Integrating the Patient and Caregiver Voice into Serious Illness Care

A Workshop hosted by the

Roundtable on Quality Care for People with Serious Illness

Workshop on Integrating the Patient and Caregiver Voice into Serious Illness Care

December 15, 2016

Keck Center of the National Academies
500 Fifth Street, NW
Room 100
Washington, DC 20001

The National Academies of
SCIENCE • ENGINEERING • MEDICINE
Roundtable on Quality Care for People with Serious Illness

December 15, 2016

Dear Colleagues:

We would like to welcome you to the first in a series of public workshops sponsored by the Roundtable on Quality Care for People with Serious Illness at the National Academies of Sciences, Engineering, and Medicine.

The focus of this workshop is Integrating the Patient and Caregiver Voice into Serious Illness Care. The workshop begins with an overview of the challenges and the opportunities for integrating the patient, family, and caregiver voices into serious illness care and ensuring that care is well aligned with the preferences, values, beliefs, and needs of the patient, family, and caregiver. This will be followed by a session exploring socio-cultural differences in serious illness care and effective ways to address those differences. The third workshop session focuses on patient-clinician communication strategies and team-based approaches to addressing patient, family, and caregiver needs at any age and any stage of illness. The workshop concludes with a session on innovations and interventions to facilitate and support the communication of needs, values, and preferences of patients, their families, and caregivers.

Each workshop session includes a question and answer session and we encourage you to participate actively in workshop discussions. Proceedings of this workshop will be published by the National Academies Press and may incorporate your comments and ideas. In addition, the workshop will be webcast, and a video archive will be available at: https://www.nationalacademies.org/hmd/Activities/HealthServices/QualityCareforSeriousIllnessRoundtable/2016-DEC-15.aspx.

We also invite you to share your insights from the workshop using the Twitter hashtag: #SeriousIllnessCareNASEM.

Thank you for participating in this workshop. We hope you can join us for the reception immediately following the workshop in the Keck Center’s 3rd floor atrium.

Sincerely,

Rebecca Kirch, JD  JoAnne Reifsnyder, PhD, RN, FAAN
National Patient Advocate Foundation  Hospice and Palliative Nurses Association
Workshop Planning Committee Co-Chair  Workshop Planning Committee Co-Chair
# Integrating the Patient and Caregiver Voice into Serious Illness Care

A Workshop hosted by the Roundtable on Quality Care for People with Serious Illness

## WORKSHOP AGENDA

The Keck Center of the National Academies  
500 Fifth Street, NW - Room 100  
Washington, DC 20001

### Overarching Workshop Objective

Examine actionable opportunities for meaningfully integrating the voices, needs, beliefs, values, traditions and practices of seriously ill adults, children, and caregivers throughout the care continuum to strengthen relationships, accelerate health system delivery reform and drive quality improvement efforts.

### December 15, 2016

<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
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<tr>
<td>8:00 am</td>
<td>Registration and Breakfast</td>
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| 8:30 am | Overview of the Roundtable on Quality Care for People with Serious Illness  
Leonard D. Schaeffer, University of Southern California (Chair) and  
James Tulsky, MD, Harvard Medical School (Vice Chair)  
Roundtable on Quality Care for People with Serious Illness  
Overview of the Workshop  
Rebecca Kirch, JD, National Patient Advocate Foundation  
JoAnne Reifsnyder, PhD, RN, Hospice and Palliative Nurses Association  
Planning Committee Co-Chairs |
| 8:45 am | Session 1: Integrating the Patient, Caregiver, and Family Voice into Person-Centered Care: Gaps, Challenges, and Opportunities  
Moderator: Amy Berman, BSN, LHD, The John A. Hartford Foundation  
Caregiver-Clinician Perspectives on Providing High-Quality Care  
Pediatric Care  
Blyth Lord, MA, Courageous Parents Network  
Richard Goldstein, MD, Boston Children's Hospital and Harvard Medical School  
Adult Care  
Susan West, Hertzberg Palliative Care Institute, Icahn School of Medicine at Mount Sinai  
Diane Meier, MD, Icahn School of Medicine at Mount Sinai and Center to Advance Palliative Care  
Opportunities for supporting spirituality, values, beliefs, priorities, and preferences to provide comfort and meaning for patients and loved ones coping with serious illness  
Karen E. Steinhauser, PhD, Center for Health Services Research in Primary Care, VA Medical Center, and Duke University Medical Center |
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<th>Time</th>
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<tr>
<td>10:30 am</td>
<td>Panel Discussion, Audience Q &amp; A</td>
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<tr>
<td>10:45 am</td>
<td><strong>Session 2: Addressing Socio-Cultural Differences in Care for Seriously Ill Children and Adults</strong>&lt;br&gt;&lt;br&gt;<em>Moderator: Robert A. Bergamini, MD, Mercy Clinic Children’s Cancer and Hematology, Supportive Care Coalition</em>&lt;br&gt;&lt;br&gt;Addressing health equity and quality of life priorities and concerns experienced by patients and caregivers among geographically and ethnically diverse and vulnerable populations&lt;br&gt;&lt;br&gt;<strong>Shonta Chambers, MSW,</strong> Patient Advocate Foundation&lt;br&gt;&lt;br&gt;Opportunities for addressing health disparities through Chaplaincy/Spiritual Care services and support including cultural humility/sensitivity&lt;br&gt;&lt;br&gt;<strong>Rev. Alice Cabotaje, M.Div.</strong>, Massachusetts General Hospital&lt;br&gt;&lt;br&gt;Promoting dignity, quality of life, and health outcomes for underserved populations and addressing ethnicity and poverty effects on preferences and care&lt;br&gt;&lt;br&gt;<strong>Stacy Fischer, MD</strong>, University of Colorado at Denver School of Medicine&lt;br&gt;&lt;br&gt;Identifying and honoring preferences in context of reducing racial disparities – addressing health disparities through improved communication and other strategies&lt;br&gt;&lt;br&gt;<strong>Kimberly Johnson, MD</strong>, Duke University School of Medicine</td>
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<tr>
<td>12:30 pm</td>
<td>Lunch</td>
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<td>1:30 pm</td>
<td><strong>Session 3: Integrating Person-Centered Care across Ages, Diagnoses and Disciplines</strong>&lt;br&gt;&lt;br&gt;<em>Moderator: Terry Altilio, LCSW, ACSW, Mt Sinai Beth Israel Medical Center</em>&lt;br&gt;&lt;br&gt;Nurturing healthier connections between patients, caregivers and clinicians through skilled communication emphasizing honesty, empathy, and hope&lt;br&gt;&lt;br&gt;<strong>Anthony L. Back, MD</strong>, University of Washington and Fred Hutchinson Cancer Research Center&lt;br&gt;&lt;br&gt;Team-based pre-habilitation and rehabilitation services integration as complement to palliative care and other supportive services focused on addressing patient and caregiver quality of life goals and priorities&lt;br&gt;&lt;br&gt;<strong>Julie Silver, MD</strong>, Harvard Medical School and Spaulding Rehabilitation Network</td>
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### The National Academies of

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<td>3:15 pm</td>
<td>Break</td>
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| 3:30 pm  | **Session 4: Innovations and Interventions to Support Communication of Needs, Values and Preferences**  
*Moderator: Ellen Goodman, The Conversation Project*

  - Simple tools that facilitate conversations about serious illness, encourage listening and empathy and nudge patients, caregivers, and providers toward better conversational behaviors
    - **Nick Jehlen**, Common Practice
  - Use of the PREPARE website for upstream care planning discussions and informed medical decision-making among vulnerable populations
    - **Rebecca Sudore, MD**, University of California, San Francisco
  - Community-based research on the sociocultural contexts of living with and caring for persons with serious illness as the basis for tailored interventions to improve systems of care in rural communities
    - **Joy Buck, PhD, RN**, West Virginia University School of Nursing
  - Findings and lessons learned from nationwide research on consumer preferences related to quality of life communication
    - **Peter Mitchell**, SalterMitchell

*Panel Discussion, Audience Q & A*

| 5:15 pm  | **Wrap-up and Reflections on the Day**  
Rebecca Kirch and JoAnne Reifsnyder  
Planning Committee Co-Chairs |
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<td>5:30 pm</td>
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<tr>
<td>5:30 pm</td>
<td><strong>Reception in Keck Center Atrium, 3rd Floor</strong></td>
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WORKSHOP NOTES

- This workshop is being recorded. Please identify your name and affiliation prior to asking questions at the microphone.

- A live webcast of this workshop is available online at: https://www.nationalacademies.org/hmd/Activities/HealthServices/QualityCareforSeriousIllnessRoundtable/2016-DEC-15.aspx

- Please use the hashtag #SeriousIllnessCareNASEM to tweet about the workshop.

- An archive of the video webcast and presentation slides will be available at: https://www.nationalacademies.org/hmd/Activities/HealthServices/QualityCareforSeriousIllnessRoundtable/2016-DEC-15.aspx

- Proceedings of the workshop will be published following National Academies procedures. Rapporteurs will compose the proceedings from the workshop transcript, and external reviewers will examine the proceedings to make sure it accurately reflects workshop discussions and conforms to institutional policies.

- Interested in receiving updates from the Roundtable on Quality Care for People with Serious Illness or the National Academies of Sciences, Engineering, and Medicine’s Health and Medicine Division?

  Sign up for the Roundtable listserv at: https://www.nationalacademies.org/hmd/Activities/HealthServices/QualityCareforSeriousIllnessRoundtable.aspx

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Roundtable on Quality Care for People with Serious Illness

Integrating the Patient and Caregiver Voice into Serious Illness Care—A Workshop

Workshop Planning Committee Roster

Rebecca A. Kirch, J.D. (Co-Chair)
Executive Vice President of Healthcare Quality and Value
National Patient Advocate Foundation

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Susan G. Komen

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Representing the Association of Professional Chaplains

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Integrating the Patient and Caregiver Voice into Serious Illness Care: A Workshop

Workshop Speakers and Moderators Roster

Terry Altilio LCSW, ACSW
Social Work Coordinator
Division of Palliative Care
Mt. Sinai Beth Israel Medical Center

Anthony L. Back, MD
Professor, University of Washington and
Fred Hutchinson Cancer Research Center
Co-Director, University of Washington Center
for Excellence in Palliative Care
Co-Founder, VitalTalk

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Medical Director for Palliative Care
Mercy Clinic Children’s Cancer and
Hematology
Representing the Supportive Care Coalition

Amy Berman, BSN, LHD
Senior Program Officer
The John A. Hartford Foundation

Joy Buck, PhD, RN
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West Virginia University School of Nursing

Rev. Alice Cabotaje, MDiv, BCC, ACPE
Clinical Pastoral Education Supervisor
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Massachusetts General Hospital

Shonta Chambers, MSW
Executive Vice President of Health Equity
Initiatives and Programs
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University of Colorado at Denver
School of Medicine

Richard Goldstein, MD
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Pediatric Advanced Care Team
Boston Children’s Hospital
Assistant Professor of Pediatrics
Harvard Medical School

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Co-Founder and Director
The Conversation Project

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CEO
Common Practice

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Senior Fellow in the Center for Aging and
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Duke University School of Medicine

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FPCN
Advanced Practice Nurse Coordinator
Palliative & Supportive Care, Center for
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Advocate Children’s Hospital

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Executive Director
Courageous Parents Network

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University of Alabama at Birmingham
Diane Meier, MD
Gaisman Professor of Medical Ethics
Vice Chair for Public Policy and Professor
Department of Geriatrics and Palliative Medicine
Icahn School of Medicine at Mt. Sinai
Director, Center to Advance Palliative Care

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Chairman and CEO
SalterMitchell

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Associate Chair, Strategic Initiatives
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Associate Professor
Duke University Medical Center

Rebecca Sudore, MD
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University of California, San Francisco

Susan West
Volunteer, Hertzberg Palliative Care Institute
Icahn School of Medicine at Mount Sinai
Ro
undtable on Quality Care for People with Serious Illness

We are grateful for the support of our sponsors, which is crucial to the work of the Roundtable.

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- National Hospice and Palliative Care Organization
- National Institute of Nursing Research
- National Palliative Care Research Center
- National Patient Advocate Foundation
- National Quality Forum
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- Social Work Hospice and Palliative Care Network
- Supportive Care Coalition
- UnitedHealth Group
Roundtable on Quality Care for People with Serious Illness

The National Academies of Sciences, Engineering, and Medicine (the Academies) has established a Roundtable on Quality Care for People with Serious Illness. Through meetings, public workshops, and background papers, the Roundtable fosters an ongoing dialogue about critical policy and research issues to accelerate and sustain progress in care for people of all ages with serious illness. Inspired by previous work at the Academies, including the 2014 Institute of Medicine report *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*, the roundtable convenes key stakeholders to focus on five priority areas:

- Delivery of person-centered, family-oriented care, including mechanisms to reduce multiple transitions between care settings during serious illness and in the final phase of life; recognition and support for the role of family caregivers; and efforts to ensure that critically ill individuals and their families understand the benefits of, and have access to, palliative care.
- Communication and advance care planning, including clinician-initiated conversations with individuals and loved ones about end-of-life care values, goals, and preferences; policies to support and incentivize such conversations; and methods to record individual preferences and ensure that they are honored.
- Professional education and development, including attention to palliative care in medical and nursing school curricula; reducing educational siloes to improve the development of interprofessional teams; and health care providers’ communication skills.
- Policies and payment systems, including policies to reduce payment siloes and incentives that will result in use of helpful services; scale-up of successful programs that integrate health care and long-term social services; policies to incentivize the provision of comprehensive palliative care; and the development of quality standards and measures.
- Public education and engagement, including strategies to promote informed understanding of advanced care and end-of-life care issues among diverse groups; efforts to motivate health care consumers to seek high-quality care for themselves and their loved ones; and efforts to normalize conversations about death and dying through storytelling and advocacy at multiple levels.

The Roundtable is limited to a three-year term in order to focus its activities on tangible, short-term goals. Roundtable activities include expert meetings, public workshops and webinars, summary publications, and targeted communications and community engagement activities. Roundtable membership includes federal agencies, health insurers, advocates, patients, health care providers, foundations, academics, and others interested in the topic.

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**Andrew M. Pope**  
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Roundtable on Quality Care for People with Serious Illness

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James A. Tulsky, MD (Vice Chair)
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Harvard Medical School

Robert A. Bergamini, MD
Supportive Care Coalition

Amy J. Berman, BSN, LHD
The John A. Hartford Foundation

Patricia A. Bomba, MD, FACP
Excellus BlueCross BlueShield

Kimberly Callinan, MPP
Compassion & Choices

Grace B. Campbell, PhD, MSW, RN
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Jeff Cohn, MD, MHCM
Common Practice

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Gordon and Betty Moore Foundation

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Carole Redding Flamm, MD, MPH
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Stephen Friedhoff, MD
Anthem, Inc.

Mark B. Ganz
Cambia Health Solutions

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The Pew Charitable Trusts

Rev. Eric J. Hall
Health Care Chaplaincy Network

Ziad Haydar, MD, MBA
Ascension Health

Pamela S. Hinds, RN, PhD, FAAN
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Haiden Huskamp, PhD
Harvard Medical School

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Federation of American Hospitals

Rebecca A. Kirch, JD
National Patient Advocate Foundation

Tom Koutsoumpas
Coalition to Transform Advanced Care

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Centers for Medicare & Medicaid Services
Bernard Lo, MD
The Greenwall Foundation

Joanne Lynn, MD
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UnitedHealth Group

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National Palliative Care Research Center

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Dignity Health

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Susan G. Komen

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We ask and answer the nation's most pressing questions about health and health care.

The Health and Medicine Division (HMD)—an operating unit of the National Academies of Sciences, Engineering, and Medicine (National Academies)—helps those in government and the private sector make informed health decisions by providing evidence upon which they can rely.

Through our consensus studies, we offer straightforward answers to questions of national importance. Our convening activities bring together actors from across the health care spectrum to explore complex topics and work toward shared understanding on critical health issues.

Each year, more than 3,000 of the world’s leading experts in industry, academia, and the health care sector volunteer their time, knowledge, and expertise with HMD. They work through committees composed to ensure the needed expertise and to avoid conflicts of interest. With the assistance of approximately 150 HMD staff members, their contributions help to advance health.

Our advice is steeped in science and led by evidence. For millions of people across the United States and around the globe, improving health is not merely an academic exercise; it is a matter of daily survival and well-being. In all we do to improve health policy and decision making, HMD is ever mindful of the impact of our work on the lives and health of individuals, families, communities, and nations.

As of March 2016, the Health and Medicine division continues the consensus studies and convening activities previously undertaken by the Institute of Medicine.

The National Academies of Sciences • Engineering • Medicine
OUR WORK
From alerting the public to the widespread problem of medical errors to setting the blueprint for the future of nursing to emphasizing the importance of end-of-life care preferences, our consensus studies provide independent, evidence-based advice on pressing issues in health and health care.

Many of the studies that HMD undertakes are requested by federal agencies and independent organizations; others begin as specific mandates from Congress. Before any National Academies report is released, it undergoes extensive peer review by a second group of experts, whose identities remain anonymous to the authoring committee until the study is published. For decades, this process has resulted in sound publications providing policy makers, the health professions, and the American people with objective advice grounded in evidence.

While our consensus committees are vital to our advisory role, HMD also convenes a series of forums, roundtables, and standing committees. These activities facilitate discussion; discovery; and critical, cross-disciplinary thinking, and when required can quickly gather experts to address matters of urgent importance, such as emerging infectious diseases and health-related disaster preparedness.

OUR NAME
As of March 2016, the Health and Medicine division continues the consensus studies and convening activities previously undertaken by the Institute of Medicine. With this change, HMD is now fully integrated into the broader work of the National Academies, which is facilitating more collaborative and interdisciplinary approaches to the most pressing challenges facing the nation and the world.
An ad hoc committee will plan, organize, and host a one-day public workshop to examine issues pertaining to integrating palliative care principles into the delivery of care for people of all ages with serious illness.

The workshop will feature invited presentations and panel discussions on topics that may include:

- Model programs and strategies that integrate palliative care principles into serious illness care delivery
- Best practices of successful integrated palliative care delivery programs
- Factors that influence care delivery models, such as geographic location; ability to mobilize community resources including volunteers; adaptability to high- and low-resource environments; and diverse populations and settings of care
- Evidence base and research needs to support and promote model programs of integrated serious illness care
- Challenges to implementing and scaling model programs, including consideration of current workforce capacity and competencies; evaluation considerations, such as the potential benefits and limitations of quality measurement; and the challenges of aligning incentives and payment with new models of serious illness care

The planning committee will develop the agenda for the workshop, select speakers and discussants, and moderate the discussions. Proceedings of the presentations and discussions at the workshop will be prepared by a designated rapporteur in accordance with institutional guidelines.
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Roundtable on Quality Care for People with Serious Illness

Planning Committee Roster

Diane E. Meier, M.D., FACP
(Co-Chair)
Director, Center to Advance Palliative Care. Gaisman Professor of Medical Ethics
Vice Chair for Public Policy and Professor, Department of Geriatrics and Palliative Medicine
Department of Medicine, Icahn School of Medicine at Mount Sinai

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(Co-Chair)
Chief Executive Officer, Oncology Nursing Society

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University of Virginia Health System

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Assistant Professor, Department of Acute and Tertiary Care
University of Pittsburgh School of Nursing
Representing the Association of Rehabilitation Nurses

Jeff Cohn M.D., MHCM
Medical Director
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Janet Corrigan, Ph.D., M.B.A.
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The Pew Charitable Trusts

Sarah Hill, Ph.D.
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Haiden Huskamp, PhD
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Harvard Medical School

Charles N. Kahn III
President and CEO
Federation of American Hospitals

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University of Colorado School of Medicine
Joanne Lynn, M.D.
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Amy Melnick, M.P.A.
Executive Director
National Coalition for Hospice and Palliative Care

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Chief, Office of End-of-Life and Palliative Care Research, Senior Policy Analyst,
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Long Term and Palliative Care Consultant,
Clinical Social Worker and Board Member
Social Work Hospice and Palliative Care Network

Katrina M. Scott, M.Div, BCC-HPCC
Oncology Chaplain
Massachusetts General Hospital
Roundtable on Quality Care for People with Serious Illness

Workshop Speakers, Moderators, and Planning Committee Members

Terry Altilio, LCSW, ACSW
Mt. Sinai Beth Israel Medical Center

Terry Altilio is Coordinator of Social Work for the Division of Palliative Care at Mt Sinai Beth Israel Medical Center. She is a recipient of a Mayday Pain and Society Fellowship Award 2006 and a Social Work Leadership Award from the Open Society Institute’s Project on Death in America, which supported a social work post graduate fellowship and a social work listserv, both of which are continuing programs. In 2013, Terry was selected to receive the Project on Death in America, Career Achievement Award from the Social Work Hospice and Palliative Network. In addition to direct work with patients and families, she lectures nationally and internationally on topics such as pain management, ethics, palliative care and psychosocial issues in end of life care. She lectures in the post-Masters Palliative and End of Life Care Program at New York University School of Social Work and Smith College School of Social Work, teaching Pain and Symptom Management and Ethics. She also is faculty for the internet Post MSW Certificate Course in Palliative Care, California State University Institute for Palliative Care. She has co-authored publications on pain and symptom management, psychosocial issues in palliative care and caregiver advocacy. She is co-editor with Shirley Otis-Green of the inaugural Oxford Textbook of Palliative Social Work published in February 2011.

Richard Averbuch, MPA
Massachusetts Coalition for Serious Illness Care

Richard Averbuch is the Executive Director of the Massachusetts Coalition for Serious Illness Care, an organization consisting of more than sixty Massachusetts-based organizations. Working at these groups are dedicated physicians, nurses, hospice workers, counselors, clergy, hospital and health plan administrators, social workers, attorneys, policymakers, researchers, and other health professionals. The mission of the Coalition is to ensure that health care for everyone in Massachusetts is in accordance with their goals, values and preferences at all stages of life and in all steps of their care. Prior to this, Richard served as Project Consultant to Blue Cross Blue Shield of Massachusetts, and previously was the Chief Marketing Officer at Massachusetts General Hospital. He has also worked in communications and health policy at Beth Israel Deaconess Medical Center, the Massachusetts Hospital Association, and the Massachusetts Business Roundtable. He holds a Master of Public Administration degree from Harvard University’s John F. Kennedy School of Government.
Anthony L. Back, MD
University of Washington, Fred Hutchinson Cancer Research Center, and VitalTalk

Anthony Back, MD, is Professor at the University of Washington and Fred Hutchinson Cancer Research Center, and codirects the Cambia Palliative Care Center for Excellence with Randy Curtis. He studies patient-clinician communication, and interventions to make clinicians more effective. He was the principal investigator for the Oncotalk interventions, wrote *Mastering Communication with Seriously Ill Patients* with Bob Arnold and James Tulsky, released the first iPhone app for clinician communication skills, and was a 2013-4 Contemplative Studies Fellow of the Mind and Life Institute. Dr. Back is co-founder of VitalTalk.

Robert A. Bergamini, MD
Mercy Clinic Children’s Cancer and Hematology and Supportive Care Coalition

Dr. Robert A. Bergamini has spent most of his 35-year career as a pediatric hematologist-oncologist, and from the beginning, included palliative care as a priority of his practice before the field was formally defined. This approach to whole person care provided a firm foundation for his current role as Mercy’s ministry-level Medical Director for Palliative Care, which serves 39 hospitals and outpatient facilities/clinics across Missouri, Oklahoma, Arkansas and Kansas. He was appointed in 2013 to the Supportive Care Coalition’s Board of Directors and is a member of the Coalition’s Executive Committee. Following his Fellowship in Pediatric Hematology Oncology at St. Louis Children’s Hospital, Washington University Department of Pediatrics, and serving as Clinical Instructor in Pediatrics at Washington University, in 1985 Dr. Bergamini entered private practice at Mercy St. Louis. Dr. Bergamini and his team established the first support group in the St. Louis area for siblings of children with cancer, and an educational support and intervention program to provide supplemental educational assistance and diagnostic testing. With the help of patients and staff, Friends of Kids with Cancer, a local charity was founded. Under Dr. Bergamini’s leadership as Mercy’s medical director of palliative care services, programs have started in three new communities and a pilot program is under way for palliative care and hospice care via telemedicine to meet the ministry’s large rural population where density is less than six people per square mile. Mercy is in the final stages of obtaining accreditation for a palliative care fellowship and effective July 1, 2017, will have two positions available. Dr. Bergamini serves as the medical liaison to local faith-based communities. Initiatives include providing palliative care education for the Diocese of Little Rock and the Archdiocese of St. Louis. Dr. Bergamini is working with the Diocese of Little Rock on introduction of POLST legislation during the next session of the Arkansas legislature.
Amy J. Berman, BSN, LHD
John A. Hartford Foundation

Amy J. Berman, BSN, LHD, is a Senior Program Officer at the John A. Hartford Foundation, and heads the Integrating and Improving Services program, focusing on developing innovative, cost-effective models of care for older adults. She also directs a number of collaborations with the U.S. Administration on Aging/AARP that address the needs of family caregivers. Prior to joining Hartford, Ms. Berman served as Nursing Education Initiatives Director at the Hartford Institute for Geriatric Nursing at New York University’s College of Nursing, and before that she worked in home health care administration. She has also served on the New York State Department of Health’s Emergency Preparedness Task Force, and is a member of numerous organizations, among them the Aging Task Force for Healthy People 2020, the Gerontological Society of America, and the Honor Society of Nursing, Sigma Theta Tau. Ms. Berman earned a B.S. in nursing from New York University, a B.S. in health care administration from the University of Massachusetts, Amherst, and a Geriatric Scholar Certificate from the Consortium of New York Geriatric Education Centers.

Joy Buck, PhD
West Virginia University School of Nursing

Dr. Joy Buck is a professor in the West Virginia University School of Nursing with joint appointments in the School of Public Health and School of Medicine. Dr. Buck earned an MSN in community-based chronic care from George Mason University (1998), a PhD in Nursing/Policy History from the University of Virginia (2005), and completed a two-year post-doctoral research fellowship in the Center for Health Outcomes and Policy Research at the University of Pennsylvania in 2007. Dr. Buck is recognized internationally for her scholarship on the historical development of hospice and palliative care in the United States. With an extensive clinical background in rural community-based HIV/AIDS and complex chronic care, Dr. Buck founded “Bridges to Healthy Transitions,” a community-based research initiative housed in the WVU Eastern Division, in 2007. Her research projects explore the influence of culture on formal and informal serious illness care and their intersection. The community and interdisciplinary students are engaged in various aspects of the “Bridges” projects and are thus sensitized to the day-to-day experiences of persons with serious illness and their families. These lessons lead to a better understanding of how to adapt care structures and processes to reduce symptom, caregiver, and intergenerational burden associated with long-standing serious illness in rural, underserved populations.
Rev. Alice Cabotaje, MDiv
Massachusetts General Hospital

Rev. Alice Cabotaje is an Association for Clinical Pastoral Education (ACPE) Supervisor and a Board Certified Chaplain with the Association of Professional Chaplains (APC). Alice is the Clinical Pastoral Education (CPE) Supervisor at the Chaplaincy Department of Massachusetts General Hospital (MGH) in Boston, MA. She runs the CPE program, a multi-cultural, inter-faith training program for those who want to learn the skills and theory in spiritual care, and for individuals seeking board certification in professional chaplaincy. Prior to joining MGH, Alice supervised CPE students in the yearlong, extended, and summer programs at the University of California San Francisco (UCSF) Medical Center and UCSF Benioff Children's Hospitals, where she did her CPE supervisory training from 2011 to 2014. She also supervised CPE students at University of California Davis Medical Center in Sacramento, California. Alice did her CPE residency at UCSF Medical Center and UCSF Benioff Children's Hospital from 2006 to 2007. Before starting her CPE supervisory education in 2011, Alice worked for three years as a Chaplain/Spiritual Care Counselor at Pathways Home Health and Hospice in the San Francisco Bay Area. In addition to her years of experience in CPE and chaplaincy, Alice has over seven years of parish ministry as Volunteer Clergy at the Peninsula Metropolitan Community Church in San Mateo, California. Along with being grounded in the Christian faith, Alice underwent training and studies in the yogic tradition under a Calcutta-based guru for 18 years. Over the last 13 years, she has been an active Zen Buddhist practitioner in the Sanbo Kyodan (Harada-Yasutani) lineage. Alice is ordained and endorsed by the Metropolitan Community Churches. She has a Master of Divinity from the Pacific School of Religion, a member school of the Graduate Theological Union in Berkeley, California, and a Bachelor of Arts in Philosophy from the University of the Philippines.

Kim Callinan, MPP
Compassion & Choices

Kim Callinan serves as the chief program officer at Compassion & Choices, the leading national nonprofit organization committed to helping everyone have the best death possible. In this capacity, Ms. Callinan is responsible for working collaboratively with the organizational management team to develop the vision, set the strategic priorities, and direct the design and management of all Compassion & Choices programming. This includes responsibility for a more than 50-person staff and a $10 million departmental budget with oversight for national and federal programs; political and field; legal advocacy and the end of life resource center. Ms. Callinan came to Compassion & Choices bringing two decades of experience creating integrated campaigns to engineer social change for government agencies, nonprofit organizations, foundations and political campaigns including supporting issue campaigns related to the uninsured and child health and political campaigns at
Roundtable on Quality Care for People with Serious Illness

the federal, state and local levels. Ms. Callinan has a master’s degree in public policy from Georgetown University, a graduate certificate in public health from the University of South Florida and a bachelor’s degree in government from Oberlin College. She also holds a certificate on the Fundamentals in Gerontology through a joint program offered by The American Society on Aging and the USC Davis School of Gerontology.

Shonta Chambers, MSW
Patient Advocate Foundation

Shonta Chambers is the Executive Vice President-Health Equity Initiatives and Community Engagement for the Patient Advocate Foundation. Shonta is responsible for the development and execution of the Foundation’s national strategy to address health equity, with a specific focus on persons with chronic, life threatening and debilitating diseases who could benefit from the portfolio of services provided by the Foundation. Shonta also serves as the Principal Investigator on record as part of DP13-1314 National Networks to Reduce Cancer and Tobacco Related Disparities. Prior to joining PAF, Shonta was the Deputy Director for Administration and Finance for the Chronic Disease Prevention Section within the Georgia Department of Public Health. Her experience includes nearly 15 years with the State of Georgia serving both the Department of Community Health (Office of Women’s Health) and the Georgia Department of Public Health. During her public health career, she functioned in a variety of capacities including Interim Director for the Chronic Disease Prevention Section. In this capacity, she provided leadership and senior level consultative support to the Department of Public Health around chronic disease prevention and health promotion best practices. The breadth of her experience includes leading efforts to integrate primary and secondary prevention strategies for a variety chronic disease and risk factor programs (Cardiovascular Health, Diabetes, Tobacco Use, Asthma, and Cancer) and women’s health. In 2011, her role was expanded to include sexual violence prevention and adolescent health and youth development. Shonta’s commitment to chronic disease prevention and health promotion is also evident in her volunteer activities. She has been an active volunteer with the American Heart/American Stroke Association for the past 14 years serving at the national and affiliate level. She is a former member of the American Heart Association Greater Southeast Affiliate and National Board of Directors. Shonta is the former chair for the Greater SE Affiliate Cultural Health Initiative Board and the National AHA Diversity Leadership Committee. In 2013, she was the recipient of the AHA’s Louis B. Russell Award for her work to increase awareness of heart disease and stroke among minority populations and for her vision to increase diversity across all AHA national committees. Shonta has served on a variety of boards, workgroups, councils, committees and taskforces, including, the Directors of Health Promotion and Education, the National Association of Chronic Disease Directors and the CDC Expert Working Group “Role of Public Health in Screening Programs in an Era of Healthcare Reform.” Shonta received her Bachelors of Arts degree (Social Work) from Talladega College and her Master of Social Work degree from the University of Michigan.
Roundtable on Quality Care for People with Serious Illness

Stacy Fischer, MD
University of Colorado at Denver School of Medicine

Dr. Stacy Fischer is an Associate Professor in the Division of General Internal Medicine at the University Of Colorado School Of Medicine. After completing a residency in Internal Medicine, Dr. Fischer studied Spanish in Latin America and worked in an underserved hospital in Peru. She returned to the University to train in geriatrics and palliative care research. Inspired by her experiences in Central/South America, she began conducting research exploring how ethnicity and poverty affects care and preferences for care at the end of life in a cohort of older, seriously ill, hospitalized patients from diverse ethnic and socioeconomic backgrounds. The results of that project informed her work in developing and testing the effects of a bicultural patient navigator to improve advance care planning, pain management, and hospice utilization for seriously ill Latinos funded through the National Institute of Aging and the Beeson Foundation. Her clinical experiences include working in a community clinic affiliated with Denver Health, a safety net hospital, serving as a medical director of home care with a large Denver hospice, and currently working on the inpatient palliative care consult service at the University of Colorado Hospital. In 2012, she received funding from the American Cancer Society to conduct a randomized controlled trial of the culturally tailored patient navigator intervention for Latinos with advanced cancer. She recently received funding from the National Institute of Nursing Research to test the navigator intervention for Latinos with serious non-cancer illness. Outside her academic career, she chairs the board of the Ray of Hope Cancer Foundation, providing emergency financial assistance to Colorado cancer patients in need.

Richard D. Goldstein, MD, FAAP
Boston Children’s Hospital and Harvard Medical School

Dr. Richard D. Goldstein is an assistant professor of pediatrics at Boston Children’s Hospital and Harvard Medical School. He is a pediatric palliative care physician and researcher, with interests in the characterization of grief in a parent after the loss of a child, and behavioral adaptation to extraordinary circumstances. He is a pediatric track course director for Palliative Care Education and Practice. In 2012, Dr. Goldstein co-founded Robert’s Program in Sudden Unexpected Death in Pediatrics, a translational clinical program approaching sudden unexpected death in children as an undiagnosed disease, bringing new diagnostic approaches and insights to the care and counseling of affected families. The program also conducts research and promotes advocacy related to the challenges of addressing sudden death in pediatrics.
Ellen Goodman has spent most of her life chronicling social change and its impact on American life. As a Pulitzer Prize-winning columnist, she was one of the first women to open up the oped pages to women's voices and became, according to Media Watch, the most widely syndicated progressive columnist in the country. Today she continues that work from her observation post as a writer, speaker, commentator and nonprofit leader. At the heart of Ellen’s work is The Conversation Project, a public health campaign and a movement, that works to change the way people talk about, and prepare for their end-of-life care. Ellen tells the story of serving as her mother’s caregiver with honesty and humor, delivering her mission and spreading the value of having “The Conversation” at conferences, lectures and workshops nationwide. She currently serves as a Prime Mover and an Ashoka fellow, for her work as a social entrepreneur offering innovative approaches to solving long-standing social problems. She’s also had a seat on the board of Encore.org for more than five years, helping people use their passions, skills and decades of experience to make a difference in our communities and the world. Ellen began her career as a researcher for Newsweek magazine in the days when only men wrote for the newsweekly. She landed a job as a reporter for the Detroit Free Press in 1965 and, in 1967, for The Boston Globe where she began writing her column in 1974 which was syndicated by the Washington Post Writers Group two years later. She wrote her twice-weekly column until 2010 when she left with a column about the virtues of “letting myself go.” She’s a seven time author and in 1980, won the Pulitzer Prize for Distinguished Commentary. Ellen is also the recipient of many other honors for her work in the field, including the American Society of Newspaper Editors Distinguished Writing Award and the Hubert H. Humphrey Civil Rights Award from the Leadership Conference on Civil Rights. She was honored with the President’s Award by the National Women’s Political Caucus and was also presented the American Woman Award by the Women’s Research & Education Institute. In 2008, she won the Ernie Pyle Award for Lifetime Achievement from the National Society of Newspaper columnists. A 1963 cum laude graduate of Radcliffe College, Goodman returned to Harvard in 1973-74 as a Nieman Fellow, where she studied the dynamics of social change, and again in 2007 as a Shorenstein Fellow. Ellen has a daughter, stepdaughter, two grandchildren and lives with her husband, Robert Levey in Boston.
Nick Jehlen
Common Practice

Nick Jehlen is co-founder of Common Practice, a company that creates practical tools that support great conversations about serious illness and end of life issues. Applying his background in human factors engineering and design, Nick has been creating innovative social interventions for over 20 years. Over the course of his career, he has collaborated with housing and voting rights advocates, healthcare staff, state employees, student groups, human service organizations, and returning veterans of the wars in Iraq and Afghanistan to build tools that create social change and empower communities. His work is informed by his ongoing study of Gandhian nonviolent methods and social movements. Nick is the lead designer of the games "Hello" and "My Gift of Grace" which have been used by families and organizations around the world to support better conversations about living and dying well. He grew up in Somerville, Massachusetts and now lives in New York City with his wife, Amber.

Kimberly S. Johnson, MD
Duke University School of Medicine

Dr. Kimberly S. Johnson is an Associate Professor of Medicine with Tenure in the Division of Geriatrics and a Fellow in the Center for the Study of Aging and Human Development at Duke University School of Medicine. She received her undergraduate education at Dillard University in New Orleans, Louisiana and her M.D. from Johns Hopkins University School of Medicine. She completed her residency training in Internal Medicine, fellowship in Geriatrics, and clinical research training (MHS) at Duke University. Dr. Johnson is board-certified in Internal Medicine, Geriatrics, and Hospice and Palliative Medicine and provides clinical care to seriously ill adults in long-term care and inpatient settings. Dr. Johnson’s research focuses on understanding and eliminating racial disparities in palliative and end-of-life care. She has published widely and is nationally recognized for her work investigating how cultural beliefs and preferences and organizational practices and policies may influence the use of hospice care by older African Americans. Dr. Johnson has received awards for her research from the American Academy of Hospice and Palliative Medicine and the American Geriatrics Society. She was the recipient of the prestigious Beeson Career Development Award in Aging Research and the National Palliative Care Research Center Career Development Award, and has received additional research funding from the NIA, Greenwald Foundation, and AHRQ.
Rebecca A. Kirch, JD
National Patient Advocate Foundation

Rebecca A. Kirch is Executive Vice President of Healthcare Quality and Value for the National Patient Advocate Foundation (NPAF), the advocacy affiliate of the Patient Advocate Foundation (PAF). In this role, she provides strategic focus and leadership in bringing the millions of patient and family voices these two organizations represent to the forefront of national health care quality improvement efforts. Rebecca joined NPAF in April 2016, previously serving 15 years with the American Cancer Society and its advocacy affiliate, the American Cancer Society Cancer Action Network (ACS CAN). As a leading health policy expert and advocate in her field, Rebecca is dedicated to improving quality of life and the quality of care for all adults, children and families confronting serious illness. She has authored numerous articles and book chapters addressing priorities of person-centered care and quality improvement practices that promote skilled communication and goal-directed care, with particular emphasis on integrating palliative, psychosocial, and rehabilitation services with disease-directed treatment. Rebecca also played a leading role in planning and executing the Institute of Medicine and American Cancer Society 2015 joint workshop on “Comprehensive Cancer Care for Children and Families.”

Kathie Kobler, MS, APN, PCNS-BC, CHPPN, FPCN
Advocate Children’s Hospital

Kathie Kobler is an Advanced Practice Nurse with over 31 years of experience caring for infants and children with serious illness and their families. She is the APN coordinator of the Center for Fetal Care and Pediatric Palliative & Supportive Care programs at Advocate Children’s Hospital, Park Ridge. Kathie is a published author and an invited professional speaker at local and national venues regarding perinatal/pediatric palliative care and bereavement issues. Kathie has served in leadership positions for the Hospice & Palliative Credentialing Center and the Hospice & Palliative Nurses Association. She is a 2014-2016 Jonas Nurse Leader Scholar, and a PhD Candidate at the University of Illinois at Chicago, with anticipated graduation in spring 2017. Kathie holds two certifications: Certified Pediatric Clinical Nurse Specialist (PCNS-BC) and Certified Hospice and Palliative Care Pediatric Nurse (CHPPN). She was named a 2016 Fellow in Palliative Care Nursing (FPCN) by the Hospice and Palliative Nurses Association/HPNA.
Blyth Lord, MA
Courageous Parents Network

Blyth Lord is the founder and Executive Director of COURAGEOUS PARENTS NETWORK, a nonprofit focused on improving the experience of parents caring for children with life-limiting illness through education, advocacy and parent-to-parent support. Blyth is also the Executive Director of the CAMERON AND HAYDEN LORD FOUNDATION, a small family grant-making foundation whose mission is to advance pediatric palliative care in the United States, as well as fund research of therapies for lysosomal storage diseases. Blyth's daughter, Cameron, and nephew, Hayden, died of Tay-Sachs disease in 2001. In the years following, Blyth has promoted the needs of families caring for children with serious illness and how providers can best meet these needs. Drawing on more than 20 years of experience as a television producer (ABC News, Medical News Network, WGBH), she produced the award-winning film, Cameron’s Arc, with the American Academy of Pediatrics to educate doctors in working with families from the time of diagnosis through to the end-of-life. Cameron’s Arc has been distributed nationally as a teaching tool to pediatric residency programs across the United States. She also produced the Parenting a Child with Life-Limiting Illness video with the National Tay-Sachs and Allied Diseases organization, as a resource for parents and the providers who work with them. These successes inspired the inclusion of parent and provider story-telling and videos that are central to COURAGEOUS PARENTS NETWORK, which she founded in 2013. A growing number of parents work with Blyth in contributing to the NETWORK and in continuously evolving its value to families. Blyth is an affiliate member of the AAP’s Section on Hospice and Palliative Medicine and a co-chair of the Section’s Parent Advisory Group. She also sits on the board of National Tay-Sachs and Allied Disease, and on the board of The Children’s Room, a bereavement support program for families who have lost parents/siblings/children. Blyth received her BA in History from Yale College, has a Masters in Education from Harvard, and lives in Newton, Massachusetts with her husband and two daughters.

Rev. Malcolm Marler, MDiv, DMin
University of Alabama at Birmingham

Rev. Malcolm Marler is the Director of Pastoral Care at UAB Medicine (University of Alabama at Birmingham) and has been a Chaplain at UAB for twenty-two years. UAB Hospital is a Level I Trauma Center and is the third largest public hospital in the U.S. with 1150 beds. Malcolm has a B.A. in Psychology (Clemson University) and Master of Divinity and Doctor of Ministry degrees (Southern Seminary) in pastoral care. UAB’s Department of Pastoral Care is developing an innovative approach that has as its foundational belief that “Community is Good Medicine.” Chaplains develop intentional support teams for their patients by training friends, neighbors, co-workers, and faith groups to provide practical, emotional, and spiritual support for persons in the inpatient, ambulatory, and community
context. Ten best practices for Support Teams such as “The Green Bean Casserole Rule” have been developed that allow team members to do what they love to do with time flexibility while most importantly simplifying for the patient (and caregivers) to get what they need when they need it by coordinating the team through one trusted friend.

Diane E. Meier, MD, FACP
Icahn School of Medicine at Mount Sinai and Center to Advance Palliative Care

Dr. Diane E. Meier is Director of the Center to Advance Palliative Care (CAPC), a national organization devoted to increasing the number and quality of palliative care programs in the United States. Under her leadership the number of palliative care programs in U.S. hospitals has more than tripled in the last 10 years. She is also Vice-Chair for Public Policy and Professor of Geriatrics and Palliative Medicine; Catherine Gaisman Professor of Medical Ethics; and was the founder and Director of the Hertzberg Palliative Care Institute from 1997-2011, all at the Icahn School of Medicine at Mount Sinai in New York City. Dr. Meier is the recipient of numerous awards, including the 2008 MacArthur Fellowship. She was named one of 20 People Who Make Healthcare Better in the U.S. by HealthLeaders Media 2010 and received an Honorary Doctorate of Science from Oberlin College in 2010. In 2012, she was awarded American Cancer Society’s Medal of Honor for Cancer Control in recognition of her pioneering leadership of the effort to bring non-hospice palliative care into mainstream medicine. Other honors include the Open Society Institute Faculty Scholar’s Award of the Project on Death in America, the Founders Award of the National Hospice and Palliative Care Organization 2007, AARP’s 50th Anniversary Social Impact Award 2008, Castle Connelly’s Physician of the Year Award 2009 and the American Academy of Hospice and Palliative Medicine Lifetime Achievement Award 2009. Dr. Meier served as one of Columbia University’s Health and Aging Policy Fellows in Washington, DC during the 2009-2010 academic year, working both on the Senate’s HELP Committee and the Department of Health and Human Services. Dr. Meier has published more than 200 original peer review papers, and several books. Her most recent book, Meeting the Needs of Older Adults with Serious Illness: Challenges and Opportunities in the Age of Health Care Reform, was published by Humana in 2014. She edited the first textbook on geriatric palliative care, as well as four editions of Geriatric Medicine. Diane E. Meier received her BA from Oberlin College and her MD from Northwestern University Medical School. She completed her residency and fellowship training at Oregon Health Sciences University in Portland. She has been on the faculty of the Department of Geriatrics and Palliative Medicine and Department of Medicine at Mount Sinai since 1983. She lives in New York City.
Peter Mitchell, Chairman and Chief Creative Officer, SalterMitchell, is a former journalist and legislative staffer. Peter got into behavior-change marketing more than a decade ago when he was asked to direct the marketing campaign for a new anti-tobacco initiative in Florida. The campaign became “truth” — an effort that transformed tobacco control and got replicated on a national scale after Florida showed the first statewide drop in teen smoking in 19 years. Since then, Peter has developed and directed dozens of behavior-change marketing campaigns across the globe — first for a large international non-profit and later as a founder of Marketing for Change™, which is now part of SalterMitchell. He’s developed dozens of social marketing campaigns over the years, including one to reduce fertilizer use near Chesapeake Bay that urged homeowners to “save the crabs, then eat ‘em,” and a pandemic-flu preparedness initiative that noted, “Four out of five people wash their hands after using the rest room. Could someone talk to the fifth guy?” He has won numerous awards (Emmy, Silver Anvil, Gold Davey, Telly, Addy, etc.) and designed behavior-change campaigns domestically and in Bangladesh, India, Jordan and Tanzania for such organizations as the U.S. Environmental Protection Agency, Florida Healthy Kids Corporation, the Massachusetts Institute of Technology, the Planned Parenthood Federation of America, and the U.S. Agency for International Development. A graduate of Colgate University, Peter also spent a decade as a reporter, including covering Florida for The Wall Street Journal, and served as the policy coordinator for Florida’s Senate President.

Murali N. Naidu, MD, FACS
Dignity Health

Dr. Murali N. Naidu is the Vice President of Surgical Services of Dignity Health. He is responsible for improving the perioperative care of patients at 39 acute care hospitals. Dignity Health’s strategy encompasses improvements in clinical outcomes, enhancement of our patients’ experiences, physician growth and integration, perioperative efficiency, supply utilization, and staff development and productivity. Dr. Naidu is a dynamic health care leader and practicing general surgeon, with extensive experience working with other top 10 U.S. health care systems as a consultant with McKinsey & Company. His interests include influencing clinicians to improve outcomes and efficiency and developing structures that provide the best care, both inside and outside the acute setting. Dr. Naidu earned his M.D. from the David Geffen School of Medicine at UCLA.
Sharon Scribner Pearce has served as the Vice President for Public Policy at the National Hospice and Palliative Care Organization (NHPCO) since 2015. In that role, Sharon serves as the primary liaison between Capitol Hill and the NHPCO leadership and membership; manages the day-to-day operations of the NHPCO Hospice Action Network (HAN); leads a dynamic team of policy professionals; and coordinates advocacy and policy work across the department and organization. Sharon arrived at NHPCO with almost 20 years of health policy experience, including six years advising members of Congress on Capitol Hill, five years as a hired-gun lobbyist at a large K Street firm, and seven years as in-house lobbyists at the National PACE Association and Girl Scouts of the USA.

JoAnne Reifsnyder, PhD, RN, FAAN
Genesis Healthcare and Hospice and Palliative Nurses Association

Dr. JoAnne Reifsnyder has been the Chief Nursing Officer of Genesis Healthcare, Inc. since July 2012 and also serves as its Executive Vice President of Clinical Operations. Dr. Reifsnyder has held executive and leadership roles in both for profit and not for profit health care settings. Prior to joining Genesis, Dr. Reifsnyder was Senior Vice President, Care Transitions, with Moorestown, NJ-based Care Kinesis, LLC. In this role, she served as a consultant to Genesis HealthCare and to Bayada Nurses, working with executives and clinical team members to develop a skilled nursing facility to home transitional care model for vulnerable older adults. Dr. Reifsnyder was Chief Quality Outcomes officer for excelleRx, Inc., a Philadelphia-based medication management therapy company. She was also co-founder and partner in Ethos Consulting Group, LLC, a company focused on program development, education/training and research/evaluation to advance end of life care. She was formerly the Director of the Hospice Program for the VNA of Greater Philadelphia and was Director of Patient Services for Samaritan Hospice in Marlton, NJ. Dr. Reifsnyder served as President of the Board of Directors for the Hospice and Palliative Nurses Association, Pennsylvania Hospice Network, and LifeChoice Hospice and currently serves on the Board of Hospice Foundation of America. She is a member of the American Nurses Association, the American Academy of Nursing, American Organization of Nurse Executives (AONE), the National Gerontological Nurses Association (NGNA) and Sigma Theta Tau International, the Honor Society of Nursing. In 2002, Dr. Reifsnyder co-developed and was the coordinator of a palliative care minor at the University Of Pennsylvania School Of Nursing, where she taught both core courses to nursing, social work and medical students. In 2009, she led the development of the first Masters’ program in Chronic Care Management at Jefferson School of Population Health.
Roundtable on Quality Care for People with Serious Illness

(JSPH), Thomas Jefferson University in Philadelphia, PA. Dr. Reifsnyder completed a postdoctoral fellowship in psychosocial oncology at the University Of Pennsylvania School Of Nursing, and holds a PhD in nursing from the University of Maryland, a Master’s Degree in nursing from Thomas Jefferson University, and a BSN from Holy Family College. She will complete the requirements for a Masters in Business Administration from George Washington University in December, 2016.

Judith A. Salerno, M.D., M.S
Susan G. Komen

Judith A. Salerno, M.D., M.S., is the President and Chief Executive Officer of Susan G. Komen®, responsible for the day-to-day operation of the organization and for setting Komen’s strategic vision. Dr. Salerno brings extensive experience in research, public health policy and community health to the role. Before joining Komen, she was the Leonard D. Schaeffer Executive Officer of the Institute of Medicine (IOM) of the National Academies, serving as executive director and chief operating officer of the Institute. In that role, she was responsible for directing the IOM’s research and policy programs and guiding the Institute’s operations on a daily basis. She also oversaw the National Cancer Policy Forum – a consortium of government, industry, academic, consumer, and other representatives that identifies and examines emerging high-priority policy issues in cancer. Before joining the IOM, Dr. Salerno was Deputy Director of the National Institute on Aging (NIA) at the National Institutes of Health, U.S. Department of Health and Human Services. She oversaw the Institute’s research into aging, including research on Alzheimer’s and other neurodegenerative diseases, frailty and function in late life, and the social, behavioral and demographic aspects of aging. As the NIA’s senior geriatrician, Dr. Salerno was vitally interested in improving the health and well-being of older persons, and designed public-private initiatives to address aging stereotypes, novel approaches to support training of new investigators in aging, and programs to communicate health and research advances to the public. Before joining the NIA in 2001, Dr. Salerno directed the continuum of Geriatrics and Extended Care programs across the nation for the U.S. Department of Veterans Affairs (VA), Washington, D.C. While at the VA, she launched widely recognized national initiatives for pain management and improving end-of-life care. Prior to this appointment, Dr. Salerno was Associate Chief of Staff at the VA Medical Center in Washington, D.C. where she developed and implemented innovative approaches to geriatric primary care and coordinated area-wide geriatric medicine training. Dr. Salerno also co-founded the Washington D.C. Area Geriatric Education Center Consortium, a collaboration of more than 160 educational and community organizations within the Baltimore-Washington region. A board-certified physician in internal medicine, Dr. Salerno earned her M.D. degree from Harvard Medical School in 1985 and a Master of Science degree in Health Policy from the Harvard School of Public Health in 1976.
Kristen Cox Santiago, M.Sc.
Cancer Support Community

Kristen Cox Santiago has substantial experience working in the healthcare industry in roles in the public, private, and not-for-profit sectors. In her current role as Senior Director, Policy & Advocacy for The Cancer Support Community (CSC), Kristen is responsible for: the development and implementation of CSC’s regulatory and legislative agenda, securing and growing relationships with policymakers and stakeholders across multiple sectors, and engaging national partners to identify areas of common work and consensus to collectively advocate for positive change for people affected by cancer. In Kristen’s previous position as Director, Strategic Initiatives & Outreach at C-Change, Kristen oversaw two of the organization’s strategic initiatives: Assuring Value in Cancer Care, focusing on improving the quality of care for individuals with cancer and their loved ones; and Sustaining a Strong National Cancer Workforce, focusing on increasing the quantity of individuals who provide care and improving the quality of the care they provide. Prior to C-Change, Kristen worked for TAP and Takeda Pharmaceuticals and The Commonwealth of Pennsylvania, and interned with the American Speech-Language-Hearing Association and the National Coalition for Promoting Physical Activity. Kristen earned a Masters of Science in Health Promotion Management at American University and a Bachelor of Arts in Speech Language Pathology from The George Washington University. Kristen is driven by a strong personal desire to impact the health status and quality of life of individuals.

Leonard D. Schaeffer
University of Southern California
Chair, Roundtable on Quality Care for People with Serious Illness

Leonard D. Schaeffer is the founding Chairman & CEO of WellPoint, the nation’s largest health benefits company by membership. WellPoint (now Anthem) serves nearly 39 million medical members and has annualized revenues of $78.4 billion. He is currently the Judge Robert Maclay Widney Chair and Professor at the University of Southern California and is a Senior Advisor to TPG Capital, a private equity firm. Schaeffer was Chairman & CEO of WellPoint from 1992 through 2004 and continued to serve as Chairman through 2005. Under his leadership, WellPoint was selected by FORTUNE magazine as America’s “Most Admired Health Care Company” for six consecutive years; named by BusinessWeek as one of the 50 best performing public companies for three consecutive years; and identified by Forbes magazine as America’s best large health insurance company. Schaeffer was selected by BusinessWeek magazine as one of the “Top 25 Managers of the Year” and by Worth magazine as one of the “50 Best CEOs in America.” In 1986, Schaeffer was recruited as CEO to WellPoint’s predecessor company, Blue Cross of California, when it was near bankruptcy. He managed the turnaround of Blue Cross of California and the IPO creating WellPoint in 1993. During his tenure,
Roundtable on Quality Care for People with Serious Illness

WellPoint made 17 acquisitions and endowed four charitable foundations with assets of over $6 billion. Under Schaeffer’s leadership, WellPoint’s value grew from $11 million to over $49 billion. In 2009, Schaeffer established a new research center at USC. The Schaeffer Center for Health Policy and Economics emphasizes an interdisciplinary approach to research and analysis to promote health and value in health care delivery and to support evidence-based health policy. He has also endowed chairs in health care financing and policy at The Brookings Institution, Harvard Medical School, the National Academy of Medicine, U.C. Berkeley and USC. Previously, Schaeffer was President and CEO of Group Health, Inc. of Minnesota, a staff model HMO. Schaeffer was also EVP and COO of the Student Loan Marketing Association, the national secondary market for student loans and earlier was a Vice President of Citibank and a consultant specializing in design and installation of large scale financial and management information systems. In the federal government, he served as Administrator of the Health Care Financing Administration (now CMS) and was responsible for the U.S. Medicare and Medicaid programs. He was also the Assistant Secretary for Management and Budget of the federal Department of Health and Human Services. Previously, Schaeffer was Director of the Bureau of the Budget for the State of Illinois and also served as Chairman of the Illinois Capital Development Board and as Deputy Director for Management, Illinois Department of Mental Health and Developmental Disabilities. Schaeffer is active on the boards of numerous businesses, philanthropic and professional organizations. He was awarded a Doctor of Humane Letters (Hon) from USC and received the inaugural USC Sol Price Award for his lifetime achievements as a business leader, policy expert and philanthropist. He was the Regent’s Lecturer at the University of California at Berkeley, a Gilbert Fellow at Princeton, and a Williams Fellow at RAND. He is a member of the National Academy of Medicine (NAM) of the National Academies. A native of Evanston, Illinois, he is a graduate of Princeton University.

Katrina Scott, MDiv, BCC-HPCC
Massachusetts General Hospital and Association of Professional Chaplains

Katrina Scott has been the Oncology Chaplain and Palliative Care Service Chaplain Liaison at Massachusetts General Hospital since 2006. Her work focuses on supporting and nourishing the spiritual resources of patients and families in dealing with a life threatening illness. She also recognizes the clinical importance of supporting health care providers in ensuring patient-centered care. She has written and presented extensively on palliative care, spiritual care, serious illness, advanced care planning and end of life care issues. Ms. Scott is Board Certified by the Association of Professional Chaplains and holds a Specialty Certification in Hospice and Palliative Care. She received her Master of Divinity from Harvard Divinity School and is endorsed by the American Ethical Union (Ethical Culture).
Susan E. Sheridan, MIM, MBA, DHL
Patient-Centered Outcomes Research Institute

Susan E. Sheridan is currently the Director of Patient Engagement of the Patient-Centered Outcomes Research Institute (PCORI). She is responsible for creating networks and engaging patients across the nation to provide broad-based input on the development and execution of PCORI’s research. Sheridan is Co-Founder and Past President of Parents of Infants and Children with Kernicterus, which works in partnership with private and public health agencies to eradicate kernicterus. In 2003, Sheridan co-founded Consumers Advancing Patient Safety, a nonprofit organization that seeks a safe, compassionate and just healthcare system through proactive partnership between consumers, providers of care and policy makers. Sheridan served at President of CAPS from 2003-2010. Sheridan served as Program Lead from 2004-2011 for the World Health Organization’s Patients for Patient Safety initiative, a program under the WHO Patient Safety Program who embraces the collective wisdom of the patient, patient empowerment and patient centered care. She speaks frequently on patient engagement across the full spectrum of healthcare at national and international events. In April 2009, Sheridan was named to Modern Healthcare’s list of Top 25 Women in Healthcare as well as Modern Healthcare’s 100 Most Powerful People in Healthcare. In 2011 Sheridan was appointed by The Secretary of Health and Human Services to serve on the Advisory Committee on Infant Mortality of the Health Resources and Services Administration for 2011-2013. Sheridan also served on the ACGME Board of Directors as a Public Director from 2012 - 2014 and is currently serving on the Board of Directors of the Society to Improve Diagnosis in Medicine. Sheridan received her BA from Albion College, her MIM and MBA from Thunderbird School of Global Management and her Honorary Doctorate of Humane Letters from Adrian College. Sheridan also served in the Peace Corps from 1987-1989 in Ecuador with her late husband, Pat.

Julie Silver, MD
Harvard Medical School and Spaulding Rehabilitation Network

Dr. Julie Silver is an Associate Professor and the Associate Chair for Strategic Initiatives at Harvard Medical School in the Department of Physical Medicine and Rehabilitation and for the Spaulding Rehabilitation Network. Dr. Silver has published many scientific reports and is well-known for her ground-breaking work on “impairment driven cancer rehabilitation” which was initially published in the journal CA: A Cancer Journal for Clinicians—a high impact factor oncology journal that is published by the American Cancer Society. Impairment-driven cancer rehabilitation was subsequently incorporated into the American Cancer Society’s Facts & Figures for the first time in 2015. She is the co-founder and co-director of the Cancer Rehabilitation Group for the American Congress of Rehabilitation Medicine—a research focused
interdisciplinary professional society. Dr. Silver developed a best practices model for cancer rehabilitation care that hundreds of U.S. hospitals adopted, and it was featured by the Discovery Channel’s TV show Innovations. She has written and edited many books and is formerly the Chief Editor of Books for Harvard Health Publications—the official publishing division for Harvard Medical School. Her work has been recognized by the American Cancer Society (Lane Adams Quality of Life Award), Massachusetts General Hospital (The One Hundred) and The Boston Globe (Top Innovator in Medicine). Dr. Silver is currently affiliated with several Harvard teaching hospitals including Spaulding Rehabilitation, Massachusetts General and Brigham and Women’s Hospitals. Her work has been featured in many media outlets including the New York Times, Wall Street Journal, Boston Globe, LA Times, USA Today, London Times and NPR.

Karen E. Steinhauser, PhD
Duke University Medical Center and VA Medical Center

Karen Steinhauser, PhD, is a Health Scientist with the Center for Health Services Research in Primary Care, VA Medical Center, Durham, and Associate Professor, Department of Medicine, Duke University Medical Center and Senior Fellow with the Duke University Center for Aging. Her research focuses on improving patient and family quality of life in serious illness. She has developed tools to assess patient and family quality of life as well as psychosocial interventions to improve the experience of serious illness for patients and those who care for them. Her latest work includes: developing a measure to assess the spiritual needs in palliative care, participating in a pilot study to address clinician resilience in palliative care, and serving as Director of the Duke Residency Professional Development Coaching program.

Rebecca Sudore, MD
University of California San Francisco School of Medicine

Dr. Rebecca Sudore is Professor of Medicine at UCSF, a clinician-researcher, and a Geriatrician and a Hospice and Palliative Care physician. She is also a Staff Physician at the San Francisco VA Medical Center. Her research focuses on the intersection of health literacy, geriatrics, advance care planning, and informed medical decision making. Her current research program is focused on designing and testing interactive, web-based interventions to prepare patients and their surrogate decision makers to make complex medical decisions over the course of serious and chronic illness.
Dr. James A. Tulsky is Chair of the Department of Psychosocial Oncology and Palliative Care at Dana-Farber Cancer Institute, Chief of the Division of Palliative Medicine at Brigham and Women’s Hospital, and Professor of Medicine and Co-Director of the Center for Palliative Care at Harvard Medical School. He has a longstanding interest in clinician-patient communication and quality of life in serious illness, and has published widely in these areas. He is a Founding Director of VitalTalk (www.vitaltalk.org), a non-profit devoted to nurturing healthier connections between clinicians and patients through communication skills teaching. Dr. Tulsky received his A.B. from Cornell University, his M.D. from the University Of Illinois College Of Medicine at Chicago, and completed internal medicine training at the University of California, San Francisco (UCSF). He continued at UCSF as chief medical resident and subsequently as a Robert Wood Johnson Clinical Scholar. He served on the faculty of Duke University from 1993-2015, lastly as Professor of Medicine and Nursing and Chief, Duke Palliative Care.

Susan West
Hertzberg Palliative Care Institute, Icahn School of Medicine at Mount Sinai

Susan West is a full-time volunteer for the Hertzberg Palliative Care Institute at the Icahn School of Medicine at Mount Sinai. After her husband’s death in 1995, she dedicated herself to helping establish Mount Sinai’s palliative care program and to raising the public's awareness about palliative care. She endowed an annual palliative care lectureship in her late husband’s memory and to honor his physician and later founding director of Hertzberg, Dr. Diane Meier. The next lecture will be the twenty-first in a series that brings distinguished speakers to a large audience at Mount Sinai. Ms. West has worked to establish an Advisory Board for the Hertzberg Palliative Care Institute. She has organized an active network of donors and has helped conceive and implement a number of fundraising programs. She coordinates the Palliative Care Speakers Bureau and is a member of the Mount Sinai Auxiliary Board.