



Patient & Family Leadership Resource Compendium for Health Care

Summer 2015

DISCLAIMER: This Compendium has been prepared through the work of participants in the Patient & Family Leadership Network convened by the National Academy of Medicine. The statements and views expressed are those of the individual contributors and not necessarily of the contributors' organizations or of the National Academy of Medicine. This Compendium was created to assist and to inform volunteer patient & family council leaders who, from its inception, have contributed and continue to contribute valuable feedback. It has not been subjected to formal review by the National Academy of Medicine and is not a report of the National Academy of Medicine or of the National Research Council.

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PROJECT STEWARDSHIP

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About this Compendium

This Compendium was created to assist and to inform volunteer patient & family council leaders and such leaders have contributed valuable feedback from its inception to its completion. It presents summary information on available evidence and information about the impact of patient and family engagement on health care outcomes and care improvement. It is intended to be a continuously updated living resource, and [suggestions](#) for inclusion are encouraged.

The document includes resources that are related to patient and family engagement, broadly, and to the impact of patient & family advisory councils (PFACs), specifically. While these topics are obviously related, there is a paucity of published research about PFAC impact and a wealth of information about patient and family engagement. Because of these limitations, we focus on providing recent peer-reviewed articles that would be helpful to patient & family council leaders who are tasked with planning and carrying out activities related to quality and safety improvement, improving the accessibility of patient portals, providing feedback to ensure that building design is patient- and family-centered, and contributing to projects that enhance value and efficiency. These published items, which explain what already has been tried, are presented in reverse chronological order.

While some research areas contain an abundance of material, the tension inherent in a document such as this one is to enlighten—which we strive to do by including one or two foundational articles—without overwhelming readers by presenting the entirety of the literature on that topic. We also recognize that patient & family council leaders are involved in projects that ultimately may be the subject of future peer-reviewed articles. In “Learning from ‘Real-World’ Examples” and “Snapshots,” we offer a sampling of current projects, toolkits, frameworks, and primers to help disseminate knowledge to the nation’s council leaders in real time. Video testimonials present these learning lessons in the words of patient and family council leaders who helped with successful implementation. These items, which explain what other PFAC leaders could try in their facility, are presented in alphabetic order, by the topic name.

Throughout the document, we refer to patient and family engagement and, in that respect, we draw from the revised definition of patient- and family-centered care presented in the 2015 Institute of Medicine report, [Transforming Health Care Scheduling and Access: Getting to Now](#).

Patient and Family-Centered Care

Patient and family-centered care is designed, with patient involvement, to ensure timely, convenient, well-coordinated engagement of a person’s health and health care needs, preferences, and values; it includes explicit and partnered determination of patient goals and care options; and it requires ongoing assessment of the care match with patient goals.

Also relevant to the work are the standards of the Joint Commission, presented below:

- **Provision of care, treatment, and services (PC)02.01.21**—The hospital effectively communicates with patients when providing care, treatment, and services.
- **PC.02.02.01**—The hospital coordinates the patient’s care, treatment, and services based on the patient’s needs.
- **PC.02.03.01**—The hospital provides patient education and training based on each patient’s needs and abilities.
- **Rights and responsibilities of the individual (RI)01.01.03**—The hospital respects the patient’s right to receive information in a manner he or she understands.
- **RI.01.02.01**—The hospital respects the patient’s right to participate in decisions about his or her care, treatment, and services.
- **RI.01.05.01**—The hospital addresses patient decisions about care, treatment, and services received at end of life.

PROFILE OF PATIENT & FAMILY COUNCILS

Patient and family advisory councils (PFACs) partner patients and families with members of the health care team and hospital staff in order to infuse the unique perspectives of patients and family caregivers into quality- and safety-improvement activities; building design; executive hiring; efficiency improvements; and strengthening materials for patients, such as portals, among other activities. They serve as peer mentors to other patients, create interactive tools, demonstrate best practices through videos and role-playing exercises, and ensure the patient and family viewpoint is reflected in everything—from how hospital bills are designed, to how daily care plans are communicated with patients, to which type of chairs patients sit in as they recover from chemotherapy.

Patient & family advisors:

- Provide an effective mechanism for receiving and responding to consumer input;
- Result in more efficient planning to ensure that services truly meet consumer needs and priorities;
- Lead to increased understanding and cooperation between patients, families, and staff; and
- Promote respectful, effective partnerships between patients, families, and professionals.

While patient- and family-engagement activities have their roots in pediatric care, the first PFACs began in the late 1990s. Today, more than [2,000 hospitals](#) across the nation have launched PFACs. The state of Massachusetts mandates their formation in all health care delivery centers and systems.

The Health Research & Educational Trust (HRET) [surveyed](#) 3,442 randomly selected hospitals on July 2013 and October 2013 about patient/family engagement (PFE) strategies, use, and challenges. Some 1,457 hospitals, or 42 percent, responded to the HRET survey. Eighteen percent of respondents identified themselves as hospital chief executive officers. In an article published in [BMJ Quality & Safety](#), the authors said the effort “represents the best current evidence about what US hospitals are doing to engage patients and families and which barriers pose the most significant challenges.” The authors identified the most widely adopted organizational practices, such as “88% had written policies on patients’ rights to identify which of their personal contacts they would like to have actively involved in their care, 86% had a policy for unrestricted visitor access in at least some units and 67% had formal policies for disclosing and apologising for medical errors.” The least frequently adopted patient & family engagement activities included “the involvement of patients and family members as either educators or content developers when training clinical staff

(7%), patient and family advisory councils meeting within the last 12 months (21%), and patient and family members sitting on the patient and family advisory councils (23%).”

Much of the “wide variation in practices” can be attributed to leadership choices or other factors, such as decisions about how to allocate resources, the authors note. The top three “significant” barriers to patient and family engagement, according to survey respondents, were competing organizational priorities (51.1 percent); time to set up and implement advisory programs (42.4 percent); and time available for such activities as shift reports at bedside or multidisciplinary rounds at bedside (31.9 percent).

The ways in which they work

Because the impetus to create a PFAC can come from within individual institutions—and from patients themselves—there is great diversity in PFAC structure, mission, and composition. In many institutions, volunteer PFAC members’ work falls within the hospital’s patient-engagement activities. Others align the focus of the advisory council with their quality- and safety-improvement efforts. There is even great variability in titles for the volunteers: Patient-Family Advisory Councils, Patient Partners, and Family Advisors, among others.

Volunteer PFAC members may serve on advisory councils that encompass all hospital activities, and they may be members of the hospital’s Board of Trustees, directly interacting with hospital leadership. In many cases, PFACs exist for specific units of the hospital, such as the cancer center or the neonatal intensive care unit, or they may be created for specific health-related topics, such as end-of-life care, facility design, quality improvement, performance improvement, or patient safety. Some PFACs are partnerships of co-chairs, with a hospital staff co-chair paired with a volunteer patient or family member co-chair. Some PFAC members serve in roles that extend beyond their specific council. “As part of this [PFAC process](#), patients and families are invited to serve on hospital committees to ensure that the consumer’s point of view, perspective, and experience are not only heard but also integrated into the service and quality improvements that are engineered to ensure high-quality, customer-centered care.”

Measuring their impact

PFACs and their affiliated hospitals use a variety of measures to gauge their impact including, but not limited to, hospital readmission rates, patient satisfaction scores and, increasingly, measurements of patient harms. One hospital added a question specific to PFACs to its Press Ganey survey while

others are strategizing how to develop and implement mechanisms to better characterize PFAC's direct impact on improving the quality, safety, and cost-effectiveness of patient care.

Competencies and roles

[Thought leaders](#) have defined a variety of core competencies for patient & family advisors, including problem-solving and being “solution-focused.”

Possible roles for patient and family advisory councils

PFAC member's individual role

Increase the skills, knowledge, and understanding of patients and families about what to expect when receiving care.

- Providing health education and health literacy
- Providing training in needed skills
- Providing peer-to-peer support

PFAC role in relation to health care team

Promote shared understanding of expectations among patients and health care professionals when seeking care.

- Participating in bedside change-of-shift reports
- Participating in multidisciplinary rounds
- Activating rapid-response teams

PFAC member's organizational role

Encourage partnerships and integrate the patient and family perspective into all aspects of hospital operations.

- Using patient volunteers as advocates to support care
- Removing restrictions on visiting policies for families
- Opening access to medical records
- Expanding use of e-mail, social media technology, and patient portals
- Redesigning internal and external communication with patients, e.g., signage, medical bills, brochures, web site pages
- Underscoring the importance of empathy and use of non-technical language when health care professionals speak with patients and relatives
- Participating in staff interviews and hiring decisions
- Advising on how to improve efficiency in facilities and workflow

PFAC member's community role

Expand the focus beyond the hospital setting and find opportunities to improve overall community health.

- Projects are tailored to the individual needs of each PFAC and the institution with whom it works
- Serving as ambassadors for health care improvement and population health initiatives in their communities
- PFAC members partner with researchers to design the scope, conduct, and dissemination of patient-centered research

INFORMATION ON IMPACT

A Learning from “real-world” examples

- **A-1:** *Catholic Health Initiatives* (CHI) successfully implemented patient- and family-centered structures and processes in its facilities across 19 states. Partnerships between patients, families, and nurse leaders were instrumental in establishing hospital-based patient and family advisory councils across the CHI health system. Achieving patient and family engagement through the implementation and evolution of advisory councils across a large health care system. Haycock, C. and C. Wahl C. 2013. [Nursing Administration Quarterly](#).
- **A-2:** People who are actively engaged in their health care are more likely to stay healthy and manage their conditions by asking their clinicians questions about their care, following treatment plans, eating right, exercising, and receiving health screenings and immunizations. Patients without the skills to manage their health care incur costs up to 21 percent higher than patients who are highly engaged in their care, according to this March 2014 *Robert Wood Johnson Foundation* issue brief about patient engagement. [More here](#).
- **A-3:** People actively involved in their health and health care tend to have better outcomes—and, some evidence suggests, lower costs—according to this Health Policy Brief published February 2013 in *Health Affairs*. [More here](#).
- **A-4:** Aligning Forces Humboldt, located at the California Center for Rural Policy at Humboldt State University, has developed a successful method for assessing and maintaining patient involvement in its work leading the Aligning Forces for Quality (AF4Q) initiative in Humboldt County, Calif. AF4Q is the *Robert Wood Johnson Foundation’s* signature effort to lift the overall quality of health care in 16 targeted communities across America, according to this March 2014 Quality Field Note. [More here](#).
- **A-5:** At *Massachusetts General Hospital* (MA), while PFACs strive to be representative of the patient population, only 41 percent actually represent the community they serve and 37 percent did not report on that measure. The facility defines aspects of diversity as including race/ethnicity, socioeconomic status, age, spirituality, physical/cognitive ability, sexual orientation, and gender. [More here](#).
- **A-6:** *Blue Shield of California Foundation’s* Clinic Leadership Institute Emerging Leaders program prepares emerging leaders to move into executive leadership positions within five to eight years to help sustain a strong community health centers field in California. The intensive, 18-month program offers in-person, multi-day seminars and

a continuum of complementary supports—including peer networking, coaching, a clinic leadership project, and an alumni component—to help participants strengthen their ability to lead health centers into the future. Sixty-six percent of participants said they advanced to a more senior role since beginning the program; 51 percent said they experienced significant growth in their responsibilities; and 52 percent said they received a salary boost of at least 10 percent. [More here.](#)

- **A-7:** *Kaiser Permanente*, which has more than 400 patient & family advisors and more than 35 Patient Advisory Councils, reduced the incidence rate of *Clostridium difficile* (*C-diff*) in one of its medical centers after involving patients in their *C-diff* simulation and revising its procedures and communications with patients. [More here.](#)
- **A-8:** Under the Colorado Accountable Care Collaborative, the State *Medicaid* agency contracts with regional organizations that serve seven geographic areas. These organizations contract with and support primary care-led medical homes in coordinating and managing care for enrolled beneficiaries. Enhanced access to coordinated care for Medicaid beneficiaries has led to fewer admissions and readmissions, less use of high-cost imaging services, and a slowdown in the growth of emergency department visits, collectively yielding an estimated \$6 million in cost savings for the State. [More here.](#)
- **A-9:** *Beth Israel Deaconess Medical Center's* (MA) PFAC involvement improved the institution's transparent and honest approach to adverse events, which it calls the Communication, Apology, and Resolution (CARE) program. In helping to develop the CARE patient brochure, PFAC members placed even greater emphases on communication and clarified such matters as how patients may initiate the process, explained legal rights, eliminated the word "money," and added clearer bulleted formatting. [More here.](#)
- **A-10:** More than 75 percent of patients who responded to a recent survey would like to use digital health care services, as long as those services meet their needs and provide the level of quality they expect, according to *McKinsey & Company's* Digital Patient Survey conducted in July 2014 in Germany, Singapore, and the United Kingdom. [More here.](#)
- **A-11:** A program in Oregon helps health organizations to establish patient and family advisory councils, according to the overview, "Engaging the Patient Perspective Produces Real Change," that appears in this *Robert Wood Johnson Foundation* March 2014 Patient Engagement Resource Guide. [More here.](#)
- **A-12:** *Fort Belvoir Community Hospital* (VA) has initiated quarterly Facebook "town hall" meetings to interact with patients. The hospital

commander, chief of staff, public affairs staff, and deputy commanders gather in a conference room for a three-hour session to respond to patients' questions and concerns posted via Facebook. [More here.](#)

- **A-13:** *The Agency for Healthcare Research and Quality's* video series, "Frontline Innovators on Providing Patient- and Family-Centered Care," features brief profiles of health care professionals sharing stories about how they have put the core concepts of patient- and family-centered care into practice: [Georgia Regents](#); the [Hasbro Children's Partial Hospital Program](#), a collaborative program of the departments of pediatrics and child psychiatry at the Alpert Medical School at Brown University; and [Holy Cross Hospital's](#) senior emergency center.
- **A-14:** *The Agency for Healthcare Research and Quality's* "Guide to Patient and Family Engagement in Hospital Quality and Safety" is a tested, evidence-based resource to help hospitals work as partners with patients and families to improve quality and safety. It provides four evidence-based strategies that hospitals can use to implement patient- and family-centered care practices. Each strategy includes educational tools and resources for patients and families, training materials for health care professionals, and real-world examples that show how strategies are being implemented in hospital settings. [More here.](#)
- **A-15:** Health Literacy as an Essential Component to Achieving Excellent Patient Outcomes. The U.S. population is more diverse than ever before in terms of race, ethnicity, language, socioeconomic status, and education level. In order to adequately serve these changing demographics, health care organizations must provide all persons with the ability to obtain, process, and understand basic health information and services needed to make appropriate health decisions. The authors of a new discussion paper write that in order to accomplish this, health care organizations must promote, sustain, and advance an environment that supports principles of health literacy. [More here.](#)
- **A-16:** *The Department of Health and Human Services (HHS)* on May 7, 2014 announced that new preliminary data show an overall 9 percent decrease in hospital-acquired conditions nationally during 2011 and 2012. National reductions in adverse drug events, falls, infections, and other forms of hospital-induced harm are estimated to have prevented nearly 15,000 deaths in hospitals, avoided 560,000 patient injuries, and approximately \$4 billion in health spending over the same period, according to HHS. These strides in patient safety are a result of strong, diverse public-private partnerships and active engagement by patients and families, including efforts from the federal Partnership for Patients (PfP) initiative and Hospital Engagement Networks, Quality

Improvement Organizations, the Centers for Medicare & Medicaid Services, the Agency for Healthcare Research and Quality, the Centers for Disease Control and Prevention, the Administration on Community Living, the Indian Health Services, and others, according to the agency. [More here.](#) [Methods used](#) to estimate the annual PFP national hospital-acquired condition rate.

- **A-17:** According to the *National Patient Safety Foundation*, patients can help prevent a hospital readmission by knowing what they need to do before and after leaving the hospital, asking questions early and often, and asking when they do not understand their follow-up care instructions. The advice is contained within a post-discharge tool the organization created to help patients and families take action to keep the patient's recovery on track and to keep patients out of the hospital. [More here.](#)
- **A-18:** The *Agency for Healthcare Research & Quality* announces a new perspective, How middle managers can influence innovation implementation, by Sarah Birken, MSPH, PhD, Postdoctoral Fellow in the Cancer Control Education Program at the Lineberger Comprehensive Cancer Center, University of North Carolina at Chapel Hill. [More here.](#)
- **A-19:** The *Healthcare Information and Management Systems Society* and the *National eHealth Collaborative* have merged to provide thought leadership on how to improve patient health through the use of information technology. [More here.](#)
- **A-20:** Effective health care leaders communicate the hospital's vision and values related to patient and family engagement, serve as role models for partnering with patients and family members, provide the necessary infrastructure and resources, involve and support clinicians and hospital staff in patient- and family-engagement initiatives, and integrate patient and family engagement into personnel policies and practices, according to the *Agency for Healthcare Research and Quality's* guide, "Information to Help Hospitals Get Started." [More here.](#)
- **A-21:** *Beth Israel Deaconess Medical Center* (MA) is connecting PFAC activity to strategic program/hospital goals. One such 2014 goal for the Intensive Care Unit PFAC was to prevent loss of dignity and respect among patients by asking such questions as "Can you think of a time when your loved one was treated with dignity or respect by a member of their health care team? What did they do to help you feel that way?" Family caregivers answered that they feel respected when "people look me in the eye when we are having a conversation" and when "nurses or doctors ask or encourage feedback. Because my voice and/or family's experience matter." [More here.](#)

- **A-22:** Although patient- and family-centered care has become a desirable attribute of health care around the globe and has been associated with health system improvements, challenges remain for organizations, including defining core elements of patient-centered care, time, and clinician support needed to accomplish such culture change. To that end, the patient-engagement strategies of a small number of “exemplar” health organizations, such as *Georgia Regents Health System* and *Cincinnati Children’s Hospital Medical Center*, will be reviewed and case studies assembled in an upcoming report. Among its key findings: Leadership support and leaders whose skills include knowing how to negotiate “the politics and practicalities” of engagement are essential for such health care transformation. “Evidence boost: A review of research highlights how patient engagement contributes to improved care.” Baker, G. 2014. Institute of Health Policy, Management and Evaluation: [University of Toronto](#).
- **A-23:** Georgia Regents Health System, leaders in patient- and family-centered care (PFCC) have hosted a variety of health care institutions since 2005 for on-site learning experiences. Their September 18-19, 2014 learning lab gave an up-close look at what PFCC looks like in the real world of health care from the perspective of patients, families, staff, physicians, and administrators. [More here](#).
- **A-24:** The palliative subgroup of the PFAC at *Cooley Dickinson VNA & Hospice* (MA) held community presentations at such venues as senior centers and independent living facilities to help explain palliative care and how it helps patients and families cope with serious illness. The presentations included a 21-minute [role-play video](#) to help train patients and community members about how to be active participants in conversations about Medical Orders for Life-Sustaining Treatment.
- **A-25:** *PatientsLikeMe* announced that patients can apply to lead the development of new health outcome measurements using the company’s Open Research Exchange™ platform. This call for participation is a way for people living with disease to become the researcher and use their own and others’ experiences to create new health measures that are more meaningful, helpful, and relevant. A new \$2.4 million grant from the Robert Wood Johnson Foundation supports two patient-led projects in 2014 to develop, test, and validate patient-reported outcomes. [More here](#).
- **A-26:** *Contra Costa Regional Medical Center and Health Centers’* (CA) leadership, staff, patients, and family members share their views on why partnering with patients is critical to improvement efforts. [More here](#).
- **A-27:** *The Josiah Macy Jr. Foundation* brought together patients,

patient advocates, health care educators, and health leaders on April 3-6, 2014 with the aim of making recommendations to reform health professions education and health care practice in partnership with patients, families, and communities. The recommendations from the conference, “Partnering with Patients, Families, and Communities: An urgent imperative for health care,” are found [here](#).

- **A-28:** *Anne Arundel Medical Center’s* (MD) commitment to strengthening the partnership between health care providers and patients and their families includes tapping the contributions of patient and family advisors. The facility considers working with PFAC members part of its patient- and family-centered care, in which patients and families are allies for quality and safety within the health system. [More here](#).
- **A-29:** Patient- and Family-Centered Care: Partnerships for Quality and Safety, from the *American Hospital Association*, describes the [core concepts](#) of patient- and family-centered care and features stories from patients, families, caregivers, and hospital leaders.
- **A-30:** *C.S. Mott Children’s Hospital* (MI) believes that greater success is achieved through the interactions between health care team members and families. The Patient & Family Centered Care Program charges patients and families with sharing personal experiences, opinions, and advice within councils, committees, or as mentors, e-advisors, or storytellers in order to improve the patient and family experience at the hospital. [More here](#).
- **A-31:** A growing body of research has demonstrated the impact of patient-centered design, which considers such factors as room size, soundproofing, artwork, and natural light on clinical outcomes, according to this *HFMA* article. According to the publication, a 2011 analysis found that incorporating such evidence-based design elements—including such patient-centered features as healing gardens, sound-absorbing materials, and large windows—added \$26.2 million to the cost of construction but a return on investment was achieved in three years due to cost savings from reduced patient falls, length of stay, and energy use. [More here](#).
- **A-32:** Today, customer-focused service is making itself felt in some of America’s medical offices, according to this *Consumer Reports* article, “A Doctor’s Office That is All About You.” According to the author, such patient-centered medical homes are the fastest-growing innovation in medical care. [More here](#).
- **A-33:** The *Regional Primary Care Coalition*, an active collaboration and learning community of health philanthropies and primary care provider coalitions serving the region’s low-income residents in

Washington, D.C., northern Virginia, and suburban Maryland, has developed a continuum of patient engagement for understanding how patients can better engage in their health care. [More here.](#)

- **A-34:** About half of health systems and physician practices have introduced a portal, according to the *KLAS* health care research firm, and the number is growing rapidly, HFMA notes in its recent article, “The Patient Portal to the Future.” [More here.](#)
- **A-35:** *Baystate Medical Center* (MA) patient and family advisors partnered with the safety committee to improve patient safety. The project involved preparing PFAC members for their roles on the committee as well as providing mentoring opportunities. Among the elements of a safe system for care: Engaging the right team to make corrective action; utilizing tools for clear, effective team communication; brief/debriefs, time-out, and teach back. [More here.](#)
- **A-36:** *Braintree Rehabilitation Hospital* (MA) PFAC members serve as peer visitors, former patients whose injury/rehabilitation matches the current patient’s; weekend volunteers, PFAC members who visit patients on weekends, when few physical or occupational therapy appointments occur; and PFAC involvement in follow-up phone calls made 30 days after discharge that ask, among other questions, whether patients understood information provided at discharge. [More here.](#)
- **A-37:** Prioritizing Measure Gaps: Person-Centered Care and Outcomes, a project undertaken by the *National Quality Forum*, envisions ideal person- and family-centered care as a framework for performance measurement and will make short- and intermediate-term recommendations to measure performance and progress on ideal person- and family-centered care. [More here.](#)
- **A-38:** The *Gordon and Betty Moore Foundation*, working with *American Institutes for Research*, created the Roadmap for Patient and Family Engagement in Healthcare Practice and Research, which identifies eight strategies to meaningful patient and family engagement with the overarching goal of improving health and health care. [More here.](#)
- **A-39:** The *Partnership for Patients’* May 27, 2014 [webinar](#), “Safety is Personal: Partnering with Patients and Families,” explained the recommendations of the National Patient Safety Foundation’s Lucian Leape Institute for hospital leaders, clinicians and staff, consumers, and policy makers in advancing patient and family engagement.
- **A-40:** In *Shared Decision-Making Strategies for Best Care: Patient Decision Aids*, the authors suggest concrete steps to fully integrate the ideals and practices of shared decision making (SDM) into routine clinical practice. The discussion paper authors identify key steps to shift expectations and behaviors of patients and clinicians: Certifying

decision aids, establishing measurement standards for SDM, using health information technology to facilitate information exchange, and expanding the role of employers and payers in supporting certified decision aids. In support of these steps, the authors summarize their views of the compelling case for implementing SDM, and underscore the potential benefits. [More here.](#)

- **A-41:** *The John A. Hartford Foundation's* third public poll examined older adults' experiences and opinions of team care and the patient-centered medical home. The survey included responses from 1,107 adults older than 65 and had a sampling margin of error of +/- 3.9 percentage points. Eighty-three percent of respondents said they already receive well-coordinated care from a team of providers and indicated that team care had improved their health. Among older adults not currently receiving team care, 61 percent said they believed team care would improve their health. "On your team: What older adults think about team care and medical home services." [More here.](#)
- **A-42:** *Boston Children's Hospital* (MA) built a teen advisory council (TAC) by choosing meeting times that worked within the school schedule; limiting meeting length to no more than 2 1/2 hours; and allowing time for teens to unwind, socialize, and eat. TACs showed administrators that they can represent the voice of teens served by the hospital, that adolescents embrace opportunities to partner with hospital staff, and that teens can function as advocates for their own needs. [More here.](#)
- **A-43:** *Ten Attributes of Health Literate Health Care Organizations.* A wide range of organizations have recognized that having health literate health care organizations benefits not only the 77 million Americans who have limited health literacy, but also the majority of Americans who have difficulty understanding and using currently available health information and health services. This *Institute of Medicine*-published paper presents 10 attributes that exemplify a health literate health care organization. [More here.](#)
- **A-44:** Consistently providing three basics, including delivering patient-centered care that is compassionate, caring, and respectful, can relieve patients' suffering and anxiety while also enhancing Hospital Consumer Assessment of Healthcare Providers and Systems survey scores, clinical outcomes, and revenue, according to this infographic published by *HFMA*. [More here.](#)
- **A-45:** When *Dana-Farber Cancer Institute* (MA) began to plan the Yawkey Center for Cancer Care, its patients and families were involved in many important decisions about design. Patients and family caregivers explain their contributions to creating a warm, healing environment for people with cancer [here.](#)

INFORMATION ON IMPACT

B Quality, safety, and value improvement

- **B-1: Asthma control improved 3-fold.** Cincinnati Children's Hospital Medical Center (OH) implemented interventions focused on standardized and evidence-based care, self-management support, care coordination and active outreach, linkage to community resources, and enhanced follow up for patients with chronically not-well-controlled asthma, which resulted in sustained improvement in asthma control in adolescent patients. The quality-improvement project included creating a Teen Asthma Advisory Board comprised of teenagers with asthma who helped to shape decisions around the use of and implementation of Web sites and documents. Overall, the initiative is credited with increasing patients with optimally well-controlled asthma from 10 percent to 30 percent. Patients and parents who were confident in their ability to manage their or their adolescent's asthma increased from 70 percent to 85 percent. Improving outcomes for underserved adolescents with asthma. Britto, M., A. Vockell, J. Munafo, P. Schoettker, J. Wimberg, R. Pruett, M. Yi, and T. Byczkowski. 2014. [Pediatrics](#).
- **B-2: Serious safety events reduced by 85%.** Vidant Health (NC) began a system-wide quality transformation in 2006 that included heightened transparency, patient-family partnerships, and leader and physician engagement. The system transformation has resulted in an 85 percent reduction in serious safety events, a 62 percent reduction in health care-associated infections, 98 percent optimal care in the Centers for Medicare & Medicaid Services/Joint Commission core measures, Hospital Consumer Assessment of Healthcare Providers and Systems performance in the top 20 percent, and more than 150 patient advisors partnering with leaders, physicians, and frontline staff. The Vidant Health quality transformation. Wynn, J., E. Draffin, A. Jones, and L. Reida. 2014. [Joint Commission Journal on Quality and Patient Safety](#).
- **B-3: Tools for limited English proficiency patients.** This paper describes two evidence-based tools for limited English proficiency patients that were found to be implementable, acceptable to audiences, and conducive to learning. One guide recommends methods to improve detecting and preventing medical errors within diverse groups of patients. The second tool, a training module, helps to improve safety through enhanced team communication and use of interpreters. Identifying and preventing medical errors in patients with limited English proficiency: Key findings and tools for the field. Wasserman, M., M. Renfrew, A. Green, L. Lopez, A. Tan-McGrory, C. Brach, and J.

Betancourt. 2014. [Journal for Healthcare Quality](#).

- **B-4: Enhanced safety through improved medicine labels.** In order to improve use of medicine labels and to leverage label design to enhance patient safety and prevent medication errors, the context in which medicines are used should be considered. Labels were improved by using standardized design, clear layouts, certain fonts, and some warning signs. Identifying facilitators and barriers for patient safety in a medicine label design system using patient simulation and interviews. Dieckmann P., M. Clemmensen, T. Sørensen, P. Kunstek, and A. Hellebek. 2014. [Journal of Patient Safety](#).
- **B-5: A coding taxonomy for patient complaints.** This literature review included 59 studies that reported 88,069 patient complaints. Patients complained most frequently about “treatment” (15.6 percent) and “communication” (13.7 percent). Subcategories were grouped into seven thematic categories, including complaints about the safety and quality of clinical care (33.7 percent of complaint issues), health care organizational management (35.1 percent), and problematic relationships between health care staff and patients (29.1 percent). Patient complaints in healthcare systems: a systematic review and coding taxonomy. Reader, T., A. Gillespie, and J. Roberts. 2014. [BMJ Quality & Safety](#).
- **B-6: Automation pares survey completion rate by half.** A cross-sectional study of 616 patients was conducted after their acute care visit to a family medicine clinic, a clinic for patients with HIV, or a clinic for patients with cerebral palsy. Patients were contacted via live telephone call and via an interactive voice response system and were asked about symptom improvement, medication problems, and interactions with the health care system. At least 96 percent of patients who received a live follow-up call completed it, compared with 48 percent of patients who interacted with the voice response system. The majority of patients had not contacted their provider or another provider regardless of their health status. Exploration of an automated approach for receiving patient feedback after outpatient acute care visits. Berner, E., M. Ray, A. Panjamapirom, R. Maisiak, J. Willig, T. English, M. Krawitz, C. Nevin, S. Houser, M. Cohen, and G. Schiff. 2014. [Journal of General Internal Medicine](#).
- **B-7: Handover-related failures decline by 25.8%.** During the 12-month study period, the authors evaluated 7,864 handovers that occurred at 23 children’s hospitals after the introduction of a structured handover tool, recording a 25.8 percent decline in handover-related failures after the quality-improvement intervention. Critical components of the handoff, such as achieving a common understanding about the patient and minimized interruptions and

distractions rose, and overall provider satisfaction rose from 55 percent to 70 percent. Decreasing handoff-related care failures in children's hospitals. Bigam, M., T. Logsdon, P. Manicone, C. Landrigan, L. Hayes, K. Randall, P. Grover, S. Collins, D. Ramirez, C. O'Guin, C. Williams, R. Warnick, and P. Sharek. 2014. [Pediatrics](#).

- **B-8: PCMH-delivered care linked to cost savings.** The authors assigned data from individual Medicare fee-for-service beneficiaries and their claims and utilization to a patient-centered medical home (PCMH) or a comparison practice, based on where they received most services from July 1, 2007 to June 30, 2008. Total Medicare payments, acute care payments, and emergency department visits dropped after PCMH recognition, with more dramatic savings for patients who were sicker. Total cost of care lower among Medicare fee-for-service beneficiaries receiving care from patient-centered medical homes. van Hasselt, M., N. McCall, V. Keyes, S. Wensky, and K. Smith. 2014. [Health Services Research](#).
- **B-9: Viewing care quality from patient's perspective.** The authors reviewed 36 studies and identified 10 quality dimensions that were perceived by patients: access, communication, discharge process, electronic medical record, pain control, patient education, physical environment, preventive services, provider knowledge and skills, and shared decision making. The researchers recommend using these dimensions in planning and evaluating health care delivery and measuring the effect of these interventions on patient outcomes. Creating a patient-centered health care delivery system: A systematic review of health care quality from the patient perspective. Mohammed, K., N. Nolan, T. Rajjo, N. Shah, L. Prokop, P. Varkey, and M. Murad. 2014. [American Journal of Medical Quality](#).
- **B-10: Activation, literacy related to blood sugar control.** The authors studied effects of functional health literacy (FHL) and patient activation on diabetes outcomes by surveying 387 patients with diabetes, hypertension, and ischemic heart disease who had received outpatient care at a regional Department of Veterans Affairs' medical center. They found that neither patient activation nor FHL was independently related to glycemic control but the two combined were significantly associated with HbA1c control. Interaction between functional health literacy, patient activation, and glycemic control. Woodard, L., C. Landrum, A. Amspoker, D. Ramsey, and A. Naik. 2014. [Patient Preference and Adherence](#).
- **B-11: Family-centered rounds improve care quality.** Family-centered rounds, which partner medical teams with patients and families in daily medical decision making, can improve care quality and patient safety, according to the author. To enhance their effectiveness,

the rounds should report on objective outcomes measures, such as improved communication, coordination, and patient satisfaction.

Family-centered rounds. Mittal, V. 2014. [Pediatric Clinics of North America](#).

- **B-12: Improving quality of ICU rounds.** When patient care rounds in the intensive care unit (ICU) are conducted by a multidisciplinary group of providers, with explicitly defined roles and a goal-oriented approach—including a best practices checklist—quality improves. Barriers to quality patient care rounds include interruptions, long rounding times, and health care provider perceptions of being undervalued by rounding physicians. A systematic review of evidence-informed practices for patient care rounds in the ICU. Lane, D., M. Ferri, J. Lemaire, K. McLaughlin, and H. Stelfox. 2013. [Critical Care Medicine](#).
- **B-13: 400,000 patients die due to medical errors.** An updated estimate of patient harms due to medical errors was developed from studies published from 2008 to 2011; the number of premature deaths associated with preventable harm to patients now is estimated at more than 400,000 per year. A new, evidence-based estimate of patient harms associated with hospital care. James, J. 2013. [Journal of Patient Safety](#).
- **B-14: Lean bedside handovers.** Lean strategies were used to develop a new process for change-of-shift bedside handoff, named “ISHAPED” (I = Introduce, S = Story, H = History, A = Assessment, P = Plan, E = Error Prevention, and D = Dialogue). Teams also worked in partnership with a Parent Advisory Council and a Patient/Family Advisory Council to design a study that explored patients’ perceptions of the handoff. Developing a patient-centered ISHAPED handoff with patient/family and parent advisory councils. Friesen, M., A. Herbst, J. Turner, K. Speroni, and J. Robinson. 2013. [Journal of Nursing Care Quality](#).
- **B-15: Improving electronic handover tools.** When handovers in patient care are not done well, valuable information may not pass from one health care provider to the next, heightening patient safety risks. Five types of socio-technical issues, including system interoperability, should be addressed to improve electronic handover tools. Socio-technical issues and challenges in implementing safe patient handovers: insights from ethnographic case studies. Balka E., M. Tolar, S. Coates, and S. Whitehouse. 2013. [International Journal of Medical Informatics](#).
- **B-16: Next steps in studying communication.** The author outlines challenges in studying how clinician-patient communication contributes to a patient’s health, such as the difficulty in teasing out direct, measurable health outcomes, and offers recommendations

for future research. The author asserts that researchers must model pathways linking clinician-patient communication to outcomes of interest. How clinician-patient communication contributes to health improvement: Modeling pathways from talk to outcome. Street, R. 2013. [Patient Education and Counseling](#).

- **B-17: Lean rounding speeds discharge, improves satisfaction.** Lean methods and scenario analyses were used to develop and implement a patient-centric standardized rounding process that improved the efficiency of rounding by reducing time spent on nonessential activities. A task that once took three attending physicians an average of 157 minutes was streamlined to require two attending physicians, who spent an average of 121 minutes. Pediatric intensive care unit patients were discharged an average of 58.05 minutes earlier, staff satisfaction rose as did customer satisfaction scores. The impact of a lean rounding process in a pediatric intensive care unit. Vats, A., K. Goin, M. Villarreal, T. Yilmaz, J. Fortenberry, and P. Keskinocak. 2012. [Critical Care Medicine](#).
- **B-18: Satisfied patients have less ED use, higher costs.** To better characterize the relationship between patient satisfaction and health care utilization, spending, and health outcomes, the authors conducted a prospective cohort study of 51,946 nationally representative adult patients and used items from the Consumer Assessment of Health Plans Survey to gauge patient satisfaction. They found the most satisfied patients had less emergency department use, more inpatient admissions, higher overall health care expenditures and spending for prescription medicines, and higher mortality. The cost of satisfaction: A national study of patient satisfaction, health care utilization, expenditures, and mortality. J. Fenton, A. Jerant, K. Bertakis, and P. Franks. 2012. [Archives of Internal Medicine](#).
- **B-19: Collaboration between departments can reduce waste.** The authors demonstrate a leadership decision-support investment model approach to address clinical, operational, and financial performance at a typical hospital. As one example, direct, collaborative relationships between hospital quality and finance departments can improve communication, which can lead to greater clarity about direct and indirect costs, reduction of waste, and harm reduction for patients. The cost of harm and savings through safety: Using simulated patients for leadership decision support. Denham, C. and F. Guilloteau. 2012. [Journal of Patient Safety](#).
- **B-20: Managing talent to create value.** The authors focused on 15 nationwide health care systems where they used semi-structured interviews to gather data from 30 executives and analyzed each organization's talent management program materials. Best practices

for health care organizations include using a multi-phased talent management system; defining, identifying, and developing high-potential leaders; and assessing outcomes. Talent management best practices: how exemplary health care organizations create value in a down economy. Groves, K. 2011. [Health Care Management Review](#).

- **B-21: The path from communication to outcomes.** The authors identify seven pathways through which clinician-patient communication can lead to better health, including increased access to care, greater patient knowledge and shared understanding, higher-quality medical decisions, and patient empowerment. They advise clinicians and patients to “maximize the therapeutic effects of communication” by focusing on communication that achieves defined outcomes, such as increasing trust, understanding, and adherence. How does communication heal? Pathways linking clinician-patient communication to health outcomes. Street Jr., R., G. Makoul, N. Arora, and R. Epstein. 2009. [Patient Education and Counseling](#).
- **B-22: Enhanced use of RNs improves quality, increases costs.** The author reports that increasing nursing hours and the proportion of nurses who are registered nurses would improve care quality and reduce deaths but would increase costs. Is what’s good for the patient good for the hospital? Aligning incentives and the business case for nursing. Needleman, J. 2008. [Policy, Politics & Nursing Practice](#).
- **B-23: Deriving meaning from partnering with patients.** The authors convened focus groups of genetics professionals, including physicians, nurses, and counselors, and asked them “What gives you meaning in patient care?” They extracted eight themes that were reflected in a questionnaire mailed to 480 clinical geneticists, genetic counselors, and genetic nurses. Some 214 providers completed the survey with women, nurses, and professionals who had been in practice longer reporting higher meaning scores. What do clinicians derive from partnering with their patients? A reliable and valid measure of “personal meaning in patient care.” Geller, G., B. Bernhardt, J. Carrese, C. Rushton, and K. Kolodner. 2008. [Patient Education and Counseling](#).
- **B-24: Patients’ roles in preventing medical errors.** Respondents were asked to assess the perceived effectiveness of 14 recommended actions for preventing medical errors. While most recommended actions were viewed as effective, respondents indicated they were unlikely to engage in many of them. Can patients be part of the solution? Views on their role in preventing medical errors. Hibbard J., E. Peters, P. Slovic, and M. Tusler. 2005. [Medical Care Research and Review](#).

- **B-25: AHRQ spends \$55 million on patient safety research.** The Agency for Healthcare Research and Quality (AHRQ) refocused its quality research mission, spending \$55 million in fiscal year 2002 on patient safety research in six domains, including health systems error reporting, analysis, and safety improvement research demonstrations; Centers of Excellence for patient safety research and practice; the effect of working conditions on quality of health care; and Partnerships for Quality: Patient Safety Research Dissemination and Education. The US Agency for Healthcare Research and Quality’s activities in patient safety research. Meyer, G., J. Battles, J. Hart, and N. Tang. 2003. [International Journal for Quality in Health Care](#).
- **B-26: Patient-centered practices enhance efficiency.** For this observational cohort study, 39 family physicians were chosen at random and 315 of their patients participated, agreeing for office visits to be audiotaped and scored for patient-centered communication. They found that patient-centered practices improved health status and enhanced care efficiency by reducing diagnostic tests and referrals. The impact of patient-centered care on outcomes. Stewart, M., J. Brown, A. Donner, I. McWhinney, J. Oates, W. Weston, and J. Jordan. 2000. [Journal of Family Practice](#).

Viewpoints

- **B-27: Banning handshakes to protect health?** Patient encounters in the health care setting commonly begin and end with a handshake. The handshake has been shown to improve the perception of the physician’s empathy and compassion, according to co-authors of this Viewpoint. While handshakes between health care practitioners and patients can comfort and calm, they also can spread disease. The authors argue that removing the handshake from the health care setting ultimately may become recognized as an important way to protect the health of patients and caregivers. Viewpoint: Banning the handshake from the health care setting. Sklansky, M., N. Nadkarni, and L. Ramirez-Avila. 2014. [JAMA](#).
- **B-28: Partnering with patients to improve safety.** The author argues that efforts to improve health care safety can succeed only with “true provider-patient partnership,” which actively involves patients and encourages health care providers to listen to them. Can you hear me now? Providers must give patients a voice in efforts to reduce medical errors. Spath, P. 2003. [Hospitals & Health Networks](#).



Learning from “real-world” examples

Enhanced care coordination for Medicaid beneficiaries in Colorado reduced readmissions and emergency department visits and resulted in \$6 million in savings. See p. 11.

AHRQ’s evidence-based guide helps hospitals, families, and patients partner to improve quality and safety. See p. 12.

INFORMATION ON IMPACT



Patient- and family-relevant measures

- **C-1: Core measures for health care progress.** With support from the Blue Shield of California Foundation, the California Healthcare Foundation, and the Robert Wood Johnson Foundation, the Institute of Medicine convened a committee to identify core measures for health and health care. The committee proposes a streamlined set of 15 standardized measures, with recommendations for their application at every level and across sectors. David Blumenthal, et al. 2015. [Vital Signs: Core Metrics for Health and Health Care Progress](#).
- **C-2: Patients help detect quality gaps.** The authors developed and validated a questionnaire to evaluate patients' experiences and outcomes in the context of a nationwide quality-improvement effort in Germany. Involving patients in detecting quality gaps in a fragmented healthcare system: development of a questionnaire for Patients' Experiences Across Health Care Sectors (PEACS). Noest, S., S. Ludt, A. Klingenberg, K. Glassen, F. Heiss, D. Ose, J. Rochon, K. Bozorgmehr, M. Wensing, and J. Szecsenyi. 2014. [International Journal for Quality in Health Care](#).
- **C-3: Informal caregivers' roles in decision making.** The researchers conducted qualitative telephone interviews with 19 informal caregivers of older individuals discharged from the hospital, which pointed to the need to discuss how frail patients with complex medical conditions and "informal" caretakers could be supported in decision-making processes to ensure the care met the patients' needs. The indispensable intermediaries: a qualitative study of informal caregivers' struggle to achieve influence at and after hospital discharge. Bragstad, L., M. Kirkevold, and C. Foss. 2014. [BMC Health Services Research](#).
- **C-4: Older patients expect high-quality care.** The researchers conducted surveys in 833 patients attending 21 hospitals and 22 general practices located in London and Essex before and after the patients' consultation in general practice and hospital outpatient departments. The patients were asked about how their actual care experience compared with the care they expected to receive. Patients older than 65 and white patients had higher overall realistic expectations of their care and greater satisfaction after the consultation, compared with younger patients and racial and ethnic minorities. The authors note that their findings contradict the stereotype of older patients being more satisfied because they arrived with lower expectations. Rather, older patients had higher expectations for their health care experience, "but they believe that they are being met." Patients' experiences of their healthcare in relation to their expectations and satisfaction: a

population survey. Bowling, A., G. Rowe, and M. McKee. 2013. [Journal of the Royal Society of Medicine](#).

- **C-5: Consumer quality index for emergency department.** Because no standardized, validated method to measure patients' experiences in accident and emergency departments existed, the author developed a consumer quality index. Data from 304 patients were analyzed and revealed that within the accident and emergency department patients cared most about trusting the competence of health care professionals, hygiene, and patients' health care expectations. The Consumer Quality index (CQ-index) in an accident and emergency department: development and first evaluation. Bos, N., L. Sturms, A. Schrijvers, and H. van Stel. 2012. [BMC Health Services Research](#).
- **C-6: A framework for measuring patient safety.** While efforts continue around the globe to make medical care safer for patients, measures that evaluate changes in patient safety are lacking. A helpful framework for measuring patient safety would illuminate the causes of harm and would facilitate design and validation of interventions, such as a safety scorecard, that reduce harm. Measurement of quality and assurance of safety in the critically ill. Pronovost, P., J. Sexton, J. Pham, C. Goeschel, B. Winters, and M. Miller. 2009. [Clinics in Chest Medicine](#).
- **C-7: Information needs rise after discharge.** Forty-four patients with planned abdominal surgery were interviewed before admission, prior to discharge, and after discharge to determine their information needs and preference for involvement. These patients identified 4.74 needs prior to admission, 5.05 needs before discharge, and 5.35 needs after discharge. A patient-centered model of care for hospital discharge. Anthony, M. and D. Hudson-Barr. 2004. [Clinical Nursing Research](#).
- **C-8: Advancing patient-centered outcome measurement.** The author explains a recent alternative for measuring health status for older patients, the item response theory, which can achieve more precise measurement through computerized adaptive testing. While computerized adaptive testing can reduce test administration time, challenges remain. Ten recommendations for advancing patient-centered outcomes measurement for older persons. McHorney, C. 2003. [Annals of Internal Medicine](#).

Learning from “real-world” examples

A National Quality Forum project will recommend how to best measure performance on person- and family-centered care. See p. 16.

INFORMATION ON IMPACT

D Patient engagement and empowerment

- **D-1: Hospital leaders key to patient/family engagement.** The American Hospital Association’s Health Research & Educational Trust reports the results of its large-scale survey on patient and family engagement in U.S. hospitals. Among the findings, 86 percent of hospitals permitted unrestricted visitor access in at least some units, 68 percent encouraged patients/families to participate in shift-change reports, and 38 percent had a patient and family advisory council. The least frequently adopted patient & family engagement activities included involving patients and family members “as either educators or content developers” when training clinical staff (7 percent), patient and family advisory councils that had met in the year prior (21 percent), and patient & family advisory councils that include patient and family members (23 percent). Herrin, J., K. Harris, K. Kenward, S. Hines, M. Joshi, and D. Frosch. 2015. [BMJ Quality & Safety](#).
- **D-2: Engaged youth judiciously use care resources.** Involving children, young people, and their parents encourages people to adopt healthier lifestyle behaviors, improves treatment, and leads to more appropriate use of health care resources. Engaging children and parents in service design and delivery. Russell, B., M. Passant, and H. Kitt. 2014. [Archives of Disease in Childhood](#).
- **D-3: Patients’ stories improve quality, safety.** The power of patient and family stories can inform processes and procedures throughout various hospital leadership meetings, and can improve the quality and safety of care. Training patients and family caregivers “how to tell stories with purpose” can bolster the strength of their narratives and contribute to quality and safety improvements. Training patient and family storytellers and patient and family faculty. Morrise, L. and K. Stevens. 2013. [The Permanente Journal](#).
- **D-4: Engaging PFACs to improve health.** Five strategies to engage patients and family members more effectively in process-improvement initiatives include recruiting patient advisory council members who will provide constructive feedback, creating a strong infrastructure for the councils, ensuring councils are continually infused with fresh viewpoints from new patient volunteers, setting clearly defined goals and implementation plans for the councils, and measuring their impact. Engaging patients to improve the healthcare experience. White, K. 2013. [Healthcare Financial Management](#).
- **D-5: Family-centered care improves discharge timing.** The authors retrospectively compared the timing of patient discharges before family-centered rounds (FCR)—multidisciplinary rounds at the patient

bedside with an emphasis on physicians partnering with patients and families—with those after FCR. Before the intervention, 40 percent of patients were discharged before 3 p.m. (n=912); after FCR, 47 percent of children were discharged prior to 3 p.m. (n=911). Time from order entry to study completion for head magnetic resonance imaging and electroencephalography was pared from 2.15 hours prior to the intervention to 1.73 hours after FCR. Family-centered rounding: Can it impact the time of discharge and time of completion of studies at an academic children's hospital? Oshimura, J., S. Downs, and M. Saysana. 2014. [Hospital Pediatrics](#).

- **D-6: Praise for patient-centered medical homes.** Ninety-four adult patients at three medical homes participated in cognitive interviews (n = 45) or structured focus groups (n = 49) providing feedback about opportunities for their involvement in shaping medical homes. Among the pluses they cited were friendly and helpful clinic staff, opportunities to improve included timely appointment scheduling and reducing clinic wait time. According to the authors, perceived gratifications far exceeded deficiencies. Obtaining the patient's voice from within three patient-centered medical homes. Kennedy, B., F. Cerise, R. Horswell, W. Griffin, K. Willis, S. Moody-Thomas, J. Besse, and P. Katzmarzyk. 2014. [Clinical and Translational Science](#).
- **D-7: Role of peer leaders in diabetes care.** The authors describe the process by which a 46-hour peer leader training program was developed that consists of three major components: Building a diabetes-related knowledge base; developing communication, facilitation, and behavior change skills; and applying skills in experiential settings. Instructional methods included group brainstorming, group sharing, role-playing, and peer leader simulations. The development of a pilot training program for peer leaders in diabetes process and content. Tang, T., M. Funnell, M. Gillard, R. Nwankwo, and M. Heisler. 2011. [The Diabetes Educator](#).
- **D-8: Patients' safety attitudes differ from safety actions.** This systematic review assessed published articles about patients' attitudes about engaging in error prevention and the effectiveness of efforts to increase patient participation. Database searches yielded 3,840 candidate articles of which 21 were included in the study. While patients endorse engaging in their safety, their actual behavior varies, the author notes. Engaging patients as vigilant partners in safety: A systematic review. Schwappach, D. 2010. [Medical Care Research and Review](#).
- **D-9: Tracking patient demand to improve urgent care.** According to the author, the traditional definition of urgent care versus routine care is at odds with how patients themselves define urgency. Trusting

patients to determine how they want to access care and using a systematic approach could track patterns of patient demand and better target care resources when they are most needed. Accessing patient-centered care using the advanced access model. Tantau, C. 2009. [The Journal of Ambulatory Care Management](#).

- **D-10: Patient-centered care for special care needs.** The authors define a system of services for children and youth with special health care needs as a family-centered network of community-based services designed to promote children's healthy development and well-being. Among the defining features of this system are coordination of child and family services, effective communication among providers and the family, and family partnership in care provision. A family-centered, community-based system of services for children and youth with special health care needs. Perrin J., D. Romm, S. Bloom, C. Homer, K. Kuhlthau, C. Cooley, P. Duncan, R. Roberts, P. Sloyer, N. Wells, and P. Newacheck. 2007. [The Archives of Pediatrics & Adolescent Medicine](#).
- **D-11: Supporting informed long-term care decisions.** Searches uncovered no eligible studies to inform the use of interventions to support the decision-making process for older people facing the possibility of entering long-term residential care. The authors note that related studies that did not meet the study design criteria (which included randomized controlled trials and quasi-randomized controlled trials/quasi-experimental trials) demonstrate substantial research interest in this topic. Interventions to support the decision-making process for older people facing the possibility of long-term residential care. Gravalin M., K. Rowell, and J. de Groot. 2007. [The Cochrane Database of Systematic Reviews](#).
- **D-12: Partnering with patients to improve outcomes.** According to the author, when clinicians treat patients as partners by including them in care planning, plan adherence and health outcomes improve. Compliance, health outcomes, and partnering in PPS: Acknowledging the patient's agenda. Huffman, M. 2005. [Home Healthcare Nurse](#).
- **D-13: Empowering patients with diabetes.** Patients with diabetes self-manage their illness, routinely making decisions that impact their health and well-being autonomously. The authors argue that effective diabetes care will require patients and health care professionals to collaborate in developing self-management plans that integrate the health care professional's clinical expertise with the patients' concerns, priorities, and resources. Patient empowerment: Reflections on the challenge of fostering the adoption of a new paradigm. Anderson R. and M. Funnell. 2005. [Patient Education and Counseling](#).
- **D-14: Effectively communicating clinical evidence.** The authors conducted a systematic review of MEDLINE from 1966 to 2003 to

identify original research regarding communication between clinicians and patients and directly addressing methods of presenting clinical evidence to patients. Researchers screened 367 abstracts and reviewed 51 full-text articles, yielding eight potentially relevant articles. They found that there is a paucity of evidence to guide how physicians can share clinical evidence most effectively with patients facing decisions; however, they describe the means to accomplish five communication tasks to frame and communicate clinical evidence. Communicating evidence for participatory decision making. Epstein R., B. Alper, and T. Quill. 2004. [JAMA](#).

- **D-15: Family-clinician relationships in the ICU.** The authors outline a research agenda to investigate the family-physician relationship in the intensive care unit (ICU) including improving health care workers' communication skills, information and communication research, promoting programs to teach communication skills to all members of the medical profession outside of the ICU, research about the tension between medical best interest and the ethics of autonomy, and enhancing public interest in advance care planning and surrogate designation. Family-physician interactions in the intensive care unit. Azoulay, E. and C. Sprung. 2004. [Critical Care Medicine](#).
- **D-16: Patient-centered advance care planning.** Patients treated in heart failure, renal dialysis, and cardiovascular surgery clinics at a Wisconsin medical center participated in a study to assess the feasibility of a patient-centered advance care planning approach to patients with chronic illnesses and their surrogates. Twenty-seven patients, paired with surrogates, participated in the treatment group, which reported greater satisfaction with the decision-making process and less decisional conflict. Patient-centered advance care planning in special patient populations: A pilot study. Briggs, L., K. Kirchhoff, B. Hammes, M. Song, and E. Colvin. 2004. [Journal of Professional Nursing](#).
- **D-17: Defining a patient-centered approach.** The authors propose three organizing principles of patient-centered access: Work at the high end of expertise; align care with need and preference; and serve when service is needed. Patient-centered access is one of the few concepts that supports all six of the Institute of Medicine's aims for the 21st century: Safety, effectiveness, patient-centeredness, timeliness, efficiency, and equitability, according to the authors. Innovations in access to care: A patient-centered approach. Berry L., K. Seiders, and S. Wilder. 2003. [Annals of Internal Medicine](#).
- **D-18: Planning patient-centered care.** This fourth article in the series describes how high-performing microsystems design and plan patient-centered care, a process that demands that the microsystem have services that meet the patients' and families' needs and "protected

time” to reflect and plan. Microsystems in health care: Part 4. Planning patient-centered care. Wasson J., M. Godfrey, E. Nelson, J. Mohr, and P. Batalden. 2003. [Joint Commission Journal on Quality and Safety](#).

- **D-19: Improving care transition for older patients.** The authors introduce a patient-centered interdisciplinary team intervention designed to improve transitions across sites where geriatric care is provided. Older patients may receive care in a number of settings. In the absence of interventions to assist older patients in making smooth care transitions, care fragmentation can result, increasing the chances of duplicated services, medication errors, and higher costs. The care transitions intervention: A patient-centered approach to ensuring effective transfers between sites of geriatric care. Parry C., E. Coleman, J. Smith, J. Frank, and A. Kramer. 2003. [Home Health Care Services Quarterly](#).
- **D-20: Fully integrating the patients’ perspective.** The authors describe how patients and families have been integrated into the care delivery model by involving them in planning, decision making, and improvement processes at all levels of the organization. Making patient-centered care come alive: Achieving full integration of the patient’s perspective. Ponte, P., G. Conlin, J. Conway, S. Grant, C. Medeiros, J. Nies, L. Shulman, P. Branowicki, and K. Conley. 2003. [The Journal of Nursing Administration](#).
- **D-21: Bridging communication gaps in the emergency department.** During the authors’ analysis of provider-patient interactions in the emergency department of an urban trauma-level hospital, they observed miscommunication about the meaning of key terms, in framing the immediate problem, and the perceived role of the emergency department. In response, they developed an operational model of communication to bridge the gap between patients and the medical profession, providing strategies to help patients explain their medical problems, and the logic behind their health care decisions. Patients as partners, patients as problem-solvers. Young, A. and L. Flower. 2002. [Health Communication](#).
- **D-22: Leveraging systems approaches to improve care.** The book documents the causes of the quality gap, identifies practices that impede quality care, and explores how systems approaches can be leveraged to implement change. The authors recommend a sweeping redesign of the American health care system and provide performance expectations, 10 new rules to guide patient-clinician relationships, an organizing framework to better align incentives with improvements in quality, and steps to promote evidence-based practice. [Crossing the quality chasm: A new health system for the 21st century](#). 2001. Washington, DC: National Academy Press.

- **D-23: Developing partnerships with patients and families.** Since 1996, patients and family members have been involved in facility design planning for various adult services at the Medical College of Georgia Hospital and Clinics, including helping to plan a freestanding community-based Center for Senior Health and planning of the redesign process for the preoperative evaluation and ambulatory surgery waiting areas. Focus groups of patients and families were convened to address the design and facility planning for the family waiting areas for the specialized care centers and the outpatient cardiology services area. Patient and family input also has been used to evaluate and change care practices in the unit and bed assignments for related kidney transplant donors and recipients. Developing partnerships among patients, families, and staff at the Medical College of Georgia Hospital and Clinics. Hobbs, S. and P. Sodomka. 2000. [*The Joint Commission Journal on Quality Improvement*](#).

Viewpoints

- **D-24: Open visitation engenders trust.** Available evidence indicates that hazards and problems regarding open visitation are “generally overstated and manageable,” according to the authors. Rather than harming patients, open visitation policies may help by providing a support system, shaping a more familiar environment, engendering trust, and creating a better working relationship between hospital staff and family members. Commentary: Restricted visiting hours in ICUs: Time to change. Berwick, D. and M. Kotagal. 2004. [*JAMA*](#).

Learning from “real-world” examples

People who lack the confidence to manage their care can incur costs up to 21 percent higher than patients who are actively engaged in care.
See p. 10.

INFORMATION ON IMPACT

E Patient portals

- **E-1: Result pending.** The research team has developed a web-based patient portal, Sugarsquare, and will provide it in addition to the usual diabetes care for pediatric patients and will evaluate efficacy using a multicenter randomized controlled trial, according to the study protocol. Parents of children younger than 13 with type 1 diabetes will be recruited from seven clinics in the Netherlands. The intervention arm will receive access to the patient portal during the 12-month study period; the control group will receive access to the portal during the last six months of the study. Data will be gathered at baseline, at six months, and at 12 months using online questionnaires. The Sugarsquare study: Protocol of a multicenter randomized controlled trial concerning a web-based patient portal for parents of a child with type 1 diabetes. Boogerd, E., C. Noordam, and C. Verhaak. 2014. [BMC Pediatrics](#).
- **E-2: 78% of clinicians used EHRs.** In 2013, 78 percent of U.S. office-based physicians used electronic health records (EHRs), a significant increase over the 18 percent who did so in 2001, according to the National Ambulatory Medical Care Survey. State-by-state basic EHR adoption ranged from a high of 83 percent in North Dakota, compared with 21 percent in New Jersey. Some 69 percent of office-based physicians already had applied or planned to apply for incentive payments aimed to increase physicians' adoption of the systems. Use and characteristics of electronic health record systems among office-based physician practices: United States, 2001–2013. Chun-Ju, H. and E. Hing. 2014. [Centers for Disease Control and Prevention](#).
- **E-3: Few clinicians use health IT for patient engagement.** Only one-quarter of physicians routinely provided their patients with the ability to view, download, or transmit health records in 2013, tasks that can become complicated when clinicians attempt to use patient portals to do so. According to the authors, patients' use of portals "has been relatively low." Meaningful Use Phase 2, however, requires adoption of computerized capabilities for patient engagement. The authors recommend that policies address barriers to broader electronic health records use to support patient engagement objectives. Despite substantial progress in EHR adoption, health information exchange and patient engagement remain low in office settings. Furukawa, M., J. King, V. Patel, C. Hsiao, J. Adler-Milstein, and A. Jha. 2014. [Health Affairs](#).
- **E-4: Lower literate patients less adept at understanding lab results.** Patients with high literacy and numeracy skills who viewed

hemoglobin A1c levels on an electronic health record portal were able to determine when the figures warranted contacting their doctor, while less numerate and less literate participants were less likely to correctly identify worrisome numbers, according to a survey. The authors asked 1,817 adults aged 40 to 70, roughly half of whom had diabetes, to complete an Internet survey. The patients were asked to imagine they had type 2 diabetes. The laboratory results they viewed included hemoglobin A1c “slightly” (7.1%) or “moderately” (8.4%) outside of the reference range. Seventy-seven percent of higher numeracy and higher literacy participants could correctly identify levels as outside of the reference range. Thirty-eight percent of lower numeracy and literacy participants could do so. Correctly interpreting reduced glucose control in the higher literacy group reduced the likelihood of calling the doctor with the 7.1% reading and increased their intention to call with the 8.4% reading. Numeracy and literacy independently predict patients’ ability to identify out-of-range test results. Zikmund-Fisher, B., N. Exe, and H. Witteman. 2014. [Journal of Medical Internet Research](#).

- **E-5: Provider encouragement impacts patient portal use.** Patients with diabetes that was better controlled and whose providers engaged in and encouraged portal use were more likely to enroll in electronic patient portals and use them, according to a review of 16 articles reporting original research using quantitative, qualitative, or mixed-methods that was published between February 1, 2005 and January 1, 2014. The study authors identified a number of barriers to patients enrolling in or using portals, including lack of capacity, desire, and/or awareness as well as a lack of provider and patient buy-in to the benefits of portals. Facilitators included recommendations from providers and family members. A systematic review of electronic portal usage among patients with diabetes. Amante, D., T. Hogan, S. Pagoto, and T. English. 2014. [Diabetes Technology & Therapeutics](#).
- **E-6: Home-bound veterans interested in portal access.** The authors identified barriers to and facilitators of using My HealtheVet, the Department of Veterans Affairs’ patient portal, by interviewing 14 home-bound veterans receiving home-based primary care, two patient surrogates, and three home-based primary care staff members. They found veterans were interested in accessing the portal, despite limited knowledge and limited computer or Internet access. Barriers to patient portal access among veterans receiving home-based primary care: a qualitative study. Mishuris, R., M. Stewart, G. Fix, T. Marcello, D. McInnes, T. Hogan, J. Boardman, and S. Simon. 2014. [Health Expectations](#).
- **E-7: Older adults need time, instruction to access portals.** The researchers explored whether 14 older adults diagnosed with chronic obstructive pulmonary disease or congestive heart failure and 19

caregivers were able to use common portal elements. Patients were interested in using a patient portal, despite requiring more time to complete tasks and asking for written instructions. Caregivers provided granular feedback on numerous problems, such as improving the color contrast and presentation of the patient's medication list. The authors found that while older adults with chronic illness were interested in using patient portals, there were multiple barriers that restricted their utility. Exploring three perspectives on feasibility of a patient portal for older adults. Barron, J., M. Bedra, J. Wood, and J. Finkelstein. 2014. [Studies in Health Technology and Informatics](#).

- **E-8: Numeracy, Internet fluency impact performance on portals.** Certain factors, such as numeracy and Internet experience, significantly impacted older adult patients' abilities to perform common tasks associated with a patient portal, according to the researchers who also found that older adults tended to overestimate their numeracy skills. The impact of numeracy ability and technology skills on older adults' performance of health management tasks using a patient portal. Taha, J., J. Sharit, and S. Czaja. 2014. [Journal of Applied Gerontology](#).
- **E-9: Texas patients find redesigned portal more usable.** This case study describes the workflow, assessment of system requirements, and design and implementation of two online portals for use by underserved patients in Texas. The redesigned portals have 548 registered clinics and averaged 355 visits per month, with average users visiting five pages per visit. In interviews, patients were asked about portal usage, usability, and desired features. Interactive web-based portals to improve patient navigation and connect patients with primary care and specialty services in underserved communities. Highfield, L., C. Ottenweller, A. Pfanz, and J. Hanks. 2014. [Perspectives in Health Information Management](#).
- **E-10: Higher educated patients more likely to use portal.** The authors sought to assess the relationship between patient activation—a combination of knowledge, self-efficacy, and engagement—and outpatient use of a patient portal through a telephone survey of 180 patients given access to a portal. Some 113 patients surveyed had used the portal; 67 did not. Researchers found no difference in patient activation among interviewees who had or had not used the portal though portal users had a higher education level, were more frequent users of the Internet, and were more likely to take two prescription medicines. Patient activation and use of an electronic patient portal. Ancker, J., S. Osorio, A. Cheriff, C. Cole, M. Silver, and R. Kaushal. 2014. [Informatics for Health & Social Care](#).

- **E-11: Patients with cancer view test results via portal.** The authors conducted a retrospective analysis of enrollment in and use of MyChart, a personal health record portal, among patients seen at a National Cancer Institute-designated cancer center. From 2007 to 2012, 6,495 patients enrolled in MyChart. During that time, the median number of log-ins was 57, and the average number of patient log-ins per year doubled. Most patients used the portal to view their test results (37 percent) and to view and respond to clinic messages (29 percent). Some 6.4 percent of patients used the portal to send requests for medical advice; 31 percent of those requests occurred outside of normal clinic hours. The heaviest portal users were patients who were younger, white, and diagnosed with an upper aerodigestive malignancy. Predictors and intensity of online access to electronic medical records among patients with cancer. Gerber, D., A. Laccetti, B. Chen, J. Yan, J. Cai, S. Gates, Y. Xie, and S. Lee. 2014. [Journal of Oncology Practice](#).
- **E-12: Scant evidence links portals to improved health.** The authors searched for hypothesis-testing or quantitative studies of patient portals tethered to a provider's electronic health record that addressed patient outcomes, satisfaction, adherence, efficiency, utilization, attitudes, and patient characteristics. Of 6,508 articles considered, they included 14 randomized, controlled trials; 21 observational, hypothesis-testing studies; 5 quantitative, descriptive studies; and 6 qualitative studies. They found insufficient evidence that patient portals improve health outcomes, cost, or utilization and write that expanding use of portals may require efforts to overcome such barriers as health literacy. Electronic patient portals: Evidence on health outcomes, satisfaction, efficiency, and attitudes: A systematic review. Goldzweig, C., G. Orshansky, N. Paige, A. Towfigh, D. Haggstrom, I. Miake-Lye, J. Beroes, and P. Shekelle. 2013. [Annals of Internal Medicine](#).
- **E-13: Patients with cancer satisfied with PHR access.** Seventeen of 22 patients in various phases of care at the BC Cancer Agency completed the study, which provided access to a secure Web-based personal health record to view their medical records and use support tools. Most patients used the personal health record to access medical records, laboratory results, and transcribed clinicians' notes. In surveys of usability, satisfaction, and concerns, 94 percent were satisfied with access to their records, 83 percent found new and useful information, 65 percent said the provider helped to answer their questions, and 29 percent reported some difficulty using the provider. Meeting the health information needs of prostate cancer patients using personal health records. Pai, H., F. Lau, J. Barnett, and S. Jones. 2013. [Current Oncology](#).
- **E-14: Provider satisfaction linked to patients' PHR use.** The authors conducted cross-sectional analysis of field data collected in the first

three months that a personal health record with secure messaging was used at the Air Force Medical Service at Elmendorf Air Force Base in Alaska. Some 283 participants completed questionnaires. Such factors as provider satisfaction, communication tactics, and the functional value of the tool were associated with patients' intent to use it. Patients who believed the tool to be empowering demonstrated higher intentions to use it. If we offer it, will they accept? Factors affecting patient use intentions of personal health records and secure messaging. Agarwal, R., C. Anderson, J. Zarate, and C. Ward. 2013. [Journal of Medical Internet Research](#).

- **E-15: Income, age factor into portal use.** The authors examined eHealth use by such factors as race, ethnicity, socioeconomic status, age, and gender, drawing data from the National Cancer Institute's 2012 Health Information National Trends Survey. They saw no evidence of a digital divide by race or ethnicity among online adults. However, patients who were lower socioeconomic status, older, and male were less likely to engage in a number of eHealth activities compared with counterparts. Predictors of eHealth usage: Insights on the digital divide from the Health Information National Trends Survey 2012. Kontos, E., K. Blake, W. Chou, and A. Prestin. [Journal of Medical Internet Research](#).
- **E-16: Insufficient evidence to link portal use to outcomes.** The authors systematically reviewed the literature to identify controlled experimental or quasi-experimental studies published from 1990 to 2011 about the impact of patient portals. Of 1,306 articles identified, they retrieved 13 for full-text analysis. They found no statistically significant changes between the intervention and control group in the two randomized controlled trials that investigated the effect of patient portals on health outcomes. While patient portals are discussed as a way to empower patients and improve quality of care, the authors concluded there was insufficient evidence to support this assumption. The impact of electronic patient portals on patient care: A systematic review of controlled trials. Ammenwerth, E., P. Schnell-Inderst, and A. Hoerbst. 2012. [Journal of Medical Internet Research](#).
- **E-17: Patients with diabetes use portals with mixed results.** The authors conducted a cross-sectional secondary data analysis to describe 29.7 percent of patients with diabetes who used the patient-provider Internet portal and found that portal use was not a significant predictor of low-density lipoprotein and total cholesterol levels. Portal use was a statistically significant predictor of glycosylated hemoglobin, however. Patient-provider internet portals—patient outcomes and use. Shaw, R. and J. Ferranti. 2011. [Computers, Informatics, Nursing](#).

- **E-18: Digital access boosts patient satisfaction.** Group Health embarked on care redesign that offered a patient Web site with access to patient-physician secure e-mail, electronic medical records, and health promotion information; advanced access to primary physicians; redesigned primary care services; direct access to physician specialists; and aligned primary physician incentives with patient satisfaction, productivity, and secure messaging with patients. Patients reported higher satisfaction with some aspects of care access, and providers reported improved quality of service provided to patients. Group Health Cooperative’s transformation toward patient-centered access. Ralston J., D. Martin, M. Anderson, P. Fishman, D. Conrad, E. Larson, and D. Grembowski. 2009. [*Medical Care Research and Review*](#).



Learning from “real-world” examples

More than 75 percent of patients who responded to a recent survey would like to use digital health services that meet their needs. See p. 11.

INFORMATION ON IMPACT

F C-suite engagement

- **F-1: Hospital leaders key to patient/family engagement.** The American Hospital Association’s Health Research & Educational Trust reports the results of its large-scale survey on patient and family engagement in U.S. hospitals. Among the findings, 86 percent of hospitals permitted unrestricted visitor access in at least some units, 68 percent encouraged patients/families to participate in shift-change reports, and 38 percent had a patient and family advisory council. The least frequently adopted patient & family engagement activities included involving patients and family members “as either educators or content developers” when training clinical staff (7 percent), patient and family advisory councils that had met in the year prior (21 percent), and patient & family advisory councils that include patient and family members (23 percent). Herrin, J., K. Harris, K. Kenward, S. Hines, M. Joshi, and D. Frosch. 2015. [BMJ Quality & Safety](#).
- **F-2: Leadership, staff views vary on safety intervention.** The authors assessed the ability to refine, implement, and demonstrate the effectiveness of Leveraging Frontline Expertise (LFLE), which was designed for use in private-sector hospitals, in an urban, East Coast-based Department of Veterans Affairs medical center. LFLE is a patient safety intervention to engage senior managers with work-systems challenges faced by frontline workers and to ensure follow-up and accountability for system change. The authors found LFLE can be implemented in the VA, can yield work-system improvements, and can increase alignment of improvement aims and actions across hierarchical levels. Participating units identified 22 improvement opportunities, 16 of which were fully or partially resolved. Senior managers had more positive attitudes toward LFLE than frontline staff. Improving patient care through leadership engagement with frontline staff: A Department of Veterans Affairs case study. 2013. Singer, S., P. Rivard, J. Hayes, P. Shokeen, D. Gaba, and A. Rosen. 2013. [Joint Commission Journal on Quality and Patient Safety](#).
- **F-3: Active boards improve process performance.** The authors updated previous research in order to explore the role and practices of governing boards in quality oversight. They merged data from The Governance Institute with data on hospital quality compiled by two federal sources that measure processes of care and mortality. The sample included 445 public and private not-for-profit hospitals. The researchers found a number of governing board practices were associated with better performance on process of care and/or risk-adjusted mortality, including requiring major new clinical programs to

meet quality-related criteria, setting quality goals at the “ideal” level, requiring the board and medical staff to be as involved as management in setting the agenda for quality discussions, and mandating that the hospital report quality and safety performance to the public. Enhancing board oversight on quality of hospital care: An agency theory perspective. Jiang, H., C. Lockee, and I. Fraser. 2012. [Health Care Management Review](#).

- **F-4: Disparate leadership, staff views on quality initiative.** The authors compared clinical frontline staff and senior managers’ perceptions about the importance of an organization-wide quality and safety collaborative, the Safer Patients Initiative, through survey responses provided by 635. Frontline staff perceived a significantly larger improvement on timeliness of care delivery, while managers perceived larger improvement on the organizational culture for safe, effective, and reliable care. The disparity of frontline clinical staff and managers’ perceptions of a quality and patient safety initiative. Parand, A., S. Burnett, J. Benn, A. Pinto, S. Iskander, and C. Vincent. 2011. [Journal of Evaluation in Clinical Practice](#).
- **F-5: Best practices for total quality management.** A systematic review of literature published between 1995 and 2009 revealed 15 peer-reviewed research papers that met the study inclusion criteria. The authors identified eight best practices that support total quality management, including commitment from top management, teamwork and participation, process management, customer focus and satisfaction, resource management, organization behavior and culture, continuous improvement, and training and education. Best practices of total quality management implementation in health care settings. Talib, F., Z. Rahman, and M. Azam. 2011. [Health Marketing Quarterly](#).
- **F-6: Physician leaders enhance safety, quality.** The authors report that physician leaders are an important factor in improving safety and quality within hospitals and bolster their argument through a case study examining the roles of four physician leaders. The leaders were established from July 2006 to April 2009 and were involved in strategic planning, identifying and leading quality and safety initiatives, physician engagement, and culture change. While the physician leads significantly contributed to implementing hospital improvement activities and were seen as influential by peers, the authors report they were challenged by ambiguous descriptions of their role and difficulty identifying effective improvement strategies. Case study of physician leaders in quality and patient safety, and the development of a physician leadership network. Hayes, C., V. Yousefi, T. Wallington, and A. Ginzburg. 2010. [Healthcare Quarterly](#).

- **F-7: Keys to successful quality improvement.** The authors report their analysis of implementation of continuous quality improvement or total quality management programs in 10 hospitals. Their two-year study was designed to identify and assess the ingredients that lead to the successful implementation of continuous quality improvement programs in acute care hospitals. Keys for successful implementation of total quality management in hospitals. Carman, J., S. Shortell, R. Foster, E. Hughes, H. Boerstler, J. O’ Brien, and E. O’Connor. 2010. [Health Care Management Review](#).
- **F-8: Leadership predicts degree of organizational learning.** The authors conducted cross-sectional surveys of hospital patient safety officers and patient care managers at 49 general acute care hospitals in Ontario, Canada, to explore organizational learning from five types of safety events: minor, moderate, major near misses, major event analysis, and major event dissemination/communication. The researchers found that formal organizational leadership for patient safety is an important predictor of learning from minor, moderate, major near-miss events, and major event dissemination, especially for hospitals with fewer than 100 beds. The relationship between organizational leadership for safety and learning from patient safety events. Ginsburg, L., Y. Chuang, W. Berta, P. Norton, P. Ng, D. Tregunno, and J. Richardson. 2010. [Health Services Research](#).
- **F-9: Six ways boards can improve quality.** The author outlines six actions that all boards should take to improve quality and reduce harm: (1) commit to measurable quality improvement within a time certain; (2) get data and hear stories to put a “human face” on harm; (3) establish and monitor system-level measures; (4) establish and maintain an environment that is respectful, fair, and just for people who suffer harm; (5) learn about how the best boards work with leadership to reduce harm; and (6) establish executive accountability for clear quality-improvement targets. Getting boards on board: Engaging governing boards in quality and safety. Conway, J. 2008. [Joint Commission Journal on Quality and Patient Safety](#).
- **F-10: Staff age, experience linked to readiness for change.** The authors conducted a Functional Organizational Readiness for Change Evaluation (FORCE) to assess the characteristics of readiness for change across two programs of 216 employees within an interprofessional rehabilitation hospital that was to be merged. Their analyses identified correlations between employees’ age, education, and experience and their readiness for change, as well as organizational characteristics, such as motivation for change, resources, organizational climate, and exposure to or use of training opportunities, that help or impede change. Evaluating organizational readiness for change: A preliminary mixed-model assessment of an

interprofessional rehabilitation hospital. Devereaux, M., A. Drynan, S. Lowry, D. MacLennan, M. Figdor, C. Fancott, and L. Sinclair. 2006. [Healthcare Quarterly](#).

Viewpoints

- **F-11: Accelerating progress in leadership training.** One factor that has slowed progress in patient safety and quality of care is the scarcity of physician-leaders who can help advance the science and practice of quality and safety, according to the authors. Even when academic medical centers have trained and skilled quality and safety leaders, the infrastructure to support their work is deficient, with poorly defined job descriptions, competing responsibilities, and limited formal roles in the medical school. The authors recommend initiatives to accelerate progress, including by investing in quality and safety science, revising quality and safety governance in academic medical centers, and integrating roles within hospitals and medical schools. Perspective: Physician leadership in quality. Pronovost, P., M. Miller, R. Wachter, and G. Meyer. 2009. [Academic Medicine](#).

Learning from “real-world” examples

Sixty-six percent of emerging leaders who took part in a leadership training program advanced to a more senior role. See pp. 10-11.

INFORMATION ON IMPACT

G Frontline staff engagement

- **G-1: Partnering with patients benefits clinicians and managers.** Health care providers and managers benefited from engaging patients in decision making, according to focus groups and individual interviews conducted with health care providers and managers from five units at three hospitals in a Canadian health care center. The research was conducted in April 2012, 18 months after “Transforming Care at the Bedside,” a program to engage patients as partners on care redesign teams, began. The perceptions of health care team members about engaging patients in care redesign. Lavoie-Tremblay, M., P. O’Connor, A. Harripaul, A. Biron, J. Ritchie, B. MacGibbon, and G. Cyr. 2014. [*The American Journal of Nursing*](#).
- **G-2: Challenges with team efficiency.** This mixed-methods study highlighted barriers to efficient team function among staff implementing patient-aligned care teams within the Department of Veterans Affairs’ patient-centered medical home model. The authors found that the role of primary care providers remained highly challenging even after the start-up phase of implementation. More skilled team members failed to delegate. And, nurse care managers reported decreased perceptions of empowerment. The empowerment paradox as a central challenge to patient centered medical home implementation in the Veteran’s Health Administration. Solimeo, S., S. Ono, M. Lampman, M. Paez, and G. Stewart. 2014. [*Journal of Interprofessional Care*](#).
- **G-3: Patient, clinician health priorities often align.** In this cross-sectional, mixed-methods study, the authors examined 192 outpatient visits with four physicians at four primary care practices. Clinicians asked the patient about the main reason for their visit and noted their understanding of the patient’s view as well as their own main concern for the patient during the visit. In 69 percent of visits, patients’ and physicians’ priorities aligned. Unaligned priorities were seen in 12 percent of visits and were linked to patients’ insurance status. How well do physician and patient visit priorities align? Tomsik, P., A. Witt, M. Raddock, P. DeGolia, J. Werner, S. Zyzanski, K. Stange, P. Lawson, M.J. Mason, S. Smith, and S. Flocke. 2014. [*The Journal of Family Practice*](#).
- **G-4: Building blocks for patient, family advisors.** Health care professionals across all disciplines and in all care environments have the opportunity to advance the practice of patient- and family-centered care, a viewpoint that considers patients and family members as valuable sources of information who can improve care quality. Building

blocks for successful patient and family advisory boards: collaboration, communication, and commitment. Taloney, L. and G. Flores. 2013. [Nursing Administration Quarterly](#).

- **G-5: Pediatricians' role in patient-centered care.** A committee of the American Academy of Pediatrics provides a definition of patient- and family-centered care in this policy statement, which also includes recommended strategies for pediatricians seeking to integrate patient- and family-centered care in hospitals, clinics, and community settings. Patient- and family-centered care and the pediatrician's role. Eichner, J., J. Betts, M. Chitkara, J. Jewell, P. Lye, L. Mirkinson, C. Brown, K. Heiss, L. Lostocco, R. Salerno, J. Percelay, S. Alexander, B. Johnson, M. Abraham, E. Ahmann, E. Crocker, N. DiVenere, G. MacKean, W. Schwab, and T. Shelton. 2012. [Pediatrics](#).
- **G-6: Insights about high-performance work practices.** The authors conducted semi-structured interviews with 67 individuals to better understand the business case for investing in high-performance work practices. Organization members interviewed did not systematically evaluate the financial return; rather, they viewed the investment as contributing to helping to meet strategic priorities and to differentiate themselves from competitors. High-performance work systems in health care, part 3: the role of the business case. Song, P., J. Robbins, A. Garman, and A. McAlearney. 2012. [Health Care Management Review](#).
- **G-7: Keys to shared decision making.** Creating incentives for health care professionals and care organizations to inform patients and incorporate patients' goals and preferences into care decisions is critical as is confirming the quality of decisions via patient surveys, according to the authors. Informing and involving patients to improve the quality of medical decisions. Fowler, F., C. Levin, and K. Sepucha. 2011. [Health Affairs](#).
- **G-8: Relationship between work practices and quality.** The authors conducted interviews with key individuals from five U.S. health care organizations seen as leaders in employing high-performance work practices (HPWPs) to determine the relationship with quality and safety. Interviewees linked HPWPs and employees' higher satisfaction/engagement and found that HPWPs improved recruitment, heightened organizational ability to address safety concerns, and trimmed staff turnover. High-performance work systems in health care management, part 2: qualitative evidence from five case studies. McAlearney, A., A. Garman, P. Song, M. McHugh, J. Robbins, and M. Harrison. 2011. [Health Care Management Review](#).
- **G-9: An evidence-based model for high-performance work.** The authors developed a conceptual model for high-performance work systems that identified practice bundles, management practices, and

factors influencing adoption and sustainability. High-performance work systems in health care management, part 1: development of an evidence-informed model. Garman, A., A. McAlearney, M. Harrison, P. Song, and M. McHugh. 2011. [Health Care Management Review](#).

- **G-10: Learning lessons from frontline staff.** The author describes “Listening into Action,” an outcome-orientated approach, that leverages ideas from frontline staff to foster more collaboration. One example: Foley catheter trays, which assemble all of the equipment necessary for an aseptic catheterization, were associated with a reduction in catheterization time. Improving staff engagement and patient care: Use of novel initiatives. Thompson, S. 2011. [British Journal of Nursing](#).
- **G-11: Impact of patient feedback on clinician performance.** Searching the literature for empirical studies of all designs, the authors identified 15 that regarded general health care clinicians who received formal feedback from patients about the physicians’ consultation skills. Only four of the seven studies that assessed change in actual performance or results found a beneficial effect, the authors report. The effect of patient feedback on physicians’ consultation skills: a systematic review. Reinders, M., B. Ryan, A. Blankenstein, H. van der Horst, M. Stewart, and H. van Marwijk. 2011. [Academic Medicine](#).
- **G-12: Nurses’ role in quality improvement.** The authors present strategies that promote active involvement of nurses in quality- and performance-improvement efforts. They argue for educating nurses about performance and quality measures, engaging nurses in identifying outcomes and collecting meaningful data, and seeking nurses’ assistance in disseminating quality reports. Engaging clinical nurses in quality and performance improvement activities. Albanese, M., D. Evans, C. Schantz, M. Bowen, M. Disbot, J. Moffa, P. Piesieski, and R. Polomano. 2010. [Nursing Administration Quarterly](#).
- **G-13: Physicians’ role in quality improvement.** The authors note that physicians are integral to quality-improvement efforts but are difficult to engage due to competing time pressures. Detroit, Memphis, Minneapolis/St. Paul, and Seattle case studies outline strategies to better align the efforts of hospitals and physicians, including hospital leadership support, physician “champions,” and communicating the importance of physicians’ contributions. Hospital strategies to engage physicians in quality improvement. Issue Brief. Liebhaber, A., D. Draper, and G. Cohen. 2009. [Center for Studying Health System Change](#).
- **G-14: Achieving integrative medicine.** This paper defines integrative medicine, which provides patient-centered care, its principles, and discusses the current state and desired future of integrative medical practice. The authors offer 10 recommendations to facilitate

systemic changes, including aligning financial incentives with health promotion and prevention, and funding outcomes research to track the effectiveness of integrative models. Integrative medicine and patient-centered care. Maizes V., D. Rakel, and C. Niemiec. 2009. [Explore \(NY\)](#).

- **G-15: Frontline staff driving improvement.** Lessons from hospitals implementing front-line staff-driven performance improvement programs, such as Transforming Care at the Bedside, illustrate how nurses, staff, and supportive hospital leadership, can improve the quality and the efficiency of hospital care. The role of nurses in improving hospital quality and efficiency: Real-world results. Needleman, J. and S. Hassmiller. 2009. [Health Affairs](#).
- **G-16: Pediatric nurses' understanding of care partnership.** The author conducted an exploratory study with 10 experienced pediatric nurses to determine what they understood by the term "partnership in care." Important qualities of enhanced partnership in care include attitudes, respect for family, communication, and parental understanding. What does partnership in care mean for children's nurses? Lee, P. 2007. [Journal of Clinical Nursing](#).
- **G-17: AAP: Core principles of family-centered care.** The American Academy of Pediatrics (AAP) provides a definition of family-centered care based on the understanding that the family is the child's primary source of strength and support. The AAP policy statement outlines core principles of family-centered care and summarizes recent literature linking family-centered care to improved health outcomes. Family-centered care and the pediatrician's role. Committee on Hospital Care. American Academy of Pediatrics. 2003. [Pediatrics](#).
- **G-18: Physicians' views of surrogate decision making.** A survey of neonatologists, pediatric intensivists, and medical intensivists affiliated with American medical schools was conducted to determine how physicians view the role of family interests in surrogate medical decision making. Some 327 of 596 surveys were returned; 39 percent of respondents were neonatologists; 35 percent were pediatric intensivists; and 26 percent were medical intensivists. The majority of respondents believed that family interests should be considered in decisions for incompetent patients. Physicians who treat children, especially neonatologists, were more open to family-centered surrogate decision making. Fewer than 10 percent of respondents preferred the traditional model in which the physician-patient relationship is exclusive. Attitudes and preferences of intensivists regarding the role of family interests in medical decision making for incompetent patients. Hardart, G. and R. Truog. 2003. [Critical Care Medicine](#).



Learning from “real-world” examples

Effective health care leaders involve and support clinicians and staff in patient engagement. See p. 13.

INFORMATION ON IMPACT

Building design

- **H-1: Ventilated air flow drives microbial biodiversity.** The authors sequenced the bacterial 16S gene from dust samples, a process that uncovered diverse indoor bacterial communities that were dominated by Proteobacteria, Firmicutes, and Deinococci. Not all bacterial communities were alike, however. Humans played direct and indirect roles on microbial biodiversity. Restroom bacterial communities differed from such communities in other locations. Rooms crowded with people or connected by people's movement housed different bacterial communities compared with rooms with fewer people or less traffic. The authors found that the source of ventilated air in offices had the greatest effect on the structure of the bacterial community. Architectural design drives the biogeography of indoor bacterial communities. Kembel, S., J. Meadow, T. O'Connor, G. Mhuireach, D. Northcutt, J. Kline, M. Moriyama, G. Brown, B. Bohannan, and J. Green. 2014. [PLoS One](#).
- **H-2: Assessing facility design post-occupancy.** Hospitals, once designed by a small number of leaders with architects, now are designed by multiple players. The authors conducted a qualitative cross-case study to help understand how clinicians could make more meaningful contributions to facility design. They held focus groups with health care teams that had occupied their new facility between six months to two years. Lessons learned: Clinicians' post-occupancy perspective of facility design involvement. Reno, K., K. Okland, N. Finis, G. LaMantia, R. Call, K. Cardon, D. Gerber, and J. Zeigler. 2014. [Health Environments Research & Design](#).
- **H-3: Decentralizing nurse stations improves patient satisfaction.** Nursing stations have been decentralized, a design change intended to increase patient safety, reduce nurse fatigue, and control noise and crowding. The authors describe the relationship between the clinical spatial environment and communication, satisfaction among nurses and patients, distances walked, and patient safety. While patient satisfaction rose with decentralization, the researchers found little change in communication patterns, nurses' satisfaction, patient falls, or pressure ulcers. Effects of nursing unit spatial layout on nursing team communication patterns, quality of care, and patient safety. Hua, Y., F. Becker, T. Wurmser, J. Bliss-Holtz, and C. Hedges. 2012. [Health Environments Research & Design](#).
- **H-4: Overheard personal details erode perception of privacy.** The authors assessed patients' perceptions of privacy and satisfaction at one urban, university-based hospital emergency department through

structured questionnaires completed by 313 patients. The majority, 75 percent, either agreed or agreed strongly that privacy was very important. Situations that eroded their perception of privacy included their personal information being overheard, overhearing others' personal information, and hearing "inappropriate conversations" among health care providers. Older patients, patients who were treated in hallways, and people who had longer stays recorded lower ratings of perceived privacy. Factors predicting patients' perception of privacy and satisfaction for emergency care. Lin, Y. and C. Lin. 2011. [Emergency Medicine Journal](#).

- **H-5: Effect of lighting levels on outcomes.** The authors argue that hospital improvement efforts have paid too little attention to the environment in which health care is provided, "which remains impersonal, noisy, and over illuminated." Their paper describes available evidence about the association between lighting in the intensive care unit and critically ill patients' outcomes. The effect of light on critical illness. Castro, R., D. Angus, and M. Rosengart. 2011. [Critical Care](#).
- **H-6: Well-designed spaces help with safety.** The researchers searched for empirical studies linking hospitals' physical design with patients' health outcomes. They found that well-designed physical spaces helped to make hospitals safer and underscore the importance of certain designs, such as rooms with one bed rather than many, effective ventilation, natural light, improved floor layouts, and work settings. A review of the research literature on evidence-based healthcare design. Ulrich, R., C. Zimring, X. Zhu, J. DuBose, H. Seo, Y. Choi, X. Quan, and A. Joseph. 2008. [Health Environments Research & Design](#).
- **H-7: Ten steps toward a cost-effective environment.** The authors challenge health care leaders planning new hospital construction or renovation to consider whether their proposal incorporates "relevant and proven evidence-based design innovations" to optimize patient safety, quality, and satisfaction. They recommend 10 steps to ensure an optimal, cost-effective hospital environment and present a return-on-investment framework. The business case for building better hospitals through evidence-based design. Sadler, B., J. DuBose, and C. Zimring. 2008. [Health Environments Research & Design](#).
- **H-8: Effect of noise levels on outcomes.** The authors studied 94 patients who had been admitted to the intensive coronary heart unit at a university-based hospital for evaluation of chest pain. During the study period, the researchers improved or degraded acoustics by changing ceiling tiles to reflect or absorb sound and monitored patients' blood pressure, heart rate, and variability in their heart rate.

The researchers found “significant differences” in pulse amplitude among patients with acute myocardial infarction and unstable angina pectoris, with lower values when sound levels were muffled and at night. Patients exposed to “bad” acoustics had a higher incidence of readmission. Influence of intensive coronary care acoustics on the quality of care and physiological state of patients. Hagerman, I., G. Rasmanis, V. Blomkvist, R. Ulrich, C. Eriksen, and T. Theorell. 2005. [*International Journal of Cardiology*](#).

- **H-9: The business case for better buildings.** A research collaborative of progressive health care organizations, together with The Center for Health Design, evaluated the impact of new buildings on health outcomes using comparative research instruments and outcome measures. The authors present a composite 300-bed hospital to illustrate evidence that supports the business case for better buildings “as a key component of better, safer, and less wasteful health care.” The business case for better buildings. Berry, L., D. Parker, R. Coile Jr., D. Hamilton, D. O’Neill, and B. Sadler. 2004. [*Healthcare Financial Management*](#).

Learning from “real-world” examples

Dana-Farber Cancer Institute involved patients and families in key design decisions when it built a center for cancer care. See p. 17.

VIDEO TESTIMONIALS: THE BENEFITS OF ENGAGEMENT

[David Andrews](#), a patient & family advisory council leader at Georgia Regents Medical Center, explains how redesigned hospital bills improve patients' understanding.

[Shari Berman](#), former co-chair of the Dana-Farber Cancer Institute's patient & family advisory council and two-time cancer survivor, explains how PFAC members' feedback was reflected in the design of a new building.

[Chrissie N. Blackburn](#), former president of the Rainbow Babies and Children's Hospital family advisory council, explains how training parents how to tell their stories adds value.

[Kim S. Blanton](#), a volunteer patient advisor at Vidant Medical Center, explains how patients contributed to lowered readmissions.

[Jim Burrows](#), a member of the family advisory council at Nemours, explains how advisors there meet virtually.

[Dominick L. Frosch](#), who oversaw the Gordon and Betty Moore Foundation's activities related to patient and family engagement, explains what it means for patients to be partners in their care.

[Ashley Lane](#), an empowered patient, discusses how she consulted with a "virtual network" of patients online to find more cost-effective care.

[Angela Miney](#), a family partner in the pediatric pulmonary division at the University of Florida, explains the value of patient engagement.

[Janet Wimberg](#), Parent Coordinator at Cincinnati Children's Hospital Medical Center, explains how being a parent helps her connect parents and teenaged patients with the Center's teen health center.

VIDEO TESTIMONIALS: THE BENEFITS OF NETWORKING PFACS

[David Andrews](#) explains how a virtual national network would help people who cannot attend patient & family advisory council meetings to participate in improving care.

[Shari Berman](#) explains that a virtual network provides a great opportunity for patient advisors to share their knowledge and experience and to brainstorm new ideas.

[Chrissie N. Blackburn](#) explains how a virtual national network would help to improve health care safety and quality nationwide, would reach vulnerable populations, and would provide insight to clinicians.

[Kim S. Blanton](#) explains how a virtual national network would be a “win-win” for patient advisors who contend with chronic illness by providing access to PFAC expertise 24 hours a day, seven days a week.

[Jim Burrows](#) explains how a virtual national network would permit hospitals across the nation to share best practices, benefiting the patients they serve.

[Angela Miney](#) explains how a national virtual network could be beneficial for patients seeking to share knowledge and for encouraging patients to be more engaged in their own care.

[Sue Sheridan](#), director of patient engagement at Patient-Centered Outcomes Research Institute, explains what a national, virtual Patient & Family Council Leadership Network means to her professionally and as a parent.

RESOURCE ORGANIZATIONS

PATIENT & FAMILY FOCUSED

- **The Agency for Healthcare Research and Quality (AHRQ)** created the [Health Care Innovations Exchange](#) to speed implementation of new and better ways to deliver health care.
“[Patient and Family Advisory Councils](#)”
- **AHRQ Patient Safety Network** features [links](#) to the latest tools, literature, and news in patient safety, as well as an annotated collection of patient safety resources.
- **American Hospital Association** represents nearly 5,000 hospitals, health care systems, networks, other providers of care, and 43,000 individual members.
“[Building Partnerships with Patients and Families Through PFACs](#)”
“[Strategies for Leadership](#)”
“[Engaging Health Care Users: A Framework for Healthy Individuals and Communities](#)”
- **Beryl Institute** is a global community of practice and premier thought leaders on [improving the patient experience](#) in health care.
Beryl Institute “[Patient Experience](#)” blog
“[Guiding Principles for Patient Experience Excellence](#)”
- **BJC HealthCare**, a nonprofit health care organization that serves residents in the greater St. Louis, southern Illinois, and mid-Missouri regions.
“[Patient and Family Advisory Council Getting Started Tool Kit](#)”
- **Blue Shield of California Foundation** is one of California’s largest and most trusted [grantmaking organizations](#) and focuses its support in two program areas: health care and coverage and Blue Shield Against Violence.
- **Centers for Disease Control and Prevention** protect America from health, safety, and security threats, both foreign and in the United States.
“[Patient Safety: What You Can Do to Be a Safe Patient](#)”
- **Colorado Hospital Association’s** “[Peaking Patient Engagement Network](#)” helps hospitals improve the quality of hospital-based care by utilizing patient and family advisory councils.
“[Patient and Family Advisory Council Toolkit](#)”
“[Peaking Patient Engagement](#)”
- **Commonwealth Fund** is a private foundation that aims to promote a high performing health care system that achieves better access, improved quality, and greater efficiency, particularly for society’s most vulnerable, including low-income people, the uninsured, minority Americans, young children, and elderly adults.
“[Patient-centered Care: What Does It Take?](#)”
- **Consumer Reports**, the largest, most trusted independent product testing organization in the world, accepts no advertising and pays for the products it tests.

[“Better Health Care: Changes to Learn About Now”](#)

[“Your Medical Data: What You Need to Know Now”](#)

- **Consumers Advancing Patient Safety** is a [consumer-led nonprofit](#) organization formed to be a collective voice for individuals, families, and healers who wish to prevent harm in health care encounters through partnership and collaboration.
- **Family-Centered Care: Putting It into Action: [The SPN/ANA Guide to Family-Centered Care](#)**. The American Nurses Association. 2003.
- **Gordon and Betty Moore Foundation** aims to partner with other organizations to pave the way for the broad adoption of [meaningful patient and family engagement](#) and, working together, demonstrate its value, remove barriers, and encourage the adoption of engagement strategies that work. Working with American Institutes for Research, the Moore Foundation created the [“Roadmap for Patient and Family Engagement in Healthcare Practice and Research.”](#)
- **Health Care For All** seeks to create a care system that provides comprehensive, affordable, accessible, and culturally competent care for everyone, especially the most vulnerable.
[“Massachusetts Hospitals’ PFAC Annual Reports—2014”](#)
- **Health Research & Educational Trust**, not-for-profit research and education affiliate of the American Hospital Association.
[“A Leadership Resource for Patient and Family Engagement Strategies.”](#)
- **Hospitals in Pursuit of Excellence** is the American Hospital Association’s [strategic platform](#) to accelerate performance improvement and support delivery system transformation in the nation’s hospitals and health systems.
- **Institute for Healthcare Improvement** is an independent not-for-profit organization that innovates, convenes, partners, and drives results in health and [health care improvement](#) worldwide and believes that everyone should get the best care and health possible.
[“Developing and Sustaining a Patient and Family Advisory Council”](#)
[“Patient Safety Leadership WalkRounds™”](#)
[“Safety Briefings tool”](#)
[“Science of Improvement: Establishing Measures”](#)
- **Institute for Patient- and Family-Centered Care** promotes collaborative, [empowering relationships](#) among patients, families, and health care professionals and facilitates patient- and family-centered change in all settings where individuals and families receive care and support.
[“Advancing the Practice of Patient- and Family-Centered Care in Hospitals: How to Get Started...”](#)
[“Creating Patient and Family Advisory Councils”](#)
[“Essential Allies: Patient, Resident, and Family Advisors: A Guide for Staff Liaisons”](#)

[“Partnering with Patients and Families to Enhance Safety and Quality: A Mini Toolkit”](#)

- **Joint Commission** is a not-for-profit organization that accredits and certifies more than 20,500 health care organizations and programs in the United States, designations that are recognized nationwide as a symbol of quality that reflects an organization’s commitment to meeting certain [performance standards](#).
[“Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care: A roadmap for hospitals”](#)
[“Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care: LGBT field guide”](#)
[Free Monographs and Papers](#)
[Links to Other Health Care Websites](#)
[Speak Up Initiatives](#)
[“The Essential Guide for Patient Safety Officers,”](#) Second Edition
- **Journal of Patient Experience**, a peer-reviewed [journal](#) affiliated with the Association for Patient Experience.
- **National Initiative for Children’s Healthcare Quality** is an independent, nonprofit organization working for more than a decade to improve [children’s health](#).
[“Powerful Partnerships: A Handbook for Families and Providers Working Together to Improve Care”](#)
- **National Partnership for Women** helps [women and families](#) by promoting fairness in the workplace; reproductive health and rights; access to quality, affordable health care; and policies that help women and men meet the dual demands of work and family.
- **National Patient Safety Foundation’s** vision is to create a world where patients and those who care for them are [free from harm](#).
[“Patient Safety Curriculum”](#)
- **NPSF Lucian Leape Institute**, composed of national thought leaders with a common interest in patient safety, functions as a think tank to identify new approaches to improving patient safety; call for the innovation necessary to expedite the work; create significant, sustainable improvements in culture, process, and outcomes; and encourage key stakeholders to assume significant roles in [advancing patient safety](#).
- **Partnership for Patients** is a [public-private partnership](#) working to improve the quality, safety, and affordability of health care for all Americans.
- **Patient Empowerment Network** is a network of people, foundations, organizations, and medical institutions dedicated to empowering patients worldwide.
[“Patient Family Advisory Councils: What they are, how they help”](#)
- **Patient Voice Institute** is a training, matchmaking, and [advocacy organization](#)

created and driven by patients to achieve more patient-centered health care.

- **PFANetwork** aims to create a community to [share resources](#), best practices, and opportunities to bring the voice of patient advisors to the table in health care improvement.
- **Planetree** has a nearly 40-year history of partnering with providers across the continuum of care to [transform organizational cultures](#) and delivering health care that puts the needs of individuals first.
 - “[Partnering with Families](#)”
 - “[Partnership Self-Assessment](#)”
 - “[Patient-Centered Care Improvement Guide](#)”
 - “[Time to Embrace a New Patient-Centered Care Rallying Cry: ‘Why Not?’](#)”
- **Robert Wood Johnson Foundation**, as the [nation’s largest philanthropy](#) devoted solely to the public’s health, has worked for more than 40 years to improve the health and health care for all Americans.
 - “[Aligning Forces for Quality](#)”
 - “[Hospital-based Strategies for Creating a Culture of Health](#)”

RESOURCE ORGANIZATIONS

RELATED TOPICS

AIDS United engages in strategic grant-making, capacity building, policy and advocacy, technical assistance, and formative research to end the AIDS epidemic in the United States.

aidsunited.org

Alzheimer’s Association works on a global, national, and local level to enhance care and support for people affected by Alzheimer’s and other dementias.

alz.org

American Cancer Society is a nationwide, community-based voluntary health organization dedicated to eliminating cancer as a major health problem.

cancer.org

American Diabetes Association funds research to prevent, cure, and manage diabetes by delivering services to hundreds of communities, providing objective and credible information, and giving voice to those denied their rights because of diabetes.

diabetes.org

American Heart Association strives to build healthier lives, free of cardiovascular diseases and stroke by providing public health education in a variety of ways.

heart.org/HEARTORG

American Liver Foundation facilitates, advocates, and promotes education, support, and research for the prevention, treatment, and cure of liver disease.

liverfoundation.org

American Lung Association works to save lives by improving lung health and preventing lung disease through education, advocacy and research.

lung.org

Asthma and Allergy Foundation of America is the leading patient organization for people with asthma and allergies. The Kids With Food Allergies Foundation division provides patient education, webinars, an allergy buyers’ guide, and a database of allergen-free recipes to help keep children safe and healthy.

www.aafa.org

www.kidswithfoodallergies.org

Epilepsy Foundation is a community-based, family-led organization dedicated to improving the lives of all people impacted by seizures.

epilepsy.com/dare-defy-seizures/epilepsy-foundation-your-unwavering-ally

Lupus Foundation of America advances the science and medicine of lupus to find a cure and improve the quality of life for all people affected by lupus.

lupus.org

Muscular Dystrophy Association is dedicated to finding treatments and cures for muscular dystrophy, amyotrophic lateral sclerosis, and other neuromuscular diseases.

mda.org

National Kidney Foundation, Inc. works to prevent kidney and urinary tract diseases, improve the health and well-being of individuals and families affected by these diseases, and increase the availability of all organs for transplantation.

kidney.org

E-COMMUNICATION CHANNELS AND FORUMS

AHRQ Health Care Innovations Exchange (an e-mail based newsletter, LinkedIn group, and web site that aim to speed implementation of new and better ways of delivering health care).

innovations.ahrq.gov

Beryl Institute offers two [patient experience list servs](#), “Patient Experience Leaders” and “Patient Advocacy,” to discuss issues related to the patient experience, service excellence, patient and family engagement, and patient advocacy.

<https://theberylinstitute.site-ym.com/?page=PXListservs>

Healthcarecommunities.org’s Partnership for Patients (PfP) list serv, an e-mail based discussion forum that supports the 1,647 PfP Community of Practice members who are hospital engagement network staff, participating hospital staff, federal partners, and support contractors working with 3,732 hospitals participating in the PfP campaign. (The PfP list serv status after December 8, 2014 is uncertain.)

listserv.healthcarecommunities.org/scripts/wa.exe?A0=PFPP_GENERAL

PFAC Google Group, a communications vehicle for Massachusetts-based PFACs maintained by Health Care for All.

<https://groups.google.com/forum/?fromgroups#!forum/massachusetts-pfac>

PFAC Network (a Groupsite maintained by the Institute for Patient- and Family-Centered Care).

pfacnetwork.ipfcc.org/main/summary

The National Academy of Medicine Leadership Consortium for Value & Science-Driven Health Care Patient & Family Council Leadership Network list serv.

PFCLN: INSTITUTIONS IDENTIFIED

- A** Banner Desert Medical Center (AZ)
Chandler Regional Medical Center (AZ)
University of Alabama at Birmingham Health System (AL)
University of Arkansas for Medical Sciences (AR)
- C** Bridgeport Hospital (CT)
Charlotte Hungerford Hospital (CT)
City of Hope (CA)
Connecticut Children's Medical Center (CT)
Contra Costa Regional Medical Center (CA)
Cynosure Health (CA)
Danbury Hospital (CT)
Department of Veterans Affairs Palo Alto Health Care System (CA)
Griffin Hospital (CT)
Kaiser Permanente (CA)
Lawrence & Memorial Hospital (CT)
Littleton Adventist Hospital (CO)
Long Beach Memorial Medical Center (CA)
Longmont United Hospital (CO)
Lucile Packard Children's Hospital at Stanford (CA)
Masonic Home and Hospital (CT)
Mattel Children's Hospital UCLA (CA)
MemorialCare (CA)
Mercy Regional Medical Center (CO)
Platte Valley Medical Center (CO)
Pomona Valley Hospital Medical (CA)
Sharp Mary Birch Hospital for Women and Newborns (CA)
Smilow Cancer Hospital at Yale-New Haven's (CT)
- St. Francis Medical Center (CA)
St. Mary's Hospital and Medical Center (CO)
St. Vincent's Medical Center (CT)
Stanford Healthcare (CA)
Torrance Memorial Medical Center (CA)
University of California San Diego (CA)
University of Colorado Hospital (CO)
VA Palo Alto Health Care System (CA)
Valley View Hospital (CO)
Yale-New Haven Hospital (CT)
- D** Bayhealth Medical Center (DE)
GW Cancer Institute (DC)
Nemours (DE)
Sibley Memorial Hospital (DC)
- F** Baptist Health South Florida (FL)
Brandon Regional Hospital (FL)
Calhoun Liberty Hospital (FL)
Florida Hospital for Children (FL)
H. Lee Moffitt Cancer Center & Research Institute (FL)
Health Central Hospital (FL)
Homestead Hospital (FL)
Joe DiMaggio Children's Hospital (FL)
Jupiter Medical Center (FL)
Miami Children's Hospital (FL)
Moffitt Cancer Center (FL)
Nemours Children's Hospital (FL)
North Shore Medical Center (FL)
Putnam Community Medical Center (FL)
Tampa General Hospital (FL)
University of Florida Health Shands Children's Hospital (FL)
West Boca Medical Center (FL)
- G** Eastside Medical Center (GA)

- G Emory Healthcare (GA)
 - Georgia Regents Medical Center (GA)
 - North Fulton Hospital (GA)
 - Phoebe Sumter Medical Center (GA)
- I Advocate Christ (IL)
 - Alegent Creighton Mercy Hospital (IA)
 - Delnor Hospital (IL)
 - Eastern Idaho Regional Medical Center (ID)
 - Elmhurst Memorial Healthcare (IL)
 - Indiana Regional Medical Center (IN)
 - Mary Greeley Medical Center (IA)
 - Mercy Medical Centers (IA)
 - Riley Hospital for Children at Indiana University Health (IN)
 - Schneck Medical Center (IN)
 - St. Luke's Magic Valley RMC (ID)
 - University of Iowa Children's Hospital (IA)
- K Children's Mercy Hospitals and Clinics (KS)
- L Ochsner Medical Center-Kenner (LA)
- M Adcare Hospital of Worcester (MA)
 - Anna Jaques Hospital (MA)
 - Anne Arundel Medical Center (MD)
 - Athol Memorial Hospital (MA)
 - Barnes-Jewish St. Peters Hospital (MO)
 - Barrett Hospital & Healthcare (MT)
 - Baystate Children's Hospital (MA)
 - Baystate Franklin Medical Center (MA)
 - Baystate Medical Center (MA)
 - Berkshire Medical Center (MA)
- Beth Israel Deaconess Medical Center (MA)
- Beth Israel Deaconess Hospital-Milton (MA)
- Beverly Hospital Corporation (MA)
- Borgess Health (MI)
- Boston Children's Hospital (MA)
- Boston Medical Center Corporation (MA)
- Braintree & New England Rehabilitation Hospitals (MA)
- Brigham and Women's Hospital (MA)
- Bronson Healthcare Group (MI)
- Cape Cod Hospital (MA)
- Carney Hospital (MA)
- Children's Mercy Hospitals & Clinics (MO)
- Cooley Dickinson VNA & Hospice (MA)
- C.S. Mott Children's Hospital (MI)
- Dana-Farber Cancer Institute (MA)
- Essentia Health (MN)
- Glencoe Regional Health Services (MN)
- Glendive Medical Center (MT)
- Hallmark Health (MA)
- Health Alliance Hospital (MA)
- Helen DeVos Children's Hospital (MI)
- Hennepin County Medical Center (MN)
- Henry Ford Health System (MI)
- Heywood Hospital (MA)
- Johns Hopkins Hospital (MD)
- Lahey Hospital & Medical Center (MA)
- Lawrence General Hospital (MA)
- Lowell General Hospital (MA)
- Marlborough Hospital (MA)
- Massachusetts Eye and Ear Infirmary (MA)

- M Massachusetts General Hospital (MA)
- MassGeneral Hospital for Children (MA)
- Mayo Clinic (MN)
- McLean Hospital (MA)
- MedStar Health (MD)
- Milford Regional Medical Center (MA)
- Nantucket Cottage Hospital (MA)
- Nashoba Valley Medical Center (MA)
- New England Baptist Hospital (MA)
- Newton-Wellesley Hospital (MA)
- Norwood Hospital (MA)
- Perham Health (MN)
- Saint Anne's Hospital (MA)
- Saint Luke's Hospital of Kansas City (MO)
- Shriners Hospital for Children Boston (MA)
- Siteman Cancer Center at Barnes-Jewish St. Peters Hospital (MO)
- South Shore Hospital (MA)
- Southcoast Hospitals Group (MA)
- Southern Maine Health Care (ME)
- Spaulding Rehabilitation Hospital Cape Cod (MA)
- Spectrum Health (MI)
- St. Joseph Medical Center (MO)
- St. Joseph Mercy Hospital (MI)
- St. Louis Children's Hospital (MO)
- Steward St. Elizabeth's Medical Center of Boston (MA)
- Sturdy Memorial Hospital (MA)
- Suburban Hospital (MD)
- Tufts Medical Center (MA)
- UMass Memorial Medical Center (MA)
- UMassMemorial Barre Family Health Center (MA)
- University of Michigan Health Systems (MI)
- Whittier Rehabilitation Hospital (MA)
- Wing Memorial Hospital and Medical Center (MA)
- Winthrop Family Medicine (ME)
- N Alegent Creighton Health Creighton University Medical Center (NE)
- Avera Creighton Hospital (NE)
- Alegent Creighton Health Lakeside Hospital (NE)
- Bergan Mercy Medical Center (NE)
- Carolinas HealthCare System (NC)
- Catholic Medical Center (NH)
- CHI Health Good Samaritan (NE)
- Children's Hospital at Dartmouth-Hitchcock (NH)
- Dartmouth-Hitchcock Medical Center (NH)
- Department of Veterans Affairs New Jersey Health Care System (NJ)
- Duke Children's Hospital & Health Center (NC)
- Duke University (NC)
- Elliot Health System (NH)
- Goryeb Children's Hospital (NJ)
- Guadalupe County Hospital (NM)
- Hassenfeld Children's Hospital (NY)
- Jefferson Community Health Center (NE)
- JFK Medical Center (NJ)
- Levine Children's Hospital (NC)
- Lexington Regional Health Center (NE)
- Littleton Regional Healthcare (NH)
- Mercy Hospital of Devils Lake (ND)
- Morgan Stanley Children's Hospital (NY)
- Morristown Medical Center (NJ)
- Nebraska Medicine (NE)
- Nebraska Methodist Hospital (NE)
- NewYork-Presbyterian Hospital (NY)
- Novant Health System (NC)
- NYU Langone's Center for Child and Family Experience (NY)

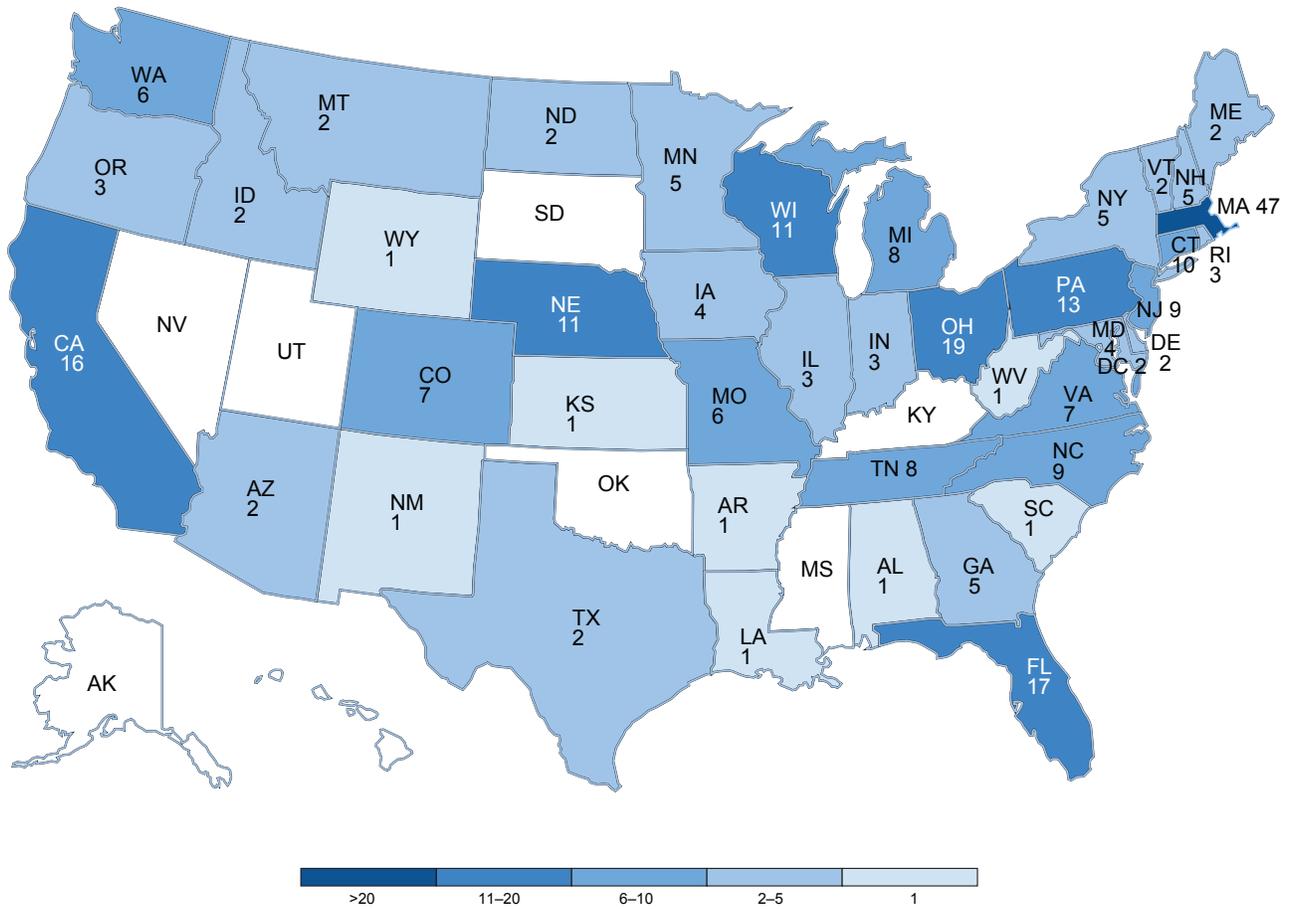
- N Omaha VA Medical Center (NE)
- Onslow Memorial Hospital (NC)
- Rochester General Hospital (NY)
- Saint Elizabeth Regional Medical Center (NE)
- Sanford Medical Center Mayville (ND)
- Sanger Heart & Vascular Institute (NC)
- Shore Medical Center (NJ)
- UNC Healthcare (NC)
- University of Medicine and Dentistry of New Jersey (NJ)
- VA New Jersey Health Care System (NJ)
- Valley Hospital (NJ)
- Vidant Health (NC)
- Virtua West Jersey Health System (NJ)
- O Akron Children's Hospital (OH)
- Akron General Medical Center (OH)
- Christ Hospital (OH)
- Cincinnati Children's Hospital Medical Center (OH)
- Cleveland Clinic Health System (OH)
- Columbia Memorial Hospital (OR)
- Fostoria Community Hospital (OH)
- Mercy Health System (OH)
- MetroHealth Medical Center (OH)
- Ohio State University Wexner Medical Center (OH)
- Providence Medical Group (OR)
- Rainbow Babies and Children's Hospital (OH)
- Samaritan Regional Health System (OH)
- Seidman Cancer Center (OH)
- St. Charles Health System (OR)
- Summa Health Systems Hospitals (OH)
- Sycamore Medical Center (OH)
- The Jewish Hospital - Mercy Health (OH)
- Toledo Hospital (OH)
- University Hospitals Case Medical Center (OH)
- University Hospitals of Cleveland (OH)
- University of Toledo Medical Center (OH)
- P Children's Hospital of Philadelphia (PA)
- Conemaugh Valley Memorial Hospital (PA)
- Excelsa Health (PA)
- Geisinger's Janet Weis Children's Hospital (PA)
- Geisinger Medical Center (PA)
- Geisinger Wyoming Valley Medical Center (PA)
- Hospital of the Fox Chase Cancer Center (PA)
- Hospital of the University of Pennsylvania (PA)
- Indiana Regional Medical Center (PA)
- Main Line Hospital Bryn Mawr Campus (PA)
- Susquehanna Health (PA)
- Washington Health System (PA)
- Williamsport Regional Medical Center (PA)
- R Hasbro Children's Hospital (RI)
- Kent County Memorial Hospital (RI)
- Women & Infants Hospital of Rhode Island (RI)
- S Medical University of South Carolina (SC)
- T Baptist Memorial Hospital-Memphis (TN)
- Children's Cancer Hospital/ MD Anderson Cancer Center (TX)
- Dell Children's Medical Center of Central Texas (TX)
- East Tennessee Children's Hospital (TN)
- Le Bonheur Children's Hospital (TN)
- LifePoint Hospitals (TN)
- Methodist Le Bonheur Healthcare (TN)

- T Methodist University Hospital (TN)
- St. Jude Children's Research Hospital (TN)
- Vanderbilt Hospital and Clinics (TN)
- V Bon Secours Richmond Health System (VA)
- Fauquier Health (VA)
- Fort Belvoir Community Hospital (VA)
- Martha Jefferson Hospital (VA)
- Sentara (VA)
- University of Vermont Medical Center (VT)
- VCU Medical Center (VA)
- Vermont Children's Hospital (VT)
- Warren Memorial Hospital (VA)
- W Aurora St. Luke's Medical Center (WI)
- Children's Hospital of Wisconsin (WI)
- Crook County Medical Services District (WY)
- Essentia Health (WI)
- Froedtert Memorial Lutheran Hospital (WI)
- Gundersen Health System (WI)
- Gundersen St. Joseph's Hospital and Clinics (WI)
- Holy Family Memorial (WI)
- Hudson Hospital & Clinic (WI)
- PeaceHealth St. Joseph Medical Center (WA)
- Providence Regional Medical Center Everett (WA)
- River Falls Area Hospital (WI)
- Seattle Cancer Care Alliance (WA)
- Seattle Children's Hospital (WA)
- University of Washington Medical Center (WA)
- University of Wisconsin Health (WI)
- Vashon Health Center (WA)
- West Virginia University Healthcare (WV)

Wheaton Franciscan Healthcare-Racine (WI)

State index of organizations represented on the NAM list serv

NAM Outreach to Patient and Family Advisory Councils (2015)



SNAPSHOTS

A SAMPLING OF PATIENT & FAMILY COUNCILS

Please be in touch to help us build the type of patient & family advisory council leadership network necessary to foster a continuously learning health system in America.

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- **Akron Children’s Hospital** (OH) established the Parent Advisory Council (PAC) to provide a venue for parents and guardians to offer input on issues that impact the care of children. In alignment with the hospital’s mission to deliver enhanced family-centered care, the Council acts as a hospital liaison to represent families and their children’s needs. [More here](#).
- The Patient and Family Advisory Council at **Anna Jaques Hospital** (MA) reports through the Board Quality Committee, a committee of the Board of Trustees, according to its annual report. In 2014, the Council reviewed and/or advised about a number of topics, including new construction, introducing a patient portal, an electronic patient discharge packet, and how to handle patient complaints that Council members learn about in the community. [More here](#).
- **Anne Arundel Medical Center** (MD) was recognized as a *Better Together* exemplar hospital because of a number of activities that included Patient-Family Advisory Council input, including welcoming patients’ families and caregivers to visit 24 hours a day. The 24-hour visitation policy, which began June 1, 2011, came about due to the work of a planning team that included patient and family advisors, clinicians, security personnel, and receptionists, and that addressed training, changing signs, and website language, among other issues. [More here](#).
- **Baptist Health South Florida** (FL) improves all aspects of the patient experience by including patients and family members in quality, safety, and service improvements. The Patient & Family Advisor Group encourages a culture of accountability, trust, system improvement, and continuous learning that involves all stakeholders in promoting safe care. [More here](#).
- **Barnes-Jewish St. Peters Hospital** (MO) initiated its Patient and Family Advisory Council (PFAC) in 2009. PFAC members identify and promote resources to help patients and families navigate through the health care experience and empower them to take ownership of their care, participate in developing and planning patient/family satisfaction initiatives, and help develop education and communication materials. [More here](#).

- **Baystate Children’s Hospital** (MA) council advisors share perspectives, opinions, and suggestions and, as “family as faculty,” educate and advise hospital staff on patient- and family-centered care values. The Patient and Family Advisory Council’s 2014 goals include tracking and measuring success. [More here.](#)
- The Patient & Family Advisory Council at **Berkshire Medical Center** (MA) will redouble its efforts to diversify its advisors to ensure that the Council better represents the community and will measure success by adding no fewer than three new advisors who add diversity by race, age, socioeconomic status, veteran status, gender, gender identity, and sexual orientation, according to its annual report. The Center has a PFAC whose meetings are conducted in Spanish and in the coming year intends to incorporate a Russian-speaking PFAC. [More here.](#)
- Members of the Patient and Family Advisory Council (PFAC) at **Beth Israel Deaconess Medical Center** (MA) participate in a hospital-wide PFAC as well as advisory councils within the Neonatal Intensive Care Unit, the Intensive Care Unit, Universal Access, and Healthcare Associates–Primary Care. Advisors have consulted on the development of the Communication, Apology, and Resolution (CARE) program; have provided the patient’s perspective on implementation of the Mass HIway, a mechanism to share medical information; and the Conversation Ready project, which creates and sustains infrastructure to support patients’ end-of-life decision making. [More here.](#)
- Seventy-three percent of the members of the Patient and Family Advisory Council at **Beth Israel Deaconess Hospital-Milton** (MA) completed a survey in the fall of 2014 and all indicated that they believed they provided valuable feedback and advice to the hospital, according to their annual report. In addition, the PFAC members said they believed they had a direct impact on hospital policy changes and decision-making. [More here.](#)
- **Boston Children’s Hospital** (MA) asked three parents and two teen advisors to serve as a Parent and Teen Advisory Group to assist the Harvard-wide pediatric health services research fellowship program. The advisors, who contributed to bi-weekly seminars during which fellows presented their work, offered “unique insights that have positively developed fellows’ research,” according to the presenters. [More here.](#)
- **Braintree & New England Rehabilitation Hospitals** (MA) have developed a Patient Family Advisory Council (PFAC) to enable patients and family members to have direct input into the development of policies, programs, and practices at its hospitals, satellites, and clinics. Current or former patients and/or family members provide feedback about patient and provider relationships, hospital research projects, quality-improvement initiatives, and patient education on safety and quality concerns. [More here.](#)

- **Bronson Methodist Hospital** (MI) Patient and Family Advisory Council members are patients, family members, and staff volunteers who advise on Bronson’s policies, procedures, and practices. The councils meet monthly for three hours and members can also serve on hospital committees, rounding, and process improvement activities. [More here.](#)
- The Patient Family Advisory Council, in its fourth year at **Cape Cod Hospital** (MA), assigns members to goals that match their experience and interest, including providing the patient’s perspective to the C-Lab Process Improvement team, according to their annual report. Volunteers who are cancer survivors worked with the oncology staff to develop a “Distress Thermometer” that patients complete; patients with high scores are seen by a social worker. Patients in the oncology waiting area are now updated on their wait status and an effort is underway to improve scheduling. [More here.](#)
- **Children’s Hospital Colorado** (CO) insists on a partnership between the health care provider, the patient, their family, and the family’s support system. The parents and hospital leadership that comprise the Family Advisory Council provide direct input on hospital initiatives, new policies and procedures. [More here.](#)
- **Children’s Hospital of Philadelphia** (PA) relies on its partnership with families to help maintain its mission of providing patient care specifically designed for each individual and their family. The hospital seeks the counsel of patient family members from diverse experiences, backgrounds, and diagnoses to inform policy and program development. Within the Children’s Hospital of Philadelphia (CHOP) network, patients and family members influence a wide array of hospital policies and programs, including efforts to redesign CHOP hospital billing, to implement the Complex Consultation Team, and to improve patient and family satisfaction. [More here.](#)
- **Children’s Mercy Hospitals and Clinics** (KS) formed its Family Advisory Board in 2003 and includes families who are primary caregivers of a child who has been cared for at Children’s Mercy Hospitals and Clinics. The advisors have served on Ohio Collaborative Solutions for Patient Safety Hospital-Acquired Conditions committees; collaborated on construction of an Accessible Family Care Station for patients, families, employees, and guests; developed guidelines for parent rooms on the inpatient units; created orientation videos; and filmed a podcast on the benefits of partnering with patient family advisors, among other activities. [More here.](#)
- **Cincinnati Children’s Hospital** (OH) gives teenage patients, former patients, and siblings of patients a voice in the decisions that affect how they receive care. The Patient Advisory Council supports current patients, helps staff see the hospital from patient perspectives, advocates on behalf of patients and identifies ways to make Cincinnati Children’s a better place for the children they serve. [More here.](#)

- **Contra Costa Regional Medical Center** (CA) engaged patients, families, community representatives, and leaders to ensure that their voices are included in efforts to expand access to timely and appropriate care, enhance quality of care, and improve communication between medical staff. Patients, family, and community partners are represented on the Behavioral Healthcare Partnership, Hospital Operations Team, Patient Experience Partnership Council, and Spiritual Care Partnership Council, as well as a variety of other quality-improvement workgroups. [More here.](#)
- Members of the Patient and Family Advisory Council at **Cooley Dickinson Hospital** (MA) helped in selecting a new President and Chief Executive Officer for the hospital by speaking with the consulting firm conducting the executive search about the leadership skills needed and by participating in interviews of two finalists, according to their annual report. Among other activities in 2014, PFAC members served on a partnership team whose feedback was instrumental in redesigning the entrance and waiting room to an Emergency Department that records more than 36,000 annual visits in order to increase natural light, expand waiting space, and improve signage. [More here.](#)
- **Dana-Farber Cancer Institute** (MA) has linked its Patient/Family Advisory Council (PFAC) with Volunteer Services, a natural connection since volunteers are often former patients or caregivers. They recorded volunteers' observations, compiling them into monthly reports that note trends, problems, and successes. The report led to action items and an enhanced ability for the PFAC to suggest broader changes to hospital leadership. [More here.](#)
- More than 670 volunteers in 2014 provided more than \$2 million in value-add to **Dell Children's Medical Center of Central Texas** (TX), including by serving on the Family Advisory Council, a partnership of family, hospital, and physician leaders. Family Advisors provide feedback on proposed policy, program, and organizational changes; serve on committees, projects, and initiatives throughout the Center; and support and promote implementation of family-centered care. [More here.](#)
- **At Duke Children's Hospital & Health Center** (NC), the Pediatric Family Advisory Council (PFAC) includes parents of children who have received or currently are receiving pediatric care at the facility. Through personal narratives, family advisors illustrate how health care professionals can fulfill the center's patient- and family-centered care mission, values, and philosophy. Family advisors have worked on a variety of activities, including quality, safety, and patient satisfaction; 24-hour visitation; rooming-in with the child; rounding with the medical team; resource room/reference materials; and discharge processes, among other programs and projects. [More here.](#)
- **Emory Healthcare** (GA) promotes patient- and family-centered care core concepts, including collaboration, participation, information sharing, dignity, and respect. The Patient and Family Advisory program partners with patients

and family members in developing and implementing programs, policies, and processes that shape patient, family, and staff experiences. [More here.](#)

- **Advisors and partners at Essentia Health** (MN and WI) are parents, spouses, and individuals of all ages who provide feedback, stories, and ideas for staff. The system’s east region includes a 19-member Family Advisory Council, and nearly 200 additional advisors assigned to such units as Ambulatory Pharmacy, adult inpatient Behavioral Health, Birthing Experience, the Heart & Vascular Center Patient and Family Advisory Council, Neurology, the Oncology Patient and Family Advisory Council, Regional Primary Care, and the Young Adult Patient Advisory Council. [More here.](#)
- **Fort Belvoir Community Hospital** (VA) recognizes that patient engagement and decision making from patients and their families are vital to the hospital achieving its mission of creating a “medical neighborhood.” Patients and family members participate in shaping the hospital’s strategic plan with top level executives, incorporating the patient perspective with Lean Six Sigma and Value-Stream Mapping strategies for improvement and efficiency. [More here.](#)
- **Georgia Regents Medical Center** (GA), which has more than 200 Patient and Family Advisory Council members, says it looks for patient and family advisory council members who have positive attitudes, a willingness to assist with positive change, and the ability to share their insights in a balanced, objective way. The May 20 Web event, “Patient- and Family-Centered Care for Adults with Chronic Conditions,” was hosted by AHRQ. [More here.](#)
- “Partners,” a quarterly newsletter of the Patient & Family Advisory (PFA) Program at **H. Lee Moffitt Cancer Center & Research Institute** (FL) includes a column written by the Patient & Family Advisory Council co-chair honoring a former PFAC leader, details about patient and family orientation, the perspective of a caregiver for a 28-year-old woman with cancer, and a column from a peer visitor involved with the PFA about how patients with cancer can care for themselves during treatment. Moffitt’s PFAC co-chairs serve on the newsletter’s Editorial Board. [More here.](#)
- Members of the Patient and Family Advisory Council at **Hallmark Health System** (MA) have provided feedback about Patient Welcome Packets, triggering a redesign of the entire packet; were the impetus behind new practices that streamlined information that Laboratory Services provides to patients; and were asked by Information Services to serve in a pilot test of the new inpatient portal prior to its rollout. [More here.](#)
- **Health Central Hospital** (FL) formed its Patient and Family Advisory Council to partner with patients on an ongoing basis after focus groups in 2011 revealed “overwhelming opportunities for improvement,” according to a July 30, 2014 webinar. Among the PFAC’s “Patient First” activities was an effort to ensure that whiteboards are consistently updated to improve communication between the team and patients throughout admission. In addition, PFAC members

visit patients and families on inpatient floors to obtain feedback about hourly rounding, bedside shift report, and the whiteboard. In the Emergency Department (ED), PFAC members who round seek feedback on wait time for ED beds, communication with the team, and responsiveness. [More here.](#)

- In response to an “epidemic rate” of suicides in the area, the Patient and Family Advisory Council at **Heywood Hospital** (MA) discussed issues surrounding mental health during many meetings and requested “Question, Persuade and Refer” training to help support the community, according to its annual report. In the coming year, it will solicit members for three committees: Multicultural Task Force/Health Equity, Schwartz Center Caregiver Rounds, and Suicide Prevention Task Force. [More here.](#)
- **Joe DiMaggio Children’s Hospital** (FL) seeks to continually improve the quality of the services offered to the community through patient and family engagement. The Patient and Family Advisory Councils urge patients and family members to work alongside health care professionals to identify issues that are more important to them than providers realize. [More here.](#)
- **The Johns Hopkins Hospital** (MD) has five patient and family advisory councils (PFACs). These include the Pediatric Family Advisory Council, which began in 2006, the Adult Patient and Family Advisory Council, which began in 2011, and three additional Councils, which began in 2014, including the Oncology, Emergency Department and Ambulatory Service Councils. In partnership with the Johns Hopkins leadership, clinicians, and staff, these councils advocate for the highest quality patient- and family-centered care and accomplish this by infusing the voice of patients into every aspect of care. A “Clinical Community” of all PFACs across the Hopkins health system was developed in 2014 and its steering committee is charged with helping to facilitate integration, communication, and collaboration as well as to identify system initiatives. [More here.](#)
- **Kaiser Permanente** (CA) believes that hospitals that involve patients and their families will deliver outstanding care and have better outcomes. To that end, Kaiser Permanente created dozens of Patient Advisory Councils (PACs) to engage patients and their families as partners. It has center-wide Advisory Councils in all of its 12 medical centers located in Southern California and for seven of its 21 medical centers located in Northern California, with the expectation the remaining 14 centers will establish them by the end of 2014. Patients also serve on Kaiser Permanente committees and teams for quality, medication safety, medical education, facility design, executive walk-arounds, staff nurse council, patient experience, and infection prevention. [More here.](#)
- After feedback from Patient and Family Advisory Council members, **Lahey Hospital & Medical Center** (MA) completed structural changes to entryways to improve their safety and convenience for visitors living with disabilities, including changing the flooring in the main lobby and adding more reserved parking spaces for people with disabilities. Other activities, according to their

annual report, included routinely reviewing the facility's Quality Scorecard, which includes the mortality index, readmission rates, quality core measures, HCAHPS, and ambulatory satisfaction scores. [More here](#).

- Members of the Patient and Family Advisory Council at **Lawrence General Hospital** (MA) in 2015 will strive to increase the number of members who represent young adults to ensure the Council represents the patients the hospital serves, according to their 2014 annual report. Among their accomplishments, the Council recruited four new members; recommended that comfort care items, such as cell phone chargers, be available at the gift shop; and created a brochure to promote the Council. [More here](#).
- Members of the Patient and Family Advisory Council at **Lowell General Hospital** (MA) actively encouraged the hospital to move forward on plans to develop a comprehensive diabetes program, filling a gap in community services. Working with a community endocrinologist, the hospital established a diabetes clinic on the Saints campus that offers one-on-one patient education as well as group classes. [More here](#).
- **Mayo Clinic Health System** in Menomonie (MN) formed its Patient and Family Advisory Council in October 2004 to help the medical center promote patient- and family-centered care. Projects undertaken by the Council include improving accessibility for wheelchair users, evaluating health history forms, and developing a script that helps to explain to new patients which paperwork is required. [More here](#).
- **McLean Hospital** (MA) PFAC members have helped to revise the "Guide to Inpatient Hospitalization," assisted with completing the inpatient group program review, served as guest faculty in trainer and employee orientation, presented to the Board of Trustees Quality of Care Committee, participated in Grand Rounds, and are helping to add family support and education material to the institution's web site. [More here](#).
- MemorialCare, which operates six hospitals including **Long Beach Memorial Medical Center** (CA), selects Patient and Family Advisory Council members to serve two-year terms. The PFAC advises MemorialCare on how to provide better patient-centered care and how to improve its services. [More here](#).
- **MD Anderson Cancer Center** (TX) in the spring of 2014 launched its first institutional Patient and Family Advisory Council made up of patients, survivors, caregivers, and family members who share the vision of improving the facility. According to MD Anderson, advice from PFAC members on programs and services is associated with safer and better health outcomes, and more judicious use of resources. [More here](#).
- **Methodist Le Bonheur Healthcare** (TN) supports and promotes a patient- and family-centered culture, driven by the belief that this partnership is mutually beneficial and will lead to better quality care at lower cost. Methodist Le Bonheur Healthcare (MLN) partners with nine Family Partner Councils, all

of which work with hospital leadership to launch several initiatives. In order to best engage Family Partner Councils, MLN provides training to Partners on how to communicate most effectively with hospital staff. These Family Partner Councils have influenced the system, through revisions to the system's visitation policy; the improvement of Advanced Directives' processes for patients and their families; and participation on several boards and committees across the system. [More here.](#)

- **Morgan Stanley Children's Hospital** (NY) respects the central role the family plays by caring for a sick child by encouraging collaboration between doctors, nurses, hospital administrators, and families. In promoting family-centered care, the Family Advisory Council seeks to provide families with all the information they need to care for their children with confidence. [More here.](#)
- A member of the Patient and Family Advisory Council at **Nantucket Cottage Hospital** (MA) co-led a two-year project to improve safe and effective use of medications by helping patients to present a complete and accurate medication list during every encounter they had with health care professionals, according to their annual report. The hospital's web site includes English and Spanish versions of the medication card and informational letters were sent to clinicians and community pharmacists. [More here.](#)
- **Nemours** (DE and FL) relies on family advisory councils to help create new services, streamline processes, and to weigh in on hiring decisions to ensure they build a better place to care for children. Nemours' Family Advisory Council (FAC) is made up of diverse group of families and employees with intimate experience with many of the inpatient and outpatient services available at duPont Hospital for Children. The volunteers advise, empower, and advocate. [More here.](#)
- The Patient and Family Advisory Council at **New England Baptist Hospital** (MA) established a presence on the hospital's web site and helped to determine PFAC-related content and design. In addition to other activities in the past year, the council regularly reviewed patient satisfaction and quality metrics, including Press Ganey patient satisfaction scores, hospital performance data, and findings by the Joint Commission, according to its annual report. [More here.](#)
- **North Shore Medical Center** (FL) encourages patients, families, and the community to provide input on the patient care and safety programs they experience. The community members and hospital employees that make up the Patient Family Advisory Council strive to represent diverse ethnic, racial, religious and socioeconomic composition characteristic of the institution. [More here.](#)
- The Patient and Family Advisory Council at **Norwood Hospital** (MA) focused its work on the topic "defining excellence in the patient care experience," according to its annual report. Among the council's accomplishments for

2014 was improving communication within the Emergency Department by informing patients and about the plan of care and any delays in tests. A suggestion to improve communication about Spiritual Care resources led to communication with Catholic parishes that support the hospital with “on call” coverage. [More here.](#)

- **NYU Langone’s Center for Child and Family Experience** (NY) is the home for a Family Advisory Council and a Youth Advisory Council. Members of these councils play an active role in providing perspectives and recommendations that guide decisions regarding all aspects of programs and services designed for children and families. [More here.](#)
- **PeaceHealth St. Joseph Medical Center** (WA) seeks to engage with its community, largely helped by its strong partnership with its current or past patients and their family members. PeaceHealth depends on patients and families to review and improve program/policy review, education material evolution, quality and safety efforts and facility planning. [More here.](#)
- Members of the **Saint Anne’s Hospital Patient and Family Advisory Council** (MA), which was formed in 2010, participate in hospital care improvement, information sharing, and policy and program development. Among their accomplishments for 2014, PFAC members suggested that care providers dress in consistent colors (e.g., navy for registered nurses, green for physical therapists, tan for respiratory therapists, eggplant for occupational therapists, and gray for laboratory staff) to help patients and families distinguish who plays which role in patient care. PFAC members also suggested that physicians receive Press Ganey training, a move associated with improved HCAHPS scores; and that patients receive information about patient-/family-initiated rapid response teams in welcome packets and patients’ rooms. [More here.](#)
- **Smilow Cancer Hospital at Yale-New Haven’s** (CT) Patient and Family Advisors work with staff and other patients and families on a variety of projects and programs to help improve services and the health care experience. Its Pediatric Advisory Council focuses on care received by children. [More here.](#)
- **South Shore Hospital** (MA) Home Care Division formed a patient & family advisory council, leveraged the power of patient stories, and contributed to such projects as updating educational materials for diabetes patients, participated in in-service training, and reviewed the palliative care brochure. [More here.](#)
- **Stanford Hospital and Clinics** (CA) recognizes the value in facilitating partnership between patients, families, and members of the health care system so that patients are able to advise hospital leaders and the health care team about the overall patient care experience. The facility has 10 Advisory Councils with a total of 100 Patient and Family Partners, a Speaker’s Bureau, Peer 2 Peer, and Lean/Improvement through its Family Partner Program. Stanford Hospital and Clinics empowers patients through condition-related Patient Advisory Councils. [More here.](#)

- **The Children’s Hospital at Dartmouth-Hitchcock** (NH) Family Advisory Board works in partnership with Children’s Hospital at Dartmouth-Hitchcock leadership to promote and enhance patient- and family-centered pediatric care and services, and strengthen communication and collaboration among families, the facility, and the broader community. Volunteers include parents of children who have received care. The board’s outcomes committee evaluates where family-centered care may be enhanced. [More here.](#)
- **The Milford Regional Medical Center** (MA) PFAC behavioral health task force aims to identify strategies to strengthen services and support for individuals with behavioral health and substance abuse issues through community partnerships and collaboration. To that end, their draft objectives include improving the care of such patients who are seen in the Emergency Department; to connect individuals and families with resources and referrals; and to bring together social service providers annually to network, to strengthen community partnerships, and to share best practices. [More here.](#)
- **The Siteman Cancer Center at Barnes-Jewish St. Peters Hospital** (MO) established its Patient and Family Advisory Council in 2008. Eighteen patient and family members and nine staff liaisons listen, plan, and develop responsive services. PFAC members help to ensure that patients and family members are recognized as essential participants of the health care team, develop patient and family education and communication materials, generate new program ideas, and raise awareness of opportunities and key resources that will help patients and family members navigate through the system. [More here.](#)
- Members of the Patient Family Advisory Council at **Tufts Medical Center** (MA) promoted “a more visibly proactive” PFAC with members integrated into various hospital settings and operations, according to their 2014 annual report. Among other activities, PFAC members consulted with Tufts Medical Center staff about the patient portal; revised the patient handbook; and consulted with surgical services regarding patient privacy and visitor practices for adults, children, and patients with special needs. [More here.](#)
- **UC San Diego Health System’s** (CA) Patient and Family Advisory Council for Women and Infants Services was founded in April 2011 and aims to improve the safety, quality, and overall care experience for women served by the health system and their families. The council is composed of UC San Diego staff and volunteers, including former and current patients and their family members. [More here.](#)
- At the **University of Arkansas for Medical Sciences** (AR), nearly 75 patients and family members serve on advisory councils and committees, including the Internal Medicine Clinic Council, the Neonatal Intensive Care Unit, the MyChart steering committee, and the Reynolds Institute on Aging Council. [More here.](#)
- **UMass Memorial** (MA) connected “the dots” through community/clinical linkages. The institution’s framework for community benefits includes the

need to broaden clinical thinking, emphasizing prevention, partnering with non-traditional stakeholders to improve population health, and addressing community-based social and physical conditions that underlie the root causes of disease. [More here.](#)

- At **UMassMemorial Barre Family Health Center** (MA), one of the first steps in forming a PFAC was to ask clinicians to recommend patients and community members who would provide constructive and useful feedback. Of 40 people invited, 20 attended the first meeting. Next steps include developing a process to add new PFAC members and to diversify their age by adding younger members. [More here.](#)
- This [full report](#) summarizes what PFACs across the state of Massachusetts are doing.
- **University Hospitals Case Medical Center** (OH) established its Patient and Family Council in 2006. The group of volunteers seeks to continuously improve the care experience for patients and those whom patients consider family, including spouses, partners, parents, children, and close friends. Patient and Family Council members have helped to revise the visitation policy to afford families more flexibility; enhance patient and family education materials; develop the UH Case Medical Center Patient Welcome Guide; provide comfort to patients' family members with "Be Our Guest" dinners; and update stroke, diabetes, heart attack, and infection control teaching books. [More here.](#)
- **The University of Washington Medical Center** (WA) recognizes the importance of patient and family involvement in health care decision making to improve the health-care experience for everyone. Patient and Family Advisors encourage a partnership among patients, families and health care professionals in an effort to create robust patient- and family-centered care. [More here.](#)
- **University of Wisconsin (UW) Hospitals and Clinics** (WI) partners with eight Patient and Family Advisory Councils in order to focus on specific populations or aspects of care delivery: the UW Health Adult PFAC, American Family Children's Hospital PFAC, Primary Care PFAC, Pediatric Primary Care PFAC, Oncology Services PFAC, Transplant PFAC, MyChart PFAC, and Yahara Clinic PFAC. [More here.](#)
- **Vermont Children's Hospital** (VT) through its Patient and Family Advisory Council has identified and worked to implement the four principles of family-centered Care: dignity and respect, information-sharing, participation, and collaboration. The current focus of the group is on navigating the long-term stays in the hospital. The hospital has brought together community representatives from local industries, education, social and children's services, state agencies and the Vermont Legislature to partner with parents and hospital staff to review progress and serve as consultants to ensure that the hospital is evolving to improve the care of children tailored specifically to its community's needs and goals. [More here.](#)

- **Vidant Health** (NC) has specially trained patient-family advisors throughout the system who volunteer time and share insights to help improve the patient experience, ensure effective communications, and inform decision making. Patient-family advisors have been consulted on building design and renovations, patient education materials, processes involving patient care and more. Feedback from advisers comes in the form of a special stamp of approval for items reviewed by patient-family advisors. [More here.](#)
- Patient representatives to the Patient and Family Advisory Council at **Whittier Rehabilitation Hospital** (MA) were chosen from the inpatient and outpatient rosters and work with the volunteer department and are members of the hospital's Peer Visitor Program, according to its annual report. In the coming year, the Council will continue to improve the process for conducting follow-up calls after patients are discharged and will work on a discharge questionnaire for pulmonary patients. [More here.](#)

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- Johns Hopkins Hospital
- Joint Commission
- National Association of Community Health Centers
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- NYU Langone Medical Center
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