Roundtable on Quality Care for People with Serious Illness

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

A Workshop | April 27, 2017

The National Academies of SCIENCES ENGINEERING MEDICINE

#SeriousIllnessCareNASEM

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

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Roundtable on Quality Care for People with Serious Illness

April 27, 2017

Dear Colleagues:

We would like to welcome you to the second 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 on *Models and Strategies to Integrate Palliative Care Principles into Serious Illness Care*. This workshop has been developed to shine a light on some of the many innovative models of care delivery that are providing high-quality services to people of all ages facing serious illness. In addition to learning about the essential features of effective care delivery models, we will have a discussion about the evolving policy landscape for serious illness care and the potential policy changes that would improve care delivery. We hope you will find the presentations informative and thought-provoking and will be inspired to incorporate the lessons learned here today into your community-based programs and work caring for people living with serious illness.

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: http://www.nationalacademies.org/hmd/Activities/HealthServices/QualityCareforSeriousIllnessRoundtable/2017-APR-27.aspx

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

Thank you for participating in this workshop.

Sincerely,

Diane E. Meier

Diane Meier, MD, FACP
Director, Center to Advance Palliative Care
Vice-Chair for Public Policy and Professor
Icahn School of Medicine at Mt. Sinai
Workshop Planning Committee Co-Chair

Brenda Nevidjon

Brenda Nevidjon, MSN, RN, FAAN
Chief Executive Officer
Oncology Nursing Society
Workshop Planning Committee Co-Chair

Agenda

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Models and Strategies to Integrate Palliative Care Principles 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
April 27, 2017

Overarching Workshop Objectives

- Explore examples and highlight essential elements of high-quality community-based palliative care delivery models that measurably improve value for very high-need populations across the continuum of care throughout the trajectory of a serious illness
- Identify barriers and opportunities to scale and spread of successful models

April 27, 2017	
8:00 am	**Registration and Breakfast**
8:30 am	**Welcome from 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** Diane Meier, MD, FACP, Director, Center to Advance Palliative Care and Vice-Chair for Public Policy and Professor, Icahn School of Medicine at Mount Sinai Brenda Nevidjon, MSN, RN, FAAN, Chief Executive Officer, Oncology Nursing Society *Planning Committee Co-Chairs*
8:45 am	**Session 1: Framing the Challenges and Opportunities: Providing High-Quality Care to People with Serious Illness** ***Moderator:* Diane Meier, MD, FACP,** Center to Advance Palliative Care and Icahn School of Medicine at Mount Sinai – High-Quality Palliative Care: the Patient-Family-Clinician Perspective **Vicki L. Garrett, RN and David Garrett,** Patient-Family Perspective **Colleen Tallen, MD,** Medical Director of Palliative Care, LeeHealth – Community-Based Palliative Care: Population Health Management Perspective **Martha Twaddle, MD,** Senior Medical Director, Aspire Health – Community-Based Palliative Care: Health System Perspective **Stacie Pinderhughes, MD,** Chair, Division of Palliative Medicine, Banner Health

	Panel Discussion, Audience Q & A
10:00 am	**Break**
10:15 am	**Session 2: Palliative Care Principles Across the Age Spectrum** ***Moderator:* Brenda Clarkson, RN**, Executive Director, Virginia Association for Hospices and Palliative Care – Pediatric Palliative Care **Deborah A. Lafond, DNP, PPCNP-BC, CPON, CHPPN** Nurse Practitioner, PANDA Palliative Care Team, Division of Hospitalist Medicine, Children's National Health System **Kathy Perko, MS, CPNP, CHPPN, CPLC** Pediatric Nurse Practitioner, Program Director, Bridges Palliative Care OHSU Doernbecher Children's Hospital – Medicare Care Choices Model **Laura Patel, MD,** Chief Medical Officer, Transitions Life Care – Adult Palliative Care in a Value-Based Payment Model **Dana Lustbader, MD, FAAHPM,** Chief, Department of Palliative Care, ProHealth Care **Panel Discussion, Audience Q & A**
12:00 pm	**Lunch**
12:45 pm	**Session 3: Promising Innovations** ***Moderator:* Judith R. Peres, LCSW-C,** Long Term and Palliative Care Consultant, Clinical Social Worker and Board Member, Social Work Hospice and Palliative Care Network – Providing Care to Patients at Home/Independence at Home CMS Demonstration Project **K. Eric De Jonge, MD,** Executive Director, Medstar Total Elder Care, Medstar Health – Reaching Patients in Rural, Underserved Areas **Michael Fratkin, MD,** CEO, ResolutionCare – Serving the Dual Eligible Population **John Loughnane, MD,** Chief of Innovation and Medical Director, Life Choices Palliative Care Program, Commonwealth Care Alliance – Transforming Care Delivery **Michael Le, MD,** Chief Medical Officer, Landmark Health, LLC **Panel Discussion, Audience Q & A**
2:30 pm	**Break**

2:45 pm	**Session 4: Providing High-Quality Comprehensive Care** ***Moderator:* Marian Grant DNP, RN, CRNP,** Director, Policy and Professional Engagement, Coalition to Transform Advanced Care – Comprehensive Care Delivery: the PACE model **David Wensel DO, FAAHPM,** Medical Director, Midland Care – Comprehensive Care Delivery: CareMore's Model **Sachin Jain, MD, MBA, FACP,** *CEO, CareMore Health System* – Comprehensive Care Delivery: Tandem 365's Model **Teresa Toland, RN,** CEO, Tandem 365 **Panel Discussion, Audience Q & A**
4:00 pm	**Session 5: Policy Directions** ***Moderator:* Lee Goldberg, JD, MA,** Director, Improving End-of-Life Care Project, The Pew Charitable Trusts – Person-Centered Care for High-Need, High-Cost Medicare Patients **G. William Hoagland, MS** Senior Vice President, Bipartisan Policy Center **Discussion: G. William Hoagland, MS and Sachin Jain, MD, MBA, FACP** **Audience Q & A**
5:00 pm	**Wrap up and Adjourn** Diane Meier, MD, FACP, and Brenda Nevidjon, MSN, RN, FAAN *Planning Committee Co-Chairs*

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Roundtable on Quality Care for People with Serious Illness

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/2017-APR-27.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/2017-APR-27.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?

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Roundtable on Quality Care for People with Serious Illness

Models and Strategies to Integrate Palliative Care Principles into Serious Illness Care—A Workshop

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Roundtable on Quality Care for People with Serious Illness

Models and Strategies to Integrate Palliative Care Principles into Serious Illness Care—A Workshop

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Roundtable Overview

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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 inter-professional 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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HEALTH AND MEDICINE DIVISION

Roundtable on Quality Care for People with Serious Illness

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ABOUT US

THE HEALTH AND MEDICINE DIVISION

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.

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.

Learn more at
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The National Academies are private, nonprofit institutions that provide independent, objective analysis and advice to the nation and conduct other activities to solve complex problems and inform public policy decisions related to science, technology, and medicine. The National Academies operate under an 1863 congressional charter to the National Academy of Sciences, signed by President Lincoln.

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Upcoming Workshop

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Roundtable on Quality Care for People with Serious Illness

Upcoming Public Workshop

Financing and Payment Models to Support Delivery of High-Quality Care for People with Serious Illness: A Workshop

The Keck Center of the National Academies
500 Fifth Street, NW - Room 100
Washington, DC 20001
November, 2017

An ad hoc committee will plan and host a one-day public workshop that will examine how various financing and payment approaches can help support delivery of high-quality care for serious illness.

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

- Integrated financing models such as Medicare Advantage programs, Program of All-Inclusive Care for the Elderly (PACE) and risk-based payment approaches such as Accountable Care Organizations (ACO) and bundled payments

- Programs such as the Medicare hospice benefit, Medicare Home Health Care, Medicaid Home Health Care, and financing and payment methods for the dual eligible population

- Incorporation of performance metrics in payment models, such as pay for performance and performance incentives

- Potential policy steps to address key gaps, challenges and opportunities related to financing and payment models to support high-quality care for serious illness

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

Jeffrey Cohn, MD, MHCM, Common Practice; **Janet Corrigan, PhD, MBA,** Gordon and Betty Moore Foundation; **Joanne Lynn, MD,** Altarum Institute; **Diane Meier, MD, FACP,** Icahn School of Medicine at Mount Sinai; **Jeri Miller, PhD,** National Institute of Nursing Research; **Joseph Shega, MD,** VITAS Hospice Care; **Susan Wang, MD,** Kaiser Permanente

April 13, 2017

The 20th century saw remarkable improvements in life expectancy (NIA, 2011). Improvements in access to clean water, disease screening and prevention, the discovery of antibiotics and vaccines, development of organ transplantation, and advances in treatment for heart disease and cancer have all contributed to an expectation that Americans will live long lives in generally good health.

A concomitant change has been that most Americans will now experience a substantial period of living with serious illness, mostly progressive and life-limiting. An estimated 45 million Americans are living with one or more chronic conditions that limit personal function and are likely to worsen rather than get better (IOM, 2015; NASEM, 2016). Although representing only 14 percent of the population, these seriously ill persons account for 56 percent of all health care expenditures—almost $1 trillion (IOM, 2015).

While the benefit of curative treatments for people living with serious illness is often limited, our health care delivery system remains almost exclusively focused on the treatment of acute and reversible illness, rather than on supporting quality of life and daily functioning. This has led to a gap between what people need and want from medical care and what they experience. When asked, most people prioritize quality of life over extension of life if the interventions needed to try to prolong life reduce quality (Cambia, 2011). Yet, many experience intense use of hospital care in the last year of life, with nearly 30 percent spending time in the intensive care unit during the month preceding death (Teno, 2013).

People with serious illness are not a homogeneous group. For the purposes of this discussion paper, the authors define people with serious illness as those with complex and pressing care needs due to a particular disease, e.g., persons with metastatic lung cancer or amyotrophic lateral sclerosis who have breathing difficulty. The definition also includes people who have some years of self-care disability, often at the ends of their lives, from conditions such as cognitive or neuromuscular impairment, strokes, organ system failures, frailty of old age, or other conditions.

Most people with serious illness are in need of both health care and social supports such as access to food, housing, personal care, transportation, and financial support. In addition to disease-focused medical care, most people need symptom relief (e.g., pain, dyspnea, and depression), care coordination and communication over time and across settings, and information and assistance in making difficult decisions. Such expertise in symptom management, shared decision making, and care coordination are features of what is known as palliative care (Meier, n.d.). The field includes primary palliative care (i.e., features integrated into usual care provided by primary and specialty care physicians, nurse practitioners, and others) and specialty palliative care (i.e., care provided by palliative care specialists, geriatricians, and others to the sickest individuals, including those enrolled in hospice).

Although palliative care is now available in most hospital and hospice settings, access to community-based palliative care (at home, in nursing homes, and in office practices) is largely absent in the United States. The population of people with serious illness is substantially broader than those who are hospitalized and those who qualify for hospice. Hospice requires that the person have a prognosis for survival of 6 months or less, as well as a willingness to forego "curative" disease-focused treatments, which leads to late referrals and gaps in access to palliative care for people earlier in the course of illness.

Caring for people with serious illness requires building new community-based care models that

- integrate the currently fragmented array of social supports and primary, specialty, and hospice services available in most communities;
- broaden the scope of palliative care beyond hospitals and into patient homes, nursing facilities, and office practices;
- make use of telehealth;
- expand the capacity and coordination of supportive social services along with medical care; and
- provide supports for family caregivers.

We use the term *community-based serious illness care programs* to refer to the growing number of programs that strive to provide this kind of comprehensive care to people with serious illness who reside in community settings. Other terms sometimes used to refer to these types of programs include: c*ommunity-based palliative care, geriatric team care,* and *advanced care programs.*

In this discussion paper, we identify guiding principles and core components of community-based serious illness care programs, provide an overview of some innovative model programs, and discuss key issues moving forward. When possible, we use the term person rather than patient, in order to underscore the centrality of the person beyond the disease label.

Guiding Principles and Core Competencies

Persons with serious illness and their families have medical, psychosocial, and spiritual needs to be met in the community setting. High-quality programs share common foundational elements necessary to match services to population needs. We will first describe guiding principles that are inherent to the ideal community-based model program. Next, we will discuss core competencies that these programs must possess to provide high-quality care.

Guiding Principles

Building on the work of others (National Consensus Project, 2013; NQF, 2016), we have identified key principles that should guide the development of community-based serious illness care programs.

Person-/Family-Centered

First and foremost, serious illness care programs should be driven by the priorities and goals of the person and family. Accommodation should be made to tailor services that are culturally responsive and language-concordant. The program should support the family unit as defined by the person. Person- and family-centeredness should continue through the end of life and include bereavement supports for the family and others close to the person who has died.

Shared Decision Making in Support of Patient Goals

Care delivery should be guided by a care plan that is focused on goals derived from a communication process that elicits the evolving values and preferences of the person and his/her family over time. An initial comprehensive assessment should be conducted to determine the person's priorities and concerns, identify gaps in the quality of care, and guide treatment goals. There should be adequate access to disease-specific information on treatment options and pros and cons in the context of personal priorities and goals to support personal control and autonomy. High-quality medical decision making requires person and family education about what to expect in terms of the disease trajectory, prognosis, and anticipated complications.

Comprehensive, Coordinated Care

People with serious illness have complicated needs. Many, if not most, require both health care and social supports (e.g., home health aides, home-delivered meals). Not all people have family caregivers, and even when caregivers are available, respite and social services are usually needed to support families and fill in the gaps. Serious illness care programs must be able to arrange for the provision of both health care and social services. For people of modest financial means, this will necessitate building relationships with local social service agencies.

Although the goal of community-based programs is to allow people to remain in their homes as long as they desire, this is not always possible. People with serious illness are at higher risk of frequent transitions from one care setting to another. Acute events may lead to emergency department or hospital visits or specialist outpatient care outside of the primary community-based program. A high-quality program coordinates and communicates with primary and specialty care to reinforce and enhance care across transitions.

Accessible

Community-based serious illness care programs should be available in all communities and accessible to all people with serious illness. This may require some degree of regional planning and coordination to ensure that local capacity is adequate to meet the needs of residents with serious illness; that all people with serious illness, regardless of insurance status, have access to serious illness care programs; and that insurance plans provide coverage and adequate payment for the services provided by serious illness programs.

It will also be important for serious illness care programs to be proactive in identifying and reaching out to all people in need of services, through processes embedded in comprehensive population health management. For some situations, the fact of serious illness is obvious, e.g., in the case of metastatic pancreatic cancer or amyotrophic lateral sclerosis with breathing difficulty. But for others, the boundary between ordinary illness and serious illness is a matter of degree and context, e.g., an elderly person with early frailty who lives with an adult daughter and gradually loses ground over years, eventually becoming completely dependent in all activities of daily living before dying of “natural causes.” For gradually worsening courses like these, serious illness programs have to create operational definitions for the populations they intend to serve.

Provide Value

To be sustainable over the long run, community-based programs must provide value and have a sustainable financial model, as noted above. A program must be able to demonstrate that it can provide high-quality care as evidenced by measures of care outcomes and patient and family perceptions, while at the same time managing costs. High-value programs carefully design care processes, deploy highly effective care teams, make wise use of technology, recognize and support the contributions of caregivers, and mobilize and buttress the resources of social service agencies by building mutually supportive partnerships.

A key challenge for some serious illness care programs, especially those in rural parts of the United States, is managing the cost of delivering home-based services to a geographically dispersed population. Strategies for managing the cost of travel time by care team members include the use of telehealth services and coordinated approaches to designating particular geographic service areas for serious illness programs.

Core Competencies

Achievement of the guiding principles for model community-based serious illness care programs requires a set of core competencies. These competencies set the standard for a high-quality program.

Identification of the Target Population

Critical to a successful program is selecting the appropriate target population. Research suggests that people with one or more serious illnesses, at least one hospital admission in the prior 12 months and/or residence in a nursing home, and functional impairment have a 47 percent risk of hospitalization and a 28 percent risk of death in the subsequent year (Kelley, 2017). Programs will benefit from screening tools that are both sensitive (i.e., identify as many of those at risk as possible) and specific (i.e., exclude individuals who do not need services or are unlikely to benefit from them).

For practical purposes, most model delivery programs target persons who are either receiving services from a particular provider organization or insured by a particular insurer, or both. Most serious illness programs identify eligible persons based on clinical and health status characteristics (diagnosis, physical and cognitive functioning, prognosis), combined with information on past health care utilization. Programs vary in the extent to which consideration is given to social issues (e.g., availability and capacity of caregivers, caregiver burden, housing, food security, and transportation). Information on functional status, while a critical predictor of future need, is not currently easily available either through claims data or medical records. Some programs, such as the state-based Programs of All-Inclusive Care for the Elderly that care for dual-eligible persons insured by Medicaid and Medicare, provide individual assessments to establish severity of disability and (sometimes) the likely future course, so as to provide the person with appropriate supportive services. The Veterans Health Administration defines eligibility for its Home-Based Primary Care program on the clinical assessment that the veteran is too sick to come to clinic. Programs in other nations, such as the Gold Standard Framework in the United Kingdom, use responses to the question of whether the primary care clinician would be surprised if the person died within the coming year (Royal College of General Practitioners, 2011).

Team-Based Care

Care of people with serious illness ordinarily requires an interdisciplinary team that includes some of the following: physicians, nurses, social workers, rehabilitation specialists, chaplains, home health aides, community health workers, and others. It is important to note that affected persons and their family caregivers are central members of successful care teams. Areas of expertise and skills needed for successful teams include pain and symptom management, expert communication capabilities, and assessment and remediation of the social contributors to ill health and suffering (such as food insecurity). Teams should be intentional about self-care, resilience, and learning from each other to enhance skills and improve the team's long-term capacity to provide support to seriously ill people.

Caregiver Training

Most persons with serious illness require substantial caregiver support. High-quality serious illness care programs help people and their caregivers identify their needs, articulate their concerns and worries, and work together to develop a responsive support plan, including social resources such as food, safe housing, transportation, personal care aides, and financial support. A recent survey by AARP found that 46 percent of caregivers perform nursing tasks (e.g., wound care, tube feeding), so training and technical backup are also important (Reinhard, 2012).

Attention to Social Determinants of Health

Safely maintaining people with serious illnesses in community settings requires careful attention to social risks such as poverty, mental illness, unsafe housing, history of or current trauma, food insecurity, lack of transportation, and low literacy. Palliative or geriatric care teams conduct comprehensive assessments of these domains, work with community partners and colleagues (such as aging services, senior housing) to address them, and track needs of both the person and caregivers over time.

Communication Training and Supports

High-quality programs incorporate education to improve patient and family knowledge of disease progression, prognosis, and burdens and benefits of various treatment options. High-quality programs also strive to develop team skills in discussing a serious diagnosis and its implications, running a family meeting, leading an advance care planning discussion, and engaging in longitudinal shared decision-making.

Some programs use "case conferences" to communicate among disciplines and coordinate patient care. The method of the conference may vary, using in-person or virtual formats. This type of meeting allows each member to organize all resources of the team around patient priorities and care gaps to improve the care plan.

Goal-Based Care Plans

Effective programs work with seriously ill people and their caregivers to develop a care plan and adapt it as the condition and treatment goals evolve over time. Documented plans improve care transitions and support treatment concordance. Leveraging interoperable electronic health records and other technologies allows for timely input and retrieval of information. Successful programs incorporate longitudinal processes of advance care planning to anticipate future decline and ascertain personal values over time related to quality of life and treatment interventions.

Symptom Management

Symptom burden is high among persons living with serious illness; therefore, symptom control is a top concern. Model programs ensure that care teams are capable of recognizing and addressing pain, breathlessness, nausea, constipation, fatigue, depression, and other symptoms. Symptoms may be rooted in physical, emotional, social, or spiritual sources. Treatment options should incorporate skills from each discipline and may be pharmacologic or non-pharmacologic.

Medication Management

Assessment of medication regimens, including drug-to-drug interactions, side effects, patient adherence, and optimization of disease control are important to the safety and quality of care, as is the ability to deprescribe. Attention to affordability and access to appropriate medications through financial counseling or referrals for financial support or through price reduction programs is effective in relieving some of the financial stress that patients and their families face.

Accessible

High-quality model programs engage in proactive outreach to target the appropriate population, and make services available when and where needed. The provision of services 24/7 with the care plan in hand is standard in quality programs.

Transitional Care

Model programs have processes in place for appropriate and informed transitions between all care settings and consistent handoffs to professionals in other settings to improve safety and adherence to a person's preferred care plan. The capacity to recognize eligibility for hospice and to make timely referrals can improve quality of care at the end of life.

Ability to Measure Value for Accountability and Improvement

Achieving measureable and meaningful outcomes is critical for sustainable programs. Programs must be able to capture both quality and cost data about the target population in order to ensure quality and demonstrate to stakeholders and funders that the program is achieving its intended outcomes. Model care programs routinely track discrete and measureable outcomes for both quality improvement and accountability purposes. Measures may include appropriate utilization of health services, symptom burden over time, resolution of clinical care gaps, and/or improved person and family experience and satisfaction.

Model Programs

In recent years, there has been significant growth in the number of community-based serious illness care programs. Dozens of programs at various stages of development have been identified, although few encompass all of the core competencies identified above (California Health Care Foundation, 2014; CAPC, 2016). The growth of such programs continues to be driven, in part, by the health care needs of an aging population, the growing numbers of individuals with multiple complex chronic conditions or serious illness in need of comprehensive care in a cost-effective manner, and service gaps for those ineligible for hospice care or not in need of hospitalization (Bainbridge, 2010).

Recent changes in health care financing, stemming in part from the provisions of the Patient Protection and Affordable Care Act (ACA) (2010) have offered incentives for community-based serious illness programs to grow. Both public and private payers have embraced value-based payment programs (e.g., readmission penalties, shared savings, risk sharing, bundled payments) that encourage the development of new models of care that reward improved care quality leading to reduced cost (Discern Health, 2016; Valuck, 2017). These changes in health care payment have opened up opportunities for new model programs that serve people with serious illness residing in non-hospital settings and fill an important need for coordinated and comprehensive services (Barbour, 2012; Kamal, 2013; Morrison, 2013; Twaddle, n.d.).

Innovative models of community-based care for people with serious illness have started to demonstrate significant clinical benefits leading to reduced need for crisis services. A literature review by the Institute for Clinical and Economic Review (ICER, 2016) described several model programs that have validated the benefits of palliative care outside of the inpatient care setting in terms of improved quality of life, health outcomes, and patient satisfaction. A growing number of research findings indicate that palliative care provided in community settings (as compared to inpatient settings) results in significant clinical benefits in improved symptom management, increased survival, and better caregiver outcomes (Bainbridge, 2016; Bakitas, et al., 2015; Rabow, 2013; Seow, 2014; and Temel, 2007), and some studies have demonstrated an associated reduction in costs (Brumley, 2007; Cassel, 2016). Comprehensive geriatric care models have also demonstrated lower costs and higher quality, including Geriatric Resources for Assessment and Care of Elders (Counsell, 2009; Hong, 2014), the Hospital at Home Program (Leff, 2005), the Independence at Home Program (CMMI, 2016) and Guided Care (Boult, 2013; Leff, 2009).

Table 1 provides examples of various models of community-based serious illness care programs. The table does not include traditional hospice programs (which provide services to persons nearing the end of life) or innovations that operate only in institutional settings (such as the INTERACT program or the Hope Hospice and Palliative Care program in Rhode Island that serves nursing home residents). These types of programs also play critical roles in caring for people with serious illness, but do not meet our definition of a comprehensive, community-based serious illness care program.

Community-based serious illness care programs have been established by many different types of organizations:

1. **Health Systems.** A growing number of serious illness care programs operate under capitated or partial risk-bearing integrated health systems that provide coordinated and comprehensive services across settings (Beresford, 2012). Examples include Kaiser Permanente's In-Home Palliative Care Program, the Veterans Affairs' Team Managed Home Based Primary Care Program, Children's National Health System's PANDA Program and Sharp HealthCare Transitions Program.
2. **Accountable Care Organizations (ACOs).** Since the passage of the ACA, accountable care organizations have grown considerably. ACOs are not integrated health systems, but rather a group of health care provider organizations that agree to work together to reduce health care costs while maintaining quality, as well as to share in any savings. An example of a community-based serious illness care program sponsored by an ACO is ProHEALTH Care Support in Lake Success, NY.
3. **Medical Groups or Outpatient Clinics.** Many inpatient palliative care providers have now expanded their programs into outpatient or medical group clinics. Many of these programs are associated with medical oncology practices (Hui, 2015; Partridge, 2014), for example, the Comprehensive Assessment with Rapid Evaluation and Treatment (CARE Track) program in Virginia (Blackhall, 2016).
4. **Home Health Agencies.** Many organizations that have traditionally provided home health or hospice services are now developing comprehensive, community-based serious illness care programs, for example, Home Connections sponsored by The Center for Hospice and Palliative Care (Kerr & Donahue, 2014; Kerr & Tangemon, 2014).
5. **Independent Organizations.** Although many community-based programs have been developed by established health care organizations, such as medical groups, hospitals, and home health and hospice agencies, there are also independent organizations entering this space. Aspire Health, headquartered in Nashville, TN, has serious illness care programs in 15 states and the District of Columbia. Numerous independent programs serve individuals dually eligible under Medicare and Medicaid as part of the Programs of All-Inclusive Care for the Elderly (PACE), which provides considerable flexibility to build programs that leverage the health care and social service assets of a community (Lynn, 2016). Examples of PACE programs include Providence ElderPlace in Portland, OR, and Huron Valley PACE in Ypsilanti, MI.

Moving Forward

The growth in community-based serious illness care programs is encouraging. Some frail elders and others with serious illness and disabilities in at least some communities are beginning to have options to receive needed health care and social supports while remaining in their homes. But much work remains to be done.

Applied health services research and systems improvement are needed to guide the future development and evolution of community-based serious illness care programs. Studies of models of care need to be broadened to overcome the constraints of a limited number of comparative studies and the heterogeneity of diverse variables such as intervention targets, diseases, socio-demographics, and complex service configurations (Bainbridge, 2011; ICER, 2016; Luckett, 2014). As these programs continue to grow, there is a need for quality and cost-effectiveness analyses that define best practices across settings, patient populations, and service structures (ICER, 2016; Meyers, 2014; Morrison, 2013). Future work should also substantiate the value of community-based serious illness care programs against a backdrop of social determinants of health, regional variations, and workforce capabilities and constraints. Further, individual and family experiences of care across the various models have yet to be fully evaluated (Beattie, 2014; van der Eerden, 2014).

Payment and benefit programs must continue to evolve for serious illness care programs to thrive. Although not the focus of this discussion paper, our review of various payment programs revealed many different approaches to financing (Discern, 2016). The field would benefit greatly from a better understanding of the impact of various financing methods on access, quality, and cost of community-based serious illness care (Aldridge, 2015; ICER, 2016).

There is also an urgent need to develop a robust accountability system for community-based programs. An expert panel recently convened by Pew Charitable Trusts and others concluded that a very small number of performance measures exist to assess care for the very final stage of life—and even fewer to evaluate the care received by those struggling with serious illnesses over longer periods of time (Pew Charitable Trust, 2017). Serious illness care programs serve some of the most vulnerable populations, including frail elders, people with physical and cognitive disabilities, those with life-threatening medical diagnoses, and those nearing the end of life. Proper oversight and transparency are key to early detection and remediation of barriers to access, as well as avoiding poor-quality care, including inappropriate under-treatment, unsafe environments, and excessive out-of-pocket expenditures.

Lastly, further thought should be given to how best to ensure access to safe, high-quality care for all people in a geographic community, especially those who lack health insurance, have limited financial resources, or have no family members to serve as caregivers and advocates. There is a need to define the roles and responsibilities of health care organizations providing serious illness care to a specified patient population and social service and support organizations that serve an entire geographically-defined community. For many people, serious illness care requires a careful blend of health care and social supports. Most social services are geographically anchored in their community's arrangements for shared resources, such as disability-adapted housing and transportation and home-delivered food; and most communities lack effective processes for planning and coordinating the social services provided by community agencies with the care provided by a myriad of different health care organizations. Adequately serving the entire population of people with serious illness in a geographic area will require broader community planning and engagement.

Table 1 | Model Programs

Base Units	Model Program	General Description	Services/Community Served	Outcomes/Effectiveness	Payment Structure
Health Systems	Kaiser Permanente, In-Home Palliative Care (IHPC)	Integrated managed care consortium based in Oakland, CA and offered in California, Colorado, Georgia and Hawaii.	Offers inpatient, outpatient, and home services. The IHPC (In-Home Palliative Care) incorporates an interdisciplinary team approach with expertise in palliative care, consisting of the patient and family plus a physician, nurse, and social worker. Patient emphasis is cancer, heart failure, and COPD patient. The physician helps coordinate care among the other health care providers. The core team is responsible for coordinating and managing care across all settings with a continuous reassessment of care needs. Comprehensive education about disease course and expected outcomes to facilitate goals of care including advance care planning and end of life care. The physical, psychological, social, and spiritual needs are comprehensively assessed and managed. Frequency of visits based upon patient need with 24-hour on call availability.	IHPC demonstrated improved patient satisfaction, increased likelihood of dying in place of choice, and less likely to utilize the emergency department or to be admitted to the hospital compared to usual care. Overall, the intervention group generated significant cost savings [1, 2, 3].	IHPC program receives fixed monthly reimbursement from Kaiser Permanente for each enrollee. Reimbursement is a capitated rate intended to cover all services.
	Sharp HealthCare, San Diego, California	Transitions program within a large health system	Home based palliative care interdisciplinary team composed of physicians, nurses, spiritual care providers, and social workers. Concurrent advanced illness disease management with primary and subspecialty care for patients with cancer, CHF, COPD, and dementia. Team provides pain and non-pain symptom management, education and awareness around illness trajectory and prognosis, elucidation of treatment choices, and psychosocial and spiritual support. Acute care phase to determine care goals followed by maintenance with less frequent home visits and telephonic support.	Intervention participants from each diagnosis group had less hospital use and lower hospital cost with lower overall costs compared to the comparison group. In the last 6 months of life, the interventions costs remained similar month to month whereas comparison group costs increased substantially [4].	Program is supported under Sharp's Medicare Advantage contract.
	Veterans Affairs Health System, Home Based Primary Care (HBPC)	Provides home-based care for patients with complex chronic conditions.	Interdisciplinary team with expertise in geriatric care and palliative care. Team includes physician and a midlevel nurse as a primary manager, social worker, dietician, therapist, and pharmacist. A 24 hour contact person is available for patients [5].	An evaluation of HBPC versus usual care demonstrated improved patient and caregiver quality of life for terminal and non-terminal patients for the HBPC group [6]. (Evaluations of the impact on costs have produced mixed results [6, 7, 8]).	Program financed as part of VA system's global budget.
ACO	ProHEALTH Care Support, Division of ProHEALTH Care Associates, An Optum Company, Lake Success, New York	Program sponsored by an Accountable Care Organization	The interdisciplinary team consists of nurses, social workers, volunteers, physicians and administrative staff with strong clinical skills in palliative care. Twice weekly in person team meetings along with weekly one on one meetings among the nurse, social worker, and physician. Telepalliative care represents an integral component along with access to 24/7 coverage. Patient identification through Medicare Claims Data with a focus to identify ACO members with advanced illness and high cost. Team engages in serious illness conversations about goals of care with completion of advance directives.	Health care costs were significantly lower in the last year and 3 months of life for Medicare part A and B, but not D. Hospital admissions were reduced by 34% in the last month of life. Intervention group had a 35% increase in hospice utilization rate with a significantly longer length of stay compared to the control group [9].	Medicare Shared Savings Program

Table 1 | Model Programs [continued]

Base Units	Model Program	General Description	Services/Community Served	Outcomes/Effectiveness	Payment Structure
Medical Groups and Outpatient Clinics	University of Virginia Emily Couric Cancer Center, Comprehensive Assessment with Rapid Evaluation and Treatment (CARE)	Integrated program of inpatient, outpatient, and hospice services. Outpatient oncology palliative care is the focus of the intervention	Physician, nurse practitioner, and nurse based program with access to social worker and chaplain services at the cancer center as needed. A weekly interdisciplinary team meeting that focuses on transitions in care, symptom management and end of life care planning.	Intervention group were less likely to be admitted to the hospital in the last month of life and were less likely to die in the hospital compared to the usual care group. The intervention group was more likely to access hospice services and benefit from a longer length of stay as well. The costs of care were significantly less in the palliative care versus usual care group [10].	Fee for service and hospital support
Home Health Agencies	Home Connections, The Center for Hospice & Palliative Care, Cheektowaga, New York	Community-based program between Home Connections and two private insurers.	The interdisciplinary team includes a palliative care-trained registered nurse (RN), social worker, volunteers, and palliative care physician that coordinate care via weekly interdisciplinary team meeting. Program focus is adults with advanced chronic illness, so patients may still be receiving aggressive or cure-focused treatments. Services include symptom management, education, supportive discussions about heath care decision making and goals, social work visits to facilitate access to community support services, respite care, and 24/7 on-call palliative care nurse support. Nurses and social workers visit participants a minimum of every 30 days. When clinically appropriate, program helps patients transition into hospice care, if desired.	Costs the same or lower for participant members than non-participants. Participants were nearly three times as likely to enroll in hospice near end of life, with a significantly longer length of stay. Program participants also had a higher rate of actionable advance directive completion, better symptom management in some domains, greater likelihood of dying at home, and higher levels of patient, caregiver, and clinician satisfaction [11, 12].	Per member per month fee.
Independent Organizations	Aspire Health	Multi-state healthcare organization providing specialized non-hospice, community-based palliative care.	Aspire incorporates an interdisciplinary team that includes physicians, nurse practitioners, nurses, social workers and chaplains. The teams primary focus is symptom management, patient-family communication, advance care planning, care coordination with other medical professionals and support services, which includes a 24/7 medical crisis prevention and urgent response. In 2016, Aspire provided over 105,000 in-home palliative care visits to almost 16,000 patients across 16 states and the District of Columbia.	When compared to national benchmarks, supported patients are less likely to be hospitalized, more likely to have had advance care planning discussions and to complete advance directives, and more likely to use hospice care and for longer periods of time.	Partners with healthcare organizations (both health plans and ACOs) that are at risk for total cost of care to provide comprehensive palliative care services for those facing advanced illness.

SOURCE: [1] Brumley et al., 2007; [2] Brumley et al., 2003; [3] Milch and Brumley, 2005; [4] Cassel et al., 2016; [5] Bekelman et al., 2016; [6] Hughs et al., 2000; [7] Edes, 2014; [8] Beales and Edes, 2009; [9] Lustbader et al., 2017; [10] Blackhall et al., 2016; [11] Kerr, Donohue et al., 2014; [12] Kerr, Tangeman et al., 2014.

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Disclaimer

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Bios

Workshop Speakers, Moderators, and Planning Committee Members

Robert A. Bergamini, MD
Mercy Clinic Children's Cancer and Hematology
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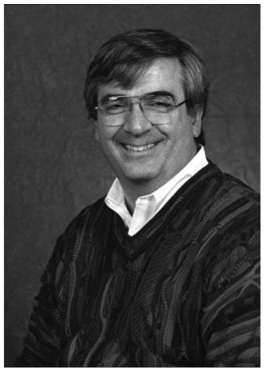


Dr. Robert A. Bergamini has spent most of his 35-year career as a pediatric hematologist-oncologist, and from the beginning, included palliative care as a priority of his practice before the field was formally defined. This approach to whole person care provided a firm foundation for his current role 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.

Leslie Blackhall, MD
University of Virginia Health System

Dr. Leslie Blackhall is Section Head for Palliative Medicine and Associate Professor of Medicine at the University of Virginia School of Medicine. Dr.Blackhall has had a career-long focus on the care of patients with life-limiting illnesses. She was a program leader for a 2012 CMS Innovation Award, which integrates patient-reported outcomes into the electronic medical record in the outpatient setting as a guide to improving the quality of life, care coordination and end-of-life care planning for patients with incurable malignancies. This program has been extended since then, through extensive intramural funding, to including patients with advanced heart failure. She is the winner of the 2015 American Cancer Society Lane Adams Quality of Life Award for her work with cancer patients. In 2015, under her leadership, the Palliative Care Section at UVA was designated a national Palliative Care Leadership Center for community-based palliative care by CAPC.

Grace B. Campbell, PhD, MSW, RN, CRRN
Assistant Professor, University of Pittsburgh School of Nursing
Association of Rehabilitation Nurses

Grace B. Campbell is Assistant Professor, Acute & Tertiary Care, University of Pittsburgh School of Nursing. Her research interest involves assessing the impact of chronic disorders on physical function and developing behavioral interventions to improve physical function. Dr. Campbell is specifically interested in fall risk, fall prevention, and the amelioration of disability in chronically ill populations including stroke and cancer. She is currently conducting a longitudinal study exploring the development and progression of chemotherapy induced peripheral neuropathy and its related functional impairments in women with ovarian cancer funded by the Rehabilitation Nursing Foundation. Dr. Campbell is also interested in using novel technologies to measure physical function in naturalistic settings, for which she received an Oncology Nursing Society Career Development Award. She teaches the Clinical Practicum course (NUR 2096 and 2097) in the Clinical Nurse Leader MSN program. Dr. Campbell is an active member of the Association of Rehabilitation Nurses, American Congress of Rehabilitation Medicine, Oncology Nursing Society, Sigma Theta Tau, and Eastern Nursing Research Society. She serves as a Subject Matter Expert for Cancer Rehabilitation on the NIH Clinical Center's Cancer Rehabilitation Expert Consortium. Dr. Campbell is a member of the Editorial Board of the Rehabilitation Nursing Journal.

Brenda Clarkson, RN
Virginia Association for Hospices and Palliative Care

Brenda Clarkson was born, raised and educated as nurse in England although she and her family have lived in the US since 1979. Her hospice career started as a volunteer in an English hospice in 1978 and she has worked exclusively in hospice while living in this country. Her hospice career has taken her to almost every state in the US as a surveyor and consultant and she has managed hospice programs in four states. Brenda was the first nurse in the nation to be certified as a hospice nurse and her long career has provided her with the opportunity to engage in most roles open to nurses in hospice care. Brenda has presented on many aspects of end-of-life care at state, regional, national and international professional meetings. After seven years working with hospice programs in Chicago, Brenda returned to Virginia in 2008 to take her current position as the Executive Director of the Virginia Association for Hospices & Palliative Care. 2015 was a landmark year for Brenda. In January, she and her co-author published a book titled The Heart of Hospice: Core Competencies For Reclaiming The Mystery and in February, Brenda was honored by the Hospice & Palliative Nurses Association as the recipient of the Vanguard Award. This prestigious award is presented to a nursing leader who has pioneered an innovative and novel approach to hospice & palliative nursing, demonstrating a deep and abiding commitment to furthering the philosophy, mission, and quality of hospice & palliative nursing practice.

Jeff Cohn MD, MHCM
Common Practice

Jeff Cohn is Medical Director at Common Practice. Dr. Cohn brings to Common Practice his deep experience in direct care for patients, and in ensuring that on an organizational level, health systems have the processes and policies in place to continually improve quality throughout their operations. Jeff works directly with clients on the use of Common Practice tools and with the Common Practice design team on the development of new tools that support improved communication and effective decision-making in healthcare. Jeff is a long-time change agent and student of behavior change. He is particularly drawn to the solutions like the Positive Deviance framework, which helps communities solve complex, intractable problems by identifying and building on what works. Jeff graduated from Jefferson Medical College, did his Internal Medicine Residency at Einstein Medical Center and his fellowship in Hematology/Medical Oncology at Emory and Johns Hopkins. He received a Masters in Health Care Management from Harvard School of Public Health. For 11 years, Jeff was Chief Quality Officer and Patient Safety Officer for Einstein Healthcare Network in Philadelphia. He also served as Chief of Hematology at Einstein, and spearheaded the creation of the palliative care program at Einstein. Most recently, Jeff was President and CEO of Plexus, a non-profit focusing on improving health of communities and organizations by using innovative methods focusing on the sociocultural aspects of change.

Janet Corrigan, PhD, MBA
Gordon and Betty Moore Foundation

Janet Corrigan is Chief Program Officer at the Gordon and Betty Moore Foundation, responsible for the Foundation's patient care portfolio. Dr. Corrigan served as President and Chief Executive Officer of the National Quality Forum for six years. Prior to that, she was director of the Board on Health Care Services at the Institute of Medicine where she led studies that produced To Err is Human and Crossing the Quality Chasm, landmark reports on medical errors and the quality or care that continue to be frequently cited and relied upon. Janet was also executive director of the 2008 President's Advisory Commission on Consumer Protection and Quality, which released the Patient Bill of Rights. Dr. Corrigan received her doctorate in health services research and master of industrial engineering degree from the University of Michigan. She also earned master's degrees in business administration and community health from the University of Rochester. With more than $6.4 billion in assets, the Gordon and Betty Moore Foundation is the ninth largest foundation in the United States. The patient care program accounts for 15 percent, more than $40 million per year, of the organization's annual grantmaking.

K. Eric De Jonge, MD
MedStar Health

K. Eric De Jonge serves as Director of Geriatrics at MedStar Washington Hospital Center and Executive Director of MedStar Total Elder Care, with a mission to expand home-based primary care in the mid-Atlantic region and across the U.S. He is on medical faculty at Georgetown and Johns Hopkins Schools of Medicine. He grew up in Chicago, Illinois, and attended Stanford University and the Yale School of Medicine. He did a residency in primary care internal medicine at Johns Hopkins Bayview and fellowships in health policy at Georgetown and Geriatrics at Johns Hopkins. In 2003, he was named National House Call Physician of the Year by the American Academy of Home Care Medicine (AAHCM). His main interest is in creating skilled and affordable teams that help frail elders live with dignity at home. In 2007, Dr. De Jonge helped develop and advocate for a Medicare reform called Independence at Home (IAH), meant to advance the field of home-based primary care and to reduce Medicare costs. The IAH demonstration began national implementation in 2012 and Dr. De Jonge directs a successful IAH site at MedStar Washington Hospital Center. He is President-elect of the American Academy of Home Care Medicine.

Susan Enguidanos, PhD
University of Southern California

Susan Enguidanos, Ph.D., Associate Professor of Gerontology at the Davis School of Gerontology at the University of Southern California. Dr. Enguidanos obtained her BA in psychology at UCLA, master's degree in public health at California State University, Long Beach, and her doctoral degree in social work at USC. Dr. Enguidanos conducts research in the field of palliative care, including a home-based model that is currently being implemented in many Kaiser Permanente facilities nationally. She has conducted extensive research in investigating ethnic variation in access to and use of hospice care, work that led to the development and implementation of theoretically-driven interventions aimed at improving access to hospice care for these populations. Dr. Enguidanos is currently working on understanding care setting transitions for seriously ill patients and developing mechanisms for improving continuity of palliative care for individuals with complicated illness. She is also Principal Investigator of a study testing a social work intervention to improve care setting transitions among older adults as they move from hospital to home. She serves as the evaluator on several other projects, including a mental health and substance abuse program for older adults and a program aimed at improving the health of seniors with multiple chronic diseases. She has published the findings from her research in several peer-reviewed journals, including Journal of American Geriatric Society, Journal of Palliative Medicine, Journal of Pain & Symptom Management, Journal of Social Work in End of Life & Palliative Care, Social Work in Health Care, and Drugs In Society.Dr. Enguidanos is the editor of Evidenced-Based Interventions for Community Dwelling Older Adults, a book that examines research focused on improving the health of seniors living in the community. She is associate editor of Home Health Services Quarterly and an active member of the Gerontological Society of America and the American Association of Hospice and Palliative Medicine, and has presented results of her work at many of these and other professional meetings and conferences. Further, her research on an end-of-life care model received a national Kaiser Permanente Award for quality and has been replicated in Kaiser facilities throughout the nation.

Michael D. Fratkin, MD
ResolutionCare

Michael Fratkin is the President of Founder of ResolutionCare. Dr. Fratkin is a father, husband, brother, son, and physician, Dr. Fratkin is dedicated to the well being of his community. *For nearly 20 years, Michael has called rural Northern California his home, where he feels deep connections to the families of those he has had the honor of caring for.* He has served his community in primary care in a community clinic system, as a medical director of our local hospice, as a leader in the community hospital medical staff, and a transformative voice for improving the experience of people facing the end of life. At a time of great demographic and cultural change in our society, Dr. Fratkin has created ResolutionCare to insure capable and soulful care of everyone, everywhere as they approach the completion of life.
ResolutionCare leverages partnerships with existing healthcare providers and payers to provide telehealth applications that bring greater quality of living and greater quality of dying. The

Palliative Care team at ResolutionCare openly shares our expertise and mentorship so people can receive the care they need where they live and on their own terms.

Vicky Garrett, RN and David Garrett
Patient-Family Perspective

Vicki received her Associates in Nursing from Anderson University in 1978 and received her Registered Nurse license from the State of Indiana in September of 1978. She later earned her B.S. degree at Western Michigan University in 1989, followed by earning her Masters of Science in Nursing from Andrews University (Michigan) in 1999. Vicki started her professional career at St. Vincent's Mercy Hospital in Elwood, Indiana in 1978. She then moved to Pennock Hospital in Hastings, MI where she worked in the operating room until March of 1988. At that time, Vicki moved to St. Mary's Hospital in Grand Rapids where she remained until her retirement in December of 2014. During her tenure at St. Mary's, she was a staff nurse, clinical supervisor, O.R. manager, and in April of 2000 she was promoted to Director of Perioperative Services, a position she held until her retirement.

Lee Goldberg, JD
The Pew Charitable Trusts

Lee Goldberg is Project Director, Improving End-of-Life Care Project, at The Pew Charitable Trusts. Lee Goldberg works to advance policies that help people receive high-quality health care near the end of their lives. Before coming to Pew, Goldberg was vice president for health policy at the National Academy of Social Insurance, where he wrote extensively on options for addressing the financing of long-term supports and services, the development of health insurance exchanges under the Affordable Care Act, and the impact of hospital consolidation on health care markets. Goldberg received a master's degree in international economics and international relations from Johns Hopkins University's School of Advanced International Studies and a law degree from George Washington University. He is a member of the California bar.

Marian Grant, DNP, RN, CRNP
C-TAC

Marian Grant is the Director of Policy and Professional Engagement at the Coalition to Transform Advanced Care (C-TAC) in Washington, DC. In addition, she is a nurse practitioner (NP) dually certified in Acute Care and Palliative Care/Hospice, an associate professor at the University of Maryland School of Nursing, an adjunct professor at the Johns Hopkins University School of Nursing, and an NP on the University of Maryland Medical Center's Palliative Care Service. Dr. Grant was a 2014-2015 Robert Wood Johnson Foundation Health Policy Fellow and worked both in Democratic Leader Nancy Pelosi's office and at the Center for Medicare and Medicaid Innovation (CMMI) on the Medicare Care

Choices Model. She currently serves as a member of the American Nurses Association's (ANA) Palliative & Hospice Nursing Professional Issues Panel Steering Team, and the Community Health Accreditation Partner's (CHAP) Palliative Advanced Illness Care Steering Committee. Grant received her Doctor of Nursing Practice (DNP) from the University of Maryland, and her Masters and Bachelors in Nursing degrees from the Johns Hopkins University. She is a co-author of *The Hospice and Palliative Care Approach to Serious Illness*, has done research as an online palliative care nurse practitioner on the Johns Hopkins Pancreatic Cancer website, and blogged for the *Journal of Palliative Medicine*. Before becoming a nurse, Dr. Grant received a Bachelors in Science from Miami University in mass communication and had a career in advertising and marketing for the Procter & Gamble Company.

Sarah Hill, PhD
Ascension Health

Sarah Hill is Director of Palliative Care for Ascension Health. In this role, she is responsible for directing palliative care efforts across the Ascension Health system of over 140 hospitals and 1900 sites of care. Dr. Hill is currently Chair of the Board of the Supportive Care Coalition, a coalition of 19 Catholic health systems committed to advancing palliative care. She was also in the past a member of the National Quality Forum's palliative and end of life care metrics committee. In 2014, Dr. Hill received the Tomorrow's Leader award from the Catholic Health Association.Dr. Hill serves on several additional workgroups on advanced care and palliative care for organizations including the Catholic Healthcare CEO Connection's Clinical Quality Leadership Forum and the Coalition to Transform Advanced Care.Dr. Hill has delivered presentations on palliative care at various national and regional events including the Catholic Health Association Annual Assembly, the Center to Advance Palliative Care annual assembly, the American Society on Aging, and the Supportive Care Congress. She has also been a speaker, guest lecturer and guest panelist on bioethics and has been a facilitator for ethics conferences. She currently serves on Sacred Heart Hospital's ethics advisory committee.
Dr. Hill received her Bachelor's degree in molecular biology/biochemistry and a minor in theology from Marquette University in 2003. She also received the Archbishop Desmond Tutu Emerging Leader Award in 2003 from the Desmond Tutu Peace Foundation. She received her Master's Degree in Health Care Ethics and Health Communication from the University of West Florida in 2006. Dr. Hill successfully defended her dissertation on perinatal palliative care ethics in August for her PhD in Health Care Ethics from Saint Louis University.

G. William Hoagland, MS
Bipartisan Policy Center

G. William Hoagland joined the Bipartisan Policy Center (BPC) in September 2012 as senior vice president. He helps direct and manage fiscal, health and economic policy analyses for BPC. Before joining BPC, he served as CIGNA Corporation's vice president of public policy beginning in 2007. Prior to joining CIGNA, Hoagland completed 33 years of federal government service, 25 spent as staff in the U.S. Senate. From January 2003 to January 2007, he served as the director of budget and

appropriations in the office of Senate Majority Leader Bill Frist. From 1982 until 2003, Hoagland was a staff member of the Senate Budget Committee, serving as that committee's staff director from 1986 to 2003, reporting to Senator Pete V. Domenici, chairman and ranking member during this period. In 1981 he served as the administrator of the Department of Agriculture's Food and Nutrition Service and as a Special Assistant to the Secretary of Agriculture. He was one of the first employees of the then newly created Congressional Budget Office in 1975, working with its first director, Alice Rivlin. Born in Covington, Indiana, he attended the U.S. Merchant Marine Academy and holds degrees from Purdue University and the Pennsylvania State University. His family's Indiana family farm was awarded by that State as a "Hoosier Homestead" for having remained in the family for over a century.

Haiden Huskamp, PhD
Harvard Medical School

Haiden Huskamp is a health economist and professor of health care policy at Harvard Medical School. Dr. Huskamp has three primary areas of research: 1) the financing and utilization of end-of-life care services; 2) mental health and substance use disorder policy; and 3) prescription drug policy. Dr. Huskamp's research on end-of-life care has examined the changing characteristics of the hospice industry and the effects of industry changes on the provision of end-of-life care, the timing of discussions about hospice care that occur between physicians and patients, and patient-level variation in hospice costs. She served on the Centers for Medicare and Medicaid Services Technical Expert Panel for Hospice Payment Reform and on the Institute of Medicine Committee on Care for Children Who Die and Their Families. Dr. Huskamp recently authored a paper on the financing of end-of-life care services published in the Institute of Medicine report "Dying in America."

Sachin H. Jain, MD, MBA, FACP
CareMore Health System

Sachin H. Jain is President and Chief Executive Officer (CEO) at CareMore Health System, an innovative health plan & care delivery system with $1.2B revenue & over 100,000 members in 8 states. He is also consulting professor of medicine at the Stanford University School of Medicine and a contributor at Forbes. Dr. Jain was previously CareMore's Chief Medical Officer (CMO) and Chief Operating Officer (COO). Prior to joining CareMore, Dr. Jain was Chief Medical Information & Innovation Officer at Merck & Co. He also served as an attending physician at the Boston VA-Boston Medical Center and a member of faculties at Harvard Medical School and Harvard Business School. From 2009-2011, Dr. Jain worked in the Obama Administration, where he was senior advisor to Donald Berwick when he led the Centers for Medicare & Medicaid Services (CMS). Dr. Jain was the first deputy director for policy and programs at the Center for Medicare and Medicaid Innovation (CMMI). He also served as special assistant to David Blumenthal when he was the National Coordinator for Health

Information Technology. Dr. Jain graduated *magna cum laude* from Harvard College with a BA in government and continued on to earn his MD from Harvard Medical School and MBA from Harvard Business School. He trained in medicine at the Brigham and Women's Medicine, earned his board certification from the ABIM, and continues to practice medicine at CareMore. He is co-founder and co-editor-in-chief of the Elsevier journal *Healthcare: The Journal of Delivery Science & Innovation* and is an elected member of the National Academy of Social Insurance (NASI). He has published over 100 peer-reviewed articles and in journals such as the *New England Journal, JAMA, Health Affairs*, and the *Harvard Business Review* blogs and was an editor of the book, *The Soul of a Doctor* (Algonquin Press). Dr. Jain is a native of Bergen County, New Jersey, but presently resides in Los Angeles, California.

Charles N. Kahn III
Federation of American Hospitals

Charles N. Kahn III is President and Chief Executive Officer of the Federation of American Hospitals, the national advocacy organization for investor-owned hospitals and health systems. Mr. Kahn became the Federation's President in June 2001. Mr. Kahn's extensive health policy expertise, outstanding leadership abilities, lengthy Capitol Hill experience, and proven campaign and communications skills make him one of Washington, DC's most effective and accomplished trade association executives. He is one of only six health care leaders who have appeared on Modern Healthcare magazine's annual "100 Most Influential People in Healthcare" list (formerly the "100 Most Powerful People in Healthcare" list) since its inception. Becker's Hospital Review included Mr. Kahn on its "50 Most Powerful People in Healthcare" list for 2015. He also appeared on the list in 2014, 2012, 2011, 2010, and 2009. In October 2015, The Hill newspaper selected Mr. Kahn as one of the capital's top lobbyists for the 15th consecutive year. Fortune magazine, for three consecutive years, named the former Health Insurance Association of America (HIAA), under Mr. Kahn's leadership, as the nation's most influential insurance trade association. Currently, Mr. Kahn is at the forefront of national initiatives to shape policy for advancing health care quality and information technology. He represents the FAH as a member of the Measure Applications Partnership (MAP) Coordinating Committee of the National Quality Forum (NQF), a multi-stakeholder private-public partnership for developing and implementing a national strategy for health care quality measurement. He also is a former member of the NQF's Governing Board. Mr. Kahn is a member of the Board of Directors of PharmMD, a medication therapy management company. He is the past Chair of the David A. Winston Health Policy Fellowship, which funds a 12-month postgraduate experience in Washington, D.C. as well as scholarships for health policy graduate students.Mr. Kahn is also the recipient of the B'nai B'rith 2016 National Health Care Award, which has recognized exceptional trailblazers in the health care industry for more than 30 years. A gala award dinner will be held in his honor on June 22nd in Washington, D.C. In August 2015, *Health Affairs* published a report authored Mr. Kahn entitled, *Assessing Medicare's Hospital Pay-for-Performance Programs and Whether They Are Achieving Their Goals*. It examined the impact of three key Medicare pay-for-performance programs: Value-based Purchasing (VBP), the Hospital-Acquired Conditions (HAC) Reduction Program and the Hospital Readmissions Reduction Program. In February, 2014, in Dead Sea, Israel, Mr. Kahn co-chaired "Measuring Quality in Hospitals – Are the Goals Conflicting?" an International Workshop sponsored by the Israel National Institute for Health Policy Research. Earlier, in

September, 2009, in Caesarea, Israel, Mr. Kahn co-chaired another International Workshop sponsored by the Israel National Institute for Health Policy Research entitled "Pay for Performance – Can it Improve the Quality and Value of Israeli Health Care?" He also serves as a member of the Israel Health Care Foundation board.

Jean S. Kutner, MD, MSPH
University of Colorado School of Medicine
University of Colorado Hospital

Dr. Jean S. Kutner is Professor of Medicine and Associate Dean for Clinical Affairs, University of Colorado School of Medicine, and Chief Medical Officer, University of Colorado Hospital. Dr. Kutner is a tenured Professor of Medicine in the Divisions of General Internal Medicine (GIM), Geriatric Medicine, and Health Care Policy and Research in the Department of Medicine at the University of Colorado School of Medicine (UC SOM). Dr. Kutner received her MD from the University of California San Francisco (UCSF) in 1991 and completed residency training in internal medicine at UCSF in 1994. Subsequently, she completed a NRSA primary care research fellowship, earning an MSPH degree with honors, and a fellowship in geriatric medicine at UC SOM (1994-1997). 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 patients with serious illness and their family caregivers. Dr. Kutner is Co-Chair of the NIH-funded Palliative Care Research Cooperative Group (PCRC). She was a member of the Institute of Medicine (IOM) Transforming End of Life Care Committee and is a past-president of the American Academy of Hospice and Palliative Medicine (AAHPM). Dr. Kutner served as the Head of the University of Colorado Division of General Internal Medicine from 2002 until 2014. Dr. Kutner became the inaugural Chief Medical Officer of University of Colorado Hospital and Associate Dean for Clinical Affairs, UC SOM in July 2014.

Deborah A. Lafond, DNP, PPCNP-BC, CPON, CHPPN
Children's National Health System

Dr. Deborah Lafond has been the Clinical Coordinator of the PANDA Palliative Care Team at Children's National Health System in Washington, DC since 2012, and was a nurse practitioner in Neuro-Oncology at Children's National Health System for 25 years prior. Dr. Lafond received her Doctorate of Nursing Practice from the University of Maryland in 2012 and her Master's Degree in Nursing from the University of Hawaii in 1991. Her doctoral capstone project investigated early integration of palliative care for children, adolescents and young adults undergoing hematopoietic stem cell transplant. As a clinician on the palliative care team, Dr. Lafond sees patients and families from all services, including many with complex chronic conditions. Dr. Lafond is a 2015 Sojourns Scholar with the Cambia Health Foundation, where her work focuses on primary palliative care education and mentorship for bedside clinicians. She is the immediate past-chair of the Association of Pediatric Hematology Oncology Nurses Evidence

Based Practice and Research Committee and currently serves as a co-coordinator for the Research Special Interest Group of the Hospice and Palliative Care Nurses Association.

Michael Le, MD
Landmark Health, LLC

Dr. Le is the Co-Founder and Chief Medical Officer of Landmark Health, one of the nation's largest and fastest growing providers of longitudinal, risk-bearing, Home-Based Medical Care, now managing risk for over 40,000 patients across 10 markets in 6 states. Prior to joining Landmark, Dr. Le served as Chief Medical Officer of Fidelis SeniorCare, where he designed and implemented an innovative and intensive care delivery model for high-acuity dual-eligible patients in the states of Washington and Michigan. Through Dr. Le's clinical delivery model, Fidelis reduced hospital utilization by over 40% and ER utilization by over 75%, while significantly improving quality and reducing costs for frail dual-eligible patients. Based on the innovative care model's results, Fidelis was awarded the CMS Duals Demonstration Project in Wayne and Macomb Counties in Michigan. Prior to Fidelis, Dr. Le served as Senior Medical Officer at CareMore, where he practiced clinically as an Extensivist in Hospitals and Nursing Homes, while also overseeing all of CareMore's High Risk Programs, including the High Risk Clinic, Social SWAT Team, Care Management, Palliative / Hospice Programs, and the House Calls Program. Prior to CareMore, Dr. Le was Regional Lead Hospitalist at HealthCare Partners, where he had accountability for in-patient utilization and quality in HCP's Long Beach Region. Dr. Le received his Bachelor of Science at University of California-Riverside, his M.D. Degree from the University of California, Los Angeles. He completed his Internal Medicine Residency at Cedars Sinai Medical Center. Dr. Le also completed a fellowship at the Institute for Physician Leadership, at the University of California, San Francisco.

John Loughnane, MD
Commonwealth Care Alliance

John Loughnane is Chief of Innovation at Commonwealth Care Alliance (CCA), a nonprofit healthcare organization recognized nationally for an innovative model of care that improves quality and reduces costs for dual-eligibles with complex care needs.
In 2009, Dr. Loughnane founded CCA's Palliative Care program and served as Medical Director until February 2017. This program completely re-engineered how end-of-life care is delivered to the most at-risk patients. By reimagining the financial and clinical structure of end-of-life care, he created a truly open-ended, "normative" primary care approach that removes barriers for patients and families, allowing them to engage in early and impactful palliative care. Dr. Loughnane is Board Certified in Family Medicine and Hospice and Palliative Care. He previously has served as Senior Vice President of Medical Services at CCA and Medical Director of the CCA's Inpatient Hospitalist Service and Commonwealth Community Care - a home based primary care practice focused on complex populations.

Dana Lustbader, MD
ProHEALTH Care

Dr. Dana Lustbader is Department Chair of Palliative Medicine at ProHEALTH, a large ACO physician group and part of Optum which serves over a million patients in the New York metropolitan area. She is the Medical Director of the home based palliative care program, which provides medical care to people with serious illness utilizing in home visits and telemedicine. She partners with health plans through innovative payment models to increase palliative care access. Prior to building community based care, Dr. Lustbader worked as a critical care physician at Northwell Health where she served as ICU Director, Section Head of Palliative Medicine and founding Program Director of the Hospice and Palliative Medicine Fellowship. She is a Professor of Medicine at Hofstra-Northwell School of Medicine. She also served as the Assistant Medical Director to LiveOnNY, providing critical care expertise to over 100 hospitals for organ donation. Dr. Lustbader is board certified in critical care medicine, internal medicine and palliative medicine. She received her medical degree from the University of Wisconsin-Madison School of Medicine, Internal Medicine residency training at NYU-Bellevue Medical Center and fellowship in Critical Care Medicine at St. Vincent's Hospital in New York City. Dr. Lustbader was a member of the Hospice and Palliative Medicine Test Writing Committee for the American Board of Internal Medicine.

Joanne Lynn, MD, MA, MS
Altarum Institute

Joanne Lynn is Director of Altarum Institute’s Center for Elder Care and Advanced Illness, which aims to ensure that frail elderly Americans can live meaningfully and comfortably at sustainable costs. She is a geriatrician, hospice physician, health services researchers, quality improvement advisor and coach, and policy advocate. The work includes implementing and measuring care plans, developing methods for counties and cities to monitor and manage frail elder care, coaching counties and cities, and developing support for caregivers. The reform model comes together as MediCaring Communities, summarized in a book available on Amazon. As part of engineering reform, the Center for Elder Care and Advanced Illness has led a project to get caregiver issues onto party platforms in both parties in all of the states, with substantial success, and also worked with many groups to gather a Forum just after the election to move along the process of demanding improvements. Dr. Lynn has been a tenured professor at Dartmouth and George Washington University, a staff member at CMS, the Bureau Chief for Cancer and Chronic Disease for Washington (DC), a researcher at RAND, and on IHI’s quality improvement faculty. She is a member of the Institute of Medicine, a Master of the American College of Physicians, a Fellow of the Hastings Institute, and an author of more than 280 peer-reviewed publications, 80 books and chapters, and a dozen amicus briefs and publications for public commissions. Her book, Handbook for Mortals, is widely used to guide patients and families through serious illness and death.

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

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.

Amy Melnick, MPA
National Coalition for Hospice and Palliative Care

Amy Melnick, M.P.A., is the Executive Director of the National Coalition for Hospice and Palliative Care (Coalition). Amy's career has focused on health care policy, legislative and regulatory advocacy, and coalition building with diverse stakeholders. Amy guides the Coalition efforts to better communicate, coordinate and collaborate within the organizations representing the interdisciplinary field of hospice and palliative care. The Coalition was founded over a decade ago by leaders from the hospice and palliative care field. One of the Coalition's first successful projects was the publication of the Clinical Practice Guidelines for Quality Palliative Care, National Consensus Project. Members now include eight national professional organizations including the American Academy of Hospice and Palliative Medicine (AAHPM), Association of Professional Chaplains (APC), Hospice and Palliative Nurses Association (HPNA), Center to Advance Palliative Care (CAPC), and the National Hospice and Palliative Care Organization (NHPCO) among others. As the Coalition's first Executive Director, Amy leads the Coalition's efforts on behalf of its Member organizations and engages with various internal and external partners to identify areas of common interest and consensus to collectively work to improve the care of people with serious illness and those at the end of life. Amy guides the Coalition operations and stakeholder engagement with various health care policy organizations such as Congress, Centers for Medicare and Medicaid Services, National Institute of Health, National Academy of Sciences-Institute of Medicine, National Quality Forum, Patient Centered Outcomes Research Institute, Patient Quality of Life Coalition and the Joint Commission. Prior to joining the Coalition, Amy was the Vice President, Advocacy, for the Arthritis Foundation in Washington D.C. where she successfully advocated for the creation of a congressionally directed federally funded research program at the Department of Defense for arthritis research. Amy has also represented physicians, scientists, and nurses, while serving as the Vice President for Health Policy at the Heart Rhythm Society. She began her career on Capitol Hill as Committee Staff at the US House of Representatives' Select Committee on Aging where she focused on issues affecting older Americans. Amy attended the London School of Economics and Political Science and received her undergraduate degree from Wellesley College and her Masters of Public Administration from George Mason University.

Jeri L. Miller, PhD
National Institute of Nursing Research

Jeri L. Miller is Chief, Office of End-of-Life and Palliative Care Research, National Institute of Nursing Research (NINR), National Institutes of Health (NIH). NINR, the lead NIH institute for end-of-life research, established the Office of End-of-Life and Palliative Care Research (OEPCR) to support the ongoing research efforts in end-of-life and palliative care science, including stimulating research initiatives, creating opportunities for collaborative activities and facilitating interdisciplinary science. In her role as OEPCR Chief, Dr. Miller coordinates the development, implementation and evaluation of end-of-life and palliative care science in interdisciplinary collaboration with the senior leadership of NINR, NIH Institutes, federal research agencies, academia, and other outside experts and constituencies. The Office builds on work Dr. Miller led as the former lead science policy analyst and Head of the NINR Office of End-of-Life and Palliative Care Research, Training, and Education, including support of numerous NIH symposia on the state-of-the-science, NINR's pediatric palliative care national awareness campaign, and the development of the report titled: "Building Momentum: The Science of End-of-Life and Palliative Care", which looks at the trends in end-of-life and palliative care research, including information on federal research awards, funding patterns, and the contributions of public and private investments in end-of-life and palliative care science. Dr. Jeri L. Miller was a previous NIH Intramural Program scientist with expertise in biomedical and clinical research.

Brenda Nevidjon, RN, MSN, FAAN
Oncology Nursing Society

Brenda Marion Nevidjon is the Chief Executive Officer of the Oncology Nursing Society (ONS), a professional association of more than 39,000 members committed to promoting excellence in oncology nursing and the transformation of cancer care. Immediately prior to her position at ONS, she was a professor at Duke University School of Nursing and taught graduate students in nursing and healthcare leadership programs. Throughout her career in Canada, Switzerland and the United States, she has focused on bridging practice settings and academic environments to advance patient care, creating innovative work environments, promoting scholarship in practitioners, and developing leaders. After two decades in oncology clinical and administrative settings, she transitioned to health care executive practice, culminating with her being the first nurse and the first women to be chief operating officer of Duke University Hospital in 1996. Her bachelors' degree is from Duke University, her master's from the University of North Carolina, and she has done doctoral work at the Fielding Graduate Institute and Duke University. She completed the Johnson & Johnson - Wharton Fellows Program in Management for Nurse Executives, was in the inaugural class of the Robert Wood Johnson Nurse Executive Program and is a fellow in the American Academy of Nursing.

Laura Patel, MD
Transitions LifeCare

Dr. Laura Patel is a full time physician, board certified in Internal Medicine, Geriatric Medicine and Hospice and Palliative Medicine. She serves as Chief Medical Officer of Transitions LifeCare in Raleigh, NC. Since she joined Transitions LifeCare in 2013, Dr. Patel has expanded both inpatient and community based palliative care programs, working to develop innovative models and partnerships. These programs have helped drive growth in hospice, and Transitions HospiceCare has seen a steady increase in average daily hospice census since 2013. Dr. Patel also oversees the Medicare Care Choices program and Transitions Kids, a unique pediatric home based palliative care program. In 2015, Transitions LifeCare and the University of North Carolina began an ACGME accredited fellowship in hospice and palliative medicine. Dr. Patel graduated cum laude from Macalester College with a degree in Biology and obtained her medical degree from the University of Minnesota. She completed her internal medicine residency and geriatric fellowship at the University of North Carolina.

Judith R. Peres, LCSW-C
Social Work Hospice and Palliative Care Network

Judith R. Peres is an Expert Consultant in the Nursing Home and Palliative/End-of-life care policy and a clinical social worker serving Medicare Beneficiaries. Her career spans over four decades in health policy development and analysis and in direct clinical work. In her capacity as a policy consultant, Ms. Peres has worked with the Altarum Institute's Center for Elder Care and Advanced Illness, the Center for Practical Bioethics and the National Institute of Nursing Research. In addition, she worked for the U.S. Department of Health and Human Services' Office of the Assistant Secretary for Planning and Evaluation, where she developed a report to Congress on advance care planning. She also served as vice president for policy and advocacy at the former Last Acts Partnership—an initiative of The Robert Wood Johnson Foundation—where she developed major policy pieces such as *Means to A Better End,* the first national report on the state of dying in the United States._Ms. Peres has led health policy efforts at the American Association of Homes and Services for the Aging (currently Leading Age) and the Villers Foundation (currently Families USA). She began this journey with 15 years at the Department of Health and Human Services working in Medicare and Medicaid reimbursement and financing policy. She has served on the Board of Directors of the Social Work Hospice and Palliative Care Network (SWHPN) since its inception in 2007. Ms. Peres has a Master of Social Work from the University of Maryland and post-graduate training at the Mind/Body Institute in Washington, DC, and Rational Emotive Behavioral Therapy at the Albert Ellis Institute in New York. She served on the Institute of Medicine committee that authored the 2014 report *Dying in America,* and will be representing SWHPN on the Roundtable on Quality Care for People with Serious Illness.

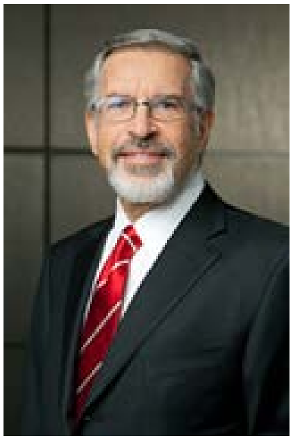
Kathy Perko, MS, CPNP, CHPPN, CPLC
OHSU Doernbecher Children's Hospital

Kathy Perko received her BSN from the University of Portland, Oregon and started her nursing career at the Children's Hospital in Seattle. She spent eight years there-focusing in pediatric oncology with a special interest in children with brain tumors. She received her MS/PNP from University of California-San Francisco with a focus on supporting children and families through the end of life.Kathy returned to the Pacific Northwest and has been working in Portland for the past 19 years. She transitioned from pediatric oncology to palliative care over the past years and was a founding member and is the Program Director of Bridges Palliative Care Program at Doernbecher Children's Hospital. The Bridges Program sees patients from pre-natal diagnosis through young adulthood. Kathy is a recipient of a Cambia Sojourns Award. She is currently serving on the Oregon Palliative Care and Quality of life Interdisciplinary Advisory Council representing the needs of children and families. Kathy is a gifted educator, combining clinical practice and child and family stories to inspire those learning about pediatric palliative care. She is a frequent speaker for medical and nursing students as well as providing community based education. She is on the national faculty for ELNEC and EPEC-Pediatrics.

Stacie Pinderhughes, MD
Banner Health

Dr. Stacie T. Pinderhughes serves as Chairperson, Division of Palliative Medicine for Banner Health. Prior to coming to Banner, she served as Chairman for the Department of Medicine at North General Hospital in New York and held an academic appointment as Associate Professor of Geriatrics and Medicine at The Mount Sinai School of Medicine in New York.Dr. Pinderhughes studied Journalism and English at Rutgers University, prior to receiving her medical degree from the University of Medicine and Dentistry of New Jersey. Dr. Pinderhughes completed her internal medicine residency at Robert Wood University Hospital in New Brunswick and her fellowship in Geriatrics at The Mount Sinai School of Medicine in New York. Following the fellowship, she attended the Harvard Palliative Care Mini Fellowship in Boston, MA. Dr. Pinderhughes holds board certification in Internal Medicine, Geriatrics, and Palliative Medicine.Dr. Pinderhughes spent 3 years as Medical Director for the only inpatient hospice unit in Harlem, New York. Dr. Pinderhughes developed a model of Hospice and Palliative Care at the end of life that was unique in the United States. This model provided care to medically underserved aging minority populations who have historically not had access to hospice services at life’s end. Additionally, Dr. Pinderhughes successfully pursued the role of mentor and educator for physicians, nurse practitioners and medical residents interested in Palliative Medicine. She has been honored as one of the Best Doctors in America in 2009-2010, 2011-2012 and 2012-2013.

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, 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
Massachusetts General Hospital

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 heath 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).

Colleen Tallen, MD
LeeHealth

Dr. Colleen Tallen serves as Medical Director of Palliative Care at Lee Health in Fort Myers, Florida. Previously, Dr. Tallen was Medical Director of Palliative Medicine within the Trinity System and associate professor at Michigan State University. She has recently assisted in Florida's Surgeon General's report on the Florida's state of palliative care. She is author of Decide While

You Can, a patient-friendly book that simplifies how to make medical decisions. She has spend over 20 years developing palliative care programs that span the continuum of care. Dr. Tallen received her medical degree from Loma Linda University and completed her family medicine residency at University of Michigan. She is board certified in family medicine and palliative medicine.

Teresa Toland, RN
Tandem365

Teresa Toland began her journey 25 years ago in community health and served for 13 years as Executive Director of a large certified Home Care Company providing certified home health services, private duty, and transportation. Being promoted to Vice President of Business Development allowed her to be successful in building partnerships with other community healthcare providers which ignited in her a strong desire to find solutions for a very fragmented and broken healthcare system.

Teresa is currently CEO for Tandem365 and is responsible for a startup business where no blueprint or conditions of participation exist. She has spent the past six years getting to know the health care systems in her community and connecting in a positive way. The success of Tandem365 relies strongly on the ability to understand what health care systems, physicians, payers, patients and caregivers need today and being prepared for a dynamic healthcare industry. She firmly believes that healthcare will continue to fail in the effort to delivery high quality care if the focus is always about the cost of delivering that care. Healthcare providers are confronted every day with situations that challenge them to balance patient needs, insurance demands, and regulatory restrictions and yet produce "quality" driven outcomes. Many American's will be left on the sideline struggling to make sound choices while attempting to understand a very fragmented complex health system.

James A. Tulsky, MD
Dana-Farber Cancer Institute, Brigham and Women's Hospital,
Harvard Medical School
Vice Chair, Roundtable on Quality Care for People with Serious 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.

Martha Twaddle, MD, FACP, FAAHPM, HMDC
Aspire Health

Martha L. Twaddle combines nearly thirty years of experience in the care of seriously ill people and their families in a variety of areas of service. She currently serves as Senior Medical Director for Aspire Health and oversees specialty palliative care teams providing home-based supportive care in Illinois and Northwest Indiana. In addition, she serves as the Executive Advisor for the Home Centered Care Institute, facilitating the development of curriculum and best practice guidelines for the emerging national HCCI Centers of Excellence. In addition, she is part of a team at Northwestern University that is evaluating the impact of communication skills training on creating systems of care for seriously ill people and their families across settings of care. Dr. Twaddle's unique talents and contributions to the field of Palliative Medicine have helped increase the understanding of and access to this continuum of care, regionally and nationally. In 2013, she was named one of the 30 most influential visionaries in Hospice and Palliative Medicine by nomination of her peers via the American Academy of Hospice and Palliative Medicine (AAHPM). She served as President of the AAHPM from 2002-2003 and on the AAHPM Board of Directors from 1997-2004. She was honored with the inaugural AAHPM Josefina B. Magno Distinguished Hospice Physician Award in 2005. She was recognized in 2016 as a Distinguished Alumni of Purdue's College of Science and "an exemplary educator and pioneering contributor to end-of-life care" as the recipient of the Compassion in Action Award by Hospice of the Valley and Santa Clara University in 2015. After graduating summa cum laude from Purdue University, Dr. Twaddle received her medical degree from the Indiana University School of Medicine in Indianapolis and completed her residency in Internal Medicine through Northwestern University McGaw School of Medicine, where she was Chief Resident. She currently serves as an Associate Professor of Medicine for Northwestern University Feinberg School of Medicine and is board certified in Internal Medicine and Hospice and Palliative Medicine. Dr. Twaddle is active in curriculum development and education to enhance the competencies of generalist, champion, and specialty level Palliative care at a local and national level, actively participates in quality research and pilots to evaluate models of care delivery, speaks regularly to local and national groups and is published extensively in peer-reviewed articles and other publications.

David Wensel, DO, FAAHPM
Midland Care

Dr. David Wensel is the Medical Director Midland Care. Dr. Wensel was born and raised in Birmingham, Alabama. I moved to Iowa in 1988 and lived there until moving to Kansas in 2010. My journey into medicine started with becoming a hospice volunteer after the death of my grandparents. I then decided to go back to school and became a paramedic to help the small town that I lived in. I also started taking classes in theology and ethics and was lucky enough to graduate from

Creighton University with a certificate in theology. After making the decision to start medical school, I always knew that a primary care specialty would fit me best. I made the decision to attend family medicine residency in North Iowa at Mercy Medical Center. It was during my residency that hospice and palliative medicine became a recognized specialty and I began the discussions with the hospice team to help start a fellowship for physicians. I became the first fellow at Mercy Medical Center North Iowa in hospice and palliative medicine in the summer of 2006. I also had the great privilege to help with starting the palliative medicine consultation service at Mercy Medical Center North Iowa. Since moving to Kansas, I had the opportunity to start a palliative medicine consultative service at St. Francis Medical Center in Topeka, and the first out patient palliative medicine clinic in a community oncology practice at Cotton O'Neal Cancer Center. I am also very active in growing our PACE program at Midland which allows me to continue my love of primary care. I am very interested in medical ethics and completed a yearlong certificate program in medical ethics at the National Catholic Bioethics Center during my residency. I became a fellow of the AAHPM in 2012. I was married to Toni in 1994 and we have three beautiful children ages 20, 18, and 15, that keep us very busy. Dr. Wensel's teaching focuses on palliative medicine and end-of-life care, with a primary focus on suffering in all its domains. I am past chair of the membership and communities committee for the American Academy of Hospice and Palliative Medicine and serve on the exam committee for the Hospice Medical Directors Certification Board. I continue to be a champion for suffering at the National PACE Association and provide education about palliative medicine and end-of-life care to physicians, nurses, social workers and chaplains. I also provide education to nursing students, medical students, residents, APRN students and pharmacy students as well. I am dedicated to improving Hospice and Palliative Care services to all patients and families on a national level.