Building the Patient and Family Advisory Leadership Network for Better Care

An Institute of Medicine meeting in association with the Blue Shield of California &
the Patient-Centered Outcomes Research Institute

November 11, 2013

The National Academies of Sciences
Lecture Room
2101 Constitution Avenue, NW
Washington, DC 20001
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SECTION I
Day of Materials
Building the Patient and Family Advisory Leadership Network for Better Care

INSTITUTE OF MEDICINE

in association with ....

Blue Shield of California Foundation
Patient-Centered Outcomes Research Institute

NOVEMBER 11, 2013
NATIONAL ACADEMY OF SCIENCES BUILDING
LECTURE ROOM
2101 CONSTITUTION AVENUE, NW
WASHINGTON, DC 20418

Meeting goals
1. Improve understanding of the national profile of hospital- and health center-based patient and family advisory councils.
2. Explore ways to improve communication and cooperation among advisory council leaders on their care system improvement activities, and between those in the council leadership community and the leadership of national care improvement efforts.
3. Consider strategies for using information technology to increase communication with and among council leadership.
4. Discuss opportunities and priorities for collaborative action to build a strong networked capacity.

8:30 am Coffee and light breakfast available

9:00 am Welcome, introductions, and meeting overview

Welcome, opening remarks, and meeting overview
Institute of Medicine
Other hosting organizations

9:15 am Patient and family advisory councils: current profiles
Speakers will discuss roles and activities of patient/family advisory councils from individual and institutional perspectives.

- Winthrop M. Hodges, Massachusetts General Hospital
- Bernard Roberson, Georgia Regents Health System
- Dennis Wagner, The Partnership for Patients
- Maulik S. Joshi, American Hospital Association

Q&A and Open Discussion
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| 11:00 am   | **Enhancing council communication and cooperation through technology** | Case studies of the use of technology to enhance patient, family, and caregiver participation in advisory councils, and the potential for communication between and among patient/family advisory council leadership.  
- *Jim Burrows*, Nemours  
- *Joanna Kaufman*, Institute for Patient- and Family-Centered Care  
- *Sue Sheridan*, Patient-Centered Outcomes Research Institute  

*Q&A and Open Discussion*  

| 12:00 pm   | **Issues and opportunities for coordinated council leadership** | Discussion of potential opportunities for collaborative action to deepen the capacity for networked patient and family advisory leadership synergy in the promotion of high-quality care, better evidence, and better value. |
| 12:45 pm   | **Summary and next steps**                         | Comments and thanks                                                                                                                   |
| 1 p.m.     | **Adjourn**                                       |                                                                                                                                       |
Building the Patient and Family Advisory Leadership Network for Better Care  
November 11, 2013  
Meeting Participants

Participants:

David Andrews  
Patient Advisory  
Georgia Regents Medical Center

Anne-Marie J Audet, MD, MSc  
Vice President, Delivery System Reform & Breakthrough Opportunities  
The Commonwealth Fund

Shari Berman  
Co-Chair, Adult Patient Family Advisory Council  
Dana-Farber Cancer Institute

Kate Berry  
Chief Executive Officer  
National eHealth Collaborative

Rachel Biblow, MSW, LCSW  
Director, Family Relations  
Children's Hospital of Philadelphia

Chrissie Blackburn  
President, Family Advisory Council  
Rainbow Babies and Children's Hospital

Kimly S. Blanton, MIS, MLS  
Patient Advisor  
Vidant Health System

Kay Burke  
Member, ICU Patient and Family Advisory Council  
University of Washington Medical Center

Jim Burrows, MBA  
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Nemours

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Harvard School of Public Health

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Patient Safety Advocate & Activist

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Program Officer, Patient Engagement  
Blue Shield of California Foundation

Jennifer Dingman  
Founder  
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Judy A. Doyle  
Parent Advisor Program Coordinator  
Akon Children’s Hospital

Hala Durrah  
Chairperson, Women and Children's Patient Family Advisory Council  
Anne Arundel Medical Center

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NIH NCATS Medical Officer, Office for Research in Women’s Health

Tim Flack, JD  
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Good Samaritan Hospital

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National Association of Community Health Centers

Lynda Griffin  
Parent Chair of Advisory Council  
Nemours Children’s Hospital, Orlando

Sara Guastello  
Director, Knowledge Management  
Planetree

Win Hodges  
Patient Advocate & Leader, Cancer Center  
Patient and Family Advisory Council  
Massachusetts General Hospital

Libby Hoy  
Family Advocate  
Founder, Patient and Family Centered Care Partners

Beverley H. Johnson  
President & Chief Executive Officer  
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Senior Vice President, Research  
American Hospital Association

Savita Katarya  
Patient Advisor, One World  
Mayo Clinic

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Program/Information Specialist  
Institute for Patient and Family-Centered Care

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PCORI

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Patient, Board of Directors  
Mary Greeley Medical Center

Toby Levin  
Co-Chair, Patient Family Advisory Council  
Suburban Hospital

Michael McGinnis, MD, MPP, MA  
Executive Director & Senior Scholar  
Institute of Medicine

Angela Nugent Miney  
Family Partner, Pediatric Pulmonary Division  
University of Florida

Jay Molofsky  
Administrator  
Open Door Community Health Centers

Julie Ginn Moretz  
Associate Vice Chancellor, Patient- and Family-Centered Care  
University of Arkansas

Kellie Myers  
Family Advisor, Patient-Family Advisory Council  
Duke University Medical Center

Scott Newport  
Family Advisor, Patient and Family Centered Care Initiative  
C.S. Mott Children’s Hospital

Annie O’Connor  
Chair, Family Advisory Council  
Morgan Stanley Children’s Hospital of NewYork Presbyterian
Teresa Pasquini
Chair, Behavioral Healthcare Partnership
Contra Costa Regional Medical Center & Health Centers

Jerry Penso, MD, MBA
Chief Medical & Quality Officer
American Medical Group Association

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Former Chair, Patient Family Advisory Council
Vanderbilt Hospital and Clinics

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Senior Vice President, Patient Safety and Quality
Director, Armstrong Institute for Patient Safety and Quality
Johns Hopkins Medicine

Michele Riedford
Chair, Patient and Family Advisory Team
Emory Healthcare

Linda Ritter, RN
Nursing Director & Coordinator, Care Advisory Team
University of Louisville Hospital

Anthony Bernard Roberson
Administrative Director, Patient Family Centered Care
Georgia Regents Medical Center

Murray N. Ross, PhD
Vice President
Director, Institute for Health Policy
Kaiser Permanente

Charlene Rothkopf
Co-Chair, Patient Family Advisory Council
President & Founder, Wellness Consulting Group, LLC
Johns Hopkins Hospital

Mimi Saffer
Director, Network Development
Children's Hospital Association

Nick Sandoval
Health Education Program Manager
Salud Para La Gente

Juliette Schlucter
Founder
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Joe Selby, MD, MPH
Executive Director
PCORI

Susan Sheridan, MBA, MIM
Deputy Director, Patient Engagement
PCORI

Lisa Stammerjohann
Chair, Delaware Family Advisory Council
Nemours

Nicola B. Truppin
Health Navigator Partners, LLC
Beth Israel Deaconess Medical Center

Dennis Wagner
Co-leader of the Partnership for Patients
Centers for Medicare & Medicaid Services

Judy Ward
Chair, Winthrop Patient & Family Advisory Council
Co-chair, Quality Counts Consumer Advisory Board

Karen Wayman, PhD
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Department of Pediatrics
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Current as of noon on 11/8/13
SECTION II
Host Background
The Roundtable

The Institute of Medicine’s Roundtable on Value & Science-Driven Health Care provides a trusted venue for national leaders in health and health care to work cooperatively toward their common commitment to effective, innovative care that consistently adds value to patients and society. A common motivation among Members is their shared concern that, despite being the world’s best in certain ways, health care in America falls far short on important measures of health outcomes and value. Despite per capita health expenditures nearly 50 percent higher than any other country, performance on issues such as infant mortality, life expectancy, and the prevalence, control, and treatment of chronic diseases ranks far down the list in international comparisons. Roundtable Members are committed to addressing these problems, and represent the leaders from core stakeholder communities, including clinicians, patients, health care institutions, employers, manufacturers, insurers, health information technology, researchers, and policy makers.

What are the Roundtable’s vision and goals?
– A continuously learning health system in which science, informatics, incentives, and culture are aligned for continuous improvement and innovation—with best practices seamlessly embedded in the care process, patients and families active participants in all elements, and new knowledge captured as an integral by-product of the care experience.
– Promote collective action and progress so that “By the year 2020, ninety percent of clinical decision will . . . reflect the best available evidence.” (Roundtable Charter, 2006)

How does the Roundtable work?
– Through stakeholder workshops and meetings: to accelerate understanding and progress toward the vision of a continuously improving and learning health system.
– Through joint projects through the work of six affinity group Innovation Collaboratives focused on:
  • Best clinical practices (health professional societies and organizations)
  • Clinical effectiveness research (innovative research scientists and institutions)
  • Communication of medical evidence (marketing experts and decision scientists)
  • Digital technology for health (health IT and care delivery experts)
  • Incentives for value in health care (health care purchasers and payers)
  • Systems engineering for health improvement (medical, engineering, and IT leaders)

How is the Roundtable making a difference?
– Describing the possible through the 13 publications in the Learning Health System series providing the foundation for the landmark IOM report Best Care at Lower Cost.
– Stewarding action projects of the Roundtable’s Innovation Collaborative stakeholders, working cooperatively to advance science and value in health and health care. Examples include:

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<td>• Improving the science of transparency</td>
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<td>• Essential principles of team-based care</td>
<td>• Essential principles for evidence communication</td>
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<td>• Building patient and family leadership for system improvement</td>
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<td>• Point-of-care evidence access</td>
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<td>• Systems engineering for high-value care</td>
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<td>• Strengthening the science of data-driven medicine</td>
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Chair
Mark B. McClellan, MD, PhD
Senior Fellow
The Brookings Institution

Members
David Blumenthal, MD, MPP
President
The Commonwealth Fund

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Former Chairman, President & CEO
Blue Shield of California

Paul Chew, MD
Chief Science Officer & CMO
Sanofi US

Helen Darling, MA
President
National Business Group on Health

Susan DeVore
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Judith Faulkner, MS
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Atul Gawande, MD, MPH
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James A. Guest, JD
President & CEO
Consumers Union

George C. Halvorson
Chairman & Former CEO
Kaiser Permanente

James Heywood
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Ralph I. Horwitz, MD
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Gary Kaplan, MD
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James Galloway, MD, Director, OHSC

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Patrick Conway, MD, MS, Chief Medical Officer

Department of Defense
Jonathan Woodson, MD, Assistant Secretary

Department of Veterans Affairs
Robert A. Petzel, MD, Under Secretary

Food and Drug Administration
Margaret A. Hamburg, MD, Commissioner
Peter Lurie, MD, MPH, Associate Commissioner

Health Resources and Services Administration
Mary Wakefield, PhD, RN, Administrator

National Institutes of Health
Francis Collins, MD, PhD, Director
Kathy Hudson, PhD, MS, Deputy Director

Office of the National Coordinator for Health IT
Jacob Reider, MD, National Coordinator


September 2013
PCORI. Research Done Differently.

We’re committed to a new approach in health research, one that:

- Focuses on **answering the questions** most important to patients and those who care for them through studies comparing different healthcare options.
- Works closely with **a range of healthcare stakeholders**, including patients, caregivers, scientists, clinicians, and payers, in the process of guiding our research.
- Works closely with **researchers** to identify research gaps and propose standards for sound research methods.
- Requires that **patients be engaged** in the studies we fund, not just as subjects but as real partners.

The Movement Has Begun. We Have...

- Established National Priorities for Research and a Research Agenda to guide the work we fund.
- Developed comprehensive methodology standards for patient-centered outcomes research.
- Awarded funding totaling $273.5 million to 197 studies that will explore a wide range of conditions, populations, and healthcare issues.
- Named our first four advisory panels to help guide the development of our research portfolio.
- Unveiled a vision for a national patient-centered clinical research data network.
- Announced an Engagement Awards program to seed patient-researcher partnerships that will help grow a patient-centered outcomes research community.

Join Us

The Patient-Centered Outcomes Research Institute (PCORI) helps people make informed healthcare decisions, and improves health care delivery and outcomes, by producing and promoting high-integrity, evidenced-based information that comes from research guided by patients, caregivers, and the broader health care community.

- Apply to review research proposals.
- Submit a research question.
- Attend a workshop or roundtable.
- Submit a research proposal.
- Watch for opportunities to apply for future advisory panels.

“**The key to our success is in our ability to incorporate perspectives from the entire healthcare community as we advance and refine our work.**”

—Joe Selby, MD, MPH, Executive Director

Learn More
pcori.org
info@pcori.org
Our Priorities for Research

PCORI’s National Priorities for Research and our Research Agenda guide our funding of studies that will help patients and those who care for them make better-informed health and healthcare decisions through comparisons of different healthcare options.

Our research priorities include:

1. Assessment of Prevention, Diagnosis, and Treatment Options
2. Improving Healthcare Systems
3. Communication and Dissemination Research
4. Addressing Disparities
5. Accelerating Patient-Centered Outcomes Research and Methodological Research

Research We Support

We follow a complementary two-path process to build a portfolio of high-impact patient-centered outcomes research.

Broad funding announcements tied to our research priorities rely on the research community, working with patients and other stakeholders, to propose studies on critical topics.

We also generate and prioritize research topics by starting with questions solicited directly from patients and other stakeholders through our website, events, and similar efforts undertaken by others. We assess these questions and submit potential topics for funding to our Board of Governors for consideration as the subject of funding announcements.

This process is guided by 21-member, multi-stakeholder PCORI Advisory Panels that help us refine these questions and ensure our work remains patient-centered. Our first four panels are:

- Advisory Panel on Assessment of Prevention, Diagnosis, and Treatment Options
- Advisory Panel on Improving Healthcare Systems
- Advisory Panel on Addressing Disparities
- Advisory Panel on Patient Engagement

We plan to establish additional advisory panels in the future. And in June 2013, we also started seeking proposals to study specific high-impact healthcare topics. The initial topics for this targeted funding are:

- Treatment Options for African Americans and Hispanics/Latinos with Uncontrolled Asthma
- Preventing Fall-Related Injuries in Older Adults
- Treatment Options for Uterine Fibroids

“This is really a dynamic time. If you are passionate about patient-centered research, get involved, because this is really exciting.” — Health system official
About the Foundation

Our Mission

Improve the lives of all Californians, particularly the underserved, by making health care accessible, effective, and affordable, and by ending domestic violence.

Our Goals

1. Create greater access to health care and domestic violence services by:
   - Generating more service options for the most vulnerable
   - Cultivating strong, sustainable provider organizations led by skilled leaders
   - Fostering consumer-informed services and solutions

2. Support system-level improvements in the healthcare and domestic violence safety nets by:
   - Enabling data-driven management and performance improvement
   - Fostering broad collaboration and integration among safety net providers
   - Spurring system-wide delivery innovations

What We Do

The Foundation is one of California’s largest and most trusted grantmaking organizations, focusing its support in two program areas: Health Care and Coverage and Blue Shield Against Violence.

Our funding ranges from providing unrestricted core support, to advancing thought leadership and research, to technical assistance, and beyond. Every dollar spent works to move California towards a future in which everyone is free of domestic violence and has access to high-quality, affordable health care. Watch the video, Ally for Change, to learn more about Blue Shield of California Foundation, its programs, and grantees.

Our Corporate Parent

Blue Shield of California Foundation is funded entirely by contributions from Blue Shield of California, a mission-based, not-for-profit health plan founded by physicians in 1939. We are a private foundation that shares the corporation's core mission of providing everyone access to quality health care. Foundation grantmaking is approved by a distinguished Board of Trustees.
SECTION III
Patient and Family Advisory Councils: Current Profiles
Kim Moore became a pioneer for patient engagement several years ago, when a new patient care tower was being built at Saint Elizabeth Regional Medical Center in Lincoln, Neb. “We wanted more than just a beautiful building made of bricks and mortar — we wanted the community and patients to have input into what went on inside,” declared Moore, who was then the hospital’s chief nursing officer and vice president for patient care services.

She helped establish the hospital’s first patient and family advisory council — a committee of about a dozen individuals, including community members and former patients. Hospital leaders quickly discovered the council members’ perspective was far different from that of health care providers. And it didn’t take long for the advisory council’s views to help spur positive changes.

When patient satisfaction surveys suggested a “lack of respect” on the part of hospital employees in the short-stay unit, the advisory council took a close look. Respect had very different connotations for patients than for staff, and the council discovered that patients felt so rushed in the short-stay unit that they interpreted it as a lack of respect.

Based on that insight, the hospital developed action plans for educating both staff and patients about the benefits of being at the hospital for the briefest period of time possible. Moore and others also revised the information provided to patients over the phone, in a video “welcome” and upon their arrival at the short-stay unit for outpatient surgery. The educational program had a quick and dramatic impact. In two years, patient-satisfaction scores went from the 31st percentile to the 86th percentile as perceptions about the short-stay unit shifted for both providers and patients.

“The council discovered that patients felt so rushed in the short-stay unit that they interpreted it as a lack of respect.”

Moore, who was named chief executive officer of 265-bed Saint Elizabeth in August 2011, said, “The patient and family advisory council helps us keep our eye on the ball amidst the many competing priorities of hospital administrators. We certainly need to keep our intense focus on our patients.”
Providers sometimes tend to make unilateral decisions on care, yet patients and their families have become increasingly well-informed, using the power of information to challenge traditional health care roles. They have become outspoken consumers.

Saint Elizabeth’s advisory council, whose 15 members include nine from the community, served as the model for a national initiative by Englewood, Colo.-based Catholic Health Initiatives (CHI), the nation’s third-largest faith-based health system, to establish similar committees at each of the organization’s 76 hospitals. With planning that kicked off in 2009 and an implementation process that debuted in 2010, CHI has successfully established advisory councils at all of its acute-care facilities in 18 states as part of its emphasis on person-centered care.

Person-centered care is a principal tenet of today’s rapidly evolving health care environment, where coordinated care across the continuum serves as a foundation for quality improvement and patient satisfaction. It also clearly highlights the mission, vision and values of the Catholic health care ministry.

Indeed, more hospitals than ever before are partnering with physicians and other providers in the hopes of delivering coordinated care with higher quality and less cost. Providers sometimes tend to make unilateral decisions on care, yet patients and their families have become increasingly well-informed, using the power of information to challenge traditional health care roles. They have become outspoken consumers.

CHI heightens and encourages the involvement of patients and their families, and the advisory councils are an important demonstration of that commitment, said Kathleen Sanford, RN, FACHE, who is CHI’s senior vice president and chief nursing officer. Individual council members have unique vantage points, she noted, and their personalized perspective provide a rich backdrop to the more traditional, clinical approach of doctors, nurses and other health care providers.

FROM INPUT TO PROTOCOLS

To many observers, person-centered care means doing what is best for patients. But if providers presume that they are the only ones qualified to figure out what is best for patients — as many still do — they may not seek out important input from the patients they are treating.

“Most of us — health care providers — have a knowledge base as a patient that most people simply don’t possess,” Sanford added. “That knowledge or perspective might change what we ask for and how we receive care when we are patients at our own facilities.”
How CHI Rolled Out Its National Program

For its national approach to patient-family councils, CHI created an evidence-based toolkit to deploy at all acute care facilities across the system. The toolkit, available electronically, includes an introductory section, guidelines for implementation and analysis, a method to audit and verify progress and a host of resources to help communicate the process — everything from key messages to internal staff to suggested newsletter articles and an orientation manual.

The documents for the toolkit were posted on the evidence-based practice page on the CHI intranet, giving all markets easy access to preprinted templates that could be filled in with local information.

One vital element of the toolkit, said Kathleen Sanford, RN, FACHE, who is CHI’s senior vice president and chief nursing officer, was a message about the patient as customer.

“We sent a clear message about the councils,” said Sanford. “People can get confused. This is not a board — not a fiduciary board. What we are talking about here is helping to make things better for our customers — that is, our patients. In years past, we thought our customers were physicians and that patients were consumers. Not anymore. Patients are customers. It’s not just morally or ethically right to treat them as customers — it’s good business, too.”

The kit sets timeline goals for implementation including structure, process and outcome measurements. Additionally, measures of success were introduced with a reporting process to CHI’s national office.

Most patient and family advisory councils are made up of about a dozen or more individuals, and they meet every two to three months. In addition to providing input on positive changes for patients, the advisory council members are regarded as community ambassadors, spreading the word about the hospital and ensuring that the clinical staff remains person-centered.

Hospitals within CHI use a variety of methods to recruit patients to serve on the patient and family advisory councils. Some hospitals posted ads in local newspapers, others solicited members during hospital rounds. One of the more creative recruitment methods used patient complaints as recruitment opportunities. All council members are volunteers, and one patient volunteer typically co-chairs the council with a hospital administrator. The councils meet quarterly, reporting their work to.

“Most advisory council members are people who either are really interested in making sure their hospitals have excellent care or who have had experiences as patients that might not have been the greatest, and they are interested in making sure they help others.”

—Kathleen Sanford

Each hospital’s community board. It is imperative that hospital leadership not only believes in the value of these advisory councils but also entrusts decisions to them — specifically in the area of patient experience.

“It’s an expectation of all of our managers — we have guidance from our national office to be certain that these councils are effective,” said Sanford.

Without this sustained, empowered participation by patients and families, hospitals will lose this important perspective, she added.

“Most advisory council members,” Sanford said, “are people who either are really interested in making sure their hospitals have excellent care or who have had experiences as patients that might not have been the greatest, and they are interested in making sure they help others.”

CHI’s local councils receive support from a national patient and family advisory council, with about half of its membership composed of patients and/or families who have received care at CHI hospitals. Earl Kinnear, who co-chairs the national advisory council, provides a unique, all-encompassing perspective. A retired primary care nurse practitioner who once worked at CHI, Kinnear also serves on the advisory council at Albany Area Hospital and Medical Center in Albany, Minn. Kinnear, his wife and his three children all have been patients at the 17-bed hospital, which is located in the central section of the state. He said one emphasis for the council is reviewing patient-satisfaction scores to help identify positive and negative trends.

“These surveys help tell us how we’re doing and the progress we’re making — as well as our weak points,” said Kinnear. “It helps to guide us as hospital providers and allows us to be leaders rather than followers.”

He said the active, engaged advisory councils around the system are spurring even greater interest from other patients and family members, helping to sustain and build momentum.

“My goal — and the goal of the advisory councils — is to help patients understand health care, and to have health care [providers] understand patients,” said Kinnear. “I’ve always found that doctors sometimes don’t communicate with nurses, and nurses sometimes don’t communicate with doctors. And doctors and nurses sometimes don’t communicate with patients — and vice versa. My goal is to involve patients in their decisions, to help them understand why doctors do what they do, and why nurses do what they do.”
We might not want to admit it, but we might not be getting the exact same treatment as the typical patient receives. That's not how we want to operate. We need that input from the typical patient.”

The definition of person-centered care at CHI comprises three integral components: personalization according to patient and family needs, preferences and values; comprehensiveness — that is, care that covers the body, mind and spirit — and collaboration, providing a direct link between providers and patients and their families. That link now also includes key community stakeholders — the members of the patient and family advisory councils. The creation of the advisory councils has helped to spread this definition and philosophy across all of the organization’s hospitals, providing a new opportunity for quality care and a focused spotlight on patients and their families.

The Saint Elizabeth advisory council learned from patient satisfaction surveys that patients were confused, or did not receive enough instruction, about operating the nurse call button.

“For CHI, person-centered care is not a matter of semantics, but vitally important to how we think about delivering care,” said Milt Hammerly, MD, vice president for medical affairs at CHI’s Institute for Research and Innovation. “We are privileged to be a part of the lives of the persons we serve — and not vice versa.”

The health care literature is replete with examples of hospitals and health systems trying their best to effectively describe patient-safety concerns from the perspective of patients and families. Patient and family advisory councils, like those created across CHI, represent a natural outgrowth of those concerns and are an important step in empowering patients about their health care decisions. Indeed, these councils can be a rich source of information that hospitals can use for significant improvements in quality and patient safety.

For example, the Saint Elizabeth advisory council learned from patient satisfaction surveys that patients were confused, or did not receive enough instruction, about operating the nurse call button in rooms. The council’s input led to a new protocol to ensure that patients and their families received additional instruction — and the hospital’s “welcome” video added more call-button information, too.

“This discussion led directly into another discussion on pain management,” said Libby Raetz, the hospital’s vice president for nursing services. “As we looked into that issue, we decided to add specific instructions in the video for patients and families, especially around the issue of patients’ expectations.”

Surveys and conversations with members of the advisory council also prompted leaders at Saint Elizabeth to provide clearer signage and directions about where families should pick up patients upon discharge. Until members of the advisory council mentioned the issue, no one recognized the confusion that sometimes existed.

Saint Elizabeth established a “mystery shopper” program to help provide leaders with an unvarnished, objective peek at the professionalism of staff and the cleanliness of facilities, among other key areas. “We hear what delighted them...
— and what concerned them,” said Raetz. “It’s another way to step back and see what we’re doing from the eyes of a patient.”

At 69-bed St. Vincent Medical Center North, located in a suburb of Little Rock, Ark., the advisory council created new policies and procedures to improve “way finding” when patients, families and visitors entered and exited the building. It also identified an issue that had become something of a cliche or stereotype about hospitals: cafeteria food. The advisory council developed a plan to work with the director of food services to review the quality and selection of items as well as the timeliness of delivery to patient rooms.

Meantime, the advisory council at St. Anthony Hospital, a critical-access facility with 25 beds in Pendleton, Ore., provided several suggestions for improving care and access, including the creation of designated parking spots for senior citizens and additional spaces for vans.

Based on input from the advisory councils, St. Joseph—Martin, a CHI facility in Martin, Ky., has implemented customer-service training for staff in addition to improvements in the patient-registration process. The result: Improved patient-satisfaction scores.

GIVING COUNCILS TEETH

CHI created a patient and family advisory council on the national level made up of 10 members — an even mix of national officials and representatives from the markets. The combination helps to encourage a free flow of information to and from the national office in a suburb southeast of Denver.

Each of CHI’s patient and family advisory councils is autonomous, but the national organization has established expectations to ensure these committees aren’t simply window dressing without any real power to make significant changes. The councils have three priorities over the next year: responsiveness of staff (including call-button issues); focus on patient advocates (the family surrogate or patient navigator); and the overall professionalism of staff. This work will parallel a national effort to continue to integrate the work of the advisory councils into evidence-based practices and clinical-quality initiatives.

“We provide guidance from our national office to ensure that our patient and family advisory councils are truly involved in key areas of safety and quality,” Sanford said. “It would be easy to pull together a group of people and say, ‘Well, we have an advisory council,’ and leave it at that. But if you don’t work with these groups on substantive issues, they will lose interest. They need to know that they are making a difference.”

“We’ve begun to hear some very good stories about the impact of the advisory councils,” she said. “Patients and advisory councils are beginning to tell us things that we should do differently — things we should do better. It’s too early at this point to gauge any real impact systemwide, but we will be closely studying the reports and suggestions to help us become more effective at true person-centered care.”

CAMILLE HAYCOCK is vice president, evidence-based practice, at Catholic Health Initiatives, Englewood, Colo.
Involving patient and family advisors in the patient and family-centered care model.

Warren N.

Source
Sutter Medical Center of Santa Rosa, Santa Rosa, CA, USA.

Abstract
Health care facilities that utilize patient and family advisors are experiencing improved outcomes in decreased length of stay, and improved reimbursements and patient satisfaction. Patient and family advisors can be strong allies in ongoing performance improvement efforts. Perhaps even more importantly, involving advisors in health care systems encourages treatment of the whole patient as he or she would want to be treated

PMID:22966526 [PubMed - indexed for MEDLINE]

Link to full article: http://www.ncbi.nlm.nih.gov/pubmed/22966526

Developing a patient-centered ISHAPED handoff with patient/family and parent advisory councils.

Friesen MA, Herbst A, Turner JW, Speroni KG, Robinson J.

Source

Inova, Falls Church, Virginia 22042, USA. maryann.friesen@inova.org

Abstract

Our hospital system used Lean strategies to develop a new process for the change-of-shift bedside handoff titled ISHAPED (I = Introduce, S = Story, H = History, A = Assessment, P = Plan, E = Error Prevention, and D = Dialogue). Several teams collaborated with a Parent Advisory Council and a Patient/Family Advisory Council to design a study to explore patient perceptions of the handoff. The findings from the study along with recommendations from the councils were used to develop education modules on implementing patient-centered handoffs.

PMID:23528749 [PubMed - in process]

Link to full article: http://www.ncbi.nlm.nih.gov/pubmed/23528749
More Hospitals Use Social Media to Gather Feedback from Patients' Families

With Some Medicare Payments Based on Patient Satisfaction, More Hospitals Are Relying on Parents as Virtual Advisers

By Laura Landro

The Informed Patient How Patients' Parents Make Themselves Heard

Hospitals are turning to Facebook, Twitter and other forms of social media to recruit patients and their families as advisers.

- Video: Hospitals Listening to Patients on Social Media

Link to full article:

http://online.wsj.com/news/articles/SB1000142412788732410820457902284310951438
Win Hodges

Massachusetts General Hospital (MGH) Cancer Center PFAC
Served since 2001 when originally formed

Mission: To ensure that the voices of patients and families are represented in an effort to enhance their entire experience at the MGH Cancer Center

- Staff co-chairs
- Meets monthly for 2 hours
- Selected Activities:
  - HOPES (Helping Our Patients through Education and Support)
  - Cancer Center Patient Guide; Website
  - Rounding pilot
  - Interviewing candidates for Cancer Center leadership positions
  - Resource for architects on cancer outpatient and inpatient floors: Yawkey Center for Outpatient Care; Lunder Building

The Ambulatory Practice of the Future (APF)
Charter member of the development team – full patient involvement from the outset in 2004. Focused on culture, patient portal (iHealthSpace.org) and office design

- New model practice:
  - Objective: Make the care experience exceptional for both patients and staff
  - 3 Care teams with MD, NP, RN, MA, Health Coach
  - Started from scratch enabling APF to hire staff committed to its philosophy and culture
  - Patients are MGH employees and their adult dependents
- Practice culture:
  - Partnership with patients
  - Focus on Wellness
  - Continuous communication and care
  - Transparency – iHealthspace.org
  - Respect for contributions of employees at every level
  - Weekly staff meetings chaired in turn by everyone on staff
Building the Patient and Family Advisory Leadership Network for Better Care
Patient and Family Advisory Councils: Personal Experience

The APF Care Alliance
*Founded and chaired APF Care Alliance 2010*

Mission: The mission of the APF Care Alliance, a partnership of patients, family members and providers, is to promote innovation and the optimization of the care experience for all

- Patient co-chairs
- Meets monthly for 1 hour, patient members conference call monthly for 1½ hours, patient member attends weekly 1 hour staff meeting
- Patient members are partners, not advisors, and own projects
- Patient Engagement: Patient Experience Surveys; Patient Portal – iHealthSpace.org
- APF Innovation Learning Program
  [https://apf.partners.org/collaborators/partners](https://apf.partners.org/collaborators/partners)

The MGH General PFAC
*Invited 2011*

Mission: Guided by the MGH Mission, Credo and Boundaries, the PFAC is dedicated to ensuring that our patients and families have a successful, compassionate, and supported healthcare experience

- Staff co-chairs
- Meets monthly for 1½ hours
- Selected Activities:
  - Resource for all PFACs at MGH
  - Hosting 2013 Joint PFAC Dinner
  - Exploring opportunities to standardize PFACs

Patient Centered Outcomes Research Institute (PCORI)

- Emphasis on patient involvement at every step of the process starting with grant drafting and submission
- PCORI grant applications must address:
  - Impact
  - Potential
  - Technical merit
  - Patient Centeredness
  - Stakeholder engagement
Brigham and Women’s Hospital (BWH) PCORI PFAC
*Joined 2013*

Objective: To improve the discharge transition from inpatient to outpatient to better accommodate patient needs and to prevent readmissions

- Staff chair
- Meets monthly for 1½ hours

Selected Activities:
  - Defining how to be helpful to patients and families to achieve objective
  - Evaluating and amending drafts of communications

**Distinctions: PCORI PFACs vs Traditional PFACs**

**Future Role:** PFACs evolving from an advisory to a collaborative role
September 2013

Dear Colleague:

As health care provider organizations search for ways to improve care outcomes while simultaneously lowering costs, the concept of patient and family engagement has become a priority. To advance this priority, the Health Research & Educational Trust, an affiliate of the American Hospital Association, with support from the Gordon and Betty Moore Foundation, is collecting credible survey data that documents the extent of progress hospitals have made in engaging patients and their family members.

Your hospital was randomly chosen from the American Hospital Association's hospital database to participate in this survey. If you choose to take part, your responses will be kept completely confidential and will be released only as part of group summaries. Hospitals that respond to the survey will receive tailored reports comparing their use of patient and family engagement strategies with those of similar hospitals, and with all hospitals.

The results of the survey will inform efforts hospitals can undertake to speed the implementation of effective approaches to engage patients and their family members.

We encourage you to complete and return this important survey. Should you have any questions about this study or the survey, please contact Becca Chimis at 312-422-2659 or rchimis@aha.org.

Thank you for participating in this important effort.

Sincerely,

Rich Umbdenstock
President and CEO
PATIENT AND FAMILY ENGAGEMENT SURVEY

Login ID:
Password:
PATIENT AND FAMILY ENGAGEMENT SURVEY

1. Has the hospital conducted a formal self-assessment to determine the extent to which various patient and family engagement practices are used in the hospital?
   - □ Yes, within the last 12 months
   - □ Yes, more than 12 months ago
   - □ No

This group of questions relates to how the hospital partners with patient and family advisors.

2. Does your hospital have a patient and family advisory council that is hospital-wide, only in a unit or units of the hospital, or no hospital-wide patient and family advisory council?
   - □ Hospital-wide
   - □ Only in one or more units, but not hospital-wide (Skip to question 7)
   - □ There are no patient and family advisory councils (Skip to question 7)

3. Does the patient and family advisory council have bylaws or a written charter?
   - □ Yes
   - □ No

4. How many times has the patient and family advisory council met in the last 12 months?
   - _____________ time(s)

5. What percent of the patient and family advisory council members are patients and family members?
   - _______%

6. How long has the hospital had a patient and family advisory council?
   - □ Less than 12 months
   - □ 12 months to 24 months
   - □ More than 24 months

7. This question lists committees and work groups that may exist in the hospital. If your hospital uses a different name for its committee/workgroup, please choose the closest match. For example, your hospital may have a Quality Council. The closest match would be Quality/Performance Improvement/Patient Safety Team.

For each committee/work group, please indicate (1) whether or not it exists, (2) whether or not the committee/work group is led or co-led by a patient or family member, and (3) whether or not there are at least TWO patients or family members that serve on the committee/work group.

<table>
<thead>
<tr>
<th>Committee or Work Group</th>
<th>(1) This Committee/Work Group exists in this hospital</th>
<th>(2) Led or Co-led by Patient or Family Member</th>
<th>(3) There are at least TWO patients or family members that serve on the Committee/Workgroup</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Facility Design</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Patient Experience</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Patient/Family Education</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Hospital's Board of Trustees</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Board Quality and Patient Safety Committee</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>
This Committee/Work Group exists in this hospital

<table>
<thead>
<tr>
<th>Quality/Performance Improvement/Patient Safety Teams</th>
<th>Yes</th>
<th>No</th>
<th>Yes</th>
<th>No</th>
<th>Yes</th>
<th>No</th>
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<tbody>
<tr>
<td>Please specify projects or teams</td>
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Other, please specify:

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<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Yes</th>
<th>No</th>
<th>Yes</th>
<th>No</th>
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</thead>
</table>

This group of questions relates to family presence (visitor) policies and practices.

8. Is there a written policy that supports patients’ rights to identify their preferences with respect to which family members or other partners in care they would (and would not) like to have actively involved in their care?

☐ Yes    ☐ No

9. Please indicate whether or not the hospital has a policy or guidelines that facilitate unrestricted access, 24 hours a day, to hospitalized patients by family and other partners in care according to patient preference.

☐ Exists across all units (Skip to question 10)    ☐ Exists across some units (Skip to question 10)    ☐ Does not exist in any hospital unit

For each of the following hospital units, please indicate whether or not the hospital has a policy or guidelines which facilitate unrestricted access, 24 hours a day, to hospitalized patients by family and other partners in care according to patient preference.

<table>
<thead>
<tr>
<th>Unit</th>
<th>This Unit Does Not Exist in This Hospital</th>
<th>Has a Policy/Guidelines Which Facilitate Unrestricted Access</th>
</tr>
</thead>
<tbody>
<tr>
<td>Behavioral Health (Substance Abuse, Mental Health, Psychiatric)</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Emergency Department</td>
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<tr>
<td>Maternity Unit</td>
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<tr>
<td>Medical Unit</td>
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<tr>
<td>Surgical Unit</td>
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<tr>
<td>Pediatric Unit</td>
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<tr>
<td>Other (Non-ICU) Specialty Units</td>
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<tr>
<td>Coronary Care Units (CCU)</td>
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<tr>
<td>Medical Intensive Care Units (MICU)</td>
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<tr>
<td>Neonatal Intensive Care Units (NICU)</td>
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<td>Pediatric Intensive Care Units (PICU)</td>
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<td>Post Anesthesia Care Unit (PACU)</td>
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<tr>
<td>Surgical Intensive Care Units (SICU)</td>
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<tr>
<td>Other ICU Unit</td>
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<tr>
<td>Other Unit</td>
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</tbody>
</table>
This group of questions relates to practices that help patients make decisions

10. Are patients provided with decision aids for various health conditions? Patient decision aids are informational health materials and literature that help people become involved in decision making by making explicit the decision that needs to be made, providing information about treatment options and outcomes, and helping the patient clarify personal values.

- Yes
- No (Skip to question 12)

11. Please indicate whether or not patients receive decision aids through each of the following methods:

- A formal or central hospital service that provides all patients with decision aids for various health conditions
- Decision aids are provided to patients by specialty units

12. Does the hospital calculate readability levels or scores of any informational health materials distributed by the hospital (using tools such as Kincaid, Flesch Index, SAM: Suitability Assessment of Materials)?

- Yes
- No

13. Does the hospital consistently provide non-written materials such as picture books, videotapes, or audiotapes to convey important information to patients with limited ability to obtain, process or understand basic health information and services needed to make appropriate health decisions?

- Picture Books
- Video Tapes
- Audiotapes or multi-media presentations

14. Please indicate whether or not the hospital provides patients and families with the following materials in different languages.

- Both written and non-written materials
- Just written materials
- Just non-written materials

15. In general (exceptions being the right to access psychotherapy, notes or information compiled for use in litigation and records the provider determines could result in harm to you or another person), can patients examine their health record while they are in the hospital?

- Patients can examine their health records anytime while in the hospital.
- Patients can examine their health record by appointment only or in consultation with their physician.
- Patients are not allowed to examine their health record while in the hospital.

16. Is information given to patients on how to access their health record?

- Yes
- No
17. Please indicate whether or not patients can update the following information in their health record.

<table>
<thead>
<tr>
<th>Information</th>
<th>Yes</th>
<th>No</th>
<th>Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Who the patient's preferred family or partners in care are</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>How family or care partners may participate in care and decision making</td>
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<tr>
<td>Demographic information</td>
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<td>Progress notes</td>
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<tr>
<td>Family medical history</td>
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<tr>
<td>Allergic episodes</td>
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<td>Lab test results</td>
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<tr>
<td>Do not resuscitate (DNR) orders</td>
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<tr>
<td>Proxies</td>
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<tr>
<td>Advanced directives</td>
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<tr>
<td>Any information</td>
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</table>

18. Does the hospital provide patients access to a patient portal (a secure online website that gives patients convenient 24-hour access to personal health information from anywhere with an Internet connection)?
   - ☐ Yes
   - ☐ No

**This group of questions relates to practices used at the bedside.**

19. Are patients and/or family members encouraged to participate in the nurse bedside change of shift report?
   - ☐ Yes, across all units (Skip to question 20)
   - ☐ Yes, across some units (Skip to question 20)
   - ☐ No, not in any hospital unit

For each unit listed below, please indicate whether or not patients and/or family members are encouraged to participate in the nurse bedside change of shift report.

<table>
<thead>
<tr>
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<td>Surgical Intensive Care Units (SICU)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other ICU Unit</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other Units</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

20. Are multidisciplinary rounds (planning and evaluating patient care with health professionals from a variety of health disciplines) consistently conducted at the bedside with patients and/or family members?

- Yes, across all units (Skip to question 21)
- Yes, across some units (Skip to question 21)
- No, not in any hospital unit

For each of the following units, please indicate whether or not multidisciplinary rounds (planning and evaluating patient care with health professionals from a variety of health disciplines) are consistently conducted at the bedside with patients and/or family members.

<table>
<thead>
<tr>
<th>Unit</th>
<th>This Unit Does Not Exist in This Hospital</th>
<th>Multidisciplinary rounds are consistently conducted at the bedside with patients and/or family members</th>
</tr>
</thead>
<tbody>
<tr>
<td>Behavioral Health (Substance Abuse, Mental Health, Psychiatric)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emergency Department</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maternity Unit</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical Unit</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pediatric Unit</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Surgical Unit</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other Non-ICU Specialty Units</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Coronary Care Units (CCU)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical Intensive Care Units (MICU)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neonatal Intensive Care Units (NICU)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pediatric Intensive Care Units (PICU)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Post Anesthesia Care Unit (PACU)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Surgical Intensive Care Units (SICU)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other ICU Unit</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other Units</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
21. How often are patients’ daily care objectives listed on a white board (also known by the terms marker board, dry-erase board, dry-wipe board, pen-board) in their room?

22. How often do patients or family members add their own notes to the white boards?

23. How often is the white board reviewed with the patient and family?

24. Does the hospital provide a way for patients and their families to call for assistance from a Rapid Response Team (RRT)?

- The hospital does not have a Rapid Response Team (RRT) (Skip to question 28)
- Patients or family members can directly call for assistance from the Rapid Response Team (RRT)
- Patients or family members have to request assistance from a Rapid Response Team (RRT) through hospital staff members
- The hospital has a Rapid Response Team (RRT) but patients can't activate it (Skip to question 27)

25. How long have you had a policy for families to be able to activate Rapid Response Teams?

- 12 months or less
- More than 12 months

26. Is information shared with families and other partners in care on how to activate or request assistance from Rapid Response Teams?

- Yes
- No

27. On average, over the past 12 months, how many rapid response calls were either activated or requested by patients or family members each month?

- 0
- 1 every other month
- 1 a month
- 2 to 3 a month
- More than 3 a month
28. How frequently is teach-back used during the discharge planning process in each of the units listed below? Teach-back is a way to confirm that the health care provider has explained what the patient needs to know in a manner that the patient understands. Patient understanding is confirmed when they accurately explain it back to the health care provider in their own words. If needed, the health care provider can re-explain and check again.

<table>
<thead>
<tr>
<th>Unit</th>
<th>Never</th>
<th>Seldom</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always</th>
<th>This Unit Does Not Exist in the Hospital</th>
</tr>
</thead>
<tbody>
<tr>
<td>Behavioral Health (Substance Abuse, Mental Health, Psychiatric)</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Emergency Department</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Maternity Unit</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Medical Unit</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Pediatric Unit</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Surgical Unit</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Coronary Care Units (CCU)</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Medical Intensive Care Units (MICU)</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Neonatal Intensive Care Units (NICU)</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Pediatric Intensive Care Units (PICU)</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Post Anesthesia Care Unit (PACU)</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Surgical Intensive Care Units (SICU)</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

29. Does the hospital have a formal policy for disclosing and apologizing for medical errors to patients and families?  ✔ Yes  ☐ No (Skip to question 31)

30. How long has the hospital had a policy for disclosure and apology in place?
    ✔ Less than 12 months  ☐ 12 months to 24 months  ☐ More than 24 months

31. When a root cause analysis (RCA) investigation is conducted, are patients and/or family members routinely interviewed?  ✔ Yes  ☐ No

32. When a root cause analysis is conducted, are patients and/or family members routinely included as members of the root cause analysis team?  ✔ Yes  ☐ No

This group of questions relates to equipping staff to engage patients and their families through training and education.

33. Does the hospital provide training for physicians, nurses and other clinical staff on partnering with patients and families in the care plan decision-making process?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Don't Know</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physician Training</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Nurse Training</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Other Clinician Training</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
34. For each of the following training areas, please indicate whether or not patients or family members participate as educators or content developers in the training of physicians, nurses and other clinical staff, or do not participate in that training area at all.

<table>
<thead>
<tr>
<th>Training Area</th>
<th>Physician Training</th>
<th>Nurse Training</th>
<th>Other Clinical Staff Training</th>
<th>Patients or family members do not participate as educators or content developers in this training area</th>
</tr>
</thead>
<tbody>
<tr>
<td>New employee orientation</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>In-service education for clinical staff</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Programs for medical staff</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Partnering with patients and families in the care plan decision-making process</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

35. What proportion of the hospital's physicians, nurses, and other clinical staff has received training on partnering with patients and families in the care plan decision-making process?

<table>
<thead>
<tr>
<th></th>
<th>0%</th>
<th>Between 1% and 25%</th>
<th>Between 26% and 50%</th>
<th>Between 51% and 75%</th>
<th>Between 76% and 99%</th>
<th>100%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physicians</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nurses</td>
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<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other Clinicians</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

36. For each of the following practices, please indicate whether or not there is formal training provided to physicians, nurses and other clinical staff in how to communicate with patients.

<table>
<thead>
<tr>
<th>Patient Communication Training</th>
<th>Training Provided to:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Physicians</td>
</tr>
<tr>
<td>--------------------------------</td>
<td>------------</td>
</tr>
<tr>
<td>How to encourage patients and families to ask questions</td>
<td></td>
</tr>
<tr>
<td>How to encourage patients and families to give their opinions and express concerns</td>
<td></td>
</tr>
<tr>
<td>Approaches for eliciting the values of patients and families</td>
<td></td>
</tr>
<tr>
<td>Approaches for eliciting the goals of patients and families</td>
<td></td>
</tr>
<tr>
<td>Approaches for eliciting the needs of patients and families</td>
<td></td>
</tr>
<tr>
<td>How to create opportunities to hear from patients and family members about their perspective of the care experience at the hospital</td>
<td></td>
</tr>
<tr>
<td>How to respond when people complain</td>
<td></td>
</tr>
<tr>
<td>How to involve patients and families in process improvement, redesign work, and/or committees</td>
<td></td>
</tr>
<tr>
<td>Using teach-back methods</td>
<td></td>
</tr>
<tr>
<td>Disclosing and apologizing for medical errors</td>
<td></td>
</tr>
</tbody>
</table>
The next group of questions relate to barriers to implementing patient and family engagement practices and monitoring and measuring engagement strategies.

37. Please rate each item below as to your perception of the degree it presents a barrier to your hospital in implementing patient and family engagement strategies on a scale ranging from 1 (no barrier) to 5 (significant barrier).

<table>
<thead>
<tr>
<th>Barrier</th>
<th>No Barrier</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Differences in language between patient and health care provider</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cultural differences between patient and health care provider</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Leadership commitment to patient and family engagement activities</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Amount of financial support for patient and family engagement activities</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Support for patient and family engagement from clinicians</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Support for patient and family engagement from hospital administrators</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Training of clinical providers in how to engage with patients</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Availability of clinical information systems</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient’s willingness to participate in care activities</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>The literature/evidence supporting the “usefulness” of patient and family engagement practices</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time available for rounds, change of shift, etc.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time it takes to set up and implement advisory programs</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Privacy/HIPAA concerns</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Risk management concerns</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Competing organizational priorities</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Degree of transparency of medical cost information enabling patients to compare the price of health care services and products so they can make informed choices among doctors and hospitals</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Degree of transparency of quality information enabling patients to compare the quality of health care services</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>
38. Please indicate whether or not each of the following metrics is regularly or periodically used by the hospital to track the implementation of patient and family engagement strategies.

<table>
<thead>
<tr>
<th>Metric</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>The number of advisory councils across the hospital</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ratio of patient and family members to staff on advisory councils</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of patient and family advisors serving on committees or Quality Improvement (QI) teams</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of staff trained in partnering with families</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of staff trained in communicating to support patient and family engagement</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Changes in patients' ratings of hospital care as patient and family engagement strategies are implemented</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Changes in clinical process and outcomes as patient and family engagement strategies are implemented</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Changes in market or financial performance as patient and family engagement strategies are implemented</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other (please specify)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

39. What is your position in the hospital?
   - [ ] Chief Executive Officer (CEO)
   - [ ] Chief Operating Officer (COO)
   - [ ] Chief Medical Officer (CMO)
   - [ ] Chief Nursing Officer (CNO)
   - [ ] Other (Please specify) ________________________________

40. Other than the practices identified in this survey, please describe below any additional successful patient and family engagement practices that you have implemented in your hospital or system.

Please provide below your contact information so that we can learn more about your hospital's promising practices.

Name: ____________________________________________

Title: ___________________________________________

Phone: __________________________________________

Email: __________________________________________

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SECTION IV
Communication Strategies
Click on any icon to view that member’s information, photos, and stories. Use the zoom function or search options to find specific areas.

### USA (119 RESULTS)

<table>
<thead>
<tr>
<th>NAME</th>
<th>CITY, STATE</th>
<th>CONGRESSIONAL DISTRICT &amp; REP</th>
<th>AVAILABLE MEDIA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Steve P.</td>
<td>Urbandale, IA</td>
<td>IA-3, Rep. Tom P. Latham (R) Sen. Charles E. Grassley (R), Sen. Thomas Harkin (D)</td>
<td></td>
</tr>
<tr>
<td>Jessica H.</td>
<td>Oconomowoc, WI</td>
<td>WI-5, Rep. F. James Sensenbrenner (R) Sen. Ron Johnson (R), Sen. Tammy Baldwin (D)</td>
<td></td>
</tr>
<tr>
<td>Liliana S.</td>
<td>Harlingen, TX</td>
<td>TX-34, Rep. Filemon Vela (D) Sen. Ted Cruz (R), Sen. John Cornyn (R)</td>
<td></td>
</tr>
<tr>
<td>Mary G.</td>
<td>Campbell, CA</td>
<td>CA-18, Rep. Anna G. Eshoo (D) Sen. Barbara Boxer (D), Sen. Dianne Feinstein (D)</td>
<td></td>
</tr>
<tr>
<td>Donna S.</td>
<td>Virginia Beach, VA</td>
<td>VA-2, Rep. E. Scott Rigell (R) Sen. Timothy Kaine (D), Sen. Mark Warner (D)</td>
<td></td>
</tr>
<tr>
<td>Name</td>
<td>City/State</td>
<td>District</td>
<td>Represents</td>
</tr>
<tr>
<td>---------------</td>
<td>--------------</td>
<td>-------------------</td>
<td>------------------------------------------------</td>
</tr>
<tr>
<td>Marion B.</td>
<td>Virginia Beach, VA</td>
<td>VA-2, Rep. E. Scott Rigell (R) Sen. Timothy Kaine (D), Sen. Mark Warner (D),</td>
<td></td>
</tr>
<tr>
<td>Christy G.</td>
<td>Plano, TX</td>
<td>TX-3, Rep. Sam Robert Johnson (R) Sen. Ted Cruz (R), Sen. John Cornyn (R),</td>
<td></td>
</tr>
<tr>
<td>Brandie N.</td>
<td>Dallas, TX</td>
<td>TX-24, Rep. Kenny Ewell Marchant (R) Sen. Ted Cruz (R), Sen. John Cornyn (R),</td>
<td></td>
</tr>
<tr>
<td>Maria G.</td>
<td>Saint Louis Park, MN</td>
<td>MN-5, Rep. Keith Maurice Ellison (D) Sen. Alan Stuart Franklin (D), Sen. Amy Jean Klobuchar (D),</td>
<td></td>
</tr>
<tr>
<td>Kristin C.</td>
<td>Hartford, CT</td>
<td>CT-1, Rep. John B. Larson (D) Sen. Christopher S. Murphy (D), Sen. Richard Blumenthal (D),</td>
<td></td>
</tr>
<tr>
<td>Melaku L.</td>
<td>Rowlett, TX</td>
<td>TX-32, Rep. Pete A. Sessions (R) Sen. Ted Cruz (R), Sen. John Cornyn (R),</td>
<td></td>
</tr>
<tr>
<td>Marc L.</td>
<td>Irvine, CA</td>
<td>CA-45, Rep. John Bayard Taylor Campbell (R) Sen. Barbara Boxer (D), Sen. Dianne Feinstein (D),</td>
<td></td>
</tr>
<tr>
<td>Joe C.</td>
<td>Midlothian, TX</td>
<td>TX-6, Rep. Joe Linus Barton (R) Sen. Ted Cruz (R), Sen. John Cornyn (R),</td>
<td></td>
</tr>
<tr>
<td>Indi T.</td>
<td>Saint Louis, MO</td>
<td>MO-1, Rep. Wm. Lacy Clay (D) Sen. Roy Blunt (R), Sen. Claire McCaskill (D),</td>
<td></td>
</tr>
<tr>
<td>Michele O.</td>
<td>San Antonio, TX</td>
<td>TX-21, Rep. Lamar S. Smith (R) Sen. Ted Cruz (R), Sen. John Cornyn (R),</td>
<td></td>
</tr>
<tr>
<td>Name</td>
<td>Location</td>
<td>State</td>
<td>Congressional District</td>
</tr>
<tr>
<td>--------------</td>
<td>-------------------</td>
<td>--------</td>
<td>------------------------</td>
</tr>
<tr>
<td>Anna H.</td>
<td>Sacramento, CA</td>
<td>CA</td>
<td>CA-6</td>
</tr>
<tr>
<td>Sheryl R.</td>
<td>Oconomowoc, WI</td>
<td>WI</td>
<td>WI-5</td>
</tr>
<tr>
<td>Suzie S.</td>
<td>Sacramento, CA</td>
<td>CA</td>
<td>CA-6</td>
</tr>
<tr>
<td>Missy W.</td>
<td>Portland, ME</td>
<td>ME</td>
<td>ME-1</td>
</tr>
<tr>
<td>Lindsey S.</td>
<td>Denver, CO</td>
<td>CO</td>
<td>CO-1</td>
</tr>
<tr>
<td>Lara M.</td>
<td>Seattle, WA</td>
<td>WA</td>
<td>WA-7</td>
</tr>
<tr>
<td>Laura F.</td>
<td>Washington, DC</td>
<td>DC</td>
<td>DC-0</td>
</tr>
<tr>
<td>Tonya W.</td>
<td>Kansas City, MO</td>
<td>MO</td>
<td>MO-6</td>
</tr>
<tr>
<td>Teresa T.</td>
<td>Kansas City, MO</td>
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Care Provider Feedback

The quality of the interaction between a child/family and his or her physician is key to providing a great experience. From your perspective, what are the three to five things that physicians can do or say during your family’s appointment that would make it a great interaction?

- What can I do to help you deal with the information you have been given today? Here’s how to reach me if you have questions. Is there anything else you are concerned with that I have not touched on today? Is there anything I have told you that you don’t completely understand? Is there anything your child is concerned with? Are all questions I think every Dr needs to ask.

- I agree with Dorothy's comments. I would also add: (1) Many of our doctors have an 'entourage' with them. The 'entourage' must all introduce themselves when they first come into the exam room, (2) Smile, (3) Engage with the child, as well as the family (my son has limited cognitive ability, but that's no reason to ignore him), (4) If the doctor disagrees with something the parent/caregiver is doing, don't just say 'it's wrong' but ask probing questions to understand why - might learn something critical here, (5) Listen, listen, listen and ask probing questions to show you are listening to the parent/caregiver, and (6) Don't be condescending or dismiss our kids, despite their medical issues. For example, I was explaining some pain my son was experiencing and was told by an AIDHC doctor, "That's the way it is with these types of kids." WHOA! Needless to say, I now go to CHOP to a different doctor who addressed the pain issue IMMEDIATELY.

- On a recent visit to the Endocrinologist, we had originally been told that the appointment would only be with the doctor as a follow up and expected to only be there about 30 minutes as before. We were there over 2 hours with a parade of the "entourage". While they did interact with both my daughter and I, better communication is needed as far as who will be seeing my daughter, the purpose and time frames.

- Be friendly and interact with both parents and child! I can't tell you how awesome it is to have a doctor who interacts with your child. My daughter is only 2 1/2, but her hematologist/oncologists interact with her on her level every single time they see her - and she loves them because of this! And when your child isn't fighting the doctor because she likes them and is comfortable with them, it makes everything go a lot smoother. Also, make sure parents understand the treatment plan and have no questions left unanswered. Our hematologist/oncologists always ask us if we have questions and tell us that no question is a dumb question, leaving us plenty of opportunities to bring up or ask about anything we are concerned about, and we feel comfortable doing so because of that. And please don't rush! I know these doctors are very busy and tend to lots of kids, but I hate feeling rushed because it makes me feel like we're not important enough right then.

- I appreciate when the doctor treats "all of my child". She sees the neurology team. The best neurologist from that team focused not just on the major symptom of her condition, but also included things like being sure she hits her developmental milestones, her ability to walk, basically her overall well being and not just her seizures.
He was openly available to me and I knew he listened to my concerns. If something fell outside of his area of expertise, he knew who to recommend us to and was on top of making positive improvements with her total health. He’s no longer with this hospital and it’s a huge disappointment. I'm now working with a traditional neurologist who is more scientific than focusing on all of the effects this condition has on my daughter.

- What I find most important is that they listen to me and my concerns. That they take their time with us and make sure that we are not rushed through an appointment. I also appreciate that when we are given news that we don’t want to hear, that they are empathetic and understanding. We have been so fortunate to receive consistent high quality care at Nemours. :)

- I too know that the Drs at Nemours are VERY grounded. They truly care and are approachable, even giving their cell phone number to contact should any question /concern arise. I have utilized other hospitals over our son’s life and NONE compare to the personal care here at Nemours.

- Given that my most recent experiences were with a teenager, it is important for doctors to recognize the developmental stage of the patient and not treat a 15 or 16 year old as if they were 5 or 6. Further, with multiple difficulties, it is important for the MD to recognize the underlying causes; for a child with cancer who had varying sorts of treatments, it is important for the MD to realize that many problems were caused by the cancer treatments, not by some birth defect. Finally, MDs should be encouraged to work with teenagers as if the patient would soon be in charge of their own treatments; help with the transition from Mom and Dad.

- I truly think they should listen more than they speak and realize that a parent knows their child more than they ever will. Having a diagnosis doesn't define a child; it just roughly sets the path in the forest. We as parents will actually navigate through the woods and make it the best path in the woods. When my daughter was diagnosed with the same life threatening disease as my son I will never forget him telling me to always have hope. He acknowledged that he didn’t know what her journey would entail but promised me he was committed to giving her the best life, the most time at home, and the support we needed as a family to get through this all. His words brought me great comfort at a time my heart was shattering. Just the fact he was going to fight with us and walk WITH us (not in front of us) meant everything. Doctors need to speak with the child before making new treatment plans. A doctor telling my son he needs to wear his oxygen all the time and WHY it’s important made it easier for my child to understand this new medical intervention. Allowing a child to give input into their own care takes pressure off the parent but enables the child to be a part of the decision process. Lastly, it’s okay to tell a parent that they don’t know something. We don’t expect that they know every treatment, every medicine but what we do expect is for the doctor to say, “I am not sure what to do next but I will find people who do and I will do my best to help your child”. We will respect them more for this acknowledgement that they are not "God" and all knowing.
Ambassador Program Overview

PCORI Engagement Team
October 23, 2013
About PCORI

PCORI was authorized by the Patient Protection and Affordable Care Act of 2010 as a non-profit, nongovernmental organization and is charged with helping patients, clinicians, purchasers, and policy makers make better-informed health decisions by “advancing the quality and relevance of evidence about how to prevent, diagnose, treat, monitor, and manage diseases, disorders, and other health conditions.” It does this by producing and promoting high-integrity, evidence-based information that comes from research guided by patients, caregivers, and the broader healthcare community.

PCORI’s strong patient-centered orientation directs attention to individual and system differences that may influence research strategies and outcomes. PCORI is charged with producing useful, relevant clinical evidence through the support of new research and the analysis and synthesis of existing research.

PCORI is committed to transparency and a rigorous stakeholder-driven process that emphasizes patient engagement. PCORI uses a variety of forums and public comment periods to obtain public input to enhance its work.

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Opportunity Snapshot

PCORI is launching a new collaborative volunteer initiative called the PCORI Ambassador Program that will unite individual and organizational Ambassadors around the promise of patient-centered outcomes research (PCOR). The initiative will equip, train, connect, and mobilize patients, organizations, and other stakeholders to share PCORI’s vision and mission and PCOR principles with their respective communities, participate as full partners in research, and help ensure the sharing and use of information generated from PCORI-funded projects. The PCORI Ambassador Program will be grounded in guiding principles co-created by patients and other stakeholders and will offer the Ambassadors tools to share the PCORI story; connect them with other Ambassadors who share common interests to facilitate the formation of research affinity groups; help position them as potential partners in PCORI-funded projects; and advance opportunities to participate with PCORI in a variety of engagement opportunities, including dissemination and implementation of research findings. The long-term goal is to have Ambassadors in every state, extending the reach of our engagement efforts and expanding knowledge about and participation in PCOR across the country with the ultimate goal of helping patients and those who care for them to make more informed decisions.
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Background

The Patient-Centered Outcomes Research Institute (PCORI) was created to conduct research that provides information about the best available evidence to help patients and those who care for them make more informed healthcare decisions. Our research is intended to give patients a better understanding of the prevention, diagnosis, and treatment options available and the science that supports those options.

We identified five cross-cutting areas where additional health research is needed to give patients and those who care for them more information to support decision making. PCORI’s National Priorities can be applied to and used to advance the quality of information for any health condition or disease where evidence is lacking or current decision making is suboptimal. The five priorities were developed in light of PCORI’s statutory requirements, its working definition of patient-centered outcomes research (PCOR), and previous research prioritization efforts. These National Priorities for Research encompass the patient-centered comparative clinical effectiveness research PCORI will support in its funding announcements:

- Assessment of Prevention, Diagnosis, and Treatment Options
- Improving Healthcare Systems
- Communication and Dissemination Research
- Addressing Disparities
- Accelerating Patient-Centered Outcomes Research and Methodological Research

We also issue targeted funding announcements seeking proposals to study specific high-priority topics. Recent funding announcements include:

- Disparities in Asthma, Burden and Care
- PCORI-NIH Partnership on Fall-Related Injury Prevention

On October 27–28, 2012, we invited 150 participants from across the country to a workshop entitled Transforming Patient-Centered Research: Building Partnerships and Promising Models. Three-quarters of the participants self-identified as patients, caregivers, or patient representatives; the remaining quarter represented other stakeholder groups, many of them researchers. Joe Selby, MD, MPH, the executive director of PCORI, remarked that the “readiness” of the patient and stakeholder community at the workshop “affirmed PCORI’s working assumption that the patient community is up to the challenge of playing its part in transforming the research enterprise.”

At the close of the workshop, a participant stood up and noted that PCORI had “ambassadors” in the room and that there was an opportunity to capitalize on the energy and enthusiasm of the group to be
influential in promoting patient-centered research. One of the key recommendations that emerged from the workshop was the concept of a “PCORI Ambassador Program.”

We are launching the PCORI Ambassador Program to unite individual and organizational Ambassadors around the promise of PCOR. The program will leverage the enthusiasm, influence, and collective wisdom of the healthcare community, creating a partnership built on PCOR principles, which include:

- Trust
- Transparency
- Co-learning
- Reciprocal relationships
- Partnerships
- Honesty

**Vision and Goals**

The PCORI Ambassador Program is a volunteer program designed to engage individuals and organizations in helping the PCORI Engagement Team achieve its strategic goals (see Figure 1):

- Create a diverse community of patients and other stakeholders who have the desire and training to participate in research;
- Engage this PCOR-ready community in research; and
- Disseminate and implement research findings.

The program will leverage the momentum and leadership of healthcare stakeholders and their organizations, networks, and communities. The goal is to develop a corps of trained, well-informed patient and stakeholder partners to collaborate with researchers in patient-centered research projects and help expedite the dissemination and implementation of research findings through these networks, communities, and affiliates.
The PCORI Ambassador Program will be guided by patients, caregivers, advocacy organizations, clinicians, researchers, and other stakeholders, especially those already active with PCORI. The initiative will equip, train, connect, and mobilize participants to promote PCORI’s work in their respective communities. The Ambassadors will also participate as full partners in health research and help ensure the sharing and uptake of information generated from PCORI-funded projects.

Specifically, the program will provide participants with tools to connect patients and other stakeholders with common interests and help position them as potential partners in PCORI-funded projects. Our long-term goal is to have Ambassadors in every state, extending the reach of our engagement efforts and expanding knowledge about and participation in PCOR across the country.

Who Can Participate

Ambassadors can be either individuals or organizations. All Ambassadors must complete "PCOR Science Training" and agree to the roles and expectations outlined in this document.
Volunteers for the PCORI Ambassador Program will initially be recruited from the community of consumers, patients, caregivers, clinicians, other healthcare professionals, researchers, and organizations that:

- Have participated in a PCORI workshop, roundtable, meeting, or working group;
- Have served as members of our advisory panels;
- Have served as merit reviewers or reviewer mentors;
- Are currently serving as a patient or stakeholder partner or researcher in PCORI-funded projects; or
- Have hosted a PCORI presentation, panel, breakout session, or collaborative initiative.

In 2014, we will expand training to those who are interested in becoming a PCORI Ambassador but have not had the opportunity to participate in PCORI activities.

**Ambassador Activities**

Ambassadors will be expected to share information with their respective communities about PCOR and to build awareness of opportunities to become engaged as partners in research. They will also share information about PCORI activities and principles. PCORI Ambassadors may regularly give presentations about PCOR and the work of PCORI using materials provided by the institute. This work is essential to achieve our common goals of promoting PCOR in partnership with others and disseminating and implementing best practices in PCOR and findings from PCORI-funded research.

The envisioned activities for Ambassadors are aligned with the program goals and may include:

**Creating a PCOR Community**

- Informing others about PCORI through presentations and by sharing information and distributing materials, op-eds, and letters to the editor;
- Forwarding PCORI announcements, alerts, and surveys to their membership, community, and related organizations;
- Participating in an Ambassador social network forum to share lessons learned and pursue collaborations;
- Organizing and fostering "affinity groups" aligned with PCORI's current and future research agenda; and
- Contributing as a guest blogger, co-author, webinar presenter, and Engagement e-newsletter contributor.
Engaging the PCOR Community in Research

- Participating in PCOR science training to cultivate skills for future participation as patient and stakeholder partners in PCORI research projects;
- Helping frame, collect, and propose potential comparative effectiveness research (CER) questions from communities, affiliates, disease groups, and so forth;
- Participating in, or recruiting applicants for, funding opportunities, including the Pipeline Awards;
- Participating in and recruiting networks and affiliates for survey panels; and
- Contributing to targeted funding announcement working group discussions.

Disseminating and Implementing Research Findings

- Sharing PCORI results and announcements with their networks; and
- Participating in forums and conferences to help share the PCORI story and the results of research.

Ambassador Opportunities

Volunteering to become a PCORI Ambassador provides Ambassadors with a number of opportunities, which may include:

- Receiving PCORI Ambassador communications tools and PCOR science training;
- Being recognized as a “PCOR Science-Trained Ambassador” on the PCORI Ambassador webpage, which may facilitate interaction with potential researchers seeking trained patient and stakeholder partners and opportunities for patients and stakeholders seeking PCOR researcher partners;
- Connecting with and building relationships and affinity groups with other PCORI Ambassadors and PCORI staff;
- Being identified on a PCORI Ambassador webpage as having co-authored publications, submitted guest blogs, or participated in other media opportunities;
- Being highlighted for work in patient-centered research in PCORI e-newsletters;
- Participating in PCORI informational webinars;
- Learning of opportunities to serve as PCORI reviewers or participate in working groups and on survey panels; and
- Serving as a panelist or co-presenter at PCORI-sponsored events such as workshops, roundtables, and launches;
- Collaborating with PCORI or others on events such as webinars, conferences, and panels.
Roles and Expectations

Roles of the PCORI Engagement Team

The PCORI Ambassador Program will be managed by the Institute’s Engagement Team, which will:

- Demonstrate and promote the PCOR principles of trust, transparency, co-learning, reciprocal relationships, partnerships, and honesty;
- Provide advocacy and communication tools in the form of informational toolkits, as requested by Ambassadors and at the discretion of the team;
- Establish and promote a social network to exchange information among Ambassadors and others;
- Keep Ambassadors updated on the work of PCORI and the various programs and activities that may be of interest to Ambassadors and their networks;
- Provide training that will lead to identification as “PCOR Science Trained” and hold informational webinars as requested by Ambassadors and at the discretion of the team;
- Maintain a webpage listing the PCORI Ambassadors; and
- Offer communication training to help Ambassadors discuss PCORI’s work effectively with potential patient and stakeholder partners.

Roles of PCORI Ambassadors

- Build positive relationships with the healthcare community and work in partnership with other Ambassadors and healthcare professionals to promote research that incorporates the perspectives of patients and other stakeholders;
- Demonstrate and support the PCOR principles of trust, transparency, co-learning, reciprocal relationships, partnerships, and honesty;
- Remain informed of PCORI’s initiatives and promote our programs to stakeholder networks;
- Be active participants in a wider national network of PCOR;
- Help disseminate PCORI research findings, surveys, polls, and calls for input and information;
- Participate in PCOR training to enhance PCOR readiness for opportunities as patient and stakeholder partners in PCORI-funded research; and
- Inform the PCORI Engagement Team of their activities and needs.

The following section demonstrates how we intend to develop and preserve the credibility, sustainability, and integrity of the Ambassador program, reduce the risk of misunderstandings, and best achieve the mission and collective goals of the Ambassador Program.

Program Integrity

In the event that an Ambassador does not honor the roles, expectations, or spirit of the PCORI Ambassador program, it will be at the discretion of our staff and/or the Patient Engagement Advisory Panel to determine an Ambassador’s status.
PCORI Ambassadors are volunteers, not members or representatives or agents of PCORI. They do not speak on behalf of PCORI but are partners aligned with the principles of PCORI. Statements made by Ambassadors should not be construed as statements with which PCORI necessarily agrees. The PCORI Ambassador Program will undergo periodic reviews by PCORI staff and/or the Patient Engagement Advisory Panel to ensure that objectives are being met; to evaluate program integrity and review roles and expectations, titles, and terminology; and to implement any necessary process improvement initiatives. PCORI reserves the right to cancel the program at any time.

**Conflict of Interest**

Pursuant to PCORI’s policies for transparency and fairness, all Ambassadors will be asked to fill out PCORI’s Conflict of Interest (COI) form. If an Ambassador participates in a PCORI event and shares personal information or information about family members or acquaintances in a public forum, he or she will be asked to fill out an Audio Visual Disclosure Form provided by PCORI.

**Program Evaluation**

To ensure that program objectives are met, PCORI has established an evaluation plan that will draw information from the following six sources:

- **Web Intake Form**—responses submitted by Ambassadors;
- **Reporting Activity Form**—information submitted by an Ambassador at the conclusion of each activity;
- **Yammer Analytics Dashboard**—report generating information about online community users and conversations and activity within the online community;
- **Program Surveys**—a list of questions provided after six months and one year of program launch;
- **PCORI Ambassador Tracking**—a comparison of the names of Ambassadors with the participants in future PCORI events and programs; and
- **Recognition of Completion of PCORI Training**—PCORI 101 and PCOR science training.
Pipeline to Proposal Awards Initiative:
Inaugurating PCORI’s Engagement Awards Program

Published June 17, 2013
Revised October 15, 2013

Note: This document is retained for archival purposes only. Information related to this program has changed. For current information, please see PCORI’s Pipeline to Proposal Award page, available at http://www.pcori.org/funding-opportunities/pipeline-to-proposal-awards.
About PCORI

PCORI was authorized by the Patient Protection and Affordable Care Act of 2010 as a non-profit, nongovernmental organization and is charged with helping patients, clinicians, purchasers, and policy makers make better informed health decisions by “advancing the quality and relevance of evidence about how to prevent, diagnose, treat, monitor, and manage diseases, disorders, and other health conditions.” It does this by producing and promoting high-integrity, evidence-based information that comes from research guided by patients, caregivers, and the broader healthcare community.

PCORI’s strong patient-centered orientation directs attention to individual and system differences that may influence research strategies and outcomes. PCORI is charged with producing useful, relevant clinical evidence through the support of new research and the analysis and synthesis of existing research.

PCORI is committed to transparency and a rigorous stakeholder-driven process that emphasizes patient engagement. PCORI uses a variety of forums and public comment periods to obtain public input to enhance its work.

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Opportunity Snapshot

The Patient-Centered Outcomes Research Institute (PCORI) is launching a new funding initiative, PCORI's Engagement Awards, to facilitate involvement of patient, stakeholder, and research communities in patient-centered outcomes research.

The first funding opportunity under this initiative, Pipeline to Proposal Awards, is designed to create opportunities for patients to partner with other healthcare stakeholders and become more engaged in the research process. This program will allocate resources through three successive tiers of awards designed to promote interest and capacity for the development of patient-centered outcomes research proposals.

Tier I Pipeline Awards will be managed by five Intermediate Funders (IFs) who will help patient, stakeholder, or research group awardees build strong multi-stakeholder communities and partnerships. Tier II Pipeline Awards will invest in the development and maturation of research communities and partnerships between patients, stakeholders, and research groups, and Tier III Pipeline Awards will be used to help already existing partnerships develop high-quality research proposals that can be submitted to PCORI.

The long-term goals of this initiative are to support the submission of high-quality patient-centered outcomes research proposals and to advance a nationwide network of communities that are equipped and eager to participate in research that helps patients and those who care for them make more informed decisions.
I. Background

The Patient-Centered Outcomes Research Institute (PCORI) was created to conduct research to provide information about the best available evidence to help patients and their healthcare providers make more informed decisions. PCORI’s research is intended to give patients a better understanding of the prevention, treatment, and care options available and the science that supports those options.

PCORI has identified five cross-cutting areas where health research is needed to give patients and those who care for them more information to support decision making. PCORI’s National Priorities and Research Agenda\(^1\) can be applied to and used to advance the quality of information for any health condition or disease where evidence is lacking or current decision making is suboptimal. The five priorities were developed in light of PCORI’s statutory requirements, its working definition of patient-centered outcomes research (PCOR), and previous research prioritization efforts. These National Priorities for Research encompass the patient-centered comparative clinical effectiveness research PCORI will support in its funding announcements:

1. Assessment of Prevention, Diagnosis, and Treatment Options
2. Improving Healthcare Systems
3. Communication and Dissemination Research
4. Addressing Disparities
5. Accelerating Patient-Centered Outcomes Research and Methodological Research

On October 27–28, 2012, PCORI invited 150 participants from across the country to a workshop titled Transforming Patient-Centered Research: Building Partnerships and Promising Models.\(^2\) Three-quarters of the participants self-identified as patients, caregivers, or patient representatives, while the remaining participants represented other stakeholder groups, many of them researchers. They met in Washington, DC, to offer ideas on best practices for patient engagement in research and to envision a future culture of patient-centered outcomes research where research is conducted in partnership with consumers/patients, caregivers, and the broader healthcare community.

In his closing comments, Joe Selby, MD, MPH, executive director of PCORI, remarked that the “readiness” of the patient and stakeholder community at the workshop “affirmed PCORI’s working assumption that the patient community is up to the challenge of playing its part in transforming the research enterprise.” Workshop participants shared, however, that few resources have been directed to patient, community, or other key stakeholder groups for capacity building, support, or infrastructure development for engagement in research as partners and that the majority of

\(^1\) Available at pcori.org/research-we-support/priorities-agenda/
\(^2\) A workshop report and webcast are available at pcori.org/events/transforming-patient-centered-research-building-partnerships-and-promising-models/?type=past
funding for research has been allocated to scientific and academic entities and to large healthcare delivery systems in the United States. One of the key recommendations that emerged from the workshop participants was the concept of Engagement Awards designed to facilitate involvement of patient, stakeholder, and research communities in patient-centered outcomes research—as partners.

II. PCORI's Engagement Awards

In June 2013, PCORI announced a new funding program called the Engagement Awards to support the more active integration of patient, stakeholder, and research communities in the research process. The Engagement Awards will support PCORI's engagement goals of:

- Building a knowledgeable community that can participate in patient-centered outcomes research
- Engaging an informed community in the conduct of patient-centered outcomes research
- Evaluating engagement in research to assure its impact

The program is broken into three areas of funding opportunities: (1) Knowledge Awards, (2) Training and Development Awards, and (3) Implementation Awards (see Illustration 1). The Pipeline to Proposal Awards, a specific initiative within the Training and Development Awards, seeks to shift the research-funding paradigm, allowing patients and stakeholders to engage and partner with researchers to study the issues that are most critical to them.
III. Pipeline to Proposal Awards

In June 2013, PCORI launched the Pipeline to Proposal Awards by releasing a Request for Quotes, available at on PCORI’s website³, seeking five Intermediate Funders (IFs) who will, in partnership with PCORI, manage up to 10 Tier I Pipeline Awards. The purpose of the Pipeline to Proposal Awards initiative is to build a national community of patients, stakeholders, and researchers who have the expertise and passion to participate in patient-centered outcomes research, and to create partnerships within that community that lead to high-quality research proposals. Below, we describe the goals, how these awards fit within PCORI’s mission, the funding structure for all three tiers, and the role of IFs in Tier I Pipeline Awards.

What Are the Goals?
PCORI’s strategic goals for the Pipeline to Proposal Awards include:

- Strengthening relationships between researchers, patients, and stakeholders, particularly in communities that have historically been underrepresented in research.
- Building the capacity for community partnerships to create research questions and submit patient-centered research proposals that can be considered for PCORI funding.

³ Available at pcori.org/funding-opportunities/pipeline-to-proposal-awards-initiative
• Cultivate the field of patient-centered outcomes research by increasing the number of patients, researchers, and other stakeholders who have the ability to participate in patient-centered outcomes research.
• Identify the most promising methods for engaging and communicating with patients, researchers, and other stakeholders in patient-centered outcomes research and communicate those lessons to current and future PCORI awardees.

How Will the Pipeline to Proposal Awards Contribute to PCORI's Mission?
The Pipeline to Proposal Awards must support PCORI's mission to help patients and those who care for them make better informed healthcare decisions. All awardees will receive PCORI-created trainings to ensure that they carry out their work in a way that adheres to the Institute’s guiding principles of patient-centeredness, collaboration, and embracing diversity. Finally, the work undertaken must meaningfully contribute to PCORI's long-range goals to:

• Substantially increase the quantity, quality, and timeliness of useful, trustworthy information available to support health decisions
• Speed the implementation and use of patient-centered outcomes research evidence
• Influence clinical and healthcare research funded by others to be more patient-centered

How Will the Pipeline to Proposal Awards Be Implemented?
The Pipeline to Proposal Awards will be conducted through the funding of three successive tiers of awards, with each tier designed to take another step toward producing community-led, patient-centered outcomes research proposals. **Tier I Pipeline Awards** will fund community-building and engagement projects. **Tier II Pipeline Awards** will develop research capacity, create new partnerships, and build the infrastructure needed to conduct research, and **Tier III Pipeline Awards** will fund the development of high-quality research proposals that can be submitted to PCORI (see Illustration 2).
**Tier I: Pre-Engagement/Community-Building Projects (up to $15,000 per award)**

In Tier I Pipeline Awards, PCORI is focused on building the community of patients, stakeholders, and researchers who can participate in patient-centered outcomes research.

Tier I awards can be given to any individual patient, stakeholder, or researcher—or group of patients, stakeholders, or researchers—oriented around a particular issue that can ultimately lead to a comparative effectiveness research question, even if that question cannot yet be articulated.

The Tier I awardees will be asked to conduct the following activities over nine months:

- Build relationships within communities that are based on shared interest among patients, health organizations, clinicians, and researchers.
- Create structures (e.g., advisory councils) and communication strategies that may include setting up of social media platforms or using online forums to connect community members.
- Develop an understanding, through the use of PCORI-created trainings, of PCORI’s commitment to enhancing the use of patient-centered, evidence-based information.
- Identify specific parties who are interested in research collaboration and development of a proposal for a Partnership and Infrastructure Development Project (Tier II Pipeline Awards).

To better reach patient, stakeholder, and research groups around the country, PCORI will work with five IFs with experience in grants or contract management in areas such as health advocacy, community development, community-based participatory research, or patient-centered outcomes research with activated patients, stakeholders, researchers, or their respective organizations. Funding will be allocated to five of these IFs to manage Tier 1 awards. The IFs will include four regionally focused and one nationally focused organization. Each IF will manage up to 10 Tier 1 awards. By utilizing IFs, PCORI can leverage the expertise of these organizations nationwide and tap into their existing infrastructure and knowledge of local communities. Additional information is provided below.

**Tier II: Partnership and Infrastructure Development Projects (up to $25,000 per award)**

Funding for Tier II Pipeline Awards will be available to groups, including Tier I awardees, that have successfully established partnerships between patient partners and research partners, and have demonstrated an interest in developing a patient-centered outcomes research proposal. Applicants who have not applied for or received a Tier I award may also be eligible, as long as the desired qualifications for partnership and demonstrated commitment to advancing patient-centered outcomes research are met.

Tier II awards invest in the development and maturation of research partnerships that can accomplish the end goal of creating a high-quality proposal that can be considered under PCORI’s primary research funding announcements. The awards are designed to support new or emerging research partnerships, the development of research infrastructure, and the generation of research questions and research priorities. The award period is 12 months.
Funding should be used to convene workshops, town hall meetings, virtual webinars, and other methods of communication within the community partnerships. The awards will also support partnership infrastructure development, such as governance and communications needs.

To qualify for a Tier II award, applicants must have both patient partners and research partners, with other types of partners strongly encouraged.

Applicants may request up to $25,000 in direct costs. PCORI expects that a significant portion of the funds will be allocated to the non-research partner and will carefully review proposals with a consideration of equity in allocation of resources.

**Tier III: Proposal Development Projects (up to $50,000 per award)**

Funding for Tier III Pipeline Awards will be available to groups, including successful Tier II awardees, that are well equipped to develop a PCORI research proposal but would benefit from additional assistance, particularly with regard to building the patient engagement component of the study design.

Applicants who have not applied for or received a Tier I or Tier II Pipeline Award may also be eligible provided that the desired qualifications for Tier III applicants are met. Applicants for Tier III Pipeline Awards may also be previously unsuccessful applicants for PCORI research funding. Special focus would be given to those who have submitted proposals to PCORI and were not funded but received recommendations from PCORI to strengthen the research partnership plan.

Tier III awardees are required to have a partnership between a patient and research partner in place, with other types of partners strongly encouraged.

Applicants may request up to $50,000 in direct costs. PCORI expects that a significant portion of the funds will be allocated to the non-research partner and will carefully review proposals with a consideration of equity in allocation of resources. Ideally, collaborative proposals will be based on partnerships that have demonstrated working success in the past. Projects must be completed within 12 months, and a PCORI research proposal must be prepared and ready for submission.

See Illustration 3 for a summary of funding tiers.
What Is the Role of Intermediate Funders in Pipeline to Proposal Awards?

IFs will be responsible for providing technical support and monitoring the operational and programmatic performance of the Tier I awardees, as well as completing the financial accounting and administration duties. A monitoring report will be provided to PCORI on a regular basis to ensure that its investment in community building is serving the intended goal.

Each IF must have extensive experience requisite to offer technical assistance to the project and to manage small awards to recipients with little funding experience. The anticipation is that each of the five IFs may manage the awards in slightly different ways, and PCORI welcomes IFs to employ successful models they have used in the past. However, it is critical that the core principles of PCOR and overarching goals of the Pipeline to Proposal Awards are adhered to by Tier I awardees and IFs. Therefore, PCORI will provide the IFs with guidelines for both the financial and operational and programmatic management of the Tier I awards.
PCORI will select the IFs by mid-August 2013.

PCORI expects and encourages each IF to pursue its own strategy for distributing funding and managing its awardees. One anticipated benefit of using IFs is the opportunity to compare and evaluate different methods for building diverse and effective communities. The IFs will also be asked to play a role in communicating their work with a broad group of stakeholders to amplify the impact of the Tier I awards.

IV. A Model: How the Pipeline Awards Can Work Effectively

Outlined below is a description of how PCORI envisions all three tiers of awards being effectively utilized by patients, researchers, or other stakeholders to meet PCORI’s goals. The organizations discussed in these examples are fictional and used for illustrative purposes only.

Patient Awardee
Sunshine Health Institute in Colorado (an IF) awards $15,000 Tier I Pipeline Award to a small group of patients with osteoarthritis who, due to lack of effective medical treatment, have been sharing ideas about different ways to combat their pain and immobility. The group recruits interested clinicians to join them and—using the funding—rents meeting space for convening partners from around the region. The group also uses the award to purchase software and hardware to facilitate e-communication.

During the nine-month grant period, with oversight by the Sunshine Health Institute and PCORI, the Arthritis Cluster convenes once per week, grows its group to include 75 arthritis patients, appoints a leadership council, and drafts a plan for how it will move forward in identifying comparative effectiveness research issues of most importance to its members, including the best nonsurgical treatments for knee osteoarthritis.

Upon winning a Tier II Pipeline Award, the Arthritis Cluster forges partnerships with local clinicians and non-clinician stakeholders and researchers with interests in nonsurgical treatments for knee osteoarthritis. With oversight by PCORI, the group develops a governance and communications mechanism to share information about its primary research issue and continues to invite new members (from the patient, stakeholder, and researcher groups) to join. The group uses the Tier II funding to prepare the communications plan, to continue convening in-person meetings, and for software and hardware to continue building its e-community.

Having received a Tier III Pipeline Award, the now well-coordinated Arthritis Cluster begins honing in on specific comparative effectiveness research questions around nonsurgical treatment of knee osteoarthritis and vets these ideas through collaboration with other patient, stakeholder, and researcher groups. The group uses Tier III funding for three site visits to explore other similar groups’ efforts in arthritis management. The group also uses the funding to build evaluation and communication/dissemination plans and to cover the administrative costs associated with the project director’s role.
The ultimate output from Tier III is a well-vetted research proposal with a strong engagement component that can be submitted to PCORI in response to a funding announcement. Additional outputs would be patient-centered outcomes research proposals to other funding entities, as well as shared learning among the patient, stakeholder, and research communities about the process of building community and orienting around an important research topic.

**Stakeholder Awardee**
Sunshine Health Institute in Colorado (an IF) awards a $15,000 Tier I Pipeline Award to a small local health department that, due to a large influx of type 2 diabetes patients (caused in part by the area's food desert, economic hardship, and abundance of fast-food restaurants), has begun brainstorming more effective ways to engage its patients in disease management techniques. The group uses Tier I funding to pay for meeting costs, including travel expenses for its partners, and for multiple in-person gatherings of patients and stakeholders. The group also uses the grant to cover administrative expenses associated with the project director’s role.

During the nine-month grant period, with oversight by the Sunshine Health Institute and PCORI, the health department team convenes once per week, grows its group to include 50 of its diabetes patients, appoints a leadership council, and drafts a plan for how it will move forward in identifying comparative effectiveness research issues of most importance in managing diabetes. The team members draw largely from the input of the group’s patient partners on the best ways to tackle disease management obstacles, given the community’s specific challenges.

Upon receiving a Tier II Pipeline Award, the group, now coalesced as the Diabetes Consortium, forges partnerships with additional local clinicians and non-clinician stakeholders and researchers with interests in diabetes management. With oversight by PCORI, the group develops a governance and communications mechanism to share information about its primary research issue. The group also continues to invite new members (from the patient, stakeholder, and researcher groups) to join. The Consortium uses its Tier II funding to travel to three different sites where similar diabetes groups are working on patient-centered interventions; the group also uses the funding to cover three focus groups to further refine the research issues in play.

Having received a Tier III Pipeline Award, the now well-coordinated Diabetes Consortium begins honing in on specific comparative effectiveness research questions around the most effective patient-driven disease management techniques and vets these ideas through collaboration with other patient, stakeholder, and researcher groups. The group uses Tier III funding for two major convening meetings of project partners, for administrative costs associated with the project director’s role, and for a community survey to measure the baseline for the research proposal.

The ultimate output from Tier III is a well-vetted research proposal with a strong engagement component that can be submitted to PCORI in response to a funding announcement. Additional outputs would be patient-centered outcomes research proposals to other funding entities, as well as shared learning among the patient, stakeholder, and research communities about the process of building community and orienting around an important research topic.
**Reseacher Awardee**

Sunshine Health Institute in Colorado (an IF) awards a $15,000 Tier I Pipeline Award to a local researcher who lost his mother very quickly to a rare disease. He is interested in trying to connect nationally with others impacted by the disease and develop a comparative effectiveness study evaluating the best treatment options available for the condition. The researcher uses the funding to purchase software and consulting services to establish a large e-community; he also uses the funding to convene two in-person meetings of patients and stakeholders.

During the nine-month grant period, with oversight by the Sunshine Health Institute and PCORI, the researcher builds a network of 45 patients and 35 stakeholders affected by or interested in this rare disease. The group appoints a leadership council and drafts a plan for how it will move forward in identifying comparative effectiveness research questions evaluating available treatments for the disease. The plan is drawn largely from the input of its patient partners, with great care given to the outcomes of treatment that matter to patients beyond survival, such as treatment side effects.

Upon winning a Tier II Pipeline Award, the Rare Disease Collaborative continues to invite new patients, stakeholders, and interested researchers into its network. With oversight by PCORI, the group develops a governance and communications mechanism to share information about its primary research issue. The group uses Tier II funding to engage communications experts in creating a master dissemination plan. The group also uses the funding to pay for travel and other related costs for an in-person meeting of the members of the Collaborative.

Having won a Tier III Pipeline Award, the now well-coordinated Collaborative begins honing in on specific comparative effectiveness research question around the most effective and least caustic treatment for the rare disease. The group uses Tier III funding for software and hardware to maintain a robust online community, as well as for in-person meetings and partner travel.

The ultimate output from this tier is a well-vetted research proposal with a strong engagement component that can be submitted to PCORI in response to a funding announcement. Additional outputs would be patient-centered outcomes research proposals to other funding entities, as well as shared learning among the patient, stakeholder, and research communities about the process of building community and orienting around an important research topic.
Links for Further Background from Nemours:

Dedicated to Children’s Health From the Very Beginning, Nemours
http://www.nemours.org/about.html

Hospitals Listening to Patients on Social Media: Interviews, WSJ
http://live-wsj.com/video/hospitals-listening-to-patients-on-social-media/4344618d-77aa-4f0e-83e6-124e075a0be.html#!4344618d-77aa-4f0e-83e6-124e075a0be
SECTION V
The IOM Roundtable: Patient and Public Facing Activities
Making a Difference ...

Roundtable charter, strategy, tactics, impact

September 2013

The Roundtable on Value & Science-Driven Health Care has been established by the Institute of Medicine to marshal cutting-edge science for transformative progress in health outcomes and value for every American. Drawing on the insights and leadership from throughout the scientific, clinical, commercial, voluntary, and public sectors, the Roundtable has set out a vision for a **continuously learning health system**. To achieve that vision, the Roundtable stewards a wide-ranging set of collaborative activities aimed at transforming value, science, and culture by:

- clarifying concepts and opportunities
- informing policy
- mapping strategies
- stewarding action
- spreading the word
- engaging broadly
- linking leaders
**Roundtable Charter**

**Charge:** The Institute of Medicine’s Roundtable on Value & Science-Driven Health Care has been convened to help transform the way evidence on clinical effectiveness is generated and used to improve health and health care.

**Vision:** Our vision is for the development of a continuously learning health system in which science, informatics, incentives, and culture are aligned for continuous improvement and innovation—with best practices seamlessly embedded in the care process, patients and families active participants in all elements, and new knowledge captured as an integral by-product of the care experience.

**Goal:** By the year 2020, ninety percent of clinical decisions will be supported by accurate, timely, and up-to-date clinical information, and will reflect the best available evidence. We feel that this presents a tangible focus for progress toward our vision, that Americans ought to expect at least this level of performance, that it should be feasible with existing resources and emerging tools, and that measures can be developed to track and stimulate progress.

**Context:** As unprecedented developments in the diagnosis, treatment, and long-term management of disease bring Americans closer than ever to the promise of personalized health care, we are faced with similarly unprecedented challenges to identify and deliver the care most appropriate for individual needs and conditions. Care that is important is often not delivered. Care that is delivered is often not important. In part, this is due to our failure to apply the evidence we have about the medical care that is most effective—a failure related to shortfalls in provider knowledge and accountability, inadequate care coordination and support, lack of insurance, poorly aligned payment incentives, and misplaced patient expectations. Increasingly, it is also a result of our limited capacity for timely generation of evidence on the relative effectiveness, efficiency, and safety of available and emerging interventions. Improving the value of the return on our health care investment is a vital imperative that will require much greater capacity to evaluate high priority clinical interventions, stronger links between clinical research and practice, and reorientation of the incentives to apply new insights. We must quicken our efforts to position evidence development and application as natural outgrowths of clinical care—to foster health care that learns.

**Approach:** The IOM Roundtable on Value & Science-Driven Health Care serves as a forum to facilitate the collaborative assessment and action around issues central to achieving the vision and goal stated. The challenges are myriad and include issues that must be addressed to improve evidence development, evidence application, and the capacity to advance progress on both dimensions. To address these challenges, as leaders in their fields, Roundtable members work with their colleagues to identify the issues not being adequately addressed, the nature of the barriers and possible solutions, and the priorities for action, and marshal the resources of the sectors represented on the Roundtable to work for sustained public-private cooperation for change.

Activities include collaborative exploration of new and expedited approaches to assessing the effectiveness of diagnostic and treatment interventions, better use of the patient care experience to generate evidence on effectiveness and efficiency of care, identification of assessment priorities, and communication strategies to enhance provider and patient understanding and support for interventions proven to work best and deliver value in health care.

**Core concepts and principles:** For the purpose of the Roundtable activities, we define science-driven health care broadly to mean that, to the greatest extent possible, the decisions that shape the health and health care of Americans—by patients, providers, payers, and policymakers alike—will be grounded on a reliable evidence base, will account appropriately for individual variation in patient needs, and will support the generation of new insights on clinical effectiveness. Evidence is generally considered to be information from clinical experience that has met some established test of validity, and the appropriate standard is determined according to the requirements of the intervention and clinical circumstance. Processes that involve the development and use of evidence should be accessible and transparent to all stakeholders.

A common commitment to certain principles and priorities guides the activities of the Roundtable and its members, including the commitment to: the right health care for each person; putting the best evidence into practice; establishing the effectiveness, efficiency, and safety of medical care delivered; building constant measurement into our health care investments; the establishment of health care data as a public good; shared responsibility distributed equitably across stakeholders, both public and private; collaborative stakeholder involvement in priority setting; transparency in the execution of activities and reporting of results; and subjugation of individual political or stakeholder perspectives in favor of the common good.
Roundtable Members

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Senior Fellow
The Brookings Institution

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President
The Commonwealth Fund
Bruce G. Bodaken, MPhil
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Blue Shield of California
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Office of the National Coordinator for Health IT
Jacob Reider, MD, Acting National Coordinator

ROUNDTABLE SPONSORS: Association of American Medical Colleges, AstraZeneca, Agency for Healthcare Research and Quality, Blue Shield of California, Blue Shield of California Foundation, California HealthCare Foundation, Centers for Medicare and Medicaid Services, Charina Endowment Fund, Department of Veterans Affairs, Epic Systems, Inc., GlaxoSmithKline, Gordon and Betty Moore Foundation, HCA, Inc., Health Resources and Services Administration, Kaiser Permanente, National Institutes of Health, Partners HealthCare, Patient-Centered Outcomes Research Institute, Premier, Inc., Robert Wood Johnson Foundation, Sanofi US, United Health Foundation, WellPoint, Inc. Comments, suggestions, or requests may be sent to Kate Burns at the IOM Roundtable on Value & Science-Driven Health Care: kburns@nas.edu. All projects and materials described may be accessed at http://iom.edu/vsrt or by clicking directly on embedded links.
"By 2020, ninety percent of clinical decisions will be supported by accurate, timely, and up-to-date clinical information and will reflect the best available evidence and informed personal preference." (Roundtable Charter)

"We seek the development of a continuously learning health system in which science, informatics, incentives, and culture are aligned for continuous improvement and innovation, with best practices seamlessly embedded in the delivery process and new knowledge captured as an integral by-product of the delivery experience." (Roundtable Charter)

"Care that is important is often not delivered. Care that is delivered is often not important. Improving the return on our healthcare investment is a vital imperative that will require quickening our efforts to position evidence development and application as natural outgrowths of clinical care—to foster health care that learns." (Roundtable Charter)
**Vision.** The Learning Healthcare System explores the various dimensions—evidence development and standards, care culture, system design and operation, health data, clinical research, information technology, and value—on which emerging insights and scientific advances can be applied to produce a health care system that learns.

**Effectiveness Research.** Redesigning the Clinical Effectiveness Research Paradigm: Innovation and Practice-Based Approaches reviews the growing scope and scale of the need for clinical effectiveness research alternatives, the potential for emerging research and data networks, innovative study designs, new methods of analysis and modeling to speed the availability and applicability of new knowledge about effective care.

**Evidence.** Learning What Works: Infrastructure Required for Comparative Effectiveness Research assesses the capacity needed for new knowledge and evidence about what care works best for whom under different circumstances, and the implications of new research for evidence standards.

**Systems Engineering.** Engineering a Learning Health System: A Look at the Future reviews transferrable lessons from the systems and operations engineering sciences applicable for engineering approaches to continuous feedback and improvement on quality, safety, knowledge, and value in health care.

**Cost & Outcomes.** The Healthcare Imperative: Lowering Costs and Improving Outcomes presents a 6-domain framework for understanding and measuring healthcare waste and excess costs: unnecessary services, inefficiently delivered services, excessive administrative costs, prices that are too high, missed prevention opportunities, and medical fraud.

**Data Quality.** Digital Data Improvement Priorities for Continuous Learning in Health and Health Care presents the current deficiencies in the reliability, availability, and usability of digital health data and considers strategies, priorities, and responsibilities to address such deficiencies in the pursuit of better care, improved health, and lower health care costs.

**Core Metrics.** Core Measurement Needs for Better Care, Better Health, and Lower Costs: Counting What Counts considers needs, approaches and metrics most important for tracing progress on care that is better quality, lower cost, and yields better health outcomes.

**Care Complexity.** Evidence-Based Medicine and the Changing Nature of Health Care explores the forces, such as genetic insights and increasing care complexity, driving the need for better new medical evidence; the challenges for patients and providers; and the legislative and policy changes required for an evidence-based, learning system.

**The Data Utility.** Clinical Data as the Basic Staple of Health Learning: Creating and Protecting a Public Good identifies the transformational prospects and policy imperatives for large interoperable clinical and administrative datasets to allow real-time discovery on issues ranging from disease etiology to personalized diagnosis and treatment.

**Digital Platform.** Digital Infrastructure for the Learning Health System: The Foundation for Continuous Improvement in Health and Health Care explores the revolutionary potential for improving health and health care through information technology systems, and identifies necessary policy priorities.

**Patients & the Public.** Patients Charting the Course: Citizen Engagement and the Learning Health System assesses the strategies for improving health needs, preferences, understanding, and support, and mobilizing them as agents of change.

**Value.** Value in Health Care: Accounting for Cost, Quality, Safety, Outcomes, and Innovation explores alternative perspectives and approaches for defining, estimating, and attaining value in health care, including case studies on value-enhancing strategies in development, and emphasizing the basic need for broad transparency as to cost, quality, and outcomes in care.

**Leadership.** Leadership Commitments to Improve Value in Healthcare: Finding Common Ground presents commitments from those in key health stakeholder sectors—patients, clinicians, health organizations, insurers, product manufacturers, employers, government, IT, and researchers—on priority actions they will undertake to transform quality and value in health care.
Making a Difference ... in stewarding action

IOM Innovation Collaborative Projects

Best Practices

Evidence Communication

Digital Learning

Clinical Effectiveness Research

Value Incentives

Systems Approaches for Health

Professional societies and organizations
Marketing experts and decision
Health IT and care delivery experts
Research scientists and institutions
Health care purchasers and payers
Medical, engineering, and IT leaders

VALUE: Transparency & continuous improvement

• System culture and incentives
  • Science of outcomes and cost measurement

  CEO checklist for high-value care
  Inventory of key value innovation projects
  Pilots evaluation for scale-up in value innovation
  Digital utility for clinical decisions at the point of care
  Team-based care principles and expectations
  Systems strategies for health and health care
  Core measures for engaged people, quality care, lower cost, better health
  Determining core expectations for ACOs

SCIENCE: Evidence & continuous learning

• Real-time knowledge generation
  • Infrastructure stewardship

  Comparative effectiveness research (CER) strategies
  Clinical data use for new insights: case studies
  Large simple trials to streamline clinical research
  Observational studies in clinical effectiveness research
  Improving data quality for continuous health learning
  Common Rule update assessment
  Data-driven medicine science and strategy innovation
  Return on Information systems investments (ROI)
  Harmonizing COI disclosure

CULTURE: People & continuous engagement

• Engaged people
  • Communication strategies

  Evidence communication improvement
  Patient-clinician communication principles and expectations
  Patient views on clinical data sharing for care improvement
  Patients’ roles as team members
  Patients and families partnering for best care at lower cost
  IOM LHS Commentaries
  IOM Consensus Recommendations: Best Care at Lower Cost
Making a Difference ... by informing policy

Policy Milestones*

- Ongoing health transformation and ACA implementation
- ABIM “Choosing Wisely” program (2012)
- NIH Health Care Systems Research Collaboratories (2012)
- Partnering with Patients established (2011)
- Patient-Centered Outcomes Research Institute (PCORI) launched (2011)
- ONC Federal HIT Strategic Plan and Meaningful Use Requirements (2011)
- CMS announces first Accountable Care Organization (ACO) grants (2011)
- National Public Health Improvement Initiative (2010)
- CMS Innovation Center (CMMI) established (2010)
- Affordable Care Act (ACA) passed (2010)
- VA BlueButton Initiative established (2010)
- HHS launches Data.gov (2009)
- American Recovery and Reinvestment Act (ARRA) passed (2009)
- AHRQ Effective Health Care Program established (2009)
- FDA Sentinel System initiative announced (2008)
- Joint Principles for the Patient-Centered Medical Home (2007)
- Triple Aim initiative announced by IHI (2007)
- NIH Clinical & Translational Science Award program (2006)
- DOD/AHRQ TeamSTEPPS initiative (2006)
- RWJF begins Aligning Forces for Quality (2006)
- Commonwealth Commission on High Performing Health Care (2005)
- NQF releases Serious Reportable Events (2002)

IOM Contributions**

- Ongoing work of IOM Innovation Collaboratives (2013 + ...)
  - Value and continuous improvement
  - Science and continuous learning
  - Culture and public engagement
- IOM and NAE form Collaborative on Systems Approaches for Health (2012)
- Best Care at Lower Cost published (NAP, 2012)
- CEO Checklist for High-Value Health Care released (IOM, 2012)
- Core Principles & Values of Effective Team-Based Care released (IOM, 2012)
- Common Rule & Continuous Health Care Improvement released (IOM, 2011)
- Essential Health Benefits: Balancing Coverage & Cost published (NAP, 2011)
- Patient-Clinician Communication Principles and Expectations (IOM, 2011)
- IOM series on the digital infrastructure for the learning health system (2010)
- Redesigning the Clinical Effectiveness Research Paradigm (NAP, 2010)
- IOM series on value and unnecessary costs in health care (2009)
- Initial National Priorities for Comparative Effectiveness Research (NAP, 2009)
- IOM forms Innovation Collaborative on Clinical Effectiveness Research (2009)
- Evidence-Based Medicine and Changing Health Care (NAP, 2008)
- Evidence-Based Medicine and Changing Health Care (NAP, 2008)
- IOM forms Innovation Collaborative on Digital Learning (2008)
- IOM forms Innovation Collaborative on Evidence Communication (2007)
- IOM begins initiative on the Continuous Learning Health Care System (2007)
- Crossing the Quality Chasm (NAP, 2001)
- To Err is Human (NAP, 2000)

* Examples

** Roundtable and Roundtable-related IOM activities
Roundtable-generated publications

Books

Best Care at Lower Cost (National Academies Press) 2012. *
Digital Data Improvement Priorities for Continuous Learning in Health and Health Care (National Academies Press), 2012.
Patients Charting the Course (National Academies Press), 2011.
Redesigning the Clinical Effectiveness Research Paradigm (National Academies Press), 2010.
Value in Health Care (National Academies Press), 2009.

Discussion Papers

Peter Hussey et al. From Pilots to Practice: Speeding the Movement of Successful Pilots to Effective Practice, 2013.
Sally Okun et al. Making the Case for Continuous Learning from Routinely Collected Data, 2013.
Pamela Mitchell et al. Core Principles & Values of Effective Team-Based Health Care, 2012.
Margaret O’Kane et al. Demanding Value from Our Health Care, 2012.

Journal Articles


Commentaries

2013
Risa Lavizzo-Mourey (RWJF), Treating a Chronic Condition: Efforts to Reduce Avoidable Readmissions at U.S. Hospitals
George Thibault (Macy), Forging Collaboration Within Academy and Between Academy and Health Care Delivery Organizations
Karen Daley (ANA), A Continuously Learning Health System in the United States
Leah Binder (Leapfrog Group), A Few Nudges for the Choosing Wisely Campaign
Christine Casrel (ABIM), Choosing Wisely: Grounded in Physician Professionalism
Richard Platt (Harvard University) A Win for the Learning Health System
Toby Cosgrove (Cleveland Clinic), Transparency: A Patient’s Right to Know
Davis Kirch et al. (AAMC), Achieving Clinical Quality and Patient Safety
Joseph Fifer (HFMA), Creating High-Value Health Care Consumer
Scott Armstrong et al. (Group Health), Creating Culture to Promote Shared Decision Making at Group Health
Bruce Siegel (NAPH), Improving Quality and Patient Safety for Vulnerable Populations
Aaron Wernham (Pew), Ounces of Prevention

2012
Martin Kohn (IBM), Analytics in Support of Health Care Transformation
Georges Benjamin (APHA), Transforming the Public Health System: What Are We Learning?
Gary Kaplan (Virginia Mason), The Lean Approach to Health Care: Safety, Quality, and Cost
Patrick Conway (CMS), Rapid Evidence Adoption to Improve Health Outcomes
Glen Steele et al. (Geisinger), Improved Patient Outcomes in 3 Years
William H. Frist (Vanderbilt), Personalized Medicine: Innovation to Clinical Execution
Rita Redberg (UCSF), Less Is More
Denis Cortese et al. (ASU), The First Step Toward Value-Based Health Care
Carolyne Clancy (AHRQ), More Hospitals Begin to Apply Lessons from Seven Pillars Process
Helen Darling (NBGH), Improving ROI in Health Care by Reducing Overuse and Mistake
Patricia A. Gabow (Denver Health), The Promise of Lean Processes
John Halama (Harvard), Our Learning Health Care System Journey
Janet M. Corrigan et al. (NQF), A Glide Path to High-Value Health Care
Farzad Mostashari (ONC), Applying Innovation to the Work of Government
Paul Grundy (IBM), Bringing Knowledge Home
William Bornstein et al. (Emory), Care Transformation at Emory Hospital
Susan A. Schroeder (UCSF), Trying to Practice What I Preached
David Feinberg et al. (UCLA), Healing Humankind One Patient at a Time
Bruce Bodaken (Blue Shield of California), A Path to Accountable Care
Rich Umbdenstock (AHA), Continuous Adoption of Best Practices: The New Normal
Robert A. Petzel (Veterans Affairs), Surgical Complexity Initiative
Tom Daschle (DLA Piper), Controlling Costs: A Distinction and Our Choice
Mark Chassin (Joint Commission), Taking Aim at the Right Targets
George Halvorson (Kaiser Permanente), Walking Our Way to Better Health
Donna E. Shalala (University of Miami), Free Employee Flu Shots Pay Prevention Dividends
Sheri McCoy (Avon, formerly J&J), Innovating to Improve Care and Manage Costs
Leonard D. Schaeffer et al. (USC), Benefit Design Should Reflect Value

Roundtable-generated digital footprint

Website views (2012): IOM Roundtable (33,000); Best Care at Lower Cost (129,000)
Document downloads (2012): Roundtable Books (30,724); Best Care at Lower Cost (17,212 as of 2012)*

*including NAS single-day record and more read report last quarter 2012
Making a Difference ... by engaging broadly

Participant community*

- AAMC
- AARP
- AcademyHealth
- Aetna
- Agency for Healthcare Research and Quality
- Albert Einstein College of Medicine
- Alcoa
- Alfscipts
- Altarum Institute
- America’s Health Insurance Plans
- American Academy of Dermatology
- American Academy of Family Physicians
- American Academy of Neurology
- American Academy of Nurse Practitioners
- American Academy of Nursing
- American Academy of Orthopaedic Surgeons
- American Academy of Pediatrics
- American Academy of Physician Assistants
- American Association of Colleges of Nursing
- American Association of Nurse Anesthetists
- American Board of Internal Medicine
- American College of Cardiology
- American College of Clinical Pharmacy
- American College of Nurse-Midwives
- American College of Obstetrics and Gynecology
- American College of Physicians
- American College of Preventive Medicine
- American College of Surgeons
- American Diabetes Association
- American Enterprise Institute
- American Geriatrics Society
- American Health Information Association
- American Heart Association
- American Hospital Association
- American Institutes for Research
- American Journal of Public Health
- American Medical Association
- American Medical Group Association, Inc.
- American Medical Informatics Association
- American Nurses Association
- American Osteopathic Association
- American Psychiatric Association
- American Society for Clinical Oncology
- American Society of Clinical Oncology
- American Thoracic Society
- American Urological Association
- Angen, Inc.
- Anthem
- APPO/Worldwide
- Applied Physics Laboratory
- Apractis Solutions
- Argonne National Laboratory
- Arizona State University
- Arnold & Porter, LLP
- Arthritis Foundation
- Ascension Health
- Association for Nursing Professional Development
- Association of Academic Health Centers
- Association of Clinical Research Organizations
- Association of periOperative Registered Nurses
- AstraZeneca
- AthenaHealth
- Bates White
- Baylor College
- Belk Island Deaconess Medical Center
- Bipartisan Policy Center
- BJHC HealthCare
- Blue Cross and Blue Shield State Associations
- Blue Shield of California
- Blue Shield of California Foundation
- Booz Allen Hamilton Inc.
- Boston Consulting Group
- Boston Scientific Corporation
- Brandeis University
- Bridges to Excellence
- Brigham and Women’s Hospital
- Bristol-Myers Squibb Company
- British Medical Journal
- Broad Institute
- Brookings Institution
- Brown University
- Burroughs Wellcome Fund
- California Health and Human Services
- California HealthCare Foundation
- California Technology Assessment Forum
- Cancer Commons
- CareEvolution
- Carnegie Mellon University
- C-Change
- Cedars-Sinai Medical Center
- Center for Advancing Health
- Center for Connected Health
- Center for Democracy & Technology
- Center for Healthcare Decisions
- Center for Healthcare Quality & Payment Reform
- Center for IT Leadership
- Center for Medical Technology Policy
- Center for Outcomes Research & Evaluation
- Center for Studying Health System Change
- Centers for Disease Control and Prevention
- Centers for Medicare & Medicaid Services
- Center for Health Care Innovation
- Charina Endowment Fund
- Childbirth Connection
- Children's Hospitals (various, nationwide)
- CIGNA
- Citigroup
- City University of New York
- Cleveland Clinic
- Clinical Data Interchange Standards Consortium
- Cobb Institute
- Cochrane Collaboration
- Columbia University
- Commonwealth Fund
- Community Advocates
- Community Care of North Carolina
- Community Health Center, Inc.
- Congressional Budget Office
- Consumers Union
- Cornell University
- Corporation for National Research Initiatives
- Council for Affordable Quality Healthcare
- Council of Accountable Practice
- Council of Medical Specialty Societies
- Coviden
- Critical Path Institute
- Dartmouth-Hitchcock Health System
- Deloitte Consulting
- Denver Health & Hospital Authority
- Department of Defense
- Department of Health and Human Services
- Department of Veterans Affairs
- DMAC: The Care Continuum Alliance
- Dossia Consortium
- Duke University
- ECRI Institute
- eHealth Initiative
- Eli Lilly and Company
- Emory University
- Epic Systems, Inc.
- Food and Drug Administration
- Geisinger Health System
- General Electric Company
- George Washington University
- Georgetown University
- GlaxoSmithKline
- Google, Inc.
- Gordon and Betty Moore Foundation
- Government Accountability Office
- Group Health Cooperative
- Harvard University
- Hastings Center
- Health 2.0
- Health Affairs
- Health Evolution Partners
- Health Privacy Project
- Health Resources and Services Administration
- Healthcare Financial Management Association
- Healthcare Leadership Council
- HealthPartners
- Healthwise
- Henry J. Kaiser Family Foundation
- Hospital Corporation of America, Inc.
- IBM
- Indian Health Service
- Informmed Medical Decisions Foundation
- Institute for Clinical Systems Improvement
- Institute for Healthcare Improvement
- Institute for Healthcare Operational Excellence
- Intel Corporation
- Intermountain Healthcare
- Johnson & Johnson
- Joint Commission
- Journal of the American Medical Association
- Kaiser Permanente
- Kaner Family Foundation
- Leapfrog Group
- Lewin Group
- Marshfield Clinic
- Massachusetts Group Insurance Commission
- Massachusetts Institute of Technology
- Massachusetts Medicaid Program
- Mayo Clinic
- McKesson Corporation
- McKemey & Co.
- Medco Health Solutions, Inc.
- Medicare Payment Advisory Commission
- MedStar Health
- Medtronic, Inc.
- Memorial Sloan-Kettering Cancer Center
- Merck Research Laboratories
- Microsoft
- Milbank Memorial Fund
- MITRE Corporation
- National Academy for State Health Policy
- National Association of Insurance Commissioners
- National Association of Medicaid Directors
- National Business Group on Health
- National Committee for Quality Assurance
- National eHealth Collaborative
- National Governor’s Association
- National Health Policy Forum
- National Institutes of Health
- National Partnership for Women & Families
- National Patient Safety Foundation
- National Quality Forum
- National Science Foundation
- Nemours
- New England Journal of Medicine
- New York Academy of Medicine
- Northwestern University
- Novo Nordisk Inc.
- Observational Medical Outcomes Partnership
- Office of the National Coordinator for Health IT
- Ohio State University
- Palo Alto Medical Foundation
- Partners HealthCare
- Patient-Centered Outcomes Research Institute
- PatientsLikeMe
- Permanente Federation
- Peter G. Peterson Foundation
- Pfizer, Inc.
- Premier, Inc.
- Public Health Informatics Institute
- Quintiles
- RAND Corporation
- Regenstrief Institute, Inc.
- Research!America
- Rhode Island Quality Institute
- Robert Wood Johnson Foundation
- RTI International
- Sanofi US
- Service Employees International Union
- Siemens Healthcare
- Society of General Internal Medicine
- Society of Thoracic Surgeons
- Stanford University
- Stryker
- ThedaCare Center for Healthcare Value
- United Biosource Corporation
- UCLA
- UnitedHealth Group
- UnitedHealth Foundation
- University of Arkansas
- University of California (Irvine)
- University of California (San Francisco)
- University of Chicago
- University of Iowa
- University of Miami
- University of Michigan
- University of Minnesota
- University of Missouri
- University of Pennsylvania
- Urban Institute
- U.S. Preventive Services Task Force
- Value Captive
- Vanderbilt University
- Vermont Blueprint for Health
- Virginia Mason Health System
- Walgreen Co.
- WebMD
- WellPoint, Inc.
- WestWireless
- White House Office of Science & Technology Policy
- Yale University

* Examples of organizations lending expertise to the work through active participant involvement in the Roundtable and its Innovation Collaboratives, including as members, planning committee members, speakers, authors, chairs, reviewers, and project program staff. A complete, ongoing list is available here: iom.edu/vsrt_participantcommunity.
Communicating with Patients on Health Care Evidence

Chuck Alston, Lyn Paget, George Halvorson, Bill Novelli, Jim Guest, Patrick McCabe, Karen Hoffman, Christopher Koepke, Melissa Simon, Sharyn Sutton, Sally Okun, Paul Wicks, Tresa Undem, Valerie Rohrbach, and Isabelle Von Kohorn*

September 2012

*Participants in the Evidence Communication Innovation Collaborative of the IOM Roundtable on Value & Science-Driven Health Care

The views expressed in this discussion paper are those of the authors and not necessarily of the authors’ organizations or of the Institute of Medicine. The paper is intended to help inform and stimulate discussion. It has not been subjected to the review procedures of the Institute of Medicine and is not a report of the Institute of Medicine or of the National Research Council.
http://www.iom.edu/evidence.
Communicating with Patients on Health Care Evidence

Chuck Alston, MSL Washington; Lyn Paget, Informed Medical Decisions Foundation; George Halvorson, Kaiser Permanente; Bill Novelli, Georgetown University; Jim Guest, Consumers Union; Patrick McCabe, GYMR; Karen Hoffman, Consumer Reports National Research Center; Christopher Koepke, Centers for Medicare & Medicaid Services; Melissa Simon, Northwestern University; Sharyn Sutton, Social Enterprise Consultants; Sally Okun, PatientsLikeMe; Paul Wicks, PatientsLikeMe; Tresa Undem, Lake Research Partners; Valerie Rohrbach, Institute of Medicine; and Isabelle Von Kohorn, Institute of Medicine

Our aim is to accelerate the routine use of the best available evidence in medical decision making by raising awareness of and increasing demand for medical evidence among patients, providers, health care organizations, and policy makers. This paper is the product of individuals who have worked to develop principles and strategies to guide evidence communication among providers and patients, communication that holds the potential to yield better care, better health, and lower costs. The authors are participants drawn from the Evidence Communication Innovation Collaborative (ECIC) of the Institute of Medicine (IOM) Roundtable on Value & Science-Driven Health Care, which seeks to improve public understanding, appreciation, and evidence-based discussion of the nature and use of evidence to guide clinical choices. The Collaborative is inclusive—without walls—and its participants include communication experts, decision scientists, patient advocates, health system leaders, health care providers, and more.

THE LEARNING HEALTH CARE SYSTEM AND EVIDENCE COMMUNICATION

The charter of the IOM Roundtable on Value & Science-Driven Health Care envisions a learning health care system and states that “by the year 2020, 90 percent of clinical decisions will be supported by accurate, timely, and up-to-date clinical information, and will reflect the best available evidence.” A continuously learning health system can deliver truly patient-centered care only when patient preferences—informed by medical evidence and provider expertise—are elicited, integrated, and honored. Shared decision making is the process of integrating patients’ goals and concerns with medical evidence to achieve high-quality medical decisions. A 2011 Cochrane systematic review of 86 clinical trials found that patients’ use of evidence-based decision aids led to a) improved knowledge of options; b) more accurate expectations of possible benefits and harms; c) choices more consistent with informed values; and d) greater participation in decision making. Providing patients with clearly-presented evidence has been shown to impact choices, resulting in better understanding of treatment options and screening recommendations, higher satisfaction, and choices resulting in lower costs. Simply stated, engaging patients in their own medical decisions leads to better health outcomes.

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1 Participants in the Evidence Communication Innovation Collaborative of the IOM Roundtable on Value & Science-Driven Health Care.

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Unfortunately, people often have poor knowledge of key facts about important health decisions they make, and there are important differences between what providers think patients should know and what patients want to know.\textsuperscript{6,7,8} Furthermore, implementation of shared decision making is low in the United States. A national survey of adults asked about the experiences of people who considered at least 1 of 9 preference-sensitive medical decisions involving medications, surgery, or screening. The study found that health care providers made a recommendation 8 out of 10 times, and that the clinician recommendation was most often in favor of the intervention—in approximately 90 percent of medication decisions, 65 percent of elective surgery decisions, and 95 percent of cancer screening decisions. Patients also reported that they were not routinely asked about their preferences. Providers’ elicitation of patient preferences was lowest for cancer screening (about 40 percent of the time) and highest for knee-/hip-replacement surgery (80 percent of the time). Health care providers nearly always discussed the “pros” of the intervention (more than 90 percent of the time) but infrequently discussed the “cons” or reasons not to take action, though there was a wide range (20 percent for breast cancer screening versus 80 percent for lower back surgery).\textsuperscript{9}
Communicating the importance of medical evidence and a balanced representation of options is the first step toward accelerating patient engagement in shared decision making. Currently, reporting and interpretation of medical evidence are patchy at best and commonly biased, inaccurate, and confusing. At the same time, data show that the public fears that reliance on medical evidence will limit treatment options and jeopardize freedom of choice, limit what insurance will pay for, and lower the quality of care. This paper updates the evaluation of people’s expectations and describes communication strategies and messages that are effective in raising awareness about—and driving demand for—high-quality, shared medical decisions.

Foundational to the discussion in this paper is the first finding (see page 6)—that people want deep and meaningful involvement in medical evidence and decision making. As shown in Figure 1, people want to be listened to and want the full truth from their health care providers, including information about the diagnosis and the risks and impact of treatment options.

**ELEMENTS OF HIGH-QUALITY MEDICAL DECISIONS**

Achieving high-quality medical decisions requires multiple components. First, people must have timely access to the best available medical evidence. Second, providers must provide sound counsel based upon their clinical expertise and without bias. Lastly, the patient’s and family’s preferences (goals and concerns) must be actively elicited and fully honored. This multi-faceted decision-making process recognizes that, in most cases, there is no “right” decision. The answer to any given medical question is patient-specific; it depends upon the medical evidence, the providers’ clinical expertise, and the unique and individual preferences of the patient and family.

**Figure 1. People want involvement in evidence and decisions**

*Bars show the percent of people surveyed who strongly agree with the statement: “I want my provider…”*
To engage patients as equal partners in shared decision making, a strong effort is needed to improve understanding of the important role of medical evidence. Most patients cannot recall a time when their care provider discussed scientific evidence as the basis for better care, yet, a majority of patients do want to know and talk about the options that are available to them—regardless of whether they ultimately make the final decisions regarding their care. High-quality communication is embedded in the foundation of increasingly popular collaborative care models that promote shared decision making (including the patient-centered medical home, accountable care organizations, and care coordination teams). The concept of evidence in a medical context means different things to different people. For some, the evidence about a treatment, including its risks and benefits, is foundational to making sound medical decisions. For others, it is feared as a harbinger of “cookie-cutter medicine.” Evaluating evidence is the heart of comparative-effectiveness research, which aims to determine what is proven to work best in medicine yet was equated with rationing in the debate over health reform. Public discourse about evidence may generate fear that carries over into medical encounters. Important conversations about medical evidence that include risk and benefit to patients in a meaningful manner cannot happen without effective, evidence-based methods to communicate that evidence.

**APPROACH**

The work described in this discussion paper took place over several years in three distinct phases which built upon each other. In the first phase, participants in ECIC worked with RTI International to conduct an environmental scan to understand ongoing efforts to raise awareness about the importance of evidence in medical decision making. The environmental scan led to the development of a framing concept that was refined by ECIC participants. In the second phase, participants sought to understand the applicability of this framing concept to people experienced in medical decision making—those with at least one disease—and to develop a specific message concept and language to improve understanding, appreciation, and discussion among patients and providers on the use of medical evidence to guide clinical choices. To achieve the goals of the second phase, GYMR Public Relations, working in partnership with Lake Research and MSL Washington, conducted individual interviews and focus groups in fall 2011 in three U.S. cities and subsequently developed preliminary messaging for various stakeholders to use when talking about evidence. Finally, in the third phase, participants fielded a nationally representative poll of U.S. adults to quantify the prevalence of the attitudes, beliefs, and preferences uncovered in the qualitative research and compared proposed messaging language. The poll was designed by ECIC participants in conjunction with Consumer Reports, which conducted the survey in March 2012 using the Knowledge Networks online polling service.

**FRAMING THE MESSAGE: ENVIRONMENTAL SCAN AND QUALITATIVE RESEARCH RESULTS**

The environmental scan revealed that the focus of most campaigns to raise awareness about and increase demand for medical evidence was general in nature. Examples include the Agency for Healthcare Research and Quality’s “Questions are the Answer” campaign and the Joint Commission’s “Speak Up” patient-safety initiative. The research revealed the importance of seating more specific campaigns about medical evidence within the context of a clinical encounter that takes into account three vital—and equally important—elements: the expertise of
the provider, the medical evidence, and the patient’s preferences (goals and concerns). These three aspects—which we depict as three separate but interlocking circles that, when combined, result in an informed medical decision—were posited to be the best framework for raising awareness about the role and importance of medical evidence for future communication and patient-engagement strategies.

We tested the applicability and acceptability of the three aspects of informed medical decisions during the second phase using individual interviews and focus groups with patients. The GYMR Public Relations report to ECIC presented refined messages designed to raise awareness about medical evidence, to which focus group participants responded positively. Key themes that emerged from the interviews and focus groups included that people want to be involved in treatment decisions, want their options to be clearly communicated, and expect the truth—the whole truth—about their diagnoses and treatments. The framing language that resonated best with patients in the interviews and focus groups to explain the importance of medical evidence was

**Making sure you get the best possible care starts with you and your doctor making the best decision for you. Your doctor can help you understand what types of care work best for your condition, based on medical evidence. Because there are always new treatments, doctors use this evidence to keep up with which work best. Your doctor’s experience helps him or her evaluate and apply the evidence to your situation. The doctor also needs to listen to you so he or she understands your values, preferences, and goals. This is important because every patient is different, and when there are options, it is important for the doctor to know what is important to you.**

The second-best framing language was

**When you and your doctor sit down to talk about what tests or treatments to do, the conversation should involve the best medical evidence. But the research is constantly changing as we learn more, so the recommendations may change over time, too. As new treatments are developed, they are compared to the ones that exist today to determine if they’re really better. This is all part of the process of continuously improving our health care choices.**

The elements from the framing languages that were key in successful messages include framing messages in a positive way, embedding discussions of medical evidence in the context of a strong relationship with a trusted provider, using language that conveys to patients that the
focus is on them, and expressing that the goal is to provide patients with the best possible care. Specific phrases that were particularly effective included

- **Making sure you get the best possible care starts with you and your doctor making the best decision for you**
- **Understand the best types of care based on the most recent medical evidence**
- **Your doctor needs to listen to you, understand your needs and concerns, and answer your questions**
- **Every patient is different**

**QUANTIFYING THE IMPACT: NATIONAL SURVEY RESULTS**

In the third phase of research, we sought to quantify the impact of the three aspects of informed medical decisions, as well as specific message concepts. We surveyed a nationally representative sample of 1,068 U.S. adults who had seen at least one health care provider in the previous 12 months. The majority of those surveyed (88 percent) identified a physician as their main health care provider, and 68 percent indicated that they were satisfied with their main health care provider. A full description of the sample is shown in the Appendix.

With regard to communication of medical evidence, we had five main findings:

- First, we found that people desire a patient experience that includes deep engagement in shared decision making.
- Second, we discovered a gap between patients’ desire for engagement in their own health care and what they say is actually happening in clinics and hospitals across the country with regard to the process of decision making, communication, and the role of patient preferences.
- Third, we found that people want but do not experience coordinated health care designed to promote communication and shared decision making.
- Fourth, we found that people who were more engaged uniformly reported a better experience—specifically, greater satisfaction with their health care provider.
- Finally, we quantified people’s preferences for how to discuss medical evidence.

**A Desire for Deep Engagement**

We looked at a number of characteristics of patient engagement and found that people desire deep engagement in the process and content of decision making, including respectful communication that acknowledges goals and concerns, detailed discussion of evidence and options, and clear involvement in weighing the options.

**Respectful Communication That Acknowledges Goals and Concerns**

Respondents clearly view communication as a two-way conversation with their provider, with an emphasis on active listening and adequate time. Those surveyed strongly agreed that they expect their provider to listen to them (82 percent), and would prefer that their provider take the time to understand their goals and concerns (54 percent). Interestingly, in both of these areas there was a significant gender difference, with women indicating stronger preferences than men for listening (87 versus 77 percent [p<0.05]) and elicitation of goals and concerns (60 versus 48
percent \( p<0.05 \)). Importantly, only 59 percent described themselves as “extremely comfortable” with asking questions of their provider, and just 57 percent described themselves as “extremely comfortable” with telling their provider if they don’t understand something. This discomfort indicates that it remains essential for providers and their institutions to shape an environment of open, meaningful communication about medical evidence.

Discussion of Evidence and Options

The vast majority (80 percent) of people strongly agreed that they expect their health care provider to tell them the full truth about their diagnosis, even though it may be uncomfortable or unpleasant to hear at the time. More than two-thirds (69 percent) said they want their provider to tell them the risks of the treatment options so they will know how each might affect them, and 65 percent want to hear about each option’s potential impact on quality of life. More than half (53 percent) wanted to know about each option’s cost to themselves and their family. Almost half (47 percent) of those surveyed said that they want their health care provider to discuss the option of not pursuing a test or treatment, and an additional 41 percent said they “somewhat agreed” with this statement. When it comes to making decisions, though, just one-quarter of patients said that their provider told them where to get more information to help them decide, and only 5 percent said that their provider gave electronic information. Unsurprisingly, 30 percent of people said they “very often” get health information from a source other than their health care provider. The most common sources were their spouse or partner (15 percent), the Internet (9 percent), and a friend or family member who works in health care (6 percent).

Involvement in Weighing the Options

People indicated that although they desire a trusting, respectful relationship with their provider in which the evidence and options are discussed, they do not want their provider to filter the options or make choices for them. The majority of people agreed (52 percent “strongly” and 38 percent “somewhat”) that they want to be offered choices rather than having their provider offer only the option he or she recommends. Only 17 percent of people said that they preferred to know only the options that their provider feels are right for them based on his or her experience. Importantly, the preference for involvement did not vary significantly by gender, age, income, race or ethnicity.

The Gap Between Expected and Actual Engagement in Health Care

We found a distinct disconnect between what patients want in a medical encounter and their actual experiences of communication, discussions of the evidence, and involvement in the decisions during the course of their health care. Sixty-one percent strongly agreed that their provider listens to them. Half strongly agreed that their provider explains the risks of their options. Yet, only 36 percent strongly agreed that their provider clearly explains the latest medical evidence. Less than half (47 percent) said that their provider takes into account their goals and concerns, and only 37 percent said that their provider explains the option of not pursuing a test or treatment. Finally, in an era of increasing complexity and need for good teamwork, less than half said they receive coordinated care. Figure 2 depicts the gap in these five key areas between what people want and what they receive in their health care.
Care Coordination for the Chronically Ill: A Lost Opportunity

To understand people’s expectations and experiences of care coordination, we asked those surveyed whether their health care providers do—or ought to—work as a team to coordinate their health care and share information about their health to be sure that they receive the right care to stay healthy. Among those who could benefit most from coordinated care—the 409 people surveyed who reported having one or more chronic conditions (38 percent of the total sample)—97 percent agreed that their care ought to be coordinated. Yet, only 54 percent of those with chronic conditions said that their care was currently coordinated. Given the health and cost savings to be gained by coordinating care for the chronically ill, this gap, shown in Figure 2b, represents an enormous lost opportunity.
The Link Between Patient Engagement and Satisfaction

In addition to quantifying the gap between the engagement people want and the engagement they get, we found that those who experienced good communication, involvement in decisions, and honoring of their goals and concerns uniformly reported being more satisfied with their care. For example, over three-quarters of those who reported that their provider used clear language and listened were satisfied with their provider, compared with less than a third of those whose provider did not use clear language or listen. Figure 3 displays the relationship between patient engagement and satisfaction in nine patient engagement–related areas. The correlation between engagement and satisfaction underscores the need to measure and provide valuable elements that are both important and meaningful in a patient’s experience.

Interestingly, those surveyed indicated that their health care provider’s in-person communication skills are more important to their satisfaction than access to digital communication vehicles such as email and online access to test results and prescription refills (and more important than even the amount of time providers spend with patients). We want to be clear that we do not believe this finding should be interpreted as a devaluation of the importance of health informatics or the transformative potential of digital technology for health care. Rather, we believe these data indicate that people desire most strongly a trusting, personal relationship with their provider in which all contributions are valued—something they apparently do not often experience.

**Figure 3. Satisfaction is linked to shared decisions**
*People who are satisfied with their health care provider are more likely to say that their provider...*

- Explains the latest medical evidence
- Explains the option of doing nothing
- Helps me make a decision after considering all the options
- Takes time to understand my goals and concerns
- Explains the benefits of my options
- Explains the risks of my options
- Explains my condition
- Is clear and uses language I understand
- Listens to me

<table>
<thead>
<tr>
<th>Satisfied with provider</th>
<th>Not satisfied with provider</th>
</tr>
</thead>
<tbody>
<tr>
<td>0%</td>
<td>20%</td>
</tr>
<tr>
<td>20%</td>
<td>40%</td>
</tr>
<tr>
<td>40%</td>
<td>60%</td>
</tr>
<tr>
<td>60%</td>
<td>80%</td>
</tr>
<tr>
<td>80%</td>
<td>100%</td>
</tr>
</tbody>
</table>
How to Discuss Medical Evidence

To understand how people feel about the three aspects of informed medical decisions, we asked people to rate the importance of 1) the providers’ clinical expertise, 2) medical evidence, and 3) their own preferences and goals. We found strong support for all three. Figure 4 shows the percentage of people who said that each part was important or very important in their health care. Patients view evidence about what works for their condition as more important than both their provider’s opinion (in second place) and their personal preferences (in third place). The differences were significant but not wide, suggesting the three parts stand well together. There was a significant gender gap on one aspect; more females indicated that their personal goals and concerns are “very important” in the decision-making process (64 percent) than males (50 percent).

Finally, to determine the specific language that can be used to communicate about medical evidence, we asked people how confident they were that a particular phrase described the information they need to make decisions about treatments with their provider. Table 1 shows the level of confidence in the six statements tested.

![Figure 4. Strong support for the three parts of informed medical decisions](image)

<table>
<thead>
<tr>
<th>Language</th>
<th>Confidence*</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is proven to work best</td>
<td>79%</td>
</tr>
<tr>
<td>The most up-to-date medical evidence, including information about the risks and benefits, about what works best</td>
<td>76%</td>
</tr>
<tr>
<td>Best practices in the medical field</td>
<td>75%</td>
</tr>
<tr>
<td>What medical science shows about each option’s benefits and risks</td>
<td>71%</td>
</tr>
<tr>
<td>What the research shows</td>
<td>68%</td>
</tr>
<tr>
<td>Guidelines developed by national medical experts about what works best</td>
<td>65%</td>
</tr>
</tbody>
</table>

* Differences of 3 percent are significant at a 95 percent confidence level.
CONCLUSIONS

We conducted research in three stages—environmental scan, qualitative interviews and focus groups, and quantitative survey—to understand Americans’ desire for and experience of engagement in medical evidence and shared decision making. We found that people want deep engagement in conversations about their health care, including detailed medical evidence. They do not want their provider to make decisions for them or offer only some of the options. It is incumbent upon providers and institutions to create the environment and provide the tools to make this possible. Furthermore, we found a gap between what people want and what they get with regard to engagement in health care. Given the health benefits and cost savings demonstrated when patients are actively involved in shared decision making about their health care, this gap represents a lost opportunity to achieve the triple aim—better care, lower costs, and better health.

In addition to wanting involvement in medical decisions, people are aware that there are benefits to care coordination and believe that their care should be better coordinated. People with chronic conditions are even more aware of this need than the general population. Given that the high costs of care for chronic conditions can be lowered through good care coordination—and that people actively want to be involved in better-coordinated care—this gap is both costly and unnecessary.

Patient experience is a focus in the health care arena today. Our data indicate that deep engagement in shared decision making is not only desired by people but is a core component of their experience as patients. Ongoing efforts should focus on the importance of measuring and providing what is important and meaningful to patients. Health care providers and others who seek to engage patients can confidently use the language provided here to describe medical evidence in a way that resonates positively with the general public. People are particularly receptive to conversations about medical evidence in the context of discussions with a trusted, expert health care provider who takes their goals and concerns into account.

INDICATED ACTIONS

The goal of this research is to accelerate the routine use of the best available evidence in medical decision making by raising awareness of and increasing demand for medical evidence among patients, providers, health care organizations, and policy makers. Our findings point toward indicated actions to help achieve this goal. We believe there are three key areas of action

<table>
<thead>
<tr>
<th>Strong Patient Support for Sharing Data to Improve Evidence: More to Come</th>
</tr>
</thead>
<tbody>
<tr>
<td>To explore willingness to share health data to build the evidence database, we asked respondents to say whether they &quot;strongly agree,&quot; &quot;somewhat agree,&quot; &quot;somewhat disagree,&quot; or &quot;strongly disagree&quot; with the statement &quot;My health data should be used to help improve the care of future patients who might have the same or similar condition.&quot; In keeping with patients' desire to interact meaningfully with information and evidence, 89 percent strongly or somewhat agreed with this statement, and just 3 percent strongly disagreed. This finding indicates that people recognize the common-sense value of sharing information to improve health and health care—and possibly that there is a thirst in the general population for care improvement through data sharing. The fact that the vast majority of respondents agreed with this statement bears further exploration, which will be undertaken by ECIC in the near term.</td>
</tr>
</tbody>
</table>
that can help ensure that every medical decision is an informed medical decision, shared between the health care provider and the patient and family.

**Cultural Changes**

To achieve the vision of care patients and families desire and deserve, it will be important to recognize and act upon the gap between what they want from their health care system and what they currently receive. Patient awareness of and engagement in the three elements of an informed decision (clinical expertise, medical evidence, and individual goals and concerns) will need to become part of the routine culture of medical decision making. This cultural shift will require that clinicians be encouraged, empowered, and motivated to facilitate informed medical decisions whenever and wherever they practice. The communications literature indicates that encouraging clinicians to adopt the practice of informed medical decision making may be most successful if they are made aware of the benefits to their patients. Within the practice environment, some tools are available to facilitate the integration of balanced presentation of information—including risks, benefits, and “unknowns”—with patients’ goals and concerns, but broader adoption of these tools is needed. The data presented here show clearly the gap between what patients want and what they get and can serve as a stimulus for activation. By coupling knowledge of the broad desire among the public for deeper involvement in health care decision making with information about existing tools—such as mobile technologies, programs in care coordination, and more—patients, families, and other advocates can help drive change with their health care providers and within their health care settings.

**Incentive Alignment and Infrastructure Support**

With the advent of new payment models focused on managing the health of populations and coordinating care comes a distinct opportunity to advance informed decision making. Patient-centered medical homes, health care exchanges, and accountable care organizations structured to embrace informed medical decision making as a central tenet will enable models of care that deliver on the promise of patient activation and engagement. To support sustainability of these models, public and private payers can provide incentives to clinicians and patients to engage in informed medical decision making.

Several opportunities exist at the institutional level to promote informed medical decisions by making the right thing easy to do. Institutions can help identify high-quality decision aids and make these easily and routinely accessible to clinicians, patients, and families. Institutions can also assist by identifying and making available time, space, and personnel to carry out the process of informed medical decision making. Within the world of health information technology, electronic health records (EHRs) hold the potential to increase patient and family engagement in health care. EHR systems designed to meet “meaningful use” criteria can advance patient and family engagement by including tools designed to promote “meaningful choice.”

A national resource to help facilitate routine use of the best information for medical decisions, including decision aids, is an electronic clinical library that will allow all caregivers and patients to have easy access to medical textbooks, journal articles, and medical protocols. High-quality care sites can feed current best practice tools, protocols, and insights into the electronic library in a context of continuous improvement and shared learning. Such an
electronic resource is possible today and should be made available to both clinicians and patients as a foundational tool for continuously improving care and increasing the proportion of medical decisions that are truly informed—and shared—medical decisions.

Quality Standards and Accountability

A widespread system designed to standardize, certify, and disseminate decision aids would help clinicians identify high-quality tools they can trust. Those who educate health professionals can empower clinicians by routinely integrating the concepts, practices, and tools of informed medical decisions into professional education. Accreditation and licensing bodies can further these efforts by building in requirements for skills in informed medical decision making. Legislatures can enact laws that recognize and promote informed medical decision making as superior to standard informed consent for treatment. Quality measures for improvement, performance, and reporting can include the process and outcomes of informed medical decision making.

Conclusion

These three areas of action will be enhanced by a deeper appreciation of how to help people understand the evidence relevant to their well-being and their care and to drive demand for that evidence. Immediate areas for research include understanding the unique perspectives of sub-segments of the American population; delving into the most effective ways of encouraging clinicians to promote informed medical decision making in the routine course of care; and providing incentives for informed medical decision making in practice.

By focusing on these target areas in patient engagement, clinician stewardship, institution and policy facilitation, and research promotion, those dedicated to improving evidence communication can realize a profound and immediate opportunity to improve the health of Americans.

REFERENCES

6. http://mdm.sagepub.com/content/30/5_supp.


## APPENDIX

### Characteristics of the Sample (N=1,068)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>513 (48)</td>
</tr>
<tr>
<td>Female</td>
<td>555 (52)</td>
</tr>
<tr>
<td><strong>Age group</strong></td>
<td></td>
</tr>
<tr>
<td>18-34</td>
<td>214 (20)</td>
</tr>
<tr>
<td>35-54</td>
<td>368 (34)</td>
</tr>
<tr>
<td>55+</td>
<td>486 (46)</td>
</tr>
<tr>
<td><strong>Race/ethnicity</strong></td>
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</tr>
<tr>
<td>White</td>
<td>762 (71)</td>
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<tr>
<td>Black</td>
<td>90 (8)</td>
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<tr>
<td>Hispanic</td>
<td>153 (14)</td>
</tr>
<tr>
<td>Other</td>
<td>63 (6)</td>
</tr>
<tr>
<td><strong>Main health care provider</strong></td>
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</tr>
<tr>
<td>Doctor</td>
<td>940 (88)</td>
</tr>
<tr>
<td>Nurse practitioner</td>
<td>51 (5)</td>
</tr>
<tr>
<td>Physician assistant</td>
<td>30 (3)</td>
</tr>
<tr>
<td>Specialist</td>
<td>25 (2)</td>
</tr>
<tr>
<td>Nurse</td>
<td>5 (0.5)</td>
</tr>
<tr>
<td>Nurse-midwife</td>
<td>3 (0.3)</td>
</tr>
<tr>
<td>Other</td>
<td>13 (1)</td>
</tr>
<tr>
<td><strong>Current state of health</strong></td>
<td></td>
</tr>
<tr>
<td>Excellent or very good</td>
<td>592 (55)</td>
</tr>
<tr>
<td>Good</td>
<td>326 (31)</td>
</tr>
<tr>
<td>Fair or poor</td>
<td>141 (13)</td>
</tr>
<tr>
<td><strong>At least one chronic condition</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>409 (38)</td>
</tr>
<tr>
<td>No</td>
<td>627 (62)</td>
</tr>
<tr>
<td><strong>Years with current health care provider</strong></td>
<td></td>
</tr>
<tr>
<td>0-5</td>
<td>495 (46)</td>
</tr>
<tr>
<td>6-10</td>
<td>246 (23)</td>
</tr>
<tr>
<td>11+</td>
<td>298 (28)</td>
</tr>
<tr>
<td><strong>Currently insured</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>913 (88)</td>
</tr>
<tr>
<td>No</td>
<td>128 (12)</td>
</tr>
<tr>
<td><strong>How often do you bring a list of questions to ask your health care provider?</strong></td>
<td></td>
</tr>
<tr>
<td>Always</td>
<td>138 (13)</td>
</tr>
<tr>
<td>Usually</td>
<td>245 (23)</td>
</tr>
<tr>
<td>Sometimes</td>
<td>363 (34)</td>
</tr>
<tr>
<td>Never</td>
<td>299 (28)</td>
</tr>
</tbody>
</table>

NOTE: numbers may not sum to 1,068 due to non-response to individual questions. Percents may not sum to 100 percent due to rounding.
Demanding Value from Our Health Care: Motivating Patient Action to Reduce Waste in Health Care

Margaret O’Kane, Kathleen Buto, Tanya Alteras, Katherine Baicker, Judith Fifield, Robert Giffin, Jim Hansen, and Robert Saunders*

July 2012

*Participants in the Value Incentives Learning Collaborative of the IOM Roundtable on Value & Science-Driven Health Care

The views expressed in this discussion paper are those of the authors and not necessarily of the authors’ organizations or of the Institute of Medicine. The paper is intended to help inform and stimulate discussion. It has not been subjected to the review procedures of the Institute of Medicine and is not a report of the Institute of Medicine or of the National Research Council.
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**Explanation of contents**: The following discussion paper includes two appendixes that are intended as companion and complementary items to the main text. They can also be used as pull-out, standalone resources for a variety of audiences.

This discussion paper can be accessed at: www.iom.edu/PatientsForValue.
Demanding Value from Our Health Care: Motivating Patient Action to Reduce Waste in Health Care

Margaret O’Kane, National Committee for Quality Assurance; Kathleen Buto, Johnson & Johnson; Tanya Alteras, National Partnership for Women & Families; Katherine Baicker, Harvard University; Judith Fifield, University of Connecticut; Robert Giffin, Covidien; Jim Hansen, Dossia; and Robert Saunders, Institute of Medicine

Health care costs have doubled as a share of the economy over the past three decades (Martin et al., 2012), causing stress on family, employer, and government budgets. Furthermore, these expenses contain substantial waste and often do not improve patient health. One important way to improve this situation is by engaging patients and the public around value. There are numerous challenges to achieving this goal, including several unanswered questions about how best to routinely approach patients on the issue. Yet, some insights are developing. First, the success of value initiatives depends on their understanding of, and connection to, patient goals, motivations, values, and aspirations. To further engage people around value requires that comparative cost and quality information is available and comprehensive enough to support individuals’ care decisions. Finally, value needs to be embedded in all aspects of health care decisions—from incentives to benefit design—to support patients and consumers as they seek to increase the value they achieve from their care. Given the size of the task, effective change will require coordinated efforts from all stakeholder groups.

WHY IS IT IMPORTANT TO ENGAGE PEOPLE IN HEALTH CARE VALUE?

In recent years, concerns have been growing about the rising cost of health care. In 2012, health care will consume an estimated 18 percent of the economy, or almost $2.8 trillion. Moreover, costs are increasing rapidly, having risen by 88 percent in the last decade (Martin et al., 2012). These rising costs stress family, employer, and national budgets. Rising health care costs have eaten away at income gains for the last decade, leaving a family’s real wages essentially flat. In the same time frame, insurance premiums for families and individuals have more than doubled (Auerbach and Kellermann, 2011). These cost problems can be quite acute for those struggling with serious medical conditions, with 40 percent of such patients reporting that health care costs are a serious financial problem for them or their families (NPR, RWJF, and Harvard, 2012). If this type of spending produced outstanding results, it could potentially be justified. However, the health care system contains substantial waste that does not improve patient health and produces little value.

Greater engagement of patients and the public has the potential to transform every dimension of health care. This is especially true for improving health care value. Focusing care

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1 Participants in the Value Incentives Learning Collaborative of the IOM Roundtable on Value & Science-Driven Health Care. While the manuscript reflects contributions from the authors, authorship does not imply endorsement of every point expressed in the document. In addition, although the individuals who provided assistance submitted many constructive comments and suggestions, they were not asked to endorse the final draft of the discussion paper before its release.

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on patient needs can promote higher-quality care and better use of resources, which has been demonstrated in several prior studies. For example, several studies have found that patient-centered communication is associated with fewer diagnostic tests and lower costs (Epstein et al., 2005). Another study found lower use of health care services and lower overall cost with physicians who employ a patient-centered practice style (Bertakis and Azari, 2011). Furthermore, studies of shared decision making have found that patients who receive thorough information on benefits and risks tend to choose less-invasive treatments; one study found that well-informed patients were 20 percent less likely to choose surgery than other patients (O’Connor et al., 2009; Stacey et al., 2011). These examples demonstrate the impact that patients and consumers can have on improving health care value when they are involved in their own care.

Patients and consumers may be increasingly receptive to beginning a conversation about value. While most Americans are generally happy with their specific coverage and care, most also see the need for improvements to the overall system (Blendon et al., 2011; RWJF, 2011). For example, 65 percent of Americans grade the quality of their care as an A or a B; approximately the same percent rate the overall quality of American health care as grade C or below (Blendon et al., 2011). Moreover, changes in the structure of health insurance, such as the shift toward high-deductible health plans, have increased the level of costs borne directly by patients and consumers. In 2010, 30 percent of workers had an individual deductible of $1,000 or higher for their employer-sponsored insurance (KFF and HRET, 2011). On a national level, policy discussions have begun to focus on defined-contribution plans, like premium support and vouchers, amid growing anxiety about the ability to control ever-rising health care costs (Haskins et al., 2011).

Another opportunity to engage people in value lies in the growing interest in, and ability of the public to look for, information that can guide their decisions in many aspects of their lives. In a recent survey, almost 60 percent of individuals were willing and able to do detailed research before buying a car, and 50 percent do so before buying a major appliance (Lynch and Smith, 2011). While decisions in health care are different from decisions about consumer goods, there are some similar principles at play. Accordingly, there are signs that consumers are increasingly looking for health care information. In 2011, 80 percent of Internet users looked online for some type of health information (Fox, 2011). Before a doctor’s visit, patients are looking for information to help them better explain their symptoms, while after the doctor’s visit, they are looking for information to better explain what the doctor said and alternative treatment options. People’s growing interest in accessing health information presents a new opportunity for engaging conversations around value.

While certain initiatives have reported success in involving people in improving health care value, more work needs to be done to understand how to engage patients consistently. Several themes are beginning to emerge from research and practice on strategies for communicating and discussing value and applying those insights to care decisions. This paper highlights key lessons learned about engaging people in value: the need to understand what patients view as value; the need to ensure the availability, utility, and use of cost and quality information; and the need to provide more than just information to support patient value decisions. These lessons can be the basis for the continuing work that needs to be done.

Further information about ways to engage patients in value is included in Appendix A, which summarizes this information in short document intended for broad accessibility. Appendix
WHAT ARE THE KEY CHALLENGES IN INVOLVING PEOPLE IN HEALTH CARE VALUE?

Given the unsustainable path of growth in health costs, attention needs to be focused on improving health care value. Fundamentally, value is what is gained for a given cost. Yet, this simple definition is complicated by the fact that different stakeholders have different perspectives on what procedures, treatments, technologies, and care practices are valuable and how valuable they are (IOM, 2010). Given the importance of patient perspectives in the health care system, definitions of value should consider how care improves patients’ overall health, their quality of life, their experience of care, and the overall health of the public.

One challenge is that many patients and consumers are reluctant to talk about value (Hibbard and Sofaer, 2010; RWJF, 2011). In some cases, value can be perceived as a code word for rationing, implying that care may be cheapened or that patients would have less time with their clinicians (RWJF, 2011). These perceptions translate into tepid support for incentives that encourage people to consider value when selecting clinicians, health care organizations, or medical treatments.

Another challenge is that many individuals are unsure about the usefulness of detailed research into health care options. One survey found that 40 percent of people were uncertain that they could find a better-qualified doctor through detailed research while 60 percent were not confident that they could reduce the cost of health care by shopping around (Lynch and Smith, 2011). Part of the reason that many individuals believe research will not improve their health care options is the common perception that all hospitals or clinicians are of similar quality—or even that all health care meets minimum quality standards (Blendon et al., 2011; Carman et al., 2010; Hibbard and Sofaer, 2010; KFF, 2008, 2011). If quality does not vary, there is little to be gained by careful research of different health care options. Yet, multiple studies have shown that wide differences exist in the quality of care delivered by different hospitals and physicians. These quality differences occur independently of cost—sometimes better-quality care cost more, but often it costs less.

Several other challenges exist when seeking to engage patients in health care value. Unlike the decision to purchase a consumer good, health care decisions can be made under very difficult circumstances when patients are under physical, mental, and emotional stress. It is unlikely that an individual suffering a heart attack is going to research hospitals while in an ambulance. In addition, patients vary in their need to make major health decisions. In a given year, most people will use few health care services—in 2008, half of the population accounted for 3.1 percent of the total health care costs (Cohen and Yu, 2011). On the other hand, patients who deal with chronic diseases like diabetes or high blood pressure will continue to struggle with their disease for years or decades and will need to devote ongoing attention to managing these conditions. These patients will respond differently to incentives and may have different views on health care value than a patient facing an acute health care condition (Loewenstein et al., 2012). Finally, making decisions about value can be very difficult and therefore is only done by the most engaged and motivated patients (Hibbard and Sofaer, 2010). Understanding the challenges patients face is fundamental to promoting engagement in health care value.
One Patient’s Struggle to Find a Physician

Mr. A, a previously healthy 37-year-old man, suffered a heart attack 3 years ago and was diagnosed with several unusual cardiac conditions. He developed a relationship with a cardiologist at a large health center in his area and appreciated his physician’s attention to adverse effects from medication. In the spring of 2009, Mr. A’s cardiologist moved to another area, requiring him to select a new clinician for his care. As he looked for a new physician, he couldn’t find the information he wanted. He disliked the top physician lists, feeling that they weren’t asking the questions he cared about, and struggled to find basic information on many of the cardiologists in his area. Further, as his conditions were unusual, he questioned whether the general findings reported on many websites would actually apply to someone like him. His story highlights the issues that many patients have in learning about potential clinicians and the need to customize information to different patients.

SOURCE: Howell, 2009

FIRST LESSON LEARNED: UNDERSTAND WHAT PATIENTS VIEW AS VALUE

One important lesson is that the success of value initiatives depends on their understanding of, and connection to, patient goals, motivations, values, and aspirations (Rollnick et al., 2008). A person’s internal motivations can be a powerful resource for long-term change (Wiegand, 2011). This underlines the importance of discovering a patient’s goals and how they fit into the value discussion.

Misconceptions often exist about what patients view as value. In seeking to improve the patient-centeredness of care, some health care organizations and providers have focused on aspects such as food and hotel-like amenities (Rau, 2011). Yet, previous studies have found that substantial differences often exist between the factors providers believe are important to people and the factors patients identify as valuable (Hibbard and Sofaer, 2010). Summaries of this research have found that patients value many aspects of their care, including technical performance but also including other factors (Bechtel and Ness, 2010). The factors patients consider when evaluating health care can be categorized into the following groups:

- Patient-centeredness;
- Affordability and accessibility;
- Communication and information;
- Courtesy and emotional support (from all members of staff);
- Efficiency in the use of patients’ time with good coordination between all care elements;
- High technical quality; and
- Structure and facilities in which care is delivered (Sofaer and Firminger, 2005).

One theme that consistently runs through these categories is that people value a personal relationship with their clinician (RWJF, 2011). Individuals prefer a continuous relationship with someone who knows about them as a person, understands their history, and communicates with them. This type of patient-centered relationship also has been associated with positive health
outcomes. In one study, HIV patients who felt that their provider knew them as a person were more likely to take antiretroviral therapy, adhere to that treatment, and have better outcomes (Beach et al., 2006).

Another area that patients consider in their value calculus is whether their doctor stays up to date with the latest medical evidence. Focus group research has found that patients are generally supportive of medical evidence and efforts to identify the treatments that produce the best results for patients. However, research also shows that patients can become concerned about medical evidence if it is seen as limiting their options, since more care, especially newer care, can be perceived as better. Further, consumers may believe that evidence-based guidelines only apply to the average patient and are inflexible (Carman et al., 2010). Patients, therefore, weigh the interaction between options, new knowledge, and customization to their condition in deciding the value of new medical evidence.

Beyond value in medical care, there are emerging lessons about what consumers value in health insurance plans. Focus groups have found that consumers do not define value in health insurance based solely on price. Rather, consumers also account for a plan’s covered medical services and how much they would pay out of pocket for those services (Quincy, 2012).

Yet, patients are not homogeneous in their views. Opinions about value vary from state to state, from town to town, and from individual to individual. As recognized by the concept of shared decision making, the right answer for a given patient depends on his or her personal characteristics, values and goals, and support networks.

SECOND LESSON LEARNED: MAKE SURE THE BEST INFORMATION IS EASY TO FIND AND USE

Another important lesson in engaging patients in value is that comparative cost and quality information should be available and comprehensive enough to support individuals’ care decisions. Too often, beyond anecdotes and stories, individuals have little trusted information that they can use to make decisions. Even among patients who are engaged, it is frequently unclear where to go for reliable sources of information about their providers, hospitals, or health plans (Howell, 2009).

Current cost- and quality- reporting efforts have gained limited traction with the public—few people know about them, and fewer use them in making decisions (Fung et al., 2008; KFF, 2008; Lynch and Smith, 2011). One survey found that approximately 14 percent of respondents noted that they had seen and used information comparing the quality of different health insurance plans, doctors, or hospitals (KFF, 2008), while another found that less than 30 percent of individuals research potential physicians (Lynch and Smith, 2011).

Challenges in Applying Information to Care

One reason for the limited use of reported information is that information is routinely presented in a way that is not meaningful to people. Complex information that cannot be applied easily to an individual’s health care situation will not be used (Hibbard and Sofaer, 2010; Hibbard et al., 2012; Hibbard and Peters, 2003; Shaller Consulting, 2006; Vaiana and McGlynn, 2002). The presentation of the information may be as important as the information itself—the context, language, graphics, and format of information help people use it easily (Hibbard and Sofaer, 2010; Vaiana and McGlynn, 2002).
Several factors can affect whether people use reported information, such as whether they have multiple health care options in their geographic area, whether financial incentives encourage patients to seek high-value providers or health care organizations, and whether their physicians or family recommend a particular provider (Blendon et al., 2011; KFF, 2011; Lynch and Smith, 2011; Sinaiko, 2011; Sinaiko and Rosenthal, 2011; Tu and Lauer, 2009). Another factor is the salience of the presentation; statistics may not be as powerful as anecdotes or personal examples when individuals are making health care decisions (RWJF, 2010). One study found that patients presented with statistical information made different decisions than those presented with statistical information and a single contradictory anecdote—the number of patients choosing a given treatment dropped by 20 percentage points when they were given an anecdote that contradicted the statistics (Fagerlin et al., 2005). This highlights the need to deliver information in a way that resonates with people’s goals and preferences.

There are specific concerns when information is presented online. Given the ubiquity of the Internet as an information source, more health care value information is increasingly presented there. Online information is of varying quality and comprehensiveness, ranging from basic consumer reviews—where patients write about their experiences—to complex sites with objective quality and value measures which can present very technical material. Given how common review sites are in other aspects of everyday life, it is likely that their prevalence in health care is going to increase over time.

In considering online information, it is important to recognize that people from different age groups have differing interest in using online information sources for health care decisions (Lynch and Smith, 2011). When considering how to display cost and quality information online, there are several best practices gained from focus group and survey research. First, a simple, uncluttered format with easily understandable information tends to be preferred by most people. All terms should be explained clearly, especially those whose meaning depends on one’s perspective. Second, building trust is important as conflicts of interest are a common concern—individuals want to know the source of information as well as the sponsors who provided financial support (RWJF, 2010).

Another factor that influences people’s use of health information is the complexity of the information and the technical language used to describe health care options, from health plans to treatments. Understanding the terminology and concepts needed to make value decisions can be daunting, especially when that information is presented in complex and lengthy documents. These problems are compounded for the nearly half of all American adults with lower rates of health literacy (IOM, 2004). Even for those with higher levels of health literacy, focus group research finds that common health benefit terms—like deductible, co-insurance, and out-of-pocket limits—can be difficult to apply, making comparison shopping and informed selection difficult for consumers (IOM, 2012; Quincy, 2012).

In the specific case of providing cost and price information, several considerations are relevant. Without useful information about quality, consumers can equate higher cost with higher quality (Hibbard et al., 2012; Mehrotra et al., 2012). For example, one survey of California residents found that 35 percent believed higher price was associated with better care, while 65 percent assumed the care was probably about the same, regardless of price (Shannon, 2011). If this perception leads more people to seek high-cost providers, then cost reports without quality information have the potential to increase costs. To prevent this problem from occurring, cost information needs to be meaningfully integrated with information about the quality of health care services and providers to highlight that higher-quality care can be delivered at lower cost.
(Carman et al., 2010; Hibbard and Sofaer, 2010; Hibbard et al., 2012; Mehrotra et al., 2012; Sinaiko and Rosenthal, 2011).

When providing price and cost information, many patients and consumers are specifically interested in their estimated out-of-pocket cost. Yet, several factors make it difficult to provide estimates of out-of-pocket costs. It is rarely known what health care services are needed for a specific health condition; each health plan tends to use a different benefit structure with different levels of cost sharing; and the negotiated rates for services are rarely disclosed for proprietary, antitrust, or contractual reasons. As an example, in a Government Accountability Office survey of 19 Colorado hospitals, none was able to provide a complete estimate of the consumer’s cost for a full knee replacement (GAO, 2011). Without such basic information, people have little ability to seek better value.

### Finding the Price of Care

Finding the price of a particular treatment or test can be very difficult. Brad, a student from North Carolina, experienced this problem after developing a sinus infection. As Brad had a high-deductible, catastrophic insurance policy that covered only four physician visits a year, he was very concerned about the cost of treating this condition. His physician prescribed lab work and a CT scan, but Brad knew that his insurance would not cover the CT scan. At first, he asked admissions for the price. Admissions didn’t know, so they called the imaging department, which also didn’t know. Finally, admissions found the price of a sinus CT scan ($900) in a little-used black binder. Brad declined the CT scan, but went to the lab. Unfortunately, his physician had referred Brad to a lab that was out of network for his insurance. A month later, he received a bill for $478. Brad learned that when looking for medical care, even routine services, finding the cost of care is frequently the biggest challenge.

SOURCE: Shah, 2010

### Strategies for Success

These factors speak to the need to simplify information to highlight what the consumer needs to know, when they need to know it (Quincy, 2011; RWJF, 2011). To be useful for decision making, information must be available just in time, immediately understandable, and applicable to the health care situation under consideration. A study of 70 health plan report cards concluded that the most useful report cards presented information in a form that consumers could understand at a glance and then explore more deeply if interested (Cronin, 2011). Meeting this goal often requires involving people in the design of reporting schemes to understand their preferences and needs (Bechtel and Ness, 2010; Quincy, 2012; Shaller Consulting, 2006). Several other industries outside of health care have developed sophisticated methods for translating complex information to a public audience in a format that can be used for decision making. These methods can provide inspiration for new health care communication strategies that are usable and accessible to patients and the public.
As different populations have different needs, preferences, and abilities, strategies customized to meet those needs are more likely to succeed (Kling et al., 2008; RWJF, 2011; Wiegand, 2011). People vary in their ability to manage their health, the family and community resources they can draw upon for their care, and their motivations and interest to be involved in their care. Some people, including those struggling with serious conditions, are very well informed about their care options, follow clinical research, and play an active role in their care. Those patients taking an active role in their care will have different information needs (and respond to information differently) than less-engaged patients (Hibbard and Cunningham, 2008; Hibbard et al., 2004). To engage individuals who are currently less activated in health care, initiatives may need to encourage small steps, start where people are, and measure and assess their progress (Hibbard and Tusler, 2007).

Another opportunity for expanding the availability of value information is by involving clinicians in this effort. Clinicians are trusted sources of information for many patients, and people often turn to them for help in making decisions. As such, their involvement is critical in moving toward increased patient engagement. However, those clinicians, often in primary care, many times lack the information they need to help their patients with value decisions. Although such discussions require substantial time and effort, clinicians receive few incentives for undertaking these important conversations. In addition, clinicians have few practical tools at their disposal for discussing value with their patients, further limiting their ability to engage in these efforts.

Similarly, families and caregivers can play an important role in discussing value with patients. Families, friends, and caregivers are a key source of information that people use in making decisions. People often value the recommendations or opinions of friends and family over objective data about the quality of providers (Sinaiko, 2011). Further, families and caregivers can play an important role in decision making, from choosing what clinicians to visit

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**Customizing Messages Increases Their Potential Usefulness**

While information is important in itself, the more customized the information is to a particular patient, the more likely it is to be used. As an example, one study looked at how likely patients were to take a particular cholesterol medication (a statin). Some patients were given a generic guide to cholesterol, while others received feedback customized to their knowledge about cholesterol, their beliefs and values, and the barriers they identified to taking a medication. At the end of 6 months, 70 percent of the patients who received the more customized messages were still taking their medication, compared to 61 percent of those who received generic materials.

While this is a clinical example, the same principle is true for information about value. Adapting the message to an individual’s beliefs, knowledge, and goals will be more likely to succeed than offering generic information.

SOURCE: Stacy et al., 2009
to selecting treatments and scheduling physician visits. As such, they also need to be involved in value conversations and given tools they can use in having conversations with their loved ones.

**Policy Implications**

An improved understanding about how to provide health care quality and cost information has implications for several current initiatives. These include efforts to communicate health benefit information in state health insurance exchanges, especially the proposed “coverage facts label,” as those materials are designed to assist consumers in making health insurance purchasing decisions (AHIP and BCBSA, 2011; IOM, 2012; NCQA, 2012; Quincy, 2012). These also include public reporting efforts to help patients and consumers make informed selections of clinicians and health care organizations, such as Hospital Compare, Physician Compare, and private-sector initiatives. Finally, other improvement initiatives, like Partnership for Patients, depend on public engagement strategies to increase awareness and attention to patient safety.

**THIRD LESSON LEARNED: INFORMATION ALONE IS NOT ENOUGH**

A third lesson for engaging people in value is that information alone is not enough to support health care value decisions. In fact, simply supplying more information is unlikely to focus attention on health care value. Rather, multiple strategies are needed to support patients and consumers as they seek to maximize the value of their care.

One reason that multiple strategies are needed is that most health care decisions are complex and are made under considerable uncertainty. In complex situations, people tend to use rules of thumb to make decisions and tend to stick with default options (Halpern et al., 2007). In addition, in complex situations people often will delay decisions or not make them altogether, thereby staying with the status quo, if the situation becomes overly complex (Kling et al., 2008).

One example of complexity in health care decision making is in health benefit arrangements. Health benefits can often be complex, with different levels of cost sharing for different types of care. For instance, some high-deductible plans specifically provide preventive

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<th>Supporting Chronic Disease Management</th>
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<td>Many patients in America have long-term, chronic diseases, like diabetes or asthma, that require them to take medications for long periods of time. Many people stop taking their medications regularly, which can cause their disease to get worse because it’s not being treated properly. To improve this problem, Pitney Bowes redesigned its prescription drug program. It lowered the amount that employees had to pay to fill prescriptions to treat diabetes and heart disease. As a result, more employees stayed on their medications. For employees with diabetes, pharmacy costs were lowered 7 percent, emergency room visits were reduced by 26 percent, and insurance costs for diabetes patients were reduced by 6 percent. While financial incentives are only one factor affecting an individual’s health care behavior, thoughtfully designed incentives can support patients as they seek to maintain their health.</td>
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<td>SOURCE: Choudhry et al., 2010a; Mahoney, 2005</td>
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coverage and chronic care maintenance at low or no cost sharing to encourage preventive care. Yet, a recent study found that many people with high-deductible plans still use preventive services less than people with plans with lower deductibles even though preventive care is specifically exempted from the plan’s cost-sharing requirements (Beeuwkes Buntin et al., 2011). This suggests that the more complex the incentive structure, the more difficult it will be to achieve the desired effect.

**Strategies for Success**

One way to support consumer decisions about value is providing financial incentives that reward quality and value in health care. Yet, these incentives will not be successful unless they are designed with an understanding of how people actually respond to financial motivators (Loewenstein et al., 2012). For example, simply increasing the proportion of costs that are paid by patients will lower their use of health care, but may not focus attention on high-value care (Chernew et al., 2008; Choudhry et al., 2010b; Hsu et al., 2006).

Behavioral economics has shown that the way that people actually respond to incentives may be different than predicted by traditional economic theories (Loewenstein et al., 2012). In practice, people react to incentives according to several common factors that can be predicted (Volpp et al., 2009b). For example, people are adverse to loss (they have stronger feelings about losing a given amount of money than gaining the identical amount), they are optimistic about their chances of success, and they tend to focus on the present over the future. These findings have substantial implications for designing more effective health care incentives that help people meet their health and health care goals (Volpp et al., 2008a). For example, incentives that reward people in the same time frame as a given action will be more successful—an annual reward will likely not encourage someone to exercise three times a week or take a pill once a day (Volpp et al., 2008b, 2011). Rather, more frequent incentives may needed to support those types of behaviors. In short, the structure of the incentives is as important as their size. While these general rules are true, different populations respond in distinct ways to incentives, meaning that incentives need to be customized to be effective (Choudhry et al., 2010a, 2011; Volpp et al., 2009a).

**Lottery Rewards for Medication Adherence**

There are new ways to encourage people to take health-promoting actions. In a study at the University of Pennsylvania, participants at risk for stroke and bleeding were prescribed the drug warfarin and given a reminder device. The device did something else, too—it kept track of whether participants had taken their medication as planned, and then entered them into a daily lottery. The lottery structure was a 1-in-5 chance of winning $10 each day, and a 1-in-100 chance of winning $100 each day. Participants were told every day if they had won, or if they would have won if they’d taken their medication as their prescription indicated. The study found that the number of missed doses went down dramatically. Health outcomes also improved, although only during the course of the study. Why was this successful? The incentive provides quick rewards. It also incentivizes people who are averse to loss, since no one wants to miss out on winning the lottery.

SOURCE: Volpp et al., 2008b
Another strategy for success recognizes that information can be more useful if embedded into decisions, especially in default options. As noted earlier, the default option can have a big impact on patient behavior. Customizing default options makes it easier to apply quality and value information to a care situation while ensuring that individuals continue to have choice in their health care options. Several research studies have shown that thoughtful use of default options, as well as other methods of embedding information in decisions, can be effective in promoting health and high-value care (Keller et al., 2011; Wisdom et al., 2010).

Policy Implications

New forms of benefit design, such as value-based insurance design and reference pricing, seek to shape incentives according to value. The lessons learned about incentives have implications for health care payers designing consumer financial incentives, from consumer-directed health plans to tiered benefit structures to value-based insurance design. They have further implications for employers seeking to incorporate incentives in their health and wellness programs. Finally, given the importance of default options, these should be carefully considered for state health insurance exchanges, employer-based plans, and public programs.

CONCLUSIONS

Engaging and investing patients in health care value will require coordinated action from all stakeholder groups. For each stakeholder group, the three lessons learned have different implications, as noted in the list below.

Patients, Consumers, the Public

- Researchers have found that the quality and value of medical care varies substantially among doctors, hospitals, communities, and other parts of health care—even among highly reputable physicians and other providers.

Clinicians

- Different choices are appropriate for different patients, and clinicians cannot provide high-value care without engaging patients to understand their goals, values, and motivations.
- Clinicians play an important role in discussing cost and quality information with patients.

Health Care Payers (Insurers and Employers)

- Incentives have been shown to be effective if they are thoughtfully designed to reward and encourage greater value.
- Engaging patients in developing incentives can improve their effectiveness by understanding patient needs, motivations, and goals.
Consumers and patients often lack the information they need on quality and value to compare and evaluate health care options—from clinicians to treatments to hospitals. Cost and quality need to be improved overall to ensure the sustainability of the health care system. Given the size of the problem, everyone involved in the health care system—patients, doctors, hospitals, employers, and others—needs to work for a high-quality, high-value system.

Insurance exchanges offer an opportunity to promote value, provide more information on cost and quality, and offer other tools to help consumers and patients make decisions.

Research is needed to better understand effective ways to engage people around value. More research needs to be done to create practical tools that can be used by patients, their families and caregivers, and clinicians in conversations about value.
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Making the Case for Continuous Learning from Routinely Collected Data

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*Participants drawn from the Clinical Effectiveness Research Innovation Collaborative of the IOM Roundtable on Value & Science-Driven Health Care.

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Making the Case for Continuous Learning from Routinely Collected Data

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BACKGROUND

Most people who receive health care in the United States recognize that the system is complicated and fragmented. What they are less likely to know is that opportunities to learn from the care provided in hospitals, clinics, and doctors’ offices are most often lost. As health care records move to electronic systems, the data routinely collected as part of medical care (such as blood pressure measurements, weight, medications lists, disease diagnoses, and past medical histories) hold the promise to dramatically increase the opportunities for learning and improving care on a national scale. Turning data collected at the time of care into knowledge that can be used in clinical practice is essential if we are to achieve a learning health system—a system that continuously and seamlessly uses health care data from across the entire system to answer important questions that matter to patients and their health care providers.

New technologies enable the collection, storage, and analysis of vast amounts of data. As consumers we experience the impact of these “big data” every day—from smartphones that collect information about location and behaviors to Internet browsers that serve up personalized ads based on previous shopping habits. As health care becomes more digital, clinical datasets are also becoming larger and more numerous. These data, gathered largely through the normal course of receiving health care, provide great potential for extracting useful knowledge to achieve the “triple aim” in health care—better care for individuals, better health for all, and greater value for dollars spent.

We are individual participants in the Institute of Medicine’s (IOM’s) Clinical Effectiveness Research Innovation Collaborative (CERIC), an affinity group of researchers, health care providers, advocates, and government officials convened under the auspices of the IOM Roundtable on Value & Science-Driven Health Care, who come together regularly to identify gaps and opportunities to generate better evidence for making informed health care decisions. In our discussions, we have recognized that patients and the public can be effective advocates for resetting expectations that routinely collected clinical data should be used to advance knowledge and support continuous learning to ensure better care, lower costs, and improved health, and that, in fact, most feel the information is already being used in this fashion.

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1 Participants drawn from the Clinical Effectiveness Research Innovation Collaborative of the IOM Roundtable on Value & Science-Driven Health Care
In this paper, we outline the various sources of clinical data that are increasingly available for learning to better inform health and health care decisions. We explore meaningful case studies reported in the lay press of how data are being used to

- improve disease monitoring and tracking;
- better target medical services for improved health outcomes and cost savings;
- help inform both patients and clinicians to improve how they make decisions during clinical visits;
- avoid harm to patients and unnecessary costs associated with repeat testing and delivery of unsuccessful treatments; and
- accelerate and improve the use of research in routine medical care to answer medical questions more effectively and efficiently.

We expand on the critical importance of engaging stakeholders, especially the public, patients, and clinicians, to make a compelling case for the routine collection of data to support a continuously learning health system built on mutual trust and greater transparency. To help us accomplish this, we looked at examples of clinical practices, programs, and research initiatives such as the Patient-Centered Outcomes Research Institute (PCORI), the Distributed Ambulatory Research in Therapeutics Network (DARTNet), the High Plains Research Network (HPRN), and a consumer information strategy effort under way in the United Kingdom (UK).

**THE OPPORTUNITY TO LEARN FROM INCREASING SOURCES OF DATA**

The availability and reliability of large volumes of relevant longitudinal digital data from a variety of clinical and nonclinical sources are core features of a system that learns from each care experience, a *learning health system*. Common clinical repositories include data from electronic health record (EHR) systems used to manage patient care and claims data necessary for billing purposes. In some cases, data sources can be linked, using either institution-specific identifiers or matching algorithms, to create disease-specific patient registries that enable research. Integration of large pools of disparate clinical data from EHRs and claims is a major function of health information exchanges, which will be increasingly important to ensure seamless management of health information across institutions. Nonclinical sources of patient information may also include data from retail sales of over-the-counter medications, dietary supplements, walking and running shoes, and personal preferences and behaviors.

Patient-generated sources of data include patient portals, surveys, and online communities. Patient portals allow patients to access their medical records and contribute information that is often not found in the institutional records, including use of over-the-counter drugs or health care preferences. Outcomes data collected directly from patients may include important assessments of health-related quality of life and satisfaction with care. PatientsLikeMe and similar data-driven online communities provide patients with tools to collect and share their experiences of living with common disorders, like diabetes, or rare ones, like amyotrophic lateral sclerosis (ALS). Patient-reported data can offer insights into what worked and what did not, and these data can be shared with others with the same disorder. Additionally, data collected by patients between visits with their health care providers can be used to focus attention on specific symptoms, medication effects, or other issues of concern, and, with appropriate permissions, have been used to conduct research to answer important questions that matter to the patient.
community. Efforts such as the Collaborative Chronic Care Network at Cincinnati Children’s Hospital have the capability to link patients’ contributions to their health records to providers and facilities to inform their care. In addition to patient portals, there are other innovative versions of patient-centered health records that encourage patients to report not only outcomes, but also unusual reactions to medications and barriers to adherence to prescribed regimens. Eventually, much of this activity is likely to move to mobile platforms, including smartphones and tablets.

Integration of data outside the realm of clinical data (retail data) requires the use of algorithms containing personal data such as credit account information, an address, or a telephone number. Efforts to integrate large datasets have been accomplished in finance applications but have been slow to be applied to health care. There are, however, noteworthy examples that have created a building momentum for the use of routinely collected clinical data for research, surveillance, and the improvement of care in general, culminating in the development of health information exchanges in several states and in partnership with the Department of Health and Human Services’ Office of the National Coordinator. An early example of a health information exchange is the Indiana Health Information Exchange (http://www.ihie.org), which, in partnership with the Regenstrief Institute, actively pursues research in quality and safety to inform improvements in health care for the region. There are a number of examples of disparate networks of clinical data that have been brought together for research. One example of this work is the HMO Research Network, a consortium of 19 health care delivery organizations that work together to conduct research with administrative and clinical data extracted from their members’ systems. In order to do this work while preserving privacy, data are downloaded at scheduled intervals from clinical systems to the research centers and are maintained “virtually,” using standardized formats. Using this approach, the data remain behind institutional firewalls and are not stored centrally. When a question is asked that requires data from multiple partners—for example, the association of a treatment with a particular outcome—a program can be written and shared with programmers at each site and the results achieved without having to move or physically combine datasets. This distributed approach is also used by the Mini-Sentinel, a Food and Drug Administration (FDA)-sponsored safety surveillance project with the potential to monitor drugs, vaccines, devices, and other areas of FDA surveillance and regulatory concern in more than 120 million persons. These “distributed” data network approaches allow large insurance companies and integrated delivery systems to maintain control over their vast databases and at the same time contribute data to investigations of great public value.

**SUCCESES IN IMPROVING CARE AND HEALTH THROUGH THE USE OF CLINICAL DATA**

The clinical data described in the section above are of little use to anyone if they remain unanalyzed and in the same silos that characterize traditional paper records. It is in the analysis of the data, and in the application of the results, that the potential to drive continuous improvement in health lies. The questions that researchers, hospital administrators, and public health officials are asking of these data are targeted to improve safety, efficiency, and value and further our understanding to improve the health of individuals and the population.

As the availability of digital data has increased, accounts of how these data are used have appeared in professional journals as well as in the lay press. We found reports from broad-circulation newspapers, including the *New York Times*, *USA Today*, and the *Chicago Tribune*. 
These articles demonstrate the potential for the use of routinely collected clinical information to detect and respond to disease outbreaks, target medical services to those who need them most, help patients and clinicians make better decisions, avoid errors that can harm patients, and speed medical research. These concrete examples of how the use of health information can improve the lives of individuals, anchor the case for the routine collection and use of health data to drive a continuously learning health system, and suggest that public awareness of the value of routinely collected data may be increasing.

Better Surveillance and Improved Response

Regular collection and analysis of health information holds great promise for earlier detection and response during disease outbreaks. The rapidly expanding use of EHRs allows public health officials at both the federal and state levels to get a better, more rapid picture of what is happening across the country or in local communities. The _Escherichia coli_ (E. coli) cases from the Jimmy John’s restaurant’s clover sprouts in the U.S. Midwest in 2012 and the international H1N1 flu pandemic of 2009 both offer examples of how public health officials were able to use information sent electronically from hospitals to detect a pattern in disease cases. In the case of _E. coli_, it was a rash of _E. coli_ cases reported by clinical laboratories that alerted officials, and in the case of H1N1, it was a higher-than-usual number of individuals with flu-like symptoms. These incidents were then investigated more closely, and the public health response was tailored to fit the need. The pattern of the _E. coli_ outbreak was detected, and the restaurant chain promptly stopped serving sprouts, limiting the morbidity and potential mortality and the associated costs. In the case of the H1N1 pandemic, officials were able to monitor the evolution of the pandemic and keep clinicians apprised of the rise and eventual taper of cases.

Better Targeting of Health Care Services

Electronic records, including laboratory results and registries, can be used to better target the delivery of health care services. In Massachusetts, Hepatitis B cases in women of childbearing age are flagged for attention, as infection in pregnant mothers can have dire health consequences for their babies. These babies are vaccinated and their progress monitored. This approach uses the results of a routine test to place health care resources where they can have greatest impact on the health of babies, thereby preventing future medical problems and saving the resources needed to treat them. Similarly, in New York City, information from registries is used to follow patients with problematic chronic conditions, such as asthma, over time. This allows clinicians to ensure that their patients have appropriate follow-up and receive needed therapy, and also alerts clinicians when their patients have visited emergency departments or have been hospitalized. This electronic monitoring has been found to have better results than traditional paper-based systems in reducing emergency room visits and hospital admissions, saving 39 percent of costs for children and 25 percent for adults.

Improving Decision Making and Overcoming Misinformation

The use of routinely collected data provides an opportunity for analyses that can help inform health care decisions being made every day by clinicians and patients. Wider availability of this scientifically-based information can trigger discussions in doctors’ offices, hospital
rooms, and even around kitchen tables, allowing patients, clinicians, and policy makers to benefit from more informed discussions in their clinical decision making.

As an example, the analysis of Medicaid data and pharmacy files has shown that a relatively common antibiotic, azithromycin, commonly known as Zithromax, which is used to treat respiratory bacterial and mycoplasmal infections, can cause a small but significant increased risk of sudden death.\(^9\)\(^,\)\(^10\) Given the extremely wide use of azithromycin—with more than 55 million prescriptions in 2011 alone—the implications of even a small increase in risk are far-reaching. However, analysis of the data showed that this effect is most pronounced in patients at risk for heart disease. Given this information, clinicians and patients are able to make more informed choices about antibiotics to help ensure that patients with the identified risk factors are not put at unnecessary risk.

Analysis of health information can also help ground health care decisions in empirical data and counteract misinformation. A study on the real risks and benefits of vaccinating children against chicken pox, done by looking at the medical records of children treated at Kaiser Permanente Colorado, demonstrates this nicely.\(^11\)\(^,\)\(^12\) The study showed that children whose parents refused to have them vaccinated for chicken pox were nine times more likely to become infected and to require medical care. This evidence counters the misperception that refusing vaccination is without serious medical consequences.

### Avoiding Harm and Preventing Costly Errors

Perhaps nothing has catalyzed the move toward the digitization of routinely collected clinical data through EHRs more than the promise of a safer medical care delivery system. Despite both formal regulations (i.e., state requirements that hospitals report cases in which medical care harmed a patient) and voluntary measures (i.e., the FDA’s MEDWATCH system for potential medication adverse events), reporting of instances of patient harm from medical interventions often does not occur, due to both lack of awareness and administrative burden. EHRs have the potential to improve the safety of patient care by becoming a surveillance system to identify potential errors in real time, and to serve as the surveillance backbone by collecting data that can be analyzed to identify emerging issues.\(^13\) These data, collected during the course of care, require no additional burden or even knowledge of separate reporting requirements. Further, such systems can also provide patient-specific warnings, assure timely follow-up, or alert medical staff when laboratory test results suggest abnormal findings or possible adverse drug reactions. These same systems can be used to submit new and important adverse events to the relevant agency in an automated manner with little staff effort.

Few drug safety issues have garnered more attention in the public press than the arthritis medication Rofecoxib, commonly known as Vioxx—so much so that the New York Times has a free collection of their 199 articles about Vioxx on their website. The visibility of the Vioxx case in the public eye was due to the contrast between its aggressive marketing, which included a strong message of safety, and the safety questions and potential missteps that came to light after the product had been on the market for a few years. Using Vioxx as a case study, several groups have retrospectively analyzed pooled clinical trial data\(^14\)\(^,\)\(^15\) and health care claims data\(^16\) to reveal an association between Vioxx and acute heart attacks that might have been detected sooner.\(^17\) Although retrospective analyses of large databases are commonly undertaken when investigating an association between a drug and an outcome, investigators attempted to determine whether the association between Vioxx and heart attacks could have been identified.
more quickly using large health care claims databases. They concluded that they could have detected the adverse events months earlier and potentially prevented suffering and death. However, others have criticized this conclusion because the investigators had the advantage of hindsight.

**Accelerate Medical Research**

Large electronic record repositories can also accelerate the generation of evidence so that studies that once took years can be done within a matter of months, often at lower costs. For example, MetroHealth, a health system in Cleveland, Ohio, and Explorys, a health care analytics company, used a database of 14 million medical records gathered from 12 major health systems to replicate a longitudinal Norwegian study of heart disease risk. The Norwegian study followed 26,714 people, examining height and weight, among other measures, and determined that the combination of obesity and tall stature increases the risk of blood clots, especially in men. The study took 13 years. In contrast, the MetroHealth/Explorys researchers looked at the MetroHealth database, and found the same patterns within 3 months. Further, because of the larger sample size (959,030), they were able to generate more precise estimates.

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<table>
<thead>
<tr>
<th>Data Use</th>
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<tr>
<td>Better surveillance, improved response, and targeting of health care services</td>
<td>EHR data is used to track epidemics and disease (examples include <em>E. coli</em>, H1N1, Hepatitis B, and asthma)</td>
<td>Milt Freudenheim, “Fast access to records helps fight epidemics,” <em>New York Times</em>, June 18, 2012.</td>
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By learning from routinely collected health data, we believe patients and clinicians alike should be full participants in viewing every health care encounter as an opportunity to improve outcomes, not only for the individual patient, but also for others like them.
improve outcomes, not only for the individual patient, but also for others like them. Yet, although most people would not expect to be asked to participate in research as a routine part of the health care experience, over one third of respondents in a Consumers Reports survey believe that their health data is currently being used to improve care for others.\textsuperscript{21} Does this suggest that people may be willing to participate in health services and biomedical research as a public good?\textsuperscript{22} Although the answer may be yes, there is still much to be learned from patients about their understanding of what constitutes routinely collected data, how those data are used and by whom, and what protections of their data can be expected.

**Promoting and Supporting Responsible Uses of Clinical Data**

In general, surveys show that patients support provider use of electronic medical records, but they also consistently demonstrate high levels of concern about the privacy and security of electronic data.\textsuperscript{23,24} With respect to research uses of information in medical records, surveys demonstrate that “where there are safeguards to protect identity,” at least 68 percent of the public expressed willingness to allow health information to be used “to detect outbreaks, bio-terrorism attacks, and fraud, and to conduct research and quality and service improvement programs.”\textsuperscript{25} A more recent survey conducted with a nationally representative sample of adults who had at least one medical encounter in the previous year found strong support for sharing health data to improve evidence. Eighty-nine percent of respondents strongly or somewhat agreed with the following statement: “My health data should be used to help improve the care of patients who might have the same or similar condition.”\textsuperscript{26} Consequently, the adoption of privacy, confidentiality, and security safeguards by researchers appears to be key to gaining and sustaining widespread public support for research uses of clinical data. There are laws in the United States that set standards for the use of clinical data for research. The Health Insurance Portability and Accountability Act (HIPAA) privacy and security regulations govern how health care providers and health plans (and business associates performing services on their behalf) can access, use, and disclose identifiable health information, such as health plan beneficiary numbers and admission dates, for research purposes. Entities, such as universities, that receive federal tax dollars for conducting research using identifiable health data, are required to comply with the Common Rule.\textsuperscript{27} In addition, centers that provide substance abuse treatment services using federal funds are required to comply with rules that govern the use of diagnosis and treatment information that identifies (or potentially identifies) an individual as a substance abuser.\textsuperscript{28} Health care and commercial groups conducting research using identifiable health data may also be required to comply with state health privacy laws.

These laws generally require researchers to implement protections for health data used in research. Frequently, research uses of identifiable health data must first be authorized by the patient. In addition, researchers are encouraged to use data for research purposes in the least identifiable form. For example, names, addresses, and other identifying information must often be removed or made undetectable in the research data, and use of “de-identified” data for research purposes is common (see, for example, the DARTNet initiative described below). Research can also be conducted using distributed approaches like the HMO Research Network (see above), where identifiable data remains with the source but is made virtually available for analytics purposes. Such measures help ensure the availability of data for research in ways that protect the patient’s interest in confidentiality with respect to his or her health status.
There is much debate about whether the current privacy protections for data used in research are sufficient, or whether they constitute significant obstacles to more robust uses of clinical data to improve population health. Federal regulators have begun to explore modifications to research regulations to address these concerns. The timing and outcomes of those efforts are uncertain, but the need to build public trust in the use of clinical data for research is a significant and pressing priority. Building public support for research uses of clinical data will be important for satisfactory resolution of privacy and security issues.

**Examples of Successful Engagement of Patients and Other Stakeholders**

Building the case for successful engagement of the public, patients, and their health care providers can be informed by looking at examples in which routinely collected data are being used to improve processes of care delivery and health outcomes for patients and to support research that emanates routinely from point of care.

As has been suggested by Arthur Kaplan, director of the Division of Bioethics at the New York University Langone Medical Center, clinical data is intended for multiple parties and the point of using information in health care is “ultimately, to benefit patients.” Making an effective case to patients and their clinicians about the value of routinely collected data in supporting timely and informed health care decisions may provide the leverage needed to make the case among payers, researchers, industry, regulators, and policy makers.

The sheer volume of data and what it means may be the greatest barrier to effective engagement among stakeholders. Do all stakeholders know what constitutes routinely collected data? What questions do stakeholders have that routinely collected data could answer? Is being a “data donor” important enough to stakeholders to engage in data collection activities? The examples presented here focus on opportunities for engaging the key participants in utilizing routinely collected data through the involvement of patients in all parts of the research process—within a new U.S. research funding organization, with patients in rural Colorado, with clinicians in practices across the United States, and with the general population in the United Kingdom.

**Patient-Centered Outcomes Research Institute**

PCORI is a unique U.S. research funding entity created by the Patient Protection and Affordable Care Act of 2010. It was set up specifically to conduct research to give patients a better understanding of the prevention, treatment, and care options available, and the science that supports those options. PCORI emphasizes patient and stakeholder input in the design of research questions, in the review of study proposals, and as part of funded research. To inform the design stage, PCORI offers opportunities for public comment, an engagement workshop, and an open call for research questions and other suggestions. In addition, PCORI is developing research methods that support the engagement and meaningful inclusion of patients at every step of the research process. During the funding review process, PCORI involves professional and lay reviewers in order to ensure that proposals have scientific merit and are patient-centered. Finally, research teams working on studies funded through PCORI must meaningfully involve patients and other stakeholders.
High Plains Research Network (HPRN)

HPRN consists of primary care practices, hospitals, other health care facilities, and communities located in eastern rural Colorado, a 16-county area that covers 33,000 square miles—twice the size of the state of Maryland.

The HPRN Community Advisory Council (CAC), comprised of local residents from across eastern rural Colorado, guides and informs the work done by the HPRN research team to ensure that it is relevant and meaningful to patients and their providers.

When the Centers for Disease Control and Prevention (CDC) informed the group that eastern Colorado had a very low screening rate for colon cancer compared with the rest of Colorado and the nation and offered to fund a project to address the problem, the CAC welcomed the opportunity. The CAC met with the HPRN team and doctors to better understand the problem and then set out to craft a message tailored specifically to their neighbors about the importance of colon cancer screening. The message was intentionally straightforward and designed to get a conversation going: “Colon cancer is the second leading cause of cancer death; colon cancer is preventable; testing is worth it, so talk to your doctor today.” They used multiple community outreach methods to distribute their message, such as highlighting local residents in newspaper ads and leaving conversation-starter palm cards in places where people go every day—stores, feed shops, and tractor parts suppliers. The results of this project showed that a grassroots-driven, culturally relevant colon cancer screening initiative can be successfully implemented in rural communities and can achieve positive change in the rate of screening for people in the target population.¹

High Plains Research Network’s Community Advisory Council

HPRN consists of primary care practices, hospitals, other health care facilities, and communities located in eastern rural Colorado, and was set up to translate the best scientific evidence into everyday clinical practice at the local grassroots level. With the help of its Community Advisory Council (CAC), HPRN conducts research and quality-improvement programs that matter to the people who live, work, and spend their time in the region’s small, geographically dispersed communities. Comprised of local residents from across eastern rural Colorado, the CAC guides and informs the work done by the HPRN research team to ensure that it is relevant and meaningful to patients and their providers. The CAC sees its role not as a focus group but as a full participant in the research conducted in the region.

Distributed Ambulatory Research in Therapeutics Network

Clinicians make decisions every day about interventions for their patients that may or may not be based on the best available evidence. Emerging opportunities that provide access to clinical data at the point of care for health care decision making may enhance clinician engagement in data-generating activities. The Distributed Ambulatory Research in Therapeutics Network, or DARTNet, a research network that links EHR data across primary care practices, community health centers, and other delivery organizations, is such an opportunity. The DARTNet system offers member clinicians in any practice the opportunity to actively engage in research that addresses issues of particular interest in primary care. DARTNet has also established learning communities to facilitate timely dissemination of best-practice information and tested clinical decision support tools with member clinicians and researchers.
DARTNet

DARTNet is a research network that links EHR data from 25 primary care practices, community health centers, and organizations representing more than 1,700 clinicians and more than 3 million patients. The network uses routinely collected data such as vital signs, social history, family history, and physical examination findings to supplement data from other sources, such as billing, laboratory, hospital, and prescription databases, to support patient care, improve quality, and facilitate collaborative learning and research.

A recent DARTNet project studied depression, a condition for which the majority of care is provided by primary care physicians. During routine care encounters, patients were asked specific screening questions related to depression and suicidality. The scope of the project included EHR data obtained from 81,028 episodes of depression representing 61,464 patients from 14 participating DARTNet practices. Findings from this large practice-based study showed that clinical care of depression can be enhanced by supplementing EHR data with point-of-care and prescription fulfillment data.

The Cardiovascular Risk Reduction Learning Community (CRRLC) electronically collects data on blood pressure readings, cholesterol control, and related medications. The information from the CRRLC practices are analyzed together to compare outcomes, and high-performing practices agree to be identified and share their methods. By comparing quality indicators of clinical care delivered across the network of providers, DARTNet organizations can learn from identified high-performing member practices.

United Kingdom National Health Service

The United Kingdom’s National Health Service is uniquely positioned to utilize routinely collected health data from national electronic care records for research and quality-improvement purposes. Despite differences between the U.S. and UK health care systems, there are lessons to be learned from the UK experience of using routinely collected health data in biomedical research for public good.

In spring 2012, the UK Department of Health published a consumer-oriented health and social care information strategy. The information, available online and in print, sets a 10-year framework for transforming, recording, and sharing health and care information so that it is accessible to all care providers. The message to the public is clearly stated in the consumer’s voice: “In time, professionals will be able to access bits of information taken from all of our records that will support them to find out things like who has access to services, what services need to improve, which treatments work and how services can be improved to be safer and save money.”

CONCLUSION

Optimizing use of the growing volume of electronic clinical data is a key objective of the learning health system. Clinical data collected during the course of care provides the opportunity to learn from care experiences and continuously improve future efforts toward the triple aim of better care for individuals, better health for the population, and greater value for the costs of care.

There are numerous examples from the scientific community of how digital data is revolutionizing health care in the areas of disease and medication surveillance; targeting evidence-based services that improve the quality and safety of care for fewer dollars; and
creating rich opportunities for clinical researchers to bring clarity to important questions about nebulous areas of health care. Increasingly, linked clinical data sources are being repurposed to improve care effectively and efficiently. Such data come not only from institutional EHRs but also directly from patients who are opening windows on their health care experiences in patient portals and online communities.

As participants in CERIC, we envision an exponential rate of progress in the use of health and health-related data from these varied sources to solve important problems in the prevention and treatment of disease with an eye to lowering the costs of care. Engagement of major stakeholders, most notably patients, in the notion that every health care encounter provides an opportunity to improve outcomes, not only for the individual patient but also for others like them, will be a critical component of this success.

APPENDIX

The following are additional resources for those looking for more information.

2. The Observational Medical Outcomes Partnership, http://omop.fnih.org
3. The Patient-Centered Outcomes Research Institute, http://www.pcori.org

1 Unpublished results from ECIC IOM Messaging Poll, Consumer Reports National Research Center 2012.
8 Ibid.


32 Kaplan, A. 2012. Enhancing patient autonomy through peer review to replace the FDA’s rigorous approval process. *Health Affairs* 31(10):2236-2240.


34 See http://informationstrategy.dh.gov.uk.
Patient-Clinician Communication:
Basic Principles and Expectations

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June 2011

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Collaborative and the Evidence Communication Innovation Collaborative
of the IOM Roundtable on Value & Science-Driven Health Care

The views expressed in this discussion paper are those of the authors and not
necessarily of the authors’ organizations or of the Institute of Medicine. The paper
is intended to help inform and stimulate discussion. It has not been subjected to the
review procedures of the Institute of Medicine and is not a report of the Institute of
Medicine or of the National Research Council.
Patient-Clinician Communication: Basic Principles and Expectations

Lyn Paget, Paul Han, Susan Nedza, Patricia Kurtz, Eric Racine, Sue Russell, John Santa, Mary Jean Schuman, Joy Simha, and Isabelle Von Kohorn

ACTIVITY

Marketing experts, decision scientists, patient advocates, and clinicians have developed a set of guiding principles and basic expectations underpinning patient-clinician communication. The work was stewarded under the auspices of the Best Practices and Evidence Communication Innovation Collaboratives of the Institute of Medicine (IOM) Roundtable on Value & Science-Driven Health Care. Collaborative participants intend these principles and expectations to serve as common touchstone reference points for both patients and clinicians, as they and their related organizations seek to foster the partnership and patient engagement necessary to improve health outcomes and value from care delivered.

BACKGROUND

Health care aims to maintain and improve patients’ conditions with respect to disease, injury, functional status, and sense of well-being. Accomplishment of these aims is predicated upon a strong patient-clinician partnership, in which the insights of both parties are drawn upon to guide delivery of the best care, tailored to individual circumstances. An important component of this partnership is effective patient-clinician communication.

In the 2001 IOM report Crossing the Quality Chasm, patient-centeredness was defined as one of the six key characteristics of quality care and has continued to be emphasized throughout the IOM’s Learning Health System series of publications. Dimensions of patient-centeredness include respect for patient values, preferences, and expressed needs along with a focus on information, communication, and education of patients in clear terms. Consistent and effective communication between patient and clinician has been associated in studies not only with improved patient satisfaction and safety, but also ultimately with better health outcomes, and often with lower costs. Breakdowns of communication, or disregard for patient understanding, context, and preferences, have been cited as contributors to health care disparities and other counterproductive variations in health care utilization rates. Moreover, professional ethics in health care stress the intrinsic importance of respectful and effective communication as a core aspect of informed consent and a trusting relationship.

In an era of increasingly personalized medicine and escalating clinical complexity, the importance of effective communication between the patient and the clinician is greater than ever. As the ultimate stakeholders, patients should expect an active role in, and often shared responsibility for, making care decisions that are best for them. Clinicians, in turn, should respect and support patients in this role, valuing their input and prioritizing their preferences in shaping care choices.

1 Working Group participants drawn from the Best Practices Innovation Collaborative and the Evidence Communication Innovation Collaborative of the IOM Roundtable on Value & Science-Driven Health Care.

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Whether considering risks and benefits or personal values and preferences, patients and clinicians each have unique and important information to contribute to understanding and deciding on prevention, diagnosis, or treatment options. Obtaining the highest-value care for each individual requires establishing common goals and expectations for care through shared deliberation that marshals the best information. Effective communication therefore requires clarity about patient and clinician roles, responsibilities, and expectations for health care; principles to guide the spirit and nature of patient-clinician communication; and approaches to tailor communication appropriately to circumstances (e.g., routine care, chronic disease management, life-threatening disease) and individual patient needs (e.g., health literacy and numeracy, living circumstances, language barriers, decision-making capacity).

Passage of the Patient Protection and Affordable Care Act of 2010 offers both opportunity and mandate to reorient strategies, incentives, and practices in support of health care that reliably delivers Americans the best care at the highest value—care that is effective, efficient, and most appropriate for the circumstances. As an element of best practice, the effectiveness of patient-clinician communication can be as important as that of a diagnostic or treatment tool and should be the product of similarly systematic assessment and evaluation. The principles and expectations identified in this document offer a framework to evaluate and improve patient-clinician communication, and to sharpen and focus patient discussion tools, patient safety assessment (e.g., the Agency for Healthcare Research and Quality [AHRQ], the National Quality Forum [NQF], organizational and individual performance assessment and quality improvement efforts (e.g., Consumer Assessment of Healthcare Providers and Systems [CAHPS], and clinician certification processes (e.g., the American Board of Internal Medicine [ABIM]).

BASIC PRINCIPLES AND EXPECTATIONS FOR PATIENT-CLINICIAN COMMUNICATION

Many factors affect the quality and clarity of communications between patients and clinicians. However, at the core of the matter, certain basic principles pertain and serve as the starting point for the expectations of patients and clinicians: mutual respect, harmonized goals, a supportive environment, appropriate decision partners, the right information, full disclosure, and continuous learning.
Drawing from these principles, the basic individual and mutual expectations of both patients and their clinicians can be identified. These expectations are discussed below and summarized in the accompanying box.

1. Mutual respect

- *Each patient (or agent) and clinician engaged as full decision-making partners.* Communication should seek to enhance health care decision making through the exchange of information and by supporting the development of a partnership relationship—whenever possible—based on trust and focused on the whole patient. This includes considering psychosocial needs, identifying and playing to the patient’s strengths, and building on past experience to meet immediate needs and anticipate future concerns.

- *Respect for the special insights that each brings to solving the problem at hand.* Information exchange should be characterized by listening, inquiry, and facilitation that is both active and respectful on the part of both the patient and the clinician. Information needs include patients’ ideas, preferences, and values; living and economic contexts that may affect patients’ health or decision making; the basis and evidence for alternative choices and recommendations; and uncertainties related to the proposed course of action.

2. Harmonized goals

- *Common understanding of and agreement on the care plan.* Full understanding—to the extent practicable—of care options and the associated risks, benefits, and costs, as well as patient preferences and expectations, should lead to an explicit determination of the shared agenda and goals. Factors should include health, lifestyle, and economic preferences and should accommodate language or cultural differences and low health literacy.

3. A supportive environment

- *A nurturing and secure services environment.* The success of the care plan depends on the attention paid in the service setting to patient culture, skills, convenience, information, costs, and implementation of the care decision.

- *A nurturing and secure decision climate.* The comfort and ability of the patient and clinician to speak openly is paramount to discussion of potentially sensitive issues inherent to many health decisions.

4. Appropriate decision partners

- *Clinicians, or clinician teams, with skills appropriate to patient circumstances.* With increasingly complex problems, and time often a factor for any individual clinician, it is important to ensure that the patient has access to clinicians with skills appropriate to a particular encounter; that, as indicated, alternative clinician opinions are embraced; and that provisions are made for the communication needed among all relevant clinicians.
Assurance of competence and understanding by patient or agent of the patient. Understanding by both patient and clinician is crucial to arriving at the most appropriate decision. Understanding of patient options is important: how specific they are to circumstances; the associated risks, benefits, and costs; and the needed follow-up. If indicated, an appropriate family member or similar designee should be identified to act as the patient’s agent in the care process.

5. The right information

- **Best available information at hand, choices and trade-offs thoroughly discussed.** The starting point for shared decision making should be the sharing of all necessary information. When working collaboratively to craft an appropriate care plan, clinicians should provide evidence concerning risks, benefits, values, and costs of alternative options. All options should be discussed to bring out patient preferences, goals, and concerns and to explicitly consider the impact of various options on these issues.

- **Presentation by patient of relevant perceptions, symptoms, personal practices.** The clinician’s appreciation and understanding of patient circumstances depends on accurate sharing by the patient of perceptions, symptoms, life events, and personal practices that may have a bearing on the condition and its management.

6. Transparency and full disclosure

- **Candid and explicit acknowledgment to patient of limits in science and system.** A basic element of the care process is comprehensiveness and candor with respect to the limits of the evidence, delivery system constraints, and costs to the patient that may affect the range of options or the effectiveness of their delivery.

- **Patient openness to clinician on all relevant circumstances, preferences, medical history.** Only by understanding the patient’s situation can the most appropriate care be identified. Patient and family or agent openness in sharing all relevant health and economic circumstances, preferences, and medical history ensures that decisions are made with complete understanding of the situation at hand.

7. Continuous learning

- **Effective approach established for regular feedback on progress.** Identification and implementation of a system of feedback between patients and clinicians on status, progress, and challenges is integral to the development of a learning relationship that is flexible and can adapt to changing needs and situations.

- **Established periodicity for course assessment and alteration as necessary.** Early specification of treatment strategy, expectations, and course correction points is important for ongoing assessment of care efficacy and to alert both clinician and patient to possible need for care strategy changes.
## Expectations

1. **Mutual respect**
   - Each patient (or agent) and clinician engaged as full decision-making partners.
   - Respect for the special insights that each brings to solving the problem at hand.

2. **Harmonized goals**
   - Common understanding of and agreement on the care plan.

3. **A supportive environment**
   - A nurturing and secure services environment.
   - A nurturing and secure decision climate.

4. **Appropriate decision partners**
   - Clinicians, or clinician teams, with skills appropriate to patient circumstances.
   - Assurances of competence and understanding by patient or agent of the patient

5. **The right information**
   - Best available evidence at hand, choices and trade-offs thoroughly discussed.
   - Presentation by patient of relevant perceptions, symptoms, personal practices.

6. **Transparency and full disclosure**
   - Candid and explicit acknowledgement to patient of limits in science and system.
   - Patient openness to clinician on all relevant circumstances, preferences, medical history.

7. **Continuous learning**
   - Effective approach established for regular feedback on progress.
   - Established periodicity for course assessment and alteration as necessary.

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**TAILORING IMPLEMENTATION TO NEED AND CIRCUMSTANCE**

These principles and expectations offer general guidance for successful patient-clinician communication. Moderating factors or constraints present in individual circumstances require certain tailored approaches and expectations for a particular visit—still with the aim of maximizing faithfulness to these principles to the fullest practical extent. Examples of such considerations include:
Visit reason

- Prevention
- Chronic condition management
- Acute or urgent episode

Decision characteristics

- Number of decisions to be made during the visit
- Certainty, uncertainty, and relevance to the available evidence
- Decisions related to a preference-sensitive arena or choice
- Access to and use of the Internet

Patient characteristics

- Functional capacity (level of physical or mental impairment)
- Communication capacity (language, literacy/numeracy, speech disorder)
- Receptivity (motivation, incentives, activation, learning style, trust level)
- Support (skilled family or other caregiver, financial capacity)
- Living situation (housing, community, grocery, pharmacy, recreation, safety)

Clinician and practice characteristics

- Patient volume and complexity
- Patient support systems (language aids, interpreters, physical space, digital capacity)
- Decision support systems (digital platform, information access, decision guidance)
- Professional team profile and culture
- Condition-specific skill network and referral follow-up systems
- Reimbursement and other economic barriers

DEVELOPING THE TOOLS AND PROCESSES FOR ADAPTIVE TARGETING

As touchstone reference points for patients and clinicians, the principles and expectations presented here are vital to achieving the full measure of potential health outcomes and value from care delivered. But achieving that potential requires intent, commitment, and creativity in developing the tools and processes for adaptive targeting in the myriad conditions and circumstances found in different health care settings. Noted below are questions that may stimulate thought, conversation, and innovative approaches to their successful implementation in various settings and circumstances.

For clinicians and health care organizations

- How are we doing now with respect to the principles and expectations?
- For which of them is our current culture and practice pattern most challenging?
- What initial steps might be good starting points for systems changes necessary?
• How can we enlist patients and staff working together to help develop and lead?
• How can we take advantage of initiative and help from professional societies?
• What community tools or resources might be adaptable for us?
• How can we measure the impact for feedback to patients and staff on the results?

For patients, consumers, and advocates

• What makes a clinician a good listener?
• What should we expect in conversations about health care with clinicians?
• How can available care and condition-specific materials be more easily understandable?
• Are there helpful ways to judge a care setting’s support of effective communication?
• What should we expect from clinicians to help interpret medical evidence?
• How can we best help clinicians in their efforts to improve information sharing?
• How will “continuous learning” from my care lead to better health care?

For professional societies, policy makers, health plans, insurers, and employers

• How do current practices compare with the principles and expectations?
• What ought to be our expectations for clinicians we support?
• What metrics will be most useful for quality improvement and feedback?
• What tools are most needed to assist in application and site-specific tailoring?
• Can we develop case material to illustrate approaches and feasibility?
• What information can help demonstrate material returns in outcomes and value?
• Which reimbursement incentive structures are most important to consider?

SELECTED REFERENCES

Partnering with Patients to Drive Shared Decisions, Better Value, and Care Improvement

In February 2013, the Institute of Medicine’s Roundtable on Value & Science-Driven Health Care convened a workshop, gathering patients and experts in areas such as decision science, evidence generation, communication strategies, and health economics to consider the central roles for patients in bringing about progress in all aspects of the U.S. health care system. This Meeting Summary is being released in conjunction with a complete transcript of the event, the Workshop Proceedings. Over the course of 2 days, 31 speakers commented on the importance of patient and caregiver engagement in achieving the best care at lower cost.

The discussions highlighted the critical role and capacity for patients and families to be leaders in informed care decisions, knowledge generation, and value improvement.

Individual workshop participants identified a few overarching themes and messages.

Informed, Shared Care Decisions
A meaningful care experience is when the patient is fully informed and the provider has elicited the patient’s preferences and goals.

Evidence strongly indicates that when patients are fully informed and engaged in making decisions about their care, patient satisfaction goes up, results improve, and health care costs go down, stated Gary Langer of Langer Research Associates and a number of other workshop participants. In pursuit of more and higher-quality shared decision making, the first workshop session explored how to increase demand for shared decisions, as well as the changes in infrastructure, culture, and training that would be necessary.

Overarching themes and messages:

- **Culture dominates.** “Culture eats strategy for lunch every time,” as mom-turned-advocate Cristin Lind noted. Thus, improving the quality of the care experience and using limited resources wisely will require significant culture shifts.

- **“Listen first, listen fully.”** That’s what Ekene Obi-Okoye, a premedical intern at the University of California, San Francisco, learned as she supported patients with breast cancer. By listening first and listening fully, patient and caregiver voices are integrated fully into every possible level of decision making—care, system design, and policy making—and the quality of care improves.

- **Patient engagement is a skill, not a trait.** Being an engaged patient and actively engaging patients are not intuitive skills. Patients and clinicians learn these skills over time and through partnership with a supportive care team.

- **Trust matters.** Effectively delivering cost and quality information requires trusted translators who convey information in ways that are easy to understand.

- **Prepared, engaged patients are a fundamental precursor to high-quality care, lower costs, and better health.** Achieving and exceeding these three basic aims of health and health care policy calls for partnering with patients as leaders and drivers of care improvement.
• **Patients want to be partners in their health.** When patients receive clear information about their choices, most want to be an equal decision maker when choosing their care plan, Langer observed in his presentation.

• **Strong and visionary leadership promotes culture change.** The leaders of health care organizations can ensure that shared decision making is part of routine practice by setting the standards, pointed out Grace Lin of the University of California, San Francisco.

• **Training can help patients and clinicians engage in shared decisions.** Informed conversations are facilitated by patients who learn to ask questions and clinicians who learn to listen fully, noted Sherrie H. Kaplan of the University of California, Irvine.

According to many workshop participants, improvements in reliable capture of data from the care experience will make knowledge generation more timely and clinically useful. But clinical data use requires individual patients not only to make informed choices about privacy and security, but also to be informed stakeholders in the knowledge generation process, remarked Susan Brown Trinidad of the University of Washington.

**Building trust and understanding is the foundational element in using health data for evidence development,** added Nancy E. Kass of Johns Hopkins Bloomberg School of Public Health. Clinicians frequently are asked to serve as trusted translators when it comes to discussing privacy, security concerns, and the potential benefits and harms of data sharing, a number of speakers pointed out. When patients and clinicians partner to make data more readily available, this enhances the real-time learning potential and leads to better care.

• **Various incentives promote data sharing.** Evette Ludman of the Group Health Research Institute explained that patients are motivated to share their data by altruism, trust, and clear explanations of impact, risks, and benefits.

• **Effective clinician communication strategies can help.** By facilitating conversations about new evidence development, clinicians can enable patients to advocate for using their health data for care improvement, observed patient advocate Mark Gorman.

• **Patients want to be asked about using their data.** Applying practical and trusted approaches to privacy and consent can address the imperative to draw, in a seamless fashion, on clinical data for scientific advances, Group Health’s Ludman continued.

• **Information feedback loops capture and apply lessons learned from the patient experience.** Kenneth D. Mandl, of Children’s Hospital Boston, Harvard Medical School, and Harvard-MIT Health Sciences and Technology, noted that bidirectional communication on patient-reported outcomes ensures that data are being used efficiently and effectively.

• **Distributed leadership fosters patient engagement.** When patients are partners in their health and owners of their data, health care quality improves, Genomera Genetic Alliance’s Greg Biggers remarked, echoing other speakers.
In an efficient health care system, care choices are democratized and based on the best evidence, J. Michael McGinnis of the Institute of Medicine summarized. Though the infrastructure and cultural changes necessary to transform the patient role are significant, empowering patients to become partners in—rather than customers of—the health care system is a critical step on the road to achieving the best care at lower cost, McGinnis continued.

• Patients look for choices they can understand easily and immediately. Cost and quality information is more useful to patients when it is readily available, transparent, and presented in a meaningful way, stated John Santa of Consumer Reports Health Ratings Center.

• Incentive feedback loops are a dynamic part of the care process. Multiple panel members expressed support for making quality information transparent in order for the system to learn and improve.

• Patients choose care tailored to their individual preferences. Patients primarily care about choosing the care that is right for them given their individual circumstances, although concern about out-of-pocket costs is also increasing, Tresa Undem of PerryUndem observed.

• Paying for health care is a social decision. Although many health care choices are made individually, we pay for them communally, explained Marge Ginsburg of the Center for Healthcare Decisions. Given this, patients increasingly want to weigh in on the incentive structures and trade-offs that affect them, she continued.

In an efficient health care system, care choices are democratized and based on the best evidence, J. Michael McGinnis of the Institute of Medicine summarized. Though the infrastructure and cultural changes necessary to transform the patient role are significant, empowering patients to become partners in—rather than customers of—the health care system is a critical step on the road to achieving the best care at lower cost, McGinnis continued.

If patients recognize and expect high-quality, efficient health care, providers will respond, a number of workshop speakers noted.

Since normal market forces are not at work, health care is unlike other industries in that cost is not a proxy for quality, explained Judith H. Hibbard of the University of Oregon. Indeed, presenting value information in isolation is not effective in helping patients make good decisions; information about quality must be included as well. Thus, patients and families need better access to cost and quality information, provided by a trusted source, to support informed decision making, Hibbard continued. Bringing transparency to cost and quality at the system level necessitates changes in the culture and infrastructure of collecting and communicating this information.

FIGURES: Patients want shared decision making, with up to 81% saying they want an equal say in their care decisions (left). Although some patients were less willing to participate in shared decision making, the gap between patients of varying educational levels and language abilities largely disappeared when they were provided clear and understandable information (right).
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The summary was reviewed by Christine Bechtel, National Partnership for Women & Families, and David Arterburn, Group Health Research Institute, to ensure that it meets institutional standards for quality and objectivity.

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SUMMARY

THE LEARNING HEALTH SYSTEM SERIES

ROUNDTABLE ON VALUE & SCIENCE-DRIVEN HEALTH CARE

PATIENTS CHARTING THE COURSE
Citizen Engagement and the Learning Health System
Workshop Summary

LeighAnne Olsen, Robert S. Saunders, and J. Michael McGinnis,
Editors and Rapporteurs

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—Goethe
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This report has been reviewed in draft form by individuals chosen for their diverse perspectives and technical expertise, in accordance with procedures approved by the National Research Council’s Report Review Committee. The purpose of this independent review is to provide candid and critical comments that will assist the institution in making its published report as sound as possible and to ensure that the report meets institutional standards for objectivity, evidence, and responsiveness to the study charge. The review comments and draft manuscript remain confidential to protect the integrity of the deliberative process. We wish to thank the following individuals for their review of this report:

Adam M. Clark, FasterCures
Marribeth Shannon, California HealthCare Foundation
Jason Spangler, Partnership for Prevention
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Although the reviewers listed above have provided many constructive comments and suggestions, they were not asked to endorse the final draft of the report before its release. The review of this report was overseen by Joseph E. Scherger, University of California, San Diego. Appointed by the National Research Council and the Institute of Medicine, he was responsible for making certain that an independent examination of this report was carried out in accordance with institutional procedures and that all review comments were carefully considered. Responsibility for the final content of this report rests entirely with the editors and the institution.
Institute of Medicine
Roundtable on Value & Science-Driven Health Care
Charter and Vision Statement

The Institute of Medicine’s Roundtable on Value & Science-Driven Health Care has been convened to help transform the way evidence on clinical effectiveness is generated and used to improve health and health care. Participants have set a goal that, by the year 2020, 90 percent of clinical decisions will be supported by accurate, timely, and up-to-date clinical information, and will reflect the best available evidence. Roundtable members will work with their colleagues to identify the issues not being adequately addressed, the nature of the barriers and possible solutions, and the priorities for action, and will marshal the resources of the sectors represented on the Roundtable to work for sustained public–private cooperation for change.

The Institute of Medicine’s Roundtable on Value & Science-Driven Health Care has been convened to help transform the way evidence on clinical effectiveness is generated and used to improve health and health care. We seek the development of a **learning health system** that is designed to generate and apply the best evidence for the collaborative healthcare choices of each patient and provider; to drive the process of discovery as a natural outgrowth of patient care; and to ensure innovation, quality, safety, and value in health care.

**Vision:** Our vision is for a healthcare system that draws on the best evidence to provide the care most appropriate to each patient, emphasizes prevention and health promotion, delivers the most value, adds to learning throughout the delivery of care, and leads to improvements in the nation’s health.

**Goal:** By the year 2020, 90 percent of clinical decisions will be supported by accurate, timely, and up-to-date clinical information, and will reflect the best available evidence. We feel that this presents a tangible focus for progress toward our vision, that Americans ought to expect at least this level of performance, that it should be feasible with existing resources and emerging tools, and that measures can be developed to track and stimulate progress.

**Context:** As unprecedented developments in the diagnosis, treatment, and long-term management of disease bring Americans closer than ever to the promise of personalized health care, we are faced with similarly unprecedented challenges to identify and deliver the care most appropriate for individual needs and conditions. Care that is important is often not delivered. Care that is delivered is often not important. In part, this is due to our failure to apply the evidence we have about the medical care that is most effective—a failure related to shortfalls in provider knowledge and accountability, inadequate care coordination and support, lack of insurance, poorly aligned payment incen-
tives, and misplaced patient expectations. Increasingly, it is also a result of our limited capacity for timely generation of evidence on the relative effectiveness, efficiency, and safety of available and emerging interventions. Improving the value of the return on our healthcare investment is a vital imperative that will require much greater capacity to evaluate high-priority clinical interventions, stronger links between clinical research and practice, and reorientation of the incentives to apply new insights. We must quicken our efforts to position evidence development and application as natural outgrowths of clinical care—to foster health care that learns.

**Approach:** The IOM Roundtable on Value & Science-Driven Health Care serves as a forum to facilitate the collaborative assessment and action around issues central to achieving the vision and goal stated. The challenges are myriad and include issues that must be addressed to improve evidence development, evidence application, and the capacity to advance progress on both dimensions. To address these challenges, as leaders in their fields, Roundtable members will work with their colleagues to identify the issues not being adequately addressed, the nature of the barriers and possible solutions, and the priorities for action, and will marshal the resources of the sectors represented on the Roundtable to work for sustained public–private cooperation for change.

Activities include collaborative exploration of new and expedited approaches to assessing the effectiveness of diagnostic and treatment interventions, better use of the patient care experience to generate evidence on effectiveness, identification of assessment priorities, and communication strategies to enhance provider and patient understanding and support for interventions proven to work best and deliver value in health care.

**Core concepts and principles:** For the purpose of the Roundtable activities, we define evidence-based medicine broadly to mean that, to the greatest extent possible, the decisions that shape the health and health care of Americans—by patients, providers, payers, and policy makers alike—will be grounded on a reliable evidence base, will account appropriately for individual variation in patient needs, and will support the generation of new insights on clinical effectiveness. Evidence is generally considered to be information from clinical experience that has met some established test of validity, and the appropriate standard is determined according to the requirements of the intervention and clinical circumstance. Processes that involve the development and use of evidence should be accessible and transparent to all stakeholders.

A common commitment to certain principles and priorities guides the activities of the Roundtable and its members, including the commitment to the right health care for each person; putting the best evidence into practice; establishing the effectiveness, efficiency, and safety of medical care delivered; building constant measurement into our healthcare investments; the establishment of healthcare data as a public good; shared responsibility distributed equitably across stakeholders, both public and private; collaborative stakeholder involvement in priority setting; transparency in the execution of activities and reporting of results; and subjugation of individual political or stakeholder perspectives in favor of the common good.
Foreword

Over the past decade, much attention has focused on rising costs and inadequate access in the U.S. healthcare system. However, another vital shortcoming of the current system has been its inability to truly maximize the health of individuals. As stated in the Charter of the Roundtable on Value & Science-Driven Health Care, too much care that is important is often not delivered, and too much care that is delivered is often not important.

In 2006, the Institute of Medicine chartered the Roundtable (originally, the Roundtable on Evidence-Based Medicine) to engage key stakeholders in a discussion of ways to transform healthcare delivery in this country to ensure that all Americans are receiving the best care. The Roundtable brings together patients and consumers, providers, researchers, health product manufacturers, payers, employees, and policy makers to discuss health reform priorities in a neutral venue and identify key impediments to progress toward a patient-centered learning health system. This vision of the learning health system, developed by the Roundtable, describes a health infrastructure characterized by evidence-based care that ensures proper decision making for each patient and provider, and consequently generates scientific evidence as a natural course of care. To accelerate progress toward this vision, the Roundtable convened leaders, researchers, and policy makers from the healthcare sector for a public workshop, Patients Charting the Course: Citizen Engagement and the Learning Health System.

This compilation summarizes the presentations and discussions from the workshop, which provide an overview of the nature and promise of the learning healthcare system for achieving a culture of patient-centeredness,
science, and value. The contributions and insights in this volume are imperative in formulating strategies to reform the U.S. healthcare system and improve patient-care outcomes.

I would like to offer my personal thanks to the members of the Roundtable who advocate for better health for Americans, to the Roundtable staff for their contributions to this publication and for organizing the activities, and to the sponsors who made this discussion possible: the Agency for Healthcare Research and Quality, AstraZeneca, Blue Shield of California Foundation, California Health Care Foundation, Centers for Disease Control and Prevention, Centers for Medicare & Medicaid Services, Charina Endowment Fund, Department of Veterans Affairs, Food and Drug Administration, Johnson & Johnson, Kaiser Permanente, National Institutes of Health, Office of the National Coordinator for Health IT, The Peter G. Peterson Foundation, sanofi-aventis, Stryker, and the UnitedHealth Foundation.

Harvey V. Fineberg, M.D., Ph.D.

President, Institute of Medicine
Preface

Patients Charting the Course: Citizen Engagement and the Learning Health System summarizes the 2-day workshop convened in April 2010 to identify and reflect upon current strategies and programs advancing public understanding of a transformative, patient-centered learning health system. Stakeholders and leaders within the health sector identified patients and providers as the groups who must be fully engaged to reform the current health system infrastructure, and discussed ways to involve these key constituents. The meeting provided a forum for participants to further discuss issues in communication strategies around science-driven care, patient engagement, and health information technology. This volume of presentations and discussions provides insights and reflections from government leaders, patient advocacy groups, health providers, manufacturers, and other key stakeholders about the issues that must be addressed to reform the way evidence is generated and used to improve health and health care. Participants discussed issues such as the structural details of a system of real-time and continuous learning that anticipates research needs and produces evidence that is timely and applicable; the importance of clinical data, health management, and health information technology as drivers during the information age; patient engagement to improve science and value; and the formation of a patient-centered culture focused on applying evidence and embracing team-based healthcare approaches.

The vision of the IOM Roundtable on Value & Science-Driven Health Care is for a learning health system in which evidence is both applied to ensure best care practices and generated in a timely manner. Since its inception in 2006, the Roundtable has set out to help realize this vision through
the involvement and support of senior leadership from key healthcare stakeholders. In engaging the nation’s leaders in workshops and other activities, Roundtable members and colleagues provide guidance on topics important to a patient-centered, integrated system. The objective of this workshop was to assess the current situation and the progress that has been made toward a learning health system, with a specific focus on effective strategies to improve public and patient understanding of the system’s transformative nature and methods to involve both in the change. The workshop provided a venue for leaders to share their perspectives on methods to enhance stakeholder engagement in building a new health infrastructure, as well as how to develop effective communication strategies around evidence-based care, patient self-management, and health information technology. In the discussions, fundamental ideas emerged on the roles and strategies for patients, providers, and systems as elements in the learning health system.

Participants articulated the numerous opportunities that have been made possible by the passage of the Patient Protection and Affordable Care Act of 2010 and the subsequent challenge of realizing the potential of this new, transformative platform. Despite this challenge, presenters focused on the use of health information technology to drive evidence-based care and the importance of improving the effectiveness of communication between patients and providers. Workshop discussions also highlighted continuous evaluation and collaboration across healthcare sectors as necessary elements that must be in place for the learning health system to be actualized. The Roundtable will follow this workshop with deeper consideration of a number of the highlighted issues through future workshops, commissioned papers, collaborative activities, and public communication efforts. Although the challenges are formidable—as they always are with culture change—Roundtable members, colleagues, and stakeholders are committed and well-equipped to accelerate the progress of a learning health system.

Multiple individuals and organizations donated their valuable time toward the development of this publication. We would like to acknowledge and offer strong appreciation for the contributors to this volume, for the care and thought that went into their analyses and presentations, for the ideas and observations they shared at the workshops, and for their contributions to this summary publication. In this respect, we should underscore that this volume contains a collection of individually authored papers and intends to convey only the views and beliefs of those participating in the workshops, not the express opinions of the Roundtable on Value & Science-Driven Health Care, its members, its sponsors, or the Institute of Medicine.

We are especially indebted to the members of the Planning Committee, which crafted this unusually productive and path-breaking discussion series. The members of this stellar group were: Jay Bernhardt (Centers for Disease Control and Prevention), Michael Fordis (John Baylor College),
Michael Lauer (National Heart, Lung, and Blood Institute), Joel Kupersmith (Veterans Health Administration), Murray Ross (Kaiser Foundation Health Plan), Karen Smith (formerly of AstraZeneca, now with Allergan), and Myrl Weinberg (National Health Council).

A number of Roundtable staff played instrumental roles in coordinating the workshops and translating the workshop proceedings into this summary, including Neha Agarwal, Christie Bell, Malcolm Biles, Claudia Grossmann, LeighAnne Olsen, Brian Powers, Robert Saunders, Kate Vasconi, and Catherine Zweig. We would also like to thank Greta Gorman, Christine Stencel, Vilija Teel, and Jordan Wyndelts for helping to coordinate the various aspects of review, production, and publication.

We have the potential for a transformative learning health system that could revolutionize the way care is delivered and understood. While great strides have already been made with new policy, sturdy dedication and engagement will continue to be instrumental as healthcare delivery in the United States is restructured. We look forward to building upon the ideas that have emerged in this workshop and realizing a learning health system.

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# Abbreviations and Acronyms

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<tbody>
<tr>
<td>ACA</td>
<td>Patient Protection and Affordable Care Act (2010)</td>
</tr>
<tr>
<td>ACGME</td>
<td>Accreditation Council for Graduate Medical Education</td>
</tr>
<tr>
<td>AF4Q</td>
<td>Aligning Forces for Quality</td>
</tr>
<tr>
<td>AHRQ</td>
<td>Agency for Healthcare Research and Quality</td>
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<tr>
<td>AMA</td>
<td>American Medical Association</td>
</tr>
<tr>
<td>AMIA</td>
<td>American Medical Informatics Association</td>
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<tr>
<td>ARRA</td>
<td>American Reinvestment and Recovery Act (2009)</td>
</tr>
<tr>
<td>CCCP</td>
<td>Connected Cardiac Care Program</td>
</tr>
<tr>
<td>CER</td>
<td>comparative effectiveness research</td>
</tr>
<tr>
<td>CMS</td>
<td>Centers for Medicare &amp; Medicaid Services</td>
</tr>
<tr>
<td>CNVs</td>
<td>copy number variants</td>
</tr>
<tr>
<td>CRM</td>
<td>crew resource management</td>
</tr>
<tr>
<td>CRS</td>
<td>Care Records Service (UK)</td>
</tr>
<tr>
<td>DHMC</td>
<td>Dartmouth Hitchcock Medical Center</td>
</tr>
<tr>
<td>EGAPP</td>
<td>Evaluation of Genomic Applications in Practice and Prevention</td>
</tr>
<tr>
<td>EHR</td>
<td>electronic health record</td>
</tr>
<tr>
<td>eMERGE</td>
<td>electronic MEdical Records and GEnomics</td>
</tr>
<tr>
<td>EMR</td>
<td>electronic medical record</td>
</tr>
<tr>
<td>FCC</td>
<td>Federal Coordinating Council</td>
</tr>
<tr>
<td>FDA</td>
<td>Food and Drug Administration</td>
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GDP  gross domestic product
GEDDI  Genetics for Early Disease Detection and Intervention to Improve Health Outcomes
GHP  Geisinger Health Plan
GHS  Geisinger Health System
GWAS  genome-wide association study

HCC  Hierarchical Condition Categories
HEDIS  Healthcare Effectiveness Data and Information Set
HHS  Department of Health and Human Services
HIT  health information technology
HITECH  Health Information Technology for Economic and Clinical Health Act (2009)
HPV  human papillomavirus

IHI  Institute for Healthcare Improvement
INR  International Normalized Ratio
IOM  Institute of Medicine
IPADS  International Patient Decision Aids Standards
IRB  institutional review board
IT  information technology

JAMA  *Journal of the American Medical Association*

MA  Medicare Advantage

NBCC  National Breast Cancer Coalition
NCI  National Cancer Institute
NHS (UK)  National Health Service
NIH  National Institutes of Health
NWHIN  Nationwide Health Information Network

OECD  Organisation for Economic Co-operation and Development
OMB  Office of Management and Budget
ONC  Office of the National Coordinator for Health Information Technology

PAMF  Palo Alto Medical Foundation
PCMH  patient-centered medical home
PCORI  Patient-Centered Outcomes Research Institute
PheWAS  phenome-wide scanning
PHR  personal health record
PSA  prostate-specific antigen
PXE  pseudoxanthoma elasticum

RCT  randomized controlled trial
REP  Rochester Epidemiology Project
RPIWs  Rapid process improvement workshops
RWJF  Robert Wood Johnson Foundation

SCP  shared care plan
SHARP  Strategic Health IT Advanced Research Projects
SNP  single nucleotide polymorphism
SORT  Strength of Recommendation Taxonomy
SR  systematic review
SSRI  selective serotonin reuptake inhibitor
STEPPS  Strategies and Tools to Enhance Performance and Patient Safety

USPSTF  U.S. Preventive Services Task Force
VAP  ventilator-associated pneumonia
VMMC  Virginia Mason Medical Center
INTRODUCTION AND OVERVIEW

The prosperity of a nation is tied fundamentally to the health and well-being of its citizens. It follows, then, that citizens—each one a past, current, or future patient—should represent both the healthcare system’s unwavering focus, and its fully engaged agents for change. This precept has several major implications. It means that the quality of health care should not be judged solely by whether clinical decisions are informed by the best available scientific evidence, but also by whether care accounts for a patient’s personal circumstances and preferences. It implies that careful listening should be the starting point for every patient encounter. And it suggests that the success of and innovations in healthcare delivery should depend on direct consumer engagement in the design of healthcare models and their aims.

One of the central lessons of the Institute of Medicine (IOM) report Crossing the Quality Chasm: A New Health System for the 21st Century is that much of health care in the United States has lost its focus on the patient (IOM, 2001). Instead, the healthcare system has been designed and motivated primarily by the perspectives of its component facilities, companies, payers, and providers. Crossing the Quality Chasm urges that care be refocused around six aims: care should be safe, effective, patient-centered, timely, efficient, and equitable. In the decade since the report was published, it has become even clearer that citizen and patient engagement is central to taking advantage of advances in the personalization of care based on genetics, preferences, and circumstances. Building off the Chasm
report, a learning health system requires that patients help chart the course and operation of the learning process.

In this context, the IOM, under the auspices of the Roundtable on Value & Science-Driven Health Care, focused the tenth workshop in its *Learning Health System* series on public and patient engagement and leadership. This volume, *Patients Charting the Course: Citizen Engagement and the Learning Health System*, presents a summary of the issues and perspectives addressed at that meeting.

As discussed by many participants in the meeting, most health systems today are not centered on patients. Instead, volume drives service; supply influences demand; and clinician—not patient—preferences shape practice (Wennberg et al., 2007). The notion of patient-centeredness often still feels unfamiliar, even disruptive, for many of those unexposed to the advantages of such a culture (Berwick, 2009).

Patients have shown an interest in becoming more involved and learning more about their conditions. A Pew Research Center Survey found that 61 percent of adults go online to seek information on specific diseases, medical treatments, and other health subjects. Although the increased availability of health information is important, new communication approaches are needed to provide information that is reliable, relevant, and understandable so patients can make informed healthcare decisions.

Data and information are a first step toward improving communications between providers and patients. Providers will increasingly need to discuss with patients the risks and benefits of competing treatment options and engage patients in shared decision making about their treatment choices. This represents a shift away from the historical model of medicine toward one in which physicians and patients work together to manage complex conditions, and make decisions on the basis not only of the best medical knowledge, but also the patient’s life circumstances, preferences, and personal biology.

Recent legislative efforts and national interest around these issues have provided an important impetus for progress and prompted a reassessment of priorities and the articulation of practical next steps for developing a learning health system. The American Recovery and Reinvestment Act of 2009 (ARRA) included more than $1.1 billion to enhance the nation’s capacity for comparative effectiveness research and nearly $20 billion for the adoption and use of health information technology through the Health Information Technology for Economic and Clinical Health (HITECH) Act. Through incentives for the meaningful use of electronic medical records, the HITECH Act will encourage the adoption of electronic medical records by clinician practices and hospitals, which will enable improved access to clinical information, coordination of care across multiple healthcare settings, and a comprehensive record of a patient’s medical history. This will provide
the foundation for many aspects of the learning health system, including expanded clinical data for research, patient access to their own health information, and new models of care outside the traditional clinical encounter.

Signed into law one week before the workshop, the Patient Protection and Affordable Care Act of 2010 (ACA) underscored the importance of patient choice and engagement, including provisions to promote choice, accountability, consideration of patient preferences, and shared healthcare decision making. As this law is implemented, new opportunities will become available for establishing innovative models to deliver care, creating incentives to coordinate and improve care quality and value, and expanding the clinical workforce.

THE ROUNDTABLE AND THE LEARNING HEALTH SYSTEM SERIES

The IOM Roundtable on Value & Science-Driven Health Care has since 2006 provided a venue for health leaders from various stakeholder sectors—health professionals, patients, health system leaders, insurers, employers, manufacturers, information technology, research—to work cooperatively to address their common interest in improving the effectiveness and efficiency of health care. The Roundtable members have set the goal that, by 2020, 90 percent of clinical decisions will be supported by accurate, timely, and up-to-date information and will reflect the best available evidence. Over the past five years, the Roundtable’s Learning Health System series of workshops has identified and considered the key elements whose transformation can be central to achieving this goal: clinical research, clinical data, information technology, evidence standards, healthcare tools, caregiver culture, patient engagement, and financial incentives. For each of these elements, the workshops have explored priorities and approaches integral to harnessing interests and expertise across healthcare sectors to drive improvements in the value of medical care delivered in the United States. The following publications summarizing these workshops offer perspectives on the issues involved, and identify priorities and projects in need of cooperative stakeholder engagement:

- The Learning Healthcare System (2007)
- Evidence-Based Medicine and the Changing Nature of Health Care (2008)
- Value in Health Care: Accounting for Cost, Quality, Safety, Outcomes, and Innovation (2010)
In addition to the meeting series focused on exploring concepts and strategies for the learning health system, the Roundtable operates a series of Innovation Collaboratives, aimed at stewarding joint projects among organizations key to field advancement.

Across the range of issues engaged in the Learning Health System workshops and the Innovation Collaboratives, greater public interest and patient engagement have emerged as essential and potentially transformative elements for driving health system change. Empowering and supporting the public in these new roles requires the creation of a healthcare culture that supports continuous improvement and learning; elicits and considers public perspectives on key healthcare issues; and better characterizes needed partnerships, resources, tools, and communication approaches. Listed in the front of this publication are members of the IOM planning committee\(^1\) charged with guiding the development of a workshop to consider these issues in detail. The committee worked with IOM staff to develop the workshop objectives and emphases and to plan the agenda. Box S-1 summarizes the motivating issues and objectives for the workshop.

The planning committee designed day 1 of the workshop to focus on key elements of progress in science-driven health care—care culture, clinical research and the evidence process, clinical data, health information technology systems—with specific attention to the role of patient engagement in the success of each. Day 2 was devoted to understanding opportunities to develop the communications, culture, and incentives that will help in reorienting the focus and performance of a value- and science-driven health system. The workshop agenda is provided in Appendix A, speaker

\(^{1}\) Institute of Medicine planning committees are solely responsible for organizing the workshop, identifying topics, and choosing speakers. The responsibility for the published workshop summary rests with the workshop rapporteurs and the institution.
BOX S-1
Motivating Issues and Objectives

Motivating Issues

- **Implications of knowledge advances.** Progress in medical science, basic research, information technology, and operations research offers the potential for immediate, continuous, and transformative improvement in health care. In the context of increasing understanding of the importance of individual factors to patient outcomes, reaching health care’s full potential requires a reorientation to the patient.

- **Performance shortfalls.** In terms of both effectiveness and efficiency, the nation’s healthcare system is underperforming. The United States has the highest per capita health expenditures—twice the average for other developed countries—yet consistently rates no better than the middle tier of developed nations on such key indicators as infant mortality, life expectancy, and overall health system performance.

- **Disconnects in core aims.** The core aim of health care is improved outcomes: to maintain or enhance patient status with respect to disease, injury, functional status, and sense of well-being. Yet often the system’s dominant characteristics are oriented more to clinician preferences or interests and economic rewards for volume over value.

- **Anchor misalignment.** The primary focus of care should be on outcomes rather than service volume and on the interdependent aims of patient-centeredness, better science, better value, and continuous improvement.

- **Imperative to make patients a central element.** Efforts of the IOM and others have underscored the necessity of making patient perspectives, preferences, and needs a strong, central focus of a learning health system, for several reasons, including: the basic fact that patients are the health system’s key focus and its agents for change, the fact that care has been shown to be more effective and efficient with more patient involvement, and the growth of preference-sensitive care as new interventions are developed.

- **Importance of communication.** Central to progress are the communication strategies necessary to inform and engage the public and patient communities as understanding advocates, partners, and change agents.

Objectives

- Identify the state of play with respect to the foundational elements of a learning health system, the role of patients and the public in achieving progress on each element, and the most important priorities and policy levers for accelerating progress.

- Explore and clarify the integral links among three key desired characteristics of care: science-driven, patient-centered, and value-enhancing.

- Discuss communication and public engagement strategies important to improving the awareness and patient-focused action necessary for the transition to a learning health system.
biographical sketches in Appendix B, a listing of workshop participants in Appendix C, and an overview of common themes from each workshop in the Learning Health System series in Appendix D. This publication summarizes the workshop presentations and discussions and the issues addressed. Summaries of common themes and of the workshop presentations and discussions are provided below; further detail is provided in the main text.

COMMON THEMES

Representatives from the multiple healthcare sectors represented on the Roundtable participated in the workshop discussions. Although the perspectives brought to bear were diverse, the presentations and discussions shared a focus on the issues and challenges involved in moving to care centered on patients and their families, as envisioned by the Quality Chasm report. As noted by one workshop participant, such a focus means that “it is not about my condition—it’s about me.” During the workshop, a number of common themes emerged as participants discussed the importance of a patient-focused culture in addition to the content, structure, and functioning of a patient-centered, learning health system. These themes are listed in Box S-2 and discussed in detail below.

Listening. Each patient-clinician interaction starts with uninterrupted attention to the patient’s voice on issues, perspectives, goals, and preferences. These patient views should then be used to guide clinical decisions, which often involve choices among multiple treatments that have both benefits and risks. Workshop participants reported that care often improved when staff and providers listened carefully to the concerns of patients and their families. Yet, it has been noted that physicians tend to interrupt patients within about 15 seconds of beginning to speak at the outset of the visit. On the other hand, an uninterrupted patient tends to conclude their remarks in under a minute (Beckman and Frankel, 1984). Listening fully to the patient, then, does not cause any significant delays in the physician’s schedule, and adds substantially to creating an environment where patients feel comfortable sharing their health information. Achieving this goal will require a new focus on patient communication starting early in provider education to ensure that providers have the tools they need to share complex health information with patients and help them with these decisions.

Participatory. Health outcomes improve when patients are engaged in their own care. In addition to improving health outcomes and patient adherence, participants noted that engagement can increase employee satisfaction and financial performance. People are eager to play a strong role in their own health care when given the right tools, as evidenced by the rapid uptake of
BOX S-2
Patient-Anchored Care: Common Themes

- **Listening.** Each patient-clinician interaction starts with uninterrupted attention to the patient’s voice on issues, perspectives, goals, and preferences.
- **Participatory.** Health outcomes improve when patients are engaged in their own care.
- **Reliable.** All patients should expect proven best practice as the starting point in their care.
- **Personalized.** With proven best practice as the starting point, science-based tailoring is informed by personal biological traits, circumstances, and preferences.
- **Seamless.** Care delivered by multiple providers in multiple settings should be fully integrated and seamless.
- **Efficient.** Patients, their families, and clinicians should expect care to be appropriate to the need, available resources, and time required.
- **Accountable.** All relevant aspects of the clinical experience, including patient perspectives, should be captured and routinely assessed against expectations.
- **Transparent.** Information on the outcomes of care—both effectiveness and efficiency—should be readily accessible and understandable to patients and their families.
- **Trustworthy.** Patients should expect a strong and secure foundation of trust on all dimensions—safety, quality, security, efficiency, accountability, and equity.
- **Learning.** In a learning health system, the patient is an active contributor to and supporter of the learning process.

Web 2.0 health information applications. Yet as one speaker mentioned, surveys indicate that only half of patients receive clear information on the benefits and trade-offs of the treatments under consideration for their condition. Patients’ involvement may be increased by providing them with additional information tools for learning about their health, helping them see the impact of their efforts, and acquainting them with new technologies with which to monitor their health and assist with lifestyle changes. Public participation is not limited to the clinic; the workshop highlighted new initiatives to provide access to health data and allow individuals to create new applications to improve their health.

**Reliable.** Each patient should expect proven best practice as the starting point in their care. The current variability in medical practice impacts patient care and results in uneven quality and safety for patients. Participants described tools that minimize this variation, such as dashboard displays that highlight the interventions that are due, done, or overdue and improve the consistency of the delivery of interventions to patients; other tech-
nologies that show promise include clinical decision support systems that present best practices to clinicians. Several participants also noted that, although technologies provide new opportunities, incentives, such as bundled payments and pay for performance, are needed to promote reliability and effectiveness in healthcare organizations and ensure accountability.

**Personalized.** With proven best practices as the starting point, science-based tailoring is shaped by personal biological traits, genetics, circumstances, and preferences. Since the sequencing of the human genome was accomplished, medical science has sought to personalize treatments to specific biological traits and genetics, in addition to personalizing care based on individual patient circumstances and preferences. This effort challenges the traditional approach of giving the highest priority to evidence gathered by means of large randomized controlled clinical trials, in which treatments are measured in a large population with a diverse genetic profile. Using multiple types of complementary evidence could better guide medical decisions and account for these personal factors. This new approach focuses on the applicability of results to the clinic, rather than automatically giving priority to the results of randomized controlled trials.

**Seamless.** Care delivered by multiple providers in multiple settings should be nonetheless expected to be fully integrated and seamless. As patients move among providers and settings, they often encounter communication problems, which may result in treatment errors and duplicative services. Participants described how team-based care offers the potential to rectify this disconnected care and limit human error. Effective teams are aided by an appropriate information technology infrastructure, which facilitates efficient and effective communication of health information. Encouraging the use of such teams will likely require the use of financial incentives, including bundled payments and payments that focus on outcomes; applying disincentives for poor outcomes, such as for preventable hospital readmissions; and creating incentives for delivery system reforms, including medical homes and accountable care organizations.

**Efficient.** Patients, their families, and clinicians should expect care to be appropriate to need, resources, and time required. Participants underscored the fact that currently, much of the care that is delivered is neither necessary nor efficient, with patients facing increasing out-of-pocket costs and lost time in the care process. This finding is not surprising given that the current incentive structure, focused on volume over value, encourages overuse and waste. As multiple participants noted, the United States spent roughly 17 percent of its gross domestic product on health care last year, yet this investment did not yield the health outcomes commensurate with
the costs. To gain greater value, many participants stressed that the costs and outcomes of care should be more transparent to patients, and new payment models—ranging from bundling payments for an entire episode of care, to pay-for-performance systems, to global payment—need to be implemented.

**Accountable.** All relevant aspects of the clinical experience, including patient perspectives, should be captured and routinely assessed against expectations. This information is vital not only to achieving effective patient management, but also to judging whether experiments with new delivery system models, payment incentives, or standards of care are having their intended effect on improving patient health and promoting efficiency. Measuring performance and disseminating innovations that work (and eliminating those that do not) constitute a systematic way of improving healthcare delivery. One presentation highlighted how this systematic approach to improvement allowed the speaker’s organization to enhance care by conducting comprehensive reviews of interventions for different conditions, adopting the best practices identified by that review, and measuring the performance of the revised standard of care.

**Transparent.** Information on the outcomes of care—both effectiveness and efficiency—should be readily accessible and understandable to patients and their families. Several speakers mentioned the frustration felt by patients regarding the lack of understandable information on the costs, quality, and outcomes of care, especially in light of reports about medical errors and the increasing personal burden of costs and inefficiencies of care. It was noted that, when offered a choice, patients do not routinely choose more costly or more intensive interventions. However, patients rarely have choice or information about alternatives. It is clear that information needed to improve value—better outcomes at lower cost—requires transparent information on the costs and outcomes of care.

**Trustworthy.** Patients should expect a strong and secure trust fabric on all dimensions—safety, quality, security, efficiency, accountability, and equity. In few areas of human endeavor is trust on each of these dimensions more important. Yet one presenter noted that, even though 50,000 to 90,000 deaths per year are caused by medical errors, health care lacks the basic trust elements of transparency and accountability needed to drive improvements in quality and safety. In a learning system that draws lessons from each care experience, public trust must be bolstered in all aspects of the healthcare enterprise: equitable access to reliable clinician knowledge and skills, safeguards on clinical processes, the privacy and security of medical records, and the validity and safety of clinical trials.
Learning. In a learning health system, the patient is an active contributor to, and supporter of, the learning process. Each patient experience offers the potential to deepen the knowledge base that drives care quality and outcomes—at the individual, practice, and societal levels. A focus of the workshop was the stake of the patient in fostering a digital health utility that provides needed information to patients and their clinicians, ensures synchronization among providers, and generates knowledge for progress—for example, for comparative effectiveness insights, public health activities, or postmarket monitoring of approved technologies and drugs. Reference was made, for example, to the need for a common core data set for electronic health record–based data that would allow reliable, platform-independent research across large patient populations. These are issues in which patients have a strong stake, and they must have confidence in the system’s functionality for the generation of timely and reliable new insights.

Many participants stressed that meeting these important expectations will require new tools, a new culture, and new organizational structures. This transformation must start with patients’ involvement in their own medical care and their inclusion in decision making about the treatment that is best for them. Beyond individual patient decisions, workshop participants discussed the importance of including consumers in healthcare policy making at all levels—from hospital advisory committees to clinical trials—to ensure that all levels of the healthcare system consider patients at all times.

PRESENTATION SUMMARIES

The workshop presentations and discussions reviewed progress toward a learning health system; explored the links among the three key aims of care—science-driven, patient-centered, and value-enhancing; and identified priorities, policy levers, and public engagement strategies necessary to move forward. To provide context, the workshop began with keynote remarks by Harvey Fineberg, president of the IOM. He provided an overview of the current U.S. healthcare system and offered observations on the important framework and impetus for progress provided by the foundational elements of a learning health system in the context of the ACA.

The Learning Health System in 2010 and to Come

Dr. Fineberg addressed key challenges facing the U.S. healthcare system, drawing attention to the nation’s high expenditures on health care. The United States spends $7,500 per person on health care, yet life expec-
tancy, infant mortality, and system performance lag behind those of many developed countries that spend far less (OECD, 2009). In 2009 the United States spent $2.5 trillion on health care, which, as noted, represents nearly 17 percent of gross domestic product. In the coming years, expenditures are expected to continue to climb and life expectancy is expected to worsen if the healthcare system continues to function as it does today.

A learning health system, as defined in the charter of the Roundtable on Value & Science-Driven Health Care, is a system designed to generate and apply the best evidence for care; provide evidence discovery as a natural outgrowth of patient care; and strive for innovation, quality, safety, and value in health care. In redesigning the health system to transition to this ideal, patients and the public must be engaged as active partners. Their perspectives are invaluable on topics ranging from how to personalize care and treatments to how to judge the value of care delivered. Despite the potential, evidence suggests that the system currently engages the public and patients in a limited fashion at the level of either the health system or individual healthcare decisions (Berwick, 2009; Sepucha and Barry, 2009; Zikmund-Fisher et al., 2010). Increased involvement of the public and patients is essential for progress toward a learning health system and greater value in health care.

Passage of the ACA just 7 days before this workshop added momentum and urgency to transforming the health system. However, passage of this legislation alone will not accomplish this transformation; careful implementation will be necessary to better orient health care toward science and value. In short, reform will be an ongoing process and evolve over time in response to changing national conditions. Sustaining these reform efforts will require the creation of a learning culture that nurtures systems and enables continuous learning, improvement, and innovation.

**Clinical Research, Patient Care, and Learning That Is Real-Time and Continuous**

A learning health system seeks to develop and continuously refine the evidence base needed for timely care, tailored to individual patient needs. However, the rapid pace of development of new therapies and ongoing evolution of existing treatment strategies create substantial, unmet demands on the research enterprise as current clinical research approaches require significant investments of time and resources but offer only static determinations of the average treatment effects on narrow and homogeneous populations (Greenfield et al., 2007). As a result, only a fraction of the many pressing clinical questions can be investigated, and research findings are limited in their timeliness and generalizability to real-world patient populations (IOM, 2009, 2011b).
Presenters of the papers included in Chapter 2 considered key strategies for expanding capacity and improving the volume, level, and applicability of clinical research. These strategies include developing the infrastructure and methods necessary for comparative effectiveness research, harnessing integrated healthcare delivery systems as platforms for research in real-world care settings, and engaging patients as full partners in the research enterprise.

Comparative Effectiveness Research: Patient, Clinician, and Policy Needs

By focusing on health outcomes and the information needs of patients, clinicians, and policy makers, comparative effectiveness research may improve the utility of all clinical research for guiding care decisions (FCC, 2009; IOM, 2009). Departing from the traditional, investigator-driven research paradigm, the priorities and study designs of comparative effectiveness research must reflect routine practice settings and the heterogeneity of real-world patient populations. As noted by Patrick Conway, formerly of the Office of the Secretary of Health and Human Services, this type of research provides an opportunity to take better advantage of health information technology and innovative research methods. Ensuring the success of comparative effectiveness research efforts will depend on improving the translation of its evidence into health outcomes through improved adoption and dissemination interventions as well as enhanced efforts to evaluate and publicly report the impacts of research investments.

The ARRA and ACA provided funding and expanded capacity for the entire comparative effectiveness research enterprise. To guide the investment of a portion of these new research funds, the Federal Coordinating Council for Comparative Effectiveness Research developed prioritization criteria for scientifically meritorious research, as well as a strategic framework outlining core research components (research, human and scientific capital, data infrastructure, dissemination, and translation) and priority themes (populations, conditions, and intervention types). Key initial investments include the development of data infrastructure, encompassing, for example, claims data, clinical data networks, and patient registries, as well as efforts to enhance information dissemination and use. In addition to discussing the work of the Coordinating Council, Conway suggested several next steps as important to ensure maximal impact and sustainability of the Patient-Centered Outcomes Research Institute (PCORI) created under the ACA: (1) develop an overall funding strategy, informed by clinicians,

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2 The Coordinating Council recommended priorities for the comparative effectiveness research funds provided to the Office of the Secretary of Health and Human Services ($400 million). The ARRA also allocated comparative effectiveness funds to the National Institutes of Health ($400 million) and the Agency for Healthcare Research and Quality ($300 million).
patients, and a stakeholder advisory board; (2) establish priority topics, and evaluate the current state of knowledge about each; (3) select research methods that will best address existing knowledge gaps; (4) strive for a balanced portfolio of high-impact research topics; and (5) evaluate progress, and report back to the public (VanLare et al., 2010).

Health Systems as Research Platforms: Enhancing Science, Value, and Innovation

Electronic health records and other health information technology (IT) tools have become commonplace in many large healthcare delivery organizations. The resulting increase in clinical and health data presents an opportunity to conduct research that better reflects clinical practice and is relevant to real-world patients and settings. The research enabled by health IT includes research on comparative effectiveness, health services, patient preferences, surveillance of pharmaceuticals and other therapeutics, and population health.

To illustrate the potential of better integrating health systems into the national research enterprise, John Noseworthy and Sherine Gabriel of Mayo Clinic offered several examples of Mayo’s use of clinical data to improve the safety and effectiveness of medical care. One such example, the Rochester Epidemiology Project, creates a common data resource for the study of health and illness that is large enough to facilitate routine and passive population-based research. Taking a similar approach, the Total Joint Registry supports comparative analysis of surgical techniques and implant types—including consideration of patient demographics and comorbid conditions—with respect to long-term outcomes. A third example is the Warfarin Project, which implements a standardized, rule-based algorithm for administration of this anticlotting agent and improves the algorithm through surveillance, performance data, and user feedback.

Taking a more disruptive approach, the proposed High Value Health-care Initiative would focus on improving the value of care by benchmarking the quality and costs of best practices over time, implementing models for evidence-based best practice and shared decision-making, and studying new reimbursement approaches that would better align payments with patient care outcomes. As a final example, the Enterprise Data Trust is a centralized repository for the management, integration, and sharing of information collected during care delivery—including biospecimen-related and phenotypic data—with the data being used to inform and improve future care.

Collectively, these examples suggest several key characteristics for a knowledge-driven healthcare delivery system of the future: patient-centeredness with a strong focus on quality and coordination of care;
information-enabled practice with real-time data and feedback available to providers at the point of care; a culture of collaboration, innovation, and translation of scientific knowledge into improved health for patients and communities; health information technology systems that are integrated, standardized, and interoperable; and a focus on high-value care.

Enhancing the Culture of Patient Contributions to Learning in Health Care

A learning health system is characterized by real-time and continuous knowledge generation, with patients actively engaged in the research enterprise. The patient-centered focus of comparative effectiveness research and the increased capability of health systems to use course-of-care data for learning foreshadow expanded opportunities for patients and the public to contribute to advancing knowledge. Diane Simmons and Kenneth Getz of the Center for Information and Study on Clinical Research Participation reviewed key opportunities to foster a culture supportive of greater public and patient engagement in learning in health care.

One measure of public engagement in healthcare learning is public confidence and trust in the clinical research enterprise, which has eroded over the past decade as has public awareness of and appreciation for study volunteers (Woolley and Propst, 2005). These trends are reflected in research participation rates, with enrollment dropping from 75 percent in 2000 to 59 percent in 2006 despite a concurrent 12 to 14 percent spending increase recruiting clinical trial volunteers. It may be possible to reverse this trend by examining the common motivations for research participation. According to a survey of study volunteers, key drivers for sustained participation include the need to take control of one’s medical condition and well-being, the desire to develop personal relationships with study staff, a feeling of being treated appropriately throughout the study, and the knowledge that participation will make a difference.

Based on the work of the Center for Information and Study on Clinical Research Participation, bolstering public confidence and trust could be accomplished through programs that (1) increase appreciation for study volunteers and illustrate the value of clinical research to the public health; (2) repair the credibility of research sponsors, study staff, and professionals responsible for regulating the research enterprise and protecting human subjects; and (3) engage the public as partners in the development of new medical and health advances.

Clinical Data as a Public Good for Discovery

Essential to a dynamic research enterprise is the broad availability of quality clinical and health data. Currently, data are scattered across the
healthcare system in siloed repositories, representing substantial but latent resources for advancing a variety of research streams, including drug discovery, comparative effectiveness, quality improvement, and public health surveillance (IOM, 2011a; NRC, 2009). Efforts now under way to create infrastructure for data capture, linkage, and information sharing will help make clinical data a public good. Presenters of the papers included in Chapter 3 reviewed the wide array of needs and potential uses for data in a learning health system, opportunities to better utilize data generated through public investment, and strategies to improve data integrity and develop a culture supportive of the application of the broad range of available data resources for progress in health care.

Information Needs for the Learning Health System

The Office of the National Coordinator for Health Information Technology (ONC) aims to improve health and health care through the appropriate use of information technology. Initial work has focused on encouraging broad adoption and use of electronic health records through Centers for Medicare & Medicaid Services (CMS) payment incentives so as to achieve measurable improvements in the quality, safety, and efficiency of health care. Farzad Mostashari of ONC reported on what is needed to attain a secondary goal of electronic health records: contributing to a learning health system and serving as a means for understanding and influencing other key functions such as public health, care quality, drug discovery, and clinical effectiveness research.

Current efforts to develop independent systems for these purposes are using different architectures and approaches, which poses two significant challenges to the creation of a unified, multipurpose digital infrastructure: sharing data and designing the system. Accelerating data sharing will require the creation of a limited care data set, developed from collaboration among key data users that can meet the key needs for each community. Although such an approach will not immediately satisfy all data needs of all users, it is a necessary starting point for the development of a national infrastructure that is not saddled with burdensome and excessive data demands. To meet the broader needs of each research community, the core data set should be accompanied by deeper data collection when appropriate and relevant to the circumstances. Discussing system design, Mostashari highlighted the potential benefits of creating a distributed rather than a centralized infrastructure. In the context of the fragmented and heterogeneous U.S. healthcare system, a distributed approach is likely to produce a more resilient, feasible, cost-effective, and privacy-protective infrastructure.
Opening Access to High-Value Data Sets

The vast stores of data captured by the agencies of the Department of Health and Human Services (HHS) are an important national resource for enhancing value, the science base, and the patient experience. Todd Park, HHS’s chief technology officer, provided an overview of efforts to open access to these data as part of the White House’s Open Government Initiative. Existing data from HHS agencies such as the Agency for Healthcare Research and Quality (AHRQ), CMS, the Food and Drug Administration (FDA), and the National Institutes of Health (NIH) are a tremendous public good, yet the data cannot produce transformative change without additional efforts to stimulate their use and improvement. HHS therefore is seeking to develop a data ecosystem in which an array of users can access the data supplied by HHS and others, providing opportunities for users to develop new methods for the data’s display or application in ways that improve the health of U.S. communities.

The data ecosystem concept has been tested through the Community Health Data Initiative, which seeks to help Americans better understand and take action to improve local healthcare performance. The promise of this approach has been demonstrated in the Initiative’s initial meetings and has led to the development of several applications that use data to improve understanding of national and community health issues, as well as areas for their improvement. Park encouraged additional input from the public, noting that although HHS data are useful now, their quality and utility will improve dramatically as new uses and needs for the data are developed.

Ensuring Data Integrity: Addressing Privacy Protection and Proprietary Concerns

Although Americans strongly favor legitimate biomedical, public health, and health services research, current policy does not promote access to patient data for such research. Don Detmer of the University of Virginia noted the need for new policies that expand data availability and reduce data collection costs while ensuring the privacy and security of personal health information.

Current policy places the burden of collecting clinical data on researchers, creating significant disincentives for clinicians and investigators to pursue promising lines of enquiry. To address this misalignment, Detmer proposed several policies for promoting research while protecting data security, including (1) creating a unique personal health identifier, with the ability for patients to opt out; (2) providing the availability of genetic information for research, with the ability for patients to opt out; (3) sharing clinical data for research, with the ability for patients to opt
out; and (4) developing a public–private collaboration for engaging citizens who wish to participate in clinical research studies. These policies would give the public the option of becoming full and open participants in a learning health system while ensuring that patients retain the ability to choose whether they want their health data shared for research purposes.

**Engaging Patients to Improve Science and Value in a Learning Health System**

Patients bring unique and important perspectives as well as personal agency to health care—elements essential to closing important gaps in health system performance and health management, and ensuring the effectiveness of care received. Unfortunately, patients too often are not engaged as meaningful decision makers in their own care or as partners in health research. As illustrated by the papers included in Chapter 4, the vision for a learning health system takes a broader view by making informed patients a central system goal. Achieving this goal requires medical evidence to be presented to patients in a form that is understandable and actionable, based on patient preferences, expectations, health concerns, and health literacy. Building on the foundation of an informed patient, patient engagement strategies also seek to improve collaboration, respect, and participation. As emphasized in these presentations, once engaged, patients serve as a powerful driver for enhancing value in health care by improving research, health system effectiveness, safety, outcomes, and the quality of care decisions.

**Investing Patients in the Research and Continuous Improvement Enterprise**

Patients can be engaged as full partners in research if learning transforms health care to better serve the needs and interests of individuals, families, and communities. Sharon Terry of the Genetic Alliance offered a vision for the range of contributions patients and the public can make to improve research through better use of clinical data and health information. These patient-initiated data collection efforts have established biological repositories and clinical registries that provide important resources for research and discovery. Other efforts include social networks and sites that enable the aggregation and sharing of health information, such as PatientsLikeMe®, Love/Avon Army of Women, and Facebook health groups, as well as genetics-based initiatives such as the Genetics for Early Disease Detection and Intervention to Improve Health Outcomes program at the Centers for Disease Control and Prevention. This ongoing work indicates increased public interest in participating in one’s own care, and that expanded participation will accelerate learning in the health system.
Public and Patient Strategies to Improve Health System Performance

Numerous policy statements from the public and private sectors speak to the importance of engaging patients, their families, and their communities in improving health and the experience of health care. However, no widely embraced framework exists for defining patient engagement. James B. Conway of the Institute for Healthcare Improvement proposed a two-dimensional taxonomy for such initiatives based on the chain of effect for quality (environment, organization, microsystem, and experience of care), grouped according to the elements of the Institute for Family Centered Care’s definition of patient- and family-centered care (respect, information, participation, and collaboration). Although only an initial attempt, the framework provides support for the design, measurement, assessment, and improvement of various interventions seeking to enhance different aspects of engagement.

This overarching framework underscores the importance of involving patients in their health. Decades of work illustrate the powerful potential of greater patient and public engagement to improve health system performance, including improved adherence, reduced malpractice risk, decreased adverse events, and increased employee retention. This research supports the notion that health systems can be dramatically better if staff and leaders listen to and engage with patients and families. A second, related theme from Conway’s presentation was that engaging patients and their families promotes improvements not just for one patient but also for all patients. Both themes highlight the benefits of transforming the health system by organizing it around the patient and the public.

Communicating with Patients About Their Concerns, Expectations, and Preferences

Although the necessary course of action is clear for some situations in medicine, a surprising number of clinical decisions require choice among multiple diagnostic or treatment options. According to Karen Sepucha of Massachusetts General Hospital, a high-quality choice among competing care approaches requires effective communication between patients and providers about the potential benefits and risks of each option, as well as consideration of a patient’s expectations, health concerns, goals, and personal preferences. However, the patient experience often falls short of this ideal. In general, patients are not meaningfully involved in the decision-making process, and providers do not explore patient health goals or preferences that might influence a decision (Zikmund-Fisher et al., 2010). In addition, patients receive poor information. According to one
study, just half of patients were aware of the advantages and disadvantages of the treatment or intervention under consideration, and fewer than half were able to answer correctly more than one of four to five questions about those treatments (Fagerlin et al., 2010).

These quality gaps in decision making have implications for health outcomes, patient satisfaction, and the overall value of care received. In the case of elective surgery, for example, informed patients were 25 percent less likely to choose surgery, a finding that suggests that one in four patients may be receiving unwanted care. Sepucha also reviewed existing efforts to promote shared decision making through provider training to improve communication and decision coaching skills in addition to patient coaching to facilitate discussions with providers about patient preferences and concerns. Also discussed were patient decision aids, which have been demonstrated to increase patients’ knowledge and perceptions of risk as well as improve a patient’s desire to participate in decisions (Sepucha and Barry, 2009). Improved use of these tools requires new incentives, as well as changes in the organizational structure to include patients in care decisions.

Health Information Technology as the Engine for Learning

Presenters of the papers included in Chapter 5 reviewed trends and strategies for health information technology adoption and how the necessary infrastructure can be developed as a knowledge engine, a tool for care improvement, and a portal for practical patient engagement.

Meaningful Use of Health Information Technology

David Blumenthal, formerly of ONC (now Harvard University), stressed that health information technologies, particularly electronic health records, need to be adopted more broadly if they are to contribute to learning and science-driven care. “Meaningful use” denotes an early incentive to drive adoption, with additional incentives needed for further dissemination. Dr. Blumenthal provided an update on federal efforts to create a health information technology environment based on routine, continuous learning (Blumenthal and Tavenner, 2010). Building on ONC’s statutory responsibilities under the Health Information Technology for Economic and Clinical Health Act, ONC is focusing on the nationwide exchange of health data and establishing a digital data infrastructure (Blumenthal, 2010). As the data infrastructure is built, privacy issues will need to be addressed in order to ensure access to data for research and assuring the public that their personal health information is protected.
New Classes of Data, New Opportunities to Learn

Emerging classes of healthcare data are providing new ways to measure various aspects of health care and to improve healthcare delivery, as well as translational and clinical research. Daniel R. Masys, Jack M. Starmer, and Jill M. Pulley of the Vanderbilt University School of Medicine described three examples of these data sources. The first example presents data in a novel way through dashboard displays, or real-time presentation of data, to indicate which care measures are due, done, or overdue. These displays have proved more effective than computerized alerts for individual care measures. As a second example, the Electronic Medical Records and Genomics Network uses electronic medical records to verify previous genetic studies and to discover new genetic effects with phenome-wide scanning. A final example is Vanderbilt University’s patient portal MyHealthAtVanderbilt, which supports patient and clinician communication, appointment scheduling, and access to lab results. It also acquires data on health outcomes that are seldom recorded, such as the unexpected beneficial effects of newly prescribed medications. Each of these three examples illustrates how different sources of data can be used to create a learning health organization and inform both research and care.

Web 2.0 and Patient Engagement

Health information technology is helping to bridge the gap between patients and providers by enabling communication and interaction beyond the typical clinical encounter. Kemal Jethwani and Joseph Kvedar from the Center for Connected Health at Partners HealthCare discussed the use of technology to deliver patient care outside the hospital or doctor’s office, help patients monitor their health status, and obtain relevant feedback and coaching to achieve the best possible outcomes. As an example, the Connected Cardiac Care Program enrolls heart failure patients for intensive monitoring using a weight scale, blood pressure cuff, and pulse oximeter; the patient’s data are reviewed by a nursing team that recommends follow-up care by a cardiologist if they notice concerning changes. Since the start of this program, readmission rates have been halved, and patients have reported higher awareness of how to better manage and control their conditions. Lessons learned from this and similar disease management programs include the benefits of patient engagement tools, such as consistent and meaningful feedback, coaching, and increased communication with providers, in changing patient behavior to meet clinical goals.
Patients, Clinical Decisions, and Health Management in the Information Age

The availability of health information has grown tremendously with websites, blogs, discussion groups, and forums providing ready access to information for those curious about their own or their family’s health problems. Although in general the increased abundance of information is positive, it brings several challenges. Most notably, patients now must sort through a plethora of information and judge what is reliable and what is not. Patients can easily be misdirected on the Internet, where numerous sites of uncertain benefit and possible harm abound (Tang and Ng, 2006). Likewise, when test results are provided electronically with no context, patients may be puzzled or disturbed by results that deviate from the normal range and assume the worst possible diagnosis (Hartzband and Groopman, 2010). Presenters of the papers included in Chapter 6 provided an overview of the current digital health infrastructure, ranging from health information posted online to health monitoring technologies for improving care.

Public and Patient Information Access and Use as a Core Care Component

The Internet has dramatically transformed the quantity and convenience of health information available to the public, offering users a wide range of resources from which to choose. As noted by George L. Lundberg, editor-in-chief of Cancer Commons, most patients now receive the majority of their new medical and health information from the Internet, with many accessing the information after visiting their physician to learn more about diagnoses and findings. This represents an important opportunity for physicians to deliver information to patients who are motivated and primed to learn by helping them find relevant, reliable information. In addition to making existing information more broadly available, the Internet is promoting faster translation of research through open-source science. Lundberg presented one example, the Cancer Commons, a rapid learning community focused on real-time translational cancer research and personalized oncology. These types of applications seek to build on the genomics and molecular medicine revolution while reducing the time from initial observation to successful implementation.

Health Information Technology–Based Approaches to Health Management

Through the provision of real-time information and feedback, health information technology has contributed to changing physician behavior and improving overall health system performance. However, as observed by Paul Tang of the Palo Alto Medical Foundation, if the technology
failing to engage patients and support their active participation in managing their own health, the nation will still fall short of its health goals. Tang illustrated how health information technology has been helpful in transforming the patient experience of a chronic disease such as diabetes. The Foundation provides patients with wireless glucometers that transmit glucose readings to its electronic health records system; the readings are then displayed on a diabetes dashboard and can be viewed and annotated by patients and providers. These data provide an important opportunity for patients and providers to actively monitor blood glucose and examine how it varies with daily diet, exercise, and medication regimens. Thus, patients have been able to learn how their behavior and decisions impact their health outcomes and improve their health conditions.

Health and Disease Management Outside the Clinic Doors:
There’s an App for That!

Healthcare delivery continues to change to adapt to an aging population, increased prevalence of chronic conditions, genomic medicine, and information technology advances. Dorianne C. Miller, formerly of the University of Chicago Medical School discussed three examples of innovative approaches to improve healthcare delivery by extending care outside of the clinical practice setting. The first example is a patient electronic health records portal that facilitates communication between chronically ill patients and their providers and allows patients to store all of their health-related information together in a shared care plan. This system has increased patients’ satisfaction with their clinical care and lowered costs by $3,000 per year for enrolled patients. Second is a web-based support group that allows patients to form a community that can support each member as well as provide information to the members’ clinical partners that may affect their care. Although results are not yet available, the program has drawn interest and highlighted the importance of addressing privacy and security for the participants. A final example is electronic provider visits, which extend the availability of primary care providers to care for nonurgent conditions and enhance patient–provider communications. An initial assessment of this program found that it reduced work absences, decreased costs, and lowered the number of times patients had to visit a physician’s office to solve their clinical problems. Barriers to broader adoption of these electronic applications include the social acceptability of visiting doctors via the Internet, limited access to the Internet among certain groups, a lack of electronic health records in many physician practices, and unknown reimbursement for delivering care electronically.
Applying Evidence for Patient-Centered Care: Standards and Expectations

Improving how evidence is communicated to patients is a critical challenge that must be addressed in transforming the health system to one that is centered on patients’ individual values and preferences. Presenters of the papers included in Chapter 7 explored the added value of shared decision-making tools in helping patients decide among clinical options, ways to develop evidence that better meshes with individual patient needs, and methods for communicating evidence when the evidence base is uncertain.

The Role of Evidence in Patient-Centered Care

Regardless of whether the evidence available on treatment options is clear or uncertain, patient-centered care should ensure that “patient values guide all clinical decisions” (IOM, 2001). The current method for patient feedback—the informed consent process—falls short of the goal of helping patients understand risks and benefits to make informed decisions, according to Dale Collins Vidal of the Dartmouth Institute for Health Policy and Clinical Practice. Particularly when a patient faces treatment decisions not supported by adequate evidence or when treatment can impact a patient’s quality of life, both patient and provider would benefit from a more structured decision-making process that supported informed patient choice, incorporating a discussion of treatment alternatives, the best evidence available, and the patient’s personal values. An alternative to the current decision model is shared decision making, a process that requires both patients and providers to contribute information and participate. Dartmouth has implemented shared decision making by deploying decision aids, conducting surveys of patient preferences and reported health information, providing feedback to patients about their health behaviors and conditions, and feeding forward information helpful to clinicians at the point of care. Results from experiments with shared decision making have shown its impact on treatment choices: 30 percent of patients changed their initial treatment preference, and the overall rate of surgery was 22 percent lower (Deyo et al., 2000). Further adoption of this patient decision model will require comprehensive training of healthcare providers, increased consumer health literacy, and the successful identification of implementation models.

Evidence Standards and Application: Right Care, Right Patient, Right Time

Evidence standards and their application to treatment decision making must account for specific clinical circumstances, individual variation, and the range of intervention types. As described by Clifford Goodman of The Lewin Group, evidence hierarchies and their application to patient
care have remained relatively constant despite incremental modifications. Although randomized controlled trials provide strong internal validity, overreliance on this experimental design is a critical limitation to getting the right care to the right patient at the right time. Goodman suggested the need to develop a diversity of evidence methodologies that are better tailored to specific research questions and account for real-world variations in individual circumstances, patients, and settings. An alternative evidence rating approach has been introduced by the Evaluation of Genomic Applications in Practice and Prevention initiative, which advocates a systematic process for evaluating genomic tests based on analytical validity, clinical validity, and clinical utility. Other promising approaches use multiple and complementary methods to triangulate findings. Advances in evidence standards will require engaging the public on the nature of evidence, as well as fostering greater interaction among innovators, regulators, payers, and health technology assessment organizations with respect to evidence expectations.

Translation and Communication Needs for Care in the Face of Uncertain Evidence

Ensuring that patients are informed and active partners in health care requires effective approaches to translating and communicating evidence. Unfortunately, many health messages are delivered to the public in an overly brief and simplistic manner. Fran Visco of the National Breast Cancer Coalition reviewed the effects of this communication strategy in cases where evidence is uncertain. One illuminating case study is the controversy over the U.S. Preventive Services Task Force’s updated recommendations on breast cancer screening. One reason these recommendations generated such controversy is that they conflicted with previous communication campaigns that ignored the limitations of mammographic screening, and failed to address the uncertainty surrounding the evidence behind screening. Lessons learned from this case study include the need to be honest with patients about uncertainty; the role professional societies play in influencing clinical recommendations; and the need to better educate policy makers, the media, and the public about the importance of evidence.

Team-Based Care and the Learning Culture

A system in which health professionals work as individuals limits the coordination of care, prevents the flow of information, and discourages quality improvement. Therefore, a team-based culture is key to a learning health system and improved patient care. Presenters of the papers included in Chapter 8 addressed fundamental elements of team culture, ways to create and sustain an environment that fosters the pursuit of clinical excel-
lence and continuous improvement, and the use of teams to structure care transitions that are efficient and ensure that the right person is transferred in the optimal way.

*Practical Experience with Collaborative Models in the Health Professions*

Team-based care involves more than the coordination of individuals responsible for a patient’s care. According to Allan Frankel and Michael Leonard of Pascal Metrics, successful continuous learning environments link teamwork with improvement. Currently, few in health care methodically combine these elements, probably because of differences in the origins and backgrounds in teamwork training and improvement science. Teamwork training is based on a combination of psychology, sociology, and engineering while being heavily influenced by the science of human factors. In contrast, improvement science focuses on using statistics to manage variation in stable industrial processes and derives from the teachings of skilled statisticians and managers. Weaving these disciplines together is the responsibility, and a core function, of hospital leaders and healthcare managers.

Frankel described several key barriers to the implementation of a collaborative improvement model. First, the culture of medicine often has a hierarchical structure, whether based on academic stature, hospital–physician relationships, or other factors. Second, managers currently have limited appreciation of the components of a continuous learning environment or how such an environment can be achieved. Finally, senior leaders must devise strategies and allocate resources to ensure that continuous learning systems thrive.

*Measures and Strategies for Clinical Excellence and Continuous Improvement*

Developing new models of collaborative care requires engaging all team members, including patients, in the development of evidence and its use to ensure that healthcare decisions are grounded in effectiveness, safety, and value. As noted by Joyce Lammert of the Virginia Mason Medical Center, this paradigm shift in the practice of medicine will require a fundamental change in the approach to learning and its application in providing health care—one that involves leveraging teams to support systems of clinical excellence and continuous improvement. Rapid advances in science and technology, as well as the complexity of twenty-first century care, have made old paradigms of learning and caring for patients obsolete. The necessary culture change must start in medical school, with a focus on examining patient care processes. As much of the content of medical education will be out of date by graduation, more emphasis is needed on skills for lifelong learning,
such as how to ask the right questions and use information systems to obtain just-in-time answers that are evidence-based and reflect best practices. Similar changes may be needed on the organizational level and throughout residency training as well to encourage interdisciplinary and team-based practices. Finally, moving toward a learning health system will require other changes in such areas as recruiting, the practice environment, continuing education, and the payment structure.

Care Cooperation and Continuity Across Clinicians, Facilities, and Systems

Adverse events often occur during care transitions and too often result in hospitalizations, lower quality of care, and reduced patient satisfaction. Alice Bonner, formerly of the Massachusetts Department of Public Health (now Centers for Medicare & Medicaid Services) summarized work ongoing in Massachusetts to identify and quantify issues associated with care transitions and develop and implement a statewide strategic plan for addressing those issues. The goals of this strategic plan are to disseminate current knowledge about effective care transitions, summarize the state’s current projects on care transitions, and build consensus among stakeholders on the most important principles of care transition. Key lessons learned from this process include the importance of including the patient’s voice in the process, the need to engage stakeholders early to improve cooperation across institutions, and the importance of using evaluation measures to track progress. The plan is now being implemented, with workgroups refining and deploying a statewide form and process for interfacility transfer, and education efforts on effective care transitions being initiated.

Incentives Aligned with Value and Learning

Transformative change of the health system will require incentives that are aligned with a learning health system. Incentives should focus on promoting value over volume, revamped payment schemes supporting science and value, and changes in insurance design. Presenters of the papers included in Chapter 9 provided examples of strategies that show promise for helping to realign the health system. Taken together, these papers offer key strategies that can contribute to a reengineering of the system.

Paying for Value and Science-Driven Care

If the current trajectory of healthcare spending continues, by 2020 the U.S. debt will reach 90 percent of the gross domestic product ratio (CBO, 2010). Michael Chernew of Harvard University argued that addressing this fiscal situation will require a focus on value and reduced growth in spend-
ing. Chernew discussed several incentive structures designed to promote value, from pay for performance, to episode-based bundled payments, to global payment. Although all of these approaches are promising, each has technical challenges that must be addressed before its widespread application can reduce the cost trajectory. In particular, each new payment model will require performance measurement that can account for new clinical evidence and healthcare innovation. Crucial determinants of success for these and future payment systems will be their capacity to contain costs, the way they incorporate quality and performance measures, their ability to incentivize patients appropriately, the availability of cost and quality information, and the way they encourage organizational reform.

**Generating Evidence to Guide Care**

Innovation in the American health system is driven by financial incentives that reward volume and provider revenue. According to Richard Gilfillan, formerly of Geisinger Health Plan, there are ample opportunities for improving the value for patients in the healthcare system. However, whether the system produces more or less value for patients depends on the industry’s business model. Gilfillan illustrated the impact of the current healthcare business model on innovation. Businesses proactively select innovation and learning initiatives that promise to provide a positive return on investment. Businesses further avoid innovations that might threaten their future success; an example is hospitals traditionally avoiding programs designed to decrease readmissions. Therefore, changing healthcare practice will require changing the healthcare business model toward one that rewards value. Gilfillan noted further that improvement will require multiple incentives, not just financial ones, as well as dissemination of best practices and leadership by clinicians and payers.

**Creating a Learning Culture**

Although financial incentives are clearly instrumental in transforming the health system, powerful nonfinancial incentives can be used to influence behavior and create a learning culture. Anne Weiss of The Robert Wood Johnson Foundation highlighted several of these nonfinancial incentives, from performance measurement, to technical assistance, to patient engagement. These incentives are central to the Aligning Forces for Quality strategy, which is currently being implemented in 17 regions across the country. Although still under development, the strategy has produced several insights into how to move toward a learning health system. First, health care is delivered locally, and different localities will have different needs. Second, strategic communication is critical to engage the general public, physicians,
patients, and employers in healthcare improvement. Third, progress will require participation by multiple stakeholders, from health system leaders to patients, each of whom has a role to play in measuring and improving quality. While the Aligning Forces for Quality project focused on non-financial means of creating a learning culture, such efforts are impeded by traditional payment systems that often punish learning and improvement, a fact that underscores the importance of reforming the payment system to reward quality and value.

NEXT STEPS

The workshop participants expressed optimism about building a learning health system that focuses on patients and consumers. Although many barriers may hinder this transition, transformational change is within reach. Comments offered throughout the workshop highlighted the following key questions, many of which may be addressed through the convening capacity of the Roundtable, whose exploration offers opportunities for advancement in different healthcare sectors.

Clinical Effectiveness Research

- How do various research methodologies produce results that contribute to personalized treatments, real-time learning, and clinical relevance? Should the Roundtable and its Clinical Effectiveness Research Innovation Collaborative develop a new taxonomy of research approaches that advance these goals?
- What steps can encourage greater patient involvement in the evidence process, from fostering participation in clinical trials, to initiating data collection for disease research, and developing applications from existing data?

Evidence Communication

- How can the Roundtable and its Evidence Communications Innovation Collaborative encourage the development of best practices in health communications, whereby complex information is delivered in simple and easy-to-understand formats? What steps can be taken to compile information on successful concepts, such as patient coaching, question checklists, and patient decision aids?
- What steps can be taken to encourage the education system to teach students how to analyze health information as well as related concepts, such as how to gauge risks and benefits, in order to promote broader health literacy?
• How can the Roundtable connect leaders from enterprises with expertise in consumer communications, such as media outlets and advertising, with health system leaders to transfer the lessons they have learned?
• Given that the media are a key supplier of health information, what steps can be taken to enhance the health literacy of journalists so as to improve the information delivered to the public?
• With more Americans obtaining health information from the Internet, how can the Roundtable encourage the development of websites with authoritative medical information for consumers?

Best Practices

• Given the benefits of engaging patients and families in their medical care, how might patient-centered care be encouraged throughout the medical system?
• What steps can the Roundtable and its Best Practices Innovation Collaborative take to encourage the use of technologies, such as dashboard displays or procedure checklists, that reduce variability in care management and improve the reliability of the use of best practices?
• What impediments prevent patient preferences and goals from being considered in all care decisions?
• Given the advantages of team-based care in promoting coordinated care and quality improvement, how can a team approach to care delivery be encouraged?

Electronic Health Records

• Developing a learning health system will require the use of clinical data as a reliable source for clinical research. How might the Roundtable and its Electronic Health Record Innovation Collaborative encourage the development of standards and approaches to assure the quality of these data?
• Since an effective health information utility was identified as a prerequisite for care coordination, continuous learning, and measurement of outcomes, what steps could the Roundtable and its Electronic Health Record Innovation Collaborative take to accelerate the adoption and use of such a utility?
• Given the accelerated development of medical evidence, what might the Roundtable do to explore expanded decision support at the point of care?
Value

- With the creation of new reimbursement incentives to promote value, how might the Roundtable and its Value Incentives Learning Collaborative develop a framework for ongoing assessment of the efficacy of these reimbursement experiments with respect to increasing value?
- What specific actions could be taken to reduce healthcare costs and increase value? What incentives are needed to encourage those actions?
- What incentives, financial or otherwise, are needed to encourage providers to place greater emphasis on engaging patients in their care?

REFERENCES


Appendix A

Motivating patient action on waste in health care

What have we learned?
Motivating patient action on waste in health care

What have we learned?

Health care costs have risen rapidly, stressing family, employer, and national budgets, yet these expenses often do not improve patient health and contain substantial waste. One way to reduce waste and improve overall health care value is engaging patients and the public. While questions still exist on how to routinely involve patients in health care value decisions, several key lessons are known. Implementing these lessons can help increase patient and consumer involvement in health care and improve the value of health care for the nation.

**ENGAGING PATIENTS IN HEALTH CARE VALUE | Lessons Learned**

1. **Understand what patients view as value**
   
   Improving value depends on understanding and connecting to patient goals, motivations, and values.

2. **Make sure the best information is easy to find and use**
   
   Information on quality and cost should be easy to find and comprehensive enough that individuals can truly understand and use it.

3. **Information is not enough**
   
   Information alone is not enough to support high-value decisions, but multiple strategies are needed to support patients as they seek to increase the value of their care.

This document serves as a companion item to the Institute of Medicine Discussion Paper Demanding Value from Our Health Care: Motivating Patient Action to Reduce Waste in Health Care by Margaret O’Kane et al. The full Discussion Paper can be found online at www.iom.edu/PatientsForValue. For more information contact, vsrt@nas.edu.
ENGAGING PATIENTS IN HEALTH CARE VALUE | Key Messages

Patients, consumers, and the public
- Researchers have found that the quality and value of medical care varies substantially among doctors, hospitals, and communities—even among highly reputable physicians and other providers.

Clinicians
- Different choices are appropriate for different patients, and clinicians cannot provide high-value care without engaging patients to understand their goals, values, and motivations.
- Clinicians play an important role in discussing cost and quality information with patients.

Employers and insurance companies
- Incentives have been shown to be effective if they are thoughtfully designed to reward and encourage greater value.
- Engaging patients in developing incentives can improve their effectiveness by understanding patient needs, motivations, and goals.

Health care system
- Cost and quality need to be improved overall to ensure the sustainability of the health care system.
- Consumers and patients often lack the information they need on quality and value to compare and evaluate health care options—from clinicians to treatments to hospitals.
- Given the size of the problem, everyone involved in the health care system—patients, doctors, hospitals, employers, and others—needs to work for a high-quality, high-value system.

States
- Insurance exchanges offer an opportunity to promote value, provide more information on cost and quality, and offer other tools to help consumers and patients make decisions.

Researchers and research funding agencies
- Research is needed to better understand effective ways to engage people around value.
- More research needs to be done to create practical tools that can be used by patients, their families and caregivers, and clinicians in conversations about value.
What can be done about rising health care costs?

The cost of health care is becoming increasingly unaffordable for many patients, families, businesses, and the nation. In the past decade, insurance premiums for families and individuals have more than doubled. Yet, the situation will not improve by cutting costs across the board—that would eliminate waste but also the treatments, screenings, and prevention that make people healthier. For this reason, the goal should not be to cut costs, but to improve the value of health care overall. In basic terms, this means that patients receive the best-quality care for their money.

While it is easy to talk about value, it is much harder to measure and improve it. Value means different things to different people and groups—physicians, insurance companies, manufacturers, employers, and patients have different perspectives on what is valuable in health care. Even when agreeing that something is valuable, different groups of patients will consider different treatments or medical services more or less valuable. Given that patients are key and central participants in the health care system, value should always include the patient’s perspective, accounting for how care improves the patient’s health, quality of life, and overall experience.

Why is it important for everyone to be engaged in the value of health care?

In addition to the fact that engaging patients is the right thing to do, greater engagement of patients, people, and the public has the potential to improve health care value. Studies have shown that when patients are involved in decisions and weigh risks and benefits, they choose fewer tests and treatments, and overall costs are lowered. Involving patients and consumers can have a powerful impact in improving health care value and making sure that resources are devoted to areas that improve patient health.

Engaging patients and consumers in health care value is an urgent priority. Changes in the structure of health insurance, such as the rise of high-deductible health plans, have increased the level of costs borne directly by patients and consumers. These changes require patients and consumers to play a greater role in considering the value of care.

Yet, there are opportunities to better involve patients in health care, especially people’s growing willingness and ability to research many aspects of their lives. In a recent survey, almost 60 percent of individuals were willing to do detailed research before buying a car (and were able to find useful resources for this purpose) and 50 percent do so before buying a major appliance. While health care is different from buying a car or appliance, people’s growing interest in research and ability to do so change the way they consider health care decisions.

While some strategies for involving people in health care value have succeeded, there are many unanswered questions and challenges, and there is room for improvement. However, much is now known on effective ways to team with people to discuss value, deliver better value, and help with health care decisions.
What are the key challenges to engaging people more effectively in health care value?

Understanding the challenges that patients face is fundamental in expanding their engagement in health care value. In general, making decisions based on health care value is difficult work and generally only done by the most involved and motivated patients. There are several other challenges that prevent its consideration.

Concerns about rationing
Many people are reluctant to talk about getting better value for their care. There is often a fear that value is a code word for rationed, cheap, or low-quality care. As a result, support for programs that encourage people to consider value when selecting clinicians or treatments is limited.

One patient's struggle to find a physician
Mr. A, a previously healthy 37-year-old man, suffered a heart attack 3 years ago and was diagnosed with several unusual cardiac conditions. He developed a relationship with a cardiologist at a large health center in his area and appreciated his physician’s attention to adverse effects from medication. In the spring of 2009, Mr. A’s cardiologist moved to another area, requiring him to select a new clinician for his care. As he looked for a new physician, he couldn’t find the information he wanted. He disliked the top physician lists, feeling that they weren’t asking the questions he cared about, and struggled to find basic information on many of the cardiologists in his area. Further, as his conditions were unusual he questioned whether the general findings reported on many websites would actually apply to someone like him. His story highlights the issues that patients have in learning about potential clinicians, and the need to customize information to different patients.


Lack of resources and tools
While people may conduct detailed research before buying a smartphone or a stove, few individuals do so when choosing a physician or considering medical treatments for a disease—some recent surveys suggest that less than 30 percent of patients research potential physicians before selecting one. One reason is the lack of clear, reliable resources. It is very difficult for patients to find the price or what they can expect to pay out of pocket for treating a disease. As noted in the earlier survey, 40 percent of patients indicated that they were uncertain that they could find a better-qualified doctor through more research while 60 percent were not confident that they could reduce the cost of health care by shopping around.

Few know how much quality varies
There is a widespread perception among patients that quality does not significantly vary between different hospitals or clinicians, with many believing that all health care must meet some minimum quality standards. Careful shopping seems unnecessary if all health care is expected to be of a certain quality. Yet, research has shown that wide differences exist in the quality of care delivered by different hospitals and physicians.

High prices can be seen as better quality
Without information on the quality of health care, most people are inclined to believe that a higher price means better care. Research suggests that this is not true. Expensive care is not necessarily better quality than inexpensive care; in fact, the opposite is often true. This shows the need to link prices and quality information together.
Difficult conditions for making decisions

Unlike other consumer decisions, health care decisions are often made under very difficult circumstances. For example, it is unlikely that an individual suffering a heart attack is going to research hospitals while in an ambulance. Moreover, patients who deal with chronic diseases like diabetes or high blood pressure will need to devote ongoing attention to managing and making decisions about these conditions. Patients managing these types of health conditions will respond differently to incentives and may have different views on health care value than patients facing other types of health conditions.

First lesson learned: Understand what patients view as value

One lesson is that the success of value initiatives depends how well they connect with and include patient goals, desires, and motivations. A person’s internal motivations can be a powerful resource for long-term change. This is why it is important to discover a patient’s goals and motivations.

There are often misconceptions about what patients view as value. Some organizations and hospitals have tried to become more patient-centered by focusing on customer service and food, for instance. Yet, this is not necessarily in line with what studies show patients want and care about. Instead, patients want medical care

• of high technical quality; and
• with adequate facilities.

Most patients desire a personal relationship with their care provider. Patients want someone who knows them and their history, listens to them, and communicates well. When patients have a high-quality relationship with a clinician, health outcomes can improve. In one study, HIV patients who felt their provider knew them as a person were more likely to take antiretroviral therapy, adhere to that treatment, and have better outcomes.

Patients also want their doctors to be on top of the latest science, and are generally supportive of research efforts to improve medical knowledge. However, research also shows that patients can become concerned about medical evidence if they think it might limit their

Customizing messages increases their potential usefulness

While information is important in itself, the more customized the information is to a particular patient, the more likely it is to be used. As an example, one study looked at how likely patients were to take a particular cholesterol medication (a statin). Some patients were given a generic guide to cholesterol, while others received feedback customized to their knowledge about cholesterol, their beliefs and values, and the barriers they identified to taking a medication. At the end of 6 months, 70 percent of the patients who received the more customized messages were still taking their medications, compared to 61 percent of those who received generic materials.

While this is a clinical example, the same principle is true for information about value. Adapting the message to an individual’s beliefs, knowledge, and goals will be more likely to succeed than offering generic information.

Source: Stacy et al., 2009.
options or if the evidence is perceived to create inflexible guidelines. Patients want the latest and best information, but want to maintain choice and autonomy.

Beyond value in medical care, there are emerging lessons about what consumers value in health insurance plans. They evaluate health plans not only on price, but also on the services that are covered and how much they would pay out of pocket for those services.

Yet, patients are not uniform in their views. Opinions about value vary from town to town and from state to state. The right answer for any individual depends on their personal characteristics, values and goals, and supports.

**Second lesson learned: Make sure the best information is easy to find and use**

A second lesson is that information should be easy to find and comprehensive enough so that individuals can truly understand and use it. Too often, it is hard to find reliable sources of information on health care providers, hospitals, or health plans. People then turn to the stories or opinions of their friends and family.

Existing cost and quality reports are frequently difficult to use, with information frequently presented in a confusing format or with confusing language. People will not use information they cannot easily understand. To be useful, the reports should use clear graphics and plain language to help people find what they need to know.

Other factors can affect whether people use reported information. In some areas of the country, people may have only one health care option to choose from, so there is little to gain from research. In addition, many individuals prefer to use stories, personal examples, and information that speaks directly to their own individual situation, rather than statistics, for making health care decisions.

Frequently, the information is very complex and difficult to understand, from medical terminology to health insurance benefit arrangements. Understanding the terms and concepts can be challenging, especially when they are placed within a lengthy document. Even for those familiar with health care, common health benefit terms—like deductible, co-insurance, and out-of-pocket limits—can be difficult to apply in everyday value decisions. This complexity makes comparison shopping and informed selection difficult.

**Finding the price of care**

Finding the price of a particular treatment or test can be very difficult. Brad, a student from North Carolina, experienced this problem after developing a sinus infection. As Brad had a high-deductible, catastrophic insurance policy that covered only four physician visits a year, he was very concerned about the cost of treating this condition. His physician prescribed lab work and a CT scan, but Brad knew that his insurance would not cover the CT scan. At first, he asked admissions for the price. Admissions didn’t know, so they called the imaging department, which also didn’t know. Finally, admissions found the price of a sinus CT scan ($900) in a little-used black binder. Brad declined the CT scan, but went to the lab. Unfortunately, his physician had referred Brad to a lab that was out of network for his insurance. A month later, he received a bill for $478. Brad learned that when looking for medical care, even routine services, finding the cost of care is frequently the biggest challenge.

*Source: Shah, 2010.*

These challenges highlight the need to provide simple, clear information any time a consumer needs it. To be useful for decision making, information must be
Third lesson learned: Information is not enough

A third lesson is that information alone is not enough to support high-value decisions. Rather, multiple strategies are needed to support patients and consumers as they seek to increase the value they achieve from their care.

As mentioned earlier, most health care decisions are complex and are made under considerable uncertainty. In complex situations, people tend to use rules of thumb to make decisions and tend to stick with default options. In addition, people often will delay decisions or not make them altogether. This will occur even if patients are unhappy with the current situation and would prefer to make a change.

Supporting patients with chronic diseases

Many patients in America have long-term, chronic diseases like diabetes or asthma that require them to take medications for long periods of time. Many people stop taking their medications regularly, which can cause their disease to get worse because it’s not being treated properly. To improve this problem, Pitney Bowes redesigned its prescription drug program. It lowered the amount that employees had to pay to fill prescriptions to treat diabetes and heart disease. As a result, more employees stayed on their medications. For employees with diabetes, pharmacy costs were lowered 7 percent, emergency room visits were reduced by 26 percent, and insurance costs for diabetes patients were reduced by 6 percent.

Source: Choudhry et al., 2010a; Mahoney, 2005.

One way to support consumer decisions about value is providing financial incentives that reward considering quality and value. Yet, these incentives will not be successful unless they are designed with an understanding of how people actually respond to financial moti-
vators. As patients pay more for health care, they cut back on all of their health care—whether it is of high value (like insulin for a patient with diabetes) or not.

How do people actually respond to financial incentives? People have stronger feelings about losing a given amount of money than gaining the identical amount, they are optimistic about their chances of success, and tend to focus on the present over the future. Incentives that account for these human factors (like the lottery example) have a greater chance of success. For example, a payment at the end of the year may not encourage someone to exercise three times a week, as the pain of exercising is immediate while the reward is far in the future. Finally, different types of patients respond differently to incentives. To have a better chance of success, incentives need to be customized to particular health care situations and to specific patients’ capabilities, preferences, and needs.

For more information, please consult the following resources:

**Benefits of Centering on Patients**


**Value from a Patient and Consumer Viewpoint**


**Present Cost and Quality Information Effectively**


RWJF. 2010. How to display comparative information that people can understand and use. Princeton, NJ: RWJF.


How Patients and Consumers Respond to Incentives


Case Studies


This document serves as a companion item to the Institute of Medicine Discussion Paper *Demanding Value from Health Care: Motivating Patient Action on Waste in Health Care*¹ which was authored by:

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¹The views expressed in the Discussion Paper are those of the authors and not necessarily of the authors’ organizations or of the Institute of Medicine. This Issue Brief and the paper are intended to help inform and stimulate discussion. They have not been subjected to the review procedures of the Institute of Medicine and are not a report of the Institute of Medicine or of the National Research Council.
Appendix B

Examples of Quality and Cost Reporting

Varied sites exist for consumer information
# Examples of Quality and Cost Reporting

Varied sites exist for consumer information.

## Examples of Quality Reporting

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<th>Resource</th>
<th>Description</th>
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| AHRQ Chartered Value Exchanges [www.ahrq.gov/qual/value/lnceveoer.htm](http://www.ahrq.gov/qual/value/lnceveoer.htm) | The Agency for Healthcare Research and Quality (AHRQ) organizes a network of multi-stakeholder, community-based organizations. Examples of organizations that publish quality measures and statistics include:
- Kansas City Improvement Consortium’s Quality Health Together: [www.qualityhealthtogether.org](http://www.qualityhealthtogether.org)
- Maine Health Management Coalition’s Get Better Maine: [www.getbettermaine.org](http://www.getbettermaine.org)
- Utah’s HealthScape: [www.utahhealthscape.org](http://www.utahhealthscape.org) |
| AHRQ Health Care Report Card Compendium [www.talkingquality.ahrq.gov/content/reportcard/search.aspx](http://www.talkingquality.ahrq.gov/content/reportcard/search.aspx) | The AHRQ provides a variety of resources to help reporting organizations publish quality information. As a part of this initiative, AHRQ has assembled a comprehensive list of quality reports, searchable by subject, state, sponsor, data type, and other criteria. |
| Care About Your Care [www.careaboutyourcare.org](http://www.careaboutyourcare.org) | The website provides printable handouts with tips for consumers on how to get better health care. A highlighted resource is the Robert Wood Johnson Foundation’s “Comparing Health Care Quality: A National Directory,” which provides quality reports available from around the nation. The website also provides a list of additional resources to find quality care. |
| CMS Hospital Compare [www.hospitalcompare.hhs.gov](http://www.hospitalcompare.hhs.gov) | Medicare’s hospital compare tool allows users to compare quality measures from hospitals located within or around any given zip code. The website also publishes Medicare payment information. |

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| **Consumer Health Ratings**  
  [www.consumerhealthratings.com](http://www.consumerhealthratings.com) | This online resource is provided as a free, public service by the Dahlen Company, and consolidates quality rating information for hospitals, providers, nursing homes, home health agencies, and other health care providers. |
|---|---|
| **HealthCare.gov**  
  [http://www.healthcare.gov](http://www.healthcare.gov) | Created by the Affordable Care Act, this will be a one-stop resource for quality information. The website currently links to Partnership for Patients and Medicare Physician, Hospital, Nursing Home, Home Health, and Dialysis Facility Compare. |
| **HealthGrades**  
  [http://www.healthgrades.com](http://www.healthgrades.com) | Users search for doctors (including by specialty), dentists, and hospitals in a given area. Published information includes provider demographics, accepted insurance, and whether they are accepting patients. Quality metrics are self-reported patient survey data. These surveys also generate “stars” that rank a provider from 1–5 stars. |
| **Joint Commission Quality Check**  
  [www.qualitycheck.org/consumer/searchQCR.aspx](http://www.qualitycheck.org/consumer/searchQCR.aspx) | This website provides a search engine so users can find Joint Commission accredited health care organizations. |
| **Leapfrog Group Hospital Quality Compare**  
  [www.leapfroggroup.org/cp](http://www.leapfroggroup.org/cp) | The website publishes self-reported overall patient safety ratings, with four bars that indicate progress toward meeting Leapfrog’s standards. |
| **NCQA Clinician Directory**  
  [www.recognition.ncqa.org](http://www.recognition.ncqa.org) | NCQA provides a search engine to find physicians, broken down by state, who have met the criteria for NCQA recognition programs. |
| **NCQA Health Plan Report Card**  
  [www.reportcard.ncqa.org/plan/external](http://www.reportcard.ncqa.org/plan/external) | The website is a directory of health plans searchable by name, state, zip code, and plan type. NCQA provides the plans’ overall accreditation status. Users can then compare plans to learn further details. |
| **UCompareHealthCare**  
  [www.ucomparehealthcare.com](http://www.ucomparehealthcare.com) | Users can search for physicians, hospitals, senior care, insurance, clinics, and pharmacies by zip code. The website has a “compare” function so users can look at selected health care providers side by side. Hospital and nursing home profiles include quality measures such as patient satisfaction. |
| **U.S. News & World Report Health Plans**  
  [www.health.usnews.com/health-plans](http://www.health.usnews.com/health-plans) | Users can search for how health plans are ranked, broken down by state. The website includes articles that define health insurance terminology and tips on how to pick the best plan. |
Partnering with Patients to Drive Shared Decisions, Better Value, and Care Improvement

In February 2013, the Institute of Medicine’s Roundtable on Value & Science-Driven Health Care convened a workshop, gathering patients and experts in areas such as decision science, evidence generation, communication strategies, and health economics to consider the central roles for patients in bringing about progress in all aspects of the U.S. health care system. This Meeting Summary is being released in conjunction with a complete transcript of the event, the Workshop Proceedings. Over the course of 2 days, 31 speakers commented on the importance of patient and caregiver engagement in achieving the best care at lower cost.

The discussions highlighted the critical role and capacity for patients and families to be leaders in informed care decisions, knowledge generation, and value improvement. Individual workshop participants identified a few overarching themes and messages.

Overarching themes and messages:

• **Culture dominates.** “Culture eats strategy for lunch every time,” as mom-turned-advocate Cristin Lind noted. Thus, improving the quality of the care experience and using limited resources wisely will require significant culture shifts.

• **“Listen first, listen fully.”** That’s what Ekene Obi-Okoye, a premedical intern at the University of California, San Francisco, learned as she supported patients with breast cancer. By listening first and listening fully, patient and caregiver voices are integrated fully into every possible level of decision making—care, system design, and policy making—and the quality of care improves.

• **Patient engagement is a skill, not a trait.** Being an engaged patient and actively engaging patients are not intuitive skills. Patients and clinicians learn these skills over time and through partnership with a supportive care team.

• **Trust matters.** Effectively delivering cost and quality information requires trusted translators who convey information in ways that are easy to understand.

• **Prepared, engaged patients are a fundamental precursor to high-quality care, lower costs, and better health.** Achieving and exceeding these three basic aims of health and health care policy calls for partnering with patients as leaders and drivers of care improvement.

**INFORMED, SHARED CARE DECISIONS**

A meaningful care experience is when the patient is fully informed and the provider has elicited the patient’s preferences and goals.

Evidence strongly indicates that when patients are fully informed and engaged in making decisions about their care, patient satisfaction goes up, results improve, and health care costs go down, stated Gary Langer of Langer Research Associates and a number of other workshop participants. In pursuit of more and higher-quality shared decision making, the first workshop session explored how to increase demand for shared decisions, as well as the changes in infrastructure, culture, and training that would be necessary.
• **Patients want to be partners in their health.** When patients receive clear information about their choices, most want to be an equal decision maker when choosing their care plan, Langer observed in his presentation.

• **Strong and visionary leadership promotes culture change.** The leaders of health care organizations can ensure that shared decision making is part of routine practice by setting the standards, pointed out Grace Lin of the University of California, San Francisco.

• **Training can help patients and clinicians engage in shared decisions.** Informed conversations are facilitated by patients who learn to ask questions and clinicians who learn to listen fully, noted Sherrie H. Kaplan of the University of California, Irvine.

According to many workshop participants, improvements in reliable capture of data from the care experience will make knowledge generation more timely and clinically useful. But clinical data use requires individual patients not only to make informed choices about privacy and security, but also to be informed stakeholders in the knowledge generation process, remarked Susan Brown Trinidad of the University of Washington.

**Building trust and understanding is the foundational element in using health data for evidence development,** added Nancy E. Kass of Johns Hopkins Bloomberg School of Public Health. Clinicians frequently are asked to serve as trusted translators when it comes to discussing privacy, security concerns, and the potential benefits and harms of data sharing, a number of speakers pointed out. When patients and clinicians partner to make data more readily available, this enhances the real-time learning potential and leads to better care.

• **Various incentives promote data sharing.** Evette Ludman of the Group Health Research Institute explained that patients are motivated to share their data by altruism, trust, and clear explanations of impact, risks, and benefits.

• **Effective clinician communication strategies can help.** By facilitating conversations about new evidence development, clinicians can enable patients to advocate for using their health data for care improvement, observed patient advocate Mark Gorman.

• **Patients want to be asked about using their data.** Applying practical and trusted approaches to privacy and consent can address the imperative to draw, in a seamless fashion, on clinical data for scientific advances, Group Health’s Ludman continued.

• **Information feedback loops capture and apply lessons learned from the patient experience.** Kenneth D. Mandl, of Children’s Hospital Boston, Harvard Medical School, and Harvard-MIT Health Sciences and Technology, noted that bidirectional communication on patient-reported outcomes ensures that data are being used efficiently and effectively.

• **Distributed leadership fosters patient engagement.** When patients are partners in their health and owners of their data, health care quality improves, Genomera Genetic Alliance’s Greg Biggers remarked, echoing other speakers.
• **Patients look for choices they can understand easily and immediately.** Cost and quality information is more useful to patients when it is readily available, transparent, and presented in a meaningful way, stated John Santa of Consumer Reports Health Ratings Center.

• **Incentive feedback loops are a dynamic part of the care process.** Multiple panel members expressed support for making quality information transparent in order for the system to learn and improve.

• **Patients choose care tailored to their individual preferences.** Patients primarily care about choosing the care that is right for them given their individual circumstances, although concern about out-of-pocket costs is also increasing, Tresa Undem of PerryUndem observed.

• **Paying for health care is a social decision.** Although many health care choices are made individually, we pay for them communally, explained Marge Ginsburg of the Center for Healthcare Decisions. Given this, patients increasingly want to weigh in on the incentive structures and trade-offs that affect them, she continued.

In an efficient health care system, care choices are democratized and based on the best evidence, J. Michael McGinnis of the Institute of Medicine summarized. Though the infrastructure and cultural changes necessary to transform the patient role are significant, empowering patients to become partners in—rather than customers of—the health care system is a critical step on the road to achieving the best care at lower cost, McGinnis continued.

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**FIGURES: Patients want shared decision making.** with up to 81% saying they want an equal say in their care decisions (left). Although some patients were less willing to participate in shared decision making, the gap between patients of varying educational levels and language abilities largely disappeared when they were provided clear and understandable information (right).

<table>
<thead>
<tr>
<th>% Who want an equal say in care decisions</th>
<th>% Who prefer to leave decisions to their care provider</th>
</tr>
</thead>
<tbody>
<tr>
<td>Initially</td>
<td>If clear information about treatment options is provided</td>
</tr>
<tr>
<td>&lt;HS</td>
<td>College grad</td>
</tr>
<tr>
<td>39%</td>
<td>76%</td>
</tr>
<tr>
<td>59%</td>
<td>72%</td>
</tr>
<tr>
<td>81%</td>
<td>75%</td>
</tr>
</tbody>
</table>

% When clear info is provided

<table>
<thead>
<tr>
<th>&lt;HS</th>
<th>College grad</th>
<th>Whites</th>
<th>Latinos</th>
<th>Non-English speakers</th>
<th>English speakers</th>
</tr>
</thead>
<tbody>
<tr>
<td>47%</td>
<td>76%</td>
<td>90%</td>
<td>77%</td>
<td>43%</td>
<td>72%</td>
</tr>
<tr>
<td>72%</td>
<td>72%</td>
<td>72%</td>
<td>72%</td>
<td>72%</td>
<td>90%</td>
</tr>
</tbody>
</table>

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If patients recognize and expect high-quality, efficient health care, providers will respond, a number of workshop speakers noted. **Since normal market forces are not at work, health care is unlike other industries in that cost is not a proxy for quality,** explained Judith H. Hibbard of the University of Oregon. Indeed, presenting value information in isolation is not effective in helping patients make good decisions; information about quality must be included as well. Thus, patients and families need better access to cost and quality information, provided by a trusted source, to support informed decision making, Hibbard continued. Bringing transparency to cost and quality at the system level necessitates changes in the culture and infrastructure of collecting and communicating this information.
PLANNING COMMITTEE ON PARTNERING WITH PATIENTS TO DRIVE SHARED DECISIONS, BETTER VALUE, AND CARE IMPROVEMENT**

Christine Bechtl (Chair), Advisor and Former Vice President, National Partnership for Women & Families; Terry Adirim, Director, Office of Special Health Affairs, Health Resources and Services Administration; Leah Binder, Chief Executive Officer, The Leapfrog Group; Veronica Goff, Vice President, Institute on Health Care Costs and Solutions, National Business Group on Health (formerly); Mark Gorman, Patient Advocate, Former Director of Survivorship Policy, National Coalition for Cancer Survivorship; Paul Grundy, Global Director of Healthcare Transformation, IBM; Art Levin, Director, Center for Medical Consumers; Jim Mangia, President and Chief Executive Officer, St. John’s Well Child & Family Center; Lyn Paget, Managing Partner, Health Policy Partners; Eric Racine, Vice President, Advocacy, Sanofi U.S.; Susan C. Reinhard, Director, Public Policy Institute, AARP; Craig Robbins, Medical Director, Clinical Guidelines (KP Colorado), Kaiser Permanente; John Santa, Director, Consumer Reports Health Ratings Center, Consumers Union; Susan Sheridan, Deputy Director, Patient Engagement, Patient-Centered Outcomes Research Institute; and Susan Brown Trinidad, Research Scientist, University of Washington.

*IOM planning committees are solely responsible for organizing the workshop, identifying topics, and choosing speakers. The responsibility for the published Meeting Summary rests with the institution.

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DISCLAIMER: This Meeting Summary has been prepared by Valerie Rohrbach and Barret Zimmermann as a factual summary of what occurred at the meeting. The statements made are those of the authors or individual meeting participants and do not necessarily represent the views of all meeting participants, the planning committee, The Roundtable on Value & Science-Driven Health Care, or the National Academies. IOM forums and roundtables do not issue, review, or approve individual documents. The responsibility for the published Meeting Summary rests with the Workshop rapporteur and the institution. For additional information regarding the meeting, or to read the Workshop Proceedings in full, please go to www.iom.edu/partneringwithpatients.

The summary was reviewed by Christine Bechtl, National Partnership for Women & Families, and David Arterburn, Group Health Research Institute, to ensure that it meets institutional standards for quality and objectivity.

This workshop was partially supported by the Gordon and Betty Moore Foundation and the Blue Shield of California Foundation.
### Examples of Cost Reporting*

<table>
<thead>
<tr>
<th>Resource</th>
<th>Description</th>
</tr>
</thead>
</table>
| FAIR Health  
[www.fairhealth.org](http://www.fairhealth.org) | The website helps insurers calculate out-of-network costs and allows consumers to examine the reimbursement process. Other tools for consumers include a glossary of terms and videos that help explain the reimbursement process. |
| Healthcare Blue Book  
[http://healthcarebluebook.com](http://healthcarebluebook.com) | This online tool allows users to find standard prices for a variety of procedures based upon their zip code. The website calculates average prices based upon local billing and medical payment data. |
| Hospital Price Reporting  
*Various resources available* | In several states, hospital associations are publishing price information for consumers. Examples include  
- Colorado: [www.cohospitalprices.org](http://www.cohospitalprices.org)  
- Wisconsin: [www.wipricepoint.org](http://www.wipricepoint.org) |
| Insurer Price Reporting  
*Various resources available* | Some insurers provide information to their members on the cost of health care services, and allow users to calculate out-of-pocket expense estimates. Examples include  
- Aetna Member Payment Estimator  
- Anthem Care Comparison |
| State Price Reporting  
*Various resources available* | Several states publish not only quality information for providers and hospitals within the state, but also the prices for treatments and services. Examples include  
- New Hampshire Health Cost: [www.nhhealthcost.org](http://www.nhhealthcost.org)  
- Massachusetts’ MyHealthCareOptions: [www.hcqcc.hcf.state.ma.us](http://www.hcqcc.hcf.state.ma.us) |

* Several highlighted initiatives were first identified in the October 24, 2011 U.S. Government Accountability Office report, *Health Care Price Transparency: Meaningful Price Information Is Difficult for Consumers to Obtain Prior to Receiving Care.*
SECTION VI
Logistics and Participant Biographies
Building the Patient and Family Advisory Leadership Network for Better Care
November 11, 2013

Participant Biographies
Below are excerpts from short biographies presented by participants.

David Andrews is a retired college professor from Keene State College, NH – Cognitive Neuroscience. For nine years, he has been a patient advisor at the Georgia Regents Medical Center (formerly Medical College of Georgia), serving on a number of standing patient advisory committees as well as a wide variety of short-term and special projects, and doing presentations about that work locally, nationally, and internationally. He is the patient advisor for the Georgia Hospital Association Hospital Engagement Network (HEN) and has also begun some work with patient groups in Maine where he has a summer home.

Anne-Marie J Audet, MD, MSc is vice president for the Delivery System Reform & Breakthrough Opportunities programs at The Commonwealth Fund. Audet has worked in the field of health system quality improvement for over 20 years and brings a deep understanding of the science of quality improvement, as well as an appreciation of the barriers and enablers that come into play when having to translate knowledge into real-world situations. At The Commonwealth Fund, Audet oversees the Fund’s benchmarking and public reporting site, WhyNotTheBest.org. Audet oversees a portfolio of grants that target delivery system reform and the role of coordinated care systems that integrate clinical care, behavioral and long-term and social services for high-cost, complex populations, as well as a new portfolio of work on breakthrough opportunities. Prior to joining the Fund, Audet worked in policy analysis at the American College of Physicians leading the implementation of the Medicare Health Care Quality Improvement Program in Massachusetts while working at the Massachusetts Peer Review Organization. She served as director of the Office for Clinical Effectiveness/Process Improvement at Beth Israel Deaconess Medical Center in Boston, where she was responsible for development of quality measurement systems, educational programs, and institution-wide medication safety initiatives, and as an assistant professor in medicine at Harvard University. She was also co-editor of "Clinical Crossroads," a series published monthly in the Journal of the American Medical Association. She also served on the Institute of Medicine Subcommittee on Quality Improvement Organizations' Evaluation. Audet is an assistant professor of medicine and public health at Cornell University and is a founding board member of the Massachusetts Medical Society and Alliance Charitable Foundation Board, now serving as a special advisor. Audet holds a BSc in cell and molecular biology, an MD and MSc in Epidemiology from McGill University and an SM in health policy and management from Harvard University.

Shari Berman is a two-time cancer survivor. She was diagnosed with Hodgkin’s disease in 1989, upon returning from her honeymoon, and with Breast Cancer in 1997, then a mother of 1 and 3 year old boys. Shari lost her mother to Lung Cancer in 2003 and was very involved in her mother’s care and treatment. She has the perspective of both patient and family member. After graduating from Cornell University, Shari spent 15 years in the Financial Services industry as a Human Resources Manager and Vice President. She brings business experience and project management skills to her work at Dana Farber as Co-Chair of the Adult Patient and Family Advisory Council. Shari has been a co-chair for three years and has expertise in developing patient and family advisory councils including developing by-laws, setting terms limits, recruitment and
retention of members and working in partnership with leadership of the institute. Shari has spoken on behalf of Dana Farber at several fund raising events and presentations on survivorship and patient care. She has volunteered for various cancer organizations and non-profits in her community. Shari is especially passionate about devoting her time to the council at Dana Farber as a way of taking her life experiences and using them in a positive way. Her interests are in survivorship and patient centered care.

**Kate Berry** is the Chief Executive Officer of National eHealth Collaborative (NeHC), a public-private partnership that works with its partners, including the Office of the National Coordinator for Health IT (ONC) in the U.S. Department of Health and Human Services (HHS), to engage stakeholders in a collaborative way to realize common goals that lead to transformative change. Prior to joining NeHC, Berry was Senior Vice President of Surescripts, working with a wide range of healthcare stakeholders at the national and state level to lead and coordinate electronic prescribing, electronic medical record and health information exchange initiatives. Berry was also the Executive Director of the Center for Improving Medication Management. Berry joined NeHC after a career in healthcare management consulting and as a non-profit executive. As a consultant, Berry conducted a wide range of strategic planning and related engagements with healthcare organizations. At the American Red Cross, Berry served as Executive Vice President of External Affairs and Chief of Staff. Berry holds a Masters degree in public policy from Duke University and a Bachelor of Arts degree in political science and English from Goucher College in Maryland.

**Rachel Biblow, MSW, LCSW** is the Director of Social Work and Family Services at the Children's Hospital of Philadelphia (CHOP). In this role, she has direct oversight for the administrative, operational and financial activities for Social Work services, Family Relations, Language Services, Spiritual Care, Family Centered Care Programming and the hospital resource centers. Rachel first came to CHOP in 2002 as a graduate student working in the Newborn Intensive Care Unit (NICU) and formally joined CHOP as the Social Worker for the inpatient Adolescent Medicine team in 2003. She has held multiple roles and interim assignments throughout her career and is passionate about improving quality and safety in healthcare. Rachel is an international speaker on Family Centered Care and Social Work leadership and has presented at multiple health systems and conferences. In April of 2012, she was appointed to lead the overall design and implementation of an organization-wide patient experience strategy, to improve overall patient and family satisfaction at CHOP. Through her collaborative efforts, she is establishing the necessary infrastructure, improved systems and processes to drive alignment with CHOP’s leadership principles and the hospital’s core value of Family-Centered Care to improve the overall care experience at CHOP. Rachel holds a Bachelor’s degree in Psychology, from the Pennsylvania State University and a Masters in Social Work from the School of Social Policy and Practice at the University of Pennsylvania.

**Chrissie Blackburn** is a recognized advocate for patient and family engagement in healthcare. Parent to a medically-fragile child herself, she is currently serving as president of Rainbow Babies and Children's Hospital’s (RB&C) Family Advisory Council and serves on RB&C’s quality board Committee. She also serves as one of the parent voices on behalf of the pediatric population in CMS’ Partnership for Patients Campaign's Patient and Family Engagement Network (PFE Network) and co-leads their Best Emerging Practices and Success Stories affinity group. In addition, she is a member of the steering committee for Service Excellence of Patient Experience for the University Hospital's system and University Hospital's Case Medical Center. Blackburn participates on The Ohio Children's Hospitals' Solutions for Patient Safety's Family Engagement Team, and has been invited to sit on Ohio's Quality Improvement Organization's (KePRO) Hospital Acquired Infection Learning and Action Network; she is also serving on the Children's Hospital Association’s Speak Now for Kids Advisory Board for their website launch to increase communication of parents with
medically fragile children and US congressmen and women and the importance of Medicaid. Last, she has been asked to serve on The Ohio Patient Safety Institute Board as a patient voice. In the past two years, Blackburn has encouraged dialogue among medical and nursing staff, students, and health care leaders teaching patient and family engagement and how it can improve outcomes. She has also developed a communication program for hospitals to increase and enhance patient and family engagement at the bedside with caregivers. She is passionate about patient and family engagement and recognizes it was her ability to communicate with her daughter’s care teams that played a critical role in her daughter’s quality of life. She holds a Bachelor of Liberal Studies with a focus in psychology and sociology from Bowling Green State University and is pursuing a Master of Health Care Administration degree.

Kimly S. Blanton, MIS, MLS has been a Patient Advisor at Vidant Health System, Greenville, NC, for five years. After going into anaphylaxis shock during a cardiac catheterization in 2001, Kim has been a patient in five different hospitals (of four different health systems) with over 100 hospitalizations, 12 surgeries and 17 blood transfusions. Kim has used her experiences to help her health system improve. Kim believes in the mutually beneficial partnerships of patient-centered care and is a testimony to how it can improve a patient’s health as well as the healthcare system itself. Kim currently serves on Vidant Health System’s Patient Engagement Coordinating Group; Case Management Coordinating Group; Patient Education Committee; MyChart Clinical, Inpatient, Marketing and Patient Education Committees and the Clinical Strategy Implementation Committee. At Vidant Medical Center, Kim serves on the Patient and Family Advisor Committee, Heart Institute Council and the Staff Champions as the patient representative. Kim has spoken locally and nationally on patient engagement and patient-centered care. She has presented to Vidant Quality Board and was one of two patient representatives on a roundtable discussion with National Secretary of the Department of Health and Human Services (HHS) Kathleen Sebelius and other elected officials. Kim presented at two Institute for Patient- and Family-Centered Care International Conferences and several times for the North Carolina Hospital Association. Kim has been featured in several web clips and webinars including the Vidant Health System website’s Patient Experience page. Kim holds a master’s in library science and a master’s in information management from North Carolina Central University. She worked 16 years as a Systems Administrator at East Carolina University’s Academic Library Services. She is in her twenty-second year as a Girl Scout Leader and has an unbelievable interest in anything that involves her daughter, Randi.

Kay Burke had occasion to spend quite a bit of time in the ICU with her son. He contracted bacterial endocarditis in August of 2005. During the following 18 months he would have three aortic valve replacements, a heart attack, a pace-maker, and a heart transplant. He was 16. He is now 23 and graduating from college and applying to graduate programs. She has been a member of the University of Washington Medical Center ICU Patient and Family Advisory Council for the past two years. She is also a recent member of the Grievance Committee of the hospital. One of the programs of the ICU PFAC is volunteer liaison. She works in that capacity as well, rounding on patients and families in the ICU providing information, emotional support, referrals for spiritual care, etc.

Jim Burrows, MBA is the Director of Service Excellence at Nemours. In this system-wide role, Jim is responsible for creating training programs, materials and initiatives that drive and sustain a culture of service excellence to continuously improve the child and family experience. He also ensures that the family voice is incorporated into service excellence work by utilizing and analyzing numerous sources of patient/family feedback to prioritize improvement efforts. Prior to joining Nemours in 2012, Jim spent fifteen years with Bank of America, previously MBNA America Bank. He was a Senior Vice President and held a variety of senior-level management roles, including technology administration, technology risk management, finance,
call center direction and process improvement through Six Sigma and Lean project management. Jim’s journey to healthcare began over six years ago with the birth of his daughter, who was born with severe medical complications requiring multiple surgeries and months of hospitalization with intense care. The experience of having a sick child led Jim to volunteer for the Nemours/ Alfred I. duPont Hospital for Children’s Family Advisory Council, where he soon became the Parent Chairperson. It was the combination of his personal experience, professional expertise and passion for volunteer activities to improve the child and family experience that led Jim to join the Nemours staff. With this dual perspective as a hospital director and as a parent advocate, Jim speaks to various groups regarding the child and family experience including new hire orientation, new resident orientation, town halls, Learning Development Institutes, individual inpatient and outpatient departments and other groups within Nemours. He is a member of many hospital-based committees, including the Patient Safety Committee, the Nemours Enterprise and Delaware Valley Strategy Management Teams, the Child and Family-Centered Care Committee. Jim received his undergraduate degree in Marketing from the University of Delaware and earned his MBA with highest honors in Finance from Goldey-Beacom College. He lives in Newark, Delaware with his wife Mary Beth and three children.

James B. Conway, MS is an adjunct lecturer at the Harvard School of Public Health in Boston, and a principal of the Governance and Leadership Group of Pascal Metrics in Washington DC. From 2006-2009 he was Senior Vice President of the Institute for Healthcare Improvement (IHI) and from 2005-2011, Senior Fellow. During 1995-2005, Jim was Executive Vice President and Chief Operating Officer of Dana-Farber Cancer Institute, Boston. Prior to joining DFCI, he had a 27-year career at Children’s Hospital, Boston in Radiology Administration, Finance, and as Assistant Hospital Director. His areas of expertise and interest include governance and executive leadership, patient safety, change management, crisis management, and patient-/ family-centered care. He holds a Master of Science degree from Lesley College, Cambridge, MA. Jim is the winner of numerous awards including the 1999 ACHE Mass. Regents Award, the 2001 first Individual Leadership Award in Patient Safety by the Joint Commission on Accreditation of Healthcare Organizations and the National Committee for Quality Assurance. A Lifetime Fellow of the American College of Healthcare Executives, he has served as a Distinguished Advisor to the Lucian Leape Institute for the National Patient Safety Foundation. IOM Committees have included Identifying and Preventing Medication Errors and a Learning Healthcare System. Current Board service includes: board member, Winchester Hospital; board member American Cancer Society, National and New England Region; and member, Board of Visitors, University of Massachusetts, Boston. In government service, he served since 2006-2010, as a member of the Commonwealth of Massachusetts Quality and Cost Council.

Kathy Day is a retired RN and a patient safety Advocate and Activist. She started her work after her father became infected with MRSA during rehabilitation from a minor ankle fracture in 2009. She began her work by sharing his story in many different forums. She has authored legislation, and Maine passed a law to screen all high risk patients for MRSA that year. She affiliates with the Consumers Union Safe Patient Project, and she is a member of the Maine Quality Counts Consumer Advisory Council and the Maine Quality Forum HAI committee. She currently works on the Choosing Wisely in Maine Campaign as a Leadership team consumer representative. This fall she has received two awards for her work to improve healthcare in her state, the Rising Tide Award from the Maine Patient Safety Academy and a 20 in 20 award from the Maine Health Management Coalition. Her greatest passion is to advocate for individual harmed or infected patients.

Crispin Delgado serves as a program officer for the Health Care and Coverage program at Blue Shield of California Foundation, where he supports the Foundation’s grantmaking and program work related to health reform, coverage expansion, and strengthening safety net healthcare systems. Prior to joining the Foundation,
Delgado was the health policy initiatives manager for the San Mateo County Health System, where he oversaw the department’s primary prevention strategy by working with regional entities and local cities to integrate health considerations into land-use and transportation planning processes. Delgado has also worked on numerous access-to-care and health policy issues throughout San Mateo County. Previously, Delgado spent three years as staff to the California Program on Access to Care, a program of the University of California, Office of the President, where he supported statewide and international applied health policy research focused on health care access issues for California’s most vulnerable populations. Delgado has a master's degree in public policy from the Goldman School of Public Policy at the University of California, Berkeley, and bachelor of arts degrees in international relations and Spanish from the University of California, Davis. Delgado is also a Public Policy and International Affairs Fellow.

Jennifer Dingman is a patient advocate from Pueblo, Colorado. She formed and founded the group PULSE in Colorado (http://www.pulseamerica.org/) which has become a model for other state-based patient advocate groups across the country. She lost her mother due to an adverse drug event many years ago, which sparked her interest and passion for this work. She is a part of two national PFAC models in a volunteer capacity. One is with Texas Medical Institute of Technology and Chuck Denham. This is a group of patient advocates that meets over the phone in webinars every other Saturday morning. They focus on various topics and the patient perspective is sought out to make recommendations about how to improve care on a number of fronts. These learnings are presented in an ongoing series of webinars that are free and open to the health care community, and many hospital systems participate in an ongoing basis. Jennifer is also a part of a regional PFAC that advises the Catholic Health Initiative. They also meet on a regular basis to provide feedback to health care delivery problems and hurdles. They have made many recommendations that have been implemented in Catholic Hospitals across the country to ensure that no one dies alone, and to reduce infections, among many other things.

Judy A. Doyle received her bachelor's in Business Administration, majoring in marketing. She has three children: daughter Madison, 20, Sally, 18, and son Jack, 15. It is medical experiences with Jack that brought Judy to her present position at Akron Children’s Hospital. Jack was born with Cardio-Facio-Cutaneous Syndrome (CFC). The first two years were filled with managing Jack’s many medical problems and searching for a diagnosis. The Doyles relied on the support of their pediatrician and the Internet to understand Jack’s problems, searching for a diagnosis and connecting with other parents. They sent Jack’s medical history to many of the world's top genetic doctors. Jack was finally diagnosed at the University of Utah in 2000. While Jack has significant developmental and growth delays, he is a happy kid who loves cars and cooking. He has had many medical problems that require specialized care and is followed by neurology, pain center, orthopedics, psychiatry, cardiology, ophthalmology, and his primary care pediatrician. Judy took the part-time position as the Parent Mentor Program Coordinator in August of 2001. In 2010 she expanded her role into a full-time position as Parent Advisor Coordinator and works in the hospital’s newly created Center for Patient Experience Innovation. Judy is responsible for recruitment, training, and coordinating parent involvement at Akron Children’s Hospital. She is a member of the hospital’s two main site Parent Advisory Councils. She also serves as the parent member on many hospital committees including Ethics, Patient Safety, Home Care Advisory, Board Quality and Family Experience Advisory Committee. She also serves as the team leader for the JCAHO Patient Rights & Responsibilities Chapter. Her interest in patient safety has lead to her involvement as a parent lead for the Ohio Children’s Hospitals Solutions for Patient Safety. The OCHSPS has added other hospitals from around the nation and Judy is a parent lead on the Family Engagement team. She recently co-authored an article on patient and family engagement in Nursing Administration Quarterly.
She is a trainer for Error Prevention Training and Patient Experience Workshops, both of which are required education for all hospital staff.

**Hala Durrah** is chairperson of the Women and Children’s Patient Family Advisory Council at Anne Arundel Medical Center in Annapolis, MD, and is an advisor on the Patient Family Advisory Council as well. She is a full time mother to four wonderful children and her ten year old daughter is a two-time liver transplant and a bone marrow transplant recipient. Her professional background includes event planning, non-profit work, development, and writing. She earned her bachelor's and master's degrees at the George Washington University in Washington, DC.

**Tim Flack, JD** initially came to work at Le Bonheur as a volunteer. In 2007, he and his wife, Bridgette, were one of the families who helped to found the Family Partners Council at Le Bonheur. Tim and Bridgette were introduced to Le Bonheur when their then 10 month old daughter, Madeline, was diagnosed with four congenital heart defects and underwent open heart surgery. Through his work on the Family Partners Council, Tim developed a strong interest in the issues of patient and family centered care, particularly in a pediatric setting. In January 2013, after twelve years of practicing law as a prosecuting attorney, Tim accepted the position as Le Bonheur’s first full-time director of patient and family centered care. Tim and Bridgette make their home in Memphis where they spend the majority of their free time chasing their three very active children, Madeline, age 9, Eli, age 6, and Susanna, age 3.

**Barbara Forss** was diagnosed with a rare, severe, hereditary bleeding disorder called F-VII Deficiency when she was 47 years old. Much of her life up until then was spent in and out of hospitals across the country, being treated for bleeding episodes with blood products. She endured over 50 hospitalizations, too many ER visits to count, over 20 major surgeries, and hundreds of units of Fresh Frozen Plasma, Cryoprecipitate, Prothrombin Concentrate Complexes and whole blood, just to try to control her bleeding. She bled from head to toe and everywhere in between, and had a total hysterectomy at age 31 to stop severe menorrhagia. But almost every provider who treated her said she couldn’t possibly have hemophilia, as she was a female, and that was “impossible”. She also acquired 4 major infections during hospital stays, including MRSA, C-Diff, staph and gangrene. She was often given medications and treatments before her diagnosis in 1998 that actually triggered more bleeding. When she was finally diagnosed, her whole world changed for the better. Since 2000, she has been able to infuse a clotting medicine daily that helps manage her bleeds, and has totally improved her quality of life, so that she is able to be passionately involved as a volunteer in patient and family-centered care. As a volunteer with a large hospital association on the west coast, she became their first Patient Advisor (Patient Representative at that time) in 2001, and an equal partner on many committees. In this role, she has also spoken to national audiences (such as the National Quality Forum's Quarterly Conference in 2012), about the importance of patient and family involvement in healthcare organizations. In 2012, she was certified to coach Advanced Healthcare Improvement Initiatives, through PeaceHealth’s Advanced Training Program, becoming the only volunteer Patient Advisor to do so. This program for PeaceHealth employees helped her understand the many layers it takes in healthcare settings, just to deliver good, safe, evidence-based, patient-centered care. In 2011, she was awarded the top volunteer award at PHSJMC for annual hours worked, 2100. Since 200, she has served as Patient Advisor at PeaceHealth St. Joseph’s Medical Center (PHSJMC) in Whatcom County., WA.

**Dominick L. Frosch, PhD** 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. Frosch also serves as associate professor of medicine at UCLA and consulting investigator at the Palo Alto
Medical Foundation Research Institute. Frosch’s clinical research has focused on shared decision-making and patient engagement for over a decade. 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. Frosch’s 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. Frosch has published over 70 peer-reviewed articles and chapters. He currently serves as deputy editor for the Journal of General Internal Medicine and previously served as Associate Editor for Health Psychology. He completed his PhD in clinical health psychology at the University of California, San Diego, and a fellowship as a Robert Wood Johnson Health & Society scholar at the University of Pennsylvania.

Deepa Ganachari, MPH is a researcher in the Health and Social Development Program at the American Institutes for Research (AIR). Ms. Ganachari’s current work includes a project funded by the Gordon and Betty Moore Foundation to plan and implement a convening to bring together key stakeholders in the field of patient and family engagement for the purposes of developing a roadmap for research and practice for the field. She previously worked on an effort to create a validated health insurance literacy assessment that gauges a person’s ability to make informed decisions when selecting and using health insurance. Prior to joining AIR, Ms. Ganachari worked for the Baltimore City Health Department and was awarded a fellowship to study women’s health in India.

Ellen Gitt is the Service Quality Director and Patient Advocate at Good Samaritan Hospital in Kearney, Nebraska. Ellen is the co-chair of the Good Samaritan Hospital Patient and Family Advisory Council and a member of Catholic Health Initiatives National Patient Advisory Council. She is a member of the Society for Healthcare Consumer Advocacy. Ellen has co-presented two workshops on Patient and Family Advisory Councils at Planetree International Conferences. She also serves as a “Personal Patient Advocate” for her husband, who has battled cancer for 17 years. Ellen’s husband has experienced many surgeries, treatments, hospitalizations, including three hospitalizations for treatment in Basel, Switzerland. This journey has helped Ellen to look at the healthcare experience from a patient and family member’s perspective, and inspired her to become a Patient Advocate.

Grace Gonzalez, MPH currently serves as Program Manager for the National Association of Community Health Centers Quality Center. Her areas of focus are patient centered medical home, capacity building, infrastructure development, partnership and collaboration supportive of primary care practice transformation implementation and performance measurement demonstrating systems transformation associated with implementation of patient centered medical home. Previous to her current role, she served as a senior researcher and evaluator for the Department of Health and Human Services. As a researcher and evaluator, she supported and co-directed national multisite evaluations of systems transformation initiatives at the state and local levels focused on coordination and services integration; partnership and collaboration; meaningful engagement of patient, caregiver and family members in all aspects of services delivery re-design; implementation; and policy development. She has co-led participatory evaluations inclusive of providers, patients, caregivers, and family members representative of the patient lifespan.

Lynda Griffin is the mother of 2 children, one of whom has Cystic Fibrosis. Lynda was appointed as the Family Advisory Council (FAC) Co-Chair for Nemours Children’s Hospital (NCH) in November of 2011. She has served on the FAC for more than five years. In this voluntary position, Lynda has participated in many aspects of NCH formation including committee membership, policy development, peer mentorship, expert consultation on the architectural plans, and leading FAC interviews of NCH physicians and area
leaders. Lynda routinely makes time to share her journey with the staff at NCH to help impress the value of patient and family centered care and family partnership in healthcare. Lynda believes that being part of the FAC is a journey not a destination. She believes that the FAC is not a place to come and complain but to help make it better for patients and families now and in the future.

Sara Guastello, as the Director of Knowledge Management for Planetree, has developed a range of educational and implementation resources to guide organizations in their endeavors to deliver patient-centered care. She oversees the Patient-Centered Hospital Designation Program and the associated Patient-Centered Merit Recognition Program, the only such program to recognize excellence in patient- and resident-centered care across the continuum of care. A frequent writer on patient-centered care, Sara has contributed to numerous publications. She is co-editor of the recently released Putting Patients First Field Guide: Global Lessons in Designing and Implementing Patient-Centered Care (Jossey-Bass, 2013), and led the development of The Patient-Centered Care Improvement Guide and the companion Long-Term Care Improvement Guide. She has also authored articles in the American Journal of Nursing’s Putting Patients First series, The Journal of Comparative Effectiveness Research, The Patient journal, Food Studies: An Interdisciplinary Journal, and Provider magazine. Drawing on the experiences of health care organizations implementing the Planetree model of patient-centered care, she has authored white papers on integrating the patient and family voice into hospital operations and advancing person-centered care across the continuum of care, and developed a series of toolkits spotlighting field-tested strategies for HCAHPS improvement.

Win Hodges became committed to communication and partnership in healthcare following his treatment in 1993 for stage 3 lung cancer. In 2001 he became a charter member of the Massachusetts General Hospital (MGH) Cancer Center Patient and Family Advisory Council (PFAC) and continues to be an active member. He has been a Patient Advocate and Leader of The Institute for Patient and Family Centered Care since 2006. From 2004 to 2012 Win facilitated Schwartz Center rounds in which clinicians discuss difficult situations they encounter at five hospitals in the Boston area. Win served as a patient member of the MGH Optimum Care Committee, the ethics committee for end of life care, from 2007 to 2009. Since its inception in 2004, Win has been a member of the development team designing a new model team-based primary healthcare practice, The Ambulatory Practice of the Future (APF), serving employees of MGH and their adult dependents. At the opening of the practice in 2010, he founded, chaired, and continues to serve on the APF Care Alliance, a partnership of patients and providers committed to optimizing the care experience for both patients and providers. Win has also served on the MGH General PFAC since 2011. This year Win and his wife, Margie, joined a Patient Centered Outcomes Research Institute (PCORI) PFAC as part of the team to improve the transition process from inpatient to outpatient.

Libby Hoy, as the mother of three sons living with mitochondrial disease, has more than 20 years experience navigating the health care system. As a parent, Libby quickly learned the value of creating partnerships with healthcare providers who would share the vision she and her husband had for the boys. Through these empowered partnerships, Team Hoy has been able to access the care and support the boys needed to realize their potential. More than 20 years later, the boys are living robust, healthy lives in which mitochondrial disease is a part of who they are, but certainly not the most interesting part. It is this volume of personal experience in forming partnerships with healthcare providers and organizations to access care, find solutions and improve the quality and safety of care that provides Libby working knowledge of the power and potential of patient and family engagement. Libby began volunteering as a Parent Mentor in 1995 and has been working to improve health systems and empower patients and families to be active partners in care ever since. In her role as the first Family Advocate at Miller Children's Hospital, she developed the Parent Advisory
Board and created the structure for the long term integration of the patient and family voice within the organization. Libby has presented at multiple national and international conferences on subjects related to Patient and Family Centered Care. As a consultant, Libby strives to share the evidence, practices, and methods that support PFCC culture in health care organizations. In 2010, Libby founded PFCC Partners to create a community of patients, families, providers, and health care organizations committed to shared learning of Patient & Family Centered Care practice. The mission of PFCC Partners is to partner with patients, providers, and organizations to improve the quality, safety, experience, and delivery of health care. As a collaborative partner to the Institute of Healthcare Improvement, Patient Centered Outcomes Research Institute (PCORI), and with CMS’ Partnership for Patients Project, Libby articulates the perspective of the patient and family in healthcare improvement efforts. Libby lives in Long Beach, CA, with her three sons and husband.

Beverley H. Johnson serves as the President and Chief Executive Officer of the Board for the Institute for Patient- and Family-Centered Care. She has over 25 years of experience in organizational development and management. She has worked as a health professional providing direct care in hospitals, managing a hospital unit, and teaching. She has served as a trustee of a hospital, national health care organization, and a school board. In these trustee roles, she has chaired and served on strategic planning committees and had fiduciary responsibility for nonprofit organizations. She has provided technical assistance and consultation to over 250 hospitals across the United States and Canada. She has published widely on patient- and family-centered issues and strategies. Bev is the recipient of the 2011 Dorland Health People Award for leadership in the area of patient- and family-centered care, the 2008 Stanley Graven Award for outstanding contribution to the National Perinatal Association, the 2007 Stan and Mavis Graven Award for Leadership in promoting optimal environments and developmental care for high risk infants and their families, the 2007 Changemaker Award by the Board for the Center for Health Care Design, the 1992 Lloyd Bentsen Award for leadership for family-centered care, and the 1990 Humanitarian Award from Pediatric Nursing.

Maulik S. Joshi, PH has traveled the country extensively, working closely with many of the nation’s leading hospitals and health systems in governance, strategy, and performance improvement. Maulik has had vast experiences in the hospital field and the broader health care industry, incorporating current research and expertise to help better identify, understand and address the major challenges facing today’s health care leaders, including: governance – drawn from management research and first-hand experience speaking to and serving on hospital/health systems and health quality organizations boards, the future of health care – speaking to the ever-changing health care landscape and delivery system reform and transformation, quality improvement and patient safety – outlining challenges facing the field, as well as sharing operational advice to help make a hospital/health system’s quality journey successful, and applied research – sharing key learning from research in critical areas within the health care system including care coordination, cost, disparities, and patient and family engagement. Maulik currently serves as President of the Health Research & Educational Trust (HRET) and Senior Vice President at the American Hospital Association (AHA). Prior to joining AHA/HRET he built his deep foundation in health care through key leadership positions with the Agency for Healthcare Research and Quality, the Delmarva Foundation, Institute for Healthcare Improvement, and the University of Pennsylvania Health System. Maulik also brings the governance perspective as he is on the Board of Trustees for Anne Arundel Health and Chairs the Board Quality and Patient Safety Committee, the Board Health Outcomes Committee for Advocate Health Care, and is Treasurer of the Board of Trustees for the Center for Advancing Health.
Savita Katarya has been a member of Mayo Clinic's One World Advisory Council since its inception in 2011. She also is on the leadership committee. The mission of the One World Advisory Council is to facilitate the active understanding of the health and wellness needs and experiences of culturally diverse patients and families. The vision is to enhance the quality and experience of their care at Mayo Clinic. This council is based on the principles of Patient and Family Centered Care which is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among patients, families, and health care providers (Institute of Patient Family Centered Care, 2011). She works as an Education Program Manager at Diversity Council in Rochester, MN and is actively engaged in the community for many years in working with people from diverse backgrounds. Mayo Clinic is the health care provider for her and her family for many years.

Joanna Kaufman, RN, MS serves as a Program/Information Specialist at IPFCC. She brings more than 25 years of experience in patient- and family-centered care. She is a registered nurse with a myriad of pediatric clinical experience, gained in the trenches of Strong Memorial Hospital, Charity Hospital of New Orleans, and Johns Hopkins Hospital. In 1983, she became the Executive Director of a federally funded SPRANS (Special Project of Regional and National Significance) funded by the Dept. of Health and Human Services Bureau of Maternal/Child Health. This is where she learned her first lessons about family-centered, community based coordinated care and has been committed to patient- and family-centered care ever since. From 1997-2000 Joanna was a consultant to the Veteran’s Administration, as an external performance review specialist for VISN 2, 3, 4, 5, 6, and 7. She served to improve quality of care and promote effective quality improvement (QI) strategies through site visits, medical record review, and in-depth interviews with patients and health care practitioners. As a member of the IPFCC's team, Joanna serves as a faculty member for the intensive training seminars, actively participates in webinars, and provides training and technical assistance to hospitals. Joanna manages social media communications for IPFCC, including Facebook, Twitter, and the Patient and Family Advisory Council listserv. She also collaborates on a variety of projects that involve research, writing, editing, and analysis. In 2009, Joanna became a registered World Health Organization Patients for Patient Safety Champion and a reviewer for the Journal of Adolescent Medicine.

Aingyea Kellom M.P.A. is a Program Associate for the Patient Engagement team at the Patient-Centered Outcomes Research Institute (PCORI). In this role, she is responsible for providing leadership and management of multifaceted projects dedicated to PCORI’s objectives related to patient engagement. Aingyea’s previous experience includes managing citywide volunteerism efforts, bookkeeping, and human resource management for non-profit and community development initiatives. Prior to joining PCORI, Aingyea earned a Master of Public Administration from the City University of New York as a National Urban Fellow and a member of the Pi Alpha Alpha Honor Society. Aingyea also holds a B.A. in urban studies with minors in economics and Africana Studies from Rutgers University-New Brunswick. She was one of seven chosen in the highly competitive Project L/Earn Program with the Institute for Health, Health Care Policy and Aging Research. Her research project focused on whether dual treatment for co-occurring disorders can reduce nonviolent offenses in urban areas. She also earned a certificate in non-profit management at the College of New Jersey.

Mary Kitchell has been involved in health care in various capacities throughout her adult life, and her experiences contribute to a range of perspectives. She holds B.S., M.A., and Ed.S. degrees from the University of Iowa. Her career began as a psychological consultant to the U of Iowa Department of Pediatrics and served as a clinical investigator for a prospective longitudinal study of all infants born at risk at the U of I hospitals. She is currently semi-retired and works part-time in a private behavioral health practice.
Mary has served in a variety of leadership and personal volunteer roles with her local hospital for over 30 years. For the past 13 years she has been a publicly elected trustee of her community hospital in central Iowa. She has worked on a variety of committees, particularly Quality and Patient Safety. Mary was also president of the hospital foundation and was active in the establishment of a residential hospice facility in the city. She continues to volunteer at the hospital, visiting patients on a weekly basis. Mary has been active with the Iowa Hospital Association working on the Mental Health Task Force and the Committee on Representation and Advocacy. For the American Hospital Association, she has served on the Region 6 Policy Board, the Committee on Governance, the Leadership Development Committee, and she is currently a member of the Committee on Research. Mary has been deeply occupied in developing community coalitions to address public health issues in her region. She served on the Iowa Department of Public Health’s Access to Care committee. As a long-standing member of the county Quality of Life Coalition, she has acted to forge working relationships among a range of stake-holders. With the committee’s support, she founded the local free medical clinic in 1998 and continues to act as its administrator. Most recently, this coalition was successful in securing a Federally Qualified Health Center for the city which will open January 2014. Mary has also been the president of the local United Way chapter. On a personal level, Mary has had many encounters with the health care system due to several chronic conditions. However, her most poignant interactions arose in her role as a care-giver to her disabled father. She is married to a physician, the mother of a physician, and the mother of a health care attorney.

Toby Milgrom Levin serves as Co-Chair of the Suburban Hospital Patient and Family Advisory Council, which is working to imbed patient and family centered care into hospital policies, procedures, and programs to enhance the quality and experience of patient care. She also is the founder and Co-Chair of the Hebrew Home Family Council, an independent organization dedicated to enhancing quality care for all residents at the Hebrew Home, the largest nursing facility in the state of Maryland. Until her retirement in March 2010, she served for five years as Senior Advisor and Director of Privacy Policy in the Department of Homeland Security (DHS) Privacy Office and prior to that spent 20 years as a Senior Attorney at the Federal Trade Commission focusing first on food and drug advertising regulation and then promoting consumer information privacy. She currently also serves on the Information Security and Privacy Advisory Board, a Federal Advisory Committee advising OMB, the Department of Commerce, and NIST.

Angela Nugent Miney is the parent of a child with a chronic illness and Family Partner at the University of Florida (UF Health) Pediatric Pulmonary Center (PPC). In her capacity as family partner Angela has developed a family faculty program which promotes partnerships between healthcare professionals, patients, and their families. She teaches students, faculty, patients, and family members on the importance and benefits of a family centered approach to the care of children. In addition, she is the family representative on the UF Health Shands Children’s Hospital Patient and Family Centered Care Committee, the Pediatrics Ethics Committee and the Pediatrics Pain and Sedation Committee. She has coordinated a quality improvement project based around ‘Ask Me 3’ to improve communication within the Peds Pulmonary outpatient setting. More recently she is working with a Pediatric hospitalist to improve communication between all members of the healthcare team, including the patient and family. This initiative focuses on Family Centered Rounding, use of Whiteboards, PFCC Champions’ Award and at the institutional level the development of a Family Advisory board. This latter initiative is personally very satisfying as it has been many years in the making and has involved many hours of persuasion and collaboration. Angela has no medical background other than that acquired while taking care of her daughter. She is an integral member of the Pediatric Pulmonary Division and provides many hours of technical assistance to other divisions and services in the Children’s Hospital.
Jay Molofsky has over three decades of experience in public health and community health clinic management. He has managed communicable disease programs and primary care clinics, including homeless and HIV clinic services, for the Austin/Travis County Health and Human Services Department in Austin, Texas. At Open Door Community Health Centers in Arcata, California, Molofsky has served as administrator for HIV clinical services and primary care services at several community health center sites. He also works closely with patient advisory groups and coordinates corporate patient advisory meetings on a monthly basis.

Julie Ginn Moretz, inspired by her son’s battle with heart disease—his multiple heart surgeries and heart transplant—has spent the better part of her career as a family leader to improve health care for patients and families. Julie was recently appointed associate Vice Chancellor for Patient- and Family-Centered Care at the University of Arkansas for Medical Sciences in Little Rock, where she has overall institution leadership responsibility for the development of clinical and academic programs related to patient- and family-centered care. Most recently, Julie was the Director of Special Projects with the Institute for Patient- and Family-Centered Care, based in Bethesda, MD, for nearly seven years. Julie oversaw the Institute’s nationally-acclaimed intensive training seminars, international conferences, and other educational programs. She has presented throughout North America, and led a faculty team to Saudi Arabia to share the concepts of patient- and family-centered care. Initially, Julie was Chairman of the Family Advisory Council at the Medical College of Georgia in Augusta, and then, hired as a family-leader as Director of Family Services Development to oversee programs supporting adult and pediatric services. This included managing advisory councils, developing the Family Faculty program to incorporate patient- and family-centered care concepts in medical education, and serving as a faculty tutor for first-year medical students. Julie serves on the newly-established Patient-Centered Outcomes Research Institute’s (PCORI) Advisory Panel on Patient Engagement—the first of its kind developed to ensure the highest patient engagement standards in PCORI’s work and the research it funds. Julie is the co-founder of the Children’s Heart Program, which supports special programs for children with heart disease and their families. She is a recipient of the Woman of Excellence in Health Care Award and the American Heart Association’s Lifetime Achievement Award. Julie and her family were featured in the PBS Remaking American Medicine series, Hand-in-Hand, where she was named a “Champion of Change.”

Julie, and her husband, David, have three children—Lee (27), Morgan (25) and Daniel, forever 14.

Kellie Myers and her husband, Brad, have a son who was born at Duke University Medical Center in 2008 with a Congenital Diaphragmatic Hernia. Their son spent 4 months in the Duke Intensive Care Nursery and Pediatric Intensive Care Unit, undergoing four surgeries and 21 days on ECMO. Kellie previously served on and co-chaired the ICN Family Advisory Board. She now serves on the Patient-Family Advisory Council and is a family advisor to the ICN. Kellie also serves as a mentor and assists in helping other families become advisors. Because of her involvement in the ICN, she is familiar with the ways in which the ICN currently involves families in patient care, how they work to improve family engagement, and the many programs the ICN has set up.

Scott Newport is inspired by his son, Evan, who lived for seven years. Through Scott’s experience with Evan and his family, he now helps others on the journey. Scott finds writing articles for various publications and working at C. S. Mott as a way to give back. Along with the patient and family centered care initiative at C. S. Mott, Scott also works with Michigan Family Voices, Michigan Family to Family health information center, Region 4 genetics collaborative, National Genetics Education and Consumer Network and the Michigan Fatherhood coalition. Scott has been a frequent contributor to the CHIPPS newsletter, the pediatric arm of the National Hospice and Palliative Care Organization. His occupation is a carpenter.
Annie O'Connor is the mother of three boys, the youngest of which was born prematurely at Morgan Stanley Children's Hospital (MSCH) of New York-Presbyterian in 2003. He has since undergone many surgeries and hospitalizations and continues to be treated there for multiple chronic conditions. Ann has been a member of the FAC since its founding in 2005 and has led its efforts as Chair since 2007. In addition to her work with the FAC, Ann is also a member of the hospital’s Quality Council and Patient Safety Committee, the Patient-Centered Care Cabinet and the hospital-wide PFAC Steering Committee. Ann has been invited to speak at several national healthcare conferences. Her presentations focused on Patient and Family Centered Care and the work of the MSCH Family Advisory Council in the areas of Quality and Patient Safety. In 2012, Ann was honored by the United Hospital Fund for providing exceptional service as a volunteer to a New York Metro area hospital. Prior to her volunteer experiences, Ann began her professional career at Accenture, providing management and technology consulting to the government and financial services sectors for over ten years. She graduated from Boston College with a degree in mathematics and lives with her family in Larchmont, New York.

Teresa Pasquini is a lifelong Contra Costa County resident and mom to two with her husband of 33 years. Teresa is the proud mom of a 31 year old son with schizophrenia who was diagnosed at age 16. She also has an older brother who lives with a severe mental illness. Her 40 years of lived experience with the mental health and mental illness systems of care drive her passion for partnership and improvement with a whole health perspective. Teresa is the Chair and a founding member of the Behavioral Healthcare Partnership of Contra Costa Regional Medical and Health Centers in Martinez, California. This is one of the few PFACs in the nation focused on psychiatric and behavioral health issues. She has served on the Executive Operations team of Contra Costa Regional Medical Center since January of 2010. Teresa is dedicated to local participatory change in her community and has held an appointed Family Member seat as a state mandated County Mental Health Commissioner in Contra Costa, since 2006. Teresa has shared her story of partnership at the IHI National Forum along with being chosen as an IHI Patient/Family Mentor the past two years. She has served as faculty and presenter at the Institute for Patient and Family Centered Care and presented Grand Rounds at the University of Michigan’s Psychiatric Department.

Jerry Penso, MD, MBA joined the American Medical Group Association (AMGA) in September 2012 as the Chief Medical and Quality Officer. In his role at AMGA, Penso works to design, develop, and implement AMGA's initiatives related to quality management and research on behalf of the membership. He oversees efforts of AMGA's philanthropic arm, the American Medical Group Foundation (AMGF) and plays a key role in quality initiatives of AMGA's for-profit informatics and analytic company, Anceta, LLC, a collaborative data warehouse. He contributes to setting goals and objectives in concert with AMGA's organizational strategic plan and serves as a member of the association's Strategic Planning Team. Prior to joining AMGA, Penso served as Medical Director, Continuum of Care for Sharp Rees-Stealy Medical Group (SRSMG) in San Diego. He previously practiced as a family physician with Sharp Mission Park Medical Group in north San Diego County for over fourteen years. Sharp Healthcare is the largest integrated health care delivery system in San Diego and a 2007 Malcolm Baldrige National Quality Award recipient. Penso coordinated Pay for Performance initiatives and chronic disease management, and SRSMG has been recognized as a top performing group in California’s Pay for Performance program since 2005. Penso has received numerous awards, including the Mead-Johnson Award for Graduate Education in Family Practice. He is a member of the American Academy of Family Physicians, the San Diego County Medical Association, and the California Medical Association. He received a Bachelor of Science in chemistry from the University of California, Berkeley, his medical degree from the University of Southern California, and an M.B.A. from San Diego State University.
Mary Ann Brown Peugeot’s “story” may be a bit unusual for someone who has become so involved in health care circles in the area of patient and family advisory issues. She has not experienced the adverse events that customarily get people involved, but it has been the normal everyday activities that accompany being a patient in either the inpatient or outpatient settings. This is not to say that she has had no experience with illness. Her mother’s death from inherited Polycystic Kidney Disease, her kidney donation to a brother who desperately needed a kidney due to the same disease, her husband’s near-fatal experience with multiple pulmonary emboli, and her father’s final years with back pain and congestive heart failure have given her a wealth of experience in patient and family engagement. Her devotion to being the Voice of the Patient has also been borne of the success of being a part of a patient and family advisory council that has the full endorsement and cooperation from key leadership at Vanderbilt. She served as Chair of the Council 2008-2012 and has been actively involved in driving their agenda and many accomplishments. The Council has been able to do many things that have greatly enhance patient and family centered care, and this fueled her fire and enthusiasm for being the Patient Voice for those who can’t speak for themselves. She is a self-employed CPA with a focus on taxes and planning, but her active avocation in patient and family care has led her to spend over 1,200 hours in the past few years as a volunteer in this arena. Her experience at Vanderbilt includes 7 years on the Vanderbilt Patient and Family Advisory Council, memberships on the Vanderbilt Patient Experience and Service Committee, My Health at Vanderbilt Steering Committee (patient portal), and Critical Care Tower and other facilities committees. She was the sole “patient” member on the national steering committee on Always Events for the Picker Foundation. She is a member of the JCR HEN on Patient Advisory Councils. She has also served as a speaker at various national and international conferences and on webinars on patient and family centered care.

Peter J. Pronovost, MD, PhD, FCCM is a practicing anesthesiologist and critical care physician who is dedicated to finding ways to make hospitals and healthcare safer for patients. In June 2011, he was named director of the new Armstrong Institute for Patient Safety and Quality at Johns Hopkins, as well as Johns Hopkins Medicine’s senior vice president for patient safety and quality. Pronovost has developed a scientifically proven method for reducing the deadly infections associated with central line catheters. His simple but effective checklist protocol virtually eliminated these infections across the state of Michigan, saving 1,500 lives and $100 million annually. These results have been sustained for more than three years. Moreover, the checklist protocol is now being implemented across the United States, state by state, and in several other countries. Pronovost has chronicled his work to improve patient safety in his book, Safe Patients, Smart Hospitals: How One Doctor’s Checklist Can Help Us Change Health Care from the Inside Out. In addition, he has written more than 400 articles and chapters related to patient safety and the measurement and evaluation of safety efforts. He serves in an advisory capacity to the World Health Organization’s World Alliance for Patient Safety. Pronovost has earned several national awards, including the 2004 John Eisenberg Patient Safety Research Award and a MacArthur Fellowship in 2008. He was named by Time magazine as one of the world’s 100 “most influential people” for his work in patient safety. He regularly addresses Congress on the importance of patient safety, prompting a report by the U.S. House of Representatives’ Committee on Oversight and Government Reform strongly endorsing his intensive care unit infection prevention program. Pronovost previously headed Johns Hopkins’ Quality and Safety Research Group and was medical director of Hopkins’ Center for Innovation in Quality Patient Care. Both groups, as well as other partners throughout the university and health system, have been folded into the Armstrong Institute.

Michele Riedford is the Chair of the Emory Healthcare Patient and Family Advisors Team. She has also served on the Emory Clinic Patient Satisfaction Acceleration Team, the EHC Value Acceleration Team, the
Patient Portal Management Team, and the Transplant Patient Satisfaction Acceleration Team. Her other various activities involving Patient and Family Advisory work with the Emory Healthcare team has been with the Annual EHC Strategic Planning Working Sessions FY 13, 14, & 15; the Senior Leadership Retreat; the Nursing Quality Patient Experience Retreat; and the Doc for a Day program.

**Linda Ritter, RN** is the Nursing Director and Coordinator of the Care Advisory Team at the University of Louisville Hospital. In November of 2010 a group of hospital staff comprised of health care providers, hospital administrators, and Care Advisors representing Patient and Family Centered Care, attended the national PFCC conference held in North Carolina. While this was not the first time the organization had attended this conference, it was the first time that Care Advisors attended and it proved to be the year that momentum began to build behind the PFCC initiative at U of L, Health Care. As part of the conference program, a list of goals were established by the team and while there were no real time constraints assigned to these goals, her team were able to report in their first annual report that all of the goals were met. Their Care Advisory Board is comprised of patients and families who have had inpatient or outpatient experiences at either the University of Louisville Hospital or the James Graham Brown Cancer Center. These Care advisors not only participate in the monthly meeting where issues are brought to them by staff from across the organization, they are active members on our Quality board, our Safety committee, our Ethics committee and our Falls committee. Following are a list of some of their accomplishments: revised mission/vision statement of University of Louisville Hospital and the James Graham Brown Cancer Center; developed the Family Presence policy creating 24/7 presence option for patients and families; eliminated visitation hours in the ICU’s and unlocked ICU doors; educated staff on the bedside shift report experience; involved in multiple renovations of units and in changing the signage in the organization; initiated and developed the patient and family centered care promise that all staff sign and commit to; multiple educational offerings to staff and leadership provided by Care Advisors; presented poster at the PFCC conference in Washington D.C.; developed intake process for patients bringing their own medications to the hospital; revised the white boards; and revised core employee behavioral standards.

**Anthony Bernard Roberson** is the Administrative Director of Patient 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. He is responsible for the day-to-day ongoing planning, development, implementation and monitoring of Patient Family Centered Care. Roberson is also responsible for the education of all faculty, administrators, staff and students on Patient Family Centered Care at Georgia Regents Medical Center. Roberson directs Patient and Family Engagement, Family Support and Resource Libraries, Patient Satisfaction, Volunteer Services, Culturally and Linguistically Appropriate Services, Concierge/Greeter's Services, Healing Arts, and Patient Advisors. Roberson joined Georgia Regents Medical Center Department of Utilization Management in 2000 as a Social Worker/Case Manager. He assisted in the planning, development and implementation of patient- and family- centered care in the Neuroscience Center of Excellence at Georgia Regents Medical Center. Before joining Georgia Regents Medical Center, he served as the Director of Community Development at the United Way of Aiken County in South Carolina, and was the Resident Services Coordinator at the Aiken Housing Authority. Roberson earned a B.A. in psychology at Augusta College and an M.S. in management/hospital administration at Troy State University. He holds a Human Services Certification from the University of Georgia’s Fanning Leadership Center and a Certification in Public Housing Management from the National Association of Housing and Redevelopment Organization, and has successfully completed TeamSTEPPS Master Trainer Preparation Course from the Agency for Healthcare Research and Quality. Roberson has presented and lectured extensively on Patient Family Centered Care, including the 2nd, 3rd, and 4th International Conferences on Patient- and Family- Centered
Murray N. Ross, PhD is Vice President, Kaiser Foundation Health Plan, and directs the Kaiser Permanente Institute for Health Policy in Oakland, California. Before joining Kaiser Permanente in 2002, Ross served as executive director of the Medicare Payment Advisory Commission (MedPAC), which advises Congress on issues affecting the Medicare program. Previously, he was a policy analyst at the Congressional Budget Office and later led the team charged with assessing the budgetary impact of legislative proposals affecting federal health programs. Ross earned his doctorate in economics at the University of Maryland, College Park. He enjoys running, writing, and traveling.

Charlene Rothkopf is the Founder and President of the Wellness Consulting Group, LLC, a coaching and consulting firm specializing in executive and management development, managing change, and organizational health and well-being. As a seasoned corporate executive for over 30 years, Charlene’s experience includes strategic planning, designing and implementing company-wide initiatives, talent management, and group facilitation. She currently co-chairs the Patient & Family Advisory Council for Johns Hopkins Hospital in Baltimore and serves on the Advisory Council for the Center for Leadership, Innovation, and Change (CLIC) with the University of Maryland Smith School of Business. Prior to the Wellness Consulting Group, Charlene was Executive Vice President of HR with AvalonBay Communities, Inc., a multi-family REIT, with a market capitalization of over $16B. She spent 16 years with Marriott Corporation and Host Marriott in a variety of positions including Vice President of Human Resources, Director of Benefit Operations and Communication, and Director of Training & Development. Charlene’s specialty areas include: executive coaching, organizational consulting, education & training, health & wellness coaching, and human resources. Charlene holds an undergraduate and master’s degree from the University of Maryland, and performed doctoral work at George Washington University in Human Resources Development and Management Science. She received her coaching certificate from the Maryland University of Integrative Health and was awarded her ACC credential from the International Coaching Federation. She has also earned the SPHR certification from the Society for Human Resource Management.

Mimi Saffer, MA is an executive from the information technology industry and healthcare sector now applying business practices and information systems to promote safety and quality in pediatric medicine. She joined Children’s Hospital Association in late 2010 to advance the work of the Quality Transformation Network, an extensive and growing network of children’s hospitals collaborating to improve care and outcomes. From 2004 – 2010, Mimi was Director of Strategic Relations at the American Board of Pediatrics (ABP), where she ran national campaigns to promote and spread successful quality improvement initiatives in pediatrics. She also consulted with improvement networks and patient foundations on patient registries, patient-reported data, and family advisory committees, and coached improvement projects on design and execution. At ABP, she led development of an innovative “workplace QI model” program that awards board certification credit for clinical improvement projects in the workplace; the workplace QI model is now being adopted by other certifying boards representing over 65% of nation’s physicians, as well as by children’s hospitals and large health systems. She designed a guided clinical quality improvement web tool that has been deployed to all board-certified pediatricians. She was the founding Executive Director of the Alliance for Pediatric Quality and served in that role until 2009. Prior to her work in pediatrics, Mimi worked in information technology and co-founded one of the earliest e-health companies, which used a patient-centered model to manage chronic illness and high risk pregnancy.
Nick Sandoval, a son of agricultural workers, is the Health Education Program Manager at Salud Para La Gente. He conducts diabetes management classes, and administers grants related to diabetes management, teen pregnancy prevention, and access to prenatal services for farmworker women. Prior to working at Salud, Nick coordinated a community-led community building effort in three Salinas Valley community in California’s Central Coast. Nick Sandoval has a BA in political science from the University of California at Santa Cruz. He is a veteran of the United States Marine Corps.

Juliette Schlucter has over two decades of experience working with and leading health care professionals in patient- and family-centered care assessment, programming design, and implementation. Juliette came to her work initially as a Family Advisor, following the diagnosis of Cystic Fibrosis of her son and newborn daughter 22 years ago. She has consulted on patient- and family-centered topics related to quality, safety, education, research, and outcomes with numerous health care systems and agencies. Juliette is currently leading work at the Institute for Family Centered Care at Hassenfeld Children’s Hospital at NYU Langone Medical Center and recently served as the Managing Director of Service Excellence for Nemours Pediatric Health Care System. From 1995 through 2010, Juliette provided leadership for hospital-wide implementation of patient- and family-centered care at The Children’s Hospital of Philadelphia. While at The Children’s Hospital of Philadelphia, Juliette created and served as lead author of The Promise of Partnership, a toolkit used to teach health care professionals best practice behaviors for patient- and family-centered care. The Promise of Partnership was chosen by the Institute for Healthcare Improvement (IHI) for its Open School module on patient- and family-centered care. She also co-created the Family Faculty, an award winning program in which parents teach health care professionals about the experience of illness. She established the Children’s Hospital of Philadelphia Family Advisory Council, created and developed the Family-Centered Intern program, developed a Patient and Family Advisor training curriculum and founded and wrote Partners for Excellence, a workshop to teach parents about using health care resources effectively. With Bev Johnson, President/CEO of The Institute for Patient and Family-Centered Care, (IPFCC) Juliette co-authored the chapter on Family-Centered Home Care for The American Academy of Pediatrics. Since 1996, Juliette has served as Faculty to the IPFCC. She has also served on advisory councils for the Accreditation for Graduate Medical Schools and the Association of American Medical Colleges and served on the board of the Association of the Care of Children’s Health.

Joe Selby, MD, MPH is the first Executive Director of the Patient-Centered Outcomes Research Institute (PCORI). A family physician, clinical epidemiologist, and health services researcher, he has dedicated his career to patient care, clinical research, and administration. At PCORI, he works to identify and address strategic issues and opportunities for PCORI and to implement and administer the research agenda authorized by the PCORI Board of Governors. Building on the foundational work of the Board, Selby leads the continuing development of PCORI as a research organization, overseeing the implementation of its research agenda, its external communications, and its work to establish effective on-going, two-way engagement channels with each of PCORI’s key stakeholder groups, beginning with patients. Selby joined PCORI from Kaiser Permanente, Northern California, where he was a researcher for 27 years, serving as Director of the Division of Research for the last 13 years. In this role, he led a department of more than 50 investigators and 500 research staff working on more than 250 on-going studies. An accomplished researcher, Selby has authored more than 220 peer-reviewed articles, primarily in the areas of primary care delivery; diabetes mellitus outcomes and quality improvement; colorectal cancer screening strategies; population management for chronic conditions; and quality measurement. Selby was elected to membership in the Institute of Medicine in 2009. A native of Fulton, Missouri, Selby received his medical degree from Northwestern University; his training in family medicine from Contra Costa County Family Medicine.
Program, Martinez, CA, and his master’s in public health from the University of California, Berkeley. He served as a commissioned officer in the Public Health Service with the National Health Services Corp from 1976-1983 and received the Commissioned Officer's Award in 1981. Selby was appointed PCORI executive director on May 16, 2011.

Susan Sheridan, MBA, MIM is the Director of Patient Engagement at the Patient-Centered Outcomes Research Institute (PCORI). She is responsible for creating networks and engaging patients across the nation to provide broad-based input on the development and execution of PCORI’s research. Sheridan became involved in patient safety after her family experienced two serious medical system failures. Her husband, Pat, died in 2002 after his diagnosis of spinal cancer failed to be communicated. Their son, Cal, suffered brain damage called kernicterus five days after his birth in 1995 when his neonatal jaundice was untreated. Sheridan is Co-Founder and a Past President of Parents of Infants and Children with Kernicterus, which works in partnership with private and public health agencies to eradicate kernicterus. In 2003, she co-founded Consumers Advancing Patient Safety (CAPS), a non-profit organization that seeks a safe, compassionate, and just healthcare system through proactive partnership between consumers and providers of care. Sheridan served as President of CAPS from 2003 to 2010. From 2004 to 2011, she led the World Health Organization’s Patients for Patient Safety initiative, which embraces the collective wisdom of the patient, patient empowerment, and patient-centered care. Sheridan received her bachelor’s degree from Albion College and a Master of International Management and Master of Business Administration from the Thunderbird School of Global Management.

Nicola B. Truppin, JD is the founder and principal of Health Navigator Partners, LLC, based in Boston, Massachusetts, a practice dedicated to helping patients navigate the complex health care system. Truppin trained in Health Care Negotiation and Conflict Resolution at the Harvard School of Public Health and was the administrator for Harvard Medical School clinical courses at Massachusetts General Hospital for three years and for the Clinical Investigator Training Program at Beth Israel Deaconess Medical Center for four years. Until May 2005, she served as Manager of Member/Provider Appeals & Grievances at Tufts Health Plan, where she and her staff handled member and provider coverage disputes and complaints. Also, she taught the appeals resolution process to medical residents at Tufts Health Care Institute’s annual managed care seminar. As a health care attorney, Truppin’s practice was devoted exclusively to negotiating with clinical care teams about medication treatment plans for legally incompetent patients. Her current work involves collaborative health care problem solving with patients, providers and employers. In addition to her work with HNP, Truppin coordinates the health care practice of The Mediation Group in Brookline, Massachusetts, a nonprofit alternative dispute resolution firm specializing in mediation, arbitration, facilitation, consensus building, training and consulting. Also, she is a consultant on projects at the Schwartz Center for Compassionate Healthcare, an organization dedicated to strengthening the relationship between patients and caregivers. Truppin was a 5-year member of the Consumer Health Quality Council of Health Care for All, a Massachusetts health advocacy group and is currently part of the leadership team for HCFA that convened the first state-wide conference for PFAC members from all over Massachusetts. She was patient representative for 3 years on the Quality and Patient Safety Committee of the Massachusetts Board of Registration in Medicine. At Beth Israel Deaconess Medical Center, she is currently Co-Chair of the Ethics Advisory Committee and a member of the Medication Safety Committee, the Drug Shortage Task Force, and the hospital-wide Patient Family Advisory Committee. Truppin received an A.B. from Washington University in St. Louis and a J.D. from Suffolk University Law School.
**Dennis Wagner** is a national and international leader in the fields of healthcare quality improvement, the environment and social marketing. Dennis currently works in the U.S. Department of Health and Human Services as Co-Director of the Partnership for Patients Initiative and as Associate Director for Campaign Leadership in the CMS Innovation Center. Prior to his current CMS postings, Dennis served as the Associate Deputy Director and then Acting Director of the CMS Office of Clinical Standards and Quality (OCSQ). Dennis worked for 12 years at the Health Resources and Services Administration, including a final stint as Acting Director of HRSA’s Office of Health Information Technology and Quality. While at HRSA, Dennis led a major national effort to increase the donation and transplantation of organs. Dennis was the Director and Co-Director for a series of three large, national Organ Donation & Transplantation Breakthrough Collaboratives and related initiatives. After years of relatively flat national organ donation levels, this work generated an unprecedented increase in organ donation of nearly 25% over a four-year period. In his 20+ years of service with the U.S. government, Dennis has led and helped to support a series of national and international campaigns to: improve health outcomes and drug safety through increased clinical pharmacy services; increase access to health care and reduce disparities for underserved populations; create integrated systems of health care in communities across the nation; reduce exposure to second-hand smoke in the US; reduce the public health risks of indoor radon gas; increase organ donation in Australia; clean up the Tha Chin River in Thailand; get the lead out of gasoline in Vietnam; improve air quality in Bangkok and Chiang Mai, Thailand; and promote use of improved cookstoves by the world’s poorest people. Dennis attended a one-room country school in rural Montana for grades K-8. He has a Master’s in Public Administration from Montana State University, and joined the Federal service with the US Environmental Protection Agency as a Presidential Management Intern in 1986. Dennis was a Council for Excellence in Government Fellow in 1991-92. Dennis is married to the lovely and talented Diane M. Hill, also a Montana native. They have three children: Tess (17), Grant (14) and Margo (12).

**Judy Ward** has been employed by the Maine Center for Economic Policy as the Office Manager since 1989. She currently serves as the Chair of the Winthrop Patient and Family Advisory Council and Co-Chair of the Quality Counts Consumer Advisory Board. Judy has also participated in the 2013 Maine Quality Counts Annual conference as a Planning Committee member and presented the opening remarks, 2014 Quality Counts Annual Conference Planning committee, 2013 Quality Counts Leadership Training with opening remarks, 2012 Quality Counts Annual Conference as a presenter of Patient and Family Centered Care Council involvement, 2012 Institute for Patient and Family Centered Care International Conference, Washington, DC, as a presenter on Patient and Family Centered Care Advisory Council, and Maine CASA volunteer (Court Appointed Special Advocate for children). She is also a State of Maine Dedimus Justice and Certified Maine Town Clerk and Tax Collector. Judy lives in her hometown of Winthrop, Maine, and has a daughter Chase, who started college at the University of Maine, Orono, in the fall of 2013.

**Karen Wayman, PhD** has worked since 1986 in hospital settings including Children’s National Medical Center in Washington DC, California Pacific Medical Center in San Francisco and, currently, Lucile Packard Children’s Hospital at Stanford since 1986. Dr. Wayman received her doctorate in early childhood special-education from the University of California at Berkeley in 2002. Her dissertation topic was the “Maternal Care of the Hospitalized Child: Determinants of Parental Efficacy-Beliefs.” Since 2005 Dr. Wayman has been the Packard Children’s Endowed Director of Family-Centered Care. She is responsible for the dissemination of family-centered principles and practices and oversees Family-Advisory Councils; Parent Self-Management Program; Parents as Lean Change Partners Initiative, and Family-Centered Medical Rounds. In 2012 Dr. Wayman received a grant from the Lucile Packard Foundation for Children’s Health to create the Family-Centered Care Network of Pediatric Hospitals in California. In 2013 Dr. Wayman was appointed the Director of
Complex Care and is responsible for developing a new model of family-centered patient care for children with chronic/complex conditions.

**Daniel Wolpert** had a very serious heart attack, and then wanted to give something back to the institution that saved his life and helped him get back on my feet. He started volunteering at UMass Memorial Medical Center, greeting visitors at the Heart & Vascular ICU, where he had received such excellent care. He had expressed a desire to expand his involvement to the director of Volunteer Services, so when the hospital began putting together the Patient & Family Advisory Council, he was presented with the opportunity to get involved. He has been an active member of the PFAC ever since it was founded in April of 2010. He participated in drafting the Mission & Vision Statements, as well as the Charter. He has represented a patient's voice on many projects, from revising signage on multiple campuses of the hospital to implementation of a patient web portal, and various process improvement projects throughout the hospital. He also helped plan Health Care for All's first annual state-wide PFAC conference in Massachusetts in May, 2013. At that conference, he facilitated a workshop discussion on "Running a PFAC: Best Practices and Overcoming Obstacles." He is also a small business owner (Fleet Safety Services, which helps companies stay in compliance with DOT and other regulations), and serve on the board of directors of WooFood, a small local organization that certifies restaurants that "make the healthy choice the easy choice," making it easier for people to eat healthy when dining out.

**Peggy Zimdars** has been a Patient and Family Advisory Council member at University of Wisconsin Hospital and Clinics since 2010 and is currently the co-chair elect. She initially became involved as a PFA in 2006 after sharing results of a survey of breast cancer survivors with their Carbone Cancer Center. The survey was conducted with several fellow survivors of breast cancer and asked breast cancer survivors in her area about their survivor care needs for information and follow-up. She was invited to provide input for the Breast Center and also the Survivor Task Force before being asked to serve on the Patient and Family Advisory Council. She attend the IPFCC in 2012 and have been involved in a variety of projects and committees at UWHC.
Building the Patient and Family Advisory Leadership Network for Better Care
Meeting Logistics

The National Academy of Sciences
2101 Constitution Avenue, NW | Washington, DC
Lecture Room
November 11, 2013

We are looking forward to your participation in the November 11 Building the Patient and Family Advisory Leadership Network for Better Care meeting, hosted by the Institute of Medicine in association with the Blue Shield of California Foundation and the Patient-Centered Outcomes Research Institute. If you have any questions regarding meeting logistics, please contact our office at kburns@nas.edu or 202-334-3963.

MEETING LOCATION
The meeting will take place from 9:00am to 1:00pm (breakfast available at 8:30am) on November 11, 2013 in the Lecture Room of the National Academy of Sciences Building, 2101 Constitution Avenue, NW, in Washington, DC, 20001.

DIRECTIONS AND TRANSPORTATION

Airports: The meeting site is approximately 5 miles from Washington National Airport (a 20-minute cab ride depending on the time of day) and approximately 25 miles from Dulles International Airport (a 45-minute cab ride).

Metro: The Foggy Bottom metro stop (Orange/Blue Line) is located at 23rd and I Streets NW. Walking from the metro to the NAS building takes approximately 12 minutes. The C Street Entrance to the NAS building is the closest entrance to Metro. A map is on page 2 of this memo.

Parking: The parking lot for the National Academy of Sciences is located on 21st Street NW, between Constitution Avenue and C Street. However, space is very limited, so you may want to use an alternate mode of transportation. If the lot is full, there is a Colonial Parking garage near G and 18th Streets, NW (cash only). It is about 15 minutes walking distance from the NAS building.

Detailed driving and Metro directions to the National Academy of Sciences may be found at: http://www.nationalacademies.org/about/contact/nas.html
MAP OF FOGGY BOTTOM METRO TO NAS BUILDING