



# INSTITUTE OF MEDICINE

OF THE NATIONAL ACADEMIES

## PARTNERING WITH PATIENTS TO DRIVE SHARED DECISIONS, BETTER VALUE, AND CARE IMPROVEMENT



*An Institute of Medicine Workshop  
Sponsored by the Gordon and Betty Moore Foundation and  
Blue Shield of California Foundation*



A LEARNING HEALTH SYSTEM ACTIVITY  
IOM ROUNDTABLE ON VALUE & SCIENCE-DRIVEN HEALTH CARE

FEBRUARY 25-26, 2013  
THE NATIONAL ACADEMY OF SCIENCES  
2101 CONSTITUTION AVENUE, NW  
WASHINGTON, DC

### Meeting goals

1. Build insights and recognition on the necessity of increased patient, family, and citizen engagement in achieving better outcomes and lower costs in health care.
2. Explore what has been learned about effective approaches for building patient demand and involvement in improving evidence, care, and value—including principles and barriers.
3. Consider strategies and policies for activities to be undertaken at multiple levels to advance patients, in partnership with providers, as leaders and drivers of care delivery improvement through the protected use of clinical data, informed, shared decisions, and value improvement.
4. Identify important policy and research opportunities for developing the additional insights needed to accelerate progress.

### Day 1: Monday, February 25, 2013

*Please pick up a boxed lunch in the atrium.*

12:30 pm

#### Welcome, Introductions, and Overview

##### Welcome from the IOM

Michael McGinnis (Institute of Medicine)

##### Opening remarks and meeting overview

*Dominick Frosch* (Gordon & Betty Moore Foundation)

*Christine Bechtel* (Planning Committee Chair, National Partnership for Women & Families)

12:45 pm	<b>Lunch keynote</b>
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**To Improve, Health Care Must Partner With Patients and Families**  
*Jonathan Welch*, Harvard Medical School

1:30 pm	<b>Patient-clinician communication and the tools for change</b>
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Working from the dual challenges of patients' effective use of available information and clinicians' effective integration of available knowledge, explore approaches and strategies for widespread acceleration of shared decision making.

Session questions:

- What is the **pathway** toward increased demand for shared decision making?
- What are the necessary **infrastructure** elements to support widespread shared decision making?
- What strategies exist to create a **culture of expectation** for shared decision making on the part of both providers and patients/families?
- What **competencies** are required of patients, families and clinicians to support shared decision making?

Moderator: *Lyn Paget*, Health Policy Partners

Presentations:

- **The key elements of information, connectedness, and continuity for patient engagement in health care decisions**  
*Gary Langer*, Langer Research Associates
- **Planned patienthood: setting the expectation for shared decision making**  
*Sberrie Kaplan*, University of California, Irvine
- **Clinician competencies for effective shared decision making**  
*Eric Holmboe*, American Board of Internal Medicine

*Audience participation and open discussion*

3:00 pm	<b>Break</b>
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3:15 pm	<b>Patient-clinician communication and the tools for change (continued)</b>
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- Innovative models of shared decision making:
  - **Building a culture that promotes shared decision making**  
*Grace Lin*, University of California, San Francisco
  - **The patient support corps: An innovative staffing approach to support patients in shared decision making**  
*Jeff Belkora, Margot Zarin-Pass, and Ekene Obi-Okoye*  
 University of California, San Francisco
  - **Implementing decision aids for increased patient engagement and reduced costs**  
*David Arterburn*, GroupHealth

*Audience participation and open discussion*

4:30 pm	<b>Summary and preview of next day</b>
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5:00 pm	<b>Adjourn</b>
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**Day 2: Tuesday, February 26, 2013**

7:30 am Coffee and light breakfast available

8:00 am	<b>Welcome, brief agenda overview</b>
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*Christine Bechtel*, National Partnership for Women & Families (Planning Committee Chair)

8:15 am	<b>Knowledge generation and care improvement</b>
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As many patients support sharing their protected clinical and outcomes data for research that improves care and outcomes for all patients, identify potential pathways and strategies for improved sharing and use of insights gained from the care experience.

Session questions:

- What is the **state of play** with respect to using patient data for research and care improvement?
  - Patient perceptions
  - Research realities
  - Regulatory environment
- How does **public opinion** on research for care improvement demonstrate support for increased data sharing? What barriers are present in the public's understanding of the benefits and harms of data sharing, and how might they be overcome?
- What are the necessary **infrastructure** elements to support widespread data sharing for care improvement?
- What is the **pathway** toward increased use of protected clinical and outcomes data for care improvement?

Moderator: *Sue Trinidad*, University of Washington

Presentations:

- **Ethical Challenges of a Changing Research Paradigm**  
*Nancy Kass*, Johns Hopkins Berman Institute of Bioethics
- **Meaningful choice in a learning health care system: the relationship between privacy and data sharing for research**  
*Alice Leiter*, Center for Democracy & Technology
- **The infrastructure needed for patient-engaged translational research**  
*Ken Mandl*, Boston Children's Hospital
- **Patient engagement and data sharing for improvement, innovation and discovery**  
*Peter Margolis and Jill Plevinsky*, Cincinnati Children's Hospital Medical Center

*Audience participation and open discussion*

9:30 am

**Knowledge generation and care improvement (cont.)**

- **Patient perspectives on consent for information use**  
*Evette Ludman*, GroupHealth Research Institute
- **New paradigms for patient engagement in research for care improvement:**
  - *Sally Okun and Laura Phillips*, PatientsLikeMe
  - *Greg Biggers*, Genomera
- **Research that improves care as a competitive advantage: communicating the importance of data sharing to the public**  
*Holly Potter*, Kaiser Permanente

*Audience participation and open discussion*

10:45 am

**Break**

11:00 am

**Changing Expectations: Bringing Transparency to Cost and Quality Information**

Taking into account the changing landscape for health care payment, consider methods for deepening patient, family, and provider knowledge of health care costs and quality, and their implications.

Session questions:

- What are possible **strategies** for increased patient and family recognition of high-quality, efficient health care?
- How do we increase the **culture of expectation** for patient and family health care choices that are based on value (e.g., quality and cost)?
- What **information** is needed to support patients and families in making value-based health care choices? Key considerations:
  - Kinds of information needed, ie: cost, quality
  - Presentation of information
  - Accessibility
  - Ease of use
  - Resulting behavior change

Moderator: *John Santa*, Consumer Reports

Presentations:

- **What patients perceive as valuable—and how to effectively communicate information on cost and quality**  
*Judy Hibbard*, University of Oregon  
*Shoshanna Sofaer*, Baruch College, CUNY
- **The road to increased patient engagement through public reporting of performance information**  
*Barbra Rabson*, Massachusetts Health Quality Partners
- **Raising awareness on quality and waste**  
*Daniel Wolfson*, ABIM Foundation
- **Seeking the citizen voice**  
*Marge Ginsburg*, Center for Healthcare Decisions

*Audience participation and open discussion*

1:00 pm	<b>Lunch keynote</b>
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**How American Health Care Killed My Father**  
*David Goldbill, Game Show Network*

2:00 pm	<b>Driving the demand</b>
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Explore cross-cutting strategies to advance patients, in partnership with providers, as leaders and drivers of care delivery improvement through informed, shared decision making, the authorized use of clinical data for research, and value improvement.

Moderator: *Susan Reinhard, AARP*

Presentations:

- **Behavioral economics and value generation**  
*Kevin Volpp, Philadelphia VA Medical Center*
- **Communicating “value” to the public**  
*Tresa Udem, PerryUndem*
- **Social media as a tool for change**  
*Kelly Young, Rheumatoid Arthritis Warrior*

*Audience participation and open discussion*

3:00 pm	<b>Building a pathway forward</b>
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Reflecting on the presentations and discussions over the course of the two-day workshop, participants will engage in an open dialogue to define the pathway forward for building patient demand for a continuously learning health system.

Moderator: *Christine Bechtel, National Partnership for Women & Families*

Panelists: Planning committee members

- *Mark Gorman, Patient advocate*
- *Art Levin, Center for Medical Consumers*
- *Susan Sheridan, Patient-Centered Outcomes Research Institute*
- *Terry Adirim, Health Resources and Services Administration*

*Audience participation and open discussion*

4:15 pm	<b>Summary and next steps</b>
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**Thanks from the Chair**  
*Christine Bechtel, National Partnership for Women & Families*

**Comments and thanks from the IOM**  
*Michael McGinnis, Institute of Medicine*

4:30 pm	<b>Adjourn</b>
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### **Planning Committee**

Christine Bechtel, MA, National Partnership for Women & Families (*Chair*)  
Terry Adirim, MD, MPH, Health Resources and Services Administration  
Leah Binder, MA, MGA, The Leapfrog Group  
Veronica Goff, MS, National Business Group On Health  
Mark Gorman, Patient advocate  
Paul Grundy, MD, MPH, IBM  
Art Levin, MPH, Center for Medical Consumers  
Jim Mangia, MPH, St. John's Well Child & Family Center  
Lyn Paget, MPH, Health Policy Partners  
Eric Racine, PharmD, MBA, Sanofi U.S.  
Susan C. Reinhard, RN, PhD, AARP  
Craig Robbins, MD, MPH, Kaiser Permanente  
John Santa, MD, MPH, Consumers Union  
Susan Sheridan, MBA, MIM, Patient-Centered Outcomes Research Institute  
Susan Brown Trinidad, MA, University of Washington

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