64. Epub 20200427. doi: 10.17294/2330-0698.1738. PubMed PMID: 32377549; PMCID: PMC7197885.

4. Whitebird RR, Solberg LI, Ziegenfuss JY, Asche SE, Norton CK, Swiontkowski MF, Dehmer SP, Grossman ES. Personalized outcomes for hip and knee replacement: the patients point of view. J Patient Rep Outcomes. 2021;5(1):116. Epub 20211104. doi: 10.1186/s41687-021-00393-z. PubMed PMID: 34735662; PMCID: PMC8569118.

5. Whitebird RR, Solberg LI. What's important: Postoperative care planning. Recognizing the central role of pets in many patients' lives. J Bone Joint Surg Am. 2021;103(17):1663-4. Epub 2021/04/29. doi: 10.2106/JBJS.21.00099. PubMed PMID: 33908900.

6. Whitebird RR, Solberg LI, Ziegenfuss JY, Norton CK, Chrenka EA, Swiontkowski M, Reams M, Grossman ES. What Do Orthopaedists Believe is Needed for Incorporating Patient-reported Outcome Measures into Clinical Care? A Qualitative Study. Clin Orthop Relat Res. 2022;480(4):680-7. Epub 2021/12/01. doi: 10.1097/CORR.00000000002059. PubMed PMID: 34846308; PMCID: PMC8923577.

7. Ziegenfuss JY, Grossman ES, Solberg LI, Chrenka EA, Werner A, Asche SE, Norton CK, Nelson A, Reams M, Whitebird RR. Is the Promise of PROMs Being Realized? Implementation Experience in a Large Orthopedic Practice. Am J Med Qual. 2022;37(6):489-94. Epub 20221031. doi: 10.1097/JMQ.000000000000079. PubMed PMID: 36314931.

8. Solberg LI, Ziegenfuss JY, Rivard RL, Norton CK, Whitebird RR, Elwyn G, Swiontkowski M. Is there room for individual patient preferences in the patient-reported outcome measurement revolution? J Patient Cent Res Rev. 2023;10(4) (In press).

Papers submitted for review:

Submitted to Clin Ortho Rel Research

Asche SE, Chrenka EA, Ziegenfuss JY, Solberg LI. The effect of individualized surgeon comparative feedback on arthroplasty outcomes: an interrupted time series analysis.

Submitted to the Journal of Clinical Epidemiology (rejected by being submitted to another journal)

Ziegenfuss JY, Asche SE, Solberg LI, Dehmer SP, Reams M, Grossman ES. The impact of text messaging to promote Patient Reported Outcome (PROs) completion in orthopedic practice: Findings from a randomized control study.

References

1. Wu AW, Kharrazi H, Boulware LE, Snyder CF. Measure once, cut twice--adding patient-reported outcome measures to the electronic health record for comparative effectiveness research. J Clin Epidemiol. 2013;66(8 Suppl):S12-20. Epub 2013/07/17. doi: 10.1016/j.jclinepi.2013.04.005. PubMed PMID: 23849145; PMCID: 3779680.

2. Black N. Patient reported outcome measures could help transform healthcare. BMJ. 2013;346:f167. Epub 2013/01/30. doi: 10.1136/bmj.f167. PubMed PMID: 23358487.

3. Boyce MB, Browne JP. Does providing feedback on patient-reported outcomes to healthcare professionals result in better outcomes for patients? A systematic review. Quality of life research : an international journal of quality of life aspects of treatment, care and rehabilitation. 2013;22(9):2265-78. doi: 10.1007/s11136-013-0390-0. PubMed PMID: 23504544.

4. Catt S, Starkings R, Shilling V, Fallowfield L. Patient-reported outcome measures of the impact of cancer on patients' everyday lives: a systematic review. J Cancer Surviv. 2016. doi: 10.1007/s11764-016-0580-1. PubMed PMID: 27834041.

5. Chen J, Ou L, Hollis SJ. A systematic review of the impact of routine collection of patient reported outcome measures on patients, providers and health organisations in an oncologic setting. BMC Health Serv Res. 2013;13:211. Epub 2013/06/14. doi: 10.1186/1472-6963-13-211. PubMed PMID: 23758898; PMCID: PMC3700832.

6. Greenhalgh J, Meadows K. The effectiveness of the use of patient-based measures of health in routine practice in improving the process and outcomes of patient care: a literature review. J Eval Clin Pract. 1999;5(4):401-16. doi: 10.1046/j.1365-2753.1999.00209.x. PubMed PMID: 10579704.

7. Holmes MM, Lewith G, Newell D, Field J, Bishop FL. The impact of patient-reported outcome measures in clinical practice for pain: a systematic review. Quality of life research : an international journal of quality of life aspects of treatment, care and rehabilitation. 2016. doi: 10.1007/s11136-016-1449-5. PubMed PMID: 27815820.

8. Kotronoulas G, Kearney N, Maguire R, Harrow A, Di Domenico D, Croy S, MacGillivray S. What is the value of the routine use of patient-reported outcome measures toward improvement of patient outcomes, processes of care, and health service outcomes in cancer care? A systematic review of controlled trials. Journal of clinical oncology : official journal of the American Society of Clinical Oncology. 2014;32(14):1480-501. Epub 2014/04/09. doi: 10.1200/JCO.2013.53.5948. PubMed PMID: 24711559.

9. Luckett T, Butow PN, King MT. Improving patient outcomes through the routine use of patientreported data in cancer clinics: future directions. Psychooncology. 2009;18(11):1129-38. doi: 10.1002/pon.1545. PubMed PMID: 19319920.

10. Marshall S, Haywood K, Fitzpatrick R. Impact of patient-reported outcome measures on routine practice: a structured review. J Eval Clin Pract. 2006;12(5):559-68. doi: 10.1111/j.1365-2753.2006.00650.x. PubMed PMID: 16987118.

11. Valderas JM, Kotzeva A, Espallargues M, Guyatt G, Ferrans CE, Halyard MY, Revicki DA, Symonds T, Parada A, Alonso J. The impact of measuring patient-reported outcomes in clinical practice: a systematic review of the literature. Quality of life research : an international journal of quality of life

aspects of treatment, care and rehabilitation. 2008;17(2):179-93. Epub 2008/01/05. doi: 10.1007/s11136-007-9295-0. PubMed PMID: 18175207.

12. Boyce MB, Browne JP, Greenhalgh J. The experiences of professionals with using information from patient-reported outcome measures to improve the quality of healthcare: a systematic review of qualitative research. BMJ quality & safety. 2014;23(6):508-18. doi: 10.1136/bmjqs-2013-002524. PubMed PMID: 24505110.

13. Cella D, Riley W, Stone A, Rothrock N, Reeve B, Yount S, Amtmann D, Bode R, Buysse D, Choi S, Cook K, Devellis R, DeWalt D, Fries JF, Gershon R, Hahn EA, Lai JS, Pilkonis P, Revicki D, Rose M, Weinfurt K, Hays R. The Patient-Reported Outcomes Measurement Information System (PROMIS) developed and tested its first wave of adult self-reported health outcome item banks: 2005-2008. J Clin Epidemiol. 2010;63(11):1179-94. Epub 2010/08/06. doi: 10.1016/j.jclinepi.2010.04.011. PubMed PMID: 20685078; PMCID: 2965562.

14. Magasi S, Ryan G, Revicki D, Lenderking W, Hays RD, Brod M, Snyder C, Boers M, Cella D. Content validity of patient-reported outcome measures: perspectives from a PROMIS meeting. Quality of life research : an international journal of quality of life aspects of treatment, care and rehabilitation. 2012;21(5):739-46. Epub 2011/08/26. doi: 10.1007/s11136-011-9990-8. PubMed PMID: 21866374.

15. Tucker CA, Cieza A, Riley AW, Stucki G, Lai JS, Bedirhan Ustun T, Kostanjsek N, Riley W, Cella D, Forrest CB. Concept analysis of the patient reported outcomes measurement information system (PROMIS((R))) and the international classification of functioning, disability and health (ICF). Quality of life research : an international journal of quality of life aspects of treatment, care and rehabilitation. 2014;23(6):1677-86. Epub 2014/02/07. doi: 10.1007/s11136-014-0622-y. PubMed PMID: 24500657.

16. Johnston BC, Patrick DL, Busse JW, Schunemann HJ, Agarwal A, Guyatt GH. Patient-reported outcomes in meta-analyses--Part 1: assessing risk of bias and combining outcomes. Health and quality of life outcomes. 2013;11(1):109. Epub 2013/07/03. doi: 10.1186/1477-7525-11-109. PubMed PMID: 23815754; PMCID: 3708764.

17. Camuso N, Bajaj P, Dudgeon D, Mitera G. Engaging Patients as Partners in Developing Patient-Reported Outcome Measures in Cancer-A Review of the Literature. Support Care Cancer. 2016;24(8):3543-9. doi: 10.1007/s00520-016-3151-0. PubMed PMID: 27021391.

18. Reeve BB, Wyrwich KW, Wu AW, Velikova G, Terwee CB, Snyder CF, Schwartz C, Revicki DA, Moinpour CM, McLeod LD, Lyons JC, Lenderking WR, Hinds PS, Hays RD, Greenhalgh J, Gershon R, Feeny D, Fayers PM, Cella D, Brundage M, Ahmed S, Aaronson NK, Butt Z. ISOQOL recommends minimum standards for patient-reported outcome measures used in patient-centered outcomes and comparative effectiveness research. Quality of life research : an international journal of quality of life aspects of treatment, care and rehabilitation. 2013;22(8):1889-905. Epub 2013/01/05. doi: 10.1007/s11136-012-0344-y. PubMed PMID: 23288613.

19. Wiering B, de Boer D, Delnoij D. Patient involvement in the development of patient-reported outcome measures: a scoping review. Health expectations : an international journal of public participation in health care and health policy. 2017;20(1):11-23. Epub 2016/02/19. doi: 10.1111/hex.12442. PubMed PMID: 26889874; PMCID: PMC5217930.

20. Trujols J, Portella MJ, Iraurgi I, Campins MJ, Sinol N, de Los Cobos JP. Patient-reported outcome measures: are they patient-generated, patient-centred or patient-valued? J Ment Health. 2013;22(6):555-62. doi: 10.3109/09638237.2012.734653. PubMed PMID: 23323928.

21. Pezold ML, Pusic AL, Cohen WA, Hollenberg JP, Butt Z, Flum DR, Temple LK. Defining a research agenda for patient-reported outcomes in surgery: Using a Delphi survey of stakeholders. JAMA Surg. 2016;151(10):930-6. doi: 10.1001/jamasurg.2016.1640. PubMed PMID: 27437666.

22. Kodadek LM, Lau BD, Haut ER. How can a valid research agenda for patient-reported outcomes be defined without patient input? JAMA Surg. 2016;151(10):036-937. doi: 10.1001/jamasurg.2016.1695.

23. Butt Z, Reeve B. Enhancing the patient's voice: standards in the design and selection of patient-reported outcomes measures (PROMs) for use in patient-centered outcomes research. Contracted report for the Patient-Centered Outcomes Research Institute (PCORI). Washington, DC: PCORI, 2012.

24. Institute of Medicine. Best Care at Lower Cost: The Path to Continuously Learning Health Care in America. Washington, DC: The National Academies Press; 2013.