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

DETAILS

214 pages | 6 x 9 | null
ISBN null | DOI 10.17226/18397

AUTHORS

Roundtable on Value and Science-Driven Health Care; Institute of Medicine

PARTNERING *with* PATIENTS

to Drive Shared Decisions, Better Value, and Care Improvement

WORKSHOP PROCEEDINGS

Roundtable on Value & Science-Driven Health Care

INSTITUTE OF MEDICINE
OF THE NATIONAL ACADEMIES

THE NATIONAL ACADEMIES PRESS
Washington, D.C.
www.nap.edu

THE NATIONAL ACADEMIES PRESS 500 Fifth Street, NW Washington, DC 20001

NOTICE: The workshop that is the subject of these workshop proceedings was approved by the Governing Board of the National Research Council, whose members are drawn from the councils of the National Academy of Sciences, the National Academy of Engineering, and the Institute of Medicine.

This activity was supported by Grant No. 3463 between the National Academy of Sciences and the Gordon and Betty Moore Foundation and Grant No. 7781311 between the National Academy of Sciences and the Blue Shield of California Foundation. The views presented in this publication do not necessarily reflect the views of the organizations or agencies that provided support for the activity.

International Standard Book Number-13: 978-0-309-28896-5
International Standard Book Number-10: 0-309-28896-7

Additional copies of these workshop proceedings are available for sale from the National Academies Press, 500 Fifth Street, NW, Keck 360, Washington, DC 20001; (800) 624-6242 or (202) 334-3313; http://www.nap.edu.

For more information about the Institute of Medicine, visit the IOM home page at: **www.iom.edu.**

Printed in the United States of America

The serpent has been a symbol of long life, healing, and knowledge among almost all cultures and religions since the beginning of recorded history. The serpent adopted as a logotype by the Institute of Medicine is a relief carving from ancient Greece, now held by the Staatliche Museen in Berlin.

Suggested citation: IOM (Institute of Medicine). 2014. *Partnering with patients to drive shared decisions, better value, and care improvement: Workshop proceedings.* Washington, DC: The National Academies Press.

"Knowing is not enough; we must apply.
Willing is not enough; we must do."
—Goethe

INSTITUTE OF MEDICINE
OF THE NATIONAL ACADEMIES

Advising the Nation. Improving Health.

THE NATIONAL ACADEMIES
Advisers to the Nation on Science, Engineering, and Medicine

The **National Academy of Sciences** is a private, nonprofit, self-perpetuating society of distinguished scholars engaged in scientific and engineering research, dedicated to the furtherance of science and technology and to their use for the general welfare. Upon the authority of the charter granted to it by the Congress in 1863, the Academy has a mandate that requires it to advise the federal government on scientific and technical matters. Dr. Ralph J. Cicerone is president of the National Academy of Sciences.

The **National Academy of Engineering** was established in 1964, under the charter of the National Academy of Sciences, as a parallel organization of outstanding engineers. It is autonomous in its administration and in the selection of its members, sharing with the National Academy of Sciences the responsibility for advising the federal government. The National Academy of Engineering also sponsors engineering programs aimed at meeting national needs, encourages education and research, and recognizes the superior achievements of engineers. Dr. C. D. Mote, Jr., is president of the National Academy of Engineering.

The **Institute of Medicine** was established in 1970 by the National Academy of Sciences to secure the services of eminent members of appropriate professions in the examination of policy matters pertaining to the health of the public. The Institute acts under the responsibility given to the National Academy of Sciences by its congressional charter to be an adviser to the federal government and, upon its own initiative, to identify issues of medical care, research, and education. Dr. Harvey V. Fineberg is president of the Institute of Medicine.

The **National Research Council** was organized by the National Academy of Sciences in 1916 to associate the broad community of science and technology with the Academy's purposes of furthering knowledge and advising the federal government. Functioning in accordance with general policies determined by the Academy, the Council has become the principal operating agency of both the National Academy of Sciences and the National Academy of Engineering in providing services to the government, the public, and the scientific and engineering communities. The Council is administered jointly by both Academies and the Institute of Medicine. Dr. Ralph J. Cicerone and Dr. C. D. Mote, Jr., are chair and vice chair, respectively, of the National Research Council.

www.national-academies.org

PLANNING COMMITTEE ON PARTNERING WITH PATIENTS TO DRIVE SHARED DECISIONS, BETTER VALUE, AND CARE IMPROVEMENT[1]

CHRISTINE BECHTEL (*Chair*), Advisor and Former Vice President, National Partnership for Women & Families
TERRY ADIRIM, Director, Office of Special Health Affairs, Health Resources and Services Administration
LEAH BINDER, Chief Executive Officer, The Leapfrog Group
VERONICA GOFF, Vice President, Institute on Health Care Costs and Solutions, National Business Group on Health (*formerly*)
MARK GORMAN, Patient Advocate, Former Director of Survivorship Policy, National Coalition for Cancer Survivorship
PAUL GRUNDY, Global Director of Healthcare Transformation, IBM
ART LEVIN, Director, Center for Medical Consumers
JIM MANGIA, President and Chief Executive Officer, St. John's Well Child & Family Center
LYN PAGET, Managing Partner, Health Policy Partners
ERIC RACINE, Vice President, Advocacy, Sanofi U.S.
SUSAN C. REINHARD, Director, Public Policy Institute, AARP
CRAIG ROBBINS, Medical Director, Clinical Guidelines (KP Colorado), Kaiser Permanente
JOHN SANTA, Director, Consumer Reports Health Ratings Center, Consumers Union
SUSAN SHERIDAN, Deputy Director, Patient Engagement, Patient-Centered Outcomes Research Institute
SUSAN BROWN TRINIDAD, Research Scientist, University of Washington

IOM Staff

KATE BURNS, Program Assistant (*from July 2013*)
CLAUDIA GROSSMANN, Senior Program Officer
DIEDTRA HENDERSON, Program Officer (*from March 2013*)
ELIZABETH JOHNSTON, Program Assistant
VALERIE ROHRBACH, Senior Program Assistant
JULIA SANDERS, Senior Program Assistant (*through August 2013*)
ROBERT SAUNDERS, Senior Program Officer
LEIGH STUCKHARDT, Research Associate (*through January 2013*)
ISABELLE VON KOHORN, Program Officer (*through September 2012*)
BARRET ZIMMERMANN, Program Assistant (*through October 2013*)
J. MICHAEL McGINNIS, Senior Scholar, Executive Director, Roundtable on Value & Science-Driven Health Care

[1] Institute of Medicine planning committees are solely responsible for organizing the workshop, identifying topics, and choosing speakers. The responsibility for the published workshop proceedings rests with the institution.

ROUNDTABLE ON VALUE & SCIENCE-DRIVEN HEALTH CARE[1]

MARK B. MCCLELLAN (*Chair*), Director, Engelberg Center, The Brookings Institution
DAVID BLUMENTHAL, President, The Commonwealth Fund
BRUCE G. BODAKEN, Former Chairman and Chief Executive Officer, Blue Shield of California
PAUL CHEW, Chief Science Officer and Chief Medical Officer, Sanofi U.S.
CAROLYN M. CLANCY, Director, Agency for Health Care Research and Quality (Ex Officio)
FRANCIS COLLINS, Director, National Institutes of Health (Ex Officio) (*designee:* **Susan Shurin**)
HELEN DARLING, President, National Business Group on Health
SUSAN DEVORE, Chief Executive Officer, Premier, Inc.
JUDITH FAULKNER, Founder and Chief Executive Officer, Epic Health Systems
THOMAS R. FRIEDEN, Director, Centers for Disease Control and Prevention (Ex Officio) (*designee:* **Gail Janes**)
PATRICIA A. GABOW, Former Chief Executive Officer, Denver Health
ATUL GAWANDE, General and Endocrine Surgeon, Brigham and Women's Hospital
GARY L. GOTTLIEB, President and Chief Executive Officer, Partners HealthCare System
JAMES A. GUEST, President and Chief Executive Officer, Consumers Union
GEORGE C. HALVORSON, Chairman and Chief Executive Officer, Kaiser Permanente
MARGARET A. HAMBURG, Commissioner, Food and Drug Administration (Ex Officio) (*designee:* **Peter Lurie**)
JAMES HEYWOOD, Co-Founder and Chairman, PatientsLikeMe
RALPH I. HORWITZ, Senior Vice President, Clinical Evaluation Sciences, GlaxoSmithKline
PAUL HUDSON, Executive Vice President, AstraZeneca
BRENT C. JAMES, Chief Quality Officer, Intermountain Healthcare
MICHAEL M. E. JOHNS, Chancellor, Emory University
CRAIG JONES, Director, Vermont Blueprint for Health
GARY KAPLAN, Chairman and Chief Executive Officer, Virginia Mason Health System
DARRELL G. KIRCH, President and Chief Executive Officer, AAMC
RICHARD C. LARSON, Mitsui Professor, Massachusetts Institute of Technology
JAMES L. MADARA, Chief Executive Officer, American Medical Association
MARY D. NAYLOR, Director, NewCourtland Center, University of Pennsylvania
FARZAD MOSTASHARI, National Coordinator, Office of the National Coordinator for Health Information Technology (Ex Officio)
WILLIAM D. NOVELLI, Former Chief Executive Officer, AARP; Professor, Georgetown University
SAM R. NUSSBAUM, Chief Medical Officer, WellPoint, Inc.
JONATHAN B. PERLIN, Chief Medical Officer, HCA, Inc.
ROBERT A. PETZEL, Under Secretary for Health, Department of Veterans Affairs (Ex Officio)
RICHARD PLATT, Chair, Population Medicine, Harvard Medical School
JOHN W. ROWE, Former Chairman and Chief Executive Officer, Aetna; Professor, Columbia University

[1] Institute of Medicine forums and roundtables do not issue, review, or approve individual documents. The responsibility for the published workshop summary rests with the institution.

JOE V. SELBY, Executive Director, Patient-Centered Outcomes Research Institute
MARK D. SMITH, President and Chief Executive Officer, California HealthCare Foundation
GLENN D. STEELE, President and Chief Executive Officer, Geisinger Health System
MARILYN TAVENNER, Administrator, Centers for Medicare & Medicaid Services (Ex Officio) (*designee:* **Patrick Conway**)
REED V. TUCKSON, Former Executive Vice President, UnitedHealth Group; Managing Director, Tuckson Health
MARY WAKEFIELD, Administrator, Health Resources and Services Administration (Ex Officio)
DEBRA B. WHITMAN, Executive Vice President, Policy and International, AARP
JONATHAN WOODSON, Assistant Secretary for Health Affairs, Department of Defense (Ex Officio)

Contents

1

Introduction

On February 25 and 26, 2013, the Institute of Medicine's (IOM's) Roundtable on Value & Science-Driven Health Care, with support from the Gordon and Betty Moore Foundation and the Blue Shield of California Foundation, hosted a workshop, called Partnering with Patients to Drive Shared Decisions, Better Value, and Care Improvement. The goals of the workshop were to identify and explore issues, attitudes, and approaches to increasing patient engagement in and demand for (1) shared decision making and better communication about the evidence in support of testing and treatment options; (2) the best value from the health care they receive; and (3) use of the data generated in the course of their care experience for care improvement (see Box 1-1). The focus was on building awareness and demand from patients and families for better care at lower costs and to create a health care system that learns and improves continuously.

BOX 1-1
Statement of Task

An ad hoc committee will plan and guide the development of a 2-day public workshop to identify and explore issues, attitudes, and approaches to increasing patient demand for a learning health system. Central to a learning health system is increased patient engagement in and demand for meaningful participation in the process of knowledge generation, shared decision making to select tests and treatments, and in the value of expenditures on health care. The committee will steer development of the agenda for the workshop, including selection and invitation of speakers and discussants, and moderate the discussions. The discussions will highlight what is known about patient attitudes, behaviors, and motivations related to evidence, shared decision making, costs and prices in care, privacy, and use of data to improve the effectiveness and science base for care. They will also address concrete steps that must be taken to increase patient demand and approaches for their achievement.

Chaired by Christine Bechtel, an advisor and former Vice President of the National Partnership for Women & Families (NPWF), the workshop represented a partnership among members of the medical, clinical research, health care services research, regulatory, health care

economics, behavioral economics, health care delivery, payer, and patient communities. Workshop discussions focused on

- building insights on and recognition of the necessity of increased patient, family, and citizen engagement in achieving better outcomes and lower costs in health care;
- exploring what has been learned about effective approaches for building patient demand and involvement in improving evidence, care, and value—including principles and barriers;
- considering 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; and
- identifying important policy and research opportunities for developing the additional insights needed to accelerate progress.

Strong efforts were made to include members of the patient community, and a number of patients and patient representatives were speakers, active discussants, and workshop attendees.

The publication of the workshop proceedings provides the Roundtable with a broader mechanism to inform not only vested stakeholders, but also other interested parties about what transpired at the workshop. The workshop proceedings should not be confused with a National Academies consensus report. The proceedings do not contain findings or recommendations endorsed by the National Academies or the IOM, the Roundtable, or the Planning Committee. Opinions and statements included in the proceedings are solely those of the individual persons or participants at the workshop, and are not necessarily adopted, endorsed, or verified as accurate by the National Academies. What follows in Chapters 2 and 3 are the proceedings of the meeting. Embedded in this are important lessons for the reader. The proceedings have been edited to eliminate grammatical errors. In addition, workshop speakers were provided an opportunity to edit their remarks to ensure clarity and accuracy of statements. Corresponding PowerPoint presentations may be downloaded from the workshop website (www.iom.edu/patientdemand). A copy of the workshop agenda (Appendix A), biographies of the workshop speakers (Appendix B), and a list of the workshop registrants (Appendix C) are appended.

2

Proceedings
Day 1
February 25, 2013

WELCOME, INTRODUCTIONS, AND OVERVIEW

Welcome from the Institute of Medicine

Dr. J. Michael McGinnis

DR. MCGINNIS: Good afternoon. I'm Michael McGinnis, from the Institute of Medicine (IOM), and it's my pleasure and privilege to welcome all of you to the IOM and to our wonderfully restored historic National Academy of Sciences building.

This year is our sesquicentennial year. Because we were oversubscribed, some of you are watching via video feed in the Board Room. You will be viewing under the watchful eyes of President Lincoln, who was captured in a striking portrait with the assembled scientific community of 1863, the year that Congress passed and President Lincoln signed the Charter for the National Academies. The year 1863 tells us that the National Academy of Sciences was founded during a war that led to fundamental progress in extending and deepening the democratization of our political and social processes across the citizenry. In many ways, it is entirely fitting then that we're having our conversation on patient partnering here today in the National Academy of Sciences building. Without overplaying the comparison, it seems appropriate to point out that this workshop, Partnering with Patients to Drive Shared Decisions, Better Value, and Care Improvement, is aimed at a further expansion of citizen empowerment, dedicated as it is to the democratization and deepening of the direct engagement of each individual, as participant and advocate, in the effectiveness and the efficiency of their health care, as well as in the capture of each care experience to improve the knowledge base that is the bedrock for medicine's progress.

Before we move into the day's proceedings, in addition to thanking each of you here today as presenters and participants, I would like to acknowledge and thank, in particular, three groups especially central to making our meeting possible. First, the Gordon and Betty Moore Foundation and the Blue Shield of California Foundation, for their generous support in sponsoring and leading the discussions up to the meeting. With us today are George Bo-Linn and Dominick Frosch from the Moore Foundation, and Richard Thomason from the Blue Shield of California Foundation. Thanks both to your foundations and to your colleagues for the support.

Second, thanks to the Planning Committee and its Chair, Christine Bechtel. This workshop is being hosted by the IOM Roundtable on Value & Science-Driven Health Care in accordance with the National Academies' rules and procedures. An independent Planning Committee, whose roster is in your folders, has organized the workshop with the support of the IOM staff, and they clearly have done a superb job; when you look at the list of Planning Committee members, you'll know why this meeting turned out so well.

This brings me to the third group: the IOM staff. In particular, I would like to thank Leigh Stuckhardt, who has moved on to the Centers for Medicare & Medicaid Services; Julia Sanders, with the guiding hand of Dr. Claudia Grossmann, our Senior Program Officer coordinating the work; and Valerie Rohrbach, Barret Zimmermann, and Liz Johnston, who are here to facilitate the sessions. Please join me in thanking the Foundations, the Planning Committee, and the IOM staff for their work.

I would like to flag several additional items before I turn to stage-setting comments from Dominick, on behalf of the Moore Foundation, and from Christine, on behalf of the Planning Committee. First, each of you has received the briefing materials that were assembled by the IOM staff with recommendations from the Planning Committee. You also have received a folder that contains the agenda, participant list, one-page overview of the Roundtable's work, and background material from the recent and important *Health Affairs* special issue on the topic of patient engagement, including both a table of contents from that issue and one key article. In addition to these materials, you will find a one-page summary that provides an overview of the strategy map for the work of the Roundtable. In particular, I draw your attention to this document because it includes a list of the ongoing projects that are under way in the various Collaboratives of the Roundtable, which underscores the essence of this meeting's focus on action. What we want, in effect, is to emerge from the series of conversations with an action agenda that will allow us to be more focused as we work collaboratively across our various organizations to foster progress.

The Roundtable's projects fall into three categories: value and improving the science of transparency; science and knowledge generation as real-time processes; and culture—strong public and patient engagement. The patient as a vital leader for each of these three aims—value, science, and decision making—and the focus on patients during this workshop are obviously clear. The conference sets the stage for success across all three domains, and we're very hopeful about the outcomes of the discussions in providing guidance for the work ahead. Finally, when it comes to action, I would like to acknowledge those of you in the room who are participants in the session and who bring to this conversation the kind of commitment that is so important to the progress ahead.

The Planning Committee has worked very hard to ensure that this is truly a patient-centered set of discussions. Of course, each of us at one time or another has been or will be a patient and witness, and thus brings occasionally painful perspectives to these sorts of discussions. In addition to the primary cadre of attendees from the patient community, some of the agenda sessions are organized with patients as co-presenters, in order to ensure that the perspectives at every level are truly representative of the issues at hand. We also have here in the room individuals who have built, and are building, important organizational capacities to lead change and help foster follow-up to our discussions. Examples include Michael Barry, President of the Informed Medical Decisions Foundation; David Blumenthal, President of The Commonwealth Fund; Bob Kaplan, Director of the National Institutes of Health's Office of Behavioral and Social Sciences Research; Lygeia Ricciardi, Head of Consumer Health at the Office of the

National Coordinator; John Santa, of *Consumer Reports*; Sue Sheridan, Deputy Director of Patient Engagement at the Patient-Centered Outcomes Research Institute; and Daniel Wolfson, Chief Operating Officer at the ABIM Foundation. We could go down each and every row and it would become clearly evident to us, as if isn't already, that this room contains the kind of leadership that can really make a difference moving forward. Please take advantage of our time together to link deeply with each other on behalf of our mutual commitments to progress.

Now, it is my privilege to turn the meeting over to those who will frame the sessions. First, Dominick Frosch will speak on behalf of the sponsors to put the meeting in the context of the Moore Foundation's plans for leadership in this arena. Following his comments, Planning Committee Chair Christine Bechtel will lead us into the agenda. Thank you all very much.

Opening Remarks and Meeting Overview

Dr. Dominick Frosch

DR. FROSCH: Thank you very much, Michael, and good afternoon everyone. I am delighted to be here today and to welcome such a large group for discussion on this very important topic: meaningfully engaging patients and families in their health care.

On behalf of the Gordon and Betty Moore Foundation, I want to express my sincere thanks to Michael McGinnis and the tireless staff at the Institute of Medicine for all of their hard work in developing this terrific agenda that we have here. And I especially want to thank Christine Bechtel and members of the Planning Committee for all of their work. Finally, I extend my appreciation to today's presenters for sharing your work with us here.

Now, before we delve into the specifics of how we advance the engagement of patients and families in creating a health care system that produces better outcomes and better value, I would like to spend just a few moments sharing a personal story with you. And I would like to think that this story captures some of the spirit of why we're all here and working so hard to transform health care.

Some of you know me as a researcher, and I have been interested in shared decision making for over a decade. In recent years, I have concentrated my work on trying to implement shared decision making in routine care. Later today, Grace Lin will present work that she and I led together.

But there's also a very personal side to this research and it's a large part of why I was drawn to this issue in the first place. Just before I turned 17, I was diagnosed with type 1 diabetes; it was a diagnosis that was life changing. I was fortunate enough to be diagnosed in a hospital where, after I was stabilized on an insulin regimen, I went through a training program that lasted 5 full days and taught me everything that I needed to know to be able to manage the condition, to understand what it did and what I needed to do every day to be able to avoid the complications that can result from diabetes.

Now I wasn't a model patient right away, and it took me about 6 years until I woke up one day and fully realized that all of my care was really in my hands, and that my ability to avoid the complications that can result from diabetes depended on what I did every day. So I test my blood sugar an average of eight times a day and I always know the trajectory of that blood sugar and where it's going. In the language of medicine, I practice tight control and I've been doing that for almost 20 years.

The benefit of all this is that, so far, I have been able to avoid complications, and every year I go to see an ophthalmologist for an annual exam to determine whether or not I have any traces of retinopathy. Every year as that appointment approaches, I'm a little bit nervous because I expect that maybe this will be the year when the first shoe drops and there are some initial traces of retinopathy that indicate that something may need to be done. And 3 years ago when I went for this exam, the physician made a very interesting statement. First she spent a few silent minutes conducting the exam and then she stopped and said, "Everything looks clear, no trace of retinopathy," and I said, "Whew, okay. What I'm doing is still working." But then she said this: "You must be really good at following orders." And I was taken aback a bit.

Her remark was in my view really both inaccurate and inappropriate. Inaccurate because I don't do the things to manage my condition because somebody else tells me to do them; I do them for me. And it was inappropriate because imagine if she had said this to someone who didn't know as much about managing the condition, or didn't feel as confident about managing it as I did. As a psychologist, I can say that hers was a comment that undermines patients' sense of what they can do and what they need to do to stay healthy. And it really sort of gets in the way of meaningfully engaging patients in their own care.

I tell you this story because I think it illustrates what we mean by changing the paradigm of health care delivery. The place where we want to get is one where the patient is a true partner with health care professionals. In fact, the most important team member, not someone who simply follows and obeys orders. Most patients don't want to follow orders any more than doctors do, and we need to change the culture of health care and put the tools in place to make engaging patients the way we all work because it's the right and the respectful thing to do.

It was this vision of a health care system in which patients and families are truly at the center that drew me to the Gordon and Betty Moore Foundation. Our goal in the Foundation's new Patient Care Program is bold. We want to eliminate all preventable harm and eliminate unnecessary costs, and we include among preventable harms the loss of dignity and respect that many patients experience when they encounter the health care delivery system. We see a clear path to how this goal can be achieved. We need to meaningful engage patients and families in a redesigned system that is supportive of patients and families: a system that optimally integrates medical and information technology, interdisciplinary teams, evidence-based practices, and continual learning; a system that considers patients and families as integral partners and embraces their engagement in all aspects of health care.

We know that this goal is extraordinarily ambitious, but we all know that for patients, families and ourselves, it is the right thing to do and we must strive for nothing less. We hope that you will join us in achieving this goal. I look forward to an important and engaging discussion over the next 2 days. Again, thank you all for joining us, and now let's get to work with advancing patient and family engagement. Thank you.

Ms. Christine Bechtel (Moderator)

MS. BECHTEL: Thanks, Dominick, and let me start by thanking the Planning Committee and to the IOM staff in particular, who really did the hard work of putting this great workshop together.

We are going to spend the next day and a half diving in to some of today's most critical issues in health care with experts in the field that are well known for their innovation and dedication to patient and family engagement. We would like for this to be very, very interactive.

We will focus on this idea of patient, family, and citizen engagement in the three areas that Michael outlined so eloquently—shared decision making, knowledge generation for research to improve population health, and changing our expectations for value in health care. And we'll examine the question of how we can engage patients, families, and citizens in each.

That begs the question, what is "patient and family engagement"? For most people the meaning of the phrase is kind of like a Rorschach test—it means different things to different people. I think we can do better. In fact, the *Health Affairs* article that you have in your packet begins to really dive into a more multifaceted definition of engagement, focused on engaging patients and families at three levels. The first, and the most often thought of, is of course engagement in their own care; we know a fair amount about that and we're going to continue to talk about engagement in care and find even more effective ways to do so. The second is engagement in organizational or institutional design and governance. So this could be, for example, how an institution might collaborate with a group of patients and families to design a shared decision making program to figure out how the institution can build it into the workflow, not just of their clinicians, but also of their patients and families. In other words, patients and families themselves are really part of designing the process. We've seen this strategy work successfully and have a great impact in a number of areas, whether it's designing a patient-centered medical home or having individual hospitals embed patients and families on safety committees, et cetera. Then the third level is policy making: engaging patients and families and their representatives in policy making. That might be at the national, state or the local level. We have some great examples of that today in the Health Information Technology Policy Committee, and other esteemed policy making bodies where patients, families and their representatives sit alongside clinicians and employers and health plans and researchers to shape public policy. PCORI is another good example of that as well.

So our goal is that, together with our terrific speakers, with the audience, with the Planning Committee panel, we can use this day and a half to start to outline a concrete and actionable pathway toward how we really accelerate progress in patient and family engagement in those three areas that I've outlined. The output of the day and a half will be a report of what we find and discuss, so that means that audience participation and interaction are really critical. We want to make sure that the audience has a chance to get up and not just ask questions, but also give your viewpoints and your comments.

We also have hundreds of individuals joining us online, and there is a way for you online to send in your questions, so we really encourage that as well.

Right now we're going to start in exactly the right place, in my opinion, and that is with a voice for patients and family caregivers: Dr. Jonathan Welch. He has experiences as a family caregiver, but also as a physician, and he brings a very unique perspective to this discussion that we thought was essential to lead off with. He's an instructor in medicine at Harvard Medical School and a practicing emergency physician at Brigham and Woman's Hospital in Boston, and his work focuses on patient and family-centered care. He also serves on his department's Patient and Family Advisory Council. Some of you may have seen his writing. It has been featured in *Health Affairs*, *Roll Call*, the *Washington Post*, and also the *Chicago Tribune*. So please join me in welcoming Dr. Welch.

LUNCH KEYNOTE

To Improve, Health Care Must Partner with Patients and Families

Dr. Jonathan Welch

DR. WELCH: Thank you. I'd like to begin by sharing a story about my family's journey through the health care system and what that really taught us about the importance of patient- and family-centered care. It started about 2 years ago on a sunny September morning, on a Monday morning, when I got this call that all of you, all of us, would dread. That somebody who we care about, who we love, was in real trouble and that catastrophe could be around the corner. And on the line was an emergency physician from my Wisconsin hometown and he told me that my mother was sick. My mom, who was a retired high school teacher, she taught pregnant teen mothers and tried to get their lives back on track, had been undergoing chemotherapy treatment for breast cancer and we were really grateful. The chemotherapy had kept her cancer at bay. And we really were just taking every day and being grateful for it.

But on that day she suddenly changed. My father had found my mother very somnolent at home and he called 911. And when my mother arrived at the emergency department her heart was racing, she had a high fever, and her infection-fighting cells were very low. Now, as an emergency physician, I knew exactly what was going on. This is something that I treat in my own practice. It's called neutropenic sepsis, and for our non-clinicians in the room this just essentially means that an individual's infection fighting cells are low, and at the same time there's a systemic infection.

Now there was some good news and some bad news. The bad news was that this is a life-threatening diagnosis. The good news was that there has really been a transformation over the last decade or so where the treatment of systemic infection has really been revolutionized. We now know more than 15 years ago exactly what patients with systemic infection need. Oftentimes, there are now protocols in hospitals that dictate what happens to patients with this condition. What this means is that individuals oftentimes are getting antibiotics. They are getting IV fluids and if they are particularly sick, they are getting care in an ICU center where they can get even more intensive therapies. But these studies told me something else. They told me that we were on the clock. These studies have shown that timely care of sepsis really is of the essence. It can be the difference between life and death.

And so after hearing this troubling phone call, I moved quickly from Boston to the Wisconsin Hospital where my mother was. Sequestered on that flight, really out of touch with what was going on, and knowing though that those hours really were of the essence. When I arrived in Wisconsin, I went directly to my mother's hospital bed and you can imagine, it's about 9:00, 12 hours after my mother initially went into this emergency department. She is now on a hospital floor and it's a quiet city community hospital. The lights are on. She looks pale. She looks weak and it's quiet. Her doctors have gone home for the day. It's me, my family, and her nurse.

Now I remember talking to her, and she was very stoic, and I remember her telling me she felt fair, as if this life-threatening infection were just a little bit of a bump in the road. And one of the things I was very eager to determine early on, just a quick look, was what her blood pressure was like. This is a poor man's way of essentially figuring out how people are responding to systemic infection treatments. So I went to the nurse's log and looked in her book and I saw this terrifying picture with her blood pressures crashing through the day. Her blood pressure is now

half the values of what they were when she arrived in the emergency department 12 hours earlier. And I thought, "What's going on?" I have to admit I was a little surprised that she was on a normal hospital floor, and that she wasn't in an intensive care unit already. So I did a little bit of extra detective work and very quickly I realized that these to me very familiar systemic infection treatments still hadn't been delivered.

So the clock is ticking, it is 10:00 p.m., 13 hours after my mother initially arrived at the hospital and I'm thinking about how I'm going to be the best advocate for my mother that I possibly can. I have to ask that the nurse call my mother's oncologist and that we request a transfer to the intensive care unit and I'm hopeful, after the oncologist did indeed approve this, that we are going to turn the corner. I just hoped it wasn't too late.

So I sent my family home. I stayed with my mother and we got transferred to an intensive care unit. It was about midnight, 15 hours on. Over the next hour, it became clear that things still weren't changing and many of these critical interventions weren't being implemented. And so I got confused. I was scared. I was tired. I was exhausted. And at one point my mother's nurse came into the room and she said something to me that I think was a veiled criticism of my mother's physician but at the time, to be honest with you, I was trying to get my bearings in a new hospital. I was tired and I just was very nervous about what was happening. I said, "Well, why haven't these treatments been delivered?" And she said, "Well, we do have a treatment protocol for this condition, for systemic infection, but your mother's oncologist hasn't ordered it."

This surprised me for a number of reasons. The first being that usually, in my experience, by the time somebody gets to an intensive care unit and is very sick, you have an intensive care doctor taking care of the patient. Secondly, I just still couldn't understand why these treatments hadn't been started. I felt a little bit like I was in the Twilight Zone where realties had been flipped upside down and I couldn't quite get my bearings. Over the coming hours, I really was, I was torn and I was scared. On one hand, I wondered, what is it going to be like if I advocate for my mother again; am I the pushy family member? And I knew all too well about that dynamic and how that dynamic could play out in the clinical care setting. What would happen if my mom survived this situation, and she needed to restart chemotherapy, and now I've criticized her oncologist? What is it like if you're too demanding and your ICU nurse starts avoiding your mother's room?

I was psychologically becoming off-balance, and my confidence as a doctor was eroding as I was both trying to marshal resources in the wee hours of an intensive care unit, and at the same time really becoming a caregiver for my own mother. I remember her calling me to the bedside every 15 minutes. She was very uncomfortable in her ICU bed. The lights are on and blazing. You can hear the suction, the white noise of the suction machine in the background, [and her] saying, "I'm really uncomfortable, you have to let me get up," and me always having to tell her, "We can't do that, we need to keep you here," and me kind of on my own trying to reposition her in her bed with the nurse outside the room, who I thought was probably doing more important work at the time.

Ultimately, through the night, we were able to eventually get my mom the care that she needed, and it ended up taking a request from me that we transfer outside of this hospital to another facility. And we didn't need to transfer her, but it did compel her oncologist to transfer care to a capable intensive care doctor later that morning. By the time that happened, it was about 8:00 on Tuesday morning, so 23 hours after the initial presentation to the emergency

department. And I remember my mom telling me, "This is really, really tough. This is difficult but I want you to push me. I want to live. I want to make it through this."

She did push over the coming days in the hands of this capable intensive care doctor. She did get the treatments that she needed for systemic infection. But that literature that told us that time is of the essence held true for her as well. And over the coming days, she got sicker. And I remember toward the end, when she was mostly sleeping all the time. She was not awake. And there was this one moment when she just briefly opened her eyes and she just whispered to me, very weakly, she said, "I never got to say goodbye." And she was dead by the end of the week.

Now I have to ask you, after experiencing a loss like that, this sense of wasted opportunity, what would you do? For us, it seemed like, in our minds, that mainly we had two options, both very blunt instruments, but the only tools that were available to us as family members and as a patient. And that was that we could either sue the hospital, or we could write a letter. And we didn't want to sue. I really feel like that was something that was too destructive. I'm in a high-risk field myself. I've never gone through that process, but I worry about it. We really just wanted to make sure that future patients who came through that hospital door never had the same experience that my mother had, that there was never that lost opportunity. So we constructively put together a letter, and in it we really referred to these national treatment protocols and pointed to specific elements of my mother's care where this hospital fell short and offered suggestions for improvement.

Now, I have to admit, I felt like I was well positioned to make a change in this hospital. After all, I was a physician who treated this exact complaint and condition in my own practice. I could speak in the technical language that the hospital administrators and the physicians could understand. And I felt like I had insider information here. I had almost a view that even some patients perhaps may not have had, and that was going to set us up for having a good opportunity to improve care. And initially after we sent the letter, holding our breath, there were some hopeful signs. Within a week, the head of the emergency department had called and left me a voice mail saying, "Look, we got your letter. We wanted to let you know that we've heard you. We're going to review the case. Call me if you have any questions at all." So I did, reaching the physician's voice mail, and I waited for a response. And I continued to wait. And slowly but surely, weeks passed, months passed. I was initially thinking, "Man, give them time, be patient, don't be the pushy family member. Let them do their due diligence and review the case."

But as time went on, and 4 months ultimately went on with absolutely no reply, I felt like they must have tossed this case to the side. That this was either going through a medical legal process or they just weren't going to respond to me. So 4 months later I called back. And this time my call was returned by a head administrator in the hospital, an intensive care physician himself. And we had a phone call with my wife and me, both physicians, and he said, "We reviewed the case and clearly there wasn't the degree of urgency that was really required to treat her." So we kind of hung on to that sanitized admission of error but an admission nonetheless.

Then we really focused on what could change within this hospital based on some of our suggestions in my mother's case. And some things did change; a small number of things did change. For example, protocols for systemic infection were being implemented in the coming months in the emergency department where my mother received care. Other suggestions and other problems kind of were left hanging. To this hospital we had recommended that they consider a rapid response team. I know many of you probably know what these are, but for those who don't, these are teams that are called when patients on hospital floors are quickly decompensating, and we're trying to get a rapid assessment and rapid action to hedge off the

kind of impending disaster. So, physicians and administrators come to the bedside and rapidly assess the patient. It turned out that they had one of these systems within my mother's hospital, it just wasn't called. And my sense is that probably this was done, or not done, because the nurse and perhaps even the oncologist didn't know about how to recognize the systemic infection condition.

Then still other things nothing really happened at all. There was really no system for identifying when a hospital was not enacting protocols for conditions like systemic infection. There was no warning system for that. And additionally, I think one of the biggest things that hit us toward the end of my mother's care was the lack of an intensive care physician coming in to her care. We had said it might be a good idea, especially for a subset of these patients, if intensive care doctors are brought in immediately when patients come to ICUs, and this physician said, "Look, we've tried that, but politically it's just been impossible to do." So, concluding the call, there was this one other burning question still kind of in my gut. And that was: why 4 months? What took so long? And the physician just said, "We were really trying to get improvements in care before we called you back and I'm sorry about that." That was the only apology that we ever heard from the hospital, and that concluded our entire communication with the hospital.

Now, by a show of hands, I'd like to see how many of you personally, or maybe in the care of a loved one, have had a health care experience, whether it's kind of a small bad outcome or a major bad outcome? So if you turn around and look, I mean this is a majority of people who have hands who are in the room. Now what I would ask you to do is, of those of you who raised your hands, how many of you felt that the health care system, the hospital, or the clinic where you were cared for made a change as a result of your experience? So, look at that missed opportunity there.

Now I'll just say that this is not an uncommon experience, what we're seeing here in this room. I've had clinicians, nurses in my own practice, readers who've read what I've written, come to me and say that they've had very similar experiences. This experience is exceedingly common. So what's the way forward for health care? I think there are a couple of things that we can do. The first really goes without saying: that patients and families need to play an active role in the care that they receive. And for us, this was really exemplified by the anguished 4 months of waiting as we were listening and hoping for a hospital response. That time emphasized to us how unimportant we were in the care improvement process. I think if you think about health care as any other service, when you compare it to other service sectors, other industries that make products, and you look at how those industries use user input, or customer input, to design their products and transform their care, health care really underutilizes that voice. It's not partnering with patients and families in a way that transforms the care that we deliver. And I think that has a real impact on the quality and the costs of the care that we provide.

But I think there's a way forward that has been outlined already, but I'll just say a few things from a clinician's perspective. Where do we go from here? I think there are two things that we can do. The first is that we need to find new ways of listening to patients and families. Hear their experiences, understand their frustrations in the continuity of care and know what their preferences are. The second is that we need to even more actively engage with patients to transform the care that they receive. And I think this can play out at the individual clinical level, at the health care administrative level, and then as I know we'll talk about later in the conference, at the knowledge generation level, and even as consumers in the marketplace and having transparency in quality and cost data.

I'll share a few examples here of things that I've seen after I've had this experience. On the clinical level, there's a program called Condition H at the University of Pittsburgh. This is a program where the hospital has had a rapid response team, one of these teams that bring clinicians to the bedside of a decompensating patient. But they've actually now allowed family members to kind of pull the emergency lever and enact that system. And I think if we had had that in my mother's hospital that could have been one way that there would have been a difference in her outcome, I can't say for certain. But it certainly would have been beneficial to us.

But I would emphasize that you don't need to be a doctor tracking care and knowing the intricacies of clinical care in order to play a role here that's valuable to the health care system. Especially in our era of contracting residency hours, increasing salaried physicians and individuals of my generation, who are prioritizing quality of life more than in the past. As we transition more to shift-based care within health care, there are going to be times where the family member is the only individual who knows what that patient looked like 12 hours ago on that hospital floor. So those family members really provide us with incredibly important information, and in the era of team-based care, we need to have patients and families included.

I think another example would be sharing medical notes. So clinicians' medical notes traditionally have not been available to patients, and now through electronic medical records, we're seeing that patients can get access to their notes. And there was an *Annals of Internal Medicine* piece within the last 6 months that looked at patients who had access to their notes; 75 or so percent of them said that they felt more in control of their care, and between two-thirds and three-quarters said that they were adhering to their medications more faithfully. So here's another example, especially when you look at the *Health Affairs* work that's been going on in the last couple of months and with their current issue, when you think about the activated patient, when you think about enhancing patient engagement, here's one of the mechanisms by which this actually happens.

One final clinical level innovation that I think provides us with some hope, one that I've seen that I think is a really innovative and interesting way for moving forward, is Anthony Digioia's in Pennsylvania. He's a hip and knee orthopedic surgeon. And so he's basically said this, in the era of ACOs and care redesign and transformation to taking care of patients and including patients in team-based care, we really need to design this system from the inside out again and start with the patient's perspective. So what he's done, with patient consent, he has shadowers who follow patients through the entire continuum of care, not just the surgery, from the parking lot to the pre-op appointment, to post-op period, to rehabilitation period, and they found some really interesting opportunities for improvement.

One of the big challenges that I didn't know about initially until learning about this example was that about 90 percent of patients who undergo hip or knee replacements nationally end up after surgery going to an inpatient rehabilitation facility to continue their rehab. So what Dr. Digioia and his team realized after having patients talk to these shadowers, and the shadowers making their own observations, was that there were two problems that they identified in their clinic. The first is that patients really weren't prepped for how to think about and what to do to manage their postoperative pain well. And that wasn't communicated in preoperative appointments. Additionally, they noticed that patients had a lot of pain after the postoperative period. So they went to the anesthesia literature and collected best practices, optimized pain control. They had numbers that 99 percent of patients on post-op day one said that pain was not a problem keeping them away from rehabilitation time, and they decreased the percentage of

patients going to inpatient rehab to 30 percent, down from the 90 percent national average. So these are real opportunities. You think about the cost implications of something like that, and the quality implications of why patients are needlessly suffering from pain after a surgical procedure. You see how some of these methods can start transforming care.

I think the other major area that I would just highlight briefly is on the administrative side. One of the things I always wonder about with us is if we had sat on my mother's hospital's intensive care unit quality improvement committee, and we shared her story and we pointed out how difficult it was and how detrimental it was for her not to have a critical care doctor taking care of her in those early hours, would that have been more powerful than a letter or a lawsuit? Maybe. This is I think a really important way that patients also can engage in health care. In my state, Massachusetts, we now have patient and advisory councils that are mandated by the state to be present in every hospital. And I think the best way that these processes play out is that you have these expert patients who've had good or bad experiences within the hospital. But they are able to contextualize their experience into a larger picture, really constructively sharing how they think the hospital can tackle some of its most vexing problems. And you get this new collaboration and information stream that you never ever had before.

In one of the most profound examples that I read about where a patient and family advisory council played an important role, was one hospital that bravely wrote about this experience where their patient and family advisory council told them, "We have in your clinic, in your obstetrics clinic, pregnant women with healthy pregnancies that are expected to be carried to term, sitting adjacent to women who are pregnant but where there was fetal demise or severe genetic anomalies, and where it was going to become clear that they were not going to be able to carry the pregnancy." So, you had this profoundly inhumane juxtaposition of people who were living a joyous part of their life and people who were suffering through a loss. And you hear that story and I think the first reaction that we all have is, how could they have done this? What in the world would've made a clinic set up a waiting room like this? But I think the answer is probably this. Both of those groups of patients are seen by the same clinicians. They are seen in the same clinic rooms. And a lot of the same equipment is used and utilized for both patients. So this was the care process that started from the clinician and the facility and built out, as opposed to originating from the patient experience through the continuum of care and then very early realizing something is wrong here.

So as we move forward, I think examples of partnerships like this give me hope. I think there's promise there. And the challenge now is to expand the breadth of these interventions and to roll them out, to scale up these interventions. And my hope is that many of you in this room will be building the tools and the new sets of approaches that enable us to do this. This experience for me has really opened up my eyes to the importance of patient- and family-centered care, so I'm sitting on patient and family advisory councils now and thinking about new opportunities for partnership and collaboration in care. And I think the need for those of us working in health care to incorporate patient and family voices is really urgent.

Today and tomorrow across the nation, there are patients whose survival will really depend on this. Their lives, like my mother's, and they have a photo of her here, really hang in the balance. With these lives on the clock and as hours and days tick by, we need to do everything within our power, everything possible to listen to family voices and partner with patients to avoid repeating these terrible mistakes and improve health care. Thank you.

MS. BECHTEL: Thank you so much, Jon. That was incredibly powerful and moving. And I think you could not have possibly done a better job of sharing with us the reasons that we look to

patients and family members as partners in this endeavor. So we do have a few minutes for questions, if you all want to approach the microphones. We'll start with you, and please introduce yourself as well.

DR. DARER: John Darer from Geisinger Health System, and I'm the co-PI on the Open Notes Initiative that you mentioned with folks from Beth Israel in Seattle and Harborview. What an incredible talk and thanks so much for sharing that.

In the process of the Open Notes Initiative, about 20 percent of folks shared notes with their family members, and we are now beginning to think through our next iteration of the investigation, and caregivers is a big focus. I'm curious if you can comment upon what you think it would mean to families. We know that patients really, really value the information, but we are still in that process of really understanding what caregivers need in terms of information and how that's going to be transacted. I'd love to get your thoughts.

DR. WELCH: Thank you, it's a great question. I think that family members are oftentimes, even when we're thinking about patient-centered care, still a missing piece of the puzzle in engaging patients and families in care. I think even in my own clinical practice, one of the mistakes that I see some of my own colleagues make or my residents make is that they may be great with the patient, but they kind of ignore the family member who is sitting in the room. And I think we forget that more than half the time probably, it's the family member, it's the concerned wife, who is motivating the patient to seek care. And they really, in addition to other members of the community, are going to be key tools for us to gather more information about how things are going for a patient. And I think we need to make sure that our interventions are the appropriate ones. I think there are fantastic opportunities there and I think people will be really grateful to have that information accessible to them.

MR. DEBRONKART: Hi, Dave DeBronkart. I have not a question but comments.

Jonathan, your story in *Health Affairs*, unbelievable. A few things I want to toss in. When my mom had her hip replaced a year and a half ago, at her transfer to rehab, because they didn't have electronic medical record transfer so stuff had to get printed out and typed back in, they were not interested in proofreading, so her hyperthyroid showed up as hypo in the new system—potential disaster. My two what I call "alpha sisters" were on top of everything, and the patient and family engagement there saved the day. It's really clear that that's one instance of patient and family engagement taking a burden off of the providers who are not supported by good systems, good technology, getting patients involved in teams and change teams.

I'm going to speak in a couple of months at Kingston General Hospital in Ontario. They have gotten it into their practice now to engage and involve patients on every team whether or not it apparently is something that directly affects the patients. On hand hygiene, they are hallway observers, the so-called Purell Nazis. They notice 30 to 60 percent compliance on the part of the physician.

By the way, why, with patients, do we call it compliance, and with clinicians we call it quality of care? I've got a point here. We have a cultural disconnect, and I'm not complaining here. You know, in my talk I didn't say this place sucks or anything like that, I said, look, let patients help.

So at the Kingston General Hospital, that hand hygiene team, one of the patients said, "You know what we ought to do: take each unit's numbers and post it on the door going into the unit." Shocking idea. Within 6 months the hospital is up to 92 percent hand-washing compliance. What is keeping any of us from doing this everywhere else?

One final thing, and Christine, you really should talk about your definition of patient-centered, but there was a Dutch in vitro fertilization clinic that gave their patient community a wiki and 6 months to talk, and said, "What do you guys want?" And the third thing on the list, after "We want more attempts at fertilization," the third thing was "We want empathy from our doctors, not just more information." The fourth thing was separate waiting rooms for families who've conceived.

I was saved by great medicine, and I think Govandi blames penicillin, right? He wrote an article where he said this medical miracle of penicillin made us look to the lab for all value in health care. But I think what I'm hearing here is that there's great value to be had also from listening to patients, so thanks.

MS. BECHTEL: Thank you, Dave. I just want to say one thing, which is we made a concerted effort as a Planning Committee to reach out to patient and family representatives, individual patients, family members, and consumer organizations. Dave is one of those. We're grateful for you being here today and we do have a number of you. I just wanted to give a shout out to the patients and families and consumer groups here today and encourage you to do as Dave has done and speak up as the day goes forward. Do you want to comment?

DR. WELCH: Thanks for your comments. Again, I think your important example really underlines first of all how common this kind of experience is. One of the things I think I've noticed about these important mechanisms of feedback is that we probably really need to look to other sectors or their wikis or other mechanisms for thinking about how other sectors develop products and services with the user in mind. And I think that's a great example.

The other thing I would say is, when you went through the list of priorities amongst patients at IVF clinics, is that it actually highlights a little bit of a danger zone, at least on the clinician's side; for the most part I really do think that physicians and nurses try to have their patient's best interests in mind. There's a professional ethic there that for the most part we all try to follow. The problem is that you get into this conceptual shortcoming when you think that you can intuit actually what a patient needs. And when you start finding new mechanisms for listening to patients, you get really surprised about some of the shortcomings in your care. So, we really need to develop those more, and when I think about physician and health care provider engagement, that's a real intellectual challenge that we have to confront in our field.

MS. DAY: I just wanted to thank you, Dr. Welch, for sharing your story. It was very compelling and I have a story regarding my father that's eerily similar to yours.

I'm from Bangor, Maine. I'm an independent patient safety activist and advocate. I'm a liberated, retired RN, so now I can say whatever I want. I've been a recent patient and I'm the survivor of hospital-acquired MRSA victim. The difference between your mother's case and mine is that I was sitting in the room when he went into sepsis, septic shock under the nurse's nose. She was in the room doing electronic records. My mother and I returned from lunch and I noticed that he was gray, ashen-colored, and somnolent. And she said, "Oh, he's just worn out, he's worn out because he just had a lung scan, he just got back from the lung scan." And I said, "This is different." "Oh, I think he's fine." So I raised a ruckus.

You asked what we can do. In the words of Lisa McGifford from Consumer's Union, you raise a ruckus. If you don't have a cord to pull to get the team there to take care of your loved one, you raise a ruckus. You can do that in a quiet, nice way or you can yell if you have to. But that's your loved one, and that's their life that's in the hospital's hands, and if you know the difference between them being okay and them not being okay, and who knows better than

family, seriously, then you speak out and you don't take no for an answer. So, I didn't ask a question, I answered your question; I think you said, "What do you do?"

Actually the other thing that they did for my father that they did differently is move him to ICU, but he had MRSA and they picked up all of his things from the windowsill, the other bed in the room, took everything down the hall to the ICU, rolled a clean bed into the room without cleaning it. So, I saw it from both a nurse and the patient perspective.

You asked if they had made change, and yes, they did. I wrote letters. I went to my state legislature, I won't go into all the things that I did but anyhow, they made the change of isolating all patients. And they didn't have any nosocomial MRSA the next year. My father was the third of three that year.

So, thank you so much for your work and your story and sharing your story. It's important that we all do that. Thank you.

DR. WELCH: Thank you. That's a fantastic accomplishment. I think hospitals need to find ways to culturally transform so that patients can feel comfortable speaking up, and there's still a real deep regret that I have for not really getting much more outspoken and aggressive in the wee hours of the morning.

Having said that, I've also learned now though that if you have a safety system within a hospital that relies on patients raising a ruckus in order to get the care that you need, we're probably in trouble. So, I think we're always going to need both sides of these mechanisms, but especially with sepsis care, where we are still in that 10- to 15-year window where knowledge is being brought out into the public, into the clinical space. I think we need to keep both of those things in mind, and patients being able to speak up is incredibly important.

MS. LIND: My name is Cristin Lind, and first I just want to say thank you so much for sharing your story. It's really powerful. And Christine, I'm kind of the classic mom turned advocate. My son is 10 years old. He has a genetic syndrome called Coffin-Lowry syndrome. Not that rare, not that common.

But I'm just here to share a really short example of something that's happened recently that I think speaks to one of the hugest barriers that we have when we talk about this subject, which is culture. So, 2 weeks ago I was reading a Swedish medical publication. The title of the publication roughly translates into "Dare to Let Patients Partner." And I was so excited to hear about what the Center for Person-Centered Care at the University of Gothenburg was doing, the fact that they even acknowledged that it was person-centered care and not patient-centered care, I thought was significant. I made a comment to the article and talked about some of the work that I'm doing here in the United States and supporting what conclusions they had come to. So, I support family and patient partners who are working in quality improvement teams. You just wrote a great article, Christine, which I keep quoting left and right, thank you so much. And I was really surprised because, about 24 hours later, I noticed that my comment was gone. And I was a little bit nervous because I wrote my comment in English, even though I do speak Swedish, my husband is from Sweden. And I just dropped them a note and said, "Did I do something wrong? I want to be able to make sure that I can stay part of this conversation."

Well, I got a reply about a day later saying that your comment was removed because you're not a professional health care worker. So it's a very short story, and conversation has continued with this publication. My comment has been restored, but I think that, nevertheless, their stance is that patients have a lot of space that they get to take up in the media, and there need to be places where we protect professional voices and allow them to be able to speak frankly and openly with each other.

So, I lend this little anecdote as a litmus test or a barometer of what we are facing as we talk about partnering with patients, because my new mantra is "culture eats strategy for lunch." It just is really going to come down to that often. So, I just share that and I want to say thank you so much for making sure that patients have such a strong voice here. It would have been really easy to do something else, so, thank you so much.

MS. BECHTEL: Thank you very much. We continue with the "us versus them," and I don't think health care providers want to be in that position as much as patients don't as well. So, we're going to take one comment from Paul Grundy in the room, because we do want to get into our next session, and if there's anything from the Web, maybe you all can bring that up as well. So, Paul, please go ahead.

DR. GRUNDY: Thank you, Jonathan. I have a couple of questions. The first question I have is: What was the total cost of that experience for your mom in the hospital, do you have any idea?

DR. WELCH: Great question, and I am still working to dig through her charges.

DR. GRUNDY: I think the *Time* magazine article is worth reading for all of us.

And I guess the second thought I had is that you and I are physicians that grew up in the world of Flexner, in which we're master builders. I mean, we look at the world not in a view of data or accountability toward data, but in a world where we're master builders. Where you wouldn't have done that in that system if it was somebody who was constructing your house and you saw an error occurring, because there would have been a plan, an accountability to that plan that would have been happening in the system.

And I guess the fact now in health care is we're moving away from Flexner toward a model of care in which there is going to be data and there's going to be accountability to data, and I think we need to think about that in reference to how the consumer engages with those data. Clearly, the experience in places like Denmark and others is to make sure that those data are available to the patient, to the consumer, to the person as a clear element of that. The system that you engaged and encountered with your mom is a system that's so flawed and so broken, it just has to be frustrating for you. You express that frustration so well by not knowing quite what to do at any stretch of the imagination, because you know down the road there are going to be blocks put in place for everything you really try to do.

But, that's changing, because for the first time in history, we are going to have the data to begin to hold a system accountable, and a place where those data flow in a medical home where accountability begins to occur. My question for this group and for us is, How do we really guarantee that the consumer, that the patient, is part of that? Because that is going to be absolutely essential. Thank you.

DR. WELCH: It is a great point. I, too, am hopeful as slowly but surely we move to these systems where we are holding our health care system accountable for results. And I think the hopeful thing is that we're building an evidence base that shows that these tools—patient activation, patient engagement, even from a very utilitarian standpoint, to say nothing of the intrinsic good of centering on patients—that that improves results. And if people and the citizens are paying attention to results, and hospitals and clinics are getting paid for results, I think this will become part of a larger package that transforms care.

MS. BECHTEL: Thank you again, Jon, for your terrific story, and also for giving us some insight into a productive way forward. I think my summary of that session would be defined as: it's all about culture, stupid. And I think Jon's story does a terrific job of illustrating that while we keep saying, well, gee, if patients would just get active in their care we would really have a

better system. But when they get active, what we heard from the audience, what we heard in Jon's story, is that we tell them no, they can't be part of the care team. No, they can't have their notes. No, they have to get limited to visiting hours. No, you can't be part of designing what this primary care practice looks like, we're going to design it for you and that's the system we have today.

So I'll say two things as we jump into the next session. One is I'm thrilled with the level of audience engagement and the fact that you guys are getting up not just to ask a question, but to offer your viewpoints and your experiences and I want that to continue. And I know we're running a little late, which is something that I raise only because I don't want to rein in the audience, but I do want to get a heads-up to the speakers that we want to leave time for exactly this interaction.

The second thing that I would observe is that the central theme of this discussion so far has been about partnerships. So, as we go forward and we hear from some absolutely phenomenal experts in the field and people with really innovative programs to build on, and that's our goal, to figure out how to build on what has been successful so far, look for that theme of partnership and where it's happening, and if you don't see it, we should ask about it. And we should find the ways; not everybody has done it and they can still succeed, so we need to find the ways to rein that partnership into even the most successful strategies, so that they can be accelerated and even more impactful.

So with that, I'm going to turn it over to Lyn Paget, who is going to moderate our next session. We're going to spend the rest of the day focusing on shared decision making and Lyn is one of the world's foremost experts, and she is the managing partner at Health Policy Partners. Thank you.

PATIENT-CLINICIAN COMMUNICATION AND THE TOOLS FOR CHANGE

Lyn Paget (Moderator)

MS. PAGET: I would like to ask the panel members for the next session if they would please come up and take their seats.

Thank you very much, Christine, and thank you for the opportunity to moderate this afternoon's session. I have to say that, as a resident of Boston, I hope that if I or a family member ends up in the emergency room that we will be there during Jonathan's shift.

But all kidding aside, I think that it's clear to say that, for both Dominick and Jonathan, their personal experience has informed and created a whole different way that they approach their research and their clinical care. And I think it is part of our job to decide the best way to systematically infuse that across all clinicians and across all care settings in this country, and that's no small task.

Before I introduce our speakers today, let me just review a little bit of what we hope to accomplish. This session is titled "Patient-Clinician Communication and Tools for Change," and I want to underscore "change." We need change. Why we need to change is perhaps one of the most disappointing stories of American health care. But here we are today, poised to bring us to a new place where we can be proud to be part of the renewed system that we know will allow clinicians to be our guiding experts, and where we and those we care for will be treated with dignity and respect always.

For this workshop, we are framing these presentations and those to come later this afternoon, by thinking about four necessary steps to change. And I challenge us as we listen to these sessions and these presentations to think about what it is that we're learning, because this is really a hearts and minds issue, what it is that we're learning that we can bring back to our individual spheres of influence. What is the action that we can take? How can we infuse the knowledge from today and bring it forward?

So, these four steps really guided the development of this workshop, and Christine mentioned one, which is pathways. How do we create that road or that avenue for us to open up opportunities for the kinds of changes that we know that are needed, particularly in the culture of care? Infrastructure is number two. That has to do with systems design. We've heard a little bit about that this morning. But we know for sure that in order to embed systematic and sustainable change, we really need to design things differently, and as Jonathan pointed out so eloquently, from the inside out. Making sure that the patient and family is in that inside. The third is culture. These are customs of care that are deeply embedded in our system of health care. These are not easy changes. But these are changes that are going to be required in order for us to see the kind of successful results that we want. And last is competency. And that's really an important word in my mind—competency on both sides of the coin. We're talking about skill sets. We're talking about competence. We're talking about competency so that communication happens both ways, and it's respectful, coming from both sides. That doesn't happen quite much in our system today.

As I was looking at the participant list last night, while I was watching the Academy Awards, it occurred to me that, for most of you, this is a workshop that's a distinct recognition of the professional commitment that you have made to make health care a better place for all of us. Because, as Dominick so eloquently pointed out, we are all patients. We are all people but we are all patients. So, we're really pleased today to have these dedicated professionals here with us to start this session. We have three presentations that are going to take us from the science that underscores the problem to innovative concepts for actually making infrastructural change to competencies. What does it need to look like for clinicians to be better at communicating and recognizing the value of patient and family contribution?

So, let me introduce our panel. Each of them has roughly 10 minutes to speak, and then after all the presentations, we're going to open it up for some conversation, questions, and dialogue. We're going to begin today with Gary Langer. Gary is the founder and president of Langer Research Associates. He is an internationally recognized public opinion researcher with expertise in analysis of political, policy, economic and social attitudes, questionnaire design and data interpretation, survey methodology, and survey management.

Following Gary, we have Sherrie Kaplan, who is the Assistant Vice Chancellor for Healthcare Measurement and Evaluation, as well as Professor of Medicine at University of California, Irvine, School of Medicine, and Executive Co-Director of the Center for Health Policy Research at University of California, Irvine. She is a leading social scientist in medicine and has pioneered a number of areas of research including demonstrating that patient involvement clearly leads to better outcomes.

And our last speaker today is Eric Holmboe. He is from the American Board of Internal Medicine. He is a Board Certified Internist. He is the Senior VP of the American Board of Internal Medicine and the ABIM Foundation. His research interests include interventions to improve quality of care and methods in the evaluation of clinical competence.

So, on behalf of the Planning Committee, I'd like to thank all three of you for being with us today and I'm going to turn it over to Gary. Thank you.

The Key Elements of Information, Connectedness, and Continuity for Patient Engagement in Health Care Decisions

Mr. Gary Langer

MR. LANGER: Thanks, Lyn. Thanks for having me. I'm grateful to be here. I'd like to say that I think Jonathan Welch's presentation is a call for patient involvement through the prism of his own painful personal experience, and the comments we heard after segue nicely into the presentation I want to make. I come to you not as a medical professional, but as a survey researcher. Public opinion research is my field. And the purpose of the research we do is to bring the voice of the public, in this case, the voice of patients, to the table—exactly the goal that we're hearing discussed so far this morning.

So, I am grateful for the opportunity to bring these voices to you in the quantified form that we do. I am grateful also not only to the IOM, but particularly to the Blue Shield of California Foundation, which has sponsored and partnered in this research with my group over the last few years, conducting high-quality, rigorous public opinion surveys of low-income Californians to understand better their experience of care and the motivators of their empowerment and engagement in the health care system. I'm going to talk to you a little about this.

The research program we've done with the Foundation is based on statewide surveys, telephone surveys, landline and cell phone, of a random sample of low-income Californians; those at less than 200 percent of the federal poverty level, a safety-net population, if you will. The notion is that the ACA is going to introduce competitive forces within the provision of care to this population. Providers need to respond.

So, in spring 2011 we did a baseline survey of the experiences and preferences of this population to learn about the drivers of patient loyalty and satisfaction. Two drilldowns emerged from that, two facets of that first line of research that we thought were interesting and needed further exploration. One is the expressed desire among these patients for a regular personal doctor. A primary interest of theirs was that they wanted to have one of those. And the second was the substantial, and perhaps surprising, resistance to the concept of shared decision making as we tested it.

So, we conducted an additional survey in the spring of 2012, a year ago, to explore these and other potential drivers of patient empowerment and engagement. Connectedness and continuity is the concept that we came up with that really seems to drive the empowerment and engagement of patients, particularly in terms of relationships. When you ask patients what they want in their health care, they say they want a regular personal doctor. What came to us, as we explored this theme and additional questioning, is that patients are using this concept of Dr. Welby to describe really the most familiar route to their real aim: Connectedness, a sense that someone where you go for care gets you, knows you pretty well; and continuity, the assurance that you'll be seeing the same caregiver over time.

Connectedness and continuity, as I will present this morning, drive patient engagement and patient empowerment, in a powerful way, above and beyond and apart from this simple presence of Dr. Welby. Indeed, wanting but lacking a personal doctor independently negatively predicts satisfaction with care and patient loyalty. But when connectedness and continuity as I've described them are present, are added to the equation, they independently positively predict satisfaction, empowerment, engagement alike, and having a regular personal doctor does not. It falls out of the equation.

Then we looked at shared decision making, and we were surprised by this result. Among this population, about 6 in 10 said they would like an equal say in decision making with their care provider. That is, frankly, fewer than you might expect; coming from the prism of an educated, involved base, you would expect an overwhelming majority, 8 in 10 or more perhaps, at least I did. But a fairly substantial minority, 4 in 10, said no, they prefer to leave decision making up to the care provider.

Now, what was that about? Well, we asked a few follow-up questions; one was, "What if the doctor chose options for you and explained them to you in information that you can clearly understand, would you then like to have an equal say in decision making?" And you can see what happens (see Figures 2-1 and 2-2). The role of information in decision making is a powerful factor in sign-up among patients to this concept.

And indeed it fundamentally levels the playing field. The blue lines show you the initial interest in shared decision making, and we can see some significant socioeconomic gaps. Willingness to participate in shared decision making is far lower among less empowered populations, less than high school compared to college grad, look at those blue lines, whites versus Latinos, non–English speakers versus English speakers, enormous gaps. Now when you provide information, those gaps largely disappear. That information levels the playing field in terms of willingness to participate in shared decision making; again, a powerful example of the important role of information and communication.

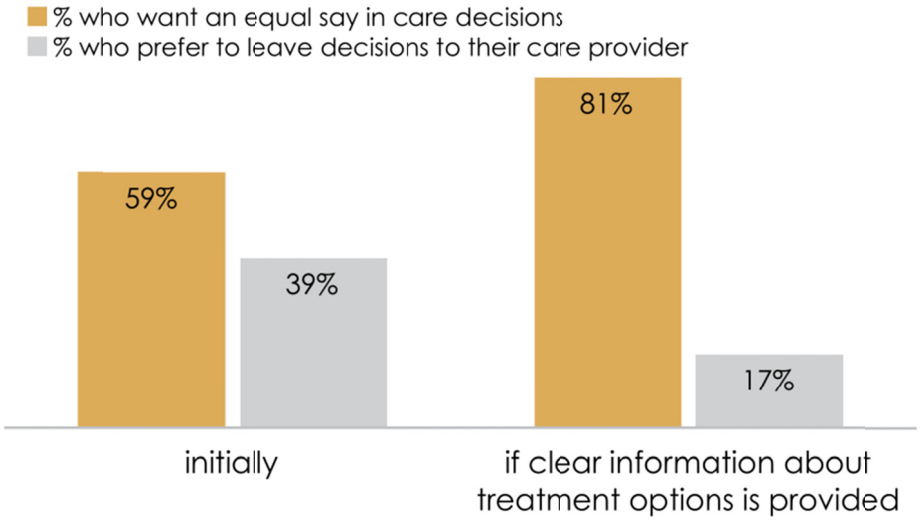

FIGURE 2-1 Preference for shared decisions with or without clear information on treatment options.
SOURCE: Reprinted courtesy of Blue Shield of California Foundation.

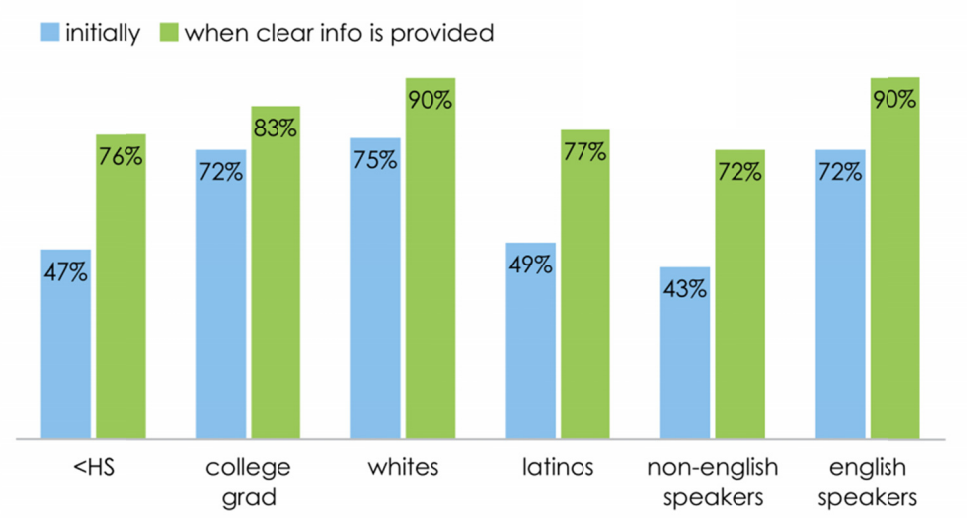

FIGURE 2-2 Preference for shared decisions with or without clear information on treatment options, by demographic.
SOURCE: Reprinted courtesy of Blue Shield of California Foundation.

We take this information through a series of regression analyses; build a mediation model that predicts a path to patient-centered care through a model of empowerment and engagement. This is what it looks like (see Figure 2-3). Connectedness and continuity as I've described them to you, the sense that someone there knows you and that you'll see the same caregiver over time, independently of demographic variables—having a regular personal doctor, health status, a place of care, insurance status and the rest—independently predict empowerment. "Empowerment" meaning feeling informed about your health, comfort in asking questions, comprehension, understanding the answers, and confidence in your ability to make health care decisions. Those empowerment measures in turn independently predict engagement, the sense that you're taking an active role in your own care, really the goal fundamentally of patient-centered care as we're discussing it. I'll point out that information, the first empowerment measure, is a particularly strong one, the standout, because it also independently predicts the other empowerment measures we talk about here.

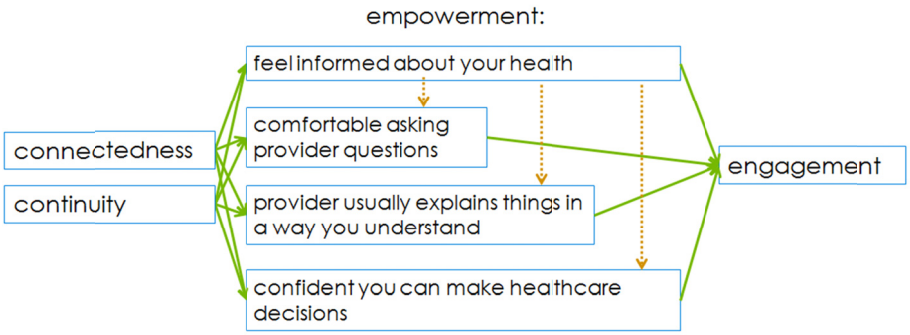

FIGURE 2-3 Schematic of The Path to Patient-Centered Care: A Model of Empowerment and Engagement.
SOURCE: Reprinted courtesy of Blue Shield of California Foundation.

I'm going to break these out a little bit to show you the impacts, the effects of these variables. It's really quite impressive I think. First is connectedness, predicting feeling informed about your health. Among low-income Californians who feel a personal connection at their place of care, 64 percent feel very informed about their health. Among those who lack a personal connection, it's 37 percent, an enormous impact or effect of that sense of connectedness. In terms of continuity as well, similarly, if you usually see the same provider, 56 percent feel very informed about their health. If you don't usually see the same provider, that goes down to 35 percent—again, a dramatic impact. Also consider connectedness in terms of predicting our other empowerment indicators of comfort, comprehension, and confidence: if you're feeling connected, feeling someone at your place of care knows you well, you're vastly more likely to feel comfortable asking questions, to say you understand the provider's instructions, and somewhat more likely to be confident in your decision-making ability.

BOX 2-1
Rx for Patient Engagement

- Connectedness and continuity pave the path to patient empowerment and engagement.
- Information is essential:
  - It predicts self-efficacy even when connectedness and continuity are held constant, and
  - It does so more strongly than education, income, gender, race, and other demographic variables.

SOURCE: Reprinted with permission from Langer Research Associates.

Continuity has similar impacts. Among those who always see the same provider, you see a lot more comfort in asking questions, a lot more comprehension of answers, and somewhat more confidence in decision making as well. These are fairly powerful impacts.

Then we talk about information and its predictive capability in comfort, comprehension, and confidence. And there it is similar as well. Among those who feel very informed about their health, comfort asking questions of their provider, comprehension particularly of the provider's answers, and confidence in decision making are all dramatically higher.

Finally is the sense to which each of these predicts the outcome, the Holy Grail of patient engagement, self-efficacy in their care. These are the percentages of patients who report having a great deal of say in their own care. Those who feel very informed are more than twice as likely to say they are engaged in their care. Those who feel very comfortable asking questions, again, are very substantially more likely to be engaged in their care; those who understand the provider's answers; those who are confident in their decisions in each case; in each of these there's a strong influence on patient engagement.

One route to patient engagement beyond the regular personal doctor we discussed earlier is team-based care. And I want to describe to you briefly its impact and some patient sentiment that we've measured in this population. Among patients who have team-based care, the satisfaction with their care is significantly higher, and their sense of information, and we've seen its importance, is significantly higher. Understanding or comprehension of the provider's instructions is higher as well. Similarly, people who have team-based care are more likely to feel

there is someone at their place of care who knows them well, connectedness. I think these last three bars show it perhaps best (see Figure 2-4). There are both positives and negatives from this stack. First, among private doctor's office patients, 51 percent say there is someone at their place of care who knows them well. On one hand, that's fairly devastating, only 51 percent of private doctor's office patients feel someone at their place of care knows them well. Clinic patients who are in team-based care, however, match that population in their sense of connectedness. It is clinic patients who don't have team-based care who fall off the charts in terms of connectedness.

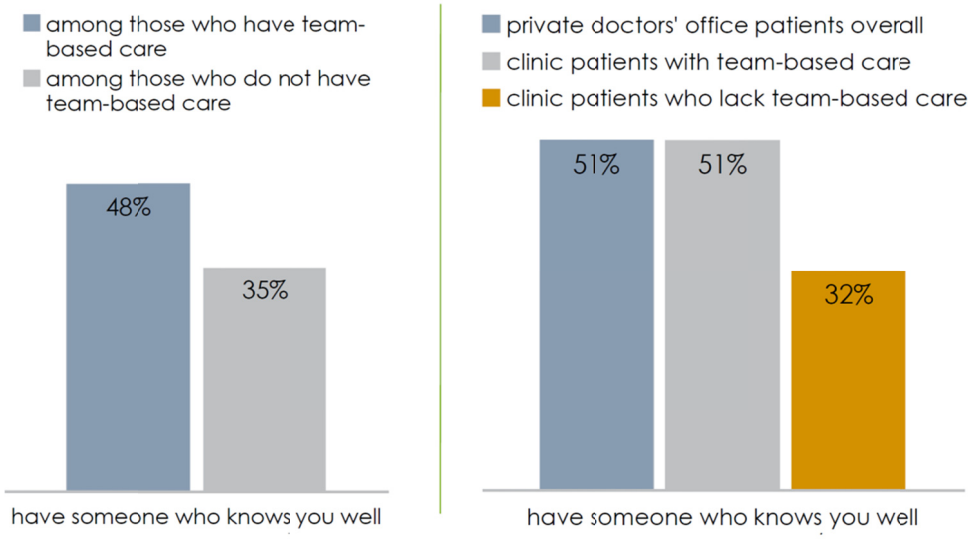

FIGURE 2-4 Patients who feel their clinician knows them well, based on care setting. SOURCE: Reprinted courtesy of Blue Shield of California Foundation.

So, team-based care at least lifts clinic patients to the level of private doctor's office patients in the sense of connectedness that patients achieve. It's helpful in that regard. That's the positive. The negative is that there is still a lot of room for improvement.

So our prescription for patient engagement then is that connectedness and continuity pave the path to patient empowerment and engagement, and that information is essential. It predicts self-efficacy, even when connectedness and continuity are held constant. And it does so more strongly than the demographic variables.

Now, I'm going to wrap up, just a last comment and just a word about measurement. In doing this research, we start with a review of the existing literature and I know there are a number of researchers here or those who are involved in publishing on the subject, and as a survey researcher, I wanted to make a couple of quick comments about this. We need to recognize that non-probability samples are not reliably generalizable. Agree/disagree and yes/no questions are inherently biasing. Unlabeled or partially labeled number scales often lack internal validity. Knowledge questions are problematic in an opinion survey format.

I'd be happy to discuss these with anyone later but there are many examples in the literature of the use of suboptimal approaches to survey research that I think could and should be addressed as we move down the road of bringing patients' voices into the discussion. Also it's worth remembering is that data analysis is very much enriched by rigorous modeling, as I've tried to present today.

Thank you very much. I appreciate it.

Planned Patienthood: Setting the Expectation for Shared Decision Making

Dr. Sherrie Kaplan

DR. KAPLAN: Thank you very much. I am going to talk to you about some stuff that we have been doing for quite a long time. In fact, this was sent to me by Alan Kaplan; apparently I gave a very similar talk at AARP in 1991. So, in terms of progress, I cannot promise anything exciting about progress, but at least I'm going to give you a fill-in about where we're going.

So, patienthood is this notion that we become patients as opposed to staying in that role. We become patients, we leave patienthood, we become patients, we leave patienthood. So, what are we asking patients to do now? Well, we ask them to choose and change health plans, choose and change providers, give "informed consent," participate in some treatment decisions (although going up that's rare still), follow through on treatment plans, pay the bill increasingly, and interpret health information, particular performance data.

So, what help do we give people being patients? Well, not very much. I mean, you can see sort of in order the things we do. And we are open enrollment. I don't know if you all have had this experience but at open enrollment time, I get the data on the health plans options available to me in font the size that takes me a very heavy magnifying glass to read, and physician directories, even these give you increasing information about quality, but they are mostly giving you information you don't know how to interpret, appointment reminders, et cetera. And we really don't give them very systematic help in making any of these; systematic is the underscore because we've got great examples of each of these individually.

So, currently there's no systematic training preparation for being a patient in the United States right now. There's no systematic training. It shouldn't surprise us then that the average patients ask fewer than four, you could argue five, lexical questions in a 15-minute office visit, including "Can you validate my parking?" and questions like that. And most patients don't participate effectively in treatment decisions, and although we have really good patient education programs in some areas, those improve knowledge but they tend not to be associated with important health outcomes. I'm going to get in trouble for that later.

But why haven't we done this yet? Well, there are some prevailing things. One is that patients are too poorly educated. They are not well enough prepared to participate effectively in care. Another one, as we just heard, is that patients don't want to participate in care. Some people really do want to be passive recipients of their care. If you increase patient participation and care, you'll lengthen the office visit untenably, and if you encourage patients to participate, they'll become difficult patients. And patient training, and I will come back to sort of challenging these myths in a second, patient training to participate in care is too new.

So why do it? Well, this is an article that we published about 2 years ago in *Medical Care* that in fact shows when the physician effect begins to stop and the patient effect takes off, and that's right about where exactly the targets for physician control are, this is blood glucose control, hemoglobin A1C values, and this is just about where the definition of "out of control" begins. So, if you want to reduce patients' values on this down to the target, you have to get patients involved. That patient effect takes off, at the definition of out of control. And the same thing is true, although it's a little harder to see for LDL.

So, to address the question of whether people should be passive about their care, we actually have some empirical data based on a bunch of questionnaire data that we've accumulated over the years about passivity. These are passive patients. They have a high provider dependence

score, and you can see that 40 percent of passive patients will have an important decline in their functional status of 10 points or more in a 1-year period.

So, maybe passivity is hazardous to your health. Greater passivity, and this is just recently where this is a manuscript under revision right now, leads to—and poorer confidence—leads to poor glycemic control, independent of race and ethnicity, and you can't see this slide, but control for the kitchen sink in terms of access to care, process of care, interpersonal care, and disease burden, management mastery is still a predictor of glycemic control.

So, what's the evidence for shared or participatory decision making? Participatory decision-making style, we've shown and I gave the conference organizers a big long bibliography, is positively associated with outcomes, health outcomes, patient retention, and patient experience ratings, and it occurs less frequently; that is, doctors don't involve patients in care without intervention. Now, some patients participate more effectively in treatment decisions than others. Younger people do. Women do, and I have some data to follow up on that. And obviously people with more active orientation to their health care do. In terms of gender in patienthood, the most common (this is from audiotape data) number of questions asked by men in a 15-minute office visit is zero. The mean number of questions asked by women is six. Women respond more, in addition, when you try to involve them in care and you develop interventions to involve them in care. Women respond, men tend not to, and I'll come back to the need for maybe remedial gender work on participatory decision-making style in a second.

So, training people to involve care, is it new? Well, my husband, when he should have been paying attention to something else in synagogue, actually came upon this algorithm in Leviticus (see Figure 2-5). So, the idea here, and the slides are obviously available, all of this information leads you to, you can actually graph this information into a treatment algorithm. It turns out that with certain kinds of symptoms, that is what you diagnose, leprosy, and then you observe them and if not, you quarantine them, and if the lesion becomes stable, you quarantine them, et cetera, et cetera. So we've been about disclosing information to patients in treatment algorithms for a long time.

So building, not on that evidence exactly but building on that notion, we actually developed what we called Coached Care. And using personalized information in the patient's medical record in an algorithm that maps treatment decisions, we actually met with patients before an office visit, coached them to be more effective during the visit, and followed them up with phone calls. And more recently, we've actually implemented that with volunteers from community-based clinics and matched for, not gender because we couldn't find enough male coaches that were really good at it, but matched for race and ethnicity. And we trained coaches to support people during those visits, and actually found that compared to controls, we have very good documented evidence of reduction in biomarkers and also reduction in symptoms and improvements in function.

This is the most recent data we have. This is also under revision. The intervention actually decreases, still decreases, hemoglobin A1C values in poor minority communities after 1-year follow-up. So, in summary, with coaching, patients can participate effectively in treatment decisions that improve patients' outcomes, and contrary to expectation, it really doesn't lengthen office visits.

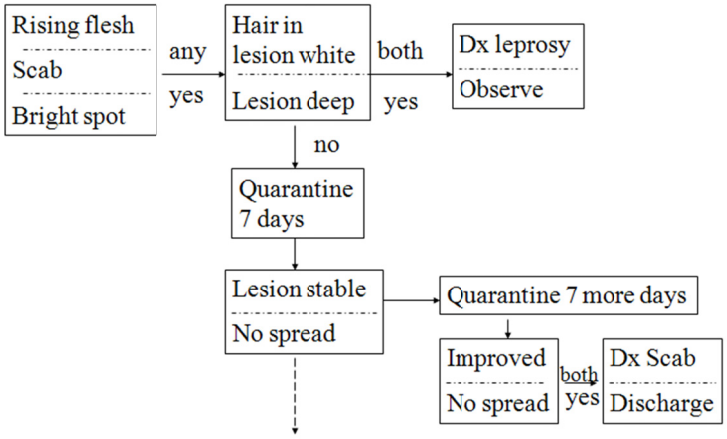

FIGURE 2-5 An early algorithim for treatment.
SOURCE: Reprinted with permission from Sherrie Kaplan.

So what should we be doing with patients? Well, building on that and all the expertise and experience in this committee and this enterprise here in our conference, we should also be involving patients in care in a much more systematic way. The details of that are in the first slide. Plus, we should also be teaching patients how to obtain, protect, and use personal health information, how to understand and navigate the health care system effectively and efficiently and, by the way, Choosing Wisely and other initiatives like that are going to make this even more important: how to teach physicians how to talk patients out of things. Make sure they understand things don't need to be done. How to protect personal safety in hospitals, and I think Jonathan's example was excellent, but we have a far way to go. Even things like if you see the rails are down on your bed, either you or your family member needs to pull them up. I mean basic stuff to keep people safe in hospitals.

And finally, where do we go next? Well, in the very voluminous briefing document that you have, there's a piece by Shelly and myself that describes the notion of centers for planned patienthood. We really need to take this on as a national policy. Right now, after 22 years of being at this, apparently longer than that, it is time to make that a national initiative, we need to teach people about patienthood. We may need to begin in childhood. Some evidence suggests that we learn these notions of patienthood very early on. We can use technology to advance the whole principle. We don't need to have actual centers, they could be virtual centers. And we need to target specific groups of patients that may be more in need of additional help or basic remedial help to participate effectively, like men, the elderly, and people with an additional disease burden that we call the "potential for benefit." Maybe we should be offering degrees in effective patienthood, so if you get a degree from our University of Planned Patienthood, you may get some benefits on your premiums. You may get additional things that were down to you, because you've actually done the work of trying to be more involved in your care. Thank you very much.

Clinician Competencies for Effective Shared Decision Making

Dr. Eric Holmboe

DR. HOLMBOE: Thank you very much for having me. I'm really excited to be able to participate here today. I'm actually feeling a little bit overwhelmed. I feel like a bit of a fraud because I'm looking at all the names on the lists and all the experts here. I'm not one of them.

But I'm going to hopefully share with you the flipside of what Sherrie just talked about with regard to the clinician competencies that are needed. And as Sherrie alluded to, there's a boatload of evidence that this stuff actually works, and we just haven't spent enough time really helping physicians, nurses, whatever, clinicians over their career, to acquire these skills, and they are very useful skills.

One other thing I'll say before I start is I think one of the things that's very important and again, in the context of Sherrie's talk, I feel this is really an obligation to make sure we help patients acquire the competencies they need to most effectively help themselves; and it's not just the patients, it's often families. I very much resonate with Jonathan's story. I literally have three parents now who are engaged in the health care system in various ways, some effectively, some quite dysfunctionally, and it's really interesting to experience that. A lot of it has to do with just their understanding of even what's happening to them. And I'm fortunate, being in the health care world, I'm a filter. I'm an interpreter to help them through that and balancing that, but it would be pretty frightening to me to think about what if I wasn't there, and people who don't have that sort of resource to help them navigate at times the very overwhelming system.

So, let me just give you a quick definition of competency. It's a term you heard from Lyn, and I totally agree, this is an important concept. And sometimes it gets overused and people treat it like it's the Holy Grail and there's a lot of cynicism around it. But I think it's a really important concept, and it's really taken hold in medical education, but I also think it has real value for continuous professional development. And this is a definition that was developed by a group of international folks. This is an international phenomenon. It's not just a U.S. sort of thing, but there's literally hundreds of countries that are embarking on trying to change the way they train their health care providers. And it's really focused on outcomes and it uses an organizing framework of competencies and I think that's really important. The outcomes are really what matter now and it's not like, well, this is what we think is important. These are the outcomes that matter and I'll get more to that in a minute.

But competency has become a framework to help us make sense and help our clinicians be better. And I really love this slide. If this is the one thing you remember from my 10-minute talk, I would have you hang onto this from Julio Frenk and colleagues, from a *Lancet* article a couple years ago. What they did is, they took a look, and you heard Flexner alluded to earlier from Paul, but this is what we used to do. We had a curriculum developed by a bunch of experts sitting around a table and then we would design tests. And that worked okay for 100 years but it's not going to work moving forward, and what Frenk and colleagues really called out is that when you design any sort of educational system across the continuum, you start with what the health needs of the population are, that's what matters. And you talk about what the health system needs are. That's where you ground [the training], and then from there you design the competency outcomes of interest, and then and only then do you really get into curriculum and assessment. If you don't meet the population needs, and we've seen this disconnect, then it's not going to work, and you're going to get the system that we currently have.

So, what's competency, and this is just again from that international group, an easy way to remember. It's "an observable ability of a health professional, integrating multiple components such as knowledge, skills, values, and attitudes." I want to highlight that attitudes matter. Attitudes are really important. We have already heard about how culture eats strategy every day for lunch, dinner, snack, breakfast, that's true. And attitudes are an incredibly important part of communication skills and patient engagement.

So, what are some of physician competencies that have been talked about?—and again these apply, I'm using a physician lens because of where I work. But these are the sort of things that are evidence-based, and I'm going to call out just a couple of them. And yes, they are written in a list, so I don't want to leave you with the kind of belief that yes, you just check these off and you're fine. No, these are highly complex. They have to interact to be most effective. But they are helpful things to keep, again, as a framework in mind (see Box 2-2).

BOX 2-2
Physician Communication Competencies

Ability to:

- Set agendas with patients
- Assess and improve patient adherence
- Elicit patients' beliefs, perspectives, and concerns about illness
- Communicate treatment plans
- Manage conflict and negotiate with patients
- Counsel patients, families, and caregivers

SOURCE: Henry et al., 2013.

So, just learning literally to set agendas with patients would seem like such a simple thing to do, but I can tell you, and Sherrie knows this well, most clinicians don't do it. They just plow right into their visits. "So, Mrs. Jones, you're here for your blood pressure today, it looks like it's up still a little high, I'm going to adjust medication, I'll see you in 3 weeks, is that okay?" Done. It's a very doctor-centered sort of approach. Instead of, "What's important to you today? What concerns are you coming into the visit with?" And there is a lot of good data that the very simple act of negotiating the agenda with the patient, which doesn't take more time, getting to Sherrie's point, makes a big difference in the visit. And then things like communicating a treatment plan, managing conflict, and then family and caregivers, all these things that you've already heard about.

Shared decision making, this is just again a definition of why it's important (see Box 2-3). But it's really about partnerships, getting to Christine's partnership collaboration team. And again you have to incorporate the patient's values, beliefs, and preferences as part of that process. And as Sherrie points out, patients will have varying amounts of interest in playing various roles within the conversation, and one of the things that often is forgotten is that there are certain parts of the visit that are a little different. Patients actually don't want to be involved in the problem solving as much as they want to be involved in the decision making, and Raisa Deber some years ago nicely called those two things out. Problem solving is why they come to see you for the visit, whether it be a nurse, nurse practitioner, or physician, they want you to

figure out what's going on. But when it comes time to make the decision, most patients want to be involved to some degree, and what the clinician has to figure out is what that degree is and how to help them do that. And then I'm not going to go through the evidence again, like I said, there's a ton of it.

BOX 2-3
Shared Decision Making

- Physicians and patients make health-related decisions collaboratively, based on best available evidence and patients' values, beliefs, and preferences.
- Patient engagement through shared decision making is linked to increased patient satisfaction, health outcomes, and quality of decisions.
- Requires competency at the patient, provider, and system level.

What about some of the process basics? This is just a really nice article from Clarence Braddock (see Box 2-4). These are just seven things, very basic, they're not complete. Michael Barry, who I see here in front is one of my heroes, can tell you a lot more about the nuance around these, but this study that was done about 10 years ago found that only 9 percent of the time did physicians even cover these seven basic things, that's it. And that's only if they did it, not if they even did it well. And so it goes to show you that these are things you would think would be important here, considering a procedure and a medication, what are my alternatives, what are the pros and cons, the side effects of what I'm taking, is this really going to help me, is there a chance it might not, thinking about joint replacement therapy as an example.

What does the patient understand? There are some simple techniques you can use, like teach-back and even follow-up, all these things which again don't require fancy tools, just part of good care and good conversation can make a difference. And this is some nice work done by Towle and others (see Box 2-5). It is also highlighted in the recent *Health Affairs*. These are just some other competencies really targeting the kind of shared informed decision making. Again, the attitude and skills are important, but here is another thing that has been shown in the literature. Many times we have to negotiate our own professional biases and emotions. We tend to frame things hoping for the outcome we think is important. "You really don't want that niacin, what you really want is that statin because niacin has all these nasty side effects, but that statin's great, you only have to take it once a day." That framing can actually greatly affect what patients choose to do, and be careful about that. Again, partnership, making sure the patient's preferred role is clear. That is part of the negotiation that we often forget about, and then again, when you present the evidence, just simple things like not using jargon, making sure it's done in understandable terms, and again, watching out for those framing effects.

BOX 2-4
Shared Decision Making Process Basics

- Discussion of patient's role in decision making
- Discussion of the clinical issue or nature of the decision
- Discussion of alternatives
- Discussion of the pros (benefits) and cons (risks) of the options
- Discussion of the uncertainties associated with the decision
- Assessment of the patient's understanding
- Exploration of patient preference

SOURCE: Braddock et al., 1999.

BOX 2-5
Physician Competencies

- Physicians must first agree that patients should be part of the decision-making process.
- Shared decision making requires attitudes and skills that many physicians may not possess or be familiar with.
- Physicians may also need to negotiate their own professional biases and emotions.
- Develop partnerships with patients.
- Establish and/or review patient preferences for information
- Establish patient's preferred role in decision-making process and uncertainty.
- Present evidence taking into account patient's own competencies, watch for farming effects.
- Help patient reflect and assess alternative decisions with regard to patient values.

SOURCE: Bernabeo and Holmboe, 2013.

So, I'm going to stop there. I just want to give you kind of a quick run-through and just highlight a couple other things I think really relate to the first talk. All these kind of behaviors, these things that are very competency based and behavioral based, they all tie in by the way to things like connectedness, continuity, and empowerment. It has been shown to be a very important part of that. We also know these very same competencies can be used in a team-based kind of model, and so Lagare's work, which was highlighted in some of the articles in *Health Affairs*, really gets at that. And at the end, all these things have to interact with regards to the clinician competencies, the patient competencies, and the system competencies. And Beth Bernabeo has a nice article that really lines up how those three things need to interact. It is not an

either/or, all three have to work in concert to be most effective. So I am going to stop there and look forward to the conversation.

Audience Participation and Open Discussion

MS. PAGET: Thank you very much Gary, Sherrie, and Eric. Okay, so folks, we have ample time for conversation, discussion, suggestions, clarifications, and keep in mind, as Christine pointed out, there is going to be a document, and so your contribution here is really valued and will live forever in that document. So think about how you can contribute, that's why you're here today.

I think that we have some really nice pieces of information to be dealing with, Gary sharing with us that information really levels the playing field, information is power, but we're challenged with how we then universalize routine use of accurate, unbiased information. Sherrie's model of coach care and asking us, Is passivity dangerous? Do we need to really believe that if patients are passive they are in an unsafe situation? Virtual centers for coach care, what do you think about that? And then Eric's presentation, starting with system needs, that we need to make sure that when we start with those needs, that we're addressing both the patient's needs as well as the clinical needs, and that clinicians negotiating with biases and emotions, that's a really important issue.

Okay, go right ahead.

DR. GARDENIER: My name is John Gardenier. I'm retired. I have my doctorate in business administration and a career in science and that doesn't seem to make sense, but it really does. My concern is the framing of the whole issue, and I think that everything that is being said about the physician-patient interaction here is helpful and useful, but it's a tiny piece of the overall problem.

When I took my doctorate I concentrated on information technology, operations research sometimes called management science or systems engineering or industrial engineering; all those terms basically mean the same thing. How do you get the system to work in an optimal way and the implementing mathematics aside from operations research with statistics and accounting? And it's that bunch of things that needs to be brought together and you need to look, I believe, at a health care management system that starts from the overview.

We know the U.S. health care system is continually getting more expensive and less effective. This should be a major concern. It takes systems engineering and expertise to help resolve that. At the individual hospital level or even the individual clinician's office level, systematic management practices should be involved to try to improve the health care system. Just information technology is just a basic thing. I don't see a lot of electronic medical record systems, but the ones I have seen certainly never had any involvement by any professionally trained information technologist. And they should. I mean the knowledge is there. We spend hundreds of thousands or millions of dollars training people to have the professional skills to do this stuff right, but in the health care business we don't use those skills. And to me that is a problem, which if implemented in a systematic manner, would incorporate what you're talking about with patient, caregiver, and provider interactions as measurable parts of an overall systemic effort at improvement.

MS. PAGET: Thank you. Thank you very much. Sherrie, you're at an academic medical center. Do you have any comment about that? Any success stories that you could share?

DR. KAPLAN: No, we are right in the middle of implementing an electronic medical record system, and it's really an amazingly difficult thing to do. And yes, because I think that that is the time when you can actually try and incorporate some of the personal health record information, but more importantly teach people how to use it. So, if you intersected the technology that creates information about the patient with a training program for how to use it effectively when you come the next time to talk to your doctor—that I think really is important.

MS. PAGET: Lots of opportunity there. Sally?

MS. OKUN: Hi, thank you very much. Great presentations. My name is Sally Okun and I'm from PatientsLikeMe. A couple of comments.

Sherrie, I want to follow up on your comments. I actually went back through some of my slide decks recently and found things that I could refer to that I talked about in the mid-90s; it is time for us to just really make some change and make it happen. So, oftentimes I find myself pretty amused at the cartoons that are still relevant today that I was using in consumer-based education at the time, and it's just really a little distressing.

A couple of tips though. I am a palliative care specialist. I've spent most of my career with patients in their homes, sitting at their kitchen tables, listening to them talk to me. And one of the things that I actually learned really early on in my work was that I couldn't go in with my own agenda. I needed to go in and just sit with them for a moment and let them tell me something. And so I would oftentimes open the conversation with, gosh, you look tired, what's keeping you up at night? Or just, what's on your mind today? Now oftentimes what I heard had nothing to do with their health or their health care or anything to do with illness, it was totally unrelated. What it offered me was an opportunity to hear how they framed things. I heard the words they used, and I heard how they would put phrases together. And then I would train myself to think about ways of taking that and give it back to them in similar ways that I would talk to them, so that I would no longer be talking in the way that Sally Okun, RN, would come in and talk, but I was starting to learn a patient vocabulary.

Now, one of the things I'm quite proud of with PatientsLikeMe is we have developed a patient vocabulary and it's been from the patients' reports themselves. And what we've done is we've taken that in and we've coded it against clinical taxonomies and clinical vocabularies but we retain the patient voice always. If someone wants to know what it translates to in a clinical term, we can tell you that, but we're more interested in what the patient actually said.

So, to your point, I think PatientsLikeMe could become a degree granting center for the Centers for Patienthood. I appreciate the comment. I think it's great and I'm really looking forward to more comments from the patients from the audience. But keep that in mind, what's on your mind or what's keeping you up at night and you'll hear and you'll learn quite a bit because patients will tell you a lot more than you think. Thank you.

MS. PAGET: Thank you.

MR. THOMAS: Hi, I am Richard Thomas. I'm the Program Director with Blue Shield of California Foundation; thanks for putting together a great panel.

My question is actually for Eric, as the representative, I think, on this panel of organized medicine. So I'm wondering if you could give us some more insight as to how physicians are viewing this drive-pull-push desire for more patient engagement. And what advice you have for those of us who are not physicians about how to create and support physician champions whether in medical education and training or elsewhere for this general effort.

DR. HOLMBOE: Wow, there are a lot of things we can do. And we actually have an expert who is standing right behind you. So, Mike Barry has spent a career developing tools, so there's

clearly ways to leverage shared decision making tools that Mike has developed in his work that I think could be very helpful.

I think right now part of it is honestly generational. The younger folks coming through see this as something valuable. This is something that is being much inculcated into them. So it is like anything, if you kind of grow up with it in your training, it just becomes part of what you do. I think that training programs have gotten much more systematic about training people and I think they have been able to show that it makes a difference. The biggest challenge we have is not so much that we lack training methods, particularly in medical school and residency, but it's that once you put the trainees out in the clinical environment it gets completely undone. And it's what Fred Hafferty calls the hidden curriculum. So say, hey, this is the right way to do it. And then this is one of my favorite stories from Dan Duffy, one of my heroes who brought it to the board: he would spend all this time teaching shared decision making to medical students, and then they would come back 2 weeks later, and he would have them go through a refresher and they would look awful. He'd say, "We just talked about this 2 weeks ago, what happened?" "Well, I tried that in the emergency room and the resident told me I don't have time for that, just simply do X." And so I think part of it is culture again, part of it's going to have to create the space.

I also think the boards can be helpful here by creating tools and mechanisms to help people get better at this. I'm always struck that when I work with older physicians, and we had a couple examples of this at Yale, that when the older physicians learn communication skills, they actually find greater satisfaction in their practice and there are actually some good data around that. Many times the reason they are struggling is that they don't have good communication skills so they become inefficient, patients keep coming back, patients aren't happy, and when they learn better communication skills it's a revelation to them. They just weren't taught it. They were taught to be so doctor-centric.

So, I think the boards are working to create some tools, but clearly there is lots of opportunity in continued professional development to build this in. So, I think the patients could use a certificate program, frankly, and so could a lot of the clinicians. And we just haven't done a good job of that. And I think Clarence Braddock's article for me really stands out. That was 1,058 audiotapes of surgeons, family medicine, and internists, and 9 percent of them even bothered to cover those things. So I think CPD as well as education, but we also need a culture that allows people to have some opportunity to use those skills.

MS. KORNBLAU: Hi, I am Barbara Kornblau and I'm the Executive Director of the Society for Participatory Medicine. What we are, by the way, we are pilot testing a pledge for physicians, which will eventually be extended to other providers.

But I just wanted to make the point, in our organization we treat patients and providers equally, it's an egalitarian organization. And I think that there is a real need for patients to be the ones, with all due respect to the engineer who stood up, I think one of the problems in health care is that a lot of things are decided from the top down. And I find as an e-patient myself that I've had to train my providers and teach them. Like the ophthalmologist who offered my father, at 95, three alternatives for treatment for his macular degeneration and told him to go on the Internet and look for it, make a decision. I had to train him that my father doesn't have to turn a computer on, he can't see, that's why he's seeing you. So the computer's not going to be very helpful to him. So you need to give alternatives. You can call me, I am the caregiver, but you can't expect him to make decisions. However, my 25-year-old can make very good decisions. If you give him

option he can go on the Internet and he can find more information than I can about just about anything in the world.

So I've taught all of my kids; I have six children with chronic conditions. They go into the doctor and they ask questions before the doctor opens his mouth. They give their history. I've trained them. They bring their file with them. And I think that that's how we're going to change the culture, is from the bottom up. And physicians will start respecting—there will be this mutual respect, where when someone comes in with the information they need that the provider, and not just physicians, PAs, nurse practitioners, everybody else in the team, will have an understanding of: this person is giving me information that's valuable, that's going to prevent medical errors, that's going to improve quality of care, and make the visit faster because I don't have to hunt and peck, they know what's important.

DR. BARRY: Mike Barry from the Informed Medical Decisions Foundation. Thanks all, a lot of great points. I'll just pick up on one that Gary talked about.

There is such clinician pushback sometimes around the shared decision making stuff that it is okay for college professors but not really for regular folks and the importance of asking the right way that Gary highlighted, that contingent on having the right tools, the feeling is quite different. To extend that in our foundation in our demonstration sites, actually catch people in the decision window, and give them information about their condition, those numbers then go up over 90 percent and that seems generalizable across age, educational level and even gender, amazingly. So again, this notion that the idea is ubiquitous, but people need different kinds of help in their situations.

MR. DEBRONKART: Yes indeed, information boosts engagement. How on Earth, it just stuns me that this is a surprise and research finding worth publishing. How on Earth can anybody participate in any discussion if they don't have information, and yet, what Cristin said about culture eats strategy for lunch, this is so important. I see this loop, all the conferences I go to where we say "Don't give patients information, they can't understand this stuff," and then they get insulted for not knowing anything.

And when I first spoke at the Meaningful Use hearings a couple years ago, I mean this is really important, that I tweeted something about a certified e-patient. It's a great idea, but it'll be for naught as long as patients get smacked down by clinicians, which is why, as Barbara said, the society has met the program with matching pledges, I the provider promise to do this, I the patient promise to do this. I told the story in my Meaningful Use testimony that 50 years ago, more than 60 years ago, my mother had to learn to drive because she had three kids and a traveling salesman husband who was never home, and in the early 1950s a lot of women didn't drive. In fact, the cultural conversation was that women drivers were depicted in cartoons and late night comics with the bumper wrapped around the telephone pole, and indeed mom within a couple of months of getting her license bumped back into a pole, put a dent in the bumper. The irony here, my dad said, "Well, good, I'm glad this happened in a harmless way so you could learn." The irony is that today insurance statistics show that women have one-third fewer accidents than the men who used to make fun of them.

Okay, so while we work on the facts, obviously people perform better when they are informed better, that applies to clinicians as well as patients but we also really need to work on the culture, because as long as people think that patients can't understand anything useful, it'll be for naught, so let's do both.

MS. ROHRBACH: Two questions from the Web. The first is from Shilpa Amin, MD: Can the panel and audience address the role of cultural competency and multilingual skills as part of

the needed skill sets in our health care communications approach with an increasingly diverse demographic shift in our patient populations?

The second question is from Petra Langer from the Schwartz Center for Compassionate Health Care: What can be done to relieve stress that many caregivers feel today, which can impede their ability to connect effectively with patients and families?

MS. PAGET: So that first question I would open up for both our panel as well as anyone in the audience who has any experience or knowledge in that area of cultural competencies.

MR. LANGER: We have data like that in our survey for Blue Shield of California Foundation. We do show first that willingness to participate in shared decision making is largely sociocultural socioeconomic in basis. Individuals who are traditionally less empowered in our society are more hesitant to take an active role in their care; less educated, lower income, noncitizen, non–English speaking.

So, cultural competency is again a way of getting across the information that levels the playing field, and we do find that these populations desire cultural competency, want to work with care providers who understand where they are coming from, who speak their language. That's an essential element of the communication that is so essential in getting across the information that leads to connectedness, continuity, engagement, and empowerment. So, we do see that in the data, yes, that cultural competency is important. And that's why facilities such as traditional safety net clinics continue I think to thrive, because they have a specialty in that area.

MS. PAGET: So the second question about caregiver stress, any of our panel members want to address that?

DR. HOLMBOE: I am no expert here, but it is a big issue. And it's going to only grow with the kind of silver tsunami that's coming for all of this. We know that that's a really growing problem. There are some good examples of respite programs. The VA has had a respite program. When I was at Yale they would give the caregiver some time when they were taking care of a family member—that was huge because they really can experience burnouts. I think we have to be attentive to that, and as we have an aging population, we're going to see probably more and more of this, and it can actually have its own health effects.

There's some literature that it too can be not only disempowering, but can also have its own health effects. So I don't have an easy answer there. Like I said, there are some examples that are usually with enclosed systems, the VA and the military being two of those, but I certainly resonate with the question as somebody who is experiencing some of that now on my own level.

MS. SALMOND: My name is Sue Salmond. I am from the University of Medicine and Dentistry in New Jersey. And I just wanted to refer to the concepts of connectedness and the coaching. We have a community health clinic in an underserved area that is really very trans-disciplinary in terms of physicians, nurses, and other health care providers working together. But perhaps the uniqueness in our model is that we hire and train from the community that we serve; community health workers that serve in the capacity of that cultural broker and help the physicians, the nurses; and other health providers understand how to teach from a culturally competent perspective, how to present information. We have teams of physicians, nurses and other health providers that are led by the community health workers, and they see clients in the community, which is where culture lives. And I think we have to look at getting out of our classic organizational health care into the community, valuing many different people on the team that can truly change health care, and we have seen a tremendous difference in patient engagement with this model.

DR. MONTORI: Victor Montori, Mayo Clinic. Our team has been working developing decision aids since 2004, and we've taken the approach of creating very lightweight, very small footprint tools that can be put in front of the patient and the clinician. And the clinician and the patient can then review them together, and the tools will contain the options and risk and benefits of each of them and they can discuss together and arrive at a decision together in the office.

Those tools have been developed with participation of the patients and the clinicians actively through a series of prototypes. So, we don't have the problem of work that usually happens in the way we normally do things, which is go to the conference room, get a bunch of experts, close the door, figure out exactly how you want to do it, refine the intervention to the point that it's perfect, then take it to the practice, put it in front of clinicians, and then write the paper about barriers and the fact that these people do not know how to use your tool and do not know how to incorporate it into their workflow; we have had that problem.

And we also had a couple of other problems. The first one is the notion that clinicians and patients will have different knowledge bases. They are looking at the same material. They could have other backgrounds and as the conversation is created they will bring those backgrounds to bear. What I've recently discovered is that if we set up the knowledge level for the patient, it's actually good enough for the clinician. Sometimes we overestimate the clinician's cognitive abilities and we try to educate the clinician, for instance, for maintenance of certification or other purposes; we actually raise the bar so high that it becomes impossible for a burnout clinician which is becoming the average clinician. And so by creating tools for patients, those tools actually help the clinician also stay up to date.

The reason I'm telling you that is that even though we are intervening during the consultation, the duration of the consultation does go up, but not massively so. So, on average it's about 3 additional minutes for a consultation average of 20 minutes. So, it's a small amount, particularly if you don't use the duration of that visit as your denominator, that duration as a relationship, a series of visiting continuity as a denominator, as well investment in time that could potentially pay off.

The fourth thing that we've uncovered is that most of the demographic determinants of whether somebody will participate in decision making fall apart. If you actually engage patients by meeting their needs, informational needs, you have young and old, women and men, participate actively in shared decision making. And we have video recordings to demonstrate that is the case, and we have done now a meta-analysis of all our randomized trials where we tested these tools, and in the meta-analysis all socioeconomic differences are based like in terms of education levels, actually these things levels it up after intervention.

The average, this will be my next-to-last point, the average age of our participants is 65. So this notion that only young people are interested or are able to participate goes away once you develop tools for everyone; that way people are happy to participate. They know what's at stake and they have a lot more experience to rely on to participate in an encounter.

My last point is that a lot of the things that we know about these things come from observation and experimentation of the system as is. And in the system as is, we find a lot of clinicians who have given up, have learned helplessness, and they feel they are not under control, that it is cost and cost containment and the economic reality that are dominating the day, and these things hurt details.

In parallel, there is an industry that is beginning to emerge around patient empowerment and shared decision making that is making these things also another factor, another thing to consider in the business plan. And in a study that we did with our designers at Mayo, we actually

interviewed patients in the hospital and asked them, "What meaningful experience of care have you experienced?" Then we collected all that and tried to find out what creates meaningful experiences of care for people that are very sick, and the way in which you can tell there is a meaningful experience was when somebody went out of their way. So if rounds came around and then one doctor came back and said, "You look confused, you look distressed, what went on?" If a doctor on the way home off the white coat actually comes back and talks with the patient and makes everything clear, are you comfortable, talks to the family member who just flew in but was late for rounds, every time somebody goes out of their way it creates a meaningful experience.

So, I would encourage us that when we talk about empowerment and shared decision making things, we keep going back to the fact that these are two human beings that actually by nature would like to have an engagement, would like to talk to each other and let's not over-script this, not make it an economic transaction, and make it a meaningful experience.

MS. TARINO: I am Danielle Tarino from the Substance Abuse and Mental Health Services Administration, which is an operating division of HHS. Eric, I really appreciated your slide that you wanted us to remember, talking about health systems and health populations. And being that we live in a country where one in five adults will be diagnosed with some sort of behavioral health issue whether it be a substance use disorder or a mental disease, we have an extremely vulnerable population who don't always know how to have those conversations with their doctors.

We deal with a lot of confidentiality and privacy issues. I have spent my entire federal career trying to figure out how to relay the information that I hear at all of these meetings to my population. And I'm having a bit of problem, because I come from a clinical world. Before I came to the government, I worked at a university in a mental health and substance abuse clinic on campus. And if you had paranoid schizophrenia and I tried to tell you and inform you that you had paranoid schizophrenia, you thought that I was out to get you. So, we have a population that is extraordinarily vulnerable, and when it comes to informed patient decisions, the families really need to be on board as well, because, the majority of the time, families are the advocates for the vulnerable communities that I have experience working with.

And also along the line of curriculum, there's an extraordinarily large amount of bias that we've heard our consumers talk about feeling from their physical care providers. In a world where we're going to be exchanging health information and my diagnoses are going to be on my electronic health record, do I want my podiatrist knowing that I once tried to commit suicide? So, as we move on with the workshops, I just came up here to kind of plant the seed of the idea of mental health and behavioral health needing to be considered in these processes, because we have a large amount of people that suffer with these conditions who have less access to information than we would think. And that's all I had. Thank you.

MS. PAGET: Thank you very much for sharing that perspective.

MS. DAY: I am back. I am perhaps the most engaged patient in the State of Maine. And that's because I've worked with, I've networked with patient safety activists and advocates through the Consumers Union Safe Patient Project. It's a phenomenal project and a wonderful group of people, and about 2 weeks before the 2011 Summit, where we all get together once a year, I was diagnosed with uterine cancer and needed cancer surgery. Well, I'm 63 years old, 62 at that time, and I'd never had surgery for anything. I've been very lucky.

So, I had all of these people to talk with and I really truly became engaged. I took a full 2 weeks to make my decision about where I would go and where I would have that surgery. And I

will comment that it's not easy to be an engaged patient. I was considering three different hospitals and I tried to find out the complication rates for the particular surgery that I was facing, and that was impossible. The infection rates were a little bit easier, but I was particularly blown away by the infection control nurse that said, "We don't have to report those infections until next year." And I said, "Unfortunately I have cancer this year." And I did not choose that hospital. It's awful that I based my choice on that but it really did turn me off.

But when you talked about engaging patients, a couple of things came to mind. Before I went into the hospital to have my surgery—and I had a wonderful outcome by the way, I'm cancer free and happy about that—I wrote a letter to the patient safety officer at that hospital, which not too many people have done. I would suggest it. I told them who I was. I told them I was scared and I wasn't there for a social call. Basically, I was there to get rid of cancer, and today I wasn't one of them, I wasn't one of us, I was one of them because it is an us and them thing when you're on the other side of it sometimes. And I laid out my expectations, and one of those expectations was that I wanted my husband to stay with me overnight. I only had to be there one night. And nobody ever responded to the letter but when I showed up for pre-op, I had all kinds of visits from administration. I was very quiet because I was scared, but they got it. They got it that I didn't just write that letter for myself, I wrote it for everybody. I wrote it for all patients.

So what came to mind when we talk about engagement and all of that is that maybe it's time to review patient rights, and rather than things being ideas and hit or miss, and maybe this hospital will allow you to keep your loved one with you overnight and that is the greatest source of comfort that I had, but that one won't, and if you're in a semiprivate room, you can't have your advocate stay with you overnight. I think it should be a patient's right to have an advocate by their side when and where they want unless it creates a hazard or puts them in jeopardy somehow. And the other right I think that we should have is the right to our own personal health information, and that shouldn't be anybody's decision, it should be our right as patients to have that information. A lot of discussions wouldn't even need to be held if they became rights.

MS. PAGET: Thank you very much. I am going to be a moderator police now and make the decision that on this side, Mark, you'll be the last on that side, and Grace, is there anyone behind you? All right. We are going to continue with this topic after the break so thank you. Perry.

DR. COHEN: I have had Parkinson's for 17 years and sometimes it is hard to get the words out. But I'll give it a shot. My name is Perry Cohen, Parkinson Pipeline Project. I want to focus on the issue of change.

I agree with all the stuff you're saying about patient empowerment, but to me technology is what's going to drive the change and our friend, the Mr. Engineer, had it right. But the other person who commented on that also had it right, that you have to have involvement of the patients and the teams that are creating the change. We have an opportunity now with $18 million or $17 million going into electronic medical records to do that engineering so that this is what's going to drive the change. And to get the patients who are involved and get the physicians more involved with patients. We also ought to be looking at the personal health records as well as the electronic medical records. I actually was working with a doctor to do that in her specialty care for Parkinson's care.

So the bottom line is it's specialty driven. Each disease entity ought to be able to organize itself to create the culture and environment to train the patients and train the doctors that have their own certification system like they do now for like the Board of Internal Medicine. That's about all I have to say.

DR. KAPLAN: One of the things about information is, we know information alone doesn't change behavior. You need training programs around how to use the information, and one of the things I wanted to make clear is with the personal health record, and the new Choosing Wisely Initiative by the American Board of Internal Medicine in concert with specialty boards, is they're teaching physicians what not to do.

At the same time, we've got an indemnified population out there committed to the notion that they deserve service and they deserve expensive service. They deserve the kinds of services they want and need. Teaching people how not to use may be a place to start—what you don't need and what kinds of things that training modules are for, if you want to know how to talk to doctors about this, link up here, or talk to a professional society. But learn how to use information and how to ask better questions, how to ask, "Do I really need this?" Those are things that we still don't do systematically with patients and I think this is a great opportunity to start.

DR. GARDENIER: My name is Turkan Gardenier from Pragmatica Corporation. For many years I have worked as a health statistician and researcher, and my comment and perhaps question to the panel members refers to the new trend for early intervention and risk benefit assessment concurrently developing with genetic marker evaluations, those getting into databases. And in any models I have seen along with patient data, there's the query about exposure assessment, air quality indices, water quality indices, and they all are in different places.

As a family, my husband was the engineer who posed the question, we were at the annual meetings of AAAS, American Association for Advancement of Science, and I heard fascinating presentations on air quality levels and their association with 911 calls, especially in July and August. And the number of apartments that had no air conditioning, and also the statistic that because of lack of CPR or adequate CPR 90 percent of the people who made the 911 calls did not survive. Well, as a senior, if I lived in a metropolitan area and didn't have much air conditioning I would move, having the flexibility to do so even before anything happened. And then I delved into the databases for environment indicators in different areas using geographical information systems, and I couldn't really understand the data there. Is it risky? Is it within standard? Or not within standard?

So, aside from training patients who already are patients, we also have to work with the databases that exist to individualize the information so that people who are semi-knowledgeable about this can make interpretations for themselves even before going to a physician.

DR. JIMISON: Hi, I'm Holly Jimison from Oregon Health Science University doing a rotation through NIH and Bob Kaplan's Office of Behavioral and Social Science Research. I have a comment and a question about the roles and responsibilities leading to defining competencies.

So to start with Eric's list of competencies where the last one was have the physician ask the patient what their preference is or decision, I want to emphasize that many physicians seem to take that as well, "What do you want to do?" being the question. As opposed to needing to make an optimal decision or even an optimal recommendation for a patient, you need to understand their values on the outcome, not just what do you think you want to do. They are the experts in diagnosis, prognosis, understanding the probabilities of complications, although oftentimes other patients are more the experts in what it's like to live with the health outcome that may be part of important information systems that get at that.

But from both patient competencies and physician competencies, I just want to make sure there's an emphasis to not just saying, "What do you want to do?" but, "You are a unique

individual with your own values and very legitimate differences of opinion on living with complications of treatment," and getting that information during the visit or before. Thanks.

DR. HOLMBOE: I'll just quickly respond. In no way do I intend to say, "So what do you want to do?" I mean that's the worst thing and again that's a skill. It's interesting, even in that study, that even what you just said, which I totally agree is not a functional way to do it, that was rarely done, which is fascinating. So even saying, "What do you want to do?" is not commonly done and you're absolutely right. I think it was wonderfully said by a patient, I apologize, a patient like me, "You've got to know who your individual is," so taking a couple minutes to get a sense of how they view their illness, who they are, is absolutely critical and it is part of that connectedness right. And then if you saw one of the first things on the list from Braddock and Wendy Levinson it was you have to have a conversation, invite them to participate. Tell me a little bit about who you are, and I want you to help me make this decision. I'm not just going to leave it out for you to lay a bunch of choices. In fact, we know that's not a very functional way, and in fact Mike Barry's work in decision aids is designed to help avoid some of that. So I totally get it and I'm glad you raised that.

MS. PAGET: I think it begs the question of the definition of what we need when we start to use these phrases like "elicit preference." That's a really good point. Okay, Grace, you're up.

DR. LIN: Grace Lin, University of California, San Francisco. I appreciate the comments from the panel and from the audience, and one of the things that struck me was the fact that, and I think Eric you touched on this, that we have a very disorganized system.

Medicine doesn't happen as a system, it happens in a silo. I'm a clinician. What happens with me and my patient happens right then. I'm not in the room with somebody else when they are talking with their patient. And so it occurs to me that we haven't really talked about how, as a clinician or as a patient, how we know we are doing well. How we know that we've achieved what patient-centered care is, how we know we've achieved that we've educated the patient appropriately, that the patient is engaged appropriately, and how we let the physician know or the hospital know or the health care system know that we have reached the goal, the goals that were laid out here in this conference.

So I just put that out there, I don't think there are easy answers but I put that out there as sort of a challenge and for comment.

DR. HOLMBOE: I just resonate with that and I think measurement, I'm sitting next to one of the gurus of measurement. I do think we have some things, and like Judy Hibbard, who I believe will be here tomorrow, her patient activist measure is actually very useful tool. We don't use enough of that.

One other comment I want to make about the system is we tend to think of the system being the information technology, and I really like the way Paul Ginsburg and the Dartmouth group think about it—no, no, no, it's not the system, it's the facilitator. Information and IT should sit as a hub of information, but system is mostly about how people work together and how they coordinate and do care as a team over multiple locations, and I think we have to be careful to not always think of systems in terms of just technology. "Systems" is mostly about people.

MS. PAGET: Thank you. I think, Grace, your point about accountability is really important. We've got to bake that into the whole conversation. Okay, Mark?

MR. GORMAN: Mark Gorman, patient advocate. Actually this has been a very rich discussion and an excellent panel, and I think certainly exceeded my expectations as a member of the Planning Committee. And Eric, you actually were here very intentionally as a representative of organized medicine so I'm glad that came through. But nobody was trying to

put you on the spot. You got the invitation because several members of the Planning Committee have been listening to you for many years talk about the concomitant competencies that clinicians need to acquire. And the discussion here today highlighted sort of the tension between everything has to be on the patient's shoulders to learn how to be effective as well as, and Dave pointed out, the most activated patient is potentially going to be profoundly frustrated encountering a brick wall.

So, we need to find a way to meet the happy medium there. You've used the word "skill" at least once, maybe a couple of times, so just to conclude, when I think about these things, it's an extremely important distinction on this physician communication skill competency. It's not a trait. It's not something that somebody got because they were raised in a household and learned to be a good communicator. I mean once, on the clinician side, these competencies are put in the box of being skills, then you have things that can be taught, you've alluded to that, for which clinicians can be accountable, and even as you just said, measured for having acquired.

So I hope that you and your colleagues in organized medicine will be encouraged to continue your good work. You alluded to multiple boards here earlier. We have to become collaborators and I'll have a couple of things to say about that in the concluding panel tomorrow. This business of culture of patients and clinicians being at each other's throats, that's got to change.

MS. PAGET: Thank you, Mark. That was a nice wrap-up. Okay, I have permission from the powers that be to give you a full 15-minute break even though we're 5 minutes late. So we are going to reconvene at 3:20. I would like to ask the panel members for the next session to come back about 3 minutes prior to 3:20 and I want to thank Gary, Sherrie, and Eric.

Break

PATIENT-CLINICIAN COMMUNICATION AND THE TOOLS FOR CHANGE (CONTINUED)

Ms. Lyn Paget (Moderator)

MS. PAGET: So, given the conversation that we've had this morning and the information that we've been going over, I think it's clear to all of us that what happens when you get in these kinds of environments and start talking about this is, we create a lot of energy, number one. But number two, we start to ask the questions around implementation. What does this really look like in the trenches? How does it affect clinicians? How does it affect patients? Are people happy, are they not happy? What does it really look like?

We know this isn't easy. We know there are challenges and what we have for this afternoon is a group of people who have been doing this not for a few months, but for several years. So their experience is a real testament to what we all need to learn in order to implement the kinds of protocols that we know will support patients and families. And we're asking the question, does this work to change the environment to one that respects the goals and concerns of every patient?

And before we start this, I just wanted to read for you something that was written in the *Health Affairs* journal that everyone has referenced this morning by Jessie Gruman. I know a lot of you know Jessie, and she writes a narrative piece about her fourth cancer diagnosis. And as she is summarizing, she makes these statements that I think are pretty compelling, and she uses a

phrase that I really want us to be thinking about. "No clinician, insurer, or regulator could have devoted as much time and attention as I did to determining how I wanted to be treated or how I want to live. In retrospect, I am awed by the gravity of the decisions I made about my health care and by the limited evidence on which those decisions were based. At the same time, it took full scale, sustained efforts by me and my family to develop and carry out my treatment plans to get the most out of my care. I am concerned about those who cannot summon such energy. They will suffer unnecessarily."

I think we've had a lot of people make the points this morning that we do have unnecessary suffering. And if we don't underscore the point that we are doing harm and not good, and that this is about colossal cultural change—but we also need to do the kinds of systems and infrastructure work that we know will sustain this from here on out. We owe this to every patient and family member and we owe it to ourselves.

With that said, I am very pleased to introduce our completely West Coast panel, thank you for making the trip here today, I'm not sure what that says about innovation but we can figure that out I guess. So, we are going to lead off today with a presentation by Grace Lin. She is an Assistant Professor of Medicine at the Phillip Marley Institute for Health Policy Studies at that University of California, San Francisco. Her research agenda focuses on resource utilization, appropriateness of care, shared decision making, and measuring the quality of decision-making process, particularly in cardiology.

Following Grace's presentation, we actually have three professionals from UCSF, including Jeff Belkora, who is an Associate Professor of Surgery and Health Policy at the University of California, San Francisco. His professional mission is to help people grow in their capacity for leadership, teamwork, and decision making. Margot Zarin-Pass is a first-year medical student at UCSF. She was previously a premed intern at the UCSF Breast Cancer Center. There she provided decision support services to patients and conducted patient engagement research. Lastly from UCSF, we have Ekene Obi-Okoye. She is a premed intern. Her current projects include studying the biology surrounding breast cancer recurrence, designing support programming for metastatic breast cancer patients, and participating in the patient decision support program at the Breast Care Center.

And to round out the presentations today, we have David Arterburn from GroupHealth in Seattle. He's a general internist and a health services researcher who holds positions as an associate investigator at GroupHealth Research Institute, and as an affiliate associate professor with the University of Washington School of Medicine in Seattle. His research covers a broad range, including comparative effectiveness of weight management interventions, pharmacoepidemiology, pharmacogenetics, bariatric surgery, and shared decision making related to elective surgery.

So welcome to all of you, and Grace, you're up.

Building a Culture That Promotes Shared Decision Making

Dr. Grace Lin

DR. LIN: Thank you, Lyn, and thank you for the opportunity on behalf of my colleagues at the Palo Alto Medical Foundation and Palo Alto Medical Education Research Institute to share our experience building a culture that promotes shared decision making. I'd like to start with an overview of the Palo Alto Medical Foundation and what we call the Partners in Medical

Decision Making Program, and then move to how we promoted awareness of our program to physicians and to patients, and then end with some lessons learned.

The Palo Alto Medical Foundation is a multispecialty medical group in the San Francisco Bay Area consisting of over 750 physicians and serving more the three-quarters of a million patients, mostly in a fee-for-service model. I tell you this just to set the stage for what I'm going to say. Being in the heart of Silicon Valley, PAMF has been an early adopter of such things as the electronic medical record and the online patient portal, as well as having commitment to patient education supporting community health education centers and shared medical appointments. What I speak to you about today is an initiative that was funded by the Informed Medical Decisions Foundation, the Partners of Medical Decision Making Program, which is a demonstration program designed to implement decision aids into primary care practices.

So, what's the problem? The problem is that the use of decision aids is not common in current practice. And here I have some quotes, one by a patient who says, "It would have been nice had it been offered during my visits to the sports doctor, the primary care doctor, the orthopedic doctor." He's been to several doctors and he says, "None of these people offered me this decision aid." But on the other side, we have physicians saying that the patients "don't really want the decision aid if I offer it, because they don't want to think about something like colon cancer screening, or you just kind of run out of time."

So, what do we need to do? We need to promote awareness to facilitate a cultural change. And who are we trying to engage? Obviously, we're trying to engage everyone from physicians to patients to institutional leadership, and so what we did was we made a strategic decision to develop a social marketing campaign to increase awareness of shared decision making and decision aids. And social marketing in this context in health care has to do with promoting a health idea. So that's what we wanted to do, a concept. And as you all know in marketing and when you promote an idea, branding is really important.

So, one of the first things we did was we actually named our program, Partners in Medical Decision Making and in it we wanted to reflect our goal, which was to promote physician-patient partnership and to empower patients. So, we then came up with these three taglines: empowering patients to make personalized decisions with their health care team, prescription strength information for better decisions, and better decisions together. And these are the taglines that are on anything that we produce, whether it's educational material, whether it's branded products as you can see here, our newsletters, so that patients and physicians and whoever is reading this are reminded that this is what Partners in Medical Decision Making is about.

We also engage practitioners in leadership through various and many channels. And you see an example of some of those here, including grand rounds, newsletters, sort of more traditional things, but I wanted to draw your attention here to academic detailing. And you might be familiar with academic detailing from the pharmaceutical industry, where the pharmaceutical representative comes to the physician's office, talks to them about their product and educates them and tries to sell them on their product basically. We took this idea and instituted the same principles. Our wonderful shared decision making navigator Caroline would go and do visits to each clinic every other week, talk to the physicians, talk to the nurses, medical assistants, whoever was involved with the decision aids, just to remind them that the decision aids were there, but also to train them on how to use the decision aids and to get feedback on the program. And this was a tremendous time investment, but really was necessary to keep the visibility of our program high in the clinics.

We simultaneously promoted decision aids to patients in the form of posters, brochures in the exam rooms, and then again, being very IT savvy, had Facebook, Twitter, blogs, newsletters, and the like, so we got mentioned there. And then we directly engaged patients through two mechanisms, which I'll briefly mention. One is the self-screening survey and the other is shared medical appointments. The brief survey was a survey when the patient checked into the clinic to assess the need for a colon cancer screening decision aid. So we had a series of questions that asked, Are you over 50? Have you had colon cancer screening? And if the patient was eligible and expressed interest in receiving the decision aid, the medical assistant or the front desk staff would give the patient decision aid prior to seeing the physician.

And really this was very successful. You can see before the screener, the clinic was passing about four decision aids per week. During the time that the screener was in use, decision aid distribution went up to about 18 to 20 per week and then all of a sudden it dropped off again. And we were wondering why. So, we went back to the clinics and what we found out was that the physicians actually, although they initially gave their approval, they withdrew it. For example, a physician said, "We don't want to continue the self screener because the volume of patients who are interested in materials is difficult to manage." In other words, they didn't like having to talk about colon cancer screening when it wasn't on their agenda. Or another physician said, "If we give the decision aid to patients, we won't be providing personalized care," which was sort of interesting because that's exactly what the decision aid is designed to do.

So, even though we were successful in engaging the patients, what we found was that the patients and the physicians, if the incentives aren't aligned and they aren't on the same page, we really were not going to be successful distributing a decision aid. And this was a theme that was prevalent throughout our in-clinic distribution and, you can see here, just briefly, this is from our Health Affairs paper, this red line represents the percentage of patients for colon cancer screening that we feel like we reached and that number by and large was under 10 percent of eligible patients. So even though we distributed over 6,000 decision aids in this project we think we reached less than 10 percent of patients. So there's a lot of work still to be done.

A more successful intervention is what we call shared medical appointments. For those of you who don't know, shared medical appointments are when a group of patients with the same condition see a physician together; instead of having individual appointments, they come together and they discuss their condition. And early on in our project, our steering committee said, "You know, I think that shared medical appointments would be a great way to institute shared decision making and engage patients and try to distribute decision aids."

So, we solicited interest from our geriatricians who were interested in doing shared medical appointments. And we set up a series of three 90-minute sessions whose goal is to engage patients in care and perform functional assessments for conditions that have a high impact on health outcomes and aren't consistently done in primary care; things like memory assessments, fall assessments, screening for depression. Really, this is a way to both achieve the physician's agenda and engage patients. And because individual assessments are made and documentation is done in the electronic health record, it can be billed as a standard level three visit, so all of these are billed at a 99213 level. We've enrolled over 150 patients to date in a variety of ages. And actually, I'm going to let this, we have a video that was produced by PAMF Public Affairs. I'm just going to show you a little bit to let you experience the shared medical appointment. *(Shows video.)* So, that just gives you a little bit of a sense of what happens at a shared medical appointment and the goals of it.

So, just to finish up quickly, what we found from our experience is that culture change is very hard. And that engagement at all levels of the health care system is really required, from the patients up to the leadership, because it doesn't happen otherwise. Physicians may need more training. Team-based models where physicians aren't the only people involved work best. And then incentives need to be aligned, as I mentioned earlier. And patients need encouragement to become engaged. And then, as we show with our shared medical appointment, models of care such as these might be more conducive to shared decision making and patient engagement.

So I thank you for your attention. I just wanted to acknowledge our funders, the Informed Medical Decisions Foundation, the PAMF leadership physician staff, and our fantastic PMDM team which Dominick mentioned. He and I led this project before he left to go to the Gordon and Betty Moore Foundation. Thank you.

The Patient Support Corps: An Innovative Staffing Approach to Support Patients in Shared Decision Making

Dr. Jeffrey Belkora, Ms. Obi-Okoye, and Ms. Zarin-Pass

DR. BELKORA: Thank you. I am Jeff Belkora. I'm with the University of California, San Francisco. And I want to present today on an innovative staffing model for supporting patients in being informed and involved in their treatment decisions. And I do want to acknowledge some funding sources. We don't have any commercial conflicts of interest to disclose, but the Informed Medical Decisions Foundation has been funding our project since 2004 as a demonstration project. Of course, I also want to thank the organizers of the conference today, the Institute of Medicine, and the sponsors, the Moore Foundation and Blue Shield. And of course the conference staff; thank you for helping us attend here.

And I say "us" because I brought two students—Ekene and Margot are actually going to do the bulk of the presentation. But I do want to just introduce what we're talking about a little bit, to say that we did start with a needs assessment about 10 years ago in the area of breast cancer, where I was lucky to have a partner, Dr. Laura Esserman, who is a real champion, along with other colleagues at the UCSF Breast Care Center, a real champion of patient-centered care. And they felt like they could be doing more to address particular patient needs. And we focused in on what patients told us in their own words which was that, during that time when they had a diagnosis but they were waiting for an appointment with the specialist, that was a time of real information anxiety. That they were conflicted, they were bombarded with either conflicting information or too much information or they didn't have enough good information. At the same time, they would be lying in bed at night thinking of issues, but then freeze up when they got to the doctor's appointment and forget to ask about those very issues that have been keeping them awake at night. And if the doctor did happen to address the questions that they had been concerned about, the information went in one ear and out the other.

So, we were happy to learn of course that there were evidence-based strategies to address these information and communication needs, specifically, many randomized control trials showing the effectiveness of decision aids in orienting patients to an unfamiliar condition in terms of knowledge and other measures. But there are also other "communication aids," I call them, that would help people with the other concerns, such as making a list of questions. A very simple act of writing things down and bringing that list into the appointment and referring to it, helps people remember, not surprisingly, what they wanted to ask about. As well as after-visit

summaries and recordings, which help people review the information in a more relaxed setting and benefit from repetition.

So, we turned our attention to really asking who can deliver these decision and communication aids in our clinic, and what we found was that we tried initially to get existing staff, for example, schedulers, to really facilitate the use of these tools, but they were already overloaded with their existing tasks. So we then had, and it was really Laura Esserman who said, well, we have these premedical interns who are in our program doing work as program and research assistants on other tasks, but what about if we had them set aside a day each week to accompany patients on their journey and facilitate the use of decision and communication aids.

And so Ekene is today one of these premedical interns. While she is coming up here, I wonder if you could get to your packet and look on the right side and find the next-to-last piece of paper, and I understand for those of you on the Web that this handout is also available to you electronically, but if you can find the one that says Question List. It's a handout for Patient Support Corps presentation, that's us. So in my packet it was the next-to-last piece of paper on the right side. And Ekene is going to tell you a little bit more about the program.

MS. OBI-OKOYE: Thank you, Jeff. So, hello. My name is Ekene. I am 1 of the 10 premedical interns at the UCSF Breast Care Center, and I am the Tuesday morning intern, which means that I call all the newly diagnosed breast cancer patients coming in with Tuesday morning appointments.

So, to demonstrate a little bit of our process, I'm going to tell you about my patient Ella. When Ella makes her appointment at the Breast Care Center, she shows up on my call list. So, I call her and I offer our services to her and she accepts. What does that service look like? Well, step one of this process is I have to determine what is the correct decision aid for her. So, during the offering call, we determine that she needs the decision aid on ductal carcinoma in situ, which is pre-cancer, stage-zero cancer, and that looks like this. It's a booklet and it comes with a DVD.

So, I put that in the mail for her and then in about 3 days, I call her, and we spend about 30 minutes going over her primary concerns, her major pressing questions. And I get them all down on a piece of paper for her, which is step two of the process and that is what you have in front of you. Is everybody looking at it? Underneath the situation heading, you can see that one of her major concerns is that she doesn't understand why she needs to have surgery if DCIS is a stage-zero cancer. Under the objective section, you can see that she's also really concerned about working, because she's a firefighter, and she is also concerned about how she's going to come out to her kids about her diagnosis. These are all the questions that are her major concerns, and I would like to say that these are her own words. I've gotten these words from her using a neutral, nondirective approach in the question listing session, not giving her any of these questions; these are all her questions.

So, I send these to her and then I send this also to her doctor. And then about a few days later, I attend her appointment with her. I have my laptop and my recorder in hand, this is what the recorder looks like, and we wait for the doctor to come in. The surgeon walks in and he has the question list in hand, and he actually uses the question list as the patient agenda for the appointment. So, he uses it to guide how the appointment runs. And I sit there and I take notes and I also record the appointment, which are steps three and four. At the end of the appointment, I produce a CD recording for Ella so that she can take that home and her husband, who couldn't make it to the appointment, can listen. And the next day I also send her the appointment summary, which is on the back of that handout.

From all of this, after 4 weeks of time has gone by, we send a survey to all the patients who have received this service. And in Ella's survey she says that she really appreciated having someone there to listen to her and listen for her. And I think that that is really what I've taken away from this service—is the ability to listen first and to listen fully, and I truly hope to take that with me as I continue on this path to becoming a doctor. And now to talk a little bit from the perspective of someone down the line, Margot.

MS. ZARIN-PASS: Yes, my name is Margot. I'm a first-year medical student at UCSF, and before that I was a premedical intern like Ekene for 2 years at the Breast Care Center. And what Ekene just told you about her patient Ella being very grateful for our service is a very typical reaction. We have years of qualitative and quantitative survey data from our patients that we've published telling us how much they appreciate the service. So, here are some representative quotes about the decision aid. One woman said, "This was exactly the material that I was looking for all over the Web, but having a hard time finding in a consolidated format that made sense." And about the question list, another patient said, "It was hugely helpful to have my questions prepared beforehand." Finally, about the recording and summary, "They were invaluable in filling in parts of the conversation that this patient and her family were finding hard to remember."

So, we know that our service is working well for our patients and we have anecdotal evidence from intern alumni like myself that they are using the skills they got as interns in their medical education and further down the line medical practice. One example of this is a friend of mine named Meredith, she's in medical school, and she has a class where they learn how to interview patients. So, her day to interview a patient, and the patient walks in, and the first words out of his mouth were "Do you think I'm going to die?" So, she tells me that she froze up for a second, not really knowing what to say. Then she remembered a "Jeffism," one of the phrases that we're taught to use with patients. And so she says to this patient, "What is your understanding of your situation?" That allows them from there to have a whole discussion about his recent diagnosis, how he feels about it, his recent hospital stay, and they have a very productive discussion there. And that is the feedback Meredith got from her facilitator and peers who were watching this interaction. That having that sort of opening question in her toolbox allowed that conversation to go so well. And she attributes that to her time in our program where we use that sort of question all the time.

So, Jeff and I got curious—do all of our alumni have this experience? Where they are using the skills they got in our program to this day? So we did a survey this summer of all 47 of our alumni. They are at various stages, and we got 21 responses. Seven of them have completed medical school. Eight are currently in medical school and other stages of the process as well. And here are some sort of typical responses we got. One person said, "Decision Services helped me actually learn the art of listening through practice, patience and silence. I learned to silence my own voice and let the content of the patient and the physician guide my own work." That's really echoing what Ekene just said about learning to listen to our patients through our program. We also got a response from someone who is currently a practicing physician saying, "Now, as a doctor, I believe the core values I developed as a premedical intern are still there: a nonjudgmental attitude, a careful approach to humor, and an avoidance of saying things that I truly can't control, like everything is going to be okay."

What this is getting into is, Ekene made reference to our neutral and nondirective style of interviewing our patients, and as premedical interns, we're not giving advice to our patients. We're not answering their questions because we're not qualified to be doing that. So, we're very

conscientious about how we talk to patients in this role. And this person is saying that they are taking those skills they learned about conscientious communication forward with them through their medical training and into practice. And so that was very gratifying for us to see, that we knew this program was a win for our patients. We now know it's sort of a win for our intern alumni and Jeff's going to talk about how we can expand it.

DR. BELKORA: Thanks, Margot. We do feel fortified in our motivation to expand this program, given the successes we've had with patients and then also the educational trajectory that we're putting premedical students on. There is a question about these paid staff interns. So how do we expand this program and keep things somewhat affordable? We'd like to get beyond the Breast Care Center to other clinics. We'd like to get beyond our institution.

So, we looked across the Bay. At UCSF we don't have an undergraduate patient population, but we realized across the Bay in Berkeley, there are 30,000 undergraduates and about 3,000 of them at any given time are premedical students. So, we decided that we would look to a volunteer workforce to extend our coaching capacity, again moving out from the Breast Care Center into other clinics. And actually Lindsey Forbes is here, who is one of the first Berkeley students, and is now working at Johns Hopkins, so our alumni are spreading all over the place.

But Lindsey and her peers are coming over now and working in our orthopedics clinic, in the urology clinic, in the spine center, and in head and neck cancer. And that's just in the first year really of the program as we've been expanding. So, we feel good about the possibility of expanding this into what we're calling the Patient Support Corps, using kind of the metaphor of a service learning program. The students, or possibly other volunteers, get academic credit or get other benefits and the mission really is to provide this workforce as coaches for patients and families, so that the patients and families can be as informed and involved as they want to be.

So, this has been working well and, in fact, the program has now been replicated at Dartmouth. And at Dartmouth they've said, well, let's not just use undergraduates. Let's also use public health students, also MPH candidates and medical students. So, we're quite optimistic about the potential for this program to expand. And of course in the days of telemedicine, it would be possible to deliver these kinds of services at least in part remotely. So, I work in rural areas in Northern California as well, and we definitely want to be able to reach people and help them with question listing and even attend their appointment if necessary by speakerphone and take notes for them and do all those sorts of things. It's all possible now, I think with technology.

But the value proposition overall for the Patient Support Corps, I have high hopes that we can make this sustainable in the sense that clinics should be willing to put some money on the table to support the administration, the training, and supervision of the volunteer workforce. And also the academic institutions, colleges, and such should also be willing to put some money on the table, I hope, because they're getting tuition and they should be diverting some of that for this kind of service learning experience.

So, we're cautiously optimistic that this can in fact scale and be sustainable because of these kind of win-win benefits for, ultimately for patients, but then also for students. We're right now in the very beginning of what we hope will be a 3-year startup period, recruiting other members to the network, we feel like we have UCSF on the West Coast, Dartmouth on the East Coast, let's fill in the rest of the country now. And we want to refine our service and product offerings and refine the business model. And frankly, we're looking for funding and other partners so this seems like a good audience for me to do a little bit of networking in. And I consider myself a mentor for Ekene and Margot, and I told them that when we come on a trip like this we're not

allowed to have dinner together, so we're going to be looking for ways to network with you all and please come find us and talk to us.

Of course, we'll also be on the panel now. So thank you very much and thanks again to Margot and Ekene for coming out.

Implementing Decision Aids for Increased Patient Engagement and Reduced Costs

Dr. David Arterburn

DR. ARTERBURN: Good afternoon. It is a pleasure to be here. I'm David Arterburn from Group Health Research Institute in Seattle, and I'll be talking with you today about our work and our story behind implementing patient decision aids to improve patient engagement and to reduce costs.

First, with a financial disclosure, that I have received research funding and salary support from the Informed Medical Decisions Foundation and serve as a medical editor for the foundation in developing their bariatric surgery decision aid. The Informed Medical Decisions Foundation, in partnership with their for-profit partner Health Dialogue, produced the decision aids that we'll be talking about today.

First, sticking with the themes for this session, I want to talk about our pathway toward shared decision making, and really there were two routes that really drove us that way, beginning with an overview of who we are. Group Health is a consumer-governed, nonprofit health care system that integrates care and health care coverage for over 600,000 Washington State residents and also some residents of Northern Idaho. That's about 1 in 10 patients in Washington State who get their care through Group Health. We have both salaried providers through which two-thirds of our patients receive their care, and a network of contracted providers.

Group Health was motivated by two things, as I mentioned. One was unwarranted variation, and I think you're all very familiar with Dartmouth Atlas and Group Health was very familiar with that work as well. But there had been 20 years of complacency around that, because we believe within our own system that we really didn't have unwarranted variation, until we actually did the analyses of our data and found, as this graph showed, that three of the regions in Group Health, the solid lines, had very different rates of knee replacement (see Figure 2-6). And that they differed actually from what the state and regional averages or rates of knee replacement were in the state, here in the dotted lines, and then with the Group Health regions in the solid lines, we had very different regional rates of knee replacement.

So, although the patients we felt were the same, providers were all salaried, we had very different rates of knee replacement, which suggested unwarranted variation that wasn't in alignment with patient preferences, but may be more likely to be driven by surgeons' opinions about treatment practices.

Another key influence here of shared decision making is that Washington State in 2007 passed legislation which recognized shared decision making and the use of it along with the high quality patient decision aid as the highest standard of informed consent for patients in Washington State. It also mandated, but did not fund, the State Health Care Authority to implement shared decision making demonstration projects, and Group Health was one of the sites that took that challenge on. And that's what I'm talking about today.

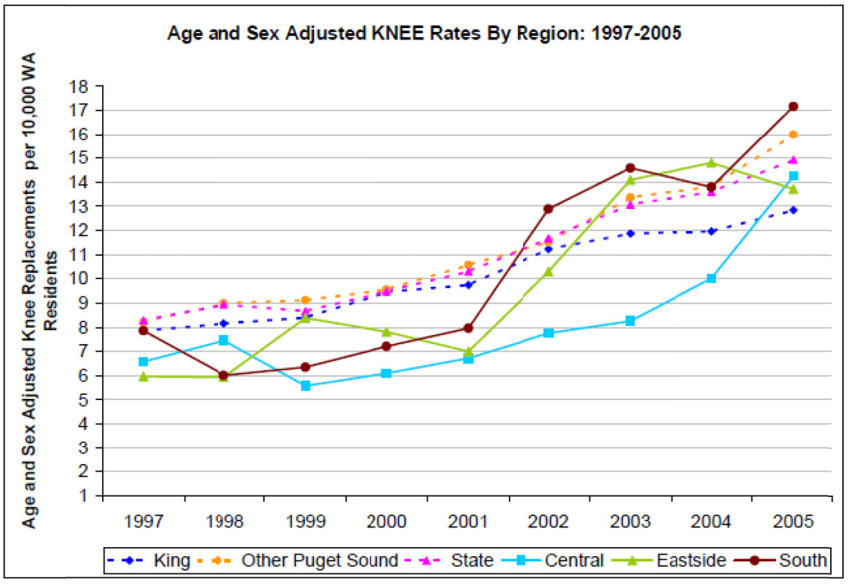

FIGURE 2-6 Group Health rates of surgical procedures rising.
SOURCE: Reprinted with Permission of David Arterburn, Group Health Research Institute.

In 2012, Washington State updated their legislation, giving the Health Care Authority the power to certify high-quality decision aids for use in Washington State. So, what were the infrastructure elements that we put in place to support shared decision making at Group Health? Well, it was a system-wide implementation with video-based patient decision aids, which you've heard about previously by Jeff and his team. There were 12 preference-sensitive health conditions that we targeted related to elective surgeries and they are listed all here (see Box 2-6). I won't go through them all, but there are six different specialty service lines throughout Western Washington where we're working with different specialty clinics and different specialty providers in Tacoma, in Olympia, in Group Health, in Seattle and in Bellevue.

We gave providers access to these patient decision aids through our electronic medical record, which was EpicCare. They could just type in SDM, shared decision making, into the order field, and it would pop up a list of all the different decision aids that they could order. They could then place the order, and that order would be routed to the patient's home through the mail where they could watch it with the patient with their family members. Patients could also be routed to watch the video online, so they could go onto our secure patient portal and watch these streaming videos. You can see that many of them actually are quite long, up to 50 minutes in many cases, but patients didn't complain about the length. These are treatment decisions that they were facing. And so we had many patients, one-quarter of our patients viewed decision aids online.

For providers, we also provided smart phrases. These are Epic tools which allow them to more easily document that they had referred a patient to a patient decision aid, or once they have actually referred them and they are seeing them back or having a conversation about the patient decision aid and the patient's treatment options, could more easily document that they discussed the content, documented their treatment preferences, and where they are going with their treatment services.

BOX 2-6
Physician Communication Competencies

- Orthopedic Surgery
  - Hip Osteoarthritis
  - Knee Osteoarthritis
- Cardiology
  - Coronary Artery Disease
- Urology
  - Benign Prostatic Hyperplasia
  - Prostate Cancer
- Women's Health
  - Uterine Fibroids
  - Abnormal Uterine Bleeding
- Breast Cancer – General Surgery
  - Early Stage Breast Cancer
  - Breast Reconstruction
  - Ductal Carcinoma In Situ
- Neurosurgery
  - Spinal Stenosis
  - Herniated Disc

SOURCE: Reprinted with permission from David Arterburn, Group Health Research Institute.

Another key piece of this implementation package was project managers, who were critical. Three FTEs of staff are working with these clinics on the frontline during our first year of implementation doing a plan/do/check/act process of working with providers and quality improvement in an ongoing way to meet the needs of the different providers. The endpoint there is ongoing quality improvement initiative, a PDCA process. And these project managers were critical throughout the process to understand the workflows and to get the decision aids in practice, because each practice had different workflows and work styles. This work with project managers led to streamlining of the process for pre, during, and post visit care, which dramatically influenced the rates of decision aid delivery.

But how did group health create a culture of expectation around shared decision making with providers and begin to build competencies for providers, which is work that we're doing? Most providers have this attitude when we first talk to them: I already do shared decision making. But we realize that that probably looks like this: Of course, it's totally up to you but if it was up to me I'd choose to have the surgery. And this is the attitude that most providers actually had toward shared decision making when we first began talking with them about it.

But GroupHealth leaders really wanted to set a different tone. And it was not, "This is nice to do if you have the time and the inclination," but is more toward, no patient should undergo a preference-sensitive procedure without documented evidence that they got all the information they needed and had a conversation with their provider in which their preferences were documented before they made their decision. Among the key steps that were required to initiate this culture change was requiring all the providers in specialty care to review the patient decision aids that their patients were going to watch. Also, within the second year, we had a half-day CME where we pulled all the specialty providers and the surgeons out of clinical practice and had them work with outside experts on training around shared decision making. We provided them monthly feedback on volume of decision aids ordered, number of surgical procedures, the total cost that those surgical procedures added up to, and the number or percent of patients who had a preference-sensitive surgery who had not watched a decision aid.

But perhaps most importantly for culture change, patient satisfaction data really influenced provider opinion about these decision aids, and I'll present some data about that a bit later. We told providers that we expected that these decision aids would improve patient knowledge, that it would improve their satisfaction with care. It would help us understand what is the real rate of demand for these procedures, and would probably reduce unwarranted variation in our care. But most importantly, we told our providers that we thought this was a question of patient safety. It's not wrong-site surgery that we're worried about, it is wrong-patient surgery that we're worried about; where uninformed patients making decisions about surgery, it's wrong patient surgery.

What were the outcomes that we observed throughout our process? Well, now 4 years into implementing this work, we've delivered over 31,000 patient decision aids in these 12 different elective surgical procedure areas, as of January 2013. Over time, we have dramatically reduced our defect measure, which means we have fewer missed opportunities for patients to receive a decision aid prior to going to elective surgery. This graph shows that at the beginning, 100 percent of our patients were going on to surgery without receiving a decision aid. Now, we're down to about 35 percent of our patients, and these are in the areas of hips, knees, low back, hysterectomy, and benign prostatectomy, in terms of the proportion of patients getting surgery who have not had an opportunity to view a decision aid. We're not all the way to 100 percent but we've made dramatic improvements over time.

We surveyed patients in the first year and this, again, influenced providers dramatically—96 percent of our patients said that these videos were very good, excellent, or good, at helping them understand their treatment choices. And 95 percent of them said that these were very good, good, or excellent, in helping them prepare to talk with their provider. And we documented outcomes with help from the Commonwealth Fund to fund an evaluation of this. We showed that implementing patient decision aids was associated with sharply lower hip and knee surgery rates and costs. Where we had 26 percent fewer hip replacement surgeries, 38 percent fewer knee replacements, and 12 to 21 percent lower costs of care for these health conditions over 6 months. We've seen similar reductions in rates of surgery in areas related to women's health, abnormal uterine bleeding, and uterine fibroids, as well as in BPH and prostate cancer. The impact on costs of care has varied by the health condition but overall, we've seen consistent reductions in rates of surgery. In the case of knee and hip osteoarthritis, we're saving on average roughly about $3,000 per hip OA, and $2,000 on knee OA per patient within the population.

So, overall our conclusions as a result of this work are that large scale implementation of patient decision aids is feasible in the scale of an organization like Group Health. And that shared decision making really appears to be headed toward achieving the triple aim of health

care, where we are getting higher patient satisfaction, lower costs of care, and improving patient quality through improved knowledge.

Our next steps are to add five to seven new decision aids in this year, five we've already committed to, two more that we're considering and two key elements that are very patient centered. One is that we're moving this conversation upstream from specialty into primary care, and having conversations and decision aid ordering being centered there for most of these health conditions. And the second key thing is that we're automating recording of patients' knowledge, their values, and their treatment choices in the electronic medical record; they can complete this information online and it goes into electronic medical record, where the provider can access it at the point of care and have a more engaged discussion with the patient about their treatment choices.

I want to acknowledge the funders as well as the many collaborators and clinicians that were involved in the work to actually get this work done and the slew of external advisors as well. And thank you very much for your time and the opportunity to present.

Audience Participation and Open Discussion

MS. PAGET: Thank you all very much. So, now is the time for you all to think about what you want to contribute to this dialogue. What kinds of questions you want to ask and while you're thinking about that, I have a question for any and all of you.

Clearly there's a role here for leadership and there's a role here for system support, infrastructural support. You all are several years into what you're doing. As you reflect back, is there anything—I'm seeing Jeff as kind of a clinical champion—is there anything that you think might have made things easier or is there anything that, as you reflect upon it, would make other institutions' process smoother in knowing what you know, because now you've got multiple years of experience? David, you want to start with that?

DR. ARTERBURN: Sure. I think the key thing that comes to mind for me is that having a partnership with the Informed Medical Decisions Foundation was really critical from the outset, because having expertise in how you do shared decision making and being able to bring that to Group Health, an organization that actually valued all these things, patient education and higher quality of care, they really understood unwarranted variation. But they really didn't have a clue how to actually get shared decision making into practice, and drawing on the resources of the Foundation and others like them, and me being able to play a role in helping translate that into the system was critical, I think.

DR. BELKORA: Well, I don't want to belabor it too much, but having a workforce, so we had the clinical champion, but then having coaches. And so if you can afford it on a staff basis, and I think as we're moving toward accountable care partnerships at our institution, I'm starting to see real investment, as opposed to, I think in the past fee-for-service organizations have been a little bit reactive, like the clock starts ticking when the patient shows up for a visit.

Now, we're investing in nurse outreach and other kinds of outreach to patients well before a visit and follow up afterwards. So, I think coaching and the kind of human element at the right level, doesn't need to be necessarily a very highly licensed person, it can be a trainee or someone somewhere in between, that would be the other key element I would point to.

MS. PAGET: Grace, what would you do differently if you had to do it all over again?

DR. LIN: That is a good question, Lyn. I think one of the things that we really underestimated was the amount of manpower and amount of time that this was going to take. We

were very optimistic, as everybody is at the beginning of projects, saying, "This is going to be great. We have a good champion. We have willing patients." And really what we found was that the steps needed to change the culture first of all take a long time, but also take a lot of sustained effort from the top down and the bottom up. The patients need to push. But also the organizational leadership needs to be there to lead the change.

MR. CLIFFORD: My name is Dave Clifford. I'm a consultant to PatientsLikeMe as well as a number of other organizations. I tend to think about these things from a policy perspective, which is somewhat different. And, looking for a solution in this framing, I think that one of the things discussed was the very positive impact of using people who had planned on becoming doctors both on outcomes in the clinic, as well as professional outcomes. Would there be any way for an organization such as the American Association of Medical Colleges to start thinking about using these sorts of experiences as a criteria or bonus points for getting into some of the higher level medical schools? To me, that seems like an implementable pathway, especially as we're reconsidering what the MCATS should look like in the future. Thanks.

MS. DAY: My name is Nancy and I'm from the State of Maine, too. And I would like to help you get into the only medical school we have in Maine. We only have one, so we can go to 100 percent quickly.

The second thing I wanted to ask David was, I have been doing some work to embed shared decision making into a new kind of value-based insurance plan. And as I talk to consumers about shared decision making, the module that seemed to resonate best with them was the one on colon cancer screening, and I was wondering why that wasn't one of the modules that you incorporate now. They seem to love to know there are choices.

DR. ARTERBURN: That has to do with a cultural timing issue, where we had an opportunity to really engage our specialty care providers, so the specialty care providers were taking ownership over these elective surgical procedures, and our state legislation actually specifically called out elective surgery as being a high-variation and high-cost concern. So, we were focusing in specialty care for that reason. Now, we're moving toward primary care, and there are many more opportunities there, and many of the treatment decisions that we're talking about will include those in the future. So we're moving toward primary care.

MS. RICCIARDI: My name is Lygeia Ricciardi. I'm with the Office of the National Coordinator for Health IT, and I wanted to make a couple of comments that I think are relevant, not only to this panel but to some other discussion earlier this morning.

There is a lot of discussion about the important role that technology can play, could play, should play in enabling real patient engagement and shared decision making. There was a comment earlier this morning about whether we should have a right as patients and consumers to have access to our information. That right exists already under the HIPAA privacy rule, but many people are not aware of that. As we bring the health system increasingly from a paper-based one to an electronically based one, it becomes easier to access that right. And specifically through something we call Blue Button. We're enabling patients to access their records directly themselves in electronic format, which again is a given right.

Under the program that we're rolling out right now, called Meaningful Use, which is a large incentive program, we are requiring participating providers and health care hospitals to provide patients access to visit summaries, so that they know what's going on when they have an interaction with the health care system as well as educational materials. And in the current stage, which is now currently rolling out, we're requiring patients to be able to view, download, and access their health care information electronically, which is a big deal. So by this fall and next

January, any patient who sees a provider who participates in this program will have that ability, and I think that will really free up a lot of opportunities for exchange of information.

MS. PAGET: Lygeia, could you comment a little bit on what the picture is going to be for assessing the patient's access and ability and success in doing so? I hear from a lot of folks, "My pediatrician has introduced a patient portal, but it's not meaningful for me in my needs." What is the office's plan—what are we going to learn?

MS. RICCIARDI: That is a great question. One of the things we have done is to build into this Stage Two requirement that patients be able to view, download, and transmit their information to actual thresholds to show that patients are actually doing so. So, 5 percent, and I know that that isn't an incredibly high number, but 5 percent of patients must actually have taken advantage of these services. Which we're thinking will really encourage providers to have a conversation, not just to turn on this functionality and say nothing about it, but to really start that conversation.

I also want to mention that we have a pledge program, called the Blue Button Pledge Program, through which we're working with providers, but also payor organizations, to encourage people to provide digital access to health information to consumers and to start having these conversations, so patients can really be partners in their care, and we're providing a lot of materials that providers and others can use.

MS. PAGET: Thank you. So that is the second pledge program we've heard about today. We might need to think about unifying our pledges in some way. Matthew.

DR. WYNIA: Hi, I am Matt Wynia. I'm with the American Medical Association. I'm the Director of Physician and Patient Engagement for the Improving Health Outcomes team and I just could not be more enthusiastic about the panel. Both this afternoon, but to me this really dovetailed nicely with where we were heading this morning.

So the issue I want to try and raise is to bring together I think, some of what David started to get at, in going into primary care. And some of what the program, well, to a certain extent both PAMF and UCSF are doing in terms of—one of the challenges or limitations of decision aids as we currently know them is that they are all about making a discrete decision around a preference-sensitive point in time, and so it's a little bit like taking a class. And when you're done with the class, you move on, and hopefully it made a big difference in your life, but you're going to continue in most instances, for my patients at least, to be managing the condition that you've got. It's not a one-time decision.

I'm an infectious disease doctor. Most of my patients have AIDS. There isn't a great decision aid out there for me. Because I'm probably making, I'm going to say 50 decisions in an average patient encounter, and none of them are entirely discrete or they are rarely entirely discrete. This is about managing a condition over a long period of time, and my patients don't need a single decision aid. It's not a class. They need course work that lasts for weeks, months; this should look in my view something more like the diabetes prevention program or lifestyle coaching.

And that's where I'm so happy to hear what you guys are doing in terms of that. Because I think breast cancer can be analogous to HIV infection. It can be a chronic condition that you manage for some period of time, not always, but it can be. And I'm wondering whether there is more thinking around moving this sort of discrete point-in-time decision aid philosophy back a step, toward managing conditions over a long period of time that are not so much a single preference-sensitive point in time, but a series of decisions that you have to make at home all the time about whether to eat this or that, whether to exercise now or later, whether to take my meds, whether to take a break, whether to trade off; the things that our patients talk to us about in terms

of the actual life situations that make it hard for them to do what they often know to be the right thing, sometimes don't know to be the right thing.

MS. PAGET: David, do you want to speak? Or should we, we also have Michael Barry next at the mic, so we could actually have Michael talk about that, too.

DR. ARTERBURN: There are decision aids that help—so there's *Living Well with Chronic Disease*. There are decision aids that can help prepare patients to understand key management philosophies about managing their diabetes, managing their depression, managing their anxiety over the long term. And also I note in our knee osteoarthritis cohort, many patients get these decision aids more than once, because they are coming back to see the orthopedic provider and the first time they said no, now they are thinking about it again.

So I agree with you, there are many opportunities here. We can't have decision aids to support all of them per se, but more of a culture change around providers and patients' expectations and the way they use information at the point of care.

DR. BARRY: Just on that point, in my own practice, where we can electronically prescribe decision aids, I just had a woman who I had prescribed a colorectal cancer screening decision aid a couple years ago, and we talked through it; then [she] comes in with her hip bothering her progressively [and] said, "Gee, do you have something about that?"

That's the kind of culture change. Now, how much of that we can do outside the context of decisions they are facing, the general education Sherrie talked about; or do we do it in the context of, if you will, earlier decisions, like about screening that first medicine you take, maternity decisions, and then norm people up for the big problems later with heart disease and cancer and other things? So it is a long haul and I think figuring out how to change the culture is what it's about.

I'll just come back to a question around the aligning incentives. Because at GroupHealth, although it doesn't make it easy, there are aligned financial incentives, and maybe we're moving in that direction with the ACO movement. There's a lot of fee-for-service medicine out there and even how clinicians are paid under an ACO umbrella may be some component of piecework there. Grace had mentioned that one of her successful interventions with a group visit was being able to bill a 99213, and as a primary care doctor we think about that all the time. People worry about, "Gee, why should we have to pay clinicians to do the right thing?" But since we're comfortable with sometimes paying clinicians to do the wrong thing, I'm okay with it.

As an example, I just got a memo from my own physicians' organization that to get billing a 99214—really the pot of gold at the end of the rainbow—in order to do the detailed exam that's part of that, it was no longer sufficient to examine two or more organ parts, you had to examine five or more organ parts. I had missed the randomized trial that showed if you examined five organ parts people were happier and healthier. But it strikes me, could we just move that to saying that if we could check the six steps of decision making, we're now developing metrics, were patients informed, did someone ask—could we move the reimbursement from doing things that clearly don't work, or more the tradition-based medicine, to now, with 86 randomized trials of shared decision making and more on the way with Cochran, to really shaping how care is paid for, to things that do make a difference?

MS. PAGET: That's a nice vision. Val, do we have something from the radio audience?

MS. ROHRBACH: Yes, two questions. The first from Kevin Kenward of the Health Research and Educational Trust. Kevin asks, "How can costs be inducted in shared decision making when physicians don't always know what the costs of a treatment or medication or procedure are?"

The next question is from David at Johns Hopkins, who asks, "Our doctor friends all tell us they don't have time during the brief time they have during a patient visit for the kind of patient engagement being discussed today. How does the panel respond to that?"

MS. PAGET: Let's take the time question first. I believe there are some data out there that are pretty much indicating that that's not an issue, but who wants to speak to that?

DR. LIN: I can start. We actually heard that a lot. We surveyed our physicians at the beginning of the project, and a lot of them said actually what David's physician said, "We're already doing shared decision making, but even if we aren't, we don't have time to do it." When we went back and we did focus groups with the physicians later on, the ones that had actually utilized decision aids—we actually held focus groups with physicians who were high utilizers and those who are low utilizers. What the high utilizers said in large part was, "You know the decision aids saved me time. The patients came in with better questions, they had a knowledge base, I could have a better conversation with them," so really I think this whole notion—I think once the physicians had the experience they no longer thought that shared decision making took too much time.

DR. ARTERBURN: Our experience at Group Health paralleled what Grace found, it was that the providers didn't think this took more time and the patients actually were just better educated and had better questions.

MS. PAGET: Thank you. The cost issue, if I'm understanding it correctly, is kind of how to build that in, and this comes up a lot because we have such variance in costs in this country, and I know that from the perspective of the developers of tools, it's all been very challenging to address the cost issue in that. And then costs in general is a very broad category because there's financial costs, there's also quality of life costs, and so forth.

But I wonder if any of you, and maybe Jeff from the breast cancer program, what do you find that is important to patients; does that come up, when the interns are soliciting questions from patiens?

DR. BELKORA: We keep track—we keep copies, deidentified copies of all the question lists that patients have and you know, we have looked at them to see what kind of recurring themes come up and in the area of costs, there is a concern. And we see it reflected in the question list about out-of-pocket costs and that sort of thing. I think the question was about financial cost; clearly patients also have a lot of questions about the costs in terms of their time and attention and quality of life and other issues. So, I have to say though that we're treating an insured population in this Breast Care Center, and so perhaps it's just not quite as salient and not as reflected in our question list as it will be when we are spreading this model much more broadly. And I think we need to point to the Choosing Wisely program and other kinds of initiatives to say this is a really big deal that we need to get our hands around.

MS. PAGET: I know we are going to spend some time tomorrow on this topic as well.

MR. ROEHR: Hi, I am Bob Roehr. I'm here today as a journalist. I'm writing for *BMJ*. I'm also drawing upon my experience as a patient activist on a couple of advisory committees at NIH, going back to HIV activism and things like that. And what I've heard today basically has been sort of a just-in-time education involvement, decision-making type thing, which is well and good as far as it goes, but I think there really needs to be a more fundamental look at educating the general American public to their obligations, in many ways, as citizens to participate in this.

You can say that when most of our health care structures were created, health care was 3, 4, maybe 5 percent of our GDP; today, it's almost 18 percent. Nobody believes it's ever going to shrink; it's going to continue to grow. It's only a question of at what rate. And when they were

created, interventions were primarily for acute conditions. Now it's predominately chronic conditions, so the role of the person is changing, the role of the patient is changing, and we have to, I think, as citizens, understand this and begin to educate our people at the primary level of their role as good citizens in taking care of their own health and participating in the health care process.

There's one model that has been developed at STEM, education, science, technology, engineering, and mathematics, which I think could be very much of a model to build upon though. That's aimed at primarily college-aged people but we could start there and move back downstream.

I think it's very important to do more than simply train people to respond to the immediate decision. We have to make the framework and the education broader than that.

MS. BROWN-TATUM: Good afternoon, I am Crystal Brown-Tatum. I'm the founder of Sisters Network, Shreveport. We're an affiliate chapter of Sisters Network, Inc., which is the only national African American breast cancer survivorship organization in the United States.

And my question is, I used to be on the Board of Susan G. Koman, and we funded a patient navigator at LSU Shreveport Hospital and it was, in my opinion, a dynamic opportunity for a nurse practitioner or PA. And after the first year of implementing the navigator, the grant was not renewed with the Northwest Louisiana affiliate, and she just went away. And based on my own horrific experience as a breast cancer patient and working with some of the most underserved women in the breast cancer arena, that patient navigator role was critical because LSU had a dynamic rate. If a woman was diagnosed with breast cancer, she was having surgery within 48 hours.

On my own journey, I had a 4-month gap in treatment from diagnosis to chemo, because I wanted to keep my hair over the summer, I didn't know any better. I didn't have anybody that was a champion for me. I just was very uneducated and ignorant and I just thought, oh, I'll just start treatment in 4 months.

So, my question is, the decision-making aids, can those replace the patient navigator role or do you feel that they strengthen the patient navigator role? If the hospital or clinic doesn't have someone that's serving as a navigator, are those tools going to be enough to possibly fill the gap that may exist because the role's not there?

MS. PAGET: Crystal, can I ask you for clarification here, is this kind of coming from a resource issue, saying if there's not funding for a navigator, can the tools stand alone?

MS. BROWN-TATUM: Yes.

MS. PAGET: What do you think, Jeff and your team?

DR. BELKORA: Well, Harold Freeman and others who have kind of defined this field of navigation have begun to just define it as helping patients overcome barriers whatever they are, and so some of the barriers are logistical access to care. Some of them are emotional support and other forms of support, and we focused in this decision-making area on the kind of cognitive information processing and decision-making issues.

So, I would say is it one or the other, I think they're complementary. A navigator that's sort of high-touch facilitation and coaching that my team provides is very complementary with the written materials. In the decision-making arena, this all boils down to critical reflection, to getting people to think and process, and so that doesn't just happen one way or the other, it happens through multiple kinds of modalities. I think you could prioritize depending on your population and the needs. In some populations, it might make more sense to invest in patient navigators who are trying to get people access to this system, and if that's the biggest barrier—I

mean I guess I would just start with sort of the biggest barriers and design the program around the local need, but I think there's room for really both.

MS. DAY: I'm just going to talk about when I finished up with my treatment, after I had my surgery, at my post-op recheck. I volunteered as a patient, actually said to my doctor, "Is there anything I can help you with?" because I was just so relieved to be over with my treatment, and she looked at me like I had two heads.

I wondered if you considered recruiting experienced patients to do some of this work; this would be for Jeffrey and the other groups, maybe would be nurses would get a great deal of experience from this. Pharmacologists and social workers would all gain from this type of experience too.

I have one more question. The other question I had is for David. What do you think about advertising for joint replacements and pelvic floor problems and that sort of thing? There's been a very creative advertisement in my local newspaper with a long full newspaper page length ad with a roll of toilet paper on it, and Consumers Union just recently used that as, what is this ad selling? It seems to me that that kind of advertising would increase procedures rather than decrease, which is when you're educating and engaging the patients, actually the procedures are going down so I wondered what your comment might be on that.

DR. ARTERBURN: I do think they are potentially competing. I think it depends on the way in which the advertisements are being done. But I think in most cases, in our region in Seattle, we have other partners that are advertising for hip and knee replacement products. And Group Health is taking a different approach, and I think it's one that's innovative, and we're eager to partner with other organizations to help try to do that even within our own community, to help translate the kind of shared decision making approach that we can, because many of our patients in outlying community areas see network providers who are in a fee-for-service setting and have the same sort of financial incentives to do the kinds of procedures and to advertise for the types of procedures. We really want shared decision making to be the norm for all our patients and it is a different approach than the advertising approach.

MS. PAGET: Jeff, do you want to speak to the first question?

DR. BELKORA: Absolutely. We have used pure volunteers already. Survivors of conditions who have either volunteered or been paid to accompany patients and do similar tasks as Ekene and Margot. And I think that is also a potentially kind of sustainable model.

So, yes on that one, and I think there was a second component for question—other professionals, right. So I think yes, absolutely the practicum experience as a social worker or as a psychologist or as a nursing student; we're using premedical students, but we've had experience with students who've gone on to other professional schools. So yes, I'm very much in favor of that.

MS. PAGET: Thank you, and we are now kind of getting close to wrap-up time, so I see we have three people, we won't make you sit down.

DR. MANTEUFFEL: I am Brigitte Manteuffel. I represent the Children's Mental Health Network at this meeting. I wanted to talk a little bit about SAMHSA's System of Care Initiative, the Children's Mental Health Initiative, and that history because it's very much related to this discussion. That initiative has been funded for the last 20 years to change the way interagency collaboration and family involvement and cultural competence and other factors are addressed in changing how systems that support the mental health needs of children with serious emotional disturbance and their families operate, so that their experience is less fragmented and so that they have the support that they need to actually keep their children in their home and keep their

families together and get their children care that actually helps them improve outcomes and gets them stabilized.

One thing that has been very important in that process has been the family involvement factor. And I evaluated the program for 13 years, and one of the things that have evolved over that time is some of the language. So, the language moved originally from family-focused to family involvement, and then a decision was made to move that language to family-driven, so that the level of engagement with the family was taken from a much more passive stance to a much more active stance. And that's been very important in driving that agenda to make sure that you move to a position of equal partnership.

Over the past 10 years we've also seen that change with youth involvement. There was a lot of resistance to involving youth in the decision making about their mental health care in the early days, when there was a greater push to youth involvement. But over that time, the program has changed its language, so that it equally represents family and youth in terms of the shared decision making process, with providers, and the acceptance of youth as partners in decision making has moved ahead by light years really, just by integrating families and youth into meetings and integrating their voice and by moving that process along.

One of the things that we've learned through the evaluation around family involvement is that communities implement as they want to roll out their grants. And there's a lot of variability in terms of how those models look, and they can range from education to advocacy and some combination in between. So, models like yours and models like patient navigator models and so forth, they run a spectrum. But in the recent few years, there's been a greater emphasis in trying to understand what the core elements are, and to understand how you can do that in a more organized and sort of data-driven approach to being able to understand what those core competencies are, and then also build a licensing requirement, so that that can also become a reimbursable service; some states have been able to make that a reimbursable service for children's mental health. So, I think there's a lot to be learned across programs, and I know how difficult it sometimes is for the mental health community and the physical health community to have time for dialogue, so I wanted to share that with you.

MS. PAGET: Thank you very much, that's really, really helpful.

MS. KORNBLAU: I just wanted to bring up again—this is Barbara Kornblau from the Society for Participatory Medicine—the importance of the patient. I hear people talking about the patient as a coach, a navigator, fulfilling the role, but I hear it sort of as an afterthought and I think that I—I haven't had breast cancer but I have two best friends who have and it looks to me like a fraternity. And they go out of their way to volunteer to help other women with breast cancer, and I see that in other chronic conditions as well, and I think that we need to harness that power because those patients have been through it, they know it, they know more about it than many providers to. They know what to look for.

I have a colleague who had a liver transplant, and part of her treatment is to look at lab results and tell the doctor when lab results go at certain levels. So I think that we need to harness the power of patients as equal partners in this to be the coaches. I appreciate medical students, and I think you are all learning a lot and students in physical therapy, occupational therapy, nursing, all of the allied health professions, but I think that we can't underestimate that role of the empowered patient, the knowledgeable patient who has been through it. And it also gives an extra sense to the person who is now going through it, because there's that camaraderie, that fraternity.

MS. PAGET: Thank you very much. Really important message. I just want to say thank you for Grace, Jeff, and Ekene, Margot, and David for traveling all this way and for sharing your experience with us. And this has been a real pleasure and rewarding for me to be a moderator today for all of these sessions, and I've thoroughly enjoyed hearing all of the comments and suggestions and ideas from our audience here and online, so thank you very much for the opportunity and I think—Christine.

SUMMARY AND PREVIEW OF NEXT DAY

Ms. Christine Bechtel

MS. BECHTEL: So, this won't take terribly long. I could take all day, but I won't because I'm actually eager to get back here for tomorrow. This is exciting stuff.

So, first I want to thank all of our panelists from both panels today again, and also just say what a terrific job Lyn did in moderating, but I also want to thank you guys, the audience, for being really engaged and really dynamic throughout this day. I think we had a great day, we heard a lot about partnership, beginning with Jonathan Welch, who shared with us a really sobering story about what happens when we fail to listen to patients and families, let alone engage with them. But he also gave us some concrete ideas for the ways that we might engage in actually redesigning the system. We heard a lot about culture change and the need for culture change, and that we can't get to genuine engagement without that kind of culture change, and when we talked, I think those threads were throughout.

But when we talked about shared decision making, I heard a number of key things that would help us accelerate our progress on the pathway. One being leadership, two being a workforce, and three also being competency, and I think we heard that in two different ways. One was competency among clinicians, and the first of all belief, maybe it's physician activation, that patients should be involved in their own decision making, that families are actually members of the care team and play an important role. We also heard about competency for patients though, and we heard both in the sense of coaching and having the skills and the confidence and the ability to really engage in their own care.

But I think we also heard a lot about, and I'm not sure this is the right phrase, it's sort of this chicken and egg theme that I keep hearing, which is one dimension of yes, we need activated and engaged patients. But then there's the other dimension of the brick wall they can run into in a health care system that is uninviting and unwelcoming in many examples to patients and families who have that desire to be involved. And we heard a lot of examples of that today, and so I think that again points us back to the need to change culture.

I think another observation that I would make is we had some examples where, once somebody got experience in doing something, whether it was shared decision making or maybe engaging patients and families in redesign, their resistance began to melt away and the culture began to change. So I think the question coming into tomorrow will be, how do we think about patients in doing just that, patients as the greatest untapped resource in health care? I heard them described today as a new data stream. How do we harness their power, as Barbara just said to us?

So with that, tomorrow we're going to tackle issues of engagement in the research enterprise. And how we engage patients as partners in generating the knowledge that we need to actually improve care on a population level. We're also going to dive into how we can engage consumers

in a different discussion around costs and quality; again we heard that previewed today. We're also going to hear from David Goldhill, who is CEO of the Game Show Network, and I don't think he's going to tell us how to do game shows, as much as I would like that, I do love *Plinko* and *The Price is Right*. However, he is going to, again, kind of coming back to our theme of, "let's start with the patient and family members," he's going to share his experience with the health care system, and it will be riveting so we're looking forward to that.

Breakfast is at 7:30 tomorrow; we're going to start at 8:00. We will have coffee, gallons and loads of it. And we will be done by 4:30, so please join me again in thanking all of our terrific speakers from today.

3

Proceedings
Day 2
February 26, 2013

WELCOME, BRIEF AGENDA OVERVIEW

Ms. Christine Bechtel

MS. BECHTEL: Welcome back. Hopefully, you have consumed enough coffee. A very exciting day that we have ahead of us. We have a really great lineup of topics and speakers and interesting points to engage with you guys. We are actually going to start the day focusing with this illustrious panel on patient and family engagement in what we have called knowledge generation for care improvement, a.k.a. research.

We are going to then move into a discussion led by John Santa, where we will talk about how we might change expectations around cost and quality for consumers. There has been a lot of discussion about that over the last couple of weeks. In particular, many of you probably saw Pauline Chen's blog. I think it was yesterday or the day before in *The Wall Street Journal*. There are a lot of topics to be had in terms of how we move to version 2.0 of the consumer use of cost and quality data.

We are going to break for lunch at 1:00 and we are going to hear, as I mentioned yesterday, from David Goldhill, who is the CEO of the Game Show Network, about his experiences trying to care for his father in our health care system.

We are then actually going to go into a discussion around some crosscutting strategies that can advance patient and family engagement and partnership. One of the observations that a planning committee member made as we were putting these workshops together was about the fact that there is a common theme that does tend to underlie all of these three topical areas we have been focused on. Of course, we have talked about partnership. But the other common thread is this idea of decision making. Yesterday we talked about decision making in care. But today we are going to talk really about the decision to share your personalized clinical data for improving population health through research. And we are going to talk about the decision to choose a high-value health care provider, the decision to use tools that would help you identify high-value health care providers. We are going to have a great discussion around some crosscutting strategies that might support that kind of information dissemination and decision making, again, through that lens of partnership.

And then we are going to end with some reflections from a very diverse and very interesting set of our planning committee members on this pathway forward. If you recall, that is really what we are thinking about. How do we accelerate progress in these areas by building on what we already know? That is what our lineup looks like for the day. We will adjourn at 4:30. Lots of tearful goodbyes, hugs, things like that. And, again, I will just encourage you guys online as well as in the audience. We really do want to continue to have a robust and dynamic discussion like

we did yesterday. We have microphones. We have e-mail and online strategy. Please do avail yourselves of them.

I am going to turn it over to Sue Brown Trinidad. She is a research scientist in the Department of Bioethics and Humanities at the University of Washington. She is going to moderate our panel. I will say that she focuses in her research on ethical, legal, and social implications of genomic research. She also is interested in studies, communication, and decision making, and health care settings, health equity, community-based participatory research, and more. She is a terrific thought leader and member of our planning committee for which we are grateful. I will turn it to you. Thank you, Sue.

KNOWLEDGE GENERATION AND CARE IMPROVEMENT

Dr. Susan Brown Trinidad (Moderator)

DR. TRINIDAD: The first thing is always, I apologize if you cannot see me. But I also saw that girl fall down at the Oscars. It is a trade-off always. We have a lot of work to do this morning before 10:45. I know my panelists and thank you all for being here. On behalf of the Planning Committee, thank all of you for being here and all of you out there as well.

I do want to point out there was a comment on the website last night saying, "Why aren't there any patients up here?" I am pleased to say that today we will have patients participating as panelists.

Knowledge generation and care improvement. The research world. I think there are a couple of big trends that are converging to bring us toward a direction that looks more like progress on a lot of the things that most of us in this room care about. Translational science and the research space. There is a lot of talk right now about how we move from the bench to the bedside. There has been less discussion of where patients fit in that translational process. I am hoping we will talk a little bit about that today. We will look at comparative effectiveness research, patient-centered outcomes. All of those things I think are beginning to grow in the direction of a critical mass to actually get patients involved in a way that is more reciprocal than what we have seen in the past.

One way of framing what we will be thinking about and talking about this morning is, what do we know? The first question is, who are we? We have been in the research realm and historically a pretty limited set of people. There was some talk yesterday about culture and the important shaping that culture has that can sometimes be invisible to us because we are in it all the time. That definition of who we are when we are thinking about what we know is starting to get broader. And I think that is a really positive development and I think bringing patients into that definition of "we" is an important piece.

The other issue is what we know, what do we know, how do we know that we know it, and what counts as knowledge. I come from the bioethics area. I have training in philosophy. All of these questions about epistemology, how do we know it is knowledge, what counts? Those are actually important issues from a policy standpoint. Whose input counts?

I just came back from Bethel, Alaska. People in villages of fewer than a thousand people. Their ideas about what their health priorities are finally beginning to get some currency in the people who are providing services. That is important and that is an important change.

We will address all of these issues. We will be shaping these around four directed questions. The first thing we will talk about is what the current state of play is. A lot is happening in the research world that is quite different from the way that things have traditionally been set up, with a bright line between the clinical realm and the research realm. That is getting blurry. And we have not yet caught up with what that means in terms of implementation or regulatory protections. Patient views about what is happening with research, research realities, and then the regulatory environment are all things that will fit under that section heading.

We will also talk a little bit about public and patient opinions. In my own work, and my colleague Evette Ludman will talk a little bit about some of the work we have done together. People are supportive of improvement. We will hear a little bit about what they want from us in the research space. We have traditionally thought of people participating in research. It turns out there are some things they like in return. We need to think about that.

Now, I would like to move on to introducing our distinguished panel. We have Dr. Nancy Kass who will start us off. She is the Phoebe R. Berman Professor of Bioethics and Public Health in the Department of Health Policy and Management at Johns Hopkins Bloomberg School of Public Health and the Deputy Director for Public Health in the Berman Institute of Bioethics. Her current research projects examine ethics for a learning health care 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.

We will hear from Alice Leiter from the Center for Democracy and Technology about meaningful choice. She is Policy Counsel for the Center for Democracy and Technolog'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.

Ken Mandl will speak to us about the infrastructure we need for patient-engaged translational research. He is from Boston Children's Hospital and is an associate professor at Harvard Medical School and the Louis Diamond Investigator at Children's Hospital Boston, where he directs the Intelligent Health Laboratory within the Children's Hospital Informatics Program. He has pioneered and published extensively in the areas of personal health records and biosurveillance. Under a major HHS initiative, he co-leads the SMART Platforms project, which seeks to create an apps store for health.

We will close with a joint presentation from Peter Margolis and Jill Plevinsky from Cincinnati Children's Hospital Medical Center. Dr. Margolis is a professor of pediatrics and director of research at the James M. Anderson Center for Health Systems Excellence at Cincinnati Children's. His work encompasses the application and study of quality improvement methods and a broad range of areas, including primary and subspecialty care, communities, and public health settings to improve the health outcomes of children, families, and communities. 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.

Thank you all very much. I will turn it over to Nancy.

Ethical Challenges of a Changing Research Paradigm

Dr. Nancy Kass

DR. KASS: Thank you, Sue. Thank you for the organizers for inviting me. I apologize that I was unable to be here yesterday. It sounds like it was a really lively and terrific discussion and I apologize. I was saying to Sue that I always feel a little awkward and embarrassed coming in what feels like the middle of the discussion, but I was not here for the beginning. Correct me and bring things to my attention afterwards for things to which I should have paid attention.

I want to start by acknowledging my partners in crime. Pieces of what I am going to be talking about today are drawn from a particular project on ethics in the learning health care system that I conducted with my fabulous and lovely colleagues. Here they are (Ruth Faden, Tom Beauchamp, Peter Pronovost, Steven Goodman, and Sean Tunis).

Let me tell you what I want to do today. I was asked to talk about changing ethical paradigms. And what I want to do is introduce you to what I am going to call paradigm one, which you might call a historic paradigm, but I guess I would also argue is one that is alive and well today. There are some good reasons for that, but I also want to argue that I think there are some problems with it. Paradigm one is what I will also call the "distinctions paradigm." I am going to tell you what the current ethical requirements of that paradigm are, and again, what I see as some of the problems.

I am then going to say just a little bit about patient engagement. Probably not necessary to say very much for this audience, but I want to bring it in as a bridge to get to paradigm number two, which is what I am going to call the "ethics in learning health care system paradigm." I will again then talk about what our ethical requirements are for paradigm number two. I will then suggest that some of what I see as the potential paradoxes that can come up in patient engagement are maybe not such a paradox at all.

I want to start with paradigm one, which is where we are coming from, and again what I will call the distinctions paradigm. To rehearse a little bit of history, in the 1960s and 1970s, the American public became aware of research that our federal government had either funded or conducted that illustrated a variety of scandals or research abuses, often involving vulnerable populations who were often led to believe that they were being cared for as patients, when instead research was being done without their knowledge and in ways that was not helpful to them, provided no benefit, and often provided some abuse. This appropriately led to American outrage and Congressional action.

Following this, in 1974, federal regulations were passed for the first time in this country to oversee human research. That led to a variety of ethics requirements, or I guess what I will call legal requirements, in the name of ethics. One that we are all familiar with is IRB review. All human research has to be looked at by an ethics committee before it can go into the field. Informed consent has to happen in most but not all cases of human research. Because the new regulations said research activities have to go through this oversight, and yet clinical care activities do not, an immediate first requirement was to define what these regulations apply to? That meant research had to be defined, and the regulations did that. Subsequently, a lot of academic scholarship also began to define what is research. Again, these distinctions and definitions became important because of the important practical application that things that were called research had to have a lot of ethical oversight, and things that were clinical care were not required to have any such oversight.

I have a slide here with five things that my colleagues and I have said are categories of distinctions, the things that have been used in the literature and in regulatory definitions to distinguish research from practice. I have put under each of them what was implied, by contrast, about clinical care. The regulations say research is an activity that is intended from the get-go to produce generalizable knowledge, the assumption being that practice is intended to help the patient at hand exclusively. Research is where there is a systematic collection of data where there is an assumption that in clinical care (again, think back to the 1970s) there is no systematic data collection; we only collect data for the patient at hand and put it in his or her chart.

There are then additional claims from the literature about what research is and how it differs from clinical practice. One such claim is that research poses risks. We have uncertainty about whether there is clinical benefit from the intervention we are giving to a patient, whereas the assumption in clinical care is that we only give treatments where we know that the benefits outweigh the risk. Another claim is that in research, there are burdens that arise from activities that are not necessary for clinical care. We ask patients to do things above and beyond what is necessary for their clinical care, extra questionnaires, extra tests. Again, the assumption is that in practice every single intervention or test, duplicated test, triplicate test, contributes to good care management. And then in research, the last piece of what we will call a distinguishing claim is that in clinical research there are protocols that dictate which treatment you or I receive as a patient, whereas in clinical care, it is physician autonomy or patient autonomy or the dyad autonomy that decided what care you get.

Problems with this paradigm: We would argue that there are practical problems, conceptual problems, and moral problems with this approach. The practical problems are that there is complete confusion. One of the things we did in our work, and I do not have time to show it, is focus groups both with patients and with providers. There are some really stunning, and I would say amusing, quotes about the ways that people try to navigate this distinction when to them the activities look remarkably similar.

There are conceptual problems. I am guessing that if I went back to this slide, each of you could point to some problems with this logic, and again some of it becomes almost comical. I was being a little tongue in cheek in talking about things like the duplicate and triplicate test, but it is actually no joke. There are multiple things done in clinical care where we do not know whether they work, and there are multiple additional burdens that are placed on us as patients for all sorts of reasons that have to do with the health care system not being properly integrated.

This slide is pointing to some of those conceptual problems. A conceptual problem for people who do not live in our kind of academic wordsmithing context, is a problem where the words and claims are not working. For a good conceptual definition you could say, for example, the characteristics of a table are blah, blah, blah. All the things that have those characteristics are a table and things that do not have those characteristics are not a table. It is a way to provide a definition.

We are saying that those words and claims of the conceptual definition of research are not working. The idea that producing generalizable knowledge happens in research but not in practice is conceptually problematic. We learn from ordinary medical care, and we learn from quality improvement activities and both types of learning are applied to future patients. Systematic data collection also is not unique to research. We collect data systematically in practice whether we want to or not. It is now required in so many ways. For your hospital to be accredited, systematic data collection on many outcomes is required. Again, for quality

improvement, it is required. There are many ways in which clinical care data must be aggregated in the current American health care context.

There are many errors and risks in ordinary clinical care. Nobody wants that to happen. It is not on purpose. People are working really hard to avoid it. But this idea that clinical care is absent of risks or will never impose an intervention that has more risks than benefits is erroneous. And at the same time, the flip side of the coin is that the research paradigm of the 1970s and 1980s, where clinical research was only about testing experimental treatments, also is false. There is so much research today that is comparing different treatments that have been FDA approved for decades to see which one is better, monitoring different treatments that have been used for 30 years to see how they really play out in different populations of patients, and in these types of studies it is hard to argue that the research poses any more risks than the regular clinical care patients would have experienced receiving those exact same treatments. And as I already said, practice will often include many unnecessary burdens.

This leads to what people in my world of ethics call a moral problem, which is that there is overprotection. Again, remember that these ethics rules—and I will be the first to say I have taught these. There are so many pieces of these that I believe in. I have sat on many IRBs in my life. The whole foundational purpose of having these ethics rules is to protect patients or healthy volunteers from what they may not be aware of as significant and important risks done, if you will, at their expense for the sake of others. It is a very important concern that we always have to have for those of us who want to dedicate part of our professional lives to learning.

At the same time, if the purpose of drawing a line between research and clinical care is to demarcate activities that need to be looked at to see if they pose too many risks to people or might be exploiting people, we may not be using the right set of criteria. The moral argument would be that there are some patients who are being overprotected and others who are being underprotected. In other words, tons of activities currently have to go to IRBs for review and oversight when the activities pose very little risk—certainly no more risk than daily clinical care; while a bunch of other activities that likely carry a lot of risks and chance for errors go forward with no oversight whatsoever.

Let me move briefly to a couple of things about patient engagement. There is a lot of discussion, appropriately, currently about patient engagement, and of course this is much of the focus of today's meeting. I imagine part of what you talked about yesterday was the need to have a lot more shared decision making in clinical care. And one of the articles that I read in preparing for this meeting, the *Health Affairs* article, which I loved, talked about shared decision making relying on three things, one of which being that doctors and patients be really open with each other about all of the evidence. There is this assumption that to have patient engagement you need good clinical evidence.

Now, there is also this idea that in research, as a sign of respect, there has to be disclosure and discussion about what the research is about. There are two paradoxes in this space that I want to raise. One starts with the commitment that shared decision making relies on good evidence. It is sort of like a catch-22, because we have so little evidence available, that it is hard to be able to tell people the evidence related to their care or options. And then there is the paradox that one of the reasons we have so little good evidence is because of the hurdles and barriers that this large system of ethics oversight, and related concerns about privacy, have put in place.

Paradox number two is that we believe ourselves to be very concerned about patients' rights and our rights as citizens to know what it is going on, and thus demand to be told all details

about all sorts of research activities, and yet because of this historical distinction between how we treat research versus clinical care, we basically say nothing to patients or communities about the extraordinary amount of data that is collected and aggregated every day in the health care system health departments and the CDC, and certainly all hospitals are routinely collecting data. This is why we know about obesity rates, cancer rates, what makes a difference in infections, in patient falls in hospitals, et cetera.

I want to really briefly introduce what I will call paradigm number two, which is to introduce alternative ways to think about ethics and the learning health care system. The learning health care system. Again, I am going to make the assumption that a lot of you in the audience are really familiar with this. It draws on language from the Institute of Medicine. The learning health care system is where care and learning are deliberately integrated. It is not just that research is going on at the same time as care. There is a philosophical view that these must be and can be integrated. There is an assumption that high-quality care and learning depend on each other. There is a synergy there. Research with experimental drugs will still happen, but that is a little bit separate and not what I am talking about.

When we can learn systematically from care, we ask questions like *What are the outcomes of different treatment choices that are given all the time? What are the outcomes of different care approaches?* This slide is the one slide that introduces some of the work that my colleagues and I have done that says a learning health care system is an ethical good. If we want evidence to give to patients for shared decision making, we have to have good evidence. And in order to ensure that such evidence is developed in an ethically acceptable way, there need to be seven foundational ethical commitments as you structure and run a learning health care system. Some will sound familiar and some maybe are a little bit less so. You always have to respect the rights and dignity of patients. You have to respect clinical judgments. You have to have a commitment to providing what you understand to be optimal clinical care to patients—it can never be compromised for the sake of learning. You must avoid imposing nonclinical burdens and risks. And certainly, talk to people about them if there will be any. And then some newer ones. We must address health inequalities. And really maybe not part of a traditional ethics guidelines, there must be some commitments on the part of clinicians and on the part of patients to participate in the learning process when it will not compromise your clinical care and when it will not pose unnecessary burdens.

I think this is my last slide, which just says, so maybe this paradox is not quite so great. Patients are clamoring for better evidence and data. We have done some focus groups with patients ourselves, where it is often the people with the most significant chronic illnesses who are saying, *Give us more data. Do not protect us so much that we cannot learn*. There are so many more books, videos, websites today that are advocating for people to contribute their data for better treatments. Patients in trusting relationships are more willing to share their data. That gives us something we have to think about.

And there are many possible strategies for engaging and disclosing and discussing this whole learning idea with patients in health care systems. It is important now to do the work to find out from patients how to do that. We were recently funded by PCORI to gather some preliminary data with patients about what their views are about disclosure, consent, and authorization in the context of a learning health care system. But I guess I will close by saying it seems that that is the way that honors what patient engagement is really designed to do and gather the data that patients need to have. Thank you.

DR. TRINIDAD: Now, we will hear from Alice and we will hold questions until the end of the panel. Thank you.

Meaningful Choice in a Learning Health Care System: The Relationship Between Privacy and Data Sharing for Research

Ms. Alice Leiter

MS. LEITER: Good morning. Thanks so much for the introduction and thank you so much for that presentation, Nancy. What I am going to talk about hopefully builds nicely upon it, because I have the great pleasure of talking to you all about the law or the system of obstacles and burdens as some of you may see it. Unfortunately, if we are going to talk about meaningful choice, if we are going to talk about privacy protections, and if we are going to talk about data sharing, you cannot really have an effective policy discussion about these issues until you first understand what is not possible legally. I will do my best despite some fairly dense slides to go not quickly in my speaking, but briefly at a high level through these first slides so that I can at least keep you somewhat awake.

First, a little bit about the Health Privacy Project at the Center for Democracy and Technology. The project is premised upon the notion that I am sure we would all agree with, that health IT and the exchange of electronic health information are really the drivers and engines of health reform with the greatest potential to improve health. And certainly, in this new electronic health environment, some progress has been made to update and resolve some of the privacy and security challenges that arose when our system got turned on its head and became digitized. But as everyone is far too familiar with, a number of questions and challenges and implementation issues still exist, not withstanding some really solid and important and meaningful efforts on the part of HHS and CMS to update the HIPAA medical privacy rule and others to better fit this new environment.

This last bullet is to hopefully toot our own horn a little bit and saying that the solutions that we advocate are really those that are practical. Too often, I think, privacy advocates are seen as hysterical. Consumer advocates are seen as hysterical. We really try to work with people like you who are like-minded to find workable solutions to not only keep privacy and security central and paramount, but to get data liquid and freely flowing, so that it can be leveraged for all of the purposes that it needs to be.

I think these first couple of bullets about what a learning health care system is are written by people in this room. I certainly know this first one comes from Nancy. There are a lot of different ways to talk about a learning health care system and to define it. For my purposes in my work, the focus is really this need to safely and securely leverage clinical data for purposes that are beyond treatment and payment, and that a learning health care system is not going to be possible unless we find ways to do this.

A little bit about HIPAA. Big question when it comes to research is, first of all, does HIPAA—again, this is the medical privacy law applied, the federal medical privacy law. These bullets are about the identifiability of the data, because if data is de-identified, HIPAA does not apply. There are numerous and technical ways to de-identify your data. There are legal standards. There are methodologies to do it. And limited data sets are familiar to all of you in the research community because they are a close cousin to de-identify data. They involve some removal of categories of information. They are permitted for research. Data holders are required

to execute data use agreements to use limited data sets or information limited data sets, but individual consent is typically not required, which makes that quite attractive.

Again, the reason that this is important is because, as many of you know, in order for information that is patient identifiable to be used for research purposes, you have to obtain patient authorization. Authorization is the legal term. Consent is more typically the policy term. We will talk a little bit about that. With a few exceptions, a privacy board waiver or an IRB waiver or some exceptions found in the law, this individual authorization is necessary. Now, that is not easy to obtain and often seen as incredibly onerous. It makes perfect sense that research on data that is qualified as de-identified is largely not regulated and therefore enormously attractive to those who are engaging in research.

Unfortunately, it is not just HIPAA that we all have to worry about. I am not going to go through all of these, but there are numerous other state and local laws and regulations that can apply depending on the nature of the data, depending on the nature of the study, everything from the common rule—which I will talk about briefly on the next slide because it governs federally funded research to state laws—to health information exchange policies, to grant conditions and sometimes even international laws.

The Common Rule, the big research rule for federally funded research unidentifiable data—it is not that it is not worth talking about it, but some of you may know about 18 months ago what is called Advance Notice of Proposed Rulemaking, kind of an early heads-up that we are going to do some regulating on this subject, was released that proposed some fairly significant changes. And the good news is that they all seemed to be designed to bring it in line with the HIPAA law. There are some gaps and there is some confusion. There are a number of headaches caused by the relationship between HIPAA and the Common Rule. We are hoping that once we get a little bit farther down the regulatory process with this rule, we will feel a little bit better.

As we heard a little bit, and I will just say more specifically that there are some really common and legitimate criticisms of this legal framework that we have right now. As you could argue from my presentation, there is a disproportionate focus on whether or not the data is identifiable and whether or not patient consent is required. Having sort of laser beam focused on whether the data is stripped of these 18 or 16 or however many identifiers, and do we need to obtain patient authorization or consent, ignores a number of other valid and hugely important privacy protections that are available to us. Unsurprisingly, there is a real tendency to be conservative on the part of researchers and their interpretation of these rules and requirements for obvious reasons. You do not want to get in trouble and it is better to be safe than sorry. Unfortunately, that ends up causing or creating obstacles and barriers to research and to data sharing more broadly that may not actually exist or should not exist.

What we would like instead? A comprehensive privacy and security framework is desperately needed, not just for medical information, but really for consumer individual information writ large. Until we have that, it is probably not going to be this open, safe, secure, facilitating of health IT and health information exchange that we would like. There should be less focus on consent and more focus on the rest of the so-called fair information practice principles. Sometimes they are FIPs. I have a slide about those in a couple of minutes or a couple of slides. The notion is that let's broaden our focus and think about all the different tools in our arsenal and try to get away from this headache of consent.

Central to this and fitting in with this broader theme of this whole meeting of consumer and patient engagement is that any privacy and security framework has to incorporate notions of consumer and patient expectations. This idea of context. When you are deciding which of the

tools to pull out from your toolbox to protect privacy is important because in different contexts patients expect different things. And what you want is for no one to ever feel surprised or shocked or upset about a particular use of their health information. But you also do not want to assume that they are going to be—that a person is going to be shocked or upset or unwilling to share health information in a particular context. You do not know that until you have had full open transparency and engagement. If we can get all of these, you really have the basis for meaningful choice.

Meaningful choice, and this does not just apply to research, but really consumer choice for use and exchange of health information in general, centers around a number of principles. The most important ones I have highlighted here. You have to be able to make the choice in advance. You have to be free to make the choice. You cannot feel like if you say no to something that something is going to be withheld from you, for example, medical treatment. And there needs to be absolutely full transparency and education about what that choice entails. Without that, it is not meaningful. This notion of opt in or opt out in the endless hours of discussion and debate that yours truly and many probably of you have sat in about what is going to be opt in or opt out should not matter as much if the choice, regardless of the system for giving it, is meaningful.

These fair information practice principles—this list that I have given—was developed or articulated by the Markle Connecting for Health Initiative, but they can be found in a number of different articulations. The Federal Trade Commission, the Department of Health and Human Services, the Office of the National Coordinator for Health IT has its own set. But they have similar themes that are the most relevant. I will not read them all out for you, but you can see that this idea of choice is but one. The idea that you should be able to consent to the use and exchange of your health information is certainly important, but so too is openness and transparency, understanding the purpose, feeling that the very least of your data that is necessary is going to be used, that you have some ability to participate and control, that the data is accurate, that it is safe, and that there is some accountability and oversight for the use of your information.

My next couple of slides are on ways to structure research networks to achieve this. Distributed networks versus centralized networks. I am running out of time and I think that that is maybe left best to more specific conversations later offline if you would like. I think ending on the fair information practices is most relevant to this presentation. I look forward to the discussion afterwards. Thank you.

The Infrastructure Needed for Patient-Engaged Translational Research

Dr. Kenneth Mandl

DR. MANDL: Hello everybody. Good morning. Thank you for those excellent presentations that set up this idea of a learning health system and one in which there is progress and protection of patients.

Now, I am going to focus on the plumbing. I am the IT talk here. And the plumbing is about how to hook patients. I do not mean this in a derogatory way because when I look at the whole idea of patient engagement, I am usually thinking about it as a patient or a father of a patient. It is very important to think about this learning health system, and that is the context in which we are discussing this today. There is an assumption that the care, the science, and the evidence are all in some way become much more aligned, interconnected, that there is a virtuous cycle, and that

the patients are very much engaged in both contributing information as well as receiving back information, so that they can improve care and improve quality of life.

Let's just look at the way we do this. How do we hook patients into a system like this technically? In 1998, I wrote my first paper and it was extremely controversial. It was the idea that doctors and patients will actually e-mail each other and that this is something that could possibly be safe. There was a sense that, what if a patient e-mails that they are having a heart attack or doctors are just going to be overwhelmed by these unruly crowds that now have unlimited access to them 24 hours a day. We actually built the first doctor/patient e-mail system and tried it in 1998. It was for pediatrics. It has a cute giraffe on it. But since then, what we found is there have been very large-scale efforts. My HealtheVet, the Epic MyChart system, which is used across Kaiser and Group Health and many places. Millions and millions and millions of messages have gone back and forth. Most of the fears were never realized. Of course, this is one form of access and getting patients engaged. But this is mostly a free text thing, just a first step in the learning health system.

Now, we have activated patients. Here are patients who come in. In the era of genomic medicine, patients plus Internet know a lot more than most of the doctors. I have here Dave, here in the second row. He has actually brilliantly formalized a whole conceptual structure around this idea of a technologically enabled and informed patient that he calls the e-Patient. Now, how do you then get information flowing back and forth between patients? There are these federal initiatives to try to do this. We have been screaming in the wilderness that patients need to have some access to their data. I am sure Alice can tell you better than I, but HIPAA was supposed to—the original HIPAA, 1976—was supposed to facilitate electronic access by patients to their data. But there was this little phrase that was in the regulation that said "if feasible." For basically since then, since 1996, every single organization has decided that it is not feasible to give them electronic access to their data. And in fact, HIPAA was of course used as an excuse not to share the data with the patients most commonly.

But then in HITECH there was language that once again promised data to the patients. That sort of did not quite work because the technological alignment was not perfect. You could get electronic access to data through, for example, a PDF file or something that really did not give you the opportunity to use your data in a Web 2.0 apps kind of way. We will talk about that a little more. But now there are projects that are quite formalized in the structure. One is called Blue Button. Blue Button is supposed to be a disruptive innovation. In the Department of Veterans Affairs, they can literally push a Blue Button, it looks like this, on their health record and get a copy of their data. The only problem is it comes out of no particular format and you cannot read it or understand anything that is in it. But it is there. You get your data. And then there is something called the Direct Project, which is about an e-mail system for health.

The question is if there is going to be this kind of data liquidity, in other words, that data is now going to move out of systems toward patients so that we can begin to—one way to begin to engage them is we have seen these portals like Epic MyChart. The one is just I am going to show you the data. Here it is on a screen. But it is trapped. It is behind the screen. You cannot get it. You can knock on the screen or something, but it is there and there is nothing you can really do with it. Then there is this Blue Button, which is are we going to actually give you a copy of the data, hopefully, one day in a way that you can use it. And then under this thing called Meaningful Use, which is how we have described the properties of health information technology that make it useful and is the basis of certification and payments. There is this new thing called CCDA. Do not worry about it. But it is a standard for how the data comes out,

supposedly in a way that is going to be really reusable by electronic systems as it communicates between electronic systems and between electronic systems for doctors and for patients.

Now, assuming the data comes out, where do we put it? You can stick it on your PC or your Smartphone. I hope you do not lose it. Or if you use one of the tens of thousands of apps that are in the Apple iTunes store or in Android, you may be able to store your data on some company's server under some privacy policy that you probably cannot find or did not read. And it may still be very useful and it may be worth the privacy trade-off, but that is where it is. Or maybe your data just lives in your institution's electronic health record. But what if you go to two different institutions? Does that work for you? Or maybe it is in something called a personal health record. This is another idea we had that the patient should get a copy of their data. It should be stored in a repository under their control and on top there should be apps that let you use the data the same way you are used to using data on iPhones now.

Clayton Christensen thought this was a very interesting idea and wrote about it in his book, *The Innovator's Prescription*, because this gets the data instead of in institutional electronic health records. It gets it under the patient's control. Then you do not need this idea of health information exchange because the data is all there under the patient's control. The idea got some traction. We created the system called Indivo and interesting things happened. Microsoft took Indivo and created with the code something called HealthVault. Google took the model and created Google Health, but they deep-sixed it within the last year. And one reason is because this data liquidity just was not there. Anyone in the country could have a Google Health record, but no one could have anything in it. That was a problem. Also, do people trust Google to manage their health data?—that is a question. It is not clear—there was this data liquidity and the trust issue. Some composite issues there.

Dossia Consortium of large employers worked with us and we actually built out Indivo for use in hundreds of thousands of their patients. And Jim Hansen is here who knows that story well. The question is, why would this great idea and these big companies jumping in, Walmart, AT&T, Intel, Dossia, Google—why isn't everyone using data in personal health records? I do not know exactly, but I think that there are other hooks too that are important. One is social. Social seems to be important. We started to do experiments. We said everyone is being offered personal health records, but everyone is hanging out on social networks. We did some experiments where we, for example, got—can we get data from patients in a social network context? And in a big website called TuDiabetes where there are tens of thousands of patients with diabetes, we actually ran a data donation drive. We activated the community. By contributing data about your diabetes, you provided community support and you populated a map. We turned it into an interesting contest and a game. We got thousands of people participating contributing data. There is this idea of data donation.

Hook number five is feedback. It turns out that if you actually give folks back information when you ask it from them, you actually make this a collaborative relationship. It becomes very interesting. Last week in *JAMA Internal Medicine*, we published a piece where we actually elucidated quite a bit of information about the harms attributable to hypoglycemia and diabetes in this population on TuDiabetes. We got some very interesting data, and data in a bidirectional communication mode where we get data from the population and we can return interventions to populations about potentially very high morbidity conditions.

Also, there is another hook. That is, I am contributing to information that helps my condition get cured or treated better. PatientsLikeMe. You are going to hear more about PatientsLikeMe that had tremendous success with the amytrophic lateral sclerosis community, Lou Gehrig's

disease, where the majority of patients in the world with Lou Gehrig's disease were sharing information about their condition.

There is this idea too beyond social networks of these kinds of registries where we actually accumulate through large health systems large numbers of patients in particular structure where we collect data from them; electronic health record data plus data that we collect meticulously plus data directly from patients. We are doing experiments with those. You will hear more from Peter, I think, about ImproveCareNow, which has many patients with inflammatory bowel disease including my own son who is a member of Peter's database. We are doing work with a professional organization called CarraNet where we have more than 50 percent of kids with pediatric rheumatologic conditions in one system with bidirectional access. And PPHNet where kids with pulmonary vascular disease. We are just getting starting on that.

I am going to wrap up to tell you that also there is a very interesting opportunity to actually go right to the point of care and do patient engagement right there right at the point of care. This is a project that I would love to tell you more about, but not right now. But this is a $15 million project from the Office of the National Coordinator where we are re-imagining electronic health records as apps platforms. And the idea is can we take an EHR and actually add to it apps that extend its functionality and that open up electronic health records to a large community of software developer innovators, so that electronic health records can have all kinds of functionality that face both patients and clinicians. I have to thank David Blumenthal who funded this project 3 years ago.

I just want to show you one small slice of the project, which is how are we using this to actually begin to engage patients. Here is an app. Hook number seven: decision support. Maybe we can actually tell patients exactly what they need to do or what their risks are. We took this picture from *Wired* magazine, which is a laboratory information system of the future, and we turned it into an app that shows your cardiac risk. It pulls data out of the electronic medical record. And instead of your standard information display in electronic health record, this is something that we actually created in 8 days. We can tweak it any way you want. It shows you your risk.

This is a tool for getting doctors and patients talking at the point of care. And the last hook here is the opportunity to actually bring your data to the point of care. This is in collaboration with Microsoft. This is at the point of care. The doc pulls out the information from the electronic medical record on diabetes and goes out to the personal health record, pulls the patient observations of diabetes and merges them together. You can actually do conversations at the point of care. These are our patients of the future. Sorry for going over 2 minutes.

Patient Engagement and Data Sharing for Improvement, Innovation, and Discovery

Dr. Peter Margolis and Ms. Jill Plevinsky

DR. MARGOLIS: We are going to give a more concrete example of how we are struggling through many of the issues that everybody else has raised. This is a bit of a tag team talk between Jill and me. I just want to acknowledge the support we have gotten from the NIH Transformative Research Program and the AHRQ enhanced registries program.

Just to motivate the discussion, I want to do it by talking about the participants in the chronic illness care system. This is Bianca, and the system of chronic illness care is not working for her. She is 11. She has Crohn's disease and she is obviously in a lot of pain. That is the least of her

problems. Without optimal treatment, she will have stomach growth, possibly experience arthritis, and a significant risk of surgery. She cannot go anywhere without knowing exactly where the bathrooms are. And normal childhood events like sleepovers are extremely difficult.

It (the system) is also not working for Bianca's doctor, whom we call Dr. Roan. She has a variety of treatment options, but the best evidence is evidence that comes from clinical trials, and it cannot provide information on what will work best for a particular patient. It is also not working for Bianca's mom (we call her Anna), because the care delivery model does not facilitate her participation. She is wondering about trying dietary modifications to see how best to control Bianca's symptoms. She keeps her eye on what is going on, but feels it is the doctor's role to come up with solutions. She does not really see the collaborative possibilities. And finally, it is not working for the one whom we call Dr. Vincent Kapur. He is a researcher interested in improving GI care. But he is faced with small and representative data sets in a lack of easy and productive ways to share data and increase the impact and reach of his research.

Our project to develop what we call a collaborative chronic care network focuses on this question. What if we could harness—what if we could create a vastly better chronic care system by harnessing the inherent motivation and collective intelligence of patients and clinicians? If you think of Wikipedia—or in science, how open sharing in the human genome project in advance of publication dramatically accelerated the discovery process. These are examples of how the production of knowledge and information and know-how can be distributed over a large group of people.

Yochai Benkler, who is a professor at the Harvard Berkman Center for the Internet, calls this form of production "network-based" or "social production." In health care, networks for clinical research have been central to accelerating discovery, and networks of patients have served as potent patient advocates for more effective research management and greater investment, and now even in developing new knowledge.

The model that we are presenting brings together all the stakeholders in the process—the patients, the clinicians, the researchers—to improve health outcomes as part of a learning health system. Our effort began in 2007, when the pediatric gastroenterology community as part of the American Board of Pediatrics Maintenance of Certification program organized a collaborative network called ImproveCareNow that was dedicated to improving the health and lives of children with Crohn's disease and ulcerative colitis. These are some data from the centers that have enrolled more than 75 percent of their patients in the register. The red lines show the variation in the monthly rates that would be expected by chance alone. What you can see is that with no new therapies and no blockbuster drugs, the percentage of children with IBD in remission has risen from about 60 to now over 75 percent. How did the clinicians do this? They did it by sharing. They were sharing knowledge, sharing know-how, sharing the work of figuring out how to improve the care delivery center. Every center has pulled their data. They have standardized their outcomes care and learned from one another about how to get better results. There are currently 51 care sites, 425 physicians, more than 15,000 patients. The ImproveCareNow network is now working with—this is 30 percent of the patients in the country with IBD.

ImproveCareNow is working with the C3N project to evolve from a network that is focused primarily on clinicians to one that involves all the stakeholders. And to do this we have concentrated on four main activities. The first is an ongoing focus on improving patient outcomes. The second is on building community. The third is on the effective use of technology. And the last is on developing the learning system, the use of system science, quality

improvement, qualitative and clinical research together. During the design phase of the project, our ethnographic research that was conducted by our partners at the design firm LIBA identified the needs and goals of patients with this disease. A particular interest for us was those patients who make a successful transition into adult care whose treatment decisions are driven by personal preferences. They come to make IBD part of their lives and want to share what they have learned and give back. We reach out to engage these young people who are innovators and lead users in the community. Jill Plevinsky, who will speak next, has made major contributions to designing and guiding and developing the system.

MS. PLEVINSKY: I am very excited to talk to you about the work going on in this project. I also wanted to tell you a little bit about my very brief patient story. I am happy to elaborate throughout the day, however. In introduction, I was diagnosed with Crohn's disease when I was 7. Growing up with a chronic illness, as a lot of you know in the audience, is not an easy task. But I was definitely very able to find comfort through support groups and Camp Oasis, which was a weeklong camp for teens with IBD. At that point, [Camp Oasis] was my first patient community that I was ever a part of. But I did not realize that we could do more than raise awareness and raise money until I became a part of the C3N project. Definitely just excited to be able to partner with physicians and researchers. I have been playing a very active role in transforming care from the ground up.

There are a few reasons why I participate. Some of these may be familiar to some of the patients in the audience as well. No one likes to be sick. Like I said, having IBD is not easy. It is a difficult battle every day. I take medications daily, need to watch my diet, and as Peter mentioned, most of us always need to know if there is a restroom close by. Rather than just be defeated by the experience, I chose to get engaged. I also trust my physicians. I have incredible faith in all of my doctors. I believe that they can do everything that they can to ensure that I get the best care possible. But I know that they need my help in order to do that. I want to help my doctor help me do that.

As also mentioned, I work as a research coordinator at Boston Children's. It is unrealistic to expect our physicians to give us the personalized care we expect if we do not help them do so. I witness every day how busy everyone is and how heavy caseloads can be. I definitely know that this partnership is essential to the success of care. With the new technologies like Ken was discussing, it is possible for patients to help.

I also want answers to difficult clinical questions based on facts, not just hunches. With IBD, there is no one perfect treatment for everyone and a lot of treatment decisions are made out of desperation. ImproveCareNow allows doctors to really access what works for certain patients across the whole country and can help one another make decisions based on data.

I also want to help make pediatric health care participatory. This movement obviously has already begun in the adult world. But as a now former pediatric patient, the fact is children and adolescents need to learn these skills too, especially as new diseases are being diagnosed at younger and younger ages. I also do not want other kids with IBD to feel as if their care is beyond their control. A lot of anxiety and depression in kids with chronic illness results from this feeling that they are not in control of their own health care. While some aspects of chronic disease are that way, it is important to remind young people that not everything is beyond their grasp and that is the first step to becoming an engaged patient in my opinion.

This is how we participate in C3N and ImproveCareNow. As part of the grant, I joined the design team to imagine new ways to create more continuous and collaborative care. It was at these meetings that we all realized it was really necessary to have a community-building

component. I along with other research team members, including physicians, researchers, nurses, and other patients, took a course by Marshall Ganz who was actually Cesar Chavez's community organizer, now professor at Harvard Kennedy School. And one of the keys to his community building being a success was distributed leadership teams, meaning that, in order for a cause to truly take off, you need to start with one centralized leadership team, develop leadership and foster that control within that team, and then let them spread out to their local communities and start individual little communities all over the globe. It is a really nice way to allow leadership and ideas to flourish within a community. This can definitely be applied to patients, physicians, researchers, and so on.

Out of this framework, we decided to create a council of patients called the Patient Advisory Council. I will refer to it as the P-A-C. There are pictures of some lovely ladies up here who are members of the council. Basically, this is a group of young people with IBD who were diagnosed as children and adolescents. And the major purpose is to obviously foster leadership within the group. We developed a patient scholar program where we allowed these patients to attend our learning sessions, which involve all the clinicians from the ImproveCareNow centers so they can hear from patients at each learning session, which is awesome for us.

We also help the collaboratives develop tools as well. We actually used a match questionnaire to draw on their skills and expertise to match them to projects within the C3N. On six projects, we decided in mobile application to track patient passive health outcomes and online social networks, self-management tools, patient activation research, external communications as well. Once we did that, we have patients on just about every team working with doctors, researchers, developers to really develop and answer what they think is important to the patient community.

In my professional life, I see firsthand how traditional clinical research and translational work is done. The learning health system approach we use is very different. Patients are always asking me if they can see their results from studies personally and the answer is often always no. But the way that ImproveCareNow is different is that we use social media, Facebook, blogging, newsletters, and things like that to monthly share our data with the members of the database, so they can see this lovely chart of the increasing remission rates within the population (see Figure 2-7). Peter is going to describe some of the technologies that we use to do this.

FIGURE 2-7 ImproveCareNow social media.
SOURCE: Reprinted with permission from Peter Margolis.

DR. MARGOLIS: We have actually been building on some of Ken's work at Harvard using the I2B2 registry to create what we call a data-in-once system, in which the same data the

clinicians enter in the electronic health record for clinical documentation is repurposed for analytics, QI, and comparative effectiveness research. We have worked with the EHR vendors Cerner, Centricity, and Epic to create standardized templates for data entry like the one shown here from Epic. The data are extracted locally from the EHR database and combined centrally for research once data are de-identified. And the data are used to automate chronic care processes like pre-visit planning … is a screenshot of the pre-visit planning tool that the clinicians use. We also use it for population management. Data are also used to produce monthly quality improvement reports where the sites can see their performance and compare themselves with all the other sites. And the registry can also be used to generate new comparative effectiveness evidence at multiple different levels—at the level of the population, the care center, and the individual. In the interest of time, I will just show two examples at the population individual level.

Doctors and patients wondered if we could use the registry to compare the effectiveness of biologic therapy, which costs about $50,000 per year, with usual care, typically steroids and thiopurines, which cost about $3,000 per year. There has never been a randomized trial in children to evaluate this question. None was likely to be done in the future because of ethical concerns of withholding treatment shown to be effective in adults. In a study that will be presented this spring, my colleagues Charlie Bailey, Marshall Joffe, and Chris Forrest from the University of Pennsylvania used new methodology to simulate a clinical trial by taking advantage of over 1,000 patients in the registry and naturally occurring variation in the use of biologic therapy (see Figure 2-8). This slide shows the percentage of patients in two groups who achieved clinical remission. The solid line is the patients receiving biologics. The dotted line is patients who did not receive them for two outcomes, clinical remission and steroid-free remission. This information will be used by the network to help guide decision making about the use of biologic therapies versus usual care.

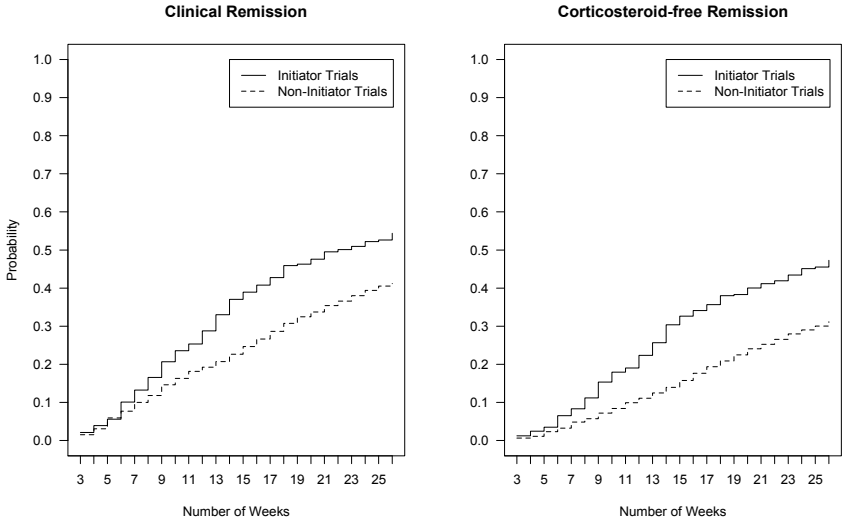

FIGURE 2-8 Cumulative probability of remission and corticosteroid-free remission for initiator and non-initiator trials during a 26-week follow-up period.
SOURCE: Reprinted with permission from Chris Forrest, Children's Hospital of Philadelphia. Data from Forrest et al., 2013.

With the ability to collect data on a daily basis, we are also prototyping how to enable N of 1 learning, so individual patients and their physicians can work together to optimize their care. These are data from a college student with ulcerative colitis who had a colectomy when she was a young child, and she has been bothered by frequent nighttime stools and exhausted from getting up all night (see Figure 2-9). On the y-axis, you can see the number of stools per night and you can see the dates on the bottom. She and her doctor, Jeremy Adler, who is a gastroenterologist at the University of Michigan at the ImproveCareNow site, decided to start collecting daily data using an SMS text system. This revealed considerable variation. For example, there was a 6-day period when she went from waking up three to four times a night to waking up no times per night. When she reviewed the data together with her doctor, she recalled that she had been put on Amoxicillin by her primary care physician for sinusitis. This reduction in symptoms happened again and led the two of them to decide, rather than testing steroids as the initial treatment, to test treatment with Rifaximin, which is a locally released antibiotic. This is work being done by my colleagues Ian Eslick at the MIT media lab, Heather Kaplan and Dr. Adler and a team of gastroenterologists.

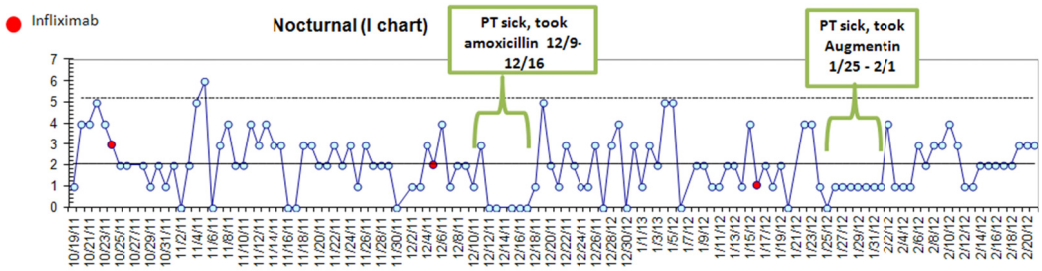

FIGURE 2-9 Data from a college student with ulcerative colitis.
SOURCE: Reprinted with permission from Jeremy Adler, M.D., M.Sc., Pediatric Gastroenterology, University of Michigan.

The regulatory aspects of data sharing in the network are complicated because the system involves chronic illness care and research together. Regulatory oversight about the use of PHI for the production of the automated pre-visit planning and population management reports are addressed through HIPAA notification and business associate agreements. These reports have patients' names on them so that they can be used to guide clinical care. It is not only inconvenient not to have a report with a code on it; it is also not safe because you need to be sure that you are giving the right treatment to the right patient. A federated IRB and consent are required for data to be used for observational research. The comparative effectiveness research that I showed you is the limited data set, whereas the intervention health research uses full PHI. There is consent for participation in those projects.

I just want to touch on, because you all have talked about it, the complexity of the regulatory challenges. Virtually every physician in the network is extremely confused about HIPAA. Many of them believe that there is no PHI shared outside their institutions. Buy-in for the federated IRB model that we are using is modest. About 38 percent of the centers have decided to rely on a central IRB despite the fact that this is a low-risk project. And the effort to gain IRB approval—legal approval is pretty extensive. It takes 22 hours for our research coordinator per center, 82 e-mails back and forth, on average 3 months to get this through IRB and business associates' agreement. The maximum is 7 months. There is a direct impact of slower approval. It is fewer kids in remission.

In summary, the ImproveCareNow collaborative chronic network is an example of what we think is a learning health system that seeks to fundamentally redesign and restructure the research process by treating clinical care operational improvement and research as part of the same system, one that defines success based on better outcomes. Our hope is to bring the system to over a hundred care centers and 50,000 patients, vastly increasing the number of children in remission.

Our experience to date is that there are a number of challenges that we need to overcome. Bringing divergent groups together and overcoming the power, the language, the scientific, and technical differentials is significant. We believe that investment in creating this idea of distributed leadership that engages and connects all the stakeholder groups has the potential to not only spawn more cooperative behavior, but also produce improved engagement and participation. The policy and organizational constraints impose significant transactional costs, time, money, and effort to collaboration. And the execution of the privacy, the ethical and regulatory documents is time consuming, resource intensive, and challenging socially.

Investment in leadership by policy makers we think will be needed to test and disseminate new approaches to mitigate these costs and these are questions that are amenable to empirical research. Collaborative networks like the ImproveCareNow, with structured data and one's technology, standardized care, and systems for virtually real-time scientific learning amount to labs where we can test and learn our way into future systems that enable patients and families and clinicians and researchers to work together to help young patients like Bianca live gracefully with chronic illness.

Audience Participation and Open Discussion

Dr. Susan Brown Trinidad (Moderator)

DR. TRINIDAD: Thank you very much. We will open up now for questions. Folks with questions, if you could head to one of the mics, please.

MR. DEBRONKART: I am thoroughly fascinated with looking into the use of science and the scientific method to produce research that can be, we hope, a stable foundation for making decisions—not just the patients, but the clinicians also, choosing among the available options. How do we move forward with as much certainty as we can have, given that there is no certainty?

I want to point to two quick things and then ask a question. First of all, on the slide about protecting people from risks that they are not aware of. Is Perry Cohen here today? Hi Perry. He has had a couple of episodes of studies into Parkinson's treatments that were cut short or cancelled, invalidated, whatever, because the people protecting the patients decided that it was all placebo effect and that was noise and so the whole study should be thrown out. With somebody with a declining disease where their days are numbered, they may want to not be protected so much. They may say if there was a placebo effect, let's figure out what that is. I would like to have that on the record.

Regarding the Blue Button, the data format may be cheesy and little and so on, but trust me as somebody who saw his own industry destroyed—typesetting—destroyed by desktop publishing, which started out as cheesy and meek, watch out, brother. There is a reason I am wearing the Blue Button here. And I get your point. We might have a gentleman's bet of $100 to see where that is 5 years from now.

My question has to do—some of you I am sure are aware of the Reproducibility Initiative. In the several years I have been watching, trying to understand medicine, the only thing that has shocked me, except for the rate of medical errors, but the only thing in research was the discovery of the publication last year of the news that when Amgen tried to reproduce 53 landmark cancer studies, they failed to get the same result on 47 of them—tied to the news that most published studies are never replicated by another lab. One of the first things I learned as a grade school science student is when three people do the same thing, they better get the same result. With this august panel, I wonder. For instance, if I were to just wave a wand right now without it changing the practice, I would add a wobble score to every published finding saying whether anybody else has ever gotten the same result, because what we do is we take the results and then put them on patients hoping we will get the same result. Thanks. Thoughts on that on reproducibility. Is it important?

DR. MANDL: There are some important approaches that are being taken to try to regularize our approach to understanding all the research that has been done. For example, as you are probably familiar, ClinicalTrials.gov and the trial registration process has been shown to give insight into what was always suspected, but has now been very well demonstrated, that there is a publication bias. Studies that are positive are published. Studies that are negative are not published. The negative studies used to be dark matter. We never could see them. We could only infer them. Now, we can begin to see them as well. Yes, reproducibility is important.

It turns out that which organization and type of organization is funding the study is somewhat predictive about whether the results will be positive or not. Industry versus academia versus other not-for-profits. This area of understanding … the evidence whether the evidence is real. The fundamental assumption that there is evidence-based medicine is potentially flawed, and that is what is so interesting about the learning health system. It is a completely new way to produce evidence, and one which has its own set of methodological challenges, but that I think are fascinating and very promising.

MR. DEBRONKART: Just one closing note on this. To me this is absolutely not just a matter of patients' rights, although obviously patients are the ones who are physically at stake. It is a disservice to the clinicians who have been trained to use evidence, for heaven's sake. I would hope that somebody would—I will propose a practice that the funders of research that just become an ethical imperative that they—for instance, I think Reproducibility Initiative in Palo Alto is proposing something like a 10 or 15 percent additional charge to have a second lab try to reproduce the result. Thanks.

DR. TRINIDAD: Thanks. Let's go here. And if I could ask the questioners to try to be as concise as possible so we can hear from everybody who is standing right now, that would be great. Thank you.

DR. GARDENIER: I am Turkan Gardenier from Pragmatica Corporation. Lots of commendation for both Dr. Mandl and Dr. Margolis. And by the way, I have heard of Dr. Margolis's name in the statistical literature before now. My question relates to the exponential increase of data in these large databases, which are being called big data now. But also the question is, do they ever get decreased? For example, in industrial engineering, in inventory control there is a LIFO-FIFO system where once you converge upon a consensus of opinion, maybe you do not need the old data anymore. And relative to replicability, there is a lot of literature on meta-analyses, for example. Once studies converge upon agreed consensus maybe you do not need any more data of that kind. Do you run into questions like that? The idea of PatientsLikeMe, for example, is very interesting because you can do clusters of individuals that

will benefit from certain therapies. Are those ideas getting integrated into the increasing results and conclusions that are generated out of the interactive features of the wonderful databases?

DR. TRINIDAD: I can speak to biobanking because in that setting in genomic research, federated databases would be envisioned as an ongoing resource because you can ask many different questions against the same data sets. There is no plan to retire any of those data. I do not know if you wanted to add anything more to that.

DR. MANDL: In terms of the data management, I do not think there are any good plans along the way that you are proposing, which is very interesting. In a slightly orthogonal issue is just that we do sometimes perhaps try to get data across every place and every setting when in fact a subset of those data would be fine. It has been demonstrated again and again that these findings are fractal in the sense that you can see them in every place you look. It may be that certain associations between drugs and adverse events, for example, we have been able to demonstrate in a single health system with statistical significance in a way that is reproducible. Some work can be done much less expensively and with smaller big data, and sooner, because you can do these studies within even a single health system or a couple of health systems. That is a very important question.

DR. MONTORI: Victor Montori from Mayo Clinic. First, congratulations to the great panel. I have a couple of things. One is to the point, what Dave brought up. I want to make people aware of the Alltrials.net Initiative, that is a worldwide petition to have all clinical trials published in full—so, one more initiative to try to get the evidence record to be complete for all the reasons that Dave pointed as important.

The second thing is a question for Dr. Kass. I actually brought your papers with me to review. One of the things that I think is striking about this new framework is that it does require a lot less mental gymnastics to try to figure out what it is that you are doing vis-á-vis the IRB, and I suspect the IRBs are going to take a long time to come around. Maybe if patients and clinicians engage in health services research work to advocate for it, we may see some interesting experiments.

But one thing you said that struck me as something that may need empirical evidence, which is, beyond the many anecdotes, what is the evidence for opportunity cost of the ethical regulation we have now in relation to research that has not taken place because of it? You said there was a lot of work that probably has not taken place because of regulatory and ethical burdens. What is the empirical evidence of that?

My last point is all of you, I think, maybe I heard what I wanted to hear, made a big case for generosity. In many different ways, you all spoke about data fluidity and other things, but based on people volunteering generously or interconnecting. I think generosity was—maybe I heard it or maybe I imagined it, but I think it was at the base of this. But some of the concerns about big data are not really … big data is not getting into the hands of people that are being driven by generosity and altruism and trying to do good as their primary mission. There is a big industry evolving now around big data where the primary mission is not altruism. It could be a secondary side effect of it. There are some interesting stories around that, including the notion of medical information being combined with credit ratings and things like that. The individuals have not given the credit rating agencies any authorization, really we thought to combine that with your medical information. And some of the data is now being authorized to be combined. Because corporations can do it, they are doing it and the oversight is minimal. Comments on that.

DR. KASS: Great question. I do not know of good quantitative empirical evidence. There are two things I want to say though, because it is such an important question that speaks to the

kinds of empirical evidence that would be helpful. There is what I will call a growing amount of anecdotes, some of which are published. We have done now four focus groups with quality improvement and comparative effectiveness researchers who speak to the times when they did not embark on a project. I think there is one category, which is of people who thought about doing a project and abandoned the idea. That is one kind of opportunity cost, and one can think about how to collect more data.

The other kind of opportunity cost is where you do not even capture—I started an idea and then it was too much of a hassle to go through the IRB. But it is really more the number of clinical contexts where—I will make something up—where when you go to the doctor today, they give you the same two options that you would have been given 10 years ago, the identical two options. And there is really no more data than anybody brings to that discussion than they did 10 years ago. That is a really different kind of opportunity cost that we do not think about as concretely, but is probably more profound. It is a very different way to reveal what we have lost by not doing the constant learning.

DR. GARDENIER: My name is John Gardenier. I am retired after a career of scientific research using quantitative methods. I now consider myself a quantitative ethicist. As a patient diagnosed with prostate cancer, I found that there seems to be no medical science. There is a lot of medical practice, but no science related to this. I thought because I am a very experienced researcher and I understand math and statistics, I could go into the Internet. I could talk to doctors and I could really find out what is the best thing to do with my cancer. I found that is absolutely untrue.

The best site was the Prostate Cancer Association, which listed all the different kinds of treatments and said they all work, but they all have risks. That was not terribly helpful. I went to seven different physicians with various kinds of radiation oncology, various kinds of surgery, this and the other. And every one of them knew exactly what I should do and they were all different. Again, where is the science there? Ultimately, I decided on cryoablation because at least it would not do any damage to my organs or create a new cancer risk. But ultimately, it did not work. I had to back it up with external beam radiation, and finally I got cancer free. Talking to doctors did not help. Talking to patients does not help because the vast majority of people treated for prostate cancer get better no matter what treatment they give them. It is a very successful practice. I cannot find out by talking to patients what the relative risk is.

I would suggest a possibility that either we design studies where there are alternative treatments that attempt to get, in a quantitative manner, at the relative risks of and relative benefits of different types of treatments. Or if we are not able to do that, please just say, "I do not know, or, we do not know."

DR. DARER: I also want to thank the panel for what I thought was just a brilliant series of discussions. My comments really mostly are for Nancy, which I thought was a brilliant framing of an issue. My name is Jonathan Darer. I am the Chief Innovation Officer for the Geisinger Health System. Innovation is this space frequently where you are implementing new things, not necessarily new drug therapies, but new modes of the delivery of care. If I want to evaluate that kind of work, it gets very complicated very quickly. I am permitted to do uncontrolled experiments all the time with no notion of whether they actually improve care. It is a very common thing. And innovation I think is this term that is picking up and nobody really is quite sure where it sits in this world of evaluation.

My comment is really about this culture issue, both from a funding perspective as well as a researcher perspective. I have run into a lot of resistance to this notion from people who consider

themselves to be more pure researchers, to actually improving the quality of care for patients. If they felt like it had a real patient at the end of it, they were not interested. It was not their purview. We even had this notion of this unsafe quality improvement activity. And they were like, "I do not care about that." I just want to know if it is research or not. I wanted to get your comments from the panel. Is this something that other folks have been seeing, and what is the roadmap toward really bringing this cultural change, which I think needs to happen in order for us to be able to evaluate much more thoughtfully this kind of new world of this combined quality improvement and translational research?

DR. MARGOLIS: This is something that we think a lot about. From a system perspective, we call it playing the whole game. What we talk about at Cincinnati Children's is the entire trajectory from what happens in the lab to what gets applied to patients. It is a matter of leadership to make it a priority that we are all aimed at the same thing, which is better outcomes for patients. What we found is that when we as leaders work in that way, it is not perfect, but there is much more alignment between the people who consider themselves researchers, the people who consider themselves quality improvement people, and the people who consider themselves doctors or patients about what they are doing and how important it is for their work to fit together. And what it produces, we think, is what we call a derived research agenda, in which the issues that patients and clinicians care about are being brought systematically to the researchers and the quality improvement people to inform the kinds of work that they do.

MR. CLIFFORD: Hi, I am Dave Clifford. I work with PatientsLikeMe. One of the questions that came to mind when Dr. Kass and Alice Leiter were speaking earlier in the panel was, "whose ethics?" We talk about ethical review, but we do not talk about the ethics of whom. If you go to one IRB and you go to another IRB and you go to a third IRB, you have different senses of ethics that are leading them to determine why things should be done. I am wondering if you can comment on collective standards for ethics, especially now that we are looking more at research processes with the patients involved directly with them or commenting or advising to those panels. For example, if I were to have a PCORI grant and it were to be a substantial grant and I had five people that were patients designing that study where in the case of Peter's work, an institution might override my ability to do that study even if the patients thought there were robust and sufficient protections. I am just wondering if you could speak a little to those balances.

DR. KASS: It is a great question. There are tons of evidence that IRBs make decisions differently, and that has led some people to say, why do we do this review at all? Is the whole thing sort of bogus? But with the other example, we still go to doctors and they give us seven different recommendations too. You can say that is good or bad.

I think ethical norms really do shift. I actually think that even under our current regulatory … there are several of us who think that maybe it is time for a culture shift that would actually result in some changes to the regulatory language. But even short of that, I think that there are a lot of different ways to interpret something, like what does it mean to be respectful to a patient? I think historically what that meant was, you have to tell a patient everything. You need to get a written signature and you need to be extremely protective. That led to a bunch of decisions that resulted in a lot less learning.

There is right now a growing recognition, but I honestly think that it is in part through people hearing more stories like those said this morning. I cannot underscore that enough. That lead people to say—I am a firm believer that people have been trying to do what they thought was the right thing. People start to gain some recognition that maybe the way to be most respectful to

patients is to listen to what they are clamoring for and figure out new models to make sure that they are not exploited and harmed and given bad treatments as far as people can best assess, while honoring what it is that they are trying to get progress around.

MS. DAY: You just basically addressed what I was going to say, please remember in your research that it all comes down to one patient at a time, and that the numbers and the data are individual people and generally suffering people.

We have a new organization in Maine that is going to collect a healthy amount of data from all payers. HealthInfoNet, I think, is what it is called. I think today or tomorrow they will be presenting to the Maine Department of Health and Human Services their project. The concern I had is the opt-in/opt-out for patients. And as a nurse that sat at a triage desk for years and had people sign consents for treatment and consents to release information to insurance companies, the opt-out approach is just against my grain. Could somebody comment on that? It seems that we need to consent for, not consent against. I do not know how else to put that. That is a concern for me.

DR. TRINIDAD: If we can, I would like—I think that one of our talks in the next panel actually is going to come very close to exactly what you are asking about. If we could maybe address that when we get there. If yours is real quick, I have to ask nobody to stand up at this point because we are running behind. I do want to make sure that we do fair by the next panel.

MR. GORMAN: I will be very quick. Mark Gorman. I am a patient advocate. The last exchange here with Nancy—IRBs and stuff prompted me. There is a stakeholder who is lurking in the background of this whole panel who must be brought into the conversation, and that is the legal departments of the institutions and their colleagues. I am really convinced, and I am trained as a lawyer, that a lot of the variability on a lot of these issues is driven by lawyers who are doing what they are trained to do. And if they do not have the context of what patients and clinicians are actually trying to do, a lot of these problems are never going to go away.

DR. TRINIDAD: Thank you very much to our first panel. Now, we are switching gears to our second half. We will start off with hearing from Evette Ludman from the Group Health Research Institute in Seattle. She is a psychologist and senior research associate and an affiliate associate professor in the Department of Psychiatry and Behavioral Sciences at the University of Washington School of Medicine. Her research focuses 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.

Following Evette, we will have a joint presentation from the folks at PatientsLikeMe. That will be Sally Okun and Laura Phillips. Sally is the vice president for Advocacy, Policy, and Patient Safety. She is responsible for the company's patient advocacy initiatives and participates and contributes to health policy discussions at the national and global level. She is the company's liaison with government and regulatory agencies. Laura M. Phillips is a patient member of PatientsLikeMe. She was diagnosed in 1999 with multiple sclerosis after being hospitalized with a debilitating headache.

Following that presentation, we will hear from Greg Biggers from Genomera. He is a patient, caregiver, and innovator and a champion for the consumer voice across all of health care and research. 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 drive the agenda and engage with one another to grow and test health science evidence.

We will wrap up this part of the panel with Holly Potter from Kaiser Permanente. She is the vice president of public relations and 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.

Thank you very much, panel. We will go ahead and start with Evette Ludman.

Patient Perspectives on Consent for Information Use

Dr. Evette Ludman

DR. LUDMAN: Thank you, Sue. I am excited this morning to be sharing with you some data about what our patients think about data sharing. I am Evette Ludman from the Group Health Research Institute. We do practical research that helps people like you and me and our families stay healthy. We are part of Group Health, a learning health care system.

The context for the data I am going to present this morning builds off what we were talking about this morning. Existing, as well as newer kinds of research, such as genome scale, require large and diverse pools of samples and data. Thus, there is a lot of interest in reusing and pooling existing data sets for efficiency and reliability. But not much is known about what people think about data sharing, especially in the case of data and samples that were already collected for a different purpose.

Group Health in partnership with the University of Washington were a participating site in a network called eMERGE. The eMERGE Network was funded to explore the feasibility of conducting genome-wide association studies using existing research cohorts and phenotypes derived from electronic medical records. All sites were required to submit de-identified study data to dbGaP, a federally administered data repository. Out of all of the eMERGE sites, only the Group Health IRB ruled that living participants in the original research cohort should be asked for their consent to submit their data to dbGaP. Fortunately, we recognized this as a chance to learn about what our members expect and what they would want regarding re-consent for data sharing.

The existing cohort study that was being examined at Group Health is the Adult Changes in Thought (ACT) study. The ACT study is a longitudinal cohort study of aging and dementia. Participants are 65 years or older with no dementia at the time they are enrolled. Currently, there are 2,000 participants ages 65 to 102 and they have been Group Health members for a median of 30 years. ACT study members were sent an informed consent document asking if they would be willing to share their data with dbGaP, the federal repository. Participants were called two to three weeks later if the document was not received back. Our study addressed the following four questions: (1) Will the ACT study participants give consent for data sharing?; (2) What are the reasons, values, and beliefs that drive their decisions about re-consent for data sharing?; (3) Do they feel that the re-consent was needed?; and (4) What do they think about the process used to ask for consent for data sharing?

Question number one. Will the ACT study participants give consent for data sharing? Eighty-six percent of them did. Of those, we recruited 400 for a telephone interview survey. Three hundred and sixty-five participants, or 91 percent of those approached, completed the interview. The telephone survey included a mixture of open-ended questions and forced choice questions.

The first question asked was, what was their main reason for deciding to sign the consent for data sharing? Not surprisingly, generosity and altruism was the number one reason, as this was an elderly population. They said, "This is something I can do. I am too old to volunteer for other stuff, but I can do this." "As I read the letter, it would not be any benefit to me, but it would help someone else down the line." "I thought that is not a bad thing to do. I think it is important for people to contribute. If everybody did not want to, what would be the point?"

The other main reason, which echoes what we heard this morning, is a sense of trust. Patients in the study liked and trusted Group Health. They also appreciated being part of the particular original study, the ACT study. And finally, they said, "Why not? It is easy to do."

We asked in the forced choice format how important or unimportant each reason was in making their decision (see Figure 2-10). As you can see, there is incredibly high endorsement of the importance of all the following reasons: Research could improve patient care, prevent or treat illness. It could help increase knowledge for society. It could help me or someone like me in the future. Group Health researchers are leading this study. And the ACT study researchers are leading this study. These were all important reasons.

	Very important	Somewhat important
Research could improve patient care and prevent or treat illness	81%	17%
Research could help increase knowledge for our society	75%	21%
Research could help me or someone close to me in the future	61%	25%
GHC researchers are leading the study	58%	40%
ACT study researchers are leading the study	52%	43%

FIGURE 2-10 Importance of reasons in making the decision to be re-consented for the study.
SOURCE: Reprinted with permission from Evette Ludman.

We also asked them about concerns they might have (see Figure 2-11). We asked them about concerns that their privacy would be invaded or that their identity might be revealed. Concern about the kind of research this data bank could be used for in the future. Concern that their information could be used by others for their own profit and concern or confusion about the study itself or not sure what they would have to do about this study. And you can see patients did endorse these things as important, but at a much lower rate than they endorsed the reasons why they would want to participate.

	Very important	Somewhat important
Concern that your privacy could be invaded or that your identity might be revealed somehow	19%	14%
Concern about the kind of research this databank could be used for in the future	25%	27%
Concern that your information could be used by others for their own profit	21%	20%
Concern or confusion about the study itself / not sure what you would have to do for the study	11%	26%

FIGURE 2-11 Importance of concerns related to the re-consent process.
SOURCE: Reprinted with permission from Evette Ludman.

We asked open-ended questions about other concerns, and only 27 individuals mentioned specific concerns. One identified concern was potential misuse of information. One was potential for profit, and finally, privacy concerns. Many of the participants did not have any concerns. They said things like, "I do not think there is anything that you could use it for that would bother me," or again they mentioned their trust in Group Health or the UW. On the other hand, the word concern may not have been specific enough. Others took it to mean interests. When we asked them about other concerns, they said things like, "I would like them to go into the cancer field." "I do not see a lot of research with ovarian cancer."

Finally, we asked them how acceptable would it have been if we had had different types of strategies rather than the opt-in strategy that we used for giving consent for data sharing (see Figure 2-12). What if we sent a letter, asked you to contact us only if you did *not* want to agree to place your information in the data bank? In other words, an opt-out strategy. About 40 percent said that would be unacceptable. What if we just let you know by letter that we had already sent your information to the data bank, in other words, notification only? You can see a large percentage, about 67 percent, said that would have been unacceptable. And what if we added your research information to the national data bank without telling you or asking for your permission? Also a large percentage (70 percent) said that would be unacceptable.

We asked: How important was it to you that we did ask your permission? Sixty-nine percent said it was very important and 21 percent said it was somewhat important that we asked their permission. Comments about this included the full range of opinion. "It is always important to ask a subject for permission." "I do not think I would be too upset if you had and did not tell me, but I think it is nice that you let people know." "You are going through an awful lot of trouble for very little."

	Completely unacceptable	Somewhat unacceptable
...sent a letter that asked you contact us only if you did not want to agree to place your information in the databank? (opt-out)	19%	21%
...just let you know by letter that we had already sent your information to the databank? (notification only)	47%	20%
...added your research information to the national databank without telling you or asking for your permission?	54%	16%

FIGURE 2-12 Acceptability of different types of strategies rather than the opt-in strategy.
SOURCE: Reprinted with permission from Evette Ludman.

In summary, even though our respondents were willing to allow their data to be shared, the majority thought it was important that researchers asked for their active consent. The drivers of participation were belief in value of medical research and trust and appreciation for the health care system, the University of Washington, and the original ACT study that they had been part of. They placed high value on the benefits of health research, trust and appreciation for their health care system, but they also highly valued their personal autonomy.

We conclude that high rates of re-consent do not equal open-ended use of previously collected research data without future need for individual consent. Our consenters endorsed reasons against as well as reasons for consenting to data sharing, although reasons for outweighed concerns in importance.

Finally, I will mention that our ACT study participants are elderly, very altruistic, and have extraordinary trust in Group Health and the ACT study research, yet they still wanted to be asked for permission. This strengthens the argument that re-consent may be appropriate in other situations; or does it? Would a younger cohort be more or less inclined to feel the need to give active consent? I leave that question to you.

New Paradigms for Patient Engagement in Research for Care Improvement

Ms. Sally Okun and Ms. Laura Phillips

MS. OKUN: Good morning. Thank you so much for the opportunity to be here today on behalf of myself and as well my co-presenter, Laura Phillips. I am from PatientsLikeMe and I am delighted to be able to give you a little more information about what we do, why we do it, and how we do it. Laura is going to tell you a little bit about her participation on this site as well.

I am going to start by saying first that, as we heard yesterday and I think as we will hear more today, everything starts with a story in health care. The story is really so personal and important for us to appreciate and understand. I want to give you just a little bit of information about the story behind PatientsLikeMe. It began as a result of the experience of the Heywood family, and who you see here is Steven Heywood. He was diagnosed at the age of 29 with ALS,

a devastating disease. Clearly, his family was overwhelmed with what they would need to do to try to change his outcome. What they found before long was that there really was not going to be a lot of change in outcome. But what they did learn along the way was that there were a lot of people that they were meeting, not clinicians and not researchers, but other patients and family who taught them more than they could ever learn from anything else that they would be able to find in the literature.

The story behind Steven's experience and his family's experience is what has motivated PatientsLikeMe to become what it is today, and that is an opportunity for patients and families to be able to connect with each other about what these experiences are like. But I want to be sure that we leave you with this one statement here. Behind every bit of data that we collect and all the data we talk about today is a patient story and getting at that story is really what we are all about. What we try to do is harness the power of patients' stories to give it some framework, to give it some substance.

What you see here is our home page. I just wanted to give you a sense of a little bit about what patients can do. This is our public home page. You can go to this page and you can click on a number of different links here to learn to connect with patients. About a third of our patients, we have 180,000 of them today, over that at this point, but about a third of them have their profiles public. You could click in there, connect to start to find patients who might be like you or a family member with a condition that they share, and you would be able to find people who have publicly put their profiles out there for you to be able to look at and review.

But the other piece of this that I think is important is to keep in mind that we have about 1,800 conditions represented. While we started out with some very serious neurological conditions, ALS being included, and you will hear more from Laura about MS, we actually have expanded that platform quite dramatically over the last year and a half, and it is really starting to represent some very unusual and rare conditions for which there are very few people who ever find each other around the globe who are now connecting with each other. I think this has come up a lot and I want to reinforce this. This is really important. These are our core values. One of the things that we decided early on—and these have stood the test of time from the very beginning 7 years ago—it is patients first. That if we do not put patients first, we will not be able to engender their trust. We have to have their trust in order for us to be able to get the data that we need in order to be able to inform them about anything new. We have to have openness on the platform. Patients come into the system knowing that the data they are going to be sharing within the system is going to be viewable by other patients. If they decide to make their profile public, which is something they have to opt-in to do, so they have to give permission to do that, it will also be shared on the Internet.

But we speak about transparency a lot. We try very hard to be sure that we are transparent with our patients about what we are using the data for when we actually do aggregate it and share that for use. We want to create wow.

I think one thing I want to be sure that people do know here is our site is free to patients. We accept no advertising on this site at all. There is no cluttering of the view for the patient with any other kinds of information other than patient-reported data. Our business model is that we aggregate the data. We de-identify it, aggregate it, make it available to people, researchers, academics, pharmaceutical companies who are looking for some patient insight, and make that available to them at a cost. That is our business model and it seems to have started to take some understanding within the system to realize that this is a way of being able to get data that is

important about patients' experiences without necessarily having other burdens on the patient as far as charges are concerned.

We take their stories. We transform their stories into data. This process is sort of an outline. They come in. They create a profile. They find support from some other patients. They might find some other people that they want to connect with. They can learn from our aggregated reports. They can download a doctor visit sheet when they go to see their physicians or the clinicians. And ultimately, they can play an integral role in their own health care.

I want to bring attention to this and then I am going to be introducing Laura's section here. This is a fundamental question that we sought to address as we created this site. One thing that we believe in firmly is that if patients give us something, we need to give them something back. I heard a little of that earlier this morning, I think, with Peter's project, that you really need to be sure that you are always giving something back for the time patients will take to give the data that they have given. But what we want to be able to do is help people answer this question. Given my status, what is the best outcome I can hope to achieve, and how do I get there? And we put hope in there purposely. It is not a given that we are going to be able to help people achieve cure for all of the conditions that we might have within the system, nor will we in our research or in our clinical trials, but we want to give them hope. That is a key component. I am going to turn this over to Laura and let her introduce herself.

MS. PHILLIPS: I am Laura Phillips. I have been a member of PatientsLikeMe since 2008. I want you to know how PatientsLikeMe has changed my life. It really saved me. When you go to the doctors and you get diagnosed, they give you information. They send you home. What do you do? You have nobody to talk to. They cannot tell you who to go talk to because they cannot give you the names of any other patients.

Going to PatientsLikeMe, you get to talk to hundreds of other patients with your same condition and same concerns. You get out of the fishbowl and you can look out and talk to other people and get ideas and learn about the treatments and what treatment is best and why this treatment worked for them and why this person liked that. You cannot describe it well enough.

You put your profile out. Other people can go and look at it. Twelve thousand people have looked at mine to see if I had anything in common with them that they can contact me on. Your own records. You are responsible for your own records. It is important to keep track of your own records so you can look back and say I was on this drug and I stopped it at some point. I do not remember when it was. I can go back and look. It is really important for patients to keep really good physical records of their own care. And they really need to keep hard copies of any tests that their doctor does for them, blood tests, MRIs, anything. They need to request a copy of that and keep it for themselves. Most patients do not think they are entitled to that. But they really need to do it. It is very important to them. When they go back and look later and see how things progress, they will know what they have done and how they got to where they are going and what they can maybe change at this point to do something different.

They can keep track of their MSRS scores that lets them know how they have progressed, have they improved. The scores can go up, but they can also go down depending on the treatment that you are on. It is important to know. You answer seven questions and that gives you your score. It makes it very easy for you to look at your own thing.

MS. OKUN: I was just going to say that MSRS scores are a "multiple sclerosis rating scale," and it is something that we actually have validated against other tools to be able to be sure that the kinds of questions we are asking actually are representing quite well and correlating to the symptoms MS patients experience.

MS. PHILLIPS: I have been on three different drugs. The first one did good for a good many years. The second one I did not want to be on, but I had to do something because the first one was not working, and the third one that I am on now was off the market temporarily and that is Tysabri, which is really I think the best treatment out there for many MS patients, if you catch it early enough—I wish I had started it 10 years earlier than I did, but I could not. For me, it is the best treatment out there. I learned a lot about the drug from other patients on the drug starting from the trial all the way through. We have people that were on the trials to get the drug to market. For me, it has been important for me to find and listen to other people on how they have done with the drugs and whatnot.

We need to be able to share our data with other people. Researchers cannot do anything if they do not know what is working and what is not. They need the information. Most of the patients give the information because it might not be able to help me, but I might be able to help my daughter should she come down with it. We do not know if it is hereditary or not. But somebody out there is going to come down with it. They need to know what will and will not work.

MS. OKUN: You think you covered it?

MS. PHILLIPS: I think so.

MS. OKUN: Thank you, Laura. I want to say a couple of things that Laura talked to me about yesterday. One was the issue of data sharing. We have talked about some of that today. For her, data sharing is just so important that she cannot really imagine not sharing her data. That the value of that for her personally is in being able to help other people who have her condition and to be able to then try to improve that situation for them.

But there was another quote that she mentioned yesterday that I do have to share. She did not in this one. And that is that when she goes to her doctor now and she has actually worked with her doctor quite closely, the doctors says to her, "What lesson do you have for me today?" I thought that was a perfect opportunity for us to understand that the physicians and clinicians—we have to say to our patients, "What can you teach me today that I can actually even use with you and then use with my other patients as well?"

I want to move right into the next part of this, which is partnering with our patients for research that matters to them. I have some results here. Some of these are in your packets. Some of them I am not going to go into too much detail on because of time. But I want to bring your attention to this (see Figure 2-13). This was a user survey we did across this site and I just pulled out one of the factors, medication adherence, which is a big economic issue. What we demonstrated was that, across the board, almost all of our conditions (and at the time we had a limited number of conditions) patients were reporting that being on this site actually helped them improve their adherence to their treatment regimens. It was particularly significant in HIV, where drug holiday conversations were quite pervasive on the forum. What a lot of the patients actually did was, they took snapshots of their charts, put them into the forum conversations to show what happened to their viral loads and other symptomatology when they took a drug holiday, and said, "Just do not do it. It is not worth it." It is incredibly important to have that kind of data sharing happening among patients.

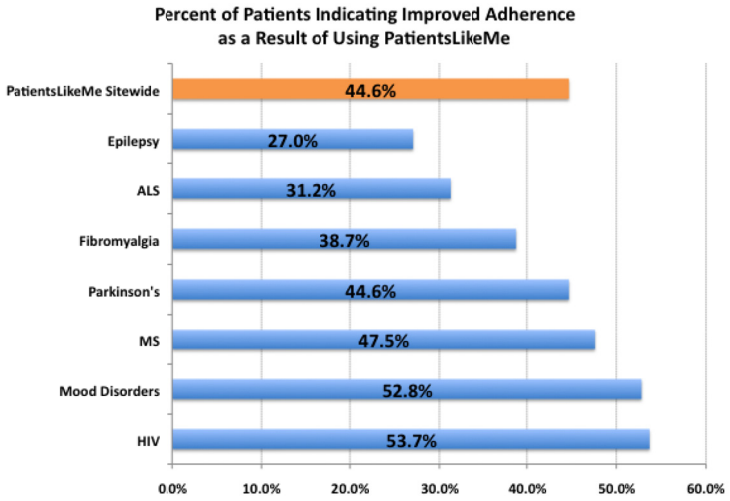

FIGURE 2-13 Percent of patients indicating improved adherence as a result of using PatientsLikeMe.
SOURCE: Reprinted with permission from PatientsLikeMe. Data from Wicks et al., 2010, 2012.

This is our epilepsy user experience and again this is in the packet. It has a lot of information in it. But it was very clear that we had patients who were really learning a lot about things that they did not know about prior. But the one thing that really struck me in this particular survey was that one-third of our epilepsy patients had never spoken with another patient with epilepsy. It is an isolating disease as it is. Imagine that you have never actually had someone else that you could share your experiences with.

The other work that we do is—this was a research project that we did on off-label use. We have a huge amount of data in our system. And patients and their clinicians are working with drugs that have not been approved for the purpose that they are using it for. We believe quite strongly that our data is actually quite useful for us to be able to better understand the prescribing practices on off-label use. I think the good example is ALS patients are using amitriptyline, which was approved in the 1960s for depression. It has never been approved for anything else, although we know we use it for lots of different things. They use it for the primary side effect of dry mouth, because it dries their secretions and quite effectively actually.

The one study I want to bring your attention to that really brought, I think, a lot of attention to the power of a social media environment was our lithium study that was done in ALS. The original study looked at 16 patients in Italy with 29 controls. It showed that there was some indication that lithium was slowing the progression of ALS. That type of news is quite important for people with ALS. What we were able to show in a relatively short period of time by using historical controls, using a matching algorithm that we created because of all the data that we had, which was functional rating scores, similar end points that are used in clinical trials, was that there was actually no indication that lithium was going to decrease the progression. We did that, and in about 6 months, we had that data. We had 10 times the amount of people that were in the study originally, and actually in the end, three additional studies were funded after our findings at the cost of $30 million; all ended in futility. I think it is just an opportunity to think about a new novel data source. You can also see that whole article written up in *Nature Biotech*. And then *The Wall Street Journal* did a little study on that.

I want to introduce you to an exciting new development that has just come out. We have recently been funded by the Robert Wood Johnson Foundation to start an open science initiative, which is going to be doing a partnership with patients and researchers, where we will begin to develop PROs, patient-reported outcome measures, that are actually iterated and worked on within the system. We can have researchers who are coming up with questions, put it out into the field, test it with patients, come back and say this did not go so well. We are going to try a different approach. But we will begin to gain a lot of knowledge about what it is going to take to come up with the right sets of PROs in order to measure patient experiences. We do not have a lot of those that are relevant today. Some of them are quite old. This will all be done in creative comments as well. All of this information will be open. We are quite excited about the opportunity and grateful to Robert Wood Johnson for the funding on that.

I am going to close with something I think we have heard a lot about. One of the things that have resonated a lot over the last day and a half is that we have to listen. This haiku I wrote in response to a—I will say it to you because I know it. "To learn, listen well, to impressions voiced by, patients first." It encompasses everything we are about and I think it is everything that we have been talking about. We need to learn to listen well and I think we are up to the task.

Thank you very much. And thank you, Laura, so much for your participation.

New Paradigms for Patient Engagement in Research for Care Improvement (Part 2)

Mr. Greg Biggers

MR. BIGGERS: Good morning. I wish a special, good very early morning to those of you watching online from my native land, the Pacific Time zone. In addition to leading Genomera, I am also on the Board of Genetic Alliance. I am helping them as an entrepreneur-in-residence launch some initiatives like Reg4ALL, which I will talk about this morning.

Sue opened our session this morning talking about epistemology, how we know, and identity, who are we. I want to highlight a couple of projects where we are learning new kinds of epistemology and where we are answering I think, maybe not so much who are we, but who is "we." We see a new form of "we" emerging. In fact, I invite you if you are the twittering tweeting type to join a bunch of us who are using a new hashtag, #thenewwe, to talk about this new world, where we stop othering one another in the research and health care ecosystem and find ways to work together in partnership.

I will talk about a couple of these projects and then also enumerate some cultural principles driving what we are doing. Here is the context for Genomera participant-driven studies. They are a bottleneck, constricting the flow of discovery in health research, the flow of evidence development. There is already a pool of questions that the health sciences should be able to answer. But everyone assumes that getting that work done is constricted by two major factors. It is either the need for government or foundation funding. Here in DC, it is on the news all the time. The sequester is coming and the threats that even agencies like the NIH are under to reduce funding. Or, it is waiting for the mass market economics of the drug industry to get around to caring about whatever a person's particular question is.

Hopefully, with no offense to my colleagues in the room from the pharma industry, if you look at what is happening there, the drug industry is under threat from absolute pharmageddon as the economics of their system collapses upon itself. We can quickly reach the conclusion that

there is little hope there to solve the long-term problem in health. And the result is too many questions go unanswered.

The Genomera community has found a way to invert those constraints to grow the number of people who can organize and operate health science studies and dramatically grow the number of people who will participate, orchestrated largely through online means, using a cloud-based technology infrastructure to reduce the cost, grow the speed, and serve a matchmaker function connecting the people necessary to dramatically grow the rate of discovery. It is a place where anyone can come with a question that health science could answer. We help them turn that question into a study with a hypothesis to test, with a protocol to follow, inclusion/exclusion criteria, things like that. The basic structure of a typical clinical study or trial made accessible to people who have questions they want to answer.

Then they can launch the study, invite others to join them. In fact, they often invite others to help design the study as it is emerging. People who will join the study follow the protocol on themselves and allow their data to be shared with the group for joint analysis. It is intensely participant-driven health research. And people are applying it to the entire spectrum of health topics, ranging from awfully complex genomics and biomarker discovery to simple surgical outcomes and everything in between. That is a quick vignette about Genomera participants driving research and evidence development.

Next, I want to talk about a new project that was funded by a grant from Sanofi at the end of last year as a winner of their collaborate activate challenge called Reg4ALL, a participant-controlled, cross-disease registry. Reg4ALL grew from a few key insights. While there are plenty of registries sprinkled around the world, industry-controlled registries are often high quality where they exist. But there are too many diseases to cover. And it has been immensely difficult to build sustainable communities of trust in those registries.

Disease advocacy organizations and their registries also lack cross-disease capabilities. They are often hampered by difficult economic sustainability questions in the nonprofit world, and too many organizations feel forced to reinvent the wheel every time they want to spin up a new registry. And all the while we are missing our most important resource, which is people and their data coordinated.

The world has various groups looking for the needles in the haystacks, and great experts are doing this work. But the haystack, it turns out, is made of needles. We are discovering that our subtle health issues influence our acute health issues. Our comorbidities are ignored in our payroll. And rare diseases may contain keys to unlocking more common conditions. In other words, my thyroid condition, my vitiligo, and the effects of an automobile collision are all integral parts of my whole health. It is time for an approach to registries that recognizes that reality, that welcomes people and their data spanning all of health and disease. We are building the software, developing a new kind of governance, and growing a community that will engage together across diseases.

Speaking of culture and the ethics-oriented panel we just heard from, we are doing it in a way with a culture of individualized locus of control as one of the cultural foundations exhibiting a participant-centric approach to everything about the registry, including granular and dynamic consent or a normal person language sharing permissions, so that a member of the Reg4ALL community exercises explicit control over what data they store, for what purposes their data can be used, what projects may use their data or not, and who may or may not contact them for additional studies or follow-up work.

We are seeing two really interesting phenomena across these two projects. The first one is a tremendous appetite to engage. We first watched and are now guiding people through a transformation and how they think about themselves in relation to the research enterprise. Beginning with N is someone else. N equals *they*. I have a question about my health. I hope that someone somewhere who I am sure I will never meet is in a trial about it, and the results will be written up in *JAMA* or the *New England Journal* or *Nature* or wherever. Eventually, my doctor or I will read about it, and we will know what to do. N equals me in this world of digital health. The data liquidity we just heard about. I ought to be able to ask that data about my own data questions about myself. It is kind of seductive to get in there and look at this. And the quantified self-world is right at this point, N equals *me*.

But then people realize that in order to handle anomalies, in order to achieve statistical significance on a population basis and to practice good scientific rigor, it is really helpful to work together and come around to this notion of N equals *we*. In these communities, with our individual locus of control, but expressing it collectively, we are marching into this future. N equals *we*, an appetite to engage.

The second phenomenon we are seeing is we are watching roles expanding and blurring people, the people doctors call patients. We tend to just call them people. They are moving from subjects to participants to often collaborators in the research endeavor. And ultimately the roadmap goes to people becoming shareholders and the benefits of research. And this continuum of roles and power has been really foundational in our thinking about participation and the governance of these projects.

What are the underlying cultural drivers of this new era of participation, of engagement in health science and development? These are the desires we are seeing over and over again that are now driving the cultural foundation for both of these projects. Let's just talk through these. This is my last slide actually. I think this is the summary of all that we have experienced in the last 3 years. The first one is control. We want influence over data, tissue, intent, outcomes, and of course, you should ask permission to use my data or tissue and offer the choice to participate. In the age of social networking and tweeting and Facebook and Foursquare, it is not that hard to ask sometimes every time you want to use a piece of data and let me know when you are doing it. We want trust. We do want to cooperate with all of the stakeholders and engage, but it has to be a conversation where a single consent event is replaced by ongoing governance, dynamic choice making where communication is bidirectional. We want impact. This is the part that often goes unsaid, because we assume it is obvious, but let's make it said. We want impact. In our communities, we are constantly asking ourselves what is at stake, and we join in common cause so that we will make a difference.

We will be shareholders in the benefits, including I think future economic benefits, because we are already shareholders in the misery and in the risks. Let's be careful here in this room, where we are excited about the new paradigms emerging. Let's be careful that we do not inadvertently bring to the world new schemes that we call sharing, but really look like a form of data share-cropping rather than true participation. We want to be owners and partners.

And finally, and I think this is the biggest change inflection point we are seeing in this cultural foundation for these projects we are doing, is we are seeing that people want to express their rights in addition to having them protected. It is exciting that we finally have the technologies and tools and policies that help us do that. A bit about these two projects and some cultural underpinnings. Thank you.

Research That Improves Care as a Competitive Advantage: Communicating the Importance of Data Sharing to the Public

Ms. Holly Potter

MS. POTTER: Hello. I am Holly Potter with Kaiser Permanente. Many of you may be familiar with me or familiar with the organization as a nonprofit health plan and care delivery organization. We serve nine million members across the country. In addition, given the makeup of this room, I suspect many of you are familiar with our use of information technology. We have one of the largest electronic health records in the world, with more than nine million members being cared for daily through the use of an electronic health record, and they have access to that data through a personal health record on kp.org.

But what many people are not aware of is we are also one of the largest non-university-based research institutes in the country. We have research institutes in each of our nine operating regions and actually conduct about 2,000 studies per year. In 2012, we published a thousand studies in peer-reviewed journals.

As a learning health care organization, we believe that research is critical to improving our clinical practice on a day-to-day basis. As many of the folks in this room have talked about this morning, there is an acknowledged gap between the evidence and practice that each patient and provider is faced with each and every day. We are very fortunate. I am sure many people in this room were influenced by the 2003 findings of Elizabeth McGlynn that demonstrated just how stark that gap between evidence and practice was. She is now part of the Kaiser Permanente Research Institute. She is leading our Center for Effectiveness and Safety Research, helping us look into how can we more effectively translate research into practice and speed the discovery of what works and what does not work for each individual patient population.

As the introduction earlier noted, I am a communications person. I am in Brand Communication at Kaiser Permanente. I am not a researcher. I am not a doctor. My job is to help various publics, ranging from our workforce to our members to other stakeholders like those in this room, better understand what Kaiser Permanente does for the sake of advancing health research and transforming health care. As I look at that role, I think one of the things that we have struggled with is helping not only our patients, but actually our providers, understand how critical that intersection is between day-to-day practice, our electronic health information, and the research that can result from that, and then ultimately translating that research into practice. This is not a simple concept and it does not come naturally. Helping people better understand the benefits is one of the objectives of the team that I lead.

One of the projects that I wanted to share here today that had some really specific findings about some of those gaps in knowledge is a program called the Research Program for Genes, Environment, and Health. In 2005, we began an endeavor to go beyond the information in our electronic health record and actually begin to systematically collect DNA data from our members. We set a very bold target of a half a million DNA samples so that we could begin to analyze longitudinal health data, genomic information, as well as the environment that our patients live in.

We are very fortunate as an organization that we have members who we often refer to as "sticky." They are particularly in our regions like Northern California, Southern California. It is not unusual for a member to be with us from the day they are born to the day they die. Because we were an early pioneer in electronic health records, we actually very often have 40 years or

more of clinical information about the patients that we serve. We see that as an opportunity to really dive deeply into better understanding the clinical outcomes that those patients experience. But because some of our patients are also not very mobile, they are not moving from one city to another very frequently. We have patients who have lived in the same city, for example, Richmond, California, since the days of the shipyard, when our health plan was created, and still live there today. What would it mean to analyze their clinical data, their genomic data, and the environment in which they live in to better understand what really influences the clinical outcomes that come to be?

As we began the process of trying to recruit members to donate DNA to this effort, we began with the way everybody does. We send a letter. Very old school. We sent letters to every member in Northern California. I was one of the people who received them. I actually was someone who knew about the study, knew about why we were doing it. And I immediately filled out the first survey and said I want to do this. I want to participate. I was part of the 25 percent response that we got back of people saying, "I am very interested in this."

Then I got the second packet, which were all the IRB consent forms. I am fairly well educated, fairly well informed. They were hard to understand. It took quite a while to fill that out. I had to fill that paperwork out, submit it, send it in, before I could even get the ability to basically spit in a cup and send my DNA back to the lab.

By the time we went from the 25 percent of people saying absolutely, I am interested in this, I care about this, I want to participate—by the time people went through the actual consent, that dropped down to 5 to 7 percent response within that 25 percent.

Fortunately, we have a very large group of people to start with. To date, we have collected 200,000 DNA samples. We have done genotyping on 100,000 of those samples for an NIH-funded study. But we also recognize that of those that were returned, it was a self-selecting group, and we had a very high percentage of predominately white women, 40 or above, which does not lead to a lot of actionable data if one of our stated intents is to look at the environmental and demographic factors that may be creating health disparities, which is one of the core objectives of this study.

We had to take a step back and really look at what was it going to take to bring in a more diverse set of data. We have tried a couple of things since then. We have done e-mail recruitment and that increased outcomes a little bit. We were able through kp.org, which is our personal health record, to change opt-in features so that people could start receiving requests for participating in this study via e-mail. We have also done clinical interventions. We specifically tested it with pregnant women. And we were able to find an uptick in participants by that doctor-patient conversation. That, while it shows promise, is also very complicated, because if we are looking holistically, number one, doctors do not need another thing on their list to do in their very short time period with their patients.

But in addition, if we want to look holistically at the populations and what is or is not causing clinical outcomes, we need to be looking at the young and healthy and people who are not actually coming into the clinic for services. We are looking at new strategies for reaching those populations and particularly have identified a gap in young men of color who we have not been able to reach through traditional mechanisms. Moving into 2013, we are looking at increasing digital strategies for communicating with those populations and recruiting them to be part of these studies.

Overall, as I noted earlier, these are complex subjects and getting people to understand not only that they are doing something altruistic for the better of science, understanding that there is

an easy in to participation is one of the challenges that we continue to struggle with because of the regulations and expectations of all of the various consent processes. Communications will continue to be a critical piece of this intervention and this effort. But we are hopeful that as we begin to publish information and demonstrate the value of this data, we will be able to continue to recruit people into this program so that we have the data necessary to do really groundbreaking research.

Audience Participation and Open Discussion

Dr. Susan Brown Trinidad (Moderator)

DR. TRINIDAD: Thank you very much. And please join me in thanking the panel and we are getting closer to getting back on time. If the folks in the audience have questions, if people on the webcast have questions and you like to send those in now, we are ready for you.

MS. CAMPBELL: My name is Janet Campbell. I am a software developer. I work on finding ways of giving patients access to their information to engage them more. That is not what my question is about.

I am having a moral quandary actually. I was thinking about this. It is really interesting. I had always taken the perspective that would be consistent with HIPAA, and some of the things that Alice was talking about, that said that if data is de-identified, there is very little potential for harm. I could consent. I would not need to consent, because how would you know it was my data? I started thinking about that though, and realized morally and ethically that if my data was being used by people whose methods I did not agree with, like by big pharma, if I did not agree with the way they practiced this, or if it was being used for purposes that I did not believe in, should I have that ability to offer consent? I think that would be what Gregory would argue.

I was wondering if maybe Nancy or anyone, actually the two panels before, could speak to that trade-off in my moral obligation, or the moral obligation to me, to be able to consent to that, versus the practicality and definitely the self-selection bias that you talked about there as well.

MR. BIGGERS: That is a deep question actually. The two projects that I highlighted today are beginning with populations of people who already know how to make themselves somewhat accessible. And fortunately for the world, those mechanisms are becoming much more widespread very rapidly. In the pioneering phases of this project, the fact that the first people to engage with other people who are already relatively comfortable using the Internet in some form has afforded us I think a temporary flexibility or maybe moral power even to access that moral choice point in a pretty context-specific and broad enough form. I think that we do not know yet how that will be operationalized as we engage with the next group of people and we let them engage with us, and we let them change us and our expectations and our governance.

Because of that, because of some of that uncertainty about how do we do that, making that moral choice accessible enough to each participant, we have emphasized some ethics team kinds of gatherings way up front of the actual operationalizing of the consent process. For example, Reg4ALL has convened an ethics team, not an IRB. These are pre-IRB kinds of things. But an ethics team that is part of the foundational set of teams running the program to help us think way in advance of when those things need to happen. I hope that was not a copout answer, but that is how we are thinking about it so far.

DR. TRINIDAD: I think that is helpful and I think what you are alluding to in terms of participatory governance models moving forward in … we have talked a lot about trust and

groups that are standing, trusted bodies possibly as a trade-off against one-on-one consent processes as things have worked in the past. Let's go to Matt and then we will go over here.

DR. WYNIA: Matt Wynia from the American Medical Association. I want to continue on this same theme because one of the things that Holly mentioned toward the end was really intriguing to me. There were a couple of reasons why it was challenging, or maybe even inappropriate, to rely on physicians asking patients to enroll. You mentioned a couple of pragmatic things. You only get sick people if you ask doctors to be in charge of enrollment. The concerns we usually have about asking doctors to be in charge of enrollment are that you get implicit pressure on the patient to enroll, because the patient wants to please the doctor often, and that there is a therapeutic misconception risk that the patient may believe that enrollment holds direct therapeutic benefit to them. After all, everything else the doctor offers is supposed to offer direct therapeutic benefits. It gets all the way back to what Nancy started with: the distinction between clinical care and research. And when you start asking doctors to enroll their patients in clinical trials, you worry a good deal about therapeutic misconception and the pressure that could come to bear.

In this instance, I think one could make an argument that in fact, maybe it is not morally obligatory for patients to be enrolled in this, but it is certainly morally praiseworthy. It is a good thing for them to do and their doctor may actually feel that. This gets to—I guess maybe the same thing the prior question was asking about, is to what extent should we use moral suasion or even notions of shame and communitarianism to encourage people to be parts of these shared communities? It is not quite as simple as just opt-in or opt-out. I think there is a sense in which some folks are asking us—I am going to try and be agnostic here—are asking us to use a bit of moral persuasion to get people enrolled and to get people involved and to share their data.

I was involved in a project a few years ago with the Hastings Center, looking at ethics and quality improvement and what kinds of review should quality improvement projects undergo since they do not have an IRB. There were a fair number of people around the table who really strongly believed that when you come to a health care setting, you are in effect taking part in an enterprise where you get benefit from all those other people who allowed their data to be used for quality improvement over the years. As a result, you had an obligation to allow your data also to be used, that there was an implicit agreement. Granted that is an implicit agreement you cannot walk out of. In many instances with QI, you actually cannot segregate those people whose data are being used and those who are not. There are a lot of practical issues there.

I want to ask the moral question about using shame, guilt, or altruism explicitly as a way to engage people in research enterprise.

MS. POTTER: I think in particular for the cohort that we did use physicians to recruit, it was with pregnant women—not only did that have the moral suasion of a physician suggesting they may want to do that, it was also the moral suasion of you can make the world a better place for your child. There certainly is that heartstring to pull. I think there is an altruism that in the health care setting we can bring into that conversation. It is interesting that you talked about physicians being perceived as putting pressure on the patient. At the same time physicians are such a trusted voice for patients, and having that conversation and building that trust about why they are being asked for that information I think is a valuable conversation to have.

MR. BIGGERS: Can I add one quick thing to that? At Reg4ALL, one of the ways we are handling that conflict is we are being cautious to not make any kinds of motivation normative for the whole community. And to help us do this, we are developing a set of guide personae, where you will actually be able to watch a video of somewhere between three and five people who

represent a kind of typed view on what level of sharing they are comfortable with. And one of those people will be almost isolationist. Very privacy concerned. They do not want to share very liberally. They want to be asked every single time. One of those people will be on the far other end of the spectrum. What the quantified self people are sometimes accused of, being data exhibitionists. We will probably have someone like that. There will be a couple in the middle. We are trying not to have that system norm, a certain kind of reason that you are participating, but still let various kinds of participation.

DR. GARDENIER: Turkan Gardenier from Pragmatica Corporation. The database that Holly Parker described of Kaiser Permanente certainly addresses a lot of data gaps that we as researchers trying to link health and environment and locational effects do face. Now, my question is if a private researcher who also happens to be in the past a member of Kaiser Permanente who is doing some research and wants to further her efforts on data gaps, would that be available to people like me? If I do not release their residence or identity, but I want to get groups of people who have lived in certain environmentally exposed areas, for example.

MS. POTTER: We do partner with others outside of Kaiser Permanente. We typically pair those researchers up with our own researchers. And then in addition of course any study that is used with the data is also subject to IRB approval. It would have to go through the traditional processes and be an approved project through all of the standard processes.

DR. GARDENIER: Through your organization?

MS. POTTER: Yes.

DR. GARDENIER: Would you have to go back to the patients?

MS. POTTER: The patient's information would all be de-identified by the time it reaches the research stage.

DR. TRINIDAD: I am just going to ask to limit questions to the folks who are currently standing so that you all will get a break.

MS. BINGHAM: My name is Paige Bingham. I am with the Medtronic Foundation. One of the quotes that Greg put on his slide was in the 1990s, patients were occasionally invited to the table, and today patients control the table or something along those lines. I raise that question because through the Medtronic Foundation's philanthropy, we have been able to support patient advocacy groups starting in 1998. One of the groups that we have supported has been the Epilepsy Foundation. Sally commented about PatientsLikeMe and a third of the population of patients indicated that they had epilepsy and had never connected with another individual with the disease, even though Epilepsy Foundation is one of the very strong organizations out there that makes an effort to connect with patients.

I do look at the range of patient organizations from Juvenile Diabetes Research Foundation that I believe a huge percentage of type 1 diabetics and their families are supported by and connect with other type 1 diabetics. And I think of Dr. Frosch's opening comments where he talked about diabetes and the need to be highly engaged family caregivers from the very beginning. I also think about the Parkinsons Action Network, which is actually meeting these 2 days right now. That is the PAN network going across American Parkinson Disease Association, national Parkinson's.

There is a combination question here, which is how do patients really get to the table. Who represents them? How do we help organize them so that they have a strong voice? And then also, how do we engage patient organizations to help the access for those that are underserved—the African American males who are not readily participating. I look at the Parkinson's UK model where they actually are actively engaged with NHS and providing clinical nurses at the regional

centers. That is a philanthropy effort through Parkinson's UK that really gets into access. We would love to hear the panel talk about patient organizations, the new ones that are developing, the old ones that exist, and how do we help individuals with the disease continue to be empowered. Thank you.

MS. OKUN: Great question. I will let you know a little bit about what we have been doing for a while now. We actually do partner with nonprofit organizations to help them get their patients who might want to be a participant on PatientsLikeMe. And we do that in a few different ways. We may work with that nonprofit and develop what we call a "landing page" that is unique to them. We have a number of those so the MS society and the psoriasis society and a number of others where they provide a link on their sites. We do not want to be siloed. We want to have an opportunity where the good work that is being done in some of these other organizations can come together with what we are trying to do. I think what we can offer is that longitudinal view of what the experience is like, and then provide that social component that could be a link to yours as well.

We have a whole variety of ways of being able to address that. I think it is becoming more and more apparent all the time with some of the very rare diseases that have small groups really that formed at the kitchen table, in fact, and some of them still at the kitchen table where they can come to our environment. We can talk with them. And we do a bit of a trade-off on that. We are looking for them to help them activate their members to become active engagers on our site, so that we can actually gather the data that they might need to answer important questions to that population. We see it as a trade-off and we work with them all the time to try to figure out the best economical way for them to be able to be a participant with us as well as still maintain the mission that they have with their own organization. We welcome that opportunity for any organizations that might want to do that with us. We are very happy to do that.

MS. STERLING: Good morning. MaryAnne Sterling from Sterling Health IT Consulting. I wear many hats, but the most important one is I just started my 17th year, that is 17 years as a caregiver, health care system navigator, and health coach for my aging parents and in-laws, three out of the four of whom have some form of dementia.

The point I want to make is not a new revelation, but I think it bears repeating. As a nation, we need to step up and recognize the critical role played by the family caregiver. We are not only key members of a patient's care team, but storehouses of rich information for research purposes. I encourage everyone to include the family caregiver in their research initiatives. Sally, I still believe we need CaregiversLikeMe.

MS. OKUN: We have had that conversation before. What we are trying very hard to do is to make our functionality much more robust for caregivers on the site. We are actually seeing more and more children as patients on the site. It is their caregivers and parents who are actually the ones providing a lot of the data entry. We actually are working very hard on that. We have a large autism population. And, again, as I talk about the rare diseases, many of them are with children. We are finding that our functionality for caregivers and their clinicians—we are actually doing some provider portals now as well where we are able to demonstrate if we can make the access available to the clinician as well as the caregiver, the patient's outcomes will actually improve overall. Thank you.

DR. MONTORI: Victor Montori, Mayo Clinic. A couple of brief points. The first one is that we need to avoid compartmentalizing our heads. Yesterday we were talking very actively of our shared decision making. And obviously one of the choices that patients can make is to participate very actively in the kind of opportunities that you are talking about. Interestingly, I do not know

that there are robust shared decision making offers for people to come in and something like Gregory was mentioning, for instance, those personae they are talking about. There may be some sophisticated ways to help people make informed decisions about participating and beyond consent and other things. Just a compartmentalization alert.

And then the second thing is going back to my previous question, which went unanswered and had to do with the issue of generosity. When you have a generosity base for repository of goodwill and data and it is used to advance science, which is a common good, and then you turn it into a revenue-generating for-profit institution, the risk that I think we run is not fear of misusing those. Of course, they are there. What concerns me is then it becomes an economic transaction. If I participate, what do I get back in terms of dollars? It becomes an economic transaction, and the behavioral economists have pointed out the motivation driven by economic transactions lasts very little. And then the goodwill that was the basis for the enterprise is not recoverable once you introduce the economic transactions. I want to bring that up as an issue and see if there are any comments this time.

MS. POTTER: I would actually love to comment. I think that is something we struggle with every day. We have 9 million patients who entrust us with their data for their patient care. We have the opportunity. We also believe the obligation to mine that data and better understand what drove those outcomes.

With that in mind, we are very strict in terms of how we regulate that usage of that data and are very careful to make sure that we never do anything to betray the trust that our patients have given us. I think as we look at this field right now, trust is something that each of us have to earn. Each of our organizations needs to learn from the patients that we work with to ensure that the data that we use truly advances the science and advances their own clinical outcomes.

MR. BIGGERS: I think the world is facing new ground on this topic, because we are seeing a much more imminent collision of generosity-based communities with economic-based corporations. By law, most for-profit corporations are economic interests, not missional interests. This has always existed. But something feels more imminent about this collision now that is happening in near real time, and I think we will learn a great deal about the conflicts and how to work them out. That is why I introduced us to this term of shareholder-ness, even for patients and participants. But something is shifting. And the network economy is going to look different. But the generosity and the goodwill I am afraid is not sustainable if it is not reciprocal. There is conflict coming.

PARTICIPANT: I just want to make one comment on that and I agree completely. I think it is important as a for-profit company, it is important for us to have those core values. They drive what we do and how we make decisions. I think that there is a tension. It is starting to collide. It is sort of, we are accustomed to having research done in what are typically considered nonprofit and nonprofit-making organizations. But where innovation really lies is within areas where people can invest money into something to try to make a difference within the usual paradigm and come out with something that could be quite different, but that actually is going to have an impact that will be for the betterment of the rest of us.

I think it is important. We have talked about this much. I feel very committed to it, and I know my company is as well, to this concept of trust and building it. And then once you have it, you had better protect it. You had better take care of it. If we are not free and open with what we are doing with the data that we are collecting, and letting patients know how that it is being used, and giving it back to them in a way that they can make useful in things that matter to them, then we will fail to get that trust. We should not then be allowed to continue and be able to collect that

data. There definitely is a tension. It is shifting. I feel it every day, but I feel like there is an opportunity for new innovation when we allow investment in new ideas. I think that would be important to have that on the table. Thanks.

DR. TRINIDAD: Thank you all very much. One last closing thought would be, I struggle sometimes with the problem being defined as a lack of trust. I think there is a problem of trustworthiness that we need to be thoughtful about. I am really appreciative of everyone that has spoken on the panel this morning. I think these are folks who have a handle on how to get at some of these issues. Now, you are off to your breaks. Thank you very much to everyone on this panel and to our earlier panel. Thanks for your attention.

Break

CHANGING EXPECTATIONS: BRINGING TRANSPARENCY TO COST AND QUALITY INFORMATION

Dr. John Santa (Moderator)

DR. SANTA: My name is John Santa and I am the moderator for this panel. I am from *Consumer Reports*. I am thrilled to be the moderator for this panel. We use the work of these panelists every day at *Consumer Reports*. We do not always get it right. Advice like they provide is crucial to us.

I am going to go right to the intro. I like to use sports analogies. I think most of you will get these. You should know actually this year I watched *Downton Abbey* rather than the Super Bowl. But I am not sure that I am familiar enough with it to use *Downton Abbey* analogies, but they are in my future.

Judy Hibbard is going to start. Judy and I are Oregonians. Like the University of Oregon Ducks where she teaches, she is going to come right at you with a spread offense, no huddle. You are going to need to listen to everything she says, because at any moment she could go right over your head and score. This is a woman whose work really is changing how we are communicating to consumers.

Following Judith, Shoshanna Sofaer. Judith and Shoshanna have teamed up a lot on their work now. Shoshanna is a New Yorker. She will tell you that she is on sabbatical. The New Yorker on sabbatical is like an Oregonian after five cans of Red Bull. Shoshanna is just so great at synthesis. She is so great especially in the question and answer session. Save those questions. She reminds me of that New York Giants receiver who in the Super Bowl, the final drive catches the ball with his head, puts it up against his helmet as he is hit, and manages to keep position of it as he falls and scores. Shoshanna is like that for a lot of really tough questions.

Following Shoshanna is Barbra Rabson from Massachusetts Health Quality Partners. Barbra really is an expert of the art of collaboration. She is in the middle of so much of what goes on in Massachusetts and trying to get the word out about performance and especially performance of physicians. In many respects, as Barbra and I know, she has to deal with the players union, and in Boston that is like dealing with the Red Sox players, a group not very easy to deal with these days. She has done a great job of that.

Dan Wolfson is really the genius behind Choosing Wisely. This guy has managed to get stuff done that many of us try decades to do with physicians and professional societies. He has

managed to get them to step up to their professional responsibilities. Now, Daniel is going to do what every good coach does. He is going to show you some film. He is going to get you right down in the trenches and show you what the interaction between the players on the playing field is like.

The last speaker is Marge Ginsburg. Marge has to be one of the last idealists in California. She actually thinks you can get the owners, players, and fans on the same playing field and get something done. It will be very interesting I think to see what she has to say.

These folks are each going to go 10 minutes. They are on the clock. I am not a replacement referee because our biggest objective is to get to the discussion part because that is what we really want to see—a free-for-all with all of you interacting with them. Thanks to the panelists.

What Patients Perceive as Valuable—and How to Effectively Communicate Information on Cost and Quality

Dr. Shoshanna Sofaer and Dr. Judith Hibbard

DR. SOFAER: To continue as much of a sports analogy as I can possibly pull off, we are doing tag-team. Judy and I have worked together for so long that it comes naturally to us to pass the ball back and forth, so that is what we are going to do.

What we are going to talk about are the challenges. A lot of people want to give consumers information about price and about cost and about resource use. Take a deep breath because this is not easy. In fact, this is potentially dangerous. Judy and I got to do a little study with a lot of help from our friends, including our friend Barbra Rabson, about the challenges in communicating with consumers about cost and resource use. It had two phases. I am going to talk about the first phase. Judy is going to talk about the really needy second phase, where we have an actual randomized trial. And then I am going to wrap up with some of the implications.

The overall study was designed to identify how could we provide consumers with comparative information about provider cost and resource use. We were funded by AHRQ. They should get the credit for this. It was done in collaboration with The Health Collaborative in Cincinnati, Ohio, which was for the first phase, and Massachusetts Health Quality Partners. Let me tell you as a resource how fabulous it is today as opposed to maybe 10 or 20 years ago, to have these kinds of partners out in the field interested in learning, interested in participating in research, and using research. I just want to put that out there because it is a change in what our environment is as researchers.

In the initial exploration, we did focus groups. And in the second phase, we did a Web-based randomized trial of alternative formats for sharing cost information. The three focus groups were conducted in Cincinnati, Ohio, with the folks from the collaborative there. All of them, we should note from a sampling perspective, were people who were getting their insurance through employers. This particular collaborative is particularly influenced by the purchaser stakeholders. That is one of the things that it has in common. And one of the things about that market is that there are a lot of folks in that market whose employers are offering them high deductible health plans or consumer-driven health plans. Of the three puny little focus groups that we did, but there have been more focus groups done since, about two of the three groups were with people who had high-deductible health plans. Note that one would have an expectation that those folks would be more price-sensitive and more cost-sensitive. Not really. Then we also had about half the participants with chronic conditions.

Here is what we found out in these groups. Consumers tend to think that when it comes to medical care, more is better. These are the mountains that we have to climb. Some consumers, many consumers, really equate higher costs with higher quality care. And as Judy says, since that is true in every other part of our economy, we should not be surprised that they have this view, not to mention the fact that the health care delivery system has carefully inculcated these beliefs in consumers these many decades. We should not be surprised.

Many consumers would rather not consider costs in their health care choices. Health insurance is something else. Health care. Some of the people in these groups were flat out offended at the idea that they might have to look at cost and take it into consideration. Also, for these groups of people, the term *value*, as we will explain, just does not compute the way that we use it. Not going there. For example, we asked consumers to respond to a list of definitions of "high value" in health care. I sent Claudia a handout for you folks, which I hope you will get, which is a list of the statements that we came up with, and we asked people to say which ones they really liked and which ones they really hated. When we said they could pick three of each, they wanted to know could they pick only three of the ones they hated. That tells you where we are going.

All of the definitions that people really liked focused pretty much exclusively on quality. All the definitions they did not like focused only on cost. Consumers are afraid that getting value means getting less than the best quality and this is a core challenge. We need to help people believe that they can get high-quality care at a reasonable price and the term "value" per se does not work, and we still need to do some more work to figure out what works. I am now going to throw the ball to my dear friend Judy Hibbard.

DR. HIBBARD: Thank you, Shoshanna. Good morning. As Shoshanna said, we are really at the beginning of this process of giving consumers information about cost. It reminds me of when we were at the beginning of giving consumers information about quality. We just put it out there and they will come. In this case, they may come to it in a way that we did not intend that they understand and use it.

There are some key challenges and there are some real potential pitfalls with putting out cost information without understanding how consumers may interpret that. In what we learned is that consumers' greatest concern in looking at cost information and using it is that they do not want to get cut-rate health care. Low cost is scary. In the way that we present information, we have to counteract that.

As Shoshanna said, we did a randomized, Web-based trial, where we tested different ways to present quality information and cost information in a way that would encourage high-value choices, that is, higher quality, lower cost. Our experiment included employees in high-deductible plans as well as those in more traditional plans.

We know that consumers do care about quality, but we also know that they have a hard time understanding and using the information that is out there. And then when you introduce cost into this, you really increase the complexity of what you are doing as well as this overlay of beliefs that you have to deal with.

We tested an approach where we looked at no quality information, where we sent what we called a low or a weak quality signal, where it was, I am sorry to say, like most quality information, a little hard to understand and take in. And then we tried with a strong signal of quality signal, and how did that affect people's choices and were they more likely to choose high value.

Just to give you some background here. Here is what the no quality signal looked like. There was comparative information. It did not include any quality information. We did actually test different ways of presenting that cost information. I am just showing you one. This is the weak quality signal. The information is there. It is a little hard to determine how these things may relate to quality. The information is not presented in a way that is easy to take in. This was the strong quality signal. It has what I call the 3-second rule, in it that if you cannot see the best options and the worst options in 3 seconds, your presentation does not really work. Here you can pick out I think within 3 seconds at least the top performers and we also showed top performers that were high cost and low cost.

What we found was that when the quality signal was absent, more people were more likely to use cost as a proxy for quality. They would choose higher cost. When we presented the weak quality signal that was moderated just a little bit, still the tendency was to use cost as a proxy for quality and to choose higher cost. When the quality signal was strong, we still saw a little bit of it, but mostly it was gone, that tendency to use cost as a proxy and choose high cost. People were more likely to choose the high value when they could quickly and easily discern that they were not compromising on quality when they chose the lower cost option. We also observed that confidence in choices was stronger when we gave people a strong quality signal.

We also saw and this is true—we have seen this in other work that actually interpreting information for consumers helps them. They are in an unfamiliar territory. And the information is complex often and difficult to use. If you interpret information for the user, it actually is more likely to get used. Our strong signal in a sense did that by saying this is better and this is not. That is a way to interpret data.

But we also interpreted data for people by calling out the high value options. We showed them where the quality was. We showed them about cost. And then we put just a check mark next to the high value options. We actually called it that. But we showed them both, so that they did not trust us that this was both high quality and lower cost. And that did help. And people were more likely to choose high value options when you essentially did some of the cognitive work for them.

Our findings actually did not differ for those who were in a high-deductible plan versus those in a traditional HMO or PPO, which was interesting because these are people who are more exposed to the cost of care. But they still had that core belief that cost is a proxy for quality. Even if they were paying out-of-pocket, they were more likely to make that high-cost choice when they were not sure about the quality.

We also found that the findings did not differ by demographics. And they did not differ based on health status. We did not include people who did not have insurance, as this was all employees.

What are our key takeaways here? Where possible, help people out by interpreting data for them. The task that people face in using comparative quality information is for them to map a good/bad scale onto that information. That is part of the task. If you do that for them, they are more likely to use the information. Instead of saying 80 percent did this and 30 percent did that, say this is good or this is excellent. That helps people.

And then the other really big takeaway is I think we always need to pair cost information with quality information, or show this information within quality strata to upfront address consumers' worries, that it is okay to choose a lower cost option then, if you are assured of the quality.

I forgot to mention. One of the things that we did learn was we went out with this experiment using dollar signs. One dollar sign, less cost; three dollars signs, more cost. We also tested dollar amounts. We thought this would work because it is easier to take in than actual numbers. But it turned out it did not work very well in the sense that a single dollar sign is actually pretty scary because we know—would you want to stay at the hotel that is the one-dollar sign? Would you want to go to that restaurant? Maybe not. It is too ambiguous and fuzzy. When we actually put the dollar amount in, people were a little more, "that much difference feels okay." A lot of websites use this dollar approach, and our findings suggested that was not really a good idea.

In addition to pairing cost information with quality information, we want to make it immediately easy to identify high performers across the various measures using that strong signal. That really means one screenshot. People should be able to see their options and not have to hold information in their mind and be able to use the 3-second rule see the best options. Calling out high value can also help consumers.

But I think that the big takeaway here is that if we do not do this right, we have raised the stakes on the quality reporting by adding cost. Because if we do not do it right, we are essentially undermining our purpose. If they do not understand the quality information, they are going to use cost as a proxy and the result will be just the opposite of what was intended. With that, I am going to hand it back to Shoshanna.

DR. SOFAER: What are these negative consequences that we think are going to happen? Not only will the—if this consumer choice thing works at all, that would mean that the market share would shift to the higher cost providers. What I am worried about actually even more is that the lower cost providers will start becoming higher cost providers. Judy was just talking last night about her very first study, about the same time I was doing my very first study in the mid-1980s, was about physician fee information. It was the physicians rather than the patients that were more interested in seeing other physicians' fee information. One of the things we have learned with quality information is that it is the providers who really pay an enormous amount of attention to this and that changed their behavior in response to it.

I am really worried, as Judy is, about continuing down the line we have been going in terms of a rapid movement toward price transparency. I want to raise some issues that are really broader and underlining. First of all, I really question the quality of the data that we have about cost and resource use in the first place. There were lots of screams and yells about the quality of the quality information that we had, and there were a lot of things put in place to ensure the quality of that information including the creation of the whole organization called the National Quality Forum. We do not have a parallel kind of situation here. We do not know very much about the data.

And anybody who read the *Time* magazine article from a couple of weeks ago talking about how hospitals bill and what they know about costs would be terrifying to, for example, use the charge master as a basis, which is totally not reality. What we could get really in trouble with is not only that, but using wrong data.

The other thing is that the consumers are not interested, this is very clear, in overall costs. They are interested in the cost to them. They are interested in their out-of-pocket cost. My 25-years-ago research project was how to present out-of-pocket cost proxies to consumers, and they really respond to it. But what we need to recognize is that consumers are not interested in—one of the reasons they are not interested in cost at all is because they figure that is why they have health insurance. That really is why they have health insurance—so they do not have to worry about cost. We have really done a number on ourselves in terms of this situation.

Presenting bad cost data is, I think, worse than presenting no cost data, and presenting cost data alone, even if it is good, is not as good as what we have just said, which is presenting the cost data with the quality data with the framing. Ultimately, we have to work to change the mental model that consumers hold right now. And something like the Choosing Wisely campaign is in one way a step in that direction. But even just the kind of sensitization of the public to what health care costs are all about, the way that Marge Ginsburg does in a lot of her work—these are critical things that are all a part of this situation. I am exactly 33 seconds over. Thank you.

The Road to Increased Patient Engagement Through Public Reporting of Performance Information

Ms. Barbra Rabson

MS. RABSON: Good morning. It is a great honor to be here, and I want to thank the Institute of Medicine for inviting me to be a part of this panel to tell my organization's story. I am going to talk about the journey that the Massachusetts Health Quality Partners has been on to increase patient engagement through public reporting of performance information. It is a journey that we have been on for quite a while.

First, I will tell you a little bit about my organization. MHQP has been in existence for over 18 years. We are one of the oldest regional health improvement collaboratives in the country. MHQP's mission is to drive measurable improvements in health care quality, patient's experiences of care, and use of resources in Massachusetts through both patient and public engagement and through broad-based collaboration. Our commitment is to provide health information you can trust.

The last panel talked a lot about trust. I am also going to mention trust a lot. Trust is key when you are trying to get people to act on information that you give them. MHQP has dual goals of providing trusted information to physicians to improve the care they provide their patients, and providing trusted information to the public so they can better inform their decision making. Sometimes there is a tension between those two goals. The story I will tell shows some of those tensions.

MHQP is a regional health improvement collaborative that brings many stakeholders together; people who provide care, people who pay for care, and people who receive care. We have strong relationships with our physician community. Our governance has included a physician council for more than a decade, which has helped us build trust in the community. That trust is important because we want the physicians to use the data that we provide to them.

We also have a health plan council. The health plans have been a major funder of MHQP's core measurement work. And just recently in the last 18 months, our Board of Directors established a Patient and Public Engagement Council. This was a result of our board realizing that MHQP is not going to make the improvements in our mission unless we engage patients and the public. While we have had consumer representatives on MHQP's board for the last decade, we felt it was important to increase our consumer involvement and set up a council on par with our physician council and our health plan council. Members of MHQP's patient council sit on our board and executive committee, and every other working group that we have. Having the patient voice at the table for all of our work has had a significant impact on MHQP.

By way of background, MHQP has been a national pioneer for publicly reporting physician performance information. Since 2006 we have conducted and publicly reported the results of a statewide patient experience survey of 500 primary care practices in Massachusetts. We have a patient experience survey based on what the Institute of Medicine has said is important in the visit between the patient and the primary care physician (see Figure 2-14). We look at communication, integration of care, knowledge of the patient, and health promotion. We also look at some organizational issues around access, visit-based continuity, and care and service from the office staff. We collect results from 65,000 commercially insured patients in Massachusetts in each survey cycle and have seen solid improvements in patient experiences on all of the dimensions of care.

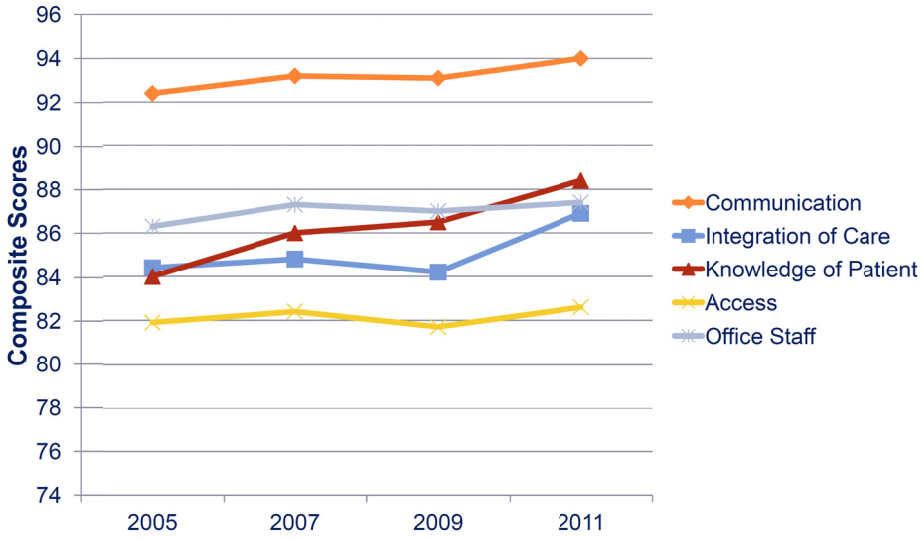

FIGURE 2-14 Patient Experience Survey statewide results—adult primary care.
SOURCE: Reprinted with permission from Massachusetts Health Quality Partners.

Since 2005 MHQP has reported on clinical data using over 30 HEDIS measures at the medical group level for over 150 medical groups. Both reports can be found on our website, and with funding from Robert Wood Johnson as an Aligning Forces for Quality alliance, we are creating a consumer facing website that will make it easier for consumers to access and use MHQP's performance data. It will look much more like what Judy Hibbard and Shoshanna Sofaer are recommending.

MHQP's board recently approved a patient and public engagement strategy recognizing that we would not achieve our quality improvement goals without patient engagement. We realized that MHQP will never be a household name and in order to get consumers interested in using MHQP's data we should partner with a consumer organization. Through a pilot also funded by Robert Wood Johnson we agreed to work together with Consumer Reports to jointly publish a special Massachusetts insert of MHQP's statewide patient experience survey results. MHQP's partnership with Consumer Reports was a milestone for MHQP in terms of our commitment to patient and public engagement. We teamed up together because both our organizations value sound data; MHQP has reliable information on physician performance and *Consumer Reports* has a 75-year history in sharing information with people in a way that helps them make

decisions. Working with *Consumer Reports*, MHQP was able to share data with 120,000 Massachusetts *Consumer Reports* subscribers.

However, some of our physicians had a visceral reaction to being rated in *Consumer Reports* along with toasters and refrigerators. When I say physicians, it was not all physicians. Many of our physicians felt it was much better to have MHQP's trusted data out there since there is so much garbage on the Web, but others just said, "You have no right to do this." They felt that it diminished their professionalism. We have a problem here if putting data out to the public in a way that consumers can understand is an affront to physicians' professional integrity. This is the problem MHQP is navigating.

While the display of the physician ratings was sensitive, the editorial that surrounded the ratings was not. The editorial focused on educating the public about *improving* their patient clinician relationship rather than finding a new doctor, and included actions for patients to take to improve their own care. The editorial included question from MHQP's survey such as "How often did your doctor explain things in a way that was easy to understand?" As patients read these questions, they could think about their own experience as a patient and ask themselves, "How often did my doctor explain things?" And then the report noted that in Massachusetts, 84 percent of patients responded "Always." Maybe your experience was different, maybe worse. The editorial also offered suggestions to get the most from your physician visit such as taking detailed notes, repeating your doctor's instructions back to them to make sure you understand the information, and if you are confused then say so.

The below figure illustrates how the data was displayed using *Consumer Reports*' standard display that their subscribers can easily interpret (see Figure 2-15). This display was different than what MHQP had used on its website in the past and some of our physicians were not comfortable with it, but our aim was to present the data in a way that consumers would find meaningful and easy to interpret.

The response was terrific. Here are just some quotes both from *Consumer Reports*' surveys and comments we got: This is what transparency looks like. This was an outstanding public service. Thank you. So what? So, Massachusetts residents have a new resource to help choose the best primary care practices. It is a milestone in providing consumers with valid, reliable, and useful health information. Let's hope consumers take advantage of it.

The day the joint publication went public MHQP had 2,500 hits on our website. Our Facebook activity went up 700 percent. Our Twitter activity went up 200 percent. There were about 4.5 million hits on the stories. *Consumer Reports*' newsstand sales went up 110 percent of this edition of the magazine.

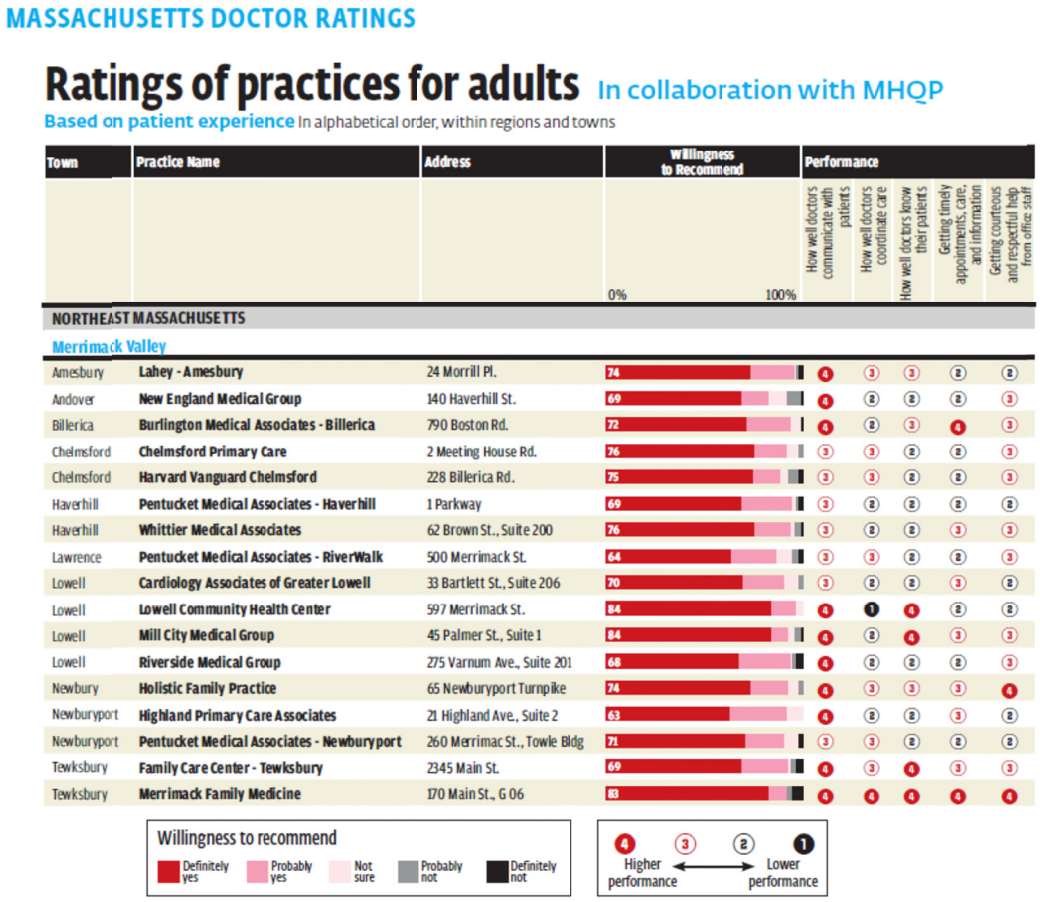

FIGURE 2-15 Massachusetts doctor ratings—*Consumer Reports.*
SOURCE: Reprinted with permission from *Consumer Reports*.

As far as lessons learned, there is tension over how physicians want data to be publicly reported and how to present data in a way that is actionable to the public. Partnering with consumer organizations to get trusted performance information is an effective way to engage patients and the public. Physicians do not want to be judged, and they do not want overall summary measures because quality performance is multifaceted and performance can be good in one area and poor in another. Patients want reports to include overall scores that summarize for them whether or not a doctor's performance is good or bad. Patients want the differences emphasized so that they can make an informed choice based on performance variations. Physicians prefer to minimize differences. We need to publicly report data in a way that is going to engage the public, and the public is eager to see physician performance data, but we also need to be sensitive to physicians' concerns. Because patients trust and turn to their physicians for care and advice, we must keep the physicians' trust in the information. We need to be respectful of both sides. It is through open and ongoing dialogue where we identify patient and provider needs and concerns that we will be able to make the progress we need to improve patient engagement through transparency of information. Thank you.

Raising Awareness on Quality and Waste

Mr. Daniel Wolfson

MR. WOLFSON: Thank you for the opportunity. Thank you, IOM. A great job. A great meeting. I appreciate the opportunity to be here. Audience participation. How many people, raise your hand, know anything about the Choosing Wisely campaign? You warm my heart. How many of you actually experienced any unnecessary care in your life or your family? How many have done that? Wow. How many have been harmed by this? Wow. Would you raise your hands again? Could people look around and see that? That is amazing.

I have a story, and I like to tell stories because I think that is a way of getting emotions going around this campaign. It is not a sad story. It is just a friend that had a stress test, age 60. Said the doctor, "You need a stress test." Well, a lot of people will fail a stress test. It is not unusual. What do you do when you fail a stress test? You get a catheterization. The catheterization showed nothing in my friend, but she had a pain in her leg and she had a burn on her chest. She was harmed, not badly, but unnecessarily.

My son walked in—and by the way, I have a blog. I promote my blog. I tell people that it is actually on a fee-for-service basis and they laugh, which is amazing. We cry when we think about health care being provided in a fee-for-service basis. My son goes into a clinic. He has a cough. He is 26 years old. He goes to the law school here, at American. He has a cough. He gets a chest X-ray. He has been overexposed to radiation unnecessarily. This is a true story. My son is a lawyer. He speaks the truth. He gets an antibiotic. A public health hazard and a hazard to himself. He gets an asthma inhaler. I do not know what for. And he gets a prescription cough medicine instead of Robitussin. The next week he is home. He is fine. He has an enormous bill. This is just stories that you probably have as well about unnecessary care.

I have another question for you. What does Choosing Wisely invoke in you when you hear that name? We think it is a pretty good name. What does it invoke in you when you hear Choosing Wisely? Good.

PARTICIPANT: There is data. There is information. There is knowledge and wisdom. Information that is in the context of experience that turns it into—

MR. WOLFSON: Anybody else? Just one word.

PARTICIPANT: Waste.

MR. WOLFSON: Thank you. To me, it invokes evidence, clinical evidence, and we need much better evidence. We have gone through the experience of doing these recommendations, and the evidence is not as good as it should be. We need better critical judgment about when tests are necessary and when they are not. We have a lot of pulling of triggers in health care now. They are protocol-based and they are not really using clinical judgment. I think last but not least, for this audience. It means patient engagement and informed conversation.

Let me tell you what is Choosing Wisely's objective. It is an initiative to help physicians and patients engage in informed conversation. We are going to see an informed conversation today. I have a video. I am going to stop talking and show a video, which I am really looking forward to. But now that I see the audience, I am really freaked out because you guys are going to criticize the tape. It is informed conversations about overused tests and procedures and support affects to help patients make smart and effective care choices.

What have we received to date from the Choosing Wisely campaign? We are going to by October 2013—and we have already received 25—but we will have over 40 specialty societies,

each identifying five things, tests and procedures that are not necessary. Under most situations, it is not an absolute. These are not "never events" in most situations, unless there is a red flag or an exception not indicated.

We will have over 200 tests and procedures identified and we are still counting. They will not be, I believe, any major specialty society in America that is not a part of the campaign in October. There are a lot of specialty societies in America as you probably know, and we will not have the tiny ones. But the major ones we will all have by October.

I want to emphasize this. This came out of a foundation, the ABIM Foundation whose goal is to advance professionalism. We have a charter that was produced in 2002 that said something about social justice. It said you must manage resources. It is a physician's responsibility as a physician to manage resources. The underpinning of this is totally within that, although we do not use that language in the campaign, but we do use it when we talk to physicians about this campaign.

We did 2 years of talking to physicians about this campaign. This just did not come out of our heads. We sat with physicians for 2 years, surveyed them, did focus groups about how we could enter a conversation about resource use. We do not use cost as an item in the campaign. We talk about better care. We talk about removal of waste. And as a by-product of that, if we save money, fine. Actually, one of our recommendations will actually increase cost. We talked about tube feeding, not doing tube feeding on people with advanced dementia and really doing manual feeding. Manual feeding in a nursing home costs more money, but much better care and actually does not kill somebody.

We have, through John Santa, over 35 translations now by *Consumer Reports* to convert, which are very technical reports. Go to choosingwisely.org to see all the lists. But these translations on Consumer Health Choices have all these translations, easy-to-read, low-literacy formats, some translated into Spanish.

We also produced this because we want this to inform conversation. We want the physicians to be skillful at talking about unnecessary care and having the courage to do that. We want the patient to think about overuse too and have the materials in front of them. It is this informed conversation that I am going to show you in a second. That has been a key point of this campaign. We want to teach the physicians about how to communicate. We teamed up with Drexel University. They have been doing a thing called doc.com for the American Association of Communication in Healthcare for years. We think they did a terrific job. Let me set that up. It is a real doctor, but it is not a real patient. It is an actor or actress in this case.

Here is a conversation. The specialty societies have two to three of these based on recommendations, so real recommendations, conversations, and real recommendations. This one is a generic one that we distribute widely to everybody. What is really neat about this—and this is the technology that we bought—was when they get to the teaching point, it is going to move down. This is how you teach effective and efficient communication skills to physicians. It is a little patronizing to the patient, but it is listening and being empathetic to the patient (see Box 2-7).

Video Shown

BOX 2-7
Script of Video Shown During Mr. Wolfson's Presentation

Doctor: So Mrs. Rogers, I have done your history. We have done your physical and your neurological exam, and I am happy to say that everything looks really normal.

Actor Patient: It does not feel normal, doc. I have been dealing with this for the past week and it is not getting better. I feel like something is going on.

Doctor: What are you worried about?

Actor Patient: I recently reconnected with a college roommate who told me she had been diagnosed with a brain tumor.

Doctor: I am sorry to hear that.

Actor Patient: Leading up to that diagnosis, she had been having headaches for long periods of time. I am worried that this could be something like that.

Doctor: I understand. You are really concerned. And I can understand given the stress you have and that recent news, that that must be really worrisome for you. But I can tell you that when I did your physical exam, your neurological exam, I took a look behind your eye. There was no sign of any increased pressure that might be symptomatic of a brain tumor. When you looked at your visual fields, and I tested your visual fields and I said look here, look there, there was nothing abnormal about that. That is all very reassuring that this is not related to a tumor. It is really most likely just stress or tension headache.

Actor Patient: You think we should get a CAT scan just to be sure?

Doctor: Well, a CAT scan really is not indicated at this time, because when your history and our physical exam are normal, and when you are looking at tension headaches, we do not need to do a CAT scan at all. Actually, it can pose more harm with unnecessary radiation.

Actor Patient: Really?

Doctor: Absolutely. That is one less test that we have to order. One less thing you have to wait for and be concerned about. Would you feel more reassured if I give you some information on when CAT scans and MRIs are necessary?

Actor Patient: Maybe. Yes.

Doctor: I took the liberty of printing out a handout for you that goes over when CAT scans are necessary for headaches.

MR. WOLFSON: *A* Consumer Reports *is being given to her.*

Doctor: And basically, from studies that they have done with people with common headaches, there is no CAT scan necessary. Like we said, it could pose more of a risk. You can take that home and read it.

Now, are there things that we can do to help you reduce your stress to help your headaches?

(End of Video)

MR. WOLFSON: I am way over my time, aren't I? You are going to yank me. I just want to give you one quote. This is a quote that is in *Modern Healthcare* this week by a cardiologist—by one doctor in Montana in a conversation with each patient, and later in a note to the referring physician. That doctor cites the Choosing Wisely campaign, a specialty initiative, created to curb overuse. "We have created a medical oncology based on over prescription and over consumption

on the part of both physicians and patients. What Choosing Wisely has done is legitimize our ability to cut back on what is unnecessary." We have given cover to the health care professionals and patient advocates about overuse. Thank you.

Seeking the Citizen Voice

Ms. Ginsburg

MS. GINSBURG: Good morning. I am here to argue for another role for patients as citizens who are helping to define the principles and values that should govern our most challenging policy dilemmas. I am going to use the term "citizens" and "public" interchangeably, meaning the collective or social perspective, rather than the individual perspective.

Why is a social perspective needed now? The public certainly has plenty on its plate trying to absorb the role of patients. To illustrate, I am going to give you an example of something that came up in the 1990s, a real pharmaceutical breakthrough. I am sure you guys all recognize this. When Viagra was introduced in the mid-1990s, erectile dysfunction went from being a personal annoyance to a ubiquitous medical problem. Kaiser Permanente interestingly took a bold—as it turns out, futile—stand saying that it was not going to cover it. In its explanation, Dr. Sharon Levine, who is a national Kaiser leader, testified. "We must ask ourselves when astronomically expensive new drugs for toenail fungus, afternoon drowsiness, and hay fever come to market at the same time as expensive drugs for conditions that threaten life and cause serious disability, will we be able to create a social consensus on how to balance the costs of each with the benefits derived? Or will we simply avoid responsibility until the entire insurance system comes crashing down around us?"

All the ills of the health care system cannot actually be foisted on to erectile dysfunction. This example illustrates the difficulty of saying no to anything that is new in health care. What makes health care particularly relevant as an issue for a societal perspective is because it is highly individualized and personal to each particular person, but it is paid for communally. When there are more options than resources, as there always will be in health care, then whatever standards are applied should be based on an understanding of social priorities. But how do we begin to understand those priorities?

We have many ways in this country, as you know, of getting public input. I certainly cannot elucidate them all. And they are all important and they are all necessary. But this type of town hall meeting, say, is definitely public input, but it is definitely not public deliberation. What we need by deliberation, really, is the societal version of shared decision making. But with a lay public that sees itself first and foremost as patients and family members, can people switch roles? Can they actually reflect on their inner patient and try to come up with what is acceptable as an outer citizen? You can imagine that some of those challenges will be formidable.

I want to briefly go through what I see as the different roles. How do we articulate the role of the individual as a patient decision maker and the role of the citizen as a societal decision maker? (See Figure 2-16.) As you know obviously, the chart on the left has a number of characteristics that I think all of you are familiar with. The individual in deciding among treatment options considers all the treatment options that are available. It considers the benefits and burdens to them as an individual. It looks at the impact on themselves and their family, reflects on their personal goals and values and the extent to which their treatment options will meet those goals and values, and ultimately their decision is what is in their best interest. But that same person

acting as a citizen in trying to look at what is going to impact the many, rather than impact the individual, has a different role entirely. In this case, they are not looking at necessarily individual treatment options, but looking at different policy options that deal with a particular health care issue … needs to consider the trade-offs among those options, informed by other people's views, because if it is a societal perspective then it is never about the individual by themselves. We actually do not often know what our own views are when we look societally, until we start talking to others who look like us. Rather than PatientsLikeUs, it is CitizensLikeUs.

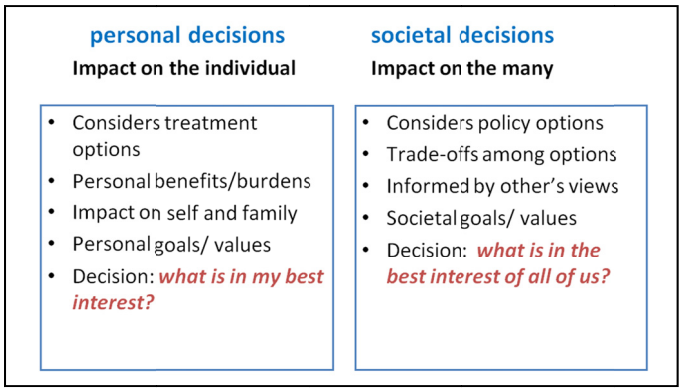

FIGURE 2-16 The impact of different roles in decision making.
SOURCE: Reprinted with permission from the Center for Healthcare Decisions.

And the goal of course is, what are those societal values that we are trying to achieve, if in fact we need to make these difficult decisions—all decisions to be made here from the societal perspective? All have trade-offs. They all have tensions embedded in them. Whatever you pick, someone else is going to disagree with it. It is going to be wrong on one hand, and right on the other. But at the end, the decision is what is in the best interest of all of us.

I want to point—you do have your package of information online that has all the various materials. And of course, I want to call out to you in complete self-interest, on page 182 of your booklet is a chapter on public deliberations that was in the *Essential Benefits* report that was put together as part of the implementation of the ACA. I would urge you all to memorize it.

What are the kinds of topics that we are talking about that are related particularly to coverage and cost? Not all of public deliberation is about money. There are many other issues that are involved in health care. But right now money is a very big one. Here are examples of projects we have done over the last few years. Should the cost of the treatment ever be a factor in treatment or coverage decisions?

We did a project with Medicaid beneficiaries in California and asked them to figure out how to cut 15 percent out of the budget, which is what the governor was facing several years ago and every year since then. Uninsured Californians design a basic benefits package. We did this pre-ACA. I do not think the government necessarily took our report. They might well have. But we wanted to find out, what does basic mean? How is basic different than not basic? What are those characteristics of health care that are so critical that they absolutely must be covered and which ones should not?

On a project we did last year on the principles of a fair cost-sharing model that we did on behalf of the California Exchange. What I want to do is just—because there is no way to give

you answers to all of what people said. I captured just a few of the quotes that came from a number of these different projects of how people actually react to this role. Putting our personal experiences aside, because there is a lot of stuff on there that I personally would not use, but we are talking about the working people in Sacramento. By the way, they were using a process called CHAT I think some of you may be familiar with. It is a computer simulation that we have used a lot in helping people decide what a health care coverage should really look like when there are more options than there are resources. But what you have here is the recognition. This does not come quickly of someone who realizes, "Oh, wait a second. If we are sitting here trying to decide for a much larger group of people, then what I want may not necessarily be the most important thing and it is time to think about what other people want."

Another quote. "I think when you are designing it for the whole state, then you have to look at not just individuals, but everybody combined." This is a breakthrough in thinking. Most people do not know that in fact insurance coverage has to do with pooled risk. Everybody puts in. Some people take out a lot. Some people take out a little. Most of the public thinks health insurance has their name written all over the dollars in there that go to them. The fact that they are sharing these resources and that means one has to look at the needs for everyone is a critical insight.

"I have real mixed feelings about it. It is very expensive and it only happens to a few people, but if it is someone that you care about, it is the biggest deal in the world." Here we are talking about the tension of do we spend money on something that affects very few people and very expensive, or is it better to spend it on something where a lot of people use, but maybe they could afford it individually—a lot of that tension of what is fair, when in fact you cannot get everything.

"I am just stating why I would want it. We do not have to vote for it, but still I just want to be heard." This one I really love because what happens in processes like this is that not everybody gets what they want. It is a communal process of making a decision of what is fair. We have someone who says I get it. I am not going to get my way on this one. But my opinion is important and it counts and I want to make sure you know what that is. That is extremely powerful when people decide afterwards whether this process was something that they could live with.

I want to make one point about the project we did with Medi-Cal beneficiaries in California about cutting the budget 15 percent. This was the most uncomfortable project I had ever done, because I thought we were going to be strung up to go to actual beneficiaries and say, "Using this CHAT process takes 15 percent away from what you have now." I worried that people would just walk out, that they would not want to participate. That was not their response at all. And one of the last questions we asked on a survey question afterwards was "If the Medi-Cal budget is cut, I think it is important for Medi-Cal users to have a role." And obviously, 89 percent agreed strongly. Give us a voice. Not just our advocates. And there are many consumer advocates whose voices are very important, but the fact that they want to have a voice themselves if something is going to impact them directly.

Current issues. Unfortunately, I do not have time to go over them. There are lots of issues now that are just ripe for civic deliberation. I just want to mention the last one because that is one we are doing. Revisiting Medicare benefits, we are starting this project statewide in California to relook at the way Medicare is designed and what it serves and what it does not serve. We have 20 organizations working with us on this project. I have a handout and a small number of copies.

I am happy to give them for anybody who is interested. We welcome other states as well to join in this, if you want to learn more about it.

Last quote. The wisdom of the masses. "If these decisions were easy, we would not be here." Thank you.

Audience Participation and Open Discussion

Dr. John Santa (Moderator)

DR. SANTA: Please come to the microphones. Let's move to the discussion phase.

DR. VOLPP: Kevin Volpp, University of Pennsylvania, Philadelphia, PA. I have a question for Daniel. The Choosing Wisely initiative is something which I think is really amazing, really visionary, really unprecedented. A lot of us are really hoping that this initiative does what you are hoping it will, which is providing cover for physicians to do less of these low-value services.

But one concern is that the reason a lot of these services are on the list is that there have been strong incentives for both the providers and the health systems they work in to provide these services. They are providing them not because they do not know that the value is marginal, but there are a lot of decision-making biases that lead them to think maybe for this patient this is beneficial, even if I understand that for other patients, on average, it is not. I am wondering how you see that evolving. There is obviously somewhat of a shift going to a more population-based financing, but we do not know how far that is going to go and how quickly that is going to go. In the meantime, all these providers are out there in a fee-for-service world where there are very strong incentives to keep doing what they are doing.

DR. WOLFSON: Good question, Kevin. We have the right messenger credibility with the specialty societies and *Consumer Reports*. We have the right message that has been honed I think pretty well and we have the right time. Is it the right time? If this was 5 years ago, this campaign would go nowhere. I think the environment in some parts of this country is changing toward value. If we do not have that, this campaign is dead in the water. We are hoping that ACOs—any organization that is trying to look at a value equation rather than a volume equation—will want to do this. People who are stuck on fee for service and volume-based will not want to do this campaign. Hopefully, they will be in the minority and they will not look good when we have a different metrics to look at what is value in the system. I totally agree with you. We will not have any uptake unless we have an environment that is conducive.

We have 20, 30 large health systems that are on the phone with us on a quarterly basis telling us what they want to do, including the VA. There are a lot of organizations that want to do this, but there are a lot of organizations that are not ready for it. We need to get the early adopters.

DR. SANTA: I cannot resist. Brent James, Intermountain, elective deliveries at 30 weeks, inappropriate inductions, hard stop on inappropriate inductions. In 2011, he saved Utah $50 million. Reduced inappropriate inductions from 28 percent to 2 percent. The system lost $9 million. The problem is not Brent James and others not doing this, the problem is, why do we still have a system that has spent $9 million on making babies sicker? Good for Brent that he got it done and did not need to keep making money making that baby sick.

DR. WOLFSON: And they have a health plan that helps them. Let me say something about Intermountain, because they have used Choosing Wisely. It is called Choosing Wisely at Intermountain. They put out a brochure. They are having a lecturer with their patients. I asked them—Intermountain, you have the best care, best quality. Why are you doing this Choosing

Wisely thing? They said, "We do not want to be the only one on the cornfield talking about this. We need your backing and the credibility of the specialty societies to keep this moving."

MR. LEVIN: Thank you, John. Art Levin, Center for Medical Consumers. This is a question for our double play team, for Shoshanna and Judith. I agree and understand about the need to translate and put information data in a format that is easily understandable and recognizable. I wonder if that raises an issue of who is the trusted translator and how do we deal with that. How do we create some way for the public to know which translation is accurate and which is fantasy?

DR. HIBBARD: Thank you for that question. I talked about this in a very blithe way. But it really puts a burden on the report sponsor. It is more responsibility to interpret information than just to simply put it out.

In terms of a trust source, I think we still need that trust regardless of how we put the information out. One thing that supports the trust is when the information is underneath. Up here, we have an overall score or three summary measures that tell us the big picture. But underneath that, you should have the information so that people can see and the same with the cost information and value. That is the overall cost. We can put that check mark there, but we do not want to that conclusion. We want to be able to see the information. But we do not want to overwhelm people with all of the information upfront.

DR. SOFAER: It is a very good question, Art, because I think it has a whole other layer of concern, and that has to do with what happens to the fundamental relationship between a clinician and a patient. We in public reporting, and even in patient engagement, we are often in a situation that really reflects what Barbra Rabson was talking about, and how they have to walk in that narrow corridor in terms of getting patients to be skeptical, helping them understand that all doctors are not spectacular and wonderful human beings, that a large percentage are, but that you do have to be careful. To try to explain the kind of financial pressures that physicians are under is also very terrifying.

We do have to be very careful to not totally undermine positive relationships between clinicians and patients, at the same time that we do, in a sense, say to patients, "You are not insulting your doctor by asking her or him a question." That is what many of them feel. Or as Dominick's research has said, they are worried that they are going to be punished, which is wild. I have to tell you. This is not just true of physicians. I have done research with patients about nurses, the most trusted profession, and it is even true with nurses that they are afraid that they are going to get retribution. Let me tell you.

I think we have to keep a watch on this because it is very important that we not go overboard and get everybody to mistrust doctors or mistrust the health system. We have a thousand voices blooming in our society, and a lot of things are going at people. That *Time* magazine article. One of the things about that *Time* magazine article was they really gave physicians as a group a pass. It was all about the hospitals that were the evil empire. I commented on that. You get other voices on that.

But the other thing, just practically speaking, we know a good deal about who is and is not trusted. The government—they want the information from the government. They do not necessarily want the government to make the decisions for them. Their employer. It depends. The insurance companies. Forget about it. Medical societies. Not bad. Coalitions like MHQP, independent nonprofit organizations. That is whom they trust. That is whom we really have to go

with. We really need to know also that that landing page that was talked about earlier, that has to say right away who are these people and why should you trust them, otherwise we are lost.

DR. CARMAN: Kristin Carman for the American Institutes for Research. I want to make a couple of quick connectors and then make a small offering of some information if you are interested. The first connector is on Choosing Wisely. We actually met with the ABIM Foundation folks based on the work we did on a communication toolkit that we developed for the California HealthCare Foundation and NBGH. We really focused on this communication about value. There is a lot of talk about cost and value. And what we found is that where you are talking about, Dan, the notion of Choosing Wisely is about applying evidence, the benefit of talking about wise and wide use of resources and Choosing Wisely, and we found—what we communicated is that everyone gets nervous about this notion of when you start talking about value of my health care, you are talking about putting a bargain basement pricing on it. But we can all talk about wise use of resources. We have to do that every day in our life.

It is a really important point, because it also, per Marge's conversation, starts to nudge people a little bit past just what is in it for me, but starting to think about, I even have to think about managing resources. And suddenly the conversation opens up that everybody has to figure this out. It is a subtle thing, but a really crucial communication piece.

The other thing that I wanted to note back to Dr. Volpp's comment is, Marge, and we have a framework in the *Health Affairs*' recent edition where we talk about a framework for patient engagement—I will talk about it in the far right corner—but we are talking about patients and families and consumers being engaged in decision making and a policy-making level. It is going to have a huge impact on people's linkage and uptake into all of this as well. This notion of public deliberation and the public being involved in deciding on this architecture, in deciding on what is supposed to be happening at a policy level, I think is going to be much more impactful on an individual level for individuals just as it is for physicians.

And finally I just want to note for those of you interested in public deliberation, AHRQ has just put up on the Effective Health Care website a great deal of early materials from our study. We were doing a very large randomized controlled study of public deliberation on how consumers think about applying evidence in health care to themselves, their physicians, insurers, public entities, and purchasers and otherwise. I do not have the linkage, but it is on the Effective Health Care Program. There is a large literature review and then lots of materials that help starting wrapping your brain around what this looks like and how this method can be used. We will be having findings in a bit.

MS. RABSON: Community forum is what you should be looking for. Can I also just say that Kristin and her team did a fabulous article on public reporting on cost and quality that is in the recent *Health Affairs*. I put that in the materials that you have. Take a look at that. She does a really nice job talking about how quality reporting tends to come from nonprofit organizations, and then all the cost reporting is separate for, now for-profit, organizations like Castlight that have access to claims and big money. There is this disconnect that we are going to have to reconcile.

MS. MOBLEY: Erica Mobley from the Leapfrog Group, attending on behalf of Leah Binder who expresses her regrets she could not be here today. Shoshanna and Judy, I want to thank you for your fantastic and fascinating work. I cite your studies all the time in talking to a wide variety of stakeholders. I am so grateful that we have that information available.

My question is somewhat related to the last question from this side of the room. Shoshanna already partially answered it. But if we found that people do not trust their employer, health plan,

to provide them with this cost and quality information, and they just assume that it is the employer health plan, trying to save money, are they better off not providing it all? Should this information only be coming from groups like the Massachusetts Coalition that are considered unbiased?

DR. SOFAER: Partner. That is what you have to do. Because when you are part of a multi-stakeholder collaborative of some kind, and you have a partner, that automatically means that it is not just your interest that is there. It has been an interest that has been to some extent moderate. Certainly, we get the message all the time over and over again for AHRQ sites, for the Chartered Value Exchanges, the idea that they are an independent community or state-based collaborative of different stakeholders. That goes over well. You have to use the right language obviously. Or partnering with John Santa.

DR. WOLFSON: I forgot to mention, and thank you for reminding me, that the employers like Leapfrog are a part of the Choosing Wisely campaign, and the National Business Group on Health and the Pacific Business Group on Health came out with an employer kit that you can find on your website as well that explains for an employer to begin to talk to the employees about this. We have received a grant from the Robert Wood Foundation to work with regional health collaboratives. In those regional health collaboratives are usually employers and health plans. People like Barbra are going to hopefully be working with us as well as state societies and specialty societies. I just want to recognize the Leapfrog's great support and under John Santa's leadership.

PARTICIPANT: What about adding some patient groups, Daniel?

DR. WOLFSON: We have many groups, including—I will let John answer the question.

DR. SANTA: First of all, let me say I think this is going to be a daunting task. Check out Change Health, who is mostly working through insurers, and see if you can get them to talk to you about the engagement results they are experiencing from their strategy. They reach out and communicate to folks who are covered and say, "You did not get a very good deal on your health care the last time you had an interaction. You did not get the cheapest drug." They have a very active engagement model. At least from their numbers, they are very impressive. It is going to be hard for organizations like ours to afford that.

In 2013, many of the folks in this room are lining up to purchase physician data. It is expensive. It is complex. I do not know if we will be able to afford it. I think you are going to see in-the-field folks who have very substantial resources and technology who may or may not play by all of these rules and may figure out ways to totally change them.

The one I am most proud of, that a colleague of mine, Tara Montgomery, figured out, is we have a wonderful partner in Choosing Wisely—is Wikipedia, one of the five largest websites in the world. We do not say what is going on in Choosing Wisely. Wikipedians do. And we now have Choosing Wisely content up and a couple hundred Wikipedia pages, topics that are related to the first 45 and getting to work. Wikipedia just launched their Choosing Wisely page a couple of days ago. We are getting to tens of millions of people through Wikipedia. We are going to have to be smart, do things in a variety of out-of-box ways to do this.

MR. WOLFSON: I just want to recognize AARP who is in this room as part of this campaign and the National Partnership for Women and Families is a part of this consumer-oriented side. Thank you for your support.

MS. BRUESSOW: Diane Bruessow, Gay and Lesbian Medical Association. On this panel and throughout the entire discussion, I have heard language using doctor and nurse, health care provider, clinician. As a physician assistant, I am a little more tuned into this and I am actually

looking for more explicit information. But I also understand. It is not just what we are doing in this room and throughout the discussion, but it is also what our patients do. My question is directed toward Barbra and Dan as well. Do you know whether your respondents, when you ask them about their doctor, if they actually are responding as who their primary care provider is that may be inclusive of PAs and NPs? Were you explicit in any way in differentiating? Did you make an explicit decision about saying doctor PA/NP? Can you tell me a little bit about that?

I would actually ask the same question of Dan, if you do not mind putting two questions out there. There are, I think, 100,000 members of AAPA and we practice so PAs have practiced autonomously. We may not get the kind of—if you are trickle down, it may not happen with autonomous providers and has there been any discussion to broaden the audience?

MS. RABSON: Great question and something we have dealt with for a long time. The survey that we do is actually a survey of the primary care physician. When we send it out, we have the primary care physicians' name and the first question is our understanding is that you have Dr. Cammack as your physician. And the reason we do that is from a methodological standpoint. If you ground it in a particular individual, people have a better response rate. The response is more reliable.

Having said that, we know that primary care is a team sport. It is not just the primary care physician. In fact, we have a visit continuity question that we threw out because people said—one of the questions was, "Did you get to see your doctor or your clinician?" And if they did not, sometimes—we did not say they said okay. We just said—we are grappling with this. We actually received hate mail from the nurse practitioners. Both my kids were delivered by nurse practitioners and it was horrendous to get hate mail. It is an issue, but it is a methodological issue.

We do a top-down survey based on the claims. We target physicians. Now, in Massachusetts, nurse practitioners are able to bill. We are looking to—they do not always bill under the nurse practitioner. It is an issue that we are on to. We are making some progress. It is really important and we are going to have to get there. Every year we look at our survey and now we are using the patient-centered medical home model. It is even more important that we have that. But there is this challenge from a research perspective about centering this on an individual. We will get there, but it is not there yet.

MR. WOLFSON: We are trying to figure out what our next steps are. This is on the table. I would love to talk to you. It is non-answer. I know.

MS. BRUESSOW: Actually, I would like to introduce you to Jim Delaney who is the president of the AAPA before the meeting is over.

MR. WOLFSON: Good. I would love to talk to him.

MR. DEBRONKART: Stick to your guns, please. In my speaking all over creation, I have heard a lot of responses from different physician communities, local, and medical communities where—

PARTICIPANT: Who should stick to their guns?

MR. DEBRONKART: Dave DeBronkart.

PARTICIPANT: No. Who should stick to their guns?

MR. DEBRONKART: Dave DeBronkart. The message that I heard consistently is there is evidence. There is information out there. I have never in my career seen a profession that screams in protest and whines at any attempt to measure it. The reality is we all have tons of data that some providers are more effective and safer than others. We cannot let that information be buried or disregarded.

Regarding consumer behavior—at a Robert Wood Johnson conference a year and a half ago somebody made the point that it is abusive to keep people uninformed and then insult them for being clueless. That pretty much is the situation. A year and a half ago my COBRA ended and I went on high deductible, $10,000 high deductible. I blogged a lot about this. I will not go into it in depth. But the first thing I got was a CAT scan for $1,736 out of my pocket. Every line item on the EOB said the single word "hospital." I asked my insurance company and said, what are these? They said, we do not know. I said, what if they are errors or fraud. And they said, if there were, we would do something. I am not kidding.

Many years ago in my career, I got involved with a professional supervisory discipline called HPT, Human Performance Technology. And if an employee is failing to do a particular task, you have to consider, do they know how to do it. Do they know when they are supposed to do it? Do they have the necessary information? It is a mistake, a trouble-shooting mistake, a diagnostic error to not consider whether the person clearly had the information—this is where they do the cognitive work. Give them the equivalent of a *Consumer Reports* car reliability guide. Please let's do that.

Literacy. The term "health literacy." It drives me nuts. Even the article about a health literate care model in *Health Affairs*. The interventions—I have always said you cannot discuss literacy unless you discuss in the same breath the clarity of what they were presented. The interventions described in the article were all about improving the clarity, but they still call it literacy. Do what we can to put the information clearly in the consumer's hands, and then we will see whether people know what they are talking about.

This is so persuasive. At TEDMED last year, the chief medical officer for Quest Labs gave an insulting talk about how patients make lousy consumers. While in the process of shopping for my next CAT scan, I call his lab to see what the blood tests would cost. He said the lab said, "We do not know. Ask your insurance company." I called them and they said, "We do not know." I could go on and on.

The bottom line of all this is given that—I would say, Judy and Shoshanna, uninformed consumers think that more expensive is better. Can we design some interventions? Treat that as a baseline. Design some interventions and measure afterwards.

DR. SOFAER: I think we would love to do that. I think we do not really know how, Dave. That is the reality. I think going back to the word you used, John, this is daunting to change the minds of people. In the meantime, what we are suggesting is at least, do not make it worse. At least give patients and consumers a chance to not have to overspend.

MR. DEBRONKART: Before I sit down, my great concern is that with the coming changes in medicine, this is not just a matter of wrapping up the bad performance. I want the best performance to be rewarded and how can consumers choose that if they do not have the information?

DR. SANTA: Let's be as efficient as possible.

MS. RABSON: Just one response about sharing cost and quality information. Even though we have quality information and we have cost information, they do not align. For example, how much does this mammogram cost? Did your doctor's office recommend a mammogram? Was it an effective mammogram? Did you get the results? We have a long way to go even on the measurement road and moving into specialty measures and the data. Daunting is the right word, since it is sort of a 360 how to present it, but also getting access to the right data.

MR. WOLFSON: I caution addressing the public about cost at this time still. I think we just got out of rationing and death panels, and we are not out of them yet, probably. But I think we are getting out of there. I think couching this discussion in a different way will help us, and talking about cost will get us back to rationing in-depth panels. It drives me nuts when people are talking about end-of-life and they say it saves money. I am not sure it does and I would not want to frame it in that conversation like that.

DR. MARGOLIS: I am Peter Margolis from Cincinnati Children's. I am interested actually in hearing a little bit about how you are thinking about presenting data over the next couple of years. I see what you are doing now. And as obviously somebody who is interested in transparency, it is important to me.

I also look at data transparency from a systems engineering perspective. Most of the variation that we see among physicians is actually due to the system in which physicians practice. That system includes board recertification and payment and training and data feedback and all kinds of things. The variation is relatively small among physician practices. There are some physician practices that are outliers and outperform everybody else.

If our real goal is to cause improvements in outcomes to take place, it seems to me that we want to use data presentation in order to stimulate action among caregivers, rather than fear. Can you just talk a little bit how you see this evolving over the next couple of years, what you would like to do in the future, and how you imagine doing experiments, and whether there are opportunities to do experiments and how to do this better?

DR. HIBBARD: What we are going to see is more linkages between where people are going on the Web and the kind of comparative data. If people are going to read about knee replacements, they may not be thinking of the issues that they should be thinking of, and embedding in those sites, WebMD or the different sites that people are going to go to learn about their condition or their procedure, that will then highlight for them that these are the things to be thinking about. Here is some comparative data for your region to think about.

The other issue that I see emerging is that comparative performance data, especially on procedures, does not address the issue of appropriateness often. One of the things that we can do is, when we are presenting comparative outcome data on hip replacement or knee replacement or especially the back surgeries, where appropriateness is a big issues, is to embed in those sites decision support. Wait a minute. Not everyone benefits from back surgery. Are you going to benefit, and use this button to find out about for you, if back surgery is right. Those are some directions that I see.

DR. SOFAER: I just want to mention that the Agency for Healthcare Research and Quality has just started a new initiative called Improving the Science of Public Reporting. The three of us are all involved with one of the projects that we were funded, as is Kristin Carman, who spoke a couple of moments ago. She is actually leading the project. These are all efforts to use R21s, which are more exploratory research, to push those boundaries in public reporting.

What we are focusing on is what Judy was talking about: linkages between the kind of information that people are naturally looking for and the kind of information that we would like them to see. We happened to have chosen childbirth as our focal point because that is what we call a shoppable condition. But I think we really do have to start thinking out of the box.

And a project that I was involved several years ago, it became very clear that really patient engagement needed to be the overarching frame in which comparative quality cost information is put out there. If you look at the engagement of behavior framework that the Center for

Advancing Health has issued with 42 behaviors that represent engagement, one whole bucket of that is choosing and using your providers.

You can also give people information that they can use because we think about this all and it's about choice. But what about asking your doctor some specific questions and giving people advice about what questions to ask based on what the information is. I have to tell you. As good as we can make it, it is boring. I have been doing this for a long time. It is not terribly interesting. I helped Barbra with her first issue of her public report. Compared to most of the things that I look at on the Web, it is boring.

MR. SANTA: Just a quick comment. We are not going to be boring. We are going to take the folks who are not trusted by consumers and we are going to attack them. We are going to attack the drug industry, the device industry, and I am sad to say, hospitals. We are going to attack them on safety. We are not going to break anything that cannot be fixed. But when there is a fix, we are going to attack them and attack them and attack them. We are going to collaborate with physicians because we think they are still capable of behaving professionally. Let's hope we are right.

MR. ALSTON: Chuck Alston with MSL Washington. My perspective is based on 6 years of research with Aligning Forces for Quality. And just for what it is worth, almost word for word our research validates everything that was said this morning, with one exception, and maybe Tresa is going to talk about it this afternoon. We did focus groups last year. Part of the groups was Medicare patients that had supplemental coverage. Part of the other groups was people with thousand dollars and up deductibles. They were two separate conversations that bore no resemblance to one another. We began to see some things in the high deductible that we had never heard before. Now, we were not doing choice architecture like you were. We were just having a discussion because RWJ wanted to take the temperature. The anger was palpable. People on their own brought up tests that did not need to be done or procedures that did not need to be done. This was unsolicited. And in 6 years of doing work on quality, cost, we had never heard anything like this before.

There is something changing out there, now that the price is being made apparent and that they see that there is a cost other than their insurance premium, and it was also worth noting that everybody and every group knew their premium down to the penny that they paid each month.

MS. ROHRBACH: I am reporting questions from the webcast. The first is from Kevin Kenworth of the Health Research and Educational Trust who asks, "With such variability in costs for the same treatments and procedures, how are these costs determined and how is this cost information explained to the patient?"

I have a second question from Alan Kaplan who is the co-author of a recent review paper called Family Caregiver Alliance and he directs his question to Mr. Wolfson asking, "Can you comment on the possible impact on the Choosing Wisely campaign on the standard of care and malpractice litigation?"

DR. SANTA: Why don't you do the second one first?

MR. WOLFSON: That is a really good question. What I have heard is two sides. One side is you develop a new standard that people could shield from liability. The other side of course is you are not doing a test. You are exposing yourself to more liability. I do not know the answer. I would think that doing the right thing is more defensible. I also think there is a flip side. You did the wrong thing and you hurt somebody. You did something unnecessary and you hurt somebody. I think that will certainly count as being liable.

But this is a big concern of a lot of physicians. Emergency room physicians are coming to see

me based on this notion that we should get involved in medical tort reform. I do not know where we stand except we want to keep focused on what we are trying to do. But it is a huge issue. It is real. It is real because it is in the minds of physicians when they do tests and procedures and saying I have to cover my basis. Of the many things that drive overuse, there is certainly a lot to say about liability.

DR. SANTA: Let me try the first question. Go to NQF. There is a variety of cost measures that have been approved by NQF. NCQA, for example, has RRUs, relative resource units. They are by diseases. For example, heart disease, diabetes, COPD I think. Look at those methodologies.

One that we have found very interesting and we have written about is the HealthPartners comprehensive cost measures, the only NQF comprehensive cost measure that has been approved. To HealthPartners' credit, they have put it in the public domain. You can look at all the information on their website. They will help you understand it. I think it is a first and really important step in terms of understanding cost.

MR. WOLFSON: I am serving on an NQF cost measure committee that will look at it again.

DR. BELKORA: Jeff Belkora from the University of California, San Francisco. I would like to ask Daniel if he could comment a little bit on—I was encouraged about the idea that the Choosing Wisely campaign is not just about overuse. It is also about underuse. For example, with the story you told about in-person feeding as opposed to tube feeding. I wonder if that is something that can be more emphasized because, as a consumer, I am suspicious of focusing on just one side of the equation. I think there are a lot of people in our system who are at risk for underuse. I understand that in orthopedics, for example, older and minority patients may not be getting access to hip and knee replacement surgeries that actually maybe appropriate and underused in those populations. It would seem to me that telling the Goldilocks' story about Choosing Wisely, that it is about getting it just right. In some cases, that is going to mean more treatment. In many cases, it is going to mean less. Is that some direction you are going?

MR. WOLFSON: We certainly want to get the message across about appropriate care and best care. Frankly, some of us have been working for 30 years on underuse. I think it is about time we focused solely on overuse. Our campaign is going to continue to look at overuse. Waste is the beginning of a conversation. We hope that we can evolve maybe into more difficult conversations about marginal benefit, palliative care, and end of life. We wanted to start with the basic. We are a small foundation. We are leveraging lots of organizations out there in trying to stimulate them. I think if we changed our message to underuse, we would not get across our objectives.

DR. BELKORA: I am not suggesting you change the message to underuse. I am suggesting that maybe you put aside your personal history or the collective personal history people who had been working on it or do not feel like that is—I think it is a credibility issue for consumers. I think it is a big mistake to say Choosing Wisely, your message, your brand is perfectly suited to saying we need to thread the needle and get appropriate care, and in many cases, maybe the majority of cases, we are worried about overuse. Maybe higher risk if you have insurance. And you are not in a marginalized or underserved community. You are maybe at higher risk of being exposed to the risk of overuse. But there are many people who are exposed to the risk of underuse. It is just a recommendation I would have.

DR. SANTA: Let me share with you that in our consumer translations, we have heard over and over again if you break it, you have to fix it. If you tell me what not to do, you need to tell me what to do. The section that we have on what you should do is the most popular section and

actually people want to hear about what they should do that does not involve a physician, that they do not need to go to a physician for. You are right. I think you are on the right track. I think we are trying to do both.

DR. SOFAER: We did something in the three Cincinnati groups and then we did another eight groups for the Robert Wood Johnson Foundation Aligning Forces for Quality. There was one thing that we did in those groups, which was different from anything else. And that is that we used something that is called a Prometheus model, which was set up as a reimbursement model. What Prometheus does is it breaks health care costs into two buckets. In some circumstances, those two buckets are in reverse relationship to each other. Let me explain. The first bucket is getting typical, what one might call "recommended care" for a chronic condition. It is the cost of that typical care. And then there are the costs of the avoidable complications related to that condition. When we show people a chart, which I do not have with me, that shows the relationship and compares doctors in terms of how they do on these two buckets, a fascinating thing happens. The consumers interpret the bucket with avoidable complications as a quality measure inherently, because their view is avoidable complications should not happen. That is bad quality care. If they are getting more avoidable complications, they are a bad doctor.

What is fascinating to me though is that by doing that breakdown, we are implicitly saying some costs are good. You need to get what you need to get because if you do not get what you need to get, you may end up with all of these other expenses that were essentially avoidable and often even higher than what it would cost to do that. That is a very complex set of ideas. We were kind of stunned in our groups that people got it and that they immediately started to interpret this number, the cost for avoidable complications, as a very acceptable quality measure. I think we have to be very creative about this.

MS. RICH: My name is Pamela Rich and I am from the National Business Group on Health. We are a membership organization of over 360 large companies. I would like to add a perspective to the mix when it comes to the employer and price transparency and quality transparency tools. This is something that we have been working on for quite some time with our members and something we hear about all the time. It takes a big cultural change as has been mentioned. Employers, consumers for that matter, do not know how to shop for health care. They know how to shop for everything else, but they do not know how to shop for care.

We are hearing all the time about our members who are large employers taking upon themselves to partner with transparency vendors like Castlight, like Change Healthcare, like Truven Health to implement price transparency tools that offer not only prices for services, but quality metrics as well and do what we talked about earlier. Embedding information into these tools so that employees can find a decision aid, can find information about their health care need, and it is all in one place. From what our employers have told us about the engagement levels, they are off the charts. Once employees know how to do this, they go back and they do it over and over again for the services that they can.

Although this is a daunting task, I think it can be done and I think that there is hope for Americans being able to shop for services. I just hope that once the health care exchanges open up, the private marketplaces, that these tools will also be available in those.

PARTICIPANT: National Business Group on Health is a member of the Choosing Wisely campaign.

MS. DAY: Kathy Day, patient safety activist. We have not had a lot of conversation about the uninsured here, and I think we have to really keep that in mind. A lot of us who are insured tend to be a little bit smug when we approach our own health care and I am one of them. When I

faced surgery for uterine cancer 2 years ago, I heard from my first doctor that, because of my girth, I needed robotic surgery. I went to the second doctor and she did not guarantee that up front, but she went for robotic surgery. I looked for all of the complications. I connected with other patients online. I researched. I made phone calls. It is hard to get quality information. I did not even consider getting cost information because I have this great federal insurance plan. My husband is a federal retiree. Don't shoot me, please. I did not even consider the cost. But I did get an itemized bill because I am interested, and it blew me away. I had a bill for $44,000 for an overnight stay after I had robotic surgery. Some of those little tiny disposable instruments that go on the end of the five arms of the da Vinci robot were many thousands of dollars. I am a little embarrassed that I did not get an estimate.

When I take Louie, that is my Pekinese Maltese mix, to the vet, they give me an estimate. And then I can sit with the doctor and I can ask out of these four or five diagnostic measures, which are the priorities. Which one or two are the priorities? That is the exact kind of conversations I think that we need to be having, all of us, with our providers when we approach health care.

DR. SANTA: Thank you. We have 4 minutes. Two questioners left. Go ahead.

MS. KORNBLAU: Barbara Kornblau, the Society for Participatory Medicine. I want to go back to the example of the feeding tube versus feeding. In a prior life, I was an occupational therapist and I taught people in nursing homes to feed themselves. And what would happen is they would say to me you cannot make that recommendation, because in order for it to be skilled care, they need the feeding tube. Number one. Number two, there was not enough staff. Because there was not enough staff, my clients would aspirate and they would yell at me and say, "You said she could eat." Well, if you feed at a normal pace or you allow her to feed yourself, she can eat. I think that is why everybody in nursing homes has tubes. When nursing homes are owned by hedge funds, the only thing they can cut back on is staff.

DR. MONTORI: Victor Montori, Mayo Clinic. First, congratulations for fighting against the corruption in health care, which is I think—that is the word that came to mind when you asked what word comes to mind about Choosing Wisely, for me was corruption because—care about itself and how to get bigger than about patients. This is trying to revert that. I congratulate you for what is going to be a great battle. I want to join you.

The second thing is that that battle has some interesting edges. When do you get quick wins and when do you keep pushing? We heard one about a second ago regarding robotic surgery. *JAMA* this week has an article showing that for that particular kind of procedure—that it was for benign disease—robotic surgery for hysterectomy is not superior to laparoscopic surgery and costs more money. If somebody had to choose wisely, they would have to choose against robotic surgery in that circumstance. There will be some edges that have to be crossed over in that situation, and some fights will have to be fought. They may need to be prioritized lower for the campaign to be successful. I am interested to hear about the strategy related to that.

And related to that issue, there is good evidence that for-profit hospitals and for-profit dialysis facilities are associated with higher mortality and higher cost. If one were to choose wisely, one should avoid for-profit hospitals and for-profit dialysis units. And again, we have problems with crossing certain ages and bumping into some toes. I would like some comments in regard to that.

MR. WOLFSON: I think you brought up a marginal benefit discussion, and whether we move away from $210 billion worth of waste and go to marginal benefit is an open question for us. Some people are saying keep focused on just waste. If we take out that, that will be great.

Marginal benefit is very difficult. I think if we are going to do that, we are going to study for about 2 years about how to talk about it. Right now, we have no way of thinking about how to talk about it. I am glad Mayo is going to join the campaign. We need everybody in this room to join the campaign. I wish I had time to say that. This campaign will be nothing unless we have everybody in this room participating and doing research to see what is effective in implementation.

DR. SANTA: Just a comment. As my earlier comments suggested, I think we need folks who have both confrontation and collaboration skills. And we need folks who are comfortable around really aggressive conflict and confrontation.

MR. WOLFSON: I will do the collaboration. You do the conflict.

DR. SANTA: I was at a meeting yesterday where industry was over here, doctors over here, consumers. There was a lot of conflict. By the end, it was amazing how everybody said this is the best discussion we have ever had.

PARTICIPANT: With all of this conflict, what is our hope out there for patients to really think like citizens? Do you really think that that is possible? But what do I take back to the docs?

DR. GINSBURG: It actually came up in a discussion group we had in a project called Visible Fairness having to do with the use of cost-effectiveness as a coverage decision. And what one woman said was, "I support it. I get it. I think it should be used, but I do not want to hear it from my doctor when they are taking care of me. Do it behind the scenes, but I want to know is this treatment right for me? If it is not, fine. I do not get it. But do not talk to me that cost went into the equation." That is the divide. The patient at the bedside and the patient who is now in the voting booth or whatever is that there are only so many miracles you can do to get them to completely merge at the same time. You can bring up cost directly.

But I guess where I am so wedded to is when you take the public and you put them around the table and you ask them to help live it, they are ready for the most part, lots of nuances here, to dump low-value care. The question is do the other stakeholders—are they brave enough to say, "Let's see how we actually put that into practice in a way that really marries the values of this larger group without totally trampling on the values of the individual"? I think it can be done.

DR. SANTA: Thanks, everyone. Let's have lunch.

LUNCH KEYNOTE—HOW AMERICAN HEALTH CARE KILLED MY FATHER

Mr. Mark Gorman (Moderator)

MR. GORMAN: So our lunch keynote today is David Goldhill. Christine and I just met David personally, just a few minutes ago. I think we are going to have a very interesting, and possibly even somewhat provocative and challenging, talk from him, but fully in the context of what we have been talking about over the last day and the remainder of our meeting about how to engage patients better.

David is the President and CEO of the Game Show Network, I am not going to read all his background, it is in the materials in the green folder, he has a long and distinguished career in television. We can ask him at some point—are you going to be with us for the rest of the afternoon?

MR. GOLDHILL: No, I will not, unfortunately.

MR. GORMAN: In our brief Q&A after his talk, if you want to ask some preemptive questions about using the mass media to try and get our message across, we might try to pick his brain on that. David is also a son, he has got some prominence in the health care field as a result of his experience with his father's illness, although that's not primarily what he's going to talk about with us today. He also will be speaking to us partly on his experience as a father and as a patient himself. But the principal focus he wants to share with us is his perspective on the topics of our workshop from that of a businessman, a highly successful businessman, dealing with the issues of how to engage patients in making better use of their health care and their health care dollars in our system.

MR. GOLDHILL: Thank you, Mark. I left a shameless plug for my new book up on the screen here. It's not really what I'm going to talk about today. What I want to talk about relating to the issue of shared decision making is something very radical in our current context. What my work has been about since my father's death has been looking at health care as an industry. And specifically as an industry serving consumers, what patients are called in everything else.

And one of the questions I ask really is, can we find industrial reasons that it's so broken? It is unusual to have an industry this size that is so bad at so many things. And that's probably a moment to say that there are parts of this presentation that may very well offend some of the people in the room. So I want to make clear that I really do come at this from an outsider's perspective, which doesn't mean that I don't have a lot of respect for all the excellent work that's done in the field, and I hope no one takes it that way. It's more about comparing what we talk about in health care, how we think about health care, with how we think about everything else.

I will tell you that this book that I've written is an argument for rebalancing the system to be a true consumer-driven industry. And when I talk about rebalancing, what I mean is taking us away from assuming there is going to be someone between us—and by us here I mean the patients—and the providers. Almost every interaction is intermediated in this system. And what's missing is consumers as the direct economic force. There's a lot of work I know going on in this conference about how this profession can be better at providing care, at being safe, at offering quality, and at providing appropriate amounts of care.

But since the dawn of professions—all professions—we have a lot of data that says no profession is ever very good at reforming itself. Whether we like it or not, the fundamental economic incentives that a society provides drive behavior. I want to come back to that in a second.

Let me just start with why I'm here. This is a picture of my dad and my first son taken about 4 years before his death. We brought my dad into a hospital for precautionary reasons. They admitted him, he was a bit short of breath. Within between 24 and 48 hours, he had developed a series of infections that meant he never left the hospital. We all know the numbers, they're very large, the type of people who suffer errors, preventable infections, what have you, and the enormous damage that causes. That's not what I want to talk about.

I think it was 4 or 5 weeks after my dad's death, I read an article that Atul Gawande wrote about the effort to get hand washing and other sanitary protocols into hospitals. That's the first time I learned how common hospital-acquired infections were. I had no idea, I'm not part of the health care system. But I learned something else that has really driven everything I've written about and thought about since then, which is that it's really strange that a business needs to be lobbied for a low cost way to save customers' lives.

I was in the movie theater business. It doesn't seem like a comparable business. But we had very strict rules on how long between a soda spilling on a floor and it being mopped up. Very

strict. Why? Because someone might slip and fall. You think, "Oh well, you're just trying to avoid being sued. What difference does it make?" We had very strict rules, and they were enforced. And if you see a well-run movie theater chain, people are spilling stuff all the time and people aren't sliding around.

Now this isn't about slipping over sodas, to some degree it's more complex. But what does it say that these reformers have to run around the country basically begging hospitals to adopt something that costs almost nothing that saves lives? Now if you're in the profession, you say, "Well, have to do a better job." If you're in business, what you say is "something is wrong with those incentives." "Incentives" is misunderstood, and I want to come back about it. But one of the things that need to be understood about incentives is they're not just about money. We talk a lot about money in health care, which is really weird, of course, because we deal endlessly in matters of life and death. And my interest in health care, although I will talk a lot about money, isn't about money. It is about knowing that I'm going to be a patient one day, knowing my kids are going to be patients, still having a mother who is a senior citizen, and recognizing that money is a proxy for quality and the incentives around quality and service. That's why I'm here.

I mentioned incentives. I must tell you in the time I've spent in health care in the last 5 or 6 years, I have been amazed at how many people there are who are near saints. Undoubtedly a lot of you focus on the bad apples and the doctors who shouldn't be practicing and the institutions who aren't well run. But I have to tell you I've been in the business world my whole life. I was a banker to start off my career. We had nobody in banking who went into banking to make the world a better place. I know I didn't. But in health care we have a lot of people like that. And so it tells you the power of economic incentives that almost everything that happens in health care, if you step back and stop thinking of health care as special, you can explain by an economic incentive.

There's one thing I ought to make clear about an economic incentive. It's not binary. It's not if Medicare pays you per procedure, you operate on every single patient no matter how healthy. It's all about at the margin, at the moment where I'm at the border between do I recommend a procedure or not. It's the marginal physician, the marginal institution, the marginal procedure. That's where incentives operate. And I notice a lot of people in this field don't understand that. They'll say I would never give somebody a drug they didn't need or a test they didn't need. That's not what an incentive is, that's not how it works. It works at the margin, and that's what makes it so powerful, is it moves decisions from A to B when they're close.

There is no escape from incentives. As the communist world found out, you simply cannot eliminate incentives. You can hide them, you can distort them, you can morph them; they always exist. All of us are dominated by incentives. We all have to feed our families and ourselves. The other thing is they're not static. And this is something that is very much misunderstood by the government. The government thinks it can give you a penalty for killing a patient, we've changed the incentives. But it's static. Real incentives have feedback loops, and I want to come back to that. So, if you want to incent people to use technology, you don't have meaningful use rules because they're rules, they're targets. You have competition. And I want to show how that works in the world outside of health care and why information technology has failed inside of health care.

But first I want to talk about all of the fictions and myths that prevent us from seeing that health care should be a consumer driven industry. And that's really what I'm going to talk about for the rest of this. All of the things we all believe, we all nod our head at, as absolutely true, that are completely false—and that represent pure IOM thinking, and in some cases in fairness were

true a while ago, but with health care at 18 percent of GDP and a substantial amount of everybody's consumption, they're no longer true.

Let me start with the biggest thing we all believe, which is that none of us can afford health care without insurance. Besides the fact that that can't possibly be true, somebody must pay for it, it's not true for the overwhelming bulk of our population. So Becky is an actual 23-year-old who started with us 2 years ago. And I sat down and said, if I looked at all of the ways that Becky is going to pay into the health care system over her lifetime, everything, her share of premiums, my share of premiums, I'm just taking out of her pay, where else would I get it from? Her Medicare taxes, the percent of her federal and state taxes that go to fund Medicare and Medicaid, her Medicare premiums down the road, how much is Becky going to put in the system?

I put a couple of big assumptions on this. One is that Becky is the sole breadwinner in her family, which reduces the number. The second is that Becky remains solidly middle class her whole life, which reduces the number. Becky started out earning $35,000 a year, I assumed her income grew 3 percent a year, which historically has been the case in this country for most people just by aging. Just by getting older your income grows. I also assume Becky never gets really sick. She never has meaningful out-of-pocket costs. And then I did one other assumption so absurd that you probably shouldn't even look at the slide. And that assumption is that health care costs grow only at the CBO's projections, which are 10 years. And so the balance of Becky's life, health care costs grow at zero.

I had Becky live to 80 and I had her husband leave her at 65 so she wouldn't have to pay his bills. So Becky will put almost $1.9 million into our health care system over her life. If I look at her real compensation—what I pay her really, not just her salary but all her benefits and everything—that's close to 30 percent of what she'll earn over her life. She'll fund her kids, she'll fund her spouse.

For those of you who are skeptical about the analysis, if health care costs grow at zero from now till the end of time, Becky's number will only be $1.2 million. Now why is this the first slide? Because everything I'm about to say has to be in reference to this slide. We are talking to a population that we're asking to put in a middle-class lifestyle $1.2 to $1.8 million, if they're lucky, over their lives. And when you talk about the value of these intermediaries, remember that.

One other thing before I move into this more quickly. Let's talk about the neediest in our society. So, between Medicare and Medicaid the federal and state governments will spend about $850 billion in subsidy this year on top of what the beneficiaries pay themselves. If we wanted to we could give 100 million people $8,500 a year to spend on their health care. For a family of four that's $34,000.

I'm not suggesting we do that. But when you think about just the money, remember how much is in the system today. And we think we're protecting ourselves, what we're really doing is deluding ourselves. What this system is great at is hiding how much Becky and everyone else is putting in. We all know why we have to have an insurance-based system. You want everyone to agree with you at a health care conference, make the following statement: Only 10 percent of people in the country consume 70 percent of the health care in a year. So we know we must have insurance. So has anyone not heard that statement?

Here is the problem with that statement. One hundred percent of the cars every year are bought by less than 10 percent of the population. One hundred percent of college educations

every year are paid for by less than 10 percent of the population. One hundred percent of the weddings. One hundred percent of the refrigerators. Now, it's a little unfair, but it's worth thinking about health care, instead of being something special, as being an expensive good and service that we all use over our lives like all these other things. We use it a lot some years and very little other years. We have tons of industries like that.

Now, health care is a little different because there are some people who every single year are in that top 10 percent who are just sick over their lives for long periods of time. But for most of us we're going to spend a year or two in that top 10 percent, just like we're going to buy four or five cars and go to college and maybe send kids to college and have one, two, or three weddings, and buy a refrigerator every decade. Expensive capital goods and services all look like this. Health care is not special. What makes health care special is that the other 90 percent of us use 30 percent. That's not true in any other good or service. That only 30 percent is over $800 billion a year. By itself it would be the largest consumer industry in the country.

We all know that consumers can't do the work necessary to be health care consumers. So what's the point? That's why we need the system we have now, because there's somebody out there taking care of it for you. I don't think anybody who says that has ever looked at any other industry. Because what makes consumer-driven industries consumer-driven is that the providers do all the work. They're chasing you.

I think a lot of people in health care economics seem to think that Walmart was created when an angry mob marched on Neiman Marcus and said we demand lower prices. What happens in the world outside of health care is somebody wakes up in the morning and says you know how I'm going to make my billion? I'm going to be the low price leader. You think anyone has ever said that in health care? You know how I'm going to make my billion? I'm going to be the service leader. I'm going to be the quality leader. I'm going to be the appropriate amount of medicine leader, and I'm going to invest in that brand and make sure everybody knows about it.

So, all over I hear, well, consumers just can't possibly—you get hit by a bus, you can't negotiate your care. So let's be clear about this. In consumer-driven anything, you don't negotiate anything. You don't go into Walmart and say, "Toothpaste, huh? What was the cost of that toothpaste? I only want to pay 5 percent over cost." They give you a price, they say it's the price, you pay it or don't pay it. In our system we have this. This is the real cost of having an intermediary. My son had a ruptured appendix, and he needed an appendectomy, at least according to 99.9 percent of medical literature. He had an emergency appendectomy, and here's the first response from our insurance company: Our medical reviewer has determined we cannot approve your hospital stay for acute appendicitis, we do not have enough facts to show it was medically necessary.

Now, I don't blame them. It's what I would do if I ran an insurance company. Make it as hard as possible, administrative complication goes into the rate base, it's smart. But whenever somebody says to me the problem with consumer-driven care is consumers have to do so much work, I really wonder what on Earth they're comparing it to. I'm the CEO of this company that these guys insure. I had to fight with them.

Many of you know who Kenneth Arrow is. He wrote one of the most important policy papers in health care, arguing that information asymmetry between customer and doctor meant that you could never possibly have a functioning market, the customer would just do whatever the doctor said. This is one of those things that I think we've outgrown in health care. And we've outgrown it for a few reasons. One is we have TripAdvisor, or we have PatientsLikeMe, to be more

specific about our care. And we have a lot of ways that people get information about health care other than from their doctor that truly didn't exist when Kenneth Arrow wrote 50 years ago.

But here's what's more important: we require our patients to do that work. And I know that's a lot of what the work is going on here. Health care is no longer just about your house is on fire, we have to put it out, we have to fix this. Health care is not like auto repair. It's increasingly about a variety of treatment alternatives, often long term, involving interaction between the patient and the health care system. That requires patient effort. And so whatever you believe about Kenneth Arrow's original point, it's irrelevant. There is no health care system without patient involvement; there are too many decisions patients have to make.

The last thing of course is we've now had about 50 years, 60 if you just look at private insurance, of having intermediaries play the role that Kenneth Arrow said they should play; they should be the customer for us. And they're horrible at it. They're just unimaginably bad at it. And so if you still think Kenneth Arrow was right, you have to consider the story about the bear and the two guys in the forest. Everybody knows this. The bear is chasing the two guys, one guy stops to change into sneakers. And his friend says you idiot, you can't outrun a bear. And he says I don't have to outrun a bear, I just have to outrun you. And so whatever you think about the theoretical correctness of Kenneth Arrow, all we have to do as consumers is be better than intermediaries for the system to be a lot better. Maybe you saw Steven Brill's piece last week about prices in health care. This is a point he makes very strongly. Prices in health care have no meaning. So if we move to a consumer-driven system this still isn't what would happen.

On the left you see Medicare's statement to us from the hospital for killing my father. They charged only $636,000 for the service. And then on the right you see my effort to say if I had rented out a room at the Four Seasons, which is the most expensive hotel in New York at $1,000 a night. I leased a million dollars of hospital equipment, put it in his room. Gave him an hour a day with a physician which is probably about five or six times what he got, and gave him nurses around the clock. I also gave him room service we included in here. That most extravagant possible treatment is $155,000.

Now, obviously nobody paid $636,000. Because in the health care system we don't use prices the way we do everywhere else, to communicate actual information on costs, scarcity, need for investment, you name it. Here is what we communicate, because every bill communicates something important. And I'm sure all of you have gotten bills from your insurers. They communicate the following: You're lucky to have us, you can never handle this yourself. My aunt got a bill from her insurer which said the hospital charges were $105,000, her share was $300, and the insurance company had paid $800 and the rest was other insurance credits. Nothing is being communicated there except thank goodness you have insurance.

A lot of people think we can fix this just through payment reform, or by making health care cheaper. That if we can just improve efficiency in health care, we can bring cost down and make it more responsive. And we've been doing this forever, right? Productivity in health care has gone through the roof, but of course it has had no impact on prices, because there are no competitive mechanisms for it to have an impact on prices.

Let me give you the ultimate example. I love this example. Many of you obviously know that the Reagan administration enacted a prospective payment system for hospitals. And that for the most part most hospital bills—in-patient for a long time, out-patient for shorter—have been what would be called "bundled" or "fixed payment" on diagnosis. And the impact on usage has been extraordinary. The days-in-hospital per Medicare beneficiary have dropped by 63 percent since prospective payment. The total days-in-hospital—even though we have so many more Medicare

beneficiaries, the population has almost doubled—itself has declined by almost 50 percent. And the total days in the hospital are down almost 60 percent.

You will never see a reform that has a greater impact on true cost. When this reform happened, a night spent in hospital was by far the most expensive element in the system. So you know what happened. Once we cut 60 percent of the cost out of the system, prices tumbled. Right? No. Weirdly, we reimburse five times as much, which is somehow bigger than minus 60. If we'd cut the hospital days by 99 percent, the result would not have been we save money, we would have reimbursed by more. And here is a hint to what is really going on. So, Medicare reimburses five times what it did before prospective payment reform. The hospitals claim their costs have grown seven and a half times. So, in other words, Medicare has cut the usage in half, paid five times as much, and convinced itself it's getting a better deal. It only paid five-seventh of the increase in cost.

One of the problems with not using prices is it causes us to do things and think things that are weird. So, here's what we think is happening in health care. We think that Medicaid is paying a lot less than Medicare, which is paying a lot less than private insurance. This is from a single study done in Michigan on I believe appendectomies in the mid-2000s. It's obviously very hard to get true comparable pricing. So, here's what we think. There is some cost shifting going on, something unique to health care that private insurance is really paying. Because we all know all Medicare patients are served at a loss, so private insurance is paying for that and for Medicaid, right?

And you only can believe that if you've never been outside the health care system. Because here's hamburger pricing. McDonald's makes money at 99 cents. They're not actually being subsidized by DB Bistro. Cheesecake Factory makes money at $11.95. DB Bistro makes money at $32. They don't sell many of them. There's foie gras on the burger. I've had it. I've had all three of those. What's important about all three of those? They're all hamburgers. They're all lunch. If you stand outside of health care, what you would say is if I've got three different price regimes that are this wildly different, what I've got is three different products. And I think it's something actually that people who focus on price miss, which is where the customer is obsessed with volume as in private insurance, I charge a lot of money. Where the customer is obsessed with price, as in Medicare and Medicaid, I do a ton of volume, which means I perform the service differently.

Now, I'm not here to tell you how doctors perform their services and hospitals do. But this can't be false. This is how the world actually works. We may not recognize it in health care, we may not believe it in health care, but if you have a price imposed upon you, you figure out a way to make money at those prices. If you were really losing money on Medicare and Medicare patients, you wouldn't take them, there would be no cost shifting.

Here's something else from outside the island. What is innovation? What is growth and technology? There are only two industries where anyone seriously says technology is driving up costs. We say it in health care, we say it in defense. So, in 1965, there were somewhere between 10 and 20,000 computers on Earth. There weren't many more people who knew how to use them. And that's what a hospital room looked like in 1965. Both industries have undergone a lot of technological change. In computers, what happened is 100 percent of the world population got PhDs in computer science, which enabled us all to carry a little computer in our pocket, the single most complicated thing on Earth. I've actually got two of them right in front of me. If in 1965, you said every person on Earth was going to have one of these, you would have been committed. The most personal, individualistic, heterogeneous service on Earth is the one on the

right (health care). The one on the left (smartphone) is the most accessible industry on Earth, even though 45 years ago or 50 years ago it was thought of as impossibly complicated for anybody other than 50,000 to 100,000 people on Earth to understand. The one on the right (health care) is now complex beyond understanding for even the people in this room, who know more about it than anything else.

That's my dry cleaning bill on the left. This is the most important lesson that I can offer, which is do not have your dry cleaning done in New York. The prices are ridiculous. This is the most expensive dry cleaner in New York. And what is interesting about what they have done is in response to the Congressional Dry Cleaning Technology Act, they invested in information technology and they took it an extra step. They actually can tell you every single shirt. Look at the first one. A Barneys New York shirt, blue, solid cotton. A Paul Smith, white with stripes, light blue. Why? Interestingly, that's incredibly bad for them. Because when they lose one, I know exactly what shirt it is. So what do they do? They sat there and said all the other dry cleaners now have computerized bills. I'm going to take it a step further so I can charge more. So, yes, I take the risk of if I lose a shirt, I can't say three shirts, I only took in two shirts, that's a mistake in the bill. You say you lost my Paul Smith shirt. So, that's now the digital age works, right? It's that we're all endlessly playing with stuff, what makes sense. That dry cleaner literally made this decision to compete with the guy across the street.

This is my completely unfair representation of the Meaningful Use Rules, and these are the instructions to an iPad. All of you who have bought an iPad know an iPad has no instructions. That's how information technology actually works; if it's not usable, it's useless. And we know this everywhere, except one place.

This is going to be an unfair slide, I'm sorry. I'm going to bring this one on Otis Brawley. Otis Brawley wrote, if your institution has a center of excellence you probably have an excellence problem. If you call yourself patient-centered, you aren't, you're talking to yourself. This is how people talk to customers. This is a customer-centered retail establishment. They don't use the word *customer-centered* anywhere, no one does.

This is the single stupidest idea in the history of mankind, and as a result it completely transformed the world economy; in thinking about innovation around health care, you have to think about the shipping container. So, the shipping container has changed everything in our world. And it was a terrible idea. What happened? The most expensive thing you can do is put something on a ship and run that ship across the world, right? Incredibly expensive to send a ship somewhere. So what did the shipping container do? The shipping container said, do you know what we're going to do? We're going to fill ships with empty space, instead of having ships carefully loaded to maximize the use of space. You put a motorcycle on a car or a ship, that's a puzzle, right? How do I fit that? We're not going to do that. We're going to put everything in a box. Most of a box is empty space. If you ever opened up a shipping container, most of it is empty space. And so ships are filled with empty space. Could there be a dumber idea to take the most expensive thing you can do, ship, and fill a ship with empty space?

Well, of course, what the shipping container did was it meant that you could load and unload ships almost instantaneously, within hours. I've lived next to the Port of Miami, they turned massive ships around in hours. You can build much bigger ships. It's actually impossible to build a big ship unless you use a standardized container. You can't reach everything to make sure that the toys are packed correctly with the motor vehicles.

And so everybody hated this idea because it cost everybody their job. It meant that all the ports that were great ports lost out to new ports that invested in computerized shipping, and it is

the reason that the prices of most goods have declined over the last 50 years and that supply chains are now earth long, instead of having to be near a river or near the plant. The economic transformation of this may be greater even than the Internet. It's in the trillions of dollars in cost saved. And it's a terrible idea. Everybody in the business hated it.

So it's about a very important phrase, which is "creative destruction." I was at a meeting the other day where the head of one of our local hospitals in New York got angry at me for saying that there was no real incentive for saving cost in health care. He said that he had sat down with a group of the other hospitals, the insurers, the doctors, the nurses, and a couple other people, and they all sat around and tried to find the best cost saving ideas. So, it's the reason we don't ask turkeys what to serve for Thanksgiving. Really innovative ideas hurt peoples' businesses. And so when we sit around and say, how do the stakeholders agree, we're not talking about real innovation. It's sad, it's ugly, it's the reality of our world, but it's what's changed every single other industry on Earth. Real innovation is truly disruptive and truly destructive.

I'm actually going to skip over this except to make one point. Obviously, there are some bigger public policy issues here, and there are a couple things that I think aren't widely understood about where the United States stands. The United States actually spends relatively little of its health care spending out-of-pocket. Less than most OECD countries. It's now closer to 11 percent. France spends a little less, the UK spends a little less. Not a lot less. Most countries have more consumer skin in the game. The United States spends relatively little of its health spending from the government, but the gross number itself is one of the highest in the world.

Now for a little perspective, here's Singapore. Singapore is the only rich country with a truly consumer-driven health system. Fifty-four percent of the amount spent in Singapore is spent out-of-pocket. And what's interesting about that 54 percent is every single health care decision in Singapore is made by a patient. They actually buy it. Even if they're going to be fully reimbursed, the government isn't the payer, the patient is. We're so used to insurers and Medicare paying on our behalf, we forget they could also give the money to pay and that would transform the system. In Singapore, only a third is explicit health spending. Interestingly, some of it is to run a parallel health care system that competes on price. Singapore spends only $2,400 per capita on public health, but here's the killer. Singapore spends 4 percent of GDP on health care. It's as rich as we are, people live as long, the health care system is as good. Fourteen percent of GDP less than us, and less than almost any other single payer or other country.

It's a lot of policy stuff. Let me come back to what I think this really is about. One of the things that is unique about health care is that there are 310 million of us that have a health care story. Sometimes it's as simple as the doctor forgot who I am, or they lost my test, or the generalist didn't talk to the specialist, or one specialist didn't talk to another. Sometimes it's much more serious. Sometimes it's about being taken for procedures that were meant for another patient. My father was twice. And as we all know, they tell you if you have a family member in a hospital, try to be there at all times. Imagine if FedEx said we'll deliver your package, but it's best to hold onto it during the process. In a high-tech world this is insane. We're so used to it we don't even realize how absolutely absurd that is, but we all know it's necessary. And obviously all the way to the extremes of people dying from mistakes.

We talk a lot in health policy about very big picture things—about money, because there's a lot of it, about big incentives and big economic ideas. What needs to inform us, though, is that this all translates into the little picture and that every single one of us has a story. That's way too many of us to have a story. Thanks very much.

MR. GORMAN: We have time for a few questions.

DR. MONTORI: Hi, Victor Montori, Mayo Clinic. Thanks for a very good presentation. I'm disappointed I didn't get offended. I was looking for it. The Cheesecake Factory thing I think just went through the threshold.

The newspaper piece that was published at the *Star Tribune* in Minneapolis put it together as well. You make the case that there is insufficient for-profit health care. And you were not here, but in the previous panel we were talking about how there is actually good evidence that for-profit health care is actually more expensive and is associated with increased mortality. And I suspect that it's because of the conditions or environment in which it learns to operate. You're suggesting a fundamental change in the conditions or environment. Do you want to elaborate on that?

MR. GOLDHILL: Thank you for bringing that up. You've made the point for me, but I think it's so important it's worth pointing out. We have the worst of both worlds. We have a profit-driven system with the wrong customer. So your point is exactly right.

First of all, there are no nonprofit systems. We're all working for a living. So, at some level, all of us are doing this to pay our way. There may be no shareholders, but they are still people earning a living, and how they're incented is important. But your point is completely correct.

I wrote a piece for Bloomberg about 2 months ago saying the profit-driven system is producing terrible results, the nonprofit system is delivering, for the most part, terrible results. The problem is the economic incentives for both are fundamentally the same, and they're distorted by the fact that we've decided to let an intermediary be the customer for everything.

And I would argue that between the market power that these intermediaries have allowed providers and that the intermediaries themselves have, and the policital power accumulated, the way to make money in health care is for the most part to do bad things. And the fact that we don't do terrible things speaks to how many good people there are in health care. Because in fact, purely economically, if health care was an investment bank, remember what we have. We have a system that says we'll pay for any care the patient needs. And we've got somebody with a monopoly in determining how much the patient needs. If in investment banking we said we will subsidize any deals bankers think are worth doing, we would be an entirely deal-based economy. The only reason in health care we're not is, again, because of the professional requirements of people.

But I think those incentives can be changed meaningfully. And without them, the for-profit system and the not-profit system are both going to produce terrible results. The relative difference I can't tell.

PARTICIPANT: I agree with you, I feel like you're my twin. And I wanted you to know that in Portland, we have been trying to get the consumers in Portland to design a new benefit package to ask for warrantees for certain services and to change things up substantially. And a large orthopedic consortium got together and redesigned how they're going to provide services. And they're going to charge one flat fee and they're going to give a warrantee for services. So if anything goes wrong for a long period of time the patient can come back and know that that's all covered under the warrantee. And because of that, they built in shared decision making to make sure that people who get the services really want the services. They prep the patient much more up front, and then they prepare them for after the fact, including how to rearrange your furniture for when you come back and what to do with your throw rugs, et cetera. So I think it is very important.

The second thing I wanted to tell you is a couple of years ago we had the author of a book called *The Healing of America* come to Maine, I think that's why he won't go anywhere else. The poor fellow, Maine is eight hours long and we took him over most of Maine. We reached 16,000 people, and we had over a million media impressions which in Maine is good because that's how many people we have. And what I learned from going over most of Maine with him is that our system has a lot of unnecessary un-value-added costs, beginning with just how we reimburse for services. And each of these insurance companies has a different way of doing things. It's not uncommon for hospitals in Maine to have twice as many people who are doing billing than they do beds in the hospital. And they have very expensive computer systems that they have to work. Most countries have one electronic medical record that they buy for everybody; we have a thousand, and everybody has to connect to those different thousand. So I think we don't do a lot of things to try and make sure that we get more value from our system. And when we keep on paying for insurance the way it's offered to us, and not ask for something different, we are contributing to the problem.

MR. GOLDHILL: Thank you. One point that you raise that I think is worth thinking about, one of the things we think about in health care that we actually don't think about in anything else is that there is the right way to pay for things. In anything else, we're willing to have things exist side by side. Different business models, different ways of paying. I think it's actually a mistake in health care.

I think one of the nice things about bringing consumers into a more balanced role is that we'll have people compete for their business on different things. People will bundle their services and say here's my package you can buy. Others will do fee for service.

In fact, rather than sit around and say what's the right way to pay, I think what we need to think about is that having different business models exist at the same time is the feedback loop that causes endless innovation and endless improvement. There are very few things on Earth that there's only one thing to buy, but in health care our best minds are endlessly looking for the perfect way. And I think that conceptually is an error.

The other thing I should mention is when I talk about patients, what I'm really talking about is balance, bringing consumers into the system, not having everything be intermediated. It doesn't mean you get rid of the government role or get rid of insurers' role completely, but it does mean rebalancing the system.

MS. BECHTEL: I'm Christine Bechtel and I work for a consumer advocacy organization here in town. I want to fundamentally ask you, what's the pathway? That's sort of the theme of this meeting. And I think conceptually there is not much that you've described that someone in this room would say that's not the right idea in terms of a way.

But the question is the way to get there, and I want to preface that question by saying historically, the words *consumer-driven health care* have a bad connotation for the consumers, because that's usually the place like high-deductible health plans, where we just voice the problems that the health insurance companies and the employers and congress have been unable to solve, so let's get them to fix it.

I don't think that's what you're saying. But I think on the other hand it would be helpful to know what is the pathway, the next three things we need to do to make progress in that system? Is it blow up the insurance companies? That's kind of what I heard. Is it end meaningful use?

MR. GOLDHILL: My belief actually is the more that consumers pay out-of-pocket, the more good things happen, including meaningful reduction in prices. Interestingly, before we decided that preventive care should be covered without a deductible, we were starting to see real

competition in the preventive care services. We were starting to see minute clinics that did things for fractions of prices available in the mainstream health care system, and that's what you see. If you've spent any time in communities that are heavily illegal immigrant, you actually see how a cash-based health care system works. We're all of the belief that if it costs less, it can't be good. And some of these are good and some of them aren't good. Obviously these aren't the best customers in the system, they're the lowest price paying. But in fact systems do develop.

So what can we do? Well, I think some of it is about to be done for us. The reality is we're a couple years away from no company in America being able to offer anything other than very high deductible health care insurance. And when you get that sort of scale of people paying out of their own pocket I suspect you'll see the provider industry start to reorganize itself to get their business, and the same thing that we were seeing in preventive care before the Affordable Care Act.

I've called for insurance to shrink, to cover only the most catastrophic things. I'm spending $23,800 for an employee's family plan this year in standard deductible. I think if you had a very high deductible, say somewhere in the $15,000 to $20,000 range, the premium is probably somewhere in the $5,000 to $7,000 range. Which means I could write that person a check if it was tax neutral for $15,000 a year. Which means they basically have enough money to cover their deductible every year and a half or 2 years. And the reality is if you had millions of people with that, as opposed to just those that were too disadvantaged to have anything else, I think you'd have a very different health care system. Same amount of money, just flowing differently into people's pockets and into the system. But I must admit, it's very hard to get political support for that. I think what we're going to see happen is it happens anyway. When you look at how the exchanges will work, the cost of standard health insurance, because of the exchanges, is going to go through the roof. There's no other way they can work. They're price-capped. None of their customers care about prices? What does that do to prices? It causes them to go through the roof.

And that's going to drive the rest of our businesses. They're already high to begin with. I think you're very close to seeing the end of standard deductible health insurance privately offered outside of the government context. And that will change, that will make a big change.

DR. COHEN: My name is Perry Cohen and I'm a Parkinson's patient. My first job, after I got my master's degree with Massachusetts Blue Cross Blue Shield, I was an analyst. And one of the things I learned there is that the insurance that the doctors and the hospitals get paid really wasn't patient protection…. I'm going to pass.

MR. GOLDHILL: Can I address your point though, Perry? I think one of the strange things about public policy debates about health care is the role that's assigned to insurers. You hear politicians talk all the time about relying on insurers to control the cost of care.

I guess none of those politicians have been in the insurance business. Because insurers have no way of growing their profits by demand for care shrinking. And demand for care is volume times price. And what people get confused by is when they put in a claim and an insurer says, like mine did, nope, we're not paying for that—sounds like they're pretty tough on cost. But the fact is we've had private insurance dominate pay in this country now basically since the mid-1950s. We saw cost go up much faster than GDP and inflation, and insurer profits have been fine. If you spent time in other insurance businesses, for example when there's a hurricane, the stock prices of the insurance companies go up, not down. Why? Because premiums are going to go up, margins go up.

The idea that insurers are going to somehow bring discipline to a system—if none of us needed any health care and insurers did such a good job of driving a better system, we were all

so healthy, there wouldn't be health insurance. They'd earn nothing. And so insurers at best have an ambivalent relationship with cost. They don't want to pay for your procedure, but they do want your company to have higher premiums next year. That hasn't made them great guardians of the system, at least in terms of cost. And I think many of us would probably argue they're not great guardians in terms of quality and safety either. I don't know if that gets at your question.

DR. COHEN: Yes, it does. But the point I was trying to make is that the health care system is really more doctor- and provider-centered, rather than patient-centered. I like your idea of having the patients be the purchasers more so.

MR. GOLDHILL: Thank you. I think we're unable to achieve the balance that a lot of people in this room have been talking about the last couple of days unless you bring the economic incentives in line with the therapeutic ones, which is to have patients take more control, be more active. It doesn't mean they all will, but it means the system will push that more on them.

In the same way that in any other industry things are made easy for us, the health care system does the opposite. We've got to do the work if we want to do the work. That shouldn't be the case.

DR. COHEN: Well, there is an advantage of patients being involved, a health care advantage.

MR. GOLDHILL: And that's where this comes from. This comes from that more than economics. Because I think unless the economics match what you're hoping to accomplish, you're not going to accomplish it.

DR. COHEN: Thank you.

MR. GORMAN: We'll have two more here, and then Lyn.

PARTICIPANT: Not as an argument for status quo, but just in looking for an expansion of the concepts, competition requires more than one provider, and in small-town America and rural America there may not be enough room to make investments for more than one provider group or set of hospitals, et cetera. The current system of course creates that sort of environment, and there is competition emerging in small cities, where you have hospitals that are duplicating capacity to the same area, and then of course getting patients through it that are able to pay for it.

In the re-imagined system that you have, how would it work not in New York or in large urban environments, but what happens in rural America environments where competition may not be able to play out?

MR. GOLDHILL: It's a great question. In a re-imagined system, it really does look like other things, which is there's also not enough scale for competition in most goods and services in rural America. What happens is, and I think this is more likely to happen in health care than anything else, is that the competitive price in truly rural areas is the cost of traveling to a less rural area to achieve a service. That's what keeps anybody from charging insane amounts in rural areas for anything. Health care is actually not that different. And it's a very difficult thing for people to understand. We have plumbers in rural America. They can't charge you a million dollars to fix your faucet because the town is only a thousand people and therefore only one plumber. That plumber can only charge what it takes for a plumber from the next big town to drive over. That is the only marginal difference he can charge.

In this country, in health care, we've somehow decided health care is so different that we need to regulate the rural markets in such a way to assure there's never any competition. That's all we've done. And that concerns me. Because again, there are lots of expensive goods and services consumed by people in rural America.

And the other day, someone said to me, I agree with you that much of health care is now about things that we have time—they're chronic illnesses, I'm going to have my hip replaced—they're all sorts of things we can actually make a decision and we have time for the system to say use this procedure instead of that, this one is safer, that one is cheaper, whatever. There is time for that decision making. But a lot of health care is still about emergency stuff. And how can that possibly work in a consumer-driven system? So, if you've ever had a flat on a highway you know that the tow truck that came to you didn't say, "Let me see your balance sheet before I decide how to charge you for this." The economy figures out ways to handle emergency services. Most people pre-pay that stuff so that they know there is somebody there at a reasonable price when they have a flat tire. But even if you haven't prepaid there is a limit. And that limit is created by really functioning markets existing around us.

One of the problems with billing $640,000 for killing somebody—when you know you're never going to collect, it has nothing to do with cost, price reimbursement, anything else—is that none of us have comparable prices to even think about. There's no market for anything that's real in a way we can understand it. So I'm not disagreeing with your point. It does cost more to live in a rural area than an urban area. But it costs a certain amount more, and it does in every other good and service.

MS. PAGET: Hi, my name is Lyn Paget. I'm from Boston, Massachusetts, and I have about 18 questions for you, but I'm actually going to only ask two quick ones. One is that we of course have pretty active exchanges. In addition to working in the health policy arena, I run a small business unrelated to health. And quite frankly I haven't seen the competitive pricing from the exchanges that I would hope to see.

Second, is I agree with you completely on the high-deductible plans, that's our future. What do you think the protection mechanism is going to be to keep those premiums at some point, matching what we're paying now without a high deductible? That was my number one question. My number two was if there's one thing if you could pick as a disruption similar to the container, what would it be?

MR. GOLDHILL: That's a really good question, so let me ignore it. First of all, just quickly on the exchanges, any business that competed on price on an exchange structure is beyond stupid, it's never going to happen. You tell somebody you cannot underwrite, you cannot design the benefit package, compete on price, there is going to be one price on every exchange. It may not happen the first year, but it's inevitable. Exchanges were designed by people who have never bought or sold anything in their lives. That's the only explanation for it. They've never competed in anything ever. They think it's supposed to be like commodity exchanges I guess, but in commodity exchanges or Expedia or wherever else they use as an example, you don't care who the customer is. So you offer this broad range of products and whoever has a credit card can buy it. In insurance markets, all you care about is who the customer is, and you have to be completely blind to that. Nobody is going to compete on exchanges, it's going to be a wonderful mechanism for raising prices.

But in terms of what's disruptive, my argument is what is truly disruptive, what changes everything, is that we're paying out-of-pocket. And that rather than look at these thousands and thousands of goods and services as a single thing, health care, we say to ourselves there are some things, some people, some conditions, that need insurance. Born unlucky, terrible accident, got one of those diseases that's just horrible, right? We need to insure that as a society, because we want to. And I actually believe in national health insurance to cover that. Single pool, all of us.

A lot of health care is just routine. Just like anything else. And insuring it makes it less responsive, higher priced, and of lower quality. And then there is stuff in the middle, which we save for. We're used to this. Most people in this country actually will buy a house at some point in their lifetime. None of us have problems with the idea that the down payment comes out of savings. The bulk of it we borrow depending upon what stage of life we're at. If we're older, we may just pay for the whole house because we've had savings. Routine maintenance comes out of our pocket, accident comes out of insurance—a house burning down or anything. None of us have problems that there's four, five, six, seven different ways at a time we might fund our shelter or our food. Nobody says we need to pay for the poor to have food the same way we need to fund upscale restaurants. Nobody says that. No one seriously says that. But in health care, which is the broadest possible range of goods and services, we somehow think it all has to be the same way and that's enormously distortive to the system.

So once we start paying for more and more of it—and it needs to be real scale, it can't just be the poorest of us who pay out-of-pocket, it has to be all of us who pay out-of-pocket—this industry will restructure itself like every other industry on Earth did. 1965, the customers of the computer business were NASA, the Defense Department, the IRS. The customers of the computer business are sitting in this room. That change happened because somebody said they could sell to these folks. It changed everything.

The last point you made which is the hard point, how do we stop it from happening all over again, just with catastrophic. I have a half-baked answer to it, which is in my half-baked book, and that is that we should think about moving to defined benefit. One of the interesting things about health care of course is that it has very little marginal cost. So, prices have a lot of room for variation, which means that actual cost for providing a service is relatively low, no matter what people think. This is true of industries like airline, software, telecoms. But the actual marginal cost of producing a pill is almost nothing. For providing a physician's service is the physician's time, which is a wide variation of possible price. Of using a diagnostic machine, it's almost zero, although because of the market's dysfunction they actually charge you for that, but they shouldn't.

If you actually had a defined benefit system for catastrophic care, say we're going to collect a trillion dollars of premiums, we're going to pay out a trillion dollars according to this schedule of diagnoses, the entire system would have to reorganize itself to fund care at that price. And it's so different from the way we think about it now that I don't push it, because if we can move to catastrophic it would be 10 years before what you mentioned happened happens to the point where we have to think about it.

But ultimately at some point we want to say we want this country to be healthy, we're not going to spend so much money on health care, we're going to spend more on consumption and recreation and diet and environment and exercise and lower stress in our life, those are the things that drive health. And the only way to do it at some point is for some part of the system to probably have a budget. The catastrophic function probably should. But that's a little theoretical at this point. Thank you, though.

MR. WOLFSON: This is Daniel Wolfson, I spent most of my career actually with prepaid group practices. And one thing we realized even though we were capitated a group, that is changing the incentives was just half the game, it was really the start. So I wanted you to react to that, because I think it's a little bit more complicated than just changing the incentives. We've been talking about shared decision making here and the difficulties of that.

And the other thing is Shelly Greenfield was here yesterday and he did a study a long time

ago that showed when you increase the cost to the consumer you delay care. And it was a trivial amount actually at that time. So I wanted you to react to that. And I'm not sure if you've said this, you're leaning toward consumer health savings accounts.

MR. GOLDHILL: Oh no, I do believe in consumer health savings accounts. I believe in mandatory, catastrophic. Basically what I say is, let's take what I think is the best idea on the left, which is single pool national insurance, but the best idea on the right, which is leave as much of health care as possible to become a normal industry. And I think the way to do that is to shrink insurance to catastrophic, make it mandatory. Because our system starts at such an insanely high price point, we can only really pay for it with savings accounts, we can only really let people save against it until the prices start coming down to a point as they have, for example, in Singapore. The average person in Singapore's health savings account would fund 11 hospitalizations as of 2 years ago. I don't think the average person's savings account can afford one. Not health savings account, savings account period, just to give you a sense of the difference.

I want to talk about incentives though. The key to incentives being incentives and not goals is they have a natural feedback loop. When the government has meaningful use rules, you have to hit the numbers, you have to hit the targets. When we have hospital readmission rules, you have to hit the numbers, you have to hit the targets. Same with hospital infection and all the other things that are going to have bonuses and penalties. It doesn't ever work.

The feedback loop that consumers provide is we don't know what's going to work. That first dry cleaner who went to an IT system so you got a fancy computer printout bill instead of the 12 shirts written down, he got a lot of customers. The guy across the street saw it and said, "I have to do that." He's not losing any shirts, customers are more impressed, he seems more organized. So he did that, and he said, "I have to add something." So he added, "I divide between shirts and pants or men and women." If you've been to dry cleaners you can literally see this in action. It never stops.

The bill I showed you from the high price guy is going to be the bill that the low price guy has in a year or two. The key is a feedback loop. My first meeting of Leapfrog, when they asked what was my view of what would finally cause hospital related deaths to end, I said that it would be a billboard that said go to uptown hospital, downtown will kill you. It's funny, somebody said to me, "I would never go to a hospital that advertised, because it just tells me something about their commercial approach." And I held up my iPad. This person was a big techie person. I said you know, "I almost didn't buy this because Apple advertised it. I thought, shouldn't they be spending that money on research and design? I'm a little suspicious. How good could this be if they had to tell me about it?"

And really we think health care is so different, we don't think to ourselves that one way to solve quality might be to have competitive advertising. It's a feedback loop. There is no incentive that is a silver bullet, nothing. It's the accumulation of who am I responsive to. And yes, some of it will wind up being petty. Customers will wind up preferring hospitals that are painted in this year's color. That sounds terrible to people in health care. But outside of health care, if you're used to serving consumers, it gives you a chance to prove you're responsive. If you spend any time in a hospital as just a patient, it is astonishing to you how far hospitals have fallen behind the DMV, not to mention any single consumer business on Earth. At every single stage you have to be told you are just a patient.

And again, it's not because the people are bad. The people are great. Trust me, they're much better than bankers. But if you're a customer of an investment bank, you're made to feel like

you're a prince, because they're going to charge you a lot of money. In hospitals we're all spending a lot of money. All of us are spending a million dollars over a lifetime, and we're all paupers. And again, we talk about money a lot. This isn't about money. It really is about incentives for quality care, safety, appropriateness, and I think a lot of what you're talking about in here, which is having a doctor/patient relationship, a provider/patient relationship that brings to bear what you need for the best outcome, which is a patient that understands there's no one out there taking care of them except for him. I think that will add to all the work you're doing in here on that subject. Thanks, Mark.

MS. BECHTEL: That was a mind melter. So, we knew that not one person could follow that, so we have three. So, let me invite the next panel up to the stage. I think this panel follows brilliantly on both Mr. Goldhill's speech, but also the panel before that around value. This panel is on driving the demand. And I think, before David, I probably would have said, is it even responsible to drive demand for something that doesn't exist? But now I'm rethinking that.

Anyway, let me go ahead and introduce Susan Reinhard, who is a member of our planning committee, and she is going to moderate this session. She is the Senior Vice President at AARP, heads its public policy institute, and she's also the chief strategist for the Center to Champion Nursing in America at AARP. Go ahead and don't worry about the time because we're going to take that away from the wrap-up Planning Committee members at the end.

DRIVING THE DEMAND

Dr. Susan Reinhard (Moderator)

DR. REINHARD: Thank you, and thank you for staying. And I hope most of us can stay until we really do hear the committee members synthesize this. But I know we need to get going. I do have to make one comment about the introduction yesterday. Is Sherrie Kaplan still here? I don't know if you remember this, but one of Sherrie's PowerPoints was how she had written for the AARP public policy institute in 1991. Now, I wasn't running the AARP public policy institute in 1991, but I did read a lot of it, and I actually remember patienthood, that was what she was writing about. And then it occurred to me, that's almost 25 years ago, that we ought to get her to do a 25th anniversary paper on that and incorporate a lot of these ideas. So I'll have to follow up after this conference.

So, I just do want to also mention that I have my AARP hat on of course. I have lots of different hats, as all of us do. But AARP does have a pretty big stake in this discussion. I'm sure that's part of why we've been involved in this, and in all three of the areas that we're going to be talking about.

I love the title for this, I can't take the credit for Driving the Demand, I really do love that title. It has a lot of power into it. But behavioral economics, this is something that AARP, as the largest consumer membership organization actually in the universe, is very interested in what Kevin is going to be talking about. We keep trying to figure out what we can learn about what drives people to make health care decisions in health. I should also say retirement security. What can behavioral economics teach us? Communications, and how we can message important information. AARP has like hundreds of people working on communications, always about that message. And we get lots of information. Consumers get tons of information. So how do you

message it and help them sort through all of that information? And then certainly social media and how to use it as a tool for change.

So, I do feel privileged to moderate this panel, and I'm going to start by going over the session goal. Each of these panelists, as we've just been reassured, get their full 10 minutes, so that's good, and you get that opportunity to exchange with them as you have after each session, so it's been pretty good—including people outside the room, if they're still watching on the Web.

So, you have this description of the session goal in front of you. It's exploring cross-cutting strategies to advance patients—you could say consumers—of course in partnership with providers, as leaders. We haven't talked about leaders yet. Leaders and drivers of care delivery improvement through informed shared decision making and authorized use of clinical data for research and value improvement.

So, we're going to take this from three points of view as I said. First with the focus on behavioral economics and value generation. I hope that we talk about that word, value, and how Shoshanna warned us that term itself isn't necessarily understood by consumers. Kevin, many of you know him, is the Founding Director of the Center for Health Incentives and Behavioral Economics at the Leonard Davis Institute, which is one of only two NIH-funded centers on behavioral economics in health in the United States. He is co-director of the Penn Medicine Center for Innovation, and he is a professor of medicine at the University of Pennsylvania School of Medicine and Healthcare, Management at the Wharton school, and, I have to add, he is a practicing physician at the Philadelphia VA Medical Center, so that always keeps him grounded.

Second, we will consider communicating value to the public, and Tresa Undem—we've worked with Tresa at AARP, many of you have already referred to her. Tresa is a partner at PerryUndem Research in communication, she leads public opinion research on a whole variety of health-related policy issues, including health reform implementation, delivery system reform, access, affordability, cost, quality; she is perfect for this panel.

And then we will turn to a true patient leader. And we are delighted that she is going to be discussing social media as a tool for change. This is Kelly Young. Kelly is the founding president of the Rheumatoid Patient Foundation. So in a very short period of time—I think hopefully she'll tell a little bit of her story—she went from zero to 100 in how she has moved. Talk about leadership in this whole area. She is the founder of 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. In 2006, she was diagnosed with rheumatoid arthritis after years of periodic symptoms and trying to sort that out, and she works to provide ways for patients to be better informed and have a greater voice in their health care.

So, it's a really good mix of a panel as you can see, and we're going to start with Kevin.

Behavioral Economics and Value Generation

Dr. Kevin Volpp

This section is omitted at speaker's request.

Communicating "Value" to the Public

Ms. Tresa Undem

MS. UNDEM: Again, my name is Tresa. I am going to jump right in, because I have not too much time. And it was a real struggle putting together this presentation because we've gone at this in our research issue from so many different angles, not totally head-on. And I'll sort of end on that note, why I think that is. But we've done a number of studies on health care cost, quality, payment reform. Chuck from MSL we worked with, for RWJ on a recent project that he mentioned on health care cost, and just where our consumers are—going to draw a lot on that. We've done work for Aligning Forces, communication work for them, with Chuck as well as Patrick McCabe at GYMR—delivery system reform, comparative effectiveness. We're now doing a lot of work on exchanges. So probably about 80 percent of my work is health care, and about 100 percent of that relates to cost and quality in some way.

So what I'm going to go through is first just where the public is on value, because I think we need to meet the public where they are at, or any audience that you're trying to communicate to them, you need to understand where they are. And then I am going to talk about some global recommendations around talking to the public, consumers, and patients about value, cost and quality, some overall points. And then some key takeaways. I went through some different studies we did on shared decision making on payment reform, and I just sort of cherry-picked some of the best sort of practical advice we could give around these topics.

So, first, where the public is. The public is not there yet as we all know, but we're on the way. Listening to David, I think what he is seeing I've been seeing in the last year or so, the last couple years, as people pay more out-of-pocket they really are snapping awake, they're really becoming alert. They're changing behaviors.

So, the study we did for RWJ, there were a couple Medicare focus groups as Chuck said, they were different. And then it was everybody had a deductible of $500 or more—that was the screening to get in. And these people, it's shocking, they were changing behaviors. One or two in every group said, "I'm not going to fast food anymore," or "I'm exercising more," because they're paying more. It was really shocking to see this. They're forgoing unnecessary care. I have a guy who said, "My doctor ordered an X-ray for my foot, he thought it was broken, I thought it was gout, I said I'm not paying the $400, I'll wait a week or two, see what happens, didn't need it. I'm going to call the nurse instead of going in to the doctor." All of these sort of consumer behaviors—I just never saw 4 years ago, or even 3 years ago, or 5 years ago. The downside, people are forgoing necessary care. That's absolutely happening, especially among the uninsured. Broken bones, even for preventive care, all of it.

But in terms of the attitude around value, I think that is shifting. We had one or two people in every group ask about cost before they were going to get a procedure or test at a hospital. Again, this didn't happen 3 years ago. We never heard this. I know there has been a lot of research that the public links quality with cost, and we've seen that in our research as well. We're starting to see that shift a little bit, especially with people who are paying more out-of-pocket and are more alert to these issues.

With these focus groups, we gave people the hypothetical situation, this surgery costs this much here, this much here. What do you think the difference is? About half of people said something related to quality. Maybe they have better technology, maybe they specialize in that procedure. About half said it was unrelated to quality. Maybe it's a socioeconomic status of the

market, maybe it's their concierge, maybe they're a teaching hospital that costs more. I'm seeing that kind of change, I'm seeing some openings for that talking about cost.

The final point on value is we're just seeing there are all of these factors coming together that are really driving people to be engaged. You just have to be engaged in health care now. You have to take on more responsibility. It's a fragmented system. We have caregivers bringing their file folders from doctor to doctor. You have less time with your doctor. So you leave and you go home and you spend 2 to 3 hours on the Internet. By the way, this is really just women. There are a lot of things going on, even with exchanges. Now this is a self-service environment, you have to make these decisions about your health care plan, what health care plan is right for you. I think all of these factors provide an opening for talking about value and getting the public there.

So, just some global recommendations on talking to the public. The first thing is, talk about the impact on the patient. The patients don't care about the health care system. Consumers don't care about the health care system. We're out there talking about payment reform or talking about changes, the number one thing they want to know is, how does this affect me? And then the second thing is their doctor. And that's what they care about. When you talk about quality, link it to the quality between themselves and their doctor and how those specific things are going to change. So really think about the individual patient, emphasize solutions more than problems. We've seen this a lot. The public is skeptical, they are worn down, they don't want to hear about problems. But especially in health care, you almost see a wall come up when you, for example, talk about getting the wrong tests. I mean they just don't want to think about it. I think you need a psychologist to help figure that out. But there's just a wall up. Talk about getting the right test, not the wrong test. Talk about solutions, back into problems. I'll give you an example of that in a second.

I think what we're seeing is the top motivator for changing for engagement again is out-of-pocket cost. And also getting the best care possible, I think Chuck may have come up with that language. Getting the best care possible we've seen is again another big motivator and another thing to talk about. The Choosing Wisely Campaign chose their name wisely. And all of the work we've done in the last couple years, the best phrase we've found to talk about cost is that health care is so expensive it's important we spend every dollar wisely. The goal is not to spend more money; it's to spend money in ways that best serve the patient. But that phrase, spend dollars wisely, is the one phrase that sort of everybody can get behind. It doesn't trigger a bunch of negative reactions.

As we're thinking about different efforts, whether it's shared decision making, delivery system reform, when we link it in messaging to credible prestigious health care systems like the Mayo clinic or like a local respected health care system, that peaks interest and it also lowers peoples' fear about the change. If they're doing it, why can't I? So that's been successful in a number of different topics. Use examples. Value is such an abstract thing for consumers, it's just really hard to get your head around. You don't have experience, you don't have exposure. So examples are really important. I'll give you an example of an example in a minute.

Talking about women, I was doing an interview in Dallas a couple weeks ago on hospital readmissions, and I had this guy who was about 55 years old, really quite healthy, I think he had some chronic conditions but quite healthy, I think he golfs every week. He was recently remarried so he was divorced for a time, taking care of himself. And I said, "Does your wife have to bug you about getting in to see a doctor?" Trying to get at his wife's role. Newly married, he was on his own. He said, "Yes, she does, and she lays out my medications every night for me." And I just thought, really? Does this happen? How did you survive on your own?

And again, it just reminded me that it's really women who are making these decisions and who are really going to lead the change. It's women 35 to 64 who have a parent who's getting sick, who have a child who has asthma and has been dealing with the health care system, who have a husband who won't get a colonoscopy. Women in these age groups are really the ones who are going to lead efforts, I think.

I'm just going to touch on a couple different things we've studied around value. First, on shared decision making, I think there are people in this room who know a lot more than me. But when you're talking to patients about this, the top motivation that we've found is getting the best care possible. That's a reason to participate in decision making. Because I know me best, I know my body best. Improving the doctor/patient relationship. And then learning more about health and your treatments.

We found that one piece of advice when you're talking about shared decision making or communicating that to the public, the examples we think to use are surgery and medications, you guys probably already know this—surgery is seen as the most risky. These two things are what patients most want involvement in: surgery number one, then medications. Because of side effects, and there is still an instinct to not want to go on the medication if you don't need to. Diagnostic tests, screenings, they're more apt to just say the doctor can tell me when I need to take that.

We tested a different number of different messages. A takeaway message that worked well among consumers as part of getting the best care possible is having a doctor who listens to you, answers your questions, includes you in making decisions about what treatments are best for you. So, just a few takeaways around that. Price transparency. So we did in this recent RWJ study, we wanted to get the public's reaction to the wide range of prices. And we tested about eight different examples. This is the one that did the best. A recent study looked at hospital charges to remove an appendix. In California, the price ranged from $1,500 to $182,000. These were not outliers. Many were more than $100,000 and many were less than $2,000. While some patients were sicker, about a third of the price differences could not be explained.

This again woke people up. This was persuasive to people. And they thought okay, I'm going to start paying attention to this. It was motivating. We looked at a number of different examples. The reason this one did best was number one, that huge variation, just the range itself. The second one was using dollar amounts. Some of the ones we tested, we said this was 12 times as expensive or 7 times more likely to get this procedure. It was really the dollar amount that appealed to people, that they were not outliers, that the statement about the cost could not be explained was very important, and that this was a routine procedure. People thought it should first of all cost less, and the prices should be more routine. That was a very good example on that.

One last thing. We did a few years ago for the National Partnership for Women and Families, they asked us to do research on delivery system reform. How do we talk about care coordination, medical home, health IT, payment reform? And that was our introduction. And we said back away slowly from payment reform and turn around and run and don't talk about it at all. It was so hard. And then RWJ decided they wanted to figure out how to talk about payment reform. And it took us about 25 focus groups to get it right between both projects.

So, just a few dos and don'ts. I think this highlights some lessons we learned for other topics as well. Don't talk about how doctors are paid. That's where consumers start thinking all doctors drive Porsches, and they get down that road which is really distracting, takes them off issue. Instead, we found that when we said "how insurance companies pay for care," so, shifting that

focus from how doctors are paid to how insurance companies pay for care. And it wasn't really villainizing insurance companies, it just seemed to neutralize the discussion.

Don't talk about doctors giving too many tests because of incentives and that kind of thing. People don't want to throw the doctors under the bus. So talking about blame, again, a little bit better on the insurance company. But again it was just more sort of neutralizing, saying "Right now insurance companies pay doctors based on how many patients they can squeeze in in a day or how many different procedures." Rewards and incentives fails every single time, 100 percent of the time with the public. Doctors shouldn't be rewarded for something they already should be doing. They already should be providing quality care, they shouldn't be rewarded for that. So, we found instead, "Make sure the way insurance pays for health care is consistent with the way you want to receive it, sort of take at that high level."

Getting the wrong tests. Again, talk about getting the right tests instead. Getting necessary tests. Whenever we have that language "unnecessary" in it, three people in the focus group say, "Unnecessary to whom?" So we found "getting the same test twice" helps, we also found, for some reason, "tests you don't need," for some reason that does better than just flat unnecessary test.

I think I'll just wrap up. And there is a study online from RWJ on this. But we did walk away with a successful, effective way to talk about payment reform, it is shocking. And it's really about finding the best ways to provide quality care, backing into it. This means X, Y, and Z, how patients see quality. It also means communication and coordination with your doctors. Then we bring up finding better ways to pay for care in the way you want it based on medical evidence, your doctor's recommendations. The goal is not to spend more money, but to spend money more wisely.

I think that's it. I think the last thing I will say is part of the problem here, is the public doesn't have an understanding of rising health care cost, they just don't. If there was a baseline understanding of that, I think all of our jobs would be much easier. I don't see a coordinated effort around that. Consumers think about health care cost in terms of health insurance cost. That's changing with the high deductibles. But there is just a real lack of knowledge about rising health care cost. So I think that's the last thing I will say. Thank you.

Social Media as a Tool for Change

Ms. Kelly Young

MS. YOUNG: Being a patient doesn't define me. I'm a Redskins fan. And a mom, and a teacher. But I grew up here in Washington. I was born on the Marine Corps base, and I learned to be tough as a kid, and as a young mom. I did a lot of tough things. One summer I spread two tons of concrete stucco on the outside of my house. And this is me with a 6-week-old baby and two other children under 5 backpacking in the mountains in California. So I was healthy and strong.

And I woke up one morning 7 years ago with my toe joint so swollen I couldn't walk on my foot. Within a day the other foot was the same. A couple weeks later I woke up at 2:00 a.m. thinking I'd been shot in my shoulder. I had all five of those kids at home. I have a high tolerance for pain. This pain in my shoulder was like labor. One hour later the other shoulder was the same. This continued. My knees, and then my ankles, and then my wrists. You get the idea. So somebody who could do 100 pushups, I couldn't pull up the sheets, couldn't put the socks on my baby. You might think it's neat, I can't iron, right?

I got on state-of-the-art treatment within a few months, but it continued to spread. Who knew there are joints in your vocal cords that can leave you silent? Little joints here along your ribs that can make it hurt to breathe. Patients learn a lot of anatomy from this disease. But everybody offers you juice and Tylenol Arthritis. One neighbor actually walked away shaking his head, saying you're too young to have that. And it doesn't seem like the doctors understand either. Every time I saw my rheumatologist, I would say, when can I run again? And she would say, soon you will be running on the beach. But that didn't happen.

So, where do people turn when their life is upsidedown and nothing works and they can't get help and nobody gets it? Well, they go to the Internet, and that's where I went. Twitter and Facebook, Blogger, where I started my blog. First I talked with dozens, and then hundreds, and then thousands of other patients. And I met people and read their experiences at the same time I was devouring journal articles and seeing what the medical profession was saying about this disease.

And I still have people ask me every day what this woman is saying, what I asked back then: Why is this so different from what we've been told it is? See, if you ask a patient, RA is a disease, it makes you ill. It causes disability, pain, and lots of health problems. But there's a false conception of RA that it's just a type of arthritis with occasional extra-articular symptoms, like coronary artery disease. It killed my grandfather. The prevalence with RA is twice that in the general population. And this is only one of many ways that RA affects the heart.

Here is a partial list of ways that RA affects the body outside of the joints. Your veins, your eyes, your heart, your lungs. But I learned that only 60 percent of us show up positive for tests for inflammation, even when we have this disease activity. They test CRP and sed rate, and yet this is what's used by rheumatologists to measure disease activity. And the other thing that's used so often by rheumatologists is external swelling; 96 percent of us in a very large study have inflammation that's detectable with ultrasound, and patients, believe me, know it's there, but the external swelling is not. And so the rheumatologist would judge these patients to be in remission. And unfortunately, not a large percentage of us have an excellent response to treatment.

This is a typical clinical trial. We have about one-third nonresponders to the treatments that are available. And we hear from the media to eat blueberries, that it's just a little morning stiffness, and we're sarcastically asked, why is your disease so expensive when it's so subtle and you don't know if you have it? And when the FDA is approving a new drug for the first time in a decade, a new kind of drug for RA, it's described as an inflammatory disorder that affects the small joints of the hands and feet.

So here are a few shots from my website. This is how I have spent the last 4 years, working far more than full-time, talking to patients, trying to get good information, the most solid and current information, and bring that to patients. But at the same time, bring that patient experience back to the scientific and medical communities.

Ann is one of the stories on my site. Her feet never swelled, but RA destroyed them. I have a few pictures, I have lots more of the six surgeries she had on her feet. And after 20 years with the disease, she finally had a little swelling in her hands. That's the main diagnostic criterion for RA, swelling in your hands. We asked 1,500 of our patients in our community whether they had swelling without damage or damage without swelling. Because we started to realize we're not the only ones. We defined damage as bone erosion seen on X-ray or permanent deformity. You put these two together and you see that three-fourths of the patients in our community said that they'd had either damage without swelling or swelling without damage. And only 6 percent had the swelling and damage correlate perfectly.

So we've come to recognize that the disease experience living with RA is distinct from what we call textbook RA, what's being considered in research and most clinical trials. We're told it's just a type of arthritis, that it mainly affects the hands, that when joints are affected, you can tell because they're red and swollen, that there are seldom systemic symptoms, and that patients tend to exaggerate that. Unfortunately what we see is that patients minimize symptoms, hide symptoms, delay care, and the vast majority of them do experience systemic symptoms.

So, I wonder, would this be a really good idea? It was a dream come true for movies at first, right? What if we could go up, like we get the blood pressure machine at the Publix, and stick our arm in? What if they could take out a little blood and the CRP or the sed rate were good enough, and then they could tell us whether we were under control?

I've also been a thyroid patient since I was 15, and I know that in endocrinology, this is kind of a struggle with patients, whether or not you can just measure the TSH and get your prescription and know whether you have enough. We know what's obviously missing is the patient experience, the patient voice. So, 2 years ago we created the first nonprofit foundation in this country specifically for rheumatoid patients where we're bringing the patient experience out of the box.

We have done two surveys in the last 2 years as preliminary to more extensive studies and surveys that we've been collaborating with in the Mayo Clinic and other institutions. But just to give you an idea how motivated patients are to participate in making change, our last survey we had 1,000 people answer that survey in the first 24 hours, 2,000 within 48 hours, and we cut it off on the third day at 2,500. Over the last couple years we have created a couple of posters to present at the American College of Rheumatology in our exhibit, and the copy of both sides of this poster from that survey is in the handbook for the workshop. Of course, we did not discover patient-reported outcomes. This man on the left is a hero to me. He is Dr. Ted Pink, he's kind of the godfather of patient-reported outcomes in RA. And he has worked for decades to prove that patient-reported outcomes are the most accurate predictor of disease outcome in RA. And yet these are seldom used to measure disease activity.

And so patients ask me every day, why does my doctor say that I'm in remission because of my labs, when my disease is so much worse? And I have to explain to them no, there is no test that can show that. What test did they do? There isn't even an RA test to show that you have RA with a blood test. You have some inventive methods for imaging, such as a nuclear bone scan or a musculoskeletal ultrasound, that are not widely used yet in this country because we do not have the machines and we don't have the training yet for them. And we know that we need better communication about evidence. But what the patients I know would like to tell you is that we need communication with patients that will create better evidence.

This is a wonderful abstract I just found the other day in Tokyo, where they're rejecting evidence-based medicine in favor of evidence of their own patients that they will use to help their other patients. This is just a quick blip from our recent, first-ever Rheumatoid Awareness Day, just to show you that we also use social media for advocacy and awareness. But take a quick gander at these numbers. Almost four million impressions on Twitter. A 12-day campaign, our first ever press release, 250 comments in 1 hour on Facebook. These are motivated patients. They want to make an impact, they want change.

People seek patient communities for information, but it is support that holds all that together. People run toward a patient community like this in social media, because what they're being told and what they're reading does not make sense with their experience. And I'm not sure, I hope

you can see it back there, even my hands swell sometimes. People don't want to be patients. People want to be healthy. But people who become patients need and deserve evidence that more reliably reflects their condition and that they can use to help make better decisions. And that kind of evidence only comes from participation with patients. Thank you.

Audience Participation and Open Discussion

Dr. Susan Reinhard (Moderator)

DR. REINHARD: Thank you. And please, this is your time. I'll just say a few words as people are getting up, assuming that you're going to interact with these fabulous presenters. I just want to say a few words as you're doing that and just summarize a little bit that for Kevin—and there's so much that you could say about what you had to say, Kevin—just this idea that cost sharing is still somewhat, I don't want to say mysterious, but there is a lot going on in the equation.

And yet, Tresa is saying in the last 3 years it seems to be making a difference. Those are the two connections I made, that you didn't see that even a few years before that. What's going on? I don't know if it's the recession, I'd love to hear more about other peoples' thoughts about why it does seem to be grabbing people more.

And then of course, Kelly, where do people go when nobody gets it? And it just seems like this social media is offering something that just wasn't there before, and boom, people are finding a vehicle to express themselves and earlier presentations of using those stories as data, just connecting back to our previous discussion. So, let me turn to those who were waiting to talk.

DR. SOFAER: So, I'm concerned about the last speaker who spoke also about incentives, but Tresa is telling us that that word is a terrible word. The problem that I have, and I'm seeing it popping up in health care over and over again, is that we are incenting people—and this is for both patients and providers who don't understand what they're being incented to do, they don't even know that there is an incentive there. I feel like it is magical thinking, what we sometimes do around incentives. And maybe it's because of what David says, that if you don't have a feedback loop the incentive isn't going to show.

But I guess I would like to ask all of the panelists, what is it that we can do to use incentives effectively, as opposed to just use them and think of them as some kind of magic bullet? We did some focus groups to follow up on the focus groups I reported on earlier, and we had some presentations about provider tiering, where there were lower copayments for some providers. People had no idea at all why there was a lower copayment for some than others. Some very cynical people would say, "Oh yeah, I'm being pushed to that provider." We had one person say, "Maybe they're trying to give these doctors more money, so that's why they're giving them a higher copay." The extent to which incentives are not understood or misunderstood, what does that mean about our ability to use them?

MS. UNDEM: I think people understand incentives when it's explained to them.

DR. SOFAER: But we don't, and it's often part of the—

MS. UNDEM: We don't, you're right. And it's part of the big mystery of health care cost. And they're increasing, and people don't know, and I think we haven't explained it to the public. I think we're trying to find ways to do that. I don't know.

DR. SOFAER: We also have right now, five different economic incentive-based value purchasing things going on in the Medicare program, all directed at the hospitals. I don't know how they can tell the difference with penalties and rewards and all that stuff.

DR. VOLPP: Every system has underlying incentives. A lot of times they're not well communicated. I think on the patient side it is really critical that we think about how to make these programs much simpler than they are. Because it's just ridiculously complex and I think very few people really understand the benefits.

One of the things that we hope is that in the future, we might have a far simpler world where you can imagine that there is a constellation of high-value treatments, and all of those treatments should have no cost sharing. There is no reason for us to be putting cost barriers in the way of a diabetic patient taking their Statin, it's just self-defeating. And what typically happens now is that typically there isn't a lot of thought behind this. So there is a copayment for a medication based on what the medication costs that has nothing to do with the value it provides. So if we had a much simpler system, you could imagine we'd have no cost sharing for a whole array of high-value treatments we actually want people to use, and then you could have much higher cost sharing for treatments that people probably shouldn't be using and which might actually harm them. But we're a long way from figuring that out.

MR. WOLFSON: I have a comment and a question. I wanted to just underscore what Tresa said about don't follow your instincts with messages, they're usually wrong. And we were going to call the campaign Stewardship Campaign. That was going to be our name. And we tested that out and the physicians said, "You mean like a union steward, or you want me to steward all of society's resources?"

And as we learned from the research, as soon as you went beyond the patient/physician relationship and their well-being and the well-being of the patient—as long as you talked about quality improvement of their patients you were fine. If you talked about an organization and if you went to the society you totally lost them. So, it's really important. And I also just want to correct that you did select Choosing Wisely. At least half of it. And testing out messages is what we did and the words really did make a big difference. I have a question for you. As far as the incentives, are we talking about a difference of premium versus point of care cost? Is that what's maybe making a difference in what you're learning about cost now versus what Kevin is talking about? Because they're much different.

MS. UNDEM: I think where I'm really seeing it is in the deductible. So, paying—is that called point of care cost? I don't know the right language. But it's less about people paying the premiums, it's more about having the high deductibles and when they have to go, they're deciding do I need this or do I not, and they're making those decisions because of the deductible.

MS. OKUN: Sally Okun from PatientsLikeMe, very good conversation, I'm enjoying it a lot. I think to Tresa's point, vocabulary is so critically important. I communicate a lot with patients online, and a lot of times I have to be very careful and mindful of how I'm choosing the words because the communication first of all is not face-to-face. And then there are always embedded messages within e-mail or other kinds of electronic messaging that you have to be so mindful and careful about, so I find myself getting more and more aware of that all the time.

I want to follow up with Kelly, though. As a colleague in the social media space, I'm interested. You've actually quite obviously provided a way of being able to meet an unmet need for the population of patients that you're meeting with RA. I'm always wondering because this is an area we're always interested in, is there anything you feel the social media space is not

meeting at this stage that we could be doing better, and how might you articulate that based on what your experiences have been?

MS. YOUNG: Did you mean specifically for RA?

MS. OKUN: Well, your experience has been with RA. Obviously you are gathering a lot of patients and their opinions, and you're talking with them a lot about the things that maybe they're not getting in the traditional sense, but they're getting a lot from having the opportunity to complete surveys or just to connect online.

And my worry is even in our work where we spend a lot of time doing user evaluations and doing persona-based design and trying to understand what do the users of social media really want to meet the needs that they have—I'm just wondering if there's anything among your population of patients that you've been working with that you really felt like, I just wish we could do this, and it would make a difference for so many other people with RA to meet an unmet need that they have that social media still is not even meeting.

MS. YOUNG: I have a very long list of to-do and projects for my own website, RAWarrior.com. I've worked between 60 and 80 hours a week as volunteer for 4 years. So I don't have enough time or staff to get done everything.

So we created the nonprofit a couple of years ago and we have a working board and we have some volunteers and one staff and we hope to be able to work harder, build that into a large organization, and help patients to meet patient needs through that using the resources of patients and partnering together with organizations and government.

As I said, with Mayo Clinic, we'll work with anybody. We want to see these needs met. But I have to say, what you ask me is something that I'm asked three or four times a month, I get an email or a question asking, can you please tell me what the unmet needs are, and I say we're working very hard on meeting those.

MS. OKUN: That's a great answer. And I think that we are trying really hard to do the same. It's a new place, it's a new place to do things, and so I think all of us who are in that space really need to be always testing our assumptions that we're trying to meet the needs that people have out there.

MS. YOUNG: I had to run past it because I was running short, but that slide about information and support with the three points underneath, I'll go ahead and send you that too. I really think this is what drives patients and these are the unmet needs.

Whether it's confusion about what the researcher really is or confusing research, conflicting research, about whether a shot works better than an infusion or how different is that than traditional DMR—there's conflicting research. But all kinds of questions like that that are specific about information about the treatment to information about the disease, these same kinds of questions I imagine that would apply for other conditions.

MS. OKUN: They do. And I think again, as a person who is trying to think forward and really be thinking, what can we be doing in another year or 2, 3, 4 years with this new novel environment where we actually are going to expand the abilities beyond what we can do today?

MS. YOUNG: I think the big difference is when people are looking for information in cooking and gardening and other things, the big difference between that and a condition if you're a patient or you're caring for a patient is that support part. That's what holds that together and creates that atmosphere where that information can be freely exchanged.

MR. DEBRONKART: Kevin and Tresa, I want to say last year, truly my life was changed when I read Kahneman's book, *Thinking Fast and Slow*. And I came to understand the body of research that drives what you're talking about. I honestly don't think anybody can think about

designing an intervention that's really going to change behavior without studying that field really to the point where they really understand it. So thank you. Very important, I'm glad it came up here.

I've known Kelly for a long time, and when she spoke I heard things at a different level than the words that are coming out of her mouth. And what I saw was, I got this thing about what are the nutrients that travel through the information circulatory system, and what drives that? And please if you are at all interested in what a patient community can do, go study Kelly's blog, because this is not an ordinary blog. I do blogging where I spout my mouth. She has so many links and resources, and it's a technically incredible website.

And the thing that occurred to me, this morning we heard about Marshall Ganz saying distributed leadership, and they said, we have this issue of if we can't get change through the establishment, how do we get it where it needs to be? Well how about we go through sort of the underground railroad of information going directly to the people whose lives are at stake?

And what I've seen over the last couple of years on Kelly's blog, if we want change it's really worth studying this, what's going on there that causes these supposedly slacker consumers who we can't get to change behavior to step up and be hungry for information. What's going on here that's different than the paradigm? Thanks.

DR. MONTORI: One aspect resonating with Kelly's presentation in relation to the outcomes that we measure and that we incent or promote in pay-for-performance or other strategies that are doomed from my point of view but still exist. And the quality of life in patient reported outcome stories is very interesting. But one outcome that I would like particularly the patient communities in the room to start paying more attention to is the notion of burden of treatment. There are a lot of discussions out there about burden of illness and how it affects the ability to function. But in the case of patients, particularly that accumulate multiple chronic conditions, the burden of treatment plays a huge role in impairing peoples' ability to perform and to live lives that are spontaneous.

And so there is a notion out there of a new kind of medicine that tries to reduce the burden of treatment in patients like alongside pursuing patient goals, and that's called minimally disruptive medicine. And so I want the patient community in the room to be more attuned to this and to begin to advocate for alongside measures of quality of life, measures of burden of treatment.

MS. LIND: Hi, I'm Cristin Lind and I was the one who stood up yesterday and talked about my concern about culture eating strategy for lunch. And so I've been thinking about that as we've gone through the last day and a half, and I was very happy to hear you talk, Kelly, because I think you kind of raised something that I as a mom who for many years wasn't activated and wasn't engaged and then suddenly was. And I'm very curious about how something like that could happen. How could somebody as unengaged as I was be standing here in this room today?

And as we think about partnering with patients and engagement and activation and trust and cultural competence, I think that there is also a very special role for patients and families as representatives in the health care system to be a bridge, to be a liaison between medicine and patients.

And I hope that I'm articulating this well, but I'm going to try to wrap it up. Whether it's as family and patient partners on QI teams or through patient and family navigators or liaisons, I think that as we think about trying to build a pathway toward partnership, we think about what is a very specific role that people with lived experience can play in bridging this partnership which has a lot of cultural obstacles to it. So, thank you so much.

MR. ROEHR: Hi, I'm Bob Roehr. One of the problems I have, everyone likes value, but so often in the past, value has been defined as value to the health care system or to someone else, not necessarily to the patient. And when it has been defined as value to the patient, it has been defined according to data and generally according to the mean or the average.

So it doesn't deal very well with the outliers, the people who don't respond well to drug A, but do respond to drug B, even though it's the secondary one with higher copays or whatever else. The system also doesn't respond very well to different values of the patient in terms of what they're seeking, whether it is relief from certain symptoms, better functionality, quality of life versus quantity of life, things like this.

So, I think we have to start thinking of value as being very individualized to the health plan of the patient based on their desires and what works for them, and not simply fall back into what is easiest for the system, which is a bunch of numbers.

DR. VOLPP: I think it's a really important point. And I see this as one of the big challenges to implementing recommendations like the Choosing Wisely Initiative. Because in essence, as you've said, there is a heterogeneity of treatment effect, and so, on average, the service may be extremely low-value, but there is going to be some portion of people for whom it may be at least moderately high-value. And figuring out how to come up with defensible and simple rules that, for example, a health plan could use to adjudicate who gets this coverage and who doesn't is actually very complicated.

We've had a number of discussions with health plans about trying to do that, and it becomes a stumbling block very quickly. So, somehow we have to figure this out. I don't think it's a reason not to proceed to help the 95 percent or 90 percent or 80 percent or whatever it is for people who are low value. But it is a big challenge to figure out.

MS. KORNBLAU: Barbara Kornblau from the Society for Participatory Medicine. I just want to give kudos to Kelly. I have arthritis and I worked with a lot of arthritis support groups in the Miami area. And what we did is if someone called the Arthritis Foundation and they were diagnosed with RA, they were immediately referred to one of my friends, Linda, who has had 31 joint replacements. And she would give them the introduction and help them through the system. So I just want to stress that power of patients again.

And one additional point, and that is on quality of life. We measure quality of life. Providers will often ask people how much sleep do you get, are you taking your meds, all those standard questions. And one of the studies that I've worked on in my occupational therapy hat looked at a concept called occupational autonomy. And it was very simple; it was being able to choose to do the occupations or things that are meaningful and purposeful to you when you wanted to do them. To be able to do the things you wanted to do when you wanted to do them. And we call that quality of life.

And I think it's very important to ask the patient when you have chronic pain, when you have days that you can do things and can't do things, to just say what do you want to be able to do? What's your goal? What can't you do now that you want to be able to do? Let's work toward that.

DR. REINHARD: Thank you so much. Please join me in congratulating them.

BUILDING A PATHWAY FORWARD

Ms. Christine Bechtel (Moderator)

MS. BECHTEL: We have had an absolutely terrific day and a half, and we thought that maybe the best way to kind of wrap up, given how intense we knew it would be, would be to ask a number of our esteemed planning committee members to join us here and provide their observations, having been here with us all along the way and having been part of the discussions that really had a substantive role in shaping the agenda.

So, I have up here with me first Mark Gorman, who is a patient advocate and a cancer survivor. Many of you know him from his leadership role at the National Coalition for Cancer Survivorship. We have Art Levin from the Center for Medical Consumers. We have Sue Sheridan from PCORI, the Patient-Centered Outcomes Research Organization. And we have Terry Adirim from the Health Resources and Services Administration, or HRSA.

So, I've asked you guys to give a 2-minute snapshot, key takeaways, whatever it is you'd like to say, and then we'll have a little back and forth. So let's start with Mark.

MR. GORMAN: I have a few talking points that I put together last night, which I will get to in 1 second and I will be very close to my 2-minute limit here.

But I am trying still to wrap my head around a lot of what David Goldhill had to say. And I think one point that is buried in there is I think I hear him saying that the status quo which nobody is happy with depends a lot on an assumption that the patients who are supposedly the principal beneficiaries of the health care enterprise are at some level just incapable of being able to fend for themselves. So, we have the intermediaries in the insurance industry that have built up, and all kinds of other people trying to protect us from harm being done to us. That does need to be challenged, and I think that's actually a central theme that we're trying to get at today.

Other observations that I think are worth sharing. I was taken by the three-level framework for engagement that was just mentioned at the beginning of the meeting yesterday that's in the policy brief from *Health Affairs* that was in the materials. And there is another I guess longer paper that maybe actually you guys can dig out and make available to us that has been referred to as well. In cancer advocacy, this sort of three level, what we've referred to as an advocacy continuum, was described by Ellen Stovall and Elizabeth Clark in 1996, and has been used by those of us in cancer patient advocacy extensively ever since then. We've used slightly different kind of language though, which I think is very helpful to insert here. We've talked about personal or self-advocacy on one end of this advocacy continuum, community advocacy in the middle, and then public interest or policy advocacy on sort of the other end of the continuum. My observation working with cancer survivors over close to a dozen years now is that individuals actually can evolve along that continuum.

And I think this is implicit in this paper, and I've learned from doing policy or public interest advocacy training with cancer survivors and their families over the years that initially the word advocacy and this whole language of advocacy is kind of off-putting to them, until I've explained to them how they've always been, in order to navigate health care successfully in the cancer context, effective self-advocates. Then they start to warm up to the idea. But the skills in being an effective self-advocate are actually transferable skills to being effective as an advocate for the patient perspective in the public interest arena. It's just you have to learn how to be able to frame the context of your experience and story differently. Instead of trying to get good care in

your immediate clinical encounter, you're trying to use your experience to policy makers and not just legislatures.

So that's one point. Another point I think is important to make is let's not hope for too much of an outcome from one particular element of patient engagement. I refer you all to Dr. Berwick's paper on the wedges for dealing with waste, I think he called it, which was published in *JAMA* at the end of April of last year. And he cites failures of care delivery, failure of coordination, overtreatment, which we've spent a lot of time talking about here, administrative complexity, pricing failures. We heard a whole talk about pricing failures and fraud and abuse cumulatively as driving the problems with health care costs.

The kind of patient engagement we've been talking about here can be helpful in the clinical encounter, but we can't solve all these problems there. However, getting back to my idea of the advocacy continuum with the stages of evolving patient engagement—as Kelly just explained to us from her own story's experience, people become motivatable to become advocates on the policy or public interest aspect of trying to deal with health care problems as a result of their need, oftentimes, to become effective advocates on their own behalf. So I'll stop there. I had maybe one more paragraph but maybe I'll insert it another time.

MR. LEVIN: So, I have 20 pages of handwritten notes sitting here. I want to assure you that there is going to be a report of the workshop, so I feel that there will be the opportunity to show you the details that way.

So, I am going to talk a little bit about strategy in politics. I think we would all agree that what we talked about during this day and a half is complex. It's difficult politically, and culturally. We heard that culture eats strategy for lunch. Maybe. I think that if you're a good strategist, you need to take that into account and just maybe you can bite it back.

I think we're in an era where people are struggling to keep their heads above water in all aspects of their life. And I mean as patients, as families, as caregivers, as clinicians, as CEOs of hospitals, people running rehabs and long-term care; for everyone these are difficult, difficult times politically and economically a lot of uncertainty. And we're dealing with a sector that is probably the most resistant to change of any I know. So, we have a sort of difficult job ahead of us.

I think that we have to be careful about how big a boat we are trying to float at any one time here. We have to really get to be strategic and political in how we think about it. So, I would suggest—and I'm not going to ask Michael to sponsor it, but he might—to convene a priority setting exercise, hopefully driven by the people we've been focused on: patients, families, and caregivers. We want to put caregivers in, because some people don't have family members as caregivers, they have friends and others. I think we need to think about what's the most important place. And by we, I mean the bigger we, the royal we. Where do we need to begin? What's the most urgent? And then we sort of need to create another grid, which is what's the most attainable. What do we think we'd have the best chance of getting? And then crosswalk those and see if we could come up with one or two potential "wins" in the short term that would get us moving along the pathway.

I think we need to always be cognizant of the barriers. We need to evaluate what the barriers are and how difficult it is to overcome them. We all agree we need payment reform. Do we really think we're going to get to that payment reform nirvana tomorrow? I don't think so. I think that there is a long battle ahead of us.

I would argue that engagement is not a theoretical exercise, that we must present real and practical values and benefits to what we're suggesting. And let me just give you a quick analogy.

I have argued with efforts to educate the public about the benefits to them of HIT and HIE that we don't have much to show them. We're asking them to enter into a social contract to give us their data and for us to use it, and we're sort of promising that their care is going to get better. It's very hard to demonstrate that. So, I think we have in sort of creating this priority list, we have to think about where can we really deliver, to use Ken's word, the "hook"? Where can we really say to patients, we promise you this, and we're going to deliver it next year to you, and you're going to see the value of what we're talking about. We need to demonstrate that a learning health care system and shared decision making, has real value for the public

Lastly, the one thing I worried about, and I think somebody else has mentioned this, that we're spending tens of billions of dollars on health information technology exchange. I don't see very much attempt to integrate patients, families, and caregivers into the process, other than give them a portal and let them look at their lab values. I think we need to be thinking far differently about that. For one, they should be in at the ground floor. It's a problem because vendors don't even have clinicians in at the ground floor, which is one of the problems with the usefulness of their product. But we really need to have that community of patients, families, consumers, whatever we want to call them, caregivers, really engaged in this. And we have to design a system that meets their needs. And maybe patient portal and looking at lab values is good for some people. It might not be the priority of some other people. I don't think we understand what is, as yet, but I worry that the horse will be out of the barn, we will have spent tens of billions of dollars on a system that doesn't even begin to deal with the concerns that we've been talking about for the last day and a half.

DR. ADIRIM: I'm Terry Adirim. I am from the Department of Health and Human Resources, the Health Resources and Services Administration. My agency serves the underserved by providing funding to health care entities to provide health care services. I had the great pleasure of being on this planning committee. I want to thank you so much for including me. I learned so much from my colleagues and I learned so much from all of you in the last day and a half.

My remarks are very brief, and they're centered around recapping what I heard from our workshop speakers were the barriers to achieving partnering with patients to drive shared decision making, and to summarize some of the approaches and solutions that came from our speakers.

Health care has been transforming very quickly. An example includes a recent experience I had with the health care system. I got a mammogram, and received the results from the radiologist by e-mail before my doctor did, which I thought was kind of amusing.
These changes give all of us the opportunity to impact the way medicine is practiced going forward. And I think listening to all the patients over the last day and a half really gives me a sense of urgency to do this and I really appreciated hearing everybody's stories.

So, what I heard over the last day and a half—that some of the barriers to achieving what we're all trying to achieve, is that we're still seeing within patients some passivity with regard to their health care, that there is a top-down authoritative culture within the medical profession, among both physicians and other practitioners. In fact, at this workshop someone told me about one of her experiences in the emergency department where a nurse authoritatively told her something, it wasn't entirely accurate and gave her a look like who was she?

I also heard articulated that there is a skills gap for both practitioners and patients with regard to how to practice shared decision making. There are also barriers with regard to access to

information. And many of these gaps and challenges, as my colleagues have articulated, are due to technological challenges that I think we need to overcome.

Part of the issue is that health care is not really a system because it is fragmented and siloed. It's not really oriented to patients and patient needs. It's really focused—and I'll be the first to say as a physician—it's really centered on the practitioners and our needs. So, until we change that culture it's going to be very difficult to make the changes that we're looking for.

I think there are also real or perceived external pressures on us as practitioners. As everybody has talked about over the last day and a half, are the challenges within the payment structures. Fee-for-service payment leads to pressure to see more patients. And there are also regulatory and policy issues, including the way that we interpret these regulations and policies that are real barriers to being able to get where we want to go.

With regard to solutions, what I've heard from all of you is that we really need a multi-prong, multidisciplinary approach. And what I took away from our keynote speaker is that we can learn a lot from people outside of medicine and people in other industries. Even though I didn't agree with some of what he had to say, it is useful to include all views while determining strategies to improve health care. For example there is so much with regard to the manufacturing industry with regard to quality and other industries such as systems engineering to improve efficiency that we in medicine can learn from. So we need to bring other people to the table.

Yesterday, in fact, a speaker mentioned that some of the issues could be ameliorated through a systems engineering approach. Some of us may agree and others may not but it would be useful to include some customer-focused strategies in our thinking about health care improvement. Even things on when and where patients get their treatment. Who said that you have to go to the doctor's office to get your treatment? Who said that primary care must be available only on Monday through Friday 9 to 5? So, even just engineering the system so it's more patient focused would be something to move toward.

I heard a lot of physician and patient blaming language, and I caution people from blaming any people about this. Blaming does not help us to indentify the issues to address. It's the process, not the people. So I think that we really need to spend a lot more time focusing on the process.

We really need to address competency development, and training. We need to look at where we're training our health care providers, how we're training them. We are moving more toward team-based approaches, and I know at my agency a lot of the funding for health care is moving to interdisciplinary approaches care. So we're moving in that direction, we need to keep promoting that.

I think, too, listening today to our speakers, that we need a new research paradigm. Emerging is a more inclusive type of patient approach, and I think that's really good, especially when it comes to governments' opening up of data sources, use of data, and the giving back to patients who participate. And as we heard today that technology and social media are very important tools for reaching patients and facilitating communication between patients and their clinicians.

Transparency too was a running theme over the last day and a half especially with regard to research. With regard to that there may need to be regulatory solutions. Transparency with regard to health care costs is important. And the *Time* article that came out recently made a huge impression with many of us with regard health care pricing. I think though we need to approach health economics with caution because health care is not a commodity like other commodities or like my iPad. Everybody will eventually enter the system and need health care and many of us

believe that we're entitled to it. So there may need to be different economic principles applied to health care.

MS. SHERIDAN: Great, that's a nice segue for me. It's been fascinating for me to participate in this because I wear two hats. I am the Director of Patient Engagement at PCORI, Patient-Centered Outcomes Research Institute, but I also wear the hat of a mom. Like Cristin, I have a son who is a young man, who has cerebral palsy, multiple disabilities—we are frequent fliers in the health care system. And his condition was caused by newborn jaundice 17 years ago that was completely preventable.

I also speak as a widow. I speak as a widow, where my husband Pat died 12 years ago of cancer. And it was a cancer that was diagnosed properly but the pathology got lost for 6 months and it was not communicated. So I listened the past 2 days through the patient lens, and also the research lens. And it's a lovely combination.

PCORI is about the perspective, the wisdom, and the outcomes of the patient population. When I say patients, it includes caregivers, family members, and advocates. Combining that with rigorous research I think that THAT is going to be the kind of science that drives change.

And so what I walk away with today is hope. I am aware of barriers, I am aware of government challenges, I am aware of cost. But 10 years ago there would not have been patients in this room, and today we have patients in this room. And we have a lot of patients in this room.

And I want to thank Dave and Kelly and Perry and Cristin and Greg and Ronny and Linda—all of you. We are here because of you. And you are our teachers, and we're all teachers and learners. You gave us vision today, and this is important for us to focus on vision and hope.

So, what I heard today—and I'm sorry if I don't remember your names—I heard today to listen to what patients are clamoring for. I love that, because we are clamoring. And I heard that we want to be safe. We want to be informed, we want to be empowered. We want compassion. We want to survive. We want outcomes that we decide and we want quality of life amongst many other things. And I think addressing some of these challenges that we have, if we keep this paramount we can make a difference.

So, Greg Biggers mentioned the "new we," and I loved that. Thank you, Greg. And we're talking about a new we. Sally talked about a patient-powered network which I think is really important to think about. Patients are powerful. Our data is powerful. Our experiences are powerful.

So, something that was described earlier today—I suffered this when I was a patient advocate. We wanted change and we wanted it fast. So, we demanded solutions from The Joint Commission and from NIH and from CDC and from researchers who partnered with us. And they said hang on, good solution, but we need evidence. So, we backed up a little bit and we joined researchers and we developed the evidence and we gave it to CDC and we gave it to The Joint Commission and we gave it to those who regulate and create protocols for our country. And we saw change. It took us 8 years, but it happened. It happened in partnership. It happened in partnership with HHS, with researchers, with parents, and those parents drove that change.

So, what I'm seeing regarding patient engagement is coming from the research world at PCORI. We are bringing patients in. And we are learning. We want you to help us. We're trying to infuse patients at every step of research. And so we're inviting patients to submit research questions. Tell us what's missing. Tell us what you need us to research based on you and your life and your challenges and what information is missing.

We're bringing patients in and we're training them. We have patients who are sitting at the table with scientists reviewing proposals and deciding what PCORI funds through their lens.

We're bringing patients in to help disseminate when we have research results. Traditionally, research goes into peer-reviewed journals; moms and dads and patients typically don't read those. How do we find these creative pathways? We bring the patients in to help us do that.

And then how do we evaluate ourselves? We want the patient population and caregivers and stakeholders, we want clinicians to tell us how are we doing and how can we do this better. So we're creating an infrastructure right now, bringing people in as much as possible as we can. We're going to be empaneling a patient engagement advisory panel in about 6 weeks to help guide us, help make sure that we are patient-centered and we are engaging patients every step of the way.

So, what I am hearing and feeling over the past 12 years as a patient advocate or activist, whatever we call ourselves, we were pushing. We were calling for change, we were pushing. I'm seeing a shift now, where we are going to be pulling for change. We are going to be in front pulling along the system with us as partners. And that's a difference. And I see that pull effect going on with these discussions.

So, in conclusion, I think that we have an opportunity to make a difference in patient lives by really bringing in the patient points at every step of the way, whether it's research, whether it's as a patient themselves, if it's in policy making, if it's at the institutional level. Let's look for every avenue where we can plug the patients in.

Peter Margolis said, what if? Consider the what if. What if we did this? What if we had patient-powered networks and patients sitting on QIs and IRBs and in research? And that's what I invite you to envision. I challenge you and I invite you. And I think that collectively we can make a difference. Thank you.

MS. BECHTEL: So, I have three questions, one in each of the areas that we talked about. I probably have 500, but I've tried to narrow it down to three so that anyone who feels like taking a shot at it could.

The first is in shared decision making. We heard from Gary Langer that more than 80 percent of patients would like to have shared decision making. We know from actually the research that Tresa talked about earlier that my organization asked them to do, we tested the idea of shared decision making in juxtaposition to some other health reforms like payment reform and IT and patient-centered medical home. And it wasn't particularly compelling, because everybody said that's just a fundamental right.

So, I think we have a situation where there is a lot of openness and willingness to engage from patients. So I guess my question is what you guys sort of think the holdup is. Because I'm not sure it's consumers on this. As we think about a pathway forward for shared decision making, where do we start?

Audience Participation and Open Discussion

MR. LEVIN: I have to do a disclaimer. I'm on the Board of The Foundation for Informed Medical Decisions, so I just want to make that clear. I think shared decision making is important. I think we're talking about a democratic process. Sort of philosophically, I see this as democracy. In my more than 30 years of advocacy talking about the need for giving patients and families and caregivers the information they need to make informed choices before it was ever a foundation, I just saw that as basic democracy.

And if you go back to when I started, we lived in a really closed world. There was one medical reporter, Larry Altman of *The New York Times*, who was an MD. There was no one else

around. If you wanted to look at the PDR it wasn't in Barnes & Noble, you only got it if you were a practitioner. You couldn't get into a medical library. You could get into regional medical libraries like the library of medicine, but it was a nightmare to get through it.

So it really was the control of information. That's the opposite of a democratic state. So I always thought of it as a basic principle that in a democracy we needed to share information. There is also—and I have forgotten the name of the report although Michael may remember it—in 1982 there was a President's Report commissioned on biomedical—long name. And there was one chapter of that, which is one book on self-autonomy in decision making. And this is going way back. So they probably did this study in the 1980s. And they asked people from various backgrounds, demographics, do you want information so that you can make a more informed choice? And the vast majority of people said yes. And this was in an era when there was no information. So I think that longing for information, that longing for participation, has been around for a long time.

The other thing is if we really believe in informed consent as an ethical and medical imperative, how do you give informed consent if you don't have any information? You're just signing a piece of paper which is mostly what happens now. It's a sham. People are not really giving informed consent to whatever it is they're being asked to undergo.

So I really think that shared decision making is a critical point. I think there are ways out there where people are experimenting. Washington State, for example. You can imagine mandating things. You can imagine payers saying we're going to pay more or we're not going to pay, unless there's some documentation that's reliable that there's a shared decision making process.

So I think that may be one of the priorities in the sense that we sort of understand it well, we have a lot of evidence about its effectiveness. And it's probably doable. It's not easy, but it's probably doable. And we have a lot of examples throughout the country where people have done this successfully, either through mandates or on their own initiative or through grant programs. So it would be a good place to begin.

MS. SHERIDAN: Something I think that in terms of shared decision making and participation, I was at the WHO for 7 years working with patients all over the world, and the WHO did a survey on outcomes and if patients wanted to participate in assuring their own outcomes. And we sent out a survey, got a response from 59 countries, and the overwhelming response was yes, we want to participate. It didn't matter the culture, the country, the government, the economic status, yes.

And then we said, what do you need to participate? And the answer was an invitation. And so have we, as a health care system, appropriately invited our patients and caregivers to participate in improving good outcomes? It was a simple response by the patient population, and the WHO honestly thought it was one of the sexiest pieces of surveys that they've ever done because it was so simple that it was overlooked prior to this. And so I ask, are our clinicians, are our hospitals, are our systems, is our government, are we extending that invitation to come participate with us?

MS. BECHTEL: I think that is actually a good segue into a question about value. I thought the sessions today were really phenomenal. But they pointed to a real tension point for me. So on the one side we had—and Chuck Alston has a great slide on this, where he says value, VALU, is a four letter word for patients, for consumers. And we heard a lot about why that is today. And we heard Marge Ginsburg talk about the need for more public deliberation, and how do we shift expectations. In fact, that was the title of the session, changing expectations.

On the other hand, we heard from Dave Debronkart, and this has been my experience as well

and we've heard from a couple of other folks in the room, that when they were all ginned up to go get the cost information to find the high-value providers, because clearly they had either deliberated their way there or they had a high-deductible health plan, what we found was that the system was absolutely ill-equipped to give it to them.

So, on the one hand, it feels to me like we want to invite patients to engage in this discussion about value and cost and quality. And on the other hand, when they accept the invitation, we say you go over there, we're not ready for it. So I think Dave also used that four-part hierarchy of data, information, knowledge, and wisdom. So if we think about that, I don't even know where on the spectrum we're at with respect to cost information. We're not at the knowledge part, we know that.

AUDIENCE: Are we at the data part?

MS. BECHTEL: That's what I want to know, right. Are we even at the data part? How do we move forward?

MR. GORMAN: I would say that we're not at all. For most of the last year I've been branching out in my life as a patient advocate. I've spent a lot of time in Texas with my 92-year-old mother who is in good spirits, but has a lot of things going on. Last May, she was in hospital for a month. Part of that was necessary, but when the summary came from Medicare and I added up all the punitive charges, it was close to $500,000.

What David was talking about before, there is virtually no honest pricing information available. So pricing has completely failed. It's what Dr. Berwick is talking about as one of the problems. Pricing has completely failed to send signals that are meaningful to patients in any role as buyers, except we're starting to get some and maybe more on high-deductible plans. But even there, I think people are going to end up in sort of one-off negotiations at the time of service and the point of service with the provider they're talking to with an eye toward what is going to be the impact on the deductible. I mean it's not going to be market-based decision making.

MR. LEVIN: Excuse my ignorance on this, but I'd like to ask people at the table out there. Is there any evidence giving people cost with how it works right now makes any difference? Because if we're all evidence based—

DR. SOFAER: (Off mic response)

MS. BECHTEL: For those of you who couldn't hear because poor Shoshanna doesn't have a mic, was that her work found that it actually could be dangerous to give consumers cost information. And I would say I think you mean in this context in particular, in this health care system. My sense is that—and I would love to know what you guys think, my sense is that what David Goldhill was really arguing was that if we open it up, actually forget giving them cost information, just make consumers responsible for burying the cost, the market will restructure itself.

Now, I have to tell you, being at the age where a lot of people in this room are probably going to be on Medicare, certainly before I will, but before this David Goldhill system comes about, I don't want to be caught in the middle. So I have to tell you. I mean, what do you guys think about this idea that let's just put the burden on them because in some period of time the market will restructure? Will it work?

MR. LEVIN: There is no question that people are more sensitive to what they have to pay if they have to actually pay it out-of-pocket. I think that's a no-brainer. Is that the right way to deal with health? David was up there saying we'll deal with catastrophic illness, we'll deal with this, we will deal with that. One of the assurances of that, I was glad to hear he was in favor of National Health Program, very nice.

But I think we really have to pilot that kind of idea to see what the risks are. We have a growing vulnerable population, not just by age, but by all kinds of disabilities and disease that require a lot of care. I know the 90-10 is an interesting artifact, and I think all the things we said are sort of fascinating challenges to the exceptionalism of health care.

Whether the answer is to simply give all of us the $10,000 or the $15,000 to go out and buy our own care, I'm not sure. Because I don't really know if we're ready, if we can equip people with the information and the skill sets they need to make the right choices. I don't think we've been very successful in doing that even without the challenge of, you're going to pay for this out of your own pocket.

So it isn't really a marketplace, right? If I know what a copier is supposed to do—so when a company makes a bad copier, it means I go to the copier and I push the button and it jams or it doesn't produce a copy. I'm not sure we know if I break my knee what the outcome necessarily should be. I want to be better, but I don't know how much better it can be. It's a very different world. I don't think you can make just a transfer that this is like any other business, it's like any other marketplace. It is in some respects, it isn't in others.

DR. ADIRIM: I agree with that because what happens is if you're responsible for paying for something which could have a huge impact on whether or not you have a good quality of life or live or die, you have people in certain age groups who would forgo that care. It has been shown in certain studies that people of a certain age group, older, elderly, will give up whatever they have for younger generations. So that's why social security was created, so that we could take care of elderly people. I don't think health care runs by the same economics as other commodities. So I think you have to be very careful.

That said, I think he had an interesting point because there is a difference between emergency type care, critical care, versus preventive care. So perhaps doing demonstrations or models where people would pay for routine care as opposed to more catastrophic, what's now considered higher cost care, could be something to look at and then develop that evidence that you're looking for, whether or not you can change people's behavior with regard to use of health care.

MS. SHERIDAN: Well, maybe this is a bit Pollyanna-ish but going back to patient engagement and having patients guiding change in research—and the reason that I say this is just the "what if," Peter's "what if." If we did bring in patients at every level of research and solutions and systems and policy making, could we expedite change? And could we expedite better health care and better outcomes? And the reason why I think this is because, when I referenced what this mothers group in changing the standard of care for newborn jaundice, within 4 years of when we started with our researchers and the system, Brent James from Intermountain Health and Hospital Corporation of America implemented the solution even before there was evidence, and they reduced newborn readmissions by 30 percent. Somebody was saving money.

And so I think the patient piece of driving change can be an expediter. Patients rarely give up, and honestly the researchers that we've worked with said the patients kept us on task and they kept us going when we were wearing out. But it was also the other way around. When the patients were getting worn out and frustrated, the researchers kept us going.

And so can we use patients as a catalyst to expedite change that will help save us money? I know that's not a short-term solution, it's not the whole solution. But it's part of the solution that I witnessed that I think it would be great to study. I know somebody who might be able to study that.

MS. BECHTEL: Might have the funding for it, huh? A neurologist told me that when you hear a new idea, it fires the same receptors as pain in your brain. So I was feeling a little bit of pain in David's presentation, but I don't want to dismiss it because I get the point. All it takes is the one doc practice who everybody suddenly realizes they'll see patients after hours, they post their prices on their website. We have little teeny examples here and there of people doing that.

And I think it is really notable to point out what Tresa said, and what Chuck Alston also said in his public comment, that for the first time just in the last year or two, they're really sensing a bigger or deeper anger and frustration with cost issues and that there may be kind of a change on the horizon.

So, I'll say before we wrap up, maybe we got the agenda order backwards. Maybe it has to be the research pathway first to set the stage and provide the evidence for shared decision making, which is how we're going to get ultimately to value. So we're going to wrap up and turn it back to our host Michael McGinnis here. But before we do that, any burning comments from our panel?

MR. LEVIN: Just one comment I want to make. I think it's important to keep in mind the rapidity of change right now; we're in a world of rapid change. And a lot of what we have talked about is today, and not about tomorrow. And so by tomorrow, what we talked about today will be out of date. It's a new paradigm of thinking that we really have to be thinking far down the road. We have to deal with today's problems, but we have to deal with tomorrow's problems even more. So we need to really always be doing that stretch.

And as people have mentioned, we have a whole new generation coming up who doesn't have a laptop like I do or a desktop, but really a device in their pocket. And it's the way they get information. They go out to a restaurant, they don't read a magazine; they look it up, get the rating.

So, we just have to bear in mind the rapidity of changes is overwhelming. And we really have to sort of train ourselves to say whoops, we're thinking in today's world and we really need to think about what tomorrow's world is going to look like.

SUMMARY AND NEXT STEPS

MS. BECHTEL: I want to say two thank yous. One is to the planning committee members, not just those up here on the stage, but those in the audience, if you want to stand and we can recognize everybody. And I also want to say thank you to our host, the Institute of Medicine and Michael McGinnis for his passion and commitment, and the staff for their support. We're very grateful for your interest in the topic. Thank you.

DR. MCGINNIS: Thank you, Christine, and thanks to all of you. This has been an extraordinarily rich and stimulating set of discussions, informed, directed, and inspired, as Susan said, by the patients who are here to help lead the discussion. In many ways, it has been a pioneering activity for the Institute of Medicine and the National Academies in focus, in scope, and in importance.

This workshop embraces the central challenges that face the health care system today—better outcomes, lower costs, faster progress—and it has done so by seeking the Holy Grail of motivating and mobilizing the people who are served by health and health care in our nation as drivers for change—how can we democratize and grow the influence of people on care improvement, on lower costs, and on quicker progress? Not surprisingly, when pursuing a holy

grail, the path can be elusive or, at least uncertain. That is clearly the case here. As Art just pointed out, we are looking into the future. We have to keep our eyes on the future very squarely, continuing to look as far beyond the horizon as we can, because things are changing very rapidly and we can't be held back or held down by perspectives shaped in circumstances today that may not pertain tomorrow.

We have heard a number of very interesting ideas, as well as a number of expressive take-home phrases. I have jotted down a few of them in each of our three categories: care decision strategies, value and quality, and knowledge generation. With respect to care decision strategies, we heard that a meaningful care experience is when someone goes out of their way. We heard "listen first, listen fully." We heard "patient engagement is a skill, not a trait." We heard "connectedness and connectivity count." From one provider, we heard "decision aids save me time." And we heard that "culture eats strategy for lunch every time." We have heard that "real innovation is truly disruptive," and, for us, truly disruptive would be the movement of care choice to the point of the individual. We heard about "the power of distributed leadership." These concepts shape our thoughts about what we can do with respect to care decision strategies that will improve the future of health and health care.

On the count of value and quality, we heard that "money is a proxy for quality in every industry but health care." And, of course, that is true. However, we also heard that "wise use of resources resonates with people" and offers a foundation on which we can build. We were advised to let quality lead on value. We heard about the importance of the 3-second rule—"if it's not engageable in 3 seconds, forget about it"—as a means of motivating change. We heard that absolute dollars register more than dollar signs when conveying information on outcomes and quality and cost. We heard the question, "Who is the trusted translator?" as a very important perspective to bear in mind. We heard that real incentives have feedback loops, and that "getting the dynamic of the feedback loop right is just as important as getting the initial message right."

In the area of knowledge generation, we heard that "patients represent untapped data streams." We heard about the "paradox of protection." In protecting patient privacy and prerogative, we have left patients unprotected with respect to the loss of evidence that otherwise could be generated. We heard that there is little hope of solving the long-term problem without integration of care and learning. We heard that data sharing will drive change, but "data sharing is not sharecropping." This offers us an important admonition that "permission matters" when we are expanding our ability to mine clinical data. As a nod to the higher calling in knowledge generation, we heard that we owe it to ourselves, to our families, and to society to draw upon this resource for improving the public good in its most fundamental fashion.

From these and many other take-home phrases throughout the course of this workshop, we've heard a number of suggestions about what needs to happen as we look to the future with respect to care processes, with respect to scientific insights, and with respect to price, cost, and value. In the care decision arena, we clearly need to focus on ways in which decision aids and decision information can be mobilized and delivered as efficiently as possible. To begin to work on the issues of trust, we need to work on the challenges affiliated with the multiple loci of information that is produced, and improve access to trusted information across the board. Of course, programs like Choosing Wisely are fundamentally important steps in that respect, and there is much more that we can do. We also can explore, it was suggested, possible approaches to shared decision making as a covered benefit. What are the strategies here to provide the economic incentives possible? If we're really interested in care culture that changes both professional care culture and other elements of the culture that shape our future care delivery

processes, we can make sure that we're clearly future-oriented as we train health professionals. We can make it clear in our training processes that it's not just team care, but that it is team care with the patient firmly embedded in the center of the process, and that the learning really draws from the patient.

In the quality and value arena, possibilities include those just mentioned about marshaling information on quality, costs, and value in a more reliable fashion: building the science of transparency. To do that, we are going to have to better marry the processes of gathering cost information with those of gathering quality information, so that we have a more level playing field in sharing information with the public. We need to work on the graphic strategies for communicating information on quality, cost, and value. We should not despair of the fact that our current set of data points on cost and pricing is lacking at this point. We have a fundamental societal obligation to improve those data points. We can't just ignore them. This may be our most fundamental challenge: doing everything we can to marshal honesty in our information on costs and prices.

In the knowledge-generation arena, we have to develop a communication strategy to better make the case to the public that they can and should be advocates for using their information for care improvement. We need to develop practical, trusted approaches to privacy and consent as we deal with the imperative to draw on clinical data in a seamless fashion for scientific advances. And we need feedback approaches that will bring the utility of the information closer to home and to patients themselves; not just to society as a whole, but to patients themselves.

Moving forward, we will review the transcript to identify common themes and strategies. We urge you to send in any other thoughts that you have, and we will send out an appeal for input on ways in which we can both refine the strategies that are most important, and again, as Art said, develop some priorities around ways in which we can all work together to move forward.

I want to take this opportunity now to again thank Claudia and Julia for the great work that they did in putting this meeting together. I thank each of you, both presenters and participants in the effort, and again thank our Planning Committee who made this meeting possible: Terry Adirim, Leah Binder, Veronica Goff, Mark Gorman, Paul Grundy, Art Levin, Jim Mangia, Lyn Paget, Eric Racine, Susan Reinhard, Craig Robbins, John Santa, Susan Sheridan, Susan Trinidad, and last, but certainly not least, Christine Bechtel. Thank you all very much.

REFERENCES

Bernabeo, E., and E. S. Holmboe. 2013. Patients, providers and systems need to acquire a specific set of competencies to achieve truly patient-centered care. *Health Affairs* 32:250-258.

Braddock, C. H., K. A. Edwards, N. M. Hasenberg, T. L. Laidley, and W. Levinson. 1999. Informed decision making in outpatient practice: Time to get back to basics. *JAMA* 282(24):2313-2320.

Forrest, C. B, W. V. Crandall, L. C. Bailey, P. Zhang, M. M. Joffe, R. B. Colletti, J. Adler, H. I. Baron, J. Berman, F. del Rosario, A. B. Grossman, E. J. Hoffenberg, E. J. Israel, S. C. Kim, J. R. Lightdale, P. A. Margolis, K. Marsolo, D. I. Mehta, D. E. Milov, A. S. Patel, J. Tung, M. D. Kappelman. 2013. Comparative effectiveness of anti-TNFα therapy for pediatric Crohn's Disease. Under review.

Henry, S. G., E. S. Holmboe, and R. M. Frankel. 2013. Evidence-based competencies for improving communication skills in graduate medical education: A review with suggestions for implementation. *Medical Teacher* 35(5):395-403.

Towle, A., and W. Godolphin. 1999. Framework for teaching and learning informed shared decision making. *BMJ* 319:766-769.

Wicks, P., M. Massagli, J. Frost, C. Brownstein, S. Okun, T. Vaughan, R. Bradley, and J. Heywood. 2010. Sharing health data for better outcomes on PatientsLikeMe. *Journal of Medical Internet Research* 2(2):e19.

Wicks, P., D. L. Keininger, M. P. Massagli, C. de la Loge, C. Brownstein, J. Isojärvi, and J. Heywood. 2012. Perceived benefits of sharing health data between people with epilepsy on an online platform. *Epilepsy & Behavior* 23(1):16-23.

Appendix A

Workshop Agenda

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
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 and Betty Moore Foundation)
Christine Bechtel (Planning Committee Chair, National Partnership for Women & Families)

12:45 pm	**Lunch keynote**

To Improve, Health Care Must Partner with Patients and Families
Jonathan Welch, Harvard Medical School

1:30 pm	**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

Audience participation and open discussion

3:00 pm	**Break**

3:15 pm	**Patient-clinician communication and the tools for change (continued)**

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

Audience participation and open discussion

4:30 pm	**Summary and preview of next day**

5:00 pm	**Adjourn**

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

9:30 am	**Knowledge generation and care improvement (cont.)**

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

Audience participation and open discussion

10:45 am	**Break**

11:00 am	**Changing expectations: Bringing transparency to cost and quality information**

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

Session questions:

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

Moderator: *John Santa*, *Consumer Reports*
Presentations:

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

Audience participation and open discussion

1:00 pm	**Lunch keynote**

How American health care killed my father
David Goldhill, Game Show Network

2:00 pm	**Driving the demand**

Explore cross-cutting strategies to advance patients, in partnership with providers, as leaders and drivers of care delivery improvement through informed, shared decision making, the authorized use of clinical data for research, and value improvement.

Moderator: *Susan Reinhard,* AARP
Presentations:

- **Behavioral economics and value generation**
  Kevin Volpp, Philadelphia VA Medical Center
- **Communicating "value" to the public**
  Tresa Undem, PerryUndem

- **Social media as a tool for change**
  Kelly Young, Rheumatoid Arthritis Warrior

Audience participation and open discussion

3:00 pm	**Building a pathway forward**

Reflecting on the presentations and discussions over the course of the 2-day workshop, participants will engage in an open dialogue to define the pathway forward for building patient demand for a continuously learning health system.

Moderator: *Christine Bechtel,* National Partnership for Women & Families
Panelists: Planning committee members

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

Audience participation and open discussion

4:15 pm	**Summary and next steps**

Thanks from the Chair
Christine Bechtel, National Partnership for Women & Families

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

4:30 pm	**Adjourn**

Planning Committee

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

Staff officer: Claudia Grossmann, PhD
cgrossmann@nas.edu
(202) 334-3867

Appendix B

Biographical Sketches of Workshop Speakers and Planning Committee Members

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 an MPH from the University of Washington. As former U.S. Department of Veterans Affairs (VA) Health Services Research & Development (HSR&D) 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 more than 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 HMORN 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 United Kingdom. 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 BSc in Applied Mathematics from Brown University. His graduate training at Stanford University included an MSc in Statistics and culminated with a PhD in Engineering. In

2008, the U.S. Agency for Healthcare Research and Quality selected his UCSF Decision Services Program as 1 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 U.S. 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 and a community development organization and advises startups. With more than 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 6 years has focused on implementing them in routine clinical practice and 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 Foundation Health & Society Scholar at the University of Pennsylvania. Dr. Frosch serves as Patient Care Fellow at the Gordon and 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 Agency for Healthcare Research and Quality–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 California to capture seniors' and boomers' priorities for the Medicare of the future. In 2011, Ms. Ginsburg was a member of the Institute of Medicine's Committee on Essential Health Benefits to develop the principles for coverage under the Patient Protection and Affordable Care Act. She is a member of the National Committee for Quality Assurance's Committee on Performance Measurement, the Medi-Cal Performance Advisory Committee, and others to improve health

care in California. She received her nursing degree from the University of Maryland and an MPH from University of California, Berkeley. In a prior life, she worked for the United Farm Workers, ran a free clinic in Philadelphia, was a Peace Corps nurse in Nepal, and other stuff one does in one's 20s and 30s. An avowed late bloomer, she discovered the "health decisions" movement in 1991 and has not budged since.

David Goldhill, MA, is president and chief executive officer of the Game Show Network (GSN), which operates a U.S. 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 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, titled "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* was published by Knopf in January 2013. Goldhill graduated from Harvard University with a BA degree in history and holds an MA degree in history from New York University.

Judith Hibbard, DrPH, is a Senior Researcher and Professor Emerita at the University of Oregon. During the past 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 Agency for Healthcare Research and Quality, 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 more than 150 peer-reviewed publications. Her recent work appears in issues of *Health Affairs*, *Medical Care*, and *Health Services Research.* Dr. Hibbard holds a master's degree in Public Health from the University of California, Los Angeles, and her doctoral degree is from the School of Public Health at the University of California, 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 ABIM, 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 *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 Foundation 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 the University of California, Los Angeles, 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 health care system, from health care 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 health care. Dr. Kaplan was also a member of the Institute of Medicine 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 Ethics Review Committee Secretariat. Dr. Kass received her BA from Stanford University, completed doctoral training in health policy from the Johns Hopkins Bloomberg 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 (NCI) Committee to develop Recommendations for Informed Consent Documents for Cancer Clinical Trials, and served on the NCI's central institutional review board. 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 health care 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 3-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 5-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 (AAPOR) for a 6-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 AAPOR.

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. She spent 3 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 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 Information Technology's Standards & Interoperability Framework. Ms. Leiter earned a BA 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 (UCSF). 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* and *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 master's 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 more than 150 peer-reviewed publications as well as 2 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-Massachusetts Institute of Technology (MIT) Health Sciences and Technology. Mandl has pioneered and published extensively in the areas of personal health records and biosurveillance. Under a major HHS initiative, he co-leads the Substitutable Medical Apps, Reusable Technologies Platforms project, which seeks to create an "app store" for health. He co-directs a Centers for Disease Control Center of Excellence in Public Health Informatics working to define the role of online social networks in health care 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 U.S. 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 National Institutes of Health's National Library of Medicine. Dr. Mandl has published more than 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 master's 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 3 years in the National Health Service Corps in Rochester, New York, and Los Angeles, California, before pursuing a fellowship in clinical epidemiology. He was a Robert Wood Johnson Foundation Clinical Scholar at the University of North Carolina (UNC) at Chapel Hill, where he also earned his PhD in Epidemiology. In 1994, Dr. Margolis was named a Robert Wood Johnson Foundation 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.

J. 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's) 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; University of California, Los Angeles; 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 has been the graduating commencement speaker at each.

Ekene Obi-Okoye is a University of California, San Francisco (UCSF) Breast Care Center premedical 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 nonprofit on Harvard's campus and served on the board of the Kuumba Singers of Harvard College, a choir dedicated to celebrating Black creativity and spirituality.

Sally Okun, RN, MMHS, is the Vice President for Advocacy, Policy and Patient Safety at PatientsLikeMe in Cambridge, Massachusetts. 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. Ms. Okun 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. Ms. Okun also developed and manages the PatientsLikeMe Drug Safety and Pharmacovigilance Platform. Prior to joining PatientsLikeMe, Ms. Okun, 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, Massachusetts Department of Mental Health, Hospice Education Network, and the Robert Wood Johnson Foundation. Ms. Okun participates on the Institute of Medicine's (IOM's) Roundtable on Value & Science-Driven Health Care 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 IOM's discussion papers *Principles and Values for Team-Based Health Care* 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. Ms. Okun 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 could not because they have never experienced MS. When comparing her experiences with others on PatientsLikeMe, Ms. Phillips has found that a good majority of patients have similar deficiencies, a fact that on their own they would not have looked into or followed up on with their doctors. As much as doctors and researchers know, there are numerous untold things they do not 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.

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 health care 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, DC. 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 collaboration in the nation with *Consumer Reports* to jointly release performance results on Massachusetts 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, a national network of regional health improvement collaborative. She also serves on the Board of the Massachusetts eHealth Collaborative 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 MPH 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 (CUNY). 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 more than 60 publications in peer reviewed journals and has completed more than 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. Ms. Undem has conducted many communications projects related to health care costs and quality for clients such as the Robert Wood Johnson Foundation, the National Partnership for Women & Children, and the Institute of Medicine. She has briefed numerous state and federal policy makers on her work, including members of Congress, White House staff, Secretary Sebelius, and Centers for Medicare & Medicaid Services leadership. Tresa holds a master's 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 (CHIBE LDI), one of two National Institutes of Health–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, an award presented at the White House as the highest honor given by the U.S. 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 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 PhD 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 American Board of Internal Medicine Foundation, where he leads the Choosing Wisely campaign, a multiyear effort to promote conversations between physicians and patients about utilizing the most appropriate tests and treatments and avoiding care that may be 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 (RA), after years of periodic symptoms. She has worked for 4 years to provide ways for patients to be better informed and have a greater voice in their health care. 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 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, Ms. Young created RAwarrior.com, a comprehensive website about RA of about 700 pages and the hub of one of the largest and most vibrant patient communities online. She also writes periodically for other newsletters and websites. Ms. Young is the founding president of the Rheumatoid Patient Foundation, the first nonprofit that exists solely to improve the lives of rheumatoid patients. Ms. Young serves on the Mayo Clinic Center for Social Media Advisory Board. She has participated as a patient advocate with the Food and Drug Administration, Patient-Centered Outcomes Research Institute, U.S. Department of Health and Human Services Office of the National Coordinator for Health Information Technology, and other organizations. There are more than 20,000 connections on her highly interactive Facebook page. She created and moderates the weekly Twitter chat on rheumatology topics, which can be followed with the hashtag she created: #rheum, used by large numbers of patients and caregivers as well as medical and industry professionals to communicate about rheumatology topics.

Margot Zarin-Pass is a first-year medical student at University of California, San Francisco (UCSF). She was previously a premedical intern at the UCSF Breast Care Center. There, she provided decision support services to patients and conducted patient engagement research.

Appendix C

Workshop Participants

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

Terry Adirim, MD, MPH
Director, Office of Special Health Affairs
Health Resources and Services Administration

Charles Alston
Senior Vice President and Director of Public Affairs
MSL Washington

Clinton W. Anderson, PhD, Director
Associate Executive Director, Public Interest Directorate
Lesbian, Gay, Bisexual, and Transgender Concerns Office
American Psychological Association

David Arterburn, MD, MPH
Associate Investigator
Group Health Research Institute

Anne-Marie J. Audet, MD, MSc, SM
Vice President
Health System Quality and Efficiency
The Commonwealth Fund

Kim Bailey
Research Director
Families USA

Michael J. Barry, MD
President
Informed Medical Decisions Foundation

Christine Bechtel, MA
Vice President
National Partnership for Women & Families

Jeffrey Belkora, PhD
Associate Professor, Surgery and Health Policy
Director, Decision Services
University of California, San Francisco

Greg Biggers
Council Member and CEO, Genomera
Genetic Alliance

Paige Bingham
Manager
PatientLink Programs
Medtronic Foundation

Meryl Bloomrosen, MBA
Vice President
Public Policy and Government Relations
American Medical Informatics Association

David Blumenthal, MD, MPP
President
The Commonwealth Fund

Marilyn Sue Bogner, PhD
Chief Scientist
Institute for the Study of Human Error, LLC

Crystal Brown-Tatum
Chapter President
Sisters Network

Diane Bruessow, PA-C, DFAAPA
Government Affairs Committee, Chair, 2012-13
Gay and Lesbian Medical Association

Janet Campbell
Software Developer
Epic Systems

Dottie Caplan, MBA
Director, Partners in Patient Health
Sanofi U.S.

Kristin L. Carman, PhD
Co-Director
Health Policy & Research Program
American Institutes for Research

Carolyn Carroll, PhD
Senior Statistician
STAT Tech, Inc.

Mary Teresa Casey, RD, LD
Director, Division of ESRD,
Population and Community Health
Center for Clinical Standards and Quality
Centers for Medicare & Medicaid Services

Bowen Chung, MD, MSHS
Adjunct Scientist, RAND Corporation
Assistant Professor, Department of Psychiatry Harbor-UCLA Medical Center

David Clifford
Independent Consultant
PatientsLikeMe

Perry D. Cohen, PhD
Director
Parkinson Pipeline Project

Megan Collado, MPH
Associate, Health Care Financing and Organization
AcademyHealth

Kathleen Connors de Laguna, RN, MSPH
Health Insurance Specialist
Office of Electronic Health, Standards and Systems
Centers for Medicare & Medicaid Services

Richard Conroy, PhD
Program Director
Division of Applied Science and Technology
National Institute of Biomedical Imaging and Bioengineering

Jonathan Darer, MD, MPH
Chief Innovation Officer
Division of Clinical Innovation
Geisinger Health System

Helen Darling
President
National Business Group on Health

Kathy Day, RN
Patient Safety Advocate and Activist

Dave DeBronkart
e-Patient Dave

James E. Delaney, MSPA PA-C
President
American Academy of Physician Assistants

Melissa Dorsey, MHA
Health Insurance Specialist/Government Task Leader
Division of ESRD Population and Community Health
Center for Clinical Standards & Quality
Centers for Medicare & Medicaid Services

Joyce Dubow
Senior Health Care Reform Director
Office of Policy and Strategy
AARP

Rosemarie Filart, MD, MPH, MBA
Medical Officer
National Center for Advancing Translational Science
National Institutes of Health

Sylvia K. Fisher, PhD
Director, Office of Research and Evaluation
Office of the Administrator
Health Resources and Services Administration

Lindsay Forbes
Research Program Coordinator
Johns Hopkins Berman Institute of Bioethics

Laura P. Forsythe, PhD, MPH
Program Officer
Patient-Centered Outcomes Research Institute

Emily C. Freeman, MSc, PhD
Associate Director
U.S. Medical-Health Services
Bristol-Myers Squibb

Susan M. Friedman
Deputy Director, Department of Government Relations
American Osteopathic Association

Dominick L. Frosch, PhD
Fellow, Patient Care Program
Gordon and Betty Moore Foundation

Tamyra C. Garcia, MPH
Special Assistant, Quality Improvement Group
Center for Clinical Standards and Quality
Centers for Medicare & Medicaid Services

John S. Gardenier, DBA
Statistical Ethicist
National Center for Health Statistics, Retired

Turkan K. Gardenier, PhD
Director of Research
Pragmatica Corporation

Rosemary Gibson
Section Editor
JAMA Internal Medicine

Marge Ginsburg
Executive Director
Center for Healthcare Decisions

David Goldhill
President and Chief Executive Officer
Game Show Network

Mark Gorman
Patient Advocate
Former Director of Survivorship Policy
National Coalition for Cancer Survivorship

Elizabeth Goss, JD
Partner
Turner & Goss

Katherine Green
Development Project Coordinator
Family Medicine Education Consortium

Sheldon Greenfield, MD
Professor of Medicine and Executive Co-Director
Health Policy Research Institute
University of California, Irvine

Paul Grundy, MD, MPH
Global Director of Healthcare Transformation
IBM

Jim Hansen
Vice President
Accountable Delivery System Institute
Lumeris

Judith H. Hibbard, DrPH
Professor of Health Policy
Department of Planning, Public Policy & Management
University of Oregon

Eric Holmboe, MD
Chief Medical Officer and Senior Vice President
American Board of Internal Medicine

Lisa Hopp, PhD, RN, FAAN
Professor, School of Nursing
Director, Indiana Center for Evidence-Based Nursing Practice
Purdue University Calumet

Ralph I. Horwitz, MD
Senior Vice President
Clinical Sciences Evaluation
GlaxoSmithKline

Linda House, RN, BSN, MSM
Executive Vice President, External Affairs
Cancer Support Community

Andrew Hu
Senior Director
Policy & Research
P*h*RMA

Thomas E. Hubbard
Vice President of Policy Research
Network for Excellence in Health Innovation

Holly B. Jimison, PhD, FACMI
Office of Behavioral and Social Sciences Research
Office of the Director
National Institutes of Health

Jesse Joad, MD, MS
Professor Emeritus,
University of California, Davis
Vice President for Education,
Gay and Lesbian Medical Association

Sherrie H. Kaplan, PhD
Executive Co-Director
Health Policy Research Institute
University of California, Irvine

Nancy E. Kass, ScD
Professor of Bioethics and Public Health
Berman Institute of Bioethics
Johns Hopkins Bloomberg School of Public Health

Michael W. Kelleher
Senior Program Director
Network for Excellence in Health Innovation

Barbara L. Kornblau, JD, OTR
Executive Director
Society for Participatory Medicine

Gary Langer
Founder and President
Langer Research Associates

Emily Oshima Lee
Policy Analyst, Health Policy
Center for American Progress

Alice Leiter, JD
Policy Counsel
Center for Democracy & Technology

Art Levin, MPH
Director
Center for Medical Consumers

Grace Lin, MD
Assistant Professor in Residence, Division of General Internal Medicine
University of California, San Francisco

Cristin Lind
Family Leader
E-caregiver, www.DurgasToolbox.com
Federation for Children with Special Needs

Evette J. Ludman, PhD
Senior Research Associate
Group Health Research Institute

Wendy Lynch, PhD
Co-Director
Center for Consumer Choice in Health Care
Altarum Institute

Katy Mahraj, MSI
Analyst, Information & Technology Strategies
Altarum Institute

Kenneth D. Mandl, MD, MPH
Associate Professor
Children's Hospital Boston, Harvard Medical School, and Harvard-MIT Health Sciences and Technology

Brigitte Manteuffel, PhD
Advisory Council Member
Children's Mental Health Network

Peter Margolis, MD, PhD
Professor of Pediatrics and Director of Research
James M. Anderson Center for Health Systems Excellence
Cincinnati Children's Hospital Medical Center

J. Michael McGinnis, MD, MPP, MA
Senior Scholar
Institute of Medicine

Coles Markis Mercier, MS
Health Insurance Specialist, BHIS
Center for Clinical Standards and Quality
Centers for Medicare & Medicaid Services

Anne Michaels
President, MNA Inc.
Special Projects, National Foundation for Mental Health

Erica Mobley
Communications & Membership Manager
The Leapfrog Group

Victor M. Montori, MD, MSc
Professor of Medicine and
Director, Healthcare Delivery Research Program
Divisions of Endocrinology and Diabetes and Health Care and Policy Research
Mayo Clinic

Liz Morgan
Head of Community
PatientsLikeMe

Linda M. Morgan, MBA, RPh
Research Advocate
Parkinson's Disease Foundation

Nancy Morris
Communications and Member Services Director
Maine Health Management Coalition

Ben Moulton, JD, MPH
Senior Legal Advisor
Informed Medical Decisions Foundation

Michael (Mick) D. Murray, PharmD, MPH
Professor
Regenstrief Institute and Purdue University

Shelley Fuld Nasso
Health Policy Consultant
National Coalition for Cancer Survivorship

Daniel Nugent, Esq.
Senior Policy Manager
National Minority AIDS Council

Ekene Obi-Okoye
Premedical Intern, Decision Services
University of California, San Francisco

Sally Okun, RN, MMHS
Vice President, Advocacy, Policy & Patient Safety
PatientsLikeMe

Lyn Paget, MPH
Managing Partner
Health Policy Partners

Jumin Park
PhD Candidate, Nursing
University of Maryland, Baltimore

Douglas W. Phillips
Caregiver

Laura M. Phillips
Patient
PatientsLikeMe

William F. Pilkington
Chief Executive Officer
Cabarrus Health Alliance

Jill Mara Plevinsky, MA
Clinical Research Coordinator, Center for Inflammatory Bowel Disease
Boston Children's Hospital
Chair, The Patient Advisory Council for ImproveCareNow and C3N Project
Cincinnati Children's Hospital

Holly Potter
Vice President, Brand Communication
Kaiser Permanente

Barbra G. Rabson
Executive Director
Massachusetts Health Quality Partners

Susan C. Reinhard, RN, PhD
Director
Public Policy Institute
AARP

Lygeia Ricciardi, EdM
Acting Director, Office of Consumer eHealth
Office of the National Coordinator for Health Information Technology

Pamela Rich, MPH
Senior Analyst
Institute on Health Care Costs and Solutions
National Business Group on Health

Bob Roehr
Reporter
BMJ

Susan W. Salmond, EdD, RN, ANEF, FAAN
Dean and Professor
UMDNJ–School of Nursing

John Santa, MD, MPH
Director
Consumer Reports Health Ratings Center
Consumer Reports

Suzanne Schrandt, JD
Deputy Director, Patient Engagement
Patient-Centered Outcomes Research Institute

Susan Sheridan, MBA, MIM
Director, Patient Engagement
Patient-Centered Outcomes Research Institute

Joanna E. Siegel, SD
Senior Health Research Scientist
Agency for Healthcare Research and Quality

Melissa A. Simon, MD, MPH
Director of Patient Navigation
Lurie Comprehensive Cancer Center
Northwestern University

Brad Smith
Co-Director
Center for Consumer Choice in Health Care
Altarum Institute

Mary Smith, MSHS
Guidelines Analyst
American Society for Radiation Oncology

Shoshanna Sofaer, MD, DrPH
Professor and Robert P. Luciano Chair of Health Care Policy
School of Public Affairs
Baruch College/City University of New York

Mary Anne Sterling, CEA
Principal Consultant
Sterling Health IT Consulting

Ellen Stovall
Senior Health Policy Advisor
National Coalition for Cancer Survivorship

Danielle Tarino
Public Health Advisor
Performance Measurement Branch
Substance Abuse and Mental Health Services Administration

Richard Thomason, MA
Director, Health Care and Coverage
Blue Shield of California Foundation

Veronica Todaro, MPH
Director of National Programs
Parkinson's Disease Foundation

Amy Traver
Villers Fellow
Familes USA

Susan Brown Trinidad, MA
Research Scientist, Center for Genomics & Healthcare Equality
Department of Bioethics & Humanities
University of Washington

Tresa Undem
Partner
PerryUndem

George Velasco
Guidelines Analyst
American Society for Radiation Oncology

Kevin Volpp, MD, PhD
Staff Physician, Philadelphia VA Medical Center
Director, Center for Health Incentives and Behavioral Economics
Leonard Davis Institute
University of Pennsylvania

Lola A. Walker
Technical Officer, Community Mobilization
Program Innovation and Policy Unit
Elizabeth Glaser Pediatric AIDS Foundation

Sandy Walsh
President
California Breast Cancer Organizations

Jonathan Welch, MD
Instructor in Medicine
Research Scientist
Brigham and Women's Hospital

Ross White
Public Policy Associate
The Hastings Center

Daniel Wolfson
Executive Vice President and Chief Operating Officer
American Board of Internal Medicine Foundation

Matthew K. Wynia, MD, MPH, FACP
Director, Physician Engagement for Improving Health Outcomes
American Medical Association

Kelly Young
Rheumatoid Arthritis Warrior

Margot Zarin-Pass
Medical Student
University of California, San Francisco

IOM Staff

Daniel Bethea
Web Content Assistant

Claudia Grossmann, PhD
Senior Program Officer

Elizabeth Johnston
Program Assistant

Valerie Rohrbach
Senior Program Assistant

Julia Sanders
Senior Program Assistant

Robert Saunders
Senior Program Officer

Barret Zimmermann
Program Assistant