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

An Institute of Medicine Workshop sponsored by the Blue Shield of California Foundation

February 25-26, 2013
The National Academies
2101 Constitution Avenue, NW
Washington, DC 20418
Workshop Framing Materials
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PARTNERING WITH PATIENTS TO DRIVE
SHARED DECISIONS, BETTER VALUE, AND CARE IMPROVEMENT

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

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

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

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

Day 1: Monday, February 25, 2013

Please pick up a boxed lunch in the atrium.

12:30 pm  Welcome, Introductions, and Overview
Welcome from the IOM
Michael McGinnis (Institute of Medicine)

Opening remarks and meeting overview
Dominick Frosch (Gordon & Betty Moore Foundation)
Christine Bechtel (Planning Committee Chair, National Partnership for Women & Families)
To Improve, Health Care Must Partner With Patients and Families
Jonathan Welch, Harvard Medical School

Patient-clinician communication and the tools for change

Working from the dual challenges of patients’ effective use of available information and clinicians’ effective integration of available knowledge, explore approaches and strategies for widespread acceleration of shared decision making.

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

Moderator: Lyn Paget, Health Policy Partners

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

Break

Innovative models of shared decision making:
- Building a culture that promotes shared decision making
  Grace Lin, University of California, San Francisco
- The patient support corps: An innovative staffing approach to support patients in shared decision making
  Jeff Belkora, Margot Zarin-Pass, and Ekene Obi-Okoye
  University of California, San Francisco
- Implementing decision aids for increased patient engagement and reduced costs
  David Arterburn, GroupHealth

Summary and preview of next day
Day 2: Tuesday, February 26, 2013

7:30 am  Coffee and light breakfast available

8:00 am  **Welcome, brief agenda overview**

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

8:15 am  **Knowledge generation and care improvement**

As many patients support sharing their protected clinical and outcomes data for research that improves care and outcomes for all patients, identify potential pathways and strategies for improved sharing and use of insights gained from the care experience.

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

**Moderator:** Sue Trinidad, University of Washington

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

*Audience participation and open discussion*
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<tr>
<th>9:30 am</th>
<th>Knowledge generation and care improvement (cont.)</th>
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| o Patient perspectives on consent for information use  
   Evette Ludman, GroupHealth Research Institute  
| o New paradigms for patient engagement in research for care improvement:  
  - Sally Okun and Laura Phillips, PatientsLikeMe  
  - Greg Biggers, Genomera  
| o Research that improves care as a competitive advantage: communicating the importance of data sharing to the public  
   Holly Potter, Kaiser Permanente  

Audience participation and open discussion

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<th>10:45 am</th>
<th>Break</th>
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<th>11:00 am</th>
<th>Changing Expectations: Bringing Transparency to Cost and Quality Information</th>
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Taking into account the changing landscape for health care payment, consider methods for deepening patient, family, and provider knowledge of health care costs and quality, and their implications.

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

Moderator: John Santa, Consumer Reports

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

Audience participation and open discussion
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<tr>
<th>Time</th>
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<tr>
<td>1:00 pm</td>
<td>Lunch keynote</td>
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<td><strong>How American Health Care Killed My Father</strong></td>
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<td><em>David Goldhill</em>, Game Show Network</td>
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<td>Driving the demand</td>
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<td>Explore cross-cutting strategies to advance patients, in partnership with providers, as leaders and drivers of care delivery improvement through informed, shared decision making, the authorized use of clinical data for research, and value improvement.</td>
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<td>Moderator: <em>Susan Reinhard</em>, AARP</td>
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<td>o Behavioral economics and value generation</td>
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<td><em>Kevin Volpp</em>, Philadelphia VA Medical Center</td>
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<td>o Communicating “value” to the public</td>
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<td><em>Tresa Undem</em>, PerryUndem</td>
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<td>o Social media as a tool for change</td>
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<td><em>Kelly Young</em>, Rheumatoid Arthritis Warrior</td>
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<td><em>Audience participation and open discussion</em></td>
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<td>3:00 pm</td>
<td>Building a pathway forward</td>
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<td>Reflecting on the presentations and discussions over the course of the two-day workshop, participants will engage in an open dialogue to define the pathway forward for building patient demand for a continuously learning health system.</td>
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<td>Moderator: <em>Christine Bechtel</em>, National Partnership for Women &amp; Families</td>
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<td>o <em>Susan Sheridan</em>, Patient-Centered Outcomes Research Institute</td>
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<td>Summary and next steps</td>
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<td><em>Thanks from the Chair</em></td>
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<td><em>Christine Bechtel</em>, National Partnership for Women &amp; Families</td>
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<td><em>Michael McGinnis</em>, Institute of Medicine</td>
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<td>Adjourn</td>
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John Santa, MD, MPH, Consumers Union
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February 25-26, 2012

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Current as of 12pm, February 22nd
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<th>Name</th>
<th>Title</th>
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<tbody>
<tr>
<td>Daniel Bethea</td>
<td>Web Content Assistant</td>
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<tr>
<td>Claudia Grossmann, PhD</td>
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<td>Julia Sanders</td>
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<td>Robert Saunders</td>
<td>Senior Program Officer</td>
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<tr>
<td>Barret Zimmermann</td>
<td>Program Assistant</td>
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Welcome, Introductions, and Overview
Patient Engagement. People actively involved in their health and health care tend to have better outcomes—and, some evidence suggests, lower costs.

WHAT’S THE ISSUE?
A growing body of evidence demonstrates that patients who are more actively involved in their health care experience better health outcomes and incur lower costs. As a result, many public and private health care organizations are employing strategies to better engage patients, such as educating them about their conditions and involving them more fully in making decisions about their care.

“Patient activation” refers to a patient’s knowledge, skills, ability, and willingness to manage his or her own health and care. “Patient engagement” is a broader concept that combines patient activation with interventions designed to increase activation and promote positive patient behavior, such as obtaining preventive care or exercising regularly. Patient engagement is one strategy to achieve the “triple aim” of improved health outcomes, better patient care, and lower costs.

This Health Policy Brief summarizes key findings on patient engagement published in the February 2013 issue of Health Affairs.

WHAT’S THE BACKGROUND?
Modern health care is complex, and many patients struggle to obtain, process, communicate, and understand even basic health information and services. Many patients lack health literacy, or a true understanding of their medical conditions. What’s more, the US health care system often has seemed indifferent to patients’ desires and needs. Many practitioners fail to provide the information that patients need to make the best decisions about their own care and treatment. And even when patients do receive detailed information, they can be overwhelmed or lack confidence in their own choices. Those with low levels of health literacy find it difficult to follow instructions on how to care for themselves or to adhere to treatment regimens, such as taking their medicines.

Recognizing these problems, the 2001 Institute of Medicine report, Crossing the Quality Chasm: A New Health System for the 21st Century, called for reforms to achieve a “patient-centered” health care system. The report envisioned a system that provides care that is “respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions.” Out of this recognition, in part, the field of patient engagement has emerged.

FRAMEWORKS FOR ENGAGEMENT: There are many aspects to patient engagement. Kristin Carman of the American Institutes for Research and coauthors propose a framework that conceptualizes patient engagement taking place on three main levels (Exhibit 1).

The first level is direct patient care, in which patients get information about a condition and
answer questions about their preferences for treatment. This form of engagement allows patients and providers to make decisions based on the medical evidence, patients’ preferences, and clinical judgment. In the second level of engagement, organizational design and governance, health care organizations reach out for consumer input to ensure that they will be as responsive as possible to patients’ needs. In the third level, policy making, consumers are involved in the decisions that communities and society make about policies, laws, and regulations in public health and health care.

**Shared Decision Making:** One strategy consistent with the first level of engagement described by Carman and coauthors is shared decision making, in which patients and providers together consider the patient’s condition, treatment options, the medical evidence behind the treatment options, the benefits and risks of treatment, and patients’ preferences, and then arrive at and execute a treatment plan. The strategy is often used with patients who have “preference-sensitive” conditions or treatment options—that is, they may or may not choose particular treatments, or to be treated at all, depending on their own feelings about the risks versus the benefits of treatment, their ability to live well with their conditions, or other factors.

For example, although one patient with knee pain may wish to have knee replacement surgery, another may worry about the risks that the surgery may not completely relieve pain or restore mobility and may choose to forgo it in favor of managing the pain with medication and weight loss. In such cases, there are multiple, reasonable treatment options, each with their own risks and benefits, and the “correct” path forward should be guided by a patient’s unique needs and circumstances.

France Légaré and Holly Witteeman at the Université Laval in Quebec note that shared decision making involves several essential elements. First, providers and patients must recognize that a decision is required. Next, they must have at their disposal, and understand, the best available evidence. Finally, they must incorporate the patient’s preferences into treatment decisions.

There are various modalities through which shared decision making can be conducted. A typical process is to use decision aids—leaflets, books, videos, websites, and other interactive media—that give patients information on the risks and benefits of various treatment options and help them make the choice that most reflects their personal values. Some organizations, such as the Informed Medical Decisions Foundation and the private company Health Dialog, have developed balanced, expert-reviewed decision materials. Using these decision aids, shared decision making can be conducted in person between providers and patients, or remotely, as described below.

David Veroff at Health Dialog and coauthors conducted a large randomized study involving patients with one or more of six different preference-sensitive conditions: heart conditions, benign uterine conditions, benign prostatic hyperplasia, hip pain, knee pain, and back pain. One group of patients received enhanced decision-making support by trained
21%

**Increased medical costs**

Patients with the lowest activation scores—having the least skills and confidence to actively engage in their own health care—incurred costs up to 21 percent higher than patients with the highest activation levels.

**Patients who received enhanced decision-making support** ultimately had overall medical costs that were 5.3 percent lower than for those receiving only the usual support. They also had 12.5 percent fewer hospital admissions and 20.9 percent fewer preference-sensitive heart surgeries. The authors concluded that shared decision making through these relatively low-cost, remote models can extend the benefits of patient engagement to broad populations.

**Patient activation:** Many studies have shown that patients who are “activated”—that is, have the skills, ability, and willingness to manage their own health and health care—experience better health outcomes at lower costs compared to less activated patients. In an effort to quantify levels of patient engagement, Judith Hibbard of the University of Oregon has developed a “patient activation measure”—a validated survey that scores the degree to which someone sees himself or herself as a manager of his or her health and care.

Hibbard and coauthors studied the relationship between patients’ activation scores and their health care costs at Fairview Health Services, a large health care delivery system in Minnesota. In an analysis of more than 30,000 patients, they found that those with the lowest activation scores, that is, people with the least skills and confidence to actively engage in their own health care, incurred costs that averaged 8 to 21 percent higher than patients with the highest activation levels, even after adjusting for health status and other factors (Exhibit 2). And patient activation scores were shown to be significant predictors of health care costs.

**Broader patient engagement:** Consistent with the second and third levels of engagement that Carman and coauthors describe are programs in which health care organizations structure themselves to meet patients’ needs and preferences—and in which those preferences help to shape broader responses on a societal scale. An example is the Conversation Project and the Conversation Ready Project—two efforts to elicit patients’ attitudes and choices about end-of-life care and predispose providers to give care consistent with those choices.

The Conversation Project, initiated by Boston-based journalist Ellen Goodman and colleagues, is a grassroots public campaign that encourages people to think about how they want to spend their last days and to have open and honest discussions with their families and health care providers. By having these important conversations before a crisis occurs, patients can consider and clearly communicate their wishes and forestall situations in which those decisions are made by others and not fully aware.

The Conversation Ready project, initiated by Maureen Bisognano, president and chief executive of the Institute for Healthcare Improvement, and IHI colleagues, is an effort to make certain that the nation’s health systems and providers have the skills to elicit and receive patients’ and families’ views about end-of-life care, document them, and carry them out. Ten “pioneer” health care organizations working with the institute have committed to being “Conversation Ready” within one year—and to developing replicable and scalable models of change that others can adopt as well.

For example, one of the systems, Gundersen Lutheran, which is based in LaCrosse, Wisconsin, has created Respecting Choices—a 501(c)3 not-for-profit aimed at engaging individuals in end-of-life decision making. Among other actions, the health care system prompts all patients at the age of 55 to discuss their wishes with their primary care provider.
Researchers have identified a number of common factors and obstacles that may need to be overcome to carry out effective patient engagement and activation strategies. Some are attributable to patients and their characteristics and proclivities and others to those of providers.

**FACTORS INVOLVING PATIENTS:** For patients to engage effectively in shared decision making, they must have a certain degree of health literacy. Howard Koh, assistant secretary for health at the Department of Health and Human Services, and his coauthors propose a new Health Literate Care Model that assumes that all patients are at risk of not understanding their health conditions or how to deal with them. Health care organizations adopting this model would work to increase health literacy and patient engagement over the entire care span.

Koh and colleagues propose, for example, that health care organizations first adopt the Care Model, formerly known as the Chronic Care Model, a mode of delivering health care that draws on clinical information systems, decision support, and self-management support to provide comprehensive care for chronically ill patients. Then, health literacy strategies would be incorporated into the model, such as the “teach-back” method, in which providers ask patients to explain back to them what the patients have learned, their own understanding of their condition, the options available to them, and their intentions to act on the information.

**DIVERSE BACKGROUNDS:** Elizabeth Bernabeo and Eric Holmboe of the American Board of Internal Medicine examined shared decision making and concluded that it is “patient specific.” Specifically, they said, a patient’s degree of engagement may be affected by such factors as cultural differences, sex, age, and education, among others. As a result, specific competencies, such as language skills or an awareness and understanding of religious beliefs, may be required on the part of clinicians and delivery systems to effectively engage patients with diverse cultural backgrounds and socioeconomic status.

**COGNITIVE ISSUES:** Robert Nease and colleagues of Express Scripts have noted that there are well-known limitations to human decision-making skills and the ability to maintain attention that serve as barriers to patient engagement. They argue that there may be better ways to influence patients’ decision making, such as through “choice architecture,” in which decisions to be made are structured so as to “nudge” a patient toward a particular choice. For example, in a pilot study by Express Scripts, patients were required to use preferred, lower-cost drugs before they could “step up” to other options. They were given information about the step-therapy program and given 60 days in which to “opt out” if they wanted to switch to a nonpreferred medication. The opt-out rate was only 1.5 percent, indicating that choice architecture is a potential alternative to other patient engagement approaches.

**AVERTION TO CONSIDERING COSTS:** One area in which it may be especially hard to engage patients is considering costs in the context of making decisions about their health care. Roseanna Sommers, a Yale Law School student, and coauthors convened 22 focus groups of insured people and asked them about their willingness to weigh costs when deciding among nearly comparable clinical options—for example, to receive a computed tomography scan or undergo a more expensive magnetic resonance imaging after having had a severe headache for three months. Most participants were unwilling to consider costs and generally resisted the less expensive inferior options.

The authors identified a number of factors that lead patients to ignore cost. These factors include patients’ preference for care they perceive to be the best, regardless of expense; an inclination to equate cost with quality; inexperience in considering trade-offs among cost and quality; disregard for costs borne by insurers or society as a whole; and the impulse to act in one’s own self-interest even though resources are limited.

One antidote to consumers’ aversion to considering costs might be giving them cost and quality information that they find most useful and relevant to their concerns. Jill Matthews Yegian of the American Institutes for Research and coauthors found that consumers want to be able to compare information about individual physicians and to obtain cost data that reflect their own out-of-pocket expenses for an entire episode of care, not for individual procedures and services. Therefore, the authors contend, state and federal policy makers should look for ways to assemble such infor-
mation and make it clear and accessible for consumers.

**FACTORS INVOLVING PROVIDERS:** A recurring theme in the February 2013 issue of *Health Affairs* is the need for significant changes in the culture and operations of medical practice to implement patient engagement strategies. Studies have identified numerous barriers, including time constraints, insufficient provider training, a lack of incentives, and information system shortcomings.

In one study, Grace Lin of the University of California, San Francisco, and coauthors explored the use of decision aids—DVDs and booklets about colorectal cancer screening and treatment for back pain—at five primary care clinics in Northern California that expressed a willingness to use them. Despite that support, the actual distribution rates for these items remained low, even after staff training sessions and other promotional activities. Some physicians felt that patient input was not warranted, although others had difficulty moving away from traditional physician-directed decision making. Most physicians cited a lack of time as a major barrier.

That perspective echoed a finding in the systematic review of 38 studies by Légaré and Witteman, which was that clinicians pointed most frequently to time constraints as the primary barrier, even though there was “no robust evidence that more time is required to engage in shared decision making in clinical practice than to offer usual care.”

Mark Friedberg of the RAND Corporation and coauthors evaluated a three-year demonstration project on shared decision making conducted at eight primary care sites in different parts of the United States. They discovered three main barriers to implementing shared decision making: overworked physicians, insufficient provider training, and clinical information systems that failed to track patients throughout the decision-making process. The researchers note that payment reforms and incentives may be needed for shared decision making to take hold.

**WHAT ARE THE POLICY IMPLICATIONS?**

Federal and state policy makers have embraced patient engagement as a strategy to address health care costs and improve quality. Here are some of the ways.

The Affordable Care Act identifies patient engagement as an integral component of quality in accountable care organizations (ACOs) and in patient-centered medical homes. Shared decision making is so valued in the law that a separate section (3506) calls for new Shared Decision-Making Resource Centers to help integrate the approach into clinical practice. No funds have yet been appropriated to implement this section, however.

Patient engagement is also central to Section 3021 of the law, which creates the Center for Medicare and Medicaid Innovation. Under the law, the center is to examine how support tools can be used to improve patients’ understanding of their medical treatment options. The health care law also created the Patient-Centered Outcomes Research Institute, charged with funding research that will assist patients, caregivers, clinicians, payers, and policy makers in making informed health decisions.

Because patient activation can be directly linked to improved outcomes, a measurement of patients’ level of activation could be adopted as an intermediate measure for ACOs, patient-centered medical homes, and other new and emerging delivery and payment structures, Hibbard and her coauthors observe. The need for additional measures of patient engagement is discussed further below.

**STATE POLICY:** In 2007 Washington became the first state to enact legislation encouraging shared decision making and decision aids to address deficiencies in the informed consent process. The legislation also required a pilot project to study shared decision making in clinical practice. Massachusetts is also incorporating patient engagement into its health policies. Now, to be certified by the state, ACOs and medical homes must include shared decision making. Patient engagement and consumer choice will also be fundamental to health insurance exchanges, where as of October 2014 people and small businesses will be able to shop for coverage.

So-called “navigators” and federally supported, state-run consumer assistance agencies will be able to assist consumers with their purchasing, as well as with issues that arise with their health coverage. Rachel Grob of National Initiatives and coauthors reviewed state efforts to meet the law’s consumer assistance goals and found that in fewer than half the states, consumers are getting the assistance they need to navigate a rapidly chang-
PATIENT ENGAGEMENT

Despite evidence that has been compiled to date of the importance of patient engagement, experts in the field agree that more research will be needed to determine best practices for engaging patients, as well as to more fully demonstrate the relationship of patient engagement to cost savings. In the meantime, considerable efforts are under way to hold health care organizations accountable for engaging patients.

For example, the National Committee for Quality Assurance, a nonprofit organization that tracks the quality of care provided by health plans and health care organizations, requires a variety of assessments to determine how actively patients are being engaged in their health and care. Organizations wishing to be certified as meeting requirements for patient-centered medical homes, for example, must undertake surveys of patients that ask about whether clinicians engage them in shared decision making or provide support for them to manage their conditions. But there is wide agreement that even more could be done to measure how and how well health care organizations engage patients, and help to realize individuals’ full potential to maintain and improve their health.

RESOURCES


To Improve, Health Care Must Partner with Patients and Families
As She Lay Dying: How I Fought To Stop Medical Errors From Killing My Mom

A woman with cancer dies after receiving poor care for an infection. Her physician-son calls on the health system to involve patients and families in improving safety.

BY JONATHAN R. WELCH

Back when I was training to become an emergency physician, I’d worry about the day I’d be involved in a medical error. It seemed inevitable. With land mines everywhere—the possibilities of missed diagnoses, delayed treatments, miscommunication—it felt like almost anything could lead to catastrophe. I imagined attending the in-house case review afterward, chastened as my hospital colleagues dissected my decisions. Yet I also thought—and hoped—that something positive would come from the process, that lessons from an error would sharpen my clinical skills and improve care in the hospital.

But when I was entangled in my first medical error, I played an unexpected role: I was a thirty-three-year-old son trying to save my mom’s life.

The Phone Call

The call came to me in Boston out of the blue on a sunny Monday morning in September 2010. On the line was an emergency physician in the Wisconsin town where I’d grown up, telling me my mom was sick. He sounded harried, and I heard papers rustling in the background.

My mom was already fighting breast cancer, but he was calling about a new development. During the preceding year, my mom had received a steady course of chemotherapy. She’d first been diagnosed with breast cancer fourteen years earlier, but she’d gone into remission. Then in 2008, at age fifty-nine, she’d started complaining about chest pain. It turned out her cancer had returned and spread to her breastbone. Since restarting chemotherapy, my mom had been holding her own, and her cancer was stable.

But she’d suddenly worsened on the morning of the phone call. When my dad found her barely responsive in a chair at home, he’d called 911. At 9 a.m., my mom had arrived at the emergency department of the local hospital. She had a high fever; her heart was racing; and her white blood cell count, indicating how capable her immune system was of fighting infection, was extremely low.

I knew what was wrong: neutropenic sepsis. I often diagnose and treat cancer patients with this condition. It meant that my mom had a serious systemic infection complicated by her body’s severe shortage of infection-fighting cells, which had been nearly eliminated during chemotherapy. The condition is well known, is easily diagnosed, and has a clear and standard treatment protocol.

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I also knew we were on the clock. The first twenty-four hours of my mom’s hospitalization would be critical to saving her life. Studies of sepsis have shown that early and aggressive treatments
during that time can make the difference between life and death. The needed interventions include continuously monitoring vital signs, giving antibiotics, and providing lots of fluids. If a patient is especially sick, he or she needs to be moved to an intensive care unit (ICU) and have a special central intravenous (IV) line inserted to receive powerful medications.

My mom was in serious trouble. I caught the next flight home.

The Clock Is Ticking
Once I was in Wisconsin, I hurried to my mom’s hospital bed, where the rest of my family already was gathered. I arrived about 9 p.m. “How are you doing?” I asked her. “Fair,” she replied, her voice guttural and weak. How typical of her, I thought, she’s describing her serious condition as if it’s just an off day.

Sequestered during my flight, I’d been cut off from updates. But I’d kept doing the math. The hospital now was twelve hours into its critical opportunity to halt her systemic infection. I was eager to know my mom’s heart rate and blood pressure, two basic indicators of whether she was getting better. I peered above her hospital bed, looking for the cardiac monitor providing this information. It wasn’t there.

Confused, I approached my mom’s nurse, thinking the monitor might be near her work station. But it wasn’t there, either. Unless my mom had been improving, this situation was dangerous. Without a monitor, her doctors and nurses could miss sudden changes in her vital signs that would require swift action.

I leaned over and took a look at my mom’s medical chart. Some infrequent vital signs had been recorded. And I saw a clear, terrifying picture. My mom’s blood pressure had crashed during the day. Her numbers now were half of what they’d been at her arrival in the emergency department. My mom’s emergency physician and oncologist had taken few, if any, of the essential and obvious interventions needed to save her life. The nurse seemed calm, as if everything was normal.

What was their problem? Was I missing something? I felt trapped in an alternate reality where the medical rules were the opposite of everything I’d learned and practiced, where doctors and nurses were oblivious to impending disaster.

By now it was past 10 p.m., and my mom’s oncologist, who was in charge of her care, had left the hospital for the day. I couldn’t figure out what he’d been thinking.

I did know, however, what my mom needed: to be in the hospital’s ICU. There, a knowledgeable intensive care doctor would start the standard treatments for a systemic infection.

“I want my mom transferred to the ICU right away,” I told the nurse. “She’s getting worse.” That was an understatement. The transfer was approved, and I sent my family home for the night. I stayed on, relieved that my mom would finally get the care she needed. I hoped it wasn’t too late.

Getting Her To The ICU
My mom was moved to the ICU around midnight, fifteen hours after she’d arrived at the hospital. I figured I’d get a bit of rest once her central-line IV and other treatments were started.

But during the next hour, I slowly realized little was changing. I didn’t see an intensive care doctor, or any doctor for that matter. No central-line IV was inserted; no powerful medications were started. What was going on?

By 1 a.m. I was panicking. The next time I saw my mom’s nurse, I asked about the treatment plan. Her response was a not-so-veiled criticism of my mom’s doctor. “We do have a sepsis treatment protocol,” she said, “but your mother’s oncologist hasn’t ordered it.”

“Her oncologist?” I was surprised. At the hospital where I work, critical care doctors are the specialists who treat ICU patients with systemic infections. Wasn’t that the case here? “Your mother’s oncologist hasn’t consulted the intensive care specialist,” she told me.

My mom now had been in the hospital for sixteen hours without receiving the sepsis protocol—made up of a standard group of treatments and actions—that she needed to save her life. The clock kept on ticking toward 2 a.m.

I wish I’d done more at that point—raised hell, insisted on waking both my mom’s oncologist and the hospital’s intensive care doctor at home, demanded that they come to the hospital. Instead, by that point I felt lost and powerless. I’d already insisted that my mom be moved to the ICU. What would happen if I made additional demands? Would the ICU nurse start avoiding my mom’s room? If I criticized my mom’s oncologist, what would happen to their relationship? I knew there could be a downside to being too demanding in a hospital.

I was losing my own confidence as a doctor, becoming instead the helpless son of a sick patient, someone who couldn’t get anything at the hospital to work. Every ten minutes or so my mom called me, uncomfortable in the stiff bed, asking me to get her up. “Please,” she begged. I couldn’t do that with her blood pressures so low; I could only help her change positions. By now I was psychologically off balance, torn between staying by her side and mobilizing hospital staff members to find her the needed care.

By 3 a.m. I’d given up on the hospital. My single thought was: “We’ve got to get her out of here.” I began making plans to transfer my mom to another hospital in the morning. During the next hours, the transfer request forced my mom’s oncologist to relinquish primary responsibility to a capable intensive care doctor who provided the right treatments. Ultimately no hospital transfer was needed.

But...by the time the sepsis protocol was finally put in place, it was 8 a.m. on Tuesday. A total of twenty-three hours without appropriate treatment had passed since my mom had entered the hospital. She still had a chance to survive, but because of the squandered
During the following days my mom battled hard. But her infection and the delay in treatment proved too much. Toward the end, in a final moment of brief lucidity, she opened her eyes and whispered, “I never got to say good-bye.” She was dead by the end of the week.

**‘Do You Want To Sue?’**

In the midst of grieving and preparing for my mom’s funeral, I was also lost in a haze of disbelief. I didn’t understand what had happened. Why had so many things gone wrong?

When I discussed my mom’s case with my Boston colleagues, they were incredulous. “Do you want to sue?” they asked. Although I never thought I’d be that person—a plaintiff in a malpractice lawsuit—that option was easy to consider. I felt angry and abandoned by my mom’s oncologist, the emergency physician, and the nurses who remained quiet while she didn’t receive the treatments she needed. I no longer trusted my hometown hospital.

As the weeks progressed, however, the thought of a lawsuit didn’t sit well. The prospect of lengthy legal proceedings seemed counterproductive—an emotional delving into old sorrow with every deposition. I came to believe that suing the hospital and the doctors involved would interfere with our family’s accepting my mom’s death and the normal grieving process.

As a doctor in a high-risk field, I also considered how destructive a malpractice suit could be. If we sued, my mom’s oncologist would be a central figure in the case, as the debacle fell squarely in his lap. He was imperfect, but he’d treated my mom’s cancer, both fourteen years ago and during her recent recurrence, and she’d respected him. He was nearing retirement, and a lawsuit would be a terrible way to end his career.

I didn’t want to do that to him, even though he’d never explained his inaction. As a physician I felt an odd empathy; a lawsuit would desecrate his years of service. We had to find an alternative. A lawsuit just wasn’t in line with our midwestern family mind-set.

**An Alternative To Litigation**

As the prospect of a lawsuit became unpalatable, we started looking for other options. Whatever we chose, we wanted the hospital to provide an explanation for what happened. And we wanted an apology. Additionally, because the hospital had wasted opportunities to save my mom, we wanted assurances that it would never make these mistakes again.

“If you want to improve quality,” a colleague suggested, “why don’t you write a letter?” We could address the letter to the hospital’s administrators, he suggested, describing my mom’s experience and suggesting specific ideas for improving how systemic infections were treated.

But would our hometown hospital actually use the letter to drive change? Or would the letter, lacking legal teeth or financial consequences, be politely filed away and forgotten? Perhaps it might be seen as a threat, a sign that a lawsuit was on the horizon. In that case, I imagined hospital administrators forwarding the letter to the risk-management department, where fear of litigation would immediately suspend any opportunity to improve quality. Still, a letter seemed our best option.

My family crafted our letter carefully and positively. In it, we suggested specific ways that the hospital could achieve national standards for treating systemic infection. Given the technical nature of our concerns, we asked that I be contacted as our family’s spokesperson. We mailed the letter to the hospital president, chief medical officer, and chair of emergency medicine, and then we held our collective breath.

**After Sending The Letter**

Within a week, I received a voice-mail message from the director of the hospital’s emergency department. “Hi, Dr. Welch, I did receive your letter today. ...I have already had discussions with the chief of the intensive care unit, and we are planning to review this case. ...I wanted to let you know and touch base with you to see if you wanted to have any further discussion right now.”

Finally, I thought, we’re getting somewhere. I returned the call and left a message, asking to be called back. I then waited for a response. But there wasn’t one. In fact, there wasn’t a return phone call, or any communication from the hospital, for four months. Initially I thought the administrators there might still be reviewing the case. “Give them time,” I told myself. But as the months ticked by—I’m surprised now that I let so much time pass—I began to think our letter had been tossed aside.

Angry, and with my family now reconsidering a lawsuit, I called the director of the emergency department again. This time my call was returned by one of the hospital’s top administrators.

The administrator, himself an intensive care physician, discussed the case in a conference call with my wife, who is also a doctor, and me. He’d reviewed the case with two other doctors and, he admitted, the hospital’s actions didn’t reflect “the degree of urgency” required. A sanitized, verbal admission of error, but an admission nonetheless.

Some of our letter’s concerns were being addressed, and changes were made in the hospital. For instance, we were told, the emergency department was beginning to enact new guidelines for treating systemic infection.

Other concerns were left unresolved. The administrator we dealt with stated that the hospital already had a system for responding to patients who were rapidly getting sicker, but that my mom’s oncologist and nurse hadn’t enacted it.

And in some areas, where change was needed, nothing occurred. No system was created to alert the hospital when critical protocols, like the one for systemic infection, hadn’t been ordered. The administrator also told us that the hospital wouldn’t have intensive care physicians assume immediate responsibility for all new ICU patients. The hospital had tried to move toward that model earlier, he said, but there were “political barriers” to doing so.

Concluding the call, he explained that the hospital hadn’t responded for four months because he was waiting for improvements to be enacted, and he apologized for not updating us sooner. “I’m sorry,” he said. It was the only time our family heard those words.
A Better Way

Looking back now at my mom’s experience, I hope my family’s letter had some effect on the quality of the hospital where she died. Yet even where change occurred, we had a passive role. Our four months of anguish waiting for a response emphasized that.

Today, I imagine an alternative scenario in which patients and families are able to participate actively in quality improvement. At some hospitals, this is already occurring. The University of Michigan Health System, for one, has made it a policy to communicate openly and directly with patients and families after medical errors or complaints happen, reviewing incidents and even relying on peer review from medical specialists in relevant fields. Like me, they view litigation as a last resort and strive to make changes to the systems and processes that lead to breakdowns in care. As a result, the system has made many changes to clinical care based on patient complaints and input.

If such a program had been available to my family, we would have met with someone from the emergency department and learned about the new systemic infection protocols being put in place. We would have met with the ICU’s quality committee and made our case for intensive care physicians’ becoming involved immediately in the care of all new ICU patients. Sharing my mom’s story directly with those who opposed such a policy would, I believe, have been more powerful than any letter or lawsuit.

In the Boston hospital where I work, we strive as a group to improve the quality of care we offer our patients. We review our process and outcome measures, and we create and track new approaches for improving care. We also make changes after examining specific patient cases. And yet, I now realize, before this experience I never sought patient or family feedback in any of these quality improvement activities.

Hospitals—and those of us who work in them—often fall short of understanding the experiences of hospitalized patients and their families and the perspectives they have that might improve care. Integrating patients and families into a hospital’s quality and safety culture needs to become one of the important elements of patient-centered care.

In some settings, this type of care is not a fantasy. With funding from the Josie King Foundation—named after a toddler who died through hospital medical errors—the University of Pittsburgh Medical Center and the Children’s Hospital of Pittsburgh implemented a program called Condition H (for Help). The program allows patients and families to call a hotline when—like I did—they feel that they are not receiving the care they need. When the number is called, a rapid response team of a physician, patient relations coordinator, nursing coordinator, and floor staff arrives in minutes to remedy the problem. The program has been deemed a success, and similar family-initiated rapid response teams are now being implemented across the country.

Unfortunately, programs like these had not yet made their way to my hometown in Wisconsin. And with my mom’s death, our family’s connection to the hospital where she died came to an abrupt end. Her oncologist wrote a discharge summary, her medical records were archived, and her team of doctors and nurses moved on to the next patient. The hospital closed the case. But it wasn’t closed for us. We wanted to create something positive out of our nightmare, yet we were forced to choose between two imperfect options: lawsuit or letter.

As hospitals strive to improve their quality, they’ll need to develop new patient-inclusive approaches for doing so. Patients and families, for instance, need to be included on quality improvement committees.

In Massachusetts, where I practice, all hospitals are required to have patient and family advisory councils. The Agency for Healthcare Research and Quality offers a guide to help organizations develop these councils, which are charged with improving all aspects of patient and family care. At the University of Washington Medical Center in Seattle, for example, a patient- and family-centered advisory council has resulted in the provision of “room service”-type food catering to patients, revisions to the center’s education and training materials, and other program and policy changes. Having these councils even more deeply engaged in quality improvement will be an important next step.

Finally, patients and families should be interviewed after hospitalizations, especially when there’s a bad outcome, and asked questions such as these: “Were you ever frustrated, confused, uncomfortable, or scared? Did your time in the hospital work out the way you wanted it to? Did our treatments get you closer toward your goals? How can we improve?” My family could have provided clear and helpful answers to such questions. In many instances, patient and family viewpoints would add new perspectives and important information that could drive opportunities for improvement.

Strategies like these can improve hospital safety and quality. Today, I’m eager to further a patient-centered agenda in quality improvement. I attend patient and family advisory councils, and I’m working to incorporate patient input in all aspects of my work, using best practices from the Institute for Healthcare Improvement as well as the Institute for Patient- and Family-Centered Care. The need for those of us working in health care to thoughtfully and decisively incorporate patient and family voices into care is urgent.

Today—and tomorrow—in hospitals across the nation, there are patients whose survival and well-being will depend on it. Their lives, like my mom’s, hang in the balance. With lives on the clock, and as hours and days tick away, we need to listen to every voice and do everything possible to avoid repeating terrible mistakes.

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Patient-Clinician Communication and the Tools for Change
The Patient Is In: Listening To Low-Income Californians

Editor’s note: For more on engaging patients to be active participants in their own care, see the February issue of Health Affairs, “New Era Of Patient Engagement.”

The dramatic expansions in health insurance coverage included in the Patient Protection and Affordable Care Act (ACA) will give millions of low-income Americans greater choice in where and how they receive their health care. Until now, most of the discussion around our changing healthcare landscape has focused on the goals of payers and providers, rather than the needs and desires of patients. Although policymakers have emphasized the importance — and necessity — of engaging patients differently under reform, there have been few data to inform these discussions.

Against this backdrop, Blue Shield of California Foundation commissioned a series of representative, random-sample surveys of Californians aged 19 to 64 with household incomes less than 200 percent of the federal poverty level. The ultimate goal of these surveys is to bring the voices of low-income Californians into the conversation about how best to deliver care in the ACA-shaped future in order to inform policy choices and help providers prepare for a reformed healthcare system.

Resetting Expectations

The first report, On the Cusp of Change: The Healthcare Preferences of Low-Income Californians, based on a spring 2011 survey, revealed that fewer than half of low-income residents feel satisfied with their current health care and six in ten report being interested in switching to a new facility if they had the insurance to cover it. With full implementation of the ACA rapidly approaching in 2014, providers serving low-income Californians will have to change the way that they practice in order to retain their current patients, and attract those who are newly eligible for coverage.

The results indicate that staff courtesy, facility cleanliness, the amount of time patients spend with the doctor, and how involved patients are in making decisions are among the strongest independent predictors of overall quality-of-care ratings. The results also clearly demonstrate the critical role of the doctor-patient relationship. Not only does having a well-regarded personal doctor greatly increase respondents’ overall satisfaction and loyalty, but lacking and wanting a personal doctor is a key driver of respondents’ interest in seeking out a new healthcare facility.

What Patients Want

The results of a follow-up survey in spring 2012 were published in a report titled Connectedness and Continuity: Patient-Provider Relationships Among Low-Income Californians. Report findings revealed a striking “connection chasm” between low-income patients and their providers. The survey found that eight in ten low-income Californians think it’s important to have someone at their healthcare facility “who knows them pretty well,” yet just 38 percent currently have such a connection. Continuity with a care provider also is lacking — only a third of those surveyed report that they always see the same care professional on each visit.

This “connection chasm” has significant implications. Low-income Californians with a personal connection, or who regularly see the same provider, are far more likely than others to be satisfied with the quality of their care. These patients also report feeling very informed about their health, very comfortable asking questions of their provider, able to comprehend their providers’ medical explanations, and very confident in their ability to make healthcare decisions and take an active role in their care. In short, connected patients are more empowered and engaged in their care, as well as more satisfied with the care they receive.
Currently, connectedness and continuity are primarily established through a traditional doctor-patient relationship. Yet, the one-on-one, physician-based model is not the only option. Statistical modeling shows that having a personal doctor, in and of itself, does not independently predict healthcare empowerment, engagement or satisfaction among low-income Californians. Instead, it is connectedness and continuity that independently predict these key outcomes — regardless of whether the care experience is via a traditional doctor-patient relationship or other means. This suggests that alternatives to the traditional model can effectively and efficiently deliver the care patients want and need, provided they establish connectedness and continuity.

Among low-income Californians, utilization of alternative models of primary care is relatively low — just a quarter say they have team-based care and 18 percent report having a healthcare navigator or coach. But positive regard for these models among current users is uniformly high, and openness to trying them among non-users is broad. For example, a near-unanimous 94 percent of current team-based care patients like the approach, and 81 percent of those who don’t have team-based care are willing to try it. Majorities are also open to trying group care, a healthcare coach, and using text- and Internet-based communication tools as part of their care.

Even more promising is the finding that team-based care helps to establish the connectedness low-income Californians seek. Indeed, while there is a broad connectedness gap between low-income patients who get their care from clinics and those who receive care at private doctors’ offices, that gap disappears among clinic patients who have team-based care. Specifically, among patients who receive care at a private doctors’ office, 51 percent say someone knows them well; among patients in team care programs at clinics, an identical 51 percent say the same. By contrast, among clinic patients who lack team-based care, connectedness falls to just 32 percent.

Modeling shows that the desire for a more personalized healthcare experience helps to drive openness to alternative care models, further underscoring the potential for these alternative programs to satisfy the need for connectedness and continuity. Wanting greater continuity in a care provider is a key predictor of both interest in a health coach and willingness to try team-based care. Moreover, openness to both team care and a health coach is higher among those who want, but currently lack a personal doctor, who have communication problems with their current care provider, and who desire a greater say in decisions about their care.

**Identifying What Works**

There is near-universal agreement in the healthcare field that encouraging engagement and shared decision-making will yield better outcomes for patients, providers, and the health system overall. Despite this consensus among experts, results from a second 2012 survey, *Empowerment and Engagement among Low-Income Californians: Enhancing Patient Centered Care* [4], found that four in ten low-income Californians prefer to leave healthcare decisions to their provider. Having an equal say appears more intimidating than appealing to some specific groups within the low-income population, particularly those of lower socioeconomic status.

However, providing clear information can shift that playing field. A follow-up question in the survey asked those who preferred to leave decisions to their provider how they would feel if their doctor has “selected treatment options for you — a choice of things you might do, any of which is medically appropriate — and you’ve been given information that you understand about these options. Under these conditions, interest in shared decision-making swelled to 81 percent, a 22-point increase once information is present.

Notably, many of the differences in initial preferences are greatly, or even entirely, attenuated when the offer of shared decision-making is accompanied by clear information. For example, between low-income Californians who lack a high school diploma and with those who have a college degree, there is a 25-point gap in initial preference for equal say (47 percent vs. 72 percent). That gap shrinks to just 7 points (76 percent vs. 83 percent) when clear information is added to the mix.

Clear provider-patient communication and easy-to-understand information are not only critical to shared decision-making, but also contribute to the broader goal of patient empowerment and engagement. By testing some of the basic principles of patient-centered care from the patient’s perspective, we produced a data-driven mediation model, based on a
series of regression analyses, showing how these concepts can lead to a more engaged patient population. (See exhibit below, click to enlarge.) Here too, communication and information play key roles.

As seen in this model, connectedness and continuity are important starting blocks; they directly predict patient empowerment (defined as self-reported health information, comfort asking questions, comprehension of providers’ medical explanations and self-confidence). The product of that empowerment, in turn, is greater self-reported engagement in healthcare decisions.

Comparing marginal results on these factors across subgroups is striking. First, in terms of the importance of connectedness, low-income Californians who feel someone at their facility knows them well are 27 points more likely than others to feel very informed about their health (64 vs. 37 percent), 19 points more likely to report being very comfortable asking questions of their care provider (73 vs. 54 percent), 19 points more likely to always understand their providers’ instructions (56 vs. 37 percent) and 10 points more apt to be very confident in their ability to make care decisions. Continuity shows a similar relationship with these empowerment outcomes.

The data demonstrating the link between empowerment and engagement are equally clear. Low-income Californians who feel very informed about their health are 29 points more likely than those who feel less informed to report currently having a great deal of say in their care decisions. Those who feel very comfortable asking questions of their care provider, who always understand their providers’ instructions, and who feel very confident in their decision-making abilities are likewise 20, 23 and 22 points more apt than their less-empowered counterparts to report being actively engaged in their health care.

An important additional finding of the mediation model is that connectedness and continuity, as promising as they are, are not the only paths to increased patient empowerment. Even in the absence of connectedness and continuity, information remains an independent predictor of comfort, comprehension, confidence, and ultimately engagement.

Notably, the extent to which patients feel informed about their health predicts their engagement independently of – and more strongly than – their education, income, gender, race/ethnicity, language spoken at home, and the type of care facility they use. This suggests that clear information can help level the healthcare playing field across different population groups.

**Implications For Safety-Net Providers**

Although some of the perceptions of low-income Californians related to health care are self-evident, the health system has been very slow to respond. The window of opportunity and urgency created by the ACA should be used to accelerate progress on authentic patient engagement. In aggregate, these results suggest a compelling road map for safety-net providers over the next few years.

First, safety-net providers must recognize the importance of directly engaging patients —
who will now have a choice in their health care — to understand their expectations and decision-making criteria. The expert opinions of policymakers and providers are not a substitute for hearing from patients directly.

Second, to retain patients, safety-net providers must improve the perceived quality of care within their facilities, focusing on mutable characteristics such as safety, courtesy, cleanliness of the facility, and time spent with the doctor.

Third, providers must address the important role of ongoing, personal relationships in a patient-centered medical practice and implement models of care that enhance patient connectedness and continuity. Notably, providers do not have to remain tied to the traditional primary care model of a patient linked to a doctor to achieve these goals. Alternative models of care show great promise in establishing the personalized health care experience many low-income Californians seek.

Lastly, all healthcare providers should appreciate the value of relevant, easy-to-understand health information in empowering patients to take an active role in their care. The charge from these research findings is clear: information is a critical tool to deliver patient-centered care. Information empowers patients, regardless of socioeconomic background, and even in the absence of connectedness and continuity. Safety-net facilities that train providers and staff to convey information in a way that crosses language, sociocultural, and educational barriers will encourage a more fully engaged patient population.

Although many of the healthcare preferences of low-income patients are self-evident, the health system has been very slow to respond. These reports clearly identify the inevitability of change within California’s safety net. However, it is the urgency created by the ACA that must ultimately be leveraged to accelerate progress towards a truly patient-centered healthcare system.

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URL to article: http://healthaffairs.org/blog/2013/02/11/the-patient-is-in-listening-to-low-income-californians/

URLs in this post:
[1] New Era Of Patient Engagement: http://content.healthaffairs.org/content/32/2.toc
1. Description of the problem and policy significance

Most of us, if we have been lucky, have not had much practice being patients. We learn the skills of “patienthood” -- how to evaluate health insurance plans and coverage; our rights and obligations as patients; how to choose or change physicians; how to participate effectively with our physicians in treatment decisions, weigh risks and benefits of treatment against our personal preferences; how to influence the quality and safety of care we receive; even how and when to refuse care -- through a haphazard, trial-and-error process, if we learn at all. The U.S. health care system is arguably the most complex in the world. Technologies that enhance and support health care are advancing at an unprecedented pace. Consumers or “patients” are being regularly bombarded with information. Pharmaceutical companies are now marketing medications directly to the public. Most major network newscasts have a health care segment; news “magazine” shows often have a staff physician brought in to brief the public on the results of the most recent scientific studies, controversies in disease management, efficacy of new drug therapies or technologies, issues related to health insurance and organization of health care delivery, etc., often on the same day they appear in the scientific media. Sophisticated Web search engines put vast amounts of health care information at the fingertips of motivated individuals. Comparisons of health insurance plans
appear with increasing frequency in the popular press. Even quality of care profiles are publicly reported for hospitals, health plans, and in many states, individual physicians.

Yet we have no national policy for training the present or future health care consuming public how to use this information to be effective, efficient patients. It should come as no great surprise, therefore, that the average patient asks fewer than 5 lexical questions during a 15 minute office visit, that most patients do not actively participate in the decision-making process during treatment, that most patients assume that all healthcare is evidence-based and error free, and that “informed consent” is rarely that. Most find even making choices between insurance plans frustrating and daunting.

When we first began to test a program that we now call “Coached Care” for training patients to participate in their chronic disease care some 20 years ago, the healthcare community regarded us with no small degree of skepticism. The idea of guiding patients through a systematic review of their medical record using branching guidelines for quality of care for their disease, and teaching them to ask questions and participate in treatment decisions was controversial, if not threatening. Since then, a substantial body of evidence has accumulating documenting the beneficial effects of effective patient participation in care on patients’ health outcomes. And still we lack an organized national policy promoting training programs for teaching patients any of the fundamental skills of effective patienthood.
Now, the convergence of developments in three separate societal sectors make this an opportune time to examine the evidence for elements of effective patient training, to develop a research agenda for furthering the exploration of innovations in training effective patients, and to frame a national policy to maximize the patient’s role in healthcare. First, following on three reports of the Institute of Medicine called for greater involvement of patients in care as a quality improvement strategy (*Crossing the Quality Chasm*, 2001; *To Err is Human*, 2004; *Cancer Care for the Whole Patient* 2007), the Joint Commission for Accreditation of Health Care Organizations’ 2008 National Patient Safety Goal #13 was to “Encourage patients’ active involvement in their own care as a patient safety strategy”. The formation of the Patient Centered Outcomes Research Institute underscores the inclusion of the patient’s voice in the evaluation of healthcare interventions and innovations. Second, clinical research findings increasingly point to the “heterogeneity of treatment effects”, indicating that physicians may need to tailor treatment regimens to the characteristics and preferences of their patients. Third, the advent of inexpensive Personalized Digital Assistants and other user friendly digital devices, coupled with the call for a “personalized health record”, make the potential for an integrated, patient held medical record that could facilitate continuity of care and patient participation in care, a reality.

2. The Need

- Although the recent Comparative Effectiveness Research initiative and the Patient Centered Outcomes Research Institute will yield better and more comprehensive data, they will fall short of the aim to
improve patient care without effective training programs for physicians and patients in risk-benefit communication, participatory decision-making, tailoring of treatment to match patient circumstances without compromising quality of care, etc.

- Without training in and support for how to use the healthcare system effectively and efficiently, the costs of care are likely to continue to escalate
- Safety initiatives that fail to involve patients in the protection of their own safety are unlikely to be maximally successful
- Without pre-treatment preparation of patients for what to expect from care, and without effective and supportive post-discharge follow-up for inpatients, the current pattern of expensive treatment failures (or suboptimal treatment outcomes) and avoidable readmissions is likely

III. The Solution: Centers for “Planned Patiencedhood”

A substantial body of evidence has accumulated documenting the benefits of effective patient participation in care on patients’ health outcomes, effective elements of physician training to improve patient outcomes, and patient focused approaches to altering the healthcare delivery system in order to improve chronic disease care. Programs aimed at improving outcomes of chronic disease that target provide and system level changes alone ignore the patient’s critical role in effective chronic disease management. Such programs are often not sustainable when resources are removed and are not generalizable across healthcare settings.
Different from traditional patient education efforts, the focus of the proposed centers would be to train patients at the participating academic medical centers in the spectrum of skills needed to maximize the quality of the personal care (including both processes and outcomes) and safety. The integrated intervention program we propose would focus on the patient as the primary target, but would add provider and system interventions to support the enhancement of a broad spectrum of effective, transferable patienthood skills. Specifically the program will have the following features:

**Centers for Planned Effective Patienthood**

**System Features**
- Patient navigators
- Nurse-staffed training programs for "coaches" and patient educators
- Leadership commitment to “effective patienthood”

**Physician Training**
- Interpreting and translating evidence to deliver personalized medicine
- Communicating with patients and risks and benefits
- Taking a “life context history” of a patient to tailor treatment
- Skills to promote participatory decision-making with patients

**Patient Training**
- “Coaching” by community health workers to promote participatory decision-making
- In-hospital safety strategies
- Interpreting quality of care data
- How/when to change/choose a physician
- Tailoring treatment by discussing needs, preferences and life context with doctor
- Pre-operative preparation
- Using the healthcare system effectively
- The media savvy patient
**Why Academic Medicine Centers?**

- A Harris Poll in 2009 that asked about ‘trustworthy industries’ showed that only 7% of respondents listed health plans, slightly above oil and tobacco industries.
- Academic medical centers remain a trusted source of information by the public.
- As the research home for both evidence and complex or ‘tertiary’ care, academic medical centers hold great promise for effective translation of evidence into practice, while training patients in an effective role in that translation.
- Of the healthcare delivery systems, academic medical centers should have the fewest conflicts of interest in the creation and use of evidence to improve patient care.

**IV. What are the barriers to an effective national policy for “planned patiencthood”?**

The notion of patient involvement in healthcare represents a profound paradigm shift in the roles of patient and provider. Despite acceptance in recent years of the premise that patients should be allowed to participate in their care, there are very few examples of programmatic efforts by providers or healthcare organizations to facilitate that participation. Barriers to the creation and implementation of a national policy initiative could include:

a) **Professional resistance:** Physicians are currently the target of multiple initiatives aimed at improving their performance, including linking compensation to quality of care measures, improving their efficiency, including linking compensation to patient volume, etc., all of which could be perceived as eroding physician
autonomy. It will be important to discern what have been professional societies’ policies and positions on the role of the patient in healthcare? Do some physicians or specialty groups prefer greater autonomy over treatment decisions than others?

b) Patient resistance: Do some patients prefer to be passive? If so, which patients, and what are the consequences for their health outcomes?

c) The knowledge gap: Even with training, are patients at too great an information deficit to participate meaningfully in care?

d) Costs: Who pays for patient skills training programs? Would they be likely to save or increase costs of healthcare delivery?

e) Risk management: If patients participate in treatment decisions, do they share in the responsibility for the outcomes of those decisions?

f) Politics: What are the positions of the national advocacy groups, political parties, and large employer groups on the training of patients for effective participation in healthcare decision making?

V. A Pilot Program: The University of California, Irvine Medical Center

The University of California Irvine Medical Center and its community-based clinics, in response to the Center for Medicare and Medicaid Services demonstration projects under Delivery System Reform Incentive Program is creating an integrated Center for Planned Patienthood. Coached Care is being implemented for all patients with diabetes and with heart failure seen at our institution. Serving an extremely diverse population, this program is being integrated as a routine part of clinical and support services. The Coached Care program in diabetes was shown to reduce hemoglobin A1c values by .5% over a one-year period among a poor and minority
patient sample. We are now evaluating the program’s impact on readmission rates and patient experience measures, warehousing and updating the successful elements and program features of the Centers with innovative intervention methods, strategies and modes of administration (e.g. information technology) for improving effective patienthood and assessing resource requirements to ensure sustainability.

At the conclusion of this pilot program, we hope to identify the potential programmatic strategies that could be implemented in varied healthcare settings or other venues to conduct effective patient skills training. To have the potential for widespread implementation, patient skills training programs would have to be adapted for use in organized healthcare settings (e.g. the VA, Kaiser-Permante), community clinics, private practices and schools (elementary through universities). If shown to be effective in improving patients’ efficient use of care, insurers might also support participation of its members in these programs.

VI. National Advisory Committee

In order to promote the development of a national policy for creation of Centers for Planned Patient, a number of experts representing stakeholders from diverse healthcare groups should be convened to constitute a National Advisory Committee including:

- Researchers evaluating strategies for increasing patient participation in care
- Representatives of the National Quality Forum, the National Committee for Quality Assurance, and the Joint Commission for Accreditation of Healthcare Organizations
- Experts in media training (e.g. Brian Primack, University of Pittsburgh)
Experts in patient numericity (e.g. Steven Woloshin, Lisa Schwartz, Dartmouth University)
Experts in training patients to choose health plans (e.g. Susan Goold, University of Michigan)
Experts in consumer use of quality data (e.g. Judith Hibbard, University of Oregon)
Experts in personal health records (e.g. David Blumenthal, Harvard University)
Representatives of consumers (e.g. John Santos of Consumer Reports)
Representatives from payors
Representatives from national physician groups
Representatives from academic medical centers

**Summary**

The timing for making such a proposal coincides with the convergence of multiple emergent national initiatives -- Comparative Effectiveness Research, the Patient Centered Outcomes Research Institute, the movement toward personalized medicine, Evidence-Based Medicine, linking quality to value, and the appreciation of the importance of the patient's role in effective healthcare. Our healthcare system is arguably the most complex in the world. And yet we currently have no national policy for training patients or physicians to ensure effective patient participation in care. We propose that Centers for Planned Effective Patienthood are an innovation whose timely implementation is acutely needed.
An Effort To Spread Decision Aids In Five California Primary Care Practices Yielded Low Distribution, Highlighting Hurdles

ABSTRACT Despite the proven efficacy of decision aids as interventions for increasing patient engagement and facilitating shared decision making, they are not used routinely in clinical care. Findings from a project designed to achieve such integration, conducted at five primary care practices in 2010–12, document low rates of distribution of decision aids to eligible patients due for colorectal cancer screening (9.3 percent) and experiencing back pain (10.7 percent). There were also no lasting increases in distribution rates in response to training sessions and other promotional activities for physicians and clinic staff. The results of focus groups, ethnographic field notes, and surveys suggest that major structural and cultural changes in health care practice and policy are necessary to achieve the levels of use of decision aids and shared decision making in routine practice envisioned in current policy. Among these changes are ongoing incentives for use, physician training, and a team-based practice model in which all care team members bear formal responsibility for the use of decision aids in routine primary care.

Increasing patient engagement has been advocated as a top priority for improving health care quality.1 Providing patients with information about their clinical options and activating patients to participate in informed discussions regarding their care are the foundation of shared decision making and a potential mechanism for increasing patients’ engagement in their care.

These concepts are particularly relevant when preference-sensitive decisions are being made, such as the choice of method for colorectal cancer screening or of treatment for back pain.2 In preference-sensitive decisions, more than one available option exists, each of which carries different risks and benefits, and patients’ treatment preferences can vary.3

Although many potential pathways may be taken to help facilitate preference-sensitive decisions, the use of decision aids has been a commonly proposed and studied intervention. Decision aids, which are specifically designed to provide patients with the information necessary to engage in shared decision making with their care providers, serve as an adjunct to clinical consultations. They come in a variety of formats, including video, print, and online.

The use of decision aids has been shown to increase patients’ knowledge of available treatment options and to help clarify patients’ preferences.4 For example, national clinical practice guidelines suggest that the decision to undergo colorectal cancer screening be a shared one between physicians and patients, because multiple efficacious screening methods are available.5 Studies have shown that patients’ preferences for specific methods of colorectal cancer screening vary, and the use of decision aids on this topic has been linked to increases in screening rates.6

However, there is evidence that despite physi-
DECISION AIDS

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Physicians’ general support for shared decision making, patients are not typically given all of the relevant information about their options, and shared decision making is not routinely taking place.2–4 The recent addition of increased patient engagement and shared decision making as regulatory requirements highlights the urgent need to understand and resolve this discrepancy. For example, to be eligible to participate in Medicare’s Shared Savings Program, an accountable care organization must implement processes to promote patient engagement, including shared decision making.9

More than eighty randomized trials have demonstrated the efficacy of decision aids for increasing patient engagement in clinical decision making. Further investigation is now needed to understand how to effectively integrate the successful interventions into routine care.4

To examine this issue, we used data from an implementation project designed to integrate the distribution of decision aids into routine clinical care, conducted in five primary care practices in Northern California from January 2010 to June 2012.

The objectives of this project were twofold. First, it explored processes for distributing decision aids to patients in the clinical setting. Second, it identified barriers and facilitators to implementation—that is, the appropriate incorporation of those aids into the clinical encounter. Instead of testing specific hypotheses, the project collected information that could yield new insights on how best to achieve the widespread adoption envisioned in current policy, to be examined in other settings.

Study Data And Methods

The Institutional Review Board at the Palo Alto Medical Foundation Research Institute approved all aspects of the study.

SETTING Five primary care clinics in Northern California, all members of the same larger health care organization, were approached to assess their interest in participating in the project. All agreed to participate.

The project was first presented to each clinic’s leadership team by the project’s physician champion, who served as a liaison between the project team and the clinics. Although affiliated with the same parent organization, each clinic functioned as a separate unit and had its own leadership team, clinic culture, and workflows. And although geographically proximate, each clinic was located in a different suburban city (see Appendix Exhibit 1).10

DECISION AID DISTRIBUTION STRATEGIES

Project team members collaborated with clinics to tailor decision aid distribution methods to individual clinic workflows. Each clinic had a physician and staff champion responsible for promoting the program. Clinics were offered access to decision aids, provided by the Informed Medical Decisions Foundation, on a variety of topics. The leadership team at each clinic, which included both physicians and leaders of clinical support staff, selected decision aid topics for distribution. For a list of the decision aid topics selected, see Appendix Exhibit 2.10

Of the sixteen decision aids distributed, fourteen were DVDs with an accompanying booklet containing the same information as the DVD. The remaining two aids were booklets alone. Several of these decision aids have been shown to be efficacious in clinical studies.11–13

The main objective of the project was to provide decision aids to patients. Successful distribution was defined as providing the decision aid to an eligible patient. The distribution strategies employed at the clinics included physician-directed distribution to patients, either by the physician in person or through the medical assistants; solicitation of patients’ interest at the point of care; and direct mailing (see Appendix Exhibit 1).10

At all of the clinics, project team members engaged in academic detailing visits every other week14 and social marketing efforts to promote distribution of the decision aids. These efforts included offering lunch presentations and training sessions for physicians and staff; rewarding high distributors with modest incentives, such as coffee mugs and lunch bags; and helping revise workflows as needed.

In addition, promotional brochures and posters designed to increase patients’ interest in decision aids were placed in each clinic’s entrance, waiting areas, and exam rooms (see the online Appendix for details).10

DATA SOURCES For thirty months—January 2010–June 2012—four types of qualitative and quantitative data on decision aid implementation were collected: ethnographic field notes, survey responses, focus-group results, and decision aid distribution data.

ETHNOGRAPHIC FIELD NOTES: Project team members led by a trained anthropologist conducted participant observations of the implementation process.15 The observers conducted site visits every other week to observe the implementation process, engage in informal discussions with clinic staff and physicians, and observe formal meetings in which decision aid distribution was discussed. Ethnographic field notes documenting approximately 325 encounters were recorded (see the online Appendix for details).10
SURVEY RESPONSES: A survey assessing attitudes, behaviors, facilitators, and barriers related to decision aids and shared decision making was developed, based on the existing literature (see the Appendix for details). The final instrument had ten questions and was sent in April 2012 to 502 physicians and 204 clinic staff, including nurses, medical assistants, and licensed vocational nurses.

Survey response rates were 50.4 percent for physicians and 52 percent for clinic staff.

FOCUS-GROUP RESULTS: Seven focus groups, three with physicians and four with clinic staff, were conducted between June and October 2011. Fourteen primary care physicians and twenty-five clinic staff members, representing all five clinics, participated.

Project team members developed tailored focus-group guides covering participants’ knowledge and attitudes about the use of decision aids and shared decision making. The guides also addressed barriers and facilitators to implementing both decision aids and shared decision making in actual practice (see the Appendix).10

DECISION AID DISTRIBUTION DATA: Decision aid distribution began in four of the five clinics in January 2010; because of changes in leadership at the fifth clinic, distribution began there in July 2010. Each clinic initially distributed decision aids on only a small number of topics, adding topics as physicians and staff adjusted to the distribution and expressed interest in additional topics (Appendix Exhibit 2).10 Data were collected on the monthly distribution of all sixteen decision aids between January 2010 and June 2012. However, because of limitations, we were not able to calculate the number of eligible patients from the electronic health records until October 2010, yielding a total of twenty-one months of data.

For colorectal cancer screening and back pain topics, the number of patients eligible to receive decision aids was determined through electronic health records and claims data, allowing for a more precise assessment of what proportion of eligible patients received a decision aid. Patients were eligible for the screening aid if they were age fifty or older and due for screening based on an indicator in the electronic health record. Eligibility for back pain decision aids was determined by the presence of International Classification of Diseases, Ninth Revision (ICD-9), diagnosis codes for back pain in claims data.

DATA ANALYSIS Ethnographic field notes and transcripts of focus-group discussions were coded by the project team. Key barriers and facilitators to decision aid distribution raised in both the field notes and focus groups were coded using Atlas.ti qualitative analysis software, version 6.2.

Survey data were collected and coded using Vovici software, and analyses were conducted using the statistical software Stata, version 11.0. Distribution data were analyzed using descriptive statistics.

LIMITATIONS This study drew on multiple forms of data to assess the attitudes and beliefs of the study participants and to analyze the barriers and facilitators of the implementation project at different points in time. The advantage to this approach is the rich data it provides across the duration of the project. However, there are also several limitations.

Because data were collected at multiple points in time, we could not assess attitudinal change over time, which may or may not have occurred as a result of the project.

In addition, focus groups and surveys were based on voluntary participation, and therefore the results reflect the opinions of only those who chose to participate. The possibility of bias due to self-selection also applies to the clinics, as all five that participated chose to do so. That fact may indicate a more positive predisposition toward shared decision making than would have been the case for physicians, clinical staff, or clinics that did not volunteer to participate in the study.

These limitations imply that our findings may not be generalizable to all providers or settings. However, the richness and complexity of the data obtained yield multiple preliminary hypotheses to be tested in other settings.

This study explored the distribution of decision aids—an important first step toward patient engagement, but one that cannot be equated with actual use of the aids. Because we collected no feedback on the effect or use of the aids in the clinical encounter, the findings cannot speak to whether or not the decision aids affected the behavior of patients or providers within the context of clinical consultations.

In addition, the aids were primarily distributed at the point and time of care. They might have had a greater impact on discussions with providers if patients had been able to view them prior to a consultation. Furthermore, only decision aids from the Informed Medical Decisions Foundation were used, leaving open the possibility that distribution rates might have differed had aids on the same topics, but from other sources, been supplied.

Of the decision aids distributed, 24.2 percent were on topics other than colorectal cancer screening and back pain. We could not determine what percentage of patients eligible for those aids actually received them, because of limitations of the electronic health record data.

Furthermore, there may be reasons why
patients who were not eligible to receive aids for colorectal cancer screening and back pain were captured in our estimate of patients to whom the aids should have been distributed. For example, a physician might have forgotten to document that colorectal cancer screening had already been offered to a patient. Therefore, the number of eligible patients for those aids may have been overestimated and, as a result, the success of distribution efforts underestimated.

**Study Results**

Despite extensive efforts by the project team, distribution of decision aids was only modestly successful. During the study period, a total of 4,055 decision aids were handed or mailed to patients across all five clinics. The average monthly distribution across all clinics varied over time (Exhibit 1). For back pain and colorectal cancer screening—the topics that accounted for 75.8 percent of the decision aids that were distributed— aids reached only 10.7 percent and 9.3 percent of eligible patients, respectively.

Targeted interventions, such as competitions for prizes, temporarily increased distribution rates. However, the overall aggregate rate of distribution for the decision aids for colorectal cancer screening and back pain was 9.7 percent. In only five of the twenty-one months measured did more than 10 percent of eligible patients receive one of the two decision aids.

Despite low overall distribution, survey results suggest that physicians were supportive of decision aids and shared decision making in general. Ninety-six percent of surveyed physicians indicated that offering patients material intended to increase shared decision making was at least somewhat important. In addition, 92 percent of physicians indicated that patients should be involved in the decision-making process, and 87 percent agreed that engaging in shared decision making is beneficial to patients.

What might account for the incongruity between the attitudes expressed in the survey and the relatively low rates of decision aid distribution? The major barriers and facilitators to decision aid distribution identified in the field notes and focus groups, described next, may provide insights.

**Physicians’ Involvement Was Low** Seventy-three percent of surveyed physicians stated that they would use decision aids frequently or very frequently if the aids were available. However, the field note observations suggested that most physicians were not engaged in the distribution of decision aids, and the distribution data indicated that physicians were responsible for distributing only 26.8 percent of the aids.

Physicians’ support of the aids and inclination to distribute them could have increased after the initial use of the aids. However, our distribution data suggest that this was not the case, as there did not seem to be any sustained increase in

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**Exhibit 1**

Number Of All Decision Aids Distributed And Proportion Of Patients Who Received Aids For Colorectal Cancer Screening Or Back Pain

![Graph showing distribution of decision aids and proportion of patients reached](image)

**Source** Authors’ collected distribution data, October 2010–June 2012. **Notes** The red line depicts the percentage of potentially eligible patients who received a decision aid for either colorectal cancer screening or back pain across all five clinics in the study; it corresponds to the left-hand y axis. The blue line depicts the total number of decision aids that were given out across all five clinics for all available topics; it corresponds to the right-hand y axis.
decision aid use over time (Exhibit 1). A few factors that may underlie physicians’ limited involvement in the distribution of decision aids were documented in field observations and focus group discussions. First, some physicians appeared to disagree that the decisions addressed in the aids were indeed preference sensitive—that is, these physicians felt that patients’ input was not truly warranted or desirable. This was evident in physicians’ concern, documented in the field notes, that a patient who used a decision aid might opt to follow a course of action other than the one his or her physician recommended.

For example, the physician-champion in one clinic sent the following e-mail message to the project’s physician champion: “Just want to pass on...that [the physician] had concerns about one of her patients choosing to do [a] stool occult blood test instead of the colonoscopy she recommended. [The physician] was concerned about passing [out] this [colorectal cancer screening decision aid] for the future.”

Second, although physicians indicated their support for shared decision making on surveys, in practice they had difficulty moving away from more traditional, physician-directed decision making, as clinic staff observed. A licensed vocational nurse in one clinic commented in a focus group: “I don’t think physicians are taught how to...make decisions in a shared way...with the patient. I think they’re taught that...they’re the ones who are the ‘experts’ and the patient is there just to absorb this information and then do it [what the physician recommends].”

Third, when physicians reported using decision aids, their descriptions of the process suggested that they did not fully grasp the intended use of decision aids to facilitate shared decision making. Instead, in field notes and focus groups, physicians described using the decision aids to replace discussion rather than to foster engagement with the patient. One physician in a focus group expressed a preference for “print materials or web-based materials or things that you can refer people to,” observing that “we don’t have time to have the conversation.”

Fourth, despite major promotional efforts by the project team to train physicians and clinic staff on the project and the decision aids provided, physicians in focus groups described their lack of familiarity with the aids’ content. Promotional efforts included numerous presentations about the aids and shared decision making at grand rounds and clinic staff meetings, in-clinic lunchtime viewings of the aids, and the distribution of brief synopses of their content. In one clinic, the clinical supervisor even personally delivered copies of all of the decision aids available in that clinic to the physicians, encouraging them to view the aids.

In light of these efforts, physicians’ stated lack of familiarity suggests the presence of underlying issues that the project’s promotional efforts could not overcome.

**TIME WAS LARGEST PERCEIVED BARRIER FOR PHYSICIANS** Eighty-one percent of the surveyed physicians perceived a lack of time as the largest barrier to practicing shared decision making (Exhibit 2). The example of the implementation of a short patient self-screener in one of the clinics that assessed eligibility for colorectal cancer screening demonstrates these concerns clearly.

The self-screener was provided to patients when they checked in for an appointment. If patients were eligible and interested in receiving the decision aid, clinic staff gave it to them as they reached the exam room. Patient demand was high, and distribution increased fivefold within two weeks. However, the field notes documented that the self-screener was discontinued after three weeks because physicians reported that they did not have enough time to answer patients’ questions about colorectal cancer screening.

In focus groups, many physicians also described time as a major barrier to the distribution of decision aids. One physician who did not
distribute decision aids frequently reported: “Realistically, I think it would be very difficult to...ask the physician to do that warm handoff [of a decision aid] when it seems like every day, there’s something more that they’re asked to do as far as preventive [medicine]. ...You just kind of run out of time.”

In contrast, physicians who used decision aids observed that they could save time. One said: “I like [the decision aids]. I like to take them out and show the patients what’s in the booklets and...I don’t spend as much time doing that as I would explaining things without [the decision aids], but then they get the information to take home with them.”

Finally, the survey data suggest that physicians might be more willing to use decision aids if structural changes were made to decrease the time needed for distribution, or if incentives were offered for use (Exhibit 3). For example, as documented in field notes, having the decision aids in exam rooms increased the likelihood that physicians would use them.

A project team member reported that the medical assistant “decided on her own to put the [decision aids] in the exam rooms so that they would be more convenient to give out. She said that before she put them in the room, [the physician] used to request about one [decision aid] every month, but once she moved them, [the physician] gives out many more than that.”

**CLINIC STAFF WERE MORE RECEPTIVE**

Compared to the physicians, clinic staff members were more open to being involved in the distribution process. As documented in field notes and focus-group discussions, clinic staff expressed substantial support and enthusiasm for decision aids.

One clinical supervisor said: “To me that’s what shared medical decision is all about, that all the parties that are taking care of [a patient’s] health get involved. And I’m giving...tools for [the patient] to have a discussion with the physician. ‘Okay, why do you want me to have a colonoscopy? You gave me this DVD, and I can see these are the other options. Why do you think...the colonoscopy is better for me?’ So [the patient] already...has a foundation. ...I just love these [decision aids].”

Unlike the physicians’ verbal support for decision aids, the staff’s support was associated with greater distribution. Clinic staff accounted for 73.2 percent of the decision aids that were distributed. As documented in field notes, a larger proportion of clinic staff attended training sessions than physicians, particularly when new decision aid topics were introduced to a clinic.

Decision aid distribution was also more easily incorporated into the routine workflow of the clinic staff than into that of the physicians. Some clinics even made assessing the need for a decision aid part of standard procedures for preparing exam rooms.

In one clinic, the clinical supervisor made aid distribution part of staff performance standards, emphasizing its importance in the care of each patient. In a second clinic, the clinical supervisor promoted decision aid distribution as part of the clinic staff’s normal duties. These efforts positioned distribution of the aids as an essential task and may have contributed to their more consistent distribution at these two clinics than at the other three.

**SUPPORTIVE CULTURE WAS LACKING**

Clinic staff involvement did help attain moderate success in decision aid distribution. However, staff contributions appeared to be hindered by the lack of a supportive clinic culture. As documented in field notes, a nurse supervisor at one clinic wanted to have all medical assistants screen patients for

### Exhibit 3

<table>
<thead>
<tr>
<th>Intervention</th>
<th>Expected effect of intervention on interest in using aids (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Had access to a service that provided decision counseling to patients by qualified health coaches</td>
<td>Would increase my interest 82</td>
</tr>
<tr>
<td>Received reminders in electronic health record or through lists of eligible patients</td>
<td>47</td>
</tr>
<tr>
<td>Additional incentives were provided for doing shared decision making in practice</td>
<td>74</td>
</tr>
<tr>
<td>Use of decision aids was a quality measure for certain conditions</td>
<td>56</td>
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*Source* Authors’ physician survey, April 2012.
eligibility for a colorectal cancer screening decision aid, but she found that some physicians’ attitudes presented barriers.

And field notes about another clinic show that the clinical supervisor said that the medical assistant “came to see her...saying that she...feels that [she] will never get a chance to be the top distributor because her doctor always says no to her when she prompts him with the [decision aids]....She said that she thinks many of the doctors feel this way, and commented sarcastically that they ‘don’t want the patients to start thinking’ because they will ask too many questions that there isn’t time to answer during the appointment.”

Eighty-two percent of surveyed physicians indicated that a lack of organizational support for shared decision making was not a serious barrier to the use of decision aids (Exhibit 2). Nevertheless, many of them also indicated that they would be more likely to use decision aids if the organization provided supportive resources such as electronic reminders (Exhibit 3). Thus, their overall responses suggested that they thought an organizational culture supportive of the use of decision aids was necessary for the aids’ implementation to succeed.

Discussion

The current study illustrates the many challenges involved in attempts to incorporate the use of decision aids into routine clinical practice. However, the findings should not be interpreted as evidence that interventions designed to educate and activate patients, such as the distribution of decision aids, should be abandoned as a method for increasing patient engagement.

Patients must have access to information on their clinical options if they are to engage in medical decision making, and the necessary information is extensive. Even if substantial changes were made to physicians’ work schedules, they could not be expected to provide all of the information that patients require. Decision aids represent a valuable resource that has been shown to be efficacious in research settings and that—if successfully implemented—could be a highly effective tool for increasing patients’ engagement in routine clinical practice.

Nevertheless, the current findings suggest that decision aids will not reach the hands of patients to the extent envisioned by policies such as those inherent in Medicare’s Shared Savings Program9 or the Affordable Care Act unless the major structural and cultural barriers that discourage true patient engagement in routine clinical practice are addressed.

Physicians’ reluctance to cede traditional decision-making roles and to recognize the preference-sensitive nature of many clinical decisions appeared to underlie their reluctance to distribute decision aids. In addition, many felt that time pressure discouraged their use of the aids—even though those who regularly distributed the aids felt that they actually saved time.

Although some success was achieved by having clinic staff distribute the aids and by using incentives to increase the distribution, it was short-lived. These results indicate that such tactics have only limited power and produce only temporary solutions. In addition, some conditions require a physician’s assessment to determine whether a decision aid will be relevant to a patient. A distribution model relying on clinic staff may be less useful in such cases.

Without efforts to change traditional attitudes of physicians and staff toward patient involvement in decision making and to overcome perceived structural barriers, any efforts to increase patient engagement through the distribution of decision aids will not be sustainable. Experience has repeatedly shown that implementing large-scale changes in the structure and culture of health care is a complex and long-term process that requires multifaceted solutions. We offer some suggestions to begin that process.

First, physicians need better training in engaging patients in the decision-making process. A physician may think it his or her proper role to convince a patient to take a recommended action rather than to facilitate an informed decision that is based on the available options and consistent with the patient’s preferences.

One reason for physicians’ observed reluctance to engage patients in the decision-making process may be a lack of comprehensive training in communication and shared decision-making skills. A recent systematic review found that educating health professionals about shared decision making, together with the provision of decision aids, improved the adoption of shared decision making in clinical practice.16 Thus, proposed interventions and policies designed to promote decision aid use and facilitate greater patient engagement should include physician training—which was not extensively built into the intervention described here—to maximize the chances of success.

Second, engaging patients in shared decision making requires a team-based practice model. Empowering clinic staff to distribute decision aids was more successful than relying solely on physicians. Physicians must respond to a growing list of demands.17 Moreover, the current physician-centric system, which compensates only physicians’ efforts in caring for patients, encourages them to work in isolation.18
Yet the effective distribution of decision aids appears unlikely unless members of the care team collaborate with each other toward that end. Clinic staff involvement can support, although it cannot substitute for, physician involvement in patient engagement. Offering incentives for the creation of systems promoting team-based care, such as patient-centered medical homes, may increase the involvement of clinical staff and the likelihood that decision aids will be distributed and used. In addition, decision aid distribution must be considered a routine responsibility and component of care, as short-term incentives to encourage it do not lead to sustained changes in behavior.19

Third, incentives for patient engagement must be aligned. One of the largest barriers to physicians’ use of decision aids was their perception that it would increase the length of the consultation, with no increased compensation for the additional time. In truth, current payment schemes fail to reward providers for taking any extra time to fully inform patients and engage them in the decision-making process.

Initiatives such as accountable care organizations—as well as certification processes for decision aids, resource centers for shared decision making, and quality measures including the ones called for in the Affordable Care Act—are critical to establishing a medical system and culture that properly reward efforts to increase patient engagement. The exact mechanisms by which such initiatives will be implemented still need to be specified.

Fourth, quality measures need to assess and reward patient engagement. Although the patient organization whose clinics participated in this study does not engage in this practice, many institutions use quality metrics for colorectal cancer screening that reward physicians for persuading patients to have a colonoscopy. Perhaps mistakenly, they equate ensuring that patients receive a colonoscopy with providing high-quality care.

Such policies send the message to providers that eliciting patients’ preferences is neither necessary nor desired, despite evidence showing that offering choices of screening methods to patients may result in a larger proportion of patients’ being screened.4 New quality measures that assess how well physicians actually engage patients in the decision-making process, as called for in the Affordable Care Act, are urgently needed to help eliminate such counterproductive beliefs and practices.

Conclusion

Attempting to make the distribution of decision aids a routine aspect of primary care, as documented in the current study, faces a number of challenges. These challenges suggest that major cultural and structural changes will be necessary to achieve the level of patient engagement proposed in national and state initiatives such as the Affordable Care Act and the proposed Massachusetts bill to increase patient engagement in health care decisions.20

Without system changes that reward efforts to facilitate shared decision making, such as the use of decision aids, it will be difficult to overcome the ingrained medical practices and attitudes that discourage the use of aids as a means of facilitating patient engagement. To achieve patient-centered decisions, policy measures to stimulate greater patient engagement must not only address the mechanics of implementing decision support but also create a culture and structure that promote patient engagement from medical school through practice. Only then will the patient’s voice truly be incorporated in medical decisions.

NOTES

6 Joseph DA, King JB, Miller JW,
In this month’s *Health Affairs*, Grace Lin and coauthors describe a thirty-month experiment in which decision aids were distributed in five California primary care practices that agreed to use them to increase patient engagement and facilitate shared decision making. In the end, fewer than one in ten eligible patients received decision aids for colorectal cancer screening and back pain. Focus groups, field notes, and surveys suggested major structural and cultural barriers that would have to be overcome before the decision aids gained wider distribution. These barriers include lack of training for physicians and their unwillingness to cede more authority to other members of the care team.

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Laurel Trujillo is medical director of quality at the Palo Alto Medical Foundation’s Palo Alto Foundation Medical Group and chair of the foundation’s Quality Improvement Steering Committee. She leads all external quality reporting and improvement initiatives for the 1,000-physician multispecialty group, including the Integrated Healthcare Association’s Pay for Performance Program, Medicare Physician Quality Reporting System, and quality improvement efforts that are part of shared-savings contracts.

Trujillo earned a master’s degree in health education from John F. Kennedy University and a medical degree from the University of California, San Francisco.
A 60-YEAR-OLD WOMAN PRESENTED TO HER physician for an annual physical examination. As part of the examination, she and her physician discussed colorectal cancer screening, which her physician had discussed with her at her last yearly physical. The decision at that time had been for colonoscopy, and the patient was referred to the gastroenterologist. Since the patient never followed through with the colonoscopy, the topic was broached again. As part of a quality improvement initiative designed to promote shared decision-making, the patient was given a decision support intervention (DESI) to review the options (fecal occult blood testing [FOBT], flexible sigmoidoscopy, or colonoscopy, described in a booklet and DVD) and was told to let her physician know about her decision.

The patient reviewed the DESI, decided that she wanted to pursue FOBT, and informed her physician about her choice. The physician responded that FOBT was not appropriate, and that the patient should consider only flexible sigmoidoscopy or colonoscopy. The patient was confused and upset that the very physician who had provided her the decision support material was not honoring her informed choice. To date, she has not followed through with colon cancer screening.

Routine screening for colorectal cancer is recommended in patients older than 50 years, and therefore discussion of colorectal cancer screening was an important and appropriate part of the primary care preventive care visit for this patient. Major clinical practice guidelines list several acceptable options for colorectal cancer screening, including the options discussed in the DESI.1-3 Guidelines also recommend incorporation of patient preferences into care, practicing shared decision-making, and focusing on strategies that maximize the number of individuals who get screening.2

However, studies suggest that shared decision-making is not routinely occurring in primary care, especially for colorectal cancer screening.4 In addition, over half of adults preferred FOBT to colonoscopy when given time to consider detailed information about colorectal cancer screening tests.5 Despite the data indicating patient preferences for less invasive testing, colonoscopy rates are increasing, and evidence suggests that the test may be overused, particularly in the Medicare population.6,7 Decision support interventions, like the one given to this patient, are a way to facilitate shared decision-making and have been associated with greater knowledge, more accurate risk perceptions, and increased participation in the decision-making process.8

However, decision support is most effective as part of a shared decision-making process, in which physician and patient discussion leads to a mutual decision that is both evidence based and incorporates the patient’s preferences.

The physician had good intentions in terms of recommending that the patient be screened for colorectal cancer and helping the patient make an informed choice by providing high-quality information and decision support. The patient also did her part to become an active and informed participant in the decision-making process. However, although the evidence base supported use of FOBT as a screening modality and the patient stated her preference for the less invasive test, the physician’s preference for a more invasive and technologically advanced procedure precluded a full shared decision-making conversation, ultimately resulting in a missed opportunity to screen the patient for colorectal cancer.

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REFERENCES


Partners in Medical Decision Making (PMDM) Project Summary

What are patient decision aids?

Patient decision aids are informational tools that provide comprehensive information about the decision to be made. They are available in multiple formats (pamphlets and DVDs) and are intended to assist patients in making a choice among different options to address a specific clinical problem, such as screening for or treating a disease. Decision aids can stimulate patients’ active involvement in decision-making with their physician and increase their satisfaction with the decision-making process. They also have the potential to address several shortcomings in the current primary care system that prevent optimal patient-centered decision-making, such as the lack of time to provide complete information about treatment options and fully eliciting patient preferences, and engaging in the communication necessary for shared decision-making.

What is the Partners in Medical Decision Making Program?

The Informed Medical Decisions Foundation awarded a grant to Palo Alto Medical Foundation in 2009 as one of eight national demonstration sites to study the best methods for creating a sustainable model of shared decision-making and decision aid use in primary care practice. Through a partnership between PAMF, Palo Alto Medical Foundation Research Institute, and the University of California, San Francisco, the Partners in Medical Decision Making program aims to determine efficient ways to identify patients at an appropriate time point to engage in shared decision-making and determine the most effective delivery methods for decision aids and for incorporating shared decision-making into primary and specialty care. We are currently distributing decision aids from the Informed Medical Decisions Foundation in 5 primary care clinics, 1 specialty clinic, and at shared medical appointments. In total, we have distributed over 6000 decision aids to PAMF patients over the past three years.

How are patients identified and referred to a decision aid?

Decision aid topics and distribution workflows were selected in collaboration with clinic administrative teams and tailored to each individual site. Decision aids are provided to patients at the discretion of their health care team. Program brochures and posters also invite patients to request decision aids either in person from either their health care team or via mail from the PMDM Navigator if they would like to receive a copy.

For questions or more information about the study, please contact a member of the study team:

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Partners in Medical Decision Making
Prescription Strength Information for Better Decisions
Service Delivery Innovation Profile

Personalized Support Improves Patient-Physician Communication and Enhances Decisionmaking for Breast Cancer Patients

Snapshot

Summary
The Decision Services unit in the Breast Care Center at the University of California, San Francisco offers newly diagnosed patients a personal assistant to accompany them to key consultations with surgeons and oncologists. These premedical interns help patients develop a written list of questions and concerns for their providers, accompany patients to their medical appointments to take notes and record the visits, and make sure all patient questions are addressed by the attending physician. The goal is to help the patient communicate more effectively with his or her physician and hence improve patient decisionmaking. An evaluation of specific components of the program found that it has improved visit preparation, patient-provider communication, and patient decisionmaking and knowledge. Similar findings have come out of meta-analyses and other systematic evaluations of various aspects of the program that have been implemented in other settings. The program is now expanding into other clinics at the University of California, San Francisco through its successor program, the Patient Support Corps, which deploys undergraduate students as patient advocates earning academic credit through a service learning program.

Evidence Rating (What is this?)
Strong: The evidence consists of meta-analyses and other systematic evaluations of specific components of the program implemented at the University of California, San Francisco and in other settings.

Developing Organizations
University of California, San Francisco, Breast Care Center Decision Services

Date First Implemented
2003
The program was implemented in its current form in 2003. Components of the program had been developed and tested earlier.

Patient Population
Gender > Female; Vulnerable Populations > Women

What They Did

Problem Addressed
Many newly diagnosed breast cancer patients are overwhelmed with their situation and do not know which questions to ask the doctor or how to use the information provided to make treatment decisions. Research suggests that certain strategies can address these problems, including connecting patients with decision aids, helping them list questions, and making notes and audiorecordings for them. Yet few programs offer such services.

- **Significant information needs**: A recent systematic review found that cancer patients have significant information needs throughout the diagnostic and treatment process.¹
- **Multiple barriers to meeting these needs**: Breast cancer patients face many barriers that often prevent them from getting the information they need. Some patients withhold questions and concerns during consultations for fear of wasting the doctor’s time, while others do not know how to raise their concerns or have a discussion with their doctor. One study found that 64 percent of breast cancer patients reported three or more barriers to communication with their physician.² A needs assessment conducted at the University of California, San Francisco (UCSF) found that breast cancer patients faced significant barriers to gathering information, asking questions, and remembering responses. Specifically, patients told of reviewing inadequate, conflicting, or overwhelming information before appointments and not knowing which questions to ask. Many would “freeze up” during appointments and forget to ask important questions. When they did ask questions, the doctor’s answers would often “go in one ear and out the other.” Since the initial needs assessment, researchers continue to document these barriers, most recently among highly educated and affluent patients whose fear of being labeled “difficult” inhibits questioning and other important behaviors.³
- **Often unrealized potential of prompting and support**: Research shows that prompting patients to write down their questions increases their participation in consultations⁴,⁵ and that providing audiorecordings and summaries of visits increases patient recall and satisfaction.⁶ However, few cancer programs offer such services.

Description of the Innovative Activity
The Decision Services unit in UCSF’s Breast Care Center assigns a personal assistant (a premedical intern) to help patients get appropriate decision aids, brainstorm and write down a list of questions and concerns for their providers, make notes and recordings of their visits, and make sure all questions are addressed by the attending physician. The goal is to help the patient communicate more effectively with doctors and hence improve decisionmaking related to treatment. Key elements of the program are described below:
• **Pre-appointment preparation:** After patients schedule their medical visit, a premedical intern sends them an educational video and written decision aid. (Between 2010 and 2011, 672 patients received such materials.) The intern also attempts to contact patients to offer help in developing questions for their providers and to accompany them to their visits to assist with audiorecording and taking notes and to generally support them in communicating with their provider. During the question-listing session, the interns use a checklist to help stimulate patient questions, concerns, and priorities; they do not provide any medical advice or clinical information. Between 2010 and 2011, interns attempted to contact 1,771 clinic visitors to offer assistance; 1,030 responded and were found to be eligible for such services, 584 accepted the service, and 356 ultimately worked with interns to develop a list of questions and concerns over the telephone using the worksheet. The worksheet helps clarify six areas (known as SCOPED), as outlined below:
  - **Situation:** The diagnosis or other key facts
  - **Objectives:** The patient’s priorities, goals, and concerns
  - **People:** Patient and provider team roles and responsibilities
  - **Evaluation:** How the choices affect the objectives (including prognosis)
  - **Decisions:** Which choice is best and next steps

• **Assistance during appointment:** The intern e-mails the completed question list (known as a consultation plan) to the physician, who reviews it before the consultation. The intern also accompanies patients to their visits, audiorecords the session, takes notes, and reminds patients of any questions that were not addressed by the doctor.

• **Postvisit support:** The intern creates a written summary of the provider’s responses to the patient’s questions, with the summary being organized in parallel structure to the original question list. The patient receives both the audiorecording of the visit (on compact disc) and the printed consultation summary.

• **End products:** The end products include the following:
  - **Consultation plan:** A list of questions and concerns in the patient’s words, given to all parties before the visit
  - **Consultation recording:** An audiorecording of the patient visit
  - **Consultation summary:** A summary of the physician’s responses to patient questions and concerns
  - **Internal process-oriented records:** Collection of data by staff every facet of the program, from the reasons patients accept or decline services to the surveys conducted before and after service delivery

**References/Related Articles**


**Contact the Innovator**

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Results
An evaluation of specific components of the university program found that it has improved visit preparation, patient-provider communication, and patient decisionmaking and knowledge. Similar findings have come out of several meta-analyses and other systematic evaluations of various aspects of the program that have been implemented in other settings.

- **Improved visit preparation, decisionmaking, communication, and knowledge at UCSF’s Breast Care Center:**
  Evaluations of various aspects of the program found that it has improved visit preparation, patient-provider communication, and patient decisionmaking/knowledge, as outlined below:
  - **Better visit preparation:** A 2009 evaluation of 137 question-listing sessions found that participating patients had an average (mean) of 23 questions after the session, up from 9 before. Self-efficacy scores from 115 of these patients (those responding to a survey) averaged 8.1 (on a scale of 1 to 10), up from 6.7 before the session.7
  - **Better communication:** A quasi-experimental evaluation of 119 patients found that consultation planning reduced barriers to communication and improved both patient and physician satisfaction in the intervention group compared with controls.8 An evaluation of 37 patients using both the question-listing and audiorecording services found that they improved patient-provider communication. Physicians reported that the program gives them a means for better understanding the patient’s concerns and needs because it helps patients organize and clarify their thoughts in advance of the appointment.9
  - **Better knowledge and decisionmaking:** Several studies suggest that the program has enhanced decisionmaking and knowledge, as outlined below:
    - An evaluation of 37 patients found that the preappointment planning session resulted in a mean change in decisional self-efficacy of 7 percent and that pre-appointment planning and assistance during the appointment were associated with a 19-percent reduction in decisional conflict (although some of this effect may be attributable to the clinical consultation itself).9
    - A quasi-experimental evaluation of 24 patients found that recording the consultation improved the quality of decisionmaking compared with those in a control group.8
    - A 2009 evaluation of the recording and note-taking service found that 89 percent of those responding to a survey had reviewed the notes from their consultations within 6 weeks of their visits.7
    - An evaluation of 383 responses to condition-specific quizzes found that the number of correct responses increased from 46 to 73 percent after patients reviewed the decision aids sent to them. The same evaluation found that decisional conflict, a measure of a patient’s uncertainty regarding the best course of action, improved after patients reviewed the decision aids.7
  - **Similar findings in other settings:** Meta-analysis and other systematic evaluations of specific program components are consistent with the findings from the university, as outlined below:
    - **Higher satisfaction and better recall:** A meta-analysis of 11 randomized, controlled trials (RCTs) involving more than 1,013 patients and clinicians found that “between 83 and 96 percent of participants found recordings or summaries of their consultations to be valuable. Five out of nine studies reported better recall of information for those receiving recordings or summaries. Four out of seven studies found that participants provided a recording or summary were more satisfied with the information received.”8
    - **Asking more questions:** A general meta-analysis of 33 RCTs involving 8,244 patients found that interventions to help patients address information needs before consultations (for a range of conditions and settings) generated small but statistically significant increases in question-asking and patient satisfaction. These increases were greater than those achieved through use of inperson coaching and written materials alone.10 A separate systematic review of question prompting in cancer patients found that the approach encouraged patients to ask more questions, particularly about their prognosis.11
    - **Increased knowledge:** A Cochrane Collaboration review of 27 RCTs found that decision aids were associated with a statistically significant 15-percent improvement in knowledge.12

Evidence Rating (What is this?)
**Strong:** The evidence consists of meta-analyses and other systematic evaluations of specific components of the program implemented at the University of California, San Francisco and in other settings.

How They Did It

Context of the Innovation
The Decision Services unit at the university is part of the Breast Care Center. One of the Breast Care Center’s goals is to tailor treatment to patient preferences and biology, based on medical evidence and clinical performance. The Decision Services unit emerged from doctoral research at Stanford University by Jeff Belkora and colleagues with their adviser, Laura Esserman, who is now the Director of the Breast Care Center. Their line of research started in 1994 when Dr. Belkora analyzed data from a series of 23 focus groups with 250 breast cancer survivors conducted at the Palo Alto Community Breast Health Project. These sessions revealed a shared sense of confusion and anxiety about treatment options and decisions, stemming in large part from information overload and other barriers to patient-provider communication. After Dr. Belkora and colleagues conducted an additional needs assessment with patients, it became clear that the patients were not always able to express their priorities and preferences to clinicians in the context of a clinical consultation nor retain the advice and information presented during the visit. This finding led to the idea of creating a consultation planning and recording program to assist patients in preparing for their encounters through the use of a structured preconsultation worksheet. Other
researchers were also evaluating use of prompt sheets, summaries, and recordings at the same time.\textsuperscript{8,10} Later, researchers integrated question-listing and audiorecording with the work on decision aids.\textsuperscript{12}

**Planning and Development Process**

Key steps in the planning and development process included the following:

- **Developing formal charter:** Program leaders created a formal charter laying out the vision for the program.
- **Surveys/ Stakeholders:** A survey of key institutional stakeholders found no major resistance to the concept. Physicians were receptive to the idea as long as it did not interfere with the usual clinical workflow.
- **Assessing patient needs:** A patient needs assessment identified the key types of support that patients wanted from the program.
- **Adapting existing conceptual framework:** The university adapted the Ottawa Decision Support Framework by linking specific services to patient visits. This conceptual framework focuses on helping patients express their needs (questions and concerns) before a visit, including an audiostreaming and summarizing during the visit (e.g., audio recording the provider’s answers to patient questions), evaluating the impact of the decision support after the visit, and anticipating the patient’s next pass through the “visit cycle” (e.g., if they go from the surgeon to a plastic surgeon or oncologist).
- **Using decision-analytic framework to guide prompt sheet and consultation summaries:** The Breast Care Center decided to use SCOPED to guide the development of the prompt sheet and consultation summaries. This decision framework builds on decades of development in engineering, psychology, economics, nursing, education, statistics, and other fields.
- **Screening interns:** Premedical interns are screened through “critical incident” interviews that ask for examples of how prospective candidates have been effective or ineffective in past jobs at relevant skills such as nondirective interviewing; low-inference paraphrasing and summarizing; displaying emotional intelligence in stressful situations; complying with applicable policies, procedures, and regulations; and communicating across cultures and generations.
- **Training:** Each premedical intern undergoes a comprehensive 2-day training program that includes sessions on key policies and procedures (e.g., how to offer the service and set appropriate boundaries and expectations with patients) and simulations of the various components of the services (using de-identified cases), and review and practice on key models of low-inference paraphrasing and summarizing and on the SCOPED checklist. Following the formal session, interns are closely supervised and observed for 6 weeks. After this period, facilitators are certified for solo practice. To maintain certification, interns attend weekly case review meetings led by the developer of the program or another experienced facilitator. These meetings use the critical incident technique to reflect on productive and unproductive practices. In 2008, the university also developed a 150-page policy and procedures manual and a 200-page reference guide to assist interns on an ongoing basis.
- **Design, testing, and ongoing evaluation:** The program unit applies program theory to guide continuous improvement, using interlocking plans: a strategic plan summarizing the context, charter, purpose, vision, mission, and goals of the program; a service utilization plan summarizing how patients will interact with premedical interns and what support the interns will provide; an operational plan describing what human resources, supplies, information technology facilities and other resources will need to be marshaled in support of the program; an evaluation plan describing how to collect, manage, analyze, and report data for key audiences; and a financial plan describing the costs of this program. The goal is to continuously improve and adapt to a changing environment while staying true to the underlying conceptual model and principles. Evaluation is an ongoing process, with assessments of early iterations of the program playing a key role in the refinement and improvement process. In 2008, the university invested in an online, multiuser, relational database to capture program data more efficiently. Program leaders plan to use this resource to share de-identified materials with patients and researchers, thus stimulating continuous improvement. Finally, the university recently adopted the RE-AIM framework (reach, effectiveness, adoption, implementation, maintenance), the Plan-Do-Study-Act improvement methodology, and the critical incident technique to facilitate further improvement.

**Resources Used and Skills Needed**

- **Staffing:** At the university, frontline program staff consist of 5 to 10 premedical interns who have been accepted into a 1- or 2-year program between college and medical school. In general, however, frontline staff can be paid employees or volunteers, and they may be peers (e.g., survivors, former patients), students (e.g., premedical, medical, nursing, counseling), or professionals (e.g., nurses, social workers). At the university, internships are highly competitive, attracting applicants from across the country. University interns spend 4 days per week working with faculty as research assistants and 1 day per week engaged in the program. The program also has a paid administrator who coordinates scheduling and oversees frontline staff. In the last year, the program has expanded to other clinics at UCSF under the umbrella of the Patient Support Corps, which trains and deploys undergraduate students as patient advocates.
- **Costs:** The estimated cost of providing the service ranges from $50 to $150 per patient visit, depending on the level of support offered and the utilization rate of the service by patients (higher utilization spreads the fixed costs over more patient visits). At the university, research or program assistantships pay the full stipend for the interns, so the cost of paying their salaries is not borne by the program.

**Funding Sources**

University of California, San Francisco; Informed Medical Decisions Foundation

The program is funded through Breast Cancer Center research funds, grants, and donations. Supporting agencies over the years have included the Arthur Vining Davis Foundation, the U.S. Department of Defense, and the Informed Medical Decisions Foundation, which is currently providing funding. Going forward, program leaders plan to explore the potential for insurers to reimburse program services.

**Tools and Other Resources**

- The program Web site is at: [http://www.decisionservices.ucsf.edu](http://www.decisionservices.ucsf.edu).
- Information about the Patient Support Corps can be found at: [http://www.patientsupportcorps.org](http://www.patientsupportcorps.org).
- Jeff Belkora’s Web site (available at: [http://www.jeffbelkora.com](http://www.jeffbelkora.com)) provides a list of relevant academic references.
Getting Started with This Innovation

- **Find strong clinical champion:** Laura Esserman, MD, Director of the university's Breast Care Center, participated in every step of development and rollout. Physicians must initially be at least tolerant of the program. Most will recognize the benefit to patients and will be supportive as long as it does not disrupt workflow.

- **Use or adapt formal processes and frameworks:** At the university, use of the Ottawa Decision Support Framework, SCOPED, RE-AIM, and Plan-Do-Study-Act has contributed to program success.

- **Build and maintain steady referral pipeline:** Although the program can be run from within a clinic or in a centralized resource center, tight integration and coordination with the clinic schedule is necessary to achieve enough volume for the service to justify having trained staff. To that end, provide continuous feedback to referral sources (e.g., clinic schedulers) and supervise program staff.

- **Explain role clearly to frontline staff:** Frontline staff must understand their role clearly, including that they must remain neutral, avoid giving medical advice or information, and maintain certain role boundaries with patients. For example, even though program staff are often easier to reach than physicians, they cannot relay messages from doctors to patients. Likewise, program staff must not touch medical records or perform any task for which they are not trained, as the risk of errors that could compromise quality and safety is too great.

- **Hire paid administrator:** This individual oversees frontline staff and coordinates the integration of the program into clinic workflow.

Sustaining This Innovation

- **Consider telephone consultations:** The service can be delivered by telephone or in person. As a cognitively oriented program, the service is well suited to the telephone, especially if the patient has access to e-mail or a fax machine and can review drafts of the consultation plan. In other settings, prompt sheets have even been self-administered by patients, who use them as a set of "frequently asked questions" and circle or modify the ones that apply.

- **Tap into multiple funding sources:** The university's Breast Care Center faculty members believe that this program helps attract highly productive premedical interns, so they are willing to pay 100 percent of interns’ salaries, even though they only absorb 25 percent of their working time. The program (which is looking for highly qualified research assistants), premedical interns (who are looking for patient interactions), patients (who are looking for support), and the university medical center (which is committed to providing patient-centered care).

- **Consider using trained volunteers:** Other organizations have been able to attract volunteers to perform the service because it features such heavy patient and physician interaction, is intrinsically rewarding, and can help people gain experience as they position themselves for career changes or further training. The volunteers must be properly screened, trained, and supervised by professionals. Volunteers could receive academic or other credit.

- **Consider adopting individual components (if entire program is not possible):** As noted earlier, discrete elements of the program, such as consultation planning, have been found to be effective on their own.

- **Consider charging fees to those who can afford it:** The program could generate revenues through use of a sliding-scale fee schedule that requires full payment from those who can afford it but offers a reduced rate or free service to low-income patients. In an environment where patients pay out of pocket for complementary therapies and coaches, some might be willing to pay the $50 to $150 cost.

- **Document program on continuous basis:** The university has created a reference guide that documents almost every aspect of the program. This living document is continuously updated. Because the program operates in an environment where one must be sensitive to patient and provider confidentiality and the potential for error or conflict, the university is particularly focused on documenting the boundaries, conditions, and scripts that govern the program’s practices.

- **Engage in continuous improvement:** The university seeks feedback from all stakeholders, including physicians, patients, family members, clinic staff, nurses, and administrators and reports to stakeholders whenever program changes occur as a result of such feedback. For example, after physicians requested that examination rooms not be used for consultation planning, that service was moved into conference rooms and later to the telephone.

Use By Other Organizations

The UCSF program has provided technical assistance and training to national and international organizations, who are disseminating elements of the program. The innovators use the vehicle of the Patient Support Corps (http://www.patientsupportcorps.org) to spread this concept to other clinics at UCSF and to other organizations. This service learning program allows students to earn academic credit while they accompany patients to visits. They help patients connect with high-quality information, list questions, and make notes and recordings of their consultations with providers. Dartmouth has joined the Patient Support Corps and replicated the program with several clinics in their medical center. The Cancer Support Community (http://www.cancersupportcommunity.org) has implemented the question-listing/question-coaching aspect of this program nationally in the United States. Its implementation is called Open to Options and is available through a nationwide toll-free helpline (1-888-793-9355) in English and Spanish. Open to Options is also available in person at 14 of its 42 office locations, with a full rollout planned through 2014. The Edinburgh Cancer Centre in Scotland studied the full UCSF program in a randomized, controlled trial for prostate cancer patients and found increases in decisional self-efficacy and reductions in decisional conflict and regret.13 Various components of the program have been adopted by resource centers in northern California, including the Palo Alto Community Breast Health Project, the Cancer Resource Center of Mendocino County, and the Humboldt Community Breast Health Project. The Cancer Resource Center of Mendocino County has consulted on consultation planning, recording, and summarizing program in different forms for hundreds of patients facing various types of cancer, including breast, prostate, ovarian, colorectal, head and neck, and lung. The Pancreatic Cancer...
Foundation and the Education Network to Advance Cancer Clinical Trials have also implemented elements of the UCSF decision support program.


7 Unpublished data available from Jeff Belkora, PhD, Director of Decision Services, Breast Care Center, Assistant Professor, Surgery and Health Policy, Institute for Health Policy Studies, University of California, San Francisco, California.


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Knowledge Generation and Care Improvement
For four decades the United States has had regulations to oversee research with human subjects. Early in this history, empirical research by Paul Appelbaum and colleagues resulted in a troubling finding: research subjects who are patients often blur the distinction between clinical research and treatment and view research activities as treatments best suited for their particular medical needs. This blurring phenomenon, in which patients presume that research is treatment, was labeled the “therapeutic misconception.” Research ethics scholarship has considered strategies to minimize the therapeutic misconception and analyzed why and how clinical research is fundamentally different from clinical practice. For example, Robert Levine argued that the two need a clear-cut separation and that the notion of therapeutic research is illogical terminology.

In 2006, Franklin Miller also argued for sharp conceptual and moral boundaries between research and therapy:

Medical care has a personalized focus. It is directed to helping a particular person in need of expert medical attention. Clinical research essentially lacks this purpose of personalized help for particular individuals. . . . The distinctive purpose of clinical research [is] to develop generalizable knowledge.

Drawing a sharp distinction between research and therapy can be appealing, but a growing number of activities in health care cannot be comfortably classified as either research or therapy, the one excluding the other. Participating in a clinical trial may be regarded by a woman with melanoma as her best “treatment option,” even if the specific treatment she receives is determined by random assignment. Quality improvement research designed to evaluate whether computer reminders of possible drug interactions might reduce medication errors does not alter the patient’s experience of clinical care, stands to improve clinical outcomes for future patients, and probably leads to better outcomes for the patients receiving care while the intervention is being tested. The recent and substantial federal investments in comparative effectiveness research,

practice-based research networks,

and large databases of aggregated health care claims support strategies to incorporate research questions into clinical settings and activities, generally with fewer constraints or burdens on both health professionals and patients than clinical research traditionally has imposed.

The rise of quality improvement research and comparative effectiveness research in health care settings constitutes progress toward the goal of what the Institute of Medicine has called a “learning healthcare system,” in which we are “drawing research closer to clinical practice by building knowledge development and application into each stage of the healthcare delivery process.” As clinical research and clinical practice move closer to a deliberately integrated system, the distinction between the two is increasingly blurred, although the sharp distinction in U.S. regulations and research ethics literature
Conceptual, moral, and empirical problems surround the received view that we can and should draw sharp distinctions between clinical research and clinical practice.

remains in place. In the 1970s and for two decades thereafter, this distinction was helpful: for some forms of research, it sheds light on which activities require ethical oversight. Research that is closely integrated with health care—notably, health delivery research—was then uncommon, however. That is no longer the case, and regulations and research ethics need to change to accommodate the new landscape.

In this paper, we argue that conceptual, moral, and empirical problems surround the received view that we can and should draw sharp distinctions between clinical research and clinical practice. We start with the history of the research-practice distinction in the reports of a U.S. national commission and in U.S. federal regulations, and then offer a critical assessment of five characterizations of research that have been used in policy documents and the scholarly literature to try to make a sharp distinction between research and practice. We challenge the clarity and the tenability of these characterizations as a way of distinguishing research from practice.

As examples from both practice and research demonstrate, these five claims provide neither clear conceptual boundaries nor clear, morally relevant differences between clinical research and clinical practice. In our view, they have created practical moral problems for professionals in various fields in determining which health care activities are subject to third-party ethical oversight. The received view of the research-practice distinction leads to overprotection of the rights and interests of patients in some cases and to underprotection in others. We contend that a new ethical foundation needs to be developed that facilitates both care and research likely to benefit patients, and that provides oversight that, rather than being based on a distinction between research and practice, is commensurate with risk and burden in both realms.

**Unethical Research Prompts U.S. Human Research Protections**

The first U.S. federal regulations governing research with human subjects appeared in 1974. The National Research Act creating the National Commission for the Protection of Human Subjects was also passed in 1974 as a way of addressing public outcries regarding several human research studies that seemed harmful, exploitative, or unfair to vulnerable populations—the most prominent of which was the Tuskegee Syphilis study. Although these studies had been conducted by physicians on people who understood themselves to be patients, the studies were considered unambiguous instances of scientific research rather than clinical care, and they were almost uniformly viewed as unethical. A public consensus emerged that research primarily serves the interests of science and of future patients rather than the interests of patients at hand, and that research is therefore prone, in ways clinical care is not, to exploit patients or expose them to unjustified harms. Traditional mechanisms for protecting the welfare of patients, such as reliance on professional integrity and the licensing of physicians, were widely judged insufficient to safeguard the rights and interests of patient-subjects.

The subsequent sweeping policy changes in the 1970s at the federal level required most human research to be overseen by a system that included review prior to the conduct of the research by an institutional review board charged with ensuring that research has a favorable benefit-risk balance, an adequate consent process, and a fair system of selecting subjects. Federal regulations thus came to demand impartial third-party oversight for research, but required nothing comparable for clinical practice (although the National Commission had judged, during the course of its deliberations, that innovative practice needed parallel oversight). It was therefore essential, from a practical perspective, that “research” be defined in a way that could reliably identify which activities conducted in a clinical context with patients were subject to regulations and oversight, and which were not.

**How Research Has Been Distinguished from Treatment**

Of the five characterizations of research that have been offered to make a sharp distinction between research and practice, two have been almost universally accepted as defining features, and the other three are widely held empirical assumptions or representations about how research is different from practice in morally relevant ways. The two defining features are that research (1) is designed to develop generalizable knowledge and (2) requires a systematic investigation. The three empirical assumptions are that clinical research (1) presents less net clinical benefit and greater overall risk than does clinical practice, (2) introduces burdens or risks from activities that are not otherwise part of patients’ clinical management, and (3) uses protocols to dictate which therapeutic
or diagnostic interventions a patient receives. We examine each.

**Research Is Designed to Develop Generalizable Knowledge**

The one characteristic that is used nearly universally to define research and to distinguish it from practice is that research is designed with the objective of producing generalizable knowledge. The first published use of the term “generalizable knowledge” appears in the *Belmont Report*, which states that whereas practice refers to interventions that are designed solely to enhance the well-being of an individual patient . . . and that have a reasonable expectation of success, . . . research designates an activity designed to test a hypothesis, permit conclusions to be drawn, and thereby to develop or contribute to generalizable knowledge.”

In U.S. federal regulations, “research” is defined as “a systematic investigation, including research development, testing and evaluation, designed to develop or contribute to generalizable knowledge.” The Council for International Organizations of Medical Sciences (CIOMS) international ethics guidelines use similar language, adding some examples of generalizable knowledge that rely heavily on *Belmont*, namely, “theories, principles or relationships, or the accumulation of information on which they are based, that can be corroborated by accepted scientific methods of observation and inference.” The bioethics literature unvaryingly echoes the *Belmont* and regulatory claims that having an objective to produce generalizable knowledge is the central defining feature of research. Typical examples in this literature: “The overarching objective of clinical research is to develop generalizable knowledge,” and, “this quest for generalizable knowledge in the service of improved health is what unites biomedical research.”

Research is described in many policy documents and in the bioethics literature as an activity designed—or, alternatively, intended—to produce generalizable knowledge. In this account, generalizable knowledge does not demarcate an activity as research if knowledge is obtained as an incidental finding or an unplanned by-product of clinical practice; rather, its production must be planned from the start.

As health care organizations move increasingly to become integrated systems of care and learning, the development of generalizable knowledge will be an explicit objective of these arrangements. Learning health care systems are by definition institutions designed and intended to simultaneously deliver the care patients need while capturing the experience of clinical practice in systematic ways that produce generalizable knowledge to improve care for both present and future patients. In such a system, the intent to produce generalizable knowledge will become an unreliable way of distinguishing research from practice. Here, the objective of delivering the best possible clinical care for the patient at hand is integrated with the objective of learning in reliable, ongoing, and generalizable ways from real-world experience with patients. For example, a system that ensures that critical measurements taken in the course of clinical care are made and recorded with high quality, with the intent that these measurements be used both to modify patient care as needed and also as part of cohort designs or other observational studies, is a system that is designing clinical care to simultaneously treat patients at hand and also to facilitate the production of generalizable knowledge.

One could always insist that the research involved in a learning health care system (for example, the aggregation and analysis of the measurement data for future purposes) is distinguishable from the practice involved (for example, the taking and recording of measurements for immediate patient care). But this objection misses the point. In a learning health care environment, practice is a continuous source of data for the production of generalizable knowledge, and the knowledge that is produced is used to continuously change and improve practice. Practice cannot be what it is, and cannot be of the highest quality that morally it must be, independent of its intimate connection to ongoing, systematic learning.

Even outside the context of a learning health care system, many activities have previously been designed to simultaneously contribute to generalizable knowledge and to produce the best clinical outcomes for patients. In an older vernacular, this activity was classified as therapeutic research. One of the best examples, in our assessment, is pediatric oncology, which has more or less from its outset been so designed, in that an extremely high proportion of children with cancer are treated under multicenter research protocols. In fact, despite Levine’s influential claim that the term “therapeutic research” is illogical, in various areas of adult oncology and in other areas of medicine as well, many patients seek to receive their medical care through clinical trials that are designed to produce generalizable knowledge. In explaining the nature of the medical care and “treatment options” available in clinical trials, numerous Web sites at the Food and Drug Administration and the National Institutes of Health use language such as “treatment option,” “new treatment,” “new research treatments,” “treatment IND [investigational new drug],” “research treatments,” “new drug or treatment,” “new methods of . . . treatment of a disease,” “treatments for medical problems,” and the like. For many patients who participate, clinical trials intended to produce generalizable knowledge are offered as treatment options that may present the best available treatment for their conditions.

Another problem with the “generalizable knowledge” criterion, when used as a defining criterion, is that it assumes that producing generalizable knowledge is a binary function—that an activity either does or does not do this. As such, it does not acknowledge that there are different degrees of
Practice cannot be what it is, and cannot be of the highest quality that morally it must be, independent of its intimate connection to ongoing, systematic learning.

generalizability. Sometimes, as is often the case with quality improvement research, generalizability does not extend beyond the health system being studied. It might even be limited to future patients of a particular physician or physician group, such as when ascertaining surgeon-specific success or complication rates. In other situations, the intent might be to generalize to all patients with a given condition treated anywhere.

Some might argue that we have not shown that generalizable knowledge does not distinguish research from practice, and that our examples show only that research can occur in conjunction with practice—a claim that has never been in doubt. But consider further the example of pediatric oncology, in which virtually all patients are enrolled in clinical trials and enrollment in the trial is considered to be a standard of care. The practice context is constructed to bring the most pertinent forms of scientific understanding to bear on clinical care, and clinical care generates new scientific learning. Generating and using generalizable knowledge can thus be a deliberate and integrated aspect or part of practice, not a set of maneuvers logically distinct from it. Research therefore cannot be distinguished from practice by appeal to the criterion of generalizable knowledge.

Our arguments do not diminish the importance and value of the concept of activities that yield generalizable knowledge in medical science. We merely reject the claim that generalizable knowledge is uniformly serviceable as the primary criterion to differentiate clinical research and clinical practice. We do not say that research and practice can never be distinguished by appeal to the criterion of generalizable knowledge. In many forms of clinical research, they can. But in an environment comparable to a learning health care system, which we expect to become an increasingly important form of medical practice, production of knowledge generalizable at some level beyond the patient at hand will become an essential part of the routine practice of medicine—just as it has been for decades in pediatric oncology. In such a context, it cannot be a defining condition to distinguish research from practice.

Research Requires a Systematic Investigation

Most policy and guidance documents for research oversight or research ethics characterize research as being in some respect systematic. The U.S. Code of Federal Regulations, for example, states that one condition of the definition of “research” is that it is “a systematic investigation, including research development, testing and evaluation.” While the systematic collection of data according to a predefined method may be important to the production of generalizable knowledge in the biomedical context, this feature cannot serve to distinguish research from a large body of clinical practice today. The systematic collection of data is ubiquitous in contemporary clinical medicine. In many health care contexts, the systematic collection of data is now viewed as good clinical practice and even as obligatory. Hospitals must systematically collect data on a variety of health care services and outcomes in order to be accredited in the United States.

Most U.S. hospitals are part of the Centers for Medicare and Medicaid Services’ (CMS) Hospital Inpatient Quality Reporting program, which requires data to be collected on numerous outcomes to determine if a hospital meets quality benchmarks.

Data about performance on these and other outcomes are often made public and can be used by researchers, influencing private and public sector decisions about health care purchasing and rates of provider reimbursement. Virtually all major insurance companies have purchased or established organizations that systematically collect and analyze the administrative data generated through health claims that are used for a variety of purposes, including quality improvement, provider performance measurement, and safety surveillance, as well as being sold to life sciences companies to assist in their postapproval research and marketing needs.

The number of hospitals in the United States with electronic medical record systems is growing, although currently only a small portion can use their information technology systems for the “meaningful uses” of improving “quality, efficiency, or safety” for their own patients. Nonetheless, several large health care systems in the United States have implemented programs that continuously collect data on clinical services and outcomes to improve the quality of care delivered to their own patients. Intermountain Healthcare, for example, encourages its clinicians to identify ideas for clinical improvement, creates internal protocols, and tracks outcomes, using a computerized system, to continuously improve treatment guidelines for its patients. The Veterans Health Information Systems and Technology Architecture (VistA) is a second example. VistA is described as “an integrated inpatient and outpatient electronic health record for VA patients, and administrative tools to help VA deliver the best quality medical
care to Veterans.32 VistA systematically collects data in and about ongoing clinical practice to simultaneously improve clinical services and facilitate the production of knowledge to be used more broadly.33 Another example are Practice-Based Research Networks (PBRNs), which are groups of primary care clinicians and practices that, with federal funding, jointly create infrastructure for systematic investigation of questions related to community-based practice and to improve the quality of care in these centers. This system to collect data is designed not only to integrate research into practice but also to improve the quality of the care delivered.34

In each of these three examples, it is futile to try to distinguish a research activity from a practice activity by showing that it relies on the systematic collection of data. The language of "systematic investigation" is of no help unless increased weight is given to the concept of an "investigation"—which may simply be another word for "research," in which case the definitions are viciously circular. The production of generalizable knowledge and the systematic collection of data were helpful in distinguishing research from practice when the delivery of health care was largely treated as a given practitioner's art, patients' health information was not easily aggregated or disseminated, and regulators did not require data to be collected on a routine basis. But in the current environment, the science of health care delivery is required to deliver high quality care, and regulators and payers also regularly require the systematic collection of data. Accordingly, the use of features such as systematic investigation to distinguish research from practice is of decreasing value.

Research Presents Less Net Clinical Benefit and Greater Overall Risk

We now turn from the two commonly accepted conceptual conditions of "research" to three empirical assumptions often presented to identify morally relevant distinctions between research and practice (or treatment). The first of these is that research, in contrast to clinical practice, offers patients both less prospect of net clinical benefit and more overall risk. The underlying moral thesis is that research with patients requires special oversight because it is less likely than clinical practice to be in the patient's best clinical interests and more likely to impose significant clinical risk. But is this empirical thesis defensible?

Among research ethics policy documents, the Belmont Report was the first to provide definitions to distinguish practice from research, and it speaks directly to this empirical assumption. The National Commission stated that to qualify as practice, the following conditions must be satisfied: (1) the purpose of an intervention is to provide diagnosis, preventive treatment, or therapy; (2) the intervention is designed solely to enhance the well-being of an individual patient; and (3) the intervention must have a reasonable expectation of success.35 That interventions used in practice are expected to have a reasonable prospect of success is reinforced in the Food and Drug Administration's position that the basic criteria for drug approval—thereby moving a drug from research to practice—is that "the drug is safe and effective in its proposed use(s), and the benefits of the drug outweigh the risks."36 By contrast, OHRP guidance states that some kinds of research with patients use "an untested clinical intervention."37 The implication is that in research in which clinical interventions are being evaluated, the threshold of a reasonable expectation of success, in which the prospect for benefit outweighs the prospect for risk of harm, has not yet been crossed.

So ingrained is the view that research with patients is riskier and less likely to produce net clinical benefit than clinical practice that some have used this empirical assumption to argue that quality improvement studies are not research. For example, R.P. Newhouse and colleagues maintain that "in QI [quality improvement], the objective is to benefit those patients who are served. In research, the subjects put themselves at risk of harm knowing in advance that personal benefit may not result," whereas the patients in a clinical unit affected by a quality improvement program do not.38 Mary Ann Baily, explaining why a particular activity should be classified as quality improvement rather than as research, argues that it "was not designed . . . to test a new, possibly risky method."39

Others have challenged the empirical assumptions that participation in research carries considerable risk, that it is riskier to patients than receiving care outside of research, and that patients in clinical research have poorer outcomes or have a lower likelihood of net clinical benefit than patients not in research. Although empirical evidence is limited, several systematic reviews have concluded that patients in clinical trials fare no worse clinically than do patients in clinical practice.40

These findings make sense. Interventions—whether new or established—that come to be tested in clinical trials are a small fraction of those ultimately used in clinical care. There is growing recognition that many therapies, tests, and interventions administered regularly in clinical practice are of unproven value, and that many may actually be harmful; a significant percentage of clinical procedures would not satisfy the Belmont condition that practice entails a reasonable expectation of success. The Institute of Medicine now estimates that more than half of treatments in current use lack adequate evidence of effectiveness,41 and many surgical and diagnostic procedures diffuse into practice with little or no prior scientific study.42 Mounting evidence indicates that patients in ordinary clinical care are often at risk of receiving suboptimal outcomes and of being harmed, however inadvertently, as a consequence of inadequate evidence, unproven traditional practices, and biases in clinical judgment.43

Celebrated examples exist of therapies whose adoption was widespread but that later were shown to be useless or harmful. These include gastric freezing,44 carotid bypass surgery,45...
There is no good evidence to support the empirical assumption that research studies, as a class, are more likely than clinical practice to run counter to the medical best interests of patients.

These problems in medical practice can be constructively compared to the risks and the benefits of comparative effectiveness research, which is often directed at ascertaining which of two or more widely used interventions for the same indication works best for which patients. In these trials, the clinical benefit experienced by the patient-subjects is little different from that in ordinary clinical care, since both interventions under study are accepted clinical options—neither experimental nor investigational. All participants receive a therapy that conforms to Belmont’s “reasonable expectation of success.” Other clinical research studies evaluate strategies designed to prevent medical error—for example, by evaluating the effectiveness of computer reminders for physicians or of checklists for surgeons—but these studies are overlaid on whatever usual, presumably net beneficial, care patients already receive, and probably stand to reduce the harms to the patients whose care is the focus of the research experience, rather than to increase them.

None of this is to deny that some research studies expose patients to risks of harm. Of course they do. But so does standard care. The point is that there is no good evidence to support the empirical assumption that research studies, as a class, are more likely than clinical practice to run counter to the medical best interests of patients, and a fair amount of research suggests that they may serve their medical interests better.

Research Introduces Clinically Irrelevant Burdens and Risks

The second empirical assumption invoked to identify a morally relevant distinction between research and practice is that research with patients often introduces risks, burdens, or inconveniences that are unrelated to patients’ clinical care needs (and that no comparable clinically irrelevant risks or burdens are imposed in clinical care outside of research). Jerry Menikoff, for example, maintains that “doing research involves intentionally exposing persons to risks, and not for the primary purpose of treating them or making them better but rather to answer a research question. . . . doing research is often going to involve some level of risk to research subjects, risk that is being imposed for a purpose other than for their benefit.” Arthur Schafer makes a distinction between the normal risks of practice and the “added hazards, discomforts, or inconveniences” of research while maintaining that in re-
Some clinical research—but not all—imposes risks and burdens on patients beyond those necessary for sound clinical management. More pertinent to our concerns is the linked empirical assumption that clinical care, by comparison, does not impose extraneous risks or burdens on patients beyond those associated with sound clinical management. Evidence suggests, to the contrary, that even routine clinical care often includes tests, visits, and medicines where no evidence of clinical improvement or relevance exists and where interventions carry significant risks or burdens. These tests and visits may be poorly coordinated, requiring patients to make numerous trips to obtain a diagnosis or undergo a procedure, and sometimes to repeat the same tests. That these interventions are intended to help the patient does not diminish the fact that additional risks and burdens unnecessary for sound clinical management are introduced. Various studies and reviews have documented that a range of forms of the overutilization of medical services exposes patients to burdens and risks without conferring a reasonable prospect of offsetting clinical benefits.

Risks to privacy and confidentiality are also found in practice settings, not merely in those of research. Although little data exist on the frequency and seriousness of breaches of confidentiality in personal medical records, the media has provided numerous reports of lapses in data privacy practices, some of which were of significant magnitude, and some of which also resulted in unauthorized disclosures of patients’ private medical information. Many stakeholders—including physicians, health insurance companies, pharmacists, local hospitals, state bureaus of vital statistics, accrediting organizations, employers, life insurance companies, medical information bureaus, and attorneys—can gain access, for various purposes, to identifiable information from patients’ medical records. Some of these individuals and groups do not examine the medical record solely to advance the patient’s clinical management. It remains unclear that evidence exists regarding which enterprise—clinical practice or clinical research—imposes the higher level of burdens and risks on patients beyond those associated with sound clinical management.

### Research Protocols Dictate Which Interventions a Patient Receives

The third empirical assumption used in the literature to identify a morally relevant distinction between research and practice is that in clinical research, unlike clinical practice, a patient’s clinical management is often determined by a preestablished protocol. Different authors have described the ethical import of this distinction between research and practice in different ways. According to Laura Tapp and colleagues, assigning treatment by protocol entails that patient care becomes less individualized, that flexibility to use other medicines may be reduced, and that patients’ needs may not be put first. Steven Grunberg and William T. Cefalu state that in clinical research, “the selection of certain aspects of the treatment regimen is taken out of the hands of the treating physician,” and Michael Kottow argues that “when treatment decisions are made by protocol, the patient becomes ‘a therapeutic orphan.’”

Some clinical research undeniably uses an algorithm to determine which intervention a patient-subject receives. In the classic randomized clinical trial, interventions are assigned to subjects randomly. But because there is often disagreement and wide practice variation within the clinical community for the kinds of interventions tested in these trials, which intervention any given patient will receive in standard practice can be determined more by geographic location or hospital catchment area, or by which surgeon they see, than by their individual health characteristics. This contingency introduces an element of chance in the way treatment choices are made in ordinary clinical practice that often goes unacknowledged.

External constraints on care patients receive in ordinary practice are also increasing. Formularies restrict which pharmaceuticals can be prescribed (or reimbursed), often assigning patients to generic or less expensive “first-line” medications. Certain diagnostic tests that patients may seek or that physicians may want to order are not allowed under reimbursement policies that direct and restrict which treatments or tests can be employed for which patients or symptoms. Hospital management sometimes creates standardized care protocols and policies regarding various aspects of care. Most hospitals, for example, are allowed to substitute lower-cost medicines when physicians have ordered a more expensive one. Reimbursement policies often restrict the circumstances or number of times when tests such as mammograms or eye exams can be obtained, or they deny coverage altogether for certain tests and procedures. Gatekeeping strategies, requiring prior authorization or second opinions, also constrain patient or physician choice in clinical care in favor of a broader goal of improved clinical effectiveness or cost-effectiveness in the aggregate.

At the same time, efforts are under way in clinical research to design studies that can accommodate patient or physician preferences, both to increase the transportability of research findings to clinical practice and to make it easier to conduct research in nonacademic clinical settings. This goal is also present in the design of clinical trials, where the available treatment options can be wider than those in standard practice. The Clinical Antipsychotic Trials of Intervention Effectiveness, for example, randomly assigned patients with schizophrenia to one of six FDA-approved, widely used therapies, all of which have demonstrated evidence of clinical benefit. Participants could switch to another therapy at any
time, without having to withdraw from the trial, based on a clinician’s or patient’s view that the drug is not working, that the drug is not tolerable, or that another drug would be better. Similarly, in the Spine Patient Outcome Research Trial Study, which examined the role of surgery in back pain, patients assigned to nonsurgical therapy could choose to receive surgery if they felt it was necessary, and 17 percent did. Among those who continued with nonsurgical therapy, almost any modality was allowed.34

We are not claiming that clinical management is as tightly controlled in all practice settings as it is in some clinical research protocols. Our claim is that the control over therapeutic options in research and clinical care contexts is often not so widely different as some have portrayed it and that “personalization” of therapy is neither a given in clinical care (even though there is often an illusion of such) nor unobtainable in clinical trials.

**Practical and Moral Problems for Ethical Oversight**

We have argued that the conceptual cornerstone of how research is defined in policy documents and the ethics literature—namely, as a systematic investigation designed to produce generalizable knowledge—is becoming an increasingly problematic way of distinguishing research in clinical practice contexts from health care or practice activities. We have also argued that three reasons that have often been offered for why research (but not clinical care) is morally problematic—such that it must undergo formal oversight and prior review—all rest on empirical assumptions that are questionable at best.

Relying on this faulty research-practice distinction as the criterion that triggers ethical oversight has resulted in two major problems. The first is what we might call a practical problem and has received considerable attention in recent years. We have seen delays, confusion, and frustrations in the regulatory environment when IRBs labor to interpret proper guidance in activities that increasingly challenge these boundaries. This practical problem has sometimes risen to the level of a federal investigation because thoughtful and experienced professionals have interpreted regulatory guidance differently or cannot determine whether some body of procedures constitutes research or practice.75

The second, less-discussed problem is that relying on the flawed research-practice distinction as the basis for prior review and oversight has resulted in a morally questionable public policy in which many patients are either underprotected from clinical practice risks (when exposed to interventions of unproven effectiveness or to risks of medical error) or overprotected from learning activities that are of low risk from the standpoint of patients’ rights and interests and that stand to contribute to improving health care safety, effectiveness, and value.76

Unlike the research context, no third-party oversight is currently required to ensure ethical use of interventions of unproven clinical benefit and unknown risk in clinical practice. There is no prospective moral scrutiny of practice comparable to the scrutiny of research, even though practice contexts can put patients at unjustifiable risk, leaving them deeply underprotected. For example, patients may have surgery at the hands of surgeons or teams who rarely perform such an operation, despite empirical evidence that low-volume hospitals have worse outcomes than high-volume hospitals.77 In many respects, these patients are experimental subjects, often without their knowledge or consent, with the indefensible difference being that their experience will not inform the treatment of others.

Such underprotection is one side of the problem; overprotection is the other side. We are not aware of empirical data that quantify annually the numbers of low-risk observational studies and other research projects that do not alter patients’ clinical experience or increase their medical risks, or the numbers of patients who are included in such studies, but the numbers are likely to be significant. Requiring that all activities that are designed to produce generalizable knowledge and that collect data systematically must undergo prior review by an ethics committee, even when patients’ clinical care is in no respect changed, is a misplaced moral criterion of what needs review and is a deep weakness in our current system. Recent proposed changes to federal regulations justifiably suggest significantly streamlining, if not eliminating altogether, prior ethical review of some research of this sort.78
Overprotection is not simply a nuisance. The required oversight is costly in terms of time, human energy, and money. It also results in an overburdened IRB system whose ability to provide quality oversight in situations where it is most needed is likely compromised. Moreover, addressing the overprotection problem will itself facilitate the conduct of exactly the type of learning needed to decrease the problem of underprotection in clinical care. An investment of resources to ensure both the safety of patients and public trust in our learning activities is critically important and morally justified when merited by the risks and burdens to which patients might be exposed, rather than protections being based on a less justifiable practice-research distinction.

Requiring only what is classified as research to undergo the burdens and costs of extensive oversight—on the thin grounds on which we have commented—creates the situation that we are now in: the policy creates disincentives to rigorous learning, thereby increasing the likelihood that interventions will continue to be introduced into clinical practice and health care systems in the absence of scientific efforts to evaluate their effects. Given the risks of harm that can and do occur in practice, an oversight system that stalls exactly the type of learning that could reduce the serious risks of clinical care needs reconsideration. We believe it is possible to design such a system, while still allowing the substantial and necessary room for the exercise of physician autonomy and judgment.

Rethinking What Matters Morally

The traditional definitions and descriptions of clinical research and clinical practice are becoming blurred as a model of health care emerges in which practice and learning are integrated, where a central goal of the health care system is to collect, aggregate, analyze, and learn from patient-level data, and where clinicians are expected to make evidence-based practice decisions guided by the general knowledge produced from structured learning. This emerging way of organizing health care did not prevail when federal regulations governing research involving human subjects were initially developed, but it increasingly does today.

Today’s heightened interest in comparative effectiveness, integrated learning health care systems, and continuous quality improvement provides an opportunity to rethink what matters morally in protecting the rights and interests of patients. Our current regulatory system has served us well in critical respects, and conscientious investigators have appreciated the importance of ethical review of their activities. However, our system of oversight relies too heavily on the research-practice distinction to identify which activities warrant ethical review and to determine when patients are at risk and in need of oversight protection. We need to identify more efficiently which interventions work, how errors can be reduced, and when interventions or tests should be administered or avoided for groups of patients. The labels “research” and “practice” are poor proxies for what should be our central moral concerns, and they no longer serve the purpose they did three or four decades ago. It is time to create a more balanced and relevant understanding of what matters morally as American health care begins to transform to a system in which learning and clinical practice are deliberately and appropriately integrated.

Acknowledgments

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References


9. See related discussion in Largent et al., “Can Research and Care Be Ethically Integrated?”


14. The commission did not conclude that practice needs no regulation comparable to the regulation of research and did not conclude that research is riskier than practice or that patients in medical practice are not vulnerable in ways comparable to vulnerable subjects in research. It was deeply concerned about both, but had no remit to investigate practice. See National Commission, Transcript of Meeting #40, March 11, 1978, in box 33, pp. 15-33, of the Archives of the National Commission at the Library of the Kennedy Institute of Ethics, Georgetown University.


16. The commission did not include here a separate empirical assumption about the clinician investigator’s intention (that is, toward producing generalizable knowledge versus individual care) because we believe the moral importance of this difference in intention, and any conflicts it may engender, resides primarily in whether the difference produces inferior net clinical benefit or increased burdens for patients participating in clinical research.


26. 45 CFR 46.102(d).


34. Agency for Health Research and Quality, “AHRQ Practice-Based Research Networks (PBRNs): Fact Sheet.”
51. P.M. Rothwell, “External Validity of Randomized Controlled Trials: To Whom Do the Results of This Trial Apply?” *Lancet* 365 (2005): 82-93, at 86.


64. L. Tapp et al., “Quality Improvement in General Practice: Enabling General Practitioners to Judge Ethical Dilemmas,” *Journal of Medical Ethics* 36, no. 3 (2010): 184-88.


Calls are increasing for American health care to be organized as a learning health care system, defined by the Institute of Medicine as a health care system “in which knowledge generation is so embedded into the core of the practice of medicine that it is a natural outgrowth and product of the healthcare delivery process and leads to continual improvement in care.” We applaud this conception, and in this paper, we put forward a new ethics framework for it. No such framework has previously been articulated. The goals of our framework are twofold: to support the transformation to a learning health care system and to help ensure that learning activities carried out within such a system are conducted in an ethically acceptable fashion.

A moral framework for a learning health care system will depart in important respects from contemporary conceptions of clinical and research ethics. The dominant paradigm in research ethics and in federal regulations has relied on a sharp distinction between research and practice—a segregation model that dates to the influential publications of the National Commission for the Protection of Human Subjects in the 1970s. The learning health care system, by contrast, proposes that it is acceptable and indeed essential to integrate research and practice. From this perspective, the dominant ethical paradigm from the 1970s to the present time is antithetical to and problematic for the learning health care system, at a time when clinical practice is far from optimal and learning to improve care is sorely needed. Several hundred thousand people die needlessly each year from medical mistakes. There is reason to believe that adult patients receive only approximately 50 percent of recommended therapies, and that up to 30 percent of health care spending is wasted. The need to improve health care is urgent, yet the current ethics paradigm may hinder improvement. For example, the expansion of one of the most successful quality improvement interventions ever—saving thousands of lives by preventing central line-associated bloodstream infections in intensive care units—was almost halted due to concerns about research ethics oversight. But few have come forward to express concerns and oversight for the thirty thousand or so people who will die unnecessarily each year in the United States from this type of infection.

Quality improvement and comparative effectiveness research are emblematic of the kinds of ongoing learning activities that a learning health care system is designed to promote. As we argue in the first article in this supplement to the Hastings Center Report, quality improvement and comparative effectiveness research bring into sharp relief the problems with the criteria traditionally used to distinguish research and practice. The fuzziness of the distinction, coupled with the oversight burdens that are required of research but not of practice, creates dubious incentives to redesign quality improvement and comparative effectiveness activities in ways that minimize the likelihood that they will be classified as re-
Securing just health care requires a constantly updated body of evidence about the effectiveness and value of health care interventions and of alternative ways to deliver and finance health care.

A Moral Justification of the Learning Health Care System

The traditional principles that provide the moral grounding for human subjects protection in the United States became cemented as the cornerstones of research ethics in the 1970s during a period of intense societal focus on civil rights and on egregious violations of rights that occurred in highly publicized research scandals. Since the 1970s, the dominant concern has been to protect patients and other subjects from risk, abuse, and unjust distributions of the burdens of research.

An ethical imperative that was less central in bioethics in the 1970s—namely, the establishment of a just health care system—provides an important moral reason, generally overlooked, for a rapid transformation to a learning health care system. There is considerable disagreement about the design of a just health care system and how health care should be organized and financed to achieve it, but arguably there is broad agreement that, at minimum, a just system is one in which present and future generations are able to access adequate health care services without the imposition of undue financial burdens on patients and their families. The obstacles to securing a just health care system, so defined, are complex and include cultural, economic, and political as well as scientific and public health challenges. That said, securing just health care requires a constantly updated body of evidence about the effectiveness and value of health care interventions and of alternative ways to deliver and finance health care. A learning health care system is critical to the efficient and systematic collection and dissemination of this evidence, and we think it is a necessary condition of achieving the goal of creating and maintaining a just health care system.

The societal goal of a just health care system provides only one of three independent and equally important ethical justifications for the transition to learning health care systems. The other two are the goals of high-quality health care and economic well-being. By “high-quality health care” we mean, at minimum, technically competent health care that is based on the strongest clinical evidence and is delivered with the highest achievable patient safety. By “economic well-being” we mean, at minimum, a society in which current and future generations have the economic resources necessary to live a decent human life over the course of the life span. The im-
Table 1.
Learning Health Care System Ethics Framework

<table>
<thead>
<tr>
<th>Obligation</th>
<th>Parties Bearing the Obligation</th>
<th>Synopsis of the Obligation for Learning Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respect the rights and dignity of patients¹</td>
<td>• researchers • clinicians • health care systems administrators • payers • purchasers</td>
<td>• Assess the impact of a learning activity on the rights, respect, and dignity of patients</td>
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<td></td>
<td></td>
<td>• Assess whether a learning activity limits patient choice, as well as the value to patients of any choices so affected</td>
</tr>
<tr>
<td>Respect clinician judgments</td>
<td>• researchers • health care systems administrators • payers • purchasers</td>
<td>• Assess the impact of a learning activity on the exercise of clinician judgment</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Assess the importance of any restriction on the exercise of clinician judgment for the health and autonomy interests of patients</td>
</tr>
<tr>
<td>Provide optimal clinical care to each patient</td>
<td>• researchers² • clinicians • health care systems administrators • payers • purchasers</td>
<td>• Assess the expected net clinical benefit for patients affected by the learning activity, compared to the net clinical benefit they likely would have experienced if their clinical care had not been affected by the learning activity</td>
</tr>
<tr>
<td>Avoid imposing nonclinical risks and burdens on patients</td>
<td>• researchers • clinicians • health care systems administrators • payers • purchasers</td>
<td>• Assess the nonclinical risks and burdens to patients affected by a learning activity, compared to the nonclinical risks and burdens they likely would have experienced if they had not been affected by the learning activity</td>
</tr>
<tr>
<td>Address health inequalities</td>
<td>• researchers • clinicians • health care systems administrators • payers • purchasers</td>
<td>• Assess whether the risks and burdens of a learning activity will fall disproportionately on patients who are already disadvantaged</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Assess whether the learning activity will disproportionately benefit patients who are already socially and economically advantaged</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Assess whether a learning activity will help advance the goal of reducing unjust inequalities in health and health care or can be designed to do so</td>
</tr>
<tr>
<td>Conduct continuous learning activities that improve the quality of clinical care and health care systems</td>
<td>• researchers • clinicians • health care systems administrators • payers • purchasers</td>
<td>• Conduct and contribute to learning activities as a matter of role-specific, professional responsibility</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Assess the extent to which a learning activity will likely contribute to the quality, fairness, or value of health care services and systems by assessing the soundness of the learning activity’s objectives, design, and plans for dissemination and implementation</td>
</tr>
<tr>
<td>Contribute to the common purpose of improving the quality and value of clinical care and health care systems</td>
<td>• patients</td>
<td>• Participate in learning activities that are consonant with other obligations in the framework intended to respect the rights and interests of patients; participate in activities deemed acceptable to go forward without patients’ express informed consent</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Consider participation in learning activities that because of their impact on the framework’s other obligations cannot ethically go forward without express informed consent</td>
</tr>
</tbody>
</table>

¹This framework has implications for family members, loved ones, and surrogates of patients. Both the first and the seventh obligation extend to family members, loved ones, and surrogates when patients are children or adults whose competence is permanently or temporarily compromised and when adult patients want or need their loved ones to be involved in their care.

²If researchers do not otherwise have clinical duties to the patients who are affected by a learning activity, then they do not shoulder an obligation to provide patients with optimal clinical care.
We should assess both whether a learning activity unduly limits the choices of patients and the value of those choices to patients. Many decisions in health care are not likely to engage values of central importance to the patient.

The importance of efficient and real-time learning to the securing of quality health care is indisputable. The relationship between learning in health care and economic well-being is perhaps less apparent but is arguably as important. Broad agreement exists that the pace at which U.S. health care costs continue to escalate constitutes a serious threat to the economic prospects of the country, individuals, and families; continuous, efficient learning in health care is essential (though not sufficient) to the slowing of this pace and thus to economic well-being.\(^{13}\)

The goals of just health care, high-quality health care, and economic well-being provide independent moral reasons for the transformation of current health care organizations into learning health care systems. These goals underlie our aim in this paper to present a framework of moral obligations that both integrates and alters some basic ideas in our current research ethics and clinical ethics paradigms. For some readers, the need to improve health care quality may be the most important reason for the transition to a learning health care system, and possibly even the only justificatory reason they accept. This rationale is narrower than our three-reasons approach, but in no way undermines the moral imperative to move to learning health care systems. The improvement of health care quality is a sufficient reason alone. So, too, is a commitment to ensuring economic well-being.

What Counts as a Learning Activity?

A learning activity is one that both 1) involves the delivery of health care services or uses individual health information, and 2) has a targeted objective of learning how to improve clinical practice or the value, quality, or efficiency of the systems, institutions, and modalities through which health care services are provided. All such activities are learning activities, even if they have typically been categorized as clinical research, clinical trials, comparative effectiveness research, quality improvement research, quality improvement practice, patient safety practice, health care operations, quality assurance, or evidence-based management. We do not contest these labels or classification schemes, but they also do not control or influence our analysis. For our purposes, they are all “learning activities.”

Health care services include a wide range of interventions and interactions in which professionals are involved with patients, sometimes over long periods of time. They include encounters between patients and health care professionals in the traditional settings in which clinical services are provided, as well as in settings such as patients’ homes, pharmacies, and the workplace, and they may occur virtually through telemedicine or other Internet-based modalities. Health information includes any information that relates to an individual’s physical or mental health, the health care services provided to an individual, or the payment for an individual’s health care, whether in the past, present, or future.\(^{14}\)

The Basic Structure of the Framework

The framework we propose consists of seven obligations: 1) to respect the rights and dignity of patients; 2) to respect the clinical judgment of clinicians; 3) to provide optimal care to each patient; 4) to avoid imposing nonclinical risks and burdens on patients; 5) to reduce health inequalities among populations; 6) to conduct responsible activities that foster learning from clinical care and clinical information; and 7) to contribute to the common purpose of improving the quality and value of clinical care and health care systems.

Respecting patient rights and dignity and avoiding nonclinical risks (obligations 1 and 4) appear in most contemporary discussions of research ethics. Respecting the judgment of clinicians and providing patients with optimal clinical care (obligations 2 and 3) are presuppositions of traditional medical ethics—as, for example, in the influential catalogue of norms in Thomas Percival’s classic volume, Medical Ethics.\(^{15}\) Variations of these four obligations are prominent in contemporary discussions of medical professionalism,\(^{16}\) and they remain relevant in our framework. However, we also give each an interpretation not found in codified principles of either clinical ethics or research ethics.

Obligations 5, 6, and 7 are specific to the learning health care system context. These three obligations substantially revise traditional conceptions of the moral foundations of research ethics and clinical ethics. Obligations 5 and 6 have more than one obligation-bearer, as presented in Table 1, with the obligations falling on clinicians, investigators, health care institutions, those responsible for institutional policies and practices, payers, and purchasers. Patients are the obligation-bearers in obligation 7, which proposes to sharply reform current rules and guidelines. This obligation placed on patients to contribute, under limited and appropriate condi-
tions, to learning that is integrated with their clinical care is not present in conventional accounts of either clinical ethics or research ethics, where the assumption is that no such obligation exists.

All seven obligations are relevant to judgments about the ways in which a learning activity can negatively or positively affect the rights or interests of patients and professionals. The term “rights” refers to justified claims to something that individuals and groups can legitimately assert against other individuals or groups. The associated term “interests” refers to that which is in an individual’s interest—that is, that which supports an individual’s well-being or welfare in a given circumstance. We use the term “risk” to refer exclusively to a risk of “harm,” meaning a thwarting, defeating, or setting back of an individual’s interests.17

Seven Fundamental Obligations

Each of the seven obligations in the framework constitutes a necessary condition, within a learning health care system, of an adequate ethics. In the absence of any one of these obligations, the framework would lose a basic norm, rendering the framework deficient. However, we do not claim that this set of obligations establishes a set of sufficient conditions in a comprehensive ethical framework. Future work can be expected to specify these abstract rules to provide more granular guidance for institutions and their specific contexts and to perhaps add additional general obligations.

The seven norms presented below have some overlapping content, but no one norm can be reduced to one or more of the others. They are not morally weighted or placed in a hierarchical order of importance. Questions of weight and priority can be assessed only in specific contexts. When these norms come into conflict in particular learning activities, the goal will be to show either that one norm is of overriding importance in that context or that at least some demands of each of the conflicting norms can be satisfied, whereas others cannot.

1) The obligation to respect patients. Moral obligations to respect the rights and dignity of persons are not controversial in either clinical ethics or research ethics.18 Examples of respecting rights include obtaining informed consent, soliciting and accepting advance directives, protecting the confidentiality of health information, and evaluating the effectiveness of health care in terms of outcomes that matter to patients. Respecting the dignity of patients requires health professionals to express respectful attitudes and to treat patients as having an inherent moral worth by, for example, helping patients understand what is happening to them and following the lead of patients in involving their families and friends in their care.

Among the rights most discussed in research ethics and clinical ethics is the right to have one’s autonomy respected. The obligation to respect patient autonomy is also central to the framework we are proposing, but unlike some bioethics literature, the framework does not give it undue deference or overriding importance.19 Respecting autonomy is primarily about allowing persons to shape the basic course of their lives in line with their values and independent of the control of others.20 Not all health care decisions are likely to be attached to a significant autonomy interest of individual patients, and deference of the wrong sort can constitute a moral failure to take adequate care of patients rather than an instance of showing respect.

In interpreting the obligation to respect autonomy in learning health care contexts, we should assess both whether a learning activity unduly limits the choices of patients and the value of those choices to patients. Many decisions in health care—such as how often simple laboratory tests should be repeated during a hospitalization or whether medications should be dispensed by one qualified professional or another—are not likely to engage values of central importance to the patient.21 Learning activities that relate to such decisions can be undertaken by health professionals and institutional officials without a violation of obligations to respect the rights or dignity of patients.

2) The obligation to respect clinician judgment. The importance of clinician judgment to professional practice is well established, although what is meant by clinician judgment is not always clear. We use the term “judgment” broadly to mean the clinician’s considered beliefs about how best to care for a patient in light of multiple considerations and influences, including personal professional experience, the experience of colleagues and mentors, scientific evidence, and the clinician’s understanding of the patient’s values and priorities. Respect for clinicians’ judgments is justified for two reasons. First, the exercise of clinical judgment can further the health interests of patients in achieving the best clinical outcome.22 Second, the exercise of clinical judgment can advance the autonomy interests of patients because clinicians are often well positioned to ascertain and be responsive to their values and preferences.

Not all constraints on the behavior of clinicians—such as requirements to write notes for a supervisor or to use a uniform method for dosing orders—interfere with the exercise of clinician judgment. Some other constraints interfere with the exercise of clinician judgment, but to varying degrees. For example, formularies requiring physicians to prescribe only one branded drug among several in the same class may have little if any negative impact on the health and autonomy interests of patients that respect for clinician judgment is intended to serve. Learning activities that impose constraints of these types would be compatible with the obligation to respect clinician judgment.
When learning activities target areas in which there is clinical uncertainty about best practices or limited empirical evidence, the importance of respecting clinician judgment is weakened.

One problem with the obligation to respect clinician judgments is that even the most well-intentioned judgments of clinicians can be subject to some form of bias. A key precept of evidence-based medicine is that clinician judgment may not result in the best health outcomes for patients, especially when there is an absence of good empirical evidence or that evidence does not factor in the forming of the judgment. Evaluating the strength of the obligation to respect clinician judgment usually entails a contextual assessment of the likely impact of any proposed restriction on the exercise of clinician judgment on patients' health or autonomy interests. When learning activities target areas in which there is clinical uncertainty about best practices or limited empirical evidence, the likelihood that unrestricted clinician judgment will advance the health interests of patients is lessened, and the importance of respecting clinician judgment is weakened. For example, for most patients, there is currently little empirical evidence to support a clinician's judgment that a particular first-line hypertension drug is better than another. The obligation to respect clinician judgment in this context is not as stringent as in a case where clinician judgment is based on more robust evidence or is responsive to patient preferences for different therapeutic options.

3) The obligation to provide optimal care to each patient. Obligations to promote the welfare of others take on specific forms in health care, usually formulated as role obligations. Professional codes underscore the moral responsibilities of professionals to advance the welfare interests of each patient by providing the patient with optimal care aimed at securing the best possible clinical outcome. “Clinical outcome” encompasses the interests patients have in the promotion, preservation, and restoration of their health and the mitigation of pain, suffering, and disability. During the course of clinical care, clinical risks and burdens—in comparison to the nonclinical risks and burdens—that the patients could be expected to experience if their care had not been affected by that activity.

In assessing net clinical benefit, the risks in routine clinical practice should be considered. Some learning activities are likely to increase the prospects for net clinical benefit, whereas others are likely to decrease it. An activity designed to evaluate the impact of a computer-generated prompt to clinicians to double-check medication dosage may itself have a positive impact on the net clinical benefits for patients; it may reduce the risk that they will be harmed by a medical error. By contrast, depending on the context, a randomized clinical trial of a first-in-class medication may decrease patients' prospects for net clinical benefit relative to what would be expected if these patients receive approved medical therapies. Other learning activities—such as a prospective observational study that relies only on electronic health data to compare widely used interventions—are likely to have no appreciable effects on net clinical benefit. Accordingly, the impact of a learning activity on net clinical benefit is specific to the particulars of the activity and the related clinical context, but it is morally essential that such assessments be made in a learning health care context.

4) The obligation to avoid imposing nonclinical risks and burdens. Health care focuses on the health-related interests of patients and the reduction of risks of health-related harms, but obligations to avoid inflicting other kinds of harm and burden also apply in health care. Clinical care and clinical information can be provided or used in ways that affect patients’ interests in financial well-being, social standing and reputation, employment and insurance opportunities, dignity, privacy, and the joy of spending time with family and loved ones.

The impact of a learning activity in imposing nonclinical risks and burdens—in comparison to the nonclinical risks and burdens that the patients could be expected to experience if their clinical care did not involve the learning activity—is a moral consideration. For example, the risk that health information will be disclosed inappropriately sometimes increases as a result of a learning activity, and such disclosures can be monitored and reduced through security protections. Learning activities also may impose burdens beyond those needed for patients’ usual clinical care, such as extra visits to clinical facilities.
5) The obligation to address unjust inequalities. Our framework is rooted in a broader conception of obligations of justice than the conception that dominates traditional research ethics. Fundamental to traditional formulations and to the regulation of research are moral requirements that subject selection be fair and that the distribution of research benefits and burdens be just.24 Our framework supports the commitment to these injunctions, which are historically rooted in concerns about the abuse of disadvantaged or vulnerable subjects in research. However, these injunctions carve out only a piece of the territory of justice that needs to be considered in the ethics of a learning health care system.

In agreement with the traditional conception, our framework sets a presumptive bar against learning activities whose potential negative effects—including imposition of nonclinical burdens or the worsening of prospects for net clinical benefit—fall disproportionately on socially and economically disadvantaged patients or groups of patients. This bar protects many individuals who are homeless, poorly educated, belong to groups that have been subject to historical and continuing prejudicial treatment, or lack access to health care and physicians. Also in need of monitoring are learning activities whose positive outcomes will disproportionately benefit patients who are already socially and economically advantaged—for example, activities that rely on access to the Internet in the home. This obligation requires those who propose learning activities to consider whether the activity can be carried out in such a way that its benefits extend to the less privileged.

In ways more expansive than traditional conceptions, the learning health care system ethics framework also imposes an affirmative obligation to direct learning activities toward aggressive efforts to reduce or eliminate unfair or unacceptable inequalities in the evidence base available for clinical decision-making, in health care outcomes, and in the respectfulness with which health care is delivered. For example, it is widely acknowledged that pregnant women often respond to medications differently than other adults, but the health needs of pregnant women are rarely the focus of clinical investigation because of concerns about the impact of the medications on the fetus. A learning health care system is well positioned to identify—and should mount—ethically acceptable learning activities to address what some have identified as unjust paucity of evidence about the management of chronic illness in pregnant women.25

Learning activities also should target disparities in clinical outcomes associated with widening educational differences in adult mortality from such health conditions as lung cancer and heart disease.26 Similarly, learning activities should find strategies to reduce the disrespectful ways in which patients in sickle-cell crisis are sometimes treated when they seek pain relief in emergency rooms. Unlike other patients presenting in severe pain, these patients, who are largely young African Americans and thus subject to unjust racial stereotyping, are often treated with suspicion by clinical staff, who view them not as people suffering from a dreadful disease but as drug users hoping to manipulate the system in search of opiates.27

Although reasonable people often disagree about precisely which inequalities are unjust and for what reasons,28 the narrowing of inequalities and the elimination of discrimination in care between minority and majority patients, economically impoverished and economically secure patients, and poorly educated and well-educated patients is a national priority in the United States and in many other countries.29 The learning health care ethics framework requires that learning activities be assessed to determine whether they perpetuate or exacerbate unjust inequalities and to determine whether they can be structured to advance the goal of reducing or eliminating inequalities and discrimination in health care. This role has not traditionally been at the forefront of the list of obligations of health care institutions, where these problems of unjust inequalities have been widely overlooked.

6) The obligation to conduct continuous learning activities that improve the quality of clinical care and health care systems. The third obligation of our framework—to provide each patient optimal clinical care—has been linked to clinical ethics requirements that clinicians stay current in their knowledge and their skills.30 Until recently, there has been little discussion of the need to augment this obligation with an affirmative responsibility on the part of clinicians to contribute to that knowledge base.31 This sixth obligation makes contribution to learning morally obligatory. It also extends its reach beyond health care professionals to institutions, payers, and purchasers of health care. We envision an unprecedented transformation of responsibilities in a learning health care system that applies to physicians in private practice, pharmaceutical companies, private hospitals, and so on. Because health care professionals, officials of health care institutions, and purchasers of health care have unique access to and control over clinical care and health information, they are uniquely positioned to seek, conduct, and contribute to learning activities that can advance health care quality, economic viability, and a just health care system. No other individuals, professionals, or institutions in society have such access or control.

The learning health care system ethics framework makes this sixth obligation foundational in the structuring of health professions and health care institutions. The obligation requires that every practitioner and institution accept a responsibility to feed information into the system that increases our knowledge. Each learning activity to be conducted within the system must be individually assessed for the extent to which it holds out the prospect of contributing to the improvement of health care services and systems. This assessment should include an evaluation of the soundness of the learning activity’s objectives, design, and plans for implementation or dissemination. Learning activities today may improve only the
specific health care settings in which a learning activity takes place, with only some activities and new information being transportable to a wider body of health care institutions. This current limitation will gradually be transformed into a vast array of interconnected learning activities.

7) The obligation of patients to contribute to the common purpose of improving the quality and value of clinical care and the health care system. Traditional codes, declarations, and government reports in research ethics and clinical ethics have never emphasized obligations of patients to contribute to knowledge as research subjects. These traditional presumptions need to change. Just as health professionals and organizations have an obligation to learn, patients have an obligation to contribute to, participate in, and otherwise facilitate learning.

This obligation is justified by what we call a norm of common purpose. This norm of common purpose is similar to what John Rawls calls the principle of the common good, a principle presiding over matters that affect the interests of everyone. The common interest of members of a society in the health care system is that it be positioned to provide each person in the society with quality health care at a cost compatible with individual and societal economic well-being. We also have a common interest in supporting just institutions, including activities that reduce the unjust inequalities that were mentioned in obligation 5.

Securing these common interests is a shared social purpose that we cannot as individuals achieve. Our goals cannot be reached efficiently without near-universal participation in learning activities, through which patients benefit from the past contributions of other patients whose information has helped advance knowledge and improve care. Patients cannot discharge this obligation merely by paying a fee for the health care service they receive or by contributing to society through taxation or charitable contributions. No amount of money paid for health care services substitutes for direct participation in and contribution to learning activities. The knowledge necessary to secure a high-quality and just health care system cannot be obtained from information limited to a bounded number of patients at discrete points in time. A learning health care system must have continuous access to information about as many patients as possible to be efficient, affordable, fair, and of highest quality.

A related justification for obligation 7 is the reciprocal obligation that arises among strangers who occupy the role of patient over time. The philosopher David Hume expresses the general form of this duty of beneficence as follows: “All our obligations to do good to society seem to imply something reciprocal. I receive the benefits of society, and therefore ought to promote its interest.” In our framework, the discharge of obligations of reciprocity occurs through an established practice of making an appropriate and proportional return—returning benefit with proportional benefit, with all alike sharing, as a matter of moral obligation, the burdens necessary to produce these benefits.

In proposing that patients have an obligation to contribute to the common purpose of improving health care through learning, we are not proposing that patients have an affirmative moral obligation to participate in all learning activities regardless of the degree of additional risk or burden they may impose. Different learning activities will have differential effects on the rights and interests of patients and therefore will have different implications for patients’ obligations to participate in them. The first four obligations of this framework are intended to protect these rights and interests in the assessment of the overall ethical acceptability of particular learning activities. For example, some learning activities, such as randomized clinical trials of investigational new devices, would not be obligatory because of the potential to fail in meeting obligations 1 through 4. If this type of learning activity is otherwise ethically acceptable, however, then patients might choose to participate in it, though they should be informed and understand that they are under no obligation to do so. By contrast, other learning activities—such as participation in a registry, reviews of deidentified medical records, and being interviewed by health care staff to better improve the patient care experience—are likely to be instances in which patients do have an obligation to participate, assuming that the activities have a reasonable likelihood of improving health care quality and that appropriate data security protections are in place. These conditions are probably met currently in integrated health care systems that have invested in secure electronic health records and have mechanisms in place to adjust local norms of care in direct response to the results of learning activities.

The obligation of patients to contribute to health care learning is compatible with duties to inform patients about
learning activities and to solicit their express consent for some learning activities, as appropriate. The first obligation in our framework requires, as a matter of respect, that health care institutions have numerous and varied policies and practices in place to inform patients about the institution’s commitment to learning and about the specific learning activities that are currently underway and how they are being conducted. Activities such as randomized, controlled trials of an investigational new device could proceed only with patients’ express, affirmative agreement, obtained through a valid informed consent process.

As with the first obligation above, the obligation to contribute to learning can extend to family members, loved ones, and surrogates of patients, particularly when patients are children or adults whose competence is permanently or temporarily compromised. Whenever loved ones are intimately involved in the care of the patient, they may have information or insight critical to learning about and improving health care interventions and processes. For patients lacking cognitive or decisional capacities, loved ones and other surrogates can play a vital role in the ethics framework by representing and protecting patients’ interests of during learning activities.

It has several times been asked in the bioethics literature whether there is a duty to serve as a research subject. Some have answered the question affirmatively. Their reasons have been premised on a conception of duties to participate reciprocally in a system that produces public goods from which we all benefit and in which no one should, in this respect, be a free rider.\(^5\) In certain circumstances, even compulsory participation has been proposed.\(^6\) Although similar justice-oriented grounds are central in some of our arguments, we are proposing a more pervasive level of participation, and participation of a different type, than previous writers have recommended. We make it a condition of participating in a learning health care system as a patient that one also participates in the learning activities that are integrated, on an ongoing basis, with the clinical care patients receive.\(^7\) The scope of participation that we are proposing is far more extensive and notably different from that proposed by previous writers on duties to participate in research.

**Going Forward with the Learning Health Care System Ethics Framework**

The framework we have proposed for a learning health care system departs significantly from previous frameworks in research and clinical ethics. Its most distinctive features are twofold. First, the framework eschews the moral relevance of the traditional distinction between research and practice in a learning health care environment, focusing attention instead on the moral obligations that should govern an integrated learning health care system. Second, the framework sets a moral presumption in favor of learning, in which health professionals and institutions have an affirmative obligation to conduct learning activities and patients have an affirmative obligation to contribute to these activities. This presumption is grounded in the claims that all parties benefit from this arrangement and that the societal goals of health care quality, just health care, and economic well-being require continuous learning through the integration of research and practice.

This framework will help facilitate the transformation to a learning health care system. Going forward, the next step will be to specify the framework’s implications for oversight policies and practices, including prior review and informed consent, and to determine precisely how the framework will interact with the current human subjects regulations and institutional review board system. Given that our framework rejects the moral relevance of the traditional distinction between research and practice in a learning health care system, different operational criteria for determining which activities should be subject to oversight policies, based on the seven moral obligations, will need watchful development. For example, future work will need to use multiple criteria to determine which activities require express prospective consent and which may be addressed by routine disclosures. Critical to this work is canvassing the views of patients and other stakeholders—an effort that is already under way.\(^8\) Although the hard work of specifying the policies and practices needed to implement the framework is just beginning, we close with a few preliminary observations—first, about the implications of the framework for clinical practice, and second, about the operationalization of the first and seventh obligations.

As we argue in the first article in this set, the underprotection of patients from unjustified and often preventable harms and burdens in clinical practice is a profoundly serious moral problem. We are not proposing, nor do we think it correct, that the solution to the underprotection problem is simply to expand the current review system for research. Multiple conditions and factors contribute to the underprotection problem, and a complex set of strategies will be needed to address the problem effectively. The learning health care ethics framework is intended to be one part of the solution. First, the framework makes obligatory the kinds of learning that are necessary to reduce the harms that occur in clinical environments and resolve the uncertainties that exist around many clinical practices. Second, the framework makes such learning easier to conduct; by reducing the overprotection of patients from learning activities that do not undermine their interests or rights, it facilitates learning that can help address the underprotection of patients in clinical practice. Put slightly differently, insofar as contemporary research ethics and oversight interfere with learning activities that could reduce errors and improve clinical effectiveness, the overprotection that results is itself a source of harm to patients’ interests.

Health care institutions and clinicians are constantly adopting new practices, ranging from platforms to support
clinical decision-making built on electronic health systems to minimally invasive and robotic surgery. These innovations are often introduced without systematic assessment of their impact, perhaps to avoid crossing the unwelcome and curious divide between practice and research. Our framework makes this distinction irrelevant to questions of oversight and provides reasons why health care institutions and professionals are obligated to accompany the introduction of such innovations—as well as practices that have never been rigorously evaluated—with a commitment to systematically learn about their effects on clinical outcomes, health care value, patients’ experience, and health disparities.

We envision that a learning health care system will adopt an array of policies and practices that provide a moral link between the first obligation—to respect the rights and dignity of patients—with the seventh obligation—that patients contribute to the common purpose of improving the quality of clinical care and the health care system. For example, the learning health care system would disclose to patients in multiple ways and at various times that learning occurs constantly throughout the health care system, and that the products of such learning are constantly updated and integrated into the system of care. Concrete examples would be provided of how care has been improved as a result of learning. Such disclosure serves to underscore to patients the system’s moral commitment to continuous learning, the relationship of that learning to the quality of care they will receive, and the system’s commitment to ensuring that patients are aware of continuing learning activities and their risks and benefits. Disclosure procedures might include information provided at initial interviews or at enrollment, in postings in waiting rooms, and in newsletters and Web sites. The best ways to communicate with patients must be identified and evaluated, and these approaches to disclosure should be shared with small hospitals and practices without the resources to do so on their own.

The health care system would likewise inform patients in routine and systematic ways of the policies that are in place to provide ethical oversight of learning activities, as well as how the confidentiality of their medical information will be maintained, how privacy is insured, how information is transmitted to other health care institutions, and the like. There would also be transparency in the conduct of learning activities. Transparency might be achieved by, for example, listing the steady flow of learning activities on system Web sites (and on paper, if requested) and by accountability to the public and to patients regarding what is learned in these activities, including whether and how a learning activity has improved clinical practice. In addition, a learning health care system would publicize to patients that, while they might not be informed routinely about each learning activity—since many have little, if any, effect on patients’ interests or rights—they will be adequately informed, and their consent sought, whenever a learning activity might have a negative impact on the quality of care or impose burdens above and beyond what they would otherwise experience.

Finally, we appreciate that the learning health care system ethics framework we have proposed will be criticized as a premature and overly extensive reshaping of traditional research ethics and clinical ethics. Others may think we propose too little. We claim no more than a start on a subject that merits extensive investigation, and we welcome suggestions and commentary moving forward. The transformation to a learning health care system is still in its infancy. We are in the early days of a progressive realization of a lofty aspirational goal, but given the preventable harm, waste, and uncertainty about clinical effectiveness in health care, efforts to accelerate learning should be given high priority. Now is a good time to lay the ethical foundations of a learning health care system and to begin work on its specific moral commitments.

Acknowledgments

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References


2. Institute of Medicine, IOM Roundtable on Evidence-Based Medicine, The Learning Healthcare System, Olsen, Aisner, and McGinnis, eds., at 6, and see also 3.
3. The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research was established in 1974 by the U.S. Congress and directed to “consider” the boundaries between research and accepted practice. The commission’s basic statement of the “boundaries problem” occurs in the first section of the Belmont Report, as cited below; for the history of the commission’s complex discussion of its congressional mandate, see T.L. Beauchamp and Y. Saghai, “The Foundations of the Distinction between Research and Practice,” *Theoretical Medicine and Bioethics* 33 (2012): 45-56.


7. Institute of Medicine, Committee on the Learning Health Care System in America, *Best Care at Lower Cost*, Smith et al., eds.


11. For example, *Best Care at Lower Cost* discusses the rising cost and complexity of health care in the United States and argues that the U.S. health care system must become a learning system because it has “prominent shortcomings and inefficiencies that contribute to a large reservoir of missed opportunities, waste, and harm” that threaten “the health and economic security of Americans”; Institute of Medicine, Committee on the Learning Health Care System in America, *Best Care at Lower Cost*, Smith et al., eds., pp. 1-2 to 1-3. Similarly, Lynn Etheredge discusses the need to generate information from routine clinical encounters to improve the quality and value of health care delivered to patients; Etheredge, “A Rapid-Learning Health System.”


28. Even those who do not support the social goal of just health care, as we have presented it, have reason to support the fifth obligation based on justice-related considerations having to do with the prevention of injustices in the conduct of research and clinical practice.


34. Walter Stewart, personal communication, November 5, 2012.


ABSTRACT: No consensus exists about when researchers need additional participant consent (re-consent) to submit existing data to the federal database of Genotypes and Phenotypes (dbGaP). Re-consent for submission of their data to dbGaP was sought from 1,340 study participants, 1,159 (86%) of whom agreed. We invited the first 400 of those who agreed to complete a telephone survey about their reasoning for their consent decision and their satisfaction with the re-consent process; 365 participants completed the survey. Respondents reported that it was very (69%) or somewhat (21%) important that they were asked for their permission. Many respondents considered alternatives to consent, such as notification-only or opt-out, to be unacceptable (67% and 40%, respectively). These results suggest that re-consent for dbGaP deposition may be advisable in certain cases to anticipate and honor participant preferences.

KEY WORDS: informed consent, data sharing, dbGaP

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could argue that the public good of unrestricted biorepository research outweighs the rights of individual participants to choose whether to participate when the research presents a minimal risk to participants (Bathe & McGuire, 2009; Helgeson et al., 2007). At the other extreme, one could argue that the autonomy interests of the research participants require obtaining express permission or some other precautions for additional procedures that the original consent process did not specify, including submission of data to dbGaP (Greely, 2007). For researchers, practicability is a key consideration, as approaching research participants for additional permission can be time consuming and expensive (Colditz, 2009).

Lack of policy consensus on when re-consent is appropriate has been compounded by an absence of data on research participants’ attitudes toward data sharing through dbGaP. Where studies have investigated participant attitudes, most have used hypothetical scenarios to examine participant and potential participant concerns and preferences, particularly regarding the nature and/or necessity of consent to address data sharing (Kaufman et al., 2009; Wendler & Emanuel, 2002; Willison et al., 2007). In these studies, the proportion of participants preferring consent prior to each research use ranged from 12% to more than 50%, depending on factors such as the source of samples (clinical versus research) and anonymization. We know of no other investigations in which research participants have been asked their opinions on the need for consent (or re-consent) for sharing their data in any manner, let alone through a federal data repository.

In 2008, the Group Health Research Institute had a unique opportunity to study current research participants’ views of re-consent for data sharing as part of the multi-institution electronic MEdical Records and GEning (eMERGE) Network. This collaborative study is exploring the feasibility of conducting GWAS using existing research cohorts and phenotypes derived from electronic medical record data. In keeping with NIH policy, all sites are to submit de-identified study data to dbGaP. On the grounds that such data sharing was outside the scope of the original consent, the Group Health IRB required the investigators to seek the consent of living participants in the Adult Changes in Thought (ACT) Study, a longitudinal cohort study of aging and dementia funded by the National Institute on Aging. Thus the research participants required obtaining express permission—required re-consent. This process let us explore the following questions with a subset of those approached for re-consent: (1) What reasons inform participant decisions about whether to let their data be deposited in dbGaP? (2) What do participants think about the process used to ask for consent? (3) Do participants think about the process used to ask for consent for data sharing in the Group Health eMERGE study? And (3) Do they believe re-consent for new research activity was necessary?

Methods

Setting and Participants

The study was conducted at Group Health, a prepaid health plan serving approximately 600,000 members in Washington and Idaho. Group Health serves members insured by employers, individual coverage, Medicare, Medicaid, and state-subsidized insurance for low-income residents. Participants were members of the Adult Changes in Thought (ACT) Study, a longitudinal cohort study of aging and dementia funded by the National Institute on Aging.

In the ongoing ACT Study, randomly selected members age 65 and older in the greater Seattle area who show no evidence of dementia were invited to enroll. Cohort participants range in age from 65 to 102 and have been Group Health members for a median of 30 years prior to study enrollment (Kukull et al., 2002). The ACT Study enrolled 2,581 people between 1994 and 1996 and another 811 in 2000–2001. Since 2005, participants have been continuously enrolled to maintain a cohort size of approximately 2,000 persons. ACT Study participants receive biennial examinations to determine cognitive status.

Recruitment

The original consent form indicated that the study would be measuring genetic variables including ApoE4. However, the original ACT consent did not state that study data would be provided to a federally administered data repository; for this reason, the Group Health IRB determined that eMERGE participation—which would include submitting existing and newly generated study data to dbGaP—required re-consent. While a waiver was granted for deceased participants, eMERGE researchers were required to seek re-consent from living ACT participants (or their surrogates, for those who had experienced significant cognitive decline since enrolling in the ACT Study). A waiver was granted for deceased participants because Washington state law considers DNA and sequenced base pairs to be...
personal health information, which is protected even for deceased individuals. Thus the Group Health IRB could have required the investigators to seek consent from legally qualified representatives.

The re-consent process for the eMERGE study took place between July 2008 and April 2009. Informed consent documents were mailed to ACT Study participants with a postpaid return envelope; those who did not return the documents within 2–3 weeks received a reminder telephone call from Group Health survey staff. ACT participants with scheduled biennial visits during the eMERGE re-consent period went through the informed consent process in person (n = 353). ACT participants who had been diagnosed with definite memory changes were not asked for consent; instead, their legally qualified surrogates were asked to consent on their behalf. Of 260 surrogates asked, 141, or 54%, consented. Of 1,340 cognitively intact study participants contacted for re-consent, 1,159 (86%) agreed to participate in eMERGE and have their data deposited in dbGaP; 152 (11%) declined; and 29 (2%) were determined to be ineligible (blind, too ill, difficulty with spoken English). Of those asked for re-consent during biennial visits, 319 out of 353 agreed (90%).

Our original intent was to survey samples of both those who consented and those who declined, in order to identify key drivers of decision-making. However, only 13 (less than 10%) of those who declined re-consent agreed to participate in the telephone survey, and their data are not presented here. The survey convenience sample therefore comprised the first 400 cognitively intact ACT participants who had consented by mail to having their genetic information submitted to dbGaP. They were sent a letter in advance of being approached by telephone. The Group Health IRB approved all protocols for this study.

**Survey**

A telephone survey combining open-ended and forced-choice questions was developed in consultation with experts in ethics, law, social science, and research survey design. Questions included whether participants had been part of research studies other than ACT; whether they had discussed the decision to provide consent for deposition of their data into dbGaP with anyone else, and if so, who; and how easy or hard it was to make the decision.

An open-ended question asked: "What would you say is the main reason you decided to sign this most recent consent form for the eMERGE study?" Following this, participants were read "a list of things people might think about when they decide whether or not to give consent to release their information to a databank;" (Table 1) and asked to indicate "how important or unimportant each reason was to you in making your decision." This list of pros and cons was informed by results of a focus group study that included ACT Study participants (Trinidad et al., in press).

To assess participants’ thoughts on the process used to obtain consent, they were asked to rate how acceptable it would have been if: (1) "we had sent a letter that asked you to contact us only if you did not want to agree to place your information in the databank" (opt-out approach); (2) "we had just let you know by letter that we had already sent your information to the databank" (notification-only approach); (3) "we had added your research information to the national databank without telling you or asking for your permission" (no individual permission or notification approach). To assess whether participants felt consent was necessary, they were asked, "How important was it that we did ask you for your permission to add your health and genetic information to a databank?"

The survey was conducted by the Group Health Research Institute Survey Research Program using Sawtooth Citi3 and WinCATI computer-assisted telephone interviewing software. This technology optimizes data quality and efficiency. Survey Research Program interviewers are trained on general interviewing techniques, the use of the CATI system, and project-specific procedures, including item-by-item specifications for each item in the questionnaire. Responses to open-ended questions were entered verbatim. The survey took 13 minutes on average to complete (range 10–25 minutes). The average time between the return of consent and completion of the telephone survey was 42 days.

**Participant Check**

After survey data were collected and synthesized by the study team, we performed a participant check (Miles & Huberman, 1994) by telephone with a small sample of survey respondents. Participant checks allow researchers to assess the validity of the categories and interpretations of the data developed by study investigators. Participants were asked a series of open-ended questions that mirrored the forced-choice questions in the survey (e.g., "What were the main reasons you agreed to participate in the eMERGE research study?"). We randomly selected 15 participants who represented the spectrum of stated ease of decision to allow deposition of personal data into dbGaP (i.e., we included several who had found the decision somewhat difficult or who had found it neither easy nor
difficult, as well as some who had found it easy to decide. Interviews were conducted by an experienced research interviewer who followed an interview guide and all interviews were digitally recorded and transcribed by Group Health Research Institute Survey Research Program. Participants in this 15-minute in-depth interview were paid $25 for their time.

Analysis

One-way tables of frequency counts were used for descriptive analyses. Respondents and non-respondents were compared using Pearson’s chi square or Fisher’s exact tests for percents and F-tests for means. For open-ended items, the study team identified major categories and representative responses through qualitative thematic analysis (Miles & Huberman, 1994). The categories and themes identified in the participant check interviews were compared to those obtained in the survey to see if they converged. This triangulation of data identified consistent themes, which strengthened our confidence in the findings.

Results

Participation

Of the 400 ACT Study participants eligible to participate in the survey, 91% (n = 365) did so. Respondents had a mean age of 83 (range 67–100); 57% were female and most (85%) were white. Five participants actively refused to participate in the interview; others had difficulty with language, hearing, were disabled, or were not able to be contacted. There was no difference in gender (p = 0.50) or race (p = 0.23) between respondents and survey non-respondents. Respondents were younger (mean age = 83) than non-respondents (mean age = 87; p < 0.01). Forty percent of respondents (n = 146) had participated in medical research other than the ACT Study.

Reasoning around Re-consent

It was very easy for 68% of the respondents (n = 249) and somewhat easy for 21% (n = 77) to decide to allow their ACT Study information to be added to a national

<table>
<thead>
<tr>
<th>TABLE 1. Importance of Reasons and Concerns Contributing to Decision to Allow Consent of Previously Collected Research Data into dbGaP.</th>
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<tbody>
<tr>
<td>&quot;How important or unimportant each reason was to you in making your decision . . .&quot;</td>
</tr>
<tr>
<td>N (percent) endorsed</td>
</tr>
<tr>
<td>Research could improve patient care and prevent or treat illness</td>
</tr>
<tr>
<td>Research could help increase knowledge for our society</td>
</tr>
<tr>
<td>Research could help me or someone close to me in the future</td>
</tr>
<tr>
<td>Concern that your privacy could be invaded or that your identity might be revealed somehow</td>
</tr>
<tr>
<td>Concern about the kind of research this databank could be used for in the future</td>
</tr>
<tr>
<td>Concern that your information could be used by others for their own profit</td>
</tr>
<tr>
<td>Concern or confusion about the study itself/not sure what you would have to do for the study</td>
</tr>
<tr>
<td>&quot;GHC researchers are leading the study. Did that influence your decision?&quot;</td>
</tr>
<tr>
<td>Very important</td>
</tr>
<tr>
<td>Somewhat important</td>
</tr>
<tr>
<td>Not too important</td>
</tr>
<tr>
<td>Not at all important</td>
</tr>
<tr>
<td>Don't know/ refused</td>
</tr>
</tbody>
</table>
Opinions of Re-consent for dbGaP databank. The majority, 72% (n = 264), did not discuss the pros and cons of participation with anyone else. Of those who did, most spoke with a family member, usually their spouse; some spoke with their children.

In response to an open-ended question soliciting the main reason for agreeing to dbGaP deposition, the predominant response was a desire to help others, especially as one is aging. Other reasons included appreciation of medical/scientific research in general and the hopes that research will translate into health benefits, appreciation of and trust in Group Health, appreciation of the ACT Study and its researchers and staff, and because giving consent was easy to do and required no in-person visit.

Table 1 presents survey responses to the question, “How important or unimportant each reason was to you in making your decision?” The majority of survey participants endorsed the importance of contributing to research with the potential for improving patient care or contributing to knowledge in general. The role of Group Health researchers, and ACT Study researchers in particular, in leading the new research was cited as a strong and positive influence on the decision of many participants to re-consent. Despite their willingness to have data submitted to dbGaP, however, many participants also noted concerns about data privacy and future research uses, including potential use of their data by for-profit entities.

Opinion Regarding Options for Consent for Data Sharing

Acceptability of alternatives to consent (an opt-out approach, a notification-only approach, or no individual permission or notification approach) is presented in Table 2. It was very important or somewhat important to the majority (n = 329, 90%) of respondents that they were asked for their permission to add their health and genetic information to the databank. An opt-out approach would have been completely or somewhat unacceptable to 40% (n = 146) of respondents. A notification-only approach would have been completely or somewhat unacceptable to the majority of participants (n = 244, 67%). A similar proportion (n = 256, 70%) of respondents said it would have been completely or somewhat unacceptable if their research information had been sent to the databank without any communication from Group Health. Open-ended comments were few, but included a full range of responses, including: “I think it is important always to ask a subject for permission”; “I don’t think I would be too upset if you had and didn’t tell me, but I think it is nice that you let people know”; and “I think you are going through an awful lot of trouble for very little.”

Participant Checks

Of the 365 survey respondents, 83% (n = 304) agreed to be contacted for further follow-up. Participant checks were conducted with 15 randomly chosen survey participants who represented the spectrum of stated ease of decision to allow deposition of personal data into dbGaP. These interviews confirmed that among the most important drivers of the decision to consent were strong beliefs in the value of medical/scientific research and their trust and appreciation for Group Health, the University of Washington, and the ACT Study. Also in common with survey responses, the trust in Group Health and ACT investigators outweighed concerns regarding privacy, data security, or fear of discrimination.

<table>
<thead>
<tr>
<th>TABLE 2. Acceptability of Options for Obtaining Consent for Deposition of Previously Collected Research Data into dbGaP.</th>
</tr>
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<tbody>
<tr>
<td>“How acceptable would it have been if we had . . . N (%)</td>
</tr>
<tr>
<td>. . . sent a letter that asked you to contact us only if you did not want to agree to place your information in the databank?”</td>
</tr>
<tr>
<td>. . . just let you know by letter that we had already sent your information to the databank?”</td>
</tr>
<tr>
<td>. . . added your research information to the national databank without telling you or asking for your permission?”</td>
</tr>
<tr>
<td>“How important was it that we did ask you for your permission to add your health and genetic information to a databank?” Very important</td>
</tr>
</tbody>
</table>
The participant checks confirmed conclusions drawn from the survey responses. No major new themes or concerns were identified.

Discussion

A local IRB ruling requiring informed consent for deposition of previously collected research data into dbGaP allowed this real-time exploration of research participants’ concerns and preferences regarding re-consent for such data sharing. The great majority (86%) of participants in this longitudinal study of aging and dementia provided consent to share their de-identified study data with the national data repository. Of course, that means 14%, nearly one in seven, did not consent. Notwithstanding the very high rate of re-consent, 90% of survey respondents, all of whom had consented to sharing with dbGaP, reported that it was important that researchers had asked for their consent. Alternatives to consent were viewed as unacceptable by many survey respondents. This finding is noteworthy because it demonstrates the high value research participants place simultaneously on the benefits of health research and personal autonomy. It also complicates the supposition that high rates of participant re-consent are equivalent to condoning open-ended use of previously collected research data without future need for individual consent.

Participants in this study described “reasons against” as well as “reasons for” consenting to dbGaP-mediated data sharing, although—as demonstrated by the high rate of re-consent in this population—the balance tipped in favor of “reasons for.” Some participants acknowledged concerns such as privacy, confidentiality, and potential commercialization of research findings, but these concerns were outweighed by respondents’ belief in the benefits of genomic research and trust in the ACT Study researchers and their respective institutions.

Best Practices

The judgments and attitudes of local IRBs differ with respect to the nature and/or necessity of re-consent for wide data sharing and the deposition of previously collected research data into dbGaP. In the eMERGE Network, only one of five involved IRBs ruled that active re-consent was needed. Besides considering potential risks to participants, the Group Health IRB’s decision requiring consent was influenced by the fact that ACT was an ongoing study, meaning that investigators had current contact information for participants, and participants were used to hearing from investigators. For other kinds of studies, for example, those for which recruitment was conducted a long time ago, re-consent may be less feasible. In addition to being consistent with participant wishes (and possibly expectations), re-consent is likely also to improve the research outcomes in longitudinal cohort studies, where demonstrating respect for participants’ views may help promote ongoing participation and thus more valuable, higher quality research. For new prospective studies, researchers should gather explicit permission from participants for submission of their data into dbGaP or other repository, and include an option for participants to agree to a new study but refuse deposition of their data into dbGaP.

Research Agenda

While the unique characteristics of this cohort (e.g., older age, history of research participation and enrollment in a longitudinal study, longstanding health plan membership, strong trust in the research enterprise and specific institutions) may limit generalizability of the findings to other research cohorts, these same characteristics also make these respondents an informative “extreme case” (Gerring, 2007) for policy deliberation. ACT Study participants are elderly, have strong altruistic motives and extraordinary trust in the research team, and expressed relatively few concerns regarding privacy or other harms, yet they still wanted to be asked for permission to share their data. If a population with very high trust in both the researchers and the research institution prefers an individual re-consenting process, populations that do not have this kind of relationship with researchers may be even more likely to prefer active consent for deposition of their data in a federal repository. Further investigation of the opinions of other participant cohorts, including those for whom investigators have pursued related approaches such as notification or opt-out, will better inform biorepository research policy and practice.

Some of the limitations of the present study suggest further avenues for research. We did not assess ACT Study participants’ understanding of what it means to consent to data sharing. Continued research aimed at finding the optimal way of communicating key information about data sharing, especially for less scientifically literate populations, will be important. We also did not assess how—or even if—the fact that dbGaP is maintained by the federal government may have influenced participants’ decision-making. Future research should also explore more deeply why opt-out or notification-only consent options are not acceptable to a large proportion of study participants. Because respondents in the current study may have been biased due to the ordering of the questions, future studies should take care to randomly order
questions, especially those focused on pros and cons related to decision-making. Since the people who are included in the convenience sample may have differed from those who provided re-consent later in the process by having reservations, it is conceivable that a smaller percent of the people would have had an easy time making the decision, a smaller percent might have reported the role of GH researchers as a positive influence, and a higher percent might have had more concerns. Finally, future research should explore best practices for studies where consent was obtained long ago and make re-consent less practicable.

Educational Implications

The overall 86% consent rate of ACT Study participants contacted as part of the eMERGE project should be encouraging to researchers who fear that many participants will refuse to allow their data to be shared via dbGaP. At the same time, the 14% rate of non-consent is too great to be dismissed as insignificant or trivial. Nevertheless, our results suggest that re-consent may be advisable in certain cases to anticipate and honor participant preferences. The cost of seeking re-consent from ACT Study participants averaged approximately $US50 per participant. Researchers should to be prepared for re-consenting study participants when feasible, and NIH should be prepared to provide researchers the time and money that this step requires.

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Susan Brown Trinidad is a Research Scientist in the Department of Bioethics and Humanities at the University of Washington School of Medicine; a co-investigator in the Center for Genomics and Healthcare Equality, a NHGRI-funded Center of Excellence in ELSI research; and a member of the University of Washington IRB. She has worked on a number of ELSI projects, with a particular focus on the views of research participants, the public, and IRB members and staff. She contributed to the design and analysis of this study and assisted in drafting the manuscript.

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Eric B. Larson is Executive Director of the Group Health Research Institute and the Principal Investigator for both of the grants that supported the research and research subjects involved in the paper—the long-standing Group Health, University of Washington Alzheimer’s disease patient registry, Adult Changes in Thought (ACT) Study, and the eMERGE project. He was involved in efforts to secure funding and to work with subjects, families, and the Group Health leadership to facilitate conduct of the re-consent study. He assisted in the interpretation of results and in the review and revision of manuscript drafts.

Wylie Burke is Professor and Chair of the Department of Bioethics and Humanities at the University of Washington. Her work addresses the ethical and policy implications of genomic information in research and practice, and has commonly used qualitative methods to explore attitudes toward genomics. The present study occurred within the context of a large multi-site collaboration to advance understanding of the genetic contributors to common diseases. She contributed to this study’s design, data analysis, and manuscript preparation.

References


Research Practice and Participant Preferences: The Growing Gulf

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The irony is, if you had asked me, I probably would have consented (1). So said Andrea Beleno, a plaintiff suing the Texas Department of State Health Services over its role in the use of newborn screening blood samples in research. Carletta Tilousi, a plaintiff in the Havasupai tribe’s lawsuit against the Arizona Board of Regents, expressed similar sentiments: “I’m not against scientific research. I just want it to be done right. They used our blood for all these studies, people got degrees and grants, and they never asked our permission” (2).

A spate of recent events—e.g., other conflicts over newborn blood samples (3–5), the return of biospecimens to the Yanomamö people (6), and the best-selling account of the origins of the HeLa human cell line widely used in research (7)—has raised questions about trustworthiness of the research process at a time when new approaches to genomic research place a premium on study participation. Although many related issues deserve attention—e.g., ethical use of “leftover” clinical samples, public attitudes about data sharing, and appropriate consent for general-purpose repositories—we focus on repurposing of existing research data and samples.

Harms to Dignity

Many potential harms that might arise from participation in genomic research and how likely they are to occur are not well known. This should not imply, however, that harms to dignity have not occurred. Claims of harm include breaches of autonomy and privacy, stigmatization or other negative social consequences, and uninvited challenges against deeply held beliefs [e.g., (8–11)]. Financial settlements, restrictions on research, and destruction of samples have been used to make amends, but they cannot undo injury to individuals and their communities. Such “solutions” may delay scientific advances that could improve human health.

These issues are especially fraught for genomic research, where new, high-throughput approaches require massive data inputs. To achieve needed sample sizes and increase efficiency, genome scientists have begun to pool biospecimens and data from prior studies. However, neither the Common Rule (12), a U.S. federal policy regarding human subjects protection, nor the U.S. Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule (13), which protects the privacy of individually identifiable health information, applies to such materials. And under conditions defined by the U.S. Office for Human Research Protections (14), studies using only coded samples and data (15) are not classified as human subjects research. Current U.S. federal policies promote “secondary use” of federally funded data, mandating sharing within the research community and strongly encouraging deposition of data in public repositories such as the NIH database of Genotypes and Phenotypes (dbGaP) (16, 17).

Many disease-specific and general-purpose repositories have attracted large numbers of participants, obtaining informed “blanket” consent at the outset for a broad range of potential purposes, and some studies document participant support for reuse of research samples for new purposes (18–21). For example, over 90% of respondents in a national U.S. survey would be willing to have their samples and health data placed in a biobank for research. However, views on consent were mixed: 48% preferred one-time, “blanket” consent, whereas 42% wanted the opportunity to rescind for each use of their data (22). In one study, 15% of participants did not understand that signing the consent form would allow their excess clinical samples to be used in research (18). Studies also suggest that individuals may be less willing to share data for “government-funded” or pharmaceutical company research (23, 24). Disagreement about optimal policy continues: Some argue that stronger regulatory oversight is needed (25); others contend that opt-out models, in which consent is presumed unless explicitly denied, in conjunction with robust de-identification, provide sufficient protection (26).

Participants Value Being Asked

Recent studies at Group Health, a nonprofit health-care system based in Seattle, provide new data about participant views. As one of five sites participating in the electronic Medical Records and Genomics (eMERGE) Network, Group Health planned to use data from an existing cohort, the Adult Changes in Thought (ACT) Study (27), to investigate the accuracy of phenotypes derived from electronic medical records. ACT participants—unlike those enrolled in general-pur-
their permission for data sharing. Opt-out consent would have been unacceptable to 40% of respondents, and 67% said that notification of dbGaP submission after the fact would have been unacceptable. Seventy percent said it would have been unacceptable if their data were shared with neither notification nor permission.

Investing in Trust Relationships

For ACT participants, the reconsent process documented researchers’ respect. Being given a choice about uses of their data that were not contemplated at the time of original consent was important, not because they found particular kinds of studies objectionable, but because the request represented a tangible demonstration of the researchers’ trustworthiness and regard. It should be noted that, demographically, ACT participants represent the type of people most willing to take part in research: older, mostly white, and relatively well educated. If the majority of this population favors reconsent for wide data sharing, others may be more likely to want an opportunity to weigh in.

A broad consent form (e.g., for samples to be used in “future studies of diseases associated with aging”) may provide legal cover to the researcher who wishes to parlay single-study collections into a future biosample bank; but such protections may not promote trust between researchers and participants. Researchers and IRBs should consider how the consent process could foster respectful engagement, rather than merely mitigate risk.

For studies in which reconsent is feasible—e.g., when participant contact is ongoing or fairly recent, and most participants are still living—efforts to reengage can be a worthwhile investment. Yet careful thought must be given to reconsent when it is merited and how to avoid inadvertently harassing participants. Considerations include the practicability of the reconsent process and the degree to which new uses of data represent a substantive departure from the original study in terms of both scope and risk.

Recommendations

Current practices presuming that study participants do not wish to hear from researchers, or that participants find general, one-time consent acceptable, may be contrary to participant preferences. Establishment of repositories using de-identified, clinically collected samples—often authorized through a generic statement in the consent-to-treat form—may threaten trust in the research enterprise, potentially derailing research efforts if they receive public attention.

We propose a shift from paternalistic protections to respectful engagement with individuals and groups whose conceptions of risk, benefit, and harm deserve consideration. Such an approach would treat participants as true stakeholders in research, who willingly take on risk because they see potential benefits to society as outweighing potential harms. Researchers and IRBs need to invite perspectives of participants and communities, and funders need to make resources available to establish and maintain relationships and stewardship-based governance approaches (29, 30).

Researchers, IRBs, and funders must reconsider approaches to consent and notification for data-sharing resources. Chief among needed innovations are (i) methods to ensure that participants are informed about the use of their data in research, including potential inclusion in data repositories, and to grant the opportunity to decline participation in wide sharing; (ii) mechanisms to provide access to current information about how samples are being used, on either an individual or study-wide basis; (iii) transparent, accountable oversight processes that include community representation; and (iv) opportunities for participants to provide input concerning stewardship of their data, e.g., dialogue between researchers and participants (31), ongoing community consultation (32), or deliberative processes (33).

In some cases (e.g., if the majority of participants have died, or the original study was many years ago and participants cannot be located) such measures may prove infeasible, and a different obligation arises. At a minimum, researchers should provide clear descriptions and justifications of research procedures, in public venues readily available to individuals who may have been study participants or their families (e.g., in health system newsletters and local media). Public comment should be invited. To the extent that researchers, funders, and IRBs can engage the public in discussions about responsible, realistic study procedures, they create the opportunity for shared understanding and mutual support. They should seek new methods to foster public education and encourage dialogue about the value of data-sharing and options available to stay informed about research.

As one commentator recently wrote, “[w]e are only one scandal away from legislation that will regulate or even prohibit the use of de-identified data for research purposes.” (34) The positive message is that many participants view themselves as having an ongoing stake in research to which they have donated samples and data. They want to be asked (or at least kept informed) about changes in research. Reframing research practice to align with this interest is an important step toward ensuring long-term success of genomic investigation.

References and Notes

3. Order Granting Motion to Dismiss, Beader v. Minnesota, No. 27-CV-09-5615 (D. Minn. 2009).
15. A coded sample is considered indirectly identifiable, so long as the key that links samples with identifiers is maintained. Under HIPAA, data deemed by a qualified expert as unlikely to be re-identified are considered de-identified, as are those that do not contain any of 18 designated identifiers.
17. NIH, Policy for sharing of data obtained in NIH supported or conducted genome-wide association studies (GWAS) (NOT-OD-07-088, HHS, Washington, DC, 2007).
35. This work was supported by the eMERGE Network (National Human Genome Research Institute and National Institute of General Medical Sciences, NIH, grant no. U01 HG-004610) and the Washington State Life Sciences Discovery Fund (grant no. 265508).

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Perceived benefits of sharing health data between people with epilepsy on an online platform

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A B S T R A C T
An epilepsy community was developed on PatientsLikeMe.com to share data between patients to improve their outcomes by finding other patients like them. In a 14-day response period, 221 patients with epilepsy (mean age: 40 years, SD: 12, range: 17–72, 66% female) completed a survey about benefits they perceived. Prior to using the site, a third of respondents (30%) did not know anyone else with epilepsy with whom they could talk; of these, 63% now had at least one other patient with whom they could connect. Perceived benefits included: finding another patient experiencing the same symptoms (59%), gaining a better understanding of seizures (58%), and learning more about symptoms or treatments (55%). Number of benefits was associated with number of relationships with other patients, $F(4,216)=8.173, P<0.001$. Patients with epilepsy reported an array of perceived benefits similar to those reported by populations with other diseases. Controlled sharing of health data may have the potential to improve disease self-management of people with epilepsy.

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1. Introduction

Patients diagnosed with epilepsy face a number of challenges. Their disease is complex, and even those treated at specialty clinics are not well informed about their condition [1]. Stigma is common and can have severe consequences [2] caused by patients’ perceived “otherness” [3]. Interventions tend to focus on educating the general population to alter their attitudes and beliefs [4]. Another approach is empowering people with chronic illness by harnessing the Internet to create a community of similar people to share experiences and support one another.

The Internet has a number of useful features for social support [5] and enables “ridiculously easy group formation” [6]. Although the use of online communities in epilepsy is not new [7], recent developments include increasing uptake of high-speed Internet access, the ready availability of “Web 2.0” applications [8], mobile access, and the e-patient movement (e.g., www.e-patients.net [9]). In 2008 it was estimated that around 60% of patients with epilepsy in the United States had access to the Internet [10].

Epilepsy-specific sites such as PatientsLikeMe.com, Epilepsy.com, and SeizureTracker.com may provide patients with a number of benefits that have been recognized as important in permitting patients to live well with their epilepsy [11]. First, they may improve knowledge of their disease via high-quality content. Second, the social support can improve patients’ self-management through a number of mechanisms such as improved self-efficacy, positive social norms, and reduction of stigma [12]. Third, helping patients track their disease through online seizure diaries avoids backfilling [13] and creates the potential to record additional, valid details to share with health care professionals. Mobile applications even allow a third party (e.g., a parent) to video-record the seizure for later review.

In studies, individual online educational interventions such as WebEase have produced benefits in epilepsy self-management, medication adherence, sleep quality, self-efficacy, and social support [14], and this system will be made widely available later in 2011 [15]. Bergin et al. [16] proposed that an open, multicenter online system with data entered by clinicians (recently realized as EpiNet [17]) would help clinical management, comparative effectiveness research, and trial recruitment.

Outside epilepsy, online communities have been found to improve the quality of patient–physician interactions [18] and improve patients’ emotional well-being, perceived disease control, empowerment, medical literacy [19], and ability to cope [20]. Patients with stigmatizing...
illnesses are particularly likely to have higher Internet use for social support, finding health information and communicating with a physician online [21,22]. Although such benefits may not accrue to those who still do not have Internet access, through a “collateral health” effect, even patients who have not directly participated in an online service may still benefit [23].

PatientsLikeMe.com is a patient-centered online platform [24]. Briefly, the site allows patients with life-changing illnesses to share their medical data with other patients “like them” by longitudinally charting patient-reported outcomes, symptoms, side effects, medical history, and treatments. Because data are collected in a structured format (e.g., symptoms are coded in MedDRA, treatments are supported by the Multum database, with patient-entered data curated by health care professionals), they can be aggregated to form interactive reports that reflect real-life trends [25], and patient reported outcomes may even serve to identify treatment effects [26].

Launched in January 2010, new platform features specific to epilepsy were developed with funding provided by UCB. We developed a “seizure meter” (Figs. 1 and 2) that allows patients to record the type, frequency, and severity of their seizures on a weekly basis. In addition, there are a number of epilepsy-specific questions asked of users who complete their condition history, including driving status, family history, pregnancy, and diagnostic tests. Epilepsy-specific treatments such as antiepileptic drugs, surgical options, and dietary interventions were pre-programmed into the system, and adverse events detected from patients taking the sponsor’s (UCB’s) medications are submitted to the manufacturer’s drug safety department for safety reporting.

Finally, we developed an epilepsy-specific research platform to conduct a longitudinal research project with widely used patient-reported outcome (PRO) measures consisting of the Quality of Life Inventory in Epilepsy (QOLIE-31/P) [27], Hospital Anxiety and Depression Scale (HADS) [28], and EQ-5D [29]. These data are in the process of being collected longitudinally, with interim analyses presented as the study progresses [30]. Participants in the PRO project are shown where they stand in relation to other members of the community using physical, mental, and social summary scores derived from the QOLIE-31/P (Fig. 3), with the intention of improving their awareness of factors influencing their QOL, such as depressive symptoms, social support, and stigma [31]. All of these data are shared openly with all other members of the community, allowing users to search for one another on any of the medical variables captured (e.g., epilepsy type, seizure type, treatments).

A previous study identified a number of perceived benefits (e.g., better communication with health care professionals, learning about symptoms, improved understanding of treatments and side effects) arising from use of PatientsLikeMe among patients with amyotrophic lateral sclerosis (ALS), multiple sclerosis (MS), Parkinson’s disease, human immunodeficiency virus (HIV), fibromyalgia, and mood disorders [24]. The purpose of this study was to gather feedback on perceived benefits from use of our online service by people with epilepsy.

In addition to the generic perceived benefits identified in other conditions we also anticipated epilepsy-specific benefits. On the basis of the stigma involved in epilepsy we hypothesized that, prior to using the site, many patients with epilepsy would be relatively isolated and have few social face-to-face relationships with other patients with epilepsy, but that an online community had the potential to improve this situation. Further, we hypothesized that those who participated most with other “patients like them” in the site and formed strong ties with others would perceive greater benefits than those who did not.

2. Methods

An online survey was used to field a set of epilepsy-specific questions relating to site usage, as well as generic questions replicating

<table>
<thead>
<tr>
<th>During the week of November 7–13, 2010</th>
<th>change week ▲</th>
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</table>

Simple partial

How many Simple partial seizures did you have during the week of November 7–13, 2010?

If you don’t remember the exact number of seizures, just enter your best guess.

Complex Partial

How many Complex Partial seizures did you have during the week of November 7–13, 2010?

If you don’t remember the exact number of seizures, just enter your best guess.

Secondarily Generalized Tonic-Clonic

How many Secondarily Generalized Tonic-Clonic seizures did you have during the week of November 7–13, 2010?

If you don’t remember the exact number of seizures, just enter your best guess.

Had a seizure you’ve never had before? Want to start monitoring a seizure type you’ve had in the past? ▲ Add seizure types

Fig. 1. Data entry in the Seizure Meter allows patients to report the frequency and severity of all seizures experienced in the previous week.
earlier work [24]. Questions related to diagnostic confidence and confidence in sharing health data and how that might have changed through use of the site; quality of care (reported separately [32]); treatment history; medication adherence; decision support around treatments or symptoms; social support; epilepsy self-management; and demographics. Our questionnaire is presented in supplementary material (see Appendix). At the time of data collection the community was accessible only to members in the United States; since April 2011 it is now open internationally. On September 15, 2010, invitations were sent to 2362 patients with epilepsy who had been members for at least 30 days, regardless of their level of log-in activity. The invitation was sent as a private message within the PatientsLikeMe community. Sampled patients had their own password-protected log-in. They could complete the survey only once; we have tools to prevent multiple accounts originating from the same location. The survey was not mandatory to complete to continue using the site. No incentives were offered; the total number of questions varied slightly by participants’ own responses to filter questions. A reminder message was sent within a week to those who had not yet completed the survey. The survey remained open for a period of 14 days. Only data from completed questionnaires are presented here. As specified in the terms of use, members of PatientsLikeMe join the site with the expectation that they will be participating in research. As a service evaluation project with no anticipated adverse consequences for participation, institutional review board approval was not sought for this project. The recruitment message was sent from P.W., who can easily be contacted by potential participants, and can be viewed in supplementary material (see Appendix).

![Seizure Meter](image1.jpg)

**Fig. 2.** A Seizure Meter for a patient with epilepsy. Larger circles represent a higher frequency of seizures; darker colors represent a higher perceived severity of seizures.

![QOLIE-31/P summary scores](image2.jpg)

**Fig. 3.** QOLIE-31/P summary scores of a patient with epilepsy in context with other members of the epilepsy community.
We generated a “benefit score,” which was constructed from 20 of the 25 potential perceived benefits listed in Tables 1 and 2 (range: 0–20). We excluded perceived benefits “indicated by footnote a) likely to be tautological (i.e., positively scoring “Locating another person who helped you understand what it is like to take a specific medication for your condition” would bias toward an association with site participation) or those that might not be universally regarded as a benefit (e.g., changing physician). A single point was given if patients endorsed any of the following categories: “Very helpful,” “Moderately helpful,” “Strongly agree,” and “Agree.” No points were assigned for other responses including “Does not apply.”

Data analysis was performed by P.W. using Statistics Package for the Social Sciences (SPSS Version 18.0). Association between categorical variables was assessed using the $\chi^2$ test; normally distributed demographic data were compared using Student’s $t$ test (two groups) or between-group ANOVA (three or more groups). Where overall between-group differences on ANOVA were significant, post hoc $t$ tests with Bonferroni correction were applied to test for paired comparisons. Nonparametric between-group differences were tested using the Kruskal–Wallis test. Correlations were performed using Pearson’s $r$. Tests performed were two-tailed with $\alpha$ set at $P<0.05$.

3. Results

Invitations to participate were sent to 2362 patients with epilepsy. According to Web logs, at the time of analysis 348 members (15% of those invited) logged in and opened the private message invitation. Of these, 282 patients (81% of users logging in during this period, 12% of total) started the survey, and of these, 221 (64% of users logging in) opted out of the survey. To test for response bias we compared the demographic characteristics of responders against those of nonresponders. Responders were a little older than nonresponders (mean age: 40 years (SD: 12) for responders vs 36 years (SD 12) for nonresponders, $U = 58648.5, P<0.001$). Most nonresponders (66%) had not logged into the site since the survey invitation was sent. Responders were no different from nonresponders with respect to sex or epilepsy type ($P>0.05$).

Mean participant age was 40 years (SD: 12); two-thirds were female, 84% Caucasian. The largest proportions of respondents (44%) had at least some college education and were married (40%); most were not working for pay (53%). About half of the respondents had a partial epilepsy syndrome, with one-third reporting a generalized syndrome and 16% unknown. The most frequently reported syndrome was temporal lobe epilepsy (32%), followed by unspecified syndrome (15%), grand mal seizures on awakening (10%), other partial syndromes (8%), and juvenile myoclonic epilepsy (6%). About half the respondents had been seizure free in the preceding 7 days, but about one in five had had more than five seizures in the same period. Mean disease duration was 23 years (SD: 15) since first seizure and 19 years (SD: 14) since diagnosis. The largest proportion of respondents were on polytherapy ($\geq 2$ AEDs, 60%); commonly used AEDs included levetiracetam (both immediate release and extended release, $n = 86, 39$), lamotrigine ($n = 60, 27$), topiramate ($n = 37, 17$), and carbamazepine ($n = 36, 16$). Most respondents reported that they were treated regularly by a neurologist (70%), and only 20% by an epileptologist.

Table 1 lists items that were asked both of people with epilepsy who used the website and, separately as part of a previous study, of other PatientsLikeMe communities including those with MS ($N = 347$), Parkinson’s disease ($N = 287$), ALS ($N = 218$), fibromyalgia ($N = 150$), HIV ($N = 177$), and mood disorders ($N = 144$) [24]. The most highly endorsed benefits were for features of the site that support self-management, such as learning about symptoms (51% “very” or “moderately” helpful), understanding possible side effects of medication (47%), and recording symptoms (45%). Comparison of the two studies yielded similar results. For instance, 25% of patients with epilepsy rated the site as “very” or “moderately” helpful in decisions to change medication, relative to 27% of patients from the other communities. Where significant differences were found, these seemed to be accounted for by the fact that patients with epilepsy were more likely not to have tried a particular site feature

<table>
<thead>
<tr>
<th>How helpful has PLM been in...?</th>
<th>$\chi^2(4)$</th>
<th>$P$</th>
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<tbody>
<tr>
<td>Decisions to change the medication used to treat your condition</td>
<td>Epilepsy 12%</td>
<td>13%</td>
</tr>
<tr>
<td>All</td>
<td>13%</td>
<td>15%</td>
</tr>
<tr>
<td>Decisions about whether to change the dose of a medication for your condition</td>
<td>Epilepsy 11%</td>
<td>10%</td>
</tr>
<tr>
<td>All</td>
<td>11%</td>
<td>15%</td>
</tr>
<tr>
<td>Decisions about whether to start using a medication for your condition</td>
<td>Epilepsy 17%</td>
<td>10%</td>
</tr>
<tr>
<td>All</td>
<td>20%</td>
<td>17%</td>
</tr>
<tr>
<td>Understanding possible side effects of a medication for your condition</td>
<td>Epilepsy 27%</td>
<td>20%</td>
</tr>
<tr>
<td>All</td>
<td>36%</td>
<td>22%</td>
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<tr>
<th>How helpful has PLM been in...?</th>
<th>$\chi^2(4)$</th>
<th>$P$</th>
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</thead>
<tbody>
<tr>
<td>Locating another person who helped you understand what it is like to take a specific medication for your condition</td>
<td>Epilepsy 22%</td>
<td>18%</td>
</tr>
<tr>
<td>All</td>
<td>29%</td>
<td>13%</td>
</tr>
<tr>
<td>Decisions to stop using a medication for your condition</td>
<td>Epilepsy 14%</td>
<td>5%</td>
</tr>
<tr>
<td>All</td>
<td>10%</td>
<td>12%</td>
</tr>
<tr>
<td>How helpful has recording your symptoms been to help you manage your condition</td>
<td>Epilepsy 28%</td>
<td>17%</td>
</tr>
<tr>
<td>All</td>
<td>36%</td>
<td>23%</td>
</tr>
<tr>
<td>How helpful have symptom ratings on your profile been in understanding how your treatments are working?</td>
<td>Epilepsy 26%</td>
<td>17%</td>
</tr>
<tr>
<td>All</td>
<td>30%</td>
<td>25%</td>
</tr>
<tr>
<td>How helpful has PLM been in learning about a symptom or symptoms you experienced?</td>
<td>Epilepsy 34%</td>
<td>21%</td>
</tr>
<tr>
<td>All</td>
<td>48%</td>
<td>24%</td>
</tr>
</tbody>
</table>

* Excluded from the benefit count. N/A = Does not apply/Never tried to use for this.
Table 2
Reported benefits of the site for epilepsy management issues (N = 221).

<table>
<thead>
<tr>
<th>How helpful has PatientsLikeMe (PLM) been in the following?</th>
<th>Very helpful</th>
<th>Moderately helpful</th>
<th>A little helpful</th>
<th>Not at all helpful</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>How helpful has recording your seizures been to help you manage your condition?</td>
<td>28%</td>
<td>17%</td>
<td>20%</td>
<td>8%</td>
<td>26%</td>
</tr>
<tr>
<td>How helpful has PLM been in learning about seizures you experienced?</td>
<td>34%</td>
<td>21%</td>
<td>18%</td>
<td>7%</td>
<td>20%</td>
</tr>
<tr>
<td>To what extent do you agree with each of the following?</td>
<td>Strongly agree</td>
<td>Agree</td>
<td>Disagree</td>
<td>Strongly disagree</td>
<td>N/A</td>
</tr>
<tr>
<td>PLM has helped me take medications more regularly.</td>
<td>10%</td>
<td>17%</td>
<td>11%</td>
<td>1%</td>
<td>60%</td>
</tr>
<tr>
<td>PLM has helped me find ways to reduce treatment side effects.</td>
<td>8%</td>
<td>19%</td>
<td>15%</td>
<td>3%</td>
<td>56%</td>
</tr>
<tr>
<td>PLM has helped me find another person who has the same symptoms.</td>
<td>24%</td>
<td>35%</td>
<td>8%</td>
<td>2%</td>
<td>31%</td>
</tr>
<tr>
<td>I have received better care from my health care professional by recording symptoms on PLM.</td>
<td>15%</td>
<td>35%</td>
<td>10%</td>
<td>4%</td>
<td>36%</td>
</tr>
<tr>
<td>As a result of using the site, my quality of life is better.</td>
<td>10%</td>
<td>35%</td>
<td>12%</td>
<td>6%</td>
<td>37%</td>
</tr>
<tr>
<td>As a result of PLM, I have changed my physician.</td>
<td>5%</td>
<td>5%</td>
<td>16%</td>
<td>19%</td>
<td>54%</td>
</tr>
<tr>
<td>My health care team is supportive of my use of PLM.</td>
<td>10%</td>
<td>15%</td>
<td>5%</td>
<td>5%</td>
<td>66%</td>
</tr>
<tr>
<td>Because of PatientsLikeMe ...</td>
<td>Strongly agree</td>
<td>Agree</td>
<td>Disagree</td>
<td>Strongly disagree</td>
<td>N/A</td>
</tr>
<tr>
<td>I have a better understanding of the type of seizures that I have.</td>
<td>22%</td>
<td>36%</td>
<td>9%</td>
<td>4%</td>
<td>29%</td>
</tr>
<tr>
<td>I have insisted on seeing a specialist to treat my seizures.</td>
<td>8%</td>
<td>9%</td>
<td>19%</td>
<td>5%</td>
<td>60%</td>
</tr>
<tr>
<td>I have had fewer visits to the ER caused by my seizures.</td>
<td>9%</td>
<td>9%</td>
<td>15%</td>
<td>7%</td>
<td>60%</td>
</tr>
<tr>
<td>I know how to get the AED that my doctor prescribed for me.</td>
<td>10%</td>
<td>18%</td>
<td>13%</td>
<td>5%</td>
<td>55%</td>
</tr>
<tr>
<td>I have gained greater control over my seizures.</td>
<td>8%</td>
<td>21%</td>
<td>16%</td>
<td>9%</td>
<td>46%</td>
</tr>
<tr>
<td>I have had access to information that helped identify the best AED for me.</td>
<td>12%</td>
<td>27%</td>
<td>13%</td>
<td>5%</td>
<td>42%</td>
</tr>
</tbody>
</table>

Table 3
Reported benefit score by number of friends with epilepsy on PatientsLikeMe.

<table>
<thead>
<tr>
<th>Number of friends on PatientsLikeMe</th>
<th>Statistical test</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>1 or 2</td>
</tr>
<tr>
<td>N</td>
<td>70</td>
</tr>
<tr>
<td>%</td>
<td>32%</td>
</tr>
<tr>
<td>Mean benefit score</td>
<td>ANOVA: F(4,216) = 8.173, P &lt; 0.001</td>
</tr>
<tr>
<td>(SD)</td>
<td>(5.7)</td>
</tr>
<tr>
<td>Median benefit score</td>
<td>Kruskal–Wallis: χ²(4) = 30.159, P &lt; 0.001</td>
</tr>
<tr>
<td>(IQR)</td>
<td>(7)</td>
</tr>
</tbody>
</table>
Patients with epilepsy reported an array of perceived benefits from using PatientsLikeMe. Users gained a better understanding of their seizures (58%), learned more about a symptom or treatment (55%), felt greater control over their condition (50%), had reduced side effects (27%), improved adherence (27%), and had insisted on seeing a specialist (17%) or, in some cases, even changed their physician (10%). Perhaps as a result of these perceived benefits, 45% of users agreed that using the site had improved their quality of life. Relative to other disease populations on PatientsLikeMe [24], the epilepsy community had not yet used all of the features available to them, though this might be expected to change over time.

The most prominent benefits to be reported by users with epilepsy included features that were intentionally designed into the site, such as disease tracking (seizures and symptoms) and practical advice on disease management (minimizing side effects). Although there are no custom features on PatientsLikeMe to encourage medication adherence or changes in health care provider, the social community allowed users to identify problems and share solutions, presumably via social tools and viewing each other’s profiles. It is feasible that adding additional functionality to support these goals could increase the proportion of patients experiencing benefits.

The Internet provides opportunity for patients to find and connect with other patients like them. About a third of our respondents (30%) did not know anyone with epilepsy with whom they could talk about their condition; of these, 63% found at least one person with epilepsy with whom they could connect on PatientsLikeMe. The number of benefits perceived was associated with the number of relationships that patients had with other patients in the system. Options for communication on the site include open discussion in the forum, private message exchange, or leaving comments on each other’s profiles [33]. Many of the benefits identified relied on learning from the experience of others; presumably the more opportunities to learn from others, the easier this would be to achieve. Future research could identify tools to better connect patients within a peer group of optimal size and composition.

The concept of online tools for tracking epilepsy is not new, as evidenced by systems including Epilepsy.com, SeizureTracker.com, EpiTrax, and a number of academic research projects. However, although these systems allow patients with epilepsy to share their information with their doctors, they do not permit sharing with other patients, nor aggregation of structured data. For example, in a traditional message board it might be possible for users to start a thread about medication dosage or to write their medication regime as a “signature” at the end of each message. On PatientsLikeMe, treatment data on antiepileptic drugs are collected in a structured format and dosages are displayed as a histogram; for instance, the treatment report on levetiracetam shows dosages entered by 750 patients with epilepsy (http://www.patientslikeme.com/treatments/show/3700-levetiracetam). These structured, aggregated data reflect a larger sample collected in a more systematic way than patients using the Internet could access previously and might enhance their understanding of how typical their dosage might be.

Clearly, giving patients more access to data is not entirely without risk. Public interactions between patients are moderated by professional staff to ensure that users adhere to a code of conduct. For example, “Ideal PatientsLikeMe Members share personal experiences without trying to provide medical advice.” Fortunately the vast majority of users understand that changes to medication need to be discussed with their physician. To date, we have not identified any reports of medical harm arising from interactions between patients; this is an area that requires renewed attention in the literature [34]. However there is also the question of how prepared health care professionals may be for the change in information balance brought by the Internet [35,36], and we did identify a single case where a patient–provider relationship broke down, in part, because a patient increased his or her health literacy. The female patient wrote in the forum that her physician “complains … that I had (all of a) sudden showed up for (appointments) knowing the proper medical terms for things—that I was using terms like pre-ictal and the like…” [The physician] could no longer deal with me because, get this: “I’d got ten with a bunch of people on the Internet’ and that they were now ‘advising’ my treatment/care!”

We agree with Bergin that “not ... all epilepsy research should be conducted in the manner we have outlined here ... a double-blind randomized controlled trial is the optimal way of comparing two or more alternative treatments” [16]. However, there may be an opportunity to develop hybrid models where clinicians provide diagnostic validation and objective measures and patients use seizure-tracking tools, patient reported outcomes, adherence monitoring tools, and social networks in parallel. This has the potential to make more efficient use of physician time by highlighting issues in need of attention, improving patient adherence to medical advice, and giving patients psychosocial support. Some patients may be self-experimenting with diet, exercise, or even pharmaceutical treatments, and a standardized data collection tool has the potential to help identify any potential benefits at the individual or even group level [26].

Many of the limitations to this study are shared by all online studies, including but not limited to: participation rates, biases, accuracy of data collection, and variations in care systems. An important limitation is that we lack independent verification that site members are really patients with epilepsy. Future research directions could include collaborations with specialty clinics to recruit verified patients. The benefits identified are perceived benefits reported only by those patients who chose to participate in the survey, though the fact that these users represent 64% of all users who logged in during this period suggests these results are at least representative of regular site users. Future work should use objectively collected data such as hospital admissions and medication refills. The overall response rate (9%) was lower than in other communities [24], with response rates ranging from 14 to 29% (mean: 19%). This can be explained by a low number of log-ins for most of the invited sample. Of the invited patients who logged in to the site during the response window, 64% completed the survey. We also left the survey open for completion for a period of 14 days, which may have been too short for some patients to participate; however, typically we receive 80% of responses to...
surveys in the first 2 days after launch and have not found lengthening the recruitment window to substantially improve completion rates. An alternative approach to future work might be for a “service evaluation” survey to be triggered by a given number of site log-ins; this might ensure a more representative sample of respondents than a cross-sectional approach.

Previous research has shown that the PatientsLikeMe epilepsy population is more likely to be female, to have more patients in their twenties to forties, and to have more patients on polytherapy than patients with epilepsy in a health insurance claims database [37]. Our sample is broadly similar to that of the online study of patients with epilepsy of Escoffery et al., whose sample was 57% female and 88% Caucasian, but was a little younger (mean age 38 years) and more likely to have had at least some college education [10]. Escoffery et al. identified a number of demographic differences between online samples and their clinic samples; a larger proportion of whites were online, with a lower level of disability and higher levels of education [10]. A clear limitation to the Internet more broadly is the “information divide” that inevitably arises between those who are computer-literate and those who are not [38]. This may be particularly true of veteran populations, where only half of patients are reported to have access to the Internet [39]. It is likely that our users represent early adopters of health technology, but it is hoped that barriers to access will be reduced in the future. There may be additional unmeasured biases in the nature of patients who return to the website or completed our survey. Although PatientsLikeMe is a for-profit company and funded in part by industry, we attempt to be transparent with our members (a link on the front page of the website leads readers to a section on “How We Make Money”), and we use the platform to conduct research for industry, not as an advertising platform.

Patients with epilepsy evaluated a data-sharing website as having benefits in supporting their self-management; such technology may be more easily scaled than traditional real-world support groups and may be of value to providers and nonprofits in improving the outcomes of their patients. Future research should be conducted using traditional interventional methodologies, for example, a randomized trial of a “prescription” for patients to use PatientsLikeMe versus other types of websites such as static epilepsy information (e.g., WebMD) or a community that allows qualitative discussion but not data sharing (e.g., BrainTalk), with objectively captured outcome data.

5. Conclusion

An online community that is structured like PatientsLikeMe encourages patients to share and learn from data that are potentially more systematic than in previous efforts. Sharing of health data through the use of seizure-tracking tools, medication records, and other opportunities for patient self-report that are dynamically linked and referenced in online discussion may have the potential to improve disease management and health outcomes of people with epilepsy through improved disease knowledge and self-management. Further work is needed to yield important clinical benefits such as improved seizure control, reduced emergency room visits, and improved medication adherence through online tools for people with epilepsy.

6. Ethical approval

Please note that as detailed in the text, institutional review board approval was not sought for this project given that it was a questionnaire study involving routine questions about site use rather than an interventional study. All members of PatientsLikeMe agree to be contacted for research as a condition of joining the community, and are free to elect to opt in or opt out of individual invitations to complete survey research. In line with the Declaration of Helsinki it is made clear that there will be no adverse consequences for deciding not to participate, and participants are free to withdraw their consent at any time.

7. Conflict of interest statement

UCB funded the design and coding of the epilepsy community on PatientsLikeMe. UCB was involved in the design of the epilepsy community through clinician advice (J.I.), selection of patient-reported outcomes (D.K., C.D.), and beta-testing with epilepsy advocates (D.K., C.D., J.I.). PatientsLikeMe retained final decisions on community design, however. UCB assisted in the design of the current study (D.K., C.D., J.I.) including drafting questions, proposing analyses, and commenting on revisions of the article.

P.W., C.B., M.M., and J.H. are paid employees of PatientsLikeMe and own stock/stock options in the company. PatientsLikeMe has received research support from Abbott, Acorda, Avanir, Biogen, Novartis, Sanofi, and UCB.

D.K., C.D., and J.I. are paid employees of UCB and own stock/stock options in the company.

Acknowledgments

We are grateful to members of PatientsLikeMe for sharing their health data, to Dr. Dan Hoch for advice and experience in the development of the platform, to the epilepsy advocates who beta-tested earlier versions of the site, and to Svetlana Dimova (UCB Pharma S.A., Brussels, Belgium) for comments on drafts of the article.

Appendix A. Supplementary data

Supplementary data to this article can be found online at doi:10.1016/j.yebeh.2011.09.026.

References

[33] Frost J, Massagli MP. Social uses of personal health information within PatientsLikeMe, an online patient community: what can happen when patients have access to one another’s data. J Med Internet Res 2008 May 27;10(3):e15.
Patient assessment of physician performance of epilepsy
quality-of-care measures
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*Neurol Clin Pract* 2012;2;335
DOI 10.1212/CPJ.0b013e318278beac

This information is current as of December 11, 2012

The online version of this article, along with updated information and services, is located on the World Wide Web at:
http://cp.neurology.org/content/2/4/335.full.html

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Patient assessment of physician performance of epilepsy quality-of-care measures

Paul Wicks, PhD
Nathan B. Fountain, MD

Summary
To identify gaps in physician practice of epilepsy care, an online survey was sent to members of a Web-based epilepsy community to ascertain whether their physician performed 8 quality measures for epilepsy care. A total of 221 of 348 recently active epilepsy patients (64%) completed the survey. More than 80% of patients agreed they knew their seizure type, epilepsy syndrome, current seizure frequency, and had an EEG and neuroimaging. Fewer (60%) recalled being asked about medication side effects at each visit and safety issues annually. Only 48% report referral to an epilepsy surgery specialist and only 46% of appropriate patients had discussed reproductive issues with epilepsy. This demonstrates some potential gaps in epilepsy care and these data have been submitted to the American Academy of Neurology and the National Quality Forum.

The American Academy of Neurology (AAN) and the American Medical Association–convened Physicians Consortium for Performance Improvement have developed a set of physician performance measures with the intent of recording and improving the quality of care provided to patients with epilepsy.1 Quality of care can be assessed through a variety of means,2 but most methods require time to have elapsed following the deployment of performance measures. We sought to utilize an online epilepsy community in order to establish a patient-perceived baseline before the implementation of quality-of-care measures for epilepsy to assist with the AAN’s submission to the...
National Quality Forum. We sought to investigate whether epileptologists and neurologists were already adhering to more of these measures than nonspecialist physicians.

METHODS

The PatientsLikeMe survey system was used to construct a set of self-report questions to assess whether patients recalled that their physician performed each epilepsy quality-of-care measure. PatientsLikeMe is a previously described Web site for patients with similar medical conditions collected into communities, including a community for epilepsy patients which has been shown to have patient-perceived benefits including connecting with others, learning more about their seizures, and being more adherent to their antiseizure medication.3 Profile data (resembling a social network) are collected via self-report questionnaire on demographics, conditions and comorbidities, treatments, symptoms, epilepsy syndrome type (if known), seizure frequency, side effects, and quality of life. The survey system is designed to collect additional information from members of the communities for research and other purposes. All members of the site have explicitly consented to be contacted for research purposes. Comparison of PatientsLikeMe against a widely used US insurance claims database4 suggests the population is, on average, of a similar age (around 36 years old), but with a different distribution. Members of PatientsLikeMe tend to be adults aged 20–50 who developed seizures in childhood or adolescence, with relatively low representation of children or seniors. They are also more likely to be female (PatientsLikeMe 70% vs claims database 54%) and to be on polytherapy for their seizures (PatientsLikeMe 53% vs claims 29%).

The specific questions in the survey are listed in table 1 and parallel the 8 accepted epilepsy quality performance measures and were developed by the co-chair of the committee (N.F.).1 Response options provided for the questionnaire were graded as “strongly agree,” “agree,” “disagree,” “strongly disagree,” or “does not apply.” The approved epilepsy measures themselves

<table>
<thead>
<tr>
<th>Table 1</th>
<th>Patient assessment of quality measure performance</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Strongly agree</td>
</tr>
<tr>
<td>1a. I am confident I know the name of the seizures that I experience</td>
<td>51%</td>
</tr>
<tr>
<td>1b. At each visit, my epilepsy doctor asks me how many seizures I have had since the last visit for each type of seizure I experience</td>
<td>62%</td>
</tr>
<tr>
<td>2. I am confident I know the name of the type of epilepsy or seizure syndrome that I have</td>
<td>48%</td>
</tr>
<tr>
<td>3. I have had (or been offered) an EEG (electroencephalogram) at least once</td>
<td>89%</td>
</tr>
<tr>
<td>4. I have had (or been offered) a brain scan at least once (e.g. MRI, CT, or CAT scan)</td>
<td>86%</td>
</tr>
<tr>
<td>5. The doctor who treats my seizures asks me about the side effects of my medication at every visit</td>
<td>44%</td>
</tr>
<tr>
<td>6. I have been referred to an epilepsy specialist to discuss treatments that are not drugs, such as surgery or vagal nerve stimulation (VNS), at least once in the past 3 years; or if I am already followed by an epilepsy specialist then we have discussed these therapies; or, I have already had surgery or VNS for my epilepsy</td>
<td>35%</td>
</tr>
<tr>
<td>7. I have discussed safety issues with the physician that treats my seizures at least once in the past year (e.g., driving, bathing, injury prevention)</td>
<td>48%</td>
</tr>
<tr>
<td>8. I have spoken with the physician that manages my seizures about how my antiepileptic medications might reduce the effectiveness of any contraception/birth control I am using or plan to use in the future</td>
<td>27%</td>
</tr>
</tbody>
</table>
include explicit detailed reasons why the measures may not apply to a given patient. However, the exclusions were not provided in the survey for simplicity and because patients may be unable to reliably document these, so “does not apply” was provided for these situations.

On September 15, 2010, invitations to participate in the survey were sent to all 2,362 epilepsy patients who had been members of the site for at least 30 days, which included inactive members, on the basis that they might return to complete the survey. Members received a private message on their account, for which they would have received an e-mail notification, though for privacy’s sake this did not mention epilepsy or the nature of the study. This date predates publication of the epilepsy quality-of-care measures, so allowing for a useful pretest.¹ Eligible patients had 14 days to log in to PatientsLikeMe and respond, and a reminder message was sent within a week to those who had not yet completed the survey. Only patients who answered all questions were analyzed. Data analysis was performed using Statistical Package for the Social Sciences (SPSS v 18.0).

### Table 2  Epilepsy quality measure performance by type of physician provider

<table>
<thead>
<tr>
<th>Quality-of-care measure</th>
<th>Epileptologist (n = 44)</th>
<th>Neurologist (n = 154)</th>
<th>Primary care physician (n = 15)</th>
<th>Other (n = 8)</th>
<th>Between-group p</th>
<th>Total (n = 221)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1a. I am confident I know the name of the seizures that I experience</td>
<td>100%</td>
<td>85%</td>
<td>87%</td>
<td>88%</td>
<td>0.197</td>
<td>88%</td>
</tr>
<tr>
<td>1b. At each visit, my epilepsy doctor asks me how many seizures I have had since the last visit for each type of seizure I experience</td>
<td>91%</td>
<td>94%</td>
<td>60%</td>
<td>25%</td>
<td>&lt;0.001</td>
<td>89%</td>
</tr>
<tr>
<td>2. I am confident I know the name of the type of epilepsy or seizure syndrome that I have</td>
<td>91%</td>
<td>79%</td>
<td>80%</td>
<td>88%</td>
<td>0.062</td>
<td>81%</td>
</tr>
<tr>
<td>3. I have had (or been offered) an EEG (electroencephalogram) at least once</td>
<td>100%</td>
<td>99.4%</td>
<td>100%</td>
<td>100%</td>
<td>0.999</td>
<td>99.5%</td>
</tr>
<tr>
<td>4. I have had (or been offered) a brain scan at least once (e.g., MRI, CT, or CAT scan)</td>
<td>100%</td>
<td>97%</td>
<td>87%</td>
<td>88%</td>
<td>&lt;0.001</td>
<td>97%</td>
</tr>
<tr>
<td>5. The doctor who treats my seizures asks me about the side effects of my medication at every visit</td>
<td>73%</td>
<td>75%</td>
<td>33%</td>
<td>13%</td>
<td>0.002</td>
<td>70%</td>
</tr>
<tr>
<td>6. I have been referred to an epilepsy specialist to discuss treatments that are not drugs, such as surgery or vagal nerve stimulation (VNS), at least once in the past 3 years; or if I am already followed by an epilepsy specialist then we have discussed these therapies; or, I have already had surgery or VNS for my epilepsy</td>
<td>75% [21/28]</td>
<td>43% [43/99]</td>
<td>33% [3/9]</td>
<td>0 [0/4]</td>
<td>0.004</td>
<td>48% [n = 140]</td>
</tr>
<tr>
<td>7. I have discussed safety issues with the physician that treats my seizures at least once in the past year (e.g., driving, bathing, injury prevention)</td>
<td>73%</td>
<td>83%</td>
<td>57%</td>
<td>38%</td>
<td>0.05</td>
<td>79%</td>
</tr>
<tr>
<td>8. I have spoken with the physician that manages my seizures about how my antiepileptic medications might reduce the effectiveness of any contraception/birth control I am using or plan to use in the future</td>
<td>67% [10/15]</td>
<td>74% [31/42]</td>
<td>75% [3/4]</td>
<td>0</td>
<td>0.862</td>
<td>72% [n = 61]</td>
</tr>
</tbody>
</table>
Measure 8, counseling for women of childbearing potential, was assessed only for women between 12 and 44 years, using demographic data available to us from each patient’s existing profile data. Measure 6 was only assessed in patients with an affirmative response to “I have had a seizure in the past 7 days” or “an ER visit in the past 12 months for epilepsy” as a proxy measure of intractability since this question is contained in their online profile and is used as a surrogate for intractable epilepsy.

We created a score to determine the level of performance of the measures. The score is composed of the total number of measures with a positive endorsement. Selection of “strongly agree” or “agree” constituted positive endorsement. In order to define a physician performance score that applied to most patients, we excluded measures 6 and 8 since they only apply to subgroups of patients. Because measure 1 includes 2 items (1a, seizure type identification, and 1b, seizure frequencies), it contributes 2 points to the score. Therefore, the maximum possible score is 7. Measure performance was assessed based on the type of physician the patient sees, dividing physician specialty into epileptologist, general neurologist, primary care physician (PCP), and other specialties (including psychiatrists, internists, and all others).

RESULTS
At the time of survey completion, 348 members (15% of those invited) had logged on to PatientsLikeMe’s epilepsy community and so would have the opportunity to read the invitation. Of these, all survey questions were completed by 221 patients (64% of users logging in during this period), constituting the analyzed group, after excluding 21 patients who opted out of the survey and 61 who did not answer all questions. While 2,362 members were invited in total, this included users who had only logged in once and never returned to the site, therefore would not be representative of active site users.

Measure 6 (epilepsy surgery referral) was assessed in 140 patients with “intractable epilepsy” as defined above and measure 8 (women’s issues) was assessed in 61 women aged 12–44 years; these patients also had all other measures assessed.

To test for bias among the users who responded, we used the profile data of all other members of the community to compare against the responders. Mean age of respondents was 40 years (SD 12 years, range 17–72), which was 4 years older than nonresponders ($F_{3,1871} = 8.259, p < 0.001$). Following on from this difference, respondents had experienced seizures for a longer period of time (mean time since first seizure: 23 years [SD 15]) than nonrespondents (19 years [SD 14], $F_{3,1806} = 5.757, p < 0.001$). Women constituted 67% of respondents but this was not a statistically significant difference from nonresponders ($\chi^2 = 6.605, p = 0.086$). Most respondents (84%) were Caucasian but we do not have data on race for nonresponders.

Among respondents, 49% self-reported that they had a localization-related epilepsy syndrome, 34% a generalized syndrome, and 16% unknown or miscellaneous. Among specific
epilepsy syndromes, 32% of respondents had temporal lobe epilepsy, 15% an unspecified syndrome, 10% epilepsy with grand mal seizures on awakening, 8% other partial epilepsy syndrome, and 6% juvenile myoclonic epilepsy. Most patients (70%) were seen by a neurologist, 20% by an epileptologist, 7% by PCPs, and 3% by other specialties, e.g. internist, psychiatrist, or other. Profile data for nonrespondents were not available for race, epilepsy syndrome, or clinician specialist.

Table 2 shows the degree to which patients report their physician performed each measure, without regard to type of physician. More than 80% of patients “strongly agree” or “agree” that they know their seizure type, have been asked their current seizure frequency, know their epilepsy syndrome, and have had an EEG and neuroimaging. At least 60% recall being asked about medication side effects at each visit and safety issues annually. Only 48% of qualifying patients have been referred to an epilepsy surgery specialist and 46% of appropriate patients have discussed reproductive issues among women with epilepsy.

Table 2 shows differences of measure performance across physician specialties. The measure was considered performed if the patient scored it as “strongly agree” or “agree.” Epileptologist and neurologists consistently performed each measure more often. The group differences were significant only for seizure frequency, side effect assessment, epilepsy specialist referral, and discussion of safety issues. Difference in performance was also statistically significant for neuroimaging performance but the absolute difference was small.

The number of measures performed plotted by physician specialty are shown in the figure ($F_{3,217} = 10.551, p < 0.001$). The mean number of measures performed for epileptologists was 6.3 (95% confidence interval [CI] 5.95–6.55), general neurologists 6.1 (95% CI 5.86–6.25), PCPs 4.9 (95% CI 3.96–5.90), and other specialists 4.1 (95% CI 2.91–5.34). Epileptologists performed more measures than neurologists but the difference is not significant. Post hoc Bonferroni testing reveals epileptologists adhered to a mean of 1.3 more measures than PCPs ($p = 0.003$, 95% CI 0.34–2.30) and 2.1 more measures than other specialties ($p < 0.001$, 95% CI 0.90–3.34).
Items such as knowing the type of seizures and syndromes that the patient has may be subject to multiple influences including patient education, cognitive function, memory problems, and physician input.

Patients seen in a medical center specialty clinic reported 0.7 more measures adhered to (mean = 6.3, SD 1.0) than those seen in a private office (mean = 5.6, SD 1.5, p < 0.001, 95% CI 0.24–1.20). We found no significant association between number of measures adhered to and sex, age, education, US census region, or self-reported epilepsy syndrome type (generalized vs partial vs unknown).

DISCUSSION

Overall, the survey demonstrates some gaps between recommended care and the care delivered to epilepsy patients. As the currently approved epilepsy quality-of-care measures were purposely designed to be minimum quality standards that can be universally implemented, it is not surprising that many are already adhered to and probably do not need further emphasis if the current results are borne out. Fortunately, the gaps in care identified should be easily remedied through physician and patient education. Specific educational information should be disseminated with regard to asking patients about medication side effects, reviewing safety issues, and counseling women of childbearing potential.

One of the most important identified gaps is in referral of refractory epilepsy patients to an epileptologist. Epilepsy surgery is the most effective treatment for intractable focal seizures in appropriately selected patients. A randomized controlled trial of epilepsy surgery vs standard medical therapy demonstrated that 58% of patients are seizure-free after surgery compared to only 8% on medical therapy alone.5 Our findings are consistent with the common report that patients who eventually do undergo surgery have usually had epilepsy for a mean of almost 20 years, presumably because they were not referred for epilepsy surgery in a timely manner.5 Clearly there are great gains to be made in terms of survival, quality of life, and seizure-free years even for patients who undergo successful surgery or are not surgery candidates.6 Even when patients are not good candidates for surgery, they are still likely to benefit from evaluation by an epilepsy specialist to confirm the diagnosis, maximize medications, consider alternative therapies, and provide education and access to social and other services.7

Epileptologists adhere to more of the quality-of-care measures than physicians from other specialties. However, only 20% of patients in our sample were seen by an epileptologist regularly; most patients in our sample (70%) were seen by a general neurologist. Areas in need of further attention by general neurologists include asking about side effects of medications at each visit; appropriate referral for nonpharmacologic treatments including surgery and vagus nerve stimulation; regular discussion of safety issues such as driving; and discussing issues for women of childbearing age. Among epileptologists there is room for improvement with regard to inquiring about medication side effects, safety issues, and counseling women with epilepsy.

Quality measures are often based on claims-based recording systems and emphasize documentation rather than care. This study asked patients whether they recall their physician performing the measure-specified activities, without regard to documentation. Of course, this could be subject to significant recall bias since it is possible that patients simply forget that their physician performed a specific measure. Therefore, the current study represents a potential “real world evidence” assessment of the care that patients perceive their physicians are delivering in practice, with some of the limitations that confers.
Items such as knowing the type of seizures and syndromes that the patient has may be subject to multiple influences including patient education, cognitive function, memory problems, and physician input. We included this item because although the quality measures themselves emphasize whether a seizure or syndrome has been identified in the medical record, it may be worth future studies to investigate whether this leads to improved patient knowledge of their condition and what impact this might have on outcomes.

It is challenging to assess via self-report the validity of the epilepsy surgery item. Our definition of “intractable epilepsy” was (at best) a proxy measure, and without more precise knowledge of the patient’s subtype and seizure history it is difficult to say what sort of conversations they should have been having with their clinician. However, we do know from other studies that patients experience long latency to surgery, so this might be explored in future studies. The high proportion of women reporting the contraception discussion was “not applicable” might also provide further area for future study.

This study has several limitations based on the study design. Given the self-reported nature of the system, it is impossible to verify that “patients” are indeed people diagnosed with epilepsy due to the anonymous nature of the participants. It may be that some of our respondents did not have seizures, or had primarily psychogenic nonepileptic seizures. However, given that there are no incentives for participating in the system, it seems unlikely that many respondents would have taken the time to register for the site and complete a survey if they did not at least believe they have epilepsy. Future work is under way collaborating with epilepsy specialist centers to verify and validate patient-reported outcomes to overcome this limitation and will be of use in follow-up studies. In terms of physician types, it is possible that patients cannot reliably distinguish between a neurologist and epileptologist, but future work using more traditional means might be able to explore this further. Such studies might also explore a larger sample of patients treated mainly in primary care, given that most of our sample (90%) saw an epileptologist or neurologist; we would hypothesize the quality situation will be poorer in the primary care setting.

Because patients must actively seek out the site and be capable of Internet use, it is likely that patients who are members of a Web forum of the type used in this study are relatively sophisticated and so may be more knowledgeable than patients in the wider community about epilepsy. This sophistication might provide more reliable answers to survey questions but also could bias the results toward a population that is more sophisticated than the average patient and thus be an underestimate of the real magnitude of gaps in care. Analysis of responders showed a clear bias toward responses from older patients.

Despite the limitations of this study, it clearly demonstrates some gaps in care, and our data have been submitted by the AAN to the National Quality Forum. We hope that by illuminating these that physicians will implement the quality measures to improve care for patients with epilepsy, especially consideration of referral to an epilepsy specialist for consideration of epilepsy surgery. It also can inform future changes in the approved epilepsy quality performance measures.

REFERENCES


DISCLOSURES
P. Wicks is a paid employee of PatientsLikeMe and owns stock options in the company. The PatientsLikeMe R&D team has received funding from Abbott, Acorda, Avanir, Biogen, Genzyme, Johnson & Johnson, Merck, Novartis, Sanofi, and UCB. N. Fountain receives research support from NIH, UCB, Sepracor, Medtronic, and Neuropace, consulting fees from UCB, and serves on the National Association of Epilepsy Centers Board of Directors. Go to Neurology.org/cp for full disclosures.
Patient assessment of physician performance of epilepsy quality-of-care measures
Paul Wicks and Nathan B. Fountain
*Neurol Clin Pract* 2012;2:335
DOI 10.1212/CPJ.0b013e318278beac

This information is current as of December 11, 2012

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The Patient Engagement Pill – Lessons from Epilepsy

Introduction

The pharmaceutical drugs developed over the past two decades have helped us more effectively manage, and in some cases dramatically change, the outcomes of patients with hypertension, high cholesterol, diabetes, and even some cancers. Increasingly, though, the stroke of a prescription pen doesn’t solve all patient problems. Nor does it solve the problems in our health systems.

To really fulfill the potential of health care, we need patients who are engaged, patients who take “actions (as) individuals... to obtain the greatest benefit from the health care services available to them” (1) (See Exhibit One below).

Leonard Kish recently called patient engagement “the blockbuster drug” of the century. It’s an exciting idea, and an apt label that raises an interesting question: what would an “engagement pill” actually look like?

There’s little basic science to guide us, no animal models to refine our understanding, no clearly defined profession with the right expertise, and no clear economic framework to develop products and align incentives. But the Internet, fixed and mobile, may give us the best clues. We have already seen that when nothing else exists, patients and caregivers develop their own ways to exchange information, including online message forums or support groups.

Unlike the innovations in chemistry and biology that drove pharmacological industrialization in the 20th century, a combination of informatics, design, psychology and unanswered user needs has driven innovations in health-oriented social networking. The Internet now has the potential to become a new kind of research center, and even the means to distribute an engagement pill. It also has the potential to bring together patients, payers, researchers and clinicians to create the ultimate engaged patient.

Does it all sound too good to be true? If our experience at PatientsLikeMe with epilepsy patients is any indication, it’s already happening today.
<table>
<thead>
<tr>
<th>Domain</th>
<th>Traditional Patient</th>
<th>Empowered Patient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disease knowledge</td>
<td>Receives clinical information from healthcare professional</td>
<td>Seeks, evaluates &amp; synthesises information in collaboration with HCP</td>
</tr>
<tr>
<td>Focus of Maintaining Health</td>
<td>Treating disease</td>
<td>Living well despite disease</td>
</tr>
<tr>
<td>Monitoring</td>
<td>Responds to clinician’s questions periodically</td>
<td>Continually monitoring own outcome measures</td>
</tr>
<tr>
<td>Decision Making</td>
<td>Relatively passive, defers to others for decision-making</td>
<td>Seeks input from others for shared decision-making</td>
</tr>
<tr>
<td>View of Healthcare Providers</td>
<td>Authority responsible for treating disease</td>
<td>Members of collaborative team including patient and family</td>
</tr>
<tr>
<td>Choosing Healthcare Providers</td>
<td>Who’s local, who’s in network, who’s recommended, who’s cheap</td>
<td>Who the data says gets the best outcomes</td>
</tr>
<tr>
<td>Medication</td>
<td>Variable adherence, may not understand or appreciate consequences</td>
<td>Uses strategies and tools and relates decision about adherence to outcomes</td>
</tr>
<tr>
<td>Medical System Navigation</td>
<td>Asks clinician for referral and advice</td>
<td>Develops strategy to achieve goals</td>
</tr>
<tr>
<td>Symptom Management</td>
<td>Manages with evidence or where that is lacking, on a trial-and-error basis</td>
<td>Tracks and correlates own data against treatments to gain better understanding of condition</td>
</tr>
</tbody>
</table>

*Exhibit One: Conceptual differences between a “traditional” and “empowered” patient*
Lessons from Epilepsy

Epilepsy is a recurrent seizure disorder that affects some 2.3 million Americans, and may be responsible for as much as $10 billion in U.S. healthcare expenditures annually(2). Although many patients can control seizures with medication, even one seizure a year has substantial impact on their quality of life and the healthcare choices they make(4). Improving the engagement of patients with epilepsy may serve to improve quality of life, especially for those who will never be free of seizures (7). Even for those patients who have lived with uncontrolled epilepsy for years, an increase in engagement can substantially improve health outcomes(8).

A number of professional-led engagement programs have been piloted. These include the Managing Epilepsy Well (MEW) Network(9) which features web and phone-based programs to help epilepsy patients manage depression themselves. Such programs overcome the common limitations of traditional classroom-based approaches (10), such as high staff and facility costs, low patient motivation, and the challenges inherent in transferring knowledge from the professional to the patient. They do not, however, promote the sharing of information that is so key to helping patients become more empowered, and increasing our collective understanding of disease.

First, Connect – The Benefits of Patients Helping Each Other

PatientsLikeMe is a patient network that improves lives and a real time research platform that advances medicine. Patients with chronic illnesses such as epilepsy use the website to track their health, including treatment and symptom data, and share their experiences and data with other “patients like me.” (11). Our development of epilepsy-specific community tools (sponsored by the pharmaceutical company UCB) has been described previously(11); the key difference from other services such as MEW is the emphasis on shared data. Every patient on PatientsLikeMe can see the complete health record of every other patient. This helps them learn more about their own illness, get support from others with the same condition, and use the information to improve their outcomes. It also contributes to research, because PatientsLikeMe de-identifies and aggregates the data, and makes it available to companies focused on improving products, services and care.

Regular users of the epilepsy community on PatientsLikeMe reported a number of specific benefits from a list of twenty. For instance, 55 percent agreed it helped them learn more about seizures, 27 percent agreed it helped them be more adherent to their medication, 27 percent said it helped them reduce the side effects of treatments, and 18 percent suggested they needed fewer visits to the emergency room, all directly as a result of their interactions on the site(11).

Despite a mean seizure duration of 23 years, prior to joining the site, one in three epilepsy patients said they didn’t know anyone else “in the real world” with epilepsy with whom they could discuss their condition. After joining the site, 2/3 of these previously isolated patients reported knowing at least one person they
could connect with. In fact, the number of social ties with other patients with the same condition influenced the number of benefits they experienced\(^{(11)}\). As shown in the graph below, users without any friends on the system experienced an average of 5 benefits out of a possible 20, but those with ten or more friends had double the number of benefits. The effect remains significant even controlling for the number of times the patient logged in to the site.

\[\text{Exhibit Two: Relationship between benefits experienced by epilepsy patients and number of social ties in the social network (Reproduced with permission from Wicks et al. 2011, Perceived benefits of sharing health data between people with epilepsy on an online platform, Epilepsy & Behavior 23:16-23, Elsevier)}\]
Policy for Optimized Epilepsy Management (POEM) collaboration with the Veterans Health Administration and Epilepsy Centers of Excellence (VHA ECOPE)

The POEM project, funded by UCB, seeks to formally test the potential benefits of the platform for U.S. Veterans with epilepsy. We believe, and hope to show, that the use of the PatientsLikeMe network and the use of the epilepsy-specific tools and resources will result in measurable improvements in self-efficacy and self-management. If successful, we may explore implementing an “Information Prescription” for U.S. Veterans with epilepsy throughout the VA system, and investigate whether improved self-management of epilepsy in these patients will lead to quantifiable, concrete benefits in health outcomes such as better medication adherence, reduced ER admissions, and better interactions with healthcare professionals.

Lessons Learned

The primary lesson we have learned is that patients who connect directly with one another may be capable of improving the behaviors that enable engagement. Systems like PatientsLikeMe encourage the type of sharing and social support more often available “offline” in antenatal classes, Weight Watchers®, or Alcoholics Anonymous (17). PatientsLikeMe also merges these narratives with data-rich patient-reported outcomes.

By linking the data and the experience, each social tie is not merely a conversation, but an opportunity to look at the structured data of another patient (18), and to see their treatment history, side effects, and seizures plotted against outcomes like quality of life. Exhibit Two offers a tantalizing glimpse of a “dose response” and hints that patients themselves represent the “engagement pill”. They just need access to the tools of the new “industrial revolution” of patient engagement.

The second lesson we have learned from both epilepsy (11) and other chronic conditions (19) is that when patients share stories, offer support, or critique a poor health decision by another patient, this knowledge and advice is treated differently than when it comes from experts, health care professionals, or policy officials. The inherent empathy patients have for one another makes a significant difference.

The third lesson is that online patient community engagement is, compared to other things, a relatively safe “drug” (20), which cannot be always be said for traditional healthcare institutions or interventions (21). The safety monitoring systems for online engagement interventions focus on the prevention of bullying or cyber-stalking, as well as repelling spam or false information by peddlers of quack therapies. Unlike a static database of health information, the average profile on PatientsLikeMe is viewed multiple times per day, allowing patients themselves to act as the immune system for detecting bad actors in the system.
The fourth lesson is that online systems must remain flexible and customizable based on user needs. During the POEM pilot experience with the VA, it became obvious that our seizure meter, developed for the highly activated self-selecting epilepsy user in the general population to track the severity of their seizures, was unsuitable for the study population. This observation prompted an intensive re-engineering effort that is now reflected in the full study launch and patient experience.

Exhibit Three: Two versions of a seizure meter for patients with epilepsy. “Version One” at top required users to be able to name their seizures and recall relative severity; while elegant it was too complex for most patients, who can not name their seizures or recall severity. “Version Two” developed through POEM user testing simplifies this to a simple count of seizures, identification of relevant triggers, and optionally whether the patient lost consciousness in any of their seizures.

This leads to the last issue, which is the importance of developing a common language for patients, clinicians and researchers. Many patients from the POEM pilot study could not accurately understand the medical terms used to describe their epilepsy syndromes or seizure types. Patients expressed frustration about this, while physicians and health researchers worried about the ‘accuracy’ of the patient-reported data. True engagement requires a clear way to describe a condition, its severity, and its history that is understandable to the patient, specific enough for the clinician, and comprehensive enough for clinical researchers to draw conclusions on the impact and characterization of the disease. This will form a significant body of work which we hope to explore in the coming years with our patient-centered research partners.
Who Builds The New Pipeline?

It is worth considering briefly the enormous infrastructure of pharmaceutical development built up in the past 100 years, through basic science, animal testing, research and development pipelines, clinical trials, regulatory agencies, marketing, and the healthcare infrastructure that delivers it all. Though rigorous, it is inherently un-scalable, and will struggle to produce new interventions at the rate required by an aging population.

Many questions remain, however: What fraction of that energy are we willing to invest in this new area of engagement medicine and what fruits could it yield? What economic models do we need to support innovation in engagement on the order of magnitude devoted to medications? In years to come will we recognize (and reward) patients for their role as “active ingredients” in care? To realize the potential of the engagement pill we will need to build a new pipeline together which can adequately address the challenges of the next hundred years of medicine.

Disclosures: PW is an employee of PatientsLikeMe and owns stock/stock options in the company. The PatientsLikeMe R&D team has received research funding from Abbott, Acorda, Avanir, Biogen, Genzyme, Johnson & Johnson, Merck, Novartis, Sanofi and UCB. JDH has received research funding from UCB.
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Changing Expectations:
Bringing Transparency to Cost and Quality Information
An Experiment Shows That A Well-Designed Report On Costs And Quality Can Help Consumers Choose High-Value Health Care

ABSTRACT Advocates of health reform continue to pursue policies and tools that will make information about comparative costs and resource use available to consumers. Reformers expect that consumers will use the data to choose high-value providers—those who offer higher quality and lower prices—and thus contribute to the broader goal of controlling national health care spending. However, communicating this information effectively is more challenging than it might first appear. For example, consumers are more interested in the quality of health care than in its cost, and many perceive a low-cost provider to be substandard. In this study of 1,421 employees, we examined how different presentations of information affect the likelihood that consumers will make high-value choices. We found that a substantial minority of the respondents shied away from low-cost providers, and even consumers who pay a larger share of their health care costs themselves were likely to equate high cost with high quality. At the same time, we found that presenting cost data alongside easy-to-interpret quality information and highlighting high-value options improved the likelihood that consumers would choose those options. Reporting strategies that follow such a format will help consumers understand that a doctor who provides higher-quality care than other doctors does not necessarily cost more.

Increased transparency of health care costs and resource use is a key element of policies aimed at containing the cost of US health care. Price transparency is thought to introduce more competition and to increase consumers’ ability to factor costs into their health care choices. Publishing actual prices or the average cost of care, along with quality information, is increasingly becoming a part of public reporting for ambulatory and hospital care. The majority of states are pursuing legislation to increase price transparency, and the seventeen regional alliances supported by the Robert Wood Johnson Foundation’s Aligning Forces for Quality initiative are in the process of reporting comparative cost data. Promoting value in consumer choices reflects current public policy and payer priorities that focus on both improving quality and containing costs. The goal of reporting cost data is to reduce waste and unnecessary care without sacrificing quality of care. Because consumers bear an increasing share of the costs of care, policy makers assume that cost data will be relevant to consumers, helping them choose high-value—that is, lower-cost and better-quality—options. Yet little is known about how consumers will respond to, interpret, or apply data on health care costs and resource use.

The extent to which consumers will accurately understand the meaning of data on costs and resource use—and be able to use the information...
in decision making—is unclear. There are indications that consumers may respond to the data in unintended ways. When it comes to the amount of care, consumers tend to think that more is better. They might not understand, for example, that longer lengths-of-stay are undesirable and often avoidable.2

Similarly, there is some indication that consumers view higher prices as a proxy for quality, assuming that higher-price care is higher-quality care or that low-cost care is substandard.3,4 Higher cost is typically equated with higher quality in most other consumer goods and services, and it is reasonable to assume that consumers bring the same view to health care. Thus, there is a possibility that consumers’ misinterpretations and misconceptions of cost data may result in fewer high-value choices.

Weighing information about the cost of health care services is new for consumers. The task is compounded because consumers must integrate cost data with multiple other considerations, such as quality differences, in making their health care choices. When people are in a situation where they must process complex, unfamiliar, and important factors to make a choice, the way the information is labeled, framed, and explained will determine, to a large degree, how people interpret and use it.6 As a result, how information is presented—in the health care context and elsewhere—may be as influential in consumer choice as the information itself.6,7

We used a controlled experiment to test different approaches of describing and presenting measures of health care cost. We tested approaches that were in current usage or that prior studies suggested should help consumers interpret data on health care cost and use. The goal of our study was to identify effective strategies for presenting information on comparative cost and resource use in a way that would prompt consumers to make high-value choices.

**Study Data And Methods**

Our specific research questions were as follows: Are there ways to present data about cost more effectively, so that consumers are more likely to choose high-value providers? Are there ways to present resource use measures more effectively, to improve consumers’ choices? And are measures that are at the intersection of cost and quality more salient to consumers than measures of cost alone?

We used an experimental design in which study participants were randomly assigned to one of three groups. Each group viewed six presentations of comparative data on cost and resource use for physicians and hospitals. Each group was presented with the same descriptive data on health care providers, but the data were displayed, labeled, or framed differently.

Respondents were asked to choose among providers based on the information presented, rate their confidence in their choices, and identify what they perceived to be the highest-quality options. In addition to examining differences in how the three groups responded to questions about the data presentations, we examined within-participant differences in choices when respondents were presented with different types of displays with comparable data (as explained below).

To determine which labels to test in the study, we conducted focus group sessions and cognitive interviewing with employees in the Cincinnati area. The focus groups explored how consumers thought about value in health care and their reactions to different ways of labeling cost and resource measures. Also explored in the focus groups were different presentation approaches—for example, showing cost and quality together or separately. The cognitive interviews were used to ensure that subjects understood the study questions for the experiment in the way that they were intended. Participants were asked to use their own words to describe what they thought the study questions were asking and what the study materials were saying. The focus-group methods and results are discussed in greater detail elsewhere.8

**STUDY POPULATION** A convenience sample of 1,421 employed adults participated in this experimental study. Massachusetts Health Quality Partners sponsored the data collection and worked with two of its member employers to recruit employees for participation. Those firms sent their employees an e-mail message with a link to the online survey, encouraging them to participate.

The characteristics of the study population as a whole and of the three experimental groups are shown in the online Appendix.9 Overall, respondents were disproportionately male (62 percent), white (81 percent), and highly educated (72 percent had at least a bachelor’s degree). Sixty-four percent reported being in excellent or very good health, while 38 percent reported having at least one chronic medical condition. Seventy-eight percent were enrolled in managed care plans such as health maintenance organizations or preferred provider organizations. The remaining 22 percent were enrolled in a high-deductible health plan, with a minimum deductible of $1,000 for a single person.

There were no significant differences in demographic characteristics or health status among the three randomized groups. This suggests that
Examples Of Cost Data With No Quality Signal Presented To Consumers

<table>
<thead>
<tr>
<th>Doctor</th>
<th>Saturday hours</th>
<th>Driving distance (miles)</th>
<th>Same-day office visits</th>
<th>Cost data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr. White</td>
<td>9:00–noon</td>
<td>6</td>
<td>No</td>
<td>$</td>
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<tr>
<td>Dr. Ramsey</td>
<td>9:00–3:00</td>
<td>5</td>
<td>Yes</td>
<td>$</td>
</tr>
<tr>
<td>Dr. Abbot</td>
<td>None</td>
<td>10</td>
<td>Yes</td>
<td>$</td>
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<tr>
<td>Dr. James</td>
<td>9:00–3:00</td>
<td>5</td>
<td>Yes</td>
<td>$</td>
</tr>
<tr>
<td>Dr. Albright</td>
<td>None</td>
<td>8</td>
<td>No</td>
<td>$</td>
</tr>
<tr>
<td>Dr. Casey</td>
<td>9:00–noon</td>
<td>7</td>
<td>Yes</td>
<td>$</td>
</tr>
</tbody>
</table>

**Group 1**

**Group 2**

**Group 3**

**Source** Authors’ analysis. **Notes** The three groups received the same information, but the cost data were presented differently. The groups received access data but no quality data. "Cost data presented as 1–3 stars (represented here by small circles), with the label "careful with your health care dollars." "Cost data presented as dollar amounts, with the label "average cost for office visit." "Cost data presented as 1–3 dollar signs, with the label "average cost for office visit."

The randomization was effective.

**Cost Information** One way of labeling physician cost information that members of our focus groups had viewed positively was referring to physicians as being "careful with your health care dollars." In this approach, physicians were rated on a scale of one star (less careful) to three stars (very careful). We tested it against two other labeling approaches in current use. The first rated cost with dollar signs, using one sign to indicate the lowest cost and three signs to indicate the highest. The second presented each physician’s actual average cost per office visit.

We tested three different labeling approaches in three different ways: with no quality signal (no quality information, only data about providers’ accessibility, such as their office hours); with a weak quality signal (quality information that was hard to understand and process); and with a strong quality signal (the same quality information, presented in a way that was easy to understand and process). Each experimental group saw the data displayed with no quality signal, a weak quality signal, and a strong quality signal. For example, the group that saw the cost data labeled as dollar signs saw three data displays with different quality signals, all using the dollar signs.

Each comparative display described six providers. One of the six was always a high-value provider—that is, he or she was rated high in quality and low in cost, compared to the other providers. (In the data display with no quality information, this provider was rated high in accessibility and low in cost.) Another provider always had identical quality (or access) but higher cost. A third provider always had slightly lower quality (or access) and higher—but not the highest—cost. The other three providers’ costs were either higher or lower than that of the high-value provider.

Although the provider information was the same across the data displays with no, weak, and strong quality signals, the names of the providers were altered, and the ordering of the providers were switched. For the group with actual dollar amounts, the average amounts were not identical in each display, but they were proportionately the same. Exhibit 1 shows the cost data with no quality signal, providing information about access instead of quality. Exhibits 2 and 3 show examples of data with either a weak or a strong quality signal (more detailed versions of Exhibits 2 and 3, which were used in the experiments, are available in the online Appendix).

We also wanted to see the effect of highlighting the high-value options. Therefore, we provided respondents with one comparative display of data on cost and quality for hospitals instead of physicians. The first group of respondents saw cost and access data. The second group saw cost, access, and quality data. The third saw cost, access, and quality data, with high-value options highlighted with a check mark. The online Appendix shows the presentation
that highlighted the high-value options.9

**COMPARATIVE INFORMATION ON RESOURCE USE** We assessed different ways of labeling and displaying data about primary care physicians’ resource use, measured by the use of computed tomography scans and magnetic resonance imaging. The first group of respondents saw data that rated physicians on whether their use of imaging was high, medium, or low. The second group saw the same data with a framing statement that said, “More isn’t always better: Too many imaging tests can be harmful.” The framing statement appeared at the top of the table.

For the third group we sought to avoid the problem of respondents’ perceiving more services as better. This group saw data that rated physicians on the “appropriate use” of the scans and imaging. These data are presented in the online Appendix.9

**MEASURES AT THE INTERSECTION OF COST AND QUALITY** We also examined how consumers responded to data at the intersection of cost and quality, using the PROMETHEUS measures.10 These measures indicate the proportion of patients with a chronic condition who have a potentially avoidable complication during a calendar year. Because the measures reflect both costs and quality, they are typically used to assess providers’ efficiency.

We tested whether different ways of labeling the measures influenced respondents’ choice of providers. We showed respondents the same data on access and one of three different labels and presentation formats for the PROMETHEUS measure. The first group saw the measure described as “prevents complications that could have been avoided,” with providers rated with one to three stars. The second group saw the same information with a framing statement—again, appearing at the top of the table—that said, “It is important to remember: With high-quality health care, many patient complications can be avoided.” The third group saw the measure described as “percent of patients with complications that could have been avoided and lower costs.”

**LIMITATIONS** Our findings should be interpreted in light of the fact that the study used an experimental design with a convenience sample of employees who had a high level of education. Because of the experimental design and the random assignment of participants, we can be confident that the observed differences are a result of the differences in how information was presented. However, because the experiments asked participants to make nonbinding choices in a contrived decision situation, we are less confident that people making choices in the real world will behave in the same way as the respondents did in our study. In other words, the study had high internal validity and lower external validity.

We do know, however, that people with lower levels of education and fewer literacy skills are more influenced by how information is formatted and displayed, compared to those with more education and literacy skills.7 This suggests that the findings reported here are probably somewhat muted because of the highly educated study population. Therefore, studies that replicate our approaches with different population groups who are making binding decisions are needed to confirm our findings.

**DEPENDENT VARIABLES** There were three dependent variables. First, we asked the respondents who saw each data display which doctor they would choose. The high-value provider was defined as the provider with the highest quality (or best access) and lowest cost (or lowest use of resources).

Second, we asked, “If this were the only information you had to choose a doctor, how confident would you be with your choice?” Confidence ratings were on a five-point scale, with 1 being “not at all confident” and 5 being “very confident.”

And third, we asked respondents which provider they thought provided the highest quality of care. We considered respondents who selected the provider who had the highest cost and highest quality—rather than the provider with the lowest cost and highest quality—to be using cost as a proxy for quality.

**ANALYSIS** We began our analysis with descriptive statistics of the overall sample and compared the characteristics of the three randomized groups. Next, we conducted one-way analyses of variance, or ANOVA tests, to determine whether there were significant differences in the dependent variables among the three groups for each display.

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**EXHIBIT 3**

**Examples Of Cost Data Presented To Respondents With A Strong Quality Signal**

<table>
<thead>
<tr>
<th>Group 1</th>
<th>Quality data (strong signal)</th>
<th>Cost data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctor</td>
<td>Uses treatments proven to get results</td>
<td>Has safeguards to protect patients from medical errors</td>
</tr>
<tr>
<td>Dr. Friedman</td>
<td>Better</td>
<td>Better</td>
</tr>
<tr>
<td>Dr. Hunter</td>
<td>Better</td>
<td>Better</td>
</tr>
</tbody>
</table>

**SOURCE** Authors’ analysis. **NOTES** Groups 2 and 3 received the same information, but the cost data were presented differently, as shown in Exhibit 1. Each group received information about six doctors, as explained in the text. The information included the following key: 3 stars is very careful (lower costs); 2 stars is somewhat careful (average costs); 1 star is less careful (higher costs). In this exhibit, small circles denote stars.
We also tested for potential interactive effects using regression models, to assess whether study participants in plans with high deductibles responded differently to cost data displays than those in more traditional health maintenance organization or preferred provider organization plans. Additionally, we investigated whether there were differences in responses based on health factors—respondents’ health status, whether they had a chronic condition, and the cost burden of health care that they reported—and demographic characteristics.

We then used repeated one-way analyses of variance to assess whether respondents made significantly more high-value choices when the cost data were presented with a strong quality signal than when they were presented with a weak quality signal or no quality signal at all. We also used this within-respondent approach to test whether there were significant differences in the percentage of respondents selecting the high-value option when the PROMETHEUS measure was used.

Findings

COST INFORMATION

Exhibit 4 shows the percentage of respondents in each of the three groups who chose the high-value option (lowest cost and either highest quality or best access). When there was no quality signal and only access information, respondents who saw the dollar signs were significantly less likely to choose the high-value option than those who saw stars or dollar amounts (a difference of twenty-three and twenty percentage points, respectively).

When respondents saw cost data with a weak quality signal, the differences in selecting the high-value option were still pronounced between those seeing the dollar signs and the other two groups (Exhibit 4), but they were slightly diminished (differences of seventeen and twelve percentage points, respectively). When respondents saw the cost data with a strong quality signal, there were only small differences in the percentages selecting the high-value option (there was a six-percentage-point difference between those seeing dollar signs and the other two groups). Thus, it appears that how cost data are presented makes more of a difference when those data are not accompanied by quality data or when quality data are difficult to understand.

When respondents saw no quality data, about 80 percent of respondents in the groups who saw stars or dollar amounts (Exhibit 4) chose the high-value option (the lowest cost and the best access). However, with a strong quality signal, about 90 percent of the respondents in those two groups chose the high-value option.

Respondents who saw dollar signs were much more likely than respondents in the other two groups to choose the medium-price option. For example, with no quality signal, 24 percent of the respondents who saw dollar signs made that choice, compared with 11 percent of respondents seeing stars and 7 percent of those seeing dollar amounts.

Exhibit 4

Respondents Selecting High-Value Providers, By Type Of Cost Data And Quality Signal

<table>
<thead>
<tr>
<th>Quality Signal</th>
<th>Stars</th>
<th>Dollar Amounts</th>
<th>Dollar Signs</th>
</tr>
</thead>
<tbody>
<tr>
<td>No quality signal</td>
<td>90%</td>
<td>80%</td>
<td>85%</td>
</tr>
<tr>
<td>Weak quality signal</td>
<td>89%</td>
<td>80%</td>
<td>85%</td>
</tr>
<tr>
<td>Strong quality signal</td>
<td>90%</td>
<td>80%</td>
<td>90%</td>
</tr>
</tbody>
</table>

SOURCE Authors’ analysis. NOTES Group 1 of the respondents saw cost data presented as 1–3 stars, with the label “careful with your health care dollars.” Group 2 saw the data presented as dollar amounts, with the label “average cost for office visit.” Group 3 saw the data presented as 1–3 dollar signs, with the label “average cost for office visit.” *p < 0.05 for within-subject differences between no quality signal and weak quality signal. **p < 0.05 for within-subject differences between no quality signal and strong quality signal. ***p < 0.05 for within-subject differences between weak and strong quality signals. ****p < 0.05 for between-group differences.
amounts. We found no significant differences in how participants responded to the data displays based on the type of health plan they were enrolled in (a traditional plan or one with a high deductible), or on respondents’ health variables or demographic characteristics (data not shown).

In all three groups of respondents, confidence in choices increased when the quality signal was strengthened (Exhibit 5). Respondents’ confidence was lowest when quality information was absent (mean, 2.0), higher when the quality signal was weak (mean, 2.6), and highest when the quality signal was strong (mean, 3.2).

Respondents were most likely to identify the provider with the highest cost as having the highest quality when there was no quality signal (Exhibit 6). Of the respondents who saw dollar signs, 35 percent selected the most expensive provider as the one with highest quality, compared to 28 percent of the respondents who saw dollar amounts and 14 percent of those who saw stars. When respondents saw quality as well as cost information, they were one-half to one-third as likely to equate high cost with high quality. In addition, the differences across the three groups were smaller.

When we used a check mark to highlight high-value hospital options, as described above, we found that the respondents who saw the highlighting were significantly more likely to choose the high-value option than respondents who did not.

**Comparative Information on Resource Use** We tested three different ways to present primary care physicians’ relative use of scans and imaging tests, as explained above. Respondents who saw the data labeled “appropriate use” were three times more likely to select the high-value provider than respondents who saw the levels of imaging use presented as high, medium, or low with the framing statement, “More isn’t always better: Too many imaging tests can be harmful.” And they were approximately six times more likely to choose the high-value provider than respondents who saw the imaging use without the frame. Only 14 percent of that group selected the high-value provider. These findings indicate that a label that interprets the information—in this case, describing the use as “appropriate” or not—is more effective than just presenting the level of use.

**Measures at the Intersection of Cost and Quality** All three of our presentations of PROMETHEUS measures of potentially avoidable complications, also described above, yielded a high level of high-value choices (more than 90 percent). This was comparable to results with the strong quality signal for respondents who saw dollar amounts or stars and significantly higher for those who saw dollar signs. All three of the labeling strategies for PROMETHEUS measures also yielded a high level of confidence in choices—almost as high as when respondents viewed a strong quality signal.

**Discussion**

The results indicate that most respondents seemed amenable to making high-value choices.
However, a substantial minority of respondents shied away from low-cost providers and viewed higher prices as a proxy for higher quality. Similarly, respondents were reluctant to choose providers who used low levels of resources (in this case, scans and imaging).

The findings demonstrate that some ways of the labeling and displaying cost data are more effective than others. Some of the approaches we tested minimized respondents’ misinterpretations and increased the percentage of high-value choices they made. For example, respondents were more likely to make those choices when the cost information was displayed with quality information that was easy to interpret and process (a strong quality signal), compared to situations with no quality information or quality information that was difficult to interpret. Respondents were also more confident in their choices when there was a strong quality signal.

We found that the using dollar signs to indicate the cost of care, as is currently done in some public reports, was the least effective of the approaches we tested. It appears that consumers worry that a low-cost provider is a substandard provider. Furthermore, the findings indicate that people in health plans with high deductibles responded no differently than those in traditional plans. This fact suggests that even consumers who have to pay a comparatively large share of the cost themselves are still likely to equate high cost with high quality.

Sponsors of comparative reports can use this study’s findings to create more-effective reporting formats. Being aware of the potential misinterpretations of cost data and communicating this information more effectively will be important steps toward stimulating high-value consumer choices. Because providers identified as lower cost raise consumers’ concerns about substandard care, designing reports that send a strong quality signal alongside cost data is essential. Cost information that communicates something about quality, as the PROMETHEUS measures do, or cost that is shown along with quality information, will help overcome these fears.

**Conclusion**

Approaches for reporting quality information have been slowly evolving toward strategies that help consumers process and use the information in making choices. The process is far from complete. Many reports are still difficult to com-
prehend and use. For example, many still use technical language when they label quality indicators and report different aspects of quality on different pages, making it almost impossible to assess overall quality.

The findings from this study indicate that when a quality signal is not strong, cost information is less likely to be interpreted and used in the way it was intended. In reports that present data on both cost and quality, even more is at stake when the reporting strategies used are ineffective. With quality information alone, the risk of providing information that is hard to understand is that it is less likely to be used. When cost data are added, the risk is that the information will stimulate people to make choices opposite to the ones intended.

Consumers are more interested in the quality of health care than in its cost. Reporting strategies that will get consumers’ attention and help them use the data are those that interpret the data and help consumers see that a doctor who provides higher-quality care than other doctors does not necessarily cost more. ■

NOTES


9 To access the Appendix, click on the Appendix link in the box to the right of the article online.


ABOUT THE AUTHORS: JUDITH H. HIBBARD, JESSICA GREENE, SHOSHANNA SOFAER, KIRSTEN FIRMINGER & JUDITH HIRSH

In this month’s Health Affairs, Judith Hibbard and coauthors report on research that throws cold water on the notion that consumers will instinctively use data about health care quality to seek out providers who give the best care at the lowest cost. In their study of 1,421 employees, they found that a “substantial minority” shied away from low-cost providers and equated high health care costs with high quality. However, the authors say that when they presented cost data to respondents alongside easily interpreted quality information and highlighted high-value options, respondents were more likely to choose those options.
“There is actually very little known about how consumers might respond to and interpret cost data,” says Hibbard. “We were most surprised that plan design did not affect how participants made choices. Participants enrolled in high-deductible plans behaved no differently than people enrolled in traditional HMO [health maintenance organization] or PPO [preferred provider organization] plans. This suggests that paying more out of pocket does not change consumers’ thinking about the cost and the quality of their care.”

Hibbard is a senior researcher at the Institute for Policy Research and Innovation and a professor emerita in the Department of Planning, Public Policy, and Management at the University of Oregon. Over the past twenty-eight years, she has focused her research on consumer choices and behavior, with a particular emphasis on testing approaches that give consumers and patients more knowledge and control over their health and health care. Hibbard’s studies examine such topics as how consumers understand and use health care information, how health literacy affects choices, and assessments of patient engagement.

Hibbard holds a master’s degree in public health from the University of California, Los Angeles, and a doctorate in social and administrative health sciences from the School of Public Health at the University of California, Berkeley.

Jessica Greene is an associate professor in the Department of Planning, Public Policy, and Management at the University of Oregon. Her research focuses on the roles that individuals and clinicians play in improving health and health care quality—in the latter case, particularly, how to support individuals to make informed choices. Greene holds master’s degrees in public health and international affairs from Columbia University, and she earned her doctorate in health policy and management from New York University.

Shoshanna Sofaer is the Robert P. Luciano Professor of Health Care Policy at the School of Public Affairs at Baruch College, City University of New York, where she conducts research and publishes on topics including the design and dissemination of public reports on comparative health care quality and cost. She received her master’s degree and doctorate in public health from the University of California, Berkeley.

Kirsten Firminger is a doctoral candidate in social psychology at the Graduate Center of the City University of New York. Trained in both qualitative and quantitative methods, she has worked extensively with Sofaer on how best to provide health care quality information to the public. Firminger received bachelor’s degrees in psychology and anthropology from the University of Michigan.

Judith Hirsh is director of consumer strategy and programs at the Health Improvement Collaborative, a nonprofit organization in Cincinnati, Ohio, that brings together major stakeholders—including physicians and other providers, health systems, hospitals, employers, health plans, and community organizations—to work together on transforming health care delivery. Hirsh holds two master’s degrees, one in international relations from the George Washington University and another in marketing from Virginia Polytechnic Institute.

Jessica Greene is an associate professor at the University of Oregon.
Engaged Patients Will Need Comparative Physician-Level Quality Data And Information About Their Out-Of-Pocket Costs

ABSTRACT For patients to be engaged, they will need meaningful and comparable information about the quality and cost of health care. We conducted a literature review and key-informant interviews, reviewed selected online reporting tools, and found that quality and cost reporting fell into two categories. One emphasizes public reporting of information, supported by philanthropic or government institutions that aim to improve provider quality and efficiency. The other is characterized by proprietary websites that aim to provide personalized, integrated information on cost and quality to support consumers’ decision making on providers and services. What consumers seem to want is quality data at the physician level and cost data that reflect their personal out-of-pocket exposure. These needs will be acute under the coverage expansions inherent in the Affordable Care Act. State and federal policy thus should support all-payer claims databases, standards for electronic health records to facilitate sharing of quality data, and a unified approach to presenting information that prioritizes consumers’ needs.

When consumers are presented with information about health care quality in a controlled research environment, they are capable of using the information effectively to choose better-performing providers. But what level of information seeking and use occurs in the real world?

Surveys over the past decade reflect a troubling trend. A minority of Americans report having seen comparative health care quality information, and the percentage appears to be declining. A 2008 survey found that only 30 percent of Americans reported seeing any type of comparative health care quality information in the past year—down from 36 percent in 2006 and 35 percent in 2004. In addition, several recent studies suggest that public reporting of health care quality information has not significantly affected consumers’ selection of health care providers or market share, or that the results have been mixed. These results are disappointing in light of decades of effort and investment in the measurement and public reporting of health care quality data.

Now, through the Affordable Care Act, public reporting of cost and quality data is about to increase greatly. The act includes a wide array of provisions related to public reporting, including the creation of a national strategy for quality improvement, development of quality measures, and provider reimbursement based on cost and quality.

The law also expands coverage to millions of previously uninsured people, who will need to select health plans and providers beginning in 2014. By 2020 more than twenty-seven million people are expected to obtain their health insurance through health insurance exchanges.

Sec. 1311 of the Affordable Care Act requires exchanges to “maintain an Internet website...”

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through which enrollees and prospective enrollees of qualified health plans may obtain standardized comparative information on such plans.”

The provisions of the Affordable Care Act embody a vision of informed, engaged consumers using publicly reported information to make value-based decisions. Realizing this vision requires a clearer understanding of consumers’ priorities for cost and quality information and a tighter link between those priorities and reporting efforts.

In this article we provide an overview of key factors found to influence consumers’ demand for information on quality and cost. We then summarize evidence related to high-priority content from the consumer perspective, followed by best practices in presentation of information.

Finally, we present early insights from emerging models for delivering online quality and cost information to consumers. We offer practical guidance throughout for those developing and disseminating quality and cost information, and we conclude by identifying opportunities for various stakeholders in the health care system to improve the availability and usability of data to guide consumers’ decision making.

**Study Data And Methods**

We conducted three major activities: a targeted literature review, key-informant interviews, and a review of selected online cost and quality reporting efforts.

**LITERATURE REVIEW** Our first activity, a targeted review of the public reporting literature, was based on an organizing framework that described consumers’ ability to access, understand, and use quality and cost information, as influenced by two sets of factors.

One set comprised individual consumer traits, including knowledge, attitudes, and beliefs about health care quality and cost, and motivation to seek and use information. The other set comprised characteristics of currently available, publicly reported quality and cost information, including availability, accessibility, and how information is displayed.

Our framework, keyword search terms and results, and list of resources reviewed are described in detail in the online Appendix.

**INTERVIEWS** Next, we conducted key-informant interviews with leaders of active initiatives designed to meet consumers’ health care quality and cost information needs: Castlight, Change Healthcare, Aetna, Maine Health Management Coalition, and Consumers Union. The purpose of these interviews was to gain insights from exemplar organizations in an evolving environment, not to describe the full range of reporting efforts.

We asked these key informants about efforts to develop and deliver cost and quality information for consumers, consumer and stakeholder response, and perspectives on how to encourage consumers’ use of cost and quality information.

**REVIEW OF REPORTING EFFORTS** Finally, in conjunction with the interviews, we conducted a review of web-based quality and cost reporting efforts that interviewees either were engaged in or recommended for our review.

**FOCUS ON ONLINE SOURCES** Our literature review included research on both online and print information for consumers, since much of the evidence related to effective content selection and display is relevant across different types of media. However, our review of existing efforts focused on online approaches, which are becoming the preferred and predominant vehicle for consumer-targeted cost and quality information.

Online approaches provide greater reach, facilitate regular updates as information changes, and offer more opportunities to tailor content to the diverse needs of target audiences. They make use of such features as navigation and drill-down capabilities—allowing people interested in more information to click through to obtain additional detail—and cost calculators that take insurance plan benefits into account.

**Study Results**

**CONSUMERS’ INTEREST** Although consumers express interest in comparative cost and quality information, awareness and use of it remain low. Our literature review and key-informant interviews identified at least three reasons that may help explain why consumers say they are interested in cost and quality information yet make minimal use of it.

First, many people are unaware of the extent to which quality varies within the health care system. As a result, they are not motivated to seek information on key quality issues.

Second, much of the population—at least, the insured population—has been largely insulated from out-of-pocket expenses at the point of service. Out-of-pocket spending on health services decreased between 2006 and 2009, while out-of-pocket spending on premiums remained stable. When given relatively little cost-sharing responsibility, consumers lack incentives to consider value in decision making.

Finally, consumers’ interest in quality and cost information may be influenced by the inadequacy of existing resources and means for obtaining that information. Lackluster response from consumers may reflect issues with availability of relevant data and design of the tools
to deliver those data, rather than a lack of interest in comparative assessment of quality and cost.

In spite of these barriers, some groups of consumers are indeed interested in comparative quality and cost information. Consumers who are best primed to use such information fall into several categories.

First are those who have financial “skin in the game,” such as those with high-deductible health plans or other types of greater cost-sharing exposure. Another group consists of those with benefit designs that encourage cost-conscious choice of providers, such as reference-based pricing.

Yet another comprises those with “shoppable” conditions that both afford the time and provide the motivation to seek and compare information, such as patients contemplating elective procedures including joint replacement and bariatric surgery. Finally, those in need of maternity care and those seeking low-complexity, routine procedures such as colonoscopies round out the types of patients who are best positioned to use information on cost and quality.

Targeting consumers such as these, with higher out-of-pocket cost exposure and shoppable conditions, may be a promising strategy for efforts aimed at engaging consumers in using cost and quality information to make decisions. Nevertheless, even highly motivated consumers are likely to abandon efforts to obtain information when the information is difficult to find or understand.

For quality and cost information to be meaningful, salient, and useful, it needs both to reflect consumers’ priorities for content and to be presented in a way that makes the content accessible and understandable.

**Consumers’ Priorities** In this section we describe characteristics of effective quality and cost reports in terms of content and presentation, gleaned from the results of our targeted literature review and key-informant interviews.

Public reporting initiatives on health care quality and cost have made great strides over the past two decades. Yet they continue to be limited in some respects by the lack of availability of data that consumers find truly relevant and useful. Cost and quality data reporting—as well as upstream efforts to develop measures and gather data—should target the key components of information outlined below, to maximize consumers’ interest and engagement in the results.

**Quality Information** Current quality reports generally capture elements that resonate with experts and health care professionals, such as mortality rates and clinical quality measures, whereas consumers are often more interested in quality information that reflects elements of the patient experience or service quality.

In addition, although consumers prefer condition- or procedure-specific information reported at the individual physician level, most publicly reported quality information is neither condition- nor physician-specific; rather, it focuses on the general performance of hospitals, medical groups, or health plans.

Some local quality-reporting initiatives aim to provide clinical performance information at the individual physician level, whereas more broadly available websites such as Yelp and Vitals tend to reflect patient reviews as opposed to performance on validated quality measures or defined outcomes.

While recognizing the constraints of available data, quality reports should include as much information as possible at the level of the individual physician. Furthermore, technical aspects of quality, such as readmissions and avoidable complication rates, should be paired with more intuitive information, such as patient experience, to engage consumers and demonstrate relevance.

**Cost Information** On the cost side, consumers want to know their own out-of-pocket expenses for specific services with specific providers, given their insurance benefits. These expenses include deductibles, copayments, and any other cost sharing. Many current public reporting initiatives give total or average charges for specific services—information that is too general to meet most consumers’ specific needs.

Consumers also want information for a complete episode of care rather than for individual services delivered as part of that care. For example, if consumers are given a cost estimate for a surgical procedure, they do not want to be surprised by additional costs associated with the procedure such as anesthesiologist fees. Most useful is “price information that incorporates any negotiated discounts; is inclusive of all costs associated with a particular health care service; and identifies consumers’ out of pocket costs.”

Consumers also are likely to value cost information that is related to nonsevere, nonurgent conditions; elective procedures; or standard services that probably do not require tailoring to individual patients’ needs, such as immunizations, cholesterol screening, and colonoscopies.

**Integrated Information** When cost information is presented without accompanying quality information, consumers tend to perceive price as a proxy for quality—that is, they assume that higher cost equals higher quality. However, when price information is accompa-
Therfor, for comparative information to be truly meaningful, consumers need to be able to compare quality and cost information simultaneously for the various options they may be contemplating.

**Effective Presentation** Public reporting of health care cost and quality information needs to make use of the large body of accumulated evidence about how to present and display such material most effectively. Drawing on our review of the literature, we identified several best practices in public reporting that are inconsistently applied in practice.

Ideally, comparative reports should include a variety of techniques to help users comprehend the data, understand their personal relevance, and make choices that reflect a combination of the evidence and their personal preferences.

**Visual Display:** Research suggests that formatting and visual display of numeric data exert strong influence over how easily consumers are able to interpret and use comparative quality information. Elements of effective design include simple, clean formatting; a limited amount of information on one page; and minimal visual complexity. Overuse of graphics, typefaces, and colors distracts from the core information or complexity. Overuse of graphics, typefaces, and colors detracts from the core information or complexity.

Effective formatting and visual display also present data in ways that make it easier to identify high and low performers through the use of rankings and visual cues such as shading, coloring, or symbols to emphasize important distinctions. Symbols are most effective when accompanied by words that reinforce their meaning, such as "above average." 

**Labeling and Framing:** Clearly worded and descriptive labels can help users by providing cues about the meaning of data in terms of performance. An example would be a report that portrays physicians’ "appropriate use" of a medical procedure instead of simply reporting that their use of the procedure was low, medium, or high. Such descriptive labels have been shown to be particularly effective when people are processing complex or unfamiliar information. Relating these measures to a larger quality framework increases consumers’ understanding and the perceived value of the information to consumers.

**Context:** When asked, consumers report preferring information that reflects multiple aspects of health care quality. Yet we know that when consumers are presented with large volumes of information, they become overwhelmed and have difficulty synthesizing it, and their choices suffer. Consumers’ comprehension can be improved by the addition of limited but meaningful context to comparative cost and quality information. Examples of such contextual information include explanatory information, narratives, and real-life examples.

Understanding the context can help consumers grasp how quality and cost information is relevant to their personal situation. By enabling connections between information consumers inherently value, such as patient experiences of care, and other aspects of quality, such as hospital-acquired infection rates, information sources can provide a "bigger picture" to consumers seeking that information.

Contextual information can counteract consumers’ beliefs that interfere with their effective use of the data—for example, by illustrating that higher costs do not necessarily imply higher quality. It can also help consumers understand how to interpret seemingly contradictory information, such as data showing that a given provider performed well on one quality measure but poorly on another. Ultimately, contextual information can help consumers make more-informed choices.

Online environments have several features that facilitate the provision of contextual information. Drill-down capabilities are a particularly noteworthy example of the advantages of delivering information online, allowing consumers interested in more information to click through to details while streamlining displays for others who are satisfied with the level of information as presented.

**Emerging Models**

To meet consumers’ demand, real or anticipated, for health care quality and cost information, a number of companies and programs have emerged in the public and private sectors. Funding for these ventures has come from several sources, including venture capital, foundations, governments, and insurance plans. Our analysis found that these health care cost and quality initiatives fall into two categories: "transparency for the greater good" and "one-stop shopping." Each category, or model, has its own distinct objectives and features (Exhibit 1). The health care quality and cost reporting programs that fall under the "transparency for the greater good" model tend to be nonprofit and government initiatives focused on improving quality and efficiency, engaging consumers, and increasing awareness of variation in quality and cost. In contrast, the programs that fall under the "one-stop shopping" model tend to be private-sector initiatives that aim to provide

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Nobody
personalized, integrated information on cost and quality to support consumers’ decision making regarding care providers and services. These models are neither comprehensive nor definitive, but they provide preliminary insights into opportunities and challenges for parties engaged in efforts to inform consumers.

**TRANSPARENCY FOR THE GREATER GOOD**

Multistakeholder collaboratives across the country have long been engaged in efforts to increase transparency on both the quality and the cost of health care, with the dual objectives of supporting consumers’ decision making and driving provider improvement.26 Steady support and investment from philanthropic and government sponsors, combined with long-term commitment by these collaboratives to work through many challenging issues, have produced websites that give consumers access to increasingly broad and deep health care quality and cost information. These ventures have surmounted a number of challenges, include overcoming provider resistance, developing accepted measures of quality and cost, and building and launching the websites.

Examples of successful initiatives abound. The Robert Wood Johnson Foundation’s Aligning Forces for Quality sites, the Agency for Healthcare Research and Quality’s Chartered Value Exchanges, and a wide array of regional and state-specific initiatives have made substantial contributions to furthering the evidence base related to both the content and the reporting practices for cost and quality information.

Massachusetts Health Quality Partners, a multistakeholder coalition, recently partnered with Consumer Reports to create an accessible, consumer-friendly report on primary care quality in Massachusetts that includes both clinical and patient experience. Funded in part by the Robert Wood Johnson Foundation, the information was published in Consumer Reports using

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**EXHIBIT 1**

**Emerging Models For Delivering Consumer-Oriented Quality And Cost Information**

<table>
<thead>
<tr>
<th>Transparency for the greater good</th>
<th>One-stop shopping</th>
</tr>
</thead>
<tbody>
<tr>
<td>Goals</td>
<td>Improve quality and efficiency, engage consumers, increase awareness of variations in quality and cost</td>
</tr>
<tr>
<td>Organization type</td>
<td>Multistakeholder coalitions, state agencies; usually nonprofit</td>
</tr>
<tr>
<td>Cost data</td>
<td>Most often average charges but may feature negotiated rates; data sources include multipayer claims data and statewide discharge databases</td>
</tr>
<tr>
<td>Quality data, physicians</td>
<td>Partial list of sources: Clinician and Group Consumer Assessment of Healthcare Providers and Systems (patient experience); Ambulatory Care Experience Survey (patient experience); Healthcare Effectiveness Data and Information Set (clinical quality)</td>
</tr>
<tr>
<td>Quality data, hospitals</td>
<td>Partial list of sources: Centers for Medicare and Medicaid Services (clinical quality and patient experience); Leapfrog Group (patient safety); Statewide discharge databases (clinical quality); Healthcare Facilities Accreditation Program (clinical standards, patient safety); Joint Commission (clinical standards, patient safety)</td>
</tr>
<tr>
<td>Business model</td>
<td>Philanthropic funding; Government funding (for example, mandated availability of cost information for consumers); Offering of tools to customers as value-added service</td>
</tr>
<tr>
<td>Examples</td>
<td>New Hampshire HealthCost, Massachusetts Healthcare Quality Partners, FAIR Health, Chartered Value Exchanges, Aligning Forces for Quality sites</td>
</tr>
</tbody>
</table>

**SOURCES** Key-informant interviews, authors’ analysis.
a four-point rating system. It is also publicly available online through Massachusetts Health Quality Partners at http://mhqp.org.

The online version permits searches by location, physician, and medical group, with drill-down information on methods, data sources, and measures. However, cost information is not included in either version—an omission that could make the reports less useful to consumers. Moreover, even if cost information were included, Massachusetts Health Quality Partners does not have easy access to the two main components of personalized cost information for consumers: benefit design and negotiated provider rates.

Other multistakeholder collaboratives that have worked to incorporate cost and quality information have focused on measures of total cost and resource use—measures with salience for providers and purchasers but not consumers. For example, the Wisconsin Collaborative for Healthcare Quality offers information on severity-adjusted hospital charges for treating several conditions. Quality Health Together, a project of the Kansas City Quality Improvement Consortium, provides information on the median Medicare payment for a number of procedures.

On the cost side, a number of states are launching multipayer claims databases that allow for public reporting of provider-specific costs of services and procedures. Many of these databases provide differential estimates for insured versus uninsured consumers that account for discounted provider rates negotiated by health plans on behalf of their enrollees.

New Hampshire’s site, NH HealthCost, goes further than most by providing estimates based on provider rates negotiated by each health plan. To ensure that the cost estimate is as customized as possible, the interface asks consumers to enter their own benefit design parameters, such as their deductible and coinsurance, which the resulting estimate takes into account. Other states, such as Maine, provide average negotiated rates across plans.

**ONE-STOP SHOPPING** Organizations offering “one-stop shopping” include third-party vendors under contract to employers or health plans as well as health plans marketing services to employers. The central objectives of these companies are aggregation, customization, display, and delivery of information to consumers.

Two vendors that have gained increasing attention are Castlight and Change Healthcare. Both companies are for profit and venture funded, and both provide integrated cost and quality information through a web interface. As proprietary companies, these services are available only to organizations willing to purchase the services on behalf of their employees or members and therefore have limited accessibility to the general public.

Because each organization has access to enrollee-specific data on benefit design and provider-specific negotiated rates, their websites can generate tailored cost estimates for services and procedures that take into account the individual’s deductible, cost-sharing provisions, and providers. The sites also offer a variety of consumer-friendly features, such as personalized, up-to-date medical spending graphics, provider maps, and e-mail alerts of savings opportunities for subscribers.

These sites demonstrate a strong orientation to what consumers want from cost data. Yet they still face challenges in balancing consumers’ demand for physician-level quality information and the availability of reliable measures. Although quality information about medical groups is increasingly available, detailed individual physician-level quality information is not available on a national basis from standardized, validated data sources.

The Affordable Care Act mandates the development of physician-level quality data to be provided through Medicare’s existing Physician Compare website. The Centers for Medicare and Medicaid Services reports its intention to phase in an expansion of physician quality measures over the next several years. The first phase of new measures, from the Physician Quality Reporting System, is anticipated to occur no sooner than 2014, with data reported at the group practice level rather than for individual physicians. In addition, the law contains a number of requirements that could delay implementation, including giving physicians the opportunity to review results before they are made public.

In the interim, “one-stop shopping” sites have developed alternative approaches to meeting consumers’ demand for information at the level of the individual physician. Castlight displays physician-level patient experience data from Vitals (http://www.vitals.com), a website that invites people to rate their physicians. Change Healthcare has relied on data from Healthgrades (http://www.healthgrades.com), an organization that compiles and sells publicly available data on physician certification, sanctions, and medical malpractice. Change Healthcare recently made the transition to proprietary data sources for physician-level information.

Health plans are well positioned for meeting consumers’ interest in cost and quality information, given that they routinely survey enrollees regarding patients’ experiences with inpatient care.
care and have complete information on enrollees’ benefit designs and negotiated rates with providers. Although they have been slow to develop customized information that aligns with consumers’ interests, the pace is now picking up, particularly on the cost side.

Aetna’s Member Payment Estimator tool is an example of a health plan initiative aimed at delivering provider-specific cost information for services or procedures in real time to enrollees before they obtain services. The tool, available only to Aetna members, takes enrollees’ benefit design parameters—deductibles and coinsurance—into account in returning the cost estimates.\(^33,34\)

Aetna’s physician-level quality information is more limited and is accessible with a separate, publicly available tool, known as DocFind (http://www.aetna.com/docfind/home.do). This tool offers some provider-specific information, including network participation; board certification; and the availability of online visits, e-prescribing, and personal health records. Quality ratings are not included, except to the extent that they are signaled through the inclusion of specific physicians in Aetna’s networks of high-performing providers, such as its Aexcel network. This network features providers in twelve specialties who meet standards Aetna has adopted for clinical quality and cost-efficiency.

UnitedHealthcare and Anthem have also developed tools. United’s myHealthcare Cost Estimator (http://www.uhc.com/individuals_families/member_tools/myhealthcare_cost_estimator.htm) provides members with treatment cost estimates based on United’s claims database, while its Premium Designation Program recognizes physicians and specialty centers that meet criteria for quality and cost-efficiency (http://www.uhc.com/physicians/care_programs/unitedhealth_premium_designation.htm). Anthem offers a “Find a Doctor” tool at its central website, with limited information available to nonmembers (http://www.anthem.com/health-insurance/provider-directory/searchcriteria?qs=*bnIC7RuSLFU3qSduJIdOQ==&brand=abchs); its cost estimator tools vary from state to state.

**Discussion And Policy Implications**

As the market continues to evolve to produce tools that meet the needs of consumers, data limitations affect the feasibility of comprehensive reporting. To be credible, quality information requires adequate sample sizes and attention to the validity of measures and data. The effort and resources required to define standardized measures and gather robust quality data indicate the need for collective investment and collaborative reporting mechanisms.

In contrast, cost information is most useful to consumers when it combines provider cost data with information on consumers’ own insurance benefits. At present, cost data are most often obtained through proprietary administrative sources, which limits their availability for public reporting.

Notwithstanding the distinct features and sources of quality and cost data, consumers’ strong preference for integrated information indicates that there remains a need to pull these data sources together in a way that enables consumers to easily understand and access them.

For these reasons, we anticipate increasing experimentation with integration of cost and quality data for consumers over the next few years through both the creation of new initiatives and partnerships among those already participating in this field. Indeed, third-party vendors such as Castlight are already expanding partnerships with providers of quality data, including multistakeholder collaboratives as described above, to bolster existing offerings and complement proprietary individual-level cost data.

In addition to increasing data availability, partnerships with nonprofit organizations or government entities that are viewed as neutral and unbiased could add credibility to proprietary reporting efforts, given research findings indicating consumers’ diminished likelihood of trusting information from health plans and employers.\(^35\) In turn, collaborations with vendors and health plans present a revenue-generating opportunity for organizations whose mission is the development of quality data, and they may provide a partial solution to the problems of sustainability that many such efforts encounter.

Researchers and policy makers alike have postulated that interest in and demand for health care cost and quality information will grow in the coming years as deductibles climb, value-based benefit design takes hold, and the public gains exposure to variations in quality and cost through mainstream media reports.\(^36–38\) Even as private-sector partnerships evolve to meet this demand, policy makers will need to support more robust availability and quality of data. Statewide all-payer claims databases or other mechanisms that provide access to out-of-pocket cost information—information that reflects benefit limitations and negotiated prices or allowed amounts—can ensure that the cost information that consumers are most interested in is not restricted to proprietary uses.

Electronic health record standards that allow for the consistent collection and analysis of
clinical data across provider installations would facilitate the availability of comparable quality information. Reporting entities need to lower the burden on consumers to track down and use information; one possibility is coordination among data measurement and reporting entities to create a unified consumer interface instead of sponsoring distinct websites.

**Conclusion**

Realizing the vision of integrated, timely, and relevant health care cost and quality information for consumers requires a clear understanding of consumers’ priorities, consistent attention to principles of effective display of information, and collaboration across organizational boundaries. State and federal policy makers can spur the creation and use of consumer-oriented information by supporting all-payer claims databases to facilitate sharing of cost data, standards for electronic health records to facilitate sharing of quality data, and a unified approach to presenting information that prioritizes the consumer over competing agency agendas. The payoff will be informed, engaged consumers who base their health care decision making on evidence.

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**Support for this research was provided by the California HealthCare Foundation. The authors gratefully acknowledge the contributions of Allison Fratto, Jiani Yu, and Brenna Doyle, who contributed to the targeted literature review and key-informant interviews.**

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**NOTES**

7 To access the Appendix, click on the Appendix link in the box to the right of the article online.
9 Cunningham PJ. Despite the recession’s effects on incomes and jobs, the share of people with high medical costs was mostly unchanged. Health Aff (Millwood). 2012;31(11):2563–70.
20 Peters E, Dieckmann N, Dixon A, Hibbard JH, Mertz CK. Less is more...


26 Young GJ. Multistakeholder regional collaboratives have been key drivers of public reporting, but now face challenges. Health Aff (Millwood). 2012;31(3):578–84.


engagement component of the Agency for Healthcare Research and Quality’s Community Forum project, a three-year initiative to identify innovative and effective approaches for expanding public and stakeholder participation in comparative effectiveness and patient-centered outcomes research. She received a doctorate in health services and policy analysis from the University of California, Berkeley.

Pam Dardess is a senior research analyst at the American Institutes for Research. She has particular expertise in the areas of patient and consumer engagement; health care quality and cost reporting; and the development and testing of health education and information materials for patients, families, and clinicians. Dardess serves as the project director for the Agency for Healthcare Research and Quality’s effort to assess the effects of an intervention to increase relevancy and use of public reports of quality information and its effort to develop, implement, and evaluate a Guide to Patient and Family Engagement in Hospital Safety and Quality.

Dardess holds a number of other leadership positions, including senior researcher for the California HealthCare Foundation’s Consumer Use of Cost and Quality Information project. She received a master’s degree in public health from the University of North Carolina at Chapel Hill.

Pam Dardess is a senior research analyst at the American Institutes for Research.

Maribeth Shannon is the director of the California HealthCare Foundation’s Market and Policy Monitor program. Maribeth Shannon is the director of the California HealthCare Foundation’s Market and Policy Monitor program, which promotes greater transparency and accountability in California’s health care system. She is responsible for the management and development of the foundation’s initiatives to further transparency in the state’s health care system.

In particular, Shannon focuses on increasing the availability and usefulness of health care data, reporting of market trends, advancing health care performance measurement and reporting, and increasing the availability and usefulness of information and tools. She received a master’s degree in health administration from the University of Colorado.

Maribeth Shannon is the director of the California HealthCare Foundation’s Market and Policy Monitor program.

Kristin L. Carman is a managing director of the American Institutes for Research’s Health Program and, as noted, codirects the institutes’ Health Policy and Research Group with Yegian. Her work emphasizes explaining evidence-based information for use in decision making. Carman has led many consumer engagement research and technical assistance projects, and she currently leads multiple projects funded by the Agency for Healthcare Research and Quality and the Robert Wood Johnson Foundation. She earned both a doctorate and a master’s degree in human development and social policy from Northwestern University.

Kristin L. Carman is a managing director of the American Institutes for Research’s Health Program.
Collaborate, Innovate & Sustain

These words characterize Massachusetts Health Quality Partners’ (MHQP) approach to improving the quality of health care in Massachusetts. In 2012, MHQP member organizations and their leaders continued to guide MHQP in fulfilling its mission and vision while contributing time and valued resources toward collective efforts. As a result, MHQP has been at the center of groundbreaking work in measurement and reporting, primary care innovation, and patient and public engagement.

In short, many of MHQP’s 2012 efforts were focused on the following themes:

1. Developing and implementing quality improvement models that produce and sustain better health and better care at lower costs;
2. Expanding effective models for patient, family, and community engagement in system change, policy development, and patient care;
3. Helping Massachusetts health care stakeholders meet the evolving demands of payment and system reform; and
4. Bringing together the multiple and often disparate perspectives of Massachusetts health care stakeholders in the interest of collaborative action.

MHQP Continues its Leadership in Advancing Patient Centered Care

Our long-term, collaborative commitment to patient experience measurement, reporting, and quality improvement has propelled MHQP’s Patient Experience Survey (PES) initiatives into the spotlight, both locally and nationally.

MHQP partnered with Consumer Reports to publish the magazine’s first-ever ratings of primary care providers. Consumer Reports used MHQP’s 2011 PES results to develop a special Massachusetts supplement. The report also provided readers with practical information on how to improve their own patient care experience. In a Consumer Reports readership survey, 78 percent of Massachusetts subscribers said that physician group quality information was extremely or very important to them and 68 percent said they would like to see this information published annually. Extensive local and national media coverage helped drive more than 2000 unique visits to the MHQP website in a single day.

The National Committee for Quality Assurance (NCQA) is collaborating with MHQP to give Massachusetts physician practices the opportunity to have their MHQP 2013 Patient Experience Survey data submitted for NCQA’s Distinction in Patient Experience.

(continued on page 2)
These collaborative efforts are broadening and enhancing MHQP’s measurement and reporting capacity, while engaging a broader range of stakeholders, especially patients and families, to identify common ground in addressing complex problems.

MHQP and Newton-Wellesley PHO (NWPHO) partnered to integrate the administration of the Patient Experience Survey into NWPHO’s Patient Gateway. The Patient Gateway is a secure Web portal that allows patients fast and convenient access to their physician’s office and to their medical information. It is designed to increase communication, understanding, and active engagement among patients and their families in the interest of providing high-quality, patient-centered care. By fielding the Patient Experience Survey through the Patient Gateway, the practice can more effectively engage patients in their care and receive rapid feedback that can be acted upon in a timely manner.

MHQP Expands Role As a Catalyst for Collaboration and Quality Improvement

For more than 17 years, MHQP has brought groups and individuals together around a common vision that health care quality can be vastly improved through the measurement and reporting of reliable, trusted performance data. In 2012, MHQP stepped up the pace, convening coalitions and work groups to tackle child health quality, variation in health care quality and cost, and community engagement in quality improvement.

The Massachusetts Child Health Quality Coalition is focused on developing a comprehensive policy approach to child health and health care quality in the Commonwealth. It includes representation from parents, social and health service providers, doctors, dentists, hospitals, insurers, disease advocacy groups and state and local agencies. Multiple working groups have made important progress identifying gaps in care, exploring new measurement opportunities, and educating policy makers.

Healthier Roxbury, an initiative supported with RWJF Aligning Forces for Quality (AF4Q) funding, is helping to broaden MHQP’s connections with community-based leaders and residents committed to addressing longstanding public health concerns. This pilot project seeks to expand the engagement of Roxbury residents in improving health and health care in their neighborhood. Greater Boston AF4Q leadership and the Healthier Roxbury Advisory Group have endorsed this approach to increasing civic and personal engagement as integral to making an impact on quality and cost.

Practice pattern variation analysis and reporting (PPVA) has proven to be an effective driver of health care quality improvement within medical groups. In 2012, MHQP convened a broad, stakeholder task force to oversee the implementation of a multi-payer practice pattern variation analysis project that will move forward in 2013. The project will build upon our leading-edge work in using measurement to help practices identify opportunities for improvement where variations and gaps in care occur.

MHQP’s Patient and Public Engagement Council is made up of patients, family caregivers, and other members of the public who have been active in and have advocated for patient-centered care and for improvement in health care quality and affordability. PPEC members brought the patient and consumer perspective to MHQP’s initiatives in 2012 through participatory governance, strategic advice and direct project involvement.
MHQP Supports Exciting Innovations in Primary Care

In 2012, MHQP supported a number of initiatives that are closely aligned with the statewide cost and quality goals emerging from new payment and delivery system reforms. Specifically, MHQP has committed funding, technical assistance, and proven quality improvement models to helping the primary care delivery system improve behavioral health integration, care coordination and infrastructure.

A pilot program to address the complex needs of “super-utilizers” is underway thanks to a partnership between MHQP, Beth Israel Deaconess Hospital, and the Brookline Community Mental Health Center, with funding and technical assistance from RWJF through Greater Boston’s AF4Q designation. Super-utilizers, represent a relatively small number of very sick individuals with complex medical and social needs, who account for an inordinate number of emergency room visits and inpatient hospital stays within a community. The pilot includes technical assistance from Jeffrey Brenner and the Camden Coalition of Healthcare Providers, a group noted for its success in mapping out “hotspots” of high-cost patients in impoverished neighborhoods and developing a community care model that improves health outcomes and lowers costs for these individuals. The goal of the pilot is to test effective models that can be applied, where needed, throughout the Commonwealth.

Incorporating routine behavioral health screening and brief interventions into primary care is an increasingly effective way to improve care for patients with complex needs, provide services in patients’ usual care setting, and focus care on the “whole person” rather than on medical conditions alone. According to research by the Partners in Integrated Care (PIC) Consortium, 20-35 percent of primary care patients screen positive for depression and/or substance misuse that often goes unidentified and under-treated. MHQP was selected to participate in the PIC initiative, funded by the Agency for Healthcare Research and Quality (AHRQ), to spread this care model for integrating evidence-based behavioral health screening and treatment into adult primary care. The program partnership includes regional health improvement collaboratives in Pennsylvania, Wisconsin, and Minnesota.

Improving the patient care experience is becoming an integral part of quality recognition and compensation programs for provider organizations in Massachusetts. MHQP’s new Patient Experience Survey Quality Improvement Program was developed in 2012 to help practices respond to today’s evolving landscape and increased emphasis on providing patient-centric care. Good patient experience of care matters to patients and their families and correlates with better adherence to medical advice and treatment plans.

MHQP Partners with State Advancing a Common Measurement Agenda

This year brought continued opportunities for MHQP to work with Executive Office of Health and Human Services (EOHHS) agencies to develop a more comprehensive statewide measurement agenda that includes measuring care across commercial and publicly insured populations.

MHQP recently completed the Massachusetts Aligned Patient Experience Survey (MA-PES) project. This project was designed and conducted to efficiently meet the objectives of several state-level programs in Massachusetts by collecting data about patients’ experiences through a single survey. Programs participating in this effort were MassHealth, the Patient-Centered Medical Home Initiative (PCMI) and the Children’s Health Insurance Program Reauthorization Act (CHIPRA) Quality Demonstration Project.

MHQP partnered with MassHealth and project partners to collect and report data for commercially and publicly insured patients on CHIPRA’s 24 core measures of child health quality. Measures included prenatal through adolescent inpatient, out-patient, preventive, dental, and mental health care.

MHQP worked with MassHealth to analyze and compare MassHealth practice site HEDIS measure results with results from the commercially insured population. A key goal of the project was to assess the feasibility of comprehensive measurement program in the future across both public and commercial health insurance programs.
About MHQP
Massachusetts Health Quality Partners (MHQP) is a non-profit, broad-based coalition established in 1995 that provides reliable information to help physicians improve the quality of care they provide their patients and help consumers take an active role in making informed decisions about their health care.

MHQP’s mission is to drive measurable improvements in health care quality, patients’ experiences of care, and use of resources in Massachusetts through patient and public engagement and broad-based collaboration among health care stakeholders, including physicians, hospitals, health plans, purchasers, patient and public advocates, government agencies, and academics.

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Looking Forward to 2013

Development of MHQP’s consumer facing website continues with an anticipated launch date in the fall of 2013. The website will be a platform to meet the needs of patients and families for health care quality information that is accessible and easy to understand. The site will support people looking to become more informed users of the health care system.

The Greater Boston Aligning Forces for Quality Initiative (GBAF4Q) is expected to bring two more years of resources to the Greater Boston and Massachusetts health care markets beginning May 2013. This final phase of funding will focus on building a sustainable model of community-based infrastructure for improving the quality of health and health care in a community.

MHQP is actively committed to advancing the adoption of Patient Reported Outcome measures across health systems in Massachusetts for use both to improve individual patient care within the clinical setting as well as to provide aggregated information to help patients make more informed decisions about their care. Through GBAF4Q, MHQP is convening a broad base of health system, policy and consumer representatives for a full day launch event in late March to gain understanding of stakeholder priorities in the broad arena of patient reported outcomes, create opportunities to leverage ongoing activities collaboratively, and lay out a road map to scale efforts in Massachusetts that place the patient voice at the center of the process.
Special Report for Massachusetts residents

How Does Your Doctor Compare?

- Exclusive: Patients rate 487 adult, family & pediatric practices
- How to get the best care
- Quiz: Does your physician measure up?

Guide to Primary Care Physicians in Massachusetts Page 10
May 31, 2012

Dear Consumer Reports readers,

We are pleased to present a special insert on Massachusetts primary-care physician practices in the July 2012 edition of Consumer Reports. The Ratings shown in the following pages come from data provided by the Massachusetts Health Quality Partners (MHQP). That coalition of physicians, hospitals, health plans, purchasers, patient and public representatives, academics, and government agencies has worked to improve the quality of health-care services in Massachusetts since 1995, in part by collecting data on physician performance and making it public.

The data we present here focus on patient experiences with their doctors. Our hope is that by working with MHQP to make this important information accessible, we can help more Massachusetts citizens take advantage of it. You can learn more about the quality of care by going to MHQP’s website, www.mhqp.org.

Massachusetts primary-care doctors deserve applause for their support in the collection of this data, making it public, and collaborating with Consumer Reports and MHQP to make it widely available to consumers. They are among the first in the nation to do so.

Sharing performance data among providers is important, for several reasons. First, it generates conversations among doctors about techniques that lift the quality of care they provide to patients. And making this information available to patients leads to one of the most powerful forces driving improvement—educated health-care consumers.

We are able to do this project in part because of a generous grant from the Robert Wood Johnson Foundation related to a unique program called Aligning Forces for Quality. That program is the Robert Wood Johnson Foundation’s signature effort to lift the overall quality of health care in 16 targeted communities (including Massachusetts), reduce racial and ethnic disparities, and provide models for national reform. We think this effort is a good example of the foundation’s unprecedented commitment of resources, expertise, and training focused on turning proven practices for improving quality into real results.

We hope you find this information useful.

Sincerely,

John Santa, M.D.
Director,
Consumer Reports Health Ratings Center

Please note: We apologize that in an earlier version of these Ratings, two practices were inadvertently omitted. Those groups, Steward Medical Group - Waltham (page 12) and Harvard Vanguard Cambridge (page 21) are now included.
How does your doctor compare?

We rate adult, family, and pediatric physician groups in the Bay State

Looking for reliable information about physicians? Good luck. Doctor ratings are often little more than glorified popularity contests. The top-doctor lists found in magazines or on websites, for example, tend to be based on reputation or anecdotal reports, not hard data. And while advice from family and friends can be helpful, it is hardly comprehensive or scientific.

That’s why we’ve teamed with the Massachusetts Health Quality Partners (MHQP), a coalition of consumers, government agencies, hospitals, insurers, physicians, and researchers that is on the cutting edge of providing reliable, meaningful, and fair information about primary-care physicians to consumers.

Using a comprehensive scientific survey, they recently asked 47,565 adults and an additional 16,530 parents of children, all of whom had health insurance, about their experiences with their doctors. The findings provide important information about how well physicians communicate with their patients, coordinate medical care, know their patients, and whether patients would recommend their doctor to family and friends.

The survey also asks patients about their experiences with the rest of the office staff, such as nurses, receptionists, and the people who handle billing and insurance questions.

The scores for each doctor in a practice are pooled into one score. MHQP only scores practices that have at least three physicians.

Of course, medical care is complex, and patient experience is only one measure of quality. For example, it’s important to know how well a doctor helps patients manage conditions like arthritis, diabetes, high blood pressure, or high cholesterol. But patient experience can affect those clinical measures.

“If patients have a poor experience with their doctor, they’re not going to come back for their tests, they may not take their medications, and they may not learn how to manage these things themselves,” says Michael Cantor, M.D., quality medical director for the New England Quality Care Alliance. (To see how practices scored in those clinical measures, go to MHQP.org and click on “Clinical Quality in Primary Care.”)

Use the Ratings on the following pages to see how your doctor’s practice fared in the survey. On page 4 we give some highlights from the survey, and use questions from it to help you assess your relation-
ship with your doctor and how to improve it if necessary.

“The doctor is the medical expert, but you’re the expert about you and your child,” says Lester Hartman, M.D., the quality improvement director at Westwood-Mansfield Pediatric Associates, which got the top two scores in all categories. “It’s that collaboration between the doctor and the patient that results in the best health care for all involved.”

What we found

The good news is that whether you live in America’s medical capital of Boston, out in rural Western parts of the state, on the Cape, or anywhere else in the Bay State, you’re probably close to at least one high-scoring doctors’ practice. None of the seven regions in the state (see the map on page 9) scored better or worse overall than any other region.

The flip side: There are probably some low-scoring groups near you, too.

Most practices in the state earn one of the top two ratings across multiple measures in the survey. But nearly every practice has room for improvement. Only 13 of the 329 adult practices earned the highest score in all five Ratings categories. (See box, below, for details.)

And while practices that treat mainly children do better overall than those that treat adults, only one of the 158 pediatric groups in the state—Drs. Benjamin and Spingarn, in Newton—got top marks across all five patient-experience categories. (Note that practices that treat adults and those that treat children are ranked on somewhat different measures.)

Overall, scores for physician practices in Massachusetts have been on the upswing since the first patient-experience survey in 2005. Many practices have used the results to improve how they interact with patients (see “How Practices Can Improve,” on the facing page).

The survey also provides some information about Massachusetts’ 2006 health-reform law. While that law has increased demand for doctors, which might make it harder to find a new one, the survey shows that it hasn’t made it harder for people who already have a primary-care provider to get the care they need.

Rate your doctor

Below are 20 of the most important questions in the survey. They’re divided into six categories, which in most cases correspond to different areas in the Ratings chart, which starts on page 10:

• Communication
• Coordinating your care
• Getting to know you
• Working with the office staff
• Staying healthy
• Caring for your child

Use the questions below to score your doctor or the doctor who cares for your child. Then check the Ratings to see how your experience compares with those of other patients in the same practice, as well as how your doctor’s practice stacks up against other groups across the state.

Communication

Clear and honest communication with your doctor and other health-care providers can help keep you healthy and, if you get sick, recover faster, too. Research suggests that patients who take an active role in the doctor-patient relationship by asking questions, stating their symptoms clearly, and interrupting when necessary, have better outcomes. The ideal is shared decision-making: cooperation between an informed patient and the doctor.

1 How often did your doctor explain things in a way that was easy to understand?

☐ Never ☐ Usually
☐ Almost never ☐ Almost always
☐ Sometimes ☐ Always

Percent who said Always: 84 percent

What to do: Take detailed notes. Repeat your doctor’s instructions back in your own words to check that you got them right. If you’re confused, say so. Finally, consider bringing along a friend or relative, says Rosalind Joffe, from Newton, who has several chronic conditions and serves on the MHQP patient and public-engagement committee. “Even though I’ve gone through this for 35 years, I still don’t hear new information all that well,” she says, explaining why her husband often comes along. “I still get a little overwhelmed, and I don’t take as good notes.” If there are complicated instructions that need to be followed every day, she has her doctor write the instructions down.

2 How often did your doctor listen carefully to you?

☐ Never ☐ Usually
☐ Almost never ☐ Almost always
☐ Sometimes ☐ Always

Percent who said Always: 83 percent

What to do: Ask your doctors to repeat...
what you’ve told them, to make sure they hear you. If you still have concerns when you get home, ask for a follow-up appointment, on the phone even, and perhaps with a nurse practitioner or physician’s assistant who can spend more time with you. If you would like your doctor to make more eye contact, or sit when he or she talks with you, say so.

3 How often did your doctor show respect for what you had to say?

<table>
<thead>
<tr>
<th>Option</th>
<th>Never</th>
<th>Usually</th>
<th>Almost never</th>
<th>Almost always</th>
<th>Sometimes</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percent who said Always</td>
<td>3%</td>
<td>10%</td>
<td>20%</td>
<td>30%</td>
<td>40%</td>
<td>50%</td>
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</tbody>
</table>

What to do: Make sure your doctor knows about the care you get from other providers, including other physicians as well as acupuncturists, chiropractors, herbalists, and other alternative health-care practitioners. Explain why you saw them, what happened during the visit, and what treatments or drugs were prescribed. Make sure those providers communicate with your primary-care doctor, too. That can help you avoid duplicate care, drug interactions, and fragmented health care. Ask for copies of letters or reports that the specialist plans to send to your primary-care provider. Electronic health records can help doctors share information, but patients need to be in-
When your doctor ordered a blood test, X-ray, or other test, how often did someone from the office follow up to give you the results?

- Never
- Usually
- Almost never
- Almost always
- Sometimes
- Always

Percent who said Always: 72 percent

What to do: Your doctor should tell you when to expect test results and who will give them to you—and then deliver them as expected, even if they’re normal. “When practices have a system in place to send all test results to people, they’re less likely to miss positive results,” says Edgman-Levitan. If you don’t get your results, call. Ask for a written copy for your files, too, and see if the practice uses a secure online health portal that gives you access to test results and other information.

In the last 12 months, how often did your doctor seem to know the important information about your medical history?

- Never
- Usually
- Almost never
- Almost always
- Sometimes
- Always

Percent who said Always: 75 percent

What to do: During your first visit, your doctor should ask about your personal and family medical history. Mention all the prescription drugs, over-the-counter medications, and vitamins and other dietary supplements you take. Don’t forget to describe the surgeries or illnesses you’ve had. If necessary, research your family medical history and write it down. Finally, make sure your doctor records the information in your medical history.

How would you rate your doctor’s knowledge of you as a person, including values and beliefs that are important to you?

- Very poor
- Good
- Poor
- Very good
- Fair
- Excellent

Percent who said Excellent: 56 percent

What to do: It’s important for your doctor to know your living situation. For example, do you care for someone at home? Is there anyone to care for you? Your beliefs affect treatment decisions, too. For example, you might want to avoid medication or consider alternative treatments whenever possible.

Don’t get stuck in the waiting room

You shouldn’t have to wait weeks to make an appointment with your doctor. And once you get there, you shouldn’t routinely have to put up with long delays. If you have a pressing medical question, your doctor or someone in his or her office should be able to squeeze you in, or at least take a phone call. But as the chart below shows, patients often report problems with being seen promptly.

What to do: Try to make your routine appointments for checkups or follow-up visits as soon as you can—weeks or even months in advance. If you know you’ll be late or need to cancel, call right away—they might be able to move someone ahead, or take another patient if you cancel early. If you want an appointment on short notice but can’t be seen by your doctor, ask if a nurse practitioner or physician’s assistant could see you instead. Those professionals have advanced training that allows them to handle many medical issues. Also ask how the office handles problems that arise after business hours. Some nearby practices team up to offer expanded hours for urgent care. Larger practices might keep staff on duty for evenings and weekends for patients who find it difficult to make appointments during business hours or for urgent care.

<table>
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<tr>
<th>Percent of patients who didn’t always get ...</th>
<th>Adults</th>
<th>Children</th>
</tr>
</thead>
<tbody>
<tr>
<td>...an answer to medical questions they called in during office hours on the day they requested it.</td>
<td>42</td>
<td>19</td>
</tr>
<tr>
<td>...an appointment for care they needed right away.</td>
<td>38</td>
<td>21</td>
</tr>
<tr>
<td>...after-hours advice as soon as they needed it.</td>
<td>38</td>
<td>23</td>
</tr>
<tr>
<td>...an appointment for routine care as soon as they needed it.</td>
<td>39</td>
<td>32</td>
</tr>
<tr>
<td>...seen by their provider within 15 minutes after being taken to the exam room.</td>
<td>48</td>
<td>52</td>
</tr>
<tr>
<td>...taken to the exam room within 15 minutes.</td>
<td>60</td>
<td>57</td>
</tr>
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</table>
Cantor, a geriatrician, says frail, older patients sometimes have to choose among three competing goals: comfort, longevity, and function. Some invasive treatments might provide longevity, but at what cost to comfort and function? “Unless I understand clearly what the patient’s values are,” Cantor says, “I’m not doing my job.”

Working with the staff
Your experience in a doctor’s office depends on the staff as well as the doctor. That includes the other health-care providers, such as nurse practitioners and physician’s assistants, as well as the receptionist or the billing person. While most patients gave the staff high marks, the chart on the opposite page shows that there’s plenty of room for improvement.

How often were the front-office staff as helpful as you thought they should be?

- Never
- Usually
- Almost never
- Almost always
- Sometimes
- Always

Percent who said Always: 57 percent

What to do: Be patient, but let the staff know if you expect them to be more helpful. If you ask politely but firmly, for more help you are likely to get it. But if you don’t, follow up with the office manager or doctor.

How often did the front-office staff treat you with courtesy and respect?

- Never
- Usually
- Almost never
- Almost always
- Sometimes
- Always

Percent who said Always: 73 percent

What to do: If you have a disagreement or other unpleasant interaction with someone in the office, make sure your doctor or the office manager knows about it. It’s best to remain calm and polite, but don’t be shy. Will an apology make you feel better, or will you find it so difficult to work with the disrespectful staff member in the future that you would want to be seen by a different provider? Let them know how you feel.

Staying healthy
Quality health care means preventing disease, not just treating it. For example, your doctor should make sure you get the right screening tests and immunizations and take an active role in helping you lose weight or quit smoking. (Note that we don’t include Ratings on this measure because adult practices scored lower overall and could not be rated on the same scale as other categories.)

Did your doctor’s office remind you to get recommended preventive care, such as the flu shot, cancer screening tests, or an eye exam?

- Yes
- No

Percent who said Yes: 80 percent

What to do: Ask your doctor about the preventive screenings, tests, and vaccines that are appropriate for someone of your age and health. But even preventive care, like cancer screenings or heart tests, can have risks and benefits and aren’t right for everyone. For example, women who have had a hysterectomy usually don’t need Pap tests, and EKGs don’t need to be part of a routine exam unless you have symptoms of heart disease. So ask why the screening tests being recommended are needed.

Did you and your doctor talk about a healthy diet and healthy eating habits?

- Yes
- No

Percent who said Yes: 77 percent

What to do: If you’re worried about your weight or diet, tell your doctor. And don’t be offended if he or she brings it up. Diseases related to unhealthy eating and excess weight—including heart disease, some cancers, stroke, high blood pressure, osteoarthritis, osteoporosis, and type-2 diabetes—are among the leading causes of illness and death. Ask about getting support, like getting a referral to a certified nutritionist or a registered dietician.

Did you and your doctor talk about exercise or physical activity?

- Yes
- No

Percent who said Yes: 88 percent

What to do: Most Americans don’t get enough exercise, which can also lead to weight gain and several chronic diseases. The best exercise for you can depend on your overall health and goals. For example, people with arthritis might benefit from different exercises than someone who has diabetes or who needs to lose weight. Talk with your doctor about which makes most sense for you and, if necessary, ask for referrals to a physical therapist. Your doctor might even know about community resources, like gyms or fitness programs near you.

Did you and your doctor talk about things in your life that worry you or cause you stress?

- Yes
- No

Percent who said Yes: 68 percent

What to do: Stress can be as bad for your heart as excess weight, lack of exercise, and smoking. It can contribute to other diseases, too, such as type 2 diabetes, chronic pain, and depression. It can also undermine your immune system, which could make you susceptible to infection, and led to unhealthy behaviors, like excessive eating and drinking. So talk with your doctor about the stresses in your life, such as long hours at work, family troubles, or financial difficulties.

Did your doctor ask whether there was a period of two weeks or more when you felt sad, empty, or depressed?

- Yes
- No

Percent who said Yes: 39 percent

What to do: Asking simple questions about emotional health can be surpris-
Caring for your child
Parents were asked about how well their children’s doctors addressed preventive health care, but the questions differed from those that were asked about their own care, because the advice for children and adults differs. (Note that parents were also asked some of the same questions about working with the office staff, communicating with doctors, and other topics as were other adults. See “Don’t Get Stuck in the Waiting Room” on page 6.)

16 Did your child’s doctor talk about how your child’s body is growing?
- Yes
- No
Percent who said Yes: 90 percent

What to do: If your child’s growth in height or weight differs substantially from what’s expected, talk with your doctor about what might be the cause and what, if anything, should be done.

17 Did your child’s doctor talk about how much or what kind of food your child eats?
- Yes
- No
Percent who said Yes: 89 percent

What to do: Childhood obesity, which has reached epidemic proportions and now affects more than 12 million U.S. children, can lead to type 2 diabetes, high blood pressure, liver disease, and a host of other health problems. So talk with your physician about your child’s dietary and exercise habits, especially if you’re worried about his or her weight.

18 Did your child’s doctor talk about things you can do to keep your child from getting injured?
- Yes
- No
Percent who said Yes: 71 percent

What to do: Accidental injuries are a leading cause of death and disability among young children and teenagers.

19 Did your child’s doctor talk about the kinds of behavior that are normal for your child at this age?
- Yes
- No
Percent who said Yes: 81 percent

What to do: Your child’s doctor should help you prevent accidents by, for example, recommending that you post a poison-control number prominently in your home, put fences around swimming pools, store guns securely, and make sure that your child uses safety belts and bike helmets.

What to do: The Centers for Disease Control and Prevention now recommends vaccinations against 16 childhood diseases, including measles, whooping cough, and influenza, which have had recent outbreaks in some parts of the U.S. Together, those vaccines have saved millions of lives. But it’s key to get them on time. Your doctor should keep track of them all and schedule them appropriately, and provide you information about their benefits and risks. Also ask about other preventive exams, such as for vision and hearing.

20 Did your child’s doctor’s office remind you to get preventive care, such as vaccines, including an annual flu shot or an eye exam?
- Yes
- No
Percent who said Yes: 86 percent

Percent of parents who said their child’s doctor always:
- Explained things in a way that was easy to understand: 89.
- Listened carefully: 88.
- Spent enough time with the parent and child: 83.
- Followed up with information about test results: 72.
- Seemed to know the important information about the child’s medical history: 77.
- Seemed up to date or informed about the care the child received from specialists: 66.

This report is based on data from MHQP, a participant in the Robert Wood Johnson Foundation’s Aligning Forces for Quality initiative. Aligning Forces is the Foundation’s project aiming to lift the overall quality of health care in targeted communities throughout the country, reduce racial and ethnic disparities, and provide models for national reform. One core requirement of the program is that participating communities publicly report the type of data used here.
What's behind the Ratings

These Ratings of primary-care physician groups are published with the Massachusetts Health Quality Partners (MHQP), a nonprofit organization that has surveyed patients about their health-care experiences since 2005. The results shown here are from the most recent survey, done in the spring of 2011, and are based on patients' reports about their experiences.

MHQP rates physician practices, not individual doctors. The current data rate 329 practices that cared mainly for adults and 158 practices that saw mainly children. To be included, each doctor’s office must have had three or more doctors at the time of the survey.

How should I use these Ratings?

Use them to see how your primary-care practice fares, or to look for practices in your region that have scored particularly well. In either case, focus on two things. First look at the percentage of patients who said they would recommend the practice. Don’t focus too much on minor differences, such as between practices with scores from, say, 82 to 86. Second, look at its scores for individual aspects of performance, such as communicating with patients, coordinating care, and getting timely appointments.

How are practices rated?
The measures reported here are based on survey responses from more than 47,500 adult patients and 16,530 parents of pediatric patients. The survey asked about aspects of their health-care experience such as the strength of the doctor-patient relationship and access to care. These Ratings show results on five measures as well as patients’ willingness to recommend their doctor to family and friends.

How are the scores determined?
MHQP rates each performance measure on a scale of 0 to 100. Those scores are then divided into four categories, with 4 being best. For all measures except Doctor Communication, the practices that score a 4 are in the top 15 percent compared with other practices in the same category (adult or pediatric) statewide. Those that score a 3 are in the top half but not in the top 15 percent. A score of 2 indicates that the practice is in the bottom half, but not the bottom 15 percent. Those with a 1 are in the bottom 15 percent. Practices that score 95 points or higher earn the highest Rating of 4; practices scoring between 90 and 95 points get a 3; practices between 80 and 90 points get a 2; and practices that score below 80 points get a 1. Some practices are missing scores for measures because we only publish ratings for performance measures if we have enough data to provide statistically reliable results.

Where can I find more details?
Go to MHQP’s website at MHQP.org, where you can find the data and technical details about these ratings on the “Quality Reports” tab. MHQP also collects and publicly reports other information, such as clinical-outcomes data, which can also be found at MHQP.org.
## Ratings of practices for adults

*In collaboration with MHQP*

**Based on patient experience** in alphabetical order, within regions and towns

<table>
<thead>
<tr>
<th>Town</th>
<th>Practice Name</th>
<th>Address</th>
<th>Willingness to Recommend</th>
<th>How well doctors communicate with patients</th>
<th>How well doctors spend enough time with patients</th>
<th>Getting timely appointments and information</th>
<th>Getting courteous, helpful, and respectful help from office staff</th>
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<tbody>
<tr>
<td><strong>Merrimack Valley</strong></td>
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<td>Lahey - Amesbury</td>
<td>24 Morrill Pl.</td>
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- Not enough data to rate.
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<tr>
<th>Town</th>
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<th>Address</th>
<th>Willingness to Recommend</th>
<th>Performance</th>
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<td>78%</td>
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<td>20 Wall St.</td>
<td>79%</td>
<td>3</td>
</tr>
<tr>
<td>Burlington</td>
<td>Lahey - Burlington</td>
<td>41 Mall Rd.</td>
<td>70%</td>
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<tr>
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<td>10 Adams St.</td>
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<tr>
<td>Chelmsford</td>
<td>Merrimack Valley Internal Medicine Associates</td>
<td>20 Research Pl., Suite 310</td>
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<tr>
<td>Concord</td>
<td>Harvard Vanguard Concord Hillside</td>
<td>86 Baker Ave. Ext.</td>
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<tr>
<td>Groton</td>
<td>Groton Medical Associates</td>
<td>100 Boston Rd., 2nd Floor</td>
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<tr>
<td>Lexington</td>
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<td>482 Bedford St.</td>
<td>79%</td>
<td>3</td>
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<tr>
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<td>Lahey - Lexington</td>
<td>16 Hayden Ave.</td>
<td>72%</td>
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<td>57 Bedford St., Suite 130</td>
<td>79%</td>
<td>3</td>
</tr>
<tr>
<td>Lincoln</td>
<td>Lincoln Physicians</td>
<td>233 Concord Rd.</td>
<td>78%</td>
<td>3</td>
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<tr>
<td>Melrose</td>
<td>Hallmark Health Medical Associates</td>
<td>585 Lebanon St.</td>
<td>80%</td>
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<tr>
<td>Reading</td>
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<td>80%</td>
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<tr>
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<td>Family Care Center - Stoneham</td>
<td>3 Woodland Rd., Suite 100</td>
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<tr>
<td>Stoneham</td>
<td>Stoneham Medical Group</td>
<td>88 Montvale Ave. #3</td>
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<td>Blackwell Family Medicine</td>
<td>506 Groton Rd.</td>
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<tr>
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<td>Westford Internal Medicine</td>
<td>113 Littleton Rd., Suite 202</td>
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<td>81%</td>
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</table>

**Willingness to recommend**

- **Definitely yes**
- **Probably yes**
- **Not sure**
- **Probably not**
- **Definitely not**

**Performance**

- **Higher performance**
- **Lower performance**

- Getting courteous and respectful help from office staff
- Getting timely appointments, care, and information
- How well doctors communicate with patients
- How well doctors coordinate care
- How well doctors know patients' health and information
- How well doctors provide care

_July 2012 Consumer Reports/MHQF Health Insert_
### Ratings of practices for adults

**Based on patient experience** In alphabetical order, within regions and towns

<table>
<thead>
<tr>
<th>Town</th>
<th>Practice Name</th>
<th>Address</th>
<th>Willingness to Recommend</th>
<th>Performance</th>
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</thead>
<tbody>
<tr>
<td>Chestnut Hill</td>
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<td>25 Boylston St., Suite 204</td>
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<td>850 Boylston St., Suite 530</td>
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<td>The Fish Center for Women's Health</td>
<td>850 Boylston St., Suite 402</td>
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<td>29 Crafts St., Suite 400</td>
<td>90</td>
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<td>564 Main St.</td>
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<td>40 Second Ave., Suite 400</td>
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<td>231 Moody St.</td>
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<td>76</td>
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<td>Mount Auburn Medical Associates</td>
<td>521 Mount Auburn St., Suite 202</td>
<td>69</td>
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</table>

**METRO BOSTON**

#### Boston Central

| Boston                | Beacon Hill Primary Care                                    | Charles River Plaza, 5th Floor              | 85                        | -                              | How well do doctors communicate with patients: 3, How well do doctors coordinate care: 3, Getting timely appointments, care, and information: 3, Getting courteous help from office staff: 3, Getting information about patients: 3, Getting answers to questions: 3 |
|-----------------------|-------------------------------------------------------------|----------------------------------------------|---------------------------|------------------------------------------------------------------------------|
| Boston                | Beth Israel Deaconess Healthcare - Boston                  | 294 Washington St., Suite 219               | 66                        | -                              | -                              |
| Boston                | Beth Israel Deaconess Healthcare Associates                | 330 Brookline Ave.                          | 86                        | -                              | -                              |
| Boston                | Brigham Circle Medical Associates                          | 75 Francis St., Rm. 227                     | 92                        | -                              | -                              |
| Boston                | BU Family Medicine                                         | 771 Albany St., Dowling S South             | 71                        | -                              | -                              |
| Boston                | Bulfinch Medical Group                                     | 15 Parkman St., WAC 535                     | 86                        | -                              | -                              |
| Boston                | Child Health Foundation of Boston                          | 1 Boston Medical Center PL, Dowling 3414 South | 52                        | -                              | -                              |
| Boston                | Evans Medical Foundation                                  | 88 East Newton St.                          | 76                        | -                              | -                              |
| Boston                | Fenway Community Health Center, Haviland St               | 7 Haviland St.                              | 83                        | -                              | -                              |
| Boston                | Harvard Vanguard Copley                                     | 165 Dartmouth St.                           | 66                        | -                              | -                              |
| Boston                | Harvard Vanguard Kenmore                                   | 133 Brookline Ave.                          | 84                        | -                              | -                              |
| Boston                | Harvard Vanguard Post Office Square                        | 147 Milk St.                                | 82                        | -                              | -                              |
| Boston                | Mass General Medical Group (MGMG)                          | 50 Staniford St., Suite 300                 | 87                        | -                              | -                              |
| Boston                | MGH Back Bay                                               | 388 Commonwealth Ave.                       | 71                        | -                              | -                              |
| Boston                | MGH Downtown                                               | 294 Washington St., #210                    | 81                        | -                              | -                              |
| Boston                | MGH Internal Medicine Associates Team 1                    | 15 Parkman St., Suite 645                   | 93                        | -                              | -                              |
| Boston                | MGH Internal Medicine Associates Team 2                    | 15 Parkman St., Suite 645                   | 90                        | -                              | -                              |
| Boston                | MGH Internal Medicine Associates Team 3                    | 15 Parkman St., Suite 645                   | 85                        | -                              | -                              |
| Boston                | MGH Women’s Health Associates                              | 55 Fruit St., Yawkey 4                      | 80                        | -                              | -                              |
| Boston                | North End Community Health Center                          | 332 Hanover St.                             | 77                        | -                              | -                              |
| Boston                | South Cove Community Health Center                         | 885 Washington St.                          | 51                        | -                              | -                              |
| Boston                | The Phyllis Jen Center for Primary Care (BIMA)              | 75 Francis St., A1-02                       | 83                        | -                              | -                              |
| Boston                | Tufts Medical Center Adult Internal Medicine                | 800 Washington St.                          | 81                        | -                              | -                              |

- - Not enough data to rate.
## Willingness to Recommend

<table>
<thead>
<tr>
<th>Town</th>
<th>Practice Name</th>
<th>Address</th>
<th>Willingness to Recommend</th>
<th>Performance</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Boston Neighborhoods</strong></td>
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<tr>
<td>Brighton</td>
<td>Brookline Associates</td>
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<td>St. Elizabeth’s Health Care at Brighton Marine</td>
<td>77 Warren St., 1st Floor</td>
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<td>Brighton</td>
<td>Stanton Medical</td>
<td>280 Washington St.</td>
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<td>Dorchester House Multi-Service Center</td>
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<td>Neponset Health Center</td>
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<tr>
<td>Hyde Park</td>
<td>Carr-Mahoney-Driscoll-Barravecchio</td>
<td>695 Truman Parkway</td>
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<td>Jamaica Plain</td>
<td>Brigham Primary Physicians at Faulkner Hospital</td>
<td>1153 Centre St.</td>
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<td>Jamaica Plain</td>
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<td>1153 Centre St.</td>
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<td>Jamaica Plain</td>
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<td>Roslindale</td>
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<td>Roxbury</td>
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<tr>
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<tr>
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<tr>
<td>Brookline</td>
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<td>1180 Beacon St., Suite 1A-B</td>
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<td>Cambridge Health Alliance Primary Care Center</td>
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</tbody>
</table>
### Massachusetts Doctor Ratings

Based on patient experience

In alphabetical order, within regions and towns

<table>
<thead>
<tr>
<th>Town</th>
<th>Practice Name</th>
<th>Address</th>
<th>Willingness to Recommend</th>
<th>Performance</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>SOUTHEAST MASSACHUSETTS</strong></td>
<td></td>
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<td><strong>Norfolk County</strong></td>
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<td>3130 State Hwy, Route 6</td>
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# Massachusetts Doctor Ratings

Based on patient experience

In alphabetical order, within regions and towns

<table>
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<tr>
<th>Town</th>
<th>Practice Name</th>
<th>Address</th>
<th>Willingness to Recommend</th>
<th>Performance</th>
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Ratings of practices for children In collaboration with MHQP

Based on patient experience In alphabetical order, within regions and towns

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<th>Performance</th>
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- - Not enough data to rate.
## Massachusetts Doctor Ratings

### Ratings of practices for children

**Based on patient experience** in alphabetical order, within regions and towns

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<th>Town</th>
<th>Practice Name</th>
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<td>Getting courteous and respectful help from office staff</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>How well doctors give preventative care and information</td>
<td>Getting timely appointments, care, and information</td>
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<td>How well doctors keep patients healthy</td>
<td>How well doctors know patients</td>
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- - Not enough data to rate.
### Willingness to recommend

#### Performance

- Higher performance
- Lower performance

<table>
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<tr>
<th>Town</th>
<th>Practice Name</th>
<th>Address</th>
<th>Willingness to Recommend</th>
<th>Performance</th>
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</thead>
<tbody>
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<tr>
<td>Cambridge</td>
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<tr>
<td>Chelsea</td>
<td>Pediatric Care</td>
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<tr>
<td>Somerville</td>
<td>Broadway Health Center - CHA</td>
<td>300 Broadway</td>
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<tr>
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<td>40 Holland St.</td>
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**SOUTHEAST MASSACHUSETTS**

#### Norfolk County

<table>
<thead>
<tr>
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<th>Address</th>
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<th>Performance</th>
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<tbody>
<tr>
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<td>111 Grossman Dr.</td>
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<tr>
<td>Braintree</td>
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<td>340 Wood Rd., Suite 301</td>
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<tr>
<td>Cohasset</td>
<td>Cohasset Pediatrics - Healthcare South</td>
<td>223 Chief Justice Cushing Hwy,</td>
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<tr>
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<td>Dedham Medical Associates - Dedham</td>
<td>1 Lyons St.</td>
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<tr>
<td>Milton</td>
<td>East Milton Pediatric Associates</td>
<td>464 Granite Ave.</td>
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<tr>
<td>Needham</td>
<td>Needham Pediatrics</td>
<td>111 Lincoln St.</td>
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<tr>
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<tr>
<td>Quincy</td>
<td>Crown Colony Pediatrics</td>
<td>500 Congress St., Suite 1F</td>
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<tr>
<td>Stoughton</td>
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<tr>
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<td>Westwood/Mansfield Pediatrics</td>
<td>541 High St.</td>
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<td>South Shore Pediatric Associates - Healthcare South</td>
<td>70 Pleasant St.</td>
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#### Plymouth County

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<th>Practice Name</th>
<th>Address</th>
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<th>Performance</th>
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<tr>
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<tr>
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<td>Brockton</td>
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<tr>
<td>Hanover</td>
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<td>51 Mill St., Bldg E, Suite 17</td>
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<tr>
<td>Lakeville</td>
<td>Middleboro Pediatrics</td>
<td>2 Lakeville Business Park</td>
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<tr>
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<td>75 Washington St.</td>
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<td>53 Marion Rd., Suite 1</td>
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*Not enough data to rate.*
## Massachusetts Doctor Ratings

### Ratings of practices for children

Based on patient experience, in alphabetical order, within regions and towns.

<table>
<thead>
<tr>
<th>Town</th>
<th>Practice Name</th>
<th>Address</th>
<th>Willingness to Recommend</th>
<th>Performance</th>
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<td></td>
<td></td>
<td>0% 100%</td>
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<td></td>
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<td>How well doctors communicate with patient</td>
<td>How well doctors know patients</td>
</tr>
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<tr>
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- -- Not enough data to rate.
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<th>Address</th>
<th>Willingness to Recommend</th>
<th>Performance</th>
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<tr>
<td>Wilbraham</td>
<td>George F. Vitek, M.D., &amp; Associates</td>
<td>2207 Boston Rd.</td>
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Willingness to recommend:
- **Definitely yes**
- **Probably yes**
- **Not sure**
- **Probably not**
- **Definitely not**

Performance:
- **Higher performance**
- **Lower performance**

Note: - - Not enough data to rate.
In partnership
The Issue
As the nation increasingly focuses on ways to provide safer, higher-quality care to patients, the overuse of health care resources is an issue of considerable concern. Many experts agree that the current way health care is delivered in the U.S. contains too much waste—with some stating that as much as 30 percent of care delivered is duplicative or unnecessary and may not improve people’s health.

It is urgent that physicians and patients work together and have conversations about wise treatment decisions. That means choosing care that is supported by evidence showing that it works for patients like them; is not duplicative of other tests or procedures already received; won’t harm them; and is truly necessary.

The Campaign
Choosing Wisely® is an initiative of the ABIM Foundation to help physicians and patients engage in conversations about the overuse of tests and procedures and support physician efforts to help patients make smart and effective care choices. Recognizing the importance of physicians and patients working together, leading specialty societies, along with Consumer Reports, have joined Choosing Wisely to help improve the quality and safety of health care in America.

As part of Choosing Wisely, each participating specialty society has created lists of “Things Physicians and Patients Should Question” that provide specific, evidence-based recommendations physicians and patients should discuss to help make wise decisions about the most appropriate care based on their individual situation.

The resulting lists will stimulate discussion about the need—or lack thereof—for many frequently ordered tests or treatments. Participating specialty societies and the ABIM Foundation are using these lists to support physicians in making wise choices and will develop tools to help them have these kinds of conversations with patients.

Consumer Reports, the nation’s leading independent, non-profit consumer organization, has also joined the campaign to provide resources for consumers and physicians to engage in these important conversations. They are coordinating consumer-oriented organizations to help disseminate information and educate patients on making wise decisions.

Continuing the Professionalism Challenge
Choosing Wisely is part of a multi-year effort of the ABIM Foundation to help physicians be better stewards of finite health care resources. It continues the principles and commitments of promoting justice in the health care system through a fair distribution of resources set forth in Medical Professionalism in the New Millennium: A Physician Charter.

Learn more about Choosing Wisely at www.ChoosingWisely.org.
Specialty Societies That Released Lists in April 2012

- American Academy of Allergy, Asthma & Immunology
- American Academy of Family Physicians
- American College of Cardiology
- American College of Physicians
- American College of Radiology
- American Gastroenterological Association
- American Society of Clinical Oncology
- American Society of Nephrology
- American Society of Nuclear Cardiology

Specialty Societies That Released Lists in February 2013

- American Academy of Family Physicians
- American Academy of Hospice and Palliative Medicine
- American Academy of Neurology
- American Academy of Ophthalmology
- American Academy of Otolaryngology-Head and Neck Surgery
- American Academy of Pediatrics
- American College of Obstetricians and Gynecologists
- American College of Rheumatology
- American Geriatrics Society
- American Society for Clinical Pathology
- American Society of Echocardiography
- American Urological Association
- Society of Cardiovascular Computed Tomography
- Society of Hospital Medicine
- Society of Nuclear Medicine and Molecular Imaging
- Society of Thoracic Surgeons
- Society for Vascular Medicine

Specialty Societies Releasing Lists in Late 2013

- American Academy of Family Physicians
- American Academy of Orthopaedic Surgeons
- American Academy of Dermatology
- American College of Chest Physicians
- American College of Rheumatology
- American College of Surgeons
- American Headache Society
- AMDA – Dedicated to Long Term Care Medicine
- American Society of Clinical Oncology
- American Society of Hematology
- American Society for Radiation Oncology
- American Thoracic Society
- Heart Rhythm Society
- North American Spine Society
- Society of General Internal Medicine

Choosing Wisely Consumer Groups

- AARP
- Alliance Health Networks
- Leapfrog Group
- Midwest Business Group on Health
- Minnesota Health Action Group
- National Business Coalition on Health
- National Business Group on Health
- National Center for Farmworker Health
- National Hospice and Palliative Care Organization
- National Partnership for Women & Families
- Pacific Business Group on Health
- SEIU
- Univision (with HolaDoctor)
- Union Plus
- The Wikipedia Community

About the ABIM Foundation:
The mission of the ABIM Foundation is to advance medical professionalism to improve the health care system. We achieve this by collaborating with physicians and physician leaders, medical trainees, health care delivery systems, payers, policymakers, consumer organizations and patients to foster a shared understanding of professionalism and how they can adopt the tenets of professionalism in practice. To learn more about the ABIM Foundation, visit www.abimfoundation.org.
WHILE THE UNITED STATES GRAPPLES WITH THE challenge of health care costs that contribute to high rates of poor-quality care, burdens to business competitiveness, and looming government deficits, clearly there are areas in which health care spending does not add to the health of individuals and communities. The polarizing political environment makes it difficult to conduct rational public discussions about this issue, but clinicians and consumers can change the nature of this debate to the potential benefit of patients, the medical profession, and the nation. The initial focus should be on overuse of medical resources, which not only is a leading factor in the high level of spending on health care but also places patients at risk of harm. In fact, some estimates suggest that as much as 30% of all health care spending is wasted.1

To reduce unnecessary tests and procedures, physicians will need to play a leading role—their decisions account for about 80% of health care expenditures.2 Yet physicians do not always have the most current effectiveness data, and despite acting in good faith, they can recommend diagnostic or therapeutic interventions that are no longer considered essential. Also, research shows that physicians may need help communicating these matters to their patients. This may be especially difficult when clinicians and consumers are deluged with advertising and promotion. Clinicians often report feeling compelled to accommodate patients’ requests for interventions they know are unnecessary.3,4 At the same time, patients need trustworthy information to help them better understand that more care is not always better care, and in some cases can actually cause more harm than good.

A major goal of health care reform is enhancing “patient-centered care.” Patients, and consumer groups representing them, express increasing interest in forging true partnerships with their clinicians, with real-time access to their own medical records, to science-based comparative effectiveness information, and to health care delivery environments built to enhance both comfort and personalization of medical care. Patient engagement, as 1 of the 6 major initiatives of the National Priorities Partnership of the National Quality Forum, promises more informed and involved patients as decision makers. To make good on this promise requires transparent and credible information about the relative value and risk of various medical diagnostic and therapeutic interventions.

To help reduce waste in the US health care system and promote physician and patient conversations about making wise choices about treatments, 9 medical specialty societies have joined the ABIM (American Board of Internal Medicine) Foundation and Consumer Reports in the first phase of the Choosing Wisely campaign, including the following: American Academy of Allergy, Asthma & Immunology; American Academy of Family Physicians; American College of Cardiology; American College of Physicians; American College of Radiology; American Gastroenterological Association; American Society of Clinical Oncology; American Society of Nephrology; and the American Society of Nuclear Cardiology.

As part of Choosing Wisely, each society has developed a list of 5 tests, treatments, or services that are commonly used in that specialty and for which the use should be reevaluated by patients and clinicians. Those lists were released on April 4, 2012, at a national event in Washington, DC. Additionally, other societies, consumer organizations, and physician organizations have asked how they can become part of this effort to engage physicians and patients in conversations about tests and procedures that should rarely be used.

The early origins of this campaign can be found in “Medical Professionalism in the New Millennium: A Physician Charter.”5 Authored in 2002 by the ABIM Foundation, American College of Physicians Foundation, and European Federation of Internal Medicine, the charter has as its fundamental principles the primacy of patient welfare, pa-
tient autonomy, and social justice. It articulates the professional responsibilities of physicians, including a commitment to improving quality and access to care, advocating for a just and cost-effective distribution of finite resources, and maintaining trust by managing conflicts of interest. The charter’s commitment to a just distribution of finite resources specifically calls on physicians to be responsible for the appropriate allocation of resources and to scrupulously avoid superfluous tests and procedures.

More recently, the concept of creating lists of unnecessary tests or procedures was proposed by Brody, who called for physicians to lead the effort in identifying waste to be eliminated. According to Brody, “A top 5 list also has the advantage that if we restrict ourselves to the most egregious causes of waste, we can demonstrate to a skeptical public that we are genuinely protecting patients’ interests and not simply ‘rationing’ health care, regardless of the benefit, for cost-cutting purposes.” Grady and Redberg, in the Less Is More series of articles published in the Archives of Internal Medicine, further articulated the need to dispel the myth that “if some medical care is good, more care is better.”

The US National Physicians Alliance (NPA) put Brody’s concept into practice through its Promoting Good Stewardship in Clinical Practice project. This project resulted in a set of 3 lists of specific steps that physicians in internal medicine, family medicine, and pediatrics could take in their practices to promote the more effective use of health care resources. Analysis of NPA’s “top 5 lists” estimated that savings of more than $5 billion could be realized if the items on the lists were eliminated.

Choosing Wisely builds on the ideals of the physician charter, Brody’s challenge, and NPA’s work by expanding the number of lists created and physicians reached. Heeding Brody’s recommendation to have physicians lead the way, the specialty societies have identified the practices prone to overuse in their area. Each recommendation is also supported by clinical guidelines and evidence, including information about when these tests or procedures may be appropriate.

As of this writing, the 9 medical specialty societies involved in Choosing Wisely potentially reach 374,000 practicing physicians, with several additional societies expressing interest in joining the effort. The hope is that the lists will spark discussion between clinicians and patients about the need—or lack thereof—for many frequently ordered tests or treatments.

Recognizing the need for tools and resources to facilitate these conversations, Consumer Reports, an independent, nonprofit consumer organization, in consultation with the professional societies, will create and disseminate consumer-friendly versions of the lists and will partner with other organizations to reach diverse audiences. This is to help patients understand the recommendations and be prepared to talk with their clinicians about them.

Consumer Reports has reported what a critical issue overuse is to consumers. A 2010 reader survey of nearly 1200 healthy 40- to 60-year-old men and women, with no known heart disease, risk factors, or symptoms, showed that 44% had received screening tests for heart disease rated by Consumer Reports as very unlikely or unlikely to have benefits that outweigh the risks. Moreover, those who had received the testing did so without first getting crucial information from their physician. For example, only a few “healthy” adult respondents reported discussing with their physician how accurate the tests were (9%), whether they saved lives (1%), potential complications that might occur (4%), or what the patient would need to do if the test indicated a problem (11%). Choosing Wisely will help provide the other side of this important story.

The complete lists from each of the societies can be found at http://www.choosingwisely.org. These organizations are demonstrating leadership, vision, and courage in highlighting overuse in their own specialty. This is the highest form of medical professionalism.

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REFERENCES


6

Public Deliberation

Beginning with an overview of public engagement and the venues through which it is sought, the committee highlights the need for the public’s role in making sure that the essential health benefits (EHB) are responsive to user needs and in identifying the core societal values to guide priority setting. The unique features of “public deliberation” and its suitability for decision making around the EHB, per the committee’s Recommendations 1, 3, 4b, and 5, are explored. Examples of the use of a public deliberation process in both the private and the public sectors are presented. A set of guidelines for public deliberation is offered that the Secretary could use for informing the Department of Health and Human Services (HHS) about priorities and in directing states for their own application.

The purpose of this chapter is to provide the rationale for the committee’s support of the general public having a meaningful role in the design, implementation, evaluation, and updating of the EHB package through two important functions: (1) oversight of the EHB and (2) identification of social values to help guide decisions on what and how coverage is provided within the EHB. Most of the information here relates to this second function.

THE PUBLIC VOICE

In considering how best to capture the public voice in meaningful ways for the determination of the EHB package, this section explores the potential roles of the public, offers guidance to ensure that public processes are reasonable, and defines the value of public deliberation as a distinct approach that incorporates choices among covered benefits and benefit design in a prioritized fashion.

In recent years there has been growing emphasis on patient engagement in health care—helping individual patients become more active in health promotion and self-care, and encouraging a partnership with their physicians and other providers in planning for the services they receive. These efforts are especially important for managing chronic illness and facilitating sound treatment decisions that depend on informed patient preference. Individuals have also been encouraged to become informed consumers when making decisions about their health plans, health care services, and benefit design alternatives. Given the dramatic expansion of health care options, these types of patient or consumer engagement are important and necessary.
The Consumer Adviser

Less evident is the role of the public in advising about health care policy decisions that affect society as a whole. As health care has grown in complexity, appointments of patients, consumers, and advocates to boards, committees, task forces, and other advisory bodies are a testament to the recognition that an array of stakeholder perspectives is needed on issues that profoundly affect people’s lives.

There are numerous examples in which national and state bodies provide opportunities for consumers to comment, respond to, and offer suggestions that may affect health policy. Medicare has a public process for reviewing specific technologies individually. The Medicare Evidence Development and Coverage Advisory Committee (MEDCAC) meets in an open forum approximately four to eight times a year to review submitted evidence, listen to testimony, and deliberate about the quality of the evidence. Of the 94 at-large member positions, selected by the Secretary, 6 are reserved for patient advocates (HHS, 2010), with one participating in every meeting (HHS, 2010). Further opportunities for public input in the service coverage determination process exist, as illustrated in the case of health technology assessment for Medicare decisions as well as in Oregon and Washington State (Table 6-1), and other venues (Menon and Stafinski, 2011).

Although opportunities for input are essential, they are not a substitute for formal representation on governing and advisory bodies. The committee believes formal representation will be important for the EHB package if it is to attain and maintain the trust and confidence of those it serves (e.g., on the National Benefits Advisory Council; see Chapter 9).

The Citizen Deliberator

There is a third role for the public, distinct from the others: helping to reconcile the tension between comprehensiveness and affordability. Finding the balance between them requires strong political and social will, efforts that can be helped with public deliberation: “the use of critical thinking and reasoned argument as a way for citizens to make decisions on public policy” (McCoy and Scully, 2002, p. 117). Deliberation does not assume consensus, but “it brings into consideration knowledge and judgments coming from various perspectives so that participants develop understandings that are informed by other views” (NRC, 1996, p. 74).

A structured interactive process can elucidate the core values by which the public ultimately reaches societal decisions. As long as there are far more ways to spend health care dollars than there are dollars to spend, these core values must play a role in deciding the coverage obligations of insurance and the personal obligations of individual consumers (Fleck, 2009).

These two roles—consumer adviser and citizen deliberator—are not intended to replicate, substitute for, or undermine the work of legislative, regulatory, or professional bodies. The complexity of health care and the uncomfortable financial precipice on which it hangs requires a different level of discussion than those that are typically part of policy formation or rule making. A public deliberative process on tradeoffs among benefits and benefit design can help political and health care leaders arrive at better decisions, and going through the process of gathering input can help garner public support, trust, and buy-in (Wynia and Schwab, 2006).

Accountability for Reasonableness

Using public deliberation as a component of EHB development is wholly consistent with the concept of “accountability for reasonableness” as described in Setting Limits Fairly (Daniels and Sabin, 2008) and the literature on “voice” as described in Exit, Voice and Loyalty (Hirschman, 1970). In a pluralistic society such as the United States, there are often decisions that cannot be answered by science or logic, where different perspectives are competing. When deeply held values point to different policy decisions, the way in which these decisions are made becomes an ethical imperative. Daniels and Sabin’s contention is that if the decision process is fair and transparent, the subsequent results are more likely to be ethically justifiable and accepted as legitimate and fair. Although some may be unhappy with the results, they should nonetheless be satisfied that the process for reaching those results was reasonable, participatory, and transparent.
TABLE 6-1 Summary of Opportunities for Patient or Public Input in Selected Technology Coverage Processes in Different Regions

<table>
<thead>
<tr>
<th>Adviser and/or Decision Maker</th>
<th>Identification of Technologies</th>
<th>Selection of Technologies for Assessment</th>
<th>Undertaking of HTA*</th>
<th>Review of HTA Results and Formulation of Recommendations</th>
<th>Implementation of Recommendations and Decisions</th>
<th>Dissemination of Decisions and HTA Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>National Level USA†</td>
<td>Yes No</td>
<td>Yes Yes</td>
<td>Yes Yes</td>
<td>Yes Yes</td>
<td>Yes Yes</td>
<td>N/A N/A</td>
</tr>
<tr>
<td>CMS (decisions)</td>
<td>Patients and/or carers may refer technologies for assessment</td>
<td>Anyone may provide additional information and/or comment on potential technology topics identified by CMS staff</td>
<td>Anyone may submit information to group preparing HTA</td>
<td>anyone may register to present to the committee</td>
<td>Anyone may appeal recommendations</td>
<td>No information found</td>
</tr>
<tr>
<td>CMS Medicare Evidence Development and Coverage Advisory Committee</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Oregon, USA‡</td>
<td>Yes Yes</td>
<td>No No</td>
<td>Yes Yes</td>
<td>Yes Yes</td>
<td>No No</td>
<td>No No No</td>
</tr>
<tr>
<td>State of Oregon Health Resources Commission (recommendations)</td>
<td>Technologies may be referred by anyone</td>
<td></td>
<td>Anyone may submit information to group preparing HTA</td>
<td></td>
<td></td>
<td>Committe meetings held in public</td>
</tr>
<tr>
<td>Washington, USA§</td>
<td>Yes Yes</td>
<td>No No</td>
<td>Yes Yes</td>
<td>Yes Yes</td>
<td>No No</td>
<td>No No No</td>
</tr>
<tr>
<td>Washington State Healthcare Authority (decisions)</td>
<td>Technologies may be referred by anyone</td>
<td></td>
<td>Anyone may submit information to group preparing HTA</td>
<td></td>
<td></td>
<td>Committee meetings held in public</td>
</tr>
<tr>
<td>Washington State Healthcare Authority Health Technology Clinical Committee</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*CMS = Centers for Medicare & Medicaid Services; HTA = health technology assessment.
†Chalkidou et al., 2009; CMS, 2003, 2006a,b,c; ISPOR, 2011; Washington State Health Care Authority, 2007a.
§Washington State Health Care Authority, 2007a,b,c, 2008.
Four conditions contribute to being accountable for reasonableness:

1. **Publicity**: Decisions that establish priorities in allocating resources for health needs and their rationales must be publicly accessible.

2. **Relevance**: The rationales for priority-setting decisions should aim to provide a reasonable explanation of why the priorities selected were determined to be the best approach. Specifically, a rationale is reasonable if it appeals to evidence, reasons, and principles accepted as relevant by fair-minded people. Closely linked to this condition is the inclusion of a broad range of stakeholder perspectives in decision making. It is crucial that both individual needs and preferences and population needs and preferences should be considered.

3. **Revision and appeals**: There must be mechanisms for challenge and dispute and, more broadly, opportunities for revision and improvement of policies in light of new evidence or arguments.

4. **Regulative**: There must be mechanisms to ensure that conditions 1, 2, and 3 are met. The publicity condition exposes the rationales of decision makers.

These components are reflected in the recommendations of this committee, which also recognizes that the general public must be part of that “broad range of stakeholders in decision making.”

**Why Public Deliberation?**

The usual avenues for citizen input (e.g., petitions, elections, town hall meetings, telephone surveys) capture public opinion. However, when issues are complex, multifaceted, and require tradeoffs among desirable (or undesirable) approaches to a problem, understanding the public’s informed perspectives cannot be achieved simply by gathering public opinion (Abelson, 2010). Not only does the content of the issue require more background information than a survey can provide, but also the deliberative process itself takes the average citizen to a level of judgment that many have not experienced, moving from “What is in the best interest of me and my family?” to “What is in the best interest of all who are sharing in the cost and the use of these services?”

There are many reasons for engaging the public on issues such as health care benefits—as a basis for policy development: to educate the public on the challenges of allocating finite resources; to give purchasers information on how their constituents respond to tradeoffs; to study the impact that deliberation has on the public’s views; and to motivate individuals to greater civic participation. It is also a powerful tool for conveying the message, “Your values count.”

The elements of health care coverage and decision making are broad and deep. Many components fall under the purview of other players, such as professional associations that set standards for ethical practice; expert panels that develop and recommend clinical guidelines; researchers who study clinical effectiveness; and health plan administrators who determine if a treatment falls within the defined benefits package. The players most central to the use of medical care—physicians and patients—also have specific roles. Physicians diagnose the medical conditions and identify potential treatments for their individual patients. Patients determine which of the recommended and available treatments best meet their particular needs.

Yet none of these stakeholders has a unique claim on deciding what insurance should pay for. Insurers, legislators, and purchasers have typically been the ones to define the boundaries of coverage, yet as the options for coverage expand and available dollars do not, their perspectives cannot be assumed to reflect the views of the public, especially those to whom coverage decisions apply. These circumstances call for a societal perspective of how citizens get the most value for their health care dollar (Fleck, 2009).

When coverage is excluded or cost sharing is prohibitive, some will be disadvantaged. People with sufficient discretionary funds still will be able to pay out-of-pocket for uncovered services, while individuals without those resources will not. If the process for determining where the lines for coverage are drawn is reasonable and transparent, the results may be unfortunate for some, but they are not unfair.
COMPONENTS OF PUBLIC DELIBERATION PROCESSES

Productive processes for identifying public values as a component of determining the benefit package require attention to four elements: (1) specifying the issues that the public is being asked to address; (2) developing and conducting an effective process; (3) interpreting and using the findings to inform policy decisions; and (4) integrating transparency and accountability.

Specifying the Issues for the Public to Address

Public deliberation processes can be applied to a wide variety of coverage, policy, and practice issues. For the purpose of the EHB, the committee believes that certain deliberative questions are particularly relevant:

- When considering the many types of medical problems that could be covered by health insurance, what makes some a higher priority than others?
- How should we determine the limits to when, how, and what medical treatments should be covered?
- What is the preferred balance between various cost-controlling measures, such as comprehensiveness of coverage, cost sharing, utilization management, extent of provider network, etc.?
- What role should incentives play in encouraging high value care and discouraging low value interventions?
- If disadvantaged groups have different needs and priorities than others, what is society’s responsibility to address those needs?
- When assessing the benefit of a medical treatment, how should the cost of the treatment be factored into coverage policy? When resources are limited, what is considered a “good value”?
- If the costs of life-extending interventions are prohibitive, is it acceptable to insist on lower prices as a condition of coverage inclusion?
- If research shows that some physicians or hospitals deliver lower quality care than others, should this be relevant to benefits design?
- What should we expect of individuals in terms of their personal health care responsibility?
- If some treatments are proven to be ineffective, what impact should this have on coverage policy?

Many of the questions refer to priority setting that directly impacts patients or consumers. There are additional ways to tackle cost inflation that do not involve consumer compromises so directly. However, the issues most appropriate for public deliberation about coverage are those that present tradeoffs affecting consumers directly. In essence, the process is stating that “some choices have to be made about what we are going to pay for using the limited funds in our insurance pool. Because you are part of this pool, we need you to be involved in making these choices.”

Although this focus is on consumer tradeoffs, priority setting by the public should not be in lieu of other stakeholders—providers, insurers, pharmaceutical companies, device manufacturers, and others—taking necessary actions to reduce their own costs for the sake of a more efficient and responsible system. The concept of shared responsibility must apply throughout the EHB program, and to expect sacrifice solely by the public is both unrealistic and unfair.

Developing and Conducting an Effective Deliberative Process

There are components of deliberation that distinguish it from focus groups, town hall meetings, and other means of public input. These latter methods elicit public opinion, reflecting general perspectives and level of knowledge at a certain time. However, public opinion does not capture public values—those core beliefs and convictions that surface when people have the time and opportunity to probe their reflexive judgments and weigh difficult options carefully (Abelson et al., 2003).

The credibility of a deliberative process relies on careful attention to its design and execution. A commonly used format for deliberative processes is a group session with multiple interactive segments. Participants learn the issue or dilemma, consider alternative approaches, choose options, voice perspectives, hear the views of others,
debate choices, and identify common ground (Abelson, 2010). Because the alternative approaches all have advantages and disadvantages, deliberation means taking the time to weigh and discuss each, uncovering personal and societal convictions about what can and cannot be compromised.

When conducted by skilled, impartial facilitators, deliberation is always interactive, where demographically represented members have a chance to give their own perspectives and hear the views of others. Most important, deliberation deals with explicit tradeoffs, where decisions to accept one course of action invariably mean giving up a different one. Thus, a deliberative process for the EHB must be structured around a finite budget or specific ranking where participants’ decisions explicitly reveal a hierarchy of evaluation. It is this hierarchy requirement that encourages participants to consider carefully what has the most value and why.

The discussion process incorporates common vernacular and experiences of the lay public. Seeing how these options apply in real-life situations allows people to grasp their relevance and assess the impact on themselves and on others. Developing the discussion protocol—how participants are introduced to the dilemmas, the examples of situations that illustrate the “conflict,” the process of individual and group decisions—is generally done by experts skilled in deliberative methods. The legitimacy of the process hinges on the extent to which these sessions are (and are perceived to be) factually accurate, balanced, unbiased, representative, and designed commensurate with the knowledge and abilities of the lay public (Fleck, 2009). Other parameters that also speak to the credibility of the process include the following:

- **Number of sessions.** These sessions are far more labor-intensive than phone surveys, so the number of participants will likely be smaller. Although 10 small group sessions (totaling about 120 people) can provide the full range of views, some stakeholders may feel that more sessions are needed for the process and results to be credible to the wider public. Available time and funding often dictate the number of groups that can be conducted.
- **Location of sessions.** Geographic diversity is especially important given the variety of populations that reside within states and the nation as a whole.
- **Length of sessions.** Two- to three-hour discussions are common; more extensive meetings (half-day to multi-day) yield more and richer results but are not always practical.
- **Participant sample.** The target population needs to be defined, whether it is those who are expected to use insurance defined by the EHB, the general public, or particular subsets of the population. Diversity of other demographic features (age, gender, insurance status, ethnicity, education, household income, etc.) is also important. Although most groups are heterogeneous, at times homogeneous group discussions (such as all Spanish-language or adult disabled groups) are needed to truly capture some unique perspectives. With fewer participants than in a phone survey, attention to representative sampling will help instill confidence in the integrity of the effort.
- **Recruitment strategies.** These vary from asking the help of local organizations to posting notices, using professional recruitment firms, and other methods. The more professional the recruitment process, the more likely is demographic representation to be achieved.
- **Facilitation.** Sessions should be facilitated by experienced, neutral professionals who have no vested interest in the outcome or ties to stakeholder groups. Although the discussion protocol is the building block for a credible process, it is the facilitation that determines how participants engage and the impartiality with which the sessions are conducted.
- **Respecting privacy of participants.** For participants to feel that they can speak freely and openly, they must know that their words will not be publicly attributed to them. Although the names of all participants and the transcripts should be publicly available, individual comments should not be identified by name or demographic characteristics.
- **Participant feedback.** There are a variety of ways to assess the success of deliberative sessions, including the reactions of the participants themselves. Post-discussion surveys can determine how participants responded to the process and their assessment of whether it met the goals of being inclusive and balanced.

Although the target groups for deliberative participation are typically those most likely to be subject to the coverage limits, other stakeholders can benefit by observing the deliberative sessions or being participants in
separate sessions. Policy and health care leaders usually have no more experience in prioritizing health care benefits than does the general public. Experiencing the challenges—and noting where these elites do and do not make decisions differently from others—can be an eye-opener for policy experts.

Interpreting and Using the Findings to Inform Policy Decisions

When deliberative sessions involve larger numbers of participants, quantitative data can be collected and analyzed, but the most meaningful findings from sessions of any size are qualitative: the reasoning and rationale for participants’ choices. These qualitative data are derived from transcripts (audio and/or video) of session recordings.

Just as the development of the discussion protocol and the facilitation of the sessions should be objective and nonpartisan, so should the interpretation of the findings and the development of conclusions or recommendations. The group given this task could include different players, those intimately involved with the deliberations, and those who might bring “fresh eyes” to reviewing the transcripts and conclusions.

Most importantly, these findings should be used to inform policy decisions and public education (Sabik and Lie, 2008). This does not mean that everything the public values takes precedence over all other considerations, but the results should not be ignored or given only token attention. The success of the EHB structure will depend to a large extent on trust by the public—as those whose insurance is defined by the EHB, as taxpayers, and as interested and concerned citizens—and this trust will be damaged if deliberation is viewed as window-dressing. Building public deliberation into the EHB process can also contribute to public understanding of the need to make tough choices about the allocation of health care resources.

An effective process will have a public communication plan for both the process and its findings, with targeted audiences including the decision makers, the participants, the general public, and the entities to which the decision makers are accountable. Inattentiveness to the communication plan can jeopardize the acceptance of the findings, but an effective communication plan can help to build consensus.

Integrating Transparency and Accountability

The need for transparency extends beyond a communication plan. Indeed it should be embedded in the deliberative process as a “way of doing work.” The three components of public deliberation—specifying the issue, developing and conducting the process, and interpreting and using the findings—each must be fully transparent to those participating and those on the periphery. Transparency and accountability are the responsibility of the authority ultimately charged with making the EHB determination—the Secretary or the designated state unit. Specifically, these may be manifested in actions such as the following:

• Forming an advisory committee—with representatives of various stakeholders, including consumers and consumer advocates—to provide oversight to the public deliberation process;
• Publicizing information on why public deliberation processes are being conducted;
• Providing opportunities for others to offer suggestions for deliberative topics;
• Making available transcripts and qualitative data (redacted to maintain confidentiality of participants’ individual comments) to the public on request;
• Making available a draft version of the analysis for review and comment prior to the final version; and
• Conducting a public session to present the results of the analysis and to get feedback from policy leaders.

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1 For example, a deliberative prioritization process (CHAT) was conducted as a 2-hour educational program with 18 business and health care groups in 2009-2010 totaling 250 people. In response to this post-discussion question, Which statement most closely represents your view about participating in this CHAT session, 32 percent responded, This will affect how I consider coverage policy in the future; 63 percent responded, This has given me something to think about; 5 percent responded, No new information but it was enjoyable; none responded, This was not a good use of my time (Center for Healthcare Decisions, unpublished data).
EXAMPLES OF PUBLIC PARTICIPATION AND DELIBERATIVE PROCESSES

For many years, a number of organizations in this country have developed and/or conducted civic deliberation on a wide variety of public policy issues. The academic community also studies civic deliberation—learning how the public reaches informed decisions, the strength of those decisions, and the impact this has on individuals’ sense of civic duty. However the most noteworthy use of public deliberation to help inform new health care policy was in Oregon in 1989.

Oregon Health Plan

As part of the Oregon Health Plan to expand Medicaid to more Oregon residents, Oregon’s Senate Bill 27 of 1989 required the Health Services Commission to “actively solicit public involvement by a community meeting process.” The architects of the plan recognized that defining a “basic” level of care “must be based on criteria that are publicly debated, reflect a consensus of social values, and consider the good of society as a whole” (DHS, 2006, p. 2). Although a variety of tools were used to gain public input, the initial citizen discussion groups provided the commission with a set of core values to help guide the prioritization process. These discussion groups used a vignette approach, illustrating a range of health care situations and the impact they had on individuals. In 47 small group discussions around the state, skilled facilitators asked participants to rank order the vignettes by their importance for health care coverage and then to discuss their rationale for the rankings. The purpose was not to ascertain a numerical score but to identify the reasoning people used in considering their prioritizations. Understanding the relative importance of various states of health and the significance of different medical problems for individuals and for society helped the Health Services Commission craft its initial set of coverage categories.

These community discussions, while thoughtfully and professionally constructed and analyzed, were subject to much criticism because they did not include the necessary demographic diversity. This failure to meet the criterion of an appropriate participant sample was the consequence of insufficient funding to support the effort needed to find, recruit, and provide stipends to those on Medicaid or those who would qualify under the new state health plan. Thus, these meetings were overrepresented by well-educated, higher-income individuals, many of whom were health care professionals.

Nevertheless, Oregon’s long-standing commitment to public participation at all stages and organizational levels is well demonstrated. There is consumer representation on the commission, and meetings are held publicly usually every 1 to 2 months, with the opportunity for both public testimony and review of draft reports and recommendations.

One of the most unique aspects of the Oregon Health Plan, however, was not public engagement per se. It was that the Oregon legislation required that a process to identify public values be a component and that the results were incorporated into the structure of the plan. Other known instances where public deliberation was instrumental in effecting coverage expansion plans were in the communities of Muskegon, Michigan (Fronstin and Lee, 2005), and Galveston, Texas (Danis et al., 2010). They both used public prioritization processes in establishing plans for low-income employees of small businesses.

Both of these communities had separate funding to help underwrite the costs of the deliberative processes. To avoid situations like Oregon’s where the meetings were conducted on a shoestring budget, national and state leaders may have to ask the philanthropy community to help fund these efforts. In most cases, deliberative sessions are held episodically, so the funding needed is usually short term.

Public Sector Interest

In the past 5 years, prior to the passage of the ACA, several states have sponsored, organized, and conducted public deliberation sessions to help inform coverage expansion plans in their states.

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3 Personal communication with Vondie Woodbury, Muskegon County Health Project, February 2007.
The state departments of insurance of Ohio, Oklahoma, Montana, and North Dakota, under the direction of their state commissioners, all sponsored statewide discussion groups to identify core values and priorities for coverage for the uninsured. Although implementation of these health care expansion programs was stalled because of the economic downturn, the results of the deliberative sessions were useful in providing direction for policy leaders (Danis et al., 2010; North Dakota Insurance Department, 2011; Ohio Department of Insurance, 2009; State of Oklahoma, 2009).

In California in 2004, a public deliberation project was conducted with adult disabled Medicaid beneficiaries (Danis et al., 2006; Ginsburg and Glasmire, 2004). This was designed to see how recipients themselves would construct a benefits package that had to incorporate a 15 percent cut in the cost of coverage, the projected size of the proposed Medi-Cal budget reduction that year. State officials watched this project with interest, which provided them with important information and insights regarding recipients’ views and priorities.4

Private Sector Interest

A deliberative tool called CHAT (see details below) opened up opportunities for employers to engage their employees in priority setting for health plan benefits. The early 2000s brought rapidly rising premiums, and anxious employers were seeking ways both to educate their employees about the challenges of maintaining affordable health coverage and to gain input on the coverage issues that were especially critical to them. Allina Foundation in Minnesota sponsored a statewide project with the Minnesota Chamber of Commerce in 2001 to gain employee input on how to best structure employer-sponsored health benefits (Minnesota Chamber of Commerce and The Allina Foundation, 2001). The Center for Healthcare Decisions conducted two projects in the greater Sacramento region in 2002 (Danis et al., 2007) and 2006 (Ginsburg et al., 2006), engaging diverse groups of employees in decisions on, respectively, what aspects of coverage were most important for their company’s health insurance and what constitutes the elements of a basic health plan for the uninsured. Although the primary intent of the first project was to help employees gain knowledge and insights about health plan coverage limits, at least two employers used the results to help inform their own health plan changes (Danis et al., 2010).

CHAT (Choosing Healthplans All Together)

One particular tool for decision making has received considerable attention in the past 10 years. Developed in 1998 by two bioethicists—Drs. Susan Dorr Goold at the University of Michigan and Marion Danis at the National Institutes of Health—CHAT is a simulation exercise for designing a benefits package when there are more options than there are available funds (Goold et al., 2005). This small group process requires participants (as individuals and as a group) to make choices among competing health care priorities. It is typically conducted with each participant using an individual laptop before coverage decisions must be made as a group. The flexibility of the CHAT software allows the options to be modified as needed to expose participants to the specific choices and tradeoffs that are relevant to the policy issues being explored. An actuarial analysis is incorporated into the CHAT model to ensure that choices are a realistic representation of actual costs.

Among the tradeoffs that can be represented are such competing priorities as ranges of provider choice, degrees of cost sharing, types of cost sharing, extent of coverage categories, types of treatment available, utilization oversight, and standards of treatment effectiveness, among others. The descriptions use terms and concepts that are understood by the average consumer. Quantitative data are easy to capture, but the dominant feature of the process is the interactive dialogue, debate, and negotiation that takes place when a group of 12-15 participants seeks agreement on what aspects of coverage are most important and why. In the United States, CHAT has been used in at least 10 states to help inform state and community leaders about covered benefits and benefit design, including those mentioned previously under the section Public Sector Interest (Danis et al., 2010). In California, CHAT has been used with insured employees, Medicaid beneficiaries, the uninsured, health care professionals,

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4 Personal communication with Kim Belshe, former Secretary, California Department of Health and Human Services, July 5, 2011.
and policy leaders and as an educational program for health care and business leadership development (CHCD, 2011; Ginsburg and Glasmire, 2007; NIH, 2011).

CHAT is not the only way to conduct public deliberation about benefits. Less time-intensive and technology-dependent formats can be developed, and other processes have been used for topics related to resource allocation decisions (CHCD, 2009; CHCD and Sacramento HealthCare Decisions, 2001, 2006; Gold et al., 2007). Deliberative processes on other aspects of health care (and other public policy issues) are conducted in communities across the country by Public Agenda, National Issues Forum, AmericaSpeaks, Viewpoint Learning, and other organizations.

Participants’ Reaction

Policy leaders may wonder if the public might regard its participation in coverage decisions with suspicion or resentment. This was a particular concern when the Center for Healthcare Decisions (CHCD) conducted deliberative sessions with adult disabled Medi-Cal beneficiaries, as referenced earlier in this chapter. CHCD thought that participants would be outraged at the idea of being asked to make decisions that would reduce their own benefits (which, in fact, was their assignment using the CHAT process). Surprisingly, the general response was, We know the state is talking about cutting Medi-Cal; we’d rather have a say in this than be ignored. A post-CHAT survey question reflected this sentiment (Table 6-2).

**SUMMARY OF GUIDELINES FOR PUBLIC PARTICIPATION**

At every step of their work, national and state entities responsible for defining and refining the EHB should ensure meaningful and visible public participation. There are two broad areas in which guidelines regarding public participation are relevant: (1) in the oversight of the EHB program and (2) in the identification of social values to help guide decisions on what and how coverage is provided within the EHB. These guidelines are consistent with the criteria outlined in Figure S-2 in the Summary and include the following:

- The National Benefits Advisory Council (see Recommendation 5 in Chapter 9) and governance of the state health insurance exchanges need to ensure that the consumer or citizen voice is an active one in the development, operations, and evaluation of the EHB. This may be best achieved through public deliberation, advisory committees, and/or other means of public input and participation.
- A credible process for establishing the EHB includes a public deliberation component. These structured, interactive group sessions identify the values and priorities of key constituents (such as people whose insurance is defined by the EHB) and are germane to establishing the EHB.
- A public deliberation process is also encouraged when seeking approval of state variants in an EHB package or waivers (Recommendation 3 in Chapter 8), and at other times when meaningful changes in benefits structure are being considered. When these are conducted at the state level, these processes are under the direction of the governor or his/her designate (e.g., the exchange governing body).

**TABLE 6-2** CHAT Results from Medi-Cal Survey of Users’ Views (Adults with Disabilities) on Public Input in Areas of Budget Cut

<table>
<thead>
<tr>
<th>Agree or Disagree: If the Medi-Cal budget is cut, I think it is important for Medi-Cal users to have a role in deciding how the cuts are made (N = 131)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agree strongly</td>
</tr>
<tr>
<td>Agree somewhat</td>
</tr>
<tr>
<td>Disagree somewhat</td>
</tr>
<tr>
<td>Disagree strongly</td>
</tr>
<tr>
<td>Not sure</td>
</tr>
</tbody>
</table>

Public deliberation processes follow protocols that ensure they will be nonpartisan, reasonably representative and inclusive, and professionally designed, executed, and analyzed. The deliberative sessions are of sufficient number so as to produce meaningful and trustworthy findings.

The findings and recommendations of deliberative sessions are made public (and open to public comment) prior to final reporting.

Development of or changes in the EHB are accompanied by an explanation of how they relate to the findings of the relevant deliberative processes.

The values of an informed public are not always determinative. The concerns of public health and legislative leaders and issues of social justice (particularly relating to vulnerable populations) may take precedence over some of the priorities identified by the general public. Ultimately, policy leaders are responsible for balancing the needs and interests of multiple stakeholders with diverse concerns. Yet the inevitability of limit-setting requires a nonpartisan, transparent process for eliciting the core values of key players, including taxpayers and health plan enrollees. Health care has always been steeped in tradeoffs; this fact is simply more apparent now. Incorporating an informed citizen perspective can make these tradeoffs more responsible, responsive, and acceptable to the public.

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Driving the Demand
The dominant form of health care financing in the United States supports a reactive, visit-based model in which patients are seen when they become ill, typically during hospitalizations and at outpatient visits. That care model falls short not just because it is expensive and often fails to proactively improve health, but also because so much of health is explained by individual behaviors,1 most of which occur outside health care encounters. Indeed, even patients with chronic illness might spend only a few hours a year with a doctor or nurse, but they spend 5000 waking hours each year engaged in everything else — including deciding whether to take prescribed medications or follow other medical advice, deciding what to eat and drink and whether to smoke, and making other choices about activities that can profoundly affect their health.

The increasing attention being paid to those 5000 hours takes various forms. Employers are focusing more on employees' wellness — how they eat, whether they smoke, and how much they exercise. Medication adherence has become a more important goal, thanks to growing recognition that many people with chronic conditions fail to take their medications regularly and therefore do not get the benefits that health care can provide. Home-based biometric assessments of indicators such as glucose level, blood pressure, and weight are emerging as part of longitudinal clinical care. Transitional care models are being touted as a way of coordinating care beyond hospitalization. And hospitals and health plans are developing “hot-spotter” approaches, deploying tailored and intensive attention to managing the care of their most challenging patients.2 All these activities occur outside the conventional, billable, clinical encounter — and all reflect some sort of hovering over people in their daily lives.

Conventional approaches to improving patient engagement along these dimensions have been personnel-intensive — using visiting nurses or clinically staffed telemedicine services. Although results have been mixed, in general these programs have not fulfilled their promise. One problem is that using personnel in hovering is expensive and therefore diffi-
The third development is the expanded reach of both sophisticated and simple technologies — cell phones, wireless devices, and the Internet — that can help health experts connect to people during their everyday lives. Neither wireless devices nor behavioral economics were part of the disease-management programs that have produced mixed results in the past.

There is already considerable evidence of the promise of automated hovering. One study of patients taking warfarin deployed a home-based pill dispenser that was electronically tethered to a lottery system. Patients were automatically entered into a daily random drawing, with a small chance of winning $100 and a larger chance of winning $10. Each day, patients were electronically notified if their number had come up — which it would do about 1 day in 5 — but were eligible for the prize only if they had taken their warfarin the previous day, as signaled by the dispenser. The system provided daily engagement, the chance of a prize, and a sense of anticipated regret: no one wants to receive news of winning only to be disqualified for nonadherence the previous day. The expected value of the lottery was less than $3 per day, but the system reduced the rate of incorrect doses from 22% to about 3% and reduced the rate of out-of-range international normalized ratios from 35% to 12%. Such a system could easily be deployed to improve medication adherence among patients discharged from the hospital with congestive heart failure or after being treated for acute coronary syndromes. This system uses technology with an engagement strategy informed by behavioral economics to hover over patients.

In another clinical trial, patients with difficult-to-control diabetes were randomly assigned to receive usual care or mentorship from another patient who had previously managed to tame his or her own diabetes. The mentor merely had to call the patient once a week. The result at 6 months was glycated hemoglobin levels more than a full percentage point lower than those in the control group, created by a system requiring minimal technology to produce hovering that was "automatic" from the clinician’s perspective. This kind of hovering must be targeted to the right clinical and social circumstances. The biggest savings will probably come from reducing preventable hospitalizations or delaying entrance into nursing homes, because that’s where so much spending currently occurs. However, cell-phone mentors and automatic pill-bot-tle reminders probably won’t offer much to patients who are frequently hospitalized owing to a combination of severe illness and challenging life circumstances. These patients, at one end of the spectrum of intensity of health care needs, require a more personnel-intensive approach that focuses as much on social circumstances as on complex medical care. The best targets for automated hovering are conditions whose management depends substantially on individual patients’ behavior. Good targets are medication adherence in patients with heart failure or acute coronary syndromes and efforts to manage diet, exercise, or weight. The amount of hovering required to engage patients in healthy behaviors during those 5000 hours will depend critically on the intensity of their needs, but automated systems might be a cost-effective solution for many patients.
There are potential concerns. Some people might worry that too much hovering will erode patients’ sense of personal responsibility or that hovering in one area might distract providers or patients from other important health issues. Others may worry that hovering is too intrusive or paternalistic — though patients could easily opt out, and it’s arguably no more paternalistic than traditional approaches to improving patient outcomes. It will be important to ensure that new hovering efforts are evaluated carefully, with assessment of both intended and potential unintended consequences.

And of course, there is a considerable amount we don’t know about these approaches: the kinds of patients, conditions, or settings for which they will be the most useful; the organizations (hospitals, employers, or insurers) that should be the ones to deploy them; and how to make them heard over the din of everything else that competes for attention while remaining unintrusive enough that nudges don’t become self-defeating nags. There are both clinical and research opportunities in pursuing an approach that is just as rigorous as our approach to other areas of medicine. Careful iterative testing is essential because these new forms of patient engagement, whatever shape they take, will be central to improving population health in our future health care system.

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Assessing Value in Health Care Programs

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Any health care services provided in the United States are of low value, meaning that the cost of providing those services is high relative to the health care benefit they confer. In some cases, the care provided may have no value or even, on average, may be harmful. Examples of low- or negative-value services include unnecessary surgery or diagnostic imaging that will not change management. Given estimates that 30% of the $2.5 trillion the United States spends on health care services each year may provide little benefit,1 there is a widespread eagerness to enhance the ratio of benefits to costs.

Because value matters in health care, when new health care programs are proposed it has become common to ask, “What is the return on investment from implementing this new program?” Implicit in this question is that programs should be supported if they save money but not otherwise. Positive return on investment, meaning that more money is saved than is spent, has become the standard by which new initiatives are evaluated. This standard has been used to evaluate new programs such as the primary care medical home, disease management, and the projects submitted for the new Center for Medicare & Medicaid Services Innovation Challenge.

Although asking about return on investment might seem to make sense given concerns about health care cost and value, asking about return on investment is the wrong question when assessing whether a health care program is successful. What would happen if the rule were applied to every health care decision that is made? Besides childhood vaccination and flu shots for the elderly, few health care services save money.2 The positive return-on-investment criterion is not applied to most health care services because almost nothing satisfies it. Medicare is prohibited by law from considering cost in coverage decisions, and other insurers tend to follow suit, even if the benefits are small and the costs very large. Would anyone ever ask, “What is the return on investment in treatment of this patient’s cancer?” This is not a meaningless question, but almost certainly one that most people would think inappropriate to ask.

Cost is important and should be considered in many more settings for both existing and new services. Clinicians and policy makers should not apply one standard when tacitly continuing the status quo and a different standard when evaluating innovative programs that might be implemented. It certainly does not make sense to use one criterion—Are there clinical benefits?—for coverage decisions for treatments and a different criterion—Are health care savings greater than program costs?—for preventive services or for delivery system innovations designed to improve health. Programs designed to improve health and prevent disease should be evaluated based on whether they improve health at a reasonable price, essentially comparing whether improvements in health are achieved for less resources than through alternatives, eg, expenditures on health care services.

Health care reimbursement tends to be disease fixated and should be evaluated the same way based on the value of expenditures in achieving improvements in health.3 If an employer spends $100 000 treating late-stage emphysema or lung cancer for its employees—an expenditure with a negative return on investment but one that adds value to employees’ lives—should that employer be willing to spend money on smoking cessation programs? The answer is almost undoubtedly yes. However, if health promotion programs or health system delivery innovations are required to save money, they will likely be labeled failures even if they improve health at a lower price than many of the services that we now willingly pay for under Medicare and private insurance. If we continue with the approach of insisting on a positive return on investment to fund such programs, low-value spending will persist at higher rates than would otherwise be the case.

For example, consider a program that would improve medication adherence after acute myocardial infarction (AMI). Adherence rates to β-blockers, statins, angiotensin-
converting enzyme inhibitors or angiotensin-receptor blockers after an AMI event is poor; a recent large-scale study showed that even when copayments were lowered to $0 among insured patients, average adherence for these medications was only about 45%. If a new program could increase adherence to 70%, it is plausible that the program could significantly reduce the rate of hospital admissions for MI, stroke, and revascularization procedures. If the average cost of health events requiring hospitalization in the 12 months following a hospital admission for a new MI is about $20,000 and the new program reduced the rate of events requiring hospitalization by 10%, the new program could cost up to $2000 per year and still save money. Does that mean the program should not be adopted if it costs $3000? At that point, the calculated return on investment for the program is negative because it costs more than it saves. But wouldn’t this program still be a much better use of money than letting those MIs occur (mortality rates from AMI are typically more than 10% among hospitalized patients in the 30 days after admission, and many patients die before making it to a hospital)? If this is deemed not a good use of resources, then why are so many other services covered that yield lower value? Many insurers, including Medicare, are continuing to cover bevacizumab for metastatic breast cancer, despite the unanimous recommendation by a US Food and Drug Administration panel that it not be covered because it is not helping patients to live longer, does not control their tumors, and exposes them to serious adverse effects and despite an average annual cost of $99,000.

There are political, ethical, and emotional challenges to making explicit resource allocation issues in treating diseases and applying the same metrics used to evaluate the effectiveness of programs that prevent diseases in largely unidentified patients. It is always more difficult to shut down existing programs than to say no to new ones, a phenomenon related to inertia, also known as status quo bias. It is also more difficult to justify investments in prevention across broad populations than investments in the treatment of identifiable patients, a phenomenon known as the rule of rescue. Changing the criteria used to evaluate health system delivery innovations might help overcome these tendencies. Evaluating success using the same criteria—whether a preventive service, delivery system innovation, or treatment—may be the best way to ensure the maximal value in terms of improvements in health for the resources expended on health care services.

A recent conversation with a benefits manager from a medium-sized employer brought this point home. She reported that when asked by the chief financial officer, “What is the return on investment in putting in place this $125,000 wellness program?” she responded, “What is the return on investment on the $28 million we are spending on treating disease through our health benefits?” If cost is not considered when thinking about the value of covered treatments, it does not make sense to use positive return on investment as a criterion for determining whether promising new delivery system innovations should be covered. A better approach would be to adopt similar metrics for treatment and prevention for current and proposed care, for which the goal in all cases is achieving the most improvement possible with the resources available.

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Choosing Wisely
Low-Value Services, Utilization, and Patient Cost Sharing

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The June 2012 issue of Consumer Reports includes a cover story entitled “5 Medical Tests You Don’t Need.” The story reflects a joint Choosing Wisely initiative by Consumer Reports and the American Board of Internal Medicine aimed at encouraging physicians, patients and other health care stakeholders to think and talk about medical tests and procedures that may be unnecessary, and in some instances can cause harm. The framing of this initiative as a way to improve quality and patient safety is important. For too long, efforts to reduce the use of low-value services have been decried by critics as rationing or as schemes to enhance insurance company profits. The rationing frame has often been motivated by political posturing or stakeholder financial interests and has helped perpetuate the consequences of unchecked health spending on individuals, families, and federal and state budgets. The Consumer Reports story reveals to the general public something many in the medical profession already know: While much health care spending does provide substantial individual and social value, some of it supports care of little or no value.

Efforts to tie patient cost sharing to the benefit of the treatment in question and not just the cost through value-based insurance design (VBID) have recently proliferated within employee benefits circles. If co-payments are increased for low-value services and reduced for high-value services, standard economics predicts that patients will migrate from the former to the latter, making better use of health spending dollars. Several studies have found that patients who faced increases in medication co-payments decreased their use; of these, some also found that savings in pharmacy costs were offset by higher rates of emergency department utilization and hospitalization, so no money was saved overall—while rates of adverse events increased.

These findings seemed to imply that reducing co-payments for high-value medications in high-risk populations. However, subsequent studies have found that increasing and decreasing co-payments do not have mirror-image effects. Lowering co-payments does not improve utilization nearly as much—typically only 1 to 4 percentage points on baseline medication possession ratios (MPR) of 60% to 80%—an asymmetry that was not predictable from standard economic theory. This means that there would be 20 to 25 people whose adherence did not change for every completely nonadherent patient (MPR=0%) who became highly adherent (MPR >80%). A study in which patients who had acute myocardial infarction (AMI) were randomly assigned to standard co-payments or zero co-payments for statins, β-blockers, and angiotensin-converting enzyme inhibitors found disturbingly low MPRs of 39% in the year following AMI in the control group with improvement to only 45% in the zero co-payment group, a difference that resulted in no significant reduction in the rate of total major vascular events or health care spending.

There are several reasons for the asymmetry between the large effect of increasing co-payments and the small effect of lowering them. First, people tend to be loss averse, and as a result, co-payment increases are far more potent than co-payment decreases. Second, co-payment reductions every 30 or 90 days may be too infrequent to motivate daily medication adherence. Third, co-payment increases and decreases target different populations. Increases target adherent patients but decreases are meant to attract patients who are not taking medications. Those who do not take medication will not notice changes in prices they are not paying.

These results imply that even though VBID may not be highly effective in increasing utilization of desired services, it could be effective in decreasing utilization of low-value services. Higher patient cost sharing would deter patient demand for certain types of low-value services: patients...
would be less likely to demand that their physician order magnetic resonance imaging (MRI) for new-onset back pain or antibiotics for upper respiratory tract infections. If health plans went so far as to not cover prostate-specific antigen screening (now rated “D” by the US Preventive Services Task Force) so patients had to cover the full costs, such decisions, coupled with communications describing that such services either harm patients on average or provide extremely small benefits relative to the costs, would send a powerful signal to patients, who may generally assume that all health care services provided are of high value.

However, there are at least 2 reasons why increased patient cost sharing is an imperfect solution to this problem. First, while patient-centered care is important, many patients need guidance in deciding whether services are or are not worth it. Many items in the list of 45 low-value services identified in the Choosing Wisely campaign have clinical qualifications such as “Don’t order sinus computed tomography (CT) or indiscriminately prescribe antibiotics for uncomplicated acute rhinosinusitis.” However, few patients are able to judge whether their specific case of acute rhinosinusitis is complicated or uncomplicated. Such judgments must be made by physicians. To increase prices for low-value services across the board may deter both low-value usage and usage by some patients for whom a given service may be of higher value. Moreover, patients tend to respect the advice of their physician. If a physician recommends an MRI for a patient who has new-onset lower back pain but no motor deficits (another example on the Choosing Wisely list), many patients will assume they should undergo the test regardless of the price.

Second, even physicians often have little understanding of what procedures are of low value (a situation the Choosing Wisely campaign aims to correct) and some may have conflicts of interest that contribute to higher rates of utilization. All 45 services on the Choosing Wisely list are tests ordered by physicians, some frequently, and the difficulty of changing these practice patterns is large. Social welfare is enhanced by the use of high-value services, but individual physician income is enhanced by the use of high-margin services, and value and margin are not always aligned. To connect them, the underlying financial incentives for clinicians to provide services need to be connected to their value.

The Choosing Wisely campaign derives its great promise by reflecting the growing consensus among medical professional societies and consumer groups that many commonly used clinical services provide little or no benefit for most patients. But if it is difficult in many situations for patients to choose wisely, and if there are significant challenges in getting physicians to choose wisely, then who should be doing the choosing?

The difficulties of achieving reductions in overutilization by affecting decisions by individual patients or physicians points to the pressing need to revisit the bogeyman of health care rationing. The development of guidelines that include the assessment of cost and value are urgently needed but the Centers for Medicare & Medicaid Services, Agency for Healthcare Research and Quality, and Patient-Centered Outcomes Research Institute are all prohibited from the development of such recommendations.8 The United Kingdom’s National Institute for Health and Clinical Excellence is charged with weighing costs and benefits in coverage decisions in recognition of the fact that not all services are worth their cost. The Choosing Wisely initiative represents an important first step toward the identification of low-value services, more meaningful because it was a step taken jointly by consumer groups and professional specialties. The next step is to move beyond a list of low-value services toward the testing of approaches to reduce their use, ideally through a combination of benefit design, physician payment policies, and social and professional guidance informed by clinical evidence. Given fiscal realities, reducing low-value services is what will allow continued support for the coverage of high-value services.

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Evidenced-based Medicine or Easy-bake Oven: Tension Between Evidence and Reality

This post was inspired by the article Patient Advocates: Flies in the Ointment of Evidenced Based Care by Jessie Gruman at Health Affairs Blog. Patient advocacy and evidenced-based medicine are both intimately entwined with several matters in rheumatological care, but first a word about flies.

Patient advocates probably are flies in the ointment, and there would certainly be no flies in a perfect world. But in a perfect world, we wouldn’t be sick. In a perfect world, doctors could comprehend our pain. Treatments would work on every patient. Tests would always tell the truth…

A tug of war between medical evidence and advocates?

Jessie’s post considers the clash between 1) patient advocates who promote exceptional care for all victims of a disease, and 2) the conflicting ideal of reliance upon established scientific evidence by those who try to fairly administer health care policy or health care itself. “In past decades, the aims of advocates have frequently been at cross purposes with those of government officials charged with balancing a national research agenda.” At hand was the US Food and Drug Administration’s withdrawal of its approval for Avastin as treatment of advanced breast cancer and the fever pitch of emotion that came with it.

Did you watch any of the coverage? I agree that media tend to focus on the emotional side of issues like Avastin. Yet, the last comment by Steven Walker made a point that is significant with regard to RA: Sub-types of the disease and genetic differences make one-size-fits-all treatment impossible. Unfortunately, unlike cancer, RA doesn’t even have any of its sub-types classified yet. All RA treatment today is still trial-and-error, though evidence that subtypes do exist has begun to trickle out.

Evidence in the case of the 9/11 workers with cancer
Also in the news are the cancer-patient 9/11 World Trade Center (WTC) responders. Patient groups representing first responders from 9/11/01 are convinced that there have been an abnormally high number of cancers in previously healthy people. Several forums are full of anecdotal evidence. They believe that exposure to toxins such as asbestos in airborne debris contributed to their cancers. However, a committee who manages funds for health care claims of 9/11 WTC responders won’t add cancer to the list of compensated conditions because they don’t have evidence that WTC debris causes cancer.

The list for continued coverage does include asthma, acid reflux, carpal tunnel syndrome, and sleep apnea which some 9/11 cancer patients point out are illnesses which are far less costly to treat than cancer. However, a study has found “very little” evidence that exposure at Ground Zero caused cancer.

Evidence outweighs hunches and sympathies. But is it sufficient?

‘Insufficient evidence exists at this time to propose a rule to add cancer, or a certain type of cancer,’ to the list of diseases that qualify for aid under the James Zadroga 9/11 Health and Compensation Act, the report said. The report said only one peer-reviewed article was published on the subject in 2009 and two others were based on models to estimate the risk of cancer. ‘These limitations in the exposure assessment literature make scientific analysis of a causal association between exposure and health effects, such as cancer, quite challenging,’ it said” (Associated Press).

There is not enough evidence that the WTC debris caused cancer, but there turns out to be very little evidence period. How often are people exposed to similar events in order that we might study what they cause? One title summed the dilemma perfectly: 9/11 Cancer Study Pits Scientists Against First Responders. At least that’s how it seems.

Evidence is not the same thing as truth

Judgment is always required to decide whether particular evidence pertains to a situation. Data can certainly be incomplete. Or evidence can be misunderstood. Ask any judge.

As science advances and more facts are exposed, positions have to change with them.
That’s why we wash our hands to fight infection instead of using leeches. Yet we don’t always know what we don’t know.

If only we could wrap the golden lasso of Wonder Woman around the evidence to make it tell the truth.

Evidence-based rheumatology: Handle with care

Turning to rheumatology, consider the Pyramid treatment scheme (more recently called the Step-up Approach) used by some rheumatologists who believe that they are either conserving resources for the good of the system or shielding patients from harmful side effects. Treatment is delayed while doctors wait for evidence of permanent damage. But what of the evidence demonstrating that Rheumatoid disease may have a narrow treatment window in which treatment response is more likely, if applied aggressively enough?

Meting out care based upon evidence should require the considerable proof of its validity that we don’t have with RA. I could write all night long about the problems with establishing evidence as it relates to RA diagnosis, treatment, and monitoring of unique patients. In large part, the problem is due to the dearth of research related to actual effects and consequences of the disease in patients. With RA, some evidence is inadequate and its application flawed; there has been little correlation between genetic data, physical symptoms, and blood indicators.

The science train has not yet arrived to rescue RA patients standing at the evidenced-based medicine station. In clinical trials, the best clinicians use the best methods to assess RA, but in typical practice, these are real problems:

- There is no definitive RA test.
- Tests to measure RA activity are inadequate.
- Imaging tests like ultrasound or nuclear bone scans have high error rates because they’re entirely user dependent.
- Patients and doctors frequently appraise disease activity differently.

Evidence-based medicine puts a burden of proof on RA patients that defies logic. How does one prove symptoms such as pain, stiffness, and fatigue? Patients resort to pho-
tographing swelling because their word is not sufficient, but photos are sometimes discounted. Rheumatologists like Dr. Ted Pincus who investigate assessment of patient index data and recognize patient outcome measures as scientific evidence become heroes to patients who need accurate assessment and effective treatment to fight a disease that can cause disability or lead to early death.

In the next few years, if purposeful correlations can be established with tests like the new Vectra DA test, they may become significant in RA treatment. On a distant horizon we look forward to targeted therapies. Meanwhile, some doctors borrow principles from endocrinology, where blood tests provide realistic measurements of disease activity or treatment effectiveness. However, blood tests commonly used to measure RA systematically underscore (or overscore) disease activity at a rate over 200%.

Why do I get so many letters from patients like this: “Why are my symptoms worse when my rheumatologist says my labs show the disease is in remission?” The reason is that there aren’t any lab tests that can show any such thing, yet. When it comes to RA, I’m wondering whether “Evidence-based medicine” becomes the “Easy-bake oven” approach (not quite real).

Postblog: As this was being posted, an Arthritis Research and Therapy editorial was published recommending monitoring of immunogenicity to RA treatments. Methods for such monitoring are not yet widely available, but this would represent a good step toward the pertinent use of evidence in RA treatment. Patients often become immune to treatments and some are told their failed treatment response proves they never had RA. Evidence says otherwise.

Recommended reading

- The Value of Patient Reported Outcome Measures of Rheumatoid Arthritis
- Evidence and Truth: WTF (Where’s the Fact?)
- Patients & Doctors Differ on Assessing Rheumatoid Arthritis Disease Severity
- Rheumatoid Arthritis Test: Some Funny Factors

NOTE: Your comments are an important resource for future readers of this post in the months to come. Please find the comment link below each post.
BACKGROUND
The Rheumatoid Patient Foundation (RPF) was formed in 2011 as the first patient organization for Rheumatoid Arthritis. A part of the RPF's mission is public awareness and patient advocacy, which includes providing information from the patient's perspective. To that end, the RPF created a survey in 2011 to gain insights from the RA patient population as relates to their disease onset, symptoms, treatments, rheumatology care and personal experiences.

OBJECTIVE
The purpose of this survey was to obtain specific insights into how the disease affects patients and to gain understanding of their broad experience as RA patients.

METHODS
In 2011, the RPF introduced a 29-item questionnaire and made it available to RA patients via the RPF website, rawarrior.com, and their respective social media outlets on Facebook and Twitter. The questionnaire was hosted in a secure survey system preventing multiple entries. A brief poll was subsequently issued as well, to address a topic not included on the survey. 1,465 RA patients responded to the online questionnaire; 288 RA patients responded to the poll.

RESULTS
Patient Demographics & Basic Information
The majority of participants were female (93%), and the median age was 47 years old. A quarter of the patients surveyed had been diagnosed within the past 12 months and the average length of time since diagnosis was 6.6 years. 95% of all patients surveyed had been treated with DMARD or Biologic medications.

24% of patients reported that they were seronegative, and did not test positive for Rheumatoid Factor or anti-CCP.

51% of patients reported that they had RA symptoms for longer than a year prior to diagnosis. 19% reported having symptoms for five or more years prior to diagnosis.

Symptoms – Fever and Fatigue
80% of patients reported that they sometimes have low-grade fevers, and 99% reported sometimes experiencing RA-related fatigue. Patients who experienced fatigue more frequently, however, were more likely to experience low-grade fevers as well.

Symptoms – Pain
68% of patients reported having zero pain-free days each month. On average, respondents experienced only 2 pain-free days per month. 31% of survey respondents reported moderate to severe pain at least 15 days out of the average month. Most age groups experienced similar pain – with the exception of the youngest and oldest groups. The length of time since a patient’s diagnosis did not appear to have any effect on the patients’ reported pain levels.

Physical activity increases pain for 67% of respondents, while 18% said activity decreases pain. The top three factors cited as decreasing RA pain were medications, rest, and heat. Medications were reported to decrease pain levels by 80% of respondents.

KEY FINDINGS
The findings from this survey reveal a vast array of patient experiences and demonstrate trends that differ from conventional knowledge of rheumatoid disease.
Rheumatology Treatments and Care

The majority of respondents stated that additional medications were needed beyond disease treatment to help control remaining RA symptoms. Only 8% of respondents stated that their symptoms were completely relieved by DMARD or biologic treatments, while 36% of patients stated that they continue to live with a lot of symptoms regardless of any treatments.

42% of patients reported that they generally experienced a weak association or no association between visible swelling and other symptoms in the same joint, such as pain, stiffness or weakness. 75% of respondents reported either experiencing joint damage without swelling or dramatic joint swelling without damage, indicating that the two are frequently unassociated.

Symptoms – Morning Stiffness

23% of respondents reported that they experience the most joint pain and stiffness in the morning – consistent with the concept of ‘morning stiffness.’ However, a quarter of the respondents stated that the joint pain and stiffness lasts all day and night, and 52% experience some or most of their joint pain and stiffness in the evening or after a period of activity.

SUMMARY OF FINDINGS

Many of the results from this survey indicate patient experiences that fall outside of the standard model of RA that is presented in current medical literature. For example, although exercise is often touted as being beneficial for RA by improving mobility and lessening symptoms, two thirds of the participants reported that exercise caused an increase in RA-related pain. The survey data also challenge the concept of ‘morning stiffness’ that tends to go away after a patient gets out of bed and begins his or her day. While nearly a quarter of the respondents seem to follow this trend, the majority of them do not, citing more pain and stiffness at different times throughout the day. There is also often a perception that joint swelling and damage are directly related. However, the data suggest that patients do not report a clear link between swelling and damage in a given joint.

The patient responses recorded from this survey indicate that the majority of patients continue to live with pain and symptoms from RA, despite receiving disease treatment. More than two thirds of respondents reported living with RA pain every day. The severity and frequency of RA pain did not change based on age group except for the youngest and most elderly age groups and, remarkably, pain patterns remained consistent irrespective of the length of time since diagnosis. Most respondents also reported some level of concern regarding the medical care that is available to them.

LIMITATIONS

Women and younger patients were over-represented, possibly as a result of the online tool methodology. Patients self reported as being diagnosed with RA.

CONCLUSIONS

The data collected from this survey indicate that patient experiences and symptoms do not always mirror the archetype of RA that is traditionally presented in literature. Additional research would be valuable to challenge conventional thinking in these areas. Where discrepancies are found, steps could be taken to educate the medical community and broaden understanding of the varying ways RA presents itself in actual patient populations. It is also clear that currently available treatments are often insufficient for relieving the pain and other symptoms caused by RA, and that there remains a significant portion of the patient population that does not respond to existing treatments. Additional research should explore classifications of various patient populations and subsequent responses to treatments.
Biographies and Meeting Logistics
Partnering with Patients to Drive Shared Decisions, Better Value, and Care Improvement

Planning Committee biographies

Terry Adirim, MD, MPH is the director of the Office of Special Health Affairs (OSHA) of the Health Resources and Services Administration (HRSA) in the U.S. Department of Health and Human Services. Previously she worked in various capacities in the Office of Health Affairs at the Department of Homeland Security (DHS) as medical advisor, acting Associate Chief Medical Officer and Senior Advisor for Science and Public Health. While at DHS, she also served as the vice-chair of the FEMA Children's Work Group, which focused on incorporating the needs of children and families in disaster preparedness, response, and recovery. From 2004 to 2006, Dr. Adirim was associate professor of Emergency Medicine and Pediatrics at Drexel University College of Medicine and director of Emergency Medicine at St. Christopher’s Hospital for Children in Philadelphia Pennsylvania. From 1997 to 2004, she was associate professor of Pediatrics and Emergency Medicine at the George Washington University School of Medicine and attending physician at Children’s National Medical Center in Washington, DC. Dr. Adirim received her B.A. degree from Brandeis University, her medical degree with research distinction from the University of Miami School of Medicine, and her master’s degree in public health from the Harvard School of Public Health. She completed pediatric residency training at the Children’s Hospital of Philadelphia, fellowship training in pediatric emergency medicine at Children’s National Medical Center and primary care sports medicine at the Uniformed Services University of the Health Sciences in the Washington, DC area. Dr. Adirim continues to practice emergency medicine in the Pediatric Emergency Department at Shady Grove Adventist Hospital in Rockville, Maryland.

Christine Bechtel, MA is the vice president of the National Partnership for Women & Families, where she is responsible for strategic direction and oversight of the organization’s multi-faceted health care programs. This includes managing projects funded by the nation's largest foundations, partnerships with key business consortiums, and leading broad-based consumer coalitions that address issues ranging from patient-centered care to health IT to quality measurement. She was appointed by the Government Accountability Office in 2008 to the federal Health IT Policy Committee, where she represents patients and families, and also serves as a consumer representative on the Measure Applications Partnership. Bechtel was previously vice president of the eHealth Initiative, a Washington D.C.-based non-profit organization dedicated to improving the quality, safety and efficiency of health care through information and information technology. In this role, she led numerous initiatives to achieve consensus across the multiple stakeholders in health care on how to accelerate the adoption and effective use of health IT in a way that is responsible, sustainable, and builds and maintains the public's trust. Prior to joining eHI, Bechtel worked with American Health Quality Association where she helped Quality Improvement Organizations (QIOs) and professionals improve the quality of health care in communities across America, focusing on the ambulatory setting, health disparities, and effective use of health IT. She also served as senior research advisor at AARP where she conducted public opinion studies and advised AARP’s leadership on public attitudes surrounding national political issues including Medicare prescription drugs, generic drugs, Social Security and elections issues. Bechtel's experience also includes community-based quality improvement activities. She was director of community development for Louisiana's Medicare Quality Improvement Organization, Louisiana Health Care Review, where she was responsible for designing, implementing and overseeing innovative projects to improve health care quality for Medicare beneficiaries in Louisiana. Bechtel served as a legislative associate for United States Senator Barbara A. Mikulski (D-MD), focusing on legislative issues ranging from women’s health and stem cell research to Medicare and Social Security. She holds a bachelor's degree in politics and public policy from Goucher College in Baltimore, Maryland and a master's degree in political management from George Washington University in Washington, D.C.
Leah Binder, MA is President & CEO of The Leapfrog Group, a national organization based in Washington, DC, representing employer purchasers of health care calling for improvements in the safety of the nation's hospitals. She is an influential voice for major change in healthcare. For each of the past three years she was named on Modern Healthcare’s list of the 100 Most Influential People in Healthcare, and one of 20 people making healthcare better in Health Leaders Magazine. Ms. Binder sits on numerous national boards and committees, including the Institute of Medicine Collaboration on Patient Engagement, the National Priorities Partnership Board, and the Advisory Board of the Institute for Interactive Patient Care. She is a frequent speaker on hospital safety and quality, and the importance of payment reform and transparency. Before joining Leapfrog in the spring of 2008, Ms. Binder spent 8 years as vice president at an award-winning rural hospital network in Farmington, Maine, Franklin Community Health Network, and before that she was a senior policy advisor for the Office of Mayor Rudolph Giuliani in New York City. She started her career at the National League for Nursing, where she handled policy and communications for over 6 years. Ms. Binder has a BA from Brandeis University and two masters from the University of Pennsylvania, one from the Annenberg School of Communication and the other from the Fels Institute of Government.

Veronica V. Goff, MS is vice president of the National Business Group on Health, a national non-profit membership organization devoted exclusively to providing practical solutions to its employer members’ most important health care problems and representing large employers’ perspective on national health policy issues. She leads the Institute on Health Care Costs and Solutions. The Cost Institute identifies and disseminates best practices and promising solutions to cost, quality, patient safety, and employee engagement challenges with a focus on implementation and actionable information for employers. Goff represents the Business Group on the IOM Value Incentives Learning Collaborative and the Advisory Board of the Patient Centered Primary Care Collaborative. She recently served on NCQA’s Re-Evaluating PPC-PCMH Standards Advisory Committee and the BCBS Evidence-based Practice Center stakeholder panel on cancer and infectious disease. She has more than 25 years experience working with employers on health benefits and programs. Most recently, she was a senior consultant to the Business Group. Previously, she served as vice president for the Washington Business Group on Health, held a faculty position at the University of Virginia Health Sciences Center, and managed an on-site health promotion/fitness facility serving 8,000 AT&T employees. Goff is an American College of Sports Medicine-certified Health Fitness Specialist. She earned a M.S. degree in physical education with specialization in exercise physiology and a B.S. degree in physical education with a minor in athletic training from Southern Illinois University.

Mark Gorman is a patient advocate and cancer survivor. He is the former Director of Survivorship Policy for the National Coalition for Cancer Survivorship. He has over a decade’s experience advocating for health care that is patient-centered and that is informed by and guided by individual patients’ preferences, needs and values.

Paul Grundy MD, MPH, FACOEM, FACP is Director of Healthcare Transformation at IBM. Dr. Paul is one of only 38 IBMers and the only physician selected into IBM’s senior industry leadership forum know as the IBM Industry Academy. Though he was born in Rhode Island, Paul's first language was Creole, which he learned growing up in Freetown, Sierra Leone. Founded with the help of his Quaker ancestors, Freetown was the home, for a time, of Paul's parents and grandparents. He graduating as valedictorian from the Southern California College, he earned an M.D. from the University of California San Francisco medical school and a Masters of Public Health from the University of California Berkeley. An active social entrepreneur and speaker on global healthcare transformation, Dr. Grundy now concentrates his efforts on driving comprehensive, linked and integrated healthcare. His work has been covered by the New York Times, BusinessWeek, Health Affairs, The Economist, The New England Journal of Medicine and other newspapers, radio and television stations across the country. “I really became an IBMer because it gave the best platform in the world to use the tools of information technology and data to do for the doctor’s mind what x-ray has done for their vision,” he says. Prior to joining IBM, Dr. Grundy worked as a senior diplomat in the U.S. State Department supporting the intersection of health and diplomacy. He was also the medical director for the International SOS, the world’s largest medical assistance company and for Adventist Health Systems, the
second-largest not-for-profit medical system in the world. Dr. Grundy is the president of the Patient-Centered Primary Care Collaborative and is an adjunct professor at the University of Utah’s Department of Family and Preventive Medicine. Dr. Grundy has won numerous awards. He was made an honorary member of the American Academy of Family three Department of State Superior Honor Awards and four Department of State Meritorious Service Awards. While in the U.S. Air Force, Paul received the Defense Superior Service Award and The Defense Meritorious Service Medal.

Arthur Aaron Levin, MPH is co-founder and the Director of the Center for Medical Consumers, a New York City based non-profit organization committed to informed consumer and patient health care decision-making, patient safety, evidence-based, high quality medicine and health care system transparency. He has long had an interest in transparency and conflict of interest as it affects clinical guideline development, the FDA advisory committee process and other aspects of standard setting in health care. Levin was a member of the Institute of Medicine’s (IOM) Committee on the Quality of Health Care that published the “To Err is Human” and “Crossing the Quality Chasm” reports. Levin also was a member of the committee that issued an IOM letter report in October 2007; Opportunities for Coordination and Clarity to Advance the National Health Information Agenda, and served on the committee that wrote Knowing What Works in Health Care: A Roadmap for the Nation published in fall 2008. He just concluded service on an IOM Committee that issued its report this past Fall on HIT and patient safety and currently he is a member of a committee at work on an IOM report on the learning health care system. In addition he was a member of the IOM committee that reported to Congress on priorities for CER (Initial National Priorities for Comparative Effectiveness Research, released Summer 2009). He has also served more recently on the committee that just issued the report Best Care at Lower Cost. He is past chair and current member of the NQF Consensus Standards Approval Committee (CSAC) and is currently a co-chair of the NCQA Committee on Performance Measures (CPM). Levin ended four years of service on the FDA’s Drug Safety and Risk Management Advisory Committee (DSaRM) in May 2007 and continues to serve on select FDA Advisory Committees as a consultant expert in drug safety and risk management representing consumers. He also is on the board of the Foundation for Informed Medical Decision Making. Levin is a founding member of the Board of Directors and of the executive committee of the New York eHealth Collaborative (NYeC), a not for profit, multi-stakeholder organization charged with advancing care transformation in New York State through HIT and HIE. NYeC has responsibility for effective deployment of both New York’s HEAL grant activity directed at HIT/HIE, as well as grants from ONC. Levin earned his Masters of Public Health degree in health policy from Columbia University School of Public Health and a Bachelor of Arts degree in philosophy from Reed College.

Jim Mangia, MPH is the President and CEO of St. John’s Well Child and Family Center, a network of nonprofit federally qualified health centers and school based clinics providing free medical, dental and mental health services to more than 140,000 patient visits in south Los Angeles. Passionate about community health, prevention and social justice, Mangia built the Well Child and Family Centers from a small single-site clinic serving 1200 patients a year to one of L.A. County’s largest nonprofit health care providers with more than a dozen clinic sites. Mangia is the founder of the south Los Angeles Health & Human Rights Conference. Mangia is a leader in building a health and human rights movement in the United States and has built a myriad of innovative and collaborative services and relationships and has built strong and sustainable partnerships with school districts, government agencies, community based organizations, schools, educators and health care providers to increase access to health care services and strengthen the healthcare safety net for impoverished and economically disadvantaged children and their families. He serves on the State of California Workforce Investment Board and was appointed by the Governor as an Expert Advisor to the Let’s Get Healthy California Task Force. Mangia served on the LA Care Health Plan’s Board of Governors from 2008-2012. He served as a member of President Obama’s Health Advisory Task Force and served as the Chair of the Board of Directors of the Community Clinic Association of Los Angeles County from 2010-2012. He is currently a leader in Health Care First South LA, a safety-net Accountable Care Organization designed to redesign and integrate care for underserved populations in South Los Angeles. Mangia has testified before congressional committees, the California state legislature and the Los Angeles city council about environmental health issues affecting L.A.’s children, the critical role of prevention in community
health, health disparities and the right to health. He has received the Certificate of Congressional Recognition, special recognition in the U.S. Congressional Record, and numerous commendations for his work by city, county and state legislative bodies.

**Lyn Paget, MPH** is the Managing Partner of Health Policy Partners, an independent organization dedicated to connecting patient priorities with policy and innovation. For over 25 years, Ms. Paget has worked to enhance the quality of the patient experience in health care. With a focus on information, engagement, and partnership, she has established strategic alliances with government agencies, medical professional societies, consumer advocacy groups, health care quality organizations and policy leaders to create unity around principles for successful innovation and change. As Director of Policy and Outreach at the Informed Medical Decisions Foundation, she directed efforts in advocacy, communications and policy development to support sustainable models of patient centered care and shared decision-making. In this role, she built awareness and fostered collaboration among key stakeholder groups, advocated for new models of reimbursement, promoted quality standards for patient experience measures, and disseminated research results and knowledge to enhance the understanding of the patient’s role in medical decision-making. Ms. Paget was instrumental in the development and launch of HealthNewsReview.org – a public access web site designed to evaluate the accuracy and balance of health and medical news stories. She has participated in and led national, state and local initiatives to expand policy and legislative opportunity for sustainable models of patient engagement. She helped established and served as Vice President of the Medical Outcomes Trust, an organization created to promote the routine use of patient-based outcome measures including the SF-36 and other instruments designed to systematically assess health-related quality of life. For several years, she focused in HIV/AIDS prevention working at the AIDS Project Los Angeles and in Washington State where she led a combined city county HIV/AIDS department. Her work in Tacoma received national recognition for innovative approaches to street outreach and education programs. Ms. Paget serves on a number of national and state committees and workgroups to advance the patient’s role and involvement in health care. She has a BS in Health Education from the University of Massachusetts and a Masters in Public Health from the University of California, Los Angeles.

**Eric Racine, PharmD, MBA** is the Vice President, Partners in Patient Health, North America Corporate Affairs for Sanofi. His department is accountable for partnerships with patients and health advocates to address issues critical to improving health. Eric works across the patient and advocacy communities to engage people in their health, protect patients’ interests and advance science and innovation. Through partnering for patient health, Eric and his team helps Sanofi move beyond medicines to deliver solutions for patients, and to accelerate innovation that prevents, treats and cures disease. Since 2002, Eric has held multiple leadership positions within Sanofi spanning Pharmaceutical Operations, Market Access, Healthcare Policy, and Corporate Affairs. His work has centered on collaborative efforts with key players across the health care system including patients, healthcare professionals, hospital systems, health plans, employers and policy makers. He has also been instrumental in readying the company for changes stemming from the changing healthcare environment. Prior to joining the pharmaceutical industry, Eric held various positions in clinical pharmacy including academic, clinical, and management roles. In these roles, he improved patient outcomes and financial performance by developing and implementing new clinical programs that delivered enhanced quality of care for patients while reducing overall healthcare costs. Eric is an Adjunct-Associate Professor at both the Ernest Mario School of Pharmacy at Rutgers University and the University Of Michigan College Of Pharmacy. He has published abstracts, peer-reviewed publications and book chapters as well as been an invited guest speakers on patient centered topics such as clinical quality improvement and patient access. He is a member of boards and committees including the American Heart Association (AHA) New York Board of Directors, the American Foundation for Pharmacy Education (AFPE), and the National Dean Advisory Board for the University of Arizona, College of Pharmacy. In addition, Eric is the Treasurer for the National Health Council (NHC) Board of Directors. Eric holds a Doctor of Pharmacy (Pharm.D) and an Executive MBA degree. He and his wife are the parents of two children and reside in New Jersey.
Susan Reinhard, RN, PhD is a Senior Vice President at AARP, directing its Public Policy Institute, the focal point for public policy research and analysis at the state, federal and international levels. She also serves as the Chief Strategist for the Center to Champion Nursing in America at AARP, a national resource and technical assistance center created to ensure that America has the nurses it needs to provide care both now and in the future. Dr. Reinhard is a nationally recognized expert in health and long-term care policy, with extensive experience in conducting, directing and translating research to promote policy change. Prior to AARP, Dr. Reinhard served as a Professor and Co-Director of Rutgers Center for State Health Policy where she directed several national initiatives to work with states to help people with disabilities of all ages live in their homes and communities. Previously, she served three governors as Deputy Commissioner of the New Jersey Department of Health and Senior Services, where she led the development of health policies and nationally recognized programs for family caregiving, consumer choice and control in health and supportive care, assisted living and other community-based care options, quality improvement, state pharmacy assistance, and medication safety. She also co-founded the Institute for the Future of Aging Services in Washington, DC and served as its Executive Director of the Center for Medicare Education.

Craig W Robbins, MD, MPH has been a family physician with the Colorado Permanente Medical Group (CPMG)/Kaiser Permanente (KP) since July 1998. In KP Colorado, he currently serves as the Medical Director, Clinical Guidelines. At the KP National level, Dr. Robbins serves as the Medical Director, Evidence Based Practice in the KP Care Management Institute (CMI). In this CMI role, he is the lead physician for the KP National Guidelines Program. He is a past chair of the CPMG Board of Directors (2007-8). He was the Physician Lead for Clinical Content development during KP Colorado’s implementation of the KP HealthConnect EMR (2003-5). Dr. Robbins received his BS (1990) and MD (1993) from the University of Michigan and his MPH (1998) from the University of Pittsburgh. He completed his Family Medicine Residency (1993-6) at the University of Virginia and a Faculty Development Fellowship (1996-8) at the University of Pittsburgh Medical Center-St Margaret Hospital in Pittsburgh, PA.

John Santa, MD, MPH is the Director of the Consumer Reports Health Ratings Center. The Ratings Center focuses on explicit approaches evaluating and comparing health services, products, institutions and practitioners. Since coming to Consumer Reports he has represented consumers in multiple venues across the industry. He has previously worked in leadership positions for hospitals, physician groups and health insurers. Dr Santa was the administrator of the Office of Oregon Health Policy and Research from 2000 to 2003. He helped organize and implement an evidence-based approach to prescription drug purchasing that eventually came to be known as the Drug Effectiveness Review Project. He practiced primary care internal medicine from 1976 to 1992 and 2003 to 2008 in several settings, most recently at the Portland, Oregon VA.

Susan E. Sheridan, MIM, MBA 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 currently Acting Director of Patient Engagement at the Patient Centered Outcomes Research Institute engaging patients, caregivers and their advocacy organizations in all aspects of the research cycle. Sheridan is Co-Founder and 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, Sheridan co-founded Consumers Advancing Patient Safety, a nonprofit organization that seeks a safe, compassionate and just healthcare system through proactive partnership between consumers and providers of care. Sheridan served at President of CAPS from 2003-2010. In 2004, Sheridan was asked to lead the World Health Organization’s Patients for Patient Safety initiative, a program under the WHO Patient Safety Program who embraces the collective wisdom of the patient, patient empowerment and patient centered care. She speaks frequently on patient safety and legal reform at national and international events. In April 2009, Sheridan was named to Modern Healthcare’s list of Top 25 Women in Healthcare as well as Modern Healthcare’s 100 Most Powerful People in Healthcare. In 2010 Sheridan was awarded the “Idaho Healthcare Hero” in community outreach by the Idaho Business Review and in 2011 Sheridan was appointed by The Secretary of Health and Human Services to serve on the Advisory Committee on Infant Mortality.
of the Health Resources and Services Administration for 2011-2013. Sheridan was also recently invited to join the ACGME Board of Director as a Public Director. Sheridan received her BA from Albion College and her MIM and MBA from Thunderbird School of Global Management. She has a professional background in international banking and served in Ecuador with her late husband, Pat, as Peace Corps volunteers. She lives in Boise, ID with her children, Cal and Mackenzie.

Susan Brown Trinidad, MA is a research scientist in the Department of Bioethics and Humanities at the University of Washington. She has contributed to a number of NIH-funded studies aimed at improving understanding of the ethical, legal, and social implications of genomic research, including the New EXome Technology (NEXT) Medicine Study, the electronic Medical Records and Genomics (eMERGE) Network, and the Center for Genomics and Healthcare Disparities. Other research interests include communication and decision making in healthcare settings; health equity; narrative ethics; discourse analysis; and community-based participatory research approaches. She is a member of the UW Institutional Review Board. Previously, she served as Executive Director of Product Development for companies specializing in telephone nurse triage, patient education, and behavior-change counseling services for chronically ill patients. She holds a master’s degree in health and humanities.
PARTNERING WITH PATIENTS TO DRIVE SHARED DECISIONS, BETTER VALUE, AND CARE IMPROVEMENT

Speaker Biographies

David Arterburn, MD, MPH is a general internist and a health services researcher who holds positions as an Associate Investigator at Group Health Research Institute and as an Affiliate Associate Professor with the University of Washington School of Medicine in Seattle. He is a graduate of the University of Kentucky’s College of Medicine, and he completed his residency and chief residency in Internal Medicine at the University of Texas Health Science Center at San Antonio. He also holds a Master of Public Health from the University of Washington. As former VA Health Services Research & Development career development grantee, Dr. Arterburn has received training in health services research from three VA HSR&D programs. He has been awarded numerous federal and foundation grants and has published over 40 scientific manuscripts in the areas of obesity and shared decision making. Dr. Arterburn's current research covers a broad range, including comparative effectiveness of weight management interventions, pharmacoepidemiology, pharmacogenetics, bariatric surgery, and shared decision making related to elective surgery. Dr. Arterburn’s prior research in the area of obesity pharmacotherapy has had a significant impact on clinical practice guidelines issued by the VA, the U.S. Preventive Services Task Force, the Agency for Healthcare Research and Quality, and the American College of Physicians. Dr. Arterburn is the past Chair of the Adult Obesity Measurement Advisory Panel for the National Committee on Quality Assurance, the Founding Chair of the Health Services Research Section of The Obesity Society, and past Chair of the HINON Obesity Research Network. He serves as Medical Editor for the Informed Medical Decisions Foundation, and he is a standing member of the Group Health Human Subjects Review Committee.

Jeff Belkora, PhD is Associate Professor of Surgery and Health Policy at the University of California, San Francisco (UCSF). His professional mission is to help people grow in their capacity for leadership, teamwork, and decision-making. To this end, Dr. Belkora develops, implements, and evaluates patient engagement programs in health care. His programs have been implemented and evaluated in academic and community settings in the United States and the UK. He is the author of peer-reviewed journal articles, book chapters, and case studies on patient decision making. Dr. Belkora also disseminates his work internationally through speaking, training, and consulting engagements. Prior to joining the UCSF faculty, Dr. Belkora was a co-founder of Outcome Software, a decision analysis software company. Before Outcome, Dr. Belkora worked as a management consultant at Strategic Decisions Group. Dr. Belkora earned a B.Sc. in Applied Mathematics from Brown University. His graduate training at Stanford University included an M.Sc. in Statistics and culminated with a Ph.D in Engineering. In 2008, The US Agency for Healthcare Research and Quality selected his UCSF Decision Services Program as one of the first 100 innovations profiled in its Innovations Exchange. In 2009, Decision Services won an innovation contest sponsored by the Mayo Clinic Center for Innovation. The US Department of Health and Human Services also featured Dr. Belkora's Decision Services program in its 2010 National Healthcare Quality Report as a highlight in the area of patient and family engagement.

Greg Biggers is a patient, caregiver, innovator, and a champion for the consumer voice across all of health care and research. He serves on the Council of Genetic Alliance, a leading health advocacy organization transforming health through dissolving boundaries and fostering dialogue among all stakeholders. He is also Chief Instigator and CEO at Genomera, a community fueling the participant-
Driven research movement, where people move from subjects to research collaborators, and where patients (Genomera just calls them people) drive the agenda and engage with one another to grow and test health science evidence. Mr. Biggers also serves on the board of an elementary school, a community development organization, and advises startups. With over 20 years experience in executive, investor, and founder roles in innovative organizations, he has spent most of his career focused on growing human collaboration and engagement.

Dominick L. Frosch, PhD is a behavioral scientist with a long-standing interest in patient engagement. For the past 15 years his research has focused on shared decision-making and developing, evaluating and implementing patient decision support interventions (DESIs). He has conducted several randomized controlled trials of DESIs and for the past six years has focused on implementing them in routine clinical practice; in primary and specialty care settings. His research has drawn extensively on qualitative research methods to identify factors associated with successful implementation of DESIs, as well as patient perspectives on shared decision-making and patient centered care. Dr. Frosch 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. Dr. Frosch serves as Patient Care Fellow at the Gordon & Betty Moore Foundation, Consulting Investigator at the Palo Alto Medical Foundation Research Institute, and Adjunct Associate Professor of Medicine at the University of California, Los Angeles.

Marge Ginsburg is the Executive Director of the Center for Healthcare Decisions (CHCD), a nonprofit, nonpartisan organization that seeks the public’s informed views on health care policy. Through deliberative small-group processes, the lay public addresses difficult issues from a societal perspective. Currently, CHCD is working with American Institutes for Research on an AHRQ-funded project that conducted national discussions identifying societal values related to the use of medical evidence. Last year, CHCD worked with California’s health benefit exchange in developing a fair model for cost-sharing from the perspective of future enrollees. CHCD is now leading a multi-organizational project in Calif. to capture seniors’ and boomers’ priorities for the Medicare of the future. In 2011, Marge was a member of the Institute of Medicine’s Committee on Essential Health Benefits to develop the principles for coverage under the ACA. She is a member of NCQA’s Committee on Performance Measurement, the Medi-Cal Performance Advisory Committee and others to improve health care in California. Marge received her nursing degree from the University of Maryland and a Masters in Public Health from UC Berkeley. In a prior life, she worked for the United Farm Workers, ran a free clinic in Philly, was a Peace Corps nurse in Nepal and other stuff one does in their 20’s-30’s. An avowed late bloomer, she discovered the 'health decisions' movement in 1991 and hasn’t budged since.

David Goldhill, MA is president and chief executive officer of GSN, which operates a US cable television network seen in more than 75 million homes and one of the world’s largest digital games companies. GSN is owned by DIRECTV and Sony Pictures Entertainment. Prior to joining GSN, Goldhill was chairman and CEO of INTH, which founded and operated the TV3 television network in Russia through its sale to the Interros Group in December of 2006. He also served as president and chief operating officer of Universal Television Group, a division of Universal Studios. In this capacity, he oversaw all operations at the company’s domestic and international cable television networks (including USA and SciFi), cable and network television studios, first-run syndication business, and worldwide television distribution. Goldhill was the chief financial officer of Act III Communications, a privately-owned holding company with interests in television stations, movie theaters, magazines, and film/television production. He began his career as an investment banker with Morgan Stanley and Lehman Brothers. Goldhill published a notable cover story in the 2009 issue of The Atlantic magazine, entitled “How American Health Care Killed My Father.” The article received widespread acclaim and media attention from numerous outlets, including The New York Times, Barron’s, CNN, NPR, The Wall
Street Journal, The Huffington Post and many others. He is a member of the Board of Directors of the Leapfrog Group, an employer-sponsored organization dedicated to hospital safety and transparency. His book “Catastrophic Care” is scheduled for publication by Knopf in January 2013. Goldhill graduated from Harvard University with a B.A. degree in history and holds a M.A. degree in history from New York University.

Judith Hibbard, DrPH is a Senior Researcher and Professor Emerita at the University of Oregon. Over the last 30 years she has focused her research on consumer choices and behavior in health care. She has a particular interest in testing approaches that give consumers and patients more knowledge and control over their health and health care. Her studies examine such topics as: how consumers understand and use health care information, how health literacy affects choices, enrollee behavior within high deductible health plans, and assessments of patient and consumer activation. Dr. Hibbard is the lead author of the Patient Activation Measure (PAM). The PAM measures an individual’s knowledge and skill for self-management. The measure is being used around the world by researchers and practitioners. Dr. Hibbard advises many health care organizations, foundations, and initiatives. She has served on several advisory panels and commissions, including the National Advisory Counsel for AHRQ, the National Health Care Quality Forum, United Health Group Advisory Panel, and National Advisory Council for the Robert Wood Johnson Foundation’s Aligning Forces for Quality Initiative. She is the author of over 150 peer-reviewed publications. Her recent work appears in issues of Health Affairs, Medical Care, and Health Services Research. Dr. Hibbard holds a masters degree in Public Health from UCLA and her doctoral degree is from the School of Public Health at the University of California at Berkeley. She is recognized as an international expert on consumerism in health care and is frequently invited to speak at national and international health conferences.

Eric Holmboe, MD, a board certified internist, is Chief Medical Officer and Senior Vice President of the American Board of Internal Medicine (ABIM) and the ABIM Foundation. He is also Professor Adjunct of Medicine at Yale University, and Adjunct Professor at the Uniformed Services University of the Health Sciences. Prior to joining the American Board of Internal Medicine Dr. Holmboe was Associate Program Director, Yale Primary Care Internal Medicine Residency Program, and Director of Student Clinical Assessment, Yale School of Medicine. Before joining Yale, he was Division Chief of General Internal Medicine at the National Naval Medical Center. Dr. Holmboe’s research interests include interventions to improve quality of care and methods in the evaluation of clinical competence. A frequently-requested speaker, he is the author of more than 100 peer-reviewed articles in professional journals, including Annals of Internal Medicine, Journal of General Internal Medicine and The Journal of the American Medical Association. Dr. Holmboe is a Fellow of the American College of Physicians and an honorary Fellow of the Royal College of Physicians in London. Dr. Holmboe is a graduate of Franklin and Marshall College and the University of Rochester School of Medicine. He completed his residency and chief residency at Yale-New Haven Hospital, and was a Robert Wood Johnson Clinical Scholar at Yale University.

Sherrie H. Kaplan, PhD, MPH is the Assistant Vice Chancellor for Healthcare Measurement and Evaluation, Professor of Medicine, University of California, Irvine (UCI), School of Medicine and Executive Co-Director, Center for Health Policy Research, UCI. She came to UCI in 2003 from Tufts University School of Medicine and the Harvard School of Public Health. Dr. Kaplan received her undergraduate, MPH, MSPH and PhD from UCLA, the latter in a joint program between public health and measurement psychology. In her distinguished career as a leading social scientist in medicine, Dr. Kaplan has pioneered a number of areas of research. She has done ground-breaking research demonstrating that patients can be taught to participate effectively in medical decisions with positive effects on patients’ health outcomes. Her work on the application of psychometric techniques to the assessment of performance of varying levels of the healthcare system, from healthcare organizations to
individual physicians, has made her a national expert on this current and controversial topic. Well known for her work in the development of measures of the quality of technical and interpersonal care, health status and quality of life, and heterogeneity of treatment effects, particularly for vulnerable populations, she is now working on a variety of innovative projects, including the use of community-based minority ‘coaches’ to train patients to participate effectively in chronic disease care and reduce disparities in health and healthcare. Dr. Kaplan was also a member of the IOM committee that generated the report, *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*.

**Nancy Kass, ScD** is the Phoebe R. Berman Professor of Bioethics and Public Health, in the Department of Health Policy and Management, Johns Hopkins Bloomberg School of Public Health and Deputy Director for Public Health in the Berman Institute of Bioethics. In 2009-2010, Dr. Kass was based in Geneva, Switzerland, where she was working with the World Health Organization (WHO) Ethics Review Committee Secretariat. Dr. Kass received her BA from Stanford University, completed doctoral training in health policy from the Johns Hopkins School of Public Health, and was awarded a National Research Service Award to complete a postdoctoral fellowship in bioethics at the Kennedy Institute of Ethics, Georgetown University. Dr. Kass conducts empirical work in bioethics and health policy. Her publications are primarily in the field of U.S. and international research ethics, HIV/AIDS ethics policy, public health ethics, and ethics of public health preparedness. She is co-editor of HIV, AIDS and Childbearing: Public Policy, Private Lives (Oxford University Press, 1996). Dr. Kass co-chaired the National Cancer Institute Committee to develop Recommendations for Informed Consent Documents for Cancer Clinical Trials, and served on the NCI’s central IRB. She has served as consultant to the President's Advisory Committee on Human Radiation Experiments, to the National Bioethics Advisory Commission, and to the National Academy of Sciences. Current research projects examine ethics for a learning healthcare system including quality improvement and comparative effectiveness, informed consent in randomized trials, ethics issues that arise in international health research and ethics and public health preparedness. Dr. Kass teaches the Bloomberg School of Public Health’s course on U.S. and International Research Ethics and Integrity, is the director of the School’s PhD program in bioethics and health policy, and is the director of the Johns Hopkins Fogarty African Bioethics Training Program. Dr. Kass is an elected member of the Institute of Medicine and a Fellow of the Hastings Center.

**Gary Langer** is the founder and president of Langer Research Associates and is an internationally recognized public opinion researcher with expertise in analysis of political, policy, economic and social attitudes, questionnaire design, data interpretation, survey methodology and survey management. With more than 25 years in the field, including a long tenure as director of polling at ABC News, Langer has overseen and analyzed more than 750 attitudinal surveys on a broad range of topics. Langer’s current work includes a three year-series of surveys on patient engagement among low-income Californians for Blue Shield of California Foundation, research into attitudes on long-term care for The SCAN Foundation and a national survey on prescription drug adherence for the National Community Pharmacists Association. He and his staff also are in the midst of a five-year evaluation of community development programming in Bangladesh, as well as producing ongoing ABC News/Washington Post polls and a weekly consumer confidence survey for Bloomberg LP. Langer has won two Emmy awards and received nine Emmy nominations – including the first and only to cite public opinion polls – and was honored with the 2010 Policy Impact Award of the American Association for Public Opinion Research for a six-year series of surveys in Afghanistan and Iraq, described in AAPOR’s citation as “a stellar example of high-impact public opinion polling at its finest.” He’s a two-time winner of the University of Iowa-Gallup Award for Excellent Journalism Using Polls, produced a pair of ABC News polls recognized by the Excellence in Media Coverage of Polls Award from the National Council on Public Polls and shared a DuPont-Columbia Award for ABC’s 9/11 coverage. Langer created ABC’s industry-leading poll standards and vetting operation and has advanced disclosure initiatives through
professional organizations. He’s a frequent speaker, writer and commentator on the meaning and measurement of public opinion, and has authored or co-authored nearly 30 scholarly papers on the subject. Langer is a member of the Board of Directors of the Roper Center for Public Opinion Research, a trustee of the National Council on Public Polls and past president of the New York chapter of the American Association for Public Opinion Research. He lives in New York with his wife and two daughters.

**Alice Leiter** serves as Policy Counsel for the Center for Democracy & Technology’s Health Privacy Project. Her work focuses on developing policies for the advancement, adoption and implementation of health information technology and electronic health information exchange to improve health care. Ms. Leiter earned her JD from the Georgetown University Law Center in 2007, and while in law school spent a summer working in the general counsel’s office at the National Institutes of Health (NIH). She spent three years as an associate in the Health and Privacy & Information Management practice groups at the law firm Hogan Lovells (formerly Hogan and Hartson) before joining the National Partnership for Women & Families, where she was the director of health information technology policy. In this capacity she served as a consumer representative on the Privacy and Security Tiger Team, a subgroup of the Health Information Technology (HIT) Policy Committee, a federal advisory committee established in the American Recovery and Reinvestment Act of 2009. She also chaired the Operations Workgroup of Query Health, an initiative of the Office of the National Coordinator for Health IT’s (ONC) Standards & Interoperability (S&I) Framework. Ms. Leiter earned a B.A. in Human Biology from Stanford University in 2002.

**Grace A. Lin, MD, MAS** is Assistant Professor of Medicine at the Philip R. Lee Institute for Health Policy Studies at the University of California, San Francisco. Her research agenda focuses on resource utilization, appropriateness of care, shared decision-making, and measuring the quality of the decision-making process, particularly in cardiology. She is also practices general internal medicine, as well as being actively involved in teaching medical students and residents at UCSF. Dr. Lin’s current research projects focus on improving quality of care through helping patients and physicians make high quality decisions that are reflective of both evidence from the literature and the patient’s individual values. She is leading efforts to examine how physicians and patients make decisions about treatment for stable coronary artery disease, to investigate the effects of implementing patient decision aids into primary care practice, and to develop a metric that can be used to assess the quality of decision-making in patients with cardiac disease. She has published both quantitative and qualitative research in peer-reviewed journals including *JAMA, Health Affairs,* as well as *JAMA Internal Medicine,* where she also serves on the editorial board. Dr. Lin received her MD from the University of Michigan, and a Masters of Advanced Studies in Clinical Research from UCSF. She has received a Young Investigator Award and a career development award from the American Heart Association for her work examining the appropriateness of care in patients with coronary artery disease. Her work is currently funded by grants from the Agency for Healthcare Research and Quality and the Informed Medical Decisions Foundation.

**Evette Ludman, PhD** is a psychologist and Senior Research Associate at Group Health Research Institute, Affiliate Associate Professor in the Department of Psychiatry and Behavioral Sciences at the University of Washington School of Medicine, and Affiliate Investigator at the Fred Hutchinson Cancer Research Center. Trained as a behavioral scientist, in her 20 years as a researcher she has built a diverse research portfolio focusing on designing and evaluating innovative health services interventions to promote health behavior change and improve the quality of care for common chronic physical and mental conditions. Her professional aspirations are to increase the person-centeredness and integration of care for mental health, behavioral and medical concerns and to promote self-management support as a health care right and responsibility, ‘fomenting discontent’ with business as usual. In the past several years she has evolved a growing interest in the interplay between behavioral science, the health care
delivery system, and genetic information. She has broad experience in both quantitative and qualitative research and has over 150 peer-reviewed publications as well as two books communicating health information to the lay public. Dr. Ludman received her BA from Brown University and her MS and PhD from the University of Oregon.

Kenneth D. Mandl, MD, MPH is an Associate Professor at Harvard Medical School (HMS) and the Louis Diamond Investigator at Children’s Hospital Boston, where he directs the Intelligent Health Laboratory within “CHIP”, the Children’s Hospital Informatics Program. He is faculty in the Harvard Medical School Center for Biomedical Informatics and Affiliated Faculty at the Harvard-MIT Health Sciences and Technology. Mandl has pioneered and published extensively in the areas of personal health records and biosurveillance. Under a major a HHS initiative, he co-leads the SMART Platforms project, which seeks to create an “app store” for health. He co-directs a CDC Center of Excellence in Public Health Informatics working to define the role of online social networks in healthcare and public health. Recognized for his teaching and research, he has received the Barger Award for Excellence in Mentoring at Harvard Medical School and the Presidential Early Career Award for Scientists and Engineers, the highest honor bestowed by the United States government to outstanding scientists and engineers. He has been an advisor to two Directors of the CDC now chairs the Board of Scientific Counselors of the NIH's National Library of Medicine. Dr. Mandl has published over 130 papers in the medical literature and has been elected to multiple honor societies including the American Society for Clinical Investigation, the Society for Pediatric Research, the American College of Medical Informatics and the American Pediatric Society. He leads two postdoctoral training programs in clinical and informatics research and directs the Population Health Track of the new Masters Degree in Biomedical Informatics at HMS. Mandl is a faculty member in the HMS Center for Biomedical Informatics and in the Division of Health Sciences and Technology at Harvard and MIT.

Peter Margolis, MD, PhD is Professor of Pediatrics and Director of Research at the James M. Anderson Center for Health System Excellence at Cincinnati Children's Hospital Medical Center. His work encompasses the application and study of quality improvement methods in a broad range of areas including primary and sub-specialty care, communities and public health settings to improve the health outcomes of children, families and communities. Dr. Margolis obtained his MD from New York University and his pediatric training at the University of Colorado, where he also served as Chief Resident in Pediatrics. He subsequently spent three years in the National Health Service Corps in Rochester, NY, and Los Angeles, CA before pursuing a fellowship in clinical epidemiology. He was a Robert Wood Johnson Clinical Scholar at the University of North Carolina at Chapel Hill where he also earned his Ph.D. in Epidemiology. In 1994, Dr. Margolis was named a Robert Wood Johnson Generalist Faculty Scholar at UNC where he also served on the faculty between 1991 and 2005. In 2006, Dr. Margolis joined Cincinnati Children’s Hospital Medical Center to create a new center focused on Health Care Quality. Dr. Margolis has worked extensively with the certifying Boards and Specialty Societies to assist them in designing programs that will enable physicians to meet new Maintenance of Certification requirements focused on systems thinking and performance in practice. He also devotes considerable time to teaching quality improvement methods. He is principle investigator of an NIH Roadmap transformative research grant on redesigning systems for chronic illness care.

Michael McGinnis, MD, MA, MPP is a physician, epidemiologist, and long-time contributor to national and international health programs and policy. An elected Member of the Institute of Medicine (IOM) of the National Academies, he has since 2005 also served as IOM Senior Scholar and Executive Director of the IOM Roundtable on Value & Science-Driven Health Care. He founded and stewards the IOM’s Learning Health System Initiative, and, in prior posts, also served as founding leader for the Robert Wood Johnson Foundation’s (RWJF) Health Group, the World Bank/European Commission’s Task Force for Health Reconstruction in Bosnia, and, in the U.S. government, the Office of Research
Integrity, the Nutrition Policy Board, and the Office of Disease Prevention and Health Promotion. In the latter post, he held continuous policy responsibilities for prevention through four Administrations (Presidents Carter, Reagan, Bush, Clinton), during which he conceived and launched a number of initiatives of ongoing policy importance, including the Healthy People national goals and objectives, the U.S. Preventive Services Task Force, the Dietary Guidelines for Americans, and development of the Ten Essential Services of Public Health. At RWJF, he founded the Health & Society Scholars program, the Young Epidemiology Scholars program, and the Active Living family of programs. Early in his career he served in India as epidemiologist and State Director for the World Health Organization’s Smallpox Eradication Program. Widely published, he has made foundational contributions to understanding the basic determinants of health (e.g. “Actual Causes of Death”, JAMA 270:18 [1993] and “The Case for More Active Policy Attention to Health Promotion”, Health Affairs 21:2 [2002]). National leadership awards include the Arthur Flemming Award, the Distinguished Service Award for public health leadership, the Health Leader of the Year Award, and the Public Health Hero Award. He has held visiting or adjunct professorships at George Washington, UCLA, Princeton, and Duke Universities. He is a graduate of the University of California at Berkeley, the UCLA School of Medicine, and the John F. Kennedy School of Government at Harvard University, and was the graduating commencement speaker at each.

Ekene Obi-Okoye is a UCSF Breast Care Center pre-medical intern. Her current projects include studying the biology surrounding breast cancer recurrence, designing support programing for metastatic breast cancer patients at UCSF, and participating in the patient decision support program at the UCSF Breast Care Center. She is a recent graduate from Harvard, concentrating in History of Medicine with a secondary in African Studies. At Harvard, she was president of the largest student-run non-profit on Harvard’s campus and served on the board of the Kuumba Singers of Harvard College, a choir dedicated to celebration Black creativity and spirituality. She hopes to attend medical school in the fall of 2013.

Sally Okun, RN, MMHS is the Vice President for Advocacy, Policy and Patient Safety at PatientsLikeMe in Cambridge, MA. She is responsible for the company’s patient advocacy initiatives; she participates and contributes to health policy discussions at the national and global level; and she is the company’s liaison with government and regulatory agencies. Sally joined the company in 2008 as the manager of Health Data Integrity and Patient Safety overseeing the site’s medical ontology including the curation of patient reported health data and an ever-evolving patient vocabulary. Okun also developed and manages the PatientsLikeMe Drug Safety and Pharmacovigilance Platform. Prior to joining PatientsLikeMe Sally, a registered nurse, practiced as a palliative and end-of-life care specialist. In addition as an independent consultant she contributed to multiple clinical, research, and educational projects focused on palliative and end-of-life care for numerous clients including Brown University, Harvard Medical School, MA Department of Mental Health, Hospice Education Network and the Robert Wood Johnson Foundation. Sally participates on the Institute of Medicine’s Roundtable on Value and Science Driven Healthcare as a member of the Clinical Effectiveness Research Innovation Collaborative, the Evidence Communication Innovation Collaborative, and the Best Practices Innovation Collaborative. She is a contributing author to the Institute’s discussion papers Principles and Values for Team-based Healthcare and Communicating with Patients on Health Care Evidence. Ms. Okun serves on the Program Advisory Board of the Schwartz Center for Compassionate Care in Boston and has been a facilitator for Schwartz Center Rounds® at numerous locations around the country. Sally received her nursing diploma from the Hospital of St. Raphael School of Nursing; Baccalaureate degree in Nursing from Southern Connecticut State University; and Master's degree from The Heller School for Social Policy & Management at Brandeis University. She completed study of Palliative Care and Ethics at Memorial Sloan-Kettering Cancer Center and was a fellow at the National Library of Medicine Program in Biomedical Informatics.
Laura M. Phillips is a Patient Member of PatientsLikeMe. She was diagnosed in 1999 with Multiple Sclerosis (MS) after being hospitalized with a debilitating headache. Ms. Phillips was adopted and has no information about her birth mother's family history. Her birth father has no known history of MS in his family. She joined PatientsLikeMe in March 2008 and found others who could answer the questions doctors really couldn't since they've never experienced MS. When comparing her experiences with others on PatientsLikeMe, Ms. Phillips has found that a good majority of patients have the similar deficiencies, a fact that on their own they'd not have looked into or followed up on with their doctors. For as much as doctors and researchers know, there are numerous untold things they don’t know. Every MS patient learns so much from their own MS and it will be from their collective experiences that they will help forge the way to a cure. Ms. Phillips grew up in Arlington, VA and is the mother of two grown children. She now lives in Lexington Park, Maryland with her husband.

Jill Plevinsky is currently a clinical research coordinator for the Inflammatory Bowel Disease Center at Boston Children’s Hospital and recently completed graduate work in child development at Tufts University. She was diagnosed with Crohn’s disease at age 7 and immediately became involved in awareness, education, and fundraising efforts through the Crohn’s and Colitis Foundation, for which she served as the Philadelphia/Delaware Valley Chapter’s first youth ambassador and the founding chair of the National Youth Leadership Council. She also serves as both a member of the leadership team for her local Camp Oasis program and the founding chair of the ImproveCareNow and Collaborative Chronic Care Network Patient Advisory Council. Her passion for the integration of new social technologies and pediatric patient access to social support has allowed her panelist and presentation opportunities at both national and international meetings held at Stanford University, Mayo Clinic, Massachusetts Institute of Technology, and Harvard Medical School among others. Specifically, she hopes to become a clinical psychologist and continue to cultivate her interest in how having a chronic illness at a young age can affect this generation’s experience of social media. Through innovative research, social network analysis, and new technologies she plans to help young people with chronic illness engage in their healthcare and benefit from the accessibility of social support and health information on the Internet.

Holly Potter is vice president of Public Relations for Kaiser Permanente. She oversees efforts to promote the company’s story and achievements through both traditional and social media. In addition, her team is responsible for broad public relations, partnerships and stakeholder management programs that help to build Kaiser Permanente’s reputation among opinion leaders and partners in the health, business, philanthropic and advocacy communities. An experienced health communications strategist, she has held a variety of leadership positions directing a broad range of communications and advocacy campaigns. She brought to Kaiser Permanente a proven 15-year track record of award-winning public relations programs that influence stakeholders and shift public opinion. In her career, she has advised and partnered with senior executives in the nonprofit, government and corporate sectors to advance policy and promote brand identity. PR News named Holly PR Team Leader of the Year in 2009 and she received an honorable mention in 2010 for Digital Communications Leader of the Year. Her team at Kaiser Permanente was named a 2010 Digital PR Team of the Year and a 2010 Nonprofit PR Team of the Year by PR News. Additionally, PR News named Kaiser Permanente a Top Place to Work in public relations in both 2009 and 2010. Prior to joining Kaiser Permanente, she ran HTPotter Communications, LLC which served a variety of nonprofit and government clients in California and Washington, D.C. Her former clients include National Campaign Against Youth Violence, California State PTA, Public Health Institute, Drug Policy Alliance, San Francisco Wellness Initiative, Santa Clara County Public Health Department and the White House Council on Youth Violence.
Barbra Rabson, MPH has been the executive director of the Massachusetts Health Quality Partners (MHQP) since 1998. MHQP is a nationally recognized coalition of health care providers, plans, consumers, government agencies, academics and purchasers working together to promote measurable improvement in the quality of health care services in Massachusetts. Under Ms. Rabson’s leadership, MHQP has become one of the most trusted names in performance measurement and public reporting of health care information in Massachusetts and in the nation. She has led MHQP to issue three first in the nation statewide public releases of hospital and physician performance information, including the first in the nation collaboration with Consumer Reports to jointly release performance results on MA primary care physicians on a statewide patient experience survey. Ms. Rabson is the co-chair of the Greater Boston Aligning Forces for Quality Alliance. She is a founding member and past Board Chair of the Network for Regional Healthcare Improvement (NRHI), a national network of regional health improvement collaborative. She also serves on the Board of the Massachusetts eHealth Collaborative (MAeHC) and on the Mayor of Boston’s selection committee for the Mayoral Prize for Innovations in Primary Care. Ms. Rabson has a long track record for innovative collaboration. She received her Masters in Public Health from Yale University and her undergraduate degree from Brandeis University.

Shoshanna Sofaer, DrPH is the Robert P. Luciano Professor of Health Care Policy at the School of Public Affairs, Baruch College, City University of New York. She also serves on the faculty of the CUNY Graduate Center, in their doctoral program in public health. Dr. Sofaer’s major research and policy interests include patient engagement, patient-centered care, public deliberation to guide health policy, comparative quality and cost reporting for low literate and vulnerable populations, quality measurement, the Medicare program, improving health care for older adults and people with disabilities, tobacco control, the use of multi-stakeholder coalitions to improve population health and health care delivery, and health insurance coverage for low income people. A member of Academy Health’s Methods Council, Dr. Sofaer is widely recognized as an expert on the use of qualitative and mixed methods in health research, and teaches, presents and consults widely in that area. She has over 60 publications in peer reviewed journals and has completed over 40 research projects.

Tresa Undem, MA is a partner at PerryUndem Research & Communication. She leads public opinion research on a variety of health-related policy issues, including health reform implementation, delivery system reform, access, affordability, costs, and quality. Tresa has conducted many communications projects related to health care costs and quality for clients such as the Robert WoodJohnson Foundation, the National Partnership for Women & Children, and the Institute of Medicine. She has briefed numerous state and federal policymakers on her work, including members of Congress, White House staff, Secretary Sebelius, and CMS leadership. Tresa holds a Masters Degree from the Annenberg School for Communication at the University of Pennsylvania. She is a member of the American Association of Public Opinion Research, and has been a reviewer, presenter, and discussant at its national conferences.

Kevin Volpp, MD, PhD is the founding Director of the Center for Health Incentives and Behavioral Economics at the Leonard Davis Institute (LDI CHIBE), one of two NIH-funded Centers on Behavioral Economics and Health in the United States; Co-Director of the Penn Medicine Center for Innovation; and a Professor of Medicine at the University of Pennsylvania School of Medicine and Health Care Management at the Wharton School. He is a Scientific Advisory Board member of VALHealth, a behavioral economics consulting firm. Dr. Volpp’s research on the impact of financial and organizational incentives on health behavior and health outcomes work has been recognized by numerous awards including the Presidential Early Career Award for Scientists and Engineers (PECASE), an award presented at the White House as the highest honor given by the US government to early career scientists; the Alice S. Hersh Investigator Award from AcademyHealth; Time Magazine’s 2009 A-Z “Advances in Health” list for work on Incentives – letter “I”; the British Medical Journal Group Award
for translating Research into Practice, and the outstanding paper of the year from the Society of General Internal Medicine. He is a member of the editorial board of the Annals of Internal Medicine and an elected member of several honorary societies including the Institute of Medicine (IOM) of the National Academy of Sciences, the American Society of Clinical Investigation, and the Association of American Physicians. Dr. Volpp did his medical training at the University of Pennsylvania and Brigham and Women’s hospital and has a Ph.D. in Applied Economics and Managerial Science from the Wharton School. He is a board-certified general internist and practicing physician at the Philadelphia VA Medical Center.

**Jonathan Welch, MD, MSc** is an Instructor in Medicine at Harvard Medical School and a practicing emergency physician at the Brigham and Women’s Hospital in Boston. His work focuses on patient and family centered care, and he serves on his department’s patient and family advisory council. His writing on patient and family centered care has been featured in *Health Affairs, Roll Call, the Washington Post,* and the *Chicago Tribune.* Prior to joining the faculty, Dr. Welch completed his medical education at Harvard Medical School and his training in emergency medicine at the Harvard Affiliated Emergency Medicine Residency, a joint training program at the Brigham and Women’s Hospital, Massachusetts General Hospital, and Children’s Hospital Boston. He received his master’s degree in Health Policy at the London School of Economics, and additionally completed training in epidemiology and biostatistics at the Harvard School of Public Health. He was a Fulbright Scholar in Peru and a Harry S. Truman Scholar, and he has worked as a technical officer at the World Health Organization.

**Daniel B. Wolfson** is Executive Vice President and COO of the ABIM Foundation, where he leads the Choosing Wisely campaign, a multi-year effort to promote conversations between physicians and patients about utilizing the most appropriate tests and treatments and avoiding care that may be is unnecessary by identifying five tests or procedures commonly used in their field, whose necessity should be questioned and discussed. Previously, Mr. Wolfson served for nearly two decades as the founding president and CEO of the Alliance of Community Health Plans (formerly The HMO Group), the nation’s leading association of not-for-profit and provider-sponsored health plans. During his tenure, Mr. Wolfson earned national recognition for spearheading the development of the Health Plan Employer Data and Information Set (HEDIS™), convening the RxHealthValue coalition to provide independent information on the pharmaceutical industry, and co-sponsoring with the American College of Physicians the journal Effective Clinical Practice. Previously, Mr. Wolfson was the Director of Planning and Research at the Fallon Community Health Plan. During that time, he led the product development team that launched the nation’s first Medicare risk contract with the Health Care Financing Administration. Mr. Wolfson received his master's degree in Health Sciences Administration from the University of Michigan, School of Public Health. Prior to graduate school, Mr. Wolfson worked in the Social Services Department of Massachusetts General Hospital, counseling and discharge planning for spinal cord patients, amputees and stroke patients.

**Kelly Young** received her Bachelor of Arts in Psychology at George Mason University. In 2006, she was diagnosed with Rheumatoid Arthritis, after years of periodic symptoms. She has worked for four years to provide ways for patients to be better informed and have a greater voice in their healthcare. In 2011, she received the WebMD National Health Hero award. Through her writing, speaking, and use of social media, she has built a more accurate awareness of Rheumatoid Arthritis (RA) geared toward the public and medical community; created ways to empower RA patients to advocate for improved diagnosis and treatment; and brought recognition and visibility to the RA patient journey. In 2009, Kelly created RAwarrior.com, a comprehensive website about RA of about 700 pages and the hub of one of the most large and vibrant patient communities online. She also writes periodically for other newsletters and websites. Kelly is the founding president of the Rheumatoid Patient Foundation, the first non-profit which exists solely to improve the lives of Rheumatoid patients. Kelly serves on the Mayo Clinic Center
Margot Zarin-Pass is a first year medical student at UCSF. She was previously a pre-medical intern at the UCSF Breast Care Center. There, she provided decision support services to patients and conducted patient engagement research.
The Roundtable on Value & Science-Driven Health Care is looking forward to your participation on February 25-26th. If you have any questions regarding workshop logistics, please contact Julia Sanders at jcsanders@nas.edu or 202-334-3889.

LOCATION:
The workshop will begin at 12:30pm on February 25th and will end at 4:30pm on February 26th. Breakfast will be served on site beginning at 8:30am on February 26th, with the agenda commencing at 9am. While the agenda for this meeting has not been finalized, these times provide an accurate estimation for travel planning purposes.

LODGING:
Suggested nearby hotels include:
- State Plaza Hotel / 2117 E Street, NW / 202-861-8200 (7 minute walk)
- Hotel Lombardy / 2019 Pennsylvania Avenue, NW / 202-828-2600 (12 minute walk)
- One Washington Circle Hotel / 1 Washington Circle, NW / 800-424-9671 (16 minute walk)
- The River Inn / 924 25th Street, NW / 202-337-7600 (16 minute walk)

DIRECTIONS AND GROUND 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).

Rental Cars: Please contact Julia Sanders for approval in advance of booking a rental car. Full reimbursement is not guaranteed without proper booking instructions from Academies staff.

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.

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