



# Serious Illness Care Research: Exploring Current Knowledge, Emerging Evidence and Future Directions A Workshop

November 2-3, 2023

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

NATIONAL  
ACADEMIES

*Sciences  
Engineering  
Medicine*

November 2-3, 2023

Dear Colleagues:

Welcome to the workshop *on Serious Illness Care Research: Exploring Current Knowledge, Emerging Evidence and Future Directions* hosted by the NASEM Roundtable on Quality Care for People with Serious Illness. This workshop aims to explore the current gaps in serious illness care research, suggest best approaches to address those gaps, as well as identify high-priority areas for future research, all with the objective of improving care for people of all ages and all stages of serious illness, their families, and caregivers.

The workshop unfolds across eight sessions of a day-and-a-half-long program. The first session highlights the importance of integrating the patient, family, and caregiver perspective in research studies from design through implementation. The second session will feature an overview of where the field has been and future directions for serious illness care research. Both these sessions will provide important grounding for the workshop sessions that follow.

The third and fourth sessions feature expert panelists discussing approaches to improving the evidence base for serious illness care research from the perspective of study design and research methodology (Session 3) and outcome measures and data capture (Session 4). The fourth and final session of the first day of the workshop explores the vital issue of integrating health equity into serious illness care research.

The second day of the workshop opens with a session that will look at challenges and opportunities of implementation science related to serious illness care research across a range of health care settings: inpatient, long-term care and home and community-based settings. The final session of the workshop will weave together the key themes raised throughout the workshop as well as provide a vision for the future of serious illness care research to guide the field.

The workshop sessions include a mix of presentations, panel discussions and Q&A with workshop participants. We encourage you to engage with the panelists during the Q&A sessions. Discussions and presentations will be captured in the written proceedings with the goal of informing next steps in advancing the evidence base for serious illness care research, and ultimately improving care for those facing serious illness, their families, and caregivers.

The workshop proceedings will be published by the National Academies Press and available for free download. The webinar's meeting materials as well as a video archive of the webinar will be available at:

[https://www.nationalacademies.org/event/40554\\_11-2023\\_serious-illness-care-research-exploring-current-knowledge-emerging-evidence-and-future-directions-a-workshop](https://www.nationalacademies.org/event/40554_11-2023_serious-illness-care-research-exploring-current-knowledge-emerging-evidence-and-future-directions-a-workshop)

We hope you will find the workshop presentations informative, thought-provoking, and inspiring.

Sincerely,

**Jean S Kutner, MD, MSPH**

Distinguished Professor of  
Medicine and Associate Dean  
for Clinical Affairs, University  
of Colorado School of Medicine  
Chief Medical Officer,  
University of Colorado  
Hospital  
*Planning Committee Co-Chair*

**R. Sean Morrison, MD**

Ellen and Howard C. Katz Professor  
and Chair, Brookdale Department of  
Geriatrics and Palliative Medicine  
Icahn School of Medicine at Mt. Sinai  
Co-Director, Patty and Jay Baker  
National Palliative Care Center  
Director, National Palliative Care  
Research Center  
*Planning Committee Co-Chair*



ROUNDTABLE ON QUALITY CARE FOR PEOPLE WITH SERIOUS ILLNESS

**Serious Illness Care Research: Exploring Current Knowledge,  
Emerging Evidence, and Future Directions  
A Workshop**

**WEBCAST INFORMATION FOR ATTENDEES**

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Join the live webstream of the workshop via the link below:

[https://www.nationalacademies.org/event/40554\\_11-2023\\_serious-illness-care-research-exploring-current-knowledge-emerging-evidence-and-future-directions-a-workshop](https://www.nationalacademies.org/event/40554_11-2023_serious-illness-care-research-exploring-current-knowledge-emerging-evidence-and-future-directions-a-workshop)

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- This workshop is being webcast and recorded. The webcast and presentation files will be archived on the project webpage.
  - We welcome your involvement in the workshop. Please use the chatbox (located below the livestream video box) to submit questions, and include your name and affiliation.
  - Please use the hashtag **#SeriousIllnessCareNASEM** to tweet about the workshop.
  - 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.
- 

To receive updates on upcoming events:

Sign up for the **Roundtable on Quality Care for People with Serious Illness** listserv at:

<https://www.nationalacademies.org/hmd/Activities/HealthServices/QualityCareforSeriousIllnessRoundtable.aspx>

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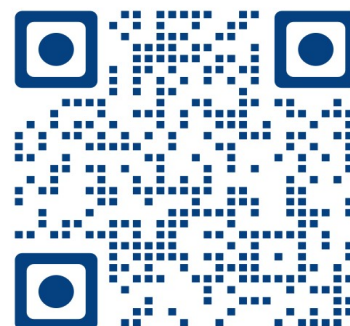
<http://www.linkedin.com/company/nasemhealth>



## ROUNDTABLE ON QUALITY CARE FOR PEOPLE WITH SERIOUS ILLNESS

### Serious Illness Care Research: Exploring Current Knowledge, Emerging Evidence, and Future Directions

#### Workshop Agenda



THURSDAY, NOVEMBER 2, 2023

**8:00–8:30 AM**    **Registration and Light Breakfast**

**8:30–8:40 AM**    **Welcome to the Workshop**

**Peggy Maguire, JD**

President  
Cambia Health Foundation

**Phillip E. Rodgers, MD**

Professor of Family Medicine and Internal Medicine  
George A. Dean, M.D. Chair of Family Medicine  
Department of Family Medicine  
University of Michigan Medical School

*Co-Chairs, Roundtable on Quality Care for People with Serious Illness*

**8:40–8:50 AM**    **Overview of the Workshop**

**Jean S. Kutner, MD, MSPH**

Distinguished Professor of Medicine and Associate Dean for Clinical Affairs  
University of Colorado School of Medicine  
Chief Medical Officer, University of Colorado Hospital

**R. Sean Morrison, MD**

Ellen and Howard C. Katz Professor and Chair  
Brookdale Department of Geriatrics and Palliative Medicine  
Director, National Palliative Care Research Center  
Icahn School of Medicine at Mount Sinai

*Co-Chairs, Planning Committee*

**8:50–9:25 AM Lived Experience Perspective**

**Benzi Kluger, MD, MS**

Julius, Helen, and Robert Fine Distinguished Professor of Neurology  
University of Rochester Medical Center

**Kirk Hall, MBA**

Patient and Advocate

**Malenna A. Sumrall, PhD**

Patient/ Care Partner Advocate  
University of Colorado-Anschutz

**Nicole Yarab, BA, RN**

Vice President, Clinical Affairs, and Information & Resources  
Parkinson's Foundation

**9:25–10:30 AM Session One**

**State of the Science of Serious Illness Care Research: Past, Current and Future**

**Moderator: Rebecca A. Aslakson, MD, PhD**

Professor and Chair of the Department of Anesthesiology  
Larner College of Medicine at the University of Vermont  
Health Care Service Chief, Network Department of Anesthesiology  
University of Vermont Health Network

*Speaker*

**R. Sean Morrison, MD**

Ellen and Howard C. Katz Professor and Chair  
Brookdale Department of Geriatrics and Palliative Medicine  
Director, National Palliative Care Research Center,  
Icahn School of Medicine at Mount Sinai

**10:30-10:45 AM Break**

**10:45-12:30 PM Session Two**

**Improving Evidence Generation to Address Gaps in Serious Illness Care Research:  
Research Methodology/Study Design**

**Moderator: Dio Kavalieratos, PhD**

Associate Professor  
Director of Research and Quality, Division of Palliative Medicine  
Department of Family and Preventative Medicine  
Rollins School of Public Health, Emory University

*Speakers*

**Douglas B. White, MD, MAS**

Professor of Critical Care Medicine, Medicine, and Clinical Translational Science  
UPMC Endowed Chair for Ethics in Critical Care Medicine  
Director, Program on Ethics and Decision Making in Critical Illness, CRISMA Center  
Department of Critical Care Medicine, University of Pittsburgh School of Medicine

**J. Nicholas Odom, PhD, RN**

Doreen C. Harper Endowed Professor of Nursing  
Director, Caregiver and Bereavement Support Services  
University of Alabama at Birmingham



**Corita Grudzen, MD, MSHS**

Division Head, Supportive and Acute Care Services  
Fern Greyer Chair in Oncology Care and Patient Experience  
Memorial Sloan Kettering Cancer Center  
Director, Center for Cancer Care Innovation  
Professor of Emergency Medicine  
Weill Cornell Medical College

**Mireille Jacobson, PhD**

Associate Professor and Assistant Dean, Leonard Davis School of Gerontology  
Co-director, Aging and Cognition Program, Schaeffer Center for Health Policy & Economics  
University of Southern California

**Kathryn Colborn, PhD, MSPH**

Associate Professor, Department of Medicine  
Division of Healthcare Policy and Research  
Biostatistics and Analytics Core Lead, ACCORDS  
Secondary Faculty, Department of Biostatistics and Informatics  
University of Colorado Anschutz Medical Campus

**Panel Discussion/Audience Q&A**

**12:30-1:30 PM Lunch, Third Floor Atrium**

**1:30-3:15 PM Session Three**  
**Improving Evidence Generation for Serious Illness Care Research:**  
**Outcome Measures and Data Capture**

**Moderator: Anna Gosline, MPA**

Senior Director of Strategic Initiatives in the Executive Office  
Blue Cross Blue Shield of Massachusetts  
Executive Director of the Massachusetts Coalition for Serious Illness Care

*Speakers*

**Antonia Bennett, PhD**

Professor, Department of Health Policy and Management  
Faculty Director, UNC Patient-Reported Outcomes Core  
Gillings School of Global Public Health  
University of North Carolina at Chapel Hill

**Jennifer Mack, MD, MPH**

Associate Professor of Pediatrics  
Harvard Medical School  
Associate Chief, Division of Population Sciences  
Faculty Vice President for the Office for Faculty Development, Professionalism, and Inclusion  
Dana-Farber Cancer Institute

**Karen Steinhauser, PhD**

Professor, Departments of Population Health Sciences and Medicine  
Senior Fellow, Duke University Center for Aging  
Duke University

**Charlotta Lindvall, MD, PhD**

Assistant Professor, Medicine  
Director of Clinical Informatics, Department of Informatics and Analytics  
Dana-Farber Cancer Institute  
Physician, Department of Psychosocial Oncology and Palliative Care  
Harvard Medical School

**Vincent Mor, PhD**

Florence Pirce Grant University Professor of Health Services, Policy, and Practice  
Brown University School of Public Health

**Panel Discussion/Audience Q&A**

**3:15-3:30 PM BREAK**

**3:30-5:00 PM Session Four**  
**Integrating Health Equity into Serious Illness Care Research**

**Co-Moderators:**

**Sheria Robinson-Lane, PhD, MHA, MS, RN**

Assistant Professor, Department of Systems, Populations and Leadership  
University of Michigan School of Nursing

**Carine Davila, MD, MPH**

Palliative Care Physician  
Equity Director, Division of Palliative Care and Geriatric Medicine  
Massachusetts General Hospital  
Clinical Instructor  
Harvard Medical School

*Speakers*

**Karen Bullock, PhD**

Louise McMahon Ahearn Endowed Professor  
School of Social Work, Boston College  
Faculty Appointment, Department of Psychosocial Oncology and Palliative Care  
Dana-Farber Cancer Institute

**Marie A. Bakitas, DNSc**

Professor, Associate Dean for Research and Scholarship  
School of Nursing  
Co-Director, Center for Palliative and Supportive Care  
Division of Geriatrics, Gerontology, and Palliative Care  
Department of Medicine, University of Alabama at Birmingham

**Carey Candrian, PhD**

Associate Professor, Division of General Internal Medicine  
University of Colorado School of Medicine

**Robert A. Winn, MD**

Director, Massey Cancer Center  
Senior Associate Dean for Cancer Innovation  
Professor, Pulmonary Disease and Critical Care Medicine  
Lipman Chair of Oncology, School of Medicine, Virginia Commonwealth University

**Panel Discussion/Audience Q&A**

**5:00-5:15 PM Workshop Day One Wrap-Up and Adjourn**

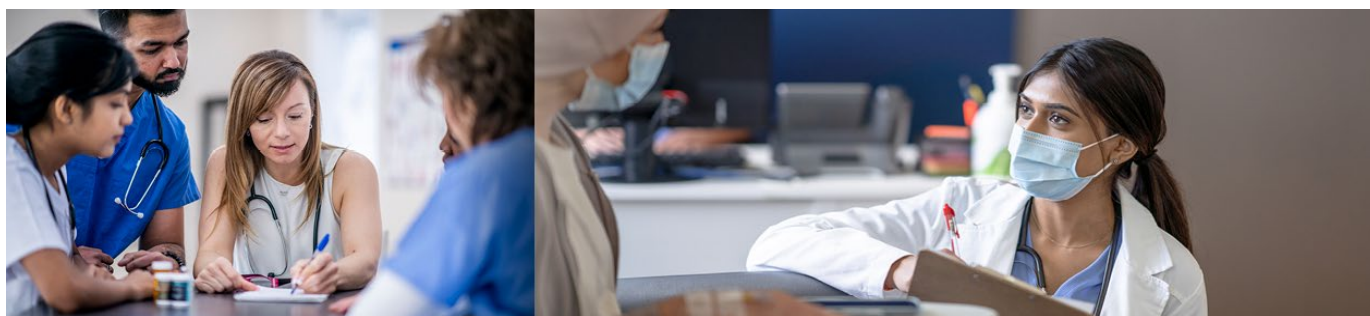
**Jean Kutner and Sean Morrison**

*Planning Committee Co-Chairs*

## ROUNDTABLE ON QUALITY CARE FOR PEOPLE WITH SERIOUS ILLNESS

### Serious Illness Care Research: Exploring Current Knowledge, Emerging Evidence, and Future Directions

#### Workshop Agenda



FRIDAY, NOVEMBER 3, 2023

**8:00–8:30 AM**    **Registration and Light Breakfast**

**8:30–8:45 AM**    **Welcome**

**Jean Kutner and Sean Morrison**

*Planning Committee Co-Chairs*

**8:45-10:20 AM**    **Session Five**  
**Implementation Science: Translating Research into Practice**

**Co-Moderators:**

**Huong Nguyen, PhD, RN**

Interim Director, Division of Health Services Research and Implementation Science  
Department of Research & Evaluation  
Kaiser Permanente Southern California  
Professor, Department of Health Systems Science  
Kaiser Permanente Bernard J. Tyson School of Medicine.

**Rebecca A. Aslakson, MD, PhD**

Professor and Chair of the Department of Anesthesiology  
Larner College of Medicine at the University of Vermont  
Health Care Service Chief, Network Department of Anesthesiology  
University of Vermont Health Network

*Speakers*

**Stephen J. Bartels, MD, MS**

James J and Jean H. Mongan Chair in Health Policy and Community Health  
Department of Medicine  
Professor of Medicine  
Massachusetts General Hospital (MGH) and Harvard Medical School  
Director, the Mongan Institute at MGH

**Meghan Lane-Fall, MD, MSHP**

David E. Longnecker Associate Professor, Anesthesiology and Critical Care  
Associate Professor, Biostatistics, Epidemiology, and Informatics  
Perelman School of Medicine, University of Pennsylvania

**Kathleen T. Unroe, MD, MHA, MS**

Associate Professor of Medicine  
Indiana University School of Medicine  
Research Scientist, Indiana University Center for Aging Research

**Al Siu, MD**

Professor, Brookdale Department of Geriatrics and Palliative Medicine  
Icahn School of Medicine at Mt. Sinai

**Panel Discussion/Audience Q&A**

**10:20-11:55 AM Session Six**

**Looking to the Future: Research Priorities for Serious Illness Care**

**Co-Moderators:**

**Scott Halpern, MD, PhD**

John M. Eisenberg Professor of Medicine, Epidemiology, and Medical Ethics and Health Policy  
Perelman School of Medicine  
Founding Director, Palliative and Advanced Illness Research Center  
University of Pennsylvania

**Jori Bogetz, MD**

Attending, Pediatric Palliative Care Program  
Associate Director of Research and Faculty, Treuman Katz Center  
Faculty, Palliative Care and Resilience Research Program  
Seattle Children's Hospital and Research Institute

*Speakers*

**Jean S. Kutner, MD, MSPH**

Distinguished Professor of Medicine and Associate Dean for Clinical Affairs  
University of Colorado School of Medicine  
Chief Medical Officer, University of Colorado Hospital

**Amy Kelley, MD, MSHS**

Deputy Director, National Institute on Aging  
National Institutes of Health

**Diane E. Meier, MD**

Founder, Director Emerita and Strategic Medical Advisor, Center to Advance Palliative Care  
Co-Director, Patty and Jay Baker National Palliative Care Center  
Professor, Department of Geriatrics and Palliative Medicine  
Catherine Gaisman Professor of Medical Ethics  
Icahn School of Medicine at Mount Sinai

**Panel Discussion/Audience Q&A**

**11:55 AM**

**Workshop Wrap-Up**

**Jean Kutner and Sean Morrison**

*Planning Committee Co-Chairs*

**12:00 PM**

**Workshop Adjourns**

## Rosters

*Serious Illness Care Research: Exploring Current Knowledge,  
Emerging Evidence, and Future Directions: A Workshop*

**Planning Committee Roster**

**Jean S. Kutner, MD, MSPH (Co-Chair)**

Distinguished Professor of Medicine and Associate Dean for Clinical Affairs  
University of Colorado School of Medicine  
Chief Medical Officer, University of Colorado Hospital

**R. Sean Morrison, MD (Co-Chair)**

Ellen and Howard C. Katz Professor and Chair  
Brookdale Department of Geriatrics and Palliative Medicine  
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Faculty, Treuman Katz Center and Palliative Care and Resilience Research Program  
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School of Social Work, Boston College  
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**Sheria Robinson-Lane, PhD, MHA, MS, RN**

Assistant Professor, Department of Systems, Populations and Leadership  
University of Michigan School of Nursing

**ROUNDTABLE ON QUALITY CARE FOR PEOPLE WITH SERIOUS ILLNESS**

*Serious Illness Care Research: Exploring Current Knowledge, Emerging Evidence,  
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**Speakers and Moderators**

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Services  
Fern Grayer Chair in Oncology and Patient  
Experience  
Director, Center for Cancer Care Innovation  
Professor of Emergency Medicine  
Weill Cornell Medical College

**Kirk Hall, MBA**

Patient and Advocate

**Scott Halpern, MD, PhD, MBE**

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Epidemiology, and Medical Ethics and Health  
Policy, Perelman School of Medicine  
Director of the Palliative and Advanced Illness  
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Leonard Davis School of Gerontology  
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Deputy Director, National Institute on Aging  
National Institutes of Health

**Benzi Kluger, MD, MS**

Julius, Helen, and Robert Fine Distinguished  
Professor of Neurology  
University of Rochester Medical Center

**Jean Kutner, MD, MSPH**

Distinguished Professor of Medicine  
Associate Dean of Clinical Affairs  
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Assistant Professor, Medicine  
Director of Clinical Informatics, Department of  
Informatics and Analytics  
Dana-Farber Cancer Institute  
Physician, Department of Psychosocial  
Oncology and Palliative Care  
Harvard Medical School

**Jennifer Mack, MD, MPH**

Associate Professor of Pediatrics  
Harvard Medical School  
Associate Chief, Division of Population Sciences  
Faculty Vice President for the Office for Faculty  
Development, Professionalism, and Inclusion  
Dana-Farber Cancer Institute

**Diane E. Meier, MD, FACP, FAAHPM**

Founder, Director Emerita and Strategic  
Medical Advisor, Center to Advance  
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Florence Pierce Grant University Professor of  
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Research Scientist, IU Center for Aging  
Research

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University of Pittsburgh School of Medicine

**Robert A. Winn, MD**

Director, Massey Cancer Center  
Senior Associate Dean for Cancer Innovation  
Professor, Pulmonary Disease and Critical Care  
Medicine  
Lipman Chair of Oncology, School of Medicine  
Virginia Commonwealth University

**Nicole Yarab, RN, BA**

Vice President  
Clinical Affairs and Information & Resources  
Parkinson's Foundation

## About the Roundtable

**ROUNDTABLE ON QUALITY CARE FOR PEOPLE WITH SERIOUS ILLNESS**

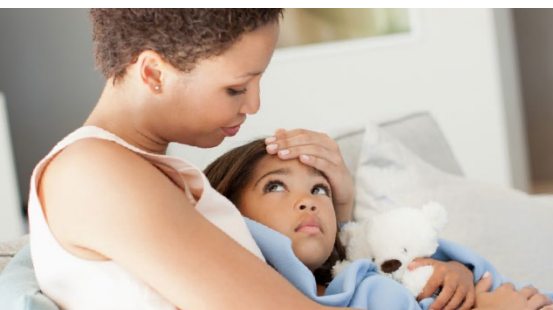
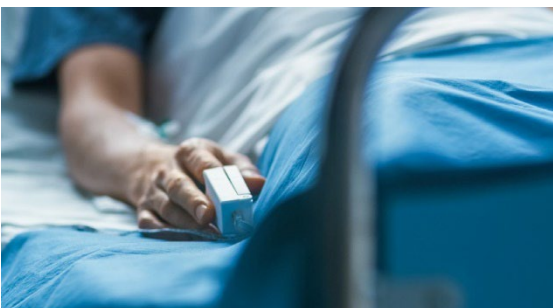
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Coalition to Transform Advanced Care  
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National Patient Advocate Foundation  
New York Academy of Medicine  
Patient-Centered Outcomes Research Institute (PCORI)

We are extremely grateful to our sponsors for their support for the work of the Roundtable on Quality Care for People with Serious Illness



# Roundtable on Quality Care for People with Serious Illness



The National Academies of Sciences, Engineering, and Medicine's Roundtable on Quality Care for People with Serious Illness fosters ongoing dialogue about improving care for people of all ages facing all stages of serious illness. To that end, the Roundtable's work and activities focus on five priority areas:

- delivery of person-centered, family-oriented care,
- communication and advance care planning,
- professional education and development,
- policies and payment systems, and
- public education and engagement

**The Roundtable on Quality Care for People with Serious Illness** convenes a diverse group of key public and private stakeholders and sponsors public workshops to explore critical topics. Membership includes patient advocates, health care professional organizations, health care providers and insurers, foundations, federal agencies, researchers, and others interested in improving care for people with serious illness.

The Roundtable serves a critical role by:

- raising the visibility of key issues on a national stage,
- influencing policies and programs,
- fostering relationships and collaboration, and
- inspiring new ideas and shaping the field.



## **PUBLIC WORKSHOPS**

### **Serious Illness Care Research: Exploring Current Knowledge, Emerging Evidence and Future Directions**

**November 2-3, 2023**

The workshop focuses on the challenges, gaps and opportunities for strengthening the evidence base for serious illness care and identifying future research priorities—with the ultimate aim of improving care for people of all ages and stages of serious illness, their families and caregivers.

### **Supporting and Sustaining the Current and Future Workforce to Care for People with Serious Illness**

**April 27-28, 2023**

The workshop explored strategies and approaches to addressing significant systems-level challenges such as workforce shortages, health professional well-being, advancing diversity, equity, and inclusion in the workforce caring for people at all ages and stages of serious illness.

### **Family Caregiving for People with Cancer and Other Serious Illnesses**

**May 16-17, 2022**

The Roundtable on Quality Care for People with Serious Illness, The National Cancer Policy Forum and the Forum on Aging, Disability and Independence held a collaborative workshop that examined opportunities to better support family caregiving for people with cancer or other serious illnesses.

### **Caring for People with Serious Illness during the COVID-19 Pandemic: Lessons Learned and Future Directions**

**November 8, 18, and 30, 2021**

The COVID-19 pandemic has illuminated and exacerbated challenges in caring for people of all ages with serious illness. The workshop explored various aspects of the impact of the pandemic through the lens of serious illness care and took place over three webinars. The first webinar focused on the impact and early responses to the pandemic, the second webinar focused on workforce and telehealth, and the final webinar focused on lessons learned for the future.

### **Integrating Serious Illness Care into Primary Care Delivery**

**June 10 and 17, 2021**

This workshop explored approaches to building a bridge between primary care and palliative care to improve care for people with serious illness across all care settings. The critical importance of the interdisciplinary care team was examined, as was the intersection between the principles of primary care and palliative care. Speakers also focused on key payment mechanisms and policies to support the integration of serious illness care into primary care settings.

## PUBLIC WORKSHOPS

### **Advance Care Planning: Challenges and Opportunities**

**October 26 and November 2, 2020**

This workshop highlighted the complexity of advance care planning (ACP). Workshop speakers explored the historical background, evolution, and different perspectives on ACP, and discussed the evidence base regarding the impact of ACP on a range of outcomes. Speakers explored the distinction between ACP and “just-in-time” or “in the moment” conversations. Workshop speakers also addressed issues such as whether the current approach to ACP is appropriate, and what changes might be considered to ensure that ACP has a greater impact on quality of care for patients with serious illness, their caregivers, and families.

### **Building the Workforce We Need to Care for People with Serious Illness**

**November 7, 2019**

This workshop examined a key challenge in providing high-quality care to people of all ages facing serious illness: developing and supporting an adequate supply of care team members, as well as ensuring that all team members acquire and maintain appropriate training and competencies. The workshop addressed challenges and opportunities related to educating, training, and retaining the full spectrum of the workforce for serious illness care.

### **Improving Access to and Equity of Care for People with Serious Illness**

**April 4, 2019**

This workshop explored challenges and opportunities to expand access and advance health equity in care for people with serious illness. Speakers discussed strategies and approaches to address health disparities and barriers to care from the patient, clinician, organizational, community, and policy perspectives.

### **Pain and Symptom Management for People with Serious Illness in the Context of the Opioid Epidemic**

**November 29, 2018**

This workshop focused on effective approaches to addressing the pain management needs of people with serious illness in the context of the opioid misuse epidemic. Workshop speakers discussed the unintended consequences of regulatory and legislative actions to address the opioid misuse epidemic on patients, families, and clinicians.

### **Integrating Health Care and Social Services for People with Serious Illness**

**July 19, 2018**

This workshop examined the range of services necessary to provide high-quality care for people facing serious illness, the strengths, and limitations of existing models of integrated services delivery, the role of family caregivers in providing social services and supports and identified gaps in research regarding the integration of health care and social services for people with serious illness.



## **PUBLIC WORKSHOPS**

### **Implementing Quality Measures for Accountability in Community-based Care for People with Serious Illness**

**April 17, 2018**

The workshop explored approaches to implementing quality measures for accountability purposes in community-based care programs for people with serious illness. Presentations focused on the implementation of quality measures from the perspective of patients and caregivers, health care providers, and private and public sector health plans. Speakers also discussed the future use of quality measures for accreditation to support accountability for high-quality serious illness care.

### **Financing and Payment Strategies to Support High-Quality Care for People with Serious Illness**

**November 29, 2017**

The workshop examined innovative payment approaches to support high-quality care for people with serious illness across a range of fee-for-service, value-based, and global budgeting arrangements. Presenters discussed the challenges and barriers to innovative strategies and explored potential policy approaches to address them.

### **Models and Strategies to Integrate Palliative Care Principles into Serious Illness Care**

**April 27, 2017**

The workshop highlighted innovative models of community-based care for people of all ages facing serious illness. Presenters and panel discussions explored community-based palliative care, pediatric palliative care, concurrent care, and the challenges and opportunities to scale and spread successful palliative care models and programs.

### **Integrating the Patient and Caregiver Voice into Serious Illness Care**

**December 15, 2016**

The workshop explored ways to identify and integrate the voices of seriously ill patients of all ages and their caregivers into person-centered care throughout the continuum of care. Presenters shared personal perspectives and experiences about priorities and values important to patients and families coping with serious illness, and approaches that support integration of these priorities and values into practice.

## ROUNDTABLE MEMBERSHIP

### Co-Chairs:

**Peggy Maguire, JD**

Cambia Health Foundation

**Phillip E. Rodgers, MD**

University of Michigan Medical School

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**Jori Bogetz, MD**

Seattle Children's Hospital and Research Institute

**Brynn Bowman, MPA**

Center to Advance Palliative Care

**Karen Bullock PhD, LCSW**

National Association of Social Workers

**Jane Carmody, DNP, MBA, RN**

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The Catholic Health Association

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Blue Cross Blue Shield of Massachusetts

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Mt. Sinai Health System

**Susan Elizabeth Wang, MD**

Kaiser Permanente

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Patient-Centered Outcomes  
Research Institute (PCORI)

## ROUNDTABLE STAFF

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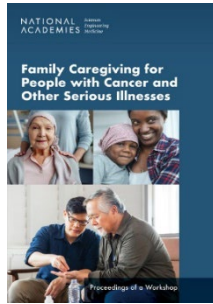
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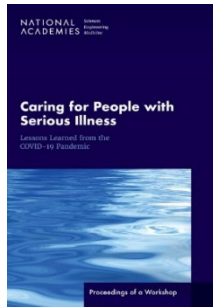
## ROUNDTABLE PUBLICATIONS



### Family Caregiving for People with Cancer and Other Serious Illnesses: Proceedings of a Workshop

<https://nap.nationalacademies.org/26721>

- *Released:* December 2022
- *Downloaded:* 758 times, top 46% of all NAP publications
- *Reach:* 63 countries and 45 states and D.C.



### Caring for People with Serious Illness: Lessons Learned from the COVID-19 Pandemic: Proceedings of a Workshop

<https://nap.nationalacademies.org/26596>

- *Released:* June 2022
- *Downloaded:* 737 times, top 48% of all NAP publications
- *Reach:* 65 countries and 42 states and D.C.



### Integrating Serious Illness Care into Primary Care Delivery: Proceedings of a Workshop

<https://nap.nationalacademies.org/26411>

- *Released:* January 2022
- *Downloaded:* 1,211 times, top 34% of all NAP publications
- *Reach:* 88 countries and 48 states and D.C.



### The Challenges and Opportunities of Advance Care Planning: Proceedings of a Workshop

<https://www.nap.edu/26119>

- *Released:* April 2021
- *Downloaded:* 1,166 times, top 36% of all NAP publications
- *Reach:* 71 countries and 48 states and D.C.



### Building the Workforce We Need to Care for People with Serious Illness: Proceedings of a Workshop

<https://nap.nationalacademies.org/catalog/25789>

- *Released:* May 2020
- *Downloaded:* 1,653 times, top 26% of all NAP products
- *Reach:* 84 countries and 50 states and D.C.

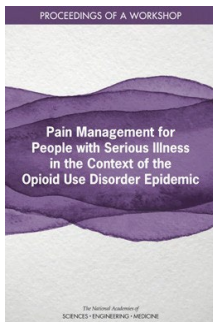
## ROUNDTABLE PUBLICATIONS



### Improving Access to and Equity of Care for People with Serious Illness: Proceedings of a Workshop

<https://nap.nationalacademies.org/25530>

- *Released:* September 2019
- *Downloaded:* 2,544 times, top 16% of all NAP publications
- *Reach:* 99 countries and 47 states and D.C.



### Pain Management for People with Serious Illness in the Context of the Opioid Use Disorder Epidemic: Proceedings of a Workshop

<https://nap.nationalacademies.org/25435>

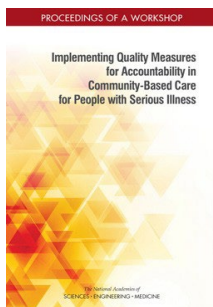
- *Released:* May 2019
- *Downloaded:* 4,603 times, top 7% of all NAP publications
- *Reach:* 111 countries and 49 states and D.C.



### Integrating Health Care and Social Services for People with Serious Illness: Proceedings of a Workshop

<https://nap.nationalacademies.org/25350>

- *Released:* January 2019
- *Downloaded:* 3,387 times, top 11% of all NAP publications
- *Reach:* 109 countries 48 states and D.C.

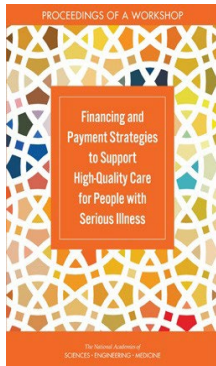


### Implementing Quality Measures for Accountability in Community-Based Care for People with Serious Illness: Proceedings of a Workshop

<https://nap.nationalacademies.org/25202>

- *Released:* October 2018
- *Downloaded:* 3,067 times, top 13% of all NAP publications
- *Reach:* 120 countries and 50 states and D.C.

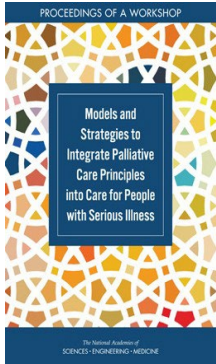
## ROUNDTABLE PUBLICATIONS



### Financing and Payment Strategies to Support High-Quality Care for People with Serious Illness: Proceedings of a Workshop

<https://nap.nationalacademies.org/25071>

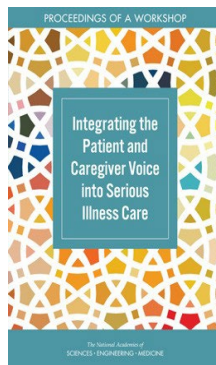
- *Released:* May 2018
- *Downloaded:* 1,831 times, top 23% of all NAP publications
- *Reach:* 97 countries and 48 states and D.C.



### Models and Strategies to Integrate Palliative Care Principles into Care for People with Serious Illness: Proceedings of a Workshop

<https://nap.nationalacademies.org/24908>

- *Released:* October 2017
- *Downloaded:* 3,450 times, top 11% of all NAP publications
- *Reach:* 112 countries and 50 states and D.C.



### Integrating the Patient and Caregiver Voice into Serious Illness Care: Proceedings of a Workshop

<https://nap.nationalacademies.org/24802>

- *Released:* July 2017
- *Downloaded:* 2,670 times, top 15% of all NAP publications
- *Reach:* 934 countries and 49 states and D.C.



## **COVID-19 RELATED WEBINARS**

### **Social Isolation and Loneliness at the End of Life in the Era of COVID-19**

**December 8, 2021**

This webinar explored topics on social isolation and loneliness during the COVID-19 pandemic and at the end of life.

### **Caring for People with Serious Illness in the Home: Lessons from the COVID-19 Pandemic**

**February 16, 2021**

This webinar featured a discussion that explored a range of issues including: providing palliative care and hospice care in the home, strategies to reach people with serious illness living in rural communities, including challenges and opportunities for telehealth, policy considerations and integrated care delivery models to effectively deploy vital health care resources.

### **Serious Illness Care, Structural Racism and Health Disparities in the Era of COVID-19**

**January 29, 2021**

This webinar featured a discussion among members of the interdisciplinary care team sharing their individual perspectives and reflecting on their front-line experiences caring for seriously ill people during the COVID-19 pandemic including lessons learned, long-term strategies to mitigate suffering for marginalized populations in the future, effective approaches to build community trust in the health care system, the role of clinical training in addressing health disparities, and models to help ensure access to care and equity for all people facing serious illness.

### **Best Practices for Patient-Clinician Communication for People with Disabilities in the Era of COVID-19**

**June 19, 2020**

This webinar showcased an overview of key patient-clinician communication challenges and disability law and policies applicable for accessible and effective communication during the COVID-19 pandemic, identified techniques to facilitate health care communication with people with disabilities, and provided tools and resources to consider for better communication in the COVID world.

### **Innovative Hospital-based Palliative Care Responses to the COVID-19 Pandemic: Perspectives from Program Leaders of Two Large Hospitals**

**June 5, 2020**

This webinar featured the key principles and lessons learned from two specific innovative and rapid hospital-based responses (the Brookdale Department of Geriatrics and Palliative Medicine and the palliative care team at Brigham and Women's Hospital) to addressing palliative care needs during the pandemic.

### **Keeping Nursing Home Residents and Staff Safe in the Era of COVID-19: Effective Testing and Cohorting to Minimize Risk of Transmission**

**June 2, 2020**

This webinar explored the challenges to effective cohorting of nursing home residents during the COVID-19 outbreak to prevent virus transmission, discuss the design and implementation of an actionable cohorting strategy based on CDC guidance, examine approaches to mitigate risk associated with new admissions, re-admissions, and residents who must routinely leave the nursing home or long-term care facility for medical appointments.

### **Keeping Nursing Home Residents and Staff Safe in the Era of COVID-19**

**April 22, 2020**  
This webinar highlighted the innovative approaches to address these complex challenges that are currently being implemented in the state of Maryland including approaches from health care professionals at Johns Hopkins University School of Medicine, the state department of health, emergency medicine professionals, and "strike teams" made up of members of the National Guard.

## OTHER ROUNDTABLE PUBLICATIONS

### **The Road to Readiness: Guiding Families of Children and Adolescents with Serious Illness Toward Meaningful Advance Care Planning Discussions**

**<https://nam.edu/the-road-to-readiness/>**

**Authors:** Lori Wiener, Cynthia Bell, Jessica Spruit, Meaghann S. Weaver, and Amanda L. Thompson

**Released:** August 2, 2021

### **Serious Illness Care and The Opioid Epidemic: Reflections On a NASEM Workshop**

**<https://www.healthaffairs.org/doi/10.1377/hblog20190605.155057/full/>**

**Authors:** Jessica Merlin, Andrew Dreyfus, and James A. Tulsky

**Released:** June 7, 2019

### **Community-Based Models of Care Delivery for People with Serious Illness**

**<https://nam.edu/community-based-models-of-care-delivery-for-people-with-serious-illness/>**

**Authors:** Jeffrey Cohn, Janet Corrigan, Joanne Lynn, Diane Meier, Jeri Miller, Joseph Shega, and Susan Wang

**Released:** April 13, 2017





**Roundtable on Quality Care for People with Serious Illness**

Serious Illness Care Research: Exploring Current Knowledge,  
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**Speaker and Moderator Biographies**



**Rebecca Aslakson, MD, PhD**

Triple boarded in critical care, anesthesia, and hospice and palliative medicine, with a PhD in clinical research, Rebecca A. Aslakson, MD, PhD, FCCM, FAAHPM, is devoted to an academic career improving the delivery of effective and equitable palliative care, particularly to surgical and critical care populations. She has led multiple studies integrating palliative care into ICU and/or surgical care settings and has been supported through over \$5

million in awards from diverse funders, such as the Patient-Centered Outcomes Research Institute (PCORI), the Agency for Healthcare Research and Quality (AHRQ), The Gordon and Betty Moore Foundation, The National Palliative Care Research Center, and the Foundation for Anesthesia Education and Research. She has over 80 peer-reviewed publications and has received national and international awards including: the 2014 American Society of Anesthesiologists Presidential Scholar Award; the 2015 American Academy of Hospice and Palliative Medicine (AAHPM) Early Investigator Award; being named a 2016 AAHPM “40 under 40” inspirational leader in palliative care; and the 2019 Grenvik Family Award for Ethics from the Society of Critical Care Medicine.

She is the Chair of the Department of Anesthesiology at the University of Vermont Larner College of Medicine and across the six-hospital University of Vermont Health Network. She lives in South Burlington, VT with her husband, their two sons, and their two beloved little rescue dogs.



**Marie Anne Bakitas, DNSc, NP-C**

Marie Anne Bakitas, DNSc, CRNP, NP-C, AOCN, ACHPN, FPCN, FAAN, is professor, Associate Dean for Research and Scholarship, School of Nursing, Co-Director, Center for Palliative and Supportive Care Research Center, Division of Geriatrics, Gerontology, and Palliative Medicine, Department of Medicine at the University of Alabama at Birmingham, and co-chair, Palliative and End-of-Life Committee, Southwest Oncology Group (SWOG). She has developed innovative methods, such as tele-health & tele-consultation, to improve and implement strategies for increasing palliative and

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supportive care access for under-represented and under-resourced persons with serious illness & their family caregivers.

Her work has been extended beyond cancer to other serious illnesses and she is working with international collaborators in Singapore, Turkey, and Iran to bring palliative care to everyone, everywhere, every time it's needed. Dr. Bakitas has published over 150 original data-based papers, book chapters and books. She is an American Academy of Nursing and Palliative Care Nursing Fellow.



**Stephen Bartels, MD, MS**

Stephen Bartels MD, MS is the inaugural James J. and Jean H. Mongan Chair in Health Policy and Community Health, Director of the Mongan Institute at Massachusetts General Hospital, and Professor of Medicine at Harvard Medical School. The Mongan Institute serves as the academic home for 12 research centers and over 145 research faculty and research fellows at MGH dedicated to training and research in population and health care delivery team science aimed at achieving health equity and improving the lives of people with complex health needs.

Before coming to MGH from Dartmouth in 2018, Dr. Bartels was the Herman O West Professor of Geriatrics, Professor of Psychiatry, Professor of Community & Family Medicine at the Geisel School of Medicine at Dartmouth, and Professor of Health Policy at the Dartmouth Institute for Health Policy and Clinical Practice. At Dartmouth he established and directed the Dartmouth Centers for Health and Aging and served as Co-Principal Investigator for Dartmouth's SYNERGY Clinical Translational Science Institute, Principal Investigator for Dartmouth's CDC Health Promotion Research Center, and Principal Investigator for two T32 post-doctoral research training programs.

Dr. Bartels has authored over 365 publications and has mentored over 50 early career investigators. Over the past several decades he has led productive research developing, testing, and implementing interventions focused on complex health conditions and health disparities, co-occurring physical and mental disorders, health care management, health coaching, health promotion interventions for obesity and smoking, aging and geriatrics, automated telehealth and mobile technology, population health science, applied health care delivery science, and implementation science.

As a national expert on implementation research, he previously served as Chair for the National Institute of Health Dissemination and Implementation Research in Health (DIRH) Study

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Section and currently oversees the implementation research and training program at the Mongan Institute and serves as Co-PI for the Methods Unit for a NCI P50 “Implementation Science Center for Cancer Control Equity”.



**Antonia Bennett, PhD**

Dr. Bennett is a Professor of Health Policy and Management, at the University of North Carolina, and is trained in health services research and patient-reported outcome methodology. Their research focuses on developing novel methods for the assessment of symptoms, function, health related quality of life and financial hardship, primarily in oncology and Alzheimer’s disease and related dementias. Dr. Bennett also leads the patient-reported outcome data collection for multiple large national trials funded by NCI, PCORI, and the Leukemia & Lymphoma Society. They direct the NCI-funded Patient-

Reported Outcomes Core at the University of North Carolina and serves on the Person and Caregiver Relevant Outcomes Core of the NIA IMPACT Collaboratory. For 10 years, Dr. Bennett directed the Measurement Core of the NINR-funded Palliative Care Research Cooperative. They recently served on the Board of Directors of the International Society for Quality of Life Research.



**Jori Bogetz, MD**

Jori F. Bogetz, MD, is an Assistant Professor of Pediatrics at the University of Washington School of Medicine, the Associate Director of Research at the Treuman Katz Center for Pediatric Bioethics and Palliative Care, and an attending physician in pediatric palliative care at Seattle Children’s Hospital. Dr. Bogetz completed her pediatric residency and an Academic General Pediatrics Fellowship at Stanford University and a Pediatric Hospice and Palliative Medicine Fellowship at MGH/Harvard

University/Boston Children’s Hospital. Her research focuses on improving care for children with severe neurological impairment and their families through interventions that support high quality communication and family-centered care. Dr. Bogetz has received funding for her research from the National Institutes of Health Eunice Kennedy Shriver National Institute of Child Health and Human Development, the Cambia Health Foundation, the National Palliative

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Care Research Center, the Seattle Children's Research Institute, and the Lucile Packard Foundation for Children's Health.



**Karen Bullock, PhD, MSW**

Karen Bullock, PhD, LICSW, FGSA, APHSW-C, is the Louise McMahon Ahearn Endowed Professor in the Boston College School of Social Work and in Global Public Health. She is a Licensed Independent Clinical Social Work (LICSW) with mental health practice experience and expertise in health disparities, health equity, serious illness care, aging and gerontology, hospice, palliative and end-of-life care decision making. She has served as Principal Investigator and/or Co-Investigator for over \$5 million in federal grant funding focused on equity and inclusion for workforce development, aging, and health network sustainability.

Dr. Bullock is a John A. Hartford Faculty Scholar and has served on several national boards and committees, including the Social Work Hospice & Palliative Care Network (SWHPN) as vice-chair and the American Cancer Society (ACS) Oncology Social Work Research Peer Review Committee, past chair. She is a member of the National Academies of Sciences, Engineering, and Medicine (NASEM) Roundtable on Quality Care for People with Serious Illness, a board member of the Palliative Care Quality Collaborative (PCQ), Steering Committee member for the Duke University REACH Equity Center, affiliate faculty at the Center to Advance Palliative Care (CAPC), and has an appointment in the Department of Psychosocial Oncology and Palliative Care at Dana Farber Cancer Institute (DFCI).



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**Carey Candrian, PhD**

Dr. Carey Candrian is an associate professor in the Division of General Internal Medicine at the University of Colorado School of Medicine. She is on the Board of Directors at GLMA: Health Professionals Advancing Health Equity and the Vice President for the Lesbian Health Fund. A social scientist by training with a PhD in communication, Dr. Candrian's research examines how communication affects outcomes in healthcare for older lesbian, gay, bisexual, transgender, and queer (LGBTQ) adults. Her work has been funded by the National

Institute on Aging, the Cambia Health Foundation, The Colorado Health Foundation, The Colorado Trust, The Next50 Initiative and The Lesbian Health Fund. She is the creator of [Eye to Eye: Portraits of Pride, Strength and Beauty](#) ( a photo exhibit of older LGBTQ women) and director of the documentary, "[Just Us: The longing and hope of LGBTQ people.](#)"



**Kathryn Colborn, PhD, MSPH**

Dr. Colborn is an Associate Professor the Division of Healthcare Policy and Research in the Department of Medicine at the University of Colorado School of Medicine. She Directs the Biostatistics and Analytics Core of the Adult and Child Center for Outcomes Research and Delivery Science. She also holds a secondary appointment in the Department of Biostatistics and Informatics in the Colorado School of Public Health, and she co-directs the Data Informatics and Statistics Core (DISC) of the Palliative Care Research Cooperative Group. She has received extramural funding for her own research and has collaborated on numerous extramural research grants. Her research interests

include design and analysis of randomized controlled trials and cluster randomized trials, analysis of electronic health record data, and health services and outcomes research.

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**Carine Davila, MD, MPH**

Carine Davila, MD, MPH, is a palliative care physician at Massachusetts General Hospital and a clinical instructor at Harvard Medical School who is passionate about improving access and quality palliative care for historically marginalized populations and particularly for Latino Spanish-speaking patients. She serves as the Equity Director for the MGH Division of Palliative Care and Medicine, co-created the palliative care integrated health equity curriculum, and co-leads Mass General Brigham's United Against Racism efforts to reduce disparities in serious illness communication for marginalized communities. She completed undergraduate studies in public policy at Princeton and received her medical

degree from the Icahn School of Medicine at Mount Sinai. She completed a residency in Internal Medicine at the University of California San Francisco and fellowship at the Harvard Interprofessional Palliative Care Fellowship. After her clinical training, Dr. Davila was selected as a Commonwealth Fund Fellow in Minority Health Policy at Harvard and pursued her Master's in Public Health from the Harvard Chan School of Public Health.



**Anna Gosline, MPA**

Anna Gosline is the Executive Director of the Massachusetts Coalition for Serious Illness Care and a Senior Director in the Executive Office of Blue Cross Blue Shield of Massachusetts, which is the administrative home and primary funder of the Coalition. In her work at Blue Cross, Anna manages a diverse portfolio of policy, community and communications projects that touch on topics ranging from payment reform and health care costs to the opioid epidemic. She also leads the development of corporate-wide initiatives focused on

serious illness and palliative care – from payment and benefits to provider partnerships and measurement, to community and policy work.

Previously, Anna was the Director of Policy and Research at the Blue Cross Blue Shield of Massachusetts Foundation where she oversaw the Foundation's \$1 million+ policy and research program. Before joining the Foundation, she managed a large-scale health system study for the state of Vermont. In a previous life, Anna was a health care journalist in the UK and Canada. Anna holds a master's degree in health policy and management from the Harvard School of

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Public Health, a graduate certificate in science writing from the University of California, Santa Cruz, and a bachelor's degree from the University of Toronto.



**Corita Grudzen, MD, MSHS**

Dr. Grudzen MD, MSHS, FACEP, is a practicing emergency physician who leads the Division of Supportive and Acute Care Services at Memorial Sloan Kettering Cancer Center (MSKCC). Dr. Grudzen is the inaugural Head of the Division of Supportive and Acute Care Services and incumbent of the Fern Grayer Chair in Oncology Care and Patient Experience at MSKCC. She is recognized as a leader in research at the intersection of acute and palliative care and notably

leads a large, federally funded research portfolio of multi-site pragmatic trials testing new models of care in patients with serious, life-limiting illness. Beginning in 2012, Dr. Grudzen served as an Innovation Advisor to the Centers for Medicare and Medicaid Innovation and is the Metric Lead on an over \$12 million Health Care Innovation Award titled, “Geriatric Emergency Department Innovations in Care through Workforce, Informatics and Structural Enhancements.” She received over \$20 million in funding from the Patient-Centered Outcomes Research Institute and the National Institute of Health to conduct two large pragmatic trials to increase emergency medicine palliative care access (EMPallA) and primary palliative care for emergency medicine (PRIM-ER).



**Kirk Hall, MBA**

Kirk Hall is a Parkinson's patient, advocate, author, and speaker. Kirk and his movement disorder doctor, Benzi Kluger, discovered a shared vision of a “patient-centered” approach to Parkinson's Disease (PD) care in 2014. This evolved into Dr. Kluger's creation of a Palliative Care Clinic at the University of Colorado Hospital (UCH). Kirk and his care partner wife, Linda, have helped provide a patient/caregiver perspective to the development of PD palliative care at both a national and international level. They receive palliative care services at UCH.



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**Scott Halpern, MD, PhD**

*Scott D. Halpern, M.D., Ph.D.* is the John M. Eisenberg Professor of Medicine, Epidemiology, and Medical Ethics and Health Policy at the University of Pennsylvania, and a practicing critical care doctor. He is the founding Director of the Palliative and Advanced Illness Research (PAIR) Center, which generates evidence to advance policies and practices with the goals of improving the lives of all people affected by serious illness and removing the barriers to health equity that commonly face seriously ill patients. He is also Director of the NIH-funded Penn Roybal Center on Palliative Care in Dementia, and the American Heart Association-funded

BETTER Center (Behavioral Economics to Transform Trial Enrollment Representativeness), which works to promote diverse participation in clinical trials. He is an elected member of the American Society of Clinical Investigation, the Association of American Physicians, and the Hastings Center.



**Mireille Jacobson, PhD**

Dr. Jacobson is an associate professor in the University of Southern California's Leonard Davis School of Gerontology and the co-director of the program on aging and cognition at USC's Leonard D. Schaeffer Center for Health Policy and Economics. She is also a research associate in the Health Care Program at the National Bureau of Economic Research, the interim Editor-in-Chief of the American Journal of Health Economics and a member of the National Advisory Council for the Agency for Healthcare Research and Quality

(AHRQ). Dr. Jacobson received a PhD in economics from Harvard University and was a post-doctoral fellow at Harvard Medical School and a Robert Wood Johnson Foundation Scholar in Health Policy Research at the University of Michigan. Dr. Jacobson has a diverse portfolio of research that uses both quasi-experimental research designs and randomized field experiments to understand financial and nonfinancial barriers to timely and effective health care, particularly for individuals with cancer or with Alzheimer's Disease and Related Dementias.

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**Dio Kavalieratos, PhD**

Dr. Kavalieratos is an Associate Professor at the Emory University School of Medicine, where he also serves as the Director of Research for the Emory Palliative Care Center. His program of health services and clinical research investigates and intervenes upon the sources of suffering experienced by people living with serious illness and their families, the healthcare decisions they make, and the quality and equity of care that they ultimately receive (or do not). His research spans multiple patient populations, including heart failure, cystic fibrosis, and cancer, and he has expertise in clinical trials, qualitative and mixed methods, and evidence synthesis. He serves on the Board of Directors of the American Academy of Hospice and Palliative Medicine and is an Associate Editor of the *Journal of Palliative Medicine*. Dr.

Kavalieratos' research has been supported by both federal and private sources, including the National Heart Lung and Blood Institute, the Cystic Fibrosis Foundation, and the National Palliative Care Research Center.



**Amy S. Kelley, MD, MSHS**

Dr. Kelley was appointed Deputy Director at the National Institute on Aging (NIA), National Institutes of Health, in 2022. Dr. Kelley works closely with the NIA director, provides strategic leadership, supervises daily operations, and serves as an ambassador and spokesperson for the Institute. Additionally, as Chief Diversity Officer, she oversees diversity, equity, inclusion, and accessibility initiatives. Prior to coming to NIH, Dr. Kelley was Hermann Merkin Professor in Palliative Care, Professor and Vice Chair for Health Policy and Faculty Development in the Brookdale Department of Geriatrics and Palliative Medicine, and Senior Associate Dean for Gender Equity in Research Affairs, at the Icahn School of Medicine at Mount Sinai in New York. Her research, which bridges geriatrics and palliative medicine by focusing on the

needs of seriously ill older adults and their families, has been funded by NIA through multiple grants, the Gordon and Betty Moore Foundation, the National Palliative Care Research Center, among others. She has published over 100 peer reviewed scientific manuscripts and her work has been recognized by the American Geriatrics Society Thomas and Catherine Yoshikawa Award for Outstanding Scientific Achievement for Clinical Investigation and the American Academy of Hospice and Palliative Medicine Excellence in Scientific Research in Palliative Care Award.

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**Benzi Kluger, MD, MS**

Dr. Benzi Kluger is a Professor of Neurology and Medicine and the Director of the Palliative Care Research Center at the University of Rochester Medical Center (New York). He is an internationally recognized leader in the emerging field of neuropalliative care and the founding President of the International Neuropalliative Care Society ([www.inpcs.org](http://www.inpcs.org)), an organization dedicated to improving models of care for persons living with neurologic illness and their families. Dr. Kluger's research focuses on developing, testing and implementing palliative care interventions for persons living with Parkinson's and other neurologic illnesses and in improving our understanding and treatment of nonmotor symptoms in Parkinson's, including fatigue and cognitive dysfunction. He is

also working on several writing projects ([www.benzikluger.com](http://www.benzikluger.com)) related to empowering people living with serious illness to better advocate for themselves and to avoid potentially dangerous and expensive medical interventions.



**Jean S. Kutner, MD, MSPH**

Dr. Kutner is a tenured Distinguished Professor of Medicine in the Divisions of General Internal Medicine and Geriatric Medicine at the University of Colorado School of Medicine and the inaugural Chief Medical Officer of UCHHealth/University of Colorado Hospital and Associate Dean for Clinical Affairs, University of Colorado School of Medicine. Dr. Kutner received her MD from the University of California, San Francisco (UCSF) and completed residency training in internal medicine at UCSF. Subsequently, she completed a NRSA primary care research fellowship, earning an MSPH degree with honors, and a fellowship in geriatric medicine at the University of Colorado School of Medicine. She is Board Certified in internal medicine, geriatric medicine, and hospice and palliative medicine and cares for patients on the palliative care service and in general

internal medicine clinic. Her research focuses on improving symptoms and quality of life for people with serious illness and their family caregivers and building capacity for palliative care research. Dr. Kutner was Co-Chair of the NIH-funded Palliative Care Research Cooperative Group (PCRC), a member of the NIH Nursing and Related Clinical Sciences (NRCS) Study

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Section and of the Institute of Medicine (IOM) Transforming End of Life Care Committee. She is a Past-President of the American Academy of Hospice and Palliative Medicine (AAHPM) and of the Society of General Internal Medicine (SGIM). She is a member of the Cambia Sojourns Scholars Program Advisory Board and is on the Board of Directors for DSST Public Schools. Dr. Kutner served as the Head of the University of Colorado School of Medicine Division of General Internal Medicine from 2002-2014.



**Meghan Lane-Fall, MD, MSHP**

Meghan Lane-Fall, MD, MSHP, FCCM is an implementation scientist and practicing anesthesiologist and intensive care physician. At the University of Pennsylvania, she is the Executive Director of the Penn Implementation Science Center at the Leonard Davis Institute of Health Economics (PISCE@LDI). Her lab's research focuses on the application of implementation science and human factors and systems engineering to improve patient safety and communication in perioperative and critical care settings. She collaborates on implementation science projects in maternal health, health

equity, and HIV/AIDS and is supported by grant funding from the National Institutes of Health (NICHD, NHLBI, NIA, OD), the Agency for Healthcare Research and Quality, the American Heart Association, and the Patient Centered Outcomes Research Institute.

Dr. Lane-Fall holds leadership roles in multiple health services research training programs at Penn, including three early career faculty development programs and Penn's Implementation Science Certificate. She has more than 80 lifetime mentees from undergraduate students to early-stage faculty. She serves as the David E. Longnecker Associate Professor and Vice Chair of Inclusion, Diversity, and Equity in the Department of Anesthesiology and Critical Care, with a secondary faculty appointment in the Department of Biostatistics, Epidemiology, and Informatics. Dr. Lane-Fall is also on the Boards of Directors of the Anesthesia Patient Safety Foundation and the Foundation for Anesthesia Education and Research. She lives in the Philadelphia suburbs with her spouse and two children.



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**Charlotta Lindvall, MD, PhD**

Charlotta Lindvall, MD, PhD, is an Assistant Professor and the Director of Clinical Informatics at the Dana-Farber Cancer Institute, Boston. She leads a cross-disciplinary research team of physicians, nurses, and computer scientists to develop AI for language analysis within the context of serious illness care. ClinicalRegex, a software developed by her lab is used to identify text-based palliative care outcomes in multiple clinical trials involving tens of thousands of patients in the United States. In addition to her research and clinical work in palliative care, she is active in discussing the ethical implications of using AI in healthcare. She has published her thoughts in well-

regarded journals including *Science*, *JAMIA*, and *Health Affairs Forefront*. Dr. Lindvall has received multiple competitive awards and prizes including a NPCRC Junior Investigator Award, a Sojourns Scholar Award, and an Innovation Award from the National Quality Forum. Funding for her research include grants from the National Institutes of Health.



**Jennifer Mack, MD, MPH**

She is an attending physician at Dana-Farber Cancer Institute and Boston Children's Hospital, Director of the Center for Outcomes and Policy Research at Dana-Farber, Associate Chief of the Division of Population Sciences at Dana-Farber, Associate Chief for Pediatric Oncology Population Sciences at Dana-Farber/Boston Children's, and Faculty Vice President for the Office for Faculty Development, Professionalism, and Inclusion at Dana-Farber. She is also an Associate Professor of Pediatrics at Harvard Medical School. Her research interests are in parent-clinician and patient-clinician communication, health care equity and quality, and palliative care.

Dr. Mack received her medical degree from Harvard Medical School in 1998. She subsequently completed her residency in Pediatrics and her fellowship in Pediatric Hematology Oncology at Boston Children's Hospital and the Dana-Farber Cancer Institute in Boston, MA. In 2005, Dr. Mack received a Master's Degree in Public Health from the Harvard School of Public Health.

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**Diane E. Meier, MD**

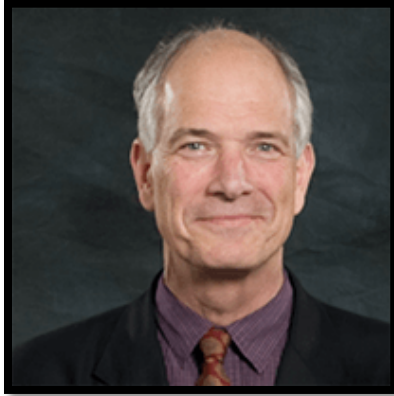
Dr. Diane E. Meier, FACP, FAAHPM, is Director Emerita and Strategic Medical Advisor of the Center to Advance Palliative Care, a national organization devoted to increasing access to quality health care in the United States for people living with serious illness. Under her leadership the number of palliative care programs in U.S. hospitals tripled since 2002.

Widely regarded as a preeminent change agent, Dr. Meier has received numerous awards that

recognize and celebrate her achievements. In September 2008, Dr. Meier was awarded a MacArthur Foundation Fellowship (MacArthur Genius Award). She was named one of “20 People Who Make Healthcare Better in the United States” by HealthLeaders Media in 2010 and was elected to the National Academy of Medicine of the National Academy of Sciences in 2013. In 2017 she received both the Gustav O. Lienhard Award of the National Academy of Medicine and the American Hospital Association’s HRET TRUST Award. Dr. Meier served as a Health and Aging Policy Fellow in Washington, DC, in 2009–10, working on the U.S. Senate Committee on Health, Education, Labor & Pensions (HELP) and at the Department of Health and Human Services.

Dr. Meier has published more than two hundred works in peer-reviewed medical literature. Her most recent book, *Meeting the Needs of Older Adults with Serious Illness: Challenges and Opportunities in the Age of Health Reform*, was published by Humana in 2014. She has been featured in the media numerous times, including the PBS NewsHour [Brief But Spectacular](#) and the [New York Times Magazine](#).

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**Vincent Mor, PhD**

Vincent Mor, Ph.D., is the Florence Pirce Grant Professor of Community Health in the Brown University School of Public Health and a senior health scientist in the health services research service at the Providence Veterans Affairs Medical Center. Dr. Mor has been Principal Investigator of over 40 NIH funded grants focusing on the use of health services and the outcomes frail and chronically ill persons experience. He has published over 450 peer reviewed articles, was recipient of a Robert Wood Johnson Foundation health policy investigator award and a MERIT award from the National Institute on Aging. In 2011, Dr. Mor was given the

Distinguished Investigator Award from AcademyHealth and was elected to the National Academy of Medicine.

Dr. Mor was one of the authors of the Congressionally mandated Minimum Data Set (MDS) for Nursing Home Resident Assessment and the architect of an integrated Medicare claims and clinical assessment database used for policy analysis, pharmaco-epidemiology and population outcome measurement. This data resource supports an NIA funded Program Project Grant, "Changing Long Term Care in America", now in its third renewal cycle and makes possible a series of large, pragmatic cluster randomized trials of novel nursing home-based interventions. Building upon this work, most recently, he and colleagues around the country were awarded a large grant from the National Institute on Aging to solicit, fund and support multi-site pilot non-pharmacologic intervention projects embedded in health care systems designed to improve the lives of persons living with dementia and their caregivers. This program is expected to test whether interventions found to be effective when implemented by researchers are still effective when embedded in a functioning health care system.



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**R. Sean Morrison, MD**

Dr. R. Sean Morrison is the Ellen and Howard C. Katz Professor and Chair of the Brookdale Department of Geriatrics and Palliative Medicine. He is also Co-Director of the Patty and Jay Baker National Palliative Care Center and Director of the National Palliative Care Research Center, national organizations devoted to increasing the evidence base of palliative care in the United States.

Dr. Morrison is the recipient of numerous awards, including the American Academy of Hospice and Palliative Medicine's PDIA National Leadership, Excellence in Research, and Visionary Awards; the

American Cancer Society's Distinguished Achievement in Cancer and Clinical Research Professor Awards; the American Geriatrics Society's Outstanding Achievement for Clinical Investigation Award; and the Jacobi Medallion (Mount Sinai's highest recognition).

His work has appeared in major peer-reviewed medical and policy journals, including the *New England Journal of Medicine*, *Health Affairs*, and the *Journal of the American Medical Association*. He edited the first textbook on geriatric palliative care and has contributed to more than 20 books on the subject of geriatrics and palliative care. As one of the leading figures in the field of palliative medicine, Dr. Morrison has appeared numerous times on television and in print to discuss his own research and to comment on matters related to older adults and those with serious illness.

R. Sean Morrison received his ScB from Brown University and his MD from the University of Chicago Pritzker School of Medicine. He completed his residency training at the New York Hospital-Cornell Medical Center followed by post-graduate fellowship training at the Mount Sinai School of Medicine in New York City. He has been on Mount Sinai's faculty since 1995.

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**Huong Nguyen, PhD, RN**

Dr. Huong Nguyen is a nurse and health services researcher whose work is broadly focused on the care of older adults with chronic and serious illnesses. She is currently serving as interim director of the Division of Health Services Research & Implementation for the Department of Research & Evaluation. She is also a professor in the Department of Health Systems Science of the Kaiser Permanente Bernard J. Tyson School of Medicine.

Dr. Nguyen conducts ongoing partnered research with operational and clinical leaders in Kaiser Permanente Southern California. She uses observational and experimental methods to improve care processes and outcomes for older adults with multiple chronic conditions across the illness trajectory and care continuum. Her current research and evaluation efforts are focused on testing a practice support bundle to facilitate earlier detection of cognitive impairment in primary care, patient and family-centered, home and community models of geriatric-palliative care to optimize the health and well-being of older adults and their family caregivers, and equitable implementation of care management and community supports for Medi-Cal beneficiaries.



**J. Nicholas Odom, PhD, RN**

J. Nicholas Odom, PhD, RN, ACHPN, FPCN, FAAN is the Doreen C. Harper Endowed Professor of Nursing in the School of Nursing at the University of Alabama at Birmingham (UAB) and Director of Caregiver and Bereavement Support Services in the UAB Center for Palliative and Supportive Care. Dr. Odom's nationally and internationally recognized program of research focuses on the development and testing of early palliative care coaching interventions for minority and historically under-resourced family caregivers of individuals with advanced cancer and heart failure using the multiphase optimization strategy. His research funding has totaled over \$9 million from the National Cancer Institute, the National Institutes of Nursing Research, the Gordon

and Betty Moore Foundation, the National Palliative Care Research Center, the Cambia Health Foundation, Sigma Theta Tau International, and the American Association of Critical Care Nursing."

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**Sheria Robinson-Lane, PhD, MSN, MHA, RN**

Sheria G. Robinson-Lane, PhD, MSN, MHA, RN is an assistant professor at the University of Michigan School of Nursing in the Department of Systems, Populations, and Leadership and affiliate faculty with both the Michigan Alzheimer's Disease Center and the Michigan Center for Contextual Factors in Alzheimer's Disease. Dr. Robinson-Lane's work aims to reduce health disparities and improve health equity for diverse older adults who aim to age in place within their communities. Her research examines the structures and strategies that support active community living for older adults including effective pain management programs and supportive family caregivers. Her work is funded by the National Institute on Aging of the National

Institutes of Health.

Dr. Robinson-Lane is a long-time clinician and gerontological nurse educator with extensive experience in both long-term care and hospice/ palliative care practice. As a recognized expert, she has advised the Centers for Medicaid and Medicare Services through technical expert panels and special convening sessions. Like many, her work shifted during the COVID-19 pandemic to provide both formal and informal community education on COVID-19, COVID vaccines, and managing care of the older adults inside and outside of institutional care facilities.

She has been recognized by the National Hartford Center of Gerontological Nursing Excellence as a distinguished educator in gerontological nursing and recently awarded The Daisy Award for Nurses Advancing Health Equity, by the University of Michigan School of Nursing. Dr. Robinson-Lane completed her PhD in Nursing at Wayne State University in Detroit along with a graduate certificate in gerontology from the same institution. She also completed a postdoctoral fellowship in Advanced Rehabilitation Research Training at the University of Michigan Medical School in the Department of Physical Medicine and Rehabilitation.

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**Albert Siu, MD**

Dr. Siu is Professor of Geriatrics and Palliative Medicine and former Chair (2003-17) of the Department at the Icahn School of Medicine at Mount Sinai. He is an internist, geriatrician, and health services and policy researcher and currently MPI of the Claude Pepper Center at Mount Sinai funded by the National Institute of Aging. He is currently a Senior Associate Editor of Health Services Research, a past member and Chair of the U.S. Preventive Services Task Force. From 1998-2002, Dr. Siu was Chief of the Division of General Internal Medicine in the Samuel Bronfman Department of Medicine and the Director of Adult Primary Care.

Dr. Siu graduated from Yale Medical School and went on to complete a residency in Internal Medicine and a fellowship as a Robert Wood Johnson Clinical Scholar at UCLA. He joined the UCLA faculty in 1985 in Medicine with a joint appointment at RAND. He served as Chief of the Division of Geriatric Medicine at UCLA from 1989 until his departure in 1993 to become a Deputy Commissioner in the New York State Department of Health. In 1995, he came to Mount Sinai as a Professor in the Department of Health Policy. Dr. Siu is a member of the National Academy of Medicine.



**Karen Steinhauser, PhD**

Karen Steinhauser, PhD, is Professor, Departments of Population Health Sciences and Medicine, Senior Fellow with the Center for Aging, Duke University and Health Scientist with the Durham ADAPT Center for Health Services Research, VA Medical Center, Durham. Her research focuses on the psychosocial and spiritual aspects of 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.

Dr. Steinhauser's latest work includes exploring approaches to improving health disparities in the clinician-patient encounter, improving patient-caregiver dyadic communication, and developing, validating, and implementing a measure to assess spiritual needs in serious illness. She also serves as Director of the Duke Graduate Medical Education Professional Development



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Coaching program and the Vice Chair for Faculty Development, Department of Population Health Sciences.



**Malenna Sumrall, PhD**

As a care partner for my husband who had Parkinson's with Dementia, I experienced neuropalliative care at its best in Dr. Benzi Kluger's clinic at the University of Colorado. His passion for this treatment model inspired me to volunteer in various ways to promote neuropalliative care. I have served on advisory councils for two of his research projects, have participated in presentations at various conferences, including the International Neuropalliative Care Society (INPCS) in 2021 and AAHPM in 2022, and I am a member of the INPCS Membership Committee. I have been leading a Zoom support group for care partners of people with a neurologic illness since

2019 and have spoken to other local support groups about neuropalliative care. In addition to that, I have been included as a co-author on several journal articles published by Dr. Kluger. I consider myself fortunate to be a part of this very important and growing movement to promote the neuropalliative model to healthcare providers and to patients and their families.



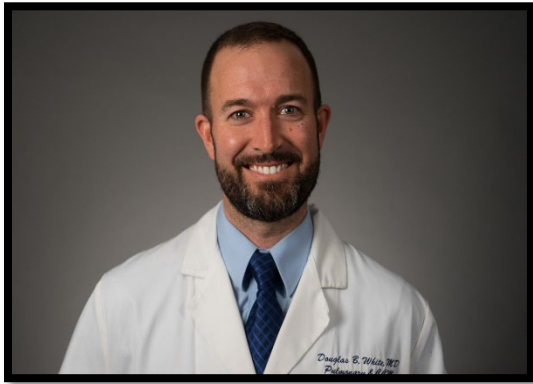
**Kathleen Unroe, MD, MHA, MS**

Kathleen Unroe, MD, MHA, MS, is an Associate Professor of Medicine at Indiana University and Scientist at the Regenstrief Institute. Her research, clinical and policy interests are focused on quality of and access to palliative care in nursing homes.

Dr. Unroe's current research includes a clinical trial of palliative care in nursing homes and a pragmatic trial of advance care planning in nursing homes. She was PI of OPTIMISTIC, an 8-year \$30.3 million CMS-funded demonstration project to reduce hospitalizations in 40 facilities. She was a Beeson K23 Career Development Awardee and a 2009-2010 Health and Aging Policy Fellow. She serves on the CMS 5 Star Care Compare Technical Expert Panel for nursing homes. Dr. Unroe earned her MD from the Ohio State University and conducted

her fellowship in Geriatric Medicine at Duke University Medical Center.

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**Douglas B. White, MD, MAS**

Dr. White is Vice Chair and Professor of Critical Care Medicine at the University of Pittsburgh School of Medicine. He holds the UPMC Endowed Chair for Ethics in Critical Care Medicine. He directs the University's Program on Ethics and Decision Making in Critical Illness, which is the first program in the country focused on ethical issues in critical care medicine.

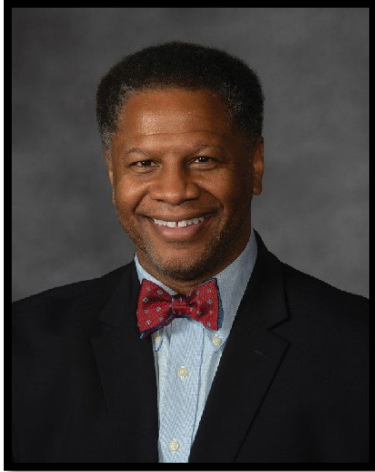
Dr. White graduated summa cum laude from Dartmouth College in 1995 with a degree in English Literature. He received his medical degree from UCSF in 1995 and was elected to the Alpha Omega Alpha honor society. Also at UCSF, Dr. White completed a residency in Internal Medicine, a fellowship in Pulmonary and Critical Care Medicine, a Master's degree in Epidemiology and Biostatistics, and a fellowship in Clinical Ethics.

Dr. White's scholarship focuses on ethical issues that arise in the care of critically ill patients and on developing interventions to improve surrogate decision making for incapacitated, seriously ill patients. He has been continuously funded by the NIH since 2005 and has also received funding from a number of foundations including the Greenwall Foundation, the Gordon and Betty Moore Foundation, and the Beckwith Institute.

He has published more than 200 peer reviewed articles and has received numerous awards for his scholarship, including the Grenvik Award for Ethics from the Society of Critical Care Medicine and the Distinguished Research Mentor Award from the University of Pittsburgh.

He is an elected fellow of the Hastings Center and the American Society for Clinical Investigation. He is a designated diversity champion at the Pitt School of Medicine.

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**Robert A. Winn, MD**

As director of VCU Massey Cancer Center, Robert Winn, M.D., oversees a cancer center designated by the National Cancer Institute that provides advanced cancer care, conducts groundbreaking research to discover new therapies for cancer, offers high-quality education and training, and engages with the community to make advancements in cancer treatment and prevention equally available to all. He is leading the nation in establishing a 21st-century model of equity for cancer science and care, in which the community is informing and partnering with Massey on its research to best address the cancer burden and disparities of those the cancer center serves, with a local focus but global impact.



**Nicole Yarab, RN, BA**

Nicole is registered nurse and nonprofit executive who oversees the Parkinson's Foundation Helpline and Global Care Network and serves as the co-PI on a PCORI-funded palliative care implementation project. She focuses on improving reach and optimizing quality care delivery and outcomes for people living with Parkinson's and their care partners. Her experience includes direct patient care, community and professional education, clinical trial and interdisciplinary care coordination, program management and development, and non-profit leadership. Nicole is passionate about delivery of patient-centered care and utilizing the multidisciplinary approach to optimize outcomes for people living with neurodegenerative diseases.