Engaging Patients and Families in the Medical Home

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HEALTH IT   PREVENTION/CARE MANANAGEMENT

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None of the investigators has any affiliations or financial involvement that conflicts with the material presented in this report.

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Executive Summary

In its landmark 2001 report *Crossing the Quality Chasm,* the Institute of Medicine (IOM) identified patient-centeredness as one of six aims for the health care system. As the concept of a patient-centered medical home (PCMH) has gained increasing attention as a means of redesigning primary care, several commentaries have noted the need for strengthening and expanding opportunities for patient engagement in current medical home demonstrations.

The purpose of this paper is to offer policymakers and researchers insights into opportunities to engage patients and families in the medical home. We present a framework for conceptualizing opportunities for engagement, briefly review the evidence base for these activities, describe examples of existing efforts, suggest key lessons for future efforts, and discuss implications for policy and research.

The proposed framework envisions opportunities for engaging patients and families in the design and functioning of the medical home in three contexts:

1. Care for the individual patient
2. Practice improvement
3. Policy design and implementation

Drawing on both published and "gray" literature, as well as input from key experts, we identified examples of promising engagement strategies by innovative providers. The largest number of tools and programs focus on engaging patients and families in the care of the individual patient, with a lesser number of examples and evidence discussed for practice and policy involvement. Table 1 summarizes examples of how patients and families can be involved in care for the individual patient, practice improvement, and policy. Our review of these examples and evidence led to the conclusions summarized after the table.

Table 1. Examples of patient engagement in medical home

Activity/Roles for Patients and Families	Value/Rationale	Existing Evidence	Research and Policy Needs	Selected Examples[a]
Patients and Families Engaged in Care For the Individual Patient				
Communication and information sharing • Learn about how the practice works • Discuss roles with team • Get help with organizing and coordinating care	The medical home model suggests a new structural relationship between patients and the health care team. A shared understanding of and respect for the roles of the patient and the family, as well as the health care team, is important.	• Observational research suggests that mutual recognition by the patient and physician of an ongoing relationship is related to better patient experiences. • However, there is no research evidence about the effectiveness of specific methods/tools to support the discussion/agreement on roles of patients and their primary care teams within the medical home.	• How should practices engage patients in these discussions? • What kinds of paper or Web-based tools support these discussions? • How do patients understand the "partnership" with the medical home? • How much variation is there in patients' preferences for partnership roles? • What is the impact on access, clinical quality, patient experience, or costs of building practice partnerships with patients?	• Templates/examples for practices to use to create patient guide to the practice (Gruman et al., 2009a) • Brochure to explain the medical home concept to patients and consumers (National Partnership for Women and Families, 2009) • Care summary provided to families of children with chronic conditions in written or electronic form (MassGeneral Hospital for Children, undated)

Table 1. Examples of patient engagement in medical home (continued)

Activity/Roles for Patients and Families	Value/Rationale	Existing Evidence	Research and Policy Needs	Selected Examples[a]
Self-care • Work with provider(s) to identify and monitor treatment and self-care goals • Get help with managing chronic illness • Participate in activities to reduce health risks • Participate in peer support groups or group visits	The medical home can support the patient and the family in developing self-management goals and overcoming barriers to achieving those goals.	• There is evidence that specific interventions can improve patient knowledge, self-efficacy, and some outcomes. There is less evidence about the impact on costs of care. • Implementation of these interventions is limited, and generalizability of programs developed in research and demonstration projects is unclear.	• What is the feasibility outside research projects, and what is the impact on the outcomes and costs of care? • What services should be provided within the medical home practice? How could the medical home link to services in the community or other settings? • What is the level of training and expertise needed to provide self-management services? What are the opportunities for peers, medical assistants, nurses, and other types of clinicians or staff? • What is the best way to adapt interventions to meet the needs of different types of patients? • How can measures of patients' confidence in self-care be used to guide self-management interventions?	• Model for supporting evidence-based changes in chronic-disease care focusing on self-management support, community, health system, delivery system design, decision support, and clinical information systems (Improving Chronic Illness Care, 2010) • Program to help participants set and achieve incremental goals to strengthen their sense of personal effectiveness in managing health needs (Stanford Patient Education Research Center, 2010) • Project to test a tool embedded in electronic health record to promote health behavior counseling (Krist et al., 2010) • Program to improve care for seniors with multiple chronic illnesses by coordinating care, facilitating care transitions, and acting as patient advocate across health care and social settings (Boult et al., 2008) • Initiative to implement for coronary artery bypass graft surgery, an evidence-based, pay-for-performance program that incorporates shared decisionmaking through a patient compact (Casale et al., 2007)

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Table 1. Examples of patient engagement in medical home (continued)

Activity/Roles for Patients and Families	Value/Rationale	Existing Evidence	Research and Policy Needs	Selected Examples[a]
Decisionmaking • Review evidence-based decision aids • Discuss risks and benefits of different options • Decide jointly with the health care provider on a treatment consistent with values and preferences	Patients and clinicians should be partners in making treatment decisions.	• Existing evidence base suggests positive impact on patient experiences and the quality of decisionmaking; there is limited information about the impact of shared decisionmaking on the outcomes or costs of care. • It is unclear how methods tested for a narrow set of preference-sensitive conditions fit other kinds of decisions. • There is limited implementation outside research settings.	• What types of shared decisionmaking methods are feasible in medical home settings? For what types of decisions? What is the best way to get these methods used at the point when patients most need them? • What are the best ways to engage patients and families in shared decisionmaking? How can these interventions balance the variation in patient/family interest in participation in decisionmaking? • What outcomes matter to patients? • How can Health IT support deployment of evidence-based shared decisionmaking tools? • What is the impact of shared decisionmaking on costs of care?	• Pilot projects to integrate shared decisionmaking and decision aids into day-to-day clinical practice, including the use of practice-based health coaches and group medical appointments (Foundation for Informed Medical Decision Making, 2010) • Initiative to test the impact of clinical decision support systems for shared decisionmaking with a reminder system for clinicians and patients (Chueh, 2008)
Safety • Review medical information and treatment results • Share information about medications and treatments received in other settings • Report on adverse events and potential safety problems.	In a trusting relationship, patients and families can work with the health care team to prevent errors.	• Few studies have considered the role of patients and families in promoting safety, and the evidence of impact is mixed. • Patients may find it difficult to behave in ways that may challenge the authority of clinicians.	• Does engaging patients and families in safety initiatives reduce the incidence of medical errors or adverse events, avoid waste, and improve patient experiences? • What kinds of initiatives are practical in different types of medical home settings? • Are patient/family reports of potential safety problems accurate? • What measurement tools are available for evaluating patient safety in the outpatient settings?	• Anonymous reporting of safety incidents by staff and patients (Neuspiel, Guzman, and Harewood, 2008) • Patient reports of safety concerns through surveys (Wasson et al., 2007) • Medication reconciliation process involving patients and providers, Mayo Clinic (Varkey, Cunningham, and Bisping, 2007)

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Table 1. Examples of patient engagement in medical home (continued)

Activity/Roles for Patients and Families	Value/Rationale	Existing Evidence	Research and Policy Needs	Selected Examples[a]
Patients and Families Engaged in Practice Improvement				
• Participate in quality improvement teams • Participate in patient/family advisory councils or other regular committee meetings • Provide feedback through surveys • Help in development of patient materials • Participate in focus groups • Do "walk-through" to give staff a patient perspective of practice workflow • Conduct peer-to-peer patient surveys	Patients and families can provide unique perspectives and enhance the ability of the practice to make improvements.	• Patient surveys are frequently used, but there is limited evidence about their usefulness in quality improvement. • There is almost no research on the impact of patient involvement in practice improvement on quality, costs, or patient experiences. Improvement projects have incorporated patient/family involvement as a component of the design, and there has been little study of the implementation or impact. • Current examples are from hospitals or collaboratives where there has been ample support for engagement. Even in these cases, success in sustaining patient/family participation is variable.	• What kinds of roles can patients/families play in quality improvement? • What tools/models promote successful involvement of patients and families in quality improvement? • What are the best models for using patient survey data to support quality improvement? • What methods can help to ensure fair and comparable patient survey data without creating too much burden (financial and otherwise) on practices? • What are the costs and benefits of involving patients and families in quality improvement? Are there unintended negative consequences? • What training do patients and practice teams need for successful engagement? • How interested are patients and families? • How might collaborative or local extension centers support the engagement of patients and families in quality improvement?	• Patient/family advisors program supporting quality and safety teams and facility design processes (MCGHealth: Nettie Engels, personal communication) • Learning collaborative that comprised pediatric practices serving children with special health care needs and that included family members as member of practice team (Minnesota Medical Home Initiative; Carolyn Allshouse, personal communication) • Regional efforts to conduct and report patient experiences of care in medical practices (e.g., Massachusetts Health Quality Partners, 2010; Pacific Business Group on Health, 2010)

Table 1. Examples of patient engagement in medical home (continued)

Activity/Roles for Patients and Families	Value/Rationale	Existing Evidence	Research and Policy Needs	Selected Examples[a]
Patients and Families Engaged in Policy				
• Serve on policy and quality improvement committees at various levels of private and public sectors • Gather input from other consumers • Participate in design of medical home demonstration programs • Participate in training for clinicians or practice teams	Patients and families can help policymakers identify priorities and design policies that address patient and family needs.	• There is little evidence about the effects of consumer involvement in health care decisions at the population level. • Anecdotal evidence suggests possible benefits in terms of changes in service systems. In addition, patients and family members who have the opportunity to serve in multistakeholder groups may benefit personally from the leadership experience.	• What kinds of roles should patients/families play in policy development? • What tools/models promote successful involvement of patients and families in quality improvement? • What training do patients and policy staff need for successful engagement? • How might collaborative or local extension centers support the engagement of patients and families in quality improvement?	• Consumer participation in governance of federally qualified health centers (National Association of Community Health Centers [NACHC], 2007) • Local networks of patients/ families that participate in evaluating care by completing surveys, answering a survey, attending meetings, participating in online group discussions, or becoming an authorized representative who visits care providers to understand their operations. (National Health Service [NHS, 2009) • Consumer participation in planning and governance of the medical home demonstration (Malouin, 2009) • Efforts to involve patients and members of the public in the development and implementation of clinical practice guidelines (Boivin et al., 2010)

[a]More information on examples of patient engagement in care for the individual patient are found in the Chapter 2 of the text and Appendix Tables A.1 and A.2. For examples of patient engagement in practice improvement, refer to Chapter 3 of the text and Appendix Table A.3. For examples of patient engagement in policy, refer to Chapter 4 of the text and Appendix Table A.4.

As articulated by the IOM, patient-centeredness is an independent aim of the health care system, and the diverse stakeholders among our expert panel and key informants agreed on the value of patient engagement as a way of achieving patient-centeredness. However, they held disparate views about the level of evidence needed to buttress policy efforts to promote patient engagement in the medical home and more broadly throughout the health care system. For some, efforts to promote engagement should be supported as a means toward achieving patient-centeredness and not judged by their impact on the IOM's other quality aims, like effectiveness and efficiency. Amid rising health care costs and tightening budgets, other stakeholders have questioned whether primary care practices and the health care system overall should be expected to invest in efforts to engage patients and families in care without evidence of improved outcomes and lower costs of care.

The existing evidence base for patient engagement in general, and the effectiveness and feasibility of specific approaches in particular, is limited and variable. For patient engagement in care of the individual, there is good evidence that specific interventions can improve patient knowledge, self-efficacy, and some outcomes, and reductions in utilization or costs of care have been reported in some studies. The best evidence relates to patient engagement strategies incorporated in multifaceted interventions such as the Chronic Care Model, where it is difficult to break out the impact of specific components. Other intervention studies are promising but may lack generalizability to routine primary care practice. Efforts to involve patients in practice improvement and policy are usually the expression of a fundamental value, consistent with the IOM goal of patient-centeredness, and therefore research evidence of impact on outcomes or costs is very limited.

Efforts to engage patients in their own care, practice improvement, or policy are not common at present. Many examples are drawn from research or demonstration initiatives, and adoption may be limited due to the evidence concerns noted above. Both financial and logistical issues limit implementation. Traditional fee-for-service reimbursement does not reward practices for engaging patients. The infrastructure, time, resources, and culture change needed to transform practices to a patient-centered focus are significant. Practices need assistance with practice redesign to engage patients and families. Payment reform may be critical to supporting engagement in care, but also engagement in practice design, since the tasks of getting patient feedback and implementing changes to improve quality require practice time and resources. Practices, particularly small primary care practices, need access to resources for and assistance with redesign to accomplish meaningful patient engagement.

Nonetheless, the existing efforts to support patient engagement in care, practice improvement, and policy suggest key lessons about successful implementation. Based on the examples reviewed and the insights of key informants, we identified several themes:

- Asking patients and families what matters most to them is a critical step in engaging them in care.

- Both providers and patients and families need new skills for this partnership.

- There is no one-size-fits-all solution; patient engagement will look very different for different practices, patient populations, and individual patient-provider interactions.

- Health information technology (Health IT) has the potential to support patient engagement in the context of thoughtfully designed care systems.

- Further research should examine the feasibility of different strategies to increase patient engagement in care, as well as their ability to achieve desired outcomes. In particular, it is critical to address key barriers to patient engagement, including the lack of capacity in individual practices for undertaking new interventions, the uncertainty about the costs and benefits of these interventions, the availability of trained clinicians and staff to implement them, and the lack of reimbursement or payment for new and potentially intensive interventions. As groundbreaking legislation supports activities such as the deployment of Health IT, the demonstration of new models of health care delivery, and the extension of health care coverage to millions of Americans, ample opportunities exist to test new and innovative strategies for engaging patients and families in care, practice, and policy.

1. Introduction

In its landmark 2001 report *Crossing the Quality Chasm,* the Institute of Medicine (IOM) identified patient-centeredness as one of six aims for the health care system. As the concept of a patient-centered medical home (PCMH) has gained increasing attention as a means of redesigning primary care, several commentaries have argued for greater emphasis on patient-centeredness in the principles that describe the expectations for the medical home, in the tools for qualifying practices as medical homes, and in the design of medical home demonstration projects and pilots (Berenson et al., 2008; Nutting et al., 2009; O'Malley, Peikes, Ginsburg, 2008). While both practical experience and a limited but growing body of research support the idea that greater engagement of patients and families in health care can contribute to improved quality and outcomes of care, patient- and family-centered care is not yet the norm in the U.S. health care system.

This paper describes the rationale, evidence, and opportunities for incorporating greater attention to patient engagement in medical home policy and practice. Our goal is to inform researchers and policymakers about these opportunities and about the key issues that are likely to affect the feasibility and sustainability of implementation. This paper draws on the published and the gray literature, as well as input from key experts, to identify examples of patient engagement. Though we briefly discuss the rationale and evidence for patient engagement strategies, this is not a rigorous evaluation of the evidence, nor is it our intent to suggest or endorse specific models.

This section discusses the roles of patients and families in recent formulations of the medical home model, and presents a framework and logic model for conceptualizing patient engagement in the medical home. Subsequent sections describe the rationale and evidence base for various strategies of patient engagement, highlight noteworthy examples, and discuss key issues identified from current implementation. The final sections summarize conclusions and implications for policy and research.

Origins and Recent Formulations of the Medical Home

The medical home is a model of the organization of primary care that provides patient-centered, comprehensive, accessible, and coordinated care and a systems-based approach to quality and safety. Over the past several years, the medical home model has gained prominence and support among multiple stakeholders for a variety of reasons. A coalition of groups of primary care physicians proffered the model as a way to mitigate the growing crisis in the availability of primary care services, while recognizing the need to improve the effectiveness and efficiency of primary care. Shortages in primary care providers exist across the country as a result of fewer physicians choosing primary care as a career (American Academy of Family Physicians [AAFP], undated; American College of Physicians [ACP], 2007). Payers, purchasers, and policymakers joined with others to support the concept as a vehicle for enhancing primary care, with the understanding that increased emphasis on primary care will lead to improved quality and moderated costs. Several studies offer support for the benefits of the medical home for cost and quality (Antonelli and Antonelli, 2004; Antonelli et al., 2008; Flottemesch et al.,

under review; Paulus et al., 2008; Reid et al., 2009; Rosenthal et al., 2008; Solberg et al., 2008; Wilhide and Henderson, 2006), and many other evaluations are under way.

The concept of a "medical home" is not new; the American Academy of Pediatrics (AAP) first used the term in 1967 to describe the ideal model of care for children with special needs (AAP, 1967; Cooley and AAP, 2004). The current focus on the medical home resulted from policy efforts to promote demonstrations of new payment models for primary care. In March 2007, the AAP, the American Academy of Family Physicians (AAFP), the American College of Physicians (ACP), and the American Osteopathic Association (AOA) collaborated to publish the *Joint Principles of the Patient-Centered Medical Home* (AAFP, AAP, ACP, AOA 2007). Working with the four primary care specialty societies, the National Committee for Quality Assurance (NCQA) developed the Physician Practice Connections®—Patient-Centered Medical Home™ (PPC-PCMH) program (NCQA, 2008). All saw the value of a standardized means of assessing the degree to which practices function as PCMHs. The PPC-PCMH standards have been endorsed by the National Quality Forum (NQF, as the Medical Home System Survey) (NQF, 2008), numerous physician organizations, and the Patient-Centered Primary Care Collaborative (PCPCC), a multistakeholder coalition of employers, consumer groups, health care providers, and others that advocate for the PCMH. The PPC-PCMH is now used in most PCMH demonstrations that include payment reform (PCPCC, 2009). Several other tools for surveying the medical home characteristics of practices have been used mostly for research projects. Some States have created their own tools for demonstration projects (e.g., Minnesota Department of Health, 2010).

As demonstration projects have proliferated, a healthy public debate has developed about how well the Joint Principles, the PPC-PCMH, and other tools embody the medical home model (Berenson et al., 2008; Nutting et al., 2009; O'Malley et al., 2008). The most common complaint is that there is not enough emphasis on the "patient-centered" nature of the medical home. Critics question how well and to what degree patients and families are involved in the development of current medical home efforts (the Joint Principles, qualifying tools, and demonstration designs), the components of the model, and the breadth and depth of expectations for medical home practices to engage patients and families in care and in quality improvement efforts.

In response, the National Partnership for Women and Families (NPWF) convened a coalition of more than 25 consumer, labor, and health care advocacy groups to identify *Principles for Patient- and Family-Centered Care: The Medical Home from the Consumer Perspective* (NPWF, 2009). Importantly, this effort was not to *react* to the Joint Principles, but to *build* a set of principles out of consumer perspectives and experiences. The Consumer Principles articulate many of the same capabilities and expectations for the medical home as the Joint Principles, such as access, communication, coordination, ongoing whole-person relationship, and commitment to quality (Table 2). The differences lie in several areas. First, the Consumer Principles state that the care team is not necessarily "physician-led"; rather, the choice of leadership by a physician, nurse practitioner, or other clinician should belong to the patient and family. Second, the Consumer Principles add a focus on mutual respect, partnership, and open communication between the patient and the care team. The Consumer Principles also call for attention to the needs of multicultural populations.

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Table 2. Comparison of joint principles and consumer principles for the medical home

	Joint Principles of the Patient-Centered Medical Home (AAFP, AAP, ACP, AOA 2007)	*Principles for Patient- and Family-Centered Care: The Medical Home From the Consumer Perspective* (NPWF 2009)	How Consumer Principles differ from Joint Principles
Care Team	• *Personal physician.* Each patient has an ongoing relationship with a personal physician trained to provide first contact and continuous, comprehensive care. • *Physician-directed medical practice.* The personal physician leads a team of people at the practice level who collectively take responsibility for the ongoing care of patients.	• In a patient-centered medical home (PCMH), an interdisciplinary team guides care in a continuous, accessible, comprehensive and coordinated manner. • The care team is led by a qualified provider of the patient's choice, and different types of health professionals can serve as team leader.	Patients choose the leader of the team, not necessarily a physician
Whole-Person Orientation	• *Whole-person orientation.* The personal physician is responsible for providing all the patient's health care needs and for arranging care with other qualified professionals.	• The PCMH "knows" its patients and provides care that is whole-person oriented and consistent with patients' unique needs and preferences.	More emphasis on patients' needs and preferences
Care Coordination	• *Care is coordinated and/or integrated* across all elements of the complex health care system (e.g., subspecialty care, hospitals, home health agencies, nursing homes) and the patient's community (e.g., family, public and private community-based services).	• The PCMH takes responsibility for coordinating its patients' health care across care settings and services over time, in consultation and collaboration with the patient and family.	More emphasis on patients' needs and preferences
Self-Management Support	• Practices advocate for their patients to support the attainment of optimal, patient-centered outcomes that are defined by a care-planning process driven by a compassionate, robust partnership of physicians, patients, and patients' families.	• Patients and their caregivers are supported in managing the patient's health.	Similar
Shared Decisionmaking	• Patients actively participate in decisionmaking, and feedback is sought to ensure that their expectations are being met.	• Patients and clinicians are partners in making treatment decisions.	Similar

Table 2. Comparison of joint principles and consumer principles for the medical home (continued)

	Joint Principles of the Patient-Centered Medical Home (AAFP, AAP, ACP, AOA 2007)	*Principles for Patient- and Family-Centered Care: The Medical Home From the Consumer Perspective* (NPWF 2009)	How Consumer Principles differ from Joint Principles
Quality Improvement	• Evidence-based medicine and clinical decision-support tools guide decisionmaking • Physicians in the practice accept accountability for continuous quality improvement through voluntary engagement in performance measurement and improvement. • Patients and families participate in quality improvement activities at the practice level • Information technology is utilized appropriately to support optimal patient care, performance measurement, patient education, and enhanced communication • Practices go through a voluntary recognition process by an appropriate nongovernmental entity to demonstrate that they have the capabilities to provide patient-centered services consistent with the medical home model.	• The PCMH provides care that is safe, timely, effective, efficient, equitable, patient-centered, and family-focused. • Seeks out and encourages patient feedback on experience of care, and uses that information to improve the quality of care the care team provides. • Collaborates with patient and family advisors in quality improvement and practice redesign. • Collects data on race, ethnicity, sex, primary language, and language services for each patient and records that information in a manner that can be reported and used to plan and respond to the health and language needs of patients in the practice. • Regularly evaluates and improves the quality, safety, and efficiency of its care using scientifically sound measures and reports that information to an entity that will make it publicly available in a way consumers can understand and access. • Routinely undertakes efforts to identify and eliminate any disparities in the quality of care received by its patients.	Focuses on multicultural population Collects health and language needs of patients Publicly reports outcomes Aims to reduce disparities
Access	• *Enhanced access* to care is available through systems such as open scheduling, expanded hours, and new options for communication among patients, their personal physicians, and practice staff.	• The patient has ready access to care. • Open communication between patients and the care team is encouraged and supported.	Similar
Payment	• Payment recognizes the added value provided to patients who have a PCMH.		Does not mention payment
Communication and Trust		• The PCMH fosters an environment of trust and respect.	Emphasizes trust and respect

Both the Joint Principles and the Consumer Principles draw on well-established literature discussing the key attributes of patient- and family-centered care. In *Crossing the Quality Chasm,* the IOM (2001) identified patient-centeredness as one of the six attributes of high-quality health care, on equal footing with the other attributes of safety, timeliness, effectiveness, efficiency, and equity. The IOM defined patient-centeredness as "providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions." Leading organizations have identified core components of patient- and family-centered care (Table 3). While their formulations have some commonalities (patient and family involvement, information sharing), there are some clear differences in emphasis. For example, the definitions of the Picker Institute (Gerteis et al., 1993; Picker Institute, undated) and the Institute for Family-Centered Care (undated [a]), both derived from work in hospital settings, focus on respect and facility issues (such as physical comfort and facility design). The Commonwealth Fund definition (Davis et al., 2005) focuses on patient-centered care as a component of a high-performing health care system and includes areas such as access and ongoing patient feedback. These various definitions demonstrate the growing consensus that more attention should be paid to including patients and families in the medical home movement, but they also point out the diversity of ideas about what constitutes patient engagement. A clear conceptualization of the different opportunities for the engagement of patient and families, and a comprehensive understanding of the existing evidence base are needed to help guide both the design and implementation of patient-centeredness in medical homes.

Table 3. Definitions of patient-centered care

Picker Institute (Undated; Gerteis et al., 1993)	Commonwealth Fund (Davis et al., 2005)	Institute for Family-Centered Care (Undated [a])
Respect for patients' values, preferences, and expressed needs • Information, communication, and education • Emotional support and alleviation of fear and anxiety • Involvement of family and friends • Continuity and transition • Physical comfort • Coordination and integration of care • Access to care	Superb access to care • Patient engagement in care • Information systems supporting high-quality care, practice-based learning, and quality improvement • Care coordination • Integrated, comprehensive care, and smooth information transfer across team of providers • Ongoing feedback to practice • Publicly available information on practices	Dignity and respect. Health care practitioners listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs, and cultural backgrounds are incorporated into the planning and delivery of care. • Information sharing. Health care practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete, and accurate information in order to participate effectively in care and decisionmaking. • Participation. Patients and families are encouraged and supported in participating in care and decisionmaking at the level they choose. • Collaboration. Patients, families, health care practitioners, and health care leaders collaborate in policy and program development, implementation, and evaluation; in facility design; and in professional education, as well as in the delivery of care.

Conceptualizing Patient Engagement in the Medical Home

Based on medical home principles articulated by consumers and physicians, as well as the previous definitions of patient-centered care, we suggest a framework for conceptualizing patient engagement in medical home design and functioning in three contexts:

1. Care for the individual patient

2. Practice improvement

3. Policy design and implementation

Table 4 offers examples of patient engagement in these different contexts, starting with efforts that focus on a patient's own care. Within each context, there are multiple opportunities for involving patients. These levels of engagement should build on each other. Thus, efforts to engage patients and families in their own care could develop a pool of informed and activated patients who can serve as effective participants in practice design. With their knowledge of practice functioning and exposure to the concerns of multiple patients, some of these practice advisors can play an effective role in representing patients in policy development or inform others who represent them. Likewise, practices that seek patient participation in quality

improvement may respond more effectively to patient and family needs, and policy can promote practice features that support patient engagement in their own care and in practice design.

Table 4. Framework for patient and family engagement in the medical home

Patients and families engaged in their own care	Communication and Information Sharing • Learn about how the practice works • Discuss roles with team • Get help with organizing and coordinating care Self-care • Work with team to set self-care goals • Get help with managing chronic illness • Participate in activities to reduce health risks • Participate in peer support groups Decisionmaking • Use evidence-based decision aids • Discuss risks and benefits of different options • Decide jointly with the health care provider on a treatment Safety • Review medical information and treatment results with the clinician or practice team • Share information about medications and treatments received in other settings • Report on adverse events and potential safety problems
Patients and families engaged in practice improvement	• Participate in quality improvement activities • Participate in patient/family advisory councils or other regular meetings • Provide feedback through surveys • Help in development of patient materials • Participate in focus groups • Do "walk-through" to give staff a patient perspective of practice workflow
Patients and families engaged in policy	• Serve on policy and quality improvement committees for various private and public initiatives • Gather input from other consumers • Participate in design of medical home or other demonstration projects • Participate in training for practice teams

What Is the Rationale for Patient Engagement Strategies?

Figure 1 presents a logic model for how patient engagement affects the function of the practice and leads to improvement in patient outcomes. In this model, patient engagement strategies seek to support patients and families to be activated and informed participants in their own care, to encourage practices to adopt and sustain proactive efforts to partner with patients, and to shape, at the system and community levels, policies and programs that are responsive to patient and family needs. This, as the IOM has articulated, is an aim of the health care system, but it can also lead to improved quality and reduced costs of care.

There is evidence for some of the relationships shown in this figure. Models of care, such as the Chronic Care Model (Bodenheimer, Wagner, and Grumbach, 2002a, 2002b), that emphasize

productive interactions improve quality, outcomes, patient experiences, and in some cases, costs of care. Epstein and Street (2008) suggest that better communication between patients and providers "improves psychological well-being through reducing anxiety and improving social support and improves physical well-being by reducing physiological arousal, enhancing access to the best treatments, and improving follow-though with care."

Patient/Family Engagement Strategies
Individual's care
Practice improvement
Policy

Informed, actively involved, participating patient and family

Accessible, well-organized, responsive health care system

Patient- and family-centered, communicative team

Costs of care

Health outcomes

Patient experiences
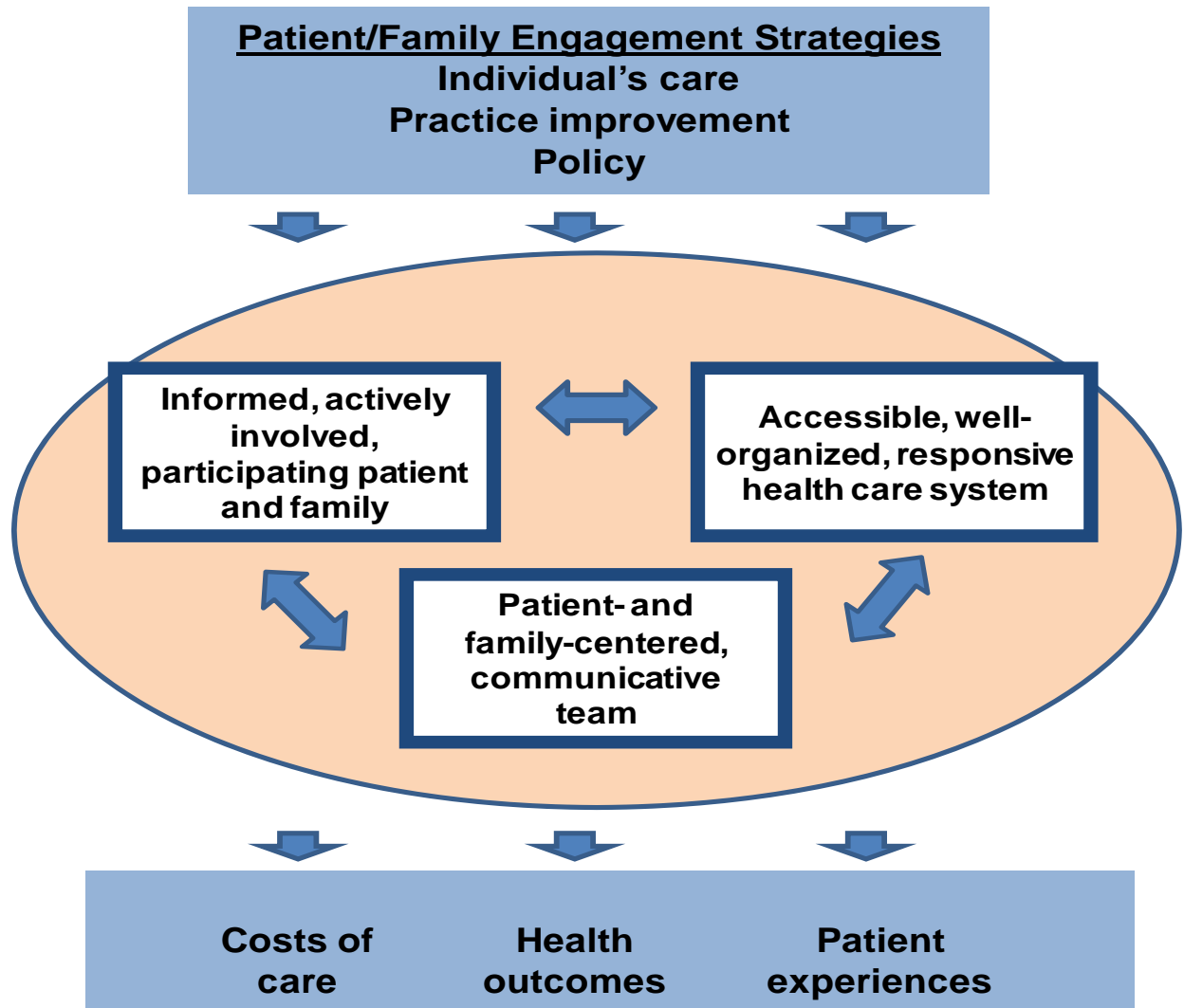
Figure 1. Logic Model for Conceptualizing the Impact of Patient Engagement
(Adapted From Epstein and Street, 2008)

Summary

The medical home is a promising model of care, but current formulations and implementation do not encompass the breadth of opportunities for engaging patients and families. Efforts to engage patients and families can occur in three reinforcing contexts: care for the individual, practice improvement, and policy development. The next chapters provide more detail on specific types of patient engagement and on what is known about their effectiveness and feasibility.

2. Engage Patients and Families in Their Own Care

A fundamental opportunity for patient engagement relates to care of the individual. This requires active steps to elicit patient and family views and preferences, and to incorporate those views and preferences into a shared plan for care. This section examines four key opportunities for engaging patients and families in the individual's care:

1. Communication and Information Sharing
2. Self-care
3. Decisionmaking
4. Safety

For each we discuss the rationale and evidence, examples, and issues for future consideration.

Communication and Information Sharing

Rationale and Evidence

The medical home model suggests a new structural relationship between patients and the health care team, since the medical home practice accepts responsibility for the patients' care and outcomes. A *patient-centered* medical home also implies a commitment to seeking and valuing the voice of the patient and family in care decisions. The medical home can help to build this relationship with the patient and family by giving information about how the practice works and discussing roles and responsibilities for both the patient and the health care team. In particular, the medical home plays a crucial role in coordinating care over time, within the practice, and across settings of care, including medical and social services. Unlike the image of the gatekeeper in early managed care efforts, the medical home advocates for patients (based on patient preferences and values) and represents the patient's overall interest in care provided within the practice or in other settings. A trusted partnership and understanding about roles provide an important foundation for patient engagement in other aspects of care, such as self-management and decisionmaking.

Explicit discussions about roles for the patient and health care team, as well as objectives of health care, are important. Research suggests that mutual recognition by the patient and physician of an ongoing relationship is highly valued by patients and is associated with greater patient and physician satisfaction, improved health outcomes, and lower costs (Baker, 1996; Baker and Streatfield, 1995; Freeman and Richards, 1990; Health Transition Fund, 2001; Macinko, Starfield, Shi, 2003; Starfield, 1998). Further, there is ample evidence that well-designed information, whether paper- or Web-based, can help to improve patient knowledge and experiences of care as well as have positive effects on self efficacy and health behavior (Coulter and Ellins, 2007). Targeted efforts to share medical information with the patient and other providers have also been helpful (Brown and Smith, 2004; Gustafson et al., 2002).

Examples

While there are no studies that illuminate how most effectively to discuss the medical home model with patients, a number of tools and reports are available to support this discussion (see Appendix Table A.1; many of these have been proposed or distributed by organizations such as the PCPCC). Some focus on giving information (for example, about getting health care or working with the health care team), while others seek to generate a mutual agreement about roles and responsibilities.

Typical of the information-giving tools are the sample "guide to the practice" of the Center for Advancing Health (CFAH)/Stoeckle Center (Gruman et al., 2009a) as well as the medical home brochure of the NPWF (2009). The CFAH/Stoeckle guide lists standard information (office hours, location, billing procedures) as well as specific instructions for other important aspects of access and communication (how to get medication refills, how to keep the practice up to date on care received from other providers). The NPWF brochure describes "what your care team should do" and "what you can do" on topics such as communication, information sharing, and support (Table 5). These kinds of agreements often also state that the patient should feel comfortable asking questions, communicating openly, and letting care teams know when they do not understand something.

Table 5. Excerpts from the National Partnership for Women and Families Medical Home Brochure

What Your Care Team Should Do	What You Can Do
1. Learn about you • Get to know you, your family, your life situation, and preferences. Remember these details about you every time you seek care, and suggest treatments that make sense for you. • Treat you as a full partner in your care.	4. Learn about caring for yourself • Know that you are a full partner in your own care. • Learn about your condition and what you can do to stay as healthy as possible. • As best you can, follow the plan that you and your medical home team have agreed is important for your health. If you have questions, ask!
2. Communicate with you • Give you time to ask questions, and answer them in a way you understand. • Make sure you know and understand all of your options for care. • Help you decide what care is best for you. Sometimes more care is not better care. • Ask you for feedback about your experience getting care.	5. Communicate with your care team • Always bring a list of questions to each of your appointments. Also bring a list of any medicines, vitamins, or remedies you use. • Always tell your medical home team when you don't understand something they said. Ask them to explain it in a different way. • Always tell your medical home team if you get care from other health professionals so they can help coordinate the best care possible. • Always talk openly with your care team about your experience getting care from the medical home so they can make care better.
3. Support you in caring for yourself • Make sure you leave the office with a clear idea of how to care for yourself. • Help you set goals for your care, and help you meet your goals one step at a time. • Give you information about classes, support groups, or other types of services to help you learn more about your condition and stay healthy.	

Source: National Partnership for Women and Families. *A medical home is about you.* Available at: http://www.nationalpartnership.org/site/DocServer/PCMH_Patient_Brochure_FINAL.pdf?docID=4601&AddInterest=1342. Accessed January 15, 2010.

While these tools mention the importance of communicating about services and medications received from other providers, they leave open the question about who will take the lead. One study found that families were more comfortable handling communication between primary care and specialty care than physicians were ceding this role to families; still, nearly a third of parents were uncomfortable serving as the intermediary (Stille et al., 2007).

Another approach is to establish an explicit agreement about the roles and responsibilities of the health care team and the patient/family. In the enacted but delayed Medicare Medical Home Demonstration, the Centers for Medicare & Medicaid Services (CMS) planned to require that medical home practices obtain a written agreement with eligible patients and have a process in place for sharing information about what it means for the practice to function as a medical home. This information was to include what patients must understand about what the medical home will do for them and what their responsibilities would be to the medical home. The CFAH similarly proposes, between patients/families and health care providers, a "pact" that would reflect agreement about roles and responsibilities and suggest "a sense of moral and social obligation which expresses the intent of all parties to work together toward a shared aim" (Gruman et al., 2009b). This idea of an agreement is also incorporated into projects at Geisinger (Casale et al.,

2007) and Massachusetts General Hospital (Chueh, 2008) that have a broader focus on shared decisionmaking (Appendix Table A.2).

Experience with formal agreements has not been entirely positive. In 2004, France instituted a registry system designed to give primary care physicians accountability for a patient population (see Appendix Table A.1). Physicians became eligible for an additional fee if they developed a shared care plan for patients with chronic disease and patients became eligible for lower cost-sharing. The requirement was later discontinued after it became clear that physicians viewed the plans as an administrative burden rather than an aid to care and that patients were not participating in developing the plans (Polton, 2009).

Information sharing can improve coordination of care. Discussing a summary medical record with patients can help them understand the providers' perspective on the visit and next steps, and be shared with other providers. The Stoeckle Center provides families and other care providers with a written summary of care for children with chronic conditions. Electronic tools can support information sharing between patients and health care teams. Tools like after-visit summaries, care plans, access to medical records, and personal medical records may enable improved communication and provide resources to patients to share with other providers and in emergencies. Personal health records and other Web-based tools offer alternative approaches to information sharing.

Issues

Effective methods for communicating with patients. Questions remain about the best way to discuss with patients how a practice works and just what are the roles and responsibilities of patients and the health care team. What information is best shared via the Web or brochures? How frequently should information be discussed by the patient and care team (first visit, once a year)? With whom in the practice should the discussion take place? Should a discussion of roles and responsibilities be formalized with an agreement?

Adapting to different populations. Understanding the preferences of patients and families about their roles and responsibilities, as well as their capabilities for participating as partners, is important, as patients will vary in what type of role (if any) they want. Different ways of discussing partnerships may be needed for populations with low literacy or a mistrust of the health care system.

Meaningful agreement. As the French example illustrates, an explicit written agreement may not achieve the desired goal of obtaining a "shared understanding" of roles and responsibilities. Understanding how to make the agreement process a meaningful step for patients/families and the health care team is critical.

Role of Health IT. While electronic tools can support information sharing, interfaces between practice-based electronic medical records (EMRs) and patient personal health records are not yet seamless and require a lot of maintenance. Developing ways to make them a seamless part of an information system is critical; this includes updating practice workflows to incorporate these tools.

Self-Care

Rationale and Evidence

Supporting patients in improving their health is a key expectation for the medical home. Efforts include helping patients with chronic diseases (1) develop and follow self-care guidelines about diet, exercise, medication adherence, and symptom recognition; as well as (2) deal with risk factors such as obesity and undertake efforts to reduce their risks. A recent review showed that a variety of efforts to support patient self-management have demonstrated positive effects on patient outcomes, knowledge, and self-efficacy. These efforts include computer-based programs that combine health information with online peer support, decision support, or help with behavior change (Murray et al., 2005). However, programs that merely offer information do not appear to be effective (Coulter and Ellins, 2007). Despite evidence of effectiveness, self-management support and patient followup are infrequently used in most health care settings (Glasgow et al., 2005). In a recent national survey of American adults with a chronic condition, 30 percent of respondents said that they frequently or occasionally leave a doctor's office or hospital confused about what they should do, 57 percent said that their health care providers did not ask whether they have help to manage their conditions at home, and 45 percent reported that their providers rarely or never refer them to patient resources such as classes, counselors, dieticians, or health educators (NCOA, 2009).

There is growing evidence about the need to adapt self-care support to patients' self-efficacy. According to Hibbard et al. (2009), activated patients engaged in more self-care behaviors, and patients who received coaching tailored to their activation level had greater improvement in their biometrics and their adherence to recommended regimens, and showed greater reductions in hospitalizations and in emergency department use than did patients coached in the usual way.

Examples

The best-known and most widely deployed examples of self-management programs are the collaborative care management principles embedded in the Chronic Care Model (Bodenheimer, Lorig, et al., 2002; see Appendix Table A.2). Self-management is a central component of the Chronic Care Model (Wagner, Austin, and Von Korff, 1996), and numerous studies have shown the ability of teams to implement and increase self-management support processes (Glasgow et al., 2002). Because the model involves multiple components, it is not possible to isolate the effects of the self-care components (Chodosh et al., 2005). There are also concerns about the sustainability of the Chronic Care Model outside research settings; a recent report attributed the discontinuation of effective Chronic Care Model programs after the trials ended to the lack of reimbursement for care management staff and other components of the intervention (Butler et al., 2008).

The Chronic Disease Self-management program developed at Stanford University has gained attention as an effective, peer-led model. Peer facilitators lead small-group training on self-management skills following a structured protocol, usually in a community-based setting with limited interaction with the patient's health care providers. The program has been shown to improve outcomes in a number of areas and may lower costs for participants (Lorig et al., 1999

and 2006); however, the evidence for this program is limited to trials conducted by the original developers and with relatively small and self-selected patient groups. Still, the Administration on Aging sponsors this self-management program in senior centers and churches across the country. Participants in group classes are more likely than nonparticipants to be white and female (Bruce, Lorig, and Laurent, 2007), but the program is apparently beneficial for minorities who participate (Lorig et al., 2008). An online version of the programs offers an opportunity to reach different populations.

Health IT provides the opportunity to support self-care (including through the programs noted above), and many practices with EMRs are using tools such as secure messaging, education, self-monitoring, and online portals (see examples in Appendix Table A.2 from Geisinger, Kaiser, and CHESS). The Ideal Medical Practices model uses a Web-based tool to assess patient needs and self-efficacy; practices can use this information to work with the patient and family to develop a care plan (Wasson et al., 2003). Recent research has tested additional capabilities, such as importing data to a personal health record, enabling patients to author a care plan prior to upcoming appointments, and offering a secure patient Web site for recording symptom-monitoring at home (Grant et al., 2008; Green et al., 2008). Neither study showed a positive impact on patient outcomes from the Health IT innovation alone (Grant et al., 2008), although one study found increases in treatment changes and the other found improved outcomes with the addition of contacts from a pharmacist (Green et al., 2008). There was evidence that the research participants tended to have milder disease and higher socioeconomic status than nonparticipants or the population with chronic disease in general. These studies raise concerns about the ability to engage the neediest group in Health IT interventions, the "stickiness" of the interventions (the degree to which patients persist in using the tools), and the importance of human contact (at least electronic) in supporting self-care (Jones and Peterson, 2008).

Other interventions seek to support patients and families who may benefit from resources outside the practice for supporting self-care. Several examples of electronic tools that identify patient needs and facilitate patient engagement with outside resources (such as smoking cessation) are described in Appendix Table A.2. ELinkS, an EMR-based tool, prompts clinicians to counsel patients on healthy behaviors and gives clinicians a tool to automate referrals to community counseling services. This makes it easier for the clinicians to identify local resources and discuss them with patients, and the community service agencies can proactively reach out to the patients (Krist et al., 2010). But the research study also included funding for the outside counseling—and when the grant funds ran out, the referrals declined. Practices also had problems maintaining the linkages with the community-based services, in part because of staff turnover. Some patients preferred to get the information and follow up themselves. The cost of services was a major factor in participation. This experience highlights the multifaceted challenges in care coordination.

Issues

Skills for self-care. Helping patients and families acquire the skills for self-care, in addition to providing information about diseases, risks, and treatments, is an important challenge for the medical home. A key step in this process is understanding how patients view their problems and their priorities for care (e.g., incontinence may be a greater priority than high blood pressure). A second step involves eliciting patients' views of their ability to change and helping them to gain

skills to become more confident in self-care. Practical models are needed for eliciting patient views about their priorities, their interest in self-care, their confidence in it, and use of this information in supporting self-care.

Deployment. Despite the evidence for self-care programs, deployment is not widespread, and determining where to focus resources for support is a primary issue, particularly under current payment systems in which reimbursement for care management and other nonvisit services is uncommon. Small practices may need assistance in understanding exactly how they can accomplish this, either within the practice or through the use of community resources. Effective methods and incentives for encouraging and supporting handoffs and collaboration between health care practices and community-based services are needed, along with the specialized efforts to support patients in setting and meeting health goals. Structural problems, such as lack of office space for group meetings, can also be barriers.

Tailoring for different populations. Using multiple modes (face-to-face, Web, mail) and multiple settings (practice, community) may be critical to reaching greater numbers and different types of patients. The proven self-care approaches have not appealed to all patients, and therefore need to be tailored or supplemented.

Opportunities for Health IT. The expansion of Health IT offers new ways to support patient engagement in self-care. A priority for future work could be to consider ways to make the interventions more acceptable and useful to a wide range of populations. Special effort also could be applied in considering how Health IT can support people with limited English proficiency and limited literacy.

Decisionmaking

Rationale and Evidence

That patients and clinicians should be partners in making treatment decisions is a common expectation for the medical home and patient-centered care; how to incorporate this expectation and include the adoption of formal shared decisionmaking processes is still open to debate. Shared decisionmaking refers to a formal process in which patients review evidence-based decision aids to understand the likely outcome of different treatment options, think about and discuss with a health care provider what is personally important about the risks and benefits of different options, and then decide jointly with the health care provider on a treatment or course of action that best reflects the patients' preferences and values (Charles, Gafni, and Whelan, 1997). This process focuses on preference-sensitive decisions, where there is not a single "best" option. There is evidence that use of evidence-based decision aids increases patients' understanding of their condition, treatment options, and outcome probabilities; improves the agreement between patients' preferences and treatment decisions; and reduces the use of discretionary surgery without apparent adverse effects on health outcomes or satisfaction (Coulter and Ellins, 2007; O'Connor et al., 2009). However, the existing evidence does not confirm benefits for health outcomes or costs.

Patients' willingness to engage in the decisionmaking process varies by the type of decision; for example, patients with cancer have an urgent need to make a decision and are more likely to view the decision aid and participate in the discussion. Where there is less urgency to the

decisions, such as with decisions about chronic conditions or preventive needs, patients are less likely to participate in shared decisionmaking efforts (Brackett et al., 2010). Most of the research on decision aids and formal decisionmaking processes has been conducted in specialty settings, which are the sites for many preference-sensitive services such as knee replacement and breast cancer treatments. There is a desire to implement shared decisionmaking process in primary care, both as a way to move the decisionmaking upstream (before a referral happens) and for services that are generally found in primary care (such as cancer screening and chronic care management).

Four States have current or pending legislation to promote the use of shared decisionmaking for the treatment of various conditions, and the recent Federal health care reform also calls for demonstration activities (Maine, 2010; Minnesota Health Services, 2010; Vermont, 2009; Washington, 2007).

Examples

The Foundation for Informed Medical Decision-Making (FIMDM) is supporting pilots in primary care practices such as Stillwater Medical Group in Minnesota and Dartmouth in Vermont (FIMDM, 2010). These pilots are disseminating decision aids through a variety of mechanisms: (1) creating health libraries where patients can view decision aids and obtain one-on-one decision support, (2) training practice-based health coaches and health educators to provide one-on-one decision support to patients after they view a decision aid, and (3) offering group medical appointments where providers can discuss decision aids with multiple patients simultaneously.

FIMDM has identified some of the key issues affecting implementation, such as developing efficient approaches to identify targeted patients, making a decision aid available to them for a range of decisions, engaging patients to use the decision aid, and providing additional counseling or decision support to patients after they have viewed the decision aid (FIMDM, 2010). For example, the implementation of shared decisionmaking may have to vary based on the type of decision. For screening decisions, viewing an aid before a scheduled visit may be useful. For chronic conditions, decision aids can be incorporated into self-management programs or group visits. For preference-sensitive conditions when elective surgery is being considered, viewing the aid prior to specialist referral or specialist visits may be important.

Issues

Adapting to patient's preferences for decisionmaking role. Efforts to engage patients in decisionmaking must consider the extent to which patients and families vary in their desire to assume such responsibility (Bruera et al., 2001; Degner and Sloan, 1992) and the many factors that affect patient preferences (Epstein and Street, 2008). Practices may need an explicit approach for identifying patient and family desire to be involved in decisionmaking. Such discussions will determine the amount of shared decisionmaking each patient would like. Patients vary widely in how much they want to be involved in decisions. Some patients make the decision, for example, to leave the decisionmaking to the doctor. When the patient does want to take an active role, the practice team needs to be prepared for possible differences in opinions. Ways to prepare staff and clinicians to anticipate and work with these conflicts are needed.

Logistics. It takes significant thought and effort to get the right tool to the right person at the right time. This is an area where research and demonstration projects are needed to identify roles of different members of the health care team, opportunities for using Health IT or shared community resources to support shared decisionmaking, and ways to make the process relevant and useful to patients and families, as well as the funding streams to support these efforts. Web-based tools to facilitate shared decisionmaking are promising but need more work. Developing Web-based tools is complex and requires specifying the content, as well as using creative design and tailoring the tool to the target audience (Glyn Elwyn, personal communication). Ensuring that tools are developed and maintained as the scientific evidence base changes is another challenge.

Meeting the needs of vulnerable populations. Few existing evidence-based decision aids are suitable for patients with low health literacy or limited English proficiency; development and testing in these populations is needed.

Safety

Rationale and Evidence

The National Priorities Partnership (2008), a collaborative effort of 28 major national organizations involved in all aspects of health care, designated safety as one of the six national priorities for the U.S. health care system. They call for promoting a culture of safety and driving to lower the incidence of health-care-induced harm, disability, and death toward zero, but most of the specific goals target inpatient, rather than primary, care. Medical homes are currently expected to use electronic tools to support patient safety (for example, e-prescribing tools that identify potential medication interactions). However, there may be additional opportunities for patients and families to work with medical home teams to promote safety. Studies show that patients can improve safety through informed choices, safe medication use, infection control initiatives, observing care processes, reporting complications, and practicing self-management (Coulter and Ellins, 2007). However, patients' willingness to take on safety actions is likely to be affected by a variety of patient, provider, and system factors. Importantly, many patients find it difficult to behave in ways that might challenge clinicians (such as questioning a physician's judgment or actions, Davis et al., 2007), and patients need a sense of self-efficacy and assertiveness to assume this role (Hibbard et al., 2007).

Examples

Tools developed by the American Hospital Association (2003) and the National Patient Safety Foundation (2008) support the creation of opportunities for patients to open a conversation about safety issues with providers (Appendix Table A.1). However, there is little information on the extent of the adoption of these tools in primary care settings.

There are tools for involving patients in reporting on potential safety problems, but use of these tools is not widespread. Most projects to encourage anonymous reporting of safety concerns have focused on clinicians and staff. For example, parents/patients accounted for only 5 percent of safety reports in an effort at Beth Israel pediatric ambulatory care clinic (Neuspiel et al., 2008). An AHRQ-funded project is under way to develop recommendations for reporting

systems that would allow consumers to report on potential safety events (Designing Consumer Reporting Systems for Patient Safety Events, 2009). The *HowsYourHealth* survey currently allows patients to report on safety concerns, but it has not been widely adopted (Wasson et al., 2007).

Efforts to improve medication reconciliation are another approach for engaging patients and families in patient safety (Appendix Table A.2). About a week before a scheduled appointment, the Mayo Clinic sends patients a letter reminding them to bring in all medication bottles or an updated list of medications. At the visit, a physician assistant meets with the patient to verify the information and make any needed changes in the medication list in the EMRs, and the physician discusses the information and makes any changes during the patient visit. A new list can then be printed for the patient (Varkey et al., 2007). Some organizations have employed Web-based personal health records to make it easier for patients to record information, but this may require patients to enter information themselves.

Issues

Role of patients/family in safety culture. Organizations that encourage clinicians and staff to report safety concerns emphasize safety as part of a culture of quality, make a commitment to following up and reporting on all reports, and train clinicians and staff on the importance of safety. Medical homes offer an opportunity to inform patients about safety behaviors and to query patients regularly about possible problems. Efforts to encourage patients to report safety concerns anonymously could be considered. Systems that allow employees to report safety concerns could be expanded to allow patients and families to report concerns as well.

Lack of definition and measures. More effort is needed to identify specific opportunities to improve patient safety in primary care settings. This will help practices and patients know what to look for and help practices track issues for improvement.

3. Engage Patients and Families in Practice Improvement

This section turns to the rationale and evidence base for engaging patients in the design, evaluation, and improvement of care delivery at individual practices, and offers examples of opportunities to do so. Patient and family participation in practice improvement activities has been a critical component of the medical home model, particularly as originated in pediatric settings.

Rationale and Evidence

In most cases, efforts to involve patients in practice improvement are the expression of a fundamental value, consistent with the IOM goal of patient-centeredness, and have therefore not been the subject of study. There is little evidence about the impact of these activities on outcomes for the practices, the clinicians and staff, or patients. The few randomized studies in the literature suggest that involving patients in the development of patient information materials may lead to more relevant, readable, and understandable tools; however, consumer input on informed-consent documents did not have an effect on patient's understanding of the research trial described (Nilsen et al., 2006). Observational studies suggest that involving patients in practice improvement enhanced staff attitudes and increased participants' use of services (Forbat et al., 2009). Leaders from organizations that have involved patients and families in practice quality improvement or redesign testify as to its importance and positive impact. In key informant interviews we conducted for this paper, one State Medicaid director told us, "I am convinced that in our experience, patients drive change faster and more appropriately than anything else" (Jeff Schiff, personal communication).

Examples

Informal methods for gaining patient and family feedback are frequently used in quality improvement and are particularly useful for getting at the more specific ideas and concerns of patients and families. Examples include keeping a suggestion book or comment cards in waiting rooms, getting family input on the development of new educational materials, asking patients and family members to do a "walk-through" of the practice to get ideas on the patient's perspective of the practice workflow, discussing different methods of involving patients in shared decisionmaking, helping design programs to improve the completion of health care proxies and advance directives, and inviting patients to interview prospective staff. In particular, these informal approaches are useful for understanding how to approach a quality problem identified through survey or other performance data. Patients can also be involved in planning data collection efforts and interpreting data from multiple sources (including chart review, patient surveys, and staff surveys).

Efforts to include patients as members of standing patient/family advisory councils, quality improvement teams, or other ongoing groups to support design and evaluation of the practice and services have been used in a number of collaborative quality improvement models, particularly in hospitals. The most advanced models derive from medical home efforts for children with

special health care needs in primary care settings as well as examples from inpatient settings led by groups like the Institute for Family-Centered Care; the applicability of these models to typical primary care settings is unclear (Appendix Table A.3 gives examples). The work of the Institute provides examples of what is possible at larger facilities and strategies that may be adaptable for primary care practices (Institute for Family-Centered Care, undated [a], [b]). These include patient/family rounds in the inpatient settings, the use of family advisors in training for new staff and for medical and nursing students, and the standing patient/family advisory council, as well as the inclusion of patient/family members in workgroups and committees on topics ranging from quality improvement teams to hospital renovations, admitting procedures, and discharge planning (Reid Ponte and Peterson, 2008). At MCGHealth, patient advisors participate in mandatory training of new employees, where a 3½-hour block of 2-day training is devoted to patient and family-centered care. A key message to staff, including those involved in housekeeping and environmental services, is that they may spend more physical time with hospital patients than clinical staff do. Patients may tell them something they have not told the doctor, nurse, or anyone else. "We try to train everyone to make a difference in the patient's life" (Nettie Engels, personal communication). In most of these efforts, providers invite patients to participate, and training on roles and expectations is usually provided.

The American Academy of Pediatrics' Medical Home Toolkit (updated 2008) suggests that practices should assess the needs of families, solicit feedback from families, have a parent/practice advisory group, establish specific communication methods or systematic inquiry of family concerns/ priorities, and display a written mission statement.

In a medical home collaborative in Minnesota, two family members served on the quality improvement team and offered suggestions for addressing problems that providers had not identified themselves (Carolyn Allshouse, personal communication). The parents on one team requested that the pediatric clinic be made wheelchair-accessible. (The providers used a different entrance to the clinic and were unaware of the problem.) Parents also started networking groups among families in the practice and community to identify needs of and communicate with families.

Surveys are commonly used for gaining feedback from patients and families and have been proposed by advocates for patient-centered care. Several standardized tools are available, including the AHRQ CAHPS Clinician and Group survey. National information on how often ambulatory practices conduct surveys is not available. There is limited evidence about how practices can use survey results to improve quality, but the available studies suggest that considerable planning and organization is needed. In a Minnesota collaborative focused on using data on patient experiences to improve quality, only two of seven medical groups demonstrated short-term improvements. Focusing on simple interventions and having engaged leadership and organizational structure for practice redesign appeared to be related to demonstrated improvement (Davies et al., 2008).

The collection and reporting of patient experience data may be facilitated by regional or statewide efforts. Examples are Massachusetts Health Quality Partners, Pacific Business Group on Health, and participating sites in the Aligning Forces for Quality program (Robert Wood Johnson Foundation, AF4Q, 2010; Massachusetts Health Quality Partners, 2010; Pacific Business Group on Health, 2010). All three efforts use versions of the CAHPS Clinician and Group Survey and report data publicly. However, they vary in level of reporting (physician

organization, practice site, or individual doctor). A quality improvement guide on the AHRQ Web site (https://www.cahps.ahrq.gov/qiguide/default.aspx) offers information on how to use patient experience data in quality improvement. The guide offers information for organizations on how to analyze the results of CAHPS surveys to identify strengths and weaknesses, develop strategies to improve performance, and implement interventions to achieve performance goals based on CAHPS results.

Another model for assessing patient experiences is the use of Web-based surveys directed by the practice. *HowsYourHealth* is an example. Practices can give patients information on how to complete the anonymous survey online; patients must provide permission to allow their results to be shared with the practice. Practices can use the survey results in real time for quality improvement at low cost (Wasson et al., 2008).

Issues/Analysis

Feasibility in routine practice. While there are successful models for involving patients in quality improvement teams or advisory councils, these come from larger practice settings or smaller practices linked to a collaborative network. There are particular concerns about applicability of models for small primary care practices. Engaging patients in practice improvement takes extra time and resources. Surveys or other informal approaches for getting feedback may be more feasible in these settings. Because of the training considerations as well as the need to listen and compromise, extra staff time is needed to involve families in ongoing activities.

Likewise, the time and resources needed to collect, analyze, and report survey data are often new expenses for the practice. Practices perceive on-site data collection as the cheapest and easiest way to collect patient survey information, but research suggests that these data may be biased (Anastario et al., in press), and experience shows that the cost may not be low, especially when tasks are assigned to an already overburdened primary care team (Susan Edgman-Levitan, personal communication). Web-based methods such as *HowsYourHealth* are appealing because of their low cost and the opportunities they offer for streamlined data collection and analysis.

Need for multiple and flexible approaches to gain patient input. Practices may need to consider multiple options for obtaining patient feedback for practice improvement. Survey data may help identify problems, but finding the solutions is likely to require other efforts, such as focus groups, informal interviews, or practice walk-throughs.

Identifying patients to participate in improvement activities. Practices need guidance on how to identify and recruit patients and families to participate in practice improvement. Experience from existing programs suggests that important considerations are the patients' and families' ability to work with the health care team, their breadth of experience with the health care setting, their ability and willingness to communicate concerns, and the patient or family member's ability to represent patients and families broadly rather than focus narrowly on a particular issue.

Training. When patients play ongoing roles on quality improvement teams or advisory groups, training is needed for them as well as for clinicians and staff. Learning together about

new constructs, such as quality improvement, puts practice staff and family members on an equal plane. For patients/family members, training might also address such issues as how to tell their story, what the privacy boundaries are, and where and how to get information on topics they do not understand.

Meaningful participation. Involving patients/family members in key roles such as setting meeting agendas, taking notes, and leading meetings conveys that they are equal members of a team or committee. Setting realistic expectations is important. For example, if renovations to a crowded waiting room are not feasible, that can be acknowledged up front so that the discussion can focus on other issues.

Sustaining participation. Practices can expect patient attrition due to family illness, loss of interest, or other competing needs. Inviting additional patients and family members or creating a family network may be helpful. Some practices give small stipends to patients and family members serving as facilitators, as well as provide meeting space and supplies for patient meetings. The enthusiasm of the practice and its willingness to embrace suggestions from patients and family members can also influence ongoing participation.

Motivation. Practices must be motivated to use patient input to improve care. Motivation can be external, based on accountability through public reporting or financial incentives, or internal, usually deriving from the desire to improve patient care. For example, hospitals are financially incentivized to report on the hospital version of the CAHPS survey as part of CMS payment policy. There is no similar incentive for practices, although they may receive financial or other rewards from private payers for high performance on surveys of patients.

4. Engage Patients and Families in Policy

Policy development and implementation is the third context for engagement of patients and families. Design of medical home policy initiatives, demonstrations, and pilots provides some immediate opportunities. While the involvement of consumer representatives is increasing in the efforts of both the public and the private sector, the degree of input varies. Besides service on multistakeholder committees, patient advocacy roles may involve gathering input from patients, synthesizing patient experiences, participating in training, and overseeing implementation. This section discusses the rationale and evidence for patient engagement in these policy initiatives, describes examples related to the medical home and other health care initiatives, and examines issues related to broader implementation.

Rationale and Evidence

As with patient involvement in practice improvement, efforts to engage patients in policy initiatives derive primarily from a core belief in patient-centeredness. The scant research evidence on the impact of patient engagement in policy contrasts with strong endorsements of the process from leaders and organizations who have been involved in these efforts. A recent review of randomized controlled trials assessing methods for involving consumers in developing health care policy and research, clinical practice guidelines, and patient information material found very few published studies, and none showed consistent benefits or addressed the costs of the interventions (Nilsen et al., 2006). One trial compared two different methods for involving the public (telephone discussion versus face-to-face group meeting), and showed that the latter is more likely to engage consumers and may result in different community health priorities (Nilsen et al., 2006). Clinical and organizational leaders in programs or organizations that have adopted patient engagement strategies testify as to their benefits (personal communications, Pat Sodomka, MCGHealth; Jeff Schiff, Minnesota Medicaid). The need for leadership and commitment to patient-centered care at the top levels of governance was a primary conclusion of Pursuing Perfection, a national program of the Robert Wood Johnson Foundation designed to help hospital and physician organizations improve patient outcomes (Robert Wood Johnson Foundation, 2005). Still, while patient involvement was a key component of this program, it is unclear how it affected the outcomes or to what extent it was implemented across the multiple organizations. Patients and family members who have the opportunity to serve in multistakeholder groups may reap the personal benefits of feeling more empowered and able to manage their self-care more effectively (Cavet and Sloper, 2004; Hubbard et al., 2007).

Examples

The concept and desirability of engaging patients in health care policy and governance is not new. When the Office on Economic Opportunity was established in the mid-1960s as part of the War on Poverty, one of its stated goals was to develop both consumer participation in identifying needs important to the community and a structure for serving those needs. Service programs, including Head Start and Neighborhood Health Center, were required to convene community councils that were to guide such activities as the establishment of program priorities, the selection of the project director, the location and hours of center services, and the evaluation of

suggestions and complaints from patients. The organization and functioning of those councils varied, but anecdotal evidence from site visits in 27 centers suggested that consumer participation led to changes (e.g., requiring Spanish-speaking clinicians or hiring clinicians who live in the neighborhood to facilitate after-hours access to care) and noted the value of having consumers from impoverished neighborhoods sit at the table with professionals and government leaders (Sparer, Dines, and Smith, 1970). Today, consumers continue to play a strong role in governance of federally qualified community health centers. In addition to giving feedback on how patients and families experience care in the clinic, consumer board members participate in decisions on hiring and service offerings. A yearly needs assessment of the community, along with the consumer's knowledge and understanding, are critical for planning services (National Association of Community Health Centers, 2007).

Consumer involvement is also a keystone in other health care efforts (see Appendix Table A.4), such as mental health and substance abuse care, which features consumers as leaders in recovery-based care (Substance Abuse and Mental Health Services Administration, 2006); consumer-led health care delivery systems such as the Group Health Cooperative (Group Health Cooperative, 2010); the priority-setting efforts of Oregon's Medicaid program; the involvement of consumers in research through the Federal Government's Office on Human Research Protection, which requires that local institutional review boards approve research involving human subjects (Director, Division of Human Subject Protections, 2000); and the inclusion of consumers on AHRQ's stakeholder panel for its Effectiveness of Health Care program. The United Kingdom has recently evolved from relying on a standing advisory forum for the local health district to establishing independent networks financed by local health districts. Patients can be involved in different ways, ranging from answering a survey and participating in online evaluation groups to becoming an authorized representative who visits providers to see how they deliver services (National Health Service, 2009).

Nationally, the NPWF has a significant initiative to engage consumer advocates and consumers in issues related to health care reform in general and the patient-centered medical home in particular. They assembled a coalition of more than 25 of the Nation's leading consumer, labor, and health care advocacy groups to develop the Consumer Principles described in Section 1. The NPWF also developed a toolkit for consumer advocates with information to help them understand the medical home, advocate for the medical home in their community and nationally, look for opportunities to participate in the design of medical home initiatives in their area, and help explain the concept to other consumers (NPWF, 2009).

Medical home demonstrations vary in their degree of patient participation in design or oversight of implementation. A survey of 19 such demonstration projects found that only 7 involved patients in activities such as serving on a task force or advisory board, participating in focus groups or other meetings, reviewing audiovisual or written materials, or participating in quality improvement activities (Malouin, 2009). While all but 2 of the 19 pilots are collecting data on patient experiences, direct involvement of patients in policymaking appears to be limited. Other regional efforts to improve quality, such as the Aligning Forces for Quality initiative supported by the Robert Wood Johnson Foundation in 14 communities nationwide, feature consumer engagement in reporting and use of community-level data on provider quality (Robert Wood Johnson Foundation, AF4Q, 2010).

Issues

Engaging patients at the policy level creates some of the same challenges for patient representatives as participating in quality improvement at the practice level. These include challenges with regard to selection, training, and preparation discussed in Chapter 3. Some other important issues are listed below.

The messenger matters. When asked to participate in multistakeholder processes, consumer organizations are sensitive about who is asking for their help and whose interests are at stake. Early and ongoing engagement in a multistakeholder process may head off these concerns.

Role of patients and consumers. It is important to distinguish whether the role for consumer organizations follows community organizing principles, which indicate that patients and families get to define the topics that are important. If the role is to respond to an existing list of policy options, or if a limited set of responses can be entertained, it is important to set those ground rules from the beginning. Similarly, involving consumers in the process via advocacy groups is different from involving patients and families directly. Patients and families provide a bottom-up view of the health care as they receive it; advocates are also aware of broader policy developments and implications. It is important to have both perspectives.

Time and resources. Consumers may need ongoing support to stay involved in advocacy and system redesign. Offering opportunities for consumers to learn alongside others is important, as is providing access to the information they need. Because many advocacy organizations have limited budgets, asking them to serve on panels may take their attention away from their core jobs. Likewise, patients and families have other responsibilities. Even small stipends can help support their participation.

5. Conclusions

This paper presents a framework and offers examples of ways patients and families can become engaged in the medical home: through activities related to their care, practice improvement, and policy development. The section provides overall conclusions about the rationale and evidence for patient engagement in all three areas. In addition, we identify, from our literature review and input from key informants, key themes that affect the feasibility and successful implementation of patient engagement strategies.

- As articulated by the IOM, patient-centeredness is an independent aim of the health care system, and the diverse stakeholders among our expert panel and key informants agreed on the value of patient engagement as a way of achieving it. However, they held disparate views about the level of evidence needed to buttress policy efforts to promote patient engagement in the medical home and more broadly throughout the health care system. For some, efforts to promote engagement should be supported as a means of achieving patient-centeredness and not judged by their impact on the IOM's other quality aims, including effectiveness and efficiency.

- Other stakeholders were troubled by the limitations of the evidence base for particular strategies and argued for the need for better evidence about impact and feasibility. With health care costs rising and budgets tightening, they questioned whether primary care practices and the health care system generally should be expected to invest in new and unproven methods to engage patients and families in care. In particular, they questioned whether engaging patients in practice improvement was necessary, feasible, or desirable, particularly if such efforts distract overburdened clinicians and practice staff from efforts to involve patients in the critical work of participating in their own care. One expert panelist recommended leaving these issues to market forces and allowing patients to seek practices that match their preferences for engagement; other panelists felt this was unlikely to be a successful strategy.

The existing evidence base for patient engagement in general, and the effectiveness and feasibility of specific approaches in particular, is limited and variable. For patient engagement in care of the individual, there is good evidence that specific interventions can improve patient knowledge, self-efficacy, and some outcomes, and reductions in utilization or costs of care have been reported in some studies. The best evidence relates to patient engagement strategies incorporated in multifaceted interventions like the Chronic Care Model, where it is difficult to break out the impact of specific components. Other intervention studies are small or lack generalizability to routine primary care practice. Efforts to involve patients in practice improvement and policy are usually the expression of a fundamental value consistent with the IOM goal of patient-centeredness, and therefore research evidence of impact on outcomes or costs is very limited.

- **Currently, efforts to engage patients in their own care, practice improvement, or policy are not common.** Many examples are drawn from research or demonstration initiatives, and adoption may be limited as a result of the evidence concerns noted above. Both financial and logistical barriers limit implementation. Traditional fee-for-service reimbursement does not reward practices for engaging patients. The infrastructure, time, resources, and culture change needed to transform a practice to a patient-centered focus is significant. Practices need assistance with redesign to engage patients and families. Payment reform may be critical to supporting engagement in care, but also engagement in practice design, since the tasks of getting patient and feedback and implementing changes to improve quality require time and resources. Small primary care practices in particular need access to resources for and assistance with practice redesign to accomplish meaningful patient engagement.

    Nonetheless, the existing efforts to support patient engagement in care, practice improvement, and policy suggest key lessons about successful implementation. Overall, key informants discussed the importance of a commitment to patient-centeredness as a core belief to the successful implementation of patient engagement strategies. They noted some key themes that embody this core commitment:

- **Asking patients and families what matters most to them is critical to engaging them in care.** Asking patients and families about their views of their health needs, understanding the context of their lives, and learning about their values and preferences are important steps in effectively engaging families in their care and providing effective care. Understanding what matters most to patients is crucial to helping them to develop a care plan and follow through with self-care. Key informants noted that efforts to engage patients in self-care must be grounded in a commitment to let patients and families lead even when it challenges the clinicians' views. In addition, seeking input from patients and families on what is working in the care process and care delivery can help practices to respond and improve in a timely way. Surveys can provide a representative snapshot of care in the practice. Informal inquiries or qualitative efforts can aid in understanding of the sources of problems and identification of possible solutions, and patients and families can help to improve care through participation in practice workgroups. Several experts told us that the suggestions given by patients and families are typically practical and discrete, and that practices and organizations which involve patients and families learn quickly how valuable this input can be.

- **Health care providers and patients need new skills to support partnership in care, improvement, and policy design.** For many patients and families, the opportunity to become engaged in care, improvement, and policy means taking on new roles and challenges that require support and training. New skills could include self-efficacy in self-management or decisionmaking, or in serving on quality improvement teams or multistakeholder committees. Likewise, to support engagement in care, clinicians and staff may benefit from specialized training in communication skills or motivational interviewing. Practice leaders need training in building effective quality improvement teams. This skill development at the

individual and practice level can support engagement at the next level through development of a cadre of informed and activated patients who can participate significantly in the design of care and of policy.

- **Patient engagement is not "one size fits all."** Flexibility and customization are needed to support populations that are diverse in education, values, health needs, preferences about their interactions with providers, and resources. Existing research suggests that offering support in different settings and modes reaches different kinds of patients. Engagement efforts should take into account patient diversity. Likewise, practices will vary in the methods they use to get input on care design and improvement. Some practices may value and sustain an ongoing patient/family advisory council, while others may find that ad hoc efforts suit the practice and their patients/families. The extent to which practices customize their care and their input process to their patients and families may be a marker of effective engagement.

- **Health IT offers the promise of making patient engagement more natural and less burdensome for both families and practices.** Computer and Internet-based tools can support communication between families and providers, provide information, support skills training, allow networking among families, facilitate connections between health care providers and between health and other social services, and enable patient feedback on care. Much experimentation is under way, and research on how to improve the usability of these tools for families and health care providers is needed, as are efficient ways to update and maintain these systems. Health IT should be viewed as a tool to support well-designed care systems, not as an end in itself.

6. Implications for Research and Policy

This review suggests a number of avenues for future research and policy efforts to build the evidence base about the impact and implementation of patient engagement strategies in care, practice, and policy. In particular, it is critical that these research and policy initiatives address some of the key barriers to patient engagement, including the lack of capacity in individual practices for undertaking new interventions, the uncertainty about the costs and benefits of these interventions, the availability of trained clinicians and staff to implement them, and the lack of reimbursement or payment for new and potentially intensive interventions.

Key Research Needs

There is a solid consensus that patient engagement is integral to high-quality health care—and indeed this is recognized in the IOM's inclusion of patient-centeredness as one of the core aims of health care and more recently in the National Priorities Partnership's call for including patient engagement as a focus for quality measurement and improvement. Still, the evidence about the most effective and efficient interventions is variable for interventions related to patient engagement in care and almost nonexistent for patient engagement in practice improvement and policy development.

A detailed analysis of the existing evidence and likely cost-benefit of these activities for all three types of engagement would be an important first step. This review should consider a variety of endpoints, including the impact on patient and clinician and staff experiences, utilization, quality of care, outcomes of care, and cost. Desired outcomes may differ for each type of engagement. Such a review should also seek to document characteristics of the intervention (staffing, intensity), population involved (clinical and demographic characteristics), and contextual factors (such as the availability of a learning collaborative activity or organizational resources for quality improvement), as well as evidence of dissemination and sustainability outside the research setting. This evidence review should build on the framework described here, with separate attention given to each of the types and contexts of engagement. The review should identify and prioritize gaps in knowledge.

The findings of this report and input from panelists and key informants highlight areas for immediate research, both quantitative and qualitative. First, the following topics are of particular interest as regards patient engagement in individual care:

- Impact on patient outcomes and cost of care, including patient experiences, patient activation or confidence in self-care, quality of care, patient outcomes, and costs of patient care.
- Impact on the practice, including clinician and staff experiences; costs of implementation, including staff and clinician time required; and training, productivity, and financial viability.
- Unintended negative consequences on the patient and the practice, such as patients' departure from the practice or reductions in practice productivity.

- Issues of dissemination and sustainability, including the cultural, organizational, and community factors that contribute to early adoption of interventions as well as to uptake by lagging practices. The focus should be on demonstrating models and addressing practical issues related to the effort and logistics of patient engagement interventions. Research should address what works in small versus large practices, and what services practice staff can deliver versus services available from community resources or an affiliated organization (such as a hospital, network, or health plan).
- The role of Health IT in helping practices adopt patient engagement strategies, as well as the use of Health IT for activities intended to reach consumers.
- Understanding how to adapt models and delivery modes to the needs of different populations, based on clinical characteristics (type of condition, level of severity), demographics (age, sex, race/ethnicity, socioeconomic status), as well as preferences for participation and confidence and interest in self-care. Of particular interest is how to adapt strategies for use with underserved populations and safety net providers.
- Interaction with and applicability to specialty care. Do the strategies for engaging patients apply equally well in specialty care settings? What are the relative roles of primary care and specialty practices in patient engagement, and how can these entities work together?

Table 1, in the Executive Summary, summarizes some of the key questions related to each of the types of engagement.

The research needs and opportunities surrounding patient engagement in practice improvement and policy development are similar. The emphasis should be on understanding their costs and benefits and, if they appear to be promising, developing feasible and sustainable models. While randomized trials may not be feasible, there is a clear need for well-designed studies that look at different ways of involving patients or their representatives in practice and policy efforts, and to evaluate their impact. Key research questions include:

- What are the steps to involving patients in a meaningful role in practice improvement and policymaking?
- What types of training do patients and staff need? Who will be the trainers?
- How can these efforts be made scalable?
- What types of changes do patients suggest? Which are adopted? Why are some not adopted?
- What is the impact on practice outcomes such as staff turnover and financial viability?
- What is the impact on patient outcomes such as functional status and work productivity?
- How might regional extension centers or other local community organizations support patient involvement in practice and policy? What role is there for Federal and State policy?
- What type of leadership and organizational culture promotes effective patient engagement? Are these characteristics that can be changed, and if so, how? Are codes of conduct about how clinicians and patients interact with each other (such as

statements of practice mission, expectations of staff, expectations of patients) useful in creating a culture conducive to meaningful involvement of patients?

Finally, better measures are needed to evaluate some of the key endpoints of patient-centeredness, patient safety, and shared decisionmaking. Methods and measures for assessing patient experiences with care are needed, in particular, low-cost and sound methodologies for incorporating patient survey results into practice workflow and improvement activities.

Policy Implications

As groundbreaking legislation supports the deployment of Health IT, the demonstration of new models of health care delivery and the extension of health care coverage to millions of Americans, ample opportunities exist for Federal and State policies to encourage patient engagement in care, practice redesign, and policy.

Expansion of Health IT. Federal and State efforts to promote meaningful use of Health IT provide important opportunities to harness these capabilities to support patient engagement. At the Federal and State levels, increased patient engagement is highlighted by meaningful-use measures that address such topics as provision of an after-visit summary and information. Importantly, these efforts to use Health IT need to be built in the context of effective care systems (e.g., an after-visit summary should contain information that supports self-care. Practice staff should have a specific role in providing and answering questions about the summary for patients).Input from patients on what information is useful and understandable (e.g., patients could review templates for summaries) should inform the summaries.

Federal requirements for demonstrating meaningful use by individual providers, as required by the American Recovery and Reinvestment Act, for 2015 and beyond can make use of ongoing experience and research to include explicit measures of patient engagement. CMS (2010) has proposed that its goals for the Stage 3 meaningful-use criteria be "consistent with other provisions of Medicare and Medicaid law, to focus on promoting improvements in quality, safety, and efficiency, focusing on decision support for national high-priority conditions, patient access to self-management tools, and access to comprehensive patient data." The Consumer Partnership for eHealth, convened by the NPWF, notes that Health IT should support patient-centered care by focusing on "patient-facing" information uses and by using Health IT to support "care redesign that is patient-centered and information-rich" (Consumer Partnership for eHealth, undated).

Technical assistance for patient engagement. In conjunction with Federal support for Health IT, regional extension centers will be providing support to thousands of primary care practices (Office of the National Coordinator for Health IT, 2010). In addition, the Patient Protection and Affordable Care Act (PPACA) authorizes a Primary Care Extension Program to provide support and assistance to providers on topics such as health promotion, chronic-disease management, and both evidence-based and evidence-informed therapies and techniques to improve community health (PPACA, 2010a, 2010b). While no funds were appropriated for the Primary Care Extension Program, both it and the Health IT regional extension centers offer policy mechanisms for providing technical assistance to support patient engagement. These

centers could also establish patient/family advisory councils or otherwise engage patient/family advocates to guide their efforts.

Demonstrations and pilots. Federal, State, and local promotion of the PCMH model provides the opportunity to explicitly demonstrate and test patient engagement—in demonstration design, in practice or delivery system redesign and evaluation, and in care. Efforts to develop accountable care organizations, responsible for both primary and subspecialty care and sometimes hospital care, also offer a significant opportunity for building and evaluating models for all three types of patient engagement.

Specific policy changes that may make innovations more feasible include:

- Establishing operational mechanisms to support payment for specific evidence-based, patient-centered care services in the current fee-for-service environment (e.g., establishing a payment code to allow practices to bill for shared decisionmaking)
- Encouraging measurement of key outcomes, including pooled resources for supporting low-cost or shared services for collecting patient survey data about risk factors and activation in care, as well as patient experiences and satisfaction.

As the new delivery models and technologies are implemented, it is critical that these opportunities for experimentation and innovation are used to learn more about effective ways to engage patients and families in care, practice design, and policy development. If full advantage of these opportunities is to be taken, the ongoing development and implementation of the patient-centered medical home may be best served by the explicit identification of an overarching framework for prioritizing opportunities for patient engagement; carefully designed evaluations that provide information about what works, what doesn't, and how much it costs; and a deliberate plan for incorporating the best knowledge of effective methods for patient engagement.

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Appendix A: Additional Tables

Table A.1. Examples of tools: engaging patients/families in the care of the individual patient

Organization	Target	Description	Content
Patient Care Partnership (American Hospital Association, 2003)	Communication and information sharing	The Patient Care Partnership poster and brochure for patients; brochure is available in multiple languages.	Plain language poster and brochure replaces the AHA's Patients' Bill of Rights and describes what patients should expect during their hospital stay: • High-quality hospital care. • Clean and safe environment. • Involvement in their care. • Protection of their privacy. • Help when leaving the hospital. • Help with billing claims.
Center for the Advancement of Health (CFAH)/Stoeckle Center (Gruman et al., 2009a)	Communication and information sharing	Creating a patient guide for a Medical Home physician practice. CFAH/Stoeckle Center suggests that each clinic or practice develop and distribute a short guide and/or use it as a template for its Web site.	CFAH created three resources that medical home practices can use to create a simple guide for their patients. The guide should include routine information such as how to contact the practice, location, hours, appointments and payment policies. The guide should also provide instructions for other kinds of communication with the practice like notifying the practice about special needs, the availability of tests and the policy for notification of test results, how to get care after hours or in an emergency, instructions for securing prescription refills, and addressing problems with medications. The resources are: • List of elements that constitute a basic guide. • Sample guide to illustrate finished product. • Template for practice to design its own guide.
National Partnership for Women and Families, 2009	Communication and information sharing	Tools and resources for patients and consumer advocates on the medical home, what it means for patients and ways that advocates can help shape and promote medical home proposals at the local and national level.	Patient Resources: • "A Medical Home Is About You" is a guide for patients and consumers on the medical home. Consumer Advocate Guides: • Consumer Principles. • Understanding the Medical Home. • Why Consumer Advocates Should Get Involved. • How Consumer Advocates Can Get Involved.
National Patient Safety Foundation NPSF, 2008	Communication and information sharing	The Universal Patient Compact: Principles for Partnership™ is a statement of principles established by NPSF that defines the elements of true and effective partnering between patients and providers.	The compact describes the role of the "health care partner": • Include you [patient] as a member of the team. • Treat you with respect, honesty, and compassion. • Always tell you the truth. Parallel statements for the patient's role: • Be a responsible and active member of the health care team. • Treat providers with respect, honesty, and consideration. • Always tell providers the truth.

Table A.1 Examples of tools: engaging patients/families in the care of the individual patient (continued)

Organization	Target	Description	Content
Primary Care Information Project, New York City (Sarah Shih, personal communication); similar process used by Cleveland Clinic, Group Health of Puget Sound, and Kaiser Permanente	Communication and information sharing	After-visit summary.	Topics covered include diagnoses; key findings from visit (such as blood pressure); treatment recommendations, including referrals to specialist or community services; and provider contact information. A template is included in the electronic health record and can be printed and provided to patients and families.
MassGeneral Hospital for Children, undated	Self-care	Written care summary for children with chronic conditions.	The summary includes information on diagnoses, medications, providers, and community supports, as well as "common presenting problems, specific suggested management and other things you should know (likes, dislikes, strengths, difficulties, what upsets/calms me)." A template for this information is included in the electronic health record and can be printed or stored on a flash drive and provided to patients and families.

Table A.2. Examples of interventions/programs: engaging patients/families in the care of the individual patient

Program (reference)	Target	Description	Evidence Base
Collaborative care management/Chronic Care Model (CCM), MacColl Institute (Improving Chronic Illness Care, 2010)	Self-care	**Purpose:** Encourage high-quality chronic disease care. **Components:** Evidence-based change concept in six areas: self-management support, community, health system, delivery system design, decision support, and clinical information systems.	Bodenheimer et al. reviewed the literature in 2002 and reported that 32 of 39 studies testing the chronic care model showed improvements in the process or outcomes of care for diabetes, and 18 of 27 studies on three chronic conditions (congestive heart failure, asthma, and diabetes) showed reduced health care costs or lower use of health care services. Studies on depression have shown improvements in outcomes but not in costs (Bodenheimer et al., 2002b; Gilbody et al., 2003). An evaluation team across 51 participating sites in four collaboratives involving almost 4,000 patients with chronic conditions showed that: • Organizations were able to improve, making an average of 48 changes in 5.8 of the 6 CCM areas. • Patients with diabetes had significant decreases to their risk of developing cardiovascular disease • Patients with heart failure were more knowledgeable, were more often on recommended therapy, and had 35% fewer hospital days. • Asthma and diabetes pilot patients were more likely to receive appropriate therapy. When contacted a year later, the care teams reported that involvement in the collaboratives was rewarding. During that year, 82% of sites had sustained the changes and 79% had spread change to other places or diseases.

Table A.2 Examples of interventions/programs: engaging patients/families in the care of the individual patient (continued)

Program (reference)	Target	Description	Evidence Base
Stanford School of Medicine, Patient Education Research Center: Chronic Disease Self-Management Program, (2010)	Self-care	**Purpose:** Help people gain self-confidence in their ability to control symptoms. **Components:** • Programs are based on self-efficacy theory and focus on helping participants to set and achieve incremental goals to strengthen a sense of personal effectiveness. In this way, the program is not focused on disease education but rather on skills development. • Content includes adoption of exercise programs, cognitive symptom management (such as guided relaxation), nutritional change, and management of fear, anger, and depression. • In-person and on-line programs are available on chronic disease, HIV/AIDS, arthritis, diabetes, chronic pain, cancer survivors, and caregivers. • Programs are usually in the community, not in a health care setting. Peer leaders conduct workshops; participants often have different kinds of chronic conditions. • Trained leaders follow a curriculum in small-group workshops that usually meet once a week for about 2 hours over a 6-week period.	Evidence from numerous controlled clinical trials show positive impact on patient outcomes and variable impact on utilization. Positive effects on physical and emotional outcomes and health related quality of life include greater energy/reduced fatigue, more exercise, fewer social role limitations, better psychological well being, enhanced partnerships with physicians, improved health status, and greater self efficacy. There is variable impact on pain symptoms. Reductions in emergency room visits (four studies), fewer hospitalizations (three studies), fewer hospital days (four studies) and outpatient visits (two studies) have been reported in these trials.
Electronic Linkage System (eLinkS, Krist et al., 2010)	Self-care	**Purpose:** Demonstrate impact of an EHR-based tool to promote health behavior counseling. **Components:** • The EHR tool allowed for automated referrals, prompted the clinician to counsel patients on health behavior needs, and offered a selection of options. When the patient agreed to a referral to telephone or group counseling, the EHR automatically e-mailed contact information to the counseling program staff, who then would contact the patient (rather than having the patient call the program). • When clinicians selected computer care, the EHR forwarded an e-mail to the patient with a link to the educational Web site and instructions for e-counseling. • Grant funding allowed the eLinkS program to provide up to 9 months of free, intensive counseling services to patients who enrolled for a 5-week period, after which the demand for referrals exceeded the project budget.	The program increased the rate patients were referred for behavioral counseling. When counseling was free, approximately one of five patients with an unhealthy behavior and an eLinkS prompt were referred for counseling. However, when patient charges were instituted, referrals decreased by 97% (from 21.8% to 0.7%): clinicians asked fewer patients about health behaviors (37% vs. 29%, p<0.001), offered fewer patients referrals (29% vs. 6%, p<0.001), and patients were less interested in accepting referrals (76% vs. 14%, p<0.001). In interviews, patients and clinicians cited cost as a major barrier.

Table A.2 Examples of interventions/programs: engaging patients/families in the care of the individual patient (continued)

Program (reference)	Target	Description	Evidence Base
Ideal Micro Practices/ HowsYourHealth/ CARE Vital Signs, Centers for Health and Aging, Dartmouth Medical School (Moore et al., 2006; Wasson et al., 2003; Wasson et al., 2008)	Self-care	**Purpose:** Support small practices with a focus on Quality Improvement (QI) and team-based care centered on the patient. **Components:** • Curriculum on developing successful clinical microsystems, a small, interdependent group of people who work together regularly to provide care for specific groups of patients. • Use of a low-cost technology— howsyourhealth.org—to support patient-centered care planning and monitoring. • CARE Vital Signs tool for assessing patient needs. CARE stands for Check what matters to patients, Act on that assessment, Reinforce the actions, and systematically Engineer or incorporate actions into staff roles and clinical processes. There are three versions, for adult, adolescent, and geriatric patients. The topics include pain, emotion, body mass index, general health habits, confidence with self-management, and possible side effects from medications. • The data are collected either by the medical assistant and patient during check in or patients complete the data in advance using howsyourhealth.org. • The results of the CARE tool provide clinicians with information on patient needs and allow the practice to prioritize and match resources to meet those needs. • In addition, the practice or microsystem can use the data to measure their patterns of performance, feedback the data to the practice, and make changes based on the data.	Data from howsyourhealth.org suggest that small practices that have adopted the clinical microsystems approach have improved patient-reported quality, experiences, and results. Patients using practices that have adopted the model are more likely to report that they receive care that is "exactly what they want and need exactly when and how they want and need it" (68% vs. 35%) compared to patients in usual settings. They are also more likely to report very high levels of continuity (98% vs. 88%), efficiency (95% vs. 73%), and access (72% vs. 53%). Patient ratings of very good information (83% vs. 67%) and clinician awareness of pain or emotional problem are also higher (87% vs. 69%).

Table A.2 Examples of interventions/programs: engaging patients/families in the care of the individual patient (continued)

Program (reference)	Target	Description	Evidence Base
Initiative to Integrate Self-Management Support into Clinical Practice, California HealthCare Foundation (Kanaan, 2008)	Self-care	**Purpose:** Implement patient self-management for diabetes in health care organizations serving low income populations. **Components:** • The practices received help in system redesign, staff training, and measurement and feedback, through conferences and collaborative learning. • The core elements to support patient self-management were motivational interviewing, along with measurement and feedback. • A sample diabetes self-care plan, focusing on self-management goals and self-efficacy, was used.	The evaluation focused on implementation issues and did not report on clinical outcomes. Key lessons were: • Practice redesign is required to support patient self-management. • It is important to set realistic expectations for staff and patients about the time it will take for improvement. • Staff and patients need training and confidence building. • While staff (other than physicians) can provide support for patient self-management, training and mentoring for medical assistants and lay workers is critical.
Patient-Centered Medical Home (PCMH) Pilot, Group Health Cooperative (Reid et al., 2009)	Self-care	**Purpose:** Evaluate impact of a medical home model. **Components:** • Structural and team changes including smaller rosters, team member co-location. • Point of care changes including promotion of e-mail and phone visits, previsit chart review and visit planning, and collaborative care planning. • Patient outreach changes, including group visits and self-management workshops. • Management changes, including daily huddles, rapid process improvement cycles, and a visual reporting system.	The evaluation compared patients receiving care in PCMH pilot sites to patients receiving care in other traditional primary care sites. The evaluation showed that, compared to patients served in traditional clinics, patients at PCMH sites had: • Fewer emergency visits, hospitalizations, and in-person primary care visits. • Higher ratings of patient experiences. • More frequent communications with their providers by phone and e-mail. • More group visits and self-management support workshops. • Staff was less likely to report burnout.
Practice-Linked Online Personal Health Records for Type 2 Diabetes Mellitus, Partners Health Care (Grant et al., 2008)	Self-care	**Purpose:** Evaluate impact of access to a diabetes-specific personal health record on diabetes control. **Components:** • Intervention arm: Access to a diabetes-specific personal health record (PHR) that imported clinical and medications data, provided patients with their clinical information linked to tailored decision support, and enabled the patient to author a "Diabetes Care Plan" for electronic submission to their doctor prior to upcoming appointments. • Control arm: PHR to update and submit family history and health maintenance information.	Patients were randomized to intervention or control. More patients in the intervention arm had their diabetes treatment regimens adjusted (53% vs. 15%) compared with active controls. However, there were no significant differences in risk factor control (HbA1c, BP, and LDL-c) between study arms after 1 year.

Table A.2 Examples of interventions/programs: engaging patients/families in the care of the individual patient (continued)

Program (reference)	Target	Description	Evidence Base
Electronic Communications and Home Blood Pressure Monitoring, Group Health (Green et al., 2008)	Self-care	**Purpose:** Determine whether Chronic Care Model care delivered over the Internet improves hypertension care. **Components:** • Home BP monitoring and secure patient Web site training only. • Home BP monitoring and secure patient Web site training plus pharmacist care management delivered through Web communications. • Control arm received usual care.	Patients were randomized to one of three arms. Patients assigned to home BP monitoring and Web training-only group had a nonsignificant increase in the proportion with controlled BP compared with usual care. However, compared with usual care, patients who received home BP monitoring and Web training plus pharmacist care had a greater reduction in systolic and diastolic components of BP, and improved BP control.
21st Century Care Innovation Project, Kaiser Permanente (King et al., 2007)	Self-care	**Purpose:** Improve patient care delivery by making primary care more patient centered; simultaneously develop a more fulfilling and sustainable work environment for physicians and staff. **Components:** • Innovation (quality improvement) teams. • Enhanced communication: e-visits, scheduled telephone appointments, and secure messaging. • Population-based care management.	Early results suggested improvement in patient experiences results.

Table A.2 Examples of interventions/programs: engaging patients/families in the care of the individual patient (continued)

Program (reference)	Target	Description	Evidence Base
Comprehensive Health Enhancement Support System (Gustafson, 2002)	Self-care	**Purpose:** Offer patient-oriented interactive, computer-based programs that provide information, help with decisionmaking and behavior change, and emotional support. **Components**: • Information services for common questions, instant library links to full-length articles, consumer guide for relevant services, links to other high-quality Web sites, and a resource directory for local and/or national services. • Communication services offer information and emotional support through bulletin boards; discussion groups to share information and support; "ask an expert" for confidential responses to questions by specialists; journaling provides a private place where users write their deepest thoughts and feelings in a timed, controlled environment; personal stories show how people cope with conditions and illnesses; and video gallery shows patients and their families describing how they coped with disease and treatment. • Analysis services help users think through key issues; health tracking collects data every 2 weeks and displays graphs showing changes over time; decision-support tools help users make important treatment decisions; and the action plan employs a decision theory model to help patients build, evaluate, and improve their behavior change strategies.	Studies in diverse conditions and populations have shown positive effects on patient experiences, self-efficacy, and health behavior. In particular, research on HIV/AIDS and breast cancer in low income minority populations shows that minority and elderly patients are as likely to use Internet-based interventions as the younger, more affluent majority but they differ in the type of services they use. Underserved groups are more likely to use information and analysis services and less likely to use discussion groups. Underserved groups benefit more from Internet-based services because they start at a greater disadvantage and the services they use have more benefit.
Fax to Quit (New York State Smokers Quitline, undated)	Self-care	**Purpose:** Support smoking cessation by linking patients to community resources. **Components**: • Health care providers refer their tobacco-using patients to the New York State Smokers' Quitline using the Fax to Quit referral form. • Patients receive followup call from a quit coach who provides a stop-smoking or stop-smokeless-tobacco counseling session, along with resource information tailored to their specific situation. • Quitline faxes back a progress report with information about the patient's tobacco-use status. • Electronic interface is available for practices with electronic health records.	Evaluation data are not available.

Table A.2 Examples of interventions/programs: engaging patients/families in the care of the individual patient (continued)

Program (reference)	Target	Description	Evidence Base
Care Transition Intervention (Coleman et al., 2004; Coleman et al., 2006)	Self-care	**Purpose:** Reduce readmissions by coordinating between hospital discharge and outpatient care. **Components**: • Provide information to patient on medication self-management and how to recognize and respond to possible "red flags." • Patient-centered health record owned and maintained by the patient to facilitate cross-site information transfer. • Support including calls or visits from a transition coach. • Timely followup care.	Research trials show that the intervention reduces readmissions and cost of care; it also increases patients' confidence in managing their condition, communication with their health care team, and understanding of their health care.
Heart 360 (American Heart Association, 2010)	Self-care	**Purpose:** Provide computer platform for patients to monitor blood pressure, weight, physical activity, and other issues relative to cardiovascular health; allow providers to monitor self-care of patients. **Components:** • Patients provide information manually or upload data directly from devices such as blood pressure monitors. • Patients provide their physicians access to their records or download and print information prior to visits. • Health care providers can sign up for a service that allows them to invite patients to use the Health Vault, and then use the information for creating patient-based and practice-based reports and for sending messages to their patients.	Evaluation data are not available.
Community and Clinician Partnership for Prevention, North Carolina Network Consortium (Kemper et al., 2009)	Self-care	**Purpose:** Assist primary care practices in making successful referrals to community-based organizations for patients with unhealthy behaviors (e.g., tobacco use, sedentary lifestyle, poor diet). **Components:** • Access to Web-based resources. • Monthly conference calls among referral "champions" from each practice to discuss progress in building partnerships. • Identified staff person at community organizations to facilitate referrals.	The program did not increase referrals to community-based organizations, even among physicians at three practices who were initially the most enthusiastic about the initiative. On the primary care practice side, providers expressed concerns about issues such as the costs of the community-based programs to the patients. On the community-based organization side, turnover disrupted referral partnerships.

Table A.2 Examples of interventions/programs: engaging patients/families in the care of the individual patient (continued)

Program (reference)	Target	Description	Evidence Base
Ambulatory Care Compact to Organize Risk and Decision Making (ACCORD) project, Massachusetts General Hospital (Chueh, 2008)	Self-care, Decisionmaking	**Purpose:** Extend clinical decision support systems currently focused on making a decision to address followup and "closing the loop." **Components:** • ACCORD maintains a database of different clinical conditions that commonly need some form of followup care (preventative care, followup of abnormal findings, medication monitoring, etc.). For each condition, templates are created with the most commonly used options for care plans. • Provider and patient come to an agreement about selecting an option for a specific ACCORD. Patient learns about the options and understands the importance of following the plan. "Watching and waiting" and informed refusal are also options. • Documentation is generated in the EHR that reflects the choice or the "watch and wait" or informed refusal options. • ACCORD sends reminders to the patient and provider when a care goal has not been met. • Patients can initiate new decision "compacts" for discussion with their provider, get relevant medical information about their treatment options, and list other resources that may help with their decision.	Research is still under way.
ProvenCare program, Geisinger Health System (Casale et al., 2007; Paulus et al., 2008)	Self-care, shared decisionmaking	**Purpose:** Test whether an integrated delivery system can successfully implement an evidence-based, pay-for-performance program for coronary artery bypass graft (CABG) surgery. **Components:** • Patient engagement via educational materials and a "patient compact" that both the patient and provider sign. • Implementation of evidence-based processes of care supported by EHR. • Fixed-price payments for preoperative, inpatient, and postoperative care.	Compared to historical experience, patients treated under the ProvenCare program had shorter hospital stays and mean hospital charges declined by 5.2%. The ProvenCare program has been extended to hip replacements, cataract surgeries, percutaneous coronary interventions, bariatric surgery, lower back surgery, and perinatal care.

Table A.2 Examples of interventions/programs: engaging patients/families in the care of the individual patient (continued)

Program (reference)	Target	Description	Evidence Base
Primary Care Pilots for Shared Decision-Making (FIMDM, 2010)	Decisionmaking	**Purpose:** Integrate shared decisionmaking and decision aids into day-to-day clinical practice. **Example:** Stillwater Medical Group implemented a process for distributing decision aids and providing care support for patients with breast or prostate cancer. • Prior to initial consultation with the specialist, patients meet with a nurse care coordinator to assess knowledge of disease and review pathology results and treatment options. • Care coordinator and patient go over decision aid. • Patient reviews materials before he or she returns to specialist for medical care planning. • Team provides support and coordination of care throughout treatment based on individual patient needs. **Other examples:** • Health libraries where decision aids can be viewed and one-on-one decision support is provided. • Practice-based health coaches and health educators provide one-on-one decision support to patients after viewing a decision aid. • Practice improvement meetings for training. • Group medical appointments where providers can discuss decision aids with multiple patients.	Research is still under way. General observations to date suggest: • Shared decisionmaking needs to be part of a commitment to patient-centered care at all levels of the organization. • Allowing sufficient time for shared decisionmaking during patient visits is critical. • Adapting the shared decisionmaking approach to the type of decision and patient population is important. For example, FIMDM suggests making decision aids available to patients prior to scheduled visits for screening decisions; incorporating into multifaceted interventions (condition management programs) or group visits for chronic disease management; and prior to specialist consultation for preference-sensitive conditions when elective surgery is being considered. • Brackett et al. (2010) found that physician satisfaction was greater when patients saw decision aids before the visit.
Anonymous reporting of potential medical errors, Beth Israel Medical Center Department of Pediatrics (Neuspiel et al., 2008)	Safety	**Purpose:** Encourage greater reporting by staff of medical errors and near misses. **Components:** • Simple, anonymous medical error report form. • Drop-off boxes made available for anyone to use. • Pediatric safety champion team committee, with representatives from all practice staff disciplines, reviews each report, identifies root cause(s) of error or near miss, and develops interventions to address the cause(s). • Monthly report on errors and their solutions.	The annual number of reports of errors or near misses increased from 5 to 80. Reports originated from physicians (45%), nurses (41%), other staff (9%), and parents/patients (5%). The reports spurred patient safety improvement activities.
Medication reconciliation, Mayo Clinic (Varkey et al., 2007)	Safety	**Purpose:** Improve the accuracy of medication lists and to avoid medication errors. **Components:** • Reminder letter to patient 1 week prior to visit. • Physician assistant reviews medication list at the	The frequency of no medication lists in the medical record fell to 6% from 26%; medication documentation discrepancies fell by more than 50%. The intervention is continuing after the pilot.

Program (reference)	Target	Description	Evidence Base
		• visit, makes changes. • Physician reviews list and updates the EHR. • New list printed and given to the patient. • Clinic-wide training for staff.	
Guided Care (Boult et al., 2008; Boyd et al., 2007; Leff et al., 2009)	Self-care	**Purpose:** Improve care for seniors with multiple chronic illnesses by coordinating care, facilitating care transitions, and acting as patient advocate across health care and social settings. **Components:** • Predictive models based on insurance claims data identify patients with the highest predicted need for complex health care in the near future. • Care coordination is provided by specially trained nurses working on-site in primary care practices. • Guided care nurses working with PCPs, specialists, caregivers, and community organizations coordinate and improve patient care across providers and settings. • Clinical components that provide comprehensive assessment, evidence-based care planning, development of a care plan for the primary care provider and other health professionals, and development of brief version of care plan for the patient and family. • Patients are referred to a self-management course. • Condition of patients monitored monthly. • Education and support for caregivers. • Program facilitates access to community resources.	Randomized trials of Guided Care have shown improvements in the quality of care. Costs are lower, primarily due to lower hospitalization and emergency room use, but the difference is not statistically significant.

Table A.2 Examples of interventions/programs: engaging patients/families in the care of the individual patient (continued)

Program (reference)	Target	Description	Evidence Base
Medical Home for Children With Special Health Care Needs (AAP, 2004; Homer et al., 2008)	Organization, self-care, decisionmaking	**Purpose:** Address unmet health needs of children with special needs. **Components:** Ideal attributes of medical home are "accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally effective" care. Specific components evaluated in this review: • Care coordination with community resources and primary and subspecialty care. • Care planning with patient and family. • Population monitoring. • Physical and operational modification. • Clinical care. • Connection with primary care provider/practice. • Cultural competence.	A review of 33 articles on 30 distinct studies examined the impact of the medical home. Six studies used randomized designs and 4 had nonrandomized comparison groups. The most common condition studied was asthma. In general, the studies demonstrated that functions associated with medical home were associated with improved family centeredness, timeliness, effectiveness, health status and family functioning, but not with measures of safety or costs of care.

Table A.3. Examples of engaging patients/families in practice design/quality improvement

Organization	Program/Project
Patient/Family Advisors MCGHealth (Pat Sodomka, Nettie Engels, personal communication)	**Setting:** Over 130 trained patient/family advisors who participate in advisory councils, quality and safety teams and facility design processes. **Components:** Patient and family advisors participate in a variety of activities including: • Serving on advisory councils for the hospital or specific clinics. • Training for new staff (advisors participate in half-day session on patient-centered care, which includes an opportunity for them to tell their personal story and discuss patient-centered care). • Observer during patient rounds (advisor completes checklist on topics including bedside manner, evidence of respect and caring, involvement in teaching and decisionmaking during rounds; and debriefs with the care team afterwards). **Evaluation:** Not available.
Medical Home Initiative for Children with Special Health Care Needs (CSHCN) (Carolyn Allshouse, personal communication)	**Setting:** Initiative convened by the Minnesota Department of Health through a Federal grant. **Components:** Pediatric practices were required to include two family members along with a physician champion and nurse care coordinator in their practice QI teams and as participants in the learning collaborative. As members of the QI team, parents offered suggestions for addressing problems that providers often did not see. Some parents also started networking groups among families in the practice and community to identify additional family needs and communicate with families. **Evaluation:** The evaluation concluded that that there were statistically significant improvements in care based on measurements using the Medical Home Index. Providers concluded, "Parent participation on their teams was a critical component to implementing effective Quality Improvement strategies." Anecdotally, the program leader noted that "parents were excited to have the opportunity to give back to the clinic and the physician with which they have a relationship. They were excited to be asked to be involved." In addition, clinic staff gained a better understanding of patient needs and issues and how they could help to meet those needs.
Parent Advisory Group at Nashaway Pediatrics (Polewarczyk and Cleary, 2004)	**Setting:** A five-physician medical group in Sterling, Massachusetts, is an example of using a parent advisory group in a pediatric practice. The advisory group was originally developed as part of a research design but has continued after that study. **Components:** The goals of the group are: • Identify strengths and weaknesses of service delivery. • Provide mechanism for families to express satisfaction and concerns. • Keep practice informed about supports, resources, and opportunities in the community. • Ongoing educational programming for families and staff. Activities were designed to improve care in the practice and also to meet the needs of CSHCN families more broadly. For example, the advisory group worked with the practice to develop and implement a short previsit survey of children that focuses on issues of concern to the family. Children complete the survey asking them to check "what I like about myself" and "what I worry about" (how I look, my family, my schoolwork, etc.). In addition, the group planned and conducted a workshop on individualized educational plans for families in the community. **Evaluation:** Not available.

Table A.3 Examples of engaging patients/families in practice design/quality improvement (continued)

Organization	Program/Project
Patient Advisory Councils, Dana Farber Cancer Center (Reid Ponte and Peterson, 2008)	**Setting:** Dana Farber Cancer Center reviewed patient-centered principles as part of planning process for joining operations with Brigham and Women's Hospital. **Components:** Advisory councils exist for both adult and pediatric patient care and are meant to serve as the "patient voice" and institutional infrastructure for including the patient and family member perspective at all levels of organizational decisionmaking. Councils are comprised of patients, family members, executive leadership, and staff. Responsibilities include: • Providing information to hospital leaders and staff about patients' needs and concerns. • Helping plan patient-care areas and new programs. • Making changes that affect patients and family members. • Encouraging patients and families to be involved and to speak up. • Strengthening communication among patients, family members, caregivers, and staff. Formal bylaws describe eligibility, recruitment, selection, membership expectations, among other topics. **Evaluation:** Reid Ponte and Peterson (2008) report that involvement of patients and families has made group leaders sensitive to the need for input from other stakeholders, such as nonclinical staff.

Table A.4. Examples of engaging patients/families in policy

Organization	Target	Program/Project
Minnesota Health Care Home Initiative (Jeff Schiff, personal communication)	Medical home planning and implementation	A patient/family/consumer council was formed to give input and oversee the development and implementation of the demonstration. In addition, Minnesota is providing opportunities for training to support the successful engagement of patients and families. The State provided scholarships for teams of clinics (that included patients and families) to attend the Institute for Family-Centered Care Intensive Seminar and $2,000 mini-grants for 10 clinics to implement/jump-start patient-family-centered care activities within the clinic. In addition, a conference for prospective health care homes included presentations by national and local speakers on the topic of patient/family-centered care and utilizing patients and families as advisors.
Maine Medical Home Initiatives (Malouin, 2009)	Medical home planning and implementation	Consumer representatives were involved in planning and governance of the Medical Home demonstration. Leaders convened focus groups with consumers to make sure that the PCMH model anticipates and integrates care for everyone, particularly those with greatest needs.
Draft Principles of Consumer-Driven Care, Center for Mental Health Services of the Substance Abuse and Mental Health Services Administration (Center for Mental Health Services, undated)	Principles for engaging patients in mental health policymaking	Substance Abuse and Mental Health Services' call for care to be "consumer-driven." The draft policy states: "Consumer-driven means consumers have the primary decisionmaking role regarding the mental health and related care that is offered and the care received. In addition, the consumer voice is paramount in determining all aspects of care for consumers in the community, State, and Nation. The consumer voice must be present and fully represented both collectively and individually with regard to all aspects of service delivery from planning to implementation to evaluation to research to defining and determining outcomes. This includes (but is not limited to) the policies and procedures governing systems of care; choosing supports, services, and providers; setting goals; designing and implementing programs; monitoring outcomes; and determining the effectiveness of all efforts to promote mental health and wellness." Federal law also requires that each State and territory convene a mental health planning and advisory council as a requirement for obtaining Federal funds. The councils must include consumers of mental health services and their families, as well as representatives of key State agencies (http://www.namhpac.org/).
Aurora Health Care Community-Based Patient Advisory Council (Leonhardt, Deborah, Pagel, 2006)	Involving consumers in patient safety activities	Aurora Health Care, an integrated delivery system in Wisconsin, received funding from the Agency for Healthcare Research and Quality to create a community-based patient safety council focused on improving medication safety for the outpatient population. Through this council, Aurora Health Care hoped to create a place where patients and health care providers could discuss the barriers and opportunities for a safe and effective medication process in the outpatient setting. They anticipated this would lead to the development of effective interventions that could be disseminated and adopted throughout the community. Based on their experiences, Aurora Health created a toolkit for developing community-based patient advisory councils. Patients, providers, and health care organizations report having benefited from this process.

Organization	Target	Program/Project
Strengthening Families (Center for the Study of Social Policy, 2008)	Engaging families in policymaking for child welfare services	Strengthening Families is a program to help families with at-risk children (often receiving child welfare services). The program focuses on developing protective factors, such as parental resilience, social connections, and knowledge of parenting and child development. A key component is family engagement. States have used a "world café" process— a way to get input from a group of people—for the dual purpose of increasing parent engagement in their children's needs and services as well as helping to develop a pool of parents to participate in policymaking at the local or State level. At community meetings, trained parent facilitators host a structured conversation among parents on a few key questions. The "world café" refers to the way the participants move from table to table where different topics are being discussed. The parent facilitators take notes and a summary of the discussion is shared with the group and collated with other "cafes" to get broader input. While the primary focus of the "cafes" is to gather information to share with policy makers, it is also an opportunity for parents to gain peer-to-peer support. Host parents also build a body of knowledge about other families' experiences that allows them to participate more effectively in a multi-stakeholder policy development and evaluation process.
National Working Group on Evidence-Based Health Care (2008)	Involving consumers in research	The purpose of this project was to support patient/consumer involvement in evidence-based health care by offering principles for patient/consumer inclusion in research and dissemination. The working group convened a forum of more than 80 patient/consumer advocates, decisionmakers, regulators, and other stakeholders to examine patient/consumer inclusion in research. The report identifies examples of patient/consumer involvement in research and suggests five critical areas where they should play a role: • Governance and accountability (including consumers on peer review panels and institutional review boards). • Priority setting (involving consumers in focus groups to identify gaps in knowledge). • Participation in study design (requiring clinical research to include consumer-focused outcomes such as quality of life). • Translation and dissemination (using patients/consumers to review draft translational materials and create strategies for communicating the information). • Implementation (including consumers as voting members of panels that develop quality measures and pay-for-performance systems).

Table A.4 Examples of engaging patients/families in policy (continued)

Organization	Target	Program/Project
Community Advisory Boards in The Ryan White HIV/AIDS Program (AIDS Alliance for Children, Youth and Families, 2008)	Involving consumers in designing care for patients with HIV/AIDS	The Ryan White HIV/AIDS program is a Federal program that delivers HIV/AIDS care to low-income people. Part of the program includes community advisory boards (CABs), which are required in clinics funded by the program. The main purpose of a CAB is to offer providers a consumer perspective regarding policies, direct services, data management, and fiscal systems. The CAB represents the community to ensure that these activities are carried out in a way that best meets consumers' needs. CAB members are a link between providers and the community, sharing information with the community about HIV/AIDS services and bringing community concerns and ideas back to the provider. The AIDS Alliance for Children, Youth and Families has developed a self-assessment tool for CABs.
Comprehensive Community Mental Health Services for Children and Their Families Program (Worthington et al., 2001)	Involving families in care for children with serious emotional disturbance	This initiative was part of a Federal grant program to assist communities in building fully inclusive systems of care for children who are experiencing a serious emotional disturbance and their families. Two parents of children with special needs participated as members of the research team from the design of the study to the preparation of the results. This included the review of materials distributed to families, help with recruitment, and interpretation of the results. As a result of this experience, the parents felt more empowered to advocate for their own children as well as be a voice in their community for services for all children with disabilities.
Healthy Communities Collaborative (HCC), Improvement Foundation, UK (Oldham, 2009; Slater, Knowles, and Lyon, 2008)	Community engagement in reducing health care disparities	The collaborative aims to: • Address health inequalities in areas of socio-economic disadvantage. • Be the catalyst for enabling communities and agencies to work together on common goals. • Harness the skills and knowledge in communities and use them to reduce inequalities. • Recognize and change poorly functioning systems using rapid improvement techniques. The collaborative is focused on low-income groups and the needs of older people, children, and families. HCC teams are a partnership of professionals and community members, led by community members. All team members are taught improvement skills and the basics of gap analysis, process mapping, social marketing, rapid change cycles, and measurement for improvement. For example, HCC community members helped cardiac nurses identify new community locations for reaching people in need of cardiac risk assessments. While data are not available on the impact of these initiatives, the program has been lauded for its approach. "In large system change it is essential that team composition includes individuals from other parts of the organization or other organizations, but the key team members are the patients. This approach ensures that discussions are focused on actual needs and experience, that there is less "group think" among the professionals, and that their behaviors become modified. Interdepartmental or inter-organizational petty rivalry is not played out in the presence of patients, who by their presence force attention to health care alone."

Table A.4 Examples of engaging patients/families in policy (continued)

Organization	Target	Program/Project
INVOLVE, United Kingdom (INVOLVE, 2009)	Involvement in national health research planning	In England, an advisory organization called INVOLVE has been funded by the Department of Health to support public involvement in National Health Service (NHS), public health, and social care research. INVOLVE, which includes patients and their families as well as representatives of voluntary organizations, health and social services managers and researchers, meets four times annually to identify and prioritize research areas and advise on implementation of research and dissemination of information to the public.
Local Involvement Networks, United Kingdom (NHS, 2009)	Involvement in health and social service policy	Local Involvement Networks (LINks) were established through 2007 national legislation with the aim of giving the public a voice in the delivery of health and social services. LINks consist of individuals and community groups, such as faith groups and residents' associations, working together to improve health and social care services. LINks replaced an earlier structure for public engagement that called for each trust to have an advisory forum of seven patients. The forums were described as an "overly prescriptive, centralized model" (NHS, 2006). The LINks are independent of the government, run by local individuals and groups, and financed by local councils. Patients/families can be involved in LINks in different ways, ranging from answering a survey, attending meetings, participating in online group discussions, or becoming an authorized representative who visits care providers to understand their operations.
Guideline International Network Patient and Public Involvement Working Group (G-I-N PUBLIC, Boivin et al., 2010)	Involvement in health care guidelines	Guideline International Network (G-I-N) is a not-for-profit organization of agencies and individuals involved in the development and use of clinical practice guidelines. G-I-N created a Patient and Public Involvement Working Group (G-I-N PUBLIC) of researchers, health professionals, and consumers who promote ways to inform and involve the public in development and implementation of clinical guidelines. Members of G-I-N PUBLIC recently reported on how different organizations involved patients and the public in guideline development and identified priorities for research and international collaboration (Boivin et al., 2010). A randomized trial is under way to examine the impact of public deliberation on priority-setting for quality indicators and policymakers' intended use of quality measures, as well as to identify factors that affect effective use of public deliberation (Boivin, 2010). G-I-N PUBLIC also maintains an online Web forum for discussion and exchange on key issues in patient and public involvement in the development and implementation of clinical practice guidelines (www.ginppi.wetpaint.com).