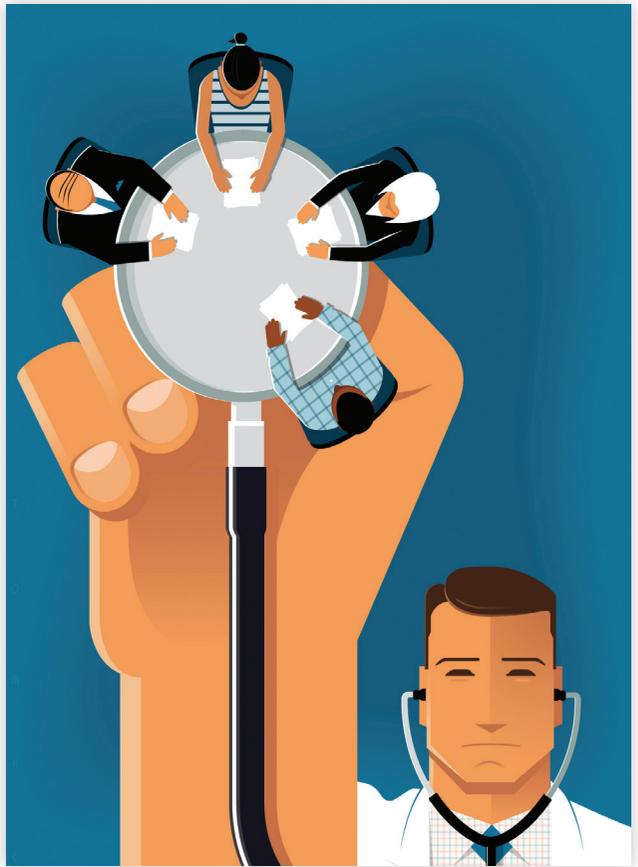


This model can make patients true partners in improving care for themselves and others.

# Patient Advisory Councils:



## Giving Patients a Seat at the Table

Anjana E. Sharma, MD, Lucia Angel, and Quynh Bui, MD

**P**atients increasingly are being asked to play a larger role in their own health care as well as that of others, whether in their local clinics or by helping shape national policy.<sup>1</sup> The patient-centered medical home (PCMH) model encourages clinics to involve patients closely in quality improvement efforts.<sup>2</sup> Yet, many PCMHs do not do so.<sup>3</sup> Clinic leaders may need more effective strategies to promote patient engagement and patient-centeredness. We propose that patient advisory councils (PACs) can prioritize the patient experience and enable patients to participate in improving quality.

A patient advisory council, also known as a “patient advisory board” or a “patient and family advisory coun-

cil,” is a representative group of patients and caregivers who meet regularly with clinic staff to help improve clinic performance. These are distinct from “community advisory boards,” which are often patient-dominated clinic boards of directors required for all Federally Qualified Health Centers (FQHCs). While FQHC boards typically focus on community relations and clinic leadership, PACs provide two-way communication between the clinic and its patients about daily clinic operations.

This article draws on our experiences working with advisory councils at several different sites: Malden Family Medicine Center in Malden, Mass., which serves a diverse population north of Boston with 34,000 encounters per year; the Family Health Center at San Francisco

General Hospital, which is the largest safety-net clinic in the San Francisco Health Network with more than 50,000 encounters a year; and the University of California-San Francisco (UCSF) Family Medicine Center at Lakeshore, which serves an ethnically and socioeconomically diverse population with approximately 11,000 patient encounters per year.

### A promising model

Advisory councils take work to develop, and their relative infancy in health care means there is a limited amount of evidence demonstrating their benefits. But some of that evidence, particularly around outpatient care and practice transformation, is promising. For example, one study

clinic experiences, propose quality improvement projects, or provide feedback (see “Using patient advisory councils to solve problems,” page 25). Not surprisingly, PACs can generate timely and robust ideas that often fall within the clinic staff members’ “blind spots,” helping address problems that they didn’t know existed.

For example, at one of our sites, a clinic-wide survey of patient satisfaction identified a problem with exam room waiting times. Presented with the data, members of the clinic’s PAC talked about their own experiences with wait times and what distressed them most. In particular, they suggested the clinic provide patients with more consistent information about delays and estimated wait times. They also worked with clinic staff to examine potential bottlenecks in the clinic flow and discovered that appointment

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showed that clinics where patients and providers jointly set clinic priorities were more likely to follow the core tenets of the chronic care model and the PCMH model than clinics where providers alone chose the priorities.<sup>4</sup> In interviews, front-line staff involved in PCMH development often name patient involvement in advisory councils as one of the key factors to successfully implementing the PCMH model.<sup>5</sup> Inpatient research has been more robust, with patient involvement credited with improving rates of both readmission for heart failure and hand washing by staff.<sup>6,7</sup>

In our experience, PACs have led to meaningful changes, including improved patient education materials, better wheelchair access for patients, clearer clinic signs, and more amenities for pediatric patients (see “Successful projects led by patient advisory council input,” page 24).

Although other avenues exist for obtaining patient input, PACs are unique. Members can describe their

schedules did not allow for the amount of time required for patient check-in, which led to progressive delays in provider schedules. Several meetings with the PAC led the clinic to schedule patients to arrive earlier. Patients in the PAC were also surprised that patient visits were scheduled for only 20 minutes. This led to the clinic adding language to new patient information packets, scheduling scripts at the front desk, and appointment reminder calls stressing the importance of checking in on time. The PAC also worked with the clinic to help inform other patients about the scheduling change. These changes resulted in fewer patients arriving late for appointments and shorter clinician wait times.

### Building a PAC

Several characteristics are essential to the success of a PAC and must be considered as part of the planning process:

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#### About the Authors

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**Engaged clinic leadership.** Clinic leadership must be committed to supporting the time staff and patients put into the PAC, as well as to respecting their input. It also helps to have a designated nonclinical staff champion to sustain momentum. Running PAC meetings usually takes about four hours a month, including setting up, holding the

meeting, and cleaning up afterward. Meeting preparation and follow up can take an additional two to 10 hours; this work may overlap with ongoing clinic quality improvement projects.

**Diverse recruitment.** Casting a broad net is helpful for obtaining a robust, diverse, and representative council. Clinics can ask providers and staff for nominations; mention the council in newsletters, flyers, and clinic signs; and notify patients of the opportunity through recruitment emails and letters. The average PAC should include between eight and 12 patients who will serve on the council for six months to one year. Clinics should also identify potential council members who can step in to fill vacancies.

**Careful inclusion criteria.** Clinics should recruit council members who will work constructively with each other. Interested patients should complete an application or interview and also pass a criminal background check. It is important to understand patients' motivations for joining the PAC – and identify those who might have specific agendas. Patients who have end-stage disease that makes it difficult to attend meetings, uncontrolled mental illness, or a history of inappropriate behavior toward staff should not be included in the council.

**Adequate funding.** Maintaining a PAC isn't free, but it doesn't have to bust the budget either. In our experience, staff members working with the council have dedicated time for PAC work. The patient members are often volunteers, although it is appropriate to provide them a financial reward such as dinner or a gift card to show respect for their time. If available, funding can also lower barriers that prevent some patient members from participating, such as a lack of transportation or childcare or a need for language interpreters. Even offering meeting refreshments or taxi vouchers can be effective. The funding can come from small grants through health care foundations or local government, contributions from an affiliated hospital, or pay-for-performance gains. However, a lack of funding should not prevent a clinic from starting a PAC because the biggest resource needed is the time and dedication of patient members and the staff champion.

**Mission statement.** PAC members, with the help of a skilled facilitator, should draft

## SUCCESSFUL PROJECTS LED BY PATIENT ADVISORY COUNCIL INPUT

DOMAIN	PROJECT
Enhanced patient communication	<ul style="list-style-type: none"> <li>• Designing welcome packets</li> <li>• Improving a call center scheduling script</li> <li>• Developing informational and educational material (e.g., waiting room video)</li> <li>• Rethinking an advanced medical directive program</li> <li>• Commenting on specialist access and patient communications</li> </ul>
Patient experience of care	<ul style="list-style-type: none"> <li>• Redesigning suggestion boxes</li> <li>• Designing patient satisfaction surveys</li> <li>• Developing a receptionist "greeting" checklist</li> <li>• Choosing books for pediatric patients</li> <li>• Planning "secret shopper" activities</li> <li>• Scripting and "selling" medical student teaching to patients</li> </ul>
Physical improvements to clinic space	<ul style="list-style-type: none"> <li>• Incorporating healthy vending machine options</li> <li>• Performing a waiting room walk-through to identify needed improvements</li> <li>• Improving clinic signs</li> </ul>
Quality improvement	<ul style="list-style-type: none"> <li>• Suggesting plan-do-study-act projects</li> <li>• Fleshing out quantitative numbers by reviewing data on cycle times, patient satisfaction, and quality measures</li> </ul>
PCMH/practice improvement initiatives	<ul style="list-style-type: none"> <li>• Helping improve clinic and phone wait times</li> <li>• Prioritizing practice improvement initiatives</li> <li>• Revising patient policy on late arrivals and reviewing results</li> <li>• Commenting on a secure patient portal's interface with an electronic health record</li> <li>• Reviewing data on medication refills</li> <li>• Providing feedback on PCMH activities, including outreach initiatives, care management support, and care coordination</li> </ul>

## Clinic leadership must be committed to supporting the time staff and patients put into the PAC, as well as to respecting their input.

their own mission statement and vision, creating something that honors their own values. This was an excellent icebreaker for the Malden PAC that allowed members to hear each other's motivations for joining the council.

Several outside resources can also help practices establish effective PACs. The Institute for Patient- and Family-Centered Care (<http://www.ipfcc.org/>) and the Patient-Centered Primary Care Collaborative (<http://www.pccc.org/>) support patient engagement and can suggest how to recruit, sustain, and renew PACs. Also, seeking the advice of a local clinic or health care organization with an experienced PAC is invaluable.

### The PAC meeting

PAC meetings are usually held once a month and last between 90 minutes and two hours

to allow enough time for detailed discussion. Meeting too infrequently can hamper continuity and productivity, while meeting too frequently can become a burden to patients and staff alike.

The meeting agenda can be drafted by a patient representative, a staff champion who may also assist with logistics and meeting facilitation, or both in collaboration.

Besides the patient members, some PACs have a clinician present, while others have a nonclinician who will review the meeting minutes with the medical director or members of the clinic's quality improvement team. Other guests may include trainees and other health care organization staff.

Meetings typically have two main agenda items. The first allows PAC members to discuss their experiences with care at the clinic and brainstorm ways to address those issues

■ Patient advisory councils meet regularly with clinic staff to improve clinic performance.

■ Engaging a nonclinical staff member to champion the council helps to ensure progress.

■ Successful councils need careful and diverse membership, adequate funding, and a clear mission.

### USING PATIENT ADVISORY COUNCILS TO SOLVE PROBLEMS

The following are real-life examples of how the authors' clinics are using patient advisory councils to tackle problems. In some cases, results are still inconclusive:

**Clinic A problem:** Clinic leaders have decided to double the size of the clinic, which is located in a dense urban area with high growth potential. They're looking for the best way to publicize this decision to their patients.

**Solution:** The medical director presented the expansion plan to the patient advisory council (PAC) members, most of whom were surprised, despite existing publicity efforts. The PAC recommended a multi-prong approach using email, the online patient portal, new signage, and advertisements in local newspapers.

**Clinic B problem:** Patient satisfaction scores for the front desk are consistently low, but practice leaders don't know how to improve them. They receive only two or three responses a month to

their patient surveys.

**Solution:** PAC members said they didn't feel welcomed into the clinic when they entered the waiting room. The PAC worked with the clinic's quality improvement team to provide customer service tips for front-desk staff, focusing on how they greeted patients.

**Clinic C problem:** The rural clinic is affiliated with a larger health care network that is encouraging sites to convert to a patient-centered medical home (PCMH). Clinic leaders want to know what parts of the PCMH model are most important to patients and want to avoid sending out potentially confusing and jargon-filled surveys.

**Solution:** After seeing a presentation on the PCMH, PAC members agreed that improving access was a main priority. The clinic began testing open-access scheduling and expanded clinic hours.

## Some staff may be uncomfortable with allowing patients “behind the curtain” and frankly discussing problems with clinic operations.

through quality improvement projects. The PACs at SFGH use this time to review patient comments from their waiting room suggestion boxes. The second agenda item features clinic staff and guests presenting projects or ideas to the PAC members for feedback. For example, a clinician at Malden wanted to put up a calendar in the waiting room showing all of the clinic’s ancillary services, such as acupuncture and nutrition. He first showed a rough draft to the PAC members, who gave him recommendations on how to make the information patient-friendly.

While a PAC meeting can generate a wealth of ideas for projects, a clinician partner, medical director, or operations leader needs to collaborate with the PAC members to select the projects that are the most feasible, worthwhile, and aligned with the PAC’s mission statement. Some PACs have also developed working relationships with their clinics’ practice improvement teams. Not all projects suggested by the PAC will be selected, and some will be referred to other departments. For example, one member at Malden drafted a set of changes to the online patient portal, which was sent to the clinic’s IT committee for review.

Successful PACs must also receive feedback, so this should be a regular agenda item. Seeing their action items and projects addressed is essential for the council members to understand their impact and feel that patient voices are making a difference. For example, one clinic’s PAC helped choose patient health education videos to play on a monitor in the clinic’s reception area. After the videos were played for several months, the clinic surveyed patients in their waiting room for their opinions about the videos. This information was brought back to the PAC, which used the feedback to evaluate its video choices. In contrast, PAC members at a different clinic drafted a set of recommendations for improv-

ing access to patients with diabetes. These recommendations were shared with the practice improvement team, but there was no follow-up on whether those recommendations were implemented.

### Potential obstacles

Some clinic staff may not understand how PACs fit into the complex ecosystem of a clinic or how they will be effective. In fact, some staff may be uncomfortable with allowing patients “behind the curtain” and frankly discussing problems with clinic operations. However, in our experience, PAC members are enthusiastic about partnering with staff to find solutions to improve the clinic. They often are already aware of the clinic’s problems and are eager to learn why they are happening and brainstorm solutions. As “advisers” they typically respect clinic limitations, and they appreciate the challenges involved in enacting change.

Another common concern is that the patients who have the availability and interest in participating in a PAC will have views that don’t represent the rest of the clinic’s population. However, we have found that the views of these patients are often the “canary in the coal mine” and are shared by many patients. Moreover, thoughtful recruiting will build a group of patients who match the diversity of patients found in the waiting room.

Sustaining a PAC is not without challenges. Both SFGH and Malden have at times struggled to keep programs going because staff didn’t have enough time to dedicate to council administrative duties, or had members leaving because of competing demands or illness. Running the meetings can also be challenging; we have each experienced issues where one PAC member is particularly vocal or dominates meetings. Setting initial ground rules about communication is helpful,

■ Council meetings can include time for patients to evaluate care experiences at the clinic and for clinic staff to present projects for council members’ feedback.

■ A clinic leader should help council members choose the most feasible and useful projects identified in meetings.

■ Staff need adequate time in their work schedule to handle the administrative tasks of a patient council.

although devising best practices for working with dominating members is still a work-in-progress. Many of these obstacles can be averted with active ongoing recruitment efforts and careful orientation of potential council members. It is critical to set guidelines for meetings and council membership, including term limits and expectations for confidentiality, meeting attendance, and behavior, and communicate them as part of the recruitment process.

PACs should not be a clinic's sole means of patient engagement. Surveys, suggestion boxes, and patient focus groups all have their place as effective methods to obtain patient feedback. Clinics should use multiple methods to gain patient assistance with quality improvement.

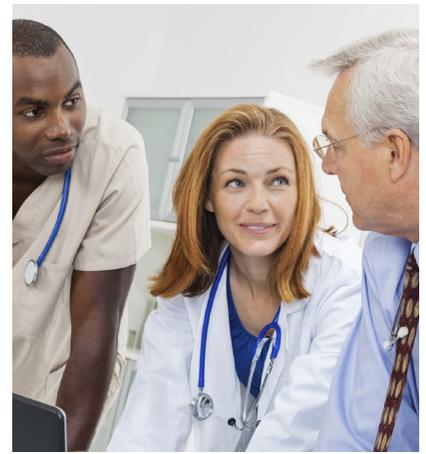
### The future for PACs

Support for PACs will grow if clinics can demonstrate positive impact. We hope to see future PACs drive their own quality improvement initiatives and share and publish data on their clinic-level efficacy. Many council members and staff we have worked with have suggested sharing successes and spreading best practices with other PACs. For example, the Lakeshore Clinic PAC was the first of its kind at UCSF, and its success led to the formation of other ambulatory PACs. The councils can now collectively provide feedback at the medical center level on ambulatory care-related issues. In the future, specialty clinics and risk management staff could consult primary care PACs with their own questions. As PACs develop, they may increase their ability to represent patients at the clinic by collecting and reviewing their own data from surveys and comment boxes.

At our practices, those who have worked with PACs can attest to the power of this level of patient collaboration. As clinics evolve from places of health care into patient-centered medical homes, PACs uniquely provide meaningful patient engagement in the life and services of the clinic. With the support of motivated leadership and with a proper foundation, any clinic can start a PAC and experience an enhanced level of patient partnership. **FPM**

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