# Overview of Patient and Family Engagement

## Chapter 2

Patients who are actively involved in their health and health care tend to have better outcomes and care experiences, and, in some cases, lower costs.[1-3] Implementing patient and family engagement strategies has led to fewer hospital-acquired infections, reduced medical errors, reduced serious safety events, and increased patient satisfaction scores.[4-6] Because of the potential for improved health outcomes and patient satisfaction, patient and family engagement has emerged as a critical strategy for improving the performance of our health care system. The United States health care system is one of the most costly in the world, yet without health outcomes to show for it.[7] One strategy that the United States is using to address this paradox is to focus on improving population health, improving patients' experience of care, and reducing per capita costs, also known as the Triple Aim.[8] Patient engagement is a pathway to helping achieve the Triple Aim.[1-3,9] As one health care executive described it, "We will never create an efficient, affordable, effective, and high quality health care delivery system unless we leverage all the assets at our disposal. The knowledge, insight, and clarity that patients and families offer are badly under-leveraged."[10] The partnerships between patients, providers, and health systems can help each meet its goals.

**The patient and family are important partners in care.**

The core of patient and family engagement lies in welcoming the patient and family as important partners in care. The Institute of Medicine of the National Academies (IOM) describes patient and family engagement as a partnership among practitioners, patients, and their families (when appropriate) to ensure that decisions respect patients' wants, needs, and preferences. The IOM further states that patients should receive the education and support that they need to make decisions and participate in their own care.[11] For patient and family engagement to work, patients must have, or be given, the knowledge, skills, and confidence to manage their health and health care.[12] In addition, health care at every level needs to be patient and family centered. The Institute for Patient- and Family-Centered Care defines patient- and family-centered care as "an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families."[13] The Institute describes the foundations for patient and family engagement as dignity, respect, information sharing, participation, and collaboration.

According to a recent survey of American health care consumers, one in three consumers is disengaged in their care.[14] These individuals report less need for care, take fewer preventive actions, have less interest in resources, and are financially less prepared than consumers who are more engaged.[14] Both patients and providers support engagement and believe that increased involvement in health care by patients and families can lead to improved experiences and outcomes.[15] These positive attitudes and support for increased engagement are critical to affecting change.

Some providers and systems have already begun to engage patients as partners or have created a culture in which patients are partners. However, many providers and systems have focused their energy on other goals and have yet to prioritize patient and family engagement. This report highlights evidence-based strategies, best practices, and various examples of successful models for organizations to measure their efforts, assess gaps, and connect to resources that support patient and family engagement.

## Current Efforts

The theme of patient and family engagement is central throughout the Patient Protection and Affordable Care Act (ACA), passed in 2010. Several provisions of the ACA directly promote patient engagement and patient-centeredness, including support of primary care medical homes, medication management, community health assessments, and incentives for chronic disease prevention under Medicaid.[a]

**Patient and family engagement has emerged as a critical strategy for improving the performance of our health care system.**

Nationally, many efforts are underway to increase patient and family engagement. The Agency for Healthcare Research and Quality, the Institute for Healthcare Improvement, the Institute for Patient- and Family-Centered Care, and the National Association for Healthcare Quality, are all working to increase and improve patient and family engagement. Several important partnerships and networks have been created with the goal of promoting patient and family engagement through research, collaboration, and shared learning. In 2011, the Centers for Medicare and Medicaid Services created Partnership for Patients to improve patient safety and quality. The Partnership worked to identify, disseminate, and expand patient and family engagement best practices to more than 3,700 hospitals that were members of its Hospital Engagement Network through 2014. Another Partnership aim was to increase collaboration between patients, families, providers, and caregivers to improve care transitions and reduce readmissions through its Community-Based Care Transitions Program.[16] The American Institutes for Research (AIR) created a Center for Patient and Consumer Engagement, which conducts research and spearheads engagement efforts such as increasing health literacy, improving communication between patients and providers, working in communities to promote engagement, and providing technical support for patient and family engagement work throughout the country.[17]

Many organizations in North Carolina are working to implement patient and family engagement strategies around our state. For example, Community Care of North Carolina (CCNC), the North Carolina Medicaid program's primary care case management contractor, takes a community and patient-centered approach to health care and seeks to engage patients in their care.[18] CCNC care managers collaborate with patients to develop patient-centered, self-management care plans that are focused on patient-centered goals, self-management education,

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[a] Patient Protection and Affordable Care Act, Pub L.

and contact information for community resources. The North Carolina Quality Center (NCQC), which was created by the North Carolina Hospital Association (NCHA) in 2004, has been at the forefront of patient and family engagement efforts across the state. Charged with leading the state's hospitals to become the safest and highest quality in the country, the NCQC most recently launched a Patient-Family Engagement Learning Network. Between April 2014 and April 2015, the Learning Network met to share best practices and evidence-based strategies and to provide support for developing and implementing a patient and family engagement plan for hospitals throughout North Carolina. The NCQC also monitors, evaluates, and reports on the processes and outcomes of its work.[19] In addition to the work of NCQC, the NCHA is also driving patient engagement through its own activities. In May of 2013, the NCHA Board declared patient and family engagement one of its Patient Safety Goals and since then has been collaborating with various hospitals throughout the state to identify leaders and guide the planning, implementation, and evaluation of patient engagement initiatives.[20]

**The knowledge, insight, and clarity that patients and families offer are badly under-leveraged.**

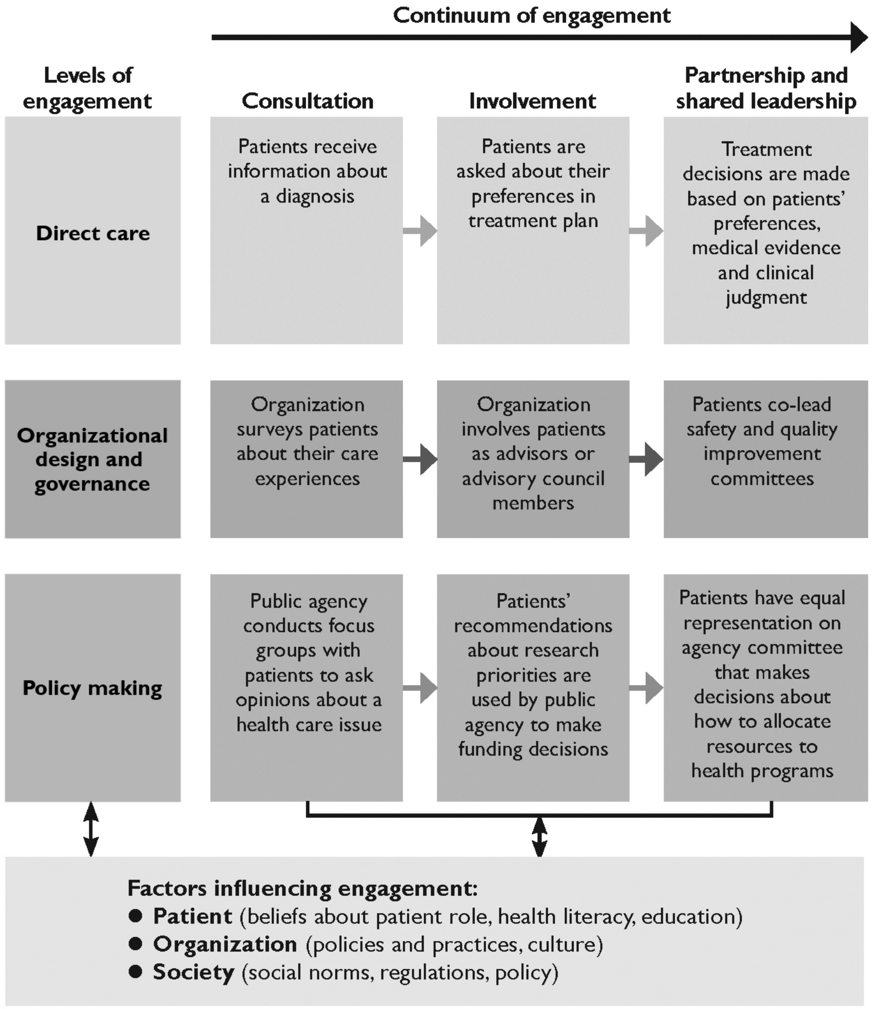
## Patient and Family Engagement Framework

In an effort to learn more about the field of patient and family engagement, the Task Force identified several options for organizing its work. While the Task Force has not endorsed a particular group's approach, the Task Force chose to use the Framework for Patient and Family Engagement to help guide its evidence gathering and the formation of its recommendations. The Framework was developed by researchers at AIR and others to help create these changes in health care. (See Figure 2.1.) AIR defines patient and family engagement as "patients, families, their representatives, and health professionals working in active partnership at various levels across the health care system to improve health and health care."[10] The Framework includes patients, family (as defined by the patient), friends, clinicians, health care providers, health care organizations and systems, and public policies and culture as participants in patient and family engagement.

The Framework demonstrates that patient and family engagement exists in multiple forms along the continuum of engagement. Traditionally, the patient-provider interaction has taken place on the lower end of the continuum of engagement, with patients having direct care consultations with their providers. Moving along the direct care continuum, patient input and shared decision-making increases to involvement and, finally, to partnership and shared leadership. The partnership and shared leadership at the higher end of the continuum has communication moving in both directions between patients and providers, and responsibility for decision making is shared. Moving along either the level of engagement or the continuum of engagement axis requires culture change that consists of support and commitment of leadership and providers, patient education, and potential changes to workflow, policies, and procedures.

**Patient and family engagement exists in multiple forms along the continuum of engagement.**

**Figure 2.1**
**A Multidimensional Framework for Patient and Family Engagement in Health and Health Care**



| Levels of engagement | Consultation | Involvement | Partnership and shared leadership |
|---|---|---|---|
| **Direct care** | Patients receive information about a diagnosis | Patients are asked about their preferences in treatment plan | Treatment decisions are made based on patients' preferences, medical evidence and clinical judgment |
| **Organizational design and governance** | Organization surveys patients about their care experiences | Organization involves patients as advisors or advisory council members | Patients co-lead safety and quality improvement committees |
| **Policy making** | Public agency conducts focus groups with patients to ask opinions about a health care issue | Patients' recommendations about research priorities are used by public agency to make funding decisions | Patients have equal representation on agency committee that makes decisions about how to allocate resources to health programs |

**Factors influencing engagement:**
- **Patient** (beliefs about patient role, health literacy, education)
- **Organization** (policies and practices, culture)
- **Society** (social norms, regulations, policy)

**SOURCE** Kristin L. Carman, Pam Dardess, Maureen Maurer, Shoshanna Sofaer, Karen Adams, Christine Bechtel, and Jennifer Sweeney, "Patient and Family Engagement: A Framework for Understanding the Elements and Developing Interventions and Policies," *Health Affairs* 32, no. 2 (2013): 223-31. **NOTE** Movement to the right on the continuum of engagement denotes increasing patient participation and collaboration.

The Framework also highlights the fact that engagement is not confined to individual health behavior or direct care interactions, but includes organizational design, governance, and policy making. Patients may interact in a variety of organizational settings, including community-based organizations, faith-based organizations, home health services, clinics, and hospitals. Patient and family needs, desires, and preferences can be included in each of these settings along the continuum of engagement. At the policy level, patients and families can provide input into setting agendas that ensure engagement of and responsiveness to patients and families. Multiple factors influence patients' engagement (such as beliefs about their role, faith, health literacy, and education), the organization (such as policies, practice, and culture), and society (such as social norms, regulations, and policy).

## The Roadmap for Patient and Family Engagement in Healthcare Practice and Research

The Roadmap for Patient and Family Engagement in Healthcare Practice and Research provides guidance for both practice and research, with practical steps that can begin immediately.[10] The Roadmap includes a vision for patient and family engagement in health care, eight change strategies to drive action towards increased patient and family engagement, and actions that various stakeholder groups can begin today.

Each of the eight strategies identifies a priority action area with significant opportunities for growth and change. The strategies include: patient and family preparation; clinician and leadership preparation; care and system redesign; organizational partnership; measurement and research; transparency and accountability; legislation and regulation; and partnership in public policy. For each strategy, the Roadmap includes a description, tactics or examples of translated actions, and milestones to help assess progress toward the ultimate goal of true patient and family engagement. Rather than assign specific organizations the responsibility for strategies and tactics, the Roadmap encourages partnership among stakeholders. The Roadmap provides strategies to help gauge the stakeholder's current efforts and opportunities to improve engagement, emphasize action across the levels of engagement, and illustrate how this work is interrelated. The strategies are described in detail below.[10]

**Patients and families must be educated, prepared, and empowered to engage effectively in their own health and health care.**

### *Patient and Family Preparation*

At all levels of engagement, patients and families must be educated, prepared, and empowered to engage effectively in their own health and health care. If patients and families are prepared, they will believe that engaging in their care and partnering with providers and organizations will help improve the quality and safety of care, which will help enable them to partner effectively across the levels of engagement. Therefore, it is necessary to provide them with the skills, knowledge, and confidence to do so effectively. Patients and families are unique, and not all will choose the same level of engagement. Thus, it is important to help prepare patients and families for the level of engagement that they want to achieve and with which they are comfortable. The Roadmap includes tactics to drive the change strategy at the levels of direct care, organization, and policy.

Tactics at the direct care level may focus on educating patients and families about their health and health care and supporting and encouraging them to take an active role both within and outside the context of a specific care encounter. Other direct care tactics include implementing patient-centered tools for patients and clinicians to support shared decision-making. At the organizational level, tactics prepare patients and families to partner with health care organizations, systems, and researchers in designing and conducting research studies. The policy level tactics help to prepare patient and family representatives to partner with other stakeholders in local, state, and national policy and programmatic decisions. The Roadmap also includes five relevant actions individuals can perform immediately to support and advance patient and family engagement. These include: providing feedback on their experiences; reviewing information to help them understand their health and health condition; preparing for their next health care visit; tracking and organizing their medical information; and volunteering to be a patient and family advisor.

### *Clinician and Leadership Preparation*

Educating, preparing and empowering clinicians and health care leaders to partner effectively with patients and families is also necessary to facilitate patient and family engagement. This includes educating and training clinicians about patient and family engagement; preparing clinicians and staff to partner with patients and families at the health care organization and system level; and establishing organization and system level expectations for patient and family engagement. To be successful at clinician and leadership preparation, clinicians and health care leaders must believe that patient and family engagement is an essential component of improving care quality and safety. Further, clinicians must be willing and prepared to engage effectively with patients and families during clinical encounters. Health care leaders must be willing and prepared to partner with patients and families on issues of organizational design and governance.

**Educating, preparing and empowering clinicians and health care leaders to partner effectively with patients and families is also necessary.**

### *Care and System Redesign*

Redesigning system processes, policies, and structures to provide opportunities for and support of partnerships between patients, families, and the health care team is necessary to facilitate patient engagement. In order to redesign care and systems, it is important to implement communication mechanisms that help clinicians elicit, understand, and respect patient perspectives and concerns. Redesign may also include structuring care processes to support and value shared decision-making, involving patients and families in care planning and self-management, and sharing information and providing specific engagement opportunities. Facilitating care coordination across different settings and supporting the ability of clinicians to care compassionately for patients can also help support systems redesign. Successful implementation of this strategy may result in family members (as defined by the patient) welcomed into the care team; patients, families, and clinicians developing care plans and making health care decisions jointly; patients and families establishing positive, meaningful relationships with their clinicians; and seamless care coordination.

### *Organizational Partnership*

Organizations can be designed or redesigned with patients and families included in the governance structure. The perspective of patients and families should be included when developing policies and procedures related to health and health care. Similar to clinician and leadership preparation, organizational redesign includes preparing clinicians, staff, and health care leaders to partner with patients and families at the organization and system level. Tactics to achieve organizational partnership involve creating roles for patients and families such as advisory councils and representation on boards.

### *Measurement and Research*

A key strategy to increasing patient and family engagement is for an organization to create measures and conduct research to improve care, facilitate changes in processes, and assess the relationships among engagement, experiences, and outcomes.[10] The tactics include developing measures of patient level experiences, goals, and outcomes as well as measures that assess the process of patient and family engagement—how and to what extent engagement occurs. Measures can be used to assess progress (or lack thereof), provide feedback to clinicians and organizations, and drive organizational change. Health care providers should also consider conducting research on how engagement leads to improved health, higher quality, reduced costs, and/or improved staff satisfaction.

**The perspective of patients and families should be included when developing policies and procedures related to health and health care.**

### *Transparency and Accountability*

This strategy for change involves making data and information transparent to promote organizational accountability for quality and safety, and enabling patients and families to be more active in their health and health care. Tactics may include giving patients access to their medical records; giving patients the ability to contribute to their medical records; providing transparent information about risks, benefits, costs of care, and treatment options; and publicly reporting cost, quality, and safety information. The milestones of a more transparent and accountable system include providing patients and their families clear and usable information about the risks, benefits, costs, and lifestyle implications of different care and treatment options.

### *Legislation and Regulation*

Regulation and legislation can motivate individual and organizational behavior change. The development and alignment of mandates and incentives can encourage patients, families, clinicians, health care leaders, and health care organizations and systems to change in ways that promote and support patient and family engagement as well as other key objectives. Tactics include providing recognition and rewards for care that fully incorporates patient and family engagement, and aligning incentives and penalties to support patient and family engagement. Requiring patient and family engagement competencies for certification or accreditation, and advancing patient and family participation through legislation are other strategies that would more strongly encourage support for patient and family engagement.

### *Partnership in Public Policy*

Tactics for partnership in public policy include creating opportunities for patient and family representatives to serve on local, state, and national committees focused on health or health care which allow for the public to contribute to health and health care policy decisions. An additional tactic is to prepare patient and family representatives to partner with other stakeholders in local, state, and national policy and programmatic decisions. This tactic allows for stakeholders and policymakers to partner with patient and family representatives in shaping public policy.

The eight key strategies for change and their tactics and milestones have been individually described. However, they are all connected and interrelated. Tactics from one strategy may help facilitate many of the others. The tactics are suggestions to bring the strategies into action, but several additional action steps can be taken.

Subsequent chapters of this report will describe the recommendations from the NCIOM Task Force on Patient and Family Engagement in each of the eight change strategies of the Roadmap.

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