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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

8:00 am	Registration and Breakfast
8:30 am	<p>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</p> <p>Overview of the Workshop Rebecca Kirch, JD, National Patient Advocate Foundation JoAnne Reifsnyder, PhD, RN, Hospice and Palliative Nurses Association Planning Committee Co-Chairs</p>
8:45 am	<p>Session 1: Integrating the Patient, Caregiver, and Family Voice into Person-Centered Care: Gaps, Challenges, and Opportunities</p> <p><i>Moderator: Amy Berman, BSN, LHD, The John A. Hartford Foundation</i></p> <p>Caregiver-Clinician Perspectives on Providing High-Quality Care</p> <p>Pediatric Care Blyth Lord, MA, Courageous Parents Network Richard Goldstein, MD, Boston Children’s Hospital and Harvard Medical School</p> <p>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</p> <p>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</p>

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	Panel Discussion, Audience Q & A
10:30 am	Break
10:45 am	<p>Session 2: Addressing Socio-Cultural Differences in Care for Seriously Ill Children and Adults</p> <p><i>Moderator: Robert A. Bergamini, MD, Mercy Clinic Children’s Cancer and Hematology, Supportive Care Coalition</i></p> <p>Addressing health equity and quality of life priorities and concerns experienced by patients and caregivers among geographically and ethnically diverse and vulnerable populations Shonta Chambers, MSW, Patient Advocate Foundation</p> <p>Opportunities for addressing health disparities through Chaplaincy/Spiritual Care services and support including cultural humility/sensitivity Rev. Alice Cabotaje, M.Div., Massachusetts General Hospital</p> <p>Promoting dignity, quality of life, and health outcomes for underserved populations and addressing ethnicity and poverty effects on preferences and care Stacy Fischer, MD, University of Colorado at Denver School of Medicine</p> <p>Identifying and honoring preferences in context of reducing racial disparities – addressing health disparities through improved communication and other strategies Kimberly Johnson, MD, Duke University School of Medicine</p> <p>Panel Discussion, Audience Q & A</p>
12:30 pm	Lunch
1:30 pm	<p>Session 3: Integrating Person-Centered Care across Ages, Diagnoses and Disciplines</p> <p><i>Moderator: Terry Altilio, LCSW, ACSW, Mt Sinai Beth Israel Medical Center</i></p> <p>Nurturing healthier connections between patients, caregivers and clinicians through skilled communication emphasizing honesty, empathy, and hope Anthony L. Back, MD, University of Washington and Fred Hutchinson Cancer Research Center</p> <p>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 Julie Silver, MD, Harvard Medical School and Spaulding Rehabilitation Network</p>

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	<p>Special issues and needs in caring for seriously ill infants and their families, including identifying parent values and preferences in context of perinatal and neonatal care and developing strategies for teams and a relationship-centered approach Kathie Kobler, MS, APN, Advocate Children's Hospital</p> <p>Opportunities for extending health system reach in addressing patient and family needs for spiritual and other care throughout the continuum using community-based chaplaincy Rev. Malcolm Marler, D.Min, University of Alabama at Birmingham</p> <p>Panel Discussion, Audience Q & A</p>
<p>3:15 pm</p>	<p>Break</p>
<p>3:30 pm</p>	<p>Session 4: Innovations and Interventions to Support Communication of Needs, Values and Preferences</p> <p><i>Moderator: Ellen Goodman, The Conversation Project</i></p> <p>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</p> <p>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</p> <p>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</p> <p>Findings and lessons learned from nationwide research on consumer preferences related to quality of life communication Peter Mitchell, SalterMitchell</p> <p>Panel Discussion, Audience Q & A</p>
<p>5:15 pm</p>	<p>Wrap-up and Reflections on the Day Rebecca Kirch and JoAnne Reifsnyder Planning Committee Co-Chairs</p>
<p>5:30 pm</p>	<p>Adjourn</p>
<p>5:30 pm</p>	<p>Reception in Keck Center Atrium, 3rd Floor</p>