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Patient-Reported Outcomes in Primary Care: What's the Upshot?



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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.

Executive Summary

Listening to patients' perspectives should be an essential part of the health care encounter. But in many instances, when it comes to treatment decisions or the assessment of treatment impact, the patient's point of view—which has been shown to frequently differ from the provider's—is considered secondary and not taken fully into account. The quality and effectiveness of health care can suffer as a result.

This situation is starting to change with the development and validation of survey instruments that facilitate the structured collection of patient reports—eliciting what are known as patient-reported outcomes, or PROs. These are essentially patients' views of, or goals for, their own health and functioning. PRO information can help primary care teams better understand the diverse health needs of patients. Their use can also help build patient trust, customize care plans that are more realistic and meaningful (and thus more likely to be successful), and create a common language to coordinate with other care providers and settings.

Exploring the feasibility of integrating PROs into primary care is the central aim of the Patient-Reported Outcomes in Primary Care -New York (PROPC-NY) initiative. Developed by United Hospital Fund and supported by a \$300,000 grant from The Engelberg Foundation and close to \$150,000 in grants from UHF, the project brought together three organizations—the Institute for Family Health, Montefiore Health System, and Northwell Health—to participate in an 18-month learning collaborative that tested the value of implementing PROs in routine care. Each organization identified a primary care practice team that selected a target patient population and a patient-reported outcome for the focus of their work. The teams set out to better understand the diverse needs of their patients; tailor care plans to patients' goals and priorities; and assess the outcomes of care as reported by patients. To do so, they used structured questionnaires to collect information from patients, make it available to clinicians at the time of the visit, and coordinate with other care providers and settings. Some of the takeaways of what they learned are noted below and are discussed in more depth in the following pages.

PROs in Primary Care: The Benefits

The use of PROs by PROPC-NY participants was largely associated with a positive experience for practice staff and their patients¹.

PRO questionnaires:

- Focused on the whole patient and the root causes of health concerns.

¹ For detailed information about the benefits of PROs, see the “field reports” from the Institute for Family Health, Montefiore Health System, and Northwell Health.

- Uncovered important information patients would not have brought up freely and that clinicians would otherwise not have been aware of.
- Exposed the interdependencies among team members and helped them work together more effectively.
- Provided a common vocabulary for discussing the nature and source of patient complaints.
- Supported patient involvement in shared care planning.
- Improved team and patient communication, coordination, and consistency in managing care and assessing the impact of interventions.

Achieving the Most from PROs: Special Considerations for Primary Care Practices

Although participants identified numerous benefits, focusing on outcomes is still quite challenging. The PROPC-NY collaborative identified several key lessons that can help practitioners realize the value of PROs in primary care:

- Create a clear outcomes pathway, which includes a series of outcomes and milestones that are made visible to the patient and care team and can be monitored and managed over time.
- Do not lose sight of the story in search of the scores.
- Invest in strong interdisciplinary teams with a special focus on developing effective staff interdependencies and complementary roles.
- Consider adopting a growth mindset in setting goals and outcomes.
- Think “out-of-the practice.” An outcomes-based care model that transcends the clinic visit requires nurturing the community’s trust.
- Close the outcomes loop. Health information technology is important, yet not sufficient. The most critical and often missing link is the patient.

A Roadmap to Broader Adoption

PROPC-NY participants are among a group of early adopters of PROs, willing to test their value despite numerous obstacles: uncertainty; the dominance of a traditional, well-established, transactional way of practicing medicine; and considerable disincentives to change. Their decision was rooted in a strong theoretical framework that uses PROs to build a pathway toward improved care, and their pilot successfully highlighted benefits and challenges and provided a roadmap for continuing this work.

Patient-Reported Outcomes in Primary Care: Implications for Practice and Policy

The delivery of primary care is evolving rapidly, as definitions of quality and value undergo a seismic shift. No more is the process of care—what is done, testing and prescribing, for example—the main focus. Now, the emphasis is increasingly centered on the impact of care, or rather, what happens to the patient as a result. A “visit-based transaction model” (prioritizing actions during the office visit) is giving way to an “outcomes-based model” (highlighting symptom resolution and well-being beyond the specific visit).² This has led to new deliberations on how “outcomes” are defined, and by whom.

To date, clinicians have, for the most part, assessed outcomes of their interventions by relying on data, such as biologic markers (obtained from blood work and imaging, for example). Although listening to patients’ expressed symptoms and goals is an essential part of the health care encounter, the patient’s perspective—which has been shown to frequently differ from the provider’s—is often considered qualitative and “soft” and is thus to some extent undervalued.³ It is also widely believed that the views of patients lack the validity of test results that can be tracked over time and used to rigorously assess outcomes.

This situation is changing, however, with the development and validation of survey instruments that facilitate structured collection of patient reports—eliciting what are known as patient-reported outcomes, or PROs.⁴ These are essentially patients’ views of, and goals for, their own health and functioning. Increasingly, these survey instruments are being used in orthopedics, oncology, and other specialties to evaluate patients’ symptoms and goals before and after procedures. Their occurrence in primary care, however, is limited.⁵

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

3 Michele Heisler, et al. “When do patients and their physicians agree on diabetes treatment goals and strategies, and what difference does it make?” *Journal of General Internal Medicine*, Volume 18, Issue 11, pp 893–902, (November 2003). doi: 10.1046/j.1525-1497.2003.21132.x; Tarlov AR, Ware JE Jr, Greenfield S, et al. “The Medical Outcomes Study: An application of methods for monitoring the results of medical care.” *JAMA*, 262(7):925-30 (August 1989).

4 David Cella, et al. “Patient-Reported Outcomes in Performance Measurement.” RTI Press (2015). https://www.rti.org/sites/default/files/resources/patient-reported_outcomes_in_performance_measurement.pdf.

5 Eugene C. Nelson, et al. “Patient reported outcome measures in practice.” *British Medical Journal* 350:g7818 (2015); Joanne Greenhalgh. “The applications of PROs in clinical practice: What are they, do they work, and why?” *Quality of Life Research* 18(1): 115–123 (2009); National Quality Forum. “Patient-Reported Outcomes in Measurement.” Contract HHSM-500-2009-00010C (2013). <https://www.qualityforum.org/WorkArea/linkit.aspx?LinkIdentifier=id&ItemID=72537>.

The PROPC-NY Initiative: Why Focus on Patient-Reported Outcomes in Primary Care

Patient-reported outcomes can help primary care teams better understand the diverse health needs of patients. PROs can also help build patient trust, customize care plans that are more realistic and meaningful (and thus more likely to be successful), and create a common language to coordinate with other care providers and settings. But even if it's increasingly recognized that hearing and understanding the patient's perspective on outcomes that are important to them is an integral part of good care, the complexities of primary care make doing so less than simple.

High-volume, heterogeneous patient populations present a range of conditions from acute symptoms expected to resolve soon after the visit to complex, chronic illnesses requiring longer-term management. Caring for such a diverse group of people with such a wide array of issues necessitates a focus on a large number of outcomes; measuring those and monitoring progress can be challenging.

This transformation from a visit-based model of care to an outcomes-based one provides a unique opportunity to explore the role of PROs in supporting these changes in practice and payment. Three participating organizations—Institute for Family Health, Montefiore Health System, and Northwell Health—committed to testing the value and feasibility of implementing PROs in routine care. They each identified a primary care practice team, a target population, and a patient-reported outcome for the focus of their work. The teams aimed to better understand the diverse needs of their patients; tailor care plans to patients' needs and priorities; and use structured, common language as well as reporting and assessments to coordinate with other care providers and settings.

Patient-Reported Outcomes and Delivery and Payment System Transformation

In a value-based health care context, how quality and value are defined and measured is obviously critical. A recent report by the Institute of Medicine, "Vital Signs: Core Metrics for Health and Healthcare Progress," identified more than 1,000 measures of quality in use within the US health care system.⁶ These include measures of structure (e.g., computerized order entry); process (e.g., screening for tobacco, advising patients to quit, referrals to smoking cessation programs); and outcome (e.g., depression remission, improved mobility and pain relief after knee surgery, patients reporting access to care when they need it). Today, most measures in use are still heavily focused on structures and

6 Institute of Medicine. "Vital Signs: Core Metrics for Health Care Progress," Washington, DC: The National Academies Press (2015).

What Are PROs?

Typically, health care outcomes concern patient characteristics that *can* be modified by appropriate interventions that the care team and patients decide on together. Outcomes are assessed by examining what happens to a patient because of a procedure—post-surgical complications, for example—or by comparing a patient’s status (e.g., improved ability to go up a flight of stairs) before and after an intervention. PROs are, by definition, self-assessed and self-reported and not derived from other sources. They establish the *patient* as the final arbiter of success.

PRO *measures*, or PROMs, are surveys, questionnaires, scales, or other instruments that gauge progress toward the identified PRO by eliciting information from patients in a formal and systematic way. PROMs foster customized and focused conversations between a clinician and patient and allow for a consistent assessment of responses to interventions over time; they also facilitate clear, consistent evaluations of a patient’s status and care coordination among multiple team members and across specialties and settings.

The organizations that participated in PROPC-NY pioneered an innovative approach on outcome measurement that holds great promise for the current and growing effort to address social determinants of health. To identify high-risk populations, many providers commonly collect sociodemographic information from patients under the assumption that such characteristics are risk factors and inherently unmodifiable. It is less common for providers to treat these patient attributes as amenable to change and track them and related outcomes over time. The PROPC-NY providers—who cared for a large number of ethnic minorities and low-income patients—attempted to do just that. They considered sociodemographic characteristics as health stressors, and care teams developed plans to influence the level of stress as the outcome. Another innovative approach consisted of creating specific goals with patients that were related to social determinants of health and then tracking the achievement of these goals as the patient-reported outcomes.

Using Patient-Reported Outcomes, the PROPC-NY implementation guide, offers greater detail on patient-reported outcomes and measures.

processes. Yet a growing consensus indicates that a successful measurement enterprise should include a significant pool of outcome measures that “matter most to people.”⁷

Research has shown that patients’ and physicians’ perceptions of outcomes differ and that taking patients’ perceptions of their own health status into account

7 Centers for Medicare and Medicaid Services. Meaningful Measures Initiative, https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/QualityInitiativesGenInfo/Downloads/CMS-Meaningful-Measures_What-It-Means-Fact-Sheet_508_2018-02-28.pdf

can lead to more effective interventions.⁸ According to Don Berwick, former Director of the Centers for Medicare and Medicaid Services (CMS) and former President of the Institute for Healthcare Improvement (IHI), “the ultimate judge of quality is the patient, end of story.” In other words, we can’t effectively address patients’ clinical problems without integrating their perspectives into every part of the clinical process—diagnosis, treatment initiation, and ongoing care management. And value cannot be assessed independently of what patients report. Yet, it is currently standard practice to do just that, and this has led to inappropriate care and to failure in improving outcomes and costs.

As with other types of information used in the clinical setting, PRO data need to be valid and reliable. Several measures of patient-reported outcomes have been developed and validated in the past two decades and are ready for implementation in practice. The National Quality Forum has endorsed over 30 measures. The Patient Reported Outcomes Measurement Information System (PROMIS), funded by the National Institutes of Health (NIH), includes families of assessment tools and measures that have demonstrated reliability, validity, precision, and responsiveness to changes in patient-reported health outcomes. The tools assess a wide variety of outcomes, such as physical function (e.g. distanced walked without pain), emotional function (e.g. depressed mood), and social function (e.g. quality of social support).⁹

However, PROMs have so far been mostly used in research. Although there are several examples of successful application of PROMs in practice, their adoption is far from universal. The barriers to change for providers are formidable and complex: technical challenges; current HIT obstacles that prevent the systematic collection of patient-reported information and the reporting of data to health care teams; gaps in scientific evidence that can impede clinicians’ efforts to interpret and use patient-reported information in care plans; fear of disruption in familiar clinical workflows; lack of familiarity in how to relate to patients differently; and financial considerations, including costs related to collection, analysis, and recording of new measures. Additionally, there have not been strong policy incentives to drive adoption.

Despite these difficulties, the shift toward an outcome-based health care system is progressing in some quarters. Key stakeholders have reached consensus regarding the need to prioritize outcomes as measures of performance and patient-reported outcomes, in particular, as an essential part of assessing value. Development and validation of new PRO measures is now a national

8 Tarlov AR, Ware JE Jr, Greenfield S, et al. “The Medical Outcomes Study: An application of methods for monitoring the results of medical care.” *JAMA*, 262(7):925-30 (August 1989).

9 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 via tablet platforms for ease of use. Accessible here: <http://www.healthmeasures.net/explore-measurement-systems/promis>

priority, and legislative and financial incentives based on PROs are emerging. And implementation knowledge is increasing. Several early adopters have successfully expanded the routine use of PROs in clinical care settings.¹⁰

Yet the spread of knowledge beyond the small set of early adopters to (eventually) all providers remains a challenge. The PROPC-NY collaborative aimed to help remedy this by contributing to the early phases of clinical adoption of PROs in New York.

PROs in Primary Care: From Theory to Practice

This report provides lessons from the PROPC-NY initiative, including benefits, challenges, and critical considerations about the use of PROs in routine care; and a discussion of the policy implications of embarking on an outcomes-based practice transformation. Much of the knowledge was synthesized from the pilot evaluations and from interviews with participants over the course of the initiative, presentations during learning collaborative meetings, and written reports and structured interviews at the end of the collaborative.

PROs in Primary Care: The Benefits

Focus practice on the whole patient and root causes of health concerns. Consistently eliciting patient-reported outcomes can center the practice around the well-being of the whole person rather than a specific organ or condition. PROs help identify the main reasons patients seek advice and care and reveal critical issues that otherwise might not emerge because of time constraints or staff or patient discomfort. Integrating patient-reported social health stressors (such as lack of access to healthy foods) into the clinical focus of the visit is invaluable, especially in safety-net settings. This is, in part, because symptoms may be related to complex interactions among biological, physical, emotional, and social factors.

Support patient involvement in shared care planning. The availability of real-time PRO responses during visits can jump-start important conversations and can allow providers to engage in richer, more effective communication with patients; this, in turn, can enhance understanding and help guide the patient's health care priorities. Ultimately, PROs can help address the sources of patients' complaints (e.g., stress related to inability to afford medications) and can align the care plan with the patient's goals. This can help guarantee that care is appropriate and that the use of unnecessary services is avoided.

10 Eugene Nelson, et al, "Patient-reported outcome measures in practice." *BMJ*, 350: g 7818 (February 2015).

Help teams work more effectively. Standardized questions ensure that key patient-reported information is collected systematically, reducing variation among providers in the data and perspectives they elicit from their patients and in what they document. PROs provide a common vocabulary for discussing the nature and source of patient complaints as well as equal access to patient information. In so doing, they can improve communication, coordination, and consistency in managing care and assessing the impact of interventions. Team members may also feel more comfortable about broaching sensitive issues, knowing that these issues have already been formally raised and that other team members (who may have expertise that they do not) can step in to help the patient.

Foster new roles for team members. The new workflows created by the introduction of PROs may encourage team members to take on new roles. These may include managing internal referrals or “warm handoffs,” flagging and following up on special issues, or managing outside partnerships with community-based organizations and tracking the outcomes of referrals to them. The benefits of setting focused and unique roles for team members can help ensure effective management of critical interactions.

PROs in Primary Care: The Challenges

Despite the benefits of implementing PROs, several barriers must be addressed before their use can be effectively expanded and scaled.

Using the results. PRO data complement clinical and other types of data to guide the choice of interventions over time. The full value of PRO data depends on the ease with which health care teams can interpret them and gather evidence linking interventions to improvements. However, current PRO questionnaires often produce results that are difficult to interpret. Although physicians can interpret results and tailor evidence-based interventions related to objective clinical data such as blood glucose levels, this is not always the case for patient-reported outcomes, such as quality of life or physical function scores. There is a dearth of knowledge about what interventions are effective and how much improvement can be expected on such PRO scores, which significantly limits their potential value.

Furthermore, primary care populations often present with multiple conditions growing out of social contexts that contribute significantly to their health outcomes. This means that addressing a single condition (e.g., asthma) that is the focus of a PRO may be ineffective for a medically complex patient; using additional PRO questionnaires or focusing attention on symptoms that cut across several conditions may be more effective. There are promising tools that can help clinicians and patients set specific goals and establish an objective way

to measure the degree to which they are achieved. Goal achievement scales allow a practice to standardize patient-reported outcome measurement while also tailoring the outcome to each individual patient.¹¹

Closing the outcomes loop. This is perhaps the most significant challenge to the adoption of an outcomes-based care model. Health care is still predominantly transactional and visit-based, and providers, patients, and payers all behave within that frame. The infrastructure for tracking patient outcomes is minimal, and progress toward ensuring adequate follow-up and adjustment of care plans requires not only improved communication among the health care team and external service providers—there must also be strategic efforts to bring all patients into the loop. The challenge of communicating with patients once they leave the practice site is real and pervasive; vulnerable patients especially may not have stable residences or communication channels (phone lines or e-mail access). Although new modes of communication and follow-up (such as patient portals) are emerging, their success depends on whether patients will use them—demonstrating the value of feedback to patients should be a national priority. This will require investment in human resources—additional staff time for patient outreach, for example—in addition to technology.

Health information technology. While it's possible to pilot PROs without an HIT infrastructure, technology is crucial to the sustainability of an outcomes-based care model that includes PROs. Reliably sharing information with patients and among health care team members is complex and can only be accomplished with technological support. Critical functionalities include ease of access to care management information and the ability to document interventions and outcomes for all members of the team; analytic capacity to generate reports on patient outcomes over time; and decision support for team members at the time of visits and beyond (e.g., alerts on the status of outcomes that need follow-up). These HIT functions should support the practice team, community-based and other service providers, and the patients themselves. It's critical that patients have easy access to decision aids they understand, information they can use to track their progress, and communication pathways with team members.¹²

Sustainability. While health care is moving away from emphasizing the volume of services over value, payers are still primarily focused on what is done during health care encounters rather than the result of interventions. An outcomes-based care model will require investment in human resources, in technologies to support new workflows and delivery models, and in databases and development of outcomes measures. It will also require external incentives to broaden its

11 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; 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): 96-12 (1999).

12 A.M. O'Connor, et al. "Decision Aids for People Facing Health Treatment or Screening Decisions." Cochrane Database of Systematic Reviews, no. 2 (2003): CD001431.

adoption and scale: payers do not yet routinely use PROs to assess value, nor are PROs consistently included as a requirement of performance reporting programs. It is therefore critical that leaders considering this type of work start on a manageable scale, set aside resources for small pilots, and develop plans for evaluating the impact of an outcomes-based care model on the performance of their organizations over the long term.

Achieving the Most from PROs: Special Considerations

The PROPC-NY implementation guide provides a step-by-step roadmap for integrating PROs into primary care. Consider these broader guidelines as well.

Articulate the rationale and criteria for PRO selection

Identify and prioritize outcomes that are most relevant to the patients who will be asked to report them. This means prioritizing groups of patients for whom PROs are most important to care planning and then selecting outcomes relevant to those groups. These might include symptom-related outcomes that will be limited to targeted groups as well as goal achievement that will be relevant to all patients.

Create an outcomes pathway. Achieving an outcome may take time. Splitting up the ultimate goal into a series of milestones that can be reached in the short term makes progress more visible and fosters adherence to the care plan. Patients can report each of these milestones as an outcome, which can then be assessed by the health care team.

Select the most appropriate tool(s) for assessing and measuring PROs. Selection criteria include time required to answer questionnaires, ease of access by patient and provider (e.g., paper or online), ability to act on results with tailored care plans, and validity.

Don't lose the story among the scores. Quantitative information provides an incomplete assessment of a patient's health status. To effectively guide shared decision-making and help develop customized care plans, questionnaire scores need to be interpreted as part of a conversation between provider and patient. This is the real value of the narrative created by structured PRO questionnaires—the ability to provide a starting point for in-depth conversations.

Build Patient and Community Engagement and Trust

Nurture patients' trust by demonstrating that the information they report is heard and used to help them achieve their goals. Gathering information and then discounting it or not acting on it sends a negative message, and patients will be much less likely to report concerns and priorities in the future.

Forge partnerships with patients and community organizations that are not only transactional in nature but are also based on shared decision-making and longer-term relationships that can nurture progress toward outcomes that matter to them. Demonstrate that *“we inquire, and we listen. We act with you. And we ask and listen again.”*

Develop the community’s trust by including its members and service organizations in a common health agenda.

Invest in strong interdisciplinary teams

Recognize staff interdependencies and complementary roles.

Sustaining an effective patient-centered, outcomes-based care model requires a strongly connected team of professionals and support staff with diverse and complementary experience and skills. Everyone from the front desk receptionist to the medical assistant to the case worker is part of the patient’s experience and has a role in improving patient outcomes.

Cultivate a culture based on shared principles and goals: improve the quality of patients’ lives as a daily objective; show a willingness to “go deep” with patients; make a commitment to demonstrate cultural competency, empathy, and a collaborative spirit.

Foster a growth-oriented mindset with ongoing, team-based training and learning opportunities and dedicated time for cross-disciplinary team meetings, debriefing, and improvement activities. Staff may need training in cultural competency and sensitivity to make patients feel safe about sharing intimate details of their lives.

Remember that creating a patient-centered, outcomes-based practice model is an evolutionary process.

Be prepared and be patient. It takes time, careful planning, and the experience gained at each phase of the practice’s transformation to master the model and reap its benefits. Implementing PROs without adequate preparation is unlikely to succeed: fundamental changes in the clinical practice paradigm are essential, especially regarding how information is valued (with equal weight given to personal reports and clinical data) and responsibility for consistent, continuing assessment of the impact of interventions.

Realize the value of patient-reported information and design an environment and processes that maximize it: a team culture that sees patient-reported information as being as central to patient management as lab work or other clinical data; efficient collection methods that eliminate duplication and ensure that patients’ time is not wasted; documentation that makes accurate information available to appropriate team members and to patients; and effective

use of the information to develop care management plans. These plans are crucial and serve as a validation that the patient was listened to and heard.

Commit to evaluating the impact of care plans and designing processes to support care that are based on outcomes rather than visits. The outcomes-based model requires a high-reliability feedback loop, which includes several key elements: data collection over time, starting with baseline information; ongoing data tracking to assess the outcomes of interventions; decision support to alert provider teams to missing data, outcomes, and assessments; and a multidisciplinary team with dedicated responsibilities and a systematic approach to managing outcomes.

Remember that patients are often “the missing link” in closing the outcomes loop. The most demanding aspect of an outcomes-based practice is its dependence on a strong, ongoing partnership between the patient and the care team. The importance of this relationship underscores the need for innovative solutions to ensure strong connections with patients after onsite visits. Patient portals have proved very promising for effective patient management and improved follow-up. Other types of “hovering” tools that can facilitate follow-up on patient outcomes are increasingly coming into use.¹³ And evolving push/pull technologies that facilitate the transmission of information from and to patients can provide positive incentives for both senders and receivers.

Implications for Policy and Research

PROPC-NY participants are among a group of early adopters. These health care professionals are willing to test the value of PROs despite numerous hurdles: uncertainty; the dominance of a traditional, well-established transactional way to practice medicine; and considerable disincentives to change. Their decision was rooted in a theoretical framework of care delivery that assesses quality using outcomes rather than processes and that values patient-reported information as a unique way to do so. Their pilot was successful in highlighting benefits and challenges and providing a roadmap for continuing this work. Advancing the model, bringing it to scale, and ensuring its sustainability, will, however, require interventions beyond the scope of individual provider organizations. This will hopefully increase knowledge, solve critical technical barriers, and identify incentives to drive adoption.

Knowledge. Even with a shift in mindset that places patient-reported information on an equal footing with laboratory data, most health care professionals find it challenging, at least initially, to use PROs to guide care plans and assess changes in outcomes over time. This is especially true for

13 David A. Asch, Ralph W. Muller, and Kevin G. Volpp. “Automated hovering in health care—watching over the 5000 hours.” *New England Journal of Medicine* 367(1): 1-3, (2012).

outcomes related to patients' physical, social, and emotional function and quality-of-life assessments. In addition, while there are conceptual models that link the use of PROs to better care and outcomes, empirical evidence of these relationships is still lacking. A widespread research agenda already exists with the National Institutes of Health, Agency for Healthcare Research and Quality, Patient-Centered Outcomes Research Institute, and other major organizations investing heavily in PRO work. Translational research that fosters adoption of evidence-based practices should be a national priority. There are too many instances of providers knowing *what* to do, but not *how* to do it—and integration of PROs in primary care practice is one such example.

Technical solutions. Significant technical barriers to routine PRO adoption persist. Investments in innovations that support access to data when needed, shared decision-making and care-planning, and high-reliability feedback loops that allow information to flow seamlessly between patient and team members should all be prioritized. Regulatory changes facilitating the creation of such feedback loops, while ensuring privacy and security, should also be explored.

Incentives. As early adopters, PROPC-NY participants were encouraged by intrinsic motivations and by small grants that supported their work and evaluations. For most primary care practices, however, external incentives—both rewards and penalties—will be required to encourage PRO adoption. One starting place would be to build on the growing movement to amplify patient voices by simplifying the national health care measurement enterprise; this could ensure a more appropriate, targeted set of measures; help to strategically develop new measures where gaps exist; and retire those that do not bring value to stakeholders. As the evidence linking the use of PROMs to improved outcomes develops, these measures could increasingly benefit public reporting programs and value-based payment systems.

A great deal of work remains to be done to bring PROs into widespread use. But the evolution of the patient conversation—from “What’s the matter with you?” to “What matters to you?” to “What matters to you matters to us”—is an affirmation that the ultimate judge of quality is the patient. And this makes the necessary investment in PROs essential.