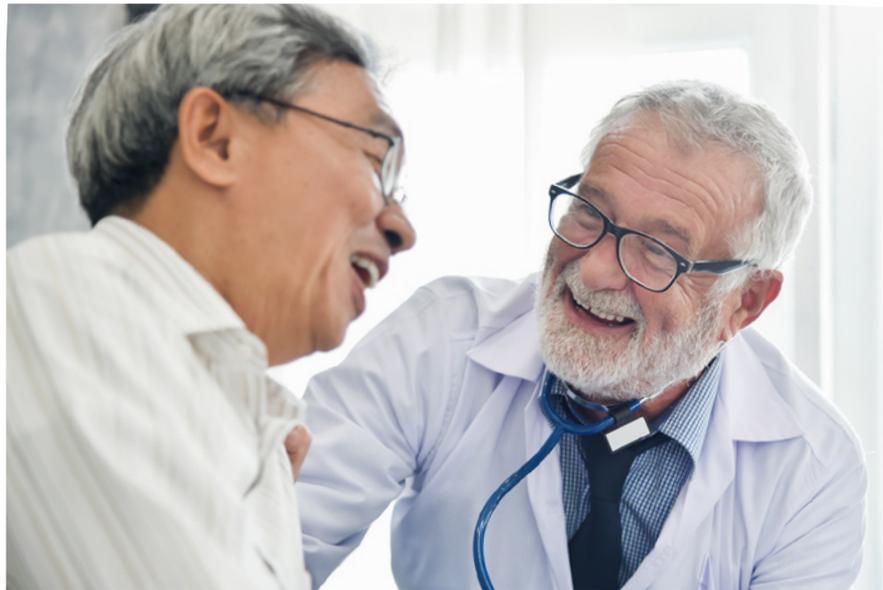


December 2018

Using Patient-Reported Outcomes in Primary Care

An Implementation Guide



Anne-Marie J. Audet, MD, MSc, SM
Senior Medical Officer, Quality Institute, United Hospital Fund

Roopa Mahadevan, MA

This publication is part of a collection of resources that grew out of a United Hospital Fund initiative to examine the role and value of patient-reported outcomes in primary care. It includes an implementation guide, three field reports, and an overview of implications for practice and policy.

The strategies, recommendations, and tools included in this publication are intended to provide a basic framework for implementing patient-reported outcomes that can be customized to meet the needs of individual practices regardless of size, academic teaching status, staffing model, patient population, or available resources. United Hospital Fund makes no representations or warranties of any kind regarding the implementation guide, including, without limitation, as to the accuracy of the information provided. The information provided is not medical or legal advice and should not be relied upon as such, nor should the information be used as a substitute for clinical or legal judgment. UHF does not assume liability for any damage or injury from the use or misuse of any information provided herein. We ask that you please acknowledge United Hospital Fund in the use of this resource, even if you modify or adapt it. Any use, modification, or adaptation of this resource is done at the user's discretion and the user assumes responsibility for the outcome.

Copyright 2018 United Hospital Fund



Contents

Foreword	ii
Introduction	1
Implementation Modules	2
Module 1: Laying the Foundation	4
What Are PROs?	4
Step 1: Identify Populations and Outcomes	5
Step 2: Define your Aims	8
Step 3: Build Culture and Capacity	13
Module 2: Workflow Process Mapping	15
Key Steps	15
PRO Workflow Process Mapping	17
Refining the Workflow	17
Module 3: Assessing Impact	20
Patient Experience Survey	20
Health Care Team Experience Survey	21
Health Care Team Structured Interview	22
Workflow Reliability Assessment	23
Module 4: Moving Toward Sustainability	25
Communication of Results	25
Exploring Sustainability Options	25
Conclusion	26
Practice Tools, Resources, and Selected Readings	27

Foreword

Every clinician knows that listening to patients is critical. But, all too often—because of busy schedules or established routines, or because the right questions aren't asked—the patient's point of view is under-valued.

United Hospital Fund is committed to strengthening patients' voices and making health care more patient-centered—which will, we believe, lead to better outcomes and greater efficiency.

Establishing the patient as the final arbiter of health care success is, in fact, the key aim of the Patient-Reported Outcomes in Primary Care-New York (PROPC-NY) initiative, developed by UHF's Quality Institute. Supported by a \$300,000 grant from The Engelberg Foundation and close to \$150,000 in grants from UHF, the initiative brought together three health care providers—the Institute for Family Health, Montefiore Health System, and Northwell Health—to take part in an 18-month learning collaborative.

The three providers created and assessed methods for eliciting first-hand reports from patients on their symptoms, status, and health goals—known as patient-reported outcomes or PROs. The lessons learned, and opportunities and challenges discovered, have been distilled and presented in this implementation guide and in accompanying resources, including “field reports” from the participating providers as well as an overview of the significance of patient-reported outcomes as a means of improving primary care.

This implementation guide offers a roadmap and tools to help providers incorporate PROs into their practices. Specifically, it includes four modules that provide information on the foundation for this work, workflow process mapping, strategies for assessing impact, and options for sustainability. The participants found that while using PROs sometimes presented challenges, the benefits were significant and generally worth the effort.

The move toward patient-centered care is directly linked to a shift in primary care that prioritizes value over volume. The work that informed this guide and UHF's PROPC-NY initiative will advance the discussion on these issues and will also support our mission of building a more effective health care system for every New Yorker.

I hope those who use the information in these pages find it helpful and enlightening.

Anthony Shih, MD
President
United Hospital Fund

Introduction

Primary care is undergoing significant change, spurred by a shift in how the quality and value of health care are defined. Instead of emphasizing only processes—*what is done*, appropriate testing and prescribing, for example—there is a growing focus on impact and *what happens to the patient as a result*. This transition from a *visit-based transaction model* (underscoring actions during the office visit) to an *outcomes-based model* (prioritizing symptom resolution and well-being beyond the specific visit) calls attention to how “outcomes” are defined and by whom. For example, an outcome such as glycemic control has become more prominent as a measure of quality, replacing the process of testing for diabetic control.¹ While this represents a significant improvement, such biological markers are not sufficient as outcome measures to gauge quality; equally as important should be patient reports following any form of intervention from health care professionals—so-called patient-reported outcomes (PROs). Patients do not seek advice because they want to make sure their blood glucose does not exceed a certain threshold—they seek advice related to symptoms that interfere with their lives. Patient-reported outcomes, therefore, provide essential information about the impact of interventions on those symptoms.

This guide and its accompanying resources provide a roadmap and tools for incorporating PROs in primary care, from concept through practical application. The materials are based on the shared experiences of participants in the Patient-Reported Outcomes in Primary Care–New York (PROPC-NY) grant initiative, an 18-month learning collaborative conceived and overseen by United Hospital Fund (UHF) and funded by The Engelberg Foundation.²

Each of the three organizations involved in PROPC-NY committed to testing the value and feasibility of implementing PROs in routine care and identified a primary care practice team, a target patient population, and a patient-reported outcome as the focus of their work.

1 Porter ME, S Larsson, and TH Lee. 2016. Standardizing patient outcomes measurement. *New England Journal of Medicine*. 374:504-506. <http://www.nejm.org/doi/full/10.1056/NEJMp1511701>

2 Adaptation of the IHI Learning Collaborative Model. 2003. *The Breakthrough Series: IHI's Collaborative Model for Achieving Breakthrough Improvement*. IHI Innovation Series white paper. Boston: Institute for Healthcare Improvement. <http://www.ihl.org/resources/Pages/IHIWhitePapers/TheBreakthroughSeriesIHLsCollaborativeModelforAchievingBreakthroughImprovement.aspx>

The participating organizations were:

- **Institute for Family Health's** Urban Horizons Family Health Center, a Bronx community health center, which sought to improve patient goal-setting and achievement related to social determinants of health.
- **Montefiore Health System's** South Bronx Health Center and Center for Child Health & Resiliency, which focused on improving families' ability to manage social and economic health stressors during pregnancy and the first year following birth.
- **Northwell Health's** general internal medicine faculty practice and residency clinic on Long Island, which aimed to improve patients' depression symptoms and physical function.

Details on each participating site and its project goals and experience are available in the field reports, which are case studies of each organization's pilot.

UHF created a curriculum of three work modules to guide the collaborative participants through structured phases of planning, implementation, and evaluation. Teams reported on their work at the end of each phase. In addition, the teams were supported by two outside faculty, a practice improvement coach, and a primary care physician leader with expertise in quality measurement. UHF invited subject matter experts to conduct webinars on special topics relevant to each module.

Three in-person meetings allowed participants to build camaraderie and share progress, challenges, and lessons. Every four to six months, UHF staff conducted one-on-one deep-dive calls with each team to address specific issues and provide technical assistance. UHF also made several visits to each practice site. To assess the reliability of its processes for collecting, using, and tracking PROs, each team conducted an evaluation—including a provider survey, patient surveys and focus groups, and chart reviews—toward the end of the collaborative. UHF staff and project faculty complemented this evaluation with structured interviews of each team.

Implementation Modules

This implementation guide follows the modular structure of the PROPC-NY learning collaborative:

- **Module 1: Laying the Foundation**
Understanding the concept and practical use of patient-reported outcomes and how they differ from other approaches to quality measurement and care delivery is an important first step toward successfully integrating them into primary care. This module discusses

these points and provides guidance on preparatory activities, including identification of a target population and selection of appropriate PROs.

- **Module 2: Workflow Process Mapping**

Implementing PROs requires both new workflows and a new organizational culture to promote their use. New workflows will necessitate that data is collected directly from the patient and made accessible for use in visit conversations and in assessing progress after the visit. This module provides guidance on how to develop new workflows with tools such as process mapping.

- **Module 3: Evaluating Impact and Exploring Sustainability**

Before PROs are implemented in routine care and their use spreads to other providers and patients, it is essential to first assess the impact of PRO pilots. This module offers examples of methods and metrics to measure impact from both the patient and health care team perspectives as well as methods to explore sustainability options.

Module 1: Laying the Foundation

What Are PROs?

Patient-reported information. Patient-reported outcomes. Patient-reported outcome measures. The terms are often used interchangeably, and while they are closely related, it is important to grasp the nuances distinguishing them (Figure 1).

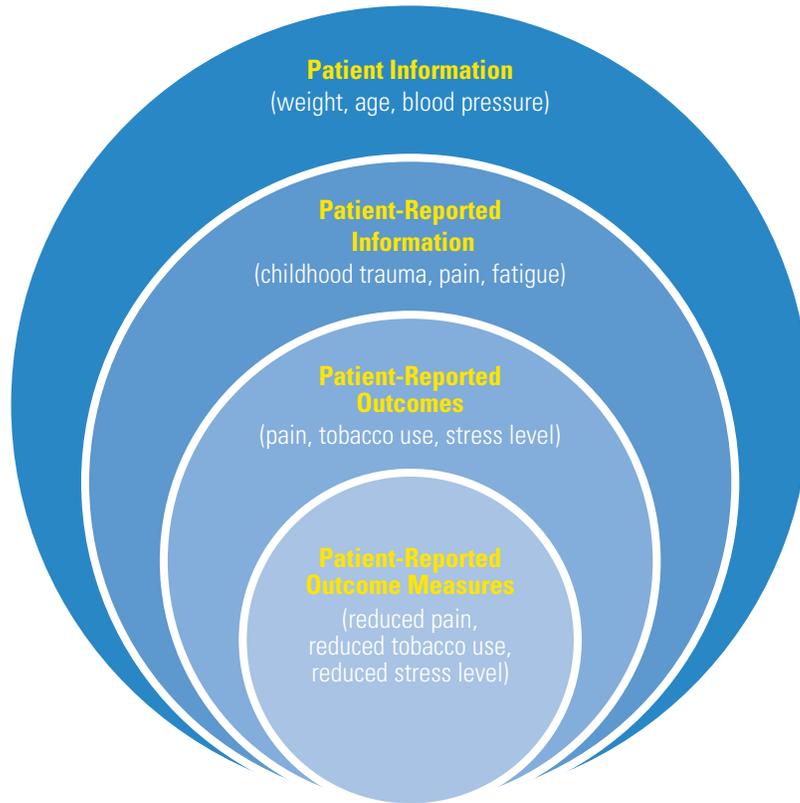
Patient-reported information (PRI) is a broad category comprising any self-reported facts or perceptions relevant to a patient's health and health care—demographic data, symptoms, or descriptions of social or physical function, for example. PRI includes intrinsic characteristics or events that are not modifiable, such as age or childhood trauma. The term also applies to reported symptoms or behaviors that *can* be modified so that changes in those symptoms or behaviors can be measured (e.g., fatigue).

Patient-reported outcomes (PROs) are self-reports by patients describing the effects of interventions and so only apply to patient characteristics that are modifiable through such interventions. Typically, health care outcomes are determined by an external assessment of what happens to a patient before and after he or she receives treatments. For example, the outcome of diet modification or drug therapy in a diabetic patient would be done by comparing a patient's blood glucose levels before and after. On the other hand, PROs are, by definition, not derived from external sources, but rather from the patient's self-assessment and report. They establish the *patient* as the final arbiter of success, whether that's reduced stress, improved breathing, or housing stability. Other examples of PROs include:

- Symptoms (pain, anxiety, fatigue);
- Physical, social, or emotional function (ability to walk up a flight of stairs comfortably; availability of social support; self-motivation; level of stress related to socioeconomic factors, such as housing instability);
- Behaviors (smoking, healthy eating, sexual activity).

Patient-reported outcome measures (PROMs) consist of surveys, questionnaires, scales, or other instruments that can track patient responses to interventions from the starting point of an intervention and over time and chart progress toward an identified PRO. These instruments use a structured form to elicit information from patients in a formal and systematic way. Rather than relying on chance that a clinician will inquire about issues important to the patient, the use of the instruments promotes customized, focused conversations between the clinician and patient. It also fosters consistency in how multiple team members evaluate the patient's status, enhancing communication and care coordination across specialties and settings.

Figure 1. From Patient-Reported Information to Patient-Reported Outcome Measures: Clarifying the Differences



The distinction between PRI, PROs, and PROMs can be tricky to recognize. Resource 1 provides a checklist that can help determine whether an identified outcome is indeed modifiable and can be reported by patients and whether a selected means of assessment is truly an appropriate patient-reported outcome measure.

Step 1: Identify Populations and Outcomes

Teams planning to introduce patient-reported outcomes often begin searching for measures they will use. However, the most appropriate starting point is the identification of which patient populations to focus on and which outcomes to prioritize. Those decisions will then guide the search for patient-reported outcome measures. In primary care, with its heterogeneous patient population, it is especially important to identify those patients whose outcomes are not being met and those whose self-reports on such outcomes would likely have a significant impact. A broad range of patient characteristics need to be considered:

- Demographics (age groups, race/ethnicity, income, neighborhood, education);
- Health status (pregnant, disabled);

- Risk status:
 - Chronic medical or behavioral health diagnoses (including multiple conditions);
 - High number of Emergency Room visits, hospital admissions, or re-admissions;
 - High-stigma conditions (HIV/AIDS, substance use);
 - Multiple medications or issues with adherence;
 - Disability;
 - Social health stressors;
- Conditions (asthma, congestive heart failure);
- Symptoms (chronic back pain, headaches).

Clinical Conditions vs. Symptoms

Research has shown gaps between patients' and clinicians' perceptions of the importance of various outcomes. Clinicians' assessment of a patient outcome will also frequently differ from the patient's own assessment. Evidence suggests that taking patients' perceptions of symptoms and health status into consideration can lead to more effective interventions.³ For example, a diabetic whose blood glucose may not be in control might also report feelings of depression. Instead of focusing only on the glucose control, the clinician could address her complaint and attend to her depression, which is likely affecting her ability to manage her diabetes.

You will need to consider whether to select outcomes based on patients' conditions (e.g., diabetes) or presenting symptoms (e.g., depression). You may find that a mix of the two is most appropriate for developing a treatment plan that reflects the patient's primary goal.

Similarly, it is appropriate to broaden the goals of treatment to include two types of outcomes: those that will be reported by patients (e.g., remission of depression, decreased pain intensity) *and* those that will be tracked via biological markers (e.g., blood glucose, blood pressure). For clinicians trained to see patients through the lens of individual conditions (such as hypertension or diabetes), this can be a challenge. But patients seek health care because they are worried about symptoms and expect to see them resolved; it is therefore critical to use more global assessments of quality of life and function (physical, social, and mental) and symptom severity—in tandem with traditional, condition-based assessments of vital signs.

3 Tarlov AR, JE Ware Jr, S Greenfield, EC Nelson, E Perrin, and M Zubkoff. "The Medical Outcomes Study. An application of methods for monitoring the results of medical care." *JAMA* 925-30 (1989).

Insight: Patient Priorities

Do not assume you know patients' priorities. You may be surprised by the outcomes they seek from each visit.

June Alcántara is a 57-year-old woman who returns to the clinic with complaints of increased urination. She is obese and has had type 2 diabetes, which she has managed with oral medications for 10 years. During this visit, her blood glucose is quite a bit over normal. With a goal of controlling her glycemia, you begin to discuss a management plan with her. You recommend a new medication and tell her to lose weight and eat a low-carbohydrate diet. Will she follow your advice?

This is Ms. Alcántara's take on the situation: "My husband left me six months ago, and he is stalking me to

make sure I do not go out with other men. He threatened to hurt me if he ever sees me alone on the street. My pharmacy happens to be on the way to his house, so I've stopped going—I am too afraid he'll see me. That's why I haven't been able to get my medications. I have to find a safe way to get them."

Without hearing Alcántara's story and explicitly addressing her concern, you will not contribute to the clinical goal of glycemic control. Once her number one priority—getting her medication safely—is addressed, however, she will have a better chance of reaching her next goal: glycemic control and an enhanced quality of life. Such step-by-step goal-setting and prioritization can only take place when the patient's voice is truly heard.

Social Health Stressors vs. Social Determinants of Health

Primary care operates within the larger context of an individual's life, and the impact of social health stressors (e.g., poor housing, lack of access to healthy food, cultural discrimination) and personal circumstances (e.g., lack of social supports, divorce, interpersonal violence) on his or her health cannot be ignored. In determining a relevant primary outcome, you may decide to prioritize the reduction of stress related to social determinants of health (see the Institute for Family Health and Montefiore field reports).

One major challenge is that most PRO measures have been developed and validated primarily for patients with discrete symptoms, conditions, and diagnoses (e.g., pain, sequelae of orthopedic surgery, cancer). Social determinants of health have yet to be fully conceptualized as modifiable health stressors that can be addressed by the health care team and handled as outcomes—whether a reduction in the severity of the stressor itself or a reduction in the patient-reported level of related stress. More research is needed to develop outcomes that can be used to assess the impact of interventions related to social determinants of health. Meanwhile, teams in the PROPC-NY collaborative developed their own PRO questionnaires to assess stress. They also began to explore patient-defined goals and goal attainment as an effective way to measure outcomes regardless of conditions.

Goal Attainment as an Outcome

While the main benefit of PROs is a focus on individual patients' health priorities, this type of personalization will be a challenge. The number of reasons patients visit primary care is large, and the number of different outcomes a practice can realistically track is limited. One approach to this problem is to develop a standard dashboard with sets of outcomes providers can choose from based on the needs of an individual patient.⁴ But there is an inherent tension between the efficiency of having an easily available, off-the-shelf set of outcomes and measures and the complexity of responding to individualized outcomes articulated by patients. One way to mitigate this is by focusing on *patient-defined goals* and *goal attainment* as the outcome. The care plan would be defined through shared decision-making between the provider team and the patient, who would jointly identify an explicit path for achieving the patient's goals and would mark milestones of progress over time.

To help providers customize their selection outcomes and measures to individual patients, the Dartmouth Institute for Health Policy and Clinical Practice is evaluating the use of the electronic medical record (EMR) as a decision-support tool. It allows the clinician to select a balanced set of outcomes. This could include biological markers (e.g., blood pressure control) as well as outcomes that are condition-specific (e.g., stool frequency in patients with Crohn's disease), those that address global function (e.g., quality of life and ability to resume activities and work post-knee replacement), and those that are created by patients (such as goal attainment).⁵

Step 2: Define your Aims

Once you have identified the population and outcomes you want to prioritize, it is important to consider what success will look like and to then set clear targets that all participants can work toward.

Measurable goals help team members establish their starting point and determine how far they must go to achieve success. For example, an aim of "improving patient-reported self-efficacy" is not as productive as "improving patient-reported self-efficacy by 40 percent within 12 months." Better yet is setting a baseline so that actual, as opposed to relative, gains can be measured (e.g., improving patient-reported self-efficacy from 20 percent to 40 percent within 12 months); you should also identify an instrument to measure "self-efficacy," so that changes can be assessed over time.

4 Rotenstein, Lisa S., Robert S. Huckman, and Neil W. Wagle. "Making Patients and Doctors Happier — The Potential of Patient-Reported Outcomes." *New England Journal of Medicine* 377, no. 14 (October 5, 2017): 1309–12. <https://doi.org/10.1056/NEJMp1707537>

5 Nelson E. 2017. *How Primary Care Can Move Towards a Patient-Centered and Outcomes-Focused Approach to Care Management*. United Hospital Fund-hosted webinar, p. 11. <http://uhfnyc.org/publications/881259>

PRO Measures Selection

Measurement burden is a reality that primary care practices know well—which is why we stress that this work is *not* about measures but about prioritizing a care model that emphasizes outcomes. Adopting the PRO model might, in fact, provide an opportunity to transform your broader approach to quality measurement, allowing you to replace measures that have relatively little value to providers and patients with those that do matter.

An efficient way to begin: create an inventory of measures already used by your practice and the specialists to whom you make referrals. This can help harmonize and simplify the battery of measures in use and help you focus on high-priority ones. Pay special attention to duplicate measures. For example, you may be using different instruments to assess mood disorders, such as PROMIS Behavioral Health, Drug Abuse Screening Test (DAST), and Screening, Brief Intervention, and Referral to Treatment (SBIRT) tools. Which are most important and effective for you? Which can lead to actionable results? Which align most with patient needs and voices?

You may find that you are already using measures such as the PHQ-9 as screening tools and that, by making changes in the workflow (including employing the tools before and after an intervention), you can also use them as outcomes measures. Consider forming a PROM oversight team or enlisting an existing, related committee to review these measures and recommend adoption approaches.

Give some thought to the data requirements, staffing responsibilities, workflows, and external reporting obligations associated with each quality measure. From a practical standpoint, this will also help you identify the resources, time, and data infrastructure you may or may not be able to commit to the implementation of PROs. You may find, for example, that the practice is already complying with numerous external requirements and has an abundance of experience with measuring progress related to processes of diabetes management; in that case, it makes more sense to consider adding a patient-reported outcome focused on diabetes, rather than to select a new clinical area or population.

The Right Measure: Considerations

The selection of a PROM instrument may not be a one-time activity; it may take a pilot test or a few months of implementation to determine whether an instrument is working for you or if a different one is needed. In any case, it is important to “get started.” Careful consideration of the following selection criteria can help set you up for success.⁶

6 National Quality Forum (NQF). *Patient-Reported Outcomes in Measurement*. Contract HHSM-500-2009-00010C (January 10, 2013). Accessible here: <https://www.qualityforum.org/WorkArea/linkit.aspx?LinkIdentifier=id&ItemID=72537>

Questionnaire Length. While you want to extract comprehensive, useful information, a lengthy questionnaire can be burdensome for patient and practice alike. It can lead to patient fatigue, poor response rates, and incomplete responses that will be harder to interpret.

A “brief” instrument would typically have fewer than 10 items, and a super-brief instrument would have one-to-four items. Both can be as effective as longer questionnaires. Another useful metric is the time it takes the patient to report information and answer questions. Anything requiring more than five minutes can be excessive in a busy outpatient setting and hard to integrate efficiently into the workflow.

Computer-adaptive technology (CAT) can mitigate the burden of lengthy instruments. The Patient-Reported Outcomes Measurement Information System (PROMIS), for example, can be used by patients to answer questions using a computer or a tablet.⁷ The PROMIS App includes a large bank of questions/items and uses branched logic to direct patients to a subsequent question based on their previous answer. This provides extremely precise scores with just a small number of questions.⁸ As patients’ symptoms change over time, their answers when asked about various aspects of their pain, function for example, will also change. As a result, the CAT will direct them to different sets of questions. Response rates may improve by addressing respondent fatigue at being asked the same questions repeatedly.

Format. Consider how format—paper vs. electronic—may affect the ability of patients and staff to administer and use questionnaires. While paper forms may be simpler to set up at the outset, the subsequent analysis of responses and integration into clinical care can involve more manual labor—especially in a high-volume practice. This is even more time-consuming if there is a requirement that the information be both collected and made available to the health care team at the time of the visit. Electronic interfaces with EMR that allow patient-reported outcomes from various sources (tablet, computer, smart phone applications) to be transferred into the patient EMR will be essential for sustainability, yet they will be more complicated to pilot on the front end and will require IT staff and resources. To secure HIT programming resources, you will probably need to demonstrate the benefits of patient-reported outcomes; to that end, consider first piloting PRO work with a paper-based workflow to show that it is manageable.

7 PROMIS (Patient-Reported Outcomes Measurement Information System), housed by the National Institutes of Health (NIH), is a set of person-centered measures that evaluates and monitors physical, social, and emotional health in adults and children. It can be used with the general population and with those living with chronic conditions. All instruments are available via Epic and tablet platforms for ease of use. <http://www.healthmeasures.net/explore-measurement-systems/promis>

8 Chen J, L Ou, and SJ Hollis. A systematic review of the impact of routine collection of patient-reported outcome measures on patients, providers, and health organizations in an oncologic setting. *BMC Health Services Research* 13:211. (2013). <https://doi.org/10.1186/1472-6963-13-211>.

Ease of patient use. Bear in mind the effort required of patients in answering questions via a paper or a computerized platform. It is particularly important to consider how patients will be supported should they have questions or need assistance regarding issues that may be deeply personal or sensitive in nature. Be clear with them about the benefit of communicating such information. Patients are typically asked to respond to many different questionnaires, but most still value the opportunity to share sensitive personal information if they understand why that information is being collected and how it will be used to help them. Ignoring their responses may result in a loss of trust or a reduced willingness to provide information in the future.

You should also take language and literacy into account. Several PROMs are still only available in English or in a limited number of languages. This is changing, and in the meantime, you may need to seek translation services for the languages that are most common in your practice.

Actionability. The ultimate goal of engaging patients in reporting outcomes that matter to them is to provide their care team with information that will facilitate planning that is more appropriate and that also involves the patient. In addition, it can also help the team and patient assess the impact of the care plan. It is critical that results from the patient outcome measure be easy to interpret, so that they can be shared and discussed with the patient, translated into concrete actions, and collected later to assess progress.

Disease-specific outcome measures related to single conditions are more readily available, and clinicians are more likely to intuitively trust that they measure what they should be measuring. The challenge for primary care practices is that each measure may be relevant to just a small number of patients with only that condition; indeed, the increasing prevalence of comorbid conditions complicates the selection of disease-specific outcome measures that will be relevant to a patient.

Generic outcome measures, on the other hand, include holistic assessments of the patient and of the impact of multiple conditions on health-related quality of life, general health status, and physical, social, or mental functions. One benefit of such measures is that they are blind to clinical conditions and thus applicable to patients with multiple chronic problems, health risk behaviors, or other complex social issues. The drawback is that translating them into action is less obvious: learning how to interpret and design care management plans based on the results of generic measures requires training. The health care system has a long history of condition-based approaches to care that focus on one condition at a time; shifting the paradigm to a holistic model that takes into account the total patient's health burden from various issues and health stressors will entail reform in medical education, health care delivery, and workforce training. There is a growing need for research to generate evidence-based guidance regarding interventions designed to improve patient-reported outcomes.

Alternatively, goal attainment scaling may be worth considering. Developed 40 years ago, this measure allows individual and population-based outcomes to be quantitatively measured (even though the outcomes result from interventions tailored to specific individuals as opposed to standardized outcomes for a general population).⁹ Goal attainment scaling has been used successfully in patients with multiple conditions and psychosocial problems.¹⁰ Scales defined by each patient are very effective in helping them set goals, define how they will assess progress toward them (expected, better than expected, worse than expected), agree on actions to achieve them, and evaluate progress over time. There is growing interest in using goal attainment scaling to overcome the challenges of assessing the impact of care for populations that present infinite combinations of clinical and psychosocial issues. The National Committee for Quality Assurance has been testing these scales as not only a potential tool for tailoring individual patients' care but also one for assessing provider performance.¹¹ (See Resource 2 for an example.¹²)

Endorsed vs. Home-grown. The validity of a PROM is essential, especially if it will be used to objectively monitor changes in outcome measure scores over time, evaluate team performance (whether the team has improved an outcome), link value to financial incentives, or enable public reporting. When it comes to the availability and use of PROMs, important gaps exist in the current US national measurement enterprise. This is changing quickly as the need for such measures is recognized by groups including the National Quality Forum, the Centers for Medicare and Medicaid Services, the National Institutes of Health, the Patient-Centered Outcomes Research Institute (PCORI), professional organizations, and academic researchers.¹³

Both standardized and homegrown measures have advantages and disadvantages. Nationally endorsed measures can provide data beyond one institution that can be used to benchmark performance. They have also been subjected to a rigorous review process to ensure they were developed using scientifically sound methods and were appropriately validated. Selecting an endorsed outcome measure has the added benefit of preparing your practice for future reporting requirements and payment models, since these measures are more likely to be incorporated

9 Ruble L, JH McGrew, and MD Toland. "Goal attainment scaling as an outcome measure in randomized controlled trials of psychosocial interventions in autism." *Journal of Autism and Developmental Disorders* 42(9): 1974–1983 (2012). *PMC* [Web] 2018.

10 Stolee P, C Zaza, A Pedlar, and AM Myers. [Clinical experience with goal attainment scaling in geriatric care.](#) *Journal of Aging and Health* 11(1): 96-124 (1999).

11 Erin Giovannetti. "Developing Person-Driven Outcomes." National Committee for Quality Assurance (2017). <http://www.allhealthpolicy.org/wp-content/uploads/2017/10/GIOVANNETTI-for-web.pdf>

12 Australian Department of Veteran Affairs. 15.5 Case example for goal attainment scaling. <http://clik.dva.gov.au/rehabilitation-policy-library/15-goal-attainment-scaling/155-case-example-goal-attainment-scaling>

13 National Quality Forum. "Patient-Reported Outcomes in Measurement," Contract HHSM-500-2009-00010C (January 10, 2013). <https://www.qualityforum.org/WorkArea/linkit.aspx?LinkIdentifier=id&ItemID=72537>

into federal or state regulatory and value-based payment incentive programs. Note that some PROMs are proprietary and must be licensed, at a fee, for use.

Homegrown instruments, on the other hand, offer the advantage of being tailored to the exact needs of the local patient population and their providers. Our work with primary care practices indicates that, in the absence of existing nationally-endorsed PROMs, it may be acceptable to select measures that have been developed or adapted (from existing non-endorsed PROMs) by in-house clinical teams. The key is to ensure that outcome measures are developed, tested, validated, and—most importantly—properly vetted and endorsed by appropriate governance committees. Homegrown measures might even be submitted by local teams for national endorsement, thereby contributing important knowledge and tools to bolster patients' evaluations of outcomes that matter to them.

Step 3: Build Culture and Capacity

Although the explicit goal of integrating PROs into primary care is to identify, collect, and address patient-reported outcomes, the fundamental work consists of adopting a new outcomes-based model of care. Putting this model into practice not only requires a realistic assessment of needed and available resources—it also calls for a firm grounding in a culture that values patient-centered care and workflows that support coordination and interdependencies among staff.

Making an inventory of the characteristics, resources, and other “levers” within your practice or large health care system can help ensure your PRO project launches successfully and takes root in a patient-centered culture—it will also improve decision-making about target populations, outcomes, and measures. Key questions to consider include:

- **Staff Capacity:** How much time will be needed for specific activities? What skills must be developed? How can strengths be recognized and leveraged?
- **Information Technology:** How does system infrastructure measure up? What kind of access to data do team members have? What workarounds are available to support documentation and follow-up? Are essential hardware and software (e.g., iPads, patient portals) available?
- **Leadership Buy-In:** Do project leadership team, C-suite executives, Board members, and other leaders have the vision, expertise, resources, mentorship, and exposure needed for this kind of practice transformation?
- **Provider Buy-In:**
 - **Champions:** Are there clear, articulate leaders to motivate, guide, and sustain the work?

- **Messages:** What kinds of values (e.g., patient trust) or skills (e.g., goal-setting) need to be nurtured?
- **Venues:** What are the best forums for gaining provider buy-in and offering training (e.g., focus groups, staff meetings, councils to discuss strategies and impact)?
- **Tools:** What other resources are needed (e.g., toolkits, videos, a new staffing model)?

After this kind of assessment, you may discover that your practice is not yet ready to fully implement an outcome-based model of care. There are, however, some feasible steps that can help you prepare for this transformation: prioritize patient-reported information and signal that you value the data they share via questionnaires, portals, satisfaction surveys, or focus groups; use a PRO instrument that is short, familiar to clinicians, and easy to administer (even if not yet fully integrated into medical records); and focus on one targeted patient population that would most benefit from, and be best equipped to participate in, goal-oriented care. Consider small steps like these that can help build the culture and capacity required to conduct the PRO implementation effectively. The next Module provides specific operational guidance for mapping PRO workflows.

Insight: Centering the Practice around Outcomes that Matter to Patients

PROs are meant to help providers meet patients' needs, but their successful use requires that both patients and providers be open and able to try new ways of communicating and addressing relevant topics that tend not to be discussed or avoided altogether. In identifying target populations, you should think about patients' ability to articulate their health priorities and about how you can provide linguistic, socio-cultural, and programmatic supports that might assist them in that process. It is important that providers are skilled at and comfortable with these discussions and can demonstrate the sensitivity and respect needed

for judgment-free and culturally and linguistically appropriate conversations with patients. Consider how the expertise and experience of social workers, nurses, community health workers, or other staff members can be leveraged to build this competence and sense of interdependency among the provider team. And, of course, turn to your patients and explain your practice and what they might expect—since this may be a change from what they are used to. Getting their views and ideas will contribute to the patient/practice partnership that prioritizes patient-reported outcomes.

Module 2: Workflow Process Mapping

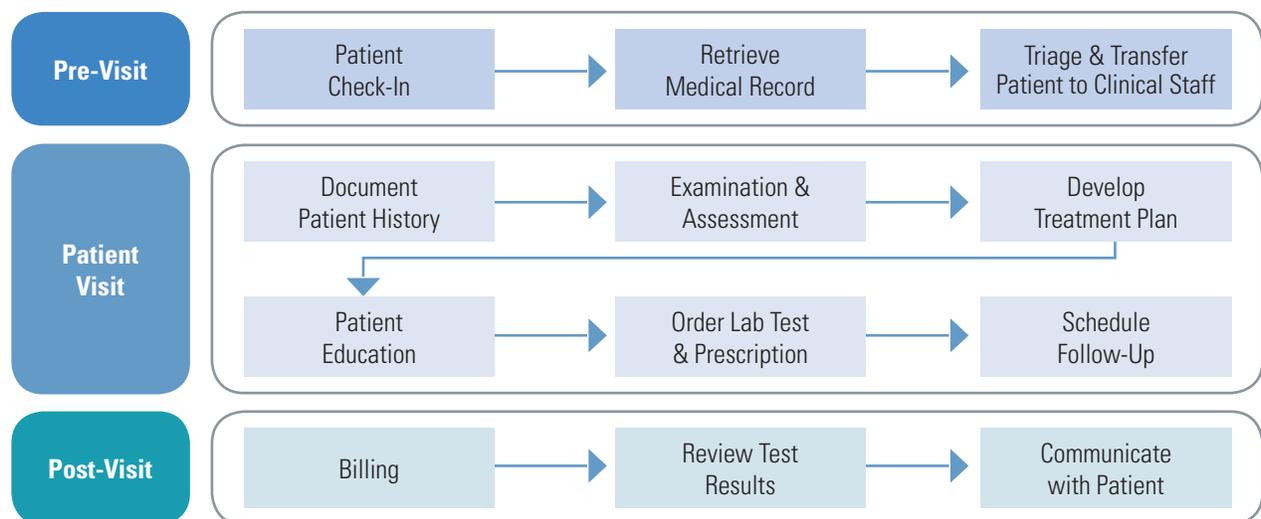
Process mapping is used to create or modify primary care delivery workflows. For example, this may include determining how abnormal tests results will be followed up, how patients will be notified, and how the practice will track the reliability of its follow-up process. Process maps visually represent the sequence of actions—how each is performed and by whom—making that sequence explicit to all members of a team involved in a particular workflow. It is an invaluable template for a team developing a new workflow (e.g., implementing PROs) and can help it assess whether the process is achieving goals as intended. It is not uncommon for a workflow evaluation to uncover a gap between what the team *thinks* the process is and what it *actually* is.

Key Steps

For primary care, workflow processes largely fall into three domains (See Figure 2):

1. Pre-visit: registration, medical record and patient information retrieval, triage and transfer of patient to clinical staff.
2. Patient visit: history, exam, care documentation (problem list, diagnoses, patient goals, treatment plan), patient education, orders and interventions, scheduling of follow-up visit.
3. Post-visit: communication with patients, caregivers, and other clinicians or facilities; follow-up with patients to assess the impact of the treatment plan.

Figure 2. Primary Care Clinic Workflow



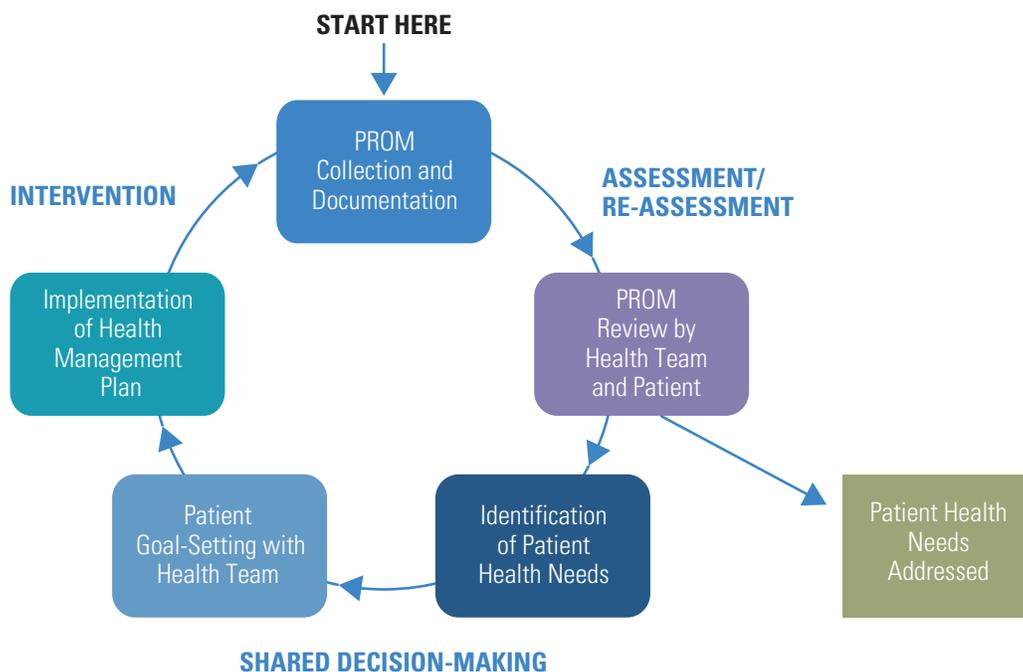
Source: Parminder K, Carolyn Steele Gray, Ashlinder Gill, James Tiessen, "The provider perspective: investigating the effect of the Electronic Patient-Reported Outcome (ePRO) mobile application and portal on primary care provider workflow," *Primary Health Care Research & Development* 19(2):1-14, Cambridge University Press (September 2017), <https://doi.org/10.1017/S1463423617000573>.

In a patient-reported, outcomes-based model, attention must be paid to the following:

- How and when patient information is collected (before the visit, onsite in waiting room, orally or via paper or electronic survey, after the visit);
- How and when it will be made accessible to each member of the team when they need it to care for the patient (during the patient encounter, for interdisciplinary care planning);
- How it will be used at the time of the visit (guidelines for talking with patients about what they reported, for goal-setting, and for creating customized care plans);
- How follow-up with patients will be accomplished; and
- How outcomes will be assessed and the feedback loop closed.

Figure 3 provides a basic sketch that highlights the key steps in a patient-reported outcomes feedback loop, the chassis for a more detailed workflow process.

Figure 3. Basic Patient-Reported Outcomes Workflow Process Steps



PRO Workflow Process Mapping

An effective way to move from the conceptual to the operational—from a basic framework to a more complex process—is to break the workflow down into three phases: pre-visit, intra-visit, and post-visit. Each phase will involve multiple steps; focusing on each one separately and then working on integrating them will be an effective way to manage complexity. The team will need to describe all the activities required at each phase, what resources will be needed, and what staff will perform those activities and when. It will be important to address the interdependencies between phases, steps, and critical decision points. It is also critical to consider vulnerabilities—where the process may fail.

Involving all relevant team members in workflow process development and securing their buy-in is essential, since they will be responsible for various activities. Building team buy-in is also a good way to perform a reality/feasibility check, particularly if you are creating a completely new workflow that entails changes in routine tasks and the investment of staff time to learn new procedures—all of which will have to take place while staff continue shouldering existing responsibilities for patient care and clinic operations. Figure 4 presents an example of a PRO workflow. Note the questions at right to be considered at each step, which can be helpful for focusing on the details of planning and implementation. Resource 3 offers additional PROM workflows used in the PROPC-NY initiative.

Make sure to consider and specify the “who, what, where, when, and how” of each of the high-level categories of the workflow. The more detailed your list of steps, the more likely the activities will be completed. Resource 4 provides an exercise to help you develop details of your workflow.

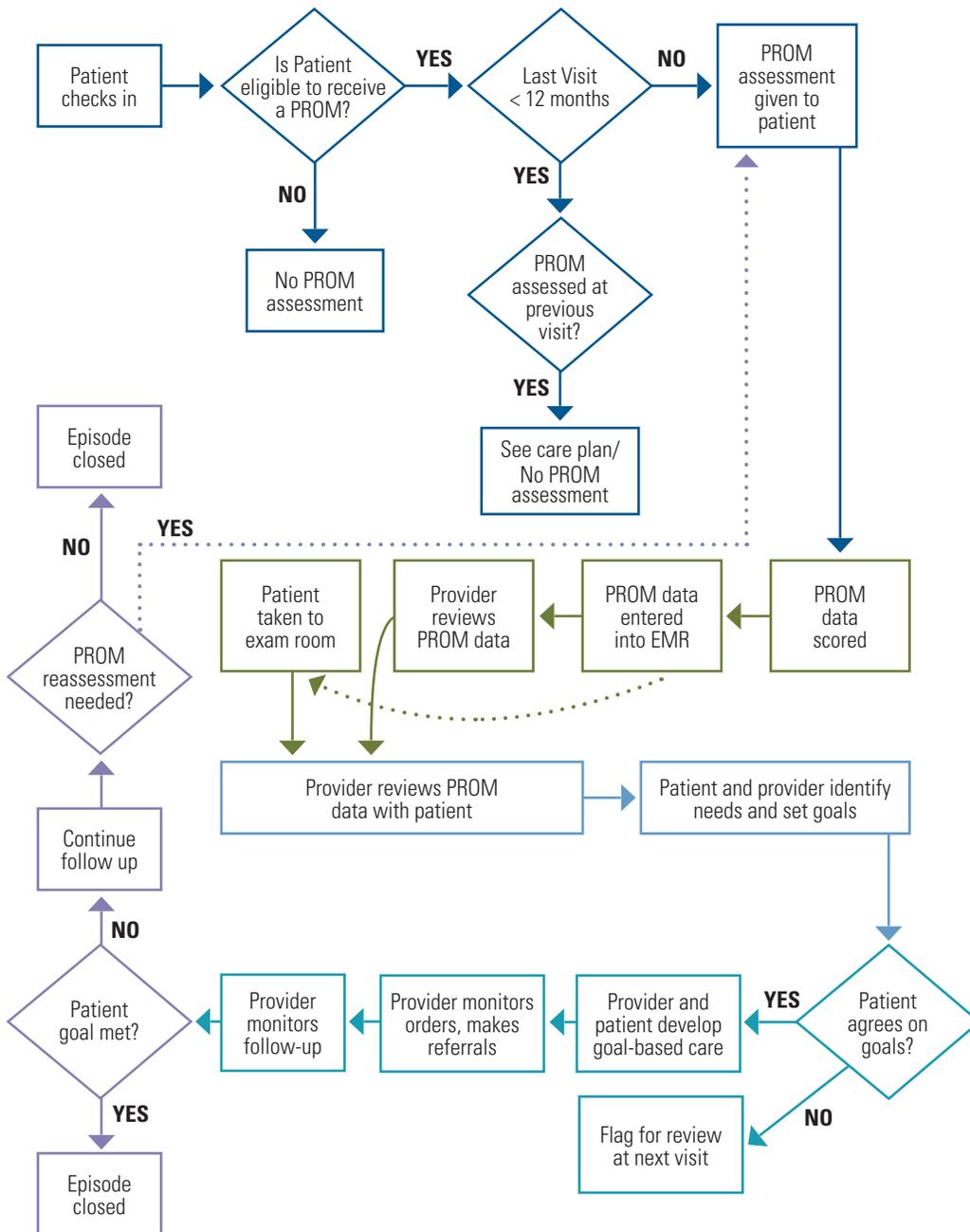
Refining the Workflow (Figure 4)

Every new or revised workflow needs to be carefully pilot-tested and continually re-visited to ensure that it is:

- Valid—designed to reach the goal you set out to achieve;
- Efficient—utilizing the right staff, right timing, right resources;
- Reliable—with key activities occurring predictably and without variation.

Following the workflow as it’s designed on paper may not be possible 100 percent of the time. As you begin to implement it, you may identify variations from what was originally specified. This may or may not be a bad thing: there may be several ways to get to the same result. For example, the task of entering PROM results into the EMR might be assigned to a medical assistant, but on some days—perhaps because of high patient volume—a nurse or other staffer may handle that task instead. If this doesn’t affect quality or create confusion or concern among staff, then it’s an acceptable variation—or perhaps even a better

Figure 4: Example of a PRO Workflow Process Map



- A. What are the eligibility criteria? How reliable are they?
- B. Who will engage the patient? Where (e.g., kiosk)?
- C. How long should the PROM assessment take?
- D. Is it a paper or electronic form?

- A. Who will score the PROM data?
- B. Where in the EMR will the PROM data be entered? Will it be linked to any other clinical or patient-reported data (e.g., previous goals)?
- C. Will the scoring staff member and provider have any conversations about the PROM score?
- D. What thresholds or criteria will be used by the provider when reviewing the PROM data?

- A. How will the provider review the PROM data with the patient? Will she use any particular tools (e.g., goal attainment scaling, visualizations)?
- B. How will open-ended conversations be integrated into discussions of PROM scores?
- C. What techniques are used by the provider/patient to identify needs and set goals?
- D. How will the patient be coached to have those conversations?

- A. What resources are available to guide goal-based care planning?
- B. How are PROM scores and other information (e.g., conversations, clinical data, goals) integrated to create a plan? How are they documented?
- C. How are interventions chosen?
- D. If a goal is not set, what kind of note/reminder is made to flag for review at the next visit?

- A. How does the provider follow up with the patient? In-person visits? Telephonic? Home visits? Portals?
- B. What is the time interval for follow-up?
- C. How is follow-up recorded in the EMR?
- D. What partnerships with external organizations are needed to do effective follow-up?
- E. What criteria are used to decide whether PROM re-assessment is needed?

way to work. In fact, it might lead to a revision of the workflow, which would include this variation as an option.

Some variations may, however, represent real threats to process reliability and fidelity and cannot be ignored. For example, the percentage of patients given follow-up PROM assessments may be much lower than expected. Using a team approach, such as root cause analysis or appreciative inquiry, you may discover underlying systemic issues that can be solved.¹⁴ These may include a lack of team guidance on explicit follow-up timeframes or the need to document follow-up PROM assessments in a section of the EMR accessible to all team members.

Resource 5 provides an exercise for creating metrics that help assess whether each step as specified is achieving expected results. Most often, workflow vulnerabilities occur with steps that involve handoffs. In such cases, the team can implement a monitoring process to oversee these critical points, review metrics, and identify improvements to the workflow.

Creating the optimal workflow process map requires time and multiple iterations: a problem is identified, a tweak is made, and the workflow is visited again. Repeated cycles of improvement will eventually yield a stable workflow, which can be monitored less frequently than in earlier phases of testing and implementation. Once the workflow is fully implemented, the team can assess its impact on longer-term patient outcomes. Module 3 provides guidance on evaluation strategies and related tools.

Insight: Obtaining Patient Information

One of the most challenging steps in a workflow prioritizing patient-reported outcomes is the gathering of such information directly from patients. This is a much more complex—and possibly unfamiliar—task than routine clinical jobs like conducting standard diagnostics and collecting their results. You may decide that getting information from the patient before or after—rather than during—the visit is the right strategy for your workflow.

Pre- and post-visit questionnaires via portals, texts, and other virtual platforms are promising innovations to consider. See, for example, “Patient Portals and Quality of Care: Improving Patient Engagement with Electronic Health Records,” Children’s Hospital of Philadelphia PolicyLab, 2014, <https://policylab.chop.edu/research-glance/patient-portals-and-quality-care-improving-patient-engagement-electronic-health>.

14 The Joint Commission. *Root Cause Analysis in Health Care: Tools and Techniques*. <http://www.jcrinc.com/assets/1/14/EBRCA15Sample.pdf> (2015); Ruhe MC, SN Bobial, D Litaker, CA Carter, et al. Appreciative inquiry for quality improvement in primary care practices. *Quality Management in Health Care* 20(1):37-48 (2011). <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4222905>.

Module 3: Assessing Impact

After implementing the PRO workflow, it is important to identify whether it is producing the anticipated results for patient care and outcomes. Several questions can help you articulate an evaluation strategy that will suit your needs.

- Is the adoption of the workflow feasible and should it be spread and/or sustained?
 - What are the implementation challenges and solutions that have been encountered? Can they be solved in a realistic timeframe?
 - *Should* the work be done? Have PROs added value to patient care?
 - Can the use of PROs be sustained? What would be required to make the use of PROs manageable and routine?
- What types of data should be collected?
 - Patient perspectives.
 - Health care team perspectives.
 - Feasibility measures.
- What data collection tools are needed?
 - Surveys, focus groups, one-on-one or structured interviews.
 - Chart reviews, project management tools.

The following sections provide examples of evaluation tools and key considerations for implementing them; Resource 6 includes evaluation tools used in PROPC-NY. Additional examples of evaluation methods that can be used in the context of PRO implementation are available in the peer-reviewed literature.¹⁵

Patient Experience Survey

Survey Domains

Eliciting patients' experiences with the PRO workflow and questionnaire is vital; their perspective on this new approach to care may be quite different from that of the health care team. They may see issues with the PRO collection process—rushed staff, poorly crafted questions, concerns about privacy—that may not

15 Snyder CF, NK Aaronson, AK Choucair, TE Elliott, et al. "Implementing patient-reported outcomes assessment in clinical practice: a review of the options and considerations." *Quality of Life Research* 21(8): 1305–14 (2012). <https://doi.org/10.1007/s11136-011-0054-x>; Snyder CF, AL Blackford, AC Wolff, MA Carducci, JM Herman, AW Wu, and the Patient Viewpoint Scientific Advisory Board (2013). "Feasibility and value of PatientViewpoint: a web system for patient-reported outcomes assessment in clinical practice." *Psycho-Oncology* 22(4): 895–901. <https://doi.org/10.1002/pon.3087>.

have been intended by staff but nonetheless have significant consequences. Questions for patients typically focus on:

- Method of administration of the PRO questionnaire.
- Anxiety/comfort with the questions themselves.
- Whether and how self-reported information is used.
- Interactions with the health care team.
- Effects on patient knowledge, attitudes, or behaviors.
- Patients' feelings after their visits.
- Patients' willingness to continue to report outcomes information.

Survey Sample

In striving for inclusivity, consider the most effective vehicles for engaging targeted populations. You should also be prepared to try several kinds of tools and ways of applying them: a paper form vs. a digital platform; collecting information in the office at the end of a visit vs. at home post-visit; and in-person interviews vs. phone interviews, or interviews conducted via paper or digital platforms (such as web-portal or text). For select patients, one-on-one interviews or focus groups may be more appropriate. Whatever the mode or method, literacy levels and specific language needs must be taken into account, so all patients can participate effectively.

Resources 6A and 6B offer examples of a patient survey and patient interview tool used in PROPC-NY.

Health Care Team Experience Survey

Survey Domains

Surveys can be useful for gathering quick and specific feedback from a provider team. They can identify particular aspects of users' involvement with PROs, including patient communication and engagement, health care teams' perceptions of their effectiveness, experiences with time or resource constraints, and views on the degree to which well-established routines are disrupted.

Surveys can focus on users' experiences and opinions about how PROs affected the following areas:

- Identification of patient concerns.
- Content of provider-patient conversations.
- Standardization of the approach to patient engagement.
- Goal-setting.

- Patient motivation and empowerment.
- Clarity in care plan development.
- Quality of care.
- Facilitation of provider/staff teamwork.
- Feasibility of implementation.
- Hurdles to effective use.
- Willingness to sustain use.

Survey Sample

The survey should be administered to each health care team member involved in the PRO workflow. When interpreting results, it is important to bear in mind that some respondents' opinions about the use of PROs may be affected by the nature of their roles, including their disciplines, job functions, titles, or tasks performed. Some team members may be involved in only one aspect of the PRO workflow—such as collecting patient information or entering scores in the EMR—while others may perform multiple roles that encompass the initial stages, the discussion of results, and the follow-up with the patient. Consider the kinds of questions you want to ask the provider team and how you might customize those questions based on the roles of its members. One approach: focus on activities (e.g., administration, care plan development, referral, and follow-up).

Remember that this is not a research project— it is an operational activity involving the redesign and rethinking of many aspects of how your practice does its work. While large samples are not needed to interpret findings, it is still important to have as many team members respond as possible—and to elicit nuanced, personal opinions from those intimately involved in the PRO workflow. Consider other sources of information that can complement survey data, such as one-on-one interviews, structured team interviews, or focus groups. Qualitative information is often more revealing than quantitative data and may help expose the motivations, frustrations, and passions underlying the work.

Resource 6C provides an example of a health care team survey used in PROPC-NY.

Health Care Team Structured Interview

Group interviews can facilitate the sharing of experiences among team members that provide new insights into the PRO implementation process, reveal interdependencies among individuals and roles, build camaraderie, and potentially strengthen the case for making changes that require personal investment.

Interview Domains

Aspects of PRO implementation that you may want to focus on might include:

- Acceptability to team members and patients;
- Utility of PROs in identifying patient priorities, enhancing patient-provider interactions and post-visit engagement, and increasing appropriateness of care plans;
- Efficiency of workflow processes, including PRO collection, data entry, analysis, use by multiple providers/staff, documentation, translation into interventions, follow-up, and re-assessment;
- Feasibility (including potential disruptions or enhancements to overall workflow) and sustainability.

A neutral moderator who can cultivate a positive, open, and safe environment in which team members can share is essential for facilitating questions and discussion.

Resource 6D provides an example of the health care team interview guide used in PROPC-NY.

Workflow Reliability Assessment

Appropriate data collection and analysis can provide quantitative insights on workflow processes integral to the operationalization of PROs in primary care. Given that every system is perfectly designed to get the results it gets, metrics can shed light on a system's reliability and feasibility as well as the gap between intent and results.¹⁶

In the case of PRO workflows, metrics can be used to assess the workflow process, such as collection reliability; the frequency of PRO use at the time of the visit; the follow-up on PROs after an intervention with the patient; and workflow consequences, such as improvements in patient-reported outcomes. Examples include:

- Thoroughness of initial administration (percentage of PROs administered successfully among eligible patients);
- Availability of initial and repeat PRO results in the EMR for patients and appropriate provider staff;
- Use of PROs for goal-setting and care-planning;
- Use of PROs to assess progress toward patient outcomes over time;

¹⁶ Attributed to Paul Batalden, Institute for Healthcare Improvement senior fellow and founding chair. <http://www.ihc.org/communities/blogs/origin-of-every-system-is-perfectly-designed-quote>.

- Average time to outcome follow-up (from baseline or previous assessment);
- Goal attainment frequency.

For each of these and for and similar metrics, you will need to define specifications (e.g., numerators and denominators for each measure, inclusion criteria), identify appropriate data sources (e.g., the medical record), and develop a data collection methodology (e.g., manual chart reviews, electronic algorithms).

Resource 6E illustrates the workflow reliability assessment form used in PROPC-NY.

Module 4: Moving Toward Sustainability

Communication of Results

Sharing evaluation results supports ongoing process improvements. Discussions about what went right, or wrong, provide valuable guidance for ongoing team efforts; positive findings can help win continued buy-in from participating staff and new attention and resources from leadership. Communication channels to consider include:

- Hallway posters;
- Standing agenda items during important organizational meetings (e.g., weekly rounds);
- Periodic reports to C-suite, board members, and other leadership;
- Updates for key committees across the larger system (e.g., patient councils, quality committee, advisory board);
- Newsletter or fliers of recognition.

Exploring Sustainability Options

If an evaluation of a pilot project suggests that PROs are contributing to improved care delivery, several options exist for continuing the work and sustaining it over time. Consider the following categories of action:

- Sustain: Continue the use of PROs as is (e.g., mature workflow, no major changes needed, continue monitoring for process reliability);
- Modify: Refine how PROs are currently used (e.g., modifications in the selected priority population, condition/symptom/outcome of focus, choice of PRO measure);
- Scale: Broaden the scope of PRO use to include a greater proportion of the practice population (e.g., additional populations, additional targeted outcomes);
- Spread: Replicate the implementation of PROs in other primary care practice sites within the larger provider organization.

Each strategy will require a different plan of action. Resource 7 provides an exercise to clearly define which resources—organizational, cultural, technological, or financial—will most likely ensure the desired results as well as guidance on leveraging those resources in the action plan.

Conclusion

Making patient-reported outcomes an integral part of primary care is a major step along the path to transforming a traditional, transaction-based care model into one that is based on goals and outcomes. By prioritizing patient-reported outcomes as much as clinical data, this approach truly places the patient at the center of the care delivery system.

Practice Tools, Resources, and Selected Readings

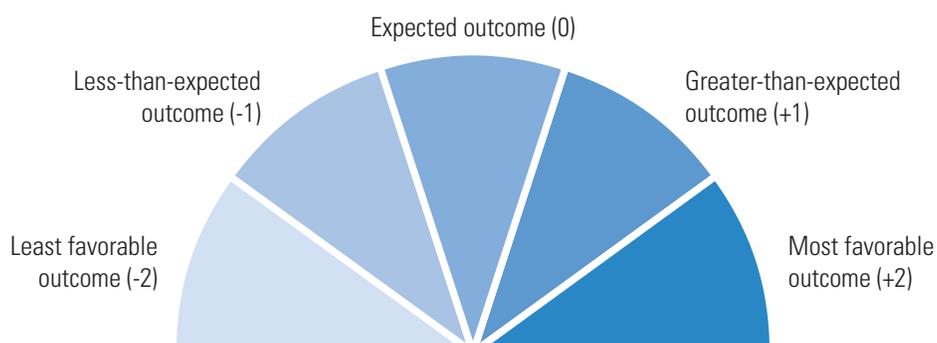
1. Is It a PROM?	28
2. Goal Attainment Scales	29
3. Sample PROM Workflows	30
4. Process Mapping: Who, What, Where, When, How	33
5. Testing the PRO Workflow	34
6. Evaluation Tools	35
A. Patient Experience Survey	35
B. Patient Phone Interview	36
C. Health Care Team Experience Survey	37
D. Health Care Team Structured Interview Protocol	39
E. Workflow Reliability Assessment Form	41
7. Sustainability Planning	43
Selected Readings	45
PROs and PROMs in Primary Care	45
Evidence-based Assessment of PROs	46
PRO Examples	47
Goal-setting	47
Case Studies, Examples, Toolkits	47

Resource 1. Is It a PROM?

Answering the following questions after tentative identification and selection of each outcome will help ensure that you are, in fact, gathering a patient-reported outcome and using an appropriate patient-reported outcome measure (PROM) to assess it.

Question	Yes	No
Can the outcome only be obtained by asking the patient to report on it?	<input type="checkbox"/>	<input type="checkbox"/>
Can it inform patient and provider goal-setting?	<input type="checkbox"/>	<input type="checkbox"/>
Can it inform the patient's care management plan?	<input type="checkbox"/>	<input type="checkbox"/>
Is the outcome under consideration partially or fully attainable via care team interventions?	<input type="checkbox"/>	<input type="checkbox"/>
Is there a standard way to measure the outcome so that it is interpreted the same way by anyone assessing it?	<input type="checkbox"/>	<input type="checkbox"/>
Can the measure be scored and reliably interpreted?	<input type="checkbox"/>	<input type="checkbox"/>
Can the scored outcome be easily accessed by any member of the provider team through the medical record?	<input type="checkbox"/>	<input type="checkbox"/>
Can the score change over a realistic timeframe and reflect provider team actions (e.g., treatment, referrals)?	<input type="checkbox"/>	<input type="checkbox"/>

Resource 2. Goal Attainment Scales

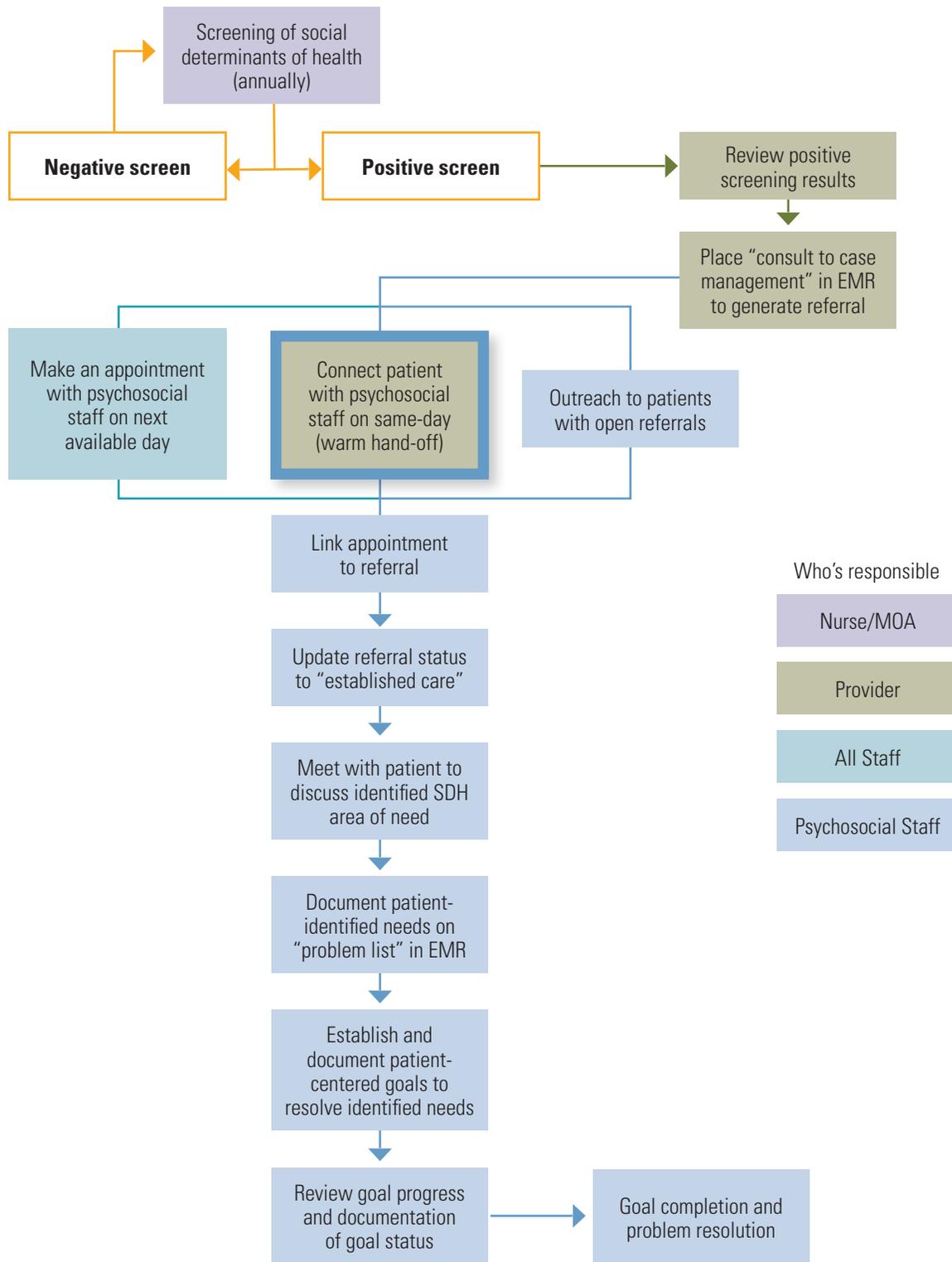


Level of Expected Outcome	Goal 1: Access treatment for knee condition and follow recovery plan	Goal 2: Improve mood/mental health	Goal 3: Improve pain management
Most favorable outcome (+2)	Knee replacement surgery has occurred within three months, and recovery is progressing better than expected, with no pain or swelling three months post-surgery as a result of following recovery plan	Patient has accessed treatment for depression and, within three months, is managing symptoms effectively 50% of the time	Patient has participated in pain management program and, within three months, is managing pain symptoms effectively 50% of the time
Greater-than-expected outcome (+1)	Knee replacement surgery has occurred within three months, and recovery is progressing as expected, with little pain or swelling three months post-surgery as a result of following recovery plan	Patient has accessed treatment for depression and, within three months, is managing symptoms effectively 25% of the time	Patient has participated in pain management program and, within three months, is managing pain symptoms effectively 25% of the time
Expected outcome (0)	Knee replacement surgery has occurred within three months, and a recovery plan is in place	Patient has accessed treatment for depression and, within three months, is learning strategies to manage symptoms	Patient is participating in pain management program and, within three months, is learning strategies to manage pain
Less-than-expected outcome (-1)	Knee replacement surgery did not occur within three months, but patient has seen surgeon and date is set; an active plan is in place for managing injury while awaiting surgery	Patient has not yet accessed treatment for depression; no change in depressive symptoms	Patient has not yet participated in pain management program; no change in ability to manage pain
Least favorable outcome (-2)	Knee replacement surgery did not occur within three months, patient has had no contact with surgeon or other health professional and no active management plan is in place	Patient has not yet accessed treatment for depression; symptoms have worsened	Patient has not yet participated in pain management program; pain has worsened

Source: Australian Department of Veteran Affairs, 15.5 Case example for goal attainment scaling, <http://clik.dva.gov.au/rehabilitation-policy-library/15-goal-attainment-scaling/155-case-example-goal-attainment-scaling>.

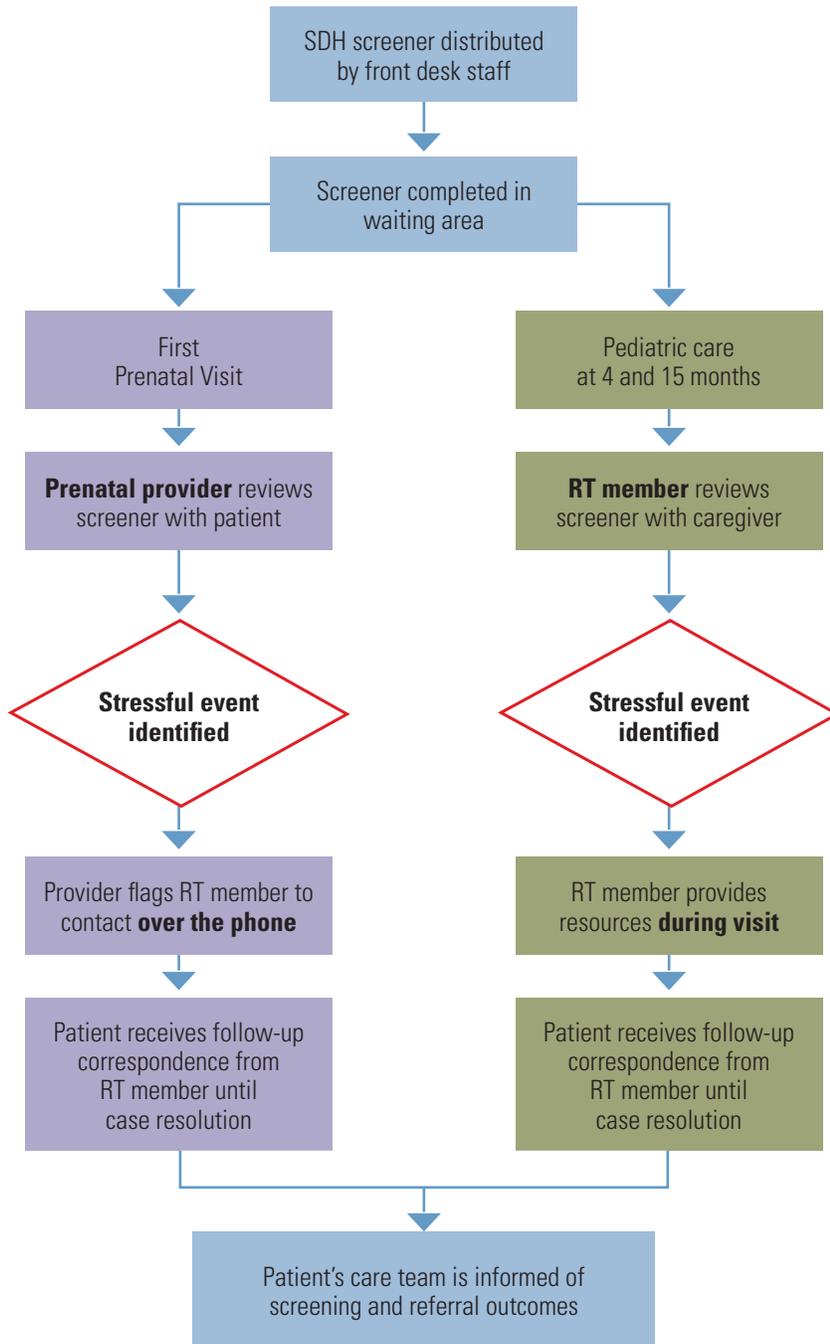
Resource 3. Sample Patient-Reported Outcome Workflows

Process Map: Social Determinants of Health



Source: Institute for Family Health

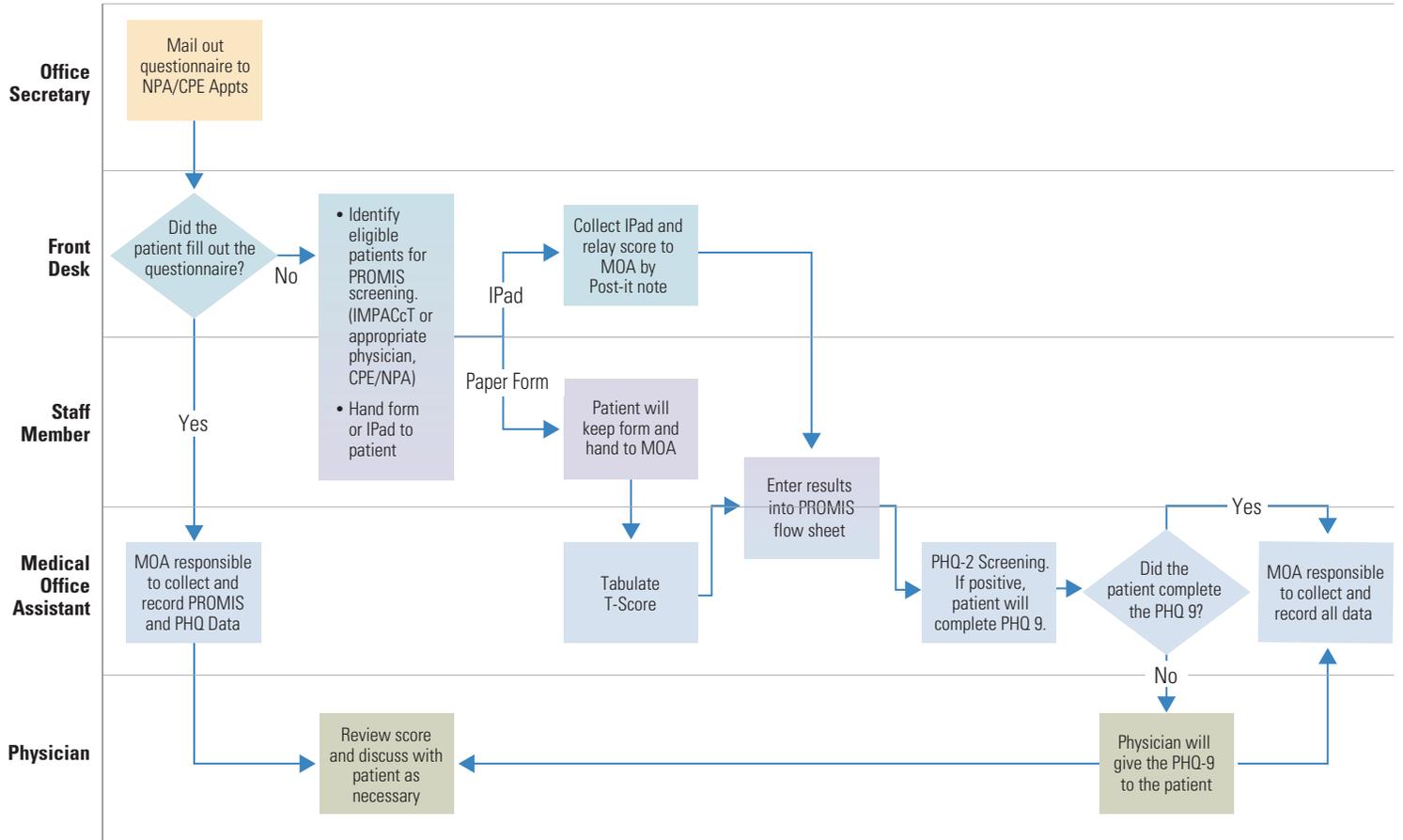
Process Map: Social Health Stressors in Prenatal and Pediatric Care



Source: Montefiore Health System

Process Map: Depression and Physical Function

Patient Appointment



Source: Northwell Health

Resource 4. Process Mapping: Who, What, Where, When, How

This table is useful for tracking key operational details for each major step of the PRO workflow. Sample steps and examples are provided.

	WHO	WHAT	WHERE	WHEN	HOW
PROM collection	Medical assistant, other staff will assist patient	Survey instrument – which one	<ul style="list-style-type: none"> • Waiting room • At home 	Upon arrival (should take no longer than 8 minutes)	<ul style="list-style-type: none"> • Paper survey • iPad survey • Portal
PROM results are recorded and made accessible to the team member seeing the patient	Medical assistant, other	Results of the survey	Medical record, separate document	Before the patient is seen by the appropriate team member	Staff transmits data from iPad to EMR
Patient goal-setting with health care team					
Implementation of health management plan					
PROM collection (re-assessment)					
PROM evaluation documented (e.g., improvement)					

Resource 5. Testing the PRO Workflow

Identify metrics that will indicate the success of every step of your process map, including points of handoffs and other vulnerabilities where the process has the potential to fail. A number of examples are given below.

Process	PLAN/DO		
	Describe process(es) tested/implemented (who, what, when, where)	Describe metrics used to test processes (e.g., for reliability, reproducibility, efficacy)	Why were these measures important? (e.g., to ID eligible patients; to track patient refusals; to facilitate teamwork)
Identifying eligible patients	(Narrative)	Specify numerator/denominator as appropriate	(Narrative)
Key handoffs	(Narrative)		
Key vulnerabilities	(Narrative)		
Introducing the PROM to the patient			
Key handoffs			
Key vulnerabilities (e.g., patients may ignore mailed materials; patients may be late to the visit, so the check-in process may be rushed; and patients or staff may forget about or ignore questionnaires)			
Scoring and inputting PROM results in medical record			
Key handoffs			
Key vulnerabilities			
Reviewing PROM results with patient			
Key handoffs			
Key vulnerabilities			
Goal-setting and developing care management plan with patient			
Key handoffs			
Key vulnerabilities			
Make referrals, draft intervention plan			
Key handoffs			
Key vulnerabilities			
Patient monitoring and follow-up			
Key handoffs			
Key vulnerabilities			
PROM re-assessment			
Key handoffs			
Key vulnerabilities			
Other			
Key handoffs			
Key vulnerabilities			

Resource 6. Evaluation Tools

6A. Patient Experience Survey

Thank you for filling out the Social Health Stressor Questionnaire before your appointment.

To serve you better, we'd like to know how much the questions helped during your visit with practice staff today. Please read each statement below and choose the answer that best describes your experience. Your participation in this survey is voluntary. You are free to not answer any question for any reason. Your responses will remain anonymous.

Thank you for filling out this survey!

During today's visit:

1. Staff asked me to talk about my answers to the questions about stress: Yes No

In your visit today:	Strongly Disagree	Disagree	Neither Disagree Nor Agree	Agree	Strongly Agree	Not Applicable
2. Staff made it easier for me to raise concerns about things that can affect me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Staff helped me think about ways I can reduce my stress.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Staff helped me decide on next steps I can take to reduce my stress.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Staff helped me find resources to reduce my stress after I leave the office.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. The resources I was offered will help meet my needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. I now feel better prepared to manage my stress.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Feel free to share anything else about your visit.

6B. Patient Interview

Interview Script

On _____ (date of visit) you attended an appointment with your doctor. At that appointment, you were asked questions about your housing situation, violence you may have experienced, and other things in your life.

Do you remember when we asked you those questions?

How did it feel to be asked those questions?

For patients who screened positive and completed a follow-up referral

We noticed in our records that you said “yes” to the question _____. Were you directed to see a social worker regarding this issue at the visit?

Tell me more about that.

What was the process like?

What happened after that?

What was the meeting with the social worker like?

What happened at the end?

How helpful was this process?

Tell me more about that.

Did anything related to this issue change for you after the meeting?

What would you have liked to have happen?

What did you think about the additional support that was offered?

Did anything get in the way of the issue being resolved?

What issues or challenges arose in your encounter(s) with the social worker?

Tell me more about that.

How did the issue get resolved?

Are there other issues you are having in your life that you think your doctor should ask about?

What are they?

Thank you for your time and participation. I want to confirm your address so that I send the MetroCard to the correct location. I have it as [read address]. Is this correct? You should be receiving the MetroCard within two weeks.

6C. Health Care Team Experience Survey

The goal of the following survey is to learn about your experience with the Social Health Stressor Questionnaire for patients as part of the Patient-Reported Outcomes in Primary Care (PROPC-NY) grant, led by United Hospital Fund's Quality Institute. For each statement, check the box that best represents your opinion. Your participation in this survey is voluntary. You are free to refuse to answer any question for any reason. Your responses will remain anonymous.

Thank you for filling out this survey!

1. Your professional discipline

- Primary care physician
- Resident
- Physician assistant
- Nurse practitioner
- Behavioral health provider
- Medical assistant
- Case manager/social worker
- Other (please specify):

2. Your role (how you interact with the patient-reported outcome questionnaire)

[select as many as applicable]

- Administering the questionnaire
- Scoring the questionnaire
- Discussing questionnaire results with the patient
- Documenting questionnaire results on paper or in the EMR
- Developing care plans based on questionnaire results
- Setting goals with the patient based on questionnaire results
- Conducting follow-up with the patient after the visit to assess outcomes
- Other (please specify):

3. Survey Questions

The Social Health Stressor Questionnaire:	Strongly Disagree	Disagree	Neither Disagree Nor Agree	Agree	Strongly Agree	Not Applicable
1. Promotes better conversations with patients	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Identifies patient issues that I did not know about	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Allows me to track progress on social health stressors over time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Helps me develop better care management plans	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Promotes patients' confidence in managing their health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Makes it more difficult to manage visit time with patients	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Promotes communication among team members	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Is hard to collect and use effectively	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Helps build trust/rapport with patients	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Improves patient satisfaction/experience	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Improves quality of care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Exposes problems that I do not feel comfortable with or am unable to address	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4. Do you want to continue using the Social Health Stressor Questionnaire?

- Yes
 No
 Maybe [please explain] _____

6D. Health Care Team Structured Interview Protocol

Collecting and documenting patient-reported outcomes

Audience: Staff involved in collecting the PRO from patients, documenting the information for use at time of visit or after the visit, and sharing the information across the team (e.g., front desk, medical assistants, case management)

1. Can you reflect on what you learned from the scoring, documentation, and sharing processes? What were the biggest barriers to making this routine? What would you tell other practices beginning this work?
2. Think about your experience with the PRO initially, and as you became more familiar with using it. Do you have examples of issues you faced when you first started to collect data from patients/document it/share access with team members at the time of the visit? How did you resolve them? How long did that take?

Using patient-reported outcomes in care management

Audience: Staff discussing findings with patients, creating care plans, and following-up (e.g., providers, social work/case management staff)

3. Tell us about whether and how the use of the PRO questionnaire affected how you spent time with the patient.
4. Tell us about how the PRO questionnaire affected the nature of your patient-provider relationship? Your relationship/engagement with the patient outside the office?
5. What are the benefits or drawbacks you saw to having a formal set of questions for patients, versus unplanned, open-ended questions?
6. Were there any particularly difficult conversations that the PRO questionnaire facilitated? Unintended consequences with patients that you would have wanted to avoid?
7. Describe your approach to goal-setting and explain how use of the PRO has facilitated or changed this.
8. How did use of the PRO questionnaire affect your protocol for patient follow-up to ensure progress on outcomes over time or to ensure that care plans were being implemented?
9. What characteristics (e.g., patient attributes, mode of communication, type of social health stressors, type of follow-up) seem to have the greatest impact on the likelihood of successful follow-up?
10. What are some strategies that you might use to improve follow-up time or goal resolution?

Workflow

Audience: ALL

11. Do you feel you have optimized the efficiency of the workflow? If not, how can it be made better?
12. What was the opportunity cost (e.g., resources or staff time taken away from other projects) of developing a workflow to include patient-reported outcomes in the care routine?

General Reflections

Audience: ALL

13. What do you see as the greatest benefits of using PROs in your practice?
Examples might include:
 - Individual patient care, population health assessment
 - Targeting and prioritizing certain groups of patients
 - Establishing trust and better patient-provider interactions
 - Identifying patient data that is essential to care management and cannot be obtained any other way
 - Improving patient-centered follow-up
14. Can you tell us your thoughts about how your practice might continue using PROs? What kind of resources would be critical to sustainability?
15. What are the opportunities to scale PROs to a larger set of primary care practices?
16. How do you view the use of PROs to measure the effectiveness and efficiency of care over more common, process-oriented quality measures?
17. What advice would you have for another primary care practice starting this work?
18. What were the three biggest surprises of this work overall?

6E. Workflow Reliability Assessment Form

Organization: _____

Dates of data collection: _____

Total number of patient charts reviewed: _____

Measure Name	Definition	Recommended Specification	Inclusion/Exclusion Criteria	Site-specific Specifications	Methods and Data Sources	Actual Measure Numerator Denominator	Measure %
1. PRO assessment <i>Was it done?</i>	% of eligible patients who completed a PRO questionnaire for baseline assessment	Num: Number of patients who completed a PRO questionnaire Denom: Total number of eligible patients					
2. PRO results – EMR availability <i>Was it documented?</i>	% of patients whose baseline PRO questionnaire results are available in the EMR in a timely [†] manner	Num: Number of patients whose PRO results are documented in the EMR in a timely manner Denom: Total number of patients who completed a PRO questionnaire					
3. PRO use for goal-setting across health team <i>Did it support goal-setting?</i>	% of patients for whom a specific goal related to the PRO results is documented in EMR	Num: Number of patients for whom a goal related to the PRO results is documented in the EMR Denom: Total number of patients who completed a PRO questionnaire					
4. PRO progress assessment <i>Was the PROM re-assessed?</i>	% of eligible [‡] patients who completed a PRO questionnaire after baseline assessment	Num: Number of eligible patients with a PRO questionnaire assessment at two points in time Denom: Total number of eligible patients who completed an assessment with PRO questionnaire					

† **Timely** = available for team members to access information at the time of the visit with the patient. A site-specific definition of “timely” should be provided.

‡ **Eligible** = patients who completed a PRO questionnaire and for whom an issue was identified for follow-up/monitoring.

Measure Name	Definition	Recommended Specification	Inclusion/Exclusion Criteria	Site-specific Specifications	Methods and Data Sources	Actual Measure Numerator Denominator	Measure %
5. PRO progress results availability <i>Was there ongoing documentation?</i>	% of eligible patients who completed a PRO for whom results of a second or subsequent questionnaire (after baseline) were documented	Num: Number of patients with a PRO questionnaire assessment at two points in time whose results are documented in the EMR Denom: Total number of patients who completed a PRO questionnaire at two points in time					
6. Average time to outcome follow-up <i>After how long was the patient re-assessed?</i>	Average time from patient's baseline PRO assessment to follow-up assessment	For those patients who require a follow-up assessment within six months or less, date of second PRO assessment minus date of first PRO assessment (in days)					
7. PRO resolution <i>Did the PROM facilitate issue resolution?</i>	% of eligible patients for whom a goal was accomplished and is no longer an active problem, or for whom improvement was noted	Num: Number of patients for whom a goal was accomplished (i.e., left the active problem list or showed improvement in PRO score) between baseline and follow-up assessment Denom: Total number of patients who had a goal documented in the EMR					
8. Refused PRO	% of patients who refused to answer a PRO questionnaire for any reason	Num: Number of forms indicating patient refusal to respond Denom: Total number of NPA+CPE visits					

Resource 7. Sustainability Planning

From the key elements of sustainability, or “levers,” listed below, select those that you believe will support your sustainability strategy and, for each, describe needed actions and resources and how you might obtain them. Include details that will help with accountability, such as specific staff assignments, dates, and contingency plans.

SUSTAINABILITY LEVERS	What Actions Need to be Taken? (e.g., training, technical changes, workflow modifications, coding, programmatic)	What Resources Are Needed? (e.g., financial, technological, training, materials, educational, business agreements)	How Will You Obtain Those Resources? (e.g., pitching to payers or leadership, grants, strategic planning, fundraising, hiring)
System competencies			
Transparent approaches to valuing staff activities			
Information technology (infrastructure/workarounds)			

SUSTAINABILITY LEVERS	What Actions Need to be Taken? (e.g., training, technical changes, workflow modifications, coding, programmatic)	What Resources Are Needed? (e.g., financial, technological, training, materials, educational, business agreements)	How Will You Obtain Those Resources? (e.g., pitching to payers or leadership, grants, strategic planning, fundraising, hiring)
Patient engagement <ul style="list-style-type: none"> • Champions • Messages • Venues • Tools 			
Physician engagement <ul style="list-style-type: none"> • Champions • Messages • Venues • Tools 			
Openness to change/learning <ul style="list-style-type: none"> • Who: team-based, function-based • How: web, in-person, frequency 			

Selected Readings

PROs and PROMs in Primary Care

Baker DW and MR Chassin. 2017. Holding Providers Accountable for Health Care Outcomes. *Annals of Internal Medicine* 167(6): 418. <https://doi.org/10.7326/M17-0691>

Basch E. 2017. Patient-Reported Outcomes—Harnessing Patients’ Voices to Improve Clinical Care. *New England Journal of Medicine* 376(2): 105–8. <https://doi.org/10.1056/NEJMp1611252>

Basch E, P Torda, and K Adams. 2013. Standards for Patient-Reported Outcome–Based Performance Measures. *JAMA* 310(2): 139–40. <https://doi.org/10.1001/jama.2013.6855>

Berwick DM, S Loehrer, and C Gunther-Murphy. 2017. Breaking the Rules for Better Care. *JAMA* 317(21): 2161–62. <https://doi.org/10.1001/jama.2017.4703>

Cella D, EA Hahn, SE Jensen, Z Butt, CJ Nowinski, N Rothrock, and KN Lohr. 2015. *Patient-Reported Outcomes in Performance Measurement*. RTI International.

Chung AE and EM Basch. 2015. Potential and Challenges of Patient-Generated Health Data for High-Quality Cancer Care. *Journal of Oncology Practice* 11(3): 195–97. <https://doi.org/10.1200/JOP.2015.003715>

Hostetter M and S Klein. Using Patient-Reported Outcomes to Improve Health Care Quality. <http://www.commonwealthfund.org/publications/newsletters/quality-matters/2011/december-january-2012/in-focus>

Kroenke K, PO Monahan, and J Kean. 2015. Pragmatic Characteristics of Patient-Reported Outcome Measures Are Important for Use in Clinical Practice. *Journal of Clinical Epidemiology* 68(9): 1085–92. <https://doi.org/10.1016/j.jclinepi.2015.03.023>

National Quality Forum. 2012. Patient-Reported Outcomes in Performance Measurement. http://www.qualityforum.org/Publications/2012/12/Patient-Reported_Outcomes_in_Performance_Measurement.aspx

Nelson EC, E Eftimovska, C Lind, A Hager, JH Wasson, and S Lindblad. 2015. Patient Reported Outcome Measures in Practice. *BMJ online*. <http://www.bmj.com/content/bmj/350/bmj.g7818.full.pdf>

Porter ME, S Larsson, and TH Lee. 2016. Standardizing Patient Outcomes Measurement. *New England Journal of Medicine* 374(6): 504–6. <https://doi.org/10.1056/NEJMp1511701>

Shortell SM, BY Poon, PP Ramsay, HP Rodriguez, et al. 2017. A Multilevel Analysis of Patient Engagement and Patient-Reported Outcomes in Primary Care Practices of Accountable Care Organizations. *Journal of General Internal Medicine* 32(6): 640–47. <https://doi.org/10.1007/s11606-016-3980-z>

Weeks WB and JN Weinstein. 2015. Patient-Reported Data Can Help People Make Better Health Care Choices. *Harvard Business Review*. <https://hbr.org/2015/09/patient-reported-data-can-help-people-make-better-health-care-choices>

Evidence-based Assessment of PROs

Cella D, EA Hahn, SE Jensen, Z Butt, CJ Nowinski, and N Rothrock. 2012. Methodological Issues in the Selection, Administration and Use of Patient-Reported Outcomes in Performance Measurement in Health Care Settings. National Quality Forum solicited report.

Detmar SB, MJ Muller, JH Schornagel, LDV Wever, and NK Aaronson. 2002. Health-Related Quality-of-Life Assessments and Patient-Physician Communication: A Randomized Controlled Trial. *JAMA* 288(23): 3027–34. <https://doi.org/10.1001/jama.288.23.3027>

Greenhalgh J. 2009. The Applications of PROs in Clinical Practice: What Are They, Do They Work, and Why? *Quality of Life Research* 18(1): 115–23. <https://doi.org/10.1007/s11136-008-9430-6>

Jensen RE, NE Rothrock, EM DeWitt, B Spiegel, et al. 2015. The Role of Technical Advances in the Adoption and Integration of Patient-Reported Outcomes in Clinical Care. *Medical Care* 53(2): 153–59. <https://doi.org/10.1097/MLR.0000000000000289>

Santana M-J and D Feeny. 2014. Framework to Assess the Effects of Using Patient-Reported Outcome Measures in Chronic Care Management. *Quality of Life Research* 23(5): 1505–13. <https://doi.org/10.1007/s11136-013-0596-1>

Snyder CF, NK Aaronson, AK Choucair, TE Elliott, et al. 2012. Implementing Patient-Reported Outcomes Assessment in Clinical Practice: A Review of the Options and Considerations. *Quality of Life Research* 21(8): 1305–14. <https://doi.org/10.1007/s11136-011-0054-x>

PRO Examples

Billioux A, K Verlander, S Anthony, and D Alley. 2017. *Standardized Screening for Health-Related Social Needs in Clinical Settings. The Accountable Health Communities Screening Tool*. Washington, DC: National Academy of Medicine.

Broderick JE, EM DeWitt, N Rothrock, PK Crane, and CB Forrest. 2013. Advances in Patient-Reported Outcomes: The NIH PROMIS® Measures. *eGEMS (Generating Evidence and Methods to improve patient outcomes)* 1(1): 12. <https://doi.org/10.13063/2327-9214.1015>

Duke CC, WD Lynch, B Smith, and J Winstanley. 2015. Validity of a New Patient Engagement Measure: The Altarum Consumer Engagement (ACE) Measure.™ *The Patient — Patient-Centered Outcomes Research* 8(6): 559–68. <https://doi.org/10.1007/s40271-015-0131-2>

Kroenke K. 2014. A Practical and Evidence-Based Approach to Common Symptoms: A Narrative Review. *Annals of Internal Medicine* 161(8): 579. <https://doi.org/10.7326/M14-0461>

Goal-setting

Tinetti ME, J Esterson, R Ferris, P Posner, and CS Blaum. 2016. Patient Priority-Directed Decision Making and Care for Older Adults with Multiple Chronic Conditions. *Clinics in Geriatric Medicine* 32(2): 261–75. <https://doi.org/10.1016/j.cger.2016.01.012>

Case Studies, Examples, Toolkits

Forsberg HH, EC Nelson, R Reid, D Grossman, et al. 2015. Using Patient-Reported Outcomes in Routine Practice: Three Novel Use Cases and Implications. *The Journal of Ambulatory Care Management* 38(2): 188. <https://journals.lww.com/ambulatorycaremanagement/pages/articleviewer.aspx?year=2015&issue=04000&article=00012&type=abstract>

International Society for Quality of Life Research. 2015. *User's Guide to Implementing Patient Reported Outcomes Assessment in Clinical Practice*. <http://www.isoqol.org/UserFiles/2015UsersGuide-Version2.pdf>

Nelson E, E Eftimovska, C Lind, A Hager, J Wasson, and S Lindblad. 2015. *Using Patient-Reported Information to Improve Health Outcomes and Health Care Value—Case Studies from Dartmouth, Karolinska and Group Health*. Lebanon, NH: Dartmouth Institute for Health Policy and Clinical Practice. http://consumerpurchaser.org/images/documents/dartmouthdasestudies_pros.pdf

Van Der Wees PJ; Nijhuis-Van Der Sanden, MW; JZ Ayanian; N Black, GP Westert; and EC Schneider. 2014. Integrating the Use of Patient-Reported Outcomes for Both Clinical Practice and Performance Measurement: Views of Experts from 3 Countries. *Milbank Quarterly* 92(4): 754–75. <https://doi.org/10.1111/1468-0009.12091>

Wu AW, RE Jensen, C Salzberg, and C Snyder. 2013. Advances in the Use of Patient Reported Outcome Measures in Electronic Health Records. Prepared for PCORI. <https://www.pcori.org/assets/2013/11/PCORI-PRO-Workshop-EHR-Landscape-Review-111913.pdf>