

A Roadmap for Patient + Family Engagement in Healthcare: Practice and Research

Grantmakers In Health Fall Forum
November 6, 2014

Definition of patient and family engagement



“Patient and family engagement [is defined] as patients, families, their representatives, and health professionals **working in active partnership at various levels across the health care system** – direct care, organizational design and governance, and policy making – to improve health and health care.”

Carman et al, 2013, *Health Affairs*

Examples of patient and family engagement

- **Direct care**
 - Patient activation, shared decision making, motivational interviewing, bedside rounds
- **Organizational design and governance**
 - Patient and family advisory councils
- **Policy making**
 - Public deliberation, patient representation on boards

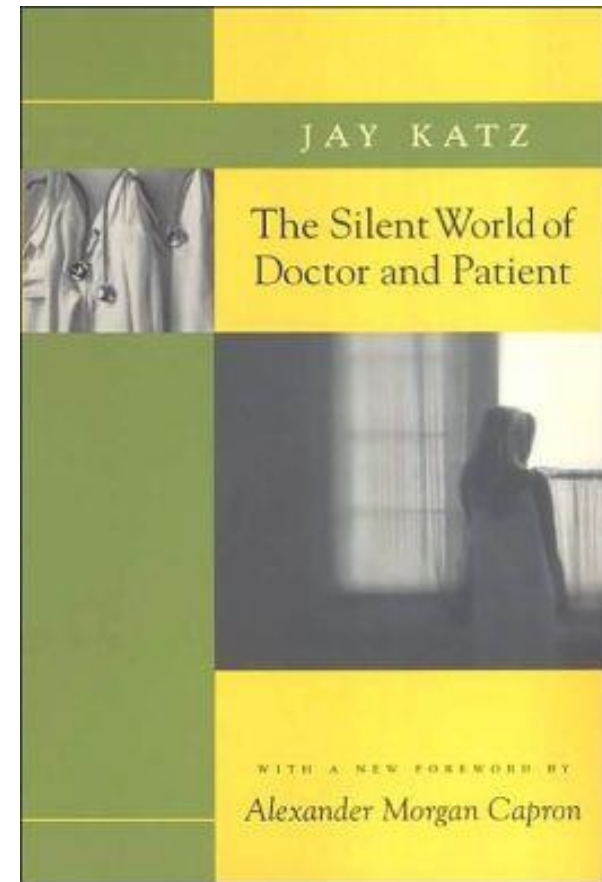
Benefits of patient and family engagement

Meaningfully engaging patients and families as true partners in their care leads to:

- Improvements in patient safety and quality
- Better health outcomes
- Better patient experiences and satisfaction
- Lower healthcare costs
- Increased health professional satisfaction and retention

Barriers to adopting patient and family engagement

- Highly fragmented, diverse field
- Lack of practical, concrete strategies to improve PFE
- Measurement lacking
- Incentives misaligned
- Traditional roles of patients remain deeply embedded in medical culture



Roadmap for PFE launched in September

A ROADMAP FOR

Patient + Family Engagement

Research and Practice

Practical strategies for implementing engagement in healthcare – starting today.

START



Key components of the process

- **Pre-work**

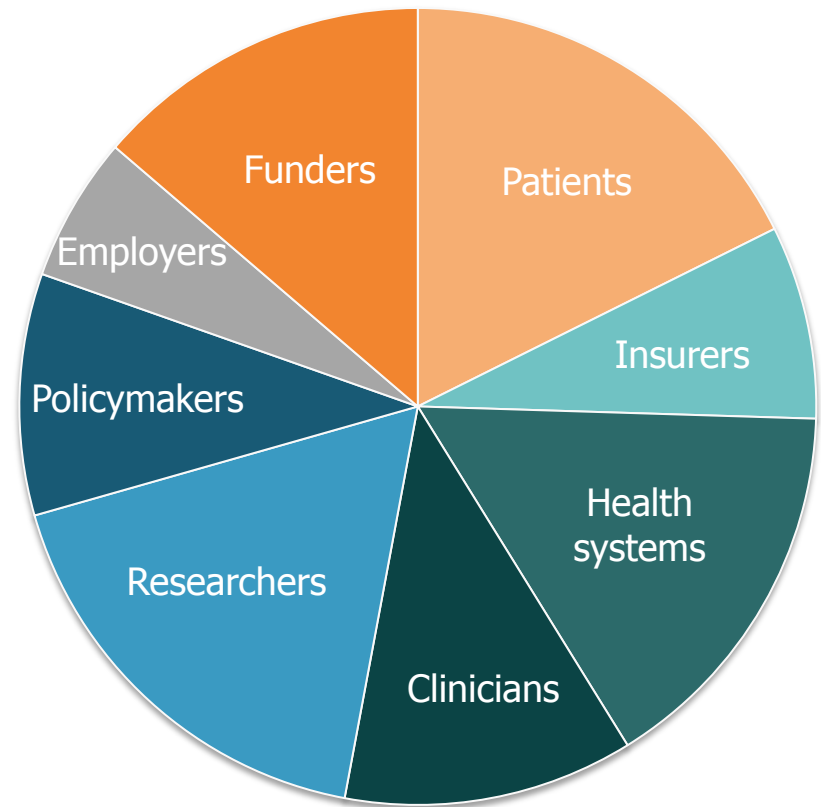
- Micro-convenings
- White papers
- Participant website

- **Participants**

- Diverse stakeholder mix
- 72 people representing 59 organizations*

- **Approach**

- Interdisciplinary groups
- Appreciative Inquiry



* See appendix for complete list of organizations involved in creation of Roadmap

A new vision for healthcare



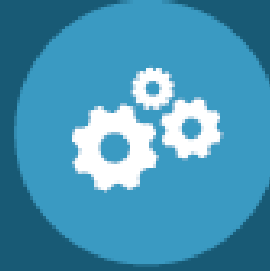
8 strategies for change



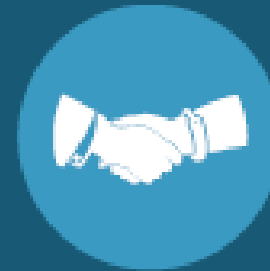
**PATIENT AND
FAMILY PREPARATION**



**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 for today

Tangible, discrete actions that provide ideas about what key stakeholder groups can do to take action *today*

Simple Actions

PATIENTS

CLINICIANS

ORGANIZATIONS

LEADERS

INSURERS

EMPLOYERS

RESEARCHERS

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 condition, symptoms, issues involved in your care, and treatment choices. Write down any questions or concerns to share with your healthcare team. To find trustworthy information, ask your healthcare provider about recommended websites or apps.
- 3. Get ready for your next healthcare visit.** Write down important health information, such as medicines you are taking and current health symptoms. Think about what's most important for your healthcare team to know about you, your

current problem, and your health history. Create a concise list of questions and let your provider know at the beginning of your visit that you would like to discuss these questions.

- 4. Keep track of and organize your medical information.** Keep a record of your medical care for your files. Ask if your healthcare provider uses electronic health records and whether there is an electronic patient portal. If so, use it to access your healthcare information and look at your health records. After a medical appointment, ask for a copy of the visit summary and tests that were done.
- 5. Contact your local clinic or hospital and volunteer to be a patient and family advisor.** Advisors share their experiences and provide input to help healthcare organizations provide better care. If your local hospital or clinic doesn't work with patient and family advisors, ask them to consider doing so.

What Can
Clinicians Do?



Commitments for change

- Convening participants made **individual public commitments** for actions they would take to advance PFE in their sphere of healthcare

Benjamin K. Chu | CONTACT THIS PERSON

Kaiser Permanente Southern California

Every successful movement needs successful models. Therefore, I commit to work toward making Kaiser Permanente a model in everything we do.

Secondly, I will make a commitment to trying to keep patient and family engagement at the front and center of the American Hospital Association agenda so that when we conduct the survey (Assessing Patient and Family Engagement Strategies in U.S. Hospitals Survey reported on in the convening) in a year or two there will be much better results.

The following individuals committed to these actions to advance patient and family engagement.

Recent Commitments

Warren Kolber | CONTACT THIS PERSON

MyDrMe

Using the "Roadmap" and other patient engagement studies, I am planning to assemble an advisory board and editorial team to develop standards, guidelines, and recommended practices for patient led health teams.

Karlin Schroeder | CONTACT THIS PERSON

Parkinson's Disease Foundation

Enter State

Enter Country

Do not allow people to contact me:

This Commitment is for:

Me Personally

My Organization

Enter Commitment*

*Required

SUBMIT COMMITMENT >

Reset

Resources


Resources—which include implementation guides & toolkits, case studies and other materials—organized by 8 change strategies

Resources

The following resources provide information to help think about how to implement the strategies and tactics listed in the roadmap

The resources—which include implementation guides and toolkits, case studies, and other materials—are organized by each of the eight change strategies.

Search by Strategy



General Resources

Center for Patient and Consumer Engagement

American Institutes for Research

Created by the American Institutes for Research, the goal of the Center for Patient and Consumer Engagement is to advance the knowledge and practice of patient and consumer engagement in healthcare. The Center provides resources and shares knowledge to further the science and application of patient and consumer engagement, and also creates a virtual community for learning and knowledge transfer.

[View Resource \(external link\)](#)

CFAH Engagement Behavior Framework

Center for Advancing Health

Submit a Resource

Contact Information

Resource Information

Upload Information

Call to action

Time for action is now

- Passage of ACA has created regulatory alignment
- Lots of small demonstrations of innovative approaches
- Urgent need for catalysts to drive and guide broader implementation and change

“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

Appendix

Organizations involved in creation of Roadmap

- AARP Services, Inc.
- ABIM Foundation
- Agency for Healthcare Research and Quality
- American Hospital Association / Health Research Educational Trust
- American Institutes for Research
- Anne Arundel Health System
- Anne Arundel Medical Center
- Blue Cross and Blue Shield of Massachusetts
- Blue Shield of California
- Blue Shield of California Foundation
- Center for Advancing Health
- Center for Medicare and Medicaid Innovation
- Centers for Medicare & Medicaid Services
- ClearHealthCosts
- Commotion
- Connecticut Center for Patient Safety
- Consumers Advancing Patient Safety
- George Washington University Medical Center
- George Washington University School of Nursing
- Georgia Regents Medical Center
- Gordon and Betty Moore Foundation
- Informed Medical Decisions Foundation
- Institute for Patient- and Family-Centered Care
- Integrated Healthcare Association
- John A. Hartford Foundation
- Johns Hopkins Medicine
- Kaiser Permanente Southern California
- Lown Institute
- Maine Health Management Coalition
- Maine Quality Counts
- MedStar Health
- Mighty Casey Media
- Mothers Against Medical Error
- MyHealth Access Network
- National Partnership for Women & Families
- North Carolina Quality Center
- Office of the National Coordinator, US Department of Health & Human Services
- Palo Alto Medical Foundation Research Institute
- Patient Voice Institute
- Patient-Centered Outcomes Research Institute
- Planetree
- Robert Wood Johnson Foundation
- School of Public Affairs, Baruch College
- Southcentral Foundation
- Stanford University School of Medicine
- The Dartmouth Center for Health Care Delivery Science
- The Hospital & Healthsystem Association of Pennsylvania
- TransforMED
- Unite Here Health
- UnitedHealth Group
- UC Berkeley, School of Public Health and Haas School of Business
- UCLA, School of Medicine
- UCSF, Center for Healthcare Value-Delivery System Initiative
- University of Oregon
- University of Oxford
- Vanderbilt University School of Medicine
- World Health Organization