

11-27-2023

## Is There Room for Individual Patient-Specified Preferences in the Patient-Reported Outcome Measurement Revolution?

Leif I. Solberg  
Jeanette Y. Ziegenfuss  
Rachael L. Rivard  
Christine K. Norton  
Robin R. Whitebird  
Glyn Elwyn  
Mark Swiontkowski

Follow this and additional works at: <https://aah.org/jpcrr>



Part of the [Health Services Research Commons](#), [Musculoskeletal Diseases Commons](#), [Musculoskeletal System Commons](#), [Orthopedics Commons](#), and the [Rehabilitation and Therapy Commons](#)

### Recommended Citation

Solberg LI, Ziegenfuss JY, Rivard RL, Norton CK, Whitebird RR, Elwyn G, Swiontkowski M. Is there room for individual patient-specified preferences in the patient-reported outcome measurement revolution? *J Patient Cent Res Rev.* 2023;10:210-8. doi: [10.17294/2330-0698.2017](https://doi.org/10.17294/2330-0698.2017)

Published quarterly by Midwest-based health system Advocate Aurora Health and indexed in PubMed Central, the Journal of Patient-Centered Research and Reviews (JPCRR) is an open access, peer-reviewed medical journal focused on disseminating scholarly works devoted to improving patient-centered care practices, health outcomes, and the patient experience.

# Is There Room for Individual Patient-Specified Preferences in the Patient-Reported Outcome Measurement Revolution?

Leif I. Solberg, MD,<sup>1</sup> Jeanette Y. Ziegenfuss, PhD,<sup>1</sup> Rachael L. Rivard, MPH,<sup>1</sup> Christine K. Norton, MA,<sup>2</sup> Robin R. Whitebird, PhD,<sup>3</sup> Glyn Elwyn, PhD,<sup>4</sup> Marc Swiontkowski, MD<sup>5</sup>

<sup>1</sup>HealthPartners Institute, Minneapolis, MN; <sup>2</sup>patient investigator; <sup>3</sup>University of St. Thomas, St. Paul, MN;

<sup>4</sup>The Dartmouth Institute, Lebanon, NH; <sup>5</sup>University of Minnesota Medical School, Minneapolis, MN

---

<b>Purpose</b>	The study aim was to test the feasibility of collecting qualitative patient-preferred outcomes or goals and the degree of their attainment as an addition to a standardized process for collecting quantitative composite patient-reported outcome measures (PROMs) from patients undergoing knee joint replacement.
<b>Methods</b>	Patients of a large Midwestern medical group scheduled to have total replacement of their knee joint have been asked to complete a PROMs survey preoperatively and at 3 and 12 months after surgery since 2014. In March 2020, an open-ended question about their most important preferred outcome was added to the existing questionnaire. The responses for all 3 time periods from the first 6 months of this addition were summarized quantitatively and analyzed by 2 reviewers.
<b>Results</b>	During that 6-month period, 1481 people completed the main survey while 1463 (98.8%) also completed the open-ended question. At baseline, 90.8% of the 590 baseline respondents identified a preferred outcome. If multiple-choice categories had been used, 82.7% of the responses would have lost some or a large amount of their preferred goals' meaning. Of the 144 who completed surveys at both baseline and 3 months, 86.1% reported another outcome in addition to pain relief, while 54.2% reported "Complete or Mostly" achieving their self-identified preferred outcome.
<b>Conclusions</b>	Most people who have joint replacement surgery and respond to a quantitative PROMs survey are willing to report on their other preferred outcomes as well. Adding an open-ended question to PROMs surveys may increase clinician focus on addressing outcomes important to each patient. ( <i>J Patient Cent Res Rev</i> . 2023;10:210-218.)
<b>Keywords</b>	patient-reported outcome measures; knee joint; arthroplasty; patient-centered care; PROMs; orthopedics

---

Over the last 10 to 15 years, there has been large and growing interest within the research, policy, and care system communities in using patient-reported outcome measures (PROMs) as a way to make medical care more patient-centered, outcome-focused, and value-driven.<sup>1-3</sup> Evidence and support for this movement has come from the founding of a large public/private research funding organization, the Patient-Centered Outcomes Research Institute (PCORI), and the National Institutes of Health's Patient-Reported

Outcomes Measurement Information System (PROMIS) data set, which built validated survey and item banks for measuring a wide variety of health outcome domains.<sup>4,5</sup> Perhaps because it is easier to measure outcomes from a distinct starting point like an operation, the surgical specialties, especially orthopedics, have been leaders in studying and implementing PROMs in health care systems and practices.<sup>6,7</sup>

Thus far, the PROMs movement has focused almost completely on identifying and using validated quantitative multi-item composite measures for a variety of symptoms and functions, producing a score that permits comparisons across providers and care systems over time.<sup>4,8</sup> Recently, however, there has been growing awareness that while this understandable and important focus on quantitative summary measures is needed

---

Corresponding author: Leif I. Solberg,  
HealthPartners Institute, PO Box 1524, Mail stop 21112R,  
Minneapolis, MN 55440-1524 (leif.i.solberg@healthpartners.com)

for comparisons, pay-for-performance, and quality improvement, it may not be as useful for making the care of individual patients more patient-centered. Kaltoft and Dowie have noted that “none of these [standardized outcome] sets embody recognition of the preference-sensitive nature of the decisions that eventually generate the outcome database.”<sup>9</sup> They recommend that PROMs should be [patient] preference-mix adjusted as well as case-mix adjusted and that patient-reported importance measures (or, PRIMs) are needed for care to be truly personalized and patient-centered.

This lack of responsiveness for standardized composite measures to diverse patient needs and preferences has led to calls for more patient input on the selection and use of PROMs. Wiering and colleagues’ study of PROM development found that 26% of available measures had had no patient input and that another 50% had only involved patients in item development or testing comprehensibility.<sup>10</sup> More importantly, patients vary in what they consider important outcomes, even for a fairly straight-forward procedure like knee arthroplasty, so composite standardized measures can’t meet that need.<sup>11,12</sup> For example, Gardner et al studied 20 patients with chronic low back pain who identified 27 unique goals, and most did not align with current clinical outcome measures.<sup>13</sup> For that reason, Shapiro et al and Naik et al have recommended use of a combination of standardized PROMs for comparisons among individual surgeons and organizations plus some way to identify and make use of individual-preferred outcomes or goals in patient care.<sup>14,15</sup> Yet, thus far, nobody has demonstrated that patients can and will identify such preferred outcomes or goals (terms that will be used interchangeably in this paper).

Our own studies of patient-identified outcome preferences have confirmed the diversity of what we call patient-preferred outcomes (PPOs) in total joint replacement or abdominal or back pain as well as demonstrating that most patients prefer to understand progress toward their own personal outcome goals rather than a score that allows comparisons with how other people have done.<sup>16,17</sup> We also have shown a weak correlation between PPOs and PROMs.<sup>18</sup> In order to test the feasibility of collecting such subjective information in a consistent way, we added an opportunity for patients to identify their own personalized goals to a standard process for collecting quantitative PROMs data from patients before and after total replacement of their knee in a large multispecialty health system. Our research questions were:

- 1) Will most patients be willing and able to identify a PPO by answering an open-ended question about it?
- 2) To what extent could these individualized PPOs

have been captured by a small list of multiple-choice options as an alternative to an open-ended question?

- 3) Will patients be able to report the degree to which those varying individual outcomes have been achieved postoperatively, using a goal attainment scale format?

These questions were addressed by adding a post-hoc analysis of data collected as part of a larger study of the relationship between individual patient data and performance feedback to surgeons on patient outcomes. As such, this substudy is best considered a pilot for more definitive efforts to answer the research questions noted.

## METHODS

### Context

The health system reported on herein contains 1800 multispecialty physicians providing care in 6 hospitals and 50 clinics in the Minneapolis-St. Paul metropolitan area of Minnesota. Its orthopedics department contains 58 surgeons, 22 of whom perform total knee arthroplasty. The department has been collecting PROMs surveys electronically from these patients since 2014, preoperatively and at both 3 and 12 months postoperatively. Response rates for the PROMs survey only have averaged 68% at baseline, 58% at 3 months, and 55% at 12 months.<sup>19</sup> After scheduling their surgery, patients with an email address on record (approximately 70%) are emailed a baseline survey invitation that contains a link to an internet survey website. Initial nonresponders are sent up to 2 reminder emails days 7 apart until they complete the survey or actively refuse. If they come into an orthopedic clinic for a visit and have not completed a survey, the front desk staff provides them with a tablet and their personalized survey link queued up so they can complete the PROMs survey while waiting.

As part of a larger study funded to understand patient goals from their arthroplasties and the impact of PROMs and performance feedback on patient outcomes, we conducted this retrospective substudy as a pilot effort to understand the feasibility of collecting patient responses to an open-ended question added to the department’s normal pre- and postoperative surveys for PROMs. Since it was developed after the larger study had been largely implemented and consisted of reviewer judgments about existing data, this pilot research might best be viewed as a pragmatic observational analysis limited to data that had already been collected.

### Data Collection

The surveys include the 12-question Oxford Knee Score for joint function, the 10 PROMIS-10 questions about mental/physical health, and the 6-question Knee Injury

and Osteoarthritis Outcome Score for Joint Replacement pertaining to joint function. In March 2020, after interviews with 65 patients before or soon after their surgical arthroplasty and a survey of 226 similar patients to identify outcomes that are important to patients,<sup>17</sup> 2 questions were added to the preoperative survey:

1. Is pain relief a goal you would like to achieve from surgery? (Yes definitely, Yes somewhat, No)
2. In addition to relief from any pain that you may be experiencing, what is the most important outcome/result that you hope to get from surgery? (open-ended, limit of 50 characters)

Similarly, 3 questions were added to the postoperative surveys:

1. To what extent have you obtained relief from any pain you had before surgery (*asked at 3 months only*)? (Completely, Mostly, Somewhat, Minimal, Not at all, Not applicable, No pain before surgery)
2. Before surgery/At 3 months after surgery, you told us that [*pip*ed in value in quotes] was your most important outcome. To what extent have you reached this outcome? (Completely, Mostly, Somewhat, Minimal, Not at all)
3. What outcome is most important to you now? (open-ended, limit of 50 characters)

Patients were first asked about the extent to which pain relief was a goal because earlier work<sup>17,20</sup> showed that when asked generally about goals, most will report seeking pain relief. Since we are interested in knowing more specifically what each patient wants to achieve in addition to pain relief, this first question was designed to encourage a more in-depth response through contrast effect after general pain relief was accounted for in the first question.<sup>21</sup> The open-ended response was limited to 50 characters to enable succinct presentation of responses to the care team on one screen in the medical record.

Baseline surveys are available for patients' beginning 3 months prior to their scheduled surgical procedure; 3-month survey windows open at 9 weeks postprocedure and end at 20 weeks; the 1-year survey window has a 6-month duration opening at 9 months and closing at 15 months postprocedure.

## Analysis

Surveys with at least 1 day in an open survey window between March 2020 — the start of the new questions — and September 2020 — the date the data were extracted — were eligible. Where there were free-text responses, they were reviewed and categorized along 3 dimensions by 2 of the authors (C.K.N., a patient investigator, and L.I.S., a family physician senior researcher). However,

we did not establish specific criteria beforehand as to what would constitute a yes to any of the research questions since this was an unplanned evaluation of existing data late in the overall study.

First, in order to determine the extent to which patient responses to an open-ended question might have been collected by a closed-ended categorical list of possible outcomes, each response was evaluated to determine whether it could be matched to 1 of 17 PPO-specific response options developed from patient interviews and surveys in an earlier study.<sup>17</sup> Recognizing that the specific options may not always work well for the responses given, the degree of fit of the open-ended response with the specific options was next qualitatively evaluated for how well they were aligned. We wanted to determine the extent to which use of an arbitrary list of goals might lose important details desired by the patients as expressed in their open-ended goal. Categorical assessments included *perfect alignment*, operationally defined as no PPO information lost or inferred by requiring a choice of specific options, *some loss*, where some information was lost or obscured by requiring specific options, and *large loss*, where most if not all information was lost or obscured by requiring choice from specific alternative options. As an example, if the option was “walk without pain or discomfort, perfect alignment would use similar words, while some loss would occur with walk for 1 mile, and large loss would occur if the respondent wanted to be able to race.

Patient-identified goals at 3 months also were categorized by reviewers as small or large changes from goals identified at baseline. The 2 reviewers compared their independent judgments on 100 sequential patients that represented all 3 time periods and discussed any differences until they had achieved consensus on how to make these assessments in a similar way. The post-hoc nature of this substudy didn't allow for more sophisticated analysis, including relationship to patient characteristics or changes in individual patient answers at the 3 different time points. However, these existing data did provide us an opportunity to learn whether information loss varied by time point and whether there were dramatically different PPOs at 3 and 12 months than at baseline.

This study was reviewed, approved, and monitored by the local institutional review board.

## RESULTS

### Survey Completion

Over the observation period of 6 months, a total of 1625 PROMs surveys were completed by 1481 unique people within the time window (out of 2506 approached): 590 at

baseline, 410 at 3 months postprocedure, and 607 at 12 months postprocedure (18 of 1625 completed the original questions but did not provide any information for the newly added questions and thus were not included in this analysis). Because of the limited data collection period of 6 months, only 144 people who completed a baseline survey also did so at 3 months (out of 239 people sent a survey at both time points), and none of the 12-month surveys came from people who had completed surveys at earlier time points.

The characteristics of the survey completers at each time point are described and compared in Table 1. Mean age was 66.4 years with a standard deviation of 8.3, 60% were female, and 94% reported White race, with no differences by time point.

### Patient Responses

At baseline (ie, preprocedure), of the 590 respondents, 96.3% reported that pain relief was “definitely” a goal from the surgery and another 3.4% said “somewhat.” When asked, “*In addition to relief from any pain that you may be experiencing, what is the most important outcome/result that you hope to get from surgery?*” 90.8% provided some response in the open-ended text box.

Responses were mapped onto 1 of 3 groups; 88.8% fell into 16 previously identified non-pain relief categories that best aligned with the patient’s wording, 5.2% recoded to pain relief, and 6.0% were coded to “none” because they provided no additional information. While 363 responses (72.0%) mapped onto just 3 categories, 7 categories were used less than 10 times apiece and 2 were not used at all (Table 2). Only 17.3% of the 504 recoded to predefined categories or recoded to pain were judged to be in perfect alignment with the category; 48.4% were

considered to have some important loss of information, and for 34.3%, most if not all information was lost by substituting the category label for the outcome that the patient had provided.

Loss of information if categories were used was most frequent for nonspecific categories like returning to an active lifestyle, where volunteered responses were usually more specific — eg, “play tennis with my grandchildren,” or “living life fully without limitations,” or “aerobic dancing.” The leisure activity category understandably lost much information about the specific activity like “able to travel and take walking tours” or “able to handle 5000 steps/day,” while “to do normal things” was rated as some loss. A seemingly more specific category like walking without pain or discomfort still could lose much information when a patient wrote about wanting to “walk without knee going out from under” or “walk without limping.”

Among the 144 people who completed both baseline and 3-month surveys, 79.9% reported attaining pain relief completely or mostly at 3 months, 13.2% said somewhat, and 6.9% said minimally, not applicable, or not at all. Asked if they had achieved their PPO self-reported at baseline (auto-populated from the baseline survey to remind them), 13.9% said they had completely achieved it, 40.3% said mostly, 31.9% said somewhat, and 13.9% said minimally or not at all. In the 3-month survey, patients were also asked what outcome was most important to them at that time; 86.1% (124 of 144) of them identified a new important outcome at 3 months. Of the 121 individuals who reported PPOs at both baseline (coded) and 3 months, 25.6% chose a large change in goal and 38% chose a small change. For example, a person who had hoped to walk down stairs more easily

**Table 1.** Patient Characteristics

Characteristic	Baseline	3 months	12 months	P	Unique patients
N	590	410	607		1463
Age in years					
Mean (SD)	66.2 (8.5)	66.4 (8.3)	66.6 (8.1)	0.867	66.4 (8.3)
Range	37–87	42–87	40–90		37–90
Sex (ref.: female)	60.7%	61.2%	59.6%	0.874	60.3%
Race (ref.: White)	92.5%	93.4%	94.7%	0.1430	93.7%

N, number; ref., reference characteristic for comparison; SD, standard deviation.



**Table 2.** Other Goals Grouped Into Standard Categories at Baseline and Degree to Which Information Was Lost (n=504\*)

Category	n (%)	Alignment (loss of information)		
		Perfect, n	Some loss, n	Large loss, n
Walk without pain or discomfort	180 (35.7%)	28	104	48
Return to an active lifestyle	116 (23.0%)	21	45	50
Return to leisure time activities	67 (13.3%)	2	43	22
Improved flexibility	35 (6.9%)	7	17	11
Go up and down stairs without pain	25 (5.0%)	7	10	8
Improved strength	24 (4.8%)	5	7	12
Return to favorite sports activities	13 (2.6%)	1	5	7
Return to work	6 (1.2%)	4	1	1
Sleep through the night	4 (0.8%)	1	2	1
Improved ability to work around my home	2 (0.4%)	2	0	0
Improved ability to care for myself	1 (0.2%)	0	0	1
Decreased numbness or weakness in my legs	1 (0.2%)	0	0	1
Sit comfortably	1 (0.2%)	0	0	1
Drive a car	1 (0.2%)	0	1	0
Improved mental health	0 (0%)			
Improved relationships	0 (0%)			
Recoded to pain relief	28 (5.6%)	9	9	10
<b>Totals</b>	<b>504 (100%)</b>	<b>87</b>	<b>244</b>	<b>173</b>

\*An additional 32 people provided text that was coded to no additional information/none, while 54 did not provide information in the free-text field.

now wanted to go up and down stairs without pain (large). Another wanted to move from having increased strength to having stamina (small).

Finally, at 12 months postprocedure, 95.4% of participants responded to what extent they had reached their self-reported PPO identified at 3 months (despite none of them having been eligible to report an outcome at 3

months due to when the question was introduced). Of the 579 who did respond, 193 (33.3%) reported completely and 267 (46.1%) reported mostly for a total of 79.4%. Of the 607 respondents at 12 months, 95 (15.7%) did not provide information regarding an updated preferred outcome at 12 months. Of the 512 who did provide text, 96 (18.8%) provided statements coded to “none” while 77 (15.0%) restated some version of pain relief. This left 339 responses (66%) that were able to be coded to the 16 non-pain relief categories. These additional outcomes along with the recoded to pain values are listed in Table 3. The top 3 outcomes identified made up 53.4% of the volume of comments compared to the 72.0% represented by the top 3 categories at baseline. At 1 year, the main

outcomes that increased in frequency were to improve flexibility (3 times as frequent) and improve strength (twice as frequent). See Figure 1 for more results.

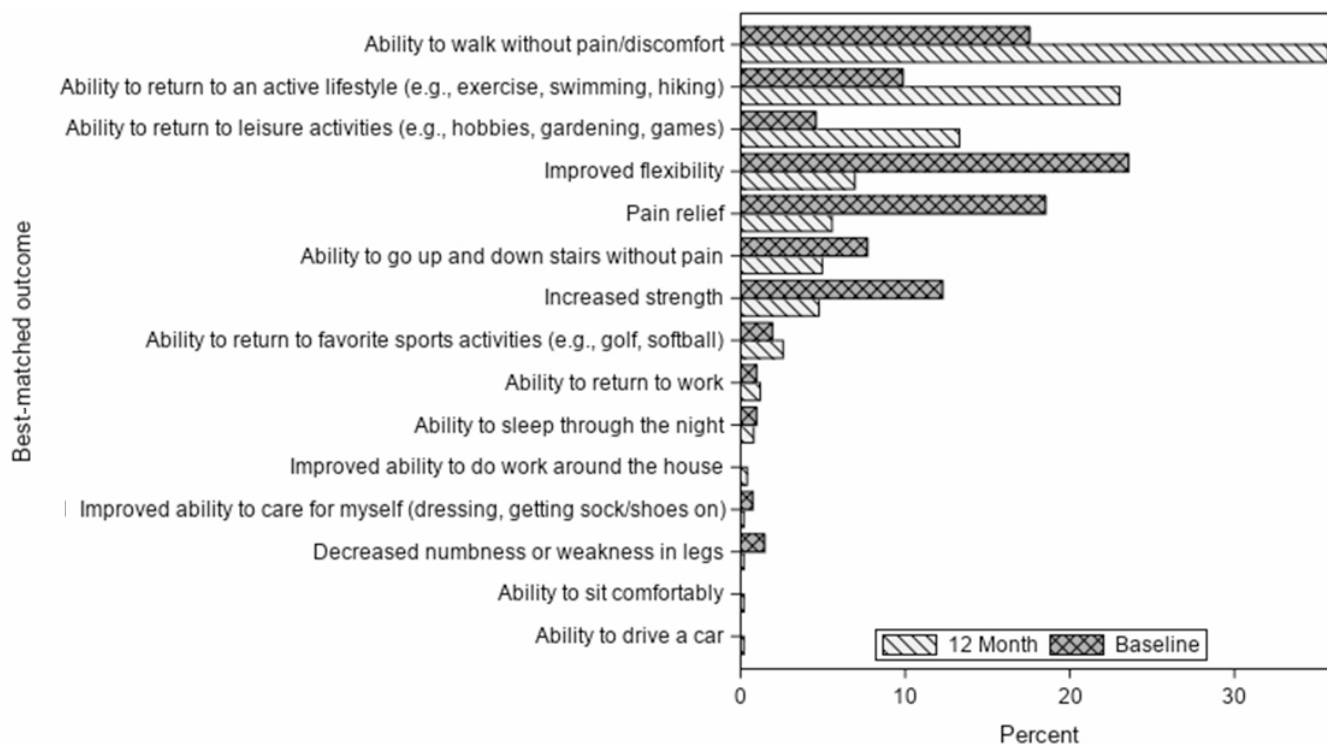
## DISCUSSION

This analysis suggests that while nearly all people undergoing total knee arthroplasty and responding to a PROMs survey are seeking pain relief as an outcome, they almost all also have and are willing to write in at least one additional or more specific preferred outcome. If instead of an open-ended question, a list of 3–5 categorical outcomes was offered to choose from, at least 75% of those other goals would likely be covered, although some to most of the patient’s informational specifics would be lost for 4 out of 5 patients. In order to incorporate those PPOs in the care of individual patients, it would then be necessary for someone on the care team to ask about the specifics of such a categorical choice (eg, what types of leisure time or sports activities or what kind of walking needs to be pain-free). Without such additional clarification, this approach may actually diminish the patient’s sense of patient-centered care. The patients surveyed in this study also demonstrated a willingness to estimate the degree to which they had

**Table 3.** Other Goals Grouped Into Standard Categories at 12 Months and Degree to Which Information Was Lost (n=416\*)

Category	n (%)	Alignment (loss of information)		
		Perfect, n	Some loss, n	Large loss, n
Improved flexibility	98 (23.6%)	18	35	45
Walk without pain or discomfort	73 (17.5%)	17	38	18
Improved strength	51 (12.3%)	12	23	16
Return to an active lifestyle	41 (9.9%)	5	13	23
Go up and down stairs without pain	32 (7.7%)	15	13	4
Return to leisure time activities	19 (4.6%)	0	13	6
Return to favorite sports activities	8 (1.9%)	3	3	2
Decreased numbness or weakness in my legs	6 (1.4%)	0	3	3
Return to work	4 (1.0%)	3	1	0
Sleep through the night	4 (1.0%)	2	0	2
Improved ability to care for myself	3 (0.7%)	2	0	1
Improved ability to work around my home	0 (0%)			
Sit comfortably	0 (0%)			
Drive a car	0 (0%)			
Improved mental health	0 (0%)			
Improved relationships	0 (0%)			
Recoded to pain relief	77 (18.5%)	11	36	30
<b>Totals</b>	<b>416 (100%)</b>	<b>88</b>	<b>178</b>	<b>150</b>

\*An additional 96 people provided text that was coded to no additional important outcome at 12 months, while 95 people did not provide text that could be coded.



**Figure 1.** Best-matched categories at baseline (n=504) and Month 12 (n=416).

attained their PPO, using a simple goal attainment scale multiple choice question.

Interest in identifying patient-specific goals and using goal attainment scaling to measure their achievement is not a new idea — it has been used in rehabilitation settings for a long time, as evidenced by Hurn and colleagues' systematic review in 2006.<sup>22</sup> The feasibility and value of such an approach has been more recently shown in low back pain, major depression, medication management, developmental disabilities, chronic disease, and other areas.<sup>23-28</sup> As interest has grown recently in patient-reported outcomes based on quantified multicomponent measures that are not individualized, that background is leading some to call for supplementing quantified measures with individual PPOs or goals along with goal attainment scaling to measure achievement.<sup>9,13,14,24,25</sup> Epstein and Teagarden noted that this era of personalized medicine shouldn't be limited to personalizing on the basis of physiologic or genetic characteristics but also on "what the patient considers to be a meaningful outcome."<sup>29</sup> That fits with what we have learned from extensive patient interviews and surveys in orthopedics and led to this paper's documentation of the feasibility of doing that.<sup>17,20</sup>

Over the past 10 years, the National Committee for Quality Assurance (NCQA) has been working on what they call *person-driven outcome measures*, using a structured approach to individualized patient-identified outcome goals combined with goal attainment scaling as a method to assess those outcomes.<sup>30</sup> They have recently published a feasibility study of this approach in 7 sites across the country and concluded that "using structured approaches to goal-based outcomes for older adults with complex care needs could be feasible in clinical care."<sup>31</sup> Since NCQA is one of the main organizations implementing quality measurements that compare health plans, it is likely that we will increasingly see measures like those described in this study.

Our purpose is not to propose that individualized goal setting and attainment should replace the standardized composite PROM scores that will continue to be important in value-based payment systems and performance-driven quality improvement. Instead, we suggest that collecting PPOs and goals provides a more patient-centered approach that is complementary to standardized measures. After learning that standardized PROMs built into the electronic health record for access during patient contacts were almost never accessed during patient encounters, we conducted a qualitative analysis of interviews with joint replacement surgeons.<sup>32</sup> We learned that there were still multiple barriers to the use of PROM scores, including their concern about

the difficulty of making these scores understandable to patients. Although they believed the scores were important for comparison and improvement purposes, they thought "patient-identified outcomes [are] more valuable in patient care than PROM scores." They would rather take the time to ask patients about what they wanted to achieve through surgery than to search for generalized scores.

### Limitations

This research was limited to a post-hoc analysis of patient responses to questions added to an existing survey as an unplanned substudy of a larger project in an effort to assess the feasibility of asking patients about their preferred outcomes in a single orthopedics group. The patient population had little diversity. We also lacked complete information on data collection because we were dependent on an existing departmental system that didn't track some details of interest to researchers. It also drew patients from a limited time period, so there was no opportunity to follow many individual patients over the entire time from preprocedure to 1-year follow-up surveys. However, comparison of responders at different time points showed no differences in age, race/ethnicity, or sex, so it is likely that even though they are different people, their answers were probably comparable to those at other time periods. In other published work we have shown little difference in patient characteristics between those who responded at both baseline and 12 months versus those who did not respond or only did so at one time point.<sup>33</sup>

### CONCLUSIONS

Study data demonstrated the feasibility of adding a few questions to standardized patient-reported outcome measures surveys to identify the outcome(s) most important to individual patients. It appears that this can be done either by asking an open-ended question or by providing a limited number of categorical answers, with the understanding that a health care professional will need to ask additional questions to clarify the specifics of that categorical choice. Patients do have and will provide information about their own goals and the degree to which they have been attained, but clinicians need to be mindful that an individual's goal may change over time, even in a situation as standardized as care after a surgical procedure. Collecting such information and providing it to those providing care seems likely to increase the patient-centeredness of that care, a hypothesis that needs evaluation. We hope there is room for obtaining and addressing patient-preferred outcomes in addition to standardized PROMs scores and that future research will test the impact of that approach on the care process and patient satisfaction.



## Patient-Friendly Recap

- Elective procedures like knee replacement surgery are increasingly measured by their ability to achieve patient-reported outcomes derived from standardized scoring scales. However, each patient may view their surgery with different goals, or “preferred outcomes” beyond pain relief, in mind.
- Authors tested the feasibility of collecting these patient-preferred outcomes, both prior to a knee operation and in follow-up surveys.
- They found that most people who respond to the standard score-based survey are willing to report their other preferred outcomes as well. Thus, adding an open-ended survey question may steer clinicians toward addressing the specific outcomes important to each patient.
- Patients also were able to rate the degree to which their preferred outcomes were achieved up to 12 months after surgery, though for some, goals changed over time. More research is needed to confirm findings from this post-hoc analysis.

## Author Contributions

Study design: Solberg, Ziegenfuss, Norton. Data acquisition or analysis: Solberg, Ziegenfuss, Rivard, Norton. Manuscript drafting: Solberg, Ziegenfuss, Norton. Critical revision: all authors.

## Conflicts of Interest

Authors Solberg, Ziegenfuss, Rivard, and Swiontkowski performed this work as employees of HealthPartners. The other authors have no conflicts of interest to declare.

## Funding Sources

This project was supported by the Agency for Healthcare Research and Quality (AHRQ grant no. R18HS025618). The content is solely the responsibility of the authors and does not necessarily represent the official views of the AHRQ.

## References

1. Austin E, LeRouge C, Hartzler AL, Segal C, Lavalley DC. Capturing the patient voice: implementing patient-reported outcomes across the health system. *Qual Life Res.* 2020;29:347-55. [CrossRef](#)
2. Billig JI, Sears ED, Travis BN, Waljee JF. Patient-reported outcomes: understanding surgical efficacy and quality from the patient’s perspective. *Ann Surg Oncol.* 2020;27:56-64. [CrossRef](#)
3. Black N. Patient reported outcome measures could help transform healthcare. *BMJ.* 2013;346:f167. [CrossRef](#)
4. Gershon RC, Rothrock N, Hanrahan R, Bass M, Cella D. The use of PROMIS and assessment center to deliver patient-reported outcome measures in clinical research. *J Appl Meas.* 2010;11:304-14.

5. Selby JV, Beal AC, Frank L. The Patient-Centered Outcomes Research Institute (PCORI) national priorities for research and initial research agenda. *JAMA.* 2012;307:1583-4. [CrossRef](#)
6. Baumhauer JF. Patient-reported outcomes – are they living up to their potential? *N Engl J Med.* 2017;377:6-9. [CrossRef](#)
7. Grogan Moore ML, Jayakumar P, Laverty D, Hill AD, Koenig KM. Patient-reported outcome measures and patient activation: What are their roles in orthopedic trauma? *J Orthop Trauma.* 2019;33 Suppl 7:S38-S42. [CrossRef](#)
8. Cella D, Yount S, Rothrock N, et al. The Patient-Reported Outcomes Measurement Information System (PROMIS): progress of an NIH Roadmap cooperative group during its first two years. *Med Care.* 2007;45(5 Suppl 1):S3-S11. [CrossRef](#)
9. Kalsoft MK, Dowie J. PROMs need PRIMs: standardised outcome measures lack the preference-sensitivity needed in person-centred care. *Stud Health Technol Inform.* 2019;262:118-21. [CrossRef](#)
10. Wiering B, de Boer D, Delnoij D. Patient involvement in the development of patient-reported outcome measures: a scoping review. *Health Expect.* 2017;20:11-23. [CrossRef](#)
11. Reuter JM, Hutyra CA, Politzer CS, et al. Characterizing patient preferences surrounding total knee arthroplasty. *JB JS Open Access.* 2018;3(4):e0017. [CrossRef](#)
12. Wiering B, de Boer D, Delnoij D. Asking what matters: the relevance and use of patient-reported outcome measures that were developed without patient involvement. *Health Expect.* 2017;20:1330-41. [CrossRef](#)
13. Gardner T, Refshauge K, McAuley J, Goodall S, Hübscher M, Smith L. Patient led goal setting in chronic low back pain – what goals are important to the patient and are they aligned to what we measure? *Patient Educ Couns.* 2015;98:1035-8. [CrossRef](#)
14. Naik AD, Catic A. Achieving patient priorities: an alternative to patient-reported outcome measures (PROMs) for promoting patient-centred care. *BMJ Qual Saf.* 2020;30:92-5. [CrossRef](#)
15. Shapiro LM, Eppler SL, Roe AK, Morris A, Kamal RN. The patient perspective on patient-reported outcome measures following elective hand surgery: a convergent mixed-methods analysis. *J Hand Surg Am.* 2021;46:153.e1-153.e11. [CrossRef](#)
16. Solberg LI, Asche SE, Butler J, et al. Patient-centered outcomes measurement: Does it require information from patients? *J Patient Cent Res Rev.* 2017;4:221-9. [CrossRef](#)
17. 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;7:157-64. [CrossRef](#)
18. Chrenka EA, Solberg LI, Asche SE, et al. Is shared decision-making associated with better patient-reported outcomes? A longitudinal study of patients undergoing total joint arthroplasty. *Clin Orthop Relat Res.* 2022;480:82-91. [CrossRef](#)
19. Ziegenfuss JY, Grossman ES, Solberg LI, et al. Is the promise of PROMs being realized? Implementation experience in a large orthopedic practice. *Am J Med Qual.* 2022;37:489-94. [CrossRef](#)
20. Whitebird RR, Solberg LI, Ziegenfuss JY, et al. Personalized outcomes for hip and knee replacement: the patients point of view. *J Patient Rep Outcomes.* 2021;5(1):116. [CrossRef](#)

21. Strack F. "Order effects" in survey research: activation and information functions of preceding questions. In: Schwarz N, Sudman S (eds). *Context Effects in Social and Psychological Research*. Springer-Verlag; 1992, pp. 23-34.
22. Hurn J, Kneebone I, Cropley M. Goal setting as an outcome measure: a systematic review. *Clin Rehabil*. 2006;20:756-72. [CrossRef](#)
23. Clarkson K, Barnett N. Goal attainment scaling to facilitate person-centred, medicines-related consultations. *Eur J Hosp Pharm*. 2021;28:106-8. [CrossRef](#)
24. Haladay D, Swisher L, Hardwick D. Goal attainment scaling for patients with low back pain in rehabilitation: a systematic review. *Health Sci Rep*. 2021;4(3):e378. [CrossRef](#)
25. McCue M, Parikh SV, Mucha L, et al. Adapting the goal attainment approach for major depressive disorder. *Neurol Ther*. 2019;8:167-76. [CrossRef](#)
26. Shogren KA, Dean EE, Burke KM, Raley SK, Taylor JL. Goal attainment scaling: a framework for research and practice in the intellectual and developmental disabilities field. *Intellect Dev Disabil*. 2021;59:7-21. [CrossRef](#)
27. Vu M, Law AV. Goal-attainment scaling: a review and applications to pharmacy practice. *Res Social Adm Pharm*. 2012;8:102-21. [CrossRef](#)
28. Tabaei-Aghdaei Z, McColl-Kennedy JR, Coote LV. Goal setting and health-related outcomes in chronic diseases: a systematic review and meta-analysis of the literature from 2000 to 2020. *Med Care Res Rev*. 2023;80:145-64. [CrossRef](#)
29. Epstein R, Teagarden JR. Comparative effectiveness and personalized medicine: evolving together or apart? *Health Aff (Millwood)*. 2010;29:1783-7. [CrossRef](#)
30. National Committee for Quality Assurance. Measuring what matters most to older adults. Accessed July 16, 2022. <https://www.ncqa.org/hedis/reports-and-research/measuring-what-matters-most-to-older-adults/>
31. Giovannetti ER, Clair CA, Jennings LA, et al. Standardised approach to measuring goal-based outcomes among older disabled adults: results from a multisite pilot. *BMJ Qual Saf*. 2021;30:157-66. [CrossRef](#)
32. Whitebird RR, Solberg LI, Ziegenfuss JY, et al. What do orthopaedists believe is needed for incorporating patient-reported outcome measures into clinical care? A qualitative study. *Clin Orthop Relat Res*. 2021;480:680-7. [CrossRef](#)
33. Solberg LI, Chrenka E, Asche SE, et al. Adjusting for variation in patient-reported outcome measures is needed to improve care after total knee arthroplasty. *J Am Acad Orthop Surg*. 2022;30:e164-e172. [CrossRef](#)

© 2023 Advocate Aurora Research Institute