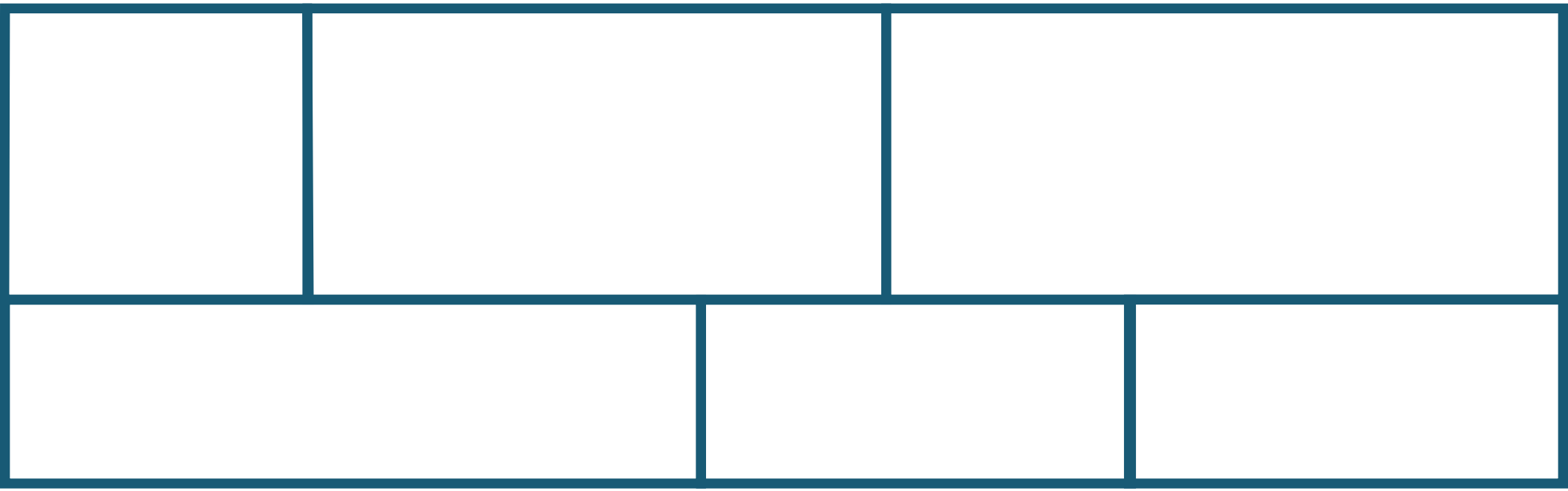
A ROADMAP FOR

Patient + Family Engagement in Healthcare

Practice and Research

Practical strategies for advancing engagement in healthcare–starting today.

START



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What You'll Find

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Why a Roadmap?

As the U.S. healthcare system tackles the triple aim of better experiences of care, better population health, and lower costs, it is imperative for health professionals to meaningfully partner with patients and families. This is the work of patient and family engagement—bringing patient and family voices to decisions about care, to healthcare organizational design and governance, and to public policy. The evidence on the benefits of doing this is compelling, so much so that patient and family engagement has been called the "blockbuster drug of the century." Meaningfully engaging patients and families at every level leads to:

- **Improvements in patient safety and quality**. When health professionals partner with patients and families, patients make more informed choices about their care, use medications more safely, practice more effective self-management, contribute to infection-control initiatives, and help reduce medical errors—all translating into measurable improvements in the quality and safety of care.
- **Better patient experiences and satisfaction**. Organizations that engage patients and families receive higher patient ratings of care and Consumer Assessment of Healthcare Providers and Systems (CAHPS) scores, especially for improved communication with doctors and nurses.
- **Increased health professional satisfaction and retention**. Patient and family engagement strategies improve health professionals' satisfaction with their work, helping to recruit and retain high-quality talent.
- **Better health outcomes**. Engaged patients have better pain control and symptom resolution, better emotional health, significantly fewer preventable hospital readmissions, better management of chronic diseases, and overall improved functioning.
- **Lower healthcare costs**. Together, these benefits can substantially lower our unsustainable collective healthcare bill.

Why a Roadmap? (continued)

Yet, despite the evidence, meaningfully engaging patients and families as true partners in their care remains the exception, not the rule. The Affordable Care Act has increased the incentive for healthcare organizations to engage patients and families, but health professionals and organizations need practical, concrete ways to partner with patients and families. And, the lack of a unified vision within the diverse field of patient and family engagement has hindered the translation of effective engagement strategies from innovation to widespread routine practice.

To fill this critical gap, the Gordon and Betty Moore Foundation engaged the American Institutes for Research to convene a diverse group of stakeholders to forge a unified vision—a roadmap—for achieving meaningful patient and family engagement across the U.S. healthcare system. Building on decades of collected experience and evidence, this extraordinary effort by patients, advocates, clinicians, researchers, payers, funders, and policymakers provides a clear path forward. In particular, the Steering Committee for this project dedicated significant time and energy, and we thank Bruce Bagley, Clarence Braddock, Katherine Browne, Melinda Buntin, Ralph Gonzales, Helen Haskell, Jean Johnson, and Marcus Thygeson for their contributions.

The call to action to make patient and family engagement the rule rather than the exception is best expressed by participating stakeholders:

> "We will never create an efficient, affordable, effective, and high-quality healthcare 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, and, as a result, today's system is underperforming and will continue to do so until the patient and family engagement movement takes firm hold in the hearts and minds of every key stakeholder."
>
> - ANDREW CARTER, PRESIDENT AND CEO
> HOSPITAL & HEALTHSYSTEM ASSOCIATION OF PENNSYLVANIA

> "No one cares more about the quality of healthcare than patients and families. What this convening has shown is that patients are ready, willing, and able to be partners with healthcare professionals to achieve better quality both in our personal care and in the improvement of healthcare in general. Some patients will insist on engagement, others only need to be asked."
>
> - DAVID ANDREWS, PATIENT ADVISOR
> GEORGIA REGENTS MEDICAL CENTER

Why a Roadmap? (continued)

This roadmap lays out the path to broader patient and family engagement by providing specific strategies that are generalizable, usable, effective, executable, sustainable, and scalable and highlights where more innovation is needed. When implemented across the full spectrum of healthcare, these strategies will help achieve the goals of the triple aim of better patient experiences of care, better population health, and lower costs. All journeys begin with a single step—some as simple as a clinician stopping to ask a patient, "What is your goal for your care?"

We hope you find the roadmap helpful on your journey of making patient and family engagement in healthcare a reality. Taking this journey means making a fundamental shift in how we think about the delivery of healthcare and the roles of all involved—health professionals, patients, and families. But it is time for us all to take action. We can and must do better.

Dominick L. Frosch, PhD

September 2014

Patient Care Program
The Gordon and Betty Moore Foundation
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Developing the Roadmap

> "This is an unprecedented moment in time for patient and family engagement. We have the opportunity to act now–to take advantage of the current energy and momentum–and make real, significant, lasting changes."
>
> - CONVENING PARTICIPANT

To develop the roadmap, we used the significant work that has already been done to advance research and practice in patient and family engagement as a starting point. At the same time, a critical goal was identifying ways to push the field forward and develop a unifying view of patient and family engagement in practice and research.

Input for the roadmap was provided over the course of many months. A key event was a two-day, in-person meeting in February 2014 that we refer to as a convening. During the convening, 72 stakeholders worked as a collaborative, multidisciplinary group that represented diverse viewpoints across healthcare—clinical care providers, healthcare leaders, patients, family members, researchers, funders, insurers, employers, and policymakers.

Prior to the convening, we solicited input from a larger group of patients and families via an online questionnaire to ask them what patient and family engagement means to them. We held a series of webinars to elicit convening participants' reactions to a patient- and family-generated vision of engagement and thoughts about societal factors that affect engagement. We worked with an eight-member steering group to shape the agenda and focus of the convening.

Developing the Roadmap (continued)

After the convening, we analyzed the thoughts, ideas, and questions of participants as captured in hundreds of pages of notes and dozens of flip charts. We reflected the ideas and themes that emerged from individuals in the field, identifying what resonated and what did not. This work reflects best practices, emerging evidence, and the combined knowledge and experience of more than 100 people and almost 60 organizations.

The final roadmap includes:

- A vision for patient and family engagement in healthcare
- A set of 8 change strategies to drive action toward increased patient and family engagement across the healthcare delivery system
- Simple actions that provide ideas about what key stakeholders can do to take action today

> As a whole, the roadmap reflects a collective imagining of new possibilities—asking *what if* we made real and meaningful changes to how we organize and deliver healthcare and truly put the patient and family at the center.

Who Is This Roadmap For?

It's our hope that a wide variety of stakeholders—individuals and organizations—will find the roadmap actionable and useful, including:

- People who care for patients and provide healthcare services
- Leaders of healthcare organizations
- Health-related professional and trade associations
- Patients, family members, and caregivers
- Individuals involved in health professions education
- Insurers
- Employers
- Researchers
- Funders
- Policymakers
- Consumer advocacy groups

The roadmap is for anyone interested in advancing work related to patient and family engagement—creating momentum for change, increasing knowledge, developing and enhancing skills, and forging a path forward.

> For many of these groups and individuals, the roadmap serves as a call to action. If you are interested in patient and family engagement, this roadmap has a range of strategies that you can use. For all groups, the roadmap highlights opportunities to create meaningful partnerships among and between stakeholder groups to foster healthcare changes that lead to better patient experiences of care, better population health, and lower costs.

> "If we don't do the work to advance patient and family engagement soon, we will have people profoundly affected by our inaction."
>
> - CONVENING PARTICIPANT

This roadmap is a catalyst, intended to spark ideas and action from individuals and organizations interested in making patient and family engagement real.

Starting right now, you can...

- **Explore this roadmap** to identify strategies and tactics that you and your colleagues can put in place, including developing a plan that incorporates multiple levels of the Patient and Family Engagement Framework[1] — direct care, organizational design and governance, and public policy.
- **Find and suggest** resources that can help you implement the strategies and tactics in this roadmap.
- **Join in and contribute** your commitments for driving action related to the research and practice of patient and family engagement.
- **Share this document** with your colleagues and netU[illegible]

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The purpose of this roadmap is to help drive action toward the end goals of patient and family engagement—better patient experiences of 3 9.4( )

8 Strategies for Change

> "The common denominator across all of these areas is the patient."
>
> - CONVENING PARTICIPANT

What is a Change Strategy?

The eight change strategies identified in this roadmap describe **priority areas for action** as we advance patient and family engagement in practice and research. They reflect areas with significant opportunity for growth and change and where improvements can help drive progress toward key patient and family engagement-related milestones and outcomes.

The roadmap does not assign who is responsible for specific actions because there is rarely one group responsible, and steps must be taken in partnership with other stakeholders. It's up to all of us—clinicians, healthcare leaders, patient and family groups, researchers, policy makers, insurers, and funders—to determine when and where we can and should act.

To learn more, resources are available to help with implementation of each change strategy.

For each of the change strategies, we provide:

- A brief **description** of the change strategy.
- Examples of **tactics**, or ways in which the change strategy can be translated into action—some familiar, and some more innovative. The tactics provided are examples and are not an exhaustive list of ways that a strategy could be implemented—they are a launching point for your own ideas and actions.
- **Milestones** to help assess whether and to what extent we are progressing toward ultimate outcomes.

How can the change strategies help drive progress toward end goals?

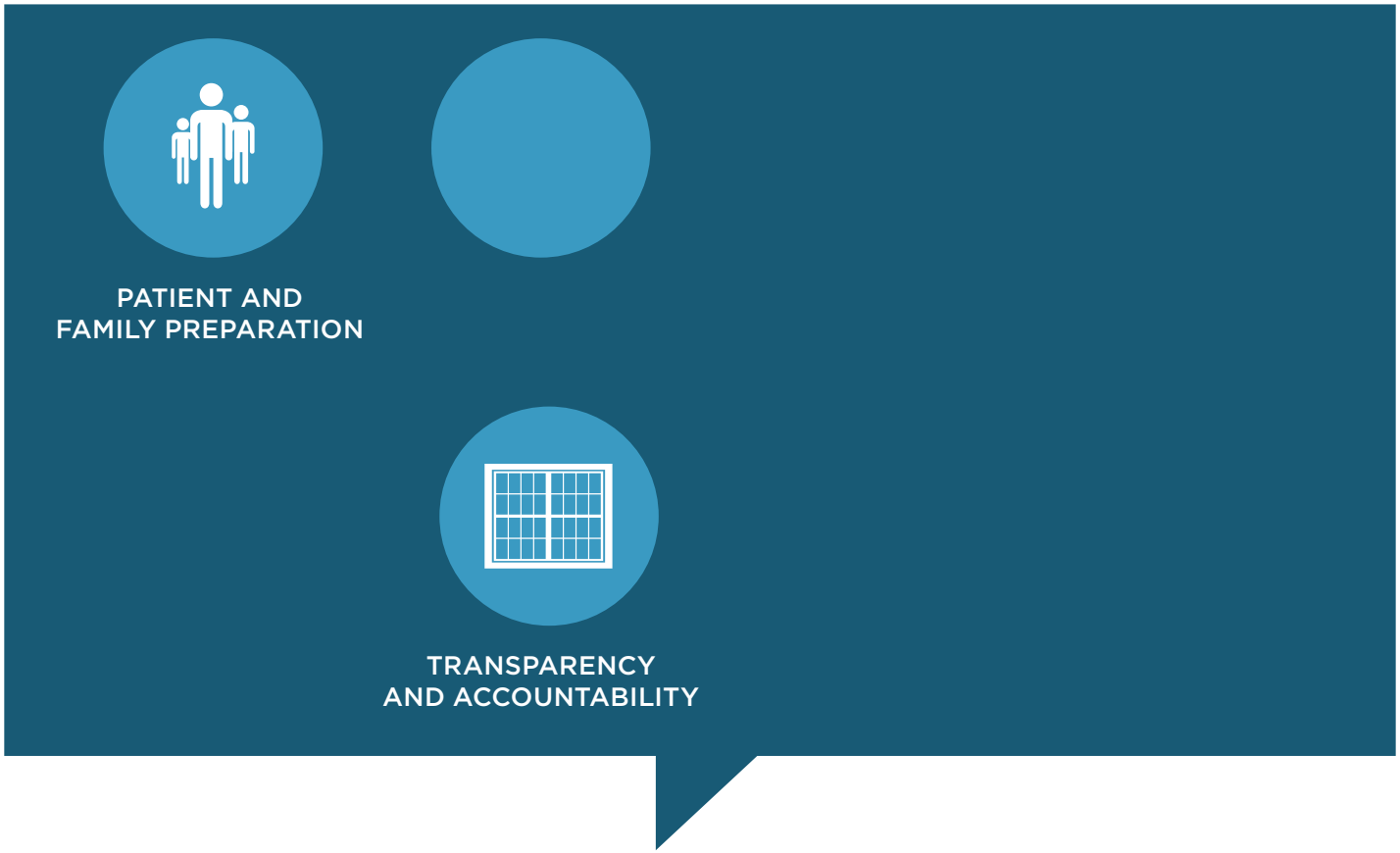
The change strategies help drive progress toward key milestones and the end goals of true patient and family engagement—better patient experiences of care, better population health, and lower costs—in several ways.

They help you assess your own efforts and identify where to take action. The change strategies are designed to help you consider your own efforts, identify areas where you could be taking action, think about how these areas relate to each other, and generate ideas about ways to move forward.

They illustrate ways to push your current efforts across all levels of engagement. The change strategies emphasize the importance of patient and family engagement at all levels—direct care, organizational design and governance, and public policy—as well as in research. Within each of the change strategies, we illustrate ways to work on patient and family engagement in direct care; in how care is organized, designed, and delivered; and in how public policies are developed and implemented.

They help break down siloes and illustrate how efforts are connected. You will notice that some tactics appear in more than one change strategy. This is illustrative of the overlapping nature of the strategies. Looking at the change strategies as a connected whole can be a powerful way to understand how you can support and amplify your efforts by working across multiple change strategies or by partnering with others who are doing complementary work. While there is no one correct sequence or order to the change strategies, all affect and are affected by each other.

One caveat: The work of advancing patient and family engagement is not just about whether the strategies are implemented but also about *how* they are implemented. The implementation of any change strategy must be a collaboration and co-production with patients and families. This means that patients and families are active partners in planning, action, and evaluation as we create new processes, systems, and paradigms.



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Patient and Family Preparation

Educate, prepare, and empower patients and families to engage effectively in their health and healthcare

BACK TO 8 CHANGE STRATEGIES

Tactics

Milestones

> "We can't keep patients in the dark and then call them stupid for not having enough information."
>
> - CONVENING PARTICIPANT

When patients and families take a more active and shared role—partnering in their health, healthcare, and the healthcare system as a whole—everyone benefits. Education and preparation are important to ensuring that patients and families can engage effectively in the ways that they want. This includes education and preparation related to their own health and healthcare and preparation to partner with clinicians and healthcare leaders to shape how care is organized and delivered. A key purpose of education and preparation is giving patients and families the skills, confidence, and authority to partner—to the degree that they want—in interactions and healthcare decision making at all levels and to provide self-care and manage illness and chronic disease effectively. Because patients and families are diverse in their desire and ability to engage, it is important to consider how we can tailor efforts to meet patients and families where they are, address specific needs and concerns, and best facilitate their engagement.



DC

Patient and Family Preparation

Key: DC Direct Care | OL Organizational Level | PL Policy Level

Tactics to Drive Action for This Change Strategy

(DC) Implement patient-centered tools for patients and clinicians to support shared decision making

- Consistently use evidence-based and tested decision-support tools.
- Develop additional condition-specific patient-education and decision-support tools.
- Capture patient and family experiences and satisfaction with decision-support tools and the outcomes of shared decision making via, for example, the use of a direct feedback loop.

(DC) Increase the use of peer education and support for patients and families

- Implement patient advocate or patient navigator programs.
- Create online or in-person peer support programs for patients and families.
- Direct patients and families to existing online networks and resources, such as PatientsLikeMe, American Diabetes Association Patient Community, Cystic Fibrosis Foundation, among others.
- Tailor outreach and support to individual patient needs and activation levels.

(DC) Support patients in managing their own health

- Ask about patients' priorities, experiences, and needs to identify barriers related to self-management.
- Help patients set individualized and realistic goals to improve health, for example, diet and exercise, that incorporate their priorities and identify small steps to achieve goals.
- Use simulation and experiential learning to teach patients how to self-monitor and manage chronic conditions, such as diabetes or asthma.
- Tailor coaching and support to patient and family needs and activation level.

Patient and Family Preparation

Key: DC Direct Care; OL Organizational Level; PL Policy Level

Tactics to Drive Action for This Change Strategy

OL Prepare patients and families to partner with healthcare organizations and systems

- Develop materials and consistent messaging to increase awareness of and explain opportunities for patients and families to partner in organizational design and governance, for example, as faculty, participating in hiring decisions, serving as organizational transformation leaders, and working as patient and family advisors.
- Develop and implement standardized training programs that explain roles, outline expectations, and prepare patients and families for partnering with healthcare organizations, including helping them understand organizational structures, unfamiliar terms, quality improvement processes, and how to effectively share their stories and input.
- Develop mentorship programs for new patient and family advisors to assist with orientation and problem solving.

OL Prepare patients and families to partner with researchers in designing and conducting research studies

- Develop materials and consistent messaging to explain opportunities for patients and families to participate in designing and conducting research studies.
- Develop and implement standardized training programs that explain roles, outline expectations, and prepare patients and families to partner with researchers, including help understanding research terminology, techniques, and processes.

Patient and Family Preparation

Key: DC Direct Care; OL Organizational Level; PL Policy Level

Tactics to Drive Action for This Change Strategy

(PL) Prepare patient and family representatives to partner with other stakeholders in local, state, and national policy and programmatic decisions

- Develop materials and consistent messaging to explain opportunities for patients and families to partner in local, state, and national policy and programmatic decisions.
- Develop and implement standardized training programs that explain roles, outline expectations, and prepare patients and families for partnership at this level, including providing background information on the program or topic being addressed.

Patient and Family Preparation

Key: DC Direct Care | OL Organizational Level | PL Policy Level

Milestones Associated With This Change Strategy

DC OL Patients and families believe that engaging in their care and partnering with providers and organizations will help improve the quality and safety of care.

DC Patients and families are prepared and able to partner effectively in direct care, including navigating and interacting with the healthcare system, making informed decisions about their individual care, and managing their health.

OL Patients and families are prepared and able to partner effectively with healthcare providers, facilities, and systems at the organizational level, including partnering in the development and implementation of organizational policies and practices.

OL Patients and families are prepared and able to partner with researchers in the design, implementation, and analysis of research studies.

PL Patients and families are prepared and able to partner with other stakeholders in shaping public policy.



Clinician and Leadership Preparation

Educate, prepare, and empower clinicians and healthcare leaders to partner effectively with patients and families

BACK TO 8 CHANGE STRATEGIES

Tactics

Milestones

> "The goal is to have patient and family engagement be part of everything clinicians and leaders do."
>
> - CONVENING PARTICIPANT

A dedicated, invested workforce of clinicians and healthcare leaders is crucial to ensuring that patient and family engagement is encouraged, supported, and welcomed. Preparing clinicians and healthcare leaders begins with academic education and training and continues through practice and continuing education. It includes preparation to help clinicians and healthcare leaders partner with patients and families not only at the direct care level but also at the organizational level, shaping how care is organized and delivered.

Clinician and Leadership Preparation

Key: DC Direct Care; OL Organizational Level; PL Policy Level

Tactics to Drive Action for This Change Strategy

(DC) Integrate patient and family engagement into the healthcare professions curriculum

- Implement mechanisms for patients and families to partner with leaders of medical, nursing, and other health professions schools on curriculum development and planning oversight.
- Develop a national curriculum to address patient and family engagement competencies.
- Partner with patients and families to deliver curriculum by, for example, using patients and families as faculty or mentors and including patient and family feedback and perspective as key parts of learner assessment.
- Provide opportunities for experiential learning, observation, and hands-on practice related to patient and family engagement.
- Formally assess students' patient and family engagement competencies and skills.

(DC) Develop standardized patient and family engagement competencies

- Identify clinician behaviors that support patient and family engagement.
- Develop a national set of competencies and assessments in patient and family engagement for healthcare professions education that reflects clinician behaviors needed to support patient and family engagement.

Clinician and Leadership Preparation

Key: DC Direct Care | OL Organizational Level | PL Policy Level

Tactics to Drive Action for This Change Strategy

DC Educate and train practicing clinicians about patient and family engagement

- Develop and deliver training programs that bring together different healthcare professionals—such as nurses, physicians, dentists, and pharmacists—to learn from each other in multidisciplinary settings.
- Develop and deliver training on specific engagement-related issues based on patient and family priorities, including shared decision making, communicating difficult information, and demonstrating empathy and respect.
- Provide opportunities for ongoing experiential learning, observation, and hands-on practice related to patient and family engagement.
- Educate clinicians about community resources, such as social workers and community-based organizations, to facilitate partnerships outside of the care delivery system.

OL Prepare clinicians and staff to partner with patients and families at the healthcare organization and system level

- Develop and implement training programs to help clinicians and staff understand how patients and families can participate in and help improve organizational design and governance, including serving as faculty, participating in hiring decisions, serving as organizational transformation leaders, and working as patient and family advisors.
- Develop and implement training programs that outline partnership expectations at the organizational level and that prepare clinicians and staff for partnering with patients and families in this capacity.

Section Menu

Clinician and Leadership Preparation



Clinician and Leadership Preparation

Key: DC Direct Care; OL Organizational Level; PL Policy Level

Milestones Associated With This Change Strategy

DC OL Clinicians and healthcare leaders believe that patient and family engagement is an important part of improving care quality and safety.

DC Clinicians are willing, able, and prepared to engage effectively with patients and families during clinical encounters.

OL Clinicians are willing, able, and prepared to engage effectively with patients and families in organizational design and governance.

OL Healthcare system and organizational leaders are willing, able, and prepared to engage effectively with patients and families as organizational partners and to deploy patient and family engagement as a strategic priority.

Care and System Redesign

Redesign system processes, policies, and structures to provide opportunities for and support of partnerships between patients, families, and the healthcare team

> "It's not about changing the patient; it's about changing the system."
>
> - CONVENING PARTICIPANT

A critical part of patient and family engagement is creating an environment where engagement is expected, welcomed, and facilitated. This includes providing concrete opportunities for patients and families to engage and be active in their care, creating policies that emphasize patient and family partnership, and developing and implementing care processes that reflect patients' and families' self-identified needs.

DC Implement communication mechanisms that help clinicians elicit, understand, and respect patient perspectives and concerns

- Employ communication techniques that support patients, including active listening, asking questions to understand the patient perspective, and using teach-back methods to assess understanding.
- Employ communication approaches, such as motivational interviewing, that encourage patients to identify and work toward their own goals.
- Create universal advance directives and orders that are readily accessible, for example, in electronic health records.
- Conduct advanced care planning.
- Develop ways for patients and families to easily report adverse safety and quality events so that clinicians are aware and can take immediate action if needed, including patient-and family-activated rapid response teams.

DC Structure care processes to support shared decision making

- Educate patients and families about shared decision making, explain that there are choices to be made, and issue specific invitations for them to participate.
- Document the shared decision making process, including the

  ₱n ues, and pre4redces.
-

Care and System Redesign

Key: DC Direct Care; OL Organizational Level; PL Policy Level

Tactics to Drive Action for This Change Strategy

(DC) Structure care processes to support patient and family involvement in care planning and self-management

- Create care plans that reflect patient and family self-identified life and health goals and document these life and health goals in the medical record.
- Use data—for example, predictive analytics—to identify patients who are likely to be at risk or have high needs for support.
- Provide tailored coaching and support to enable patient self-management of care.

(DC) Invite and partner with families as part of the healthcare team

- Establish family presence policies in healthcare organizations.
- Issue specific invitations to family members to take part in care encounters.
- Develop organizational policies that specify families as full members of the healthcare team.

(DC) Structure care processes to support information sharing and provide specific engagement opportunities

- Implement bedside rounding or bedside change of shift report that includes the patient and family as active, contributing partners.
- Implement group visits (e.g., shared medical appointments) and other interventions that encourage patient-to-patient learning.
- Implement patient-and family-centered discharge planning.
- Leverage technology to support communication and access and create touch points outside of the walls of the delivery system, for example, via tele-health options.

Care and System Redesign

Key: DC Direct Care; OL Organizational Level; PL Policy Level

Tactics to Drive Action for This Change Strategy

(DC) Implement mechanisms that enable care coordination across different settings

- Design care coordination systems between important points of transition, for example, between primary and specialty care, hospital and rehabilitation settings, and system-based and home-based care.
- Leverage technology to support and manage the flow of data across all healthcare providers and systems, for example, a community-wide health information exchange with one patient portal.

(DC) Implement mechanisms that support clinicians' emotional well-being and ability to care compassionately for patients

- Implement support programs to address clinicians' emotional well-being.
- Conduct grand rounds or continuing education sessions on topics related to the emotional health and well-being of clinicians.

Care and System Redesign

Key: DC Direct Care; OL Organizational Level; PL Policy Level

Milestones Associated With This Change Strategy

DC Patients, families, and clinicians develop care plans and make healthcare decisions together, taking into account the best scientific evidence and patients' values, preferences, and life circumstances.

DC Information about goals, symptoms, preferences, diagnoses, treatment options, risks, and benefits is shared equally among patients, families, and clinicians.

DC Family members, as defined by patients, are welcomed as full partners on the healthcare team.

DC Patients, families, and clinicians establish positive, meaningful relationships with each other.

DC Clinicians have positive experiences and find more joy and meaning in their work.

DC Links exist within and outside of the healthcare delivery system that enable seamless care coordination.



Organizational Partnership

Redesign healthcare organizations to make patients and families part of the governance structure

BACK TO 8 CHANGE STRATEGIES

Tactics

Milestones

> "If patients don't help lead change, it will be a fatal error."
>
> - CONVENING PARTICIPANT

Partnering with patients and families in the design of processes, policies, and facilities ensures that healthcare organizations and systems are structured to better reflect the patient and family perspective and needs, provide specific opportunities for patient and family engagement, ensure better outcomes, and provide better experiences for patients, families, and clinicians. Partnering with patients and families in organizational governance helps ensure that there is a clear pathway for infusing their voices and experiences into healthcare workflows, organizations, and systems—for example, hospitals, physician groups, patient-centered medical homes, long-term care facilities, accountable care organizations, and others.

Create organizational opportunities and roles for patients and families that permeate every aspect of the organization

- Establish patient and family advisory councils in hospitals, primary care settings, nursing homes, and other healthcare organizations.
- Include patients and families as members of organizational quality and safety committees, including root cause analysis teams and quality improvement teams.
- Work with patient and family advisors to improve organizational administration and efficiency, for example, billing and workflow issues.
- Partner with patients and families on hiring and staffing issues, for example, by having them interview candidates for leadership positions and participate in other hiring decisions and performance evaluations.
- Partner with patients and families to determine organizational research priorities and design organizational research projects.
- Include patients and families as full members of the organization's board.

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Organizational Partnership

Key: DC Direct Care | OL Organizational Level | PL Policy Level

Tactics to Drive Action for This Change Strategy

OL Implement organizational structures that facilitate communication between leadership and patients and families

- Create clear lines of reporting and opportunities for direct contact between patient and family advisors and leadership.
- Dedicate staff and create departments to oversee work with patient and family advisors.

OL Prepare patients and families to partner with healthcare organizations and systems through the implementation of support mechanisms

- Develop materials and consistent messaging to increase awareness of and explain opportunities for patients and families to participate in organizational design and governance, for example, serving as faculty, participating in hiring decisions, serving as organizational transformation leaders, and working as patient and family advisors.
- Develop recruitment and interview processes that enable the ongoing identification and selection of effective patient and family advisors.
- Develop and implement standardized training programs that explain roles, outline expectations, and prepare patients and families for partnering with healthcare organizations, including help understanding organizational structures, unfamiliar terms, quality improvement processes, and how to effectively share their stories and input.
- Implement processes to match patients and families with opportunities that are interesting to them and that make effective use of their skills.
- Develop mentorship programs for new patient and family advisors to assist advisors with orientation and problem solving.



Organizational Partnership

Key: DC Direct Care | OL Organizational Level | PL Policy Level

Milestones Associated With This Change Strategy

OL Clinicians and organizational leaders partner with patients and families to make decisions about facility and workflow design, organizational policies and procedures, and care delivery processes.

OL Healthcare organizations have clearly identified mechanisms and processes for infusing and integrating patient and family perspectives and experiences into the organizational structure.



Measurement and Research

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

BACK TO 8 CHANGE STRATEGIES

Tactics ›

Milestones ›

> "Measures, especially those that are publicly available, drive changes in behaviors and processes."
>
> - CONVENING PARTICIPANT

Measurement and research are critical to drive changes in behaviors and processes and to build evidence related to patient care, engagement practices, and outcomes. Measurement can provide patients and families with data to make more informed choices and provide clinicians and healthcare organizations with data to recognize successes and identify areas for improvement. Research can help assess whether, to what extent, and how engagement is occurring, and identify outcomes resulting from engagement interventions. An action-oriented, coordinated measurement and research approach that incorporates measures, goals, and outcomes of importance to patients and families is an important driver of change.

Measurement and Research

Key: DC Direct Care; OL Organizational Level; PL Policy Level

Tactics to Drive Action for This Change Strategy

(DC) Implement additional measures of patient-level experiences, goals, and outcomes

- Develop and implement condition-specific, patient-reported outcome measures.
- Develop measures that assess patient and family experiences and outcomes relative to patient-specified goals, for example, ask patients about their treatment goals, record these, and measure whether they are achieved.
- Develop patient-centered measures of cost and value.
- Explore methods that collect more detailed and personalized data about patient experiences and outcomes, such as using video to capture interactions and observations.

(DC) (OL) Implement measures that assess the process of patient and family engagement—how and to what extent engagement occurs

- Specify the behaviors of patients, families, and clinicians that constitute or support patient and family engagement.
- Specify the actions, policies, and procedures of healthcare organizations that constitute or support patient and family engagement.
- Develop and implement measures to assess patient and family engagement in direct care and patient and family partnership at the organizational level.
- Develop and implement an organizational activation measure for patient and family engagement—analogous to the Patient Activation Measure®.

Measurement and Research

Key: DC Direct Care; OL Organizational Level; PL Policy Level

Tactics to Drive Action for This Change Strategy

DC Create feedback mechanisms (using measures) to help plan patient care, provide real-time, personalized feedback to clinicians and organizations, and drive changes

- Integrate existing and new measures of patient-reported outcomes into clinical practice so that clinicians can better understand patient life experiences and quality-of-life concerns.
- Collect point-of-service data about patient experiences and levels of engagement, using tablets or other mobile technology.
- Use secret shoppers or standardized patients to assess care and engagement experiences and interactions.
- Create patient experience maps charting staff and patient input to understand expectations at various care points and identify areas for improvement.
- Create dashboards with benchmarks for quality improvement efforts.

DC OL Conduct research on how engagement leads to outcomes, including improved health, quality, cost, or staff satisfaction

- Assess how organizational engagement efforts impact organizational outcomes, such as return on investment, quality, and market share.
- Identify critical junctions where engagement is likely to make a difference to focus research in these areas, for example, sentinel events, discharge, diagnosis.
- Build the evidence base that quality of engagement is related to outcomes.



Measurement and Research

Key: DC Direct Care; OL Organizational Level; PL Policy Level

Tactics to Drive Action for This Change Strategy

OL PL Partner with patients and families in health and healthcare research

- For research projects, such as clinical trials, comparative effectiveness research, health services research, quality improvement efforts at individual organizations, and so forth—partner with patients and families to:
  - » Formulate research questions and study design.
  - » Implement and monitor the study.
  - » Analyze and interpret results.
  - » Plan and disseminate findings.
- For research funders, partner with patients and families to:
  - » Prioritize research topics and questions for funding.
  - » Review grant applications.

OL Assess outcomes of interest to patients and families in clinical research

- Include clinical metrics, such as mortality, infection, and consumer-facing metrics, such as time out of work, support needed at home, impact on daily living, quality of life, and/or patient-reported outcomes.
- Develop composite measures for balancing clinical and interpersonal aspects of care.



Measurement and Research

Key: DC Direct Care; OL Organizational Level; PL Policy Level

Milestones Associated With This Change Strategy

DC OL PL Clearly defined and measureable engagement behaviors are identified for patients, families, providers, organizations, and systems.

DC OL PL Measures of patient and family engagement processes and outcomes are available that are patient-oriented and actionable for planning individual care and for quality improvement more broadly.

DC OL PL Data are collected to develop an understanding of how engagement links to specified outcomes, such as improved health and system efficiency.

OL PL Policymakers and researchers partner with patients and families to prioritize studies and participate in the planning, conduct, and dissemination of health-related research studies.



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 healthcare

BACK TO 8 CHANGE STRATEGIES

Tactics ›

Milestones ›

> "Nothing works without transparency."
>
> - CONVENING PARTICIPANT

Creating a more transparent healthcare system and making data available enhances accountability and enables patients and families to be active in their own health and healthcare, make informed decisions, and understand variations in healthcare cost and quality. When patients and families have access to clear, comprehensive information about quality and cost, treatment options and approaches, and their own health and healthcare, they are better informed and able to engage. Making provider, organization, and system-level performance data transparent also is important for driving and informing organizational quality improvement efforts and promoting accountability.

Transparency and Accountability

Key: DC Direct Care | OL Organizational Level | PL Policy Level

Tactics to Drive Action for This Change Strategy

DC Give patients access and the ability to contribute to their medical record

- Employ portals that allow patients to access their electronic health records anywhere.
- Implement mechanisms that enable patients to see clinical notes, contribute to their medical record, and provide corrections.
- Structure electronic health record fields to enable patients to include information that is important to them, for example, patient goals.

DC Provide transparent information about risks, benefits, and costs of care and treatment options

- Provide unbiased, evidence-based information that can be easily accessed and used by clinicians, patients, and families to support care planning and decision making.
- Provide and discuss information about the effect of treatment options or care plans on patients' and families' everyday lives.
- Provide patients with personalized, estimated costs to use in decision making around various treatment options and in care planning for managing chronic conditions.
- Establish processes to document in the medical record the information shared or treatment options discussed with the patient and family.

Transparency and Accountability

Key: DC Direct Care; OL Organizational Level; PL Policy Level

Tactics to Drive Action for This Change Strategy

(OL) Provide transparent information about organizational quality and safety

- Implement procedures for sharing organizational performance related to safety—such as never events, near misses, and medical errors—with patients and families in ways that promote transparency without creating a punitive environment for clinicians.
- Share organizational-level data, such as clinical quality, Consumer Assessment of Healthcare Providers and Systems (CAHPS), or other data from quality improvement efforts, with the community to highlight successes and be forthright about where there is room for improvement.
- Share organizational-level cost, quality, and safety data with patient and family advisors.

(DC) (OL) Publicly report and disclose cost, quality, and safety information

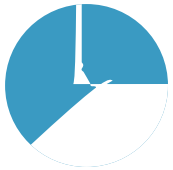
- Make all healthcare cost, pricing, and charge data public.
- Inform patients and families about how to access and use publicly available cost and quality information.
- Create dashboards of safety, quality, and cost data that enable direct comparisons, including ratings of clinicians and organizations, to support informed choices.
- Develop a publicly accessible all payer claims database for research and reporting.
- Work with patients and families to identify and report the quality, cost, and safety data that are most important to them and for all patients and clinicians.

Transparency and Accountability

Key: DC Direct Care; OL Organizational Level; PL Policy Level

Milestones Associated With This Change Strategy

- DC Patients have access to and can add information to their electronic health record, including clinical notes.
- DC Clinicians discuss risks, benefits, costs, and lifestyle implications associated with care and treatment options and decisions with patients and families.
- DC Patients, families, and clinicians have access to clear and usable information about the risks, benefits, costs, and lifestyle implications of different care and treatment options.
- DC OL Patients and families have access to clear and usable information on cost, clinical quality, patient safety, and patient experiences of care.



Legislation and Regulation

Encourage patient and family engagement through regulation and legislation

> "We need to make the current state undesirable and the future state desirable."
>
> - CONVENING PARTICIPANT

Regulatory and legislative change can increase patient and family engagement by motivating individual and organizational behavior change. The development and alignment of mandates and incentives can encourage patients, families, clinicians, healthcare leaders, and healthcare organizations and systems to change behaviors in ways that promote and support engagement.

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Section Menu

Legislation and Regulation

Key

DC Direct Care | OL Organizational Level | PL Policy Level

DC Provide recognition and rewards for care that fully incorporate patient and family engagement

- Reimburse team meetings in primary care settings that include patients and families.
- Reimburse clinicians who use certified decision aids with patients for decision making related to specified conditions.

DC Align incentives and penalties to support patient and family engagement

- Establish reimbursement standards that link to performance on patient and family engagement metrics, for example, patient-reported experiences of care, patient-reported outcomes, and patient activation outcomes, such as greater knowledge, skills, or confidence.
- Incorporate patient and family engagement into pay-for-performance metrics in the public and private sectors.
- Align incentives to encourage behaviors by patients, clinicians, and healthcare organizations that support shared progress toward patient-oriented goals.
- Tie clinician reimbursement to performance on patient and family engagement expectations and evaluations.

DC Require patient and family engagement competencies for certification or accreditation

- Require demonstration of patient and family engagement competency in clinician licensing.
- Require demonstration of patient and family engagement competency in clinician certification and re-certification.
- Require the implementation of patient and family engagement initiatives at the organizational level for accreditation.

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next page



Legislation and Regulation

Key: DC Direct Care | OL Organizational Level | PL Policy Level

Tactics to Drive Action for This Change Strategy

DC OL PL Advance patient and family participation through legislation

- Require that all hospitals create and implement a community benefit plan to improve the community environment and address community health needs.
- Require that hospitals hold at least one public meeting annually or have a significant percentage of board members who have been patients at the hospital.
- Expand consumer governance of accountable care organizations to require that a significant share of board members be consumers.
- Require that regulatory agencies include patients and families in a governance capacity, for example, patient and family participation on committees and public deliberation to bring the patient and family perspective into governance.
- Give clinicians a higher level of malpractice protection when they use certified decision aids.
- Establish a national patient safety authority that includes patient and family representatives.

Legislation and Regulation

Key: DC Direct Care; OL Organizational Level; PL Policy Level

Milestones Associated With This Change Strategy

DC Clinicians and organizations are paid for services related to engaging patients and families, such as using certified decision aids in shared decision making.

DC Incentives and penalties, such as pay-for-performance models, align with patient values and behaviors related to patient and family engagement.

DC Certification and accreditation standards include competencies in
OL patient and family engagement for clinicians and organizations.

DC Legislation that affects health and healthcare incorporates patient
OL and family engagement.
PL



Partnership in Public Policy

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

BACK TO 8 CHANGE STRATEGIES

Tactics

Milestones

> "If engagement is not happening at the public policy level, then it's pushing a rock up a mountain to make it happen."
>
> - CONVENING PARTICIPANT

Patients and families can be involved in developing, implementing, and evaluating national, state, and local healthcare policy and programs in ways that go beyond traditional mechanisms of representative democracy. Patients and families can collaborate with community leaders and policymakers—for instance, representatives from governments, health plans, and employers—to solve community and social problems, shape healthcare policy, and set priorities for the use of resources. Partnership opportunities may include involving patients and families in statewide, regional, and national conversations to develop guidelines for patient care and treatment, determine research priorities, and provide oversight for patient and family engagement initiatives.

Partnership in Public Policy

Key: DC Direct Care | OL Organizational Level | PL Policy Level

Tactics to Drive Action for This Change Strategy

PL Create opportunities for patient and family representatives to serve on local, state, and national committees focused on health or healthcare

- Establish regional and statewide patient advisory boards.
- Develop opportunities for patient and family representatives to be involved in decision making related to setting clinical quality standards, reviewing research grants, and determining research priorities.
- Create slots for patient and family representatives on any committees that have oversight authority related to healthcare.
- Require all federally funded research and regulatory agencies to include patient and family representatives in governance, decisions about research priorities, and research design.

PL Create opportunities for the public to contribute to health and healthcare policy decisions at the local, state, and national levels

- Create a citizen council to provide input into decisions about what health plans should cover, for example, formulary decisions.
- Hold public deliberation sessions to get input on specific policy concerns.
- Convene town hall meetings to discuss issues of importance at the local, state, or national level.

Partnership in Public Policy

Key: DC Direct Care; OL Organizational Level; PL Policy Level

Tactics to Drive Action for This Change Strategy

PL Prepare patient and family representatives to partner with other stakeholders in local, state, and national policy and programmatic decisions

- Develop materials and consistent messaging to explain opportunities for patients and families to partner in local, state, and national policy and programmatic decisions.
- Develop and implement standardized training programs that explain roles, outline expectations, and prepare patients and families to participate in public deliberation.
- Prepare background information on important policy topics and programs to help patients and families become familiar with key issues.

PL Prepare stakeholders and policymakers to partner with patient and family representatives in shaping public policy

- Create messages about the benefits of patient and family engagement, including greater understanding of constituents' needs.
- Share patient and family stories to illustrate the importance of patient and family engagement.
- Develop training programs to help stakeholders understand how patients and families can participate at the policy level, for example, to decide research priorities and set clinical quality standards.
- Develop and implement training programs that prepare stakeholders to partner with patients and families and that outline roles and partnership expectations.

Partnership in Public Policy

5 Simple Actions You Can Do Today

Print the Simple Actions

The Roadmap for Patient and Family Engagement in Healthcare Practice and Research outlines eight change strategies to support and advance engagement. These change strategies and the accompanying tactics are intended to ignite change, but it's also important to think about the simple things we can all do right now that will make a difference.

That's where the 5 simple actions come in.

Whether you are a patient, family member, clinician, organizational leader, policymaker, insurer, employer, or researcher, following are five things you can start doing **right now**. They are tangible, discrete actions that can make a difference.

What all of these actions have in common is that they drive toward partnership—where patients and families participate at all levels in healthcare to help achieve our common goals of better patient experiences of care, better population health, and lower costs.

What Can Patients and Families Do?

1. **Give feedback on your experiences.** Complete any surveys you get from your healthcare providers that ask about your experiences at your most recent visit. Write a letter to your local clinic or hospital about the care you received or tell your doctors and nurses what went well and what could be improved. If you experience a problem with the quality or safety of care you get, inform your healthcare provider and check back about what they do to resolve it.

2. **Look for information to help you understand your health and health condition.** Look for information online or at your library to help you understand your health

What Can Clinicians Do?

1. **Welcome input and feedback from patients and families.** Form a patient and family advisory council or office-based council. Invite patients and families to share their stories and experiences of care at your next staff meeting. Partner with patient and family advisors to improve current policies, practices, and procedures.

2. **Maximize the potential of your patient portal.** Encourage patients to use the portal and include records of their office visits as well as lab tests. Encourage patients to communicate with you by email as a way to provide brief and timely responses to patient questions.

3. **Use teach-back and other proven communication techniques.** Use teach-back methods to ensure that patients understand the information you are communicating, for example, by asking "Can you tell me when and how you are going to take this medication?" Ask open-ended questions that help you elicit information and understand the patient's values, goals, and beliefs, for example, "What is important to you as we think about your care plan?," "What is your goal for your care?," or "What questions do you have?"

4. **Ask patients what is important to them** so that you can understand whether your recommendations are a good match with their values and goals. Share your thinking about recommendations for care or treatment you present to patients or families, helping them weigh the risks and benefits to make an informed decision. Let patients know that you want to hear their view and any questions or concerns they have about your recommendations.

5. **Contact your professional societies** and encourage them to include patient and family representatives as part of the process when setting clinical recommendations or guidelines.

What Can Providers or Delivery Organizations Do? ›

What Can Provider or Delivery Organizations Do?

1. **Give patients real-time access to their medical records** so they can be informed and engaged in their care and partners in helping to catch and prevent potential mistakes.

2. **Establish family presence policies** that welcome family members to be with patients at all times. Encourage families to attend appointments and be part of the healthcare team. Identify and address any barriers to family presence, such as making space for families in exam or hospital rooms.

3. **Get patient and family input.** Invite patients and families to provide input and feedback about how you can improve the care you deliver to patients. If you've never worked with advisors before, start by asking for input on informational materials, help interpreting results of patient experience surveys, and input on policies and care processes. Create feedback loops to let patients and families who have provided input know how this input was used. Work toward co-creating materials, policies, and processes and partnering with patients and families on quality and safety committees.

4. **Organize a staff education session or grand rounds on patient and family engagement.** Educate clinicians and staff about what engagement is, the benefits of patient and family partnership, and ways they can promote and support patient and family engagement. Invite patients and families to share their stories with staff during this session.

5. **Make sure that patients and families know who to contact if they have questions or concerns about the quality or safety of care they have received.** Include the patient advocate's contact information on your organization's website. Provide patients with simple navigational tools, such as a chart of who is who in your practice or organization and who to call for different concerns.

What Can Healthcare Leaders and Policymakers Do? ›

What Can Healthcare Leaders and Policymakers Do?

1. **Lead by example and be a visible presence.** Make a direct connection with patients and families and ask them for feedback about their experiences. For example, talk to patients and families while they are waiting for healthcare appointments. Conduct leader rounds with patients in the hospital. If you are a policymaker, talk to patients and families in the community—even if it's just at the local grocery store—about their healthcare experiences.

2. **Include goals related to patient and family engagement as key components of your short- and long-term strategic plans.** Identify specific areas of opportunity with measurable objectives and strategies for achieving your goals.

3. **Add patients and families to boards and committees**, giving them support, training and mentoring to partner effectively. Make patient and family engagement a standing agenda item at every board meeting.

4. **Invite patients and families to participate in conferences and meetings** as keynote speakers or participants on panel presentations.

5. **Make patient and family engagement an agenda item** at your next meeting to explore clinician, staff, and healthcare leader perspectives about patient and family engagement. Work toward partnering with patients and families to determine policies and procedures for your organization.

What Can Insurers Do? ›

What Can Insurers Do?

1. **Provide tools that members can use** to easily understand their healthcare choices. Provide information about out-of-pocket costs at the time of service. Make sure that members know who to contact at the health plan if they have problems with their care.

2. **Target outreach and information to high priority populations with ongoing healthcare needs.** Serve as a source of support for people with chronic conditions or other ongoing healthcare needs, helping them navigate the health system and get the care they need. Provide information and support to help individuals with chronic conditions engage in better self-management of their health.

3. **Establish a member advisory council** to get input from members on informational materials, member billing and reimbursement processes, explanation of benefit statements, or online tools.

4. **Publicly report patient experiences and clinical outcomes important to patients and families.** Publicly report outcomes important to patients and families to help them make more informed decisions about their care and foster transparency within the healthcare system.

5. **Give bonus points on contracts** to organizations that engage patients and families in organizational design and governance.

What Can Employers Do? ›

What Can Employers Do?

1. **Give employees clear information about healthcare quality** so that they can make informed decisions, such as deciding where to receive care for "shoppable" conditions like joint replacement surgery.
2. **Help employees understand health insurance and healthcare costs.** Share information about what employers pay, what employees pay, and how employees' actions relate to overall healthcare costs.
3. **Actively seek contracts with health plans that reimburse or reward patient and family engagement efforts**, such as partnering with patients and families in organizational design or tracking quality metrics related to patient-reported outcomes and patient experiences of care.
4. **Create an employee advisory council** to partner with employees in decision making about health plan benefits and coverage.
5. **Join an employer coalition or business group on health** to exchange ideas with other employers about patient and family engagement and improving the quality and safety of care. If you are already a member of an employer coalition, encourage the group to focus on patient and family engagement as an important component of efforts to improve quality and safety and lower healthcare costs.

What Can Researchers Do? ›

What Can Researchers Do?

1. **Co-create research proposals with patient and families** and work with them on designing and implementing studies that answer the questions that matter most to them.
2. **Conduct research to identify behaviors that constitute and support patient and family engagement**—by patients, families, clinicians, administrators, and other health professionals—within various healthcare settings.
3. **Partner with patients and families to design process and outcome measures** to identify outcomes of most interest to patients and families.
4. **Build return-on-investment metrics** related to outcomes, experiences of care, and costs into research on patient and family engagement efforts.
5. **Look beyond the peer-reviewed literature for ways to disseminate results and information.** Share results via blogs, consumer-friendly fact sheets, and social media.

Join In

Resources and Commitments

"The power of what was created during this convening will only be fully realized when every-one takes action. Only then will we realize the power of shared goals and partnerships. Only then will we discover the power of the patient at the center of healthcare."

- SUE COLLIER, CLINICAL CONTENT DEVELOPMENT LEAD

Join In (continued)

Participants' Commitments for Action

Participants ended the convening by offering their own personal commitments—how they would immediately act to promote change in their sphere of healthcare. This step was more than symbolic—it's how real change happens. In reading the commitments of convening participants, you may find ideas to help you take immediate action as well.

Examples of Participants' Commitments

Andy Carter

The Hospital & Healthsystem Association of Pennsylvania

Societal Factors Affecting Engagement

Many societal factors influence whether and to what extent patients and families can engage in their health and healthcare—for example, social norms, regulations, and policy.[2] These societal factors are not fixed; we have the ability to influence them. We can tackle some societal factors directly—for example, requiring interoperability of health information technology (HIT) systems. Other societal factors, such as social norms, begin to shift via the additive effect of the changing behavior of patients, families, clinicians, and organizations over time.

The following list includes societal factors affecting engagement that were discussed at the convening. While it is important to recognize these factors, participants strongly believed societal factors should not prevent us from moving forward—we can take action and make progress in a less-than-perfect environment. The list can help you think about how your engagement-related efforts may intersect with broader societal factors.

Societal factors discussed during the convening ›

[2] Other important factors are associated with patients (e.g., their desire to engage, beliefs about the patient role, health literacy); clinicians (e.g., the extent to which clinicians invite and support patient and family engagement); and organizations (e.g., policies and practices, organizational culture). These factors were discussed and more directly addressed through the development of the eight change strategies.

Societal Factors (continued)

Alignment of and leadership for patient and family engagement efforts

- **Alignment of patient and family engagement efforts.** The ability of the field to develop overarching goals for patient and family engagement that resonate with all stakeholders, along with key milestones at the direct care, organizational, and policy levels, can spur progress by aligning independent and seemingly disconnected efforts to contribute to a larger culture of engagement.
- **Presence of local, state, and national leadership for patient and family engagement**. Efforts to catalyze engagement will be greatly strengthened if there is dedicated leadership at the local, state, and/or national levels. Strong leaders can help organize, coordinate, and incentivize engagement efforts across stakeholders.

Evidence for and examples of patient and family engagement

- **Evidence for patient and family engagement.** Building an evidence base for patient and family engagement helps demonstrate the importance and value of the work and helps target resources—for example, which strategies work for which populations. Generating evidence of the effectiveness of patient and family engagement can bolster key stakeholders' commitment and support implementation efforts.
- **Sharing examples and lessons learned.** To the extent that we can break down silos, share best practices and lessons learned from leaders in the field, and generate new evidence related to research and practice, it will accelerate change in the field.

Societal Factors (continued)

Health information technology (HIT)

- **Interoperability of HIT.** The fragmented nature of today's HIT systems within and across organizations makes it difficult to share information. Providing patients and clinicians with easy access to medical records, enabling system integration of information from all healthcare providers, and employing HIT in patient-centered ways are significant facilitators in achieving the goals of patient and family engagement.

Community environment and resources

- **Community support of health and well-being.** Most healthcare happens at home, so where people live can affect their motivation and ability to participate in self-care and other patient and family engagement activities. For example, the presence of a safe environment for outdoor exercise, access to healthy foods, and programs to address other community issues, such as violence and poverty, can help people engage in their own health and healthcare needs.
- **Linkages to community resources.** The community can help prepare people as they enter into and transition out of the health system. Creating connections between healthcare delivery organizations and community resources where people live can be important in initiating and sustaining change over the long run.

Societal Factors (continued)

Payment and care delivery models and health insurance design

- **Payment reform.** Shifting the focus from traditional fee-for-service payment, where higher volume means more financial reward for providers, to paying based on the quality and value of services can serve as a catalyst for clinicians and healthcare organizations to implement patient and family engagement initiatives.
- **Care delivery models.** The emergence of new care delivery models, such as patient-centered medical homes and accountable care organizations, can foster new healthcare practice patterns and signal greater recognition that clinicians, patients, and families need to work as partners to attain the outcomes we all want.
- **Health insurance design.** As consumers are asked to assume more financial responsibility for healthcare costs—for example, greater patient cost sharing in high-deductible health plans—their motivation to engage increases.

Societal norms

- **Societal expectations and norms.** Societal expectations and norms strongly shape our attitudes and behaviors. The extent to which we are able to directly or indirectly address and shift expectations and norms—for example, moving away from the traditional medical model, notions of adherence and compliance, favoring treatment over prevention, and believing that "more care is better"—will be important.

About the Framework

Patient and Family Engagement

> "Patients, families, their representatives, and health professionals working in active partnership at various levels across the healthcare system to improve health and healthcare."

Ensuring that patients and families are at the center of our rapidly changing healthcare system was the overarching goal for the roadmap.

While developing the roadmap, we recognized the need for an organizing structure that reflected the goal of meaningful patient and family partnership throughout healthcare and that captured convening participants' thinking and pushed it even further. This organizing structure came from the Patient and Family Engagement Framework.

Developed by Kristin Carman, Pam Dardess, and Maureen Maurer at the American Institutes for Research's Center for Patient and Consumer Engagement along with Shoshanna Sofaer, and staff from the National Partnership for Women & Families and the National Quality Forum, we used this conceptual framework[3] to provide structure for the convening and to ground our discussions.

[3] Carman, K. L., Dardess, P., Maurer, M., Sofaer, S., Adams, K., Bechtel, C., & Sweeney, J. (February 2013). Patient and family engagement: A framework for understanding the elements and developing interventions and policies. Health Affairs, 32(2), 223–231.

About the Framework (continued)

Key Elements of the Patient and Family Engagement Framework

The framework reflects four key elements of patient and family engagement.

- First, engagement is not just about what patients do—it's about patients, families, and health professionals working as partners to identify and re-design the parts of the system that are not working.
- Second, we should be partnering with patients and families across all critical areas of healthcare—not only during clinical encounters but also at organizational and policy levels—to determine how healthcare is organized and delivered.
- Third, not all patient and family engagement efforts are equal—there is a continuum, characterized at the far end by true partnership where information is given and received equally and decision making authority is shared.
- Finally, our efforts don't occur in a vacuum. The framework 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.

About Its Development

The development of the framework was informed by years of research and guided by the fundamental principle that we cannot achieve an improved and patient-centered healthcare system unless patients and families have, at minimum, an equal role in the system—and are not simply passive recipients of directives from the medical care system.

Using the Patient and Family Engagement Framework ›

About the Framework (continued)

Using the Patient and Family Engagement Framework

The Patient and Family Engagement Framework is not a step-by-step manual. Rather, it is a vision that encourages all of us to collaborate in bringing patients and families to the table as partners in improving health and healthcare. It can help push our thinking to new bounds, and inform brainstorming about how we can work at all levels and at the farthest end of the continuum. It can also help us think about how individual and complementary efforts might work together to drive progress toward outcomes. Ultimately, it is a tool to help illuminate where and how we need to advance our efforts, with the goal of improving health and healthcare for everyone.

We hope others will continue to use and build on this framework to develop ideas, interventions, and policies that support greater partnership with patients and families in healthcare.

To Learn More

To learn more about the Patient and Family Engagement Framework, you can watch a video to hear directly from the framework authors.

More About Creating the Roadmap

> "The Moore Foundation convening offered a rare opportunity to collaborate intensely with stakeholders from across the spectrum of care. It was an invigorating experience to listen to and learn from these dedicated and knowledgeable people. I, and other participants I spoke to, felt that our beliefs were challenged, our perspectives informed, our thinking enriched. We found ourselves modeling the very patient/provider/payer partnership we collectively envision for healthcare."
>
> - PAT MASTORS, PRESIDENT
> PATIENT VOICE INSTITUTE

In recognition of the importance of patient and family engagement, the Gordon and Betty Moore Foundation funded the American Institutes for Research (AIR)[4] to develop a roadmap for practice and research in patient and family engagement, including convening a diverse group of stakeholders to generate strategies that, when implemented, would drive progress in practice and research.

In this section, we describe the process of creating the roadmap and who was at the convening.

[4] This work was led by Dr. Kristin L. Carman, Ms. Pam Dardess, Ms. Maureen Maurer, and Dr. Thomas Workman of AIR, with support from Ms. Ela Pathak-Sen of Commotion UK.

Learn about the process of creating the roadmap ›

More About Creating the Roadmap (continued)

Process

To develop the roadmap, we used the significant work that has already been done to advance research and practice in patient and family engagement as a starting point. At the same time, a critical goal was identifying ways to push the field forward and develop a unifying vision of patient and family engagement in both practice and research. The work of creating the roadmap encompassed:

- Months of preparatory activities, including the development and dissemination of informational briefs and webinars to participants in the convening.
- A two-day, in-person meeting, referred to as a convening.
- An extensive analysis of data generated through the convening and other activities.

Throughout the process, we worked with an eight-member steering group that met biweekly over three months and provided guidance on our core tasks, reviewed drafts of all documents, and offered insights on key issues.

Learn about the preparatory activities ›

More About Creating the Roadmap (continued)

Preparatory Activities

Before the convening in February 2014, we completed a number of activities designed to enable productive discussions:

- **Identifying convening participants.** We identified and invited people who had *interest*, *influence*, and an *investment* in patient and family engagement. The goal was to have a group of participants who had *information* on existing efforts, could take *initiative* to create change, and who were *impacted* by the changes being made.
- **Convening briefs.** Working with several participants, we authored two convening briefs designed to provide an important base of knowledge for the participants and points of focus for the convening. The first brief was co-authored with patient participants and provided information on the core outcomes of patient and family engagement efforts, concentrating on things that matter most to patients and families.[5] As part of this brief, we developed and solicited patient and family responses to a series of online questions designed to elicit the patient and family vision of engagement in healthcare. The second brief focused on societal and organizational factors that influence whether and to what extent patient and family engagement occurs.[6]
- **Webinars.** The goal of the webinars was to establish a base of understanding going into the convening and to create a focus for the discussions at the event. The first series of webinars provided participants with information on the Patient and Family Engagement Framework and the purpose of the convening. The second series gave participants a preview of the patient convening brief and provided an opportunity to discuss preliminary findings.
- **Participant website.** To facilitate information-sharing, communication, and discussion before the convening, we created a secure participant website. The website included biographies of all participants. We used the website to post documents of interest, share webinar recordings, and to begin discussions via an online discussion board.

[5] Workman, T., deBronkart, D., Quinlan, C., Pinder, J. February 2014. What Do Patients Want from Patient Engagement?

[6] Thygeson, M., Frosch, D., Carman, K.L., Pande, N. February 2014. Patient and Family Engagement in a Changing Health Care Landscape.

More About Creating the Roadmap (continued)

The Convening

In February 2014, 72 people representing 59 organizations came together to contribute to the process of painting a vision of a new healthcare system, to identify strategies and tactics to help achieve that vision, and to define milestones to let us know how we are progressing.





The approach to the convening differed from other conferences and meetings to date on this topic in ways that provide important context for the findings presented in this roadmap.

- **Diverse viewpoints were represented**—those of patients, families, researchers, clinicians, health systems, employers, insurers, policymakers, and funders. Participants collaborated in interdisciplinary groups that provided everyone with an equal level of authority. No one group's viewpoint was unduly emphasized, and discussions reflected multiple views on all topics.
- **We adopted an Appreciative Inquiry[7] approach** to emphasize possibilities and build on existing strengths rather than to address or solve problems. This approach allowed participants to acknowledge potential barriers and move beyond them—asking "how can we do this?" rather than focusing on "why we can't do this."

More About Creating the Roadmap (continued)

On the morning of the first full day of the convening, participants gathered in small groups. Each group received a "roadmap"—a large laminated poster that was blank except for a winding road. The stated goal was for each group to begin building an action- and behavior-oriented roadmap outlining what individuals, organizations, and systems must do and experience for the field of patient and family engagement to reach an ideal state where patients and families are meaningfully engaged. Participants began creating their roadmaps, talking about what patient and family engagement hopes to accomplish, and placing key milestones and destinations on the map.



[7] Appreciative Inquiry (AI) is the "cooperative search for the best in people, their organizations, and the world around them. It involves systematic discovery of what gives a system 'life' when it is most effective and capable in economic, ecological,

More About Creating the Roadmap (continued)

During the afternoon of the first day, participants discussed the *how*—what needs to happen (in the form of strategies) to achieve their visions of engagement. Throughout the day, participants came together as a large group to share their draft roadmaps and get reactions from other participants.

The next day, participants revised and finalized their strategies, using an "open-space" technique to encourage creativity and free discussion, before breaking again into smaller groups to finalize their roadmaps. An important goal of this time was to identify strategies for research and practice in the field that were **g**eneralizable, **u**sable, **e**ffective, **e**xecutable, **s**calable, and **s**ustainable—that is, GUEESS-able. After the small group discussions, participants gathered again to report the highlights of their revised roadmaps. Participants ended the convening by offering their own personal commitments—how they would immediately take action coming out of the convening.

In reflecting on the design of the convening, participants noted the power of peer-to-peer learning, including the benefit of learning from participants who would not typically be considered peers, but whose contributions provided examples of how to re-orient thinking or push initiatives forward. This created a high level of energy among participants and enthusiasm for moving forward together.

Post-Convening

Thanks to this collaborative, multidisciplinary, positive approach, the convening facilitated the generation of a large number of strategies and tactics to advance the field of patient and family engagement. During the convening, participants' thoughts and ideas were captured in hundreds of pages of notes, dozens of flip charts, and five roadmaps created by the small groups. In analyzing the data, a critical goal was to keep the voice of participants at the forefront. The ideas and even much of the language in this roadmap come directly from these documented comments and suggestions.

More About Creating the Roadmap (continued)

Participants

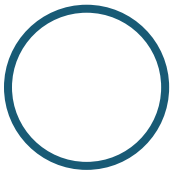
Participants in the convening were a multidisciplinary group of individuals at the forefront of patient and family engagement: clinicians, healthcare leaders, researchers, funders, employers, insurers, policymakers, patients, and family members.[8] The participants were encouraged to come together in the spirit of collaboration—not to seek endorsement of their own ideas, but to share ideas with each other and together develop a plan to move forward.

Brief biographies for the project team from the Moore Foundation and the American Institutes for Research as well as convening participants are included on the following pages.

[8] Patient and family participants received a stipend to cover their time and participation at the convening

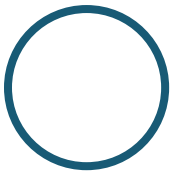
Project Team at the Gordon and Betty Moore Foundation ›

Project Team at the Gordon and Betty Moore Foundation



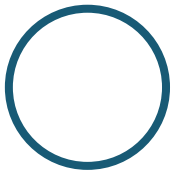
Dominick Frosch

Dominick L. Frosch is a fellow in the Gordon and Betty Moore Foundation's Patient Care Program. He oversees the foundation's activities related to advancing patient and family engagement in healthcare. Prior to joining the foundation, Dominick served as associate professor of medicine at UCLA and associate investigator at the Palo Alto Medical Foundation Research Institute. His clinical research has focused on shared decision making and patient engagement for over 15 years. He has developed and evaluated patient decision support interventions as well as explored pathways for implementing these in routine clinical practice in primary and specialty care. His research has also explored the role of prescription drug advertising and other forms of population-based health communication in shaping people's health-related attitudes and behavior. Dominick currently serves as deputy editor for the *Journal of General Internal Medicine* and previously served as Associate Editor for *Health Psychology*.



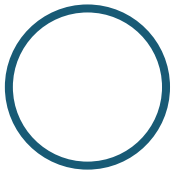
Susan Baade

Susan Baade is a program associate for the Patient Care Program at the Gordon and Betty Moore Foundation. Susan supports the Patient Care Program's grant-making and strategic operations. Before joining the foundation, Susan was the program manager for the Clinic Leadership Institute Emerging Leaders program at the Center for the Health Professions at the University of California, San Francisco. She also held positions at the National Association of Community Health Centers, Northwestern University's Feinberg School of Medicine, and the Center for Bionic Medicine at the Rehabilitation Institute of Chicago.



Loren Pogir

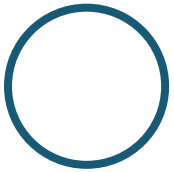
Loren Pogir is the managing director for the foundation's Patient Care Program. Prior to joining the foundation, she was the chief operating officer of the BlackRock Investment Institute at BlackRock, the world's largest asset manager. Previously, Loren held various positions in strategy, consulting, and finance in the financial services and healthcare industry. She has led many change management initiatives, including mergers and acquisitions, turnaround plans, and the creation of new organizations and initiatives. She has deep experience managing complex, cross-functional projects working with a broad set of stakeholders and is deeply passionate about partnering with the healthcare field to improve patient care.



Stacey Bailey

Stacey Bailey is a communications officer for the foundation. Her primary focus is strategic communications planning and implementation for the Patient Care Program. She helps convey the program's goal to eliminate preventable harms and unnecessary healthcare costs by meaningfully engaging patients and their families within a redesigned, supportive healthcare system. In addition, she works with the foundation's leadership in support of internal and external communications.

Project Team at the American Institutes for Research



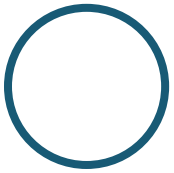
Maureen Maurer

Maureen Maurer

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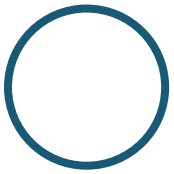
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Project Team at the American Institutes for Research (continued)



Ela Pathak-Sen

Ela Pathak-Sen is a director at Commotion. Over the life of her career, Ela has been an educator, manager, and director lea[illegible] Director [illegible]elcad



Tom Workman

Tom Workman is a principal researcher at AIR and managing director of AIR's Center for Patient and Consumer Engagement. Tom is a health communication specialist with extensive experience in translating evidence for shared decision making between patients and clients. He is a nationally known expert in environmental management for health culture change and stakeholder involvement in public health policy, and has written and presented extensively on the use of stakeholders in addressing community public health issues. Tom was a founding co-director of the Center for Public Deliberation at the University of Houston-Downtown, and continues to study and develop deliberative approaches to patient and consumer engagement in healthcare.

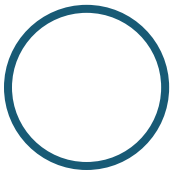
We would like to extend our sincere thanks and appreciation to:

- Deepa Ganachari, Jessica Fernandez, and Jennifer Lucado for their outstanding management of this project, assistance with data analysis, and dedication to producing a quality product.
- Jennifer Richmond for her logistical support and assistance provided to participants before, during, and after the convening.
- Jabali Williams for his vision, flexibility, and dedication in producing the PDF of this roadmap.
- AIR staff members who served as facilitators during the two-day convening, including Deepa Ganachari, Coretta Mallery, Kalpana Ramiah, and Lee Thompson.
- AIR staff members who assisted with logistics and took notes during the convening, including Amanda Borksy, Tamika Cowans, Elena Lumby, Chris Pugliese, and Mark Rosenberg.

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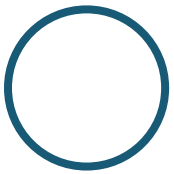
Convening Participants



David Andrews

Georgia Regents Medical Center

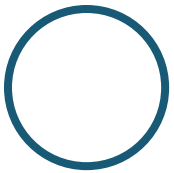
David Andrews has been a patient advisor at Georgia Regents Medical for nine years, where he has been involved in many workshops and most every facet of operation of the hospital. He is also a patient advisor to the Georgia Hospital Association Hospital Engagement Network. More recently, he has participated in several national projects to increase and improve patient engagement. Before retiring, he was a college professor in New Hampshire.



Bruce Bagley (Steering Group)

TransforMED

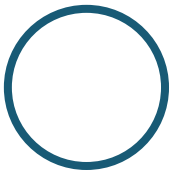
Bruce Bagley is the president and CEO of TransforMED, a wholly owned subsidiary of the American Academy of Family Physicians. TransforMED provides ongoing consultation and support to primary care practices as they seek to implement the patient-centered medical home model of care.



Michael Barry

Informed Medical Decisions Foundation

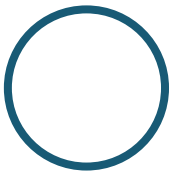
Michael Barry has been president of the Informed Medical Decisions Foundation since 2009 and was previously its chief medical editor. The Foundation is now the research and advocacy division of Healthwise. He is the past president of the Society for Medical Decision Making and the Society of General Internal Medicine in the United States. He has led many research studies, including the Patient Outcome Research Team for Prostatic Diseases. He continues to practice primary care and is medical director of the John D. Stoeckle Center for Primary Care Innovation at Massachusetts General Hospital.



Amy Berman

John A. Hartford Foundation

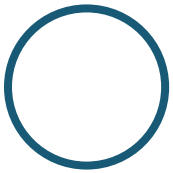
Amy Berman is a senior program officer with the John A. Hartford Foundation, where she heads investment in the development and dissemination of innovative, cost-effective models of care that improve health outcomes for older adults. Ms. Berman is also a person living with Stage IV inflammatory breast cancer. She writes and speaks on patient-centered care, decision making with serious illness, palliative care, and end-of-life care.



Clarence Braddock (Steering Group)

University of California, Los Angeles, School of Medicine

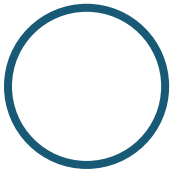
Clarence Braddock is the vice dean for education at the University of California, Los Angeles, David Geffen School of Medicine. His research interests are in physician-patient communication and informed decision making, having developed an assessment scale of the quality of informed decision making in clinical practice. Previously, he was director of clinical ethics in the Stanford Center for Biomedical Ethics and chair of the Ethics Committee at Stanford Hospital. He is also on the boards of the American Board of Internal Medicine and the Foundation for Informed Medical Decision Making.



P. Jeffrey Brady

Center for Quality Improvement and Patient Safety, Agency for Healthcare Research and Quality

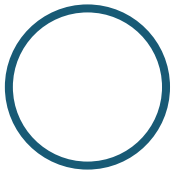
P. Jeffrey Brady is director of the Agency for Healthcare Research and Quality's Center for Quality Improvement and Patient Safety, where he leads the part of the agency that conducts such programs as Patient Safety and Healthcare-Associated Infections Research, the Patient Safety Organization Program, the National Healthcare Quality and Disparities Reports Program, and the Consumer Assessment of Healthcare Providers and Systems Program. Previously, he was a medical officer and clinical reviewer for the Food and Drug Administration's Office of Vaccines, a medical epidemiologist for the Department of Defense, and a primary care physician in the U.S. Navy.



Mary-Michael Brown

MedStar Health

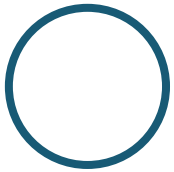
Mary-Michael Brown is vice president for nursing practice innovation at MedStar Health, a 10-hospital organization and integrated care delivery system in the Washington, D.C.-Baltimore regions. She is also a senior clinical service professor in the George Washington University Doctor of Nursing Practice program. Her areas of interest include project planning, execution, evaluation, and analysis; patient and staff satisfaction processes and tactics; personnel management; and mentoring.



Katherine Browne (Steering Group)

Center for Health Care Quality, George Washington University

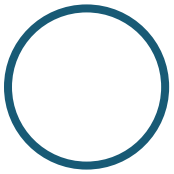
Katherine Browne is the deputy director/chief operating officer of the Center for Health Care Quality in the Department of Health Policy at The George Washington University Medical Center. There, she manages Aligning Forces for Quality, a national initiative funded by the Robert Wood Johnson Foundation that is designed to use quality improvement, public reporting of hospital and physician quality, and consumer engagement to achieve high-quality, patient-centered care in 16 communities across the country. Previously, she was managing director of the Hospital Quality Alliance.



Shannon Brownlee

Lown Institute

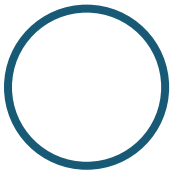
Shannon Brownlee is senior vice president of the Lown Institute, a nonprofit dedicated to improving healthcare and health. A former acting director of health policy at the New America Foundation in Washington, D.C., she is also cofounder of the Right Care Alliance. A widely published author, her 2007 book, *Overtreated: Why Too Much Medicine is Making Us Sicker and Poorer*, was named the best economics book of the year by *The New York Times*. She is on the board of FamiliesUSA, the advisory board of the American Academy of Family Practice Robert Graham Center, and the Institute of Medicine.



Melinda Buntin (Steering Group)

Department of Health Policy, Vanderbilt University School of Medicine

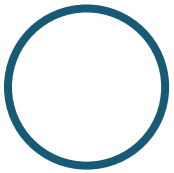
Melinda Buntin is chair of the Department of Health Policy at Vanderbilt University School of Medicine. She was previously at the Congressional Budget Office, where she was responsible for managing and directing studies of healthcare and healthcare financing issues in the Health, Retirement, and Long-Term Analysis Division. Her research has focused on insurance benefit design, health insurance markets, provider payment, and the care use and needs of the elderly.



Andy Carter

The Hospital & Healthsystem Association of Pennsylvania

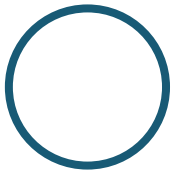
As president and CEO of The Hospital & Healthsystem Association of Pennsylvania, Andy Carter represents more than 240 acute and specialty care hospitals and health systems providing care for 12.7 million Pennsylvanians. Previously, he was president of the Ohio Children's Hospital Association, as well as president and CEO of the Visiting Nurse Associations of America.



Benjamin K. Chu

Kaiser Permanente Southern California

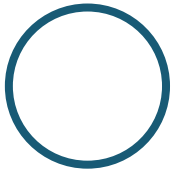
Benjamin K. Chu is a group president at Kaiser Permanente Southern California and oversees the Southern California and Hawaii regions. Previously, he was president of New York City's Health and Hospitals Corp. A primary care internist by training, Dr. Chu supports using the electronic health record as a tool for improving quality and outcomes for patient care. He is on the board of the Commonwealth Fund in New York and on the advisory committee to the director, Centers for Disease Control and Prevention.



Mary Sue Collier

American Hospital Association/Health Research Educational Trust

Sue Collier is a Clinical Content Development Lead with the American Hospital Association/Health Research Educational Trust. She previously served as the performance improvement specialist in patient-family engagement with the North Carolina Hospital Association and North Carolina Quality Center. She led early initiatives in patient- and family-centered care at Pitt County Memorial Hospital (now Vidant Medical Center) as the system's first vice president for patient-family experience and achieved national recognition for Vidant Health's innovative work. She has helped hospitals across the state achieve excellence in integrating patient safety, quality, and experience through meaningful patient-family partnerships.



Maureen Corry

Childbirth Connection, National Partnership for Women & Families

Maureen Corry is senior advisor for childbirth connection programs at the National Partnership for Women & Families. Previously, she was executive director of Childbirth Connection, where she launched Childbirth Connection's Transforming Maternity Care initiative to improve maternity care quality and value through consumer engagement and health system transformation. She is on the board of the National Quality Forum and the consumer advisory council of the National Committee for Quality Assurance.

Angela Coulter

Informed Medical Decisions Foundation
University of Oxford

Angela Coulter is director of global initiatives at the Informed Medical Decisions Foundation, Boston, and a senior research scientist in the Nuffield Department of Population Health, University of Oxford. She is a senior visiting fellow at the King's Fund in London, holds honorary fellowships at the UK Faculty of Public Health and the Royal College of General Practitioners and a trustee of National Voices. A widely published author, she also was founding editor of Health Expectations, an international peer-reviewed journal on patient and public involvement in healthcare and health policy.



Glyn Elwyn

The Dartmouth Center for Health Care Delivery Science

Glyn Elwyn is a physician-researcher, professor, and senior scientist at The Dartmouth Center for Health Care Delivery Science and The Dartmouth Institute for Health Policy and Clinical Practice. His research examines the implementation of shared decision making, user-centered design of patient decision support interventions, and the integration of these into routine healthcare. He developed the Observer OPTION and CollaboRATE tools to measure shared decision making and the International Family Practice Maturity Matrix, a measure of organizational development in primary care.

Susan Frampton

Planetree

Susan Frampton is president of Planetree, a not-for-profit advocacy, consultation, and membership organization that works with an international network of healthcare provider organizations across the continuum of care to implement Planetree's comprehensive person-centered model. Dr. Frampton has authored many publications, including the third edition of *Putting Patients First, the Patient-Centered Care Improvement Guide*, and the *Long-Term Care Improvement Guide*. She co-chairs the National Quality Forum National Priorities Partnership and the Patient-Family Engagement Action Team.

Elizabeth Gilbertson

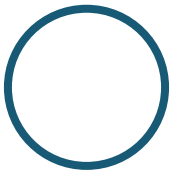
Unite Here Health

Elizabeth Gilbertson is chief of strategy for UNITE HERE HEALTH, a national Taft-Hartley health trust. Previously, she was a founder and chair/co-chair of the Health Services Coalition, a large labor-management organization that contracts with hospitals and advocates for public policy to improve healthcare quality, affordability, and access in Nevada. She currently is on the Lown Institute Advisory Council and the federal Interagency Pain Research Coordinating Committee.

Alan Glaseroff

Stanford University School of Medicine

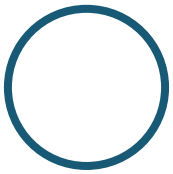
Alan Glaseroff is co-director of Stanford Coordinated Care, a service for patients with complex chronic illness. He has served on the Let's Get Healthy California expert task force since 2012 and currently serves as faculty for the Institute for Healthcare Improvement's Better Health, Lower Cost collaborative. His interests focus on the intersection of the meaning of patient-centered care, patient activation, and the key role of self-management within the context of chronic conditions.



Karen Goldman

Anne Arundel Medical Center

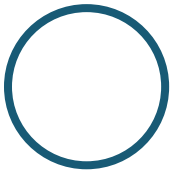
Karen Goldman is a member and co-chair of the Patient and Family Advisory Council at Anne Arundel Medical Center, where she is also a member of the Board Quality and Patient Safety Committee. She retired two years ago as director of patient relations at a large urban hospital in Maryland. Prior to that, she founded the Anne Arundel County Sexual Assault Center, which provided clinical, educational, training, and advocacy services for adult and child victims of sexual violence.



Ralph Gonzales (Steering Group)

University of California, San Francisco, Center for Healthcare Value-Delivery System Initiative

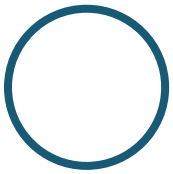
Ralph Gonzales is professor of medicine, epidemiology, and biostatistics at the University of California, San Francisco (UCSF); associate chair for ambulatory care and clinical innovation for the department of medicine; and director of the UCSF Implementation Science Program. Today, he leads several project teams in designing, implementing, and evaluating new ways to improve primary care–specialty care communication and care coordination, focusing on strategies that achieve the Triple Aim.



Katherine Gottlieb

Southcentral Foundation

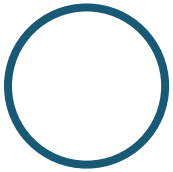
Katherine Gottlieb is president and CEO of Southcentral Foundation (SCF), which provides health and related services to 60,000 Alaska Native and American Indian people in an area of more than 100,000 square miles. Under her guidance, SCF's Nuka System of Care has earned national and international recognitions for performance excellence and innovation. In 2004, she won a MacArthur Foundation Fellowship "Genius Grant." She is a presidential appointee to the National Library of Medicine Board of Regents.



Jessie Gruman

Center for Advancing Health

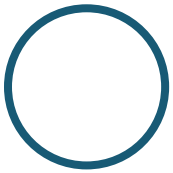
Jessie Gruman was founder and president of the Center for Advancing Health (CFAH), a nonpartisan research institute, from 1992 until her death in 2014. The mission of CFAH is to increase people's engagement in their healthcare. As president, Jessie drew on her experience of treatment for five cancer diagnoses, interviews with patients and caregivers, surveys, and peer-reviewed research to describe and advocate for policies and practices to overcome the challenges people face in finding good care and getting the most from it. Her work to create a world in which patient-centered care is the norm and engaged patients are supported and welcomed lives on, although her contributions will be greatly missed.



Helen Haskell (Steering Group)

Mothers Against Medical Error
Consumers Advancing Patient Safety

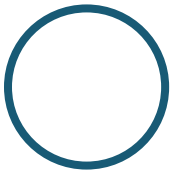
Helen Haskell works nationally and internationally on patient safety and patient engagement. Since the medical error death of her son in 2000, she has focused on many aspects of patient safety and quality from the patient's perspective, including patient-activated rapid response, infection prevention, transparency and public reporting, shared decision making, full disclosure of medical error, and patient safety curricula.



Judith Hibbard

University of Oregon

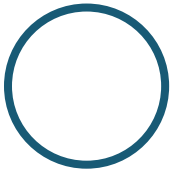
Judith Hibbard is a senior researcher and professor emerita at the University of Oregon. She is currently a visiting international scholar at the Kings Fund in London. A longtime researcher into consumer choices and behavior in healthcare, she is the lead author of the Patient Activation Measure, used around the world by researchers and practitioners, and more than 150 peer-reviewed publications. She speaks frequently on consumerism in healthcare at national and international health conferences and advises many healthcare organizations, foundations, and initiatives.



Beverley H. Johnson

Institute for Patient- and Family-Centered Care

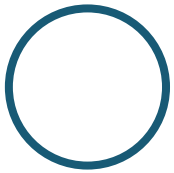
Beverley H. Johnson is president and CEO of the Institute for Patient- and Family-Centered Care. In this capacity, she has provided technical assistance to more than 250 hospitals, health systems, primary care practices, and federal, state, and provincial agencies. She directed a multi-year initiative to develop resource materials for senior leaders in hospital, ambulatory, and long-term care settings on how to partner with patients, residents, and families to enhance the quality, safety, and the experience of care. She is a widely published author and is on the board of the Patient-Centered Primary Care Collaborative.



Jean Johnson (Steering Group)

George Washington University School of Nursing

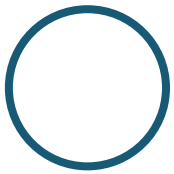
Jean Johnson is dean and professor of the School of Nursing at George Washington University. Previously, she was program director of a Robert Wood Johnson national program to take primary care education into underserved areas nationwide. She is a member of the U.S. Health Resources and Services Administration's Advisory Committee on Training in Primary Care Medicine and Dentistry and was president of the National Organization of Nurse Practitioner Faculties and of the American College of Nurse Practitioners. She has conducted research on the role of nurse staffing and quality of care in nursing homes.



Robert M. Kaplan

Agency for Healthcare Research and Quality

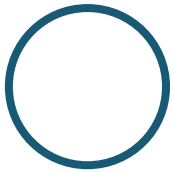
Robert M. Kaplan is chief science officer at the Agency for Healthcare Research and Quality. Previously, he was director of the office of behavioral and social sciences research in the National Institutes of Health Office of the Director. He is the former editor-in-chief of *Health Psychology* and the *Annals of Behavioral Medicine*. He co-chairs the Social, Behavioral, and Economic Sciences component of the U.S. National Science and Technology Council, is on the National Committee on Vital and Health Statistics, and on the Intergovernmental Working Group on Quality of Healthcare.



Melinda Karp

Blue Cross and Blue Shield of Massachusetts

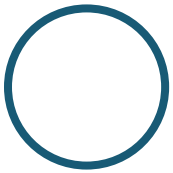
Melinda Karp is senior director of performance measurement market innovations and business integration at Blue Cross Blue Shield of Massachusetts (BCBSMA), where she is responsible for market-facing strategy development and implementation of BCBSMA performance measurement programs. Previously, Ms. Karp spent 13 years on the core leadership team at the Massachusetts Health Quality Partners, where she was director of strategic planning and business development.



David C. Kendrick

MyHealth Access Network

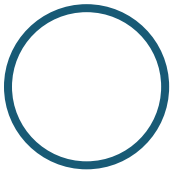
David Kendrick is the principal investigator and CEO of the MyHealth Access Network, a Beacon Community focused on improving health in Oklahoma and beyond by implementing a community-wide infrastructure for healthcare information technology. He is on the board of directors of the National Committee for Quality Assurance, serves as convening faculty for the Comprehensive Primary Care Initiative, and is the assistant provost for strategic planning, the chair of the Department of Medical Informatics, associate professor of internal medicine and pediatrics, and holds the Kaiser Chair of Community Medicine at the University of Oklahoma's School of Community Medicine.



Beverly Lunsford

George Washington University School of Nursing

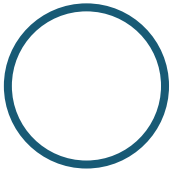
Beverly Lunsford is director of the George Washington University Center for Aging, Health and Humanities, where she brings together inter-professional faculty to provide geriatric and gerontology educational programs for practicing healthcare practitioners in many aspects of healthy aging, care management for chronic illnesses, person-centered care, palliative and end-of-life care, care of older adults with neurocognitive disorders and their families, and evidence-based falls management programs. Her research includes investigating the older adult's sense of continuity of meaning and long-term cancer survivorship in older adults.



Ellen Makar

Office of the National Coordinator for Health Information Technology, Office of Consumer eHealth, U.S. Department of Health and Human Services

Ellen Makar is senior policy advisor within the Office of Consumer eHealth, which aims to improve nationwide access, action, and attitudes toward the use of health information technology—engaging consumers and catalyzing providers and data holders to advance that engagement. Previously, she directed Nursing and Clinical Transformation at Yale New Haven Hospital, where she led transformation efforts as the EPIC electronic health record was implemented across four distinct hospitals. She is an adjunct lecturer at Yale School of Nursing and at the University of Baltimore.



Pat Mastors

Patient Voice Institute

Personal experience ignites Pat's passion for improving patient engagement and patient-and family-centered care. She is the president and co-founder of the nonprofit Patient Voice Institute, "gathering and sharing the wisdom of patients" to offer patient voices training, support, and opportunities for more robust partnership with providers. She is author of *Design to Survive*, a book that urges simplicity and partnership in the delivery of healthcare, and is creator of a unique bedside patient empowerment tool that elevates the patient's experience, autonomy, and partnership.

Susan Mende

Robert Wood Johnson Foundation

Susan Mende is a senior program officer at the Robert Wood Johnson Foundation, where she focuses on improving quality and value in healthcare, consumer and community engagement, and integration between medical and community-based care. Ms. Mende was formerly the chief operating officer for Tsao Foundation, Singapore, where she focused on community-based care of older people, training, and regional and international aging issues for the World Health Organization and the United Nations.

Debra Ness

National Partnership for Women & Families

Debra Ness is president of the National Partnership for Women & Families. She serves on the board of the National Quality Forum, was recently elected the first public member on the American College of Cardiology board, and is one of the first public members of the board of the American Board of Internal Medicine. She also serves on the board of the National Committee for Quality Assurance and chairs their Consumer Advisory Council.

Sherry Perkins

Anne Arundel Health System

Sherry B. Perkins is chief operating officer and chief nursing officer for Anne Arundel Health System in Annapolis, Maryland. Working with the Maryland Regional Action Coalition, she leads the implementation of a statewide effort to implement a standardized residency for new graduate nurses under the Robert Wood Johnson Foundation/Institute of Medicine Future of Nursing recommendations. She is on the board of the Maryland Patient Safety Center, is on the Maryland Hospital Association Council on Clinical Quality, and is immediate past president of the Maryland Organization of Nurse Executives.

Jeanne Pinder

ClearHealthCosts

Jeanne Pinder is founder and CEO of the New York startup ClearHealthCosts.com, bringing transparency to the healthcare marketplace by telling people what stuff costs. Recently ClearHealthCosts.com and two partners, KQED public radio in San Francisco and KPCC/Southern California Public Radio in Los Angeles, launched a crowdsourcing project on health prices with funding from the John S. and James L. Knight Foundation. Jeanne worked for *The New York Times* for 23 years before founding ClearHealthCosts with grants from the Tow-Knight Center at the City Universd Je

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Casey Quinlan

Mighty Casey Media

Casey Quinlan advocates for the e-patient movement and is a communication and brand strategist looking to help healthcare discover how improving patient experience will increase value and impact. She spent two decades in the news business, and after receiving a breast cancer diagnosis in 2007, she used her research, communication, and comedy skills to successfully navigate treatment. She wrote *Cancer for Christmas: Making the Most of a Daunting Gift*, a book about managing medical care and the importance of being your own patient advocate.

Jean Rexford

Connecticut Center for Patient Safety

Jean Rexford is executive director of the Connecticut Center for Patient Safety and is on the Agency for Healthcare Research and Quality's National Advisory Council for Healthcare Research and Quality. She serves with many other consumer-centered and healthcare quality groups at the state and national levels, in such roles as the consumer representative on the Food and Drug Administration Medical Imaging Drugs Advisory Committee, the National Board of Medical Examiners, on the board for the Federation of State Medical Boards, on the Connecticut Medical Examining Board, and the Connecticut HealthCare Acquired Infection Committee.

Bernard Roberson

Georgia Regents Medical Center

Bernard Roberson is the administrative director of Patient and Family Centered Care at Georgia Regents Medical Center, the not-for-profit corporation that manages the hospitals and clinics of the Georgia Regents Medical Center. There, he oversees the planning, development, implementation, and monitoring of patient- and family-centered care and the education of all faculty, administrators, staff, and students in that area.

Ted Rooney

Maine Quality Counts
Maine Health Management Coalition

Ted Rooney is project leader in Maine for Aligning Forces for Quality, a Robert Wood Johnson Foundation–funded initiative led by Maine Quality Counts in partnership with the Maine Quality Forum and Maine Health Management Coalition. He is also project advisor for the Maine Health Management Coalition's Pathways to Excellence initiatives, which measure and report the value of healthcare and work to change the reimbursement system to reward high-value care.



Lewis G. Sandy

UnitedHealth Group

Lewis G. Sandy is executive vice president, clinical advancement, at UnitedHealth Group, where he focuses on clinical innovation, payment and delivery reforms, and physician collaboration. Previously, he was executive vice president (EVP) and chief medical officer of UnitedHealthcare and EVP of The Robert Wood Johnson Foundation. He is a senior fellow of the University of Minnesota School of Public Health, Department of Health Policy and Management.

Suzanne Schrandt

Patient-Centered Outcomes Research Institute

Suzanne Schrandt is deputy director of patient engagement at the Patient-Centered Outcomes Research Institute (PCORI). She has been involved in patient education and advocacy since being diagnosed with a form of rheumatoid arthritis as a teenager. She has advocated on behalf of children and adults with arthritis and been engaged in numerous patient and clinician education initiatives aimed at increasing early diagnosis and appropriate, patient-centered management of chronic disease. She previously held positions as health reform team leader for the Kansas Health Institute and director of public health and public policy for the Arthritis Foundation.

Stephen M. Shortell

University of California, Berkeley, School of Public Health and Haas School of Business

Stephen Shortell is the Blue Cross of California Distinguished Professor of Health Policy and Management at the University of California, Berkeley, where he also directs the Center for Healthcare Organizational and Innovation Research. He conducts research on changes in physician practices over time; evaluation of accountable care organizations (ACOs); and ACO involvement in patient activation and engagement activities. He is also working on implementation of healthcare reform in California and is chair of the Berkeley Forum for Improving California's Healthcare System.

Shoshanna Sofaer

School of Public Affairs, Baruch College

Shoshanna Sofaer is the Robert P. Luciano Professor of Health Care Policy at the School of Public Affairs, Baruch College, City University of New York. Her research interests include patient engagement, patient-centered care, patient experience surveys, public deliberation to guide health policy, comparative quality and cost reporting, and developing quality measures that resonate with the public. She has more than 60 publications in peer-reviewed journals and has completed more than 40 research projects.

Ming Tai-Seale

Palo Alto Medical Foundation Research Institute

Ming Tai-Seale is a senior investigator in the Palo Alto Medical Foundation Research Institute. For the last five years, she has studied patient-centered care transformation for patients with chronic conditions. She won the 2008 Article-of-the-Year Award from AcademyHealth for work on patient-physician communication.

Richard Thomason

Blue Shield of California Foundation

Richard Thomason is director of the healthcare and coverage program at Blue Shield of California Foundation, where he leads efforts to improve access to care and strengthen the healthcare safety net through grantmaking, program activities, and technical assistance. Previously, he was the policy director for SEIU–United Healthcare Workers West. He has been on the Alameda Alliance for Health Board of Governors, the California Health Care Coalition, the Berkeley Community Health Commission, and the Alameda County Public Health Advisory Commission.

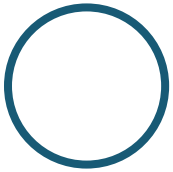
Marcus Thygeson (Steering Group)

Blue Shield of California

Marcus Thygeson, Chief Health Officer, oversees healthcare services at Blue Shield of California, including prevention and wellness

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Daniel Wolfson

ABIM Foundation

Daniel Wolfson is executive vice president and chief operating officer of the ABIM Foundation, a not-for-profit foundation focused on advancing medical professionalism and physician [illegible]

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