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Field Report: Lessons from the Patient-Reported Outcomes in Primary Care—New York Collaborative Participants

Northwell Health System

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The Patient-Reported Outcomes in Primary Care—New York (PROPC-NY) collaborative, developed by United Hospital Fund, brought together three innovative health care organizations to consider a critical question: how can providers shift their focus from what is done for patients during a visit to what happens to those patients as a result. Over the course of 18 months, the Institute for Family Health, Montefiore Health System, and Northwell Health launched a major effort to find answers. The Institute for Family Health sought to improve patient goal-setting related to social determinants of health, Montefiore focused on improving families' ability to manage social and economic health stressors during pregnancy and the first year of a child's life, and Northwell aimed to improve patients' depression symptoms and physical function. After identifying appropriate patient populations, they selected or developed appropriate tools for eliciting feedback from patients on what prompted them to seek care and what outcomes or goals matter to them most. They also developed processes for consistently collecting, analyzing, and acting on the patient-reported data. Their efforts yielded many discoveries about patient-reported outcomes, or PROs, that were both conceptual and practical.

The following field reports build on a variety of assessments over the course of the initiative: each team's end-of-project self-evaluation, including surveys of health care team members and patients, patient focus groups, and chart reviews to assess the reliability of the processes developed to collect, use, and track PROs; four structured interviews of each team by UHF staff and project faculty; and team presentations during three, day-long meetings of learning collaborative participants.

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.

Northwell Health System: Bolstering Interdisciplinary Teams through the Use of Patient-Reported Outcomes

Northwell Health's participants in PROPC–NY included a faculty primary care practice and a residency clinic. Part of Northwell's Division of General Internal Medicine, these two practices collectively serve approximately 20,000 individual patients through more than 71,000 visits each year. The patient population is largely covered by private insurance (61 percent); twenty-one percent self-pay (mostly from the residency practice clinic), and 16 percent are enrolled in Medicare and/or Medicaid. About half of the patients represent minority racial and ethnic groups. The Northwell team's experiences with the project underscore the importance of targeting specific groups of patients for PRO use and also highlight the impact of this approach on multi-disciplinary primary care teams.

At its primary care site, a well-established level 3 Patient-Centered Medical Home, Northwell sought to refine and standardize a patient-reported outcome workflow, building on experience from previous grant-supported work in substance use, medication adherence, and health literacy. Through an earlier initiative funded by the federal Substance Abuse and Mental Health Services Administration to implement the Screening, Brief Intervention, and Referral to Treatment (SBIRT) protocol, Northwell had used several questionnaires (the Alcohol Use Disorders Identification Test and Drug Abuse Screening Test) and successfully screened 30,000 patients for alcohol or drug misuse; it had also connected them to health coaches for brief interventions. PROPC-NY allowed the team to prioritize new outcomes with broader relevance across their primary care population. Additional requirements by New York's Delivery System Reform Incentive Payment (DSRIP) program regarding screening and follow-up for patients with depression prompted use of the PHQ-9 PRO questionnaire.¹

Spurred by the practice's emphasis on innovation, learning, teaching, and research, the team decided to test the use of patient-reported outcomes in part by leveraging the resources of its innovative interprofessional training program, IMPACcT (Improving Patient Access, Care, and Cost through Training).² Given the wide range of conditions and clinical risk among their primary care patient population, Northwell staff also believed that more generic functional status outcomes could complement condition-specific measures (i.e., those related

1 The Patient Health Questionnaire (PHQ) is a self-administered version of the PRIME-MD diagnostic instrument for common mental disorders. The PHQ-9 is the depression module, which scores each of the 9 DSM-IV criteria as "0" (not at all) to "3" (nearly every day). <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1495268/>.

2 Established in 2006, IMPACcT is a five-year Health Services Resource Administration (HRSA) Primary Care Enhancement Award to establish an interprofessional clinic experience based on a team-based care model for trainees in internal medicine residency program, medical school, pharmacy school, psychology training program, and physician assistant school. https://medicine.hofstra.edu/pdf/about/news/pressreleases/impacct_handbook_medstudents1.pdf.

Figure 1. Patient Health Questionnaire (PHQ-9)



Patient Health Questionnaire

Office__ Home__

Name_____DOB_____Date_____ Primary Care Provider_____

Over the **past 2 weeks**, how often have you been bothered by any of the following problems?

<i>Place a check to the right of each question to show how often you have been bothered by:</i>	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
IF YOU ANSWERED 0 (Not at all) to BOTH Questions 1 & 2 – STOP HERE	<i>Otherwise continue...</i>	↓	↓	↓
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself – or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed. Or the opposite – being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead, or of hurting yourself	0	1	2	3

How difficult have these problems made it for you to do your work, take care of things at home, or get along with other people? (Please **CHECK ONE** response below)

____ Not Difficult at all ____ Somewhat difficult ____ Very Difficult ____ Extremely Difficult

Please discuss the score and questionnaire with your Medical Provider at the Office Visit or sooner if necessary

STOP Here. The remainder will be filled out by staff at the Office Visit.

MOA Assisted with Form

TOTAL Score: _____ points

Score	Severity	Treatment Options	Follow-up PHQ score
5-9	Mild	Patient self-management	6-12 months
10-14	Moderate	Watchful waiting, consider therapy, consider medication if persistent symptoms	3-6 months
15-19	Moderately Severe	Treatment with medication and/or therapy and consider consultation with Psychiatry	At 1-2 weeks, 4 weeks then regularly
20-27	Severe		

Figure 2. PROMIS Physical Function Questionnaire



PROMIS Physical Function Questionnaire

Office__ Home__

Name _____ DOB _____ Date _____ Primary Care Provider _____

Please answer each question below by checking ONE box to the right of the question that describes how well you can do each task.	Without any difficulty (5 points)	With a little difficulty (4 points)	With some difficulty (3 points)	With much difficulty (2 points)	Unable to do (1 point)
1. Are you able to do chores such as vacuuming or yard work?					
2. Are you able to get in and out of a car?					
3. Are you able to go up and down stairs at a normal pace?					
4. Are you able to run errands and shop?					
5. Are you able to bend down and pick up clothing from the floor?					
6. Are you able to lift 10 pounds (5 kg) above your shoulder?					
Please answer each question below by checking ONE box to the right of the question that describes how much difficulty you have with each task.	Not at all (5 points)	Very little (4 points)	Some-what (3 points)	Quite a lot (2 points)	Cannot do (1 point)
7. Does your health now limit you in doing vigorous activities, such as running, lifting heavy objects, participating in strenuous sports?					
8. Does your health now limit you in bathing or dressing yourself?					
9. Does your health now limit you in putting a trash bag outside?					
10. Does your health now limit you in doing moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf?					

Please discuss the score and questionnaire with your Medical Provider at the Office Visit or sooner if necessary

STOP Here. The remainder will be filled out by staff at the Office Visit.

MOA Assisted with Form

Total Raw Score : _____ → T-Score: _____

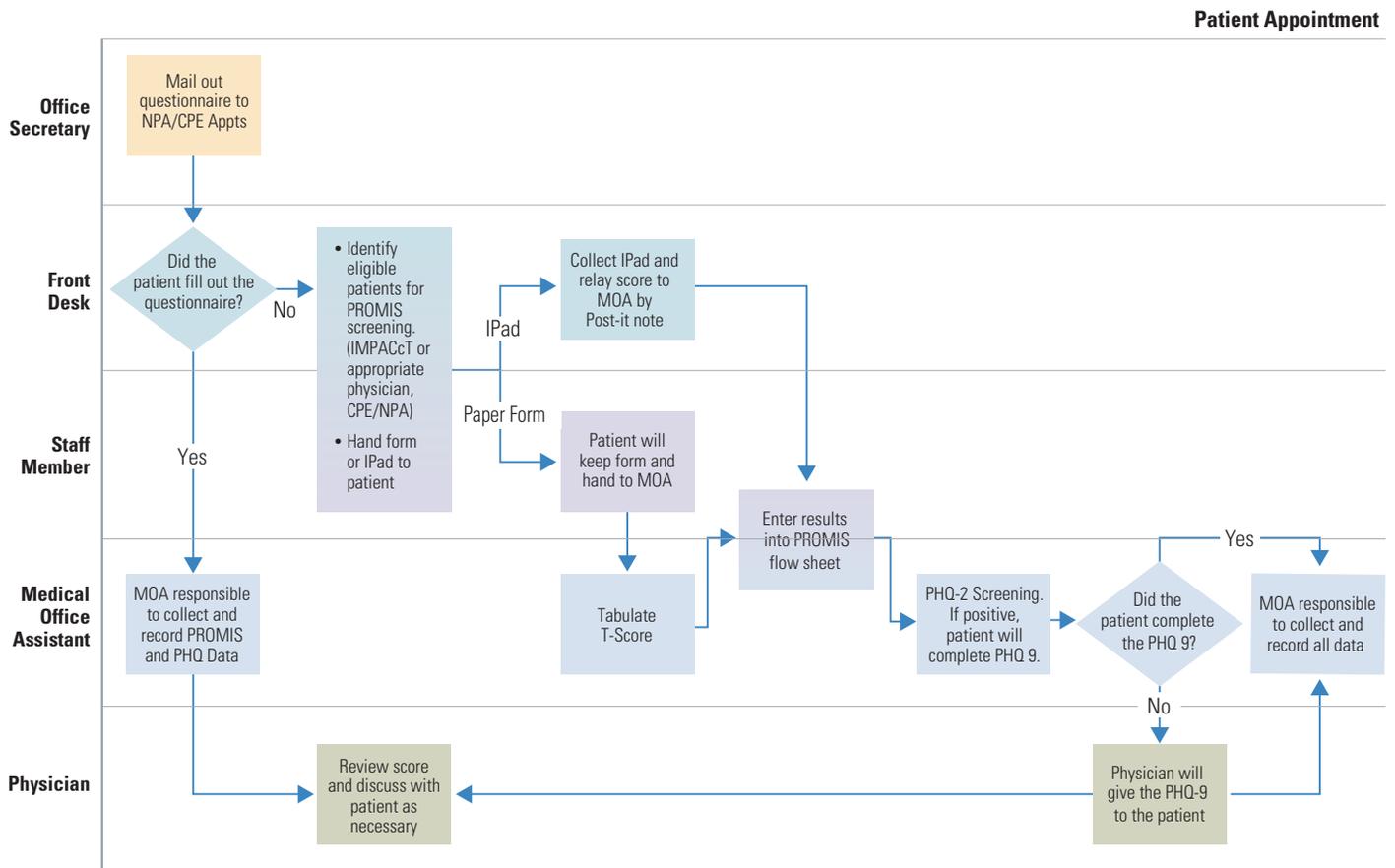
Above Average	T score GREATER than 50		Clinical judgment for any undetected impairment
Population Average	T score of 50 OR Low score on any single question		Consider referral to PT/OT, Orthopedics for any focal pathology
Below Average	T score LESS than 50		Consider PM&R or Rheumatology consult *REPEAT PROMIS in 3-6 Months*

A 10 point increase or decrease in the T-Score represents ONE standard deviation

to depression, diabetes, and asthma). To assess global functional status, the team chose the PROMIS Physical Function tool, a questionnaire developed by the National Institutes of Health as part of a larger suite of patient-reported outcomes available in the public domain.³

The teams chose to administer two PRO instruments (Figures 1 and 2) to all new patients and sent the questionnaires by mail. Patients were asked to complete them before the office appointment, but for those who didn't, questionnaires were also provided at the clinic by front-desk staff. During the visits, a multi-disciplinary team interacted with the patients. Some staff helped in filling out the questionnaires, and others entered resulting information into the medical record. Clinicians used the data to enhance clinical encounters between providers and patients and to develop subsequent care management and follow-up plans (Figure 3).

Figure 3. Northwell Health's Patient-Reported Outcomes Workflow Map



3 The Patient-Reported Outcomes Measurement Information System (PROMIS) funded by NIH includes families of assessment tools and measures that have demonstrated reliability, validity, precision, and responsiveness to changes in patient-reported health outcomes. <https://www.assessmentcenter.net/documents/PROMIS%20Physical%20Function%20Scoring%20Manual.pdf>

Findings and Lessons

Patient and provider surveys, chart reviews, and structured team interviews by United Hospital Fund project staff provided several insights into the experiences of using PROs for patients, providers, and the broader health care team.

The Patient Perspective

Patients' opinions were largely positive regardless of which PRO questionnaire they completed. A significant majority, about 70 percent, said that discussing the results with their physicians helped them think about how they could address issues that had been revealed. Some two-thirds said they felt better prepared to manage those issues, and almost as many noted that they were given resources to deal with them (Figure 4).

“I felt I was thoroughly taken care of. All my concerns were addressed above and beyond.”

“I now know if something changes and I need help, I can come to my doctor.”

Some patients (10-16 percent) reported that the questionnaire was not relevant to them, while others considered it a burden or were irritated by the language and tone of the questions.

“I had no issues on the questionnaire, so there was nothing to discuss.”

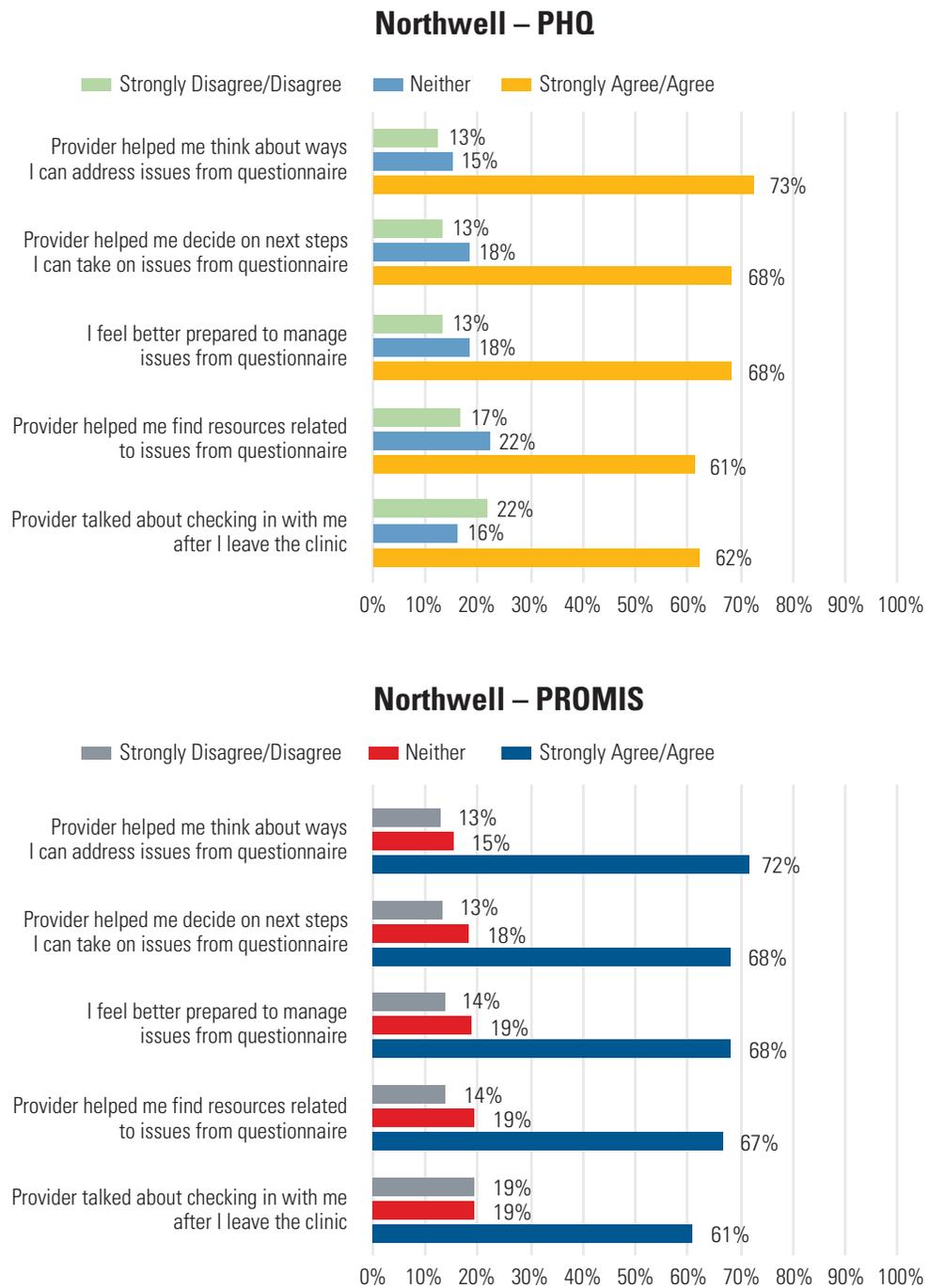
The Health Care Team Perspective

Overall, team members felt that the benefits of using PROs outweighed the challenges; most of the health care team said they wanted to continue using the tools (92 percent for PHQ, 85 percent for PROMIS). The team's perspective differed between the two PROs, with more positive opinions about the benefits of the PHQ-9 compared to the PROMIS Physical Function. (Figure 5).

PRO questionnaire administration, data collection, and documentation.

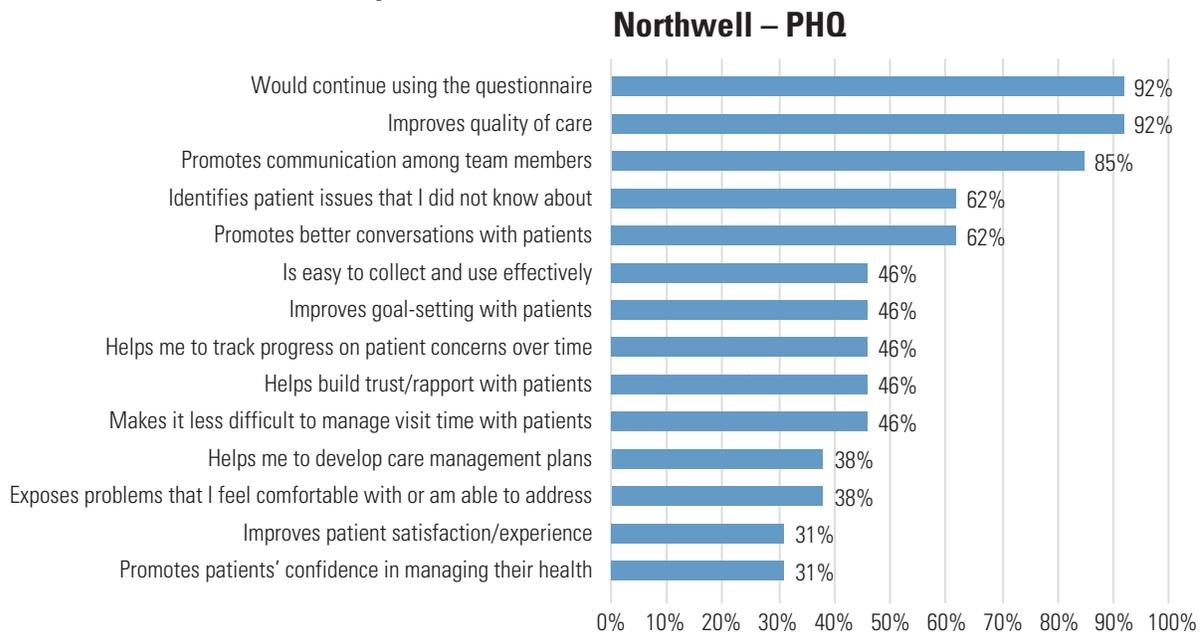
Even though both the PHQ-9 and the PROMIS Physical Function questionnaire have been validated and widely used elsewhere in practice and research, the teams found that their wording was not always easily understood by patients without guidance by the medical assistants. There were also concerns about privacy, particularly related to PHQ-9 questions dealing with sensitive issues such as suicidality.

Figure 4. Patient Survey Results



Since Northwell’s goal was to ensure that questionnaire responses were available for the patient’s meeting with their physician or other team member, it was critical that the information be documented soon after it was collected. But this proved to be a challenge—only a third of staff found the questionnaire responses easy to collect and use effectively. This was especially true for the results of the PROMIS Physical Function questionnaire: because data entry

Figure 5. Health Care Team Survey Results



into the EMR had not yet been automated, patient responses had to be scored and then documented by hand, which proved difficult to do efficiently within the structure of the visit workflow.

The team also piloted the use of the PROMIS iPad app with a small subset of patients and physicians. A total of 39 computerized PROMIS physical function questionnaires were completed. Setting up the process took minimal time, and patients found the app easy to use. Yet this approach presented several challenges. Since the app only provides an overall T-score, rather than the answers to the individual questions, clinical teams could not interpret individual answers and deemed the score alone insufficient to be useful. In addition, the complexities of integrating the app with Northwell's Allscripts EMR required staff to manually enter the information collected into the EMR, making the process unsustainable.

Physicians reported that time constraints made integrating PROs into their workflow challenging, though some noted that PROs did help them manage their time with patients more effectively. The formatting of the questionnaire appeared to affect ease of use.

“It's difficult to look at yet one more form, but the information is valuable. If formatted in a way which lends itself to interpretation via a very quick visual scan, it could be more readily acted upon.”

“I feel bad that I don't have enough time to explore more with patients.”

The variability in settings and routines was also noted as a significant challenge, with the faculty and residency practices requiring completely different workflows.

Use of PRO questionnaire information. Northwell reported that the use of PRO information influenced interactions with patients as well as those among team members.

Patient Interactions

One of the main benefits reported by team members was the creation of a structured framework for addressing patient outcomes; standardized questions ensure that key patient-reported information is asked systematically and also reduce variation among providers in what they elicit from patients and what they document. Another significant benefit was the immediate availability of standard PRO information at the time of the visit, which jump-started important conversations and allowed providers to engage in more detailed and effective communication with patients.

“I didn't know that collecting PHQ information from patients had such an impact on patient care. Now that I know that, I'm all for it.”

“Structured assessment of patient thoughts/feelings is valuable. The suicide question has been very critical. It keeps me honest about always asking it. I can genuinely say that it has saved lives.”

“One patient said to me that no one had ever asked her about her mood; she felt moved.”

“... [having the responses to the PHQ-9 before I see the patient] makes harder conversations do-able; [without it], I could have a 30-minute conversation with a patient and not uncover that she is depressed.”

Yet clinicians in a survey also cautioned that PROs are just “a tool, not a diagnosis. You can't forget about the judgment that should be part of interpretation. You have to put everything in context. We need to have a more in-depth discussion about what was reported.”

Health Care Team Coordination

Northwell participants found that the successful use of PROs depended on a strong multi-disciplinary team, in their case consisting of medical assistants, nurses, primary care physicians, and behavioral health practitioners. Staff also reported that PROs strengthened the team and highlighted interdependencies

between members. For example, it was suggested that some team members might be less resistant to asking patients to report on potentially difficult issues, if the team members knew that their colleagues could help address such issues. They also found that combined staff/provider meetings were an effective way to identify challenges, share success stories, and improve buy-in with the PRO process.

The standardized questions also provided team members with a common vocabulary for discussing patient needs and thus improved coordination—particularly between primary care and behavioral health care providers. With routine use of the PHQ-9, for example, primary care physicians were better able to identify patients reporting symptoms of depression and requiring specialized care. Because of this, they could therefore appropriately refer these patients to behavioral health team members, who did not themselves have to administer and score questionnaires and could use their time with the patients more effectively. Such enhanced coordination, however, required that all team members have privileges to input and view PRO data in the EMR.

The utility of the two PRO tools differed by discipline. For primary care physicians, the PHQ-9 was valuable for eliciting specific symptoms that they would otherwise not necessarily have asked about or suspected from the patient's demeanor; the PROMIS tool was less useful for these clinicians.

“Physical Function assessment with the PROMIS instrument didn't tell me anything I didn't already know.”

Behavioral health providers, on the other hand, were more experienced in managing patients with symptoms of depression and therefore placed high value on physical function reports to assess their own outcomes and treatment progress, particularly regarding issues like changes in psychomotor activity.

“I value the information patients report about their physical function... because I'm better at assessing depression than functional status. Because of my discipline, I need to hear about [depressive symptoms]. Primary care physicians may not as much; they need the PHQ-9.... Behavioral activation is an important part of treatment now, so I need to know the physical status of my patients.”

The teams expressed higher overall satisfaction with the PHQ-9 than the PROMIS Physical Function instrument, with 92 percent of respondents strongly agreeing that the use of the PHQ-9 improved quality of care; only 62 percent said that PROMIS did so. Participants also said it was easier to identify best practices for care management and follow-up for patients with depression than for those with physical function issues, since the evidence on how to interpret PROMIS scores and sub-questions (e.g., strength, endurance, pain) was sparser.

Despite finding significant benefits with PROs, team members underscored several challenges to scaling their use. It may be difficult to put in place appropriate staffing, as a mature and stable interdisciplinary team is essential to an outcomes-based care model. Automation of PRO administration, data collection, and EMR documentation is critical, and without an effective HIT platform, this work is not sustainable. And PRO questionnaires require fine-tuning, with further research needed on how providers can best interpret results to guide their discussion with patients regarding selection of appropriate interventions.

Insights on Implementing PROs in Primary Care

Universal vs. Selective Use of PROs

Northwell mailed the two PRO instruments to all new patients prior to their visits and asked them to complete the forms before coming to the office. The intent was to enhance the efficiency of visits by requiring less time for on-site collection of patient information and simplifying the clinic workflow. Having this information in advance would also allow the clinic to zero in on the reason for a visit, anticipate specific needs, and ensure better coordination between staff and patient.

However, most patients did not answer the questionnaires before their visits; those who did, frequently provided incomplete information or made other errors that had to be addressed in person. When surveyed about their experiences with whichever questionnaire they were given, more than one-third of patients said that the questions were not applicable to them.

These findings highlight two important considerations. First, it is important to clearly identify patient populations for whom specific kinds of outcomes are relevant. The residency site's team found that the generalized PROMIS Physical Function questionnaire was perhaps more applicable to older adults, those with disabilities, and post-surgical patients than to the entire primary care population; they also raised concerns about interpretation and customization of interventions based on the PRO instrument's scores. With thousands of patients prioritizing very different outcomes, primary care will forever be challenged to seek a balance between customization and standardization. One option in this context might be to consider a generic outcome, such as a goal attainment scale, based on each person's individual goal-setting. Such an approach offers a standard method of creating customized outcomes for patients.⁴

4 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); 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).

Northwell's findings emphasize that the successful adoption of PROs fully hinges on patient engagement, willingness, and an easy means of providing the information requested. To enhance patient engagement, the Northwell teams are experimenting with more effective use of their patient portals and patient-facing apps. Yet implementing PROs goes beyond practice redesign and new technologies, both of which are already complex undertakings. It must begin with a fundamental change in culture—with staff working to gain patients' trust and demonstrating that patient-reported information is highly valued and is incorporated into concrete actions to address health needs. Training and leadership coaching for staff on these aspects of the process are essential and should be part of ongoing clinic operations.

Reinforcing Integrated Care with a Family of PROs

Northwell's piloting of two PROs, on depression and functional status, for all new patients was an important step toward better coordinating the efforts of large multidisciplinary teams. The standardized questions of the two PRO questionnaires not only helped patients clarify and express concerns but also provided a common vocabulary to enhance team members' communication and capacity for coordination. Staff also reported that PROs drew attention to the interdependencies between team members and the essential role of nonclinical as well as clinical staff; medical assistants, for example, felt more empowered when they learned that their collection, scoring, and recording of PRO information made a difference in discussions with patients and the development of care plans.

The PROPC–NY experience suggests that the use of individual PROs or a set of PROs can foster broader health care integration—in Northwell's case, between primary care and behavioral health—by supporting communication, decision-making, and capacity-building among multi-disciplinary team members.

Looking Ahead

Northwell plans to continue routinely using the PHQ-9 to provide universal depression screening and treatment in primary care and to meet New York State's DSRIP requirements. Workflow has matured since the pilot ended, in part because Northwell has completed its HIT implementation and the upgrading of its EMR. As a result, PRO data can be captured more comprehensively and used more effectively. Additional capacity is also now available after new medical office assistants and nursing staff joined the teams. The PROMIS tool will be used on an as-needed basis. Ultimately, the PROPC–NY experience has built the framework and elements for continued progress toward an outcomes-based model of care for all patients.

Northwell's PROPC-NY Project at a Glance

Project sites	Two sites serving about 20,000 individual patients through more than 71,000 visits each year: a faculty primary care practice with 13 physicians and a residency clinic practice that trains 72 residents
Site attributes	Established in 1992; certified as a Level 3 Patient-Centered Medical Home since 2008
Project locations	Western Long Island (Nassau County) and Eastern Queens, New York with the majority of patients living in Great Neck, New Hyde Park, and Port Washington
PROPC-NY targeted population	All patients at their initial visit or annual comprehensive physical exam
Outcomes of Focus	Depression, physical function
PRO measure instruments	PHQ-9, PROMIS-10 Physical Function
Key team members involved in patient-reported outcome workflow	<ul style="list-style-type: none"> • Medical assistants (administration, scoring, documentation) • Physicians, residents, behavioral health team (communication with patients about results, care plan development) • Nurses, behavioral health team (referrals, follow-up)
HIT system	AllScripts
Assets	<ul style="list-style-type: none"> • Commitment to innovation and research • A learning culture with experience in training multi-disciplinary teams • Respected physician champions leading the effort • Experience in coordination/integration of physical health and behavioral health • Prior experience in piloting patient questionnaires to assess risk behaviors • Engaged IT leadership

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