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DOI: 10.1377/hlthaff.2012.1183 HEALTH AFFAIRS 32, NO. 2 (2013): 368–375 ©2013 Project HOPE— The People-to-People Health Foundation, Inc. By Esther Han, Sarah Hudson Scholle, Suzanne Morton, Christine Bechtel, and Rodger Kessler

Survey Shows That Fewer Than A Third Of Patient-Centered Medical Home Practices Engage Patients In Quality Improvement

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Rodger Kessler is an assistant professor in the Department of Family Medicine and the Center for Clinical and Translational Science, University of Vermont College of Medicine, in Burlington. ABSTRACT Directly involving patients and families in care improvement increasingly is viewed as an important component of patient-centered care. To assess the extent to which practices actually involve patients, we surveyed 112 patient-centered medical home practices in twenty-two states. Nearly all of these practices sought patient feedback. However, only 29 percent involved patients and families as advisers and sought feedback through surveys, and only 32 percent involved patients in a continuing role in quality improvement. Interviews showed that practices that highly value patient involvement overcame barriers to ongoing patient participation. We argue that a cultural shift is needed in how practices view patients as partners, not just in areas such as personal responsibility and self-management, but also in quality improvement and governance. Practices must gain more experience and see more examples of the benefits of engaging patients, and they may need more incentives and support for engaging them.

he Institute of Medicine included patient-centeredness as a distinct component in its landmark definition of quality in health care. As the patient-centered medical home becomes a more prevalent model for delivery system reform, questions are being raised about its ability to achieve its promise of centering care on patients and families.

Studies have linked the patient-centered medical home with improvements in the quality of care, decreases in clinician and staff burnout, and reductions in expensive services such as emergency department visits and inpatient care.²⁻⁴ The evidence about the impact on patients' experiences is mixed, and several studies have found no association with patients' ratings of care experiences.^{5,6}

The methods and extent of patient and family involvement in practice improvement can be important in supporting the patient-centeredness envisioned in the medical home model. Various definitions of the *patient-centered medical home* refer to different aspects of patient and family engagement, including engagement in care, practice improvement, and policy design.⁷

In addition, programs that qualify practices as medical homes, such as the programs of the National Committee for Quality Assurance (NCQA), contain requirements for involving patients in their care and for obtaining patients' feedback on the practice. However, little is known about how practices actually involve patients in practice improvement, the best methods for doing so, the kind of help practices need to make this involvement an ongoing part of quality improvement, or the impact of patient involvement on outcomes.

To assess the extent to which patient-centered medical homes are involving patients in quality improvement and to understand how policy efforts could better support these homes, we included questions about this topic in a survey of patient-centered medical home practices about

their behavioral health care activities. We also conducted follow-up interviews with a purposive sample of survey respondents to gain insight into respondents' motivations and the barriers they encounter.

Study Data And Methods

This study was conducted by the American Academy of Family Physicians' Collaborative Care Research Network and NCOA. A web-based survey was conducted of the 447 practices that had received NCQA Physician Practice Connections-Patient-Centered Medical Home recognition as of March 1, 2010.

NCQA defines a practice as a single geographic location where clinicians and staff share records and office systems. For practices that were affiliated—for example, part of the same medical group or hospital as other practices—one site was selected for the survey, yielding an initial survey group of 238 practices. Of these, 123 practices (52 percent) responded, and we saw no differences in response based on practice characteristics. Eleven surveys with missing data were excluded, which yielded a total study group of 112 practices from twenty-two states.

About half of the responding practices were small (fewer than five physicians; 56 percent), had the highest level of NCQA recognition (level 3; 56 percent), and were physician-owned (57 percent). Thirty-five percent of the practices reported that more than 20 percent of their patients had Medicaid, public insurance, or no insurance.

The practices reported on whether they had involved patients or families in the following four types of patient feedback or involvement in quality improvement within the past year:⁷ used a suggestion box or other ad hoc method; surveyed patients and families; obtained qualitative input from individual or small groups of patients through interviews, group meetings, or "walk-throughs"; or engaged patients and families as advisers on an ongoing basis through quality improvement teams or a patient and family advisory council.

SURVEYS We categorized patient involvement in the following three ways: high involvement when practices conducted patient surveys and included patients as advisers; medium involvement when practices either used surveys or advisers in combination with a suggestion box or other ad hoc method or used qualitative input; and low involvement, otherwise. We used chisquare tests to see if there were any differences in level of patient involvement activity based on practice size, NCQA recognition level, ownership type, or the percentage of Medicaid or

uninsured patients.

We conducted follow-up interviews with a purposive sample of practices that had completed the survey. Of the 123 practices that responded, seventy-seven gave us permission to contact them for additional information. A purposive sample of twenty-four practices representing different types and sizes were invited to participate in interviews. We limited the sample to the first ten that agreed to participate.

Six of these ten practices had level 1 NCOA recognition, one had level 2, and three had level 3. Seven of the practices had fewer than five physicians, and eight were independently owned. Collectively, they represented all primary care specialties, and two practices were federally qualified health centers. The practices also represented a range of practice demographics and geographic locations.

Whenever possible, we tried to interview a high-patient-involvement practice and a no- or low-patient-involvement practice from the same state, so that demonstration resources would be comparable. Three practices performed all four types of activities; three performed two to three types; two performed none of the types; and two had conducted patient surveys in the past but did not plan to conduct any additional activities.

Interviews were developed and conducted by two NCQA staff members with experience in qualitative research. We interviewed the most appropriate person as identified by the practice; interviewees included physicians, quality improvement directors, and practice managers. All interviews were recorded. Two NCQA staff members participated in the analysis of detailed notes.

The study was approved by the American Academy of Family Physicians' Institutional Review Board.

LIMITATIONS The practices involved in this study group voluntarily sought NCQA recognition and were early adopters of this model. (There are now more than five thousand recognized practices.) Most of the practices in the study are also involved in various medical home or quality improvement demonstrations and in all likelihood benefited from the training, resources, and community learning they received through these programs.

We did not gather detailed information on how each patient involvement method was used to improve care experience or the quality of care, nor did we have access to information on the quality of care or patient experience results. Also, only about half of the invited practices responded to our survey, and, in accordance with available resources, only ten follow-up interviews were conducted.

We did not see any systematic differences between practices based on whether or not they responded to the survey, and the interviewed practices were representative of the practices in the survey sample. Given these limitations, our results must be considered preliminary. Responding practices probably have more patient involvement activities than the average primary care practice in the United States.

Study Results

SURVEY RESULTS Ninety percent of the practices used at least one method of obtaining patient input (Exhibit 1). Surveys were the most common method: 78 percent of practices had conducted patient and family surveys within the past year. Of these, only 3 percent used the Consumer Assessment of Healthcare Providers and Systems survey tool; 40 percent reported using another standardized tool. Fifty-seven percent of the practices developed their own survey, and 67 percent of practices administered and collected the survey data on their own.

The majority of practices (63 percent) obtained qualitative input from patients through interviews, group meetings, or patient "walk-throughs" or by requesting input in writing. Suggestion boxes or other ad hoc methods of gathering input were used in 52 percent of the practices. Only 32 percent formally involved patients in ongoing teams or councils, including quality improvement teams and patient and family advisory groups.

Overall, 29 percent of practices had high patient involvement as evidenced by use of patient surveys and patient advisers (with or without other methods); another 35 percent used either

surveys or advisers (in combination with a suggestion box/other ad hoc method, or qualitative input); 16 percent performed only surveys; and the rest (20 percent) used only ad hoc or qualitative methods or none at all. Physician-owned practices were more likely than others to use surveys or ad hoc methods alone; practices serving low-income people were more likely than others to use both surveys and patient advisers (Exhibit 2).

INTERVIEW RESULTS Interviews with patient-centered practices revealed several key themes.

▶ VARIETY OF WAYS TO GET INPUT: Practices that valued patient and family involvement employed multiple methods and used the insights gained for quality improvement efforts. Importantly, these practices actively tried to identify and solve specific problems and used various methods in the process.

These practices also had physicians or staff who upheld the importance of involving patients and family members in practice improvement and proactively learning more about a patient's or family's values. As one physician stated, "To be more effective, you have to figure out what patients want out of you."

One large practice employed staff members dedicated to quality improvement who conducted surveys annually to identify areas for improvement. This practice interviewed patients or family members or conducted focus groups for additional feedback on how best to tackle specific issues; it evaluated improvement by comparing survey results before and after practice improvement initiatives.

A common problem mentioned in several interviews was a long wait when telephoning and the difficulty patients had reaching a clinician or

EXHIBIT 1

Patient Involvement Methods Used By Practices In The Sample, 2010

	Percent of	practices		
Method used in past year Conducted patient/family survey	Total (N = 112) 78	Recognition level 1 or 2 (n = 49)	Recognition level 3 (n = 63) 86	p value 0.02
Gathered qualitative input Interview, meeting, focus group Input on written documents Patient "walk-through"	63 43 37 31	55 31 27 33	70 52 44 30	0.11 0.02 0.05 0.78
Provided suggestion box or other ad hoc approach Included patient/family participation in team/council (formal) Inclusion on quality improvement or practice redesign team Patient/family advisory council	52 32 23 21	45 29 20 22	57 35 25 19	0.20 0.48 0.54 0.66
Appointment of individual patient/family advisers	16	14	17	0.65

SOURCE Authors' analysis of survey data.

Practice Characteristics Associated With Various Levels And Types Of Patient Involvement, 2010

	involvement, by degree of involvement		
Characteristic	Low patient involvement	Medium patient involvement	High patient involvement
Ownership/affiliation*** Physician-owned (n = 61) Other (n = 47)	48 21	36 32	16 47
Practice size Fewer than 5 physicians (n = 63) 5 or more physicians (n = 49)	41 28	33 37	26 35
NCQA Patient-Centered Medical Home recognition Level 1 or 2 ($n = 49$) Level 3 ($n = 63$)	47 27	29 40	24 33
Insurance mix**** 20% or less of patients with Medicaid or other public insurance or no insurance (n = 63) More than 20% of patients with Medicaid or other public insurance	51	28	21
or no insurance (n = 39)	13	46	41

SOURCE Authors' analysis of survey data. NOTES Low patient involvement consists of use of ad hoc or qualitative methods only, surveys only, or none. Medium patient involvement consists of use of surveys or patient advisory groups in combination with a suggestion box/ other ad hoc method or qualitative input. High patient involvement consists of use of both patient surveys and advisory groups. Other ownership includes ownership by hospital, health system, or health maintenance organization, as well as nonprofit or government facilities including federally qualified health centers. Pearson chi-square test. ****p < 0.01

making an appointment. A nurse manager at one multifacility practice told us that the practice used patient survey results to gauge the success of changes in its telephone answering system.

More of the practices gathered patient and family feedback to alert the practice to potential problems or to discover areas of patient dissatisfaction than to seek input on possible solutions to the problems identified or to partner with patients and families to redesign the care

▶VALUING PATIENTS' FEEDBACK: The interviews also revealed that some practices were not convinced of the value of patient feedback. One physician stated: "Patients have no understanding of what [it takes] to run an office.... They have no understanding of what goes into seeing a patient." These practices might have conducted their surveys as part of a demonstration program or to fulfill a requirement but generally were not committed to making changes based on patient and family feedback.

Several practices questioned the value of patient involvement activities because they deemed the feedback that they receive as "overwhelmingly positive" and that "our patients seem happy." Additionally, some small practices noted that because they are small, they believe that they know their patients and communicate sufficiently.

Furthermore, some practices expressed concern about responding to patient and family feedback. One physician stated, "If you ask, there's the implication that you'll do something with the answer and that you'll try to give them what they say they want." This physician, for example, decided not to pursue patient feedback because he might not have the resources to act upon it.

Percent of practices showing patient

Practices with higher levels of patient and family involvement saw a connection between improved involvement and improved care for individual patients. These practices valued patient feedback because it helped them design activities that enabled patients to be engaged in their own care. As one quality improvement manager stated, "[Patients] need to be partners in their own care.... We need to give them that respect and then begin to arm them with ways to take care of themselves."

These practices stated that robust patient involvement in every aspect of the practice, including designing effective patient engagement strategies, positively affected the way in which patients and families interacted with physicians and staff, supporting stronger relationships and enabling patients to feel more empowered to become active partners in their care.

One of the practices we interviewed received grant funding to hold prenatal care education groups for patients and family members. It sought patient and family input on what information they would find most helpful during the sessions and used survey feedback to make improvements and plan for additional groups such as patients with diabetes or patients interested in nutrition.

Others said that the responsibility for a patient's health lies solely with the patient: "My attitude is that it is their responsibility to take care of themselves. If I can facilitate that, that's where I see my role," stated one solo practitioner. These practices sought less patient and family involvement.

▶INCENTIVES FOR INVOLVEMENT: External incentives were useful in motivating sustained and comprehensive patient involvement in the long term. Some practices found that financial inducements and reporting requirements enabled them to involve skeptical or resistant physicians and staff in patient and family involvement activities.

Regarding public reporting, one physician stated that external motivation "help[s] sometimes to get the rest of the doctors and all the staff to understand that it needs to happen because not doing well would now be a matter of public embarrassment."

Another physician noted that when a demonstration project in which his practice participated began tying payment to reduced emergency department and hospitalization use, hearing from patients became especially important: "If there's an access problem, I need to fix it because there's some money on the hook if my patient doesn't call, or can't get through, or goes to the emergency room when they don't need to, or goes back to the hospital when better access and better management of their clinical problem would have made that unnecessary."

In this case, the external incentive motivated the physician to seek patients' input on access issues and to identify both the problems that could be addressed and strategies to use in solving those problems.

▶BARRIERS TO IMPLEMENTATION: A lack of resources and knowledge about successful models of patient and family involvement activities limited implementation. Several interviewees told us that although they were interested in involving patients and families more, the logistics were daunting. "It's useful, but it's extra work—if it's another minute on every patient, well that's more than we have," said one physician.

Practices also noted that they lacked expertise and resources, particularly when it came to knowing how to involve patients or family members in quality improvement teams or to create advisory bodies. One practice manager expressed the desire for more information about what other practices are doing and what activities have proved successful, along with templates and how-to guides to make implementation easier.

Discussion

Directly involving patients and families in primary care practices is increasingly viewed as an important component of patient-centered care. This is the first study to look at how primary care practices involve patients in quality improvement.

Whereas nearly all of the patient-centered medical home practices in this study obtained some type of input from patients and families, only 29 percent of practices involved patients and families as advisers and sought feedback through surveys. Also, practices that valued patient and family involvement often used multiple approaches to achieve it. These practices went beyond patient surveys to gather additional input by other methods and had processes in place to act upon the feedback. They saw patient involvement as a core strategy for improving performance on quality, cost, and experience metrics.

We concluded that practices that used few or none of these methods doubted that this input would provide meaningful information. These findings suggest that convincing skeptical practices about the usefulness of patient and family involvement requires expanding the view about the purpose and utility of these methods.

Practices that expressed positive attitudes about patient and family involvement viewed it as a strategy for helping patients engage in their individual care through self-management. A shift is needed in how practices view patients as partners, not just in areas such as personal responsibility and self-management, but in the types of quality improvement and governance roles that can lead to high-performing practices within a larger, patient- and family-centered system of coordinated and effective care.

Practices serving large percentages of lowincome people and practices affiliated with large systems involved patients more, perhaps because of greater resources and support or because of more explicit accountability requirements. For instance, federally qualified health centers are required to have community governing boards.

Demonstration programs that require patient experience measures can encourage greater patient involvement among practices seeking to improve their performance scores. The involvement might also be attributable to differing values held by practices that serve low-income patients as they seek ways to meet their patients' needs.

The medical field has a long history of doing things *for* patients and *to* patients but not *with* patients. In interviews we observed a lingering and persistent attitude that patients don't know what's best for them. As a result, some clinicians see patient and family involvement initiatives as little more than an additional requirement.

In light of this view and other barriers, public reporting of quality measures that reflect patient participation, financial incentives, and accountability could serve as important motivators for involving patients in practice improvement, as well as in self-management or patient behavior change.

Criteria for designating practices as patient-centered medical homes are also an important way of encouraging patient involvement. In the 2011 Patient-Centered Medical Home standards, NCQA increased expectations for practices to obtain feedback by giving more weight to measuring patient and family experience and including credit for gathering information on vulnerable people and using qualitative means to do so. The 2011 standards also introduced expectations for practices to involve patients and families in quality improvement. Practices can also receive special NCQA distinction for reporting patient experiences using a standardized methodology that enables benchmarking.⁸

These efforts would be further strengthened if involving patients and reporting patient experience results were core requirements and if public- and private-sector payers incorporated these expectations into their incentive programs. As we learned from our interviews, scoring practices on patient experience results could lead practices to involve patients and families more in redesigning care to meet their needs.

Practices also must understand the details of how to involve patients and families and how to use results to improve. They need how-to guidance, best-practices guidelines, testimony from practices with prior experience, and problemsolving assistance during the implementation process. Practices can benefit from training opportunities, for both clinicians and staff, as well as for patients and family members who serve on quality improvement teams or advisory groups. Demonstration programs have provided some education, support, and opportunities for collaboration for patient-centered medical homes. Additional technical assistance and guidance is necessary as practices seek to involve patients and their families more.

Conclusion

Most patient-centered medical homes use one or more methods of patient and family involvement. However, more must be done to expand an understanding of the value of involvement and the ways in which it can be achieved, particularly given the literature that questions the impact of the medical home infrastructure on patient experience.

In all likelihood, achieving true patient- and family-centeredness will require a cultural shift in how we think about patients as partners in, rather than solely as recipients of, care. Practices must gain more experience in involving patients and families as partners and using their input for improvement and must also be exposed to more examples of the benefits of this involvement.

External incentives can be helpful in catalyzing and accelerating these changes more broadly. These incentives could include financial incentives, as well as making patient feedback and the involvement of patients and families in practice design core requirements for qualifying as a patient-centered medical home.

Public reporting of the results of patient experience surveys could also spur practices to action. The practices included in this article probably have higher levels of patient and family involvement than an average primary care practice. It is critical to take advantage of the opportunity to learn from these early adopters. They show how best to move forward and encourage more practices to effectively involve patients and families in care.

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Esther Han is a medical student at the Boston University School of Medicine.

In this month's Health Affairs, Esther Han and coauthors report on a survey of 112 patient-centered medical home practices in 22 states to determine how many directly involve patients and families in care improvement. Although nearly all of these practices sought patient feedback, only 29 percent involved patients and families as advisers and sought feedback through surveys, and only 32 percent provided patients with a continuing role in quality improvement. The authors say that a cultural shift is needed so that practices view patients as partners in a broader sense, including in quality improvement and governance. Practices may also need to gain more experience and see more examples of the benefits of engaging patients and may need more incentives and support for implementation.

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Boston University School of Medicine and expects to receive her medical degree in 2014. Previously, she was a senior health care analyst for research at the National Committee for Quality Assurance (NCQA), where she managed projects focused on promoting culturally and linguistically appropriate health care services and care coordination.

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numerous responsibilities include overseeing the development and implementation of NCQA's research projects. She serves as the principal investigator for an AHRQ-CMS CHIPRA Center of Excellence in pediatric quality and leads work focused on quality measurement in behavioral health and shared decision making.

Scholle recently completed an AHRO-funded study of transformation in primary care, and her research on measurement of practice systems and patientcentered care has informed the development and evaluation of NCQA's Patient-Centered Medical Home program and evaluation program for accountable care organizations. She earned a master's degree in public health, with a focus on maternal and child health, from Yale University and a doctorate in health services research from the Johns Hopkins University.



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Christine Bechtel is vice president of the National Partnership for Women and Families, where she is responsible for strategic direction and oversight of the organization's health care programs. Her work includes managing projects funded by the nation's largest foundations, partnering with key business consortias, and leading broadbased consumer coalitions that address issues ranging from patient-centered care to health information technology (IT) to quality measurement.

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Additionally, Kessler served as the principal investigator of a recently completed survey of NCQA-recognized patient-centered medical homes. He investigated their responses to mental health, substance abuse, and health behavior services needs. He earned a doctorate in clinical psychology from the University of Vermont.