

NEW PERSPECTIVES

Improving Care Through Listening to Patients and Families

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Patients and families are being asked to take an active role in their own health care and engage as partners with their health care providers to improve their own health and that of their family members. Building a patient- and family-centered primary care practice that views patients and their families as members of the health care team demands culture change and new openness on the part of providers. Patients and families have expertise, experience, and perspectives that are critical to bringing about this transformation. Innovative health care systems are involving patients and families as leaders and advisors for peer education and support. Patients and families are participating with providers in developing medical homes and organizational systems that support collaborative self-management. Providers are also involving patients and families as advisors and partners in other quality improvement and redesign initiatives.

Patient and Family Advisory Councils (PFACs) are groups of patients, family members, and staff who partner with practices or hospitals to improve the quality of health care and the care experience. Hospital councils across the United States have contributed to important and lasting changes. Massachusetts has been a national leader in recognizing the value of the patient and family voice and is the only state that requires hospitals to establish PFACs. As a result of the law, all Massachusetts hospitals have patient and family advisors working with them to improve care. Currently, 93 PFACs in Massachusetts are actively working to help improve care in acute care and rehabilitation hospitals. However, PFACs are not

nearly as common in the ambulatory setting, even though PFACs or more informal gatherings for smaller practices represent a best practice for ambulatory centers as well.

The Patient-Centered Outcomes Research Institute (PCORI) is partnering with SGIM with an educational grant to encourage SGIM member-led investigation to improve health care systems. Health care organizations are faced with crucial decisions about improving their systems of care, but they often lack critical information about the perspectives and values of their patients or customers. Patient-centered research can help them provide better care more effectively and efficiently, leading to improved patient-centered outcomes. PCORI is particularly interested in comparing health care system-level approaches to improving the safety, effectiveness, patient-centeredness, timing, efficiency, equitability, and accessibility of care and health care practice. The PCORI Improving Healthcare Systems Program funds and manages research studies that will provide valuable knowledge to patients, their caregivers, and clinicians.

The Baldrige Program is the nation's public-private partnership promoting organizational performance excellence and emphasizes the importance of patients in performance improvement efforts. The Baldrige Customer and Market Focus Criteria addresses how an organization seeks to understand the voices of customers and meeting customers' expectations and requirements. They stress relationships as an important part of an overall listening, learning, and performance excellence strategy. Customer satisfaction and dissatisfaction results can provide vital

information for understanding a medical practice's customers and the marketplace. In many cases, such results and trends provide the most meaningful information not only on customers' views but also on their marketplace behavior, positive referrals, and their contribution to the sustainability of health care organizations operating in an increasingly competitive marketplace.

At the Massachusetts General Hospital where I work, we are working to listen and learn from patients and families through our primary care "Ambulatory Practice of the Future," which operates a "Care Alliance." This is an ambulatory PFAC that facilitates an ongoing dialog among patients and staff to promote innovation and the optimization of care. Care Alliance members have played a major role in developing and providing input about written information for new patients and staff processes as well as reviewing survey results. The Clinical Practice Committee is aiming to spread this work throughout the country by sharing these best practices on SGIM.org and at our regional and national meetings.

PFACs represent a new and critical best practice that SGIM needs to champion in ambulatory primary care settings nationwide. Not only can patients and family members shape the patient experience at hospitals, but they can also promote truly patient-centered care in ambulatory and community settings. In particular, patients and family members can assist medical practices and groups by participating on key clinic-based and system-wide committees, reviewing educational materials for patients and families, lending their wisdom to staff orientation sessions and trainings,

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bringing forward new ideas for services and service enhancements, and reviewing plans for new facilities. Patients are particularly effective at identifying obstacles to care that impact patients and families more than health care professionals realize.

Family members of patients help teach new employees and existing staff by “telling their stories” in person or on video, describing their health care experiences in ways that help support and improve family-centered practices. The Clinical Practice

Committee wants to help make these best practices the norm in primary care and multispecialty clinics as well. Please contact me (jrichter@mgh.harvard.edu) if you would like to contribute to our efforts.

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