Partnering with Patients, Families, and Communities to Link Interprofessional Practice and Education

Proceedings of a conference chaired by Terry Fulmer, PhD, RN, FAAN and Martha (Meg) Gaines, JD, LLM
April 2014 | Arlington, Virginia
This monograph is in the public domain and may be reproduced or copied without permission. Citation, however, is appreciated.

Fulmer, T & Gaines, M. Partnering with Patients, Families, and Communities to Link Interprofessional Practice and Education. Proceedings of a conference sponsored by the Josiah Macy Jr. Foundation in April 2014; New York: Josiah Macy Jr. Foundation; 2014

All photos by Kate Kunath
Accessible at: www.macyfoundation.org
Partnering with Patients, Families, and Communities to Link Interprofessional Practice and Education

Proceedings of a conference chaired by
Terry Fulmer, PhD, RN, FAAN
and Martha (Meg) Gaines, JD, LLM

Arlington, Virginia | April 2014

Edited by Teri Larson

Published by Josiah Macy Jr. Foundation
44 East 64th Street, New York, NY 10065
www.macyfoundation.org

September 2014
## CONTENTS

Preface ........................................................................ 7

Introduction .................................................................. 11

Conference Agenda .................................................. 14

Conference Participants ............................................. 20

Conference Conclusions and Recommendations ............ 27

Commissioned Paper .................................................. 47

    *A Vision for Engaging Patients, Families, and Communities in Linking Interprofessional Education and Practice*

Case Studies ................................................................ 73

1. Université de Montréal: Partners in Interprofessional Education: Integrating Patients-as-Trainers .................................................. 73

2. University of Rochester Medical Center: Patient- and Family-Centered Care Initiative ................................................................. 87

3. Veterans Health Administration (VHA): Engagement Strategies for Returning Combat Veterans. Veteran and Family Engagement and Interprofessional Education in Design and Implementation of VA Post-Deployment Care ................................................. 105


Highlights from the Conference Discussion ..................... 151

Selected Bibliography .................................................. 181

Biographies of Participants and Observers ....................... 185
This Macy Conference that was held April 3 to 6, 2014, in Arlington, Virginia was unique in many ways. It represented the Macy Foundation’s first formal initiative to bring together the worlds of health professions education, healthcare delivery, and patient and community advocacy. To do this we assembled a remarkable mixture of educators, healthcare delivery experts, patients, and patient advocates. And while the discussions at Macy Conferences are always robust, these discussions were particularly intense, vibrant, and uplifting. There was a shared sense of urgency, purpose, and hopefulness that we collectively can bring about the culture change that will enable true partnering and find the “sweet spot” that is depicted in the Conference Recommendations.

This conference represented a logical progression in the work of the Macy Foundation over the last several years. Our major theme has been the alignment of health professions education with contemporary needs in order to better prepare health professionals for a changing healthcare system. The Macy Foundation has been supporting interprofessional education (IPE) as a major tool for that educational alignment. We have come to realize that IPE and other educational innovations will not have the transformative effect we want for patient care unless they are more closely tied to the ongoing reforms in the delivery system. The realization led to the January 2013 Macy Conference “Transforming Patient Care: Aligning Interprofessional Education with Clinical Practice Redesign.” A major conclusion and recommendation from that conference was that patients, families, and communities must be engaged at each step in the process of linking education and practice redesign. This conference is a direct response to that recommendation.

In order to lay the groundwork for this conference and bring all participants up to a common level of understanding of the issues, we commissioned a “vision paper” and four case studies. The paper “A Vision for Engaging Patients, Families and Communities in Linking Interprofessional Education and Practice” was written by Angela Coulter from the University of Oxford and Michael Barry from the Informed Medical Decisions Foundation in Boston. The four case studies were from the
Université de Montréal, the University of Rochester Medical Center, the Veterans Health Administration, and the Duke University School of Medicine.

Conferees met in plenary sessions and breakout groups over three days to generate the consensus recommendations in four broad areas: changes needed in the content and conduct of health professions education, changes needed in education and healthcare organizations, steps needed to build the capacity for partnerships, and reforms needed in regulations and payment.

The conferees left the meeting energized by the commitment and insights of their colleagues and cautiously optimistic that we are on a track to improve the education of health professions, the performance of the healthcare system, and ultimately the health of the public by partnering with patients, families, and communities. In fact, they concluded unanimously that this is the only way to achieve these goals because patients, families, and communities are “the very reason our healthcare system exists.” Furthermore there is a great urgency that this must be done now to avoid more adverse consequences of a system that is not optimally integrated in a way to achieve the “partnership sweet spot”.

Meg Gaines and Terry Fulmer provided extraordinary leadership before, during, and after the conference. The planning and writing committee shaped the conference and the report to result in this fine finished product. Every one of the conferees made valuable contributions at every step in the process, and I can truly say that all learned and all taught.

We are looking forward to working with willing partners across all sectors in carrying this work forward. This kind of fundamental change is not easy, but the reward is “to further optimal health and wellness for all.”

George E. Thibault, MD
President, Josiah Macy Jr. Foundation
REFERENCES


INTRODUCTION

TERRY FULMER, PHD, RN, FAAN
MARTHA (MEG) E. GAINES, JD, LLM
CONFERENCE CO-CHAIRS

The accelerated pace of change in health care requires a fundamental rethinking of our approach to the challenges and opportunities presented. Those who practice, administer, teach, and reform health care must commit to partner with those at the center of their efforts—namely patients, families, and communities—to co-create a healthcare system worthy of the American people in the 21st century. It is the responsibility of all who practice and benefit from health care—all of us—to inform the cost-benefit calculus with our own values. At a time when designer medicine, genetic reengineering, telehealth, and remarkable feats of bioengineering are transforming healthcare practice, little is known about how patients, families, and communities will value these changes, and how they might affect their choices, decisions, and ultimately their health. It is time for us to begin a more inclusive conversation about how health care should change going forward.

There is an astonishing dearth of knowledge about what effective partnerships look like and how they are created; where the “sweet spot” for collaboration lies. Our conference sought to imagine a world where health professionals embrace partnering with patients, families, and communities as an essential aspect of achieving health, and where they are taught the skills and competencies to do so. From there, we explored what it would take to create such a world.

The resulting recommendations comprise the work of a diverse group of patients, advocates, teachers, clinicians, administrators, and policy makers who worked intensively over three days to find common language, ground, and inspiration. We were united from the start by a shared sense of urgency and a shared vision that profound change is essential. The conference began as a search for how to engage patients, families, and communities in all aspects of health care: clinical services, health professions education, and organizational and national reform. After hearing
from the diverse voices represented, the vision quickly transformed from engage to full “partnership” between those providing health care and the patients, families, and communities they serve.

There is much to be done to lay the groundwork for partnership in health care. Clinicians, faculty, patients, families, communities, hospitals and clinics, administrators, insurers, and policy makers will need to learn new skills and shed old assumptions and biases. Hope can be found in current efforts in curricular reform (team-based care), healthcare services reform (patient-centered medical homes, evidence based medicine, electronic health records, quality improvement, increased emphasis on primary care), patient care reform (shared decision-making, patient-centered care, patient and family advisory councils), and access to care reform (Patient Protection and Affordable Care Act, Medicaid expansion). Still, in order for a tectonic shift toward full partnership to occur, significant change in the gestalt of American health care will be required—and it must be borne in a new vision for education of health professionals, and the transformation of incentive structures to foster and shape these changes.

Terry Fulmer, PhD, RN, FAAN  Martha (Meg) E. Gaines, JD, LLM
Conference Co-Chair   Conference Co-Chair
THURSDAY, APRIL 3 EVENING

3:00 – 6:00  Registration
6:00 – 7:00  Welcome Reception
7:00 – 9:30  Dinner

FRIDAY, APRIL 4 MORNING

7:00 – 8:00  Breakfast
8:00 – 12:00  Session 1
8:00 – 9:45  Brief introduction of participants and opening remarks
             George Thibault, Terry Fulmer, Meg Gaines
9:45 – 10:45  Discussion of themes from commissioned paper
              A Vision for Engaging Patients, Families, and Communities in
              Linking Interprofessional Education and Practice
              Michael Barry, Angela Coulter
              Moderator: Terry Fulmer, Meg Gaines
10:45 – 11:00  Break
11:00 – 11:45  Case Study Presentations
              Case Study 1: Université de Montréal – Partners in Interprofessional
              Education: Integrating Patients-as-Trainees
              Marie-Claude Vanier, Université de Montréal
              Case Study 2: University of Rochester Medical Center –
              Patient- and Family-Centered Care Initiative
              Bradford C. Berk, University of Rochester Medical Center
              Case Study 3: Veterans Health Administration – Engagement
              Strategies for Returning Combat Veterans. Veteran and Family
              Engagement and Interprofessional Education in Design and
              Implementation of VA Post-Deployment Care
              Stephen Hunt, Department of Veterans Affairs
              Case Study 4: Duke University – The Duke Health Leadership Program
              Michelle J. Lyn, Duke University School of Medicine
## FRIDAY, APRIL 4 AFTERNOON

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>12:00 – 1:00</td>
<td>Lunch</td>
</tr>
<tr>
<td>1:00 – 5:00</td>
<td><strong>Session 2</strong></td>
</tr>
<tr>
<td>1:00 – 3:00</td>
<td>Case Study Breakout Sessions</td>
</tr>
<tr>
<td></td>
<td><strong>Case Study 1:</strong> <em>Université de Montréal – Partners in Interprofessional</em> Education: Integrating Patients-as-Trainers</td>
</tr>
<tr>
<td></td>
<td>Moderator: George Bo-Linn and Barbara Brandt</td>
</tr>
<tr>
<td></td>
<td><strong>Case Study 2:</strong> <em>University of Rochester Medical Center – Patient- and Family-Centered Care Initiative</em></td>
</tr>
<tr>
<td></td>
<td>Moderator: Bruce Hamory</td>
</tr>
<tr>
<td></td>
<td><strong>Case Study 3:</strong> <em>Veterans Health Administration – Engagement Strategies for Returning Combat Veterans. Veteran and Family Engagement and Interprofessional Education in Design and Implementation of VA Post-Deployment Care</em></td>
</tr>
<tr>
<td></td>
<td>Moderator: Stephen Schoenbaum</td>
</tr>
<tr>
<td></td>
<td><strong>Case Study 4:</strong> <em>Duke University – The Duke Health Leadership Program</em></td>
</tr>
<tr>
<td></td>
<td>Moderator: Linda Headrick</td>
</tr>
<tr>
<td>3:00 – 3:15</td>
<td>Break</td>
</tr>
<tr>
<td>3:15 – 4:00</td>
<td>Report out from Breakout Groups</td>
</tr>
<tr>
<td>3:15 – 4:00</td>
<td>General Discussion of themes of the day to set agenda for the following day</td>
</tr>
<tr>
<td></td>
<td>Terry Fulmer, Meg Gaines</td>
</tr>
<tr>
<td>5:00</td>
<td>Adjourn</td>
</tr>
</tbody>
</table>

## FRIDAY, APRIL 4 EVENING

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>7:00 – 9:30</td>
<td>Reception &amp; Dinner at The Smithsonian Castle</td>
</tr>
</tbody>
</table>
SATURDAY, APRIL 5 MORNING

**7:00 – 8:00**  Breakfast

**8:00 – 12:30**  Session 3

**8:00 – 8:45**  Brief recap of Day 1 and Charge to Breakout Groups  
Terry Fulmer, Meg Gaines

**9:00 – 12:00**  Thematic Breakout Sessions: Five breakout groups:

Breakout 1  
*Build the capacity for partnerships among patients, families, and communities and health professions education and clinical practice*  
*Facilitators: Rosemary Gibson and Linda Headrick*

Breakout 2  
*Make changes in health professions education organizations necessary to facilitate partnerships among patients, families, and communities and health professions education and clinical practice*  
*Facilitator: Barbara Brandt*

Breakout 3  
*Make regulatory and payment reforms that support and sustain partnerships among patients, families, communities, and health professions education and clinical practice*  
*Facilitator: George Bo-Linn*

Breakout 4  
*Make changes in healthcare delivery organizations necessary to facilitate partnerships among patients, families, and communities and health professions education and clinical practice*  
*Facilitator: Bruce Hamory*

Breakout 5  
*Make changes in the content and conduct of health professions education*  
*Facilitator: Stephen Schoenbaum*

**12:00 – 12:15**  Group Photo
SATURDAY, APRIL 5 AFTERNOON

12:15 – 1:00  Lunch
1:00 – 4:30  Session 4
1:00 – 2:15  Report out from breakout groups
            Moderators: Terry Fulmer, Meg Gaines
2:15 – 3:00  Response to reports from breakout groups
            Moderators: Terry Fulmer, Meg Gaines
3:00 – 3:15  Break
3:15 – 4:30  Plenary Session
4:30  Adjourn

SATURDAY, APRIL 5 EVENING

6:30 – 9:30  Reception & Dinner at Ambassador Room

SUNDAY, APRIL 6 MORNING

7:00 – 8:00  Breakfast
8:00 – 11:45  Session 5
             Conference Conclusions and Recommendations
             George Thibault, Terry Fulmer, Meg Gaines
11:45 – 12:00  Summary Remarks
               George Thibault
12:00  Adjourn
CONFERENCE PARTICIPANTS

Boel Andersson-Gäre, MD, PhD
The Jönköping Academy for Improvement of Health and Welfare
Jönköping University (Jönköping, Sweden)

Michael J. Barry, MD
Informed Medical Decisions Foundation

Bradford C. Berk, MD, PhD
University of Rochester Medical Center

George W. Bo-Linn, MD
Alvarez & Marsal

Barbara F. Brandt, PhD
National Center for Interprofessional Practice and Education at the University of Minnesota Academic Health Center

Kristin L. Carman, PhD
American Institutes for Research

Jennie Chin Hansen, RN, MSN, FAAN
American Geriatrics Society

Angela Coulter, PhD
Informed Medical Decisions Foundation
University of Oxford (UK)

Christian Farman, RN
Rykov County Hospital
(Jönköping, Sweden)

Katherine A. Flores, MD
UCSF Fresno Latino Center for Medical Education and Research

Terry Fulmer, PhD, RN, FAAN
Bouvé College of Health Sciences at Northeastern University

Martha E. (Meg) Gaines, JD, LLM
Center for Patient Partnerships at University of Wisconsin Law School

Rosemary Gibson, MSc
The Hastings Center

Paul Grundy, MD, MPH
IBM Corporation

Barbara Guthrie, PhD, RN, FAAN
Yale University School of Nursing

Bruce H. Hamory, MD
Oliver Wyman

Helen Haskell, MA
Mothers Against Medical Error

Linda A. Headrick, MD, MS*
University of Missouri, Columbia School of Medicine

Stephen Hunt, MD, MPH
US Department of Veterans Affairs
Beverley H. Johnson  
*Institute for Patient- and Family-Centered Care*

Paul Katz, MD  
*Cooper Medical School of Rowan University*

Uma R. Kotagal, MBBS, MSc  
*Cincinnati Children’s Hospital Medical Center*

Beth Lown, MD  
*The Schwartz Center for Compassionate Healthcare*

Michelle J. Lyn, MBA, MHA  
*Duke University School of Medicine*

Valerie Montgomery Rice, MD  
*Morehouse School of Medicine*

Debra L. Ness, MS  
*National Partnership for Women & Families*

Marc A. Nivet, EdD, MBA  
*Association of American Medical Colleges*

Sally Okun, RN, MMHS  
*PatientsLikeMe*

Harold A. Pincus, MD  
*Columbia University College of Physicians and Surgeons*

Carol Raphael, MPA  
*Manatt Health Solutions*

Sheldon Retchin, MD, MSPH  
*Virginia Commonwealth University*

Steven M. Safyer, MD  
*Montefiore Health System*

Gilbert Salinas, MPA  
*Institute for Healthcare Improvement Rancho Los Amigos National Rehabilitation Center*

Stephen C. Schoenbaum, MD, MPH*  
*Josiah Macy Jr. Foundation*

George E. Thibault, MD*  
*Josiah Macy Jr. Foundation*

Marie-Claude Vanier, MSc  
*Université de Montréal*

Jonathan Woodson, MD  
*US Department of Defense*

* Planning Committee Member
OBSERVERS

Jacqueline Beckerman, MPH
University of Rochester Medical Center

Frederick Chen, MD, MPH
University of Washington School of Medicine

Vincent Dumez, MSc
Université de Montréal

Peter Goodwin, MBA
Josiah Macy Jr. Foundation

Sharrie McIntosh, MHA
The Arnold P. Gold Foundation

STAFF

Yasmine R. Legendre, MPA
Josiah Macy Jr. Foundation

Ellen J. Witzkin
Josiah Macy Jr. Foundation

Teri Larson
Teri Larson Consulting

Carmelita Marrow
EMCVenues
CONFERENCE CONCLUSIONS AND RECOMMENDATIONS

PARTNERING WITH PATIENTS, FAMILIES, AND COMMUNITIES: AN URGENT IMPERATIVE FOR HEALTH CARE

In April 2014, the Josiah Macy Jr. Foundation convened a meeting whose purpose many participants described as unprecedented. It brought together patients, leaders of patient advocacy organizations, healthcare educators, and leaders of healthcare organizations to make recommendations for the urgent reform of both health professions education and healthcare practice in partnership with patients, families, and communities.

As one participant summed up the conference: “We’re spending so much time these days talking about fixing, reforming, transforming, even revolutionizing the American healthcare system. But what we’re really talking about is turning it right side up and placing the focus where it should have been all along: on the patients.”

In addition to the recommendations for transformative action contained in this conference summary, conferees also crafted and agreed to a vision statement for health professions education and healthcare practice going forward. The statement reads:

We envision a future in which individuals, families, and communities are understood to be the very reason our healthcare system exists, and that those who are caring, teaching, learning, or otherwise working within the system must partner fully and effectively with them to foster optimal health and wellness for all.

The vision statement purposefully uses the verb “partner” in place of “engage” (which was the original word used by the Macy Foundation when planning the
conference). The conferees agreed that patients, families, and communities must be welcomed to the table as equal partners, working collaboratively with all concerned to set agendas, determine policies and priorities, and make decisions and help implement them. Further, the wisdom of patients, families, and communities—gained from their experiences—must be recognized to be as important as professional expertise in these partnerships.

In developing the vision statement, conferees recognized that partnering with patients, families, and communities requires a fundamental cultural shift in traditional health professions education and clinical practice. This shift, which conferees believe is urgently needed, may be both uncomfortable and transformative because it involves moving beyond the realm of personal care decisions, consumer focus groups, satisfaction surveys, and community meetings. It is about equal, respectful, and mutually beneficial partnership at every level and in every health-related endeavor, from designing educational curricula to setting research priorities to hiring faculty and leadership to operating healthcare organizations, and much more. It is about co-creating optimal health and health care.

These changes must start immediately, and will require many years of sustained effort to become part of the culture of health professions education and health care. Conferees believe that pursuing this vision now not only is the right thing to do, but also will lead to improved quality, efficiency, and functioning within the healthcare system and to better health outcomes for all of us. They further caution that failure to partner in this way will lead to continued disintegration of health professions education and clinical practice.

THE STORY BEHIND THIS CONFERENCE

We can trace the philosophical roots of this conference back to at least September 1978 and the historic International Conference on Primary Health Care, held in Alma Ata (in today’s Kazakhstan). A landmark declaration from that global meeting was, “The people have the right and duty to participate individually and collectively in the planning and implementation of their health care.”

Unfortunately, 36 years later, the American healthcare system still wrestles with—and, until recently, largely resisted—the meaningful participation of patients, families,
and communities in co-creating optimal health and health care. In spite of efforts by patient advocacy groups—such as the National Patient Safety Foundation, which declares, “nothing about me without me”—little progress has been made toward truly integrating patients’ voices into the reform of health professions education or clinical practice.

We now have an opportunity not only to honor the Alma Ata declaration, but also to update it, recognizing that the “duty” to participate in the planning and implementation of health care belongs to all partners—patients, families, communities, and all who work, teach, and learn in the healthcare system—equally. Not only that, but we now know that health has much less to do with health care and much more to do with the myriad factors in our lives that affect our health—from the safety of our neighborhoods and our access to healthy foods to the quality of our schools, the job opportunities of our workers, and the affordability of our housing. We now understand that the partnerships needed to create optimal health for all must reach beyond the walls of our hospitals, community clinics, clinicians’ offices, and health professions schools into our communities, neighborhoods, and homes.

The Josiah Macy Jr. Foundation has been involved for many years in seeding and supporting innovations in health professions education, with a focus on turning out healthcare professionals who have a much broader view of health and wellness. These innovations involve teaching health professions students to work together in interprofessional teams and teaching them to coordinate care over time and meet a broad array of needs among increasingly diverse patients, who receive care in a variety of settings.

More recently, the Macy Foundation has come to recognize the need to link the reforms it supports in health professions education to the reforms that are well underway in clinical practice, which are focused on team-based, patient-centered care and population health. Historically, there has been too little connection between interprofessional education reform and clinical practice redesign. In January 2013, the Foundation hosted a conference to help bring the two realms together so that practice redesign can both inform educational reforms and embrace an educational mission.

One of the five recommendations from that conference was to “Engage patients, families, and communities in the design, implementation, improvement, and evaluation of efforts to link interprofessional education and collaborative practice.” There was a clear consensus among conference participants that patients, families,
and communities should be partners from the start in the effort to create an interprofessional education and care continuum that meets the needs of the public. This is the partnership “sweet spot” shown in the accompanying diagram. That recommendation led directly, in April 2014, to the Macy Foundation conference on “Partnering with Patients, Families, and Communities to Link Interprofessional Practice and Education.”
RECOMMENDATIONS FROM CONFERENCE ON PARTNERING WITH PATIENTS, FAMILIES, AND COMMUNITIES TO LINK INTERPROFESSIONAL PRACTICE AND EDUCATION

Conference participants crafted recommendations in four areas focused on fostering partnerships among patients, families, communities, and health professions education and clinical practice organizations. They are:

I. Make changes in the content and conduct of health professions education necessary to graduate practitioners who partner with patients, families, and communities.

II. Make changes in health professions education organizations and healthcare organizations necessary to facilitate durable partnerships, both new and existing, with patients, families, and communities.

III. Build the capacity for partnerships among patients, families, and communities and health professions education and healthcare organizations.

IV. Make regulatory and payment reforms that require, support, and sustain partnerships among patients, families, and communities and health professions education and healthcare organizations.

These recommendations are described more fully below, including specific actions for implementing them. And, while the recommendations are presented as a numbered list, they are interdependent and of equal importance; no single recommendation takes precedence. Many other important ideas for improving patient and family engagement in health professions education and clinical practice were raised at the conference, but we present here only those recommendations that are very clearly and directly related to the goal of creating, integrating, and sustaining effective partnerships among patients, families, and communities and health professions education and healthcare organizations. Furthermore, we urge everyone, especially those in positions of responsibility, to take steps today to begin implementing these recommendations.
RECOMMENDATION I

Make changes in the content and conduct of health professions education necessary to graduate practitioners who partner with patients, families, and communities.

To graduate healthcare providers who know how to partner with patients, families, and communities, we must change both what and how health professions students are taught.

Changes to curricular content and its delivery should take into account several principles, including the following:

- Exposure to new content should begin early and prepare learners for partnership before they enter into experiential settings, such as clinical care settings.

- The concept of partnership should infuse didactic lectures, experiential offerings, and peer-to-peer learning.

- Content related to partnerships should extend beyond formal coursework and into standard clinical practices in both inpatient and outpatient settings.

- Patients and families must be welcomed as partners in all aspects and settings of the educational process, and they should be trained as co-educators of students.

- The experiential knowledge of patients and families should be used to enrich educational content.

- Content should take into account technologies patients and families can and do access on their own or that can be supplied to help them manage their health.

To implement this recommendation, we suggest the following actions:

1. Develop a competency framework within health professions educational curricula focused on building effective partnerships with patients, families, and communities.
These effective partnership competencies should be developed with input from all stakeholders (health professions educators, practitioners, and students as well as patients, families, and communities). A national group of relevant stakeholders should be convened for this purpose. They should build on existing health professional and interprofessional competency frameworks, and on existing tools and resources developed by patient and family advocacy organizations, such as the Institute for Patient- and Family-Centered Care. Furthermore, to extend the work and its effectiveness over time, it will be essential to develop a cadre of health professions leaders who will champion partnerships among health professionals and patients, families, and communities. Thus, the content of curricula in health professions schools should emphasize leadership skills and embed partnership into leadership curricula.

2. Develop a framework for educating patients, families, and communities about effective participation in classrooms and other settings, and about serving as co-educators of health professions students.

Just as health professions students must learn about effective partnerships, so must patients, families, and community members. All stakeholders (health professions educators, practitioners, and students as well as patients, families, and communities) should come together and design a training program for patients who want to participate as partners in teaching health professions students in all settings where learning occurs. National organizations involved in patient advocacy would be logical conveners for this activity.

3. Develop comprehensive faculty development programs focused on teaching health professions students how to build and sustain effective partnerships with patients, families, and communities.

Faculty members should be held accountable for teaching health professions students about effective partnerships and for modeling what is being taught. For this to be possible, however, they must be supported by—and have the opportunity to participate in—a robust and comprehensive faculty development program that has been jointly created by health professions educators, practitioners, and students as well as patients, families, and communities.
4. Design and teach both coursework and experiential offerings in the institutions that educate health professionals to produce the effective partnership competencies mentioned above.

This educational content should be based on currently existing examples of curricula related to building effective partnerships, and it should be taught together with patients, families, communities, and healthcare practitioners. Patients’ involvement in educational activities can take many different forms. Some examples include sharing personal stories with students; role-playing interactions; consulting on curriculum development and review; co-authoring textbook chapters and journal articles; and mentoring students and/or hosting them for home visits.

5. Convene a national group of stakeholders to develop measures—including structure, process, and outcomes measures—that institutions that educate health professionals can use to assess their performance in integrating partnership into their curricula.

Institutions that educate health professionals must be held accountable for producing graduates who are competent at working collaboratively within and across disciplines and with patients, families, and communities to achieve better outcomes. Ensuring accountability will require a portfolio of structure, process, and outcomes measures of both patient and learner experiences.

6. Develop a research and evaluation agenda for new educational programs that teach forming partnerships between health professionals and patients, families, and communities.

Though some effective examples of programs aimed at forming partnerships exist, it is important to note that this approach is an emerging field. It will be necessary to link curriculum redesign and deployment efforts that teach partnership building with research and evaluation that identifies best practices in order to improve and facilitate the dissemination of these novel processes. Support for research and evaluation efforts should become a priority for funders such as the Patient-Centered Outcomes Research Institute (PCORI), grant-making foundations, and funders of health care.
7. Work with accrediting agencies for health professions education institutions and health professions certification organizations (i.e., medical boards) to mandate curricular content and competencies for health professions students around effective partnering with patients, families, and communities.

Organizations that accredit health professions education institutions can play a key role in fostering the development, spread, and improvement of competencies and curricula focused on building effective partnerships with patients, families, and communities. Implementing the foregoing sub-recommendations should provide accreditors the framework, faculty development curricula, measurements, and evidence base to play their role effectively.

RECOMMENDATION II

Make changes in health professions education organizations and healthcare organizations necessary to facilitate durable partnerships, both new and existing, with patients, families, and communities.

In the United States, our system of health care is shifting toward greater emphasis on wellness and prevention, while also managing the chronic care needs and healthcare costs of our aging and increasingly diverse population. New organizational models, such as patient-centered medical homes and accountable care organizations, are creating new patterns of healthcare practice. These changes are translating into a greater recognition that health professionals, partnering with patients, families, and communities, need to work and learn about, from, and with each other. The success of these new models requires mutual respect, trust, new skills, and accountability among all involved.

Many have noted that health professions education has not kept pace with the rapid and fundamental changes in clinical practice and the new healthcare practice models. Nor have most health professions education organizations actively or meaningfully involved patients, families, or communities in the educational mission in ways that reflect their important role in health and health care.
Both health professions education and healthcare organizations have an important responsibility to inculcate new values and develop new skills among all involved: educators; health professionals; and patients, families, and communities themselves. This vision will require leadership and governance to create changes in both practice and education organizations and the alignment between them.

1. **Leaders of both healthcare and health professions education organizations must create new vision and mission statements and operational processes that meaningfully incorporate patients, families, and communities as partners.**

Leaders of healthcare and health professions education organizations should articulate a new vision for the future; communicate the imperative for re-aligning education with practice; and set expectations for new models that include patients, families, and communities as partners in governance, teaching, clinical care, and research. To accomplish these goals, organizational leadership in both healthcare and health professions education should undertake the following responsibilities:

- **Model at every level of the organization the values and behaviors that welcome patients, families, and communities as partners.**

- **Create together with patients, families, and communities new mission, vision, and values statements that reflect partnership.**

- **Communicate values, set expectations, and establish incentives to partner with patients, families, and communities in substantive ways around the realignment of clinical practice and the education and training of health professionals.**

- **Formally assign responsibility for partnering with patients, families, and communities to a new or existing department, office, or position. The appropriate person(s) should be made responsible for ensuring that patients, families, and communities are meaningfully integrated in governance, teaching, clinical care, and research. Ideally, passionate and objective leaders need to be assigned to facilitate this alignment and to be held accountable for outcomes. This also should be recognized as a legitimate area for scholarship and as a basis for academic promotion.**
Commit to enhancing organizational human resources capacity and functionality to support transformational changes in all settings. This includes integrating patients, families, and communities as partners in decisions, structures, and systems (such as hiring, rewards, continuing education, and accountability) related to all workers (staff, professionals, faculty, and administrators) in healthcare and health professions education organizations.

2. The governance of organizations involved in the transformation of healthcare and health professions education—ranging from local health providers’ offices to large, multi-organizational systems, academic health centers, and schools for the education of health professionals—should be restructured to integrate the principles of partnership.

A new system focused on co-created optimal health should strive for a goal of partnering with patients and families so that they may live well across all settings and through time. Governance for both healthcare and health professions education organizations needs to be better aligned and restructured to achieve this goal to maintain patients’ health, provide healthcare services, and educate healthcare professionals with the active involvement of patients, families, and communities. To restructure governance, healthcare and health professions education organizations should:

- Develop processes to select members of governing boards and oversight committees who represent the diversity of the community and who understand the shift toward partnership. Orient these individuals to the essential aspects of partnerships among patients, families, and communities and health professions education and healthcare organizations to enable them to be effective in organizational governance.

- Include community members in the ongoing monitoring and quality improvement processes of the organization’s performance and capabilities, and provide any additional resources needed to attain the goals above.

- Prepare leaders at all levels (boards of trustees, chief executive officers,
vice presidents, deans, and faculty leaders) to lead their organizations in ways that are consistent with the new vision for health. They should learn about fundamental changes in health care, the current levers for healthcare change, the needed alignment between health professions education and healthcare organizations, and the need (and skills required) to partner with patients, families, and communities.

- Work with national organizations and accrediting bodies to promote leadership and governance around the concepts of alignment and partnership, and provide incentives to restructure in fundamental ways to incorporate patients, families, and communities.

3. Leaders in healthcare and health professions education organizations should commit to preparing all team members (faculty, clinicians, direct health workers, students, and patients, families, and communities) to partner in co-creating educational curricula and optimal health care.

Steps include:

- Build on existing competencies and professional requirements to ensure that learners at all levels are prepared to partner with patients, families, and communities. Set expectations for new knowledge, skills, and attitudes to facilitate cultural changes in higher education organizations that better reflect new expectations.

- Develop pilot projects, such as those described in the case studies commissioned for the conference, to partner with patients, families, and communities, and create mechanisms to evaluate and disseminate innovative models that are successful.

- Prepare and support patients, families, and community members to serve on and lead key operational and oversight committees (quality improvement, patient safety, curriculum committees, etc.)
RECOMMENDATION III

Build the capacity for partnerships among patients, families, and communities and health professions education and healthcare organizations.

A number of barriers prevent widespread, effective, and sustainable partnerships among patients, families, communities, health professions education, and clinical practice. These include society’s assumptions about how health care works and the role of health professionals; health professionals’ assumptions that patients, families, and communities do not have the expertise to participate in the design and delivery of health care or health professions education; an imbalance of power in the patient-provider relationship that leads many patients and families to feel insecure and even fearful about expressing their views; a lack of receptivity to patient and family input among many health professionals and healthcare organizations; and the lack of structures and processes essential to supporting patient, family, and community partnerships.

Television, movies, and other media send powerful messages about health care and the relationships between patients and providers. For one generation, it was the fatherly Marcus Welby; for another it was the smart and impertinent young professionals in House and ER. Throughout, the messages often are of vulnerable patients seeking help from powerful figures who may demonstrate empathy and compassion, but rarely convey a message of equal partnership.

We are aware that a number of patient and family advocacy organizations and several national organizations, such as PCORI, the Institute of Medicine, and the National Institutes of Health’s Clinical Translational Science Awards program, are developing resources to help healthcare organizations engage with patients, families, and communities. We believe these efforts likely will make important contributions to the field. The recommendations below should be informed by and coordinated with these efforts.

If we wish to move from a healthcare system based on “we are here to make you feel better” to a model of “we are partners, working together to create optimal health for you and for your community,” we need new skills and supporting structures.
1. Healthcare and health professions education organizations should establish values and behaviors that support patient, family, and community partnerships.

Both healthcare and health professions education organizations are responsible for developing and implementing robust methods for receiving and responding to issues, concerns, and insights from patients, families, and communities in ways that ensure safety and freedom from repercussions. Patients, families, and communities have knowledge, experience, and ideas that organizations can use to provide better care and education. Patients, families, and community members will share these only if healthcare and health professions education organizations respond with receptivity and respect.

Organizational leaders are responsible for creating the infrastructure and mechanisms that promote authentic patient, family, and community partnership as a core value. They also are responsible for defining the relevant behaviors expected of professionals, staff, and learners. These include global behaviors expected of everyone and role-specific behaviors appropriate to particular circumstances. The end result will be most powerful if everyone (patients, families, community members as well as everyone who is caring, educating, learning, or otherwise working in the healthcare system) helps define partnership and the behaviors that support it.

Once these behaviors are identified, measurement and feedback (at the individual, unit, and organizational level) are needed to ensure accountability and sustainability. Ultimately, national-level measures will provide opportunities for cross-organizational learning and benchmarking. For instance, a patient might be asked to respond to a survey item such as “During my visit, I felt welcomed as a full partner in efforts to improve care.”

2. Define the skills needed by everyone involved in partnerships among patients, families, and communities and health professions education and healthcare organizations.

Establishing and sustaining these partnerships requires skills that are new for many who are seeking or providing health care. A first step is for patients, families, community members, faculty, clinicians, staff, and learners to
define together what skills are needed. Here, as a place to begin, are a few examples of such skills:

- Ability to build equal, respectful, and mutually beneficial relationships among all who are engaged in health care and health professions education;

- Ability to harvest and learn from the knowledge and experiences of patients and families through direct interactions, social media, and e-health;

- Ability to support change at both the individual and organizational levels; and

- Abilities in change management and continuous quality improvement.

A consortium of consumer groups and professional groups could work together to establish and promote these skills in a way that models the desired partnerships. This work could be hosted by consumer groups, “in their houses and according to their rules.”

3. **Create processes and an organizational structure that extend from local to national levels to advance patient, family, and community partnership in health care and health professions education.**

Although various types of patient and family partnerships, such as patient and family advisory councils, currently make important contributions to many healthcare organizations, their impact is felt primarily in individual settings or systems of care. For patients, families, and communities to have impact across the spectrum of health care and health professions education, their activities must be supported nationally as well as locally.

An over-arching organizational structure dedicated to advancing patient, family, and community partnership in health care and health professions education nationally as well as locally could help foster needed research and evaluation, disseminate best practices, and create networks that connect the people and organizations doing this work. The new structure must model the stated goals, such as visibly including patients as leaders. It also must have secure funding, established in a way that avoids conflicts of interest.
One example would be a small tax on the Medicare Trust Fund, similar to the funding that supports PCORI.

The new organizational structure could:

- Develop and promulgate a national set of values and principles pertaining to partnership (these should build strategically on existing core principles).

- Develop and distribute education programs for the public, as well as curricula for multiple levels of learners (K–12, university, health professions, continuing professional development).

- Partner with social media, television, the film industry, and other communications-related organizations to create and promote educational messages consistent with the vision of health and health care set forth in this report.

**RECOMMENDATION IV**

**Make regulatory and payment reforms that require, support, and sustain partnerships among patients, families, and communities and health professions education and healthcare organizations.**

This is a time of great change in the way health care is organized, delivered, and paid for. Implementation of the Patient Protection and Affordable Care Act (ACA) has added momentum to the quest for new models of healthcare delivery and accountability that will enable us to simultaneously improve quality and lower cost. We expect these changes to help us achieve better health outcomes and improve the care experience for individuals and their families. Providers will be expected to be more accountable for their performance and use of resources; and individuals, families, and communities will bear more responsibility for their health and health care.

This climate of change and the innovations propelled by the ACA create unique opportunities for the changes in culture, attitudes, and practice that are necessary to achieving genuine partnerships with patients, families, and communities.
At a minimum, we believe the Centers for Medicare and Medicaid (CMS), and in particular, the Center for Medicare and Medicaid Innovation (CMMI), should embed partnership with patients, families, and communities into every new payment and delivery model they implement. Because CMS action so greatly influences payment and practice in the private sector, this commitment would have a force-multiplier effect that would help drive more rapid and widespread adoption of such partnership.

Hence, while payment and regulatory reform cannot serve as the sole stimulus for the transformation we seek, together with the other recommendations in this report, it can be an important catalyst, support, and means of accountability.

To implement this recommendation, we suggest the following actions:

1. **CMS and CMMI should take every opportunity, particularly those afforded by ACA implementation, to embed patient, family, and community partnership in new payment and delivery initiatives.**

Payment reform should be designed to create an understandable, coherent, mutually supportive framework of incentives and support that ensures sufficient financial motivation to care providers, patients, families, and communities. To do so, payments for partnership should be determined through robust accountability measures; coupled with sufficient support for training and technical assistance; and contextualized by transparency and feedback to ensure opportunities for continued improvement.

CMS/CMMI should specifically require partnership in the on-site governance, design, implementation, and evaluation of new payment and delivery models. The requirements should be robust enough to ensure that the criteria for partnership cannot be met simply through token representation on governing or operational bodies, or the creation of peripheral advisory groups that have little opportunity for genuine influence or decision making.

- Appropriate metrics should be used to assess the quality of the partnership process, as well as improvements in clinical quality and outcomes, and the patient- and family-centeredness of care. Patient- and family-centered metrics should be used to both evaluate quality and calibrate payment for all new delivery and payment models. These
metrics should include both patient-reported outcome measures (PROs) and measures of patient and family experience of care.

- CMS should allocate resources to more rapidly promulgate the development of PROs and advanced measures of patient- and family-centeredness and measures of patient and family experience of care that provide real-time feedback to clinicians.

- CMS/CMMI should provide adequate resources for training and technical assistance to ensure that patients, families, and communities can engage effectively in these partnerships. Adequate support and training should also be provided to ensure that clinicians, educators, and administrators have the necessary skills for effective partnership.

2. **Requirements for partnership with patients, families, and communities should be integrated into the various types of ACA support for graduate medical education (GME) and workforce development.**

   - Federal financial incentives for health professions education and training should be linked to demonstrated commitment to integration of partnership as described in the above sections of this report. Incentives should be linked to both front-end criteria that educational organizations must meet as well as accountability metrics that evidence an effective partnership process is in place.

   - These requirements should be accompanied by federal support for training and technical assistance that ensures that patients, families, and communities as well as educators and learners have the necessary skills for effective partnership.

3. **Convene a summit of major education accreditors and professional certification bodies, with education leaders, clinicians, patients, families, and communities, to produce a framework and position statement that reflects a commitment and action plan for incorporating partnerships with patients, families, and communities into accreditation, certification, and maintenance of certification (MOC) standards across the professions.**
Large-scale transformation of education for healthcare professionals will not occur without the commitment of educational organizations and program leaders, who are heavily influenced by their respective accrediting bodies and the professional requirements for certification. Therefore accreditation and certification standards can catalyze the incorporation of partnerships with patients, families, and communities into both educational curricula and the clinical practice experience. Redesigned accreditation standards and certification competencies will speed dissemination of the structure and process elements needed to foster partnership in education and training processes. They will also encourage organizations to change more rapidly towards the professional culture, attitudes, and behaviors necessary for genuine partnership with patients, families, and communities.
It is extraordinary how often we talk as if health professionals are the sole providers of health care without questioning this assumption. Their expertise and experience is crucial, of course, but collectively, the decisions and actions of ordinary lay people make an even greater contribution to public health. Effective health care is impossible without the active participation of those in receipt of it—patients, their families, and their communities. What should we be doing to maximize this valuable asset?

In this paper, we will argue that radical changes are needed in the way health professionals—clinicians, educationalists, researchers, managers, and policymakers—view patients, their families, and communities. We start from a conviction that transforming the quality, affordability, and sustainability of modern health systems must involve recognizing, supporting, and strengthening the contributions of lay people. We will begin by briefly summarizing the major health policy challenges as we see them; we will then outline the various ways in which patients, families, and communities contribute to their own health and how their efforts can be supported through productive partnerships; and we will end by considering the implications for interprofessional practice and education.
DEVELOPING PRODUCTIVE PARTNERSHIPS

Dramatic advances in medical knowledge have brought numerous benefits in terms of more accurate diagnoses and more effective treatments, but they have also made health care more complex and difficult to manage. Patterns of care vary strikingly by geographic region and disparities in health and health care for different populations are widespread. Nowadays, many people experience care that is fragmented, poorly coordinated, overly disease-centered, inefficient, and inappropriate for their needs. This applies especially to those with chronic conditions, who consume roughly two-thirds of healthcare resources, and their numbers are growing. Demographic change and aging populations mean that increasing numbers of people are living with more than one long-term health problem. It makes no sense to treat these people as if they were simply collections of body parts to be passed around from one specialist to the next, yet professional training and reward systems incentivize specialization, not holistic care. Clinicians cluster in their specialty groups, with the greatest rewards going to the super-specialists, while the efforts of generalists are often under-valued. The disease-centered focus of modern health systems seems increasingly unfit for their intended purpose, more in tune with the needs of professionals than patients.

Recent years have seen a proliferation of initiatives in many countries designed to tackle these problems. In the United States, the movement toward primary care medical homes and accountable care organizations (ACOs) aims to improve quality and value by catalyzing broader, deeper, and more meaningful patient engagement (1, 2). ACOs are designed to address the “Triple Aim” of health care reform: better care for individuals, better health for populations, and lower costs. According to the Centers for Medicare and Medicaid Services (CMS) rules, ACOs, “must . . .

1. promote evidence-based medicine and beneficiary engagement, internally report on quality and cost metrics, and coordinate care;

2. adopt a focus on patient centeredness that is promoted by the governing body and integrated into practice by leadership and management working with the organization’s health care teams; and

3. have defined processes to fulfill these requirements.”
The movement is gathering momentum. By December 2013, more than 360 ACOs had been established, serving over 5.3 million Americans with Medicare (3). ACOs also now care for large numbers of non-Medicare patients, leading to calls for all-payer participation in the move away from traditional fee-for-service payment (4). ACOs must meet 33 performance standards to achieve shared savings under the program, including seven patient-centered metrics derived from the Clinician and Group Consumer Assessment of Healthcare Providers and Systems (CAHPS) patient surveys. Indicators include several important aspects of patients’ and caregivers’ experiences, including communication with providers, health promotion and education, and shared decision-making. These legislative steps to ensure that ACOs are accountable to the people they serve, and not just to the payers, are an important move toward promoting patient-centered care, but they will need to be accompanied by organizational and cultural changes on the ground if they are to have a lasting effect.

**Figure 1: Co-Producing Health**

People can play a distinct role in promoting the health of themselves, their families, and their communities by:

- Understanding the social determinants of illness and the factors that influence health, especially those within their control
- Self-diagnosing and treating minor conditions
- Knowing when and where to seek advice and professional help
- Choosing appropriate healthcare providers
- Selecting appropriate treatments
- Monitoring symptoms and treatment effects
- Being aware of safety issues and preventing errors
- Coping with the effects of chronic illness and self-managing their care
- Adopting healthy behaviors to prevent occurrence or recurrence of disease
- Providing feedback to enable assessment of the quality of care
- Ensuring that healthcare resources are used appropriately and effectively
- Participating in clinical and health services research
- Articulating their views in debates about healthcare priorities
- Helping to plan, govern, and evaluate health services
- Working collectively to tackle the causes of ill-health
So what should be done to ensure that medical care better meets the needs of current and future patients? A recent BMJ editorial called for “a fundamental shift in the power structure in healthcare” and a recognition that “expertise in health and illness lies outside as much as inside medical circles” (5). We agree. Professionals must learn to respect patients’ knowledge and expertise if health systems are to be transformed. The first step is to acknowledge the many ways in which individuals protect, promote, and manage their own health (6) (Figure 1).

So patients, their families, and their communities are co-producers of health, contributing value to the health of individuals and populations in multiple ways. Their contribution is large and could be even greater if these roles were appropriately acknowledged and properly supported. As co-producers, they have a right to receive information and support to perform their role effectively and they should be given opportunities to shape the services they use. Self-care is the most prevalent form of health care, yet its importance is often unappreciated. Most people look after their own and their families’ health most of the time. Professionals who assume that patients lack competence in these areas risk undermining their efforts. Patients may indeed lack knowledge and confidence, but it is incumbent on providers to foster their self-reliance, not belittle it. Because it is so prevalent, small shifts in self-care in either direction could make a major impact on the demand for professional care. Strengthening people’s capacity to look after themselves and their families could generate significant cost savings. Weakening it by overselling the benefits of professional interventions is an expensive mistake. With better support, the contributions of patients and caregivers could create even greater value.

Patients need to be treated as partners in care, not just as passive recipients. Once the lay contribution to health care is fully recognized, the attitudinal and organizational changes required to improve the system become more obvious. Instead of doing things to patients, there is a subtle shift toward working in partnership with them. A paternalistic and dependency-creating medical culture, where clinicians assume they know best, is seen for what it is: anachronistic and out of sync with the way people expect to be dealt with in other aspects of their lives. Time spent informing, educating, consulting, and involving patients is not time wasted. On the contrary, it is a worthwhile investment that will repay dividends later on.

Patient, family, and community engagement can take a variety of forms and there are various opportunities or levels where this can occur, the main ones being in the
direct care of patients or their families, in organizational design and governance, and in policy making (7). Patients, families, and communities can also be involved in teaching and training, in research, in development of clinical guidelines, in quality and safety improvement, and in public health initiatives. Health professionals sometimes struggle to see how patient, family, or community engagement fits with their clinical and other priorities, so this may need to be spelled out for them. The primary reason for working in partnership with patients and families is because it’s the right thing to do, but it can also be helpful to think in terms of specific policy objectives when planning how health professionals will engage with them (Figure 2).

Patients, family members, and other lay people can make important contributions to key policy objectives in a variety of ways that should resonate with the concerns of clinical staff. These may include the quality and safety of care, communications, health literacy and health promotion, selecting appropriate treatments and encouraging self-care, participating in teaching and research, designing services.

---

and maximizing health more generally. The type of engagement can vary from informing and consulting, through more active involvement, to full sharing of power and responsibility. What people want and need in terms of engagement may differ and any number of different activities along the continuum may be appropriate at any one time. The important thing is that the opportunities for involvement are there, not blocked by professional, organizational, or policy barriers. The aim wherever possible must be to build productive partnerships between lay people and providers, based on mutual respect and collaboration. Below we outline some examples showing how this approach is already beginning to transform health care in some places.

1. PRODUCTIVE PARTNERSHIPS FOR SELECTING TREATMENTS

Health professionals undergo many years of training to develop and refine their capabilities for diagnosing and treating diseases, but most patients have to learn how to manage health problems through experience only. There is huge public interest in health issues. Medical knowledge is now more widely accessible than ever before and people are eager to absorb it and share their experiences; hence, the popularity of websites such as patientslikeme.com. But, when it comes to making decisions about how best to diagnose, treat, or manage a health problem, most people need help in the form of reliable information and counseling from a well-trained clinician to determine the best course of action for them. This is a situation where well-functioning collaborative relationships are required.

There are often many different ways to treat a health problem, each of which may lead to a different set of outcomes. At most decision points there are a number of treatment, care, or support possibilities to consider; indeed, it is quite unusual for there to be a simple choice between undergoing a medical intervention or not. Decisions that can affect a person’s quality of life in important ways should not be left to physicians alone. Patients need to know about the potential benefits and harms of the options they face, and they should be encouraged to participate in selecting the best treatment for them. This process, known as shared decision-making, involves the provision of reliable, balanced, evidence-based information about treatment options, outcomes, and uncertainties, together with counseling from a clinician or health coach to clarify options and patients’ preferences.
Providing this type of information verbally in a busy clinic can be challenging, so one solution is to provide a decision aid summarizing the key facts for use in the clinic or at home. Patient decision aids take a variety of forms, from simple one-page sheets to sophisticated web-based tools. Most include evidence-based information about different treatments and outcome probabilities, plus values-clarification exercises to help people weigh up the pros and cons of the options. Their use leads to better understanding of treatment options, more accurate risk perceptions, greater participation in decision-making, greater comfort with decisions, no increase in anxiety, and fewer patients choosing major surgery (8).

Despite convincing evidence of benefit from informing and involving patients in this way, large numbers of patients still undergo treatments without being told the full facts and without the ability to give proper informed consent (9, 10). They also risk undergoing invasive treatments that they could have avoided if they had known about alternative ways of managing their condition. The good news is that shared decision-making is now being successfully implemented in various sites around the US and internationally, and many clinicians and patients have embraced the concept. The bad news is that it has not yet become the norm in clinical practice. The problem seems to lie in an outdated medical culture that resists attempts to transfer decision-making power to patients, together with a misalignment of incentives, making it slow to percolate into the mainstream (11). Physicians’ belief that there is insufficient time to provide information and discuss options with patients is another very important barrier, though this may be more problematic in perception than in reality. Experience shows that it is possible to embed patient information and decision support into routine practice without disrupting established routines. But information alone is not enough. Clinicians must learn new skills, such as how to communicate risk in a comprehensible manner, how to elicit patients’ values, and how to involve them in clinical decision-making (Box 1).

2. PRODUCTIVE PARTNERSHIPS FOR STRENGTHENING SELF-CARE

According to the United Nations, the treatment and management of non-communicable diseases is the greatest challenge facing health systems around the world today (13). Since most of these conditions cannot be cured, strategies used by health professionals to engage, support, and empower patients are key to improving health outcomes. Patients who are better informed, more involved, and more
Box 1: Involving Patients in Treatment Decisions

Eight demonstration sites around the US have been working together to test the feasibility of implementing shared decision-making in routine clinical care (www.informedmedicaldecisions.org/shared-decision-making-in-practice/demonstration-sites). The sites, which received support and funding from the Informed Medical Decisions Foundation, tackled the task by focusing on several key steps—introducing the concept to relevant patient groups, engaging and training staff, identifying decision points, distributing decision aids, clarifying options, supporting patients and providers in the decision-making process, monitoring implementation, measuring impact, and learning from feedback.

The demonstration sites have achieved considerable success. For example, staff and providers at the Mercy Clinics in Iowa are mobilizing health coaches to support patients facing complex decisions. The health coaches distribute decision aids during face-to-face consultations, answer any questions a patient may have, and encourage them to review the decision support materials. Patients can take these away to review at home, returning later to meet with their provider to discuss any concerns and to decide on the best course of action.

Another member of the shared decision-making collaborative—the team at Massachusetts General Hospital (MGH)—has created a streamlined process for professionals to prescribe patient decision aids through the electronic medical record. To date more than 16,000 of these have been ordered by 650 clinicians. The MGH program also provides training in shared decision-making to 15 primary care practices (physicians, nurses, and office staff) and to 120 internal medicine resident physicians-in-training each year.

An evaluation of the demonstration site program pointed to various challenges that had to be overcome, including overworked physicians, insufficient provider training, and inflexible clinical information systems (12). Several sites found that they could not rely on physicians to distribute decision aids; the system functioned much better when managed by office staff. Decision aid distribution worked best when it was triggered automatically, based on information in clinical records or referral letters. Effective teamwork also was critical, with success depending on the extent to which nurses and other practice staff, as well as physicians, engaged in the process.
“activated” (i.e., those who recognize that they have an important role in managing their condition(s) and have the skills and confidence to do so) will experience improved health and better quality of life (14).

The Chronic Care Model stresses the need to transform health care for people with long-term health conditions from a system that is largely reactive, responding when a person is sick, to one that is much more proactive, focused on supporting patients’ abilities to self-manage their health (15). The model advocates an active role for patients, who are encouraged to become both more knowledgeable about the factors affecting their condition (including strategies for preventing exacerbations or ameliorating symptoms), and more actively involved in planning their care. The clinician’s responsibility is to assess the extent of the patient's self-management knowledge, skills, and confidence, and to strengthen this where necessary; and to ensure that relevant interventions and services are available, including community resources external to formal health services (16). Those skills are not routinely taught in either professional schools or continuing education courses.

At the heart of the model is an informed and activated patient supported by a well-prepared primary care team working together proactively to determine priorities, establish goals, create action plans, and review progress. Collaborative personalized care planning aims to ensure individuals’ values and concerns shape the way in which they are supported to live with and self-manage their health. Instead of focusing on a standard set of disease management processes, this approach encourages patients to work with clinicians to determine their specific needs and their informed preferences for treatment, lifestyle change, and self-management support. Personalized care planning involves encouraging patients with chronic conditions to play an active part in determining their own care and support needs (17). In pre-arranged appointments, they engage in a collaborative care planning process—identifying priorities, discussing care and support options, agreeing to goals they can achieve themselves, and co-producing a single holistic care plan with their care coordinator, regardless of how many long-term conditions they have. The collaboratively developed plan is incorporated in the electronic medical record, accessible by both the patient and care coordinator, and is used to review progress. This approach involves recognizing that the experience and personal assets that the patient brings to the care planning process is as important as the clinical information in the medical record.

Planning care in this collaborative manner has the potential to achieve better outcomes than more directive or didactic approaches. Effective management
of chronic conditions usually involves both tests and treatments prescribed by clinicians, and actions that patients must do for themselves, such as taking medication appropriately, making lifestyle changes, or monitoring the effectiveness of treatment. Some patients may not need support for self-management or behavior change, but for those that do, collaboratively set goals and self-selected behavioral targets are often more motivational than clinician-assigned goals (18). Well-prepared care coordinators with access to electronic directories of available resources can ensure that patients are aware of the full range of support services available to them, including those provided by community groups. Continuity of care is also very important. Providers who have a good understanding of a patient’s home, family, and community circumstances are better placed to advise on appropriate support options than those who have no such knowledge. Health and social care professionals who view their role as supporting the efforts of patients and their families can achieve so much more.

**Box 2: Redesigning Primary Care**

The Center for Medicare and Medicaid Innovation’s Comprehensive Primary Care Initiative four-year demonstration project began in 2012, and involves almost 500 primary care practices in seven areas around the country (http://innovation.cms.gov/initiatives/comprehensive-primary-care-initiative/). Building on the primary care medical home model, this approach to service delivery includes five important functions: risk-stratified care management, access and continuity, planned care for chronic conditions and preventative care, patient and caregiver engagement, and coordination of care across the medical neighborhood. Practices receive additional payments for these services, as well as shared savings. Engaging patients in developing care plans addressing health risks, circumstances, and values is stressed. Other patient-centered features of the initiative incorporated into program milestones include the use of patient decision aids, measurement of patients’ experience of care, and the involvement of patient and family advisory councils.
3. PRODUCTIVE PARTNERSHIPS FOR IMPROVING QUALITY AND SAFETY

The most successful commercial companies know that maintaining a single-minded focus on the end user is the only way to guarantee success. The same ought to be true in health care, but this insight is often crowded out by a multitude of competing priorities, including guidelines, policies, procedures, and reporting requirements that are very far from person-centered. Giving due priority to patients’ experience is important, both for its own sake and because it can make a real difference to health outcomes. For example, studies have found that patients whose treatment is deemed patient-centered are more likely to trust their clinicians (19), more likely to adhere to treatment recommendations (20), and less likely to die following a major event such as acute myocardial infarction (21). And there is evidence that the quality of patients’ experience is closely related to staff experience—happy staff make happy patients (22). So effective managerial support, good working conditions, and positive staff morale are essential to providing a good-quality experience for patients. Monitoring patients’ experience via regular surveys is also helpful, but not sufficient, to ensure that services are truly patient-centered. Surveys should be supplemented with other ways of ensuring that staff members focus on patients’ needs and address any deficiencies identified in the surveys.

The term “patient-centered” is bandied about a great deal nowadays, but just adding that term to a name is no guarantee that attitudes to patient engagement have changed in any fundamental way. For instance, a survey of physician practices that had achieved early recognition as Patient-Centered Medical Homes found that less than one third involved patients and families in a continuing role in quality improvement (23). Dedicated leadership is required and staff must learn to value patient feedback. This does not always come naturally and defensive reactions are common. External levers—such as public reporting and financial incentives—are sometimes necessary to provide the necessary motivation. Sharing power with patients will often appear threatening to those who are ill-disposed to the concept. It is always wise to expect resistance and to have a plan ready for dealing with it (24). Patients may take time to get used to the idea that they have a contribution to make. People’s expectations are shaped by their past experiences, and many patients have experience of interactions with providers where it was made clear to them that only their passive acquiescence was expected. Gentle persuasion, education, and ongoing support may be needed to encourage patients to play a
more active role, particularly those from vulnerable populations, and they may need to be given express ‘permission’ to express their views (25).

Patients have made important contributions to research too; indeed, most medical research would be impossible without the active participation of patients. In recent developments, research-funding bodies, such as the Patient-Centered Outcomes Research Institute (PCORI), have taken major steps to involve patients in determining research priorities; deciding what gets funded; and participating in the design, implementation, and dissemination of studies. This evolution is happening at an international level too. The Cochrane Collaboration, an important global initiative to publish systematic reviews of research evidence on the effectiveness of medical interventions, has involved healthcare consumers in its work for more than 20 years.

Patients also should have the opportunity to provide input into clinical practice guidelines (26, 27). In England, the National Institute of Health and Care Excellence (NICE), which produces evidence-based guidance and advice for healthcare providers and payers across the National Health Service (NHS), believes that patient engagement improves the quality and relevance of their products (28). They strive to involve lay people and organizations representing their interests in all aspects of their work, from suggesting topics for assessment to direct involvement on guideline development committees. They advertise openly for lay members—at least two for each advisory committee or working group—and offer support, training, and payment to those who become actively involved. NICE also seeks advice on moral and ethical issues from an independently run Citizens Council, comprising 30 members recruited to reflect the diversity of the adult population of the UK.

In many countries, patients are making important contributions to health professional training programs by helping clinical trainees practice their consultation skills, by appearing in videos talking about their experiences (for example, see healthtalkonline.org), and, in some cases, by direct teaching in classroom settings. This type of involvement has been found to offer multiple benefits for all involved—learners, patients, and trainers (29). Other patients and their families welcome trainees into their homes to learn more about the experience of living with illness. Community placements are particularly helpful for motivating students in the early years of medical training (30). Students gain confidence and learn things that cannot be readily absorbed from reading books or listening to lectures.
Many patients are motivated to get involved as a direct result of their healthcare experiences. In the United States, the National Patient Safety Foundation offers many opportunities for lay people to learn about and get involved in patient safety initiatives, but these efforts are now making waves internationally too (http://www.npsf.org/).

One such example is the World Health Organization’s Patients for Patient Safety (PFPS) program, which was established in 2005 (http://www.who.int/patientsafety/patients_for_patient/en/). It is now a global network of patient advocates working together with policymakers and providers in more than 50 countries to promote safer health care. Many PFPS advocates have direct personal experience with medical errors and are prepared to talk publicly about what happened to them as a means of alerting people to the consequences of unsafe systems. They are keen to avoid being pigeonholed as mere victims, however, and they are actively engaged in devising and promoting far-sighted programs for patient safety and patient empowerment that encourage a constructive dialogue about safety issues; campaign for better reporting systems; and encourage an honest, open, and transparent approach when errors occur.

Specific PFPS campaigns have focused on safer use of medicines, hand hygiene to save lives, and the health of mothers and babies in the risky first seven days following childbirth. These topics sometimes stray into contentious areas, so political sensitivity and well thought-through tactics for building consensus are essential. The impact of the global network is a good example of what can be achieved when patients and providers make common cause to advocate for healthcare reform.
There is nothing new about community participation in health care. Patient groups and lay representatives have been actively engaged in advocacy for health improvements and in policy forums at local, national, and international levels since the nineteenth century at least (31). Examples range from small-scale, voluntary, community and patient groups providing specific local services to well-coordinated national campaigns and global networks. In some cases, these movements have had a profound influence. For example, feminist campaigns helped transform the way gynecological problems were treated; and people with HIV/AIDS successfully campaigned to improve public awareness of their condition, leading to reduced stigma and a greater emphasis on prevention.

Nowadays, community groups are influencing health policy and practice in numerous ways. Many committed activists leap at the opportunity to serve on health boards and governing bodies, to contribute to local consultations, or to review and comment on reports and published performance data as part of the processes designed to hold providers and funders to account. Some are engaged in setting up and running local community-controlled health facilities.

Sometimes described pejoratively and unfairly as “the usual suspects,” the pillars of the community who willingly respond to invitations to join planning groups or sit on policy committees are well placed to articulate the perspective of their own circles, but they cannot be expected to represent the diversity of views among the much larger population of service users. Other ways must be devised to obtain a more representative selection of views from the local community. Broader involvement is particularly important if the aim is to tackle health inequalities. A wide range of methods has been advocated for securing community engagement—from surveys and consultations through to full community control—but this is an under-researched topic and we lack sufficiently rigorous evaluations to determine which techniques are most appropriate for which purpose. Assessments of a community’s health needs and patterns of illness can be more powerful if they involve local people and try to see the picture of health care through their eyes, alongside expert statistical descriptions—so-called community epidemiology. Another way of thinking about this challenge is to replace the traditional deficit mindset in health care with its focus on health problems and deficiencies with a focus on identifying and mobilizing community assets. An asset approach aims to learn about and build on the innat
capacity of individuals and communities, making best use of this knowledge to mobilize and empower local people to take action on health issues.

Box 4: Improving Maternal and Newborn Health

Maternal and neonatal mortality is a serious problem in many low- and middle-income countries. Worldwide, an estimated 273,465 mothers died in 2011 from complications of pregnancy and childbirth, and 2.9 million infants did not survive the first month of life (32). Following the World Health Organization’s (WHO’s) Alma-Ata Declaration, which included participation in health care as a key principle, community mobilization has been used to good effect in some countries to tackle the problem of maternal and child mortality. Based on the belief that health education is more empowering if it involves dialogue and problem solving, instead of didactic message giving, community mobilization aims to empower local people by helping them gain information, skills, and confidence to take control over important aspects of their lives, including their health (33). Engaging community groups in discussing and acting on pregnancy and child health issues has an important role in improving care practices, increasing the use of safer motherhood services, promoting timely referral when problems arise, and reducing social disadvantage.

Community mobilization strategies focused on maternal and neonatal health were implemented in rural areas in Nepal, India, Bangladesh, and Malawi, and evaluated in a series of seven randomized controlled trials (32). In each case, women’s groups were identified or set up, and facilitated by local women who were not health workers but who received appropriate training and support. Each of the groups adopted a participatory learning and action cycle involving regular discussion meetings. They focused on issues such as hygiene in home deliveries, health-promoting practices in antenatal care, and safer postnatal care at home. The result was a substantial reduction in neonatal and maternal mortality—maternal mortality fell by 37% and neonatal mortality by 23% and the intervention was deemed cost-effective by WHO standards. It was estimated that community mobilization along these lines could save the lives of 283,000 newborn infants and 41,000 mothers annually if it was implemented across all of the 74 poorest countries.
Implications for Interprofessional Practice and Education

Patients have been described as the greatest untapped resource in healthcare (34). Recognizing their capacity and that of local communities as assets and co-producers of health—and not simply as resource-users—could do much to transform the quality and sustainability of health systems. What’s needed is a shift away from the reactive, disease-focused, fragmented model of care that we’ve all come to expect, toward one that is more proactive, holistic, and preventative, in which people are encouraged to play a central role in managing their own care. This represents a major departure from the way most health professionals have been trained to think and act, so the transformation cannot happen without a redesign of training programs. Building successful productive partnerships requires new skills. These are illustrated in the case studies we have described and are summarized in the diagram below (Figure 3).
Some of these skills are already taught in basic training programs, but most are not. Some staff members develop relevant expertise during their specialist training or through their personal experience, but many do not. Responsibility for patient and family engagement is not the domain of a particular specialty or professional group; it should be seen as an essential component of care provided by all. Working collaboratively with patients, families, and communities depends on a high level of collaboration between professional staff and excellent teamwork. This in turn relies on knowledge of, and respect for, people from different disciplinary backgrounds, so interprofessional education is essential for developing and practicing these crucial skills.

Devising curricula to develop relevant skills, especially curricula that will work in an interprofessional context, is no easy task. Take the example of shared decision-making. As we demonstrated above, despite strong evidence that patients benefit from being fully engaged in decisions about their care, there are many obstacles to its widespread uptake in mainstream clinical practice. Those providers who have embraced the concept, successfully introducing it into routine care, have found that one of the keys to success lies in giving multidisciplinary teams the opportunity to learn and practice together (35). A program to introduce shared decision-making into clinical practice in the UK aimed to engage clinicians by developing new skills, knowledge, and attitudes at the level of clinical microsystems (36). While some clinicians were very supportive, others claimed they had little to learn and no need to change, despite evidence from patients’ reports contradicting this. These initial reactions changed during the course of a series of skills development workshops when they began to realize, through participating in role play and other exercises, that their practice wasn’t as optimal as they had originally believed. Getting clinicians to that “light bulb moment” is often the hardest part of any program designed to change clinical behavior.

There is a growing demand for interprofessional training on how to engage, inform, and involve patients, families, and communities, but no consensus on what, when, and how it should be taught. Most experts agree that two broad sets of skills need to be learned: relational competencies (active listening, negotiated agenda-setting and prioritizing, demonstrating empathy and emotional intelligence, facilitating involvement, clarifying the decisions that need to be made, clarifying values and preferences, and supporting deliberation); and risk communication (being aware of the evidence, communicating information about benefits and harms, discussing uncertainties, clear presentation of probabilities, and use of decision aids) (37, 38).
Those designing training programs must specify clear learning objectives and outcomes. These might include topics such as awareness of patients’ information needs and how to communicate relevant information, nondirective interviewing, explaining risks and probabilities, personalized care planning, and self-management support.

The good news is that there is evidence that, with effective teaching and ample opportunity to practice, effective interpersonal and risk communication skills can be learned and reproduced, resulting in better consultations (39). Short-term training for professionals (less than 10 hours) may be just as effective as longer courses if it is well-designed. There also is evidence that the effects of this type of training on health outcomes are enhanced when they are accompanied by interventions directed at patients, such as provision of educational materials or decision aids. While most studies have looked at the effects of training for single professional groups, the effects of interprofessional education are less well understood. Nevertheless, a recent review of healthcare team-training programs concluded that there is moderate- to high-quality evidence that team-training has a positive impact on collaborative team behavior and on care processes, leading to better outcomes for patients (40). Meanwhile, a Cochrane review of the broader field of interprofessional education reinforces the evidence of beneficial effects on collaborative team behavior and on care processes (41). However, more well-designed studies are required to confirm its impact on patient outcomes.

The importance of including patients, families, and community members in the design of interventions to meet population health needs, including education and training, is increasingly recognized (42). They also can be involved more directly in the delivery of these interventions. Traditionally, patients were involved in teaching only as passive participants; for example, to illustrate symptoms, physical findings, or procedures, but there are clear benefits when they are given a more active role. Direct contact with patients can help develop trainees’ communication skills, professional attitudes, empathy, and clinical reasoning. The employment of actors as “simulated patients” is now commonplace in medical training, but increasingly there is a move to engage real patients to talk about their experiences or to provide formal tuition on particular aspects of the curriculum. This can offer benefits to learners and trainers, and to the patients themselves, many of whom welcome the opportunity to use their disease or condition positively in a way that deepens understanding among health professionals (29).
It is important to plan carefully for patient involvement in educational programs. Attention must be paid to the patient-teacher’s emotional well-being and stamina, especially if they have to recount distressing experiences. Students may also find it upsetting to listen to such stories, so their well-being needs to be considered too. Participants must be given full information about what is involved before they are asked to commit themselves, and they should be given training, remuneration, and appropriate support.

CONCLUSIONS

Patients are co-producers of health so their important role needs to be recognized in the way health professionals are trained. Building effective patient-professional partnerships should be seen as a key clinical competency, to be developed and assessed at all levels of professional education and among all health professionals. Generalist training for doctors, nurses, and other clinicians should be encouraged, reversing the trend toward increasing specialization, which tends to diminish the patient’s role and leads to fragmented care. This would help to build a workforce that is better able to cope with multi-morbidity and can be more flexibly deployed.

Above all, there should be more opportunities for interprofessional learning, with a view to encouraging better teamwork and the development of new roles, such as care navigators and health coaches, who can provide direct support to patients in their self-care activities. Learning new skills alongside team members is the best way to ensure that these will be implemented in everyday practice. Working effectively with patients, families, and communities demands knowledge and practical experience of a very wide range of competencies, many of which are not currently covered in traditional training courses. These include relational competencies, risk communication, improvement science, and working with local communities. Professional training bodies should make special efforts to incorporate these competencies into their programs, ensuring they are assessed adequately and included in recertification procedures.

The clinical practice environment is changing rapidly worldwide. In the United States, the linked medical home and ACO movements are transforming care to be more patient-centered and team-based. These trends urgently need to be matched by a fundamental reinvention of interprofessional training to ensure that healthcare providers are better prepared to work with patients, families, and communities, and
to focus on health, rather than simply health care, in true partnership with the people and populations they serve.

REFERENCES


Patient Story from Université de Montréal

The first time I heard about patients-as-trainers, I wanted to be part of it. I thought it would be a great opportunity to be closer to the students and have impact on their perception of the relationship between patients and providers. All of the patients interested in this new activity received training on mentorship, followed by a discussion on the role and responsibility of the mentor. Then, we broke into small groups with the students. My team of one male and two female students was very diverse, their ages ranged between 24 and 36 years, and they were at different levels in their training programs in three different professions. At our first meeting, they wanted to talk about my illness, their professions, and care transitions. Subsequent topics included building trust, mental and physical pain, and a discussion of the patient-provider partnership.

By providing simple examples, I was able to illustrate how each of the three professions could build or rebuild trust, and how they could humanize their attitudes and behaviour toward patients. I was able to see that students learned a lot from these three meetings. They also showed that they were able to recognize attitudes and behaviours that could hurt the relationship between the patient and the medical team. This was a very fulfilling experience because we developed a connection based on empathy and respect. I was respectful of their professional knowledge and life experiences, and they were respectful of my expertise regarding my illness and my care, and my life experience. I also was able to compare my perception of the health system with theirs and assess if I was biased by my hospitalization experiences. In the end, I could see that their perception was comparable to mine. We had great exchanges and discussions, and I would participate in the mentorship again anytime!

Catherine Marchand
Patient-as-Trainer
UNIVERSITÉ DE MONTRÉAL

PARTNERS IN INTERPROFESSIONAL EDUCATION: INTEGRATING PATIENTS-AS-TRAINERS

Main authors: Marie-Claude Vanier\textsuperscript{1,2}, Vincent Dumez\textsuperscript{1,3}, Eric Drouin\textsuperscript{1,4}, Isabelle Brault\textsuperscript{1,5}, Sue-Ann MacDonald\textsuperscript{1,6}, Andrée Boucher\textsuperscript{3,4}, Nicolas Fernandez\textsuperscript{3}, Marie-Josée Levert\textsuperscript{1,5}

In collaboration with: The Interfaculty Operational Committee, Interprofessional Education Collaboration and Healthcare Partnership, Université de Montréal

1. Interfaculty Operational Committee (IOC)
2. Faculty of Pharmacy
3. CPASS, Center for Applied Pedagogy in Health Sciences (CAPHS)
4. Faculty of Medicine
5. Faculty of Nursing
6. School of Social Work

Note: Throughout the text the notion of “patient” includes “caregivers” and “families”

PROBLEM STATEMENT

Many experts and practitioners consider that a paradigm shift in healthcare programs and services is needed and overdue. It is our contention that we need to move away from traditional paternalistic approaches, wherein physicians and other health professionals determine course and outcomes, and shift toward the inclusion of the patient as an equally valued member of the healthcare team, creating a true partnership between clinicians, patients, and caregivers. Future health professionals
and social sciences professionals trained with this new healthcare partnership model will likely become agents of change and contribute to healthcare transformation. This paper describes a successful approach to integrate patients in interprofessional education (IPE) courses.

BACKGROUND AND CONTEXT

A recent editorial in BMJ argues that many healthcare systems in industrialized countries are costly, wasteful, fragmented, and depersonalized. It points out that clinicians and patients need to work in partnership to improve healthcare and challenge deeply engrained practices and behaviours. It also calls for increased patient engagement in the design and implementation of new policies, systems, and services as well as in clinical decision-making (1). A full-blown partnership approach, in which patients and caregivers actively participate in goal setting and care, means that patients must be integrated strategically and methodologically at multiple levels to improve healthcare delivery.

It is our opinion that a paradigm shift in care delivery must take root in the initial stages of training for long-lasting change to take hold, and we believe this full partnership between patients and professionals should also be implemented in education. This training should begin early, with the involvement of patients in the preclinical training of health professionals, before they are exposed to stereotypes and old school concepts. Early exposure will allow gradual development and reinforcement of competency in building healthcare partnerships, and integration of concepts and consolidation of competency during clinical training. Ultimately, we expect these students to become agents of change when they join the workforce.

In order to understand and act constructively towards this transformation of the healthcare system, innovative training approaches of current and future health professionals are required. Likewise, patients need to develop knowledge and competencies to become active partners in their care and also for some, partners in health professional education. Patients, with their experiential knowledge, can contribute significantly in healthcare delivery as well as in training of future health professionals (2,3).

Currently, IPE programs are being implemented in Canada, the United States, Australia, and Europe, as is evidenced by the publication of interprofessional
competencies frameworks (4,5). We believe that IPE constitutes a unique opportunity to make patient engagement a reality. To meet these ends, the IPE program at the Université de Montréal (UdeM) trains and calls upon patients to act as co-facilitators with health professionals in the training of students in 13 different health-related professions.

PURPOSE

This paper explains the integration process of patients-as-trainers in our IPE program, describes the patient-as-trainer role and its impact on the development and evolution of the curricula, and summarizes the results and challenges.

SECTION 1: EDUCATIONAL CHALLENGES IN IPE: SHIFTING FROM A PATIENT-CENTERED TO A PARTNERSHIP APPROACH

Université de Montréal Context: Preconditions, Conceptual Evolution, and IPE Curricula

In its current form, the IPE program comprises three one-credit undergraduate mandatory courses embedded in the first three years of preclinical education. Approximately 1,400 students are enrolled yearly in each of the three IPE courses. See Vanier et al. (6) for further details about UdeM’s IPE curriculum. Initially, patients were not involved in the planning and dispensing of these courses. An opportunity to involve patients arose when the former dean of the Faculty of Medicine created, in 2010, the Faculty Bureau of Expertise on Patient Partnership (FBEPP), which has recently been integrated into the Center for Applied Pedagogy in Health Sciences. The direction of the Bureau was entrusted to a patient who possesses a strong expertise in management consulting and lives with three chronic diseases. The Bureau’s first action was to describe and consolidate the concept of patient-as-partner. According to the vision of the Bureau, the term “patient-as-partner in care” refers to a patient:

“who is being gradually empowered to participate in the decision-making process regarding his/her care plan and to make free and informed choices; who is becoming a full-fledged member of the interprofessional team...”
handling his/her care; whose experiential knowledge and ability to develop care expertise for his/her medical condition are recognized as evidence; and who influences the interventions chosen and their prioritization in accordance with his/her life project.”

Current IPE Program and Involvement of Patients-as-Trainers in IPE Courses

One way to achieve this aim is through education. The FBEPP and Interfaculty Operational Committee (IOC) decided to embark on a feasibility project to integrate patients-as-trainers in the IPE program. It was hypothesized that patients-as-trainers’ participation could help students better understand patient experiences, better grasp the concept of healthcare partnership and its fulfillment in clinical practice, as well as model collaboration from initial training onward. The 2011 fall semester third-year IPE workshop was chosen for this initial trial project. The workshop required the enactment of an interprofessional team meeting simulation (in a small-group setting; n=11), whose aim was to develop an interprofessional plan of care for an elderly patient. As a key innovation, a patient-as-trainer co-facilitated the workshop with a faculty professor or a health professional tutor. Patients-as-trainers gave targeted feedback on student learning of the concepts of healthcare partnership and provided insights as to how the patient in the case study might react to the clinical interventions. Moreover, they shared their experiential knowledge of living with a chronic disease (or being a caregiver to such a person) to personalize learning. An added advantage of the co-facilitation: the tutor and patient-as-trainer modeled collaborative practice and brought to life both theory and concepts of healthcare partnership.

Fourteen patients-as-trainers participated in this first project, allowing 308 students to experience this innovative teaching model. In light of the positive comments received, deans approved the expansion of the patients-as-trainers project into first and second year IPE courses. The roles of patients-as-trainers varied slightly in these courses. In the first year introductory IPE course, each patient gave an account of his/her own experience and co-facilitated the session. Discussion with students about their own healthcare experiences and students’ experiences was the centerpiece of the course. The second year course focused on professional roles and application of the collaborative practice and patient partnership concepts. The patient-as-trainer advocated patient and family interests and personal objectives with regards to health care.
Because of the significant and ongoing costs of implementation and maintenance of such an infrastructure, deans requested additional data before formally approving full implementation of patients-as-trainers in Spring 2012. Positive endorsement from students and positive reception from the provincial government and the university-affiliated hospitals network to the healthcare partnership model—coupled with the growing need for well-trained health professionals in that area—underscored the importance of integrating patients-as-trainers in IPE and convinced deans to support its expansion and continuation. This is now perceived at UdeM as an important and differentiating characteristic of our health sciences and psychosocial sciences training programs, demonstrating our educators’ and institution’s leadership.

In 2012–2013, a total of 4,200 students took part in IPE courses, approximately 1,400 students in each of the three courses. Patients-as-trainers were present in all first-year course workshops, 63% of second-year workshops, and 47% of third-year workshops. During the 2013–2014 academic year, we aim to ensure the presence of a patient-as-trainer in each workshop group of the three IPE courses. Students’ appreciation data obtained during academic year 2012–2013 confirmed our

<table>
<thead>
<tr>
<th>Questionnaire Statements</th>
<th>Proportion of Students Agreeing or Strongly Agreeing</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>CSS1900 (n=1056)</td>
</tr>
<tr>
<td>Co-facilitation by a healthcare provider and a patient was relevant</td>
<td>93%</td>
</tr>
<tr>
<td>Patient’s shared experience and comments enriched the discussion</td>
<td>91.2%</td>
</tr>
<tr>
<td>Presence of a patient allowed a more concrete illustration of the concept of healthcare partnership</td>
<td>90.5%</td>
</tr>
<tr>
<td>After this course, I am now considering using the healthcare partnership approach in my future practice.</td>
<td>94.1%</td>
</tr>
<tr>
<td>Presence of a patient allowed me to better integrate the concept of healthcare partnership</td>
<td>N.A.</td>
</tr>
<tr>
<td>Patient’s participation prompted me to allow more importance to the case study patient’s (and family’s) point of view when prioritizing clinical interventions.</td>
<td>N.A.</td>
</tr>
<tr>
<td>Presence of a patient is a plus value to the workshop</td>
<td>N.A.</td>
</tr>
</tbody>
</table>

CSS = Collaboration en Sciences Santé; N.A. = Not assessed
expectations and solidified our orientation. Table 1 above summarizes students’ appreciation measured via online course assessment questionnaires that use a five-point Likert scale. Open-ended questions also revealed that many students consider patients-as-trainers’ contribution as a strong pedagogical component of these courses.

**Challenges and Strategies**

Challenges in such an adventure are numerous, and exist at the educational, logistical, and organizational levels.

At the educational level, introduction of the healthcare partnership model requires the development and adoption of a shared vision. This vision is continuously evolving. The collaboration between our academic IOC, the FBEPP, and the Collaborative Practice Committee from the university affiliated teaching hospitals network greatly contributed to the dissemination of a shared model of healthcare partnership. This has led to the publication of the first version of an implementation guide for healthcare partnership and services (7). Other educational challenges included development and updating of educational materials, such as learning guides, tutor and patient-as-trainer’s guides, online modules, and case studies, and formally training patients-as-trainers to ensure coherence of messages transmitted to students in the different workshop groups. A School of Expert Patients, offering a complete formal training curriculum for expert patients, will be created in the near future. A patient train-the-trainer program is currently being piloted with 16 patients.

Logistical issues and demands include: (1) Availability of sufficient classrooms, particularly since some patients have impaired mobility; and (2) Recruiting a sufficient number of patients-as-trainers and professors or healthcare providers as facilitators. The FBEPP is crucial in selecting each patient according to the following criteria:

- Patient has reached a phase of acceptance of his/her health problem;
- Patient is able to generalize his/her own experience to other contexts of care;
- Patient demonstrates high level of self-management for his/her care;
- Patient wants to be involved in training his/her peers, students, or healthcare providers;

- Patient possesses good interpersonal communication and interaction abilities; and

- Patient demonstrates reflective attitude by concrete actions.

At the moment, recruiting happens mainly by word of mouth, referral from clinicians, or contacts with the FBEPP. The FBEPP also intervenes to pair the right tutor with the right patient-as-trainer in order to maximize the co-facilitation dynamic, taking into account personalities and experience.

Organizational challenges include: (1) Yearly evaluation and adjustment of IPE courses and their content for continuous improvement; (2) Long-term financing of the involvement of patients-as-trainers in IPE courses; and (3) creating an expanded, sustainable program.

SECTION 2: LESSONS LEARNED AND STEPS FOR SUCCESSFUL INVOLVEMENT OF PATIENTS-AS-TRAINERS IN OUR IPE CURRICULUM

The past three years have been rich in experiences and lessons learned. We have identified the following six steps as keys to success.

Step 1: Creating organizational structures and financing

Creation of a FBEPP with a clear mandate, the existence of the IOC for the IPE curriculum, and the support of the Center for Applied Pedagogy in Health Sciences (CAPHS) allowed easy and efficient collaboration between the different persons and structures involved. In Canada, universities have mixed financing that comes from student fees and government subsidies. Since Collaboration en Sciences Santé (CSS) courses are mandatory and imbedded in the different professional curricula, a stable recurrent income to support development and coordination of these interfaculty courses is generated by student credits. Fees related to patients-as-trainers’ involvement in courses are covered by the IPE curriculum budget as well as a fee for FBEPP’s administrative services.
Step 2: A communion of values and agreeing on a conceptual framework

A solid foundation of common values and a model of partnership competencies were developed from a shared vision of collaborative practice and healthcare partnership (7). In this model, both patients and healthcare practitioners must develop the same set of partnership competencies in order for each to fulfill specific roles. This brings to the fore the need for a clear definition of the different roles for patient involvement within the FBEPP. These roles are patients-as-trainers in academic settings, patients-as-advisers in care settings, and patients-as-researchers in research projects and teams. An important element of our IPE curriculum is clarifying and re-evaluating the role of patients-as-trainers in our different educational activities to ensure that learning objectives are being met.

Step 3: Concerted development of the IPE curriculum

An integrated and collaborative structure that includes professors from all the participating programs and patient representatives from the FBEPP makes for a collective and coherent structure to guide planning and development of IPE content and pedagogical activities. Development and review of educational materials and content was also done collaboratively with members of a team working on collaborative practice improvement and continuing education at our university. Synergy also was created with the Committee on Collaborative Practice and Partnership of the Network of University Affiliated Teaching Hospitals and Clinics in order to share concepts and agree on terminology. This shared understanding was very useful for development of an avant-garde workshop for systematically involving patients in collaborative practice in continuous improvement processes. A physician of the CPASS and a patient-as-trainer of the FBEPP have thus far co-facilitated this workshop for 26 active clinical teams. The preliminary results of this deployment demonstrate the innovation capacity of patients and the efficiency of the co-building methodology for care improvement.

Step 4: Recruitment and training of IPE tutors and patients-as-trainers

Substantial efforts are put into recruiting and training tutors and patients who are passionate about health care and transforming practices. These efforts help ensure that messaging and learning during workshops are consistent with the IPE and collaborative practice visions. Most health professional tutors are recruited from
the Network of University Affiliated Teaching Hospital and Clinics, allowing transfer of knowledge and partnership competency back to the clinical teams and health organizations. Another key factor was a solid, efficient, and creative administrative team supporting the IOC.

**Step 5: Gradual introduction of patients-as-trainers**

Implementation of the IPE curriculum in the different programs and integration of patients-as-trainers in workshop groups was done gradually to avoid overwhelming pressure on the programs or on the educators involved and the FBEPP.

**Step 6: Continuing improvement**

Students evaluate the IPE courses they take on an annual basis and are asked how they perceive patients’ involvement in their academic training. Armed with this knowledge, we make adjustments to IPE courses each year. Currently, our main improvement objective is the development of longitudinal educational activities in the IPE courses, in order to increase the amount of time students from different professions spend together to learn together and from each other and from patients. This year we will pilot a new activity: a small group of volunteer students will participate in multiple meetings with a patient mentor. The pedagogical format of this activity will be inspired by the Patient Health Mentors program at Thomas Jefferson University (8) and University of British Columbia (9).

**SECTION 3: IMPACT OF PATIENTS-AS-TRAINERS ON STUDENT LEARNING: EDUCATION AND PRACTICE**

One of our chief findings is that students report feeling more confident to interact with other professionals after taking the IPE courses. Results from online student evaluations during the past academic year (2012–2013), revealed that second-year and third-year students’ confidence increased, both in terms of interprofessional interactions and their participation in an interprofessional meeting. A pre-post assessment of self-reported confidence levels on a 10-point numerical scale revealed a major improvement in proportions of students reaching a confidence level greater than 7 (Table 2).
Table 2: Before and after course completion percentage of 2nd year and 3rd year students with confidence levels 7 or greater on the 10-point scale.

<table>
<thead>
<tr>
<th>Year of study</th>
<th>Before course completion</th>
<th>After course completion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interacting with other professions in clinical placement</td>
<td>2nd year 34%</td>
<td>68.1%</td>
</tr>
<tr>
<td></td>
<td>3rd year 61.4%</td>
<td>91.1%</td>
</tr>
<tr>
<td>Participating in an interprofessional meeting</td>
<td>2nd year 28.9%</td>
<td>63.8%</td>
</tr>
<tr>
<td></td>
<td>3rd year 52.9%</td>
<td>88.1%</td>
</tr>
</tbody>
</table>

As discussed in Section 1 of this paper, students report a positive impact of patients-as-trainers on their learning and integration of healthcare partnership concepts, and a change in their vision. Indeed, more than 90% first year students agreed that, after this first IPE course, they were considering using the healthcare partnership approach in their future practice. We have not assessed yet if, when the students go into practice, they can and will implement this new model. Our next step is to implement a formal research project on the long-term impact of our IPE curriculum.

**CONCLUSION: LESSONS LEARNED**

Through the implementation of this IPE program and its enrichment with patients’ vision and participation as co-educators, we learned that co-building, co-training, and co-leading with patient representatives at each step of the process is not only possible, but also essential. Patient leaders must take the lead in acting as role models for other patients who will be involved in a patient-as-trainer role, and careful selection of patients and structured training to become patients-as-trainers are necessary ingredients to success. Careful selection of health professional tutors with experience with collaborative practice and the availability of a detailed facilitator guide also are important. Undoubtedly, administrative and organizational supports are essential constituents. Last but not least, creating synergy and links with the practice settings is fundamental to ensure relevance of course content and workshops, ultimately ensuring that students receive the best preparation for practice in clinical settings.
ACKNOWLEDGMENTS

For the period covered in this article, the Interfaculty Operational Committee (IOC) for Collaborative Practice Teaching at Université de Montréal included, in alphabetical order: Catherine Bélanger, Chantal Besner, Isabelle Brault, Louise Boulanger, Eric Drouin, Vincent Dumez, Raynald Gareau, Fanny Guérin, Paule Lebel, Diane Lefebvre, Marie-Josée Levert, Sue-Ann MacDonald, Julie Ménard, Audrey-Maude Mercier, Josée Montreuil, André Néron, France Nolin, Annie Pullen-Sanfaçon, Louise St-Denis, Pierre-Yves Therriault, and Marie-Claude Vanier. We wish to acknowledge the tremendous support of the implementation of IPE CSS courses provided by the Deans Hélène Boisjoly (Medicine), Gérard Boismenu (Arts and Sciences), Francine Girard (Nursing), and Pierre Moreau (Pharmacy), and also the former Dean of Medicine Jean Rouleau, the Vice-Dean for professional development Andrée Boucher (Medicine), and the Vice-Rector Education Raymond Lalande. We also are grateful for the skillful techno-pedagogical support of Richard Ratelle and Jean-Pierre Messier (Medicine) and their team, and the information management support of Monique Clar (Librarian).

REFERENCES


“Pervasive, sustainable culture change is difficult. Managing that change and the stress it can create for healthcare providers has been—and remains—critical to the ongoing success of the PFCC initiative.”

The Story of Brad Berk, CEO and Patient from University of Rochester Medical Center

In May 2009, lifelong cyclist Bradford Berk, MD, PhD, the CEO of the University of Rochester Medical Center (URMC), had a catastrophic accident while finishing a long bike ride near his cottage on Canandaigua Lake in upstate New York. Over the long rehabilitation that followed, as he started to come to terms with his paralysis and newfound dependency on others, Dr. Berk had a good deal of time to experience and to think. Early on, a nurse in the intensive care unit offered to wash his hair. Still on a ventilator at the time, Dr. Berk’s only sensation was in his head. “That washing was the most pleasurable thing I’d experienced in ten days,” he said. “That simple act was enormously restorative to my spirit.”

When Dr. Berk returned to lead the medical center nine months after his accident, colleagues commented on his thoughtful presence and clear pleasure in connecting with staff, patients, and community members and visitors to the URMC campus. And in the years following, URMC officially launched its Patient-and Family-Centered Care (PFCC) initiative. Pervasive, sustainable culture change is difficult. Managing that change and the stress it can create for healthcare providers has been—and remains—critical to the ongoing success of the PFCC initiative. Too, faculty providers at URMC are trying to understand how new technologies and opportunities such as the electronic medical record can be most effectively and creatively harnessed to the institution’s broad initiatives and ideals around patient- and family-driven and -centered care. In these efforts, Dr. Berk’s leadership and personal commitment to do better have offered URMC providers and the wider community with a strong platform from which to work.
The University of Rochester Medical Center (URMC) is a uniquely integrated education and healthcare delivery system—comprising a major teaching hospital (Strong Memorial Hospital), two community affiliates (Highland and F.F. Thompson Hospitals), Eastman Institute for Oral Health, the School of Medicine and Dentistry, and the School of Nursing. The mission of the URMC is to be a home of healing, learning, research, and innovation, committed to improving health and quality of life for our patients, families, and community. Over the last five years, important changes on the local and national healthcare and policy fronts, as well as personal influences on senior leadership, have compelled us to bring the full power of our organizational structure to tightly align URMC’s clinical education and research missions with our health delivery system.

In the process, we’ve both anticipated and striven for the objectives of the Triple Aim (1), including reducing costs while adding value, reframing quality through integrated practice, and creating shared responsibility for population health and education, with an end goal of person- and community-centered health improvement. Paramount to this evolution have been activities and lessons learned in the development, implementation, and sustainability planning of our Patient and Family Centered Care (PFCC) Initiative, initially developed in 2010 and implemented in 2011.
Prior to this initiative, URMC had considerable success in improving quality and safety through hospital-based interventions focusing on large-scale clinical issues, such as central line-associated blood stream infections (CLABSI) and ventilator-associated pneumonia (VAP). However, URMC had less success in domains such as patient satisfaction, which have become important in Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) measures.

Through surveys, our patients identified several general areas for improvement, including slow response times and/or not enough time with physician; absent or abrupt management of emotional needs; lack of information or inclusion in medical decision-making; and poor coordination or communication among medical staff handling their care. Categories also mentioned were response to concerns/complaints; failure to address emotional needs, to include patient in decisions regarding treatment, or to keep patient informed about treatments and care; staff not working together; and amount of time spent with physician. Communication, compassion, and attentiveness (noted as “poor”) were all identified as sources of concern or complaint. Therefore, URMC senior leadership, working with its existing patient relations team, initiated an educational intervention to address these processes. Strong emphasis was placed on improving interprofessional working relationships and behaviors that were inappropriate or lacking.

The findings above were particularly concerning given that URMC has long enjoyed particular strength in delivering and training health providers in humanistic, patient-centered care; for example, the Biopsychosocial Model of care and Unification Model in nursing were both developed here (2). However, we also are deeply aware of the larger culture of US healthcare delivery and reimbursement, which favors treating the disease first and tends to patients and families only second. Too often in this system, families and even patients themselves are viewed as obstacles rather than partners in optimal health and health care. We feared that, despite our distinctive history, some of the principles and ideals that had fueled our early educational innovations might not translate (or translate fully) into our clinical environments and collaborative arrangements.
BACKGROUND/CASE CONTEXT

These concerns moved front and center for us when, in May 2009, our Chief Executive Officer, Dr. Bradford Berk, suffered a C3-C5 cervical fracture from a bicycle accident. Over the course of his recovery as a patient, and now from his perspective as a person living with a physical disability (tetraplegic) and chronic disease, Dr. Berk was personally compelled to address these problems. Specifically, he focused on approaches to facilitate communication, attentiveness, and compassion within our system. To assure these as tangible behaviors as opposed to vague principles, Dr. Berk urged us to focus on “what’s important,” including the following behaviors:

1. Treating patients and families with dignity and respect;

2. Expressing emotions such as compassion and caring;

3. Valuing the patient and family as an integral part of the healthcare team; and

4. Demonstrating attentiveness by taking the time to listen to our patients and their families.

To disseminate these both in concept and concrete action throughout the organization, URMC developed its own version of patient- and family-centered care.

INTERVENTION: URMC PATIENT- AND FAMILY-CENTERED CARE INITIATIVE (PFCC)

Initiation and Consultation

To assist in hardwiring this important hospital-wide initiative, Beverley Johnson, president of the Institute for Patient- and Family-Centered Care, visited URMC for three days in May of 2010, providing consultation and technical assistance regarding patient- and family-centered care. As a result of her recommendations, an enterprise-wide team worked together to define the institution’s “personal” approach to PFCC. Specifically, we developed a set of PFCC core concepts that Dr. Berk personally discussed, and a set of values and behaviors for which individuals were held accountable, collectively termed “ICARE.” We also were able to use
this framework to begin discussions with our patient and family advocacy groups to facilitate their input and guidance.

Goals and Principles for URMC PFCC

Formally implemented in February 2011, the URMC PFCC is a broad, interprofessional educational and clinical initiative to 1) educate physicians, advanced practice providers, and other healthcare team members, as well as our patients and families, in the behaviors and collaborative practices associated with patient- and family-centered care; 2) review and revise operations to support that fundamental philosophy and to involve patients and family members as the central members of the care team; and, 3) assure the active identification and implementation of related practices. Unlike traditional service excellence focused on providing care for the patient, PFCC focuses on providing and implementing a care plan with the patient and his or her family.

Several clearly defined principles (with input from URMC leadership, faculty, staff, and patients/families) guided the URMC PFCC Initiative:

- ask patients to define their “family,” so that we may initiate a partnership in care.

- educate, support, and encourage patients and families to be involved in all aspects of their health and health care throughout the continuum, communicating openly and sharing all pertinent information throughout.

- seek and are sensitive to patients’/families’ diverse perspectives, preferences, and priorities, including as those evolve over the course of illness and of care.

- strive to treat our patients and families with compassion, dignity, and respect.

The goal for an interprofessional URMC PFCC is to be both a local healthcare delivery system informed by patient and community insights and experience and an academic medical center that improves the well-being of patients and communities by delivering innovative, compassionate, patient- and family-centered health care that is enriched by education, science, and technology. Another main goal is to use educational approaches to further reduce the silos that exist between microsystems
within our larger healthcare macrosystem. These are lofty goals in that, ultimately, their realization hinges on transforming individual behavior, teams, systems, and culture. To that end, we identified the need for a multi-approach educational effort, including both a bolus of instruction and distributed support for sustainability.

**Dr. Berk’s Guiding Concepts**

Dr. Berk spoke candidly to all health providers in the medical center about his own experience as well as the critical importance of compassion and provider attentiveness in dealing with patients’ concerns and emotions. Compassion is the concept that “we need to show we care,” while attentiveness is the concept that “we need to pay attention to show we care.” Dr. Berk’s personal interpretation of PFCC focused on four components: safety, quality, caring, and courage.

**Safety** is the foundation for all elements of PFCC. Patients must feel safe to trust their providers. Once a trusting relationship has been established between patient and provider(s), and between family and the healthcare delivery team, communication may dramatically improve and long-term adherence to treatment is much more likely.

**Quality** is essential for further generating trust because patients choose specific institutions and providers on the basis of their perception of high quality. Increasingly, through federal and state reporting, quality assessments will be quantitative and measures will be readily available to consumers.

**Caring** has two sides. The obvious side of caring is the compassion and the attentiveness that we show for our patients and their families. Equally important is the caring that we provide to each other at all levels of staff and across all departments and in both ambulatory and inpatient environments. Our employees need to feel cared for to provide patient/family-centered care. The staff needs to be treated with respect, supported, empowered, and recognized.

**Courage** reflects the ability of our providers to work with patients in difficult situations. Unfortunately, not all health care has a positive outcome. Patients are naturally concerned about their prognosis and worried about the consequences of interventions (whether surgical or medical). Courage is the ability of our providers to meet the challenges posed by patients as they encounter difficulties in the course of their illness. We do not expect our providers to have the answers, but we do
want them to address the concern and to not avoid the interaction because it will be difficult. The best providers are able to convey sympathy and empathy while still maintaining their professional authority and demeanor.

ICARE Values and Behaviors

As a result of outside recommendations and guiding principles from Dr. Berk, an enterprise-wide team consisting of leadership, staff, trainees, and patients worked together to further define the institution’s core values and behaviors as they relate to patient- and family-centered care. An extensive, two-year effort to define expected behaviors for all levels and specific functions involves hundreds of employees representing all job families and is currently being implemented through multiple human resource efforts. These core values and behaviors—collectively referred to as ICARE—include:

- **Integrity** — I will conduct myself in a fair, trustworthy manner and uphold professional and ethical standards. (Behaviors: *Introduce yourself. Be mindful of your actions.*)

- **Compassion** — I will act with empathy, understanding, and attentiveness toward all others. (Behaviors: *Communicate with warmth. Respond to feelings.*)

- **Accountability** — I will take responsibility for my actions and join with my colleagues to deliver “Medicine of the Highest Order.” (Behaviors: *Answer questions clearly. Involve and update.*)

- **Respect** — I will always treat patients, families, and colleagues with dignity and sensitivity, valuing their diversity. (Behaviors: *Courteous and friendly. Speak positively.*)

- **Excellence** — I will lead by example, rising above the ordinary through my personal efforts and those of my team. (Behaviors: *Take initiative to help. Recognize your colleagues.*)

A planned roll out for these new global behaviors, (aligned with the ICARE values) included town hall meetings for all staff, a new intranet site with relevant resources for staff and managers, and tool kits for managers to support staff members’ re-commitment to the revised and enhanced ICARE commitment, to be signed
annually by all employees including physicians. In addition, performance evaluations have been restructured to measure and provide feedback on ICARE-specific behaviors for all medical center employees.

**PFCC Implementation Process**

The first priority was to revise URMC’s mission and vision statements to include always placing the patient and family first. Through people, operations management, and process improvements, the goals of this PFCC initiative are to improve overall patient and family experience. Ongoing measurement, accountability at all levels, and recognition of positive performance are critical foundational components of the new model.

Four areas of focus were identified to advance culture change (outlined below). In addition to educating, supporting, and recognizing people (caregivers, patients, and families), we needed to address issues related to facility and information technology improvements. We also purposefully implemented electronic health records (EHRs) simultaneously with PFCC in spring 2011 to improve communication among providers and encourage attentiveness and compassion.

**People:** We train all medical staff and employees to be respectful and offer compassion. Fundamental to this is the fact that how well we communicate determines how effectively we convey compassion and attentiveness. We convey compassion and attentiveness to our patients by communicating about things that matter to them. Finally, our collaborative care teams must understand the healing power of touch.

**Facilities:** PFCC requires a comfortable supportive environment, including private rooms with family sleeping spaces and an atmosphere that promotes healing.

**Information Technology:** The EHR, eRecord, must promote PFCC in the process and output of data collection and the patient record. If done correctly, eRecord can provide more immediate and thorough understanding of the patient’s and their family’s circumstances as well as improve communication among providers. The EHR can also identify high-risk patients to ensure a comprehensive care plan and enhanced communication.
Delivery of Care: PFCC must encourage patient/family involvement by promoting practices to improve patient/family and provider communication (i.e., at rounding and shift change at the bedside). This can serve in two ways: first, by increasing communication and breaking down silos among multidisciplinary care teams; and second, by developing skills among our specialized Hospitalists to promote both efficient and compassionate care.

Interprofessional Educational Activities

The PFCC Clinician Training Team was formed through a collaboration of the Strong Hospital Education Committee and URMC’s Office of the Patient Experience. This committee of care providers developed several educational activities, including online learning modules, live learning sessions, an individualized coaching program, and formal presentations to clinical departments and academic units. Most of the curriculum was created based on patient/provider communication and included original videos and tutorials incorporating our medical center systems, processes, and environments. We also included case-based learning and developed standardized patient cases for practicing physicians and advanced providers.

The coaching program, spearheaded by Dr. Susan McDaniel, director of the URMC Institute for the Family, addressed and measured physician behaviors utilizing the Calgary-Cambridge Patient-Centered Observation Coding System combined with items focused on physician/family connection (3, 4) that supported or undermined patient-centered care. Finally, through unanimous support from department chairs, Grand Round presentations were conducted for all clinical departments, academic units, and service lines, as well as annual PFCC sessions for all residents and advanced practice providers. A profile of all activities is attached (Appendix A).

Patient Care Process Changes

A PFCC Leadership Team, consisting of URMC Strong Memorial Hospital leadership, key chairs and faculty members, and relevant department heads, was created to address patient care process changes. This committee utilized LEAN process improvement strategies to reinforce the creation of value in both quality and cost as we integrated PFCC into our existing culture (5). The aim was to eliminate waste in our system without diminishing the patient experience. This framework allowed us to target removal of extra steps in patient flow, simplify operational processes, and eradicate unnecessary paperwork. At the heart of the process improvement
was the implementation of monthly audits (still ongoing) of clinical operations to understand how best to include families in patients’ care experience or episode of care experience. Results of these audits revealed the need to revisit policies such as visitation (based on their input, patients are now asked to identify one or two support persons who have 24-hour visitation), rounding at the bedside, and family participation in the care process.

Senior leadership also created several Patient and Family Advisory Councils (PFACs) to provide guidance and specific recommendations for operational and communication changes. The PFACs consist of patients, family members, and community members and represent different areas: children’s hospital, cancer center, behavioral health, and a general Strong Memorial Hospital PFAC. These councils proved instrumental, not only in identifying areas of needed improvement, but also in creating a conduit for increased community involvement that was tangible, could be maintained, and fostered enhanced engagement with community stakeholders.

In addition, URMC restructured its patient relations office, as a response to feedback in functionality, to the Patient and Family Relations Office. This reframed the organizational office as one that is proactive, compassionate, and engagement-focused, as evidenced in the patient/family relations representatives. These representatives are able to do real-time service recovery by being called to the units for assistance and intervention. Through their involvement we have been able to further identify specific training needs and process improvement opportunities.

**Outcomes/Current Status of Program**

Within the first year, it became apparent through observations of disruptive physician behavior that we needed to broaden our initiative to include relationships among members of the healthcare team rather than focus solely on providers’ relationships with patients and families. A URMC-wide assessment of the consistency of providers demonstrating ICARE expected behaviors—both with patients/families and with colleagues—showed a significantly lower score for the perception of positive colleague-to-colleague interaction versus behaviors towards patients and families (56% of the 7,400 participants believed we were very consistent in demonstrating ICARE with patients and families, while only 38% scored the consistency of these behaviors high with colleagues). This incongruence and perception of incivility within some healthcare teams became alarming and undermined the work that was being conducted.
To address this gap, steps were taken to further refine and align the PFCC educational strategies with the organizational ICARE values as well as strengthen communication opportunities for team members to voice concerns. Over the past year, several departmental interprofessional ICARE Guiding Coalitions, with broad representation from both staff and faculty, have been created to focus on improving interprofessional relationships and breaking down existing silos. From a student perspective, mechanisms are in place for anonymous feedback and reporting of physicians/providers whose behavior is perceived as not being at the expected level. These mechanisms include our hospital-based reporting system, called Quantas, and through the individual schools. For our practicing care team members, addressing disruptive behavior required not only a reporting system (Quantas), but also training and process support models led by our clinical unit leaders. Additionally, our coaching program has been targeted to identify providers, and we are working to reinforce the ICARE values in all human resource processes.

Through the monthly audits, the PFCC leadership team did, however, identify areas of excellence for both patient- and family-centered care and in collaborative care models that were nurtured and reinforced by the PFCC initiative. Areas of excellence have included our Palliative Care Service, Golisano Children’s Hospital, multidisciplinary care teams in our Wilmot Cancer Center, and strong leadership in PFCC by several of our ambulatory settings within our Primary Care Network and our Highland Family Medicine Center. These incremental areas of success are encouraging, but our focus now is on how to make this excellence universal in all coordinated and integrated care areas.

To measure our patient satisfaction, URMC uses Press Ganey, Inc., as its vendor for the collection and dissemination of patient satisfaction data. Quarterly reports are used to identify opportunities for improvement in both patient and family experiences. Strong Memorial Hospital monitors its HCAHPS data and utilizes the UHC AAMC Peer group as its comparative benchmark. Over the past several years, a number of hospital-wide and nursing initiatives have been implemented to improve the patient and family experience, resulting in significant gains in patient satisfaction. Strong Memorial Hospital has exceeded the national average in all but two of the HCAHP domains (environment and pain) in which we have interdisciplinary and interprofessional teams working on improvements. Of note, our inpatient overall mean satisfaction score of 86.5 placed the hospital in the 66th percentile overall, and
our nurses in the 87th percentile as benchmarked against UHC Alliance of Academic Medical Centers.

Strong Hospital also has initiated the Unit-based Performance Program (UPP) to further link quality and safety initiatives to the patient and family experience and measurement. The UPP is adapted from the safety-based program model Comprehensive Unit-based Safety Program (CUSP) (6)—an interprofessional framework focusing on safety—that expands the focus to incorporate quality, experience, and efficiency (no longer viewing these as individual projects, and recognizing their interdependency). Designed to create a culture of continuous improvement on the units, this intervention involves contributions from the front-line staff as well as leadership from all disciplines. The culture promotes a highly reliable, ultra-safe, patient- and family-centered care system where accountability is derived through scorecards and dashboards.

Finally, and most importantly, the infrastructure established and ongoing work with our patient advisory committees will assure the continued input and feedback from patients and their families, and will inform our current and future directions. We provide monthly feedback to these groups on our efforts and solicit their input and analysis of our impact. This is a direct connection to the most important stakeholders of our PFCC initiative.

**Program and Institutional Consequences**

We are just beginning to fully realize the programmatic and institutional effects of our broad implementation of PFCC and ICARE values. Notably, education for this initiative has become a pillar in our hiring process and onboarding for all providers and staff. The PFCC has become a curricular thread in other interprofessional programs, such as Patient Safety Grand Rounds, handoff education, and the UPP, mentioned earlier. The goal is to integrate safety practices, patient- and family-centered care, and LEAN strategies into daily work. We also have successfully translated our educational programs, processes, and systems to our community affiliates, including Highland Hospital and our Primary Care Network. As URMC continues to expand our affiliate network to other hospitals, PFCC serves as an educational framework that accelerates alignment of values and culture. A case example of this is our recent partnership with F.F. Thompson Hospital in Canandaigua, New York, and the launch of Thompson Way, a parallel educational initiative focused on patient- and family-centered collaborative care.
We also have seen curricular changes in our medical and nursing schools embracing the need for interprofessional education (IPE) as a mechanism for preparation to work in a collaborative care environment. These include joint educational initiatives focused on quality and safety, on TeamSTEPPS (a team-training program developed and disseminated through a partnership of the Agency for Healthcare Research and Quality and the Department of Defense), and on joint assessment of communication and teamwork through OSCEs. Meanwhile, the concurrence of the PFCC initiative within the hospital system has both complemented and intensified the need for more IPE programming.

We also have expanded and enriched our community engagement through several community-based boards focused on various aspects of wellness. The first is our Community Advisory Committee, which has specific outreach to the faith community, Latino community, and deaf community in Western New York. The second is the Rochester Health Innovative Medicine that connects URMC and the PFCC initiative to community providers and alumni of our education programs (UME, GME, and Nursing). Lastly, the Rochester Health Impact Committee connects our institution with community stakeholders focused on political activism and reform. These committees have also further strengthened collaborative relationships among senior leadership across our multiple missions.

Summary and Key Lessons Learned

Moving forward we anticipate leveraging the lessons learned from PFCC to inform other interprofessional educational programs and collaborative care initiatives across the medical center. We fully realize that to shift healthcare services to collaborative care models requires new framing (7), interventions along the continuum of learning, and most importantly a strong voice and input from the community that we serve.

We feel we are accomplishing these tasks through several of our more recent programs. While TeamSTEPPS has long been taught in our institution, we have recently made efforts to expand that educational initiative with Triple Aim objectives in mind. First, we have extended the curriculum beyond current providers at Strong Memorial Hospital into our medical and nursing school programs and through interprofessional team training within service lines. We also have implemented a simulation-based TeamSTEPPS renewal course to incorporate applied learning through IPE efforts on quality of care.
ICARE, the interdisciplinary staff initiative, has formalized positive inquiry to impact our culture and behaviors. We have recognized that it is just as critical to focus on a collaborative “culture of respect” among staff members as it is to focus on behaviors with patients and families. Our first success in this center-wide initiative is the implementation of the ICARE management system, which has placed an emphasis on strategic recognition of positive behaviors. Senior leadership also has recognized the need for increased investment in professional development by financially supporting the acquisition of a Talent Management System that will further recognize and reward staff based on PFCC and ICARE behaviors and performance outcomes.

We see several emerging challenges to patient- and family-centered care that will need to be addressed in the near future, including the following:

- The health literacy of our community will be a primary and ongoing concern that the medical center will need to address and support through the Center for Community Health. We hope and expect the educational infrastructure created through PFCC will allow us to develop and disseminate community-based health literacy and education.

- The EHR system is changing how providers communicate with patients and families, and with each other. URMC is in the process of identifying best practices in EHR utilization and patient engagement, with plans to develop curricula for the continuum of learners in our system toward keeping humanism at the forefront of care delivery and collaborative practice, and aligning humanism and emerging technologies.

“I’ve learned that people will forget what you said, people will forget what you did, but people will never forget how you made them feel.” – Maya Angelou

This statement serves as a touchstone as we move forward. We have traveled some distance over the past five years, but the future will depend on our success in sustaining and continuing to expand our patient- and family-centered care efforts. We strive to support our healthcare teams toward the most complete recognition of patients and their families at the nexus of care and care decisions, understanding that how we communicate with one another and with our patients will promote wellness and produce the best experience of health care.
REFERENCES


## Appendix A: URMC PFCC Educational Activities

<table>
<thead>
<tr>
<th>2011 Education</th>
<th>Audience</th>
<th># of Sessions</th>
<th>Total Attendance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Town Hall PFCC - Kick-Off</td>
<td>Open to all Faculty and Staff</td>
<td>8</td>
<td>2,000</td>
</tr>
<tr>
<td>Departmental Meetings</td>
<td>Department Faculty and Staff</td>
<td>28</td>
<td>1,120</td>
</tr>
<tr>
<td>Departmental Grand Rounds</td>
<td>Departmental Faculty</td>
<td>6</td>
<td>220</td>
</tr>
<tr>
<td>Patient/Family-Led Hospital-Wide Grand Rounds</td>
<td>Open to all Faculty and Staff</td>
<td>1</td>
<td>250</td>
</tr>
<tr>
<td>PFCC Mandatory Trainings</td>
<td>Residents and APP’s</td>
<td>5</td>
<td>800</td>
</tr>
<tr>
<td>PFCC Leader Orientation</td>
<td>Physician Leaders</td>
<td>1</td>
<td>30</td>
</tr>
<tr>
<td>Individual Coaching Sessions</td>
<td>Attending Physicians</td>
<td>12</td>
<td>6</td>
</tr>
<tr>
<td>Department Heads Workshop</td>
<td>SMH Leaders</td>
<td>1</td>
<td>200</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>2012 Education</th>
<th>Audience</th>
<th># of Sessions</th>
<th>Total Attendance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Departmental Meetings</td>
<td>Department Faculty and Staff</td>
<td>32</td>
<td>1,200</td>
</tr>
<tr>
<td>Departmental Grand Rounds</td>
<td>Departmental Faculty</td>
<td>10</td>
<td>450</td>
</tr>
<tr>
<td>PFCC Leader Training Sessions</td>
<td>Departmental PFCC Physician and APP Leaders</td>
<td>12</td>
<td>30</td>
</tr>
<tr>
<td>PFCC Mandatory Trainings</td>
<td>Residents and APP’s</td>
<td>5</td>
<td>800</td>
</tr>
<tr>
<td>Nursing PFCC Champion Orientation Training</td>
<td>Unit Nursing PFCC Champions</td>
<td>1</td>
<td>75</td>
</tr>
<tr>
<td>Individual Coaching Sessions</td>
<td>Identified Faculty</td>
<td>50</td>
<td>35</td>
</tr>
<tr>
<td>PFCC modules with Standardized Patients</td>
<td>Identified Faculty</td>
<td>52</td>
<td>22</td>
</tr>
<tr>
<td>Department Heads Workshop</td>
<td>SMH Leaders</td>
<td>1</td>
<td>200</td>
</tr>
<tr>
<td>ICARE Behavioral Development Session</td>
<td>Identified High Performers from each role</td>
<td>12</td>
<td>360</td>
</tr>
<tr>
<td>2013 Education</td>
<td>Audience</td>
<td># of Sessions</td>
<td>Total Attendance</td>
</tr>
<tr>
<td>-------------------------------</td>
<td>-----------------------------------------------</td>
<td>---------------</td>
<td>------------------</td>
</tr>
<tr>
<td>ICARE Leadership Training</td>
<td>URMC Leaders</td>
<td>15</td>
<td>1,200</td>
</tr>
<tr>
<td>ICARE Training for All</td>
<td>All Employees</td>
<td>80</td>
<td>11,000</td>
</tr>
<tr>
<td>Employees</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient Family-Led Grand</td>
<td>Open to all Faculty and Staff</td>
<td>1</td>
<td>250</td>
</tr>
<tr>
<td>Rounds</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PFCC Mandatory Trainings</td>
<td>Residents and APP's</td>
<td>5</td>
<td>800</td>
</tr>
<tr>
<td>Individual Coaching Sessions</td>
<td>Identified Faculty</td>
<td>72</td>
<td>47</td>
</tr>
<tr>
<td>PFCC Modules with</td>
<td>Identified Faculty</td>
<td>40</td>
<td>26</td>
</tr>
<tr>
<td>Standardized Patients</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Department Heads</td>
<td>SMH Leaders</td>
<td>1</td>
<td>200</td>
</tr>
<tr>
<td>Workshop</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>TOTAL EDUCATIONAL ACTIVITIES</td>
<td></td>
<td>214</td>
<td>13,523</td>
</tr>
</tbody>
</table>
A Patient Story from Veterans Health Administration (VHA)

Katrina is a 30-year-old combat veteran who was injured by a bomb blast in Iraq in 2008. After several surgeries at an army base in Germany, Katrina was transferred to Walter Reed Army Medical Hospital, where she underwent nearly a year of treatment and rehabilitation for physical injuries, mild cognitive impairment, and post-traumatic stress. Prior to leaving the military, Katrina began working with a VA liaison connected to the military facility where she was recuperating. She had been on an opioid pain medication since her injuries and was in the process of being tapered off opioids at the time of her discharge.

In preparation for discharge, the VA liaison contacted the Post Deployment/OOO program manager (PM) in the VA facility nearest to Katrina’s rural home, where she lived with her parents and young daughter. The PM phoned Katrina and performed a complete psychosocial assessment, and began discussing housing, financial, and vocational/educational needs that she would face upon her return home. The PM began to educate Katrina about some of the resources that would be most useful to her going forward. In addition both the VA liaison and the PM engaged Katrina’s parents as members of the care planning team. A case management schedule appropriate to her clinical needs was set up for Katrina; this would be primarily telephone-based care coordination.

The PM arranged for Katrina to see her care team, her polytrauma team, and a PTSD counselor during linked appointments at the Medical Center. They also arranged for Katrina to receive her care at a community-based outpatient clinic nearer her home, where she also could receive ongoing care coordination and case management via telehealth. The telehealth modalities, for pain management and PTSD counseling, worked very well for Katrina. She also began taking courses through her local community college to become a healthcare technician. Her success using the telehealth modalities led Katrina and her family to participate in a training on the Veterans’ Health University video platform (VeHU) to help in the education of interprofessional teams providing post-deployment care in VA. The training, “Putting Together a Deployment Health and Pain Care Team for Veterans in Rural Areas,” was recorded and viewed by care teams across the VA.
The mission of the Department of Veterans Affairs (VA)—framed in the words of Abraham Lincoln and chiseled into the granite face of the organization’s central office in Washington, DC—is “To care for him who has borne the battle, and for his wife and his orphan.” Even missions chiseled in stone, such as the one above, must at times be revised to align with social and cultural changes and the evolution of our institutions. Given that approximately 12% of our service personnel deployed to the recent conflicts in Iraq and Afghanistan have been women—many of whom have been exposed to the full range of combat-related risk—the functional mission of VA has become and will remain “To care for those who have borne the battle, and for their loved ones.” In times of war, we are reminded on a daily basis of the importance of this pledge.

With increasing focus on patient-centered care in the broader healthcare landscape, the unique mission of VA is expressed in the statement: the difference between VA health care and general health care is the Veteran. The VA commitment is to engage our primary stakeholders not simply as “patients” but also as “veterans.” The acknowledgement of, and expressed appreciation for, the veterans’ service and sacrifice (and that of their families) is the first step in VA care; “hearing the veteran’s
“story” and tailoring health care to address the veteran’s personal healthcare needs, particularly as related to his or her military service and deployment, is the foundation of the care covenant.

This case study will examine VA efforts during the recent conflicts in Iraq and Afghanistan to engage veterans and their families in the process of care delivery, program development, and program improvements, with an eye toward the use of interprofessional education to create a collaborative spirit and structure of care.

THE SYSTEM CHALLENGE

To engage veterans of the Iraq and Afghanistan conflicts and their families in the process of providing timely, effective, and comprehensive support following combat deployment.

Veteran Engagement Challenges

1. Veterans are transitioning between two large, complex agencies (Department of Defense [DoD] and VA) that have differing missions, unique healthcare objectives, and agency-specific processes of care delivery.

2. Veterans commonly present with complex, co-occurring medical, mental health, and psychosocial impairments with relatively recent and semi-acute onset.

3. Individual veterans may hold deeply ingrained biases about mental health diagnosis/treatment that may be obstacles to seeking care, especially when such treatment might negatively impact military or future non-military careers.

4. The veteran population is distributed across the nation, including a third of which reside in rural and highly rural areas.

5. There are sub-cohorts of veterans, such as women veterans, with needs that are, in some instances, unique from those of other veterans.
VA HEALTH CARE SYSTEM

There are currently over 22 million living veterans in the US; over 8.9 million are enrolled in the Veterans Health Administration (VHA) system. The VHA is the largest integrated healthcare system in the US, with a network of 151 medical centers, 985 outpatient clinics (including 820 community-based outpatient clinics [CBOCs] and 151 hospital-based clinics), 8 mobile clinics, 300 Vet Centers, 70 mobile Vet Centers, 103 domiciliary residential rehabilitation programs, and 135 community living centers. These facilities are distributed among 21 Veterans Integrated Service Networks (VISNs), each of which includes 6–8 medical centers (1).

RECENT CONFLICTS AND HEALTH CONCERNS OF RETURNING COMBAT VETERANS

Between October 1, 2001, and September 30, 2013, approximately 2.26 million US military service members had been deployed to the Iraq/Afghanistan conflicts, which have been designated as the OOO conflicts, including: Operation Enduring Freedom (OEF; Afghanistan), Operation Iraqi Freedom (OIF), and Operation New Dawn (OND; Iraq following withdrawal of allied forces) (2).

The health concerns seen in the individuals returning from the Iraq and Afghanistan conflicts include a range of physical, mental health, and psychosocial conditions. As of September 2013, approximately 1.72 million combat veterans have left active duty military service and are eligible for VA health care; over 998,000 of these individuals have used VA services. Among those individuals, 59% reported musculoskeletal injuries; 55% were diagnosed with mental health conditions; 54% were found to have non-specific signs, symptoms, and ill-defined conditions; 47% were diagnosed with neurological conditions (including hearing loss/tinnitus; the most common singular military service-related health concern); and 37% with gastrointestinal conditions (including dental concerns).
UNIQUE CHALLENGES IN ENGAGING COMBAT VETERANS AND FAMILIES

Understanding the unique aspects of the mission, culture, and values of the DoD compared with those of VA helps us better understand the unique challenges faced by returning combat veterans, their families, and the healthcare teams supporting them (3). During deployment and while on active duty, service members’ health concerns are experienced through the lens of fitness for duty, future military career, loyalty to unit members, and commitment to mission.

Upon leaving active duty, the mission shifts to personal and family health and future well-being. Following separation from active duty, there may still be hesitancy on the part of veterans to acknowledge and address certain health concerns. While this may be particularly true for mental health issues, any health concern or impairment for a veteran may carry weight and unique meaning that differs from that of other patients in other settings. For this reason, the foundation for engagement with veterans and family members is related to their military service. Expressing appreciation for service and acknowledging the sacrifices involved in that service are the cornerstones for engagement.

Our case study will now examine these post-deployment health concerns and clinical challenges in the context of engagement strategies employed by a group of key VHA programs that have focused on the care of combat veterans returning from Iraq and Afghanistan over the past decade. In each of these programs, specific emphasis was placed on engaging veterans and their families in program development and program quality improvement. This is a representative—although not comprehensive—list of such programs.

VHA PROGRAM ENGAGEMENT STRATEGIES FOR RETURNING COMBAT VETERANS AND THEIR FAMILIES

VA Liaisons for Healthcare

It was evident early on in the course of the OOO conflicts that seamless care transition as service members left active duty under the DoD and shifted to VA care would be the lynchpin of effective post-deployment care. To support the transition process, the first VA Liaison for Healthcare was placed at Walter Reed Army Medical
Center in August 2003 to assist in transferring the most severely injured service members from Walter Reed and National Naval Medical Center in Maryland to VA polytrauma centers and medical centers nationwide. Ultimately 43 VA Liaisons for Healthcare were stationed at 21 military treatment facilities (MTFs) to transition ill and/or injured service members from DoD to the VA system of care closest to their home or most appropriate for their medical condition.

**Liaisons for Healthcare Engagement Strategy:**
VA Liaisons co-located with DoD case managers at MTFs.

VA Liaisons meet directly with service members, families, and caregivers to educate them about VA healthcare benefits and services and the VA eligibility process. The goal is for the service member to leave the MTF registered for VA healthcare and with a scheduled VA appointment. This process also facilitates additional communication, resources, or transfers back to the MTF when needed. Since the program’s inception through December 2013, VA Liaisons have transitioned 50,068 service members and veterans into VA healthcare.

**OEF/OIF/OND CARE MANAGEMENT PROGRAM**

**OEF/OIF/OND Care Management Program Engagement Strategy 1:** Care management teams contact every returning combat veteran/family member prior to or at the time of enrollment to support transition into VA, triage, screening for care management needs, and ongoing care coordination.

Each VA Medical Center has an OOO care management team to coordinate patient care services. These clinical case managers screen all OOO veterans for the need for medical, mental health, and case management services as well as assess the risk factors for psychosocial issues such as homelessness, unemployment, and substance abuse. Initially targeting severely injured service members and veterans, the program was expanded to include all OOO veterans requiring transition and care management assistance. In fiscal years (FY) 2012 and 2013, 180,000 service members and veterans were screened for the need for care management services. All severely ill and/or injured service members/veterans are provided a case manager; others are assigned a case manager as indicated by screening assessment or upon request. Since 2010, the program has maintained a case management
census of between 45,000–50,000 veterans, of whom approximately 7,000 are severely ill or injured.

**OEF/OIF/OND Care Management Program Engagement Strategy 2:** Care management teams participate in outreach activities to connect with veterans and families prior to leaving active duty or enrollment in VA to assist not only in direct care, but also in program development and improvements.

To engage more broadly with the cohort, OOO care management team members have held focus groups of OEF/OIF/OND veterans at each VA Medical Center since May 31, 2007, to identify issues and concerns unique to this population. Between 2007 and 2009, the focus groups were held quarterly at each site. Since 2009, the focus groups have been held at least annually with OEF/OIF/OND veterans and their family members as well as VHA facility leadership. The input received during these discussions is used to improve access and services at each location.

These OOO teams also have actively supported numerous other outreach events in the community targeting veterans, active duty service members, and family members. Multiple venues throughout the deployment cycle, from pre-deployment, at demobilization, and through post-deployment, were targeted to actively promote enrollment into the VA and utilization of benefits and health care.

From 2008 through 2013, OEF/OIF/OND team members participated in 16,476 such outreach events including Yellow Ribbon Reintegration, post-deployment health reassessment events, and individual ready reserve annual screening events. Annual VA welcome home events, hosted collaboratively with community partners and often held at sports and recreation venues, are held at each VA medical center. These often include job fairs. Program staff members often give presentations to community partners, veterans’ service organizations, colleges and universities, employment agencies, and others to collaborate to more effectively integrate services.

When VA is notified of a veteran in need of assistance, the care management team immediately makes contact with the veteran, family, or caregiver to further define the need and connect with the appropriate health care, benefits, and resources.
CAREGIVER SUPPORT PROGRAM

The Caregiver Law of 2010 directly benefits family caregivers by establishing a comprehensive National Caregiver Support Program with a prevention and wellness focus that includes the use of evidence-based training and support services for family caregivers. As of November 2013, there were over 12,500 participating family caregivers. More than 9,600 have completed training online via a secure website and more than 5,500 have completed training via workbook. An additional 160 family caregivers have participated in classroom training.

Caregiver Support Program Engagement Strategy 1: Create supportive caregiver education based upon the stated needs of veterans and caregivers.

A core curriculum was developed with input and guidance from subject matter experts as well as veterans and caregivers. Caregiver feedback on the content and efficacy of the core curriculum was solicited using OMB-approved surveys. This feedback informed ongoing enhancements in the curriculum.


To create an engagement avenue for caregivers, a Caregiver Support Line was established February 1, 2011. The objectives of the support line were to respond to inquiries about caregiver services; to serve as a resource and referral center for caregivers, veterans, and others seeking caregiver information; to provide referrals to local VA medical center caregiver support coordinators and VA/community resources; and to provide emotional support. As of November 12, 2013, VA’s Caregiver Support Line had received more than 102,000 calls (over 150 calls per day). Input from callers to the support line is used in quality improvement of the program.


A peer-support mentoring program was launched in January 2012. Mentors receive training before being assigned a mentee, as well as ongoing support in the mentor role. As of November 2013, more than 140 caregivers have participated in the program. Based on feedback from caregivers who have completed training, an
online alumni community was created to allow caregivers to continue to stay in touch and offer support and encouragement to one another. Posts made on VA social media platforms, such as Facebook, have created another avenue for input from veterans, family members, and the public, resulting in program enhancements.

TRAUMATIC BRAIN INJURY (TBI)/POLYTRAUMA REHABILITATION PROGRAM

Early on in the conflicts, returning combat veterans reported a multitude of symptoms potentially related to blast exposure during deployment. This health concern was brought to light as a result of direct veteran/family report, observations from DoD and VA healthcare teams working with these individuals, and patient endorsement of blast wave exposures as one of many deployment-related risks to which they had been exposed. In addition to this direct veteran and family input, extrapolations were made from veterans with moderate and severe TBI to the much broader group with milder but still noticeable impairments, and epidemiological studies examining exposure history and subsequent symptom/impairment profiles pointed to the need for additional clinical attention to this health concern.

TBI/Polytrauma Rehabilitation Program Engagement Strategy 1:
All returning combat veterans would be screened for traumatic brain injury related to deployment.

A screening program was implemented in 2007 to assess veterans for possible concussion/mild TBI. A four-question screen was administered to every OOO veteran who had deployed after September 11, 2001, and had subsequently separated from active duty service. Screening was accomplished during a veteran’s initial engagement with VA, most often in primary care, mental health, or dental clinics. Veterans with positive screens were referred to a TBI specialist for a comprehensive evaluation, definitive diagnosis, and treatment recommendations.

TBI/Polytrauma Rehabilitation Program Engagement Strategy 2:
Engaging individuals with history of TBI would involve a veteran-centered, family-oriented, collaborative treatment plan.

For veterans with a TBI diagnosis and requiring rehabilitation, an Individualized Rehabilitation and Community Reintegration (IRCR) plan of care may be developed jointly by the veteran and his/her family, TBI specialists, and all other involved team
members. Symptoms following a TBI often overlap with those associated with co-morbid mental health issues. Collaboration with primary care, mental health, and pain management providers is crucial, with care coordinated by polytrauma case managers.

Most education and training related to TBI care was case-based and interprofessional, including face-to-face conferences, virtual conferences/web based trainings, and national conference calls. Upon completion of skilled interdisciplinary rehabilitation care, the discharge IRCR may be used as a transition note with wellness-focused rehabilitation recommendations for the Patient-Aligned Care Team (PACT) or community providers. Follow-up at appropriate intervals, such as three to six months, via face-to-face or virtual modalities, allows the monitoring of functional status and assessment of need for further skilled rehabilitation interventions.

**TBI/Polytrauma Rehabilitation Program Engagement Strategy 3: Develop care delivery technologies to allow broader engagement of the 36% of enrolled veterans who receive their care in rural/highly rural settings.**

Care delivery modalities such as tele-health and e-consults have facilitated the ability of TBI/polytrauma teams to broadly engage with veterans with TBI and their families not only for initial assessment but also for the delivery of needed skilled rehabilitation interventions. In addition, secure messaging, e-consults, and home clinical video tele-health are utilized to improve access to care and to allow follow-up support for primary care, as is the Specialty Care Access Network-Extension for Community Healthcare Outcomes (SCAN-ECHO) platform for interprofessional collaboration and education.

To further develop workforce clinical expertise in TBI/polytrauma, the Office of Academic Affiliations, in collaboration with Research Rehabilitation and Development, initiated advanced fellowships allowing physicians, other clinicians, and scientists to receive one to three years of advanced preparation in TBI/polytrauma practice, clinical program development and improvement, and research. Between the time of the program’s inception in 2010 through November 2013, 22 physicians and 17 associated health professionals completed the program. The Office of Academic Affiliations is supporting the formation of the brain injury medicine subspecialty for physicians, and will devote graduate medical education position funding when the accredited fellowship programs are activated.
MENTAL HEALTH PROGRAM

To facilitate access to clinical mental health services for the OOO population, VA offers longer clinic hours, the 24/7 Veterans Crisis Line, capability to deliver services through tele-mental health, and standards that mandate rapid access to mental health services. Tele-mental health approaches can bring therapy into remote settings or even into the veteran’s home, improving access by bringing care into the environments where the veteran can most easily learn, practice self-care skills, and inform the treatment process.

VA proactively screens veterans for post-traumatic stress disorder (PTSD), depression, alcohol abuse, and military sexual trauma, providing follow-up assessment for all those who screen positive for these disorders. Any veteran who screens positive for PTSD or depression also is assessed for risk for suicide. In FY 2013, 131,651 OEF/OIF/OND veterans received treatment for PTSD in VA medical centers and clinics. The number of tele-mental health encounters for PTSD psychotherapy has tripled from 14,555 in FY 2011 to almost 47,000 in FY 2013. VA’s Office of Academic Affiliations provides funding and oversight for VA facilities to train roughly 6,400 students in mental health occupations per year, increasingly expanding interprofessional training in primary care/mental health integration (PC/MHI).

**Mental Health Program Engagement Strategy 1:**
Mental health councils, reintegration events, mental health summits.

Every VA medical center is encouraged to have a veteran’s mental health council that solicits input on VA care from veterans with mental health problems. Events focused on prevention of veteran homelessness involve VA staff interacting with veterans, family members, and community partners. In 2013, each VA facility hosted a mental health summit to help strengthen collaborative efforts with community mental health providers and services. The 3,738 summit participants responding to a survey almost universally recommended additional summits, and after-action reports were also oriented toward future collaborative efforts. While none of these engagement activities have the stated purpose of informing interprofessional education, much of the input is used in educational and training materials and events often including primary care/mental health integration teams and behavioral health providers in the PACT team-based setting.
Mental Health Program Engagement Strategy 2: Veterans Crisis Line.

VA has a comprehensive suicide prevention program, and every VA medical center has a suicide prevention coordinator or team. Screening and assessment processes for PTSD, depression, and suicidality assist in the identification of patients at risk. A chart “flagging” system assures continuity of care and provides awareness of a veteran’s risk among caregivers. High-risk individuals receive an enhanced level of care, including missed appointment follow-ups, safety planning, weekly follow-up visits, and care plans that directly address suicidality.

In 2007, VA partnered with the Substance Abuse & Mental Health Services Administration (SAMHSA) to provide universal access to 24/7 emergency care through our emergency departments and VA’s Veterans Crisis Line (www.veteranscrisisline.net or 1-800-273-TALK). As of September 2013, these services had received over 975,000 calls, over 128,000 chat connections, and over 15,000 texts, resulting in over 32,500 rescues of those in immediate suicidal crisis.

To enhance the workforce capacity of skilled practitioners in addiction treatment, the Office of Academic Affiliations collaborated with the Office of Mental Health Services in 2013 to create a new advanced fellowship in addiction treatment. This program, at seven VA facilities around the nation, provides post-residency physicians, along with advanced trainees in other professions, in-depth experience in clinical care, clinical program design and improvement, and research in this important field.

Mental Health Program Engagement Strategy 3: Peer-based programs.

Peer support services are another example of how the VHA mental health system engages veterans. Peers are involved in inpatient mental health units, psychosocial rehabilitation and recovery centers, mental health residential rehabilitation treatment programs, and substance use disorder programs. Expansion of peer support services brought an additional 800 peer specialists into the VA in 2013, with the goal being, at minimum, three certified peer specialists at each medical center and two certified peer specialists at each very large CBOC.
Mental Health Program Engagement Strategy 4:
Social media activities for outreach.

A robust online and social media outreach program is another strategy to engage veterans and families in addressing mental health concerns and community reintegration challenges. Veterans and other stakeholders are involved in the development and evaluation phases of these resources, which include focus groups and resource usability testing (such as during the recent re-design of the National Center for PTSD [NCPTSD] online website and other mobile sites). Veterans also are involved in alpha and beta testing of online and mobile products, such as self-help tools. For these efforts, contractors may locally recruit veterans to avoid potential ethical conflicts associated with recruitment by a clinician. Care is taken to ensure diversity of gender, race and ethnicity, military service membership, and service era.

On sites such as *Make the Connection* (http://maketheconnection.net/), veterans contribute and present their own stories. *My Health eVet* (https://www.myhealth.va.gov/index.html) is an online website created specifically for sharing information with veterans. To facilitate veteran feedback and input into the development of future online products for this resource, plans are in development for an online evaluation panel of veterans and service members to meet regularly via web conference. *My Recovery Plan*, a veteran-constructed care plan, is an additional means for integrating veteran input into care delivery in a manner that points toward team-based care delivery supported by training. VA and DoD developed the PTSD Coach mobile application (app) to provide education and self-management skills for PTSD patients in 2011. As of the end of FY 2013, this award-winning mobile app for iPhones and Android smartphones had been downloaded for free over 126,000 times in 78 countries. Two additional mobile apps launched in 2013 are Cognitive Behavioral Therapy for Insomnia (CBT-i) Coach and Stay Quit Coach for smoking cessation. One outcome measure of online and mobile products is utilization (number of “hits”) a product receives.
The Office of Patient-Centered Care and Cultural Transformation (OPCC&CT) is collaborating with VHA leadership and other program offices to transform the system of health care from the traditional disease-based medical model to a personalized, proactive, patient-driven model.

This transformation, combined with the strengths of the VA’s successes with chronic disease management and its recent implementation of its PACTs, will bring all aspects of care together in a coordinated program.

A patient’s health and well-being go beyond merely managing diseases. Patient-centered care does more than align itself with a patient’s needs; it makes the patient’s goals central to every decision.

The role of the OPCC&CT is to help clearly define the future state of health care, provide the tools and support the field needs to make it happen, and to help identify and remove barriers to success.

**OPCC&CT Engagement Strategy 1: Including the voice of the veteran in the cultural transformation is a key priority of the OPCC&CT.**

The director of the OPCC&CT co-chairs the National Leadership Council’s Veterans Experience Committee (VEC), which takes the organizational lead for VHA’s number one strategic priority to provide personalized, proactive, patient-driven care. The VEC has worked to ensure that every medical center director’s performance plan in FY 2014 includes developing formal and informal strategies to hear the voice of the veteran. Leaders will ensure there is a system for formal feedback sessions with veterans, to hear what matters most to them and to incorporate this input into decision-making. Leaders also will identify specific opportunities to engage veterans in patient-centered innovations. A veteran/family advisor toolkit has been developed to support the field in creating these formal and informal strategies to incorporate the voice of the veteran in the organization.
OPCC&CT Engagement Strategy 2: Another major transformation strategy has been to partner with medical centers whose leaders prioritized patient-centered care.

The OPCC&CT supported these centers of innovation to further pilot new models and continuous improvements in both the practice and experience of care. These include wide-ranging innovations spanning the spectrum of changes in environment of care to personalized health planning to integrative medicine. The OPCC&CT funded two Quality Enhancement Research Initiative (QUERI) teams to conduct a systematic evaluation to identify patient-centered care and cultural transformation movement having the greatest impact on veteran perceptions and outcomes.

As a result, a white paper identified seven major key domains impacting the transformation: 1) the key role of leadership; 2) engaging veteran patients and families; 3) enculturating staff; 4) fostering innovation; 5) staff roles and priorities; 6) role of VA organizational structures and processes; and 7) implementing changes in environment of care and its contribution to patient-centered care.

The OPCC&CT and VEC transformed the white paper into a working document, Lessons from the Field – Operational Tactics for Implementing Patient-Centered Care and Cultural Transformation. This document provided a summary of the research findings along with links to specific tools that medical center leaders and staff members may use to foster patient-centered cultural transformation at their facilities. This document has been widely distributed and is now integrated into the 2014 Senior Executive Service (SES) Performance Plan.

OPCC&CT Engagement Strategy 3: The OPCC&CT has used evidenced-based approaches to develop educational curricula in whole health, health coaching, and other foundational training sessions, which are being deployed across the country in 2014.

VHA requires 30% of all VHA staff to participate in patient-centered education during 2014.

OPCC&CT Engagement Strategy 4: The OPCC&CT has developed four field-based implementation teams (FIT) that work with VA medical centers to provide on-site support through engagements sessions for leaders and staff; information sessions for veterans and
volunteers; and facilitator workshops to sustain veteran engagement and patient-centered education and training at the facility level. The FIT staff has worked with over 50% of medical centers to support the cultural transformation.

While a lot has been accomplished in the last two years, the VHA cultural transformation is an ongoing journey, using the voices of the veterans, families, and staff to enhance patient-centered care in the organization. Many of the voices are being captured and shared via videos and stories.

OFFICE OF RURAL HEALTH

Approximately 36% of all US veterans live in rural or highly rural areas. Many of these veterans face challenges, such as traveling great distances to access care or see a benefits specialist. Further, they may not be aware of the benefits available to them. Local community partners and advocates understand the culture and resources available in their rural areas and have strong personal interest in serving the members of their community, including veterans. It is important that they know the scope of VA benefits and how to assist veterans in obtaining them. Given the increasing proportion of rural veterans and their unique healthcare needs, Congress authorized VA to establish the Office of Rural Health (ORH) in 2007. The mission of the Office of Rural Health (ORH) is to improve access and quality of care for rural and highly rural veterans through the development and/or promotion of evidence-based and innovative practices. From transportation, tele-health, and care coordination to workforce development, mental health, and community outreach, the Office of Rural Health has a diverse portfolio that specifically explores the unique nature of delivering health care to rural veterans.

Office of Rural Health Engagement Strategy 1: Regional trainings and networking events on VA benefits and community resources have brought together non-VA healthcare providers and community agencies. Feedback was overwhelmingly positive. Some examples are described below.

Example #1A: Serving those that Served Us: Understanding Veterans Benefits and Resources Community Training Event (Decorah, IA)–On June 4, 2013, the Veterans Rural Health Resource Center-Central Region organized a training
and networking event on VA benefits and community resources in Decorah, IA. This event provided an overview of VA benefits/services and introduced non-VA healthcare providers and community agencies to key contacts affiliated with VA. Fifty-seven agencies (including local non-VA healthcare providers, community service organizations, and state offices of rural health) were represented at the event. Participants were allowed the opportunity to complete a brief evaluation of the event, which included a solicitation of suggestions for improving relationships between VA and non-VA community stakeholders.

Example #1B: Veterans Benefits and Community Resource Fair (Decorah, IA)–On June 29, 2013, the Veterans Rural Health Resource Center-Central Region organized an event offering networking and veterans’ resources to the Decorah, IA, community. Participants included area agencies, organizations, and community providers (including some that had attended the June 4 training workshop). This event allowed veterans and their family members to speak with agencies, businesses, county veterans’ services officers, and VA representatives, including outreach specialists, to learn about various area resources available to them. Veterans and non-VA participants were encouraged to complete a brief evaluation of the event, soliciting suggestions for improving VA care as well as enhancing relationships between VA and non-VA community stakeholders.

Example #2: Rural Veterans Outreach (RVO) Program–The Office of Rural Health developed a rural veteran outreach toolkit to help begin crucial conversations to develop collaborative relationships and bridge the resource knowledge gap in rural areas that have little to no VA presence. One purpose of outreach is to strengthen the relationship between the community members and the VA. Working together to plan events such as those described above increases trust, demonstrates mutual goodwill, and lays the groundwork for a future partnership to serve veterans. These events are similar to a typical outreach event that VA would attend or sponsor, with one important exception: the planning committee of an RVO outreach event should include interested veterans/family members, workshop attendees, and local organizations. Ideally, the outreach event should be community-led as much as possible.

The main goals of the community outreach events are to:

- Educate veterans about their benefits.
• Enroll veterans in VHA programs and provide information on and assist them in applying for other VA benefits.

• Connect veterans with other local resources.

**Example #3: Rural Women Veterans Focus Groups**—The Veterans Rural Health Resource Center-Western Region conducted a series of focus groups to understand healthcare access and quality issues from the viewpoint of rural, female veterans. The goal was to discover information on any areas lacking in women’s health care in rural communities. In working with community partners to plan the focus groups, an avenue was created for future collaboration between rural community leaders and VA to design and implement population-based health programs. In addition, the Resource Center created a *Rural Women Veterans Focus Group Toolkit*. The purpose of the toolkit is to address planning and logistical considerations for conducting focus groups with women veterans in rural areas.

**CONTRIBUTIONS OF VETERAN AND FAMILIES TOWARD INTERPROFESSIONAL TRAINING AND PRACTICE REDESIGN IN VHA: WHAT IS AND IS NOT**

Though many programs and engagement strategies are described in this case study, there was no over-arching VHA plan or initiative with the specific objective of garnering input from veterans and families for the sole or expressed purpose of informing or shaping interprofessional education. Still, the organic evolution of this process at the program, medical center, and clinical levels resulted in accomplishing this very goal in a variety of ways and to an extent beyond what could have been anticipated. Most of the engagement strategies described were paired with interprofessional education efforts either within the programs or between staffs of the program involved and staffs of other programs involved in the care of a particular cohort (i.e., training involving rural health providers and mental health programs or mental health programs and the women veteran's program). Those programs that were integrative by definition (such as the Post-Deployment Integrated Care Initiative and the Primary Care/Mental Health Integration Program) have increasingly moved toward interprofessional conferences, conference calls, and trainings.

Veterans and their families have made it very clear that they prefer the professionals providing their care to be working together effectively to ensure care integration. This, together with the high degree of co-occurrence of physical injury, mental health
concerns, and psychosocial stressors, in many cases involving overlapping symptoms and impairments, made it clear that interprofessional, collaborative, team-based care was necessary. It was also clear that even after resources were devoted to staffing and other support needed for the new and expanded programs described, there remained a significant educational need to facilitate the current and newly hired staff to fulfill the programs and provide the intended services. There are two prongs to VHA’s strategy for education: The first addresses the education needs of our current staff to implement and advance our systems of care, while the second addresses the education and training of developing health professionals as they seek supervised clinical experiences in VA facilities. Because the care systems described earlier in this case study require interprofessional collaborative care, these education strategies must reflect and support the VA system of care.

That said there is great opportunity to promote this process more broadly and more effectively. With over 288,000 employees, VHA is one of the largest healthcare employers in the world. All of these employees are considered “learners” whose competencies include awareness of military culture, military service, and the VA mission. The VHA is the largest provider of healthcare training in the US, with more than 5,000 individual affiliation agreements at more than 1,800 educational institutions. Clinical traineeships and fellowships are provided to more than 117,000 students in over 40 professions annually. There are nearly 80,000 active volunteers and over 18,000 student volunteers.

**Staff Development**

Educational activities addressing “deployment health issues” became the norm for the interprofessional care teams, with such training occurring at the local level, the VISN level, and the national level. The Post-Deployment Integrated Care Initiative was rolled out in 2008 to support this effort, and was informed by VA-wide veteran focus groups conducted by the OOO Programs across the nation. During the focus groups, veterans asked for seamless, coordinated, “one-stop shopping” health care provided by compassionate staff experienced in post-combat care and knowledgeable in military culture.

The core concept was that all combat veterans would be evaluated and managed by an interprofessional team comprised of primary care, mental health, and social work professionals. A national, team-based “train the trainer” conference was held in Seattle in 2008, followed by similar team-based trainings in each VISN during 2009–
2010, reaching teams from each medical center in the VA system. A national face-
to-face training entitled, “Evolving Paradigms,” brought VA healthcare teams from
across the nation together for a veteran-centered, team-based conference. Veterans
were involved in planning and conducting the conference, with each session built
around a veteran’s case, and most sessions were delivered by interdisciplinary teams
and directed toward interprofessional participation. This interprofessional conference
set the trend in VA for further team-based, interprofessional trainings conducted
through all of the discipline-specific programs involved in post-deployment care.

Mental Health conferences, polytrauma conferences, and social work conferences
increasingly became, at least in part, interdisciplinary conferences. An
interprofessional post-deployment community of practice was established and has
been hosting monthly teleconference training calls for teams for six years, generally
engaging over 200 lines monthly. Trainings on electronically mediated distance-
learning platforms, such as Veterans Health University (http://www.vehu.va.gov/),
also provided interprofessional trainings (some of which included veterans in the
presentations) and increasingly are offering additional interprofessional trainings
related to veterans’ health care in general as well as deployment-related health
care concerns specifically.

The Post-Deployment Integrated Care Initiative collaborated closely with the Primary
Care/Mental Health Integration program, and the VA-wide implementation of PACTs,
which are the VA version of the Medical Home model of care delivery. In these
system-wide transformations, the notion of pairing discipline-based competencies
with team-based competencies as the standard of training more broadly
disseminated these practices (including team-based or interprofessional training)
through the system.

As part of VA’s ambitious national implementation of PACTs as a new nationwide
VA model of primary care based in the principles of the patient-centered medical
home, VA also supported Centers of Excellence in Primary Care Education
(CoEPCE). CoEPCE is a five-site, four-academic-year project emphasizing health
professions trainee education in the context of team-based primary care. CoEPCE
initially focused on collaborative learning and practice between physician residents
and nurse practitioner students, but has expanded to include integration of
clinical pharmacy and psychology residents and their faculty. A preliminary report
on this project was provided at a prior Josiah Macy Jr. Foundation Conference,
“Transforming Patient Care: Aligning Interprofessional Education with Clinical
Practice Redesign” (4).
Trainee Education

Because many of the interventions described in this monograph occurred in VHA's academically affiliated facilities, trainees of all relevant professions were immersed in the interprofessional, collaborative, team-based care environments described. It is increasingly clear that such clinical systems have a profound impact on trainee experiences. VHA's data systems do not track the specifics of trainee activities, but there is no doubt that of the approximately 120,000 health professions trainees who have VA experience each year, the majority of medical students and physician residents in fields such as physical medicine and rehabilitation, orthopedics, psychiatry, neurology, and ophthalmology will have worked along with their own supervising faculty and with the faculty and trainees in nursing, clinical psychology, prosthetics, audiology, speech pathology, physical therapy, social work, clinical pharmacy, and many other relevant professions.

Lessons Learned

Incorporating input from veterans/families in quality improvement efforts and to shape interprofessional education can and should be a specific institutional objective.

While this case study highlights a number of efforts to solicit such input and a number of parallel efforts to promote interprofessional education, that process has not been as systematic as it could and should be. Given the large numbers of VA learners noted above, the number of individuals involved in the direct engagement and solicitation of input from veterans and families in the programs described in this case presentation was relatively limited. Opportunities to solicit such veteran/family input abound and could be more broadly developed for the purposes stated above.

Education of veterans, caregivers, and family members could be more closely coordinated with education with interprofessional teams.

In the care of returning combat veterans, there was a great deal of overlap in what was involved in the education of veterans, caregivers, and family members and what was involved in educating clinical teams—with the basic theme being that veterans expressed very clearly the need and desire for “one-stop shopping” which aligns fully with our integrated post-deployment care strategies. Expanding this practice to all veteran cohorts would complement and support the VHA's movement toward care that is more personalized, proactive, and veteran-driven.
Veteran and family engagement must occur horizontally and vertically system wide.

While this case study describes only a few of the myriad of veteran/family engagement activities involved in post-deployment care over the past decade, these programs both resulted from and contributed to a qualitative shift in VA health care. Fundamental structural changes in the VHA system to support this shift toward more veteran-centered, team-based care include at the clinical level the implementation of the PACT model, supported by the Post-Deployment Integrated Care Initiative and the Primary Care/Mental Health Integration Program, and at organizational level by the creation of the OPCC&CT.

The veteran and family member engagement strategy must contain program-specific, cohort-specific, and agency-specific orientations.

Patients, family members, and even veterans are in some respects homogenous, and in other respects heterogeneous, groups. Understanding and effectively responding to both the homogeneity and the heterogeneity of these groups, and leveraging the opportunities this presents, can lead to more effective engagement of these stakeholders from the program perspective, the cohort perspective, and the organizational perspective.

Veteran and family engagement can be realized only in a system in which there is similar engagement between team members, departments, programs, and offices.

Optimal health care must be comprehensive, integrated, and interdisciplinary. Engagement between patients and providers in a healthcare system can only be effective if there is similar engagement and functional connections between the other elements in the system. Such integration within a system engenders and enables that sense of empowerment, trust, and well-being that is the ultimate engine of healthy living.
Engaging veterans and family members following deployment, while complicated by the complexity of the health concerns, involves predictable challenges. Preparedness for these challenges not only is possible, but also should be a national imperative when we deploy individuals to combat theaters.

As a result of the experiences of veterans returning home from earlier wars, and from the successes and failures we have experienced as a VA and as a nation in addressing the health concerns of these individuals, we have learned a great deal about how to most effectively support individuals returning home from war. There are predictable health and life consequences of combat, and we know the services and resources that will be needed for these individuals to optimally recover, reintegrate, and live healthy, functional, and satisfying lives following combat. Over the past decade VHA has developed systematic approaches to post-deployment care, based upon proactive engagement with veterans and their families and providing them with effective, accessible, integrated support. It is only through the input and guidance from our veterans and their families, and through our effective partnering with these individuals, that such care will be possible. That engagement and partnering must be the foundation of such care following any future deployments.

CONCLUSION

Over the past decade, the VA has employed a number of strategies to engage returning combat veterans and their families in the process of informing, shaping, and improving post-deployment care. These strategies, implemented over a broad spectrum of programs, have resulted in both quantifiable impacts on the specific programs and the veterans and families they serve. As importantly, however, they also have contributed to parallel qualitative changes in the broader VA healthcare system, including the roll out of VA’s medical home model of care (known as PACT), the creation of an Office of Patient-Centered Care and Cultural Transformation, and a system-wide shift in VA from being a care system primarily oriented toward disease management to one increasingly oriented toward personalized, proactive, patient-driven health care.

The systematic pairing of efforts to solicit veteran/family input with quality improvement activities and the informing of both content and process of interprofessional education could quite easily be developed to a much greater
and more effective extent. Providing effective support for individuals and families impacted by combat deployment is a challenge best met through patient and family engagement; patient-centered, team-based care delivery; and interprofessional education and training to support such care. Lessons learned, practices developed, and care platforms created in the process of enhancing post-deployment care, specifically with respect to veteran/family engagement in support of interprofessional education and team-based care delivery, has enhanced care for all veterans receiving services in VA. We hope these approaches may inform and enhance the healthcare services offered to individuals being served in other settings as well.

REFERENCES


APPENDIX I

Examples of Social Media Engagement Strategies:


2. The Coaching Into Care line helps family members and friends help a Veteran to seek care. Since the inception of the service in January 2010 through June 2013, Coaching Into Care (www.va.gov/coachingintocare) has logged 8,460 total initial and follow-up calls. Most callers are spouses or family members.

3. Veterans Employment Toolkit (www.va.gov/vetsinworkplace) supports Veterans seeking work and also helps employers support their employees who are Veterans or members of the Reserve or National Guard.

4. VA Campus Toolkit (www.mentalhealth.va.gov/studentveteran) helps faculty, staff, and administrators find resources to support student Veterans and learn about their strengths, skills, and needs.

5. Community Provider Toolkit (www.mentalhealth.va.gov/communityproviders) provides information about VA services and resources, understanding military culture and experience, and tools for working with a variety of mental health conditions.

6. VA’s National Center for PTSD (NCPTSD) web site, www.ptsd.va.gov, contains research-based educational materials for Veterans and families, as well as for the providers who care for them.

7. AboutFace (2012) is an online video gallery dedicated to Veterans talking about how PTSD treatment turned their lives around. This site is averaging 5,500 visits per month since its launch in May 2012. Every year in June, NCPTSD runs a national campaign to raise awareness about PTSD and its effective treatment during PTSD Awareness Month.

8. Make the Connection campaign (www.maketheconnection.net) demonstrates how Veterans of all service eras, genders, and races have successfully sought help for emotional problems. The Make the Connection website was launched in November 2011 and has been visited over 3 million times. The site’s videos
have been viewed over 6.9 million times. The campaign’s Facebook page has been “liked” over 1.8 million times, and the campaign’s YouTube channel has over 7,600 subscribers.

Examples of Collaborations and Pilots:

1. VA collaborates with DoD and other Federal/community partners, such as SAMHSA and the National Alliance on Mental Illness (NAMI), for coordinated Federal/local services for returning Veterans and their families.

2. Under the President’s Executive Order of August, 2013, Improving Access to Mental Health Services for Veterans, Service Members, and Military Families, VA, the Department of Health and Human Services (HHS), and community partners established 24 pilot project agreements to improve access to mental health service in pilot communities, and to develop partnerships in hiring providers in rural areas.

3. Another collaboration with SAMHSA is the ongoing Service Members, Veterans, and Families Technical Advisory Group. This collaboration between SAMHSA, VA, the DoD, and states began with a series of policy academy meetings in which teams from states, including the Governor’s office, VA, DoD (National Guards), and other community care providers met to develop plans to address reintegration needs of returning combat veterans. These programs now include plans to address needs of veterans of all service eras and are supported by an online technical advisory website.
VHA POST-DEPLOYMENT VETERAN ENGAGEMENT WORKGROUP

Post-Deployment Integrated Care Initiative
  Stephen C. Hunt
  Lucile Burgo

Office of Care Management and Social Work Services
  Michael Kilmer
  Peggy Kennedy
  Laura Taylor
  Janet Belisle
  Jennifer Perez

Traumatic Brain Injury (TBI)/Polytrauma Rehabilitation Program
  David Chandler
  Joel Scholten
  Lisa Perla

Mental Health Program
  Sonja Batten
  David Carroll
  Larry Lehmann

Office of Patient-Centered Care and Cultural Transformation
  Tracy Gaudet
  Laura Krejci
  Windy Hendrick
  Mercedes Gross

Office of Rural Health
  Gina Capra
  Nancy Dailey
  M. Bryant Howren

Office of Academic Affiliations
  Stuart C. Gilman
For years, I had been working in Philadelphia with vulnerable populations (mainly poor and/or homeless people) in the traditional office or shelter-based practice—wrestling with the many social determinants of health (a term not familiar to me at the time) with very little impact on outcomes or policy. But I went back to Johns Hopkins University for an MPH degree and my world opened up, giving me a vocabulary to articulate the challenges and broaden my portfolio of skills to teach medical students. Still, the working link between primary care and public health remained elusive.

The Duke Health Leadership Program (HLP) helped complete that link between the clinic and the community. The lessons learned in the program and the on-going informal mentoring have led to a strong network of community-based partnerships linked to chronic disease self-management programs; interdisciplinary care teams; clinical care in a federally qualified health center; effective collection and utilization of data; a comprehensive three-year community health assessment; and innovative programs with prisoners, refugees, and the formerly homeless. I also was able to use my experience with the HLP to develop a four-year longitudinal area of concentration in Population Health for medical students (funded for five years by HRSA), which recently graduated its first cohort.

James Plumb, MD, MPH
Professor, Department of Family and Community Medicine
Director, Center for Urban Health
Thomas Jefferson University and Hospital
PROBLEM WE SOUGHT TO ADDRESS

In the late 1990’s it was becoming increasingly apparent there was a need for new approaches to improving health in the United States. With the growing prevalence of chronic disease, widening gaps in health disparities, and heightened recognition of the role of social determinants in health outcomes, our nation was in dire need of collaborative and multi-sectorial approaches that focused on the health of populations and that engaged patients, families, and the larger community. At the Duke Department of Community and Family Medicine (CFM), we believed that such approaches would require interprofessional teams who could move beyond the traditional health care and public health sectors and understand health in a context relevant for patients, families, and the larger community.

In 1998, CFM created the Division of Community Health (DCH) to work with communities in Durham and across North Carolina to build innovative interprofessional models of care to improve health at the individual and population levels (1). The models of care utilized multi-disciplinary teams of social service (MSWs, LCSWs, family counselors, and psychologists) and healthcare providers (PharmDs, RDs, PAs, NPs, OTs, and PTs) along with non-licensed community health workers; and placed primary care and care management services in accessible locations for individuals and families—in their homes, in schools, and in neighborhoods. Examples of DCH’s varied programs include:
• In partnership with Durham’s federally qualified health center (Lincoln Community Health Center), three new neighborhood clinics were planned with their communities. They have over 17,000 patient encounters annually, and 82% of the patients served are uninsured.

• The Just For Us Program—a multi-agency, interprofessional team providing in-home primary care, nutrition, occupational therapy, and case management to elderly and/or disabled residents of Durham living in 13 public/subsidized housing centers in Durham County—was planned with the senior centers and the seniors. The program provides more than 2,000 patient visits annually.

• Four school-based health centers (in three elementary schools and one high school) that generate over 3,000 patient encounters per year—all were planned with the schools and their communities.

• Local Access to Coordinated Health Care (LATCH)—a care management program that draws on the resources of multiple agencies, including the County Departments of Health and Social Services and Lincoln Community Health Center—that has served more than 22,000 uninsured Durham residents since its inception.

In addition, DCH operates the Northern Piedmont Community Care Network (NPCC), part of the Community Care Program of North Carolina. NPCC provides care management services for more than 70,000 Medicaid enrollees across Durham, Franklin, Granville, Person, Vance, and Warren counties. The NPCC network links and coordinates services for 53 primary care practices, six hospitals, and local departments of social services, health, and mental health across the six-county region.

All of these programs began with our strategy for community engagement. Together, with our partners, we ask about and listen to concerns (literally going door-to-door in neighborhoods), analyze and share healthcare utilization and costs, explore barriers to care, identify partner needs and resources, plan/redesign services, track outcomes, and share accountability (2). Our evaluation data demonstrated that these programs have been improving hospitalization rates and emergency department use, and fulfilling unmet patient needs for meaningful access to primary care and support in managing their own health (3–5).
Unfortunately, training models by and large were not preparing health professionals (academic or community) to effectively participate in or lead the development of such innovative care models and programs. Health professional education, especially medical education, rarely emphasized population-based health concepts; the focus was usually on the individual patient and their medical needs. Existing graduate Master of Business Administration (MBA) and Master of Health Administration (MHA) programs were full-time and largely based on narrowly defined financial and economic models. The emerging distance-based programs that catered to working professionals were often still too time-consuming for working healthcare professionals and were still steeped in non-patient-centric organizational theory.

At Duke, we believed we could assist in the needed sea change by teaching practicing healthcare professionals two core elements:

1. How to define an issue so it can be dealt with through policy or operational change within a system; and

2. Essential knowledge and skills needed to develop and implement patient/family/community-centric models of health and health care to meet the health needs of a broader base of the population.

Knowing from painful experience that health professionals are more interested in skill acquisition than abstract theorizing, and knowing that skills that are not used quickly are lost, we felt it was imperative that health professionals be provided with very practical, community-engaged, collaborative strategies that would allow them to see the value and methods of effective population-based care and that could be applied immediately in their home setting. These ideas became the basis of our Health Leadership Program.

**THE HEALTH LEADERSHIP PROGRAM (HLP)**

Our primary goal for the HLP was to prepare practicing health professionals to improve health and health care in communities in partnership with their patients/communities, and to teach others to do the same. We specifically wanted graduates to be able to:
1. Understand and apply community health principles to improve health status on the population level.

2. Understand and value the expertise and resources brought to population health improvement by patients, service providers, and other sectors outside the clinic walls.

3. Partner to prioritize problems; and identify, implement, and evaluate potential solutions.

4. Develop and implement innovative strategies to teach others to do the same.

In designing and implementing the HLP, we built on our partnerships and experiences in designing, implementing, and managing health promotion and care coordination programs across Durham and North Carolina. What we were teaching was less “book learning” and more about hard-learned experiences of what is required to actually improve health outcomes in underserved communities, and how to effectively partner with groups often marginalized and with strengths that were often ignored. The resulting HLP was an eight-month, part-time model targeted at clinicians from academic and community settings who sought to build collaborative, community-based, patient-centered systems of health services. We utilized multiple strategies for teaching and learning, including three intensive weeks on campus at Duke; distance-based learning activities; a longitudinal project with participants’ home communities; and mentoring by Duke faculty.

For their projects, program participants sought partners within their communities, including community members/patients, health and human services organizations, and of course, their own organizations to:

- Assess the health status of the population and prioritize needs.

- Design a collaborative, community-based intervention to address a priority need.

- Identify financing options for establishment and sustainability of the program.

- Plan evaluation methods to assess the impact of the proposed intervention.
• When possible, implement the intervention.

• Identify possibilities for future incorporation of health professional students into the program, if the community was willing.

Since the projects were intended to be sustainable interventions, and coalition building is often a slow process, participants were not required to actually establish a program before the end of the eight months. Instead, during the last on-campus session they had to present their plan and implementation progress to date for a panel of peer and expert reviewers.

Mentoring by Duke faculty members began with helping participants to refine the issue, identify potential partners, and set them on a path to question certainty and embrace curiosity. Faculty guided the students with questions that required generative answers. The answers led to more questions, research, and analysis. The questioning process separated each learner from a point of certainty in their thoughts and beliefs to a comfortable dialogue that facilitated curiosity and cooperative learning. This was not an easy process, as participants shed long-standing beliefs about their own roles and expertise and gained new insights into the strengths and expertise of their partners. Duke faculty provided ongoing mentoring to learners (and eventually alumni) that covered change management, community politics, financing, educational design, and other needs as identified. Faculty facilitated project development by selecting and refining questions, assisting in formulating and defining outcomes, and maintaining focus and structure throughout the learning process.

Multiple strategies were used to evaluate learner and faculty performance, as well as the effectiveness of the program as a whole. Fifty-three participants completed the HLP over the four years that we offered it. The program was successful in attracting participants from a variety of health professions, including nursing, pharmacy, physical therapy, physician assistant, social work, and medicine. Many participants had clinical, administrative, and educational roles in their respective healthcare entities.
HLP CHALLENGES AND RESPONSES

Our three most formidable challenges to the program were time, money, and breaking long-held assumptions. Even though it was a part-time program, HLP participants had to take a significant amount of time away from family and practice demands, creating a financial risk for both. The costs of travel to the on-campus sessions and the $2,400 tuition also were barriers for some, especially as program budgets grew tighter at many institutions, limiting resources available for professional development.

In addition, arranging for ample mentoring and advising time for the participants was a daunting task. The key to making the experience a success for participants, regardless of their project outcomes, largely depended upon the mentoring/advising capacity of the program. Participants had to be able to develop trusting relationships with faculty, and faculty had to be able to provide quality guidance and feedback to participants in a timely fashion. This often set up a difficult dynamic for participants and faculty, given other demands on their time.

Perhaps the largest challenge was helping participants recognize previously unseen/unappreciated differences that arose as a consequence of broadening their perspective from caring for people one-at-a-time to caring also for a community. As we had learned and the participants had experienced, communities are more than just collections of people; communities have their own norms, systems, and history, about which most clinical groups know little. It is not just the need to be patient-centric or kind and respectful, nor is it just the need for attention to policy and the environment. The key change is the ability to frame issues on a continuum from the personal to the family/small group to the larger political sphere/community simultaneously, or at least as needed. While clinicians are trained to do that as an expert or authority, who then informs or advocates for what is needed, few are trained in being a partner or in the give-and-take of community leadership, in which knowing when to follow can be as important as the ability to lead.

LESSONS LEARNED AND RECOMMENDATIONS

When we began the HLP, it was not clear how much interest there would be in such a program. Our experience confirmed both the need and interest. The new
community benefits requirements for hospitals have only increased that need, and the recognition that we must address social determinants of health through multi-sectorial collaboration has continued to grow.

We also learned that, in designing training content and format to meet these needs, one size is not going to fit all. Since the inception of the HLP, content media (print, video, internet, and social media) has dramatically changed and grown almost exponentially, offering learners a range of modalities to digest material. With the advent of digital information streaming continuously, learners can select topics that range from micro issues, e.g. data mining that uncover tipping points, to macro issues resulting in revision of state policy impacting entire agencies. With substantial variety of information available at learners’ fingertips, the HLP and its learners found it necessary to be flexible in content and format in their quest to seek knowledge and effect change.

As health care continues to move out of the practice setting and into the community, a milieu of public agencies is ready to assist—to resolve chronic care issues; to address social determinants, such as inadequate housing or food supply; or to improve wellness opportunities, such as safe walking spaces (sidewalks). Other than those in pediatrics, health professionals generally are not educated or trained in the area of community advocacy and development. Essential knowledge of their communities and public systems, and a comfort level in challenging the status quo, can enable health professionals to be effective in creating change that results in healthier families and patients.

The need to train health professionals in population/community health is now more widely understood than it was when we began the HLP (6–8). A number of publications—such as the 2012 Institute of Medicine report “Primary Care and Public Health: Exploring Integration to Improve Population Health”—have identified the need for health professionals to partner with other sectors of society to address population health. New milestones for a number of medical residency programs also include population health competencies, such as quality improvement, working with the community, and understanding social determinants of health. Duke Community and Family Medicine is involved with a number of new initiatives to provide health professionals with the skills they need to respond to this changing context.

In 2011, Duke University School of Medicine launched its Primary Care Leadership Track (PCLT). This four-year, undergraduate medical education curriculum prepares
a cohort of students chosen for their interest in primary care and community health and their potential as change agents. Special components of the program include a longitudinal clerkship in primary care offices, training in the patient-centered medical home model, community service, research in community-engaged population health, and leadership training (9). While not exclusively a CFM endeavor, CFM has played a key role in program development, administration, and teaching in the PCLT. Also in 2011, CFM faculty began developing a “population health competency map” that laid out necessary competencies for health professionals in four domains: public health, critical thinking, community engagement, and team skills. Experts from other parts of the country were brought in to assist with the map, which was published in *Academic Medicine* (10).

Our experience with residency training demonstrates both the need and the challenge of change. In 2006, the Duke Family Medicine residency stopped accepting new residents in a well-publicized dispute over the program’s focus on community-based interventions, which was resolved a year later with a re-opening of the program and a renewed emphasis on improving health in Durham. In 2012, Duke’s family medicine residency program began modifying existing training, which was already unusually strong on traditional forms of community engagement, to create a curriculum based on the aforementioned population health competency map and reflecting greater emphasis on partnerships.

Demonstrating the new ethos of learning together, faculty members participate in this curriculum alongside residents. At the same time, the family medicine clinic is working to put greater attention on population health improvement inside and outside the clinic, and required population health projects for this curriculum are now becoming full-scale clinic initiatives.

CFM is also part of two initiatives—one funded by the Fullerton Foundation (with a focus on the Carolinas), and one by the Centers for Disease Control and Prevention (CDC) and the Association of American Medical Colleges—to promote and support population health training for health professionals beyond our walls. These initiatives build on work begun with funding from Duke’s Graduate Medical Education Office to develop online training modules for health professionals in community engagement and population health. The Fullerton Foundation project and the module development include public health officials, practicing clinicians, and representatives of community-based health initiatives as advisors.
We continue to recognize the need to educate health professionals already out in the field, as well as those who are in formal training. As of this writing, Duke is one month away from the public launch of *Public Health and Primary Care Together: A Practical Playbook*. The playbook is a free Web-based tool for public health and primary care groups that wish to work together to improve population health. Funded by the de Beaumount Foundation with support from the CDC and other national partners, the *Practical Playbook* will support local, state, and regional primary care teams and public health professionals interested in partnering to improve population health.

In developing these new initiatives, we have brought to bear lessons learned through the HLP, and the initiatives themselves have become significant learning laboratories that inform an evolving web of approaches to training health professionals to become population health professionals.

**REFERENCES**


At 26 years old, with my whole life ahead of me, I found out that I had severe kidney failure. My doctors thought peritoneal dialysis would be best for me while I awaited a transplant, but they were wrong and it suited me very badly. I dialyzed myself six times a day, 30 minutes each time, which was very distressing, and my results were poor. After a year on dialysis, my dad was approved as my living donor. It was by far the happiest day of my life. I decided that if I ever needed dialysis again, I would do everything myself, including deciding what form of dialysis suits me best. I’ll never let health care force me into system-centered care again.

In the following years, I studied everything about kidneys I could and became active in the Kidney Association, of which I later became president. I met several doctors during this time, and one in particular sent me over 500 scientific articles on self-dialysis. During those years, I became a well-informed patient. After five healthy years, however, I had to go back on dialysis. It was a big blow, but I had already decided that I would learn to manage my own treatment. I had met a fantastic dialysis nurse and asked her straight out, “Will you help me learn and manage my dialysis by myself?” She said, “Yes,” and we started cautiously. After four weeks, I was able to handle my own dialysis treatment. My lab results were impressive and I felt so much better. Other patients became curious and wondered if they could also be taught to manage their own dialysis treatment. I told them they could and helped them get started.

“I was completely convinced that person-centered care is the future of health care.”

After this, I was completely convinced that person-centered care is the future of health care. I had been an aerospace technician, but decided to become a registered nurse instead, so that I could make a difference for more people with serious illnesses. A few months after my second kidney transplant, in 2006, I began studying to become a nurse. I graduated in January 2010. Since then, I have worked tirelessly to try to help my patients become more independent and involved in their own health care. As both a nurse and as president of the Kidney Association of Småland, Sweden, I led the effort to create a self-dialysis ward at the county hospital. Today, it is an independent entity where many patients are able to manage their dialysis in whole or in part by themselves.

Christian Farman, RN
Nurse, Ryhov County Hospital
Chairman of the Kidney Association of Småland and Kronoberg County
Jönköping, Sweden
At 17, an accidental shooting by one of my closest friends left me with a bullet lodged in my spine. After months of acute therapy, I was discharged home. With the help of mentors and educational opportunities, I became an advocate. My passion over the past 20 years has been working on issues ranging from youth violence, gun violence, disability rights, patient advocacy, and disparities. Today, I am part of the executive team at the care facility where I received my acute rehabilitation.

This year, I moved across the country to work as a fellow with the Institute for Healthcare Improvement in Cambridge, MA. To do so, I also had to “flip” my own health care, which requires me to work with my healthcare system and do more at home versus going to the clinic. Living 3,000 miles from my own healthcare providers was daunting considering my health issues: partial paralysis, carpal tunnel, rotator cuff syndrome, tendinitis, arthritis, osteopenia, neurogenic bladder, and chronic back pain. But this kind of experimentation has led me to conclude that, as a patient, I have the ability to take charge of my care.

During my year in Cambridge, utilizing all the tools that were available to me, I was able to partner with my care team in ways that we had not partnered in the past. A registered nurse was my conduit for care. She triaged some of my health needs without having to take time away from my primary care physician. My exercise and eating habits changed. All my medication reconciliation needs were taken care of over the phone. Medical supplies were delivered to my home without delay, and labs were drawn at regional locations during my travels. The results of this effort have been striking. Last year, I had 8–10 clinical visits compared with only three this year. My lipids have improved for the first time in a very long time, and my renal function has been stable. I have not had a urinary tract infection in many months. I have saved myself money in the form of co-payments, and I have saved the healthcare system money by being healthier. My productivity has improved, with fewer absences from work. Most importantly, I feel happier and healthier, and I am amazed that I have been able to accomplish my goal of being healthy during this year away from my providers. It has transformed my sense of what is possible and has encouraged me to take further ownership of my health.

Gilbert Salinas, MPA
2013-2014 Kaiser Permanente Safety Net Fellow, Institute for Healthcare Improvement
Director of Patient and Community Relations, Rancho Los Amigos National Rehabilitation Center
The conference summary, which appears earlier in this volume, presents the recommendations from the conference, while the following pages offer a more detailed review of the passionate and dynamic discussions that took place each day. Aside from consensus around the recommendations, all conference participants expressed deep appreciation for the opportunity to participate in the conference. Many said the experience was a valuable and unprecedented learning opportunity because it brought healthcare practitioners, health professions educators, and patients together in a thoughtful, open, and honest conversation that they wished could have continued on much longer.

The structure of the conference was like that of previous Macy Foundation meetings: two-and-a-half days of intense discussion that culminated in action-oriented recommendations. The first full day of the conference was devoted to presentations and conversations around a commissioned, context-setting paper and four case studies—the full texts of which are included in this monograph. The second full day consisted of small group discussions around themes and issue areas of particular relevance that resulted in draft recommendations. And the third day—a half-day—was focused on achieving consensus around the draft recommendations that emerged from the small group discussions.

DAY 1: FRIDAY, APRIL 4, 2014

George Thibault, MD, president of the Josiah Macy Jr. Foundation, opened the meeting by welcoming the 41 participants and explaining the genesis of the conference. He described the Macy Foundation’s history of supporting innovations in health professions education, particularly interprofessional education (IPE), and its efforts to bring IPE together with clinical practice reform. “But in doing
so, in bringing the education and delivery worlds together, we realized that the conversation was incomplete,” he said. “We knew that in order to complete it, we needed to include patients, families, and communities.” With this conference, the Foundation brought patients, families, and communities to the table with innovative health professions educators and clinical practice reformers.

Thibault referenced the long history of attempts to engage patients more meaningfully in the process of healthcare delivery. He invoked the 1978 International Conference on Primary Health Care in Alma-Ata (in today’s Kazakhstan), where conferees declared health a fundamental human right and stated that people have both a right and a duty to participate in the planning and implementation of their health care. According to Thibault, “That was in 1978. So we’ve been slow to catch on to this. Slow to catch on to the interprofessional nature of education. Slow to catch on to the importance of collaborative practice. Slow to catch on to the fact that we can’t do this without the input of the patients we serve.”

He went on to explain that recent years have brought a renewed interest in primary care and placing patients at the center of healthcare delivery. He lauded the many meetings and conferences taking place on the topic, and mentioned some of the new terminology that has entered the lexicon, including “patient engagement,” “shared decision-making,” “activated patient,” and “patient-centered medical home.”

And he talked about the particular importance of the group of conferees gathered around him. “First, I don’t think there has ever been a group assembled that represents these different sectors in equal proportions,” he said. “We have educators of health professionals, healthcare delivery experts, and patients and patient advocates all assembled around the table. Second, we have a stronger focus on health professions education than most other efforts of this nature. We’re interested in how to prepare the next generation of health professionals in ways that are informed by patients, families, and communities.

“Third, we want this discussion to go well beyond the point of care delivery,” he continued. “As important as it is that patients be engaged in their own care, it is not sufficient. We want to go beyond that to involving patients, families, and communities in redesigning the education and delivery systems. And fourth, we are not here to just have discussions, but to reach conclusions and craft recommendations about how we’re going to move toward the ‘sweet spot’ of having
patients, families, and communities working in partnership with health professions educators and healthcare practitioners.”

Following Thibault’s opening remarks, conference co-chairs Terry Fulmer, PhD, RN, FAAN, dean of the Bouvè College of Health Sciences at Northeastern University, and Martha (Meg) Gaines, JD, LLM, director of the Center for Patient Partnerships at the University of Wisconsin-Madison School of Law, added their own welcomes. Fulmer remarked that she hopes to take everything she learns from the conference back to Northeastern’s College of Health Sciences, with its six departments and nine disciplines, and truly “embed, embrace, and move forward” with transforming health professions education.

Gaines followed up, commenting on the challenge presented by the topic of the conference. “We’re not here to talk about engaging patients in their own care,” she said. “Or about healthcare reform or education reform,” but about bringing patients into the effort to link reforms in both health professions education and healthcare “because patients should be at the center of both efforts.”

Conference participants then introduced themselves one by one, explaining who they are and why they were attending the conference. To provide a better sense of the group dynamics at the conference, here are several sample quotes from those introductory comments:

- [All of my medical education, training, and experiences as a practicing physician and healthcare administrator] prepared me poorly for that which should be in health care and that which actually is . . . To remove people from the opportunity of understanding, participating in, and leading their own lives [particularly when it comes to their own health care] is a shame and a tragedy and blight on our profession.

- If we remember that patients are the ‘true north’ of all of our efforts [in healthcare delivery and health professions education], then everything will line up behind that. But it can be hard to remember our true north when all of the structures, policies, and financing create a lot of mess behind the curtain.

- If we’re going to make any progress, we have to challenge current cultures in health care.
• We are all pioneers here and we can make a change for the better for all patients, not just for the well-educated patients or the patients that demand to participate.

• I’m here because [I’m on the journey] that many of us around this table are on, and that’s toward more comprehensive, integrated, coordinated, and patient-centered health care, and away from buying an episode of care that’s doctor-centered.

• I spent 20 years teaching medical students, and I wish I trained them differently. I’m here because I actually am looking for a revolution.

• I’m here because, 13 years ago, I lost a child to graduate medical education, and to a lack of interprofessional care and lack of listening to patients.

• There is pressure finally on the leadership of healthcare institutions to improve the experience of care, but instead of building an approach to partnership, . . . we’re moving backwards to what I see as customer service and service excellence, which are just quick fixes for improving the patient experience, and that makes me very sad and frightened.

• I’m interested in being here with all of you to learn and to innovate. Health care is chaotic. It’s painful, dangerous, and disruptive all at once.

• I want to be sure that when I go into my different circles of influence [within health professions education and practice], that I have a very, very broad perspective such that we are allocating our resources where we get the best return on our investment.

• I have recently grown more dismayed that what we’re [seeing] now is that a lot of [institutions] can take care of requirements [to be patient centered] in a check-the-box, [customer-service] manner . . . there are a lot of ways to improve your patient experience scores that have absolutely nothing to do with partnering with patients and involving them in the redesign of care.

• I don’t know if there will be a revolution, but certainly there will be an evolution and that slower pace of change [toward educating medical students who have the greatest capacity to serve patients, populations, and communities] will make it no less impactful. We have to change because . . . there are demographic shifts ahead.
• I want a revolution, but the one I want is a little different . . . patients, families, and communities really need to know that they have leverage, but they also need to know what their roles and responsibilities are and that we have expectations of them.

Following the introductory comments, conferees turned their attention to a presentation and discussion of a special context-setting paper that was commissioned for and distributed prior to the conference.

Presentation and Discussion of Commissioned Paper: A Vision for Engaging Patients, Families, and Communities in Linking Interprofessional Education and Practice

For the conference, Angela Coulter, PhD, and Michael Barry, MD, both of the Informed Medical Decisions Foundation, drafted the paper, “A Vision for Engaging Patients, Families, and Communities in Linking Interprofessional Education and Practice.” As mentioned, this paper was distributed to conferees ahead of time so that it could be discussed at the conference.

Coulter and Barry launched the discussion by providing a brief overview of the paper, which begins by challenging the assumption that healthcare is in the hands of professionals. Coulter explained that a person with a chronic health condition lives with and manages that condition 100% of the time, while healthcare professionals are involved with that person’s health maybe only 0.03% of the time—during face-to-face provider-patient interactions. She went on to say that we should not be talking about “empowering” or “activating” patients “who are already more involved in their own healthcare than a health professional could ever hope to be.” Coulter and Barry instead suggest that patients, families, and communities should be viewed as “co-producers” of health, bringing a specific type of expertise—in living with illness and caring at home for a person with illness—to health care that is not currently recognized as such.

According to Coulter and Barry, the concept of co-producing health is about looking at a person with illness or disability and identifying that person’s assets: what does he or she contribute to their own health and how can health professionals help strengthen that contribution? It says that health professionals should stop looking at patients and seeing only their challenges or deficits. Co-production also calls on healthcare providers and institutions to stop organizing care around their own needs and policies, and begin organizing it around the patients’ needs. It also calls on
health professionals and institutions to recognize patients as equal partners in caring for their own health.

The paper goes on to lay out a framework for productive partnerships and suggests several examples of ways to create such partnerships with patients, families, and communities. The paper includes a discussion of the types of changes that are needed at various levels—such as a commitment to interprofessional education (IPE), collaboration, and related competencies—to make such partnerships possible.

Following the brief overview of the paper, the floor was opened for discussion. One conferee reiterated the need to think about partnerships as being focused on health and wellness rather than diagnosis and treatment. The same person asked how to help patients make the best choices for their health during the 99% of time that they are not talking face-to-face with a health professional. The authors explained that it is important not to tell patients what to do—which research has shown doesn’t work well—and instead meet the patients where they are and talk with them about how to set goals and prioritize their choices.

Another commenter mentioned that it will be very difficult to move toward this type of patient-centered, collaborative partnership without changing the way the healthcare system is currently financed. The commenter pointed out that other western countries do a much better job spending on social services and health care almost equally, while the US puts the large majority of its resources into medical care while ignoring many of the social supports that influence health. Further, in the US, there have been and still are disincentives for community providers to collaborate or partner with other providers, which impacts how thoroughly and efficiently patients’ needs are met.

The comments continued with tremendous enthusiasm for the paper, including ways that it could be made even stronger. Several commenters felt that there is an urgent need for such partnerships in health care, but that the paper did not convey this urgency strongly enough. Other comments concerned just how difficult the paradigm shift in health care will be—stressing that its not about bringing in customer service experts to increase patient satisfaction scores, but about working with patients and families, in partnership, to identify the best ways to manage nursing shift changes, rounding, and other policies and practices that directly impact patients. It is also about integrating the perspectives of patients, families, and communities in macro-level policies—including in research, delivery models,
payment reforms, and more. Really, it is about a significant cultural shift within healthcare institutions and the health professions.

Another conferee mentioned that many such changes are already happening in both medical education and clinical practice, changes that do center on the patient—improving care coordination, for example—but that the challenge is measuring how well these changes actually create the desired outcome. Do they foster partnerships that ultimately improve care for patients? A suggestion was made to change the name of the central concept of the paper from partnerships that “co-produce” health to partnerships that allow patients, families, communities, healthcare providers, and health professions educators and students to “co-imagine” health. The idea being that co-production suggests a series of tactics and changes to the way things currently are that leave little room to dream up entirely new solutions.

Also remarked upon was the fact that the paper focuses on the education of health professionals, but does not give equal consideration to the education of patients and their families to prepare them for participating in partnerships at all levels—from learning more about their own health conditions to learning about advocacy and systems change.

Michael Barry then took a few minutes to summarize the primary themes he heard during the discussion of the commissioned paper, including the need for a stronger sense of urgency around the topic of partnerships; the need for healthcare payment reform as well as cultural reform to make partnerships more possible; and the need for partnerships at all levels, from the micro level involving individual patients and their providers up to the macro level involving institutional and governmental policies around healthcare delivery and health professions education.

**Presentations and Small Group Discussions of Four Case Studies**

Following discussion of the paper, four case studies illustrating patient engagement and partnership efforts in health professions education and healthcare delivery organizations were presented. As with the paper, the case studies are included in this volume and were distributed to conferees for their review prior to the conference. Also, case study presentations were kept brief to leave more time for discussion of each case study.

Following the presentations, conferees participated in one of four breakout groups,
each of which discussed the details of one of the case studies and explored its implications for developing productive partnerships with patients, families, communities, health professions educators, and healthcare providers. The conferees then came back to together to report on the main themes from those small group discussions. Below are highlights from both the presentations and group discussions for each of the four case studies.

1. Université de Montréal: Partners in Interprofessional Education: Integrating Patients-as-Trainers

Overview

This case study, which focused on efforts at the Université de Montréal in Canada to integrate the voices of patients into health professions education and clinical practice, was presented by Vincent Dumez, representing the patient perspective, and Marie-Claude Vanier, representing the faculty/provider perspective.

Dumez provided brief background on his experiences and perspective as a patient as well as on his work, for the past 25 years, as a peer-educator, helping patients like himself learn how to advocate for themselves and navigate the healthcare system more effectively. Based on his experiences, he was invited by the dean of the faculty of medicine at the Université de Montréal to help create an office of faculty-patient partnerships as well as an “ambitious” patient engagement program to leverage the knowledge and expertise of patients to help train health professions students and faculty.

Dumez mentioned the natural fit between patient partnerships and interprofessional education, which focuses on collaboration among different types of health professionals. He also talked about empowering patients and families to become involved in their care and to self-manage their health to the full extent of their capabilities, with support from their health care team. He said that, in his experiences of bringing patients together to talk about designing and implementing partnerships, there was much discussion around the need to go beyond improving communication between patients and providers to actually “humanizing” health care and placing patients interests at the center of it, but more over, to consider patients as an equal member of the care team, a full partner.

Vanier then picked up on the University’s efforts to integrate this vision for equal partnerships within the IPE training curricula for health professions students from the
13 different disciplines at the Université de Montréal. She explained that, early on, prior to the creation of the faculty-patient partnership office, the school was focused on the patient-centered approach to care. But once the office was created, in 2010, and patients became more directly involved in planning discussions, “we decided to change the system and make the shift toward teaching and promoting more important patient partnerships that involve patients in their own care.”

She went on to explain that, in order to help health professions students adapt to the new way of doing things, the school needed to bring patients into the classrooms as co-educators on collaborative practice, which they did on a pilot basis at first, and now in a more integrated fashion across the IPE curriculum and into clerkships. Vanier was careful to point out that the patients are involved as more than simply “standardized patients,” which may follow along a case study or script. At Montréal, patients are trainers, joining in the case discussions, contributing their own personal insights and experiences, and providing direct input into students’ learning and performance.

Discussion

When members of the small group that discussed this case study reported back, they listed the primary themes that threaded throughout their conversation. The first was that partnerships begin with caring, dignity, and respect. “We don’t want to lose the emotional or humanistic part of this work,” the presenter said. She went on to explain that they would describe partnership as “patients, learners, educators, and clinicians must be co-inventors of education and practice at the systems, policy, and process levels and support quality and humanistic care.” The second theme: within partnerships, patients, educators, and clinicians must respect each other and each other’s contributions, expertise, and experience equally. Third: each of the members of a partnership has an equal role in co-creating a shared vision for the future.

The fourth theme presented was that the effort to create partnerships must be driven by a business case that is both quantitative and qualitative—it must be part of a strategic priority. The fifth theme was leadership—the concept of equal partnerships must have buy-in and support at all levels. Another theme was sustainability—just like IPE must be sustained over the long-term, the partnership effort must be stewarded and supported with resources over the long-term. And finally, there must be an intentional design for the partnerships that integrate patients at all levels in order to build strong engagement capacity from inside the organization.
2. University of Rochester Medical Center: 
Patient- and Family-Centered Care Initiative

Overview

Brad Berk, CEO of the University of Rochester Medical Center, introduced the second case study, which focused on his institution’s Patient- and Family-Centered Care Initiative. He spoke of the years leading up to that initiative, during which the medical center worked determinedly to further develop customer relationships and service excellence, quality and safety improvement initiatives, and team-based care and collaboration. These efforts were all ongoing when, in 2009, Berk was in a catastrophic biking accident. His subsequent experiences as a patient at his own institution over the course of his recovery and his rehabilitation, which involved learning to live and work with tetraplegia, have guided his leadership around the interprofessional Patient- and Family-Centered Care Initiative.

Berk presented his institution’s efforts to place patients and families at the center of care through multiple strategies, including by improving workflow processes at the hospital. For example, in the intensive care unit, technology was implemented to significantly reduce the charting requirements for nurses and other providers, allowing them more direct time with patient and families—the lack of which was previously a major source of patient dissatisfaction. “We also changed from focusing on providing care to patients,” he said, “to working with patients and their families right from the get go—and, when the hospital stay is planned ahead of time, we do it before they come in so they understand what we mean by building a partnership. We also ask patients directly to define for us who their family members are because, frequently, it’s not who you expect it to be. Those family members then become our partners. We educate, support, and encourage them to be involved in all aspects of care.”

Berk spoke not only about the changes in processes and policies at the medical center, but also about the changes in culture, including the adoption of a new value system called “ICARE,” which includes, as its tenets, integrity, compassion, accountability, respect, and excellence. Significant efforts have been made over the last few years to define these behaviors for all employees, including by specific role, so that they may truly personify these values.
Discussion

The small group that discussed the Rochester case study reported on several themes that arose during their discussion. Primary among these was the need to define the core elements of successful partnerships with patients, families, and communities. Another theme focused on the importance of establishing integrated, sustainable partnerships at all levels to assure they are not episodic or temporary. The group also emphasized the power of storytelling and suggested that partnership stories be gathered and widely shared to inspire partnerships further, to drive the change process, and scale up the effort.

Another key theme discussed by the group was the power of human resources as a major tool in the transformation process. The group discussed human resources as a lever to spur the development of partnerships, including by setting hiring policies and developing job descriptions that support the culture change that is sought. Related to this theme is the need for faculty leadership as well as the need to develop among those leaders accountability for making partnerships a priority. Faculty leaders must set expectations and model behaviors that demonstrate a commitment to mutually respectful partnerships. Also discussed was the need for metrics and transparency with regard to data, so that both providers and patients understand the benefits and challenges of partnerships. Finally, the group discussed the need to create or change incentives to spur the development of partnerships.

3. Veterans Health Administration: 
Engagement Strategies for Returning Combat Veterans

Overview

Stephen Hunt from the US Department of Veterans Affairs (VA) provided an overview of the third case study on “Engagement Strategies for Returning Combat Veterans: Veteran and Family Engagement and Interprofessional Education in Design and Implementation of VA Post-Deployment Care.” Hunt, as national director of post-deployment care, talked about the challenges the VA faces trying to care for returning combat veterans whose lives have been radically altered by their experiences in places like Afghanistan and Iraq. “I don’t think that what we do in supporting them is simply medical care,” he said. “It’s even beyond health care, it’s more like life care. We’ve developed a bio-psycho-social model involving a team of providers, including a medical provider, a mental health provider, and a social worker.” He went on to explain that, even though the interdisciplinary supports
provided (and described in detail in the case study) are veteran-centered and involve veteran and family engagement, there needs to be a more systematic effort made to improve and expand that engagement.

**Discussion**

This group noted that this case study came out of the VA, which is a population-based healthcare system with a structure, mission, set of expectations, etc. They suggested that a system, with structure and alignment around clear goals and processes, also is necessary to help partnerships thrive. They suggested that partnerships must be meaningful connections for all involved—they must be equal in terms of the balance of power as well as buy-in from all sides, they must be functional and achieve measurable outcomes, and they must be sustainable. The group also suggested that it is important to identify and define the competencies necessary for partnerships, and that everyone in the partnerships must be given the opportunity to acquire the competencies needed to achieve new expectations and goals around collaboration and partnerships. Finally, the group mentioned the need to develop metrics and measures for evaluating partnerships as a means to create accountability and credibility.


**Overview**

The fourth case study, featuring the Duke Health Leadership Program (HLP), was presented by Michelle J. Lyn of Duke University School of Medicine. Lyn provided brief background that led to the creation of the program, which prepared practicing health professionals to partner with patients and families to improve health and health care in their communities—and to teach others to do the same. During the four years of the program, the HLP trained 53 health professionals in partnership, health promotion, and care coordination intended to help improve outcomes in underserved communities.

Lyn also spoke about the program’s challenges, which according to the case study included time, money, and breaking long-held assumptions. She spoke in particular about the “terrifying” aspect of the culture change that is needed to enable partnerships with patients, families, and communities to thrive. “It is terrifying
because many of our current health professionals lack training in how to effectively partner with patients, families, and communities, and the overwhelming majority of our healthcare systems lack the organizational capacity and structure to support the meaningful engagement we are talking about in this meeting,” she said. “. . . [F] or our current and future healthcare professionals it is imperative that we provide training in engagement, authentic transparency, shared decision-making, and team-building with patients, families, and communities.”

Discussion

The discussion among members of this group was wide-ranging, and the presenter said they used the case study as a “bouncing off point” for thinking about partnerships. A primary theme that seemed to run through their discussion is the need for capacity building around partnerships. They talked about the need to let trust among the various partners develop over time, and suggested that individual partners could benefit from coming together in a learning laboratory and collaborating around solving problems. The group also pointed out that conferees are talking about patients, families, and communities together as if they are the same, but they are not, and each will have a different role within partnerships and each will bring different needs, approaches, and contributions.

The group also acknowledged the changing natures of communities as well as of health systems and other institutions, and said this will necessarily affect things like the sustainability of partnerships over time. This is also relevant when thinking about healthcare reform, which is changing healthcare payment models and incentives. The group also talked about health professions students and how to develop them both as partners and leaders, and the need to think about how IPE can support partnerships. And finally, the group mentioned its discussion of the need for measurement and accountability around all facets of partnerships.

Discussion of Themes from Day One

Before adjourning for the evening, Conference Co-Chair Terry Fulmer suggested a preliminary set of key themes that arose from the day’s discussion. She presented these to the full group of conferees for consideration because the primary themes from day one would become the focus of small group discussions leading to conference recommendations on days two and three.
The first key theme Fulmer mentioned was that of culture change—true and durable partnerships will require fundamental culture change within health care. Related to culture change is the theme of organizational change in both health professions education and healthcare delivery institutions, which must alter existing policies, programs, processes, leadership, capacities, and more in order to create sustainable partnerships with patients, families, and communities.

Another major theme according to Fulmer: education around partnerships is needed for patients, families, and communities to build capacity and bring partnerships to scale. Also needed are changes in the content and conduct of health professions education in order to prepare future health professionals for partnerships. Another important theme is that of payment and regulatory reform needed to make partnerships possible and sustainable. Finally, the notion of measurement and evaluation came up again and again throughout the day.

The floor was then opened to the conferees to suggest additional themes for consideration or to amend or remove suggested themes from Fulmer’s list. One suggestion that gained traction among the conferees was the need to define the transformation that was being discussed—what do the conferees envision for the future of health care? There was a general consensus reached that the recommendations document should include a vision and/or value statement.

Another well-supported suggestion was the theme of equality in these partnerships, including the need to recognize that patients, families, and communities are the drivers of health care and they bring equivalent expertise to the table. In terms of preparing people to participate successfully in these partnerships, there needs to be education, training, and capacity building on all sides, not just for patients, families, and communities. There also needs to be an argument or business case made around the value of these partnerships—that patient-centered care is not only the right thing to do for people, but the right thing to do for the bottom line.

Finally, several conferees responded positively to the idea that partnerships allow patients, families, communities, health professions faculty and students, and healthcare providers to “co-create” health together. Much of the discussion at the very end of the day focused on the need to examine the language and assumptions on all sides of the partnership equation. Some of the specific words that were mentioned as limiting and constraining include “patient,” “healthcare professional,” and “interprofessional education.”
DAY 2: SATURDAY, APRIL 5, 2014

The second full day of the conference began with a brief recap of the key themes from day one followed by the conferees breaking into five groups to discuss those themes and begin the process of turning them into recommendations for action. In summarizing the discussion from day one and preparing conferees for day two, Conference Co-chair Meg Gaines said: “. . . As co-inventors of health, we need to make sure there is true engagement with patients, families, and communities . . . We will not create an ordinary conversation today.”

She then explained that, overnight, the conference planning committee had created and assigned five breakout groups, each organized around a key theme. The small groups were to spend the morning discussing the themes in more detail, and return in the afternoon with the beginnings of recommendations focused around their assigned theme.

The five themes assigned for small group discussion were:

- Build the capacity for partnerships among patients, families, and communities and health professions education and clinical practice.
- Make changes in healthcare delivery organizations necessary to facilitate partnerships among patients, families, and communities and health professions education and clinical practice.
- Make changes in health professions education organizations necessary to facilitate partnerships among patients, families, and communities and health professions education and clinical practice.
- Make changes in the content and conduct of health professions education.
- Make regulatory and payment reforms that support and sustain partnerships among patients, families, communities, and health professions education and clinical practice.

Gaines explained that the conference planning committee considered all of the themes suggested at the end of day one, and felt that these five captured the most salient points. Other important themes, such equality within partnerships and the need for a vision statement, could be captured in the preamble to the
recommendations document, she said. And some themes, such as leadership and measurement, were described as crosscutting the key themes and thought likely to be raised in discussions of the five.

Following some discussion to clarify the parameters of the five themes, there was general consensus that they would work well as the primary themes around which to craft recommendations, and the conferees assembled in their small groups.

Reports from Small Group Discussions of Conference Themes

That afternoon, the conferees came back together to hear reports from the five small group discussions, which are highlighted below.

**Group #1: Build the capacity for partnerships among patients, families, and communities and health professions education and clinical practice.**

Group #1 began by identifying barriers that impede partnerships from taking root. These barriers include the fact that the side of patients, families, and communities may not feel safe and may fear repercussions when partnered with health providers and educators. These feelings of vulnerability may arise because of an unequal power dynamic, an asymmetry in the amount and quality of information that is readily available, and the lack of structure and support for partnerships. The group also talked about other barriers, such as those related to payment—“the way the dollars currently flow does not really support partnerships.” And they discussed the underlying assumptions about the ways that health care currently works, stating that the culture and established processes and policies create barriers to partnerships as well.

The group then summarized its overall recommendation: organizations should be accountable for developing and implementing robust ways to receive and respond to issues, concerns, and other feedback from patients and families in a manner that ensures their safety and freedom from repercussions. Further, organizations should respond with a new set of norms and values that are guided by respect.

The group went on to explain that organizational leaders need to determine a framework for change based on a set of core values that support partnerships, and they need to support and empower everyone involved in those partnerships—employees, providers, patients, families, etc.—to implement the core values through defined behaviors for which everyone is accountable. Also discussed was the need for education for everyone involved in partnerships around the defined values and
behaviors, and the need to create measurements that reflect what is being achieved in terms of building partnerships and also as a result of partnerships. The group suggested working with national quality-focused organizations to create the right metrics.

The group also identified some competencies that are needed for everyone around relationship building and collaborating within relationships. They also recommended the creation of an organizational structure to support and advance partnerships with patients, families, and communities. Such an organization could, for example, develop a national set of standards or guidelines for partnerships and create a national partnership curriculum, adapted to each type of partner, and launch a national campaign to begin educating the public and other audiences around this work. The organization should span from local to national levels, be securely funded to avoid conflicts of interest, and be linked to other like-minded organizations.

**Group #2: Make changes in healthcare delivery organizations necessary to facilitate partnerships among patients, families, and communities and health professions education and clinical practice.**

Members of this group began by explaining that they first played with the language a little bit—recommending that patients be called individuals to recognize their autonomy, and that health professionals be referred to as care partners in order to be inclusive of the broad diversity of roles and positions found within caregiving institutions, including paraprofessionals, administrative staff, and others. Based on the need to be inclusive while also recognizing diversity, the group also drafted a vision statement for partnerships, declaring “that all community, social, and healthcare organizations work together to support individuals, families, and communities in living well across settings and through time.”

They went on to explain that “health begins with individuals, their families, and their communities. And care settings belong to the people who use them, and health care is the responsibility of all.” The group recommended that healthcare systems be restructured to reflect these principles because this is the right thing to do and it adds value.

The group then presented several recommendations specific to its assigned theme, including the need for organizational governance to create a vision, mission, values, and strategic priorities around a broadly collaborative partnership process that explicitly names patients, families, and communities as partners. The group also
talked about the need to orient trustees and other leaders toward partnership, and to also recruit leaders that have this orientation.

The group also named communications as an important priority, and recommended that organizations recognize that they are missing the involvement of individuals, families, and communities, and thus should reach out to their communities, actively engage and listen to them, and then invite them into an authentic partnership focused on redesigning the healthcare system.

The group also discussed organizational operations, and recommended that leadership at all levels and across all types of healthcare organizations create both the structure and culture for partnerships with individuals, families, and communities. This includes creating incentives for everyone to build and sustain partnerships. The group mentioned the importance of human resources as a strategic partner in organizational transformation. Also mentioned was the existence of organizations that already are deeply involved with their communities that could offer some baseline guidance.

**Group #3: Make changes in health professions education organizations necessary to facilitate partnerships among patients, families, and communities and health professions education and clinical practice.**

This group began by clarifying the target of its recommendations discussion: health professions education organizations—not students, faculty members, or curricula, but schools. And the group described what it would like to see achieved as the result of the conference recommendations as “patient experience 2.0,” arguing that we need to “go beyond patients sitting on committees and meeting students on the first day of classes, to having patients engaged in everyday decision-making at the highest levels.” The group also drew a helpful comparison to efforts to increase diversity in the health professions workforce. Health professions schools can ask themselves how they are contributing to that effort. Do they have a vision? What changes have they made? What structures are in place to help? These questions are similar to what the schools should be asking themselves regarding partnerships.

The group then presented four recommendations for changes necessary in health professions schools. First: educate leaders—from board members to deans to faculty and teachers—about partnerships so that they may create a shared vision. Second: health professions education organizations should change their pre-professional requirements for students, ensuring that students have a deep grasp of public
health and the social determinants of health, because these are the starting points for understanding community health, and that students understand health is about so much more than sick care. Further, in parallel with efforts to increase diversity, schools should be enrolling more students from underserved communities that traditionally have not had a voice in health care.

Third: every health professions school should create an office (or other formalized function) for partnerships with patients, families, and communities. This could be an office, department, director, etc., of partnerships—similar to what has been created for both IPE and diversity. The group suggested that it is also possible that already existing offices for IPE and/or diversity could be combined with partnerships to create an umbrella office that oversees all. The group also posited that IPE and partnerships with patients, families, and communities are very closely connected and that, perhaps, the two should be combined. The group’s fourth recommendation: identify a place to collect and disseminate innovative models for patient partnerships that already are happening in schools and other institutions around the country.

**Group #4: Make changes in the content and conduct of health professions education.**

Members of group #4 presented five areas in which they recommended changing the content and conduct of health professions education. The areas include content, conduct, leadership, accountability, and research and measurement. In terms of content, the group recommends that competencies related to effective partnerships be developed for health professions students and for patients, families, and communities. These competencies should build on existing frameworks and their development should be collaborative—faculty, students, and patients, families, and communities should be involved in the development of both. Some of the necessary competencies suggested by the group include clinical ethics, conflict prevention and resolution, working in partnerships, cultural competency, effective communication, and patient empowerment.

In terms of the conduct of health professions education, the group made recommendations related to changing its structure, delivery, and assessment. The group said that health professions education should be progressive, longitudinal, competency-based, and should involve patients, families, and communities across all settings and student experiences. Further, there should be a formal quality improvement component that involves all partners. The group also talked about
Skills Required for Building Successful Productive Partnerships

**Specific knowledge and skills for desired outcomes**

**Desired outcomes**
- Selecting most appropriate treatment or intervention
- Managing care efficiently
- Improving quality and patient/family experience
- Healthy Communities

**Partnership**
- Mapping decision points
- Eliciting patient’s values
- Providing evidence-based information and decision support
- Communicating risk
- Sharing decisions

**Supporting Core Skills**
- Communication | Address resistance, prevent & resolve conflicts
- Clinical Ethics | Vision and leadership | Patient empowerment

*Partnership results in optimal care and engagement of patients, families, and communities in their care and in organizational changes (Higher education and Healthcare)*

"Empowerment is: 1) supporting people to develop the knowledge, skills, and confidence to take effective action to manage their own health and make appropriate decisions about their healthcare and 2) Providing people with support to participate effectively in design and implementation of care delivery, health research, and the training and education of health professionals.

Figure adapted by Marie-Claude Varier from A. Coulter and M. Barry: “Engaging Patients, Families and Communities to Link Interprofessional Practice and Education,” which is a paper commissioned for the Macy Conference on Partnering with Patients, Families, and Communities to Link Interprofessional Practice and Education. The paper is published as part of the conference monograph.

**Legend:** This figure illustrates the skills health professionals need to create full partnership with patients, families, and communities. These skills are presented in relation to four desired outcomes (middle circle) resulting from true partnership. The specific skills (outer ellipse) are supported by core skills (bottom rectangle). Providing effective support for patients, families, and communities requires excellent teamwork, which requires knowledge of and respect for people from many different health professions. Thus, interprofessional education is essential for developing and practicing these crucial skills. Responsibility for patient and family partnership is not the domain of a particular specialty or professional group; it should be seen as an essential component of care provided by all. Most of these skills should be considered for inclusion in interprofessional curricula.
the need to develop leadership opportunities around these partnerships, including creating a faculty position for a community member or a faculty research fellowship focused on research and education around patient, family, and community partnerships. This group also talked about possibly creating a partnership office to guide scholarly work around this topic, and mentioned that criteria focused on partnership building could be developed and used in decision-making around faculty appointments, promotions, and tenure.

The group also recommended that, in terms of accountability, leaders of regulatory bodies, professional societies, and universities should develop a balanced portfolio of educational measures related to structure, process, and outcomes—and that these should be developed in partnership with patients, families, and communities as well as the different health professions. The group also suggested that there should be research demonstration and evaluation programs related to the changes this group is recommending.

**Group #5: Make regulatory and payment reforms that support and sustain partnerships among patients, families, communities, and health professions education and clinical practice.**

This group first mentioned several principles or assumptions that impact or otherwise influence its recommendations related to regulatory and payment reforms. The first principle is that capacity for partnerships must be developed, expanded, and sustained. A second principle is that regulation and payment systems can accelerate change, but alone cannot create or sustain change. Third, regulatory and payment systems must be coherent, cohesive, and integrated to both public and private payers and purchasers. Finally, the regulatory and payment reform process—like the partnerships it is intended to support—must be inclusive. The group also noted that the Affordable Care Act provides tremendous opportunities to advance this work.

The group then presented its four draft recommendations. First: identify and work with the opportunities within the Affordable Care Act to promote and grow patient, family, and community partnerships. The goal is to create clinically integrated networks that create optimal health for individuals in communities. To this end, the group supports movement away from fee-for-service payment methodologies and encourages population health management.
The group’s second recommendation: revise existing state and federal laws and regulations to ensure partnerships with patients, families, and communities through a variety of diverse levers, both financial and non-financial. This means accelerating the expansion of models developed and tested locally to disseminate and scale partnerships. It also means that payment models should be created to stimulate and sustain partnerships in a variety of care settings and organizations. Further, barriers to partnerships should be eliminated relative to licensure and scope of practice regulations.

A third recommendation: Create financial incentives for health professions education organizations to create and enhance partnerships with patients, families, and communities. This could include creating or revising accreditation and certification standards to accelerate adoption of—and remove barriers to—partnerships.

And finally, develop financial and non-financial support for innovation and research to develop, implement, evaluate, and advance partnerships with patients, families, and communities.

Discussion of Small Group Reports on Conference Themes

After each breakout group presented its draft recommendations, the floor was opened for discussion. At this point, Macy Foundation President George Thibault reminded the group that the remainder of the conference would be focused on reaching consensus, but not necessarily unanimity, around a set of action-oriented recommendations. “We want to eliminate points of great discomfort among the group in these recommendations, but we don’t want to eliminate all discomfort among each one of us. Frankly, there should be a level of discomfort in these recommendations.”

He also asked the conferees to point out any noticeable omissions as well as any redundancies, points of disagreement, and important language issues in the suggested recommendations.

First up among the many topics raised was a discussion of the notion of creating an academic office vs. department that would be responsible for partnerships. A response to the quandary was that perhaps it would be best to suggest one of the newer type of structures, such as a center or institute, which could be both an operational unit and an academic unit. This decision, however, is best left up to the individual institutions themselves, depending on their own culture and operations.
The most important factor is that the structure operates within the institution and does not sit outside of it or be otherwise separate.

This led into a related discussion about possibly combining partnerships within existing structures that oversee IPE and diversity. The comment was made that combining partnerships and diversity seems to be a logical fit, but there is a concern about also adding in IPE, which could “gobble up” the partnership effort.

Also raised were concerns about making sure partnerships are fully integrated at all levels within health professions education organizations. “I didn’t hear enough from that group about patients, families, and communities being not only involved but deeply integrated into these institutions,” said a conferee. “We need to incorporate partnership values in faculty assessment and tenure, in five-year reviews of deans and chairs, in the incentives by which we pay faculty and other staff. We need to incorporate patients actively in the development of curricula.”

Another commenter reflected on the need to support patients who take on leadership roles within health professions education and healthcare organizations—perhaps going as far as to create a certificate or degree program in patient engagement or partnership. A similar comment added the need to also support and develop board members.

The point was raised that perhaps the recommendations do not go far enough in tackling the question of who is setting the terms and conditions for partnerships—and that it truly needs to be equal. “I’ve served on groups where there are certain very profound issues that affect the wellbeing of patients and the public,” said a conferee, “but [those issues] are off limits to what is considered appropriate for patients and public members to discuss. Yet the stakes are very high . . . I think we have to acknowledge the pressure points.”

Another commenter seconded this point: “We see it pretty commonly in health care where one or two patients are up against a roomful of clinicians and they can barely hold their own . . . but if you are one of two or more consumers in a multi-stakeholder group of purchasers, providers, payers, your ability to have influence is even further diminished. We have to have a two-way process and educate everyone in the room how to operate in that environment.”

The issue of sustainability, particularly as it relates to capacity building around partnerships, also was raised. “There’s a need for ongoing technical assistance
“Just as health care keeps evolving, the measurement worlds keeps evolving, and technology keeps evolving . . . and folks sitting there representing consumers, patients, families, and communities need to have some ongoing support.”

While it is important to develop capacities among all partners to participate in partnerships, another commenter raised the point that building consumers’ capacity to partner both influences their interactions and begins to integrate them with the healthcare system, which possibly negates the contributions of lay people who have not been trained and who may have significant contributions to make. “The public is perfectly capable of giving us input even without extensive education if we set up mechanisms to provide them with more information on an issue,” the commenter said. And another said, “At one point along this spectrum of engagement, do we have people who started out as patients and we’ve turned them into professionals and we begin to lose some of what we’re after?”

As many conferees did throughout the conference discussions, a conferee again mentioned the issue of technology—particularly information technologies—and the opportunities it presents to further the goals of partnership. Also a reminder was made that “whatever is designed” in terms of partnerships needs to be designed to change patient outcomes and not just change the experience of health care.

One commenter attempted to summarize the various types of organizational capacities that need to be developed around partnerships. These include leadership, management, adaptability, and technical capacities. Leadership capacity is when institutional leaders co-create with patients, families, and communities a vision, a mission, and values around partnerships. They then co-develop the management capacities, such as the policies, processes, and systems needed to implement and integrate the vision, mission, and values. Then, the organization needs to adapt to the changes, and many need to build their capacity to adapt because changes usually happen too slowly in health care. Patients can help with that adaptation process. And finally, technical capacity must be co-developed—the tools, skills, and experiences needed to make partnerships possible. Patients bring some of these things in the form of their experiences and knowledge.

During the discussions, several conferees raised the need to include real world examples or vignettes related to patient engagement and partnerships in the documentation of the conference (beyond examples that are included in the
four case studies). Some of the brief, anecdotal examples’ mentioned during the discussion included the following:

- At the University of Washington, patient advisors are full members of the decision-making teams responsible for selecting residents. They also are on the interview teams for the selection of key faculty, such the director of intensive care.

- At the University of Cincinnati, in geriatrics, patient advisors are part of the research team working to both change and evaluate the change in the medical rounding process.

The conversation then turned to health professional students and the need to prepare them at all levels—undergraduate, graduate, and post-graduate—to engage with community members. One commenter noted that, in visiting community-based provider organizations that do a good job partnering with communities, he was told that one of the biggest frustrations for them are the providers who come to them unprepared to engage with patients.

Another commenter followed up, raising concerns about screening potential health professions students based on their backgrounds, stating that students from underserved, typically minority communities should not be held responsible for “carrying the banner” to improve care for those communities—it should be a shared responsibility of all health professionals. Someone also noted that where students come from does not necessarily predict where they will go in their professional careers; that the education and training environment has tremendous influence over those decisions.

Another comment that stirred some discussion was made around the use of shared electronic medical records as an important point of contact that can facilitate patient partnerships because it allows important information to flow both ways. It is a means of preventing errors, having people involved in their own care, and it is a learning document that creates a feedback loop.

At this point the discussion began to wind down, and was nicely wrapped up by a commenter, who said about the co-production of health, “We all have to remind ourselves that we’re building this ship together, that we’re not here to steer it.”

---

1 Note that these examples were raised by a conferee during the discussion and have not been researched or validated by the Macy Foundation, which nevertheless sees value in including them here for readers to look into if desired.
The third and final half-day of the conference was devoted to reviewing and providing feedback on the draft recommendations document, which the conference writing committee produced based on the discussions and distributed to all conferees on Saturday night.

**Conference Conclusions and Recommendations**

The first comment made regarding the draft recommendations was representative of the many comments to follow. The conferee thought that the draft “captured amazingly well what we talked about,” but that it could be improved in several ways, including reducing the amount of redundancies, creating consistency in language, tone, format, and level of specificity of the various recommendations. Other commenters thought that the draft needed to be more clear about what was meant by certain terms, including patients, community, partnership, etc.

Many thought the draft needed a more explicit sense of urgency as well as more definitive statements. And there was consensus in the room around the need to talk exclusively about “partnerships” rather than “engagement” because “engagement” does not capture the full nature of the collaborative relationships needed between patients, families, communities, practitioners, and health professions educators and learners. Also, some time was spent suggesting improvements to the draft “vision statement” that was included in the preamble section of the recommendations draft.

One significant point of discussion regarding the content of the recommendations occurred around the recommendations regarding regulatory and payment reform. It was decided that that recommendation should be simplified and made less directive.

For the most part, however, the comments focused on language, framing, tone, organization, consistency, etc. Rather than providing an exhaustive list of the various comments made, however, it is more important to note that, overall, the first draft was thought to provide an accurate summary of the recommendations discussion. The review period was a welcome opportunity for conferees to “kick the tires” of the draft and decide if the recommendations held up and should go forward—which they did, with many suggestions for improvement.
The writing committee then took over revising the draft based on feedback from the conferees, and a near-final draft was distributed to conferees in the weeks following the conference. The final, approved version appears in this monograph.

Following discussion of the draft conclusions and recommendations, the conference ended with closing remarks from the Macy Foundation’s George Thibault, who summed his experience of the conference as “inspiring.” He went on to say, “I feel very good about where we are. The amount of energy in the last three days has been remarkable. We’ve actually been modeling the very behaviors that we want to teach and we want exemplified in our healthcare system.”


Boel Andersson Gäre, MD, PhD, is professor in leadership for improvement in health and welfare and associate professor in pediatrics, and has a background in clinical practice and leadership. Dr. Andersson Gäre’s initial research was focused on epidemiology and outcomes in chronic disease in childhood. For the last ten years, her main interest has been the development of the broad, interdisciplinary field of Improvement science, including research questions around improvement, implementation, and innovation, and how to lead change. She is currently the director and research leader of the Jönköping Academy for Improvement of Health and Welfare, Jönköping University, and director of Futurum, the center for clinical research in Jönköping County Council, Jönköping.

Michael J. Barry, MD, became president of the Informed Medical Decisions Foundation in 2009. The Foundation’s mission is to inform and amplify the patient’s voice in healthcare decisions. He has been involved with the Foundation since its founding in 1989 and previously served as chief medical editor. He is a past president of the Society for Medical Decision Making (SMDM) and the Society of General Internal Medicine in the United States. Michael has led many prominent research studies, including the Patient Outcome Research Team for Prostatic Diseases. His research interests have included defining the outcomes of different strategies for the evaluation and treatment of prostate diseases, decision analysis, health status measurement, clinical quality improvement, and the use of decision aids to facilitate patients’ participation in decision making. Michael has published more than 250 original articles, chapters, reviews, and editorials. He was the inaugural winner of the Alfred Kranes Award for Excellence in Clinical Teaching at Massachusetts General Hospital (MGH). Michael continues to practice primary care and serves as medical director of the John D. Stoeckle Center for Primary Care Innovation at MGH. He is also clinical professor of medicine at Harvard Medical School and a master of the American College of Physicians.
Jacqueline Beckerman, MPH, senior director, patient experience at the University of Rochester Medical Center (URMC), has worked passionately over the last ten years to improve the healthcare experience for patients and families, as well as for providers (and care teams) themselves. First, as director of the URMC’s comprehensive Service Excellence Program, and more recently as lead for the Patient- and Family-Centered Care Initiative, she has been instrumental in developing a multi-faceted, interprofessional approach to patient- and family-centered care and involvement. Central to this effort has been a concerted emphasis on clinical/cultural transformation with a thoughtful implementation of core values; engaging patients and families as educators and leaders; proactive strategies for facilitating communication; and real-time, frontline advocacy for URMC patients, families, and providers. Jackie held earlier positions in Hospital Administration at Strong Memorial Hospital and as Director of Alumni Affairs for the University of Rochester School of Medicine and Dentistry. She is a graduate of the University of Rochester, from which she holds degrees in English and Psychology, and a Master in Public Health.

Bradford C. Berk, MD, PhD, is chief executive officer of the University of Rochester Medical Center (URMC) and senior vice president for health sciences. Since receiving his MD and PhD degrees from the University of Rochester, Dr. Berk has served on the faculties of Harvard Medical School, Emory University, and the University of Washington. Dr. Berk was recruited to URMC in 1998 as Chief of the Cardiology Division.

He founded URMC’s Aab Cardiovascular Research Institute (CVRI) and has published more than 250 articles, chapters, and books. Dr. Berk served as Chairman of Medicine from 2001 until 2006 when he became CEO. He serves on the Empire State Stem Cell Board Funding Committee and maintains an active research program in vascular biology.

In March of 2010, Dr. Berk returned to his CEO duties after a several-month leave in which he recovered from a serious spinal cord injury. Since Dr. Berk’s return, he has focused on cultural transformation at URMC, promoting development of a patient- and family-centered environment, developing capabilities to address the challenges of healthcare reform, and facilitating the translation of fundamental research discoveries into clinical applications.
George Wong Bo-Linn, MD, MHA, FACP, is a leading expert in health care with extensive senior executive experience in hospitals and health systems, physician organizations, health information technology, and quality improvement. He is a senior director with Alvarez & Marsal, a global professional services firm. Prior to that he served as chief program officer, Patient Care Program, of the Gordon and Betty Moore Foundation (~$6B assets). The Program focuses on meaningfully engaging patients and families in their own health care within a redesigned, supportive healthcare system and aims to eliminate not only preventable medical harms but also harm suffered by patients and families from loss of dignity and respect, and from care inconsistent with their wishes and values. He also served as chief medical officer for Catholic Healthcare West (now Dignity Health, ~$10B annual revenues), the fifth largest hospital system in the nation. Dr. Bo-Linn received his internal medicine training at the Johns Hopkins University and Hospital, gastroenterology fellowship at the University of Texas at Dallas, and master’s degree in healthcare administration from the Carlson Business School, University of Minnesota. He is a fellow in the American College of Physicians, frequently lectures nationally and internationally, and serves on boards of both nonprofit hospital systems and for-profit companies in fields of medical devices, supply chain optimization, information technology, telemedicine, and business intelligence-predictive analytics.

Barbara F. Brandt, PhD, is one of the nation’s foremost experts in interprofessional practice and education and a leading force in the creation of the National Center for Interprofessional Practice and Education housed at the University of Minnesota. As center director, Dr. Brandt is responsible for engaging leaders and experts across the country in this ground-breaking effort to improve health by realigning health professions education and care delivery. Dr. Brandt and her colleague Dr. Frank Cerra originated the idea of bringing practice and education together in a new Nexus for better care, added value, and healthier communities.

The $12 million center was launched in October 2012 through a cooperative agreement with the US Department of Health and Human Services, Health Resources and Services Administration. Four private foundations have signed on to invest in this innovative center: Josiah Macy Jr. Foundation, Robert Wood Johnson Foundation, Gordon and Betty Moore Foundation, and The John A. Hartford Foundation.

In addition to her responsibilities as center director, Dr. Brandt serves as associate vice president for education and professor, pharmaceutical care and health
systems, at the University of Minnesota Academic Health Center. Dr. Brandt is also responsible for University of Minnesota 1Health initiative to build interprofessional practice skills of students in a broad range of health professions.

Dr. Brandt has helped drive curricular and educational change in the health professions in other roles as well. In 2000 she was a US Public Health Service Primary Care Policy Fellow. From 2000 to 2006, she served on the board of directors of the Accreditation Council for Pharmacy Education, pharmacy's accrediting agency. As the founding board chair of the American Interprofessional Health Collaborative, she also has been host and co-chair for the Collaborating Across Borders (CAB) conferences held in Minneapolis, MN, in 2007 and Tucson, AZ, in 2011.

Dr. Brandt holds a Bachelor of Arts in the Teaching of History from the University of Illinois at Chicago and a Master of Education and a Doctor of Philosophy in Continuing Education (specializing in continuing professional education) from the University of Illinois at Urbana-Champaign. She was a James Scholar and Letitia Walsh Fellow. In 2013 she was recognized as a University of Illinois Distinguished Alumna. She completed a Kellogg Foundation-sponsored post-doctoral fellowship for faculty in adult and continuing education at the University of Wisconsin-Madison.

Kristin L. Carman, PhD, is vice president at American Institutes for Research (AIR), leading AIR’s Health Policy and Research program. Kristin also serves as director of AIR’s Center for Patient and Consumer Engagement. Kristin’s expertise includes developing approaches and interventions and providing technical assistance to support organizations and communities in engaging the public in their health and health care. Her work includes a specific emphasis on explaining evidence-based information for use in decision-making. She also is well regarded for her work assessing the performance of health care organizations and determining how best to enable improvement in organizational performance. In addition, Kristin is a nationally known expert on reporting health care quality and delivery information. Kristin was the lead author on the February 2013 journal article in *Health Affairs* entitled “Patient and Family Engagement: A Framework for Understanding the Elements and Developing Interventions and Policies.” Kristin holds a PhD and MA in Human Development and Social Policy from Northwestern University.

Frederick Chen, MD, MPH, is chief of family medicine at Harborview Medical Center and associate professor in the Department of Family Medicine at the University of Washington School of Medicine (UW) where he teaches health
policy, conducts research, and sees patients. He attended medical school at the University of California, San Francisco and received his Master of Public Health in Epidemiology from UC Berkeley. After completing his residency in family medicine at the University of Washington, Dr. Chen was a Robert Wood Johnson Clinical Scholar, where he developed his research interest in health policy and medical education. He then moved to Washington, DC, as the Kerr White Scholar at the US Agency for Healthcare Research and Quality. At UW, he has been the lead faculty for the WWAMI Underserved Pathway, medical director for the Washington State Patient-Centered Medical Home Collaborative, and a researcher in the Rural Health Research Center. He serves as senior advisor to the Health Resources and Services Administration’s (HRSA) Bureau of Health Professions for the Teaching Health Center program.

**Jennie Chin Hansen, RN, MSN, FAAN**, is chief executive officer of the American Geriatrics Society. In May 2010, she completed her two-year term as president of AARP following six years on AARP’s national board of directors. Prior service includes nearly 25 years with On Lok, Inc., a nonprofit family of organizations providing integrated, globally financed and comprehensive, interdisciplinary medical and community-based services for frail older people in San Francisco. On Lok’s groundbreaking fully capitated, integrated, and coordinated service delivery became the prototype for the 1997 federal law that incorporated the Program of All Inclusive Care to the Elderly (PACE) into the Medicare and Medicaid programs. In 2011, Hansen completed a six-year term as a federal commissioner of the Medicare Payment Advisory Commission (MedPAC). She currently serves as a board member of the SCAN Foundation and the Institute for Healthcare Improvement (IHI). She also serves on the American Hospital Association (AHA) Equity of Care Committee and is co-chair of the steering committee for the Coalition to Transform Advanced Care (C-TAC). Since 2012, she has been appointed to the national Veterans Administration Advisory Committee on Gerontology and Geriatrics and the Department of Health and Human Services’ National Institutes of Health-National Advisory Council on Aging.

Her honors include a 2004 CMS Administrator’s Award of Achievement, a 2010 Innovator in Health Award from the New England Healthcare Institute, and the 2011 Picker Award for Excellence in the Advancement of Patient-Centered Care in Long-Term Care. In addition she has received alumni awards from both Boston College and the University of California, San Francisco, including an honorary doctorate.
Angela Coulter, PhD, Hon FFPH, Hon FRCGP, is a health policy analyst and researcher who specializes in patient and public involvement in health care. She is director of global initiatives at the Informed Medical Decisions Foundation, Boston, and senior research scientist in the Nuffield Department of Population Health, University of Oxford. A social scientist by training, Angela has a doctorate in health services research from the University of London. From 2000 to 2008 she was chief executive of Picker Institute Europe. Previous roles included director of policy and development at the King’s Fund, and director of the health services research unit at the University of Oxford. She is senior visiting fellow at the King’s Fund in London, holds Honorary Fellowships at the UK Faculty of Public Health and the Royal College of General Practitioners and is a Trustee of National Voices. Angela has published more than 300 research papers and reports and several books, including The Autonomous Patient, The European Patient of the Future (winner of the 2004 Baxter Award), The Global Challenge of Healthcare Rationing, Hospital Referrals, Engaging Patients in Healthcare (highly commended by the BMA), and Understanding and Using Health Experiences. She was the founding editor of Health Expectations, an international peer-reviewed journal on patient and public involvement in health care and health policy. She has won awards for her work from the Donabedian Foundation of Barcelona in 2012 and the International Shared Decision Making Conference in 2013.

Vincent Dumez, MSc, holds a finance degree and a Master in Science of Management from Montréal’s international business school Hautes Études Commerciales (HEC). Up until 2010, Mr. Dumez was an associate in one of Montréal’s most influential consulting firms where he acted as a senior strategic consultant.

Suffering from severe chronic diseases for more than three decades, Mr. Dumez has been actively involved in the thinking and the promotion of the ‘patient partner’ concept at Université de Montréal. This involvement has come forward over the recent years through the completion of his master’s dissertation on the patient-Doctor relationship, his contribution to the training of patients, his work on various boards of community organizations, and his involvement as a speaker in forums and workshops for healthcare professionals.

In the past years, Mr. Dumez has been a key collaborator for the Education Centre (CPASS) of the Faculty of Medicine of the Université de Montréal. From October 2010 to June 2013, he had founded and led the Faculty Office of the Patient Partner Expertise. He is now co-director with Dr. Paule Lebel of a larger unit, which
integrates interprofessional collaboration and patient partnership competencies development.

Christian Farman, RN, became a nurse after 10 years in the aerospace industry, having worked as a technician with Sweden’s largest industry project, the fighter program JAS 39 Gripen in the SAAB Group. He has now been working since 2010 within the Swedish healthcare system at Ryhov County Hospital on an ear, nose, and throat (ENT) ward. He is also chairman of the Kidney Association of Småland and Kronoberg county in Sweden, where he works to improve dialysis quality, advocate for person-centered care, increase access to transplants, and improve conditions for patients with kidney disease. He is a popular speaker both in Sweden and abroad, where he often emphasizes the importance of person-centered care and ensuring the human perspective in health care, seeing human beings as active co-creators of care, and using the patient’s skills and experiences to improve care. He has presented at the Institute for Healthcare Improvement’s Annual Forum (IHI Forum) several years in a row. During the 2014 Forum, he was involved as co-chair.

Christian was the first patient to demand to learn how to manage his own dialysis treatment at Ryhov County Hospital in Jönköping. Along with a dialysis nurse, this became the starting point for the Self-Dialysis Unit in Jönköping County Hospital, which achieved worldwide fame for its way of engaging patients and working with person-centered care. From this effort emerged the embryo of the learning model “Self-Care Staircase” that was subsequently refined and is now successfully used in the Self-Dialysis Unit at Ryhov County Hospital in Jönköping. Christian’s own experience as a dialysis and transplant patient has included treatment with both self-hemodialysis in hospital in center and peritoneal dialysis over a period of two years. He has completed two successful kidney transplants. According to Christian, he has a great advantage as a nurse because he has three different starting points in building relationships with his patients: as a patient himself, as a patient representative, and as a nurse. It is important to see the person in front of you—never forgetting the human perspective when working in health care!

Katherine A. Flores, MD, received her undergraduate degree at Stanford University and her medical degree from the University of California, Davis. Since completing her residency training, she has spent her professional career as a family physician in private practice within an all-woman, bilingual medical group in Fresno, CA, which serves families from widely varying economic and ethnic backgrounds.
Dr. Flores is assistant clinical professor in Family Medicine at the UCSF School of Medicine and the director of the UCSF Fresno Latino Center for Medical Education and Research (LaCMER). The LaCMER is a unit of the UCSF Fresno Medical Education Program located in California’s Central San Joaquin Valley. The overall mission of LaCMER is to work with disadvantaged students and help prepare them to become healthcare professionals who will ultimately return to the Central Valley to provide culturally competent healthcare services to the medically underserved.

Dr. Flores has been active over the past 20 years in developing and overseeing programs that recruit and retain Latino and other underrepresented youth into the health professions. She has worked collaboratively with multiple partners to establish a comprehensive health careers pipeline program in the Central Valley of California, targeting disadvantaged youth, particularly from migrant farmworker backgrounds. The goal of these programs, the Junior and High School Doctors Academies and the Health Careers Opportunity Program at California State University, Fresno, is to academically enrich, nurture, and support disadvantaged youth from the seventh grade through college to assure their academic success and ultimate acceptance into health professional schools. Incorporated within the developed curriculum is a research focus that requires these students to explore health disparity issues in their local communities and provides them the scientific research skills necessary to address them. These programs also emphasize service learning and cultural competence.

Through her work in developing health professions pipeline programs for disadvantaged students, Dr. Flores and others jointly formed the California Health Professions Consortium to explore the development of a statewide strategy to address increasing the diversity of the healthcare workforce. The Consortium has grown to include members from academic institutions (faculty and administrators from universities and health professions schools), K-12 educators, direct service providers (hospitals, clinics, health plans, nurses, and physicians), health policy advocates, and others who have similar interests.

**Terry Fulmer, PhD, RN, FAAN,** is distinguished professor and dean of the Bouvé College of Health Sciences and professor of public policy and urban affairs in the College of Social Sciences and Humanities at Northeastern University. She received her bachelor’s degree from Skidmore College, her master’s and doctoral degrees from Boston College and her Geriatric Nurse Practitioner Post-Master’s Certificate from New York University. She is an elected member of the Institute of Medicine
and currently serves as the chair of the National Advisory Committee for the Robert Wood Johnson Foundation Executive Nurse Fellows Program.

Dr. Fulmer is nationally and internationally recognized as a leading expert in geriatrics and is best known for her research on the topic of elder abuse and neglect, which has been funded by the National Institute on Aging and the National Institute for Nursing Research. She most recently served as the Erline Perkins McGriff Professor of Nursing and founding dean of the New York University College of Nursing. She has held faculty appointments at Boston College, Columbia University, Yale University, and the Harvard Division on Aging. She has served as a visiting professor of nursing at the University of Pennsylvania and Case Western University.

Dr. Fulmer is dedicated to the advancement of intraprofessional health science education and progress in interdisciplinary practice and research. Her clinical appointments have included the Beth Israel Hospital in Boston, the Massachusetts General Hospital, and the NYU-Langone Medical Center. She is an attending nurse and senior nurse in the Munn Center for Nursing Research at the Massachusetts General Hospital. She is a fellow in the American Academy of Nursing, the Gerontological Society of America, and the New York Academy of Medicine where she served as vice-chair. She completed a Brookdale National Fellowship and is a Distinguished Practitioner of the National Academies of Practice. She has served as the first nurse on the board of the American Geriatrics Society and as the first nurse to serve as president of the Gerontological Society of America.

Martha E. “Meg” Gaines, JD, LLM, an ovarian cancer survivor, is founding director of the interdisciplinary Center for Patient Partnerships at the University of Wisconsin, whose mission is to engender effective partnerships among people seeking health care, people providing health care, and people making policies that guide the healthcare system. The Center trains future professionals of medicine, nursing, law, health systems, industrial engineering, pharmacy, and other disciplines who provide advocacy services to patients with life-threatening and serious chronic illnesses in a transdisciplinary environment.

As clinical professor and associate dean of academic affairs and experiential learning at the University of Wisconsin Law School, Ms. Gaines teaches courses related to consumer issues in health care, healthcare advocacy, healthcare reform, and patient-centered care—both online and in the classroom.
Ms. Gaines has received numerous awards for her work, including the National American Cancer Society Lane Adams Quality of Life Award. She has been featured in The New York Times and speaks widely on consumer engagement and empowerment in health care. Her publications include “An Odyssey of Hope,” “Alchemy: Medical Mediation at Its Best,” “A Social Compact For Advancing Team-Based High-Value Health Care,” and “Medical Professionalism from the Patient’s Perspective: Is There an Advocate in the House?”

Ms. Gaines earned her bachelor’s degree at Vassar College and holds Juris Doctorate and Master of Law degrees from the University of Wisconsin Law School.

Rosemary Gibson, MSc, is senior advisor at The Hastings Center, section editor for Less is More in JAMA Internal Medicine, and author of Medicare Meltdown (2013), Battle Over Health Care (2012), Treatment Trap (2010), and Wall of Silence (2003).

She is a board member of the Accreditation Council for Graduate Medical Education and is on the CLER Evaluation Committee to advance safety in sponsoring institutions.

At Robert Wood Johnson Foundation, Rosemary was chief architect of its $200 million national strategy to establish inpatient palliative care programs that now number 1600, an increase from about 10 in the 1990s. She received the Lifetime Achievement Award from the American Academy of Hospice and Palliative Medicine. She worked with Bill Moyers on the PBS documentary, “On Our Own Terms.”

Rosemary led national quality and safety initiatives in partnership with the Institute of Healthcare Improvement: Pursuing Perfection, Transforming Care at the Bedside, and Rapid Response System implementation. With nursing leaders she established QSEN and the Nursing Quality Alliance.

She is a public member of the American Board of Medical Specialties Health and Public Policy Committee and Consumers Union Safe Patient Project. She served on the AHRQ Technical Expert Panel for Consumer Reporting of Adverse Events.

Rosemary has given presentations and grand rounds on patient safety at hundreds of hospitals and keynoted meetings of the National Quality Forum, The Joint Commission, AONE, National Council of State Boards of Nursing, Federation of State Medical Boards, National Summit on Overuse held by The Joint Commission
and AMA, Society of Critical Care Medicine, among others. She has been faculty for the Dartmouth Summer Symposium on Quality Improvement and was its 2013 “wizard.”

She speaks to public audiences at the New York Public Library, the AARP National Convention, and George Mason University; legislators at the National Council of State Legislators; and constituents of the Women’s National Democratic Club, Connecticut Center for Patient Safety, Maine Quality Counts, and Maine Area Agencies on Aging, among others.

Her books have been reviewed in Publishers Weekly, the Washington Post, JAMA, Health Affairs; referenced in proceedings of the US Senate; mentioned in Congressional testimony; noted in the Wall Street Journal, New York Times, USA Today, Consumer Reports, and Boston Globe, O Magazine, Reader’s Digest, and US News and World Report. Wall of Silence was translated into Japanese; the Chinese translation of Treatment Trap won the prestigious Open Book Award from China Times. Rosemary has appeared on Chicago Tonight, WBGH’s Greater Boston, The Doctors, C-Span Book TV.

She graduated summa cum laude from Georgetown University and has a master’s degree from the London School of Economics.

Peter Goodwin, MBA, is chief operating officer and treasurer of Josiah Macy Jr. Foundation. In this role, Peter oversees the Foundation’s investments, finances, communications, and operations, and serves as secretary to the Foundation’s Board of Directors.

Peter has spent 30 years working as a professional in the nonprofit sector. After serving as a hospital administrator at Beth Israel Medical Center in New York City, he joined the Robert Wood Johnson Foundation (RWJF) as a financial analyst in 1984. With more than two decades of experience at RWJF, he served as financial officer, and in the senior leadership positions of vice president for financial monitoring, chief financial officer and treasurer, and vice president for national program affairs. He also planned and directed the renovation and expansion of RWJF’s headquarters in Princeton.

During his tenure at RWJF, he championed and implemented a number of quality improvement activities in the areas of accounting, information technology, grantee audits, mission-related investing, and grant competitions. As a 15-year member
of RWJF’s executive team, he provided regular trusted advice to two CEOs and heads of Fortune 500 companies, university presidents, nonprofit leaders and senior government officials.

Mr. Goodwin holds an undergraduate degree from Boston College and an MBA from The City University of New York, Baruch College. He is active in both national and local leadership roles in the nonprofit sector. He served for two terms on the Board of Directors of Grantmakers in Health, during which he also served as Chair of the Finance and Investment Committee. For the last fifteen years he has served as chair of the Board of Directors of the Sikora Center, Camden New Jersey. Sikora Center is an outpatient treatment facility for substance abusing women. He currently serves as a member of the Board of Directors of Garden State bioEnterprises, which produces commercial grade algae byproducts for the pharmaceutical, nutriceutical, and agricultural industries. Peter is a fellow in Leadership New Jersey, a statewide program to identify and connect leaders in government and the nonprofit and business communities.

Paul Grundy, MD, MPH, FACOEM, FACPM, known as the “godfather” of the patient-centered medical home movement, is IBM Corporation’s global director of healthcare transformation. In this role, he develops and executes strategies that support IBM’s transformation initiatives in the healthcare industry. He is also adjunct professor at the University of Utah Department of Family and Preventive Medicine. Dr. Grundy won the NCQA national quality award for 2012 and the American College of Occupational Environmental Medicine 2013 Sappington Memorial Award.

He is presently a member of the National Academy of Sciences Institute of Medicine and the IBM Industry Academy. Dr. Grundy serves as a director of the ACGME, the body responsible for accrediting graduate medical training programs; a member of the national advisory board of the National Center for Interprofessional Practice and Education; Mayo Clinic Center for Connected Care (C3); and the Medical Education Futures Study. Dr. Grundy is president of the Patient-Centered Primary Care Collaborative, a coalition he led IBM in creating in early 2006. The collaborative is dedicated to advancing a new primary care model, called the patient-centered medical home, as a means of fundamentally reforming healthcare delivery. Today, the collaborative represents employers of some 50 million people across the US; physician groups representing more than 330,000 medical doctors; leading consumer groups; and the top seven US health-benefits companies.
Dr. Grundy is a retired senior diplomat with the rank of Minister Consular from the US Department of State and was medical director for the International SOS and Adventist Health. Dr. Grundy is also known for his work on AIDS education in Africa. Dr. Grundy has received several work-related awards which include three US Department of State Superior Honor Awards, four Department of State Meritorious Service awards, the Defense Superior Service Award, and the Defense Meritorious Service medal.

Barbara Guthrie, PhD, RN, FAAN, is Independence Foundation Professor of Nursing and was, for seven years, associate dean for academic affairs at the Yale University School of Nursing (YSN). Dr. Guthrie received her bachelor's degree in Nursing from Boston University, her Master of Science in Nursing in Family Health from Duquesne University in Pittsburgh, and her doctorate from the New York University School of Nursing. Prior to accepting the position at Yale University School of Nursing, Guthrie held a dual appointment at the University of Michigan as associate professor in the Division of Health Promotion and Risk Reduction and Women Studies.

Her collaborative research efforts with adolescent females has led to her receiving funding from such agencies as the National Institute of Drug Abuse, National Cancer Institute (NCI), and National Institute for Nursing Research. She has published several articles that focus on girls’ health as a socially embedded process that is influenced by their contact with the juvenile justice system. She also has received funding from Josiah Macy Jr. Foundation for her Yale Howard Interdisciplinary Health Equity Scholars’ program. Guthrie is in the third year of a five-year, National Institute of Mental Health (NIMH) grant to implement the intensive HIV/AIDS summer institute for diverse post-doctoral fellows and junior faculty titled “Research Education Institute for Diverse Scholars” (REIDS). The REIDS program provides four post-doctoral fellows and/or junior faculty from public health, medicine, nursing, psychology, and other health-related professions the opportunity to spend two summers at Yale University, enhancing their knowledge and research skills related to community-based HIV/AIDS intervention through treatment. The ultimate goal is to increase the number of underrepresented researchers to secure NIH funding in the area of community-based HIV/AIDS across the health spectrum.

Dr. Guthrie’s service has been at the local, state, and national levels. She has served as a member of adolescent female health advisory boards, such as the first National Female Adolescent Technical Expert Group, American Bar Association Advisory
Board for Girls in Juvenile Justice Systems, Columbia University’s National Center on Addiction and Substance Abuse, Adolescent Commission on High School Students Use and Abuse of Substances, and the Girl Scouts of America’s Research Board. Currently, she is a member of the State of Connecticut’s Girls Advisory committee. Nationally, she was a member of Institute of Medicine’s Committee; its most recent report was titled “Commercial Sexual Exploitation and Sex Trafficking of Minors in the United States.” Guthrie also was a five-year member of the National Institutes of Health’s National Advisory Council of Nursing Research, and she was recently appointed to the National Institutes of Health’s Council of Councils.

**Bruce H. Hamory, MD, FACP,** is a partner and chief medical officer in Oliver Wyman’s Health & Life Sciences Practice. He is a nationally known speaker on the topic of redesigning health delivery to improve value by improving quality and reducing costs.

Prior to joining Oliver Wyman, he was executive vice president, system chief medical officer (emeritus) at Geisinger, and managing partner for xG Health Solutions. In that role, he led Geisinger’s efforts to extend its innovations in healthcare delivery and payment systems to other groups and health systems.

As Geisinger’s system chief medical officer from 1997 through 2008, he led the growth of the Geisinger Clinic from 535 to 750 physicians serving 40 locations in 35 counties and the three Geisinger hospitals. He oversaw the installation and refinement of an advanced electronic health record, led the development of a physician compensation plan incorporating pay for performance and pay for outcomes, and reorganized the Geisinger system from a geographic and departmentally based structure to a service line structure incorporating several disciplines within a service line. His other responsibilities included physician compensation, performance improvement, credentialing, clinical operations (group practice and hospitals), capital planning, as well as the educational and research activities of the system.

Dr. Hamory currently serves on the boards of Presence Health in Illinois, and of Integrated Health Solutions Network in Tennessee. He serves on the Advisory Committee for Acceleration of Change in Medical Education of the AMA, and the organizing committee for Involving Patients, Families and Communities in Interprofessional Education. He has previously served on the boards of Blue Cross Blue Shield of Massachusetts, the American Medical Group Association, and on the
advisory boards for several other national groups concerned with the quality and safety of healthcare, and the use of information technology in healthcare, as well as the integration of patient-centered medical homes with public health. Before joining Geisinger, Dr. Hamory was professor of medicine and associate dean for clinical affairs at Penn State’s Milton S. Hershey College of Medicine. He served as executive director of Penn State’s University Hospitals and chief operating officer for the Milton S. Hershey Medical Center.

**Helen Haskell, MA,** is president of the grassroots patient safety organization Mothers Against Medical Error. Since the medical error death of her young son Lewis in 2000, Helen has worked as a patient advocate in the areas of medical education reform, patient-activated rapid response, infection prevention, medical error disclosure, and patient empowerment, among others. In South Carolina, she was instrumental in the passage of the Lewis Blackman Patient Safety Act and was closely involved in the passage and implementation of the Hospital Infection Disclosure Act. In 2007 her deceased son was honored with the state-sponsored endowment of the Lewis Blackman Chair of Patient Safety and Clinical Effectiveness and in 2008 with the statewide Lewis Blackman Patient Safety Awards, now in their sixth year.

Helen is a World Health Organization champion and a director of Consumers Advancing Patient Safety, the Institute for Healthcare Improvement, and the National Patient Safety Foundation. She is a recently retired member of the AHRQ National Advisory Council, and a member of the steering committee of CUE, the consumer arm of the US Cochrane Center. She is a winner of Consumer Reports’ first national Excellence in Advocacy award and in 2009 was named by *Modern Healthcare* magazine as one of the “100 Most Powerful People in Healthcare.” Helen worked with the educational program company Transparent Learning on the production of the patient safety video *The Lewis Blackman Story*, winner of two national film awards. She is author and co-author of numerous articles and patient educational materials and regularly conducts training sessions for patients on navigating the medical system and getting the most out of their medical care.

**Linda A. Headrick, MD, MS,** is Helen Mae Spiese Distinguished Faculty Scholar, senior associate dean for education, and professor of medicine at the School of Medicine, University of Missouri in Columbia, MO. She leads a dean’s office team that supports all aspects of medical education, from pre-admissions through continuing medical education. In that role, she has enhanced the medical school’s internationally recognized curriculum by emphasizing quality improvement and
teamwork. In 2013, those efforts were recognized by an Association of American Medical Colleges (AAMC) Learning Health System Challenge Award. Dr. Headrick has contributed leadership to the AAMC’s “Teaching for Quality” (Te4Q) initiative, seeking to facilitate the integration of quality improvement and patient safety into medical education across the continuum of physician professional development. She also is a member of the Accreditation Council for Graduate Medical Education Clinical Learning Environment Review (CLER) Evaluation Committee. In addition to numerous peer-reviewed publications, Dr. Headrick has co-authored two books: *Enhancing the Professional Culture of Academic Health Science Centers: Educators’ Stories of Creating Enduring Change* (London: Radcliffe Publishing, 2013) and *Fundamentals of Health Care Improvement: A Guide to Improving Your Patients’ Care, Second Edition* (Joint Commission Resources 2012). Dr. Headrick received her AB in Chemistry at the University of Missouri-Columbia, MD at Stanford University, and MS in Epidemiology and Biostatistics at Case Western Reserve University.

**Stephen C. Hunt, MD, MPH,** is the national director of the Veteran Affairs (VA) Post-Deployment Integrated Care Initiative. He established the Gulf War Veterans Clinic at the VA Puget Sound in 1994; later re-named the Deployment Health Clinic, this interdisciplinary clinic was designated as a “best practices approach” to post-deployment care for returning combat veterans in 2006. In 2008, the model was implemented nationwide in VA. Since 2003, over 9,500 veterans from the Iraq/Afghanistan conflicts have been evaluated in the Seattle Division and a similar number in the American Lake divisions of VA Puget Sound. Dr. Hunt has spent the past 20 years providing care for combat veterans from WWII, Korea, and the Vietnam War. He has been involved in conducting clinical research on combat veterans, including those from the 1991 Gulf War, and is a member of the VA National Gulf War Veterans Illness Task Force. He is a PI on a recently completed treatment trial using Mindfulness-Based Stress Reduction for the treatment of unexplained symptoms in Gulf War I Veterans. He is the VA Co-PI on the DoD/VA Joint Pain Care Education Project, chair of the VA Outreach Governance Board, and has been actively involved in Patient-Aligned Care Team (Medical Home) implementation in VA. He regularly gives lectures and trainings on post-deployment care nationwide for both VA and non-VA clinicians and organizations and is on numerous panels, advisory groups, and work groups involved with post-deployment care. Dr. Hunt also directs the program at the VA Puget Sound that provides evaluations and care for veterans with Agent Orange exposures, ionizing radiation exposures, and other toxic environmental exposures related to military service and is involved in national programs and initiatives related to these concerns. He is clinical
associate professor of medicine in the University of Washington Occupational and Environmental Medicine Program.

**Beverley H. Johnson** is president and chief executive officer of the Institute for Patient- and Family-Centered Care in Bethesda, MD. She has provided technical assistance and consultation for advancing the practice of patient- and family-centered care to over 250 hospitals, health systems, federal, state, provincial agencies, military treatment facilities, and community organizations. She assists hospitals and ambulatory programs with changing organizational culture, facilitation of visioning retreats, and the integration of patient- and family-centered concepts in policies, programs, and practices, as well as in facility design and the education of healthcare professionals.

Bev recently served as project director for a multi-year initiative to develop resource materials for senior leaders in hospital, ambulatory, and long-term care settings on how to partner with patients, residents, and families to enhance the quality, safety, and experience of care. She served as the lead author for *Partnering with Patients and Families to Design a Patient- and Family-Centered Health Care System: Recommendations and Promising Practices*, a multi-year initiative funded by the Robert Wood Johnson Foundation and the California HealthCare Foundation. She was a co-author for the guidance publications, *Creating Patient and Family Faculty Programs* and *Advancing the Practice of Patient- and Family-Centered Geriatric Care*.

Bev serves as faculty for several statewide primary care initiatives. She is a member of the Selection Committee for the American Hospital Association-McKesson Quest for Quality Prize and the Board of Directors for the Patient-Centered Primary Care Collaborative (PCPCC). She is also a member of Premier’s QUEST/PACT Advisory Panel, the American College of Physicians’ Advisory Board for Patient Partnership in Healthcare, and the Advisory Group for the World Innovation Summit for Health.

Bev is a past recipient of the Lloyd Bentsen Award and the Humanitarian Award from Pediatric Nursing. In 2007, she received the Stan and Mavis Graven Award for leadership in promoting optimal environments and developmental care for high-risk infants and their families, and The Changemaker Award by the Board for the Center for Health Care Design. In 2008, the National Perinatal Association presented Bev with the Stanley L. Graven Award. Most recently, she was a recipient of a Dorland Health 2011 People Award.
Paul Katz, MD, graduated from the Georgetown University School of Medicine in 1973. He completed his training in Internal Medicine at the Shands Teaching Hospital at the University of Florida College of Medicine in Gainesville in 1976. From 1976 to 1979, Dr. Katz was clinical associate in the Clinical Physiology Section of the Laboratory of Clinical Investigation at the National Institute of Allergy and Infectious Diseases at the National Institutes of Health. He returned to the University of Florida in 1980 as assistant professor of medicine and immunology and medical microbiology in the Division of Clinical Immunology in the Department of Medicine. In 1984, he was appointed chief of the Division of Rheumatology, Immunology and Allergy, and associate professor of medicine at Georgetown University School of Medicine. Dr. Katz added responsibilities as vice chairman of the Department of Medicine in 1986.

In 1997, Dr. Katz was selected as the Anton and Margaret Fuisz Professor and Chairman of Medicine at the School of Medicine and Physician-in-Chief at Georgetown University Hospital. In 1998, Dr. Katz was appointed to the newly created position of chief operating officer at Georgetown University Medical Center and he continued his responsibilities as chair.

Dr. Katz was recruited to Mount Sinai Medical Center (MSMC) in Miami Beach in 2001, where he was senior vice president and chief medical officer and where he also held the rank of professor of medicine at the University of Miami. As the senior physician leader at MSMC, he had both operational and fiscal responsibility for research, undergraduate and graduate education programs, and medical affairs in addition to leading strategic initiatives focused on business growth opportunities, targeted physician recruitment, and new program development.

In December 2007, Dr. Katz became founding vice dean for faculty and clinical affairs and professor of medicine at The Commonwealth Medical College in Scranton, PA, where he helped launch that new medical school, which enrolled its first class in 2009. Dr. Katz became the founding dean of Cooper Medical School of Rowan University (CMSRU) located in Camden, NJ, in July 2010. CMSRU is the first new MD-granting medical school in New Jersey in over 30 years and arose from a partnership between the Cooper Health System and Rowan University. CMSRU enrolled its charter class of 50 students in the summer of 2012.

Uma R. Kotagal, MBBs, MSc, is senior vice president for quality, safety and transformation and executive director of the James M. Anderson Center for Health
As director of the Anderson Center, Dr. Kotagal oversees the development of disease management teams and development and institution of evidence-based clinical practice guidelines.

The primary purpose of the Anderson Center is to foster health services research and system transformation with the goal of improving the quality of healthcare delivery, translating knowledge into practice, and building the next generation of improvement leaders.

Dr. Kotagal was director of the neonatal intensive care units at the University Hospital and at Cincinnati Children’s for several years. While practicing, Dr. Kotagal recognized that care and outcomes improvement were a system property. She completed additional training, receiving her Master of Science in Clinical Epidemiology and Clinical Effectiveness from the Harvard School of Public Health, and refocused her clinical efforts on quality transformation at a systems level. She was also a visiting scholar at the Center for Risk Analysis at the Harvard School of Public Health and a visiting professor at the Tufts New England Medical Center, in the Division of Clinical Decision Making, completing further training in the field of decision and cost effectiveness analyses.

Dr. Kotagal has published extensively in the field of neonatal outcomes research, including studies on neonatal cost models, and early discharge of newborns. She published the first landmark paper on early discharge programs in the NICU setting.

Dr. Kotagal was born in Bombay, India, where she received her undergraduate and her MBBS from the University of Bombay. She did a rotating internship at the University of Bombay from 1970–1971 and another rotating internship at Detroit General Hospital from 1971–1972.

At Children’s Hospital of Michigan, Dr. Kotagal completed her pediatric residency from 1972–1974 and went on to do a fellowship in neonatology from 1974–1975. She completed a fellowship in neonatal physiology at the University of Cincinnati from 1975–1977.

Dr. Kotagal is a senior faculty member of the Institute for Healthcare. She also serves as chair of the quality steering team of the Ohio Children’s Hospital Association,
as a member of the advisory committee of the Toronto Patient Safety Center, as an associate editor of BMJ Quality and Safety and as a member of the Institute of Medicine.

Dr. Kotagal is also a member of various local, regional, and national committees in the area of child health.

Beth Lown, MD, a graduate of Tufts University School of Medicine and primary care medicine residency at Boston’s Beth Israel Hospital, is associate professor of medicine, Harvard Medical School, and a general internist at Mount Auburn Hospital, Cambridge, MA. Dr. Lown teaches learners across the spectrum of medical education and has co-directed faculty fellowships in medical education serving the Harvard Medical School community. She is the director of faculty development and director of the fellowship in medical education at Mount Auburn Hospital.

Dr. Lown is a fellow of the American Academy on Communication in Healthcare for which she has served as president and board member. She has served on communication skills task forces, materials development, and standard setting committees in clinical skills for the National Board of Medical Examiners. Dr. Lown collaborates with national and international partners in education and research in healthcare communication and compassion.

In 2010, Dr. Lown became the first medical director of the Schwartz Center for Compassionate Healthcare, a nonprofit organization based at Massachusetts General Hospital in Boston, MA. The Schwartz Center is dedicated to strengthening the relationship between patients and clinical caregivers and promoting compassionate healthcare. Dr. Lown leads the Schwartz Center’s National Consensus Project on Compassionate Healthcare, a multifaceted initiative to advance compassionate patient- and family-centered care. She has developed new educational programs to improve providers’ compassion and communication with patients and with each other across clinical settings, and is investigating measures of compassionate care. Her commitment to fostering health professionals’ empathy and compassion and honoring the dignity and uniqueness of those who seek health care has guided her career path.

Michelle J. Lyn, MBA, MHA, is chief of the Duke Division of Community Health in the Department of Community and Family Medicine, and associate director of the Duke Center for Community Research of the Duke Translational Medicine Institute.
Ms. Lyn began her Duke career in 1998, as a founding member of the Division of Community Health, and was instrumental in designing and launching more than 40 of the Division’s collaborative, community-based clinical, care management, educational, and research initiatives.

Ms. Lyn’s contributions span the Division’s clinical programs, including neighborhood clinics; school-based health centers; and the Just for Us Program, which cares for chronically ill homebound seniors in their homes. She is also instrumental to the Division’s care management services, which include a North Carolina Community Care Network covering six North Carolina counties, linking more than 50 primary care practices, four hospital systems, and local departments of social services, health, and mental health.

In addition, Ms. Lyn served as the founding program director for Duke’s Master of Health Sciences in Clinical Leadership, the Community Health Leadership Program, the Community Health Fellowship; and course director for the Community Health Elective in the School of Medicine. In 2008, Ms. Lyn was appointed associate director of the Duke Center for Community Research of the Duke Translational Medicine Institute, created through Duke’s NIH Clinical and Translational Science Award. In this role, Ms. Lyn directs a team of faculty and professional staff in the community-engaged research, educational, and liaison activities of the Center, and serves on the Leadership Team for the Durham Health Innovations initiative, which plans innovative Durham-Duke partnered approaches to improving health in Durham County.

**Sharrie McIntosh, MHA,** is senior vice president and chief program officer at The Arnold P. Gold Foundation, which is an international, public, nonprofit organization with the mission of optimizing healthcare outcomes by promoting patient-centered care that is as humane as it is technologically sophisticated. Ms. McIntosh is responsible for managing the Foundation’s current portfolio of programs, developing new programs that align with the Foundation’s strategic goals, and overseeing various initiatives, such as its initiatives focused on interprofessional team-based education and collaborative practice. She is currently overseeing the Foundation’s collaboration with the American Association of Colleges of Nursing (AACN) to develop programming to recognize nurses who exhibit leadership in compassionate, humanistic care as educators, researchers, mentors, and practitioners, as well as students who exemplify and demonstrate these qualities. The Foundation has assembled a joint advisory board featuring
nationally recognized academic and practice leaders from nursing and medicine to provide guidance on developing programming and strategies. She is also leading the Foundation’s collaboration with the Physician Assistant Education Association (PAEA) to develop initiatives and programs for PAs. Finally, she is the Co-Chair for an upcoming Macy-funded conference entitled “Advancing Compassionate, Patient- and Family-Centered Care through Interprofessional Education and Collaborative Practice.” The conference will build on current initiatives in both interprofessional education (IPE) and collaborative clinical practice to further advance professional education for compassionate and collaborative, patient-centered care, and identify best practice models. Additionally, Ms. McIntosh works with Foundation and Board leadership to develop and implement future strategic priorities, achieve resource mobilization goals, and identify and cultivate new partnership opportunities important for continuing the mission of the Foundation.

Ms. McIntosh has over 15 years of experience both as a consultant and in executive level positions in the healthcare field. Prior to joining the Gold Foundation, she served as a Vice President at The Lewin Group, a healthcare and human services consulting company, where she assisted diverse organizations to improve program performance and quality. She provided consulting services to many public sector, government clients, including the US Department of Health and Human Services and its various agencies and offices, such as the Office on Women’s Health, the Maternal and Child Health Bureau, Office on Minority Health, Administration for Children and Families, Health Resources and Services Administration, Agency for Healthcare Research and Quality, Centers for Medicare and Medicaid Services, Veterans Health Administration, and the Office of Rural Health Policy. She also consulted with hospitals, foundations, and community-advocacy groups. As a consultant, she advised organizations in the areas of effective healthcare and social services delivery, strategic planning, program design and implementation, performance measurement, program evaluation, policy analysis, and partnership development. Ms. McIntosh also served as the Affiliations Administrator at NYU School of Medicine/Langone Medical Center where she managed the affiliation contract between the School of Medicine and its hospitals (e.g., Bellevue Hospital Center). She was responsible for monitoring the financial and quality improvement performance of clinical service departments and providers, coordinating with clinical hospital leadership to identify gaps and needs and achieve service growth targets, and advising hospital leadership on the implementation of quality improvement and clinical re-design initiatives. Ms. McIntosh received a Master in Health Administration from Pennsylvania State University.
Valerie Montgomery Rice, MD, has served in numerous senior leadership positions at some of the nation’s most prestigious academic and health institutions, allowing Dr. Montgomery Rice to provide a valuable combination of experience at the highest levels of both patient care and medical research, as well as organizational management and public health policy. These assets make her an invaluable strategist, influencer, and community partner.

Dr. Montgomery Rice is a renowned infertility specialist and researcher, as well as president and dean of Morehouse School of Medicine (MSM). Before that, she served as dean and executive vice president of MSM since 2011. In this role, she oversees Morehouse School of Medicine’s widespread academic and clinical programs in health sciences and leads strategic planning initiatives for both patient care, research, and community engagement. Her current research includes a partnership with the University of Zambia, which focuses on the development of a vaginal microbicide for the prevention of HIV.

She is the founder and former director of the Center for Women’s Health Research at Meharry Medical College in Nashville, TN, where she had previously served as dean of the School of Medicine and senior vice president of health affairs. The Center for Women’s Health Research is one of the nation’s first research centers devoted to studying diseases that disproportionately impact women of color. Dr. Montgomery Rice also held numerous administrative and faculty appointments at the University of Kansas School of Medicine prior to joining Meharry Medical College.

Dr. Montgomery Rice’s dedication to healthcare research, preventative care, and mentoring are manifested in every aspect of her work and life. As such, she has been honored with membership in the American Medical Association Council of Deans, administrative board member, (2011–2015); Society for Women’s Health Research Board Member, executive committee (2012–2013 (executive committee, 2013–)); National Institute of Minority Health and Disparities and Office of Women’s Health/NIH Board Member (2013–); March of Dimes Board Member (2012–); FDA Advisory Committee for Reproductive Health Drugs (2011–); Scientific Committee, American College of Obstetricians and Gynecologists (2007–2011); President’s Commission on White House Fellowships Regional Panelist Selection Committee (2010); Strategic Planning Committee, Office of Women’s Health Research, NIH (2010); Every Life Matters, Every Dollar Counts Campaign – chair, National AIDS Fund Board of Trustees (2009 – 2010); National Center on Minority Health and Health Disparities Special Emphasis Panel (2009); National AIDS Fund Board of Trustees (2007–2011);

Dr. Montgomery Rice has been instrumental in generating multi-million dollar research grants, as well as numerous accolades, including the National Medical Association’s President’s Citation Award (2013), American Medical Women’s Association, Elizabeth Blackwell Award (2011), Recipient of the Working Mother Media Multicultural Women’s Legacy Award (2011), Recipient of the Maternal Infant Health Outreach Program Award (2009–2010), and Vanderbilt University, Maternal Infant Health Outreach Worker (MIHOW) Mentorship Award (2009) and The Links, Inc. Portia Searcy Award (2007).

A Georgia native, Dr. Montgomery Rice received her bachelor’s degree in chemistry from Georgia Institute of Technology and her medical degree from Harvard Medical School. She completed her residency in obstetrics and gynecology at Emory University School of Medicine and her fellowship in reproductive endocrinologist and infertility at Hutzel Hospital in Detroit, MI. She also completed the Executive Leadership in Academic Medicine program at Drexel University College of Medicine, Philadelphia, PA.

Debra L. Ness, MS, has, for more than three decades, been a strong advocate for fairness and social justice. Drawing on an extensive background in health and public policy, Ness possesses a unique understanding of the issues that face women and families at home, in the workplace, and in the healthcare arena. Before assuming her current role as president, she served as executive vice president of the National Partnership for Women & Families for 13 years. Ness has played a leading role in positioning the organization as a powerful and effective advocate for today’s women and families.

Ness sits on the board of the National Quality Forum (NQF) and the board of the National Priorities Partnership (NPP). She is a member of the Board of Directors and chairs the Consumer Advisory Council of the National Committee for Quality Assurance (NCQA). Ness was recently elected to serve as the first Public Member on the American College of Cardiology (ACC) Board of Trustees. She serves on the Quality Alliance Steering Committee (QASC) and sits on the Steering Committee of the AQA. Ness co-chairs the Consumer-Purchaser Alliance, a group of leading consumer, employer, and labor organizations working to improve the quality,
accountability, and affordability of health care. She serves on the Aligning Forces for Quality (AF4Q) National Advisory Committee (NAC), and she recently completed service on the Board of Trustees of the American Board of Internal Medicine Foundation (ABIMF).

In addition, Ness serves on the Executive Committee of the Leadership Conference on Civil and Human Rights and co-chairs its Health Care Task Force. She also serves on the Board of Directors of the Economic Policy Institute (EPI) as well as EMILY’s List.

Ness graduated summa cum laude from Drew University with a bachelor’s degree in psychology and sociology, and after completing graduate work in social welfare and public health policy, she received her Master of Science from Columbia University School of Social Work.

Marc A. Nivet, EdD, MBA, is chief diversity officer for the Association of American Medical Colleges, where he provides strategic vision and programmatic leadership on issues surrounding community engagement, workforce and student diversity, and health equity at universities, medical schools and teaching hospitals across the United States and Canada. Dr. Nivet has spent over 20 years in academic medicine developing creative program initiatives and innovative solutions that have helped universities and their academic health centers accelerate efforts to realize their mission of excellence in research, education and patient care. Through his numerous writings, lectures and engagements with over 80 academic health centers, Dr. Nivet is a leader in the theory and design of transformative initiatives that elevate health equity and community engagement to a strategic level. A skilled facilitator, he blends his background in finance, operations, and strategic planning with his passion for health equity to ensure that academic health centers align their transformation efforts to meet the demands of a changing healthcare environment.

Prior to joining the AAMC, Dr. Nivet served as chief operating officer and treasurer for the Josiah Macy Jr. Foundation, which strives to foster innovation in health professional education that aligns workforce training with the dynamic needs of patients. He also served as a special assistant to the Senior Vice President for Health at New York University, where he conducted state and federal policy research to support comprehensive strategy development, and held a position in management of the Sallie Mae Fund, the philanthropic arm of the SLM Corporation. Dr. Nivet’s experience in academic medicine also includes seven years as the associate
executive director of the Associated Medical Schools of New York, a consortium of the New York academic medical centers. As the associate executive director, he was charged with implementing and influencing state policy regulations on graduate medical education and developing programmatic efforts to create a diverse health workforce that more actively practices in health care shortage areas. He began his career in medical education in student affairs at the New York College of Osteopathic Medicine. Dr. Nivet earned his Doctorate in Higher Education Management from the University of Pennsylvania and his Master of Business Administration with a focus on health care management from George Washington University’s School of Business.

Dr. Nivet is a fellow of the New York Academy of Medicine, and a former president of the National Association of Medical Minority Educators. He currently serves the academic medicine community on a variety of boards and commissions. He is a member of the NIH National Advisory General Medical Sciences Council (NIGMS), HRSA Bureau of Health Professions National Advisory Council on Nurse Education and Practice, and the CDC Medical College Roundtable, and is an advisor to the ETS Policy Evaluation and Research Council. He is a trustee of both The Arnold P. Gold Foundation and the Massachusetts General Hospital (MGH) Institute of Health Professions.

Sally Okun, RN, MMHS, is vice president for advocacy, policy, and patient safety at PatientsLikeMe in Cambridge, MA. She is responsible for patient voice and advocacy initiatives, participates in health policy discussions at the national and global level, and acts as the company’s liaison with government and regulatory agencies. She joined PatientsLikeMe 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 patient folksonomy. In 2009 she developed the PatientsLikeMe Drug Safety and Pharmacovigilance Platform to meet adverse event reporting obligations of industry partners while collaborating in a social media environment.

Ms. Okun participates on numerous collaboratives of the Institute of Medicine’s (IOM) Roundtable on Value and Science-Driven Healthcare and the Committee on Core Metrics for Better Health at Lower Cost. Ms. Okun serves on the Advisory Panel on Patient Engagement for the Patient-Centered Outcomes Research Institute (PCORI); the National Quality Forum’s Person-Centered Care and Outcomes Committee; the Scientific Advisory Committee for the Reagan-Udall Foundation’s
Innovation in Medical Evidence Development and Surveillance (IMEDS) Program; and the Program Advisory Board of the Schwartz Center for Compassionate Health Care. Ms. Okun is a frequent speaker at clinical, advocacy and policy events and in April 2013 she was the first nurse ever invited to give a TEDMED talk at the Kennedy Center.

Prior to joining PatientsLikeMe, Ms. Okun, a registered nurse, practiced as a community-based palliative and end-of-life care specialist and project consultant. In more than 30 years of practice, she contributed to clinical, research, and educational projects with multiple collaborators, including Brown University, Harvard Medical School, MA Department of Mental Health, Hospice Education Network, and the Robert Wood Johnson Foundation.

Ms. Okun received her 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.

Harold Alan Pincus, MD, is senior scientist at the RAND Corporation and professor and vice chair of the Department of Psychiatry at Columbia University’s College of Physicians and Surgeons. Dr. Pincus is also director of quality and outcomes research at NewYork-Presbyterian Hospital and co-director of Columbia’s Irving Institute for Clinical and Translational Research. Previously he was director of the RAND-University of Pittsburgh Health Institute and executive vice chairman of the Department of Psychiatry at the University of Pittsburgh. He is national director of the Health and Aging Policy Fellows Program (funded by Atlantic Philanthropies), and directed the Robert Wood Johnson Foundation’s national program on depression in primary care and the John A. Hartford Foundation’s national program on building interdisciplinary geriatric research centers. He served as special assistant to the Director of the NIMH and also on White House and Congressional staffs as a Robert Wood Johnson Clinical Scholar. Dr. Pincus was vice chair of the Task Force on Diagnostic and Statistical Manual, Fourth Edition (DSM IV), and has been appointed to the editorial boards of ten major scientific journals. He has authored or co-authored over 350 scientific publications on health services research, science policy, research career development, and the diagnosis and treatment of mental disorders. Among other recent projects, he has led the national evaluation of mental health services for veterans, the redesign of primary care/behavioral health relationships in New Orleans, and a National Institutes of Health-funded national study of research
mentoring. He has also been a consultant to multiple federal and international agencies and private organizations, including the US Secret Service, Organization for Economic Cooperation and Development, and the John T. and Catherine D. MacArthur Foundation. He has chaired or served on many national and international committees, including those for the Institute of Medicine/National Academies (multiple committees, including adapting the “Crossing the Quality Chasm” strategy for mental health), the NIH, and committees on quality measurement for the World Health Organization, Medicaid and Medicare programs, Affordable Care Act, National Committee on Quality Assurance, and National Quality Forum. For over 22 years he worked one night a week treating the severely mentally ill at a community clinic.

Carol Raphael, MPA, is senior advisor at Manatt Health Solutions. She served as president and chief executive officer of the Visiting Nurse Service of New York (VNSNY), the largest nonprofit home health care organization in the United States from 1989 to 2011. Ms. Raphael expanded the organization’s services and launched innovative models of care for complex populations with chronic illness. Prior to joining VNSNY, Ms. Raphael held executive positions at Mt. Sinai Medical Center and in New York City government. In 2012, Ms. Raphael was an Advanced Leadership Fellow at Harvard University and participated in their Health Care Think Tank in April 2013. She chairs the New York eHealth Collaborative, a public-private partnership working to advance the adoption of health information technology. Ms. Raphael is chair of the Long-Term Quality Alliance at the Brookings Institution, a member of the National Quality Forum Coordinating Committee and Health Information Technology Advisory Committee where she chairs its Post Acute, Long-Term Care and Hospice Workgroup. In 2012 and 2013, she helped spearhead a Commonwealth Fund project to spur the development of high-performing integrated health plans for dual eligibles. She was a member of New York State Governor Cuomo’s Medicaid Redesign Team.

Ms. Raphael is a nationally recognized expert on healthcare policy and in particular, high-risk, complex populations with chronic illnesses and post-acute as well as long-term services and supports. In 2013, Ms. Raphael was appointed by President Obama to the bipartisan Commission on Long-Term Care. She served on numerous commissions, including the Medicare Payment Advisory Commission, the New York State Hospital Review and Planning Council, and several Institute of Medicine committees. She has served on a number of boards, including the Lifetime Blue Cross/Blue Shield Board and the American Foundation for the Blind. She is currently
vice-chair of the AARP Board and serves on the boards of Henry Schein, Inc., the Primary Care Development Corporation, Pace University, and the Medicare Rights Center. She is a member of several advisory boards, including the Harvard School of Public Health’s Health Policy Management Executive Council, the New York City Age-Friendly Commission and the Jonas Center for Nursing Excellence Advisory Board. She co-edited the book *Home-Based Care for a New Century* and was a visiting fellow at the Kings Fund in the United Kingdom.

**Sheldon M. Retchin, MD, MSPH,** is senior vice president for health sciences of Virginia Commonwealth University (VCU) and chief executive officer of the Virginia Commonwealth University Health System. As Senior Vice President of Health Sciences for VCU, he has responsibility for five health science schools: Medicine, Dentistry, Pharmacy, Nursing, and Allied Health. The five schools have a total enrollment of more than 4,400 undergraduate, professional, and graduate students. As CEO of the VCU Health System, he directs MCV Hospitals, a teaching hospital of 865 licensed beds with more than 650 post-graduate trainees in all medical and surgical specialties; the faculty practice plan, MCV Physicians, which includes approximately 650 faculty physicians; and a provider-sponsored Medicaid Health Maintenance Organization, Virginia Premier Health Plan, with about 150,000 members statewide.

**Steven M. Safyer, MD,** is president and chief executive officer of Montefiore in New York City. Montefiore is the University Hospital and Academic Medical Center for Albert Einstein College of Medicine and a full-service, integrated delivery system caring for patients from the New York metropolitan region. An accomplished physician leader and highly respected healthcare executive, Dr. Safyer has been at Montefiore since 1982, previously serving as senior vice president and chief medical officer.

Throughout his medical career at Montefiore, Dr. Safyer has been a strong advocate for underserved populations, including those incarcerated and those affected by the public health crises of HIV and tuberculosis. He has built extensive primary care networks, developed innovative business and clinical strategies to manage care and assume risk, championed the adoption of cutting-edge clinical information systems, and created nationally recognized quality and safety programs. He has nurtured a close relationship with Einstein, which has resulted in superior, comprehensive specialty care being provided in Montefiore’s Centers of Excellence in the areas of heart, transplant, cancer, The Children’s Hospital at Montefiore, and joint mobility.
Dr. Safyer received his Bachelor of Science degree from Cornell University and his medical degree from Albert Einstein College of Medicine. He completed his internship and residency in social medicine at Montefiore. He is board certified in internal medicine and a professor of medicine in the Department of Medicine and professor of epidemiology and population health in the Department of Epidemiology and Population Health at Einstein. Dr. Safyer currently serves as chair of the League of Voluntary Hospitals and Homes and past chairman of the Board of Governors for the Greater New York Hospital Association (GNYHA). He is a board member of the Hospital Association of New York State (HANYS); Association of American Medical Colleges’ Council of Teaching Hospitals (COTH) Administrative Board; Josiah Macy Jr. Foundation; New York eHealth Collaborative (NYcE); Coalition to Protect America’s Health Care; and University HealthSystem Consortium (UHC). He is an active participant on committees for organizations such as the Association of American Medical Colleges; New York State Council on Graduate Medical Education; Medicaid Redesign Team; and Chase Regional Advisory Board. He was the previous chair of the Bronx Regional Health Information Organization, an independent organization for health information sharing. A frequent lecturer on topics including population-based medicine, healthcare reform, and public health, Dr. Safyer has authored and co-authored numerous articles in peer-reviewed journals, covering subjects ranging from electronic medical records to managing the health of a population to tuberculosis in prison populations.

**Gilbert Salinas, MPA,** 2013–2014 Kaiser Permanente Safety Net Fellow at the Institute for Healthcare Improvement, is director of patient and community relations at Rancho Los Amigos National Rehabilitation Center (RLANRC). He has administrative oversight of various departments, including the patient advocate office, government relations, community relations, and patient-centered care programs. He has helped create the first Patient and Family Advisory Council at RLANRC and has extensive knowledge on developing patient-centered care programs that meet complex patient needs. Gilbert served as the co-chair for IHI’s 24th Annual National Forum. He has received local and national awards for his excellent work in the field of violence prevention, youth advocacy, patient advocacy, and gun violence prevention. Gilbert was a part of the planning and peer review committee for the former Surgeon General Dr. David Satcher’s US Department of Health and Human Services’ Report on Youth Violence. He is a past program director for the Know Barriers Violence Prevention Program, the Violence Prevention Coalition of Greater LA, and Youth Alive’s hospital-based intervention program “Caught in the Crossfire.”
Stephen C. Schoenbaum, MD, MPH, is special advisor to the president of the Josiah Macy Jr. Foundation. He has extensive experience as a clinician, epidemiologist, and manager. From 2000–2010, he was executive vice president for programs at The Commonwealth Fund and executive director of its Commission on High Performance Health Systems. Prior to that, he was medical director and then president of Harvard Pilgrim Health Care of New England, a mixed model HMP delivery system in Providence, RI.

He is currently a lecturer at the Department of Population Medicine at Harvard Medical School, a department he helped found, and the author of over 150 professional publications. He is vice chairman of the board of the Picker Institute; former president of the Board of the American College of Physician Executives; chair of the International Advisory Committee to the Joyce and Irving Goldman Medical School, Ben Gurion University, Beer Sheva, Israel; and an honorary fellow of the Royal College of Physicians.

George E. Thibault, MD, became the seventh president of the Josiah Macy Jr. Foundation in January 2008. Immediately prior to that, he served as vice president of clinical affairs at Partners Healthcare System in Boston and director of the Academy at Harvard Medical School (HMS). He was the first Daniel D. Federman Professor of Medicine and Medical Education at HMS and is now the Federman Professor, Emeritus.

Dr. Thibault previously served as chief medical officer at Brigham and Women’s Hospital and as chief of medicine at the Harvard-affiliated Brockton/West Roxbury VA Hospital. He was associate chief of medicine and director of the Internal Medical Residency Program at the Massachusetts General Hospital (MGH). At the MGH he also served as director of the Medical ICU and the founding director of the Medical Practice Evaluation Unit.

For nearly four decades at HMS, Dr. Thibault played leadership roles in many aspects of undergraduate and graduate medical education. He played a central role in the New Pathway Curriculum reform and was a leader in the new Integrated Curriculum reform at HMS. He was the founding director of the Academy at HMS, which was created to recognize outstanding teachers and to promote innovations in medical education. Throughout his career he has been recognized for his roles in teaching and mentoring medical students, residents, fellows, and junior faculty. In addition to his teaching, his research has focused on the evaluation of practices and
outcomes of medical intensive care and variations in the use of cardiac technologies.

Dr. Thibault is chairman of the board of the MGH Institute of Health Professions, chairman of the board of the New York Academy of Medicine, and he serves on the boards of the New York Academy of Sciences, the Institute on Medicine as a Profession, and the Lebanese American University. He serves on the President’s White House Fellows Commission and for twelve years he chaired the Special Medical Advisory Group for the Department of Veteran’s Affairs. He is past president of the Harvard Medical Alumni Association and past chair of Alumni Relations at HMS. He is a member of the Institute of Medicine of the National Academy of Sciences.

Dr. Thibault graduated summa cum laude from Georgetown University in 1965 and magna cum laude from Harvard Medical School in 1969. He completed his internship and residency in Medicine and fellowship in Cardiology at Massachusetts General Hospital. He also trained in Cardiology at the National Heart and Lung Institute in Bethesda and at Guys Hospital in London, and served as chief resident in medicine at MGH.

Dr. Thibault has been the recipient of numerous awards and honors from Georgetown (Ryan Prize in Philosophy, Alumni Prize, and Cohongaroton Speaker) and Harvard (Alpha Omega Alpha, Henry Asbury Christian Award, and Society of Fellows). He has been a visiting scholar both at the Institute of Medicine and Harvard’s Kennedy School of Government and a visiting professor of medicine at numerous medical schools in the US and abroad.

Marie-Claude Vanier, BPharm, MSc, a graduate of Université Laval (Quebec City, Canada), has been a pharmacist since 1989 and holds a joint clinical and academic appointment as associate clinical professor at the Faculty of Pharmacy of Université de Montréal and as clinical pharmacist at the Family Medicine Teaching Clinic of Cité de la Santé de Laval (CSL) Hospital. She is also clinician of the Sanofi Aventis endowment chair in ambulatory pharmaceutical care of these two organizations. Marie-Claude led development of a curriculum of interfaculty courses on interprofessional collaboration in partnership with patients and their caregivers for health sciences and psycho-social sciences students at Université de Montréal. Since March 2010, she is chair of the Interfaculty Operational Committee developing and coordinating these courses. In 2009, Marie-Claude was recognized in Quebec as a role model in interprofessional collaborative practice by l’Actualité Pharmaceutique.
and awarded the pharmacien de Coeur et d’action prize in the interdisciplinarity category. The Association of Faculties of Pharmacy of Canada awarded her the 2010 AFPC-Bristol-Myers Squibb National Award for Excellence in Education for her involvement in Interprofessional Collaboration Education.

Jonathan Woodson, MD, is assistant secretary of defense for health affairs. In this role, he administers the more than $50 billion Military Health System (MHS) budget and serves as principal advisor to the Secretary of Defense for health issues. The MHS comprises over 133,000 military and civilian doctors, nurses, medical educators, researchers, healthcare providers, allied health professionals, and health administration personnel worldwide, providing our nation with an unequalled integrated healthcare delivery, expeditionary medical, educational, and research capability.

Dr. Woodson ensures the effective execution of the Department of Defense (DoD) medical mission. He oversees the development of medical policies, analyses, and recommendations to the Secretary of Defense and the Undersecretary for Personnel and Readiness, and issues guidance to DoD components on medical matters. He also serves as the principal advisor to the Undersecretary for Personnel and Readiness on matters of chemical, biological, radiological, and nuclear (CBRN) medical defense programs and deployment matters pertaining to force health.

Dr. Woodson co-chairs the Armed Services Biomedical Research Evaluation and Management Committee, which facilitates oversight of DoD biomedical research. In addition, Dr. Woodson exercises authority, direction, and control over the Defense Health Agency (DHA); the Uniformed Services University of the Health Sciences (USUHS); the Armed Forces Radiobiology Research Institute (AFRRI); the Defense Center of Excellence for Psychological Health and Traumatic Brain Injury (DCoE); the Armed Forces Institute of Pathology; and the Armed Services Blood Program Office.

Prior to his appointment by President Obama, Dr. Woodson served as associate dean for diversity and multicultural affairs and professor of surgery at the Boston University School of Medicine (BUSM), and senior attending vascular surgeon at Boston Medical Center (BMC). Dr. Woodson holds the rank of brigadier general in the US Army Reserve, and served as assistant surgeon general for reserve affairs, force structure and mobilization in the Office of the Surgeon General, and as deputy commander of the Army Reserve Medical Command.
Dr. Woodson is a graduate of the City College of New York and the New York University School of Medicine. He received his postgraduate medical education at the Massachusetts General Hospital, Harvard Medical School, and completed residency training in internal medicine and general and vascular surgery. He is board certified in internal medicine, general surgery, vascular surgery, and critical care surgery. He also holds a master’s degree in Strategic Studies (concentration in strategic leadership) from the US Army War College.

In 1992, he was awarded a research fellowship at the Association of American Medical Colleges Health Services Research Institute. He has authored/coauthored a number of publications and book chapters on vascular trauma and outcomes in vascular limb salvage surgery.

His prior military assignments include deployments to Saudi Arabia (Operation Desert Storm), Kosovo, Operation Enduring Freedom, and Operation Iraqi Freedom. He has also served as a senior medical officer with the National Disaster Management System, where he responded to the September 11th attack in New York City. Dr. Woodson’s military awards and decorations include the Legion of Merit, the Bronze Star Medal, and the Meritorious Service Medal (with oak leaf cluster).

In 2007, he was named one of the top Vascular Surgeons in Boston and in 2008 was listed as one of the Top Surgeons in the US. He is the recipient of the 2009 Gold Humanism in Medicine Award from the Association of American Medical Colleges.