

Creating Change in Health Care: Developing a Shared Understanding and Roadmap for Action

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The Patient and Family Engagement Framework and the Roadmap for Patient and Family Engagement in Healthcare Practice and Research are tools designed to create a shared understanding of what patient and family engagement is and how it can be translated into concrete action.

A growing body of evidence demonstrates that meaningful patient and family engagement can help to achieve the triple aim of improved health outcomes, better experiences of care, and lower costs [1-5]. It is a sign of progress that so many practitioners and researchers in health care are talking about and addressing issues related to patient and family engagement. Despite the growing evidence and attention, however, the full promise of patient and family engagement remains mostly untapped.

The field of patient and family engagement is diverse, bringing together many areas of research, practice, and advocacy that have evolved over the last 30 years, including patient experiences of care, medical safety, shared decision making, health literacy, patient activation, health information technology, and organizational patient and family advisory councils. On the one hand, this diversity offers an opportunity to accumulate evidence and share lessons learned across a broad range of efforts. On the other hand, this diversity contributes to confusion about what constitutes meaningful patient and family engagement.

The Patient Protection and Affordable Care Act of 2010 is motivating health care organizations to engage patients and families through payment reform and increasing alignment of incentives. However, many health professionals and organizations struggle with how to implement engagement efforts in routine health care practice. The Patient and Family Engagement Framework and the Roadmap for Patient and Family Engagement in Healthcare Practice and Research are tools developed to address these challenges by creating a shared understanding of what patient and family engagement is—and how it can be translated into concrete action.

The Patient and Family Engagement Framework

Recognizing the need for a definition and organizing structure that could unite the diverse areas of patient and family engagement, staff from the Center for Patient and Consumer Engagement of the American Institutes for

Research, the National Partnership for Women & Families, and the National Quality Forum developed the Patient and Family Engagement Framework [6]. Although we use the term “patient and family engagement” for simplicity’s sake, we recognize that those who are engaged include not only patients and families but also caregivers, consumers, community members, and citizens.

At its core, we believe that engagement is about increasing the degree of partnership among all health care system participants. Thus, we define patient and family engagement as “patients, families, their representatives, and health professionals working in active partnership at various levels across the health care system—direct care, organizational design and governance, and policymaking—to improve health and health care.”

The framework, as shown in Figure 1, reflects 4 key elements of patient and family engagement. First, engagement is not just about what patients do; it is about patients, families, and health professionals working as partners to redesign the parts of the health care system that are not working. Second, we should be partnering with patients and families across all areas of health care—not only during clinical encounters but also at organizational and public policy levels—to improve how health care is organized and delivered. Third, not all patient and family engagement efforts are equal; there is a continuum, with the strongest engagement efforts being a true partnership where information is given and received equally and decision-making authority is shared. Finally, our efforts do not occur in a vacuum. The framework thus encourages us to consider the many factors that can affect whether and to what extent engagement occurs—everything from individual and organizational characteristics to the larger policy environment.

The Roadmap to Patient and Family Engagement

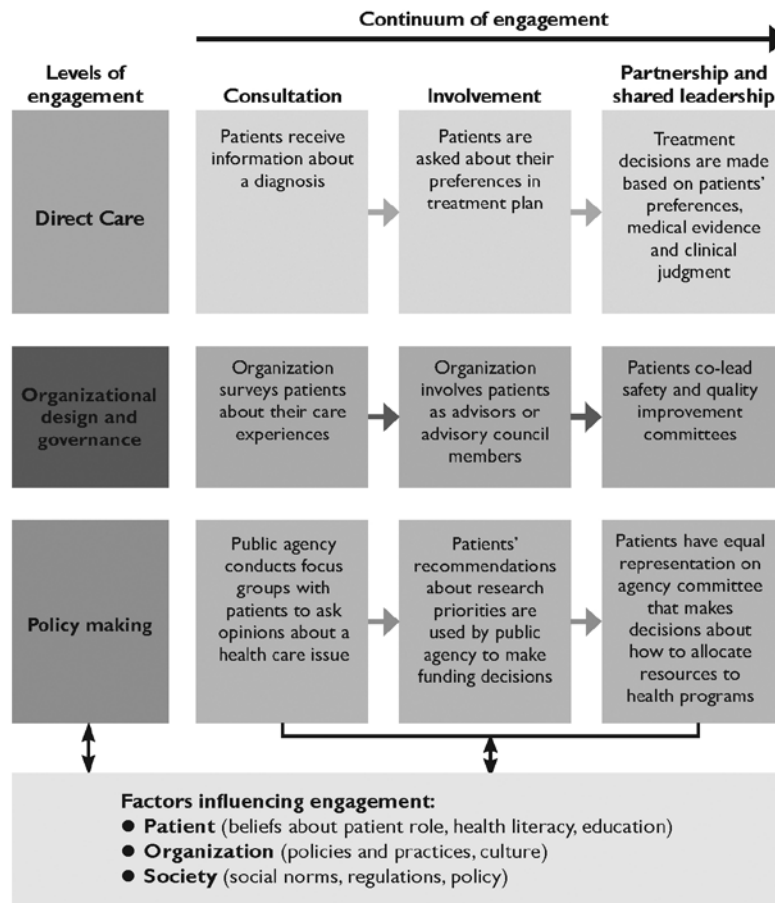
Building on the concepts in this framework, the Gordon and Betty Moore Foundation sought to create a clear road-

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FIGURE 1.
The Patient and Family Engagement Framework



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.

map that provides concrete guidance for how to achieve meaningful patient and family engagement. To that end, the Moore Foundation collaborated with the American Institutes for Research to convene a multi-stakeholder meeting of individuals steeped in practice, engaged in current research, and positioned on the leading edge of patient and family engagement. The goal of this meeting was to identify proven and promising strategies and tactics that would make meaningful engagement a reality.

Guided by an 8-member steering group, the meeting convened more than 70 people, including patients, advocates, clinicians, researchers, payers, funders, and policy-makers. Each of these parties used their experiences, knowledge, and skills to collaboratively create a dynamic tool that can guide, inform, and drive change. This tool is the Roadmap for Patient and Family Engagement in Healthcare Practice and Research [7], and it is available online at www.patientfamilyengagement.org.

A central part of the roadmap are the 8 strategies for change, which describe priority areas in practice and research where change can achieve synergistic benefits. Together, these strategies constitute a comprehensive approach for how patient and family engagement can drive health system transformation. As shown in Figure 2, the strategies are:

Patient and family preparation. Educate, prepare, and empower patients and family members to engage effectively in their health and health care.

Clinician and leadership preparation. Educate, prepare, and empower clinicians and health care leaders to partner effectively with patients and families.

Care and system redesign. Redesign system processes, policies, and structures to provide opportunities for and support of partnerships between patients, families, and the health care team.

Organizational partnership. Redesign health care organi-

FIGURE 2.
Eight Strategies for Change



zations to make patients and families part of the governance structure.

Measurement and research. Create measures and conduct research to improve care, facilitate changes in processes, and assess the relationships between outcomes, experiences, and engagement.

Transparency and accountability. Make data and information transparent to promote organizational accountability for quality and safety and to enable patients and families to be active in their health and health care.

Legislation and regulation. Encourage patient and family engagement through regulation and legislation.

Partnership in public policy. Identify and provide opportunities to integrate patient and family perspectives into public policy.

For each change strategy, the roadmap provides a brief description of what the strategy entails and lists numerous specific tactics that can be executed to advance the strategy. The tactics are drawn from existing research evidence and from promising directions where sufficient evidence may still be lacking. There are also milestones that can help in assessing implementation progress and results. In presenting these 8 strategies, the roadmap corresponds to the Patient and Family Engagement Framework by illustrating which aspect of care delivery and level each strategy addresses: direct care, organizational design and governance, or public policy.

Many of the strategies and tactics in the roadmap can be implemented right away, without changes to the current process or systems. For each strategy, the roadmap also identifies existing resources that are freely available from credible organizations. The roadmap and related resources are dynamic and evolving, so users are invited to contribute. Furthermore, the roadmap website is a place where organizations can make public commitments to advance patient and family engagement and where their progress will be followed and shared.

Not Everything Has to Happen at the Same Time or in the Same Way

The framework and roadmap are starting points to help assess and evaluate efforts to move the field forward, but there is no one right way to “do” engagement; how and what strategies are implemented depend on the organization’s prior experience, patient population, infrastructure, overall culture, priorities and needs, community, and many other variables. Any movement forward is progress toward ensuring that patients are where they belong—at the center of health care.

We hope that organizations and individuals will use these tools to think about opportunities to push their current efforts further and to identify partnerships that drive progress toward the important outcomes of improved popula-

tion health, improved experiences of care, and lower health care costs. And, although the implementation of engagement efforts is context-specific, the differences lie in how implementation is conducted, rather than the outcomes. It is important that we share lessons learned and define best practices as we work to amass additional evidence for patient and family engagement efforts.

None of us can do this work alone. But together, leveraging all resources available to us—including the knowledge and expertise of patients and families—we can create a better, more patient-centered health care system. **NCMJ**

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