

A Roadmap for Patient + Family Engagement

NC IOM Task Force on Patient and Family Engagement

Pam Dardess, MPH and Maureen Maurer, MPH
Principal Researchers, Health & Social Development Program



Our time together today

- Moore Foundation goals
- Overview of the roadmap
- 8 Change Strategies and 5 Simple Actions
- Resources and

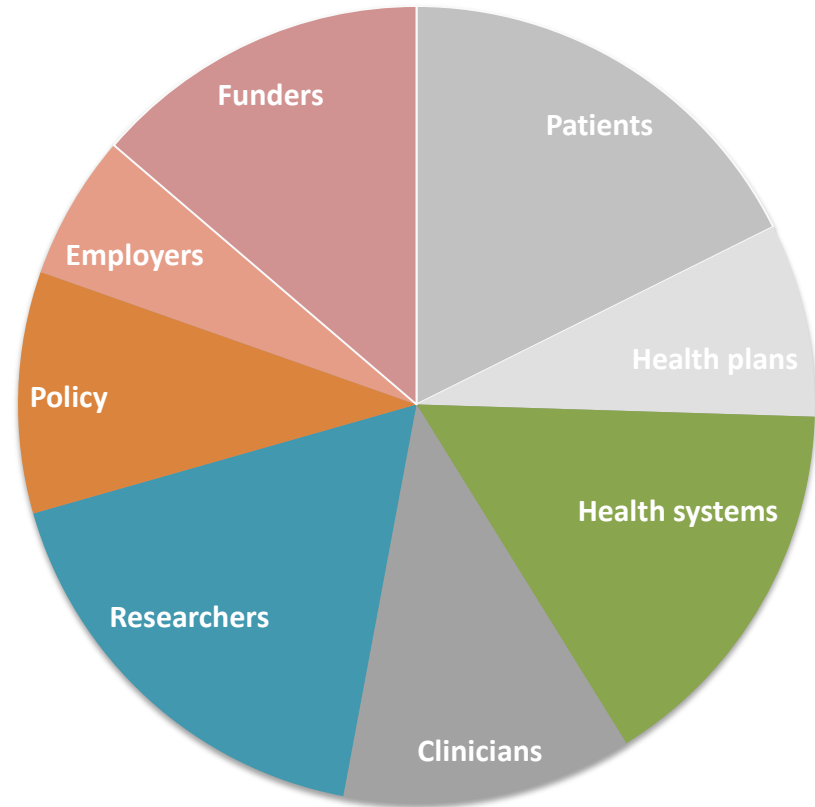
Goals and Process

Project goals

- Develop a unified roadmap for practice and research
- Move from what-ifs to action
- Build on existing work and use multiple inputs
- Convene a multidisciplinary group of key stakeholders

Key components of the process

- Pre-work
 - Micro-convenings
 - White papers
 - Participant website
- Participants
 - Diverse stakeholder mix
- Approach
 - Interdisciplinary groups
 - Appreciative Inquiry



What did we ask participants to do?



- Develop vision for the field – build physical roadmaps
 - Milestones and destinations
 - Strategies and tactics
 - Factors that affect progress
 - Timing: today, tomorrow, future

What did we learn about the process?

- Sought common ground to unite perspectives
- Power of collaboration in eliciting new ideas
- Increasing energy over the convening
- Personal investment



What happened after the convening?



- Analyzed thoughts and ideas captured in notes, flip charts, and 5 roadmaps created by breakout groups
- Kept the voice of participants at the forefront in developing the roadmap

Overview of the Roadmap

The Roadmap

A ROADMAP FOR

Patient + Family Engagement

Research and Practice

Practical strategies for implementing engagement
in healthcare – starting today.

START





What You'll Find

Introduction

Why a Roadmap?

Developing the
roadmap

Who Is This
Roadmap For?

From What-ifs
to Action:
Using the Roadmap

The Roadmap

Vision for Patient and Family
Engagement in Healthcare

8 Strategies for Change:

- Patient and Family Preparation
- Clinician and Leadership Preparation
- Care and System Redesign
- Organizational Partnership
- Measurement and Research
- Transparency and Accountability
- Legislation and Regulation
- Partnership in Public Policy

5 Simple Actions You Can Do Today

Resources and Further Information

Join In:
Resources and Commitments

Societal Factors
Affecting Engagement

About the Framework
for Patient and Family Engagement

More About
Creating the Roadmap

- Process
- Participants

Putting Patients First

This roadmap reflects a collective imagining of how to move forward with patient and family engagement in a unified way.

View the Roadmap PDF



Patient and family engagement is a burgeoning topic in healthcare as we look for ways to improve population health, provide better experiences of care, and lower healthcare costs.

In recognition of the importance of patient and family engagement, the Gordon and Betty Moore Foundation funded the American Institutes for Research to develop a roadmap for practice and research.

The roadmap serves as a call to action for anyone interested in advancing work related to patient and family engagement. It includes:

- A vision for patient and family engagement in healthcare
- 8 change strategies to drive action towards increased patient and family engagement
- 5 simple actions that different stakeholder groups can begin today

The roadmap is about creating momentum for change, increasing knowledge, developing and enhancing skills, and forging a path forward. It highlights opportunities to create meaningful partnerships among and between stakeholder groups to foster change in healthcare. It is a catalyst, intended to spark ideas and action from individuals and organizations interested in making patient and family engagement real.

BROWSE OR MAKE A COMMITMENT



FIND OR SUGGEST A RESOURCE



Watch a Video

Re-envision healthcare—with patients and families at the center—to create more positive experiences for all.



Suggested Citation

Carman KL, Dardess P, Maurer ME, Workman T, Ganachari D, Pathak-Sen E. A Roadmap for Patient and Family Engagement in Healthcare Practice and Research. (Prepared by the American Institutes for Research under a grant from the Gordon and Betty Moore Foundation, Dominick Frosch, Project Officer and Fellow; Susan Baade, Program Officer.) Gordon and Betty Moore Foundation: Palo Alto, CA; September 2014. www.patientfamilyengagement.org

www.patientfamilyengagement.org

Vision of Patient and Family Engagement



8 Strategies for Change

An in-depth look

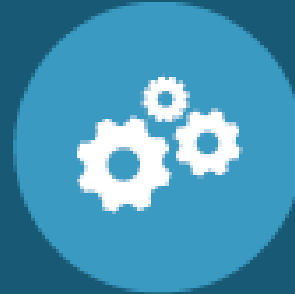
8 Change Strategies



**PATIENT AND
FAMILY PREPARATION**



**CLINICIAN
AND LEADERSHIP
PREPARATION**



**CARE AND
SYSTEM REDESIGN**



**ORGANIZATIONAL
PARTNERSHIP**



**MEASUREMENT
AND RESEARCH**



**TRANSPARENCY
AND ACCOUNTABILITY**



**LEGISLATION
AND REGULATION**



**PARTNERSHIP IN
PUBLIC POLICY**

Preparing for Engagement



Patient and Family Preparation

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



Clinician and Leadership Preparation

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



Care and System Redesign Overview

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

- Create an environment where engagement is expected, welcomed, facilitated
- Provide concrete opportunities, create policies, develop and implement care processes

“It’s not about changing the patient; it’s about changing the system.”

- CONVENING PARTICIPANT



Care and System Redesign Tactics

Tactic groups to drive action for this strategy

- Restructure care processes to support partnership in
 - Care planning
 - Self-management
 - Shared decision making
 - Information sharing
 - Care coordination
- Provide specific engagement opportunities
- Facilitate effective clinician communication
- Invite and partner with families as part of the healthcare team
- Support clinician well-being and ability to provide compassionate care



Care and System Redesign Milestones

Milestones associated with this strategy

- Develop care plans and make healthcare decisions as a team
- Information shared equally
- Family members welcomed as full partners
- Establish positive, meaningful relationships
- Clinicians find more joy and meaning in their work
- Links enable seamless care coordination



Organizational Partnership Overview

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

- Infuse patient needs and interests into healthcare workflows, organizations, and systems
- Partner for design of processes, policies and facilities

“If patients don’t help lead change, it will be a fatal error.”

- CONVENING PARTICIPANT



Organizational Partnership Tactics

Tactic groups to drive action for this strategy

- Implement structures that facilitate communication between leadership and patients and families
- Create opportunities and roles for patients and families throughout the organization
- Implement support structures to prepare patients and families for partnership
- Prepare clinicians, staff, and leaders to partner with patients and families



Organizational Partnership Milestones

Milestones associated with this strategy

- Clinicians and organizational leaders partner with patients and families to make decisions about
 - Facility and workflow design
 - Organizational policies and procedures,
 - Care delivery processes
- Clearly identified structures and processes exist for infusing and integrating patient and family perspectives and experiences

Monitoring and Accountability



Measurement and Research

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



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

Implementing Public Policy



Legislation and Regulation

Encourage patient and family engagement through regulation and legislation



Partnership in Public Policy

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

5 Simple Actions You Can Do Today

Examples for clinicians and organizations

5 Simple Actions

5 tangible, discrete actions that can make a difference that individuals can start doing right now

- Patients and family members
- Clinicians
- Providers or delivery organizations
- Leaders and policymakers
- Insurers
- Employers
- Researchers

What can clinicians do?

1. Welcome input and feedback from patients and families
2. Maximize the potential of your patient portal
3. Use teach-back and other proven communication techniques
4. Ask patients what is important to them
5. Contact your professional societies

What can providers or delivery organizations do?

1. Give patients real-time access to their medical records
2. Establish family presence policies
3. Get patient and family input
4. Organize a staff education session or grand rounds on patient and family engagement
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

Resources and Commitments

Dissemination, resources, and commitments

Examples of Commitments

“I commit to continuing the conversation about health professions education in those circles in which I find myself. A year from now, I think that one could have a national convening to look at how to drive health professions education around patient and family engagement, and I’m committed to partner with anyone in this room and anyone you know to start to plan and put on such a convening.”

Clarence Braddock

Vice Dean for Education

University of California, Los Angeles

Examples of Commitments (cont.)

“With my researcher and economist hats on, I can commit to investigating arguments that patient and family engagement may not be possible due to reimbursement and policy issues. If you encounter someone who makes this argument, please let me know so that I can investigate whether it is true, or an excuse for the status quo.”

Melinda Buntin

*Chair, Department of Health Policy
Vanderbilt University School of Medicine*

Examples of Commitments (cont.)

“If people have an idea or pilot or a test you want to run, give me a call, and I will recruit participants from Pennsylvania from members of our association. Second, I will nominate to the board of directors of our trade association a patient representative within one year. Third, I will make sure that the Hospital & Healthsystem Association of Pennsylvania’s (HAP)’s 2015 top ten organizational goals include a patient and family engagement goal.”

Andy Carter

President and CEO

The Hospital & Healthsystem Association of Pennsylvania

Questions? Discussion?

Pam Dardess, MPH

Principal Researcher, American Institutes for Research
919-918-2311, pdardess@air.org

Maureen Maurer, MPH

Principal Researcher, American Institutes for Research
919-918-2308, mmaurer@air.org

Dominick Frosch, PhD

Fellow, Patient Care Program, Gordon and Betty Moore Foundation
Dominick.Frosch@moore.org

AIR's Center for Patient & Consumer Engagement

www.aircpce.org