

## ACTION BRIEF

# Patient-Reported Outcomes

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## EXECUTIVE SUMMARY

Patient-reported outcomes (PROs) are the results of a patient's assessment of his/her physical and/or mental health, as measured using standardized survey instruments. These data are not collected in clinical practice on a wide scale in the United States, even though there is well-documented variation in outcomes. Many experts believe that consumers and purchasers should insist on the widespread adoption and reporting of PROs because of their potential for enhancing the value of care. For patients, PRO results can lead to better informed decisions for treatment and selection of providers. For purchasers, PRO reporting could help to identify which providers deliver care that patients find most beneficial.

The ultimate goal of the nation's health care system is to improve health. But we do not know the extent to which we are achieving this goal since we rarely, if ever, ask patients to report whether the care they received made a difference in their lives. Instead, we tend to equate quality with care processes—e.g., did the doctor write a prescription for the patient with asthma, rather than did the patient experience relief from their asthma symptoms. Yet, if we do not ask the patients, we will not have the information needed to effectively assess whether treatments have a positive effect on their lives nor will we be able to better engage patients about their health. Further, asking patients this type of information helps us understand the effect of new models of care, support clinicians who want to do right by their patients, reward value instead of volume, and reduce inappropriate care.

Patients who are functionally impaired especially deserve to have this information to help guide them in their choices of treatments and providers. For example, patients are interested to know which doctor or care system is most successful at restoring function to someone with knee pain, difficulty with breathing, or back pain. Purchasers and health plans also need that same information to evaluate their provider networks and ensure that their employees/members are getting the best care.

One systematic and validated way to hear from the patient is to solicit information on patient-reported outcomes (PROs). PROs refer to the changes in an individual's physical and/or mental health status, including their ability to perform normal household functions and job duties unhampered by disability, resulting from medical treatments and procedures. They are typically measured using a standardized patient survey instrument, such as exist for asthma, depression, back pain, and many other conditions.

For example, low back pain is experienced by 3 out of 5 people during their lifetimes.<sup>1</sup> How it is diagnosed and treated, and how well, can have a marked effect on an individual's ability to function both at home and at work. Information on patient recovery can be collected systematically via standardized health surveys, which can be used by both the patient and clinical team to track progress and engage in shared decision-making. Further, such information can be aggregated across patients and combined with costs to identify the high-value treatments and providers.

Yet, here in the U.S., we do not collect and use these data on a large scale, even as variation in treatments and outcomes persists and health care costs continue to rise. Where we do have information on outcomes, it centers on mortality, infection rates, readmissions, re-operations and so-called adverse events—most of which are gathered from clinical sources, not from patients themselves. Such outcomes are important to know because they are experienced by millions of Americans and are extremely costly. But clinical outcome measures provide an incomplete picture of quality, since they do not capture the patient's perspective.

While not used in mainstream health care in the U.S., PROs have a long history in scientific research, in clinical trials, e.g., for new drugs, and in other countries like the United Kingdom and Sweden, where such outcomes are routinely collected and publicly reported.

There are a number of reasons for resistance to PROs in the U.S. For example, we tend not to trust developments from overseas and we have a culture that seems to value the perspectives of the health care system over those of patients. Other logistical barriers include the lack of an electronic infrastructure to collect the information on a large, population level. Both cultural and infrastructure challenges to PRO adoption are critical to address and our nation needs leadership by all stakeholders in order to realize the promise PROs have to transform our health care system and improve our health.

Consumer organizations should insist on the adoption of PROs so that patients can make informed decisions about their care and better identify the providers that best meet their needs. Purchasers—public and private—should use their leverage with insurers and providers to require such action. Historically, the Consumer-Purchaser Alliance has focused its advocacy efforts on encouraging CMS, as the largest health care purchaser, to incorporate PROs in its accountability programs; we call upon private purchasers to move in the same direction as well. This *Action Brief* presents the case for consumer and purchaser action and describes specific steps that we can take to increase the momentum for implementation of meaningful PROs.

## WHY SHOULD CONSUMERS AND PURCHASERS CARE ABOUT PROS?

PROs measure what is important to patients—the effect on their overall quality of life and daily activities: how soon after surgery can I walk upstairs? When can I cook my own dinner without assistance? Further, PROs capture information that is vital to ensuring that the health care system is providing the best value for the money spent. At the same time, PROs represent an important gauge of absenteeism and an employee's ability to function at work.

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When 58 year-old John, an avid “black-diamond” skier, had knee replacement surgery, he really wanted to know when he could get back on the slopes. So, things like pain and physical function were top of mind for him in discussing recovery with his doctor. He was also eager to get back to work so he could pay for his lift tickets.

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When 35-year-old Mary had the first post-partum visit with her OB, the doctor did not realize she was depressed during their eight minute visit, considering they had so many other things to discuss. Routine use of a depression screening instrument known as the PHQ-9 provides a doorway to broaching this topic with patients like Mary. Consumers and purchasers should expect this sort of an evaluation with any system claiming to be a patient-centered medical home or accountable care organization.

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1. [http://www.who.int/medicines/areas/priority\\_medicines/Ch6\\_24LBP.pdf](http://www.who.int/medicines/areas/priority_medicines/Ch6_24LBP.pdf)

Second, they address many issues that providers should be discussing with their patients that ultimately will affect their clinical outcomes.

Third, PROs give consumers essential information for provider choice, e.g., which surgeons and hospitals are getting best results for their knee and hip replacement patients?

Lastly, PROs represent a key element of patient-centered care. They can be used to support shared decision-making and goal-setting, track patient progress towards meeting goals, flag unexpected complications, etc. Informed patient decision-making has been shown to reduce the frequency of costly procedures and, hence, can help patients avoid treatments that may not help and may even cause harm and can save money for purchasers and payers.

### WHERE AND HOW ARE PROS BEING USED?

PROs are commonly used in clinical trials to demonstrate the effectiveness of new drugs. Also, the United Kingdom has been collecting PROs for several common procedures since 2009.<sup>3</sup> And here in the U.S., we have begun to introduce PROs for health care in a limited way. For example, the California Joint Replacement Registry ([www.caljrr.org](http://www.caljrr.org)) collects PROs for hip and knee replacement—although using a different survey instrument than is used in the U.K.—and should soon be publicly reporting the results at the hospital level.

Certain high-value health systems have already taken the lead in integrating PROs into patient care and follow-up. For example, Geisinger Health System in northeastern Pennsylvania routinely uses PROs to assess patients' status before and after treatment for a variety of conditions. The Intensive Outpatient Care Program ([http://www.calquality.org/storage/documents/iocp\\_2012.pdf](http://www.calquality.org/storage/documents/iocp_2012.pdf)), which is funded by the Center for Medicare and Medicaid Innovation and operated by the Pacific Business Group on Health, also collects functional health status and uses other standard survey instruments to screen for depression and to measure the patient's ability to engage in improving their health. The same patients are screened again following treatment to ensure that their condition has improved. The graph on the next page shows the longitudinal change in PHQ follow-up results. The survey follow-up interval varies according to the clinical indication of the initial assessment.

Other examples of high-value health systems that have adopted PROs include Intermountain Health Care in Salt Lake City and Virginia Mason in Seattle. As one of the most innovative health systems in the country, Virginia Mason also regularly conducts on-line health risk appraisals of its members and incorporates the data in the EHR for discussion with their primary care physician.

There are also examples of health plans promoting the use of PROs, such as by Blue Cross Blue Shield of Massachusetts (BCBSMA), through its so-called Alternative Quality Contract with providers. BCBSMA has

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In the United Kingdom, every hip or knee replacement patient is asked to fill out a standard survey on their functional health status following surgery. Results are scored and aggregated and used to compare providers on a government-sponsored web site.<sup>2</sup>

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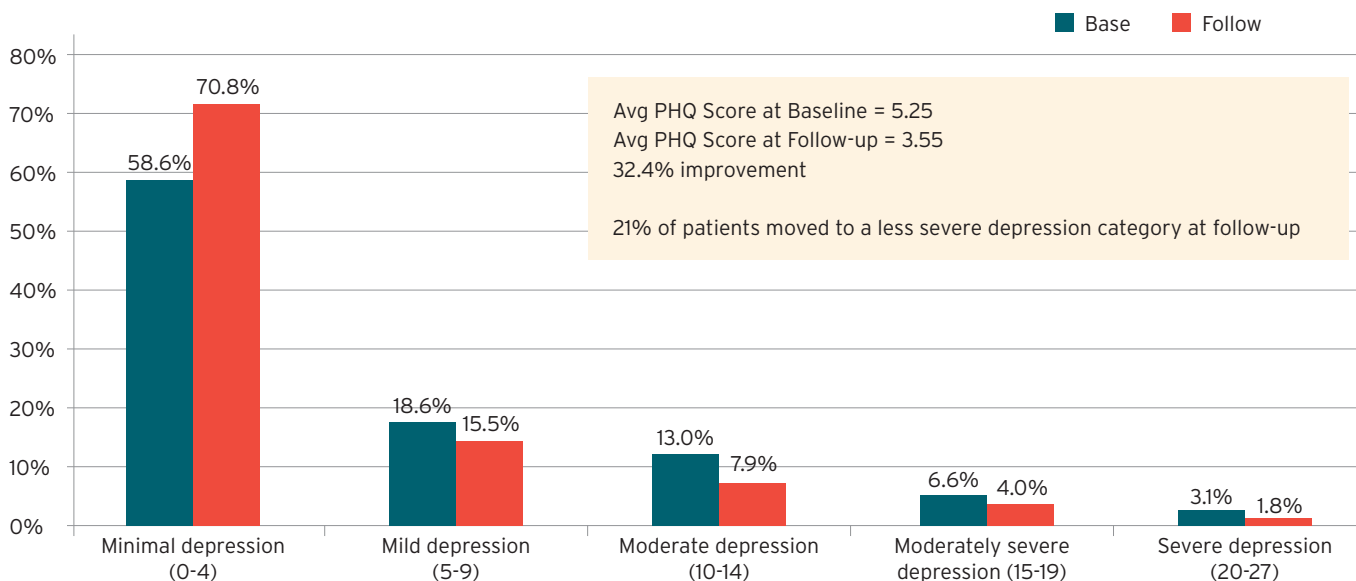
At the Dartmouth Spine Center, new patients are asked to complete a health status survey to determine the extent to which their condition limits their ability to function as they would like. Results are used to help the patient and their clinicians choose between conservative treatment and surgery.

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2. <http://www.hscic.gov.uk/catalogue/PUB14574/fin-proms-eng-apr12-mar13-scor-comp.xlsx>

3. The U.K. reporting program includes PROs for hip and knee replacement, hernia repair, and varicose vein surgery. Results are risk-adjusted and reported as the average change in patient-reported functional health status achieved for every hospital performing these procedures nationwide. See <http://www.england.nhs.uk/statistics/statistical-work-areas/proms/>.

## CHANGE IN DISTRIBUTION OF PHQ DEPRESSION LEVEL FOR 2,140 IOCP PATIENTS AS OF 12/31/14



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implemented PROs in two clinical areas—depression and hip/knee surgery—by offering bonuses to physician organizations that collect and submit the data to the health plan. BCBSMA will then use the data to build performance measures for accountability.

### CONSUMER-PURCHASER ALLIANCE POLICY INITIATIVES TO ADVANCE THE USE OF PROS

The Consumer-Purchaser Alliance is working to create an environment that promotes advancing the use of PROs to improve care and for performance reporting. Current activities include the following:

- Working with large payers, e.g., CMS, to address barriers and foster adoption of PROs through value-based purchasing programs.
- Working with the Office of the National Coordinator for HIT and CMS to require PROs in the Meaningful Use of EHRs program.
- Serving on expert panels to promote development and assessment of PRO performance measures, prioritize person-centered care and outcomes measures as a component of a national quality strategy, and advance PRO measures in new payment and delivery models.
- Engaging with sponsors of clinical registries to encourage them to incorporate PROs in their data sets.

- Encouraging funding agencies, such as the Patient-Centered Outcomes Research Institute (PCORI), to provide competitive funding opportunities for development of PRO performance measures in the public domain, hosting PRO learning networks, using PROs in shared decision-making and helping patients to use the information in making their treatment and provider choices.
- Encouraging the National Committee on Quality Assurance (NCQA) to adopt requirements for PROs in its accreditation programs.
- Encouraging federal and state health benefit exchanges to consider requiring their participating health plans to report on PROs.

### CALL TO ACTION FOR CONSUMERS AND PURCHASERS

Most physicians and hospitals are not accustomed to collecting and using PROs, nor is the health care system generally equipped to integrate this information with the patient's electronic health record. Progress on the adoption and use of PROs will continue at a slow pace unless consumers and purchasers encourage speedy adoption. The main barriers to progress must be addressed.

## BARRIER #1: LACK OF INCENTIVES FOR PROVIDERS TO WORK PROS INTO ROUTINE PROCESSES OF CARE

### Actions:

- Get payers—public and private—to build PROs into new value-based payment models – not just collecting PROs, but actually using them to improve care, reward better care, and making the results publicly available.
- In areas where PRO measures already exist<sup>4</sup>, discuss and set goals with their health plans to incorporate those measures into provider incentive programs.
- Consider restricting specialty networks to those who commit to reporting PROs.
- Get plans to require collection and reporting of PROs through their Centers of Excellence contracts.
- Require collection and reporting of PRO performance measures at the physician and hospital levels through ACOs and/or in direct contracting.
- Following the Virginia Mason example, get their plan(s) to require their primary care physicians to perform annual health risk assessments of their patients and enter the data in the EHR for follow-up.
- Encourage their employees to discuss their interest/need for PRO results with their physicians.
- Incorporate PROs into mandatory transparency requirements at the plan and provider levels. Begin by requiring them to provide information to prospective patients upon request. Eventually, require full public reporting.

### Consumers should:

- Ask their plans and providers to give them this outcome information. For example, if an individual's PCP is referring them for surgery, they should insist on a surgeon who can show them his or her outcomes.
- Continue advocating within policy-making bodies for the inclusion of PROs in public accountability and public reporting programs.
- Ask their employer (if employed) if PROs are considered in their benefits and plan contracting.

## BARRIER #2: BURDEN ON PATIENTS OF COMPLETING LENGTHY PRO SURVEYS, WHICH CAN LEAD TO LOW RESPONSE RATES

### Action:

- For many conditions, there is a choice of survey instruments that have been scientifically validated for use in the field. **Consumers and purchasers** should insist that their providers use surveys that are parsimonious and capture information that is meaningful to the patient.

## BARRIER #3: HIGH COST OF CAPTURING PROS. PRO SURVEYS ARE OFTEN CONDUCTED BY MAIL. ALSO, MOST PROVIDERS HAVE NO STRAIGHTFORWARD WAY TO INTEGRATE THE PRO DATA WITH THEIR ELECTRONIC HEALTH RECORD (EHR).

### Action:

- **Consumers and purchasers should** advocate for other providers to follow the lead of the health systems mentioned above, which have created electronic patient portals for patients to enter the data either from home or at their next clinic visit. Some of these systems have already developed the means for integrating the data with their EHRs; others are working on it.

4. See the Appendix for PRO measures that are ready to include in health plan contracting.

## BARRIER #4: LACK OF CONSENSUS ON HOW TO BUILD PERFORMANCE MEASURES USING PROS, I.E., TO SCORE THE CHANGE IN A PATIENT'S HEALTH STATUS BETWEEN TWO POINTS IN TIME.

Actions:

- **Consumers and purchasers should** advocate for wider adoption of measures that already exist and are being used in the field, e.g., for depression remission, asthma control, and (soon) hip and knee replacement surgery. They should further insist on standardization, i.e., the same PRO measures, using the same survey instruments, be used by all payers and providers for performance reporting.
- Following the BCBSMA example, **purchasers should** urge their plans to help pay for provider collection of PROs and sharing the data to further development of PRO performance measures. The Consumer-Purchaser Alliance continues to encourage federal agencies to fund the development of further measures built on PROs.

### SUMMARY

Achieving change in our massive and complex health care system is always a challenge. Consumers and purchasers need to tell their plans and providers what's important to them. Purchasers should incent providers to be innovative in delivering care that results in the best outcomes for patients. Additionally, purchasers

should use their leverage to communicate to patients what differentiates providers who deliver the most value (i.e. who does the best job at getting people to the highest level of functioning possible). Patients should demand from plans, purchasers, and providers alike that information generated from PROs are necessary to make important decisions about their care and allow them to play an active role in their own health improvement.

## Appendix

### RECOMMENDED PRO PERFORMANCE MEASURE STARTER SET

The table below shows conditions for which PROs are already developed into performance measures or are in the process of being developed by their measurement sponsors:

CONDITION	MEASUREMENT SPONSOR(S)
Asthma	Geisinger Health System Minnesota Community Measurement
Back and Neck Pain/Spine Surgery	Dartmouth-Hitchcock Medical Center Minnesota Community Measurement
CABG	Partners Health Care (Boston)
Depression	Minnesota Community Measurement Blue Cross Blue Shield of Massachusetts
Prostate Cancer	UCSF
Total Hip Replacement	California Joint Replacement Registry Minnesota Community Measurement Blue Cross Blue Shield of Massachusetts CMS
Total Knee Replacement	California Joint Replacement Registry Minnesota Community Measurement Blue Cross Blue Shield of Massachusetts CMS

These measures are either already available or soon will be available for the uses that are recommended in this Action Brief.

In addition, the following PROs could be developed from survey instruments currently in use:

- Patient activation and functional health improvement using the Patient Activation Measure<sup>5</sup> and SF-12/VR-12<sup>6</sup>
- Post-partum depression using the PHQ-9 questionnaire<sup>7</sup>
- Angina using the Seattle Angina Questionnaire<sup>8</sup>
- Pain management for cancer patients using the MD Anderson Symptom Inventory<sup>9</sup>.

Note: In addition to the set of discrete conditions shown above for which PROs are available or could be available soon, there is a generic PRO assessment tool known as PROMIS<sup>10</sup> that has been applied to many different conditions in various research studies. PROMIS is an interactive software tool that is structured so that it asks the minimal number of questions needed to assess the patient's health status from their own report. It was developed by the National Institutes of Health for use in research studies. Another strategy for the U.S. to follow is to have the health care system adopt PROMIS and then use it to track patients in priority areas. Such a strategy requires buy-in not only from the purchasers and payers, but from the physician community as well, which has become invested in the survey tools that have been adopted in their specialty areas.

5. <http://www.insigniahealth.com/solutions/patient-activation-measure>

6. [http://www.rand.org/health/surveys\\_tools/mos/mos\\_core\\_12item.html](http://www.rand.org/health/surveys_tools/mos/mos_core_12item.html)

7. [http://www.dartmouth-hitchcock.org/medical-information/health\\_encyclopedia/tn9653](http://www.dartmouth-hitchcock.org/medical-information/health_encyclopedia/tn9653)

8. Spertus JA, Winder JA, Dewhurst TA, et al. Development and evaluation of the Seattle Angina questionnaire: A new functional status measure for coronary artery disease. *J Am Coll Cardiol.* 1995;25(2):333-341. doi:10.1016/0735-1097(94)00397-9.

9. <http://www.mdanderson.org/education-and-research/departments-programs-and-labs/departments-and-divisions/symptom-research/symptom-assessment-tools/mdanderson-symptom-inventory.html>

10. <http://www.nihpromis.org/about/overview?AspxAutoDetectCookieSupport=1>