National
Priorities
Partnership
*Convened by the*
*National Quality Forum*

# PALLIATIVE CARE AND END-OF-LIFE CARE CONVENING MEETING

## SYNTHESIS REPORT

NOVEMBER 2010

# NATIONAL PRIORITIES PARTNERSHIP

*Convened by the National Quality Forum*

## PALLIATIVE CARE AND END-OF-LIFE CARE CONVENING MEETING SYNTHESIS REPORT

*This report provides a high-level synthesis of a meeting conducted as part of the efforts of the National Priorities Partnership workgroups. The purpose of this meeting was to identify actions that drive toward improved assessment and management of patients' physical symptoms and the patients' and families' psychosocial needs, as well as improve communication and coordination of care across healthcare settings for patients with chronic, advanced, and terminal illnesses.*

## I. INTRODUCTION

In its 2008 report, *National Priorities & Goals—Aligning Our Efforts to Transform America's Healthcare*,[1] the National Priorities Partnership (NPP) identified six National Priorities that, if addressed, would significantly improve the quality of care delivered to Americans. Palliative care and end-of-life care were included amongst these priorities with the aim of guaranteeing appropriate and compassionate care for patients with chronic, advanced, and terminal illnesses. More specifically, NPP identified goals emphasizing access to palliative care and end-of-life care; effective provider-patient communications; relief of physical suffering; and psychological, social, and spiritual support for patients with chronic and life-limiting illnesses.

Identifying priority areas is only the first step in improving the care experience. For real change to occur, effective action steps must be identified, shared, and implemented widely. To address the goals of each priority area, NPP established workgroups to provide guidance for developing comprehensive action plans to drive change. In response to this charge, the Palliative Care and End-of-Life Care Workgroup convened a meeting of key stakeholders on November 2, 2010, in Washington, DC. Appendix A includes the list of meeting participants. The purpose of the workshop was to develop specific actions for NPP Partners and others to consider—actions that would have the greatest potential to address the palliative care and end-of-life care goals. The workshop participants used this two-part strategy to develop their action plan:

- identify environmental barriers to achieving these goals and develop a plan to address these barriers, including specific actions that NPP and other stakeholders can take, focusing on identified drivers; and
- address infrastructure issues, including performance measurement, workforce competencies, and health information technology (health IT).

In preparation for this meeting, Diane Meier, MD, authored a context-setting white paper titled *Improving Healthcare Quality through Increased Access to Palliative Care and Hospice Services,* which is included in Appendix B. The paper provided background on the current state of hospice care and palliative care and identified actions to improve access to care for all patients in need of such services. It also noted opportunities to strengthen access to quality palliative care and hospice services included in the Affordable Care Act (ACA). Broadly, these opportunities include the development and implementation of programs to educate and train healthcare professionals in pain management; new requirements for hospices, long-term care hospitals, and rehabilitation hospitals to publicly report quality information; and the establishment of a value-based purchasing program pilot for hospices and long-term care hospitals. Participants received the paper before the workshop to stimulate discussion during the meeting and to help them lay out an evidence-based approach to use as a basis for developing their recommended action plan.

Informed by Dr. Meier’s white paper, this report offers a high-level synthesis of the workshop, including key drivers and concrete action steps for NPP Partners and other stakeholder groups that promote shared accountability and that can foster change. For the purposes of this paper, the term “palliative care” will be used to represent the continuum of palliative care services including the management of patients with complex and chronic conditions upstream as well as those approaching end-of-life.

## II. KEY MEETING THEMES

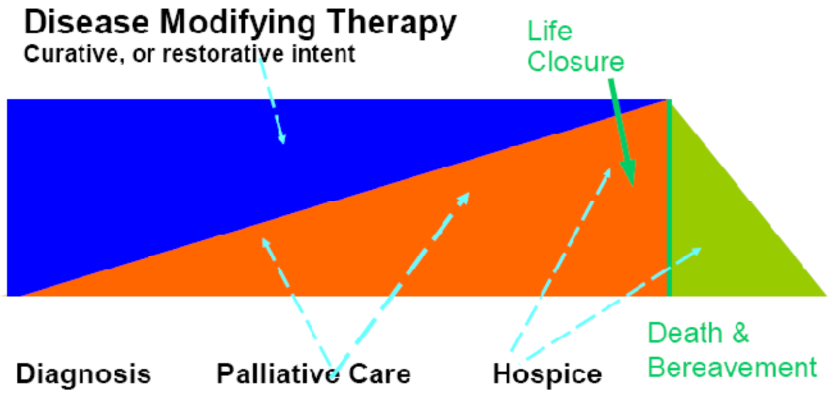
### Defining Palliative Care and Improving Public Understanding

Perhaps the most important theme to emerge during the workshop was the importance of clarity of message around the goals of palliative care. Having a clear and unified message is central to changing current public views that palliative care is equivalent to end-of-life care and to dispelling misconceptions that arose during the health reform debate that palliative care involves healthcare rationing and “death panels.” If such fears and misperceptions persist, efforts to improve access and quality will fail as a result of continued underutilization. It is important that a precise, consistent, and shared definition of palliative care is embraced and conveyed by all healthcare professionals and communicated effectively to patients and their families and to the public as a whole. To improve public understanding, palliative care must be accurately portrayed as care that espouses patient- and family-centered care, with the goal of optimizing quality of life by anticipating, preventing, and treating suffering throughout the full continuum of an illness.

A comprehensive definition of palliative care must balance the standardization of core tenets but also allow for customization that is responsive to patient and family caregiver values and preferences, which vary greatly based on many issues, including ethnic and cultural background. Patient- and family-centered palliative care must include a plan of care that emphasizes relief from pain and other debilitating physical symptoms but also attends to emotional, social, and spiritual needs. All of these aspects must be addressed to ensure that high-quality palliative care is being delivered to promote the best possible quality of life. Additionally, it is important to convey that the provision of palliative care services occurs along a continuum, with initiation taking place relatively early in the disease process and continuing throughout an illness, whether the illness is chronic, advanced, or terminal in nature.

As illustrated in Figure 1 below, in the early stages following a diagnosis of a serious illness, therapy is largely curative, with palliative care introduced when necessary to ensure the patient is able to maintain a good quality of life. During the majority of time along the palliative care continuum, patients continue to receive life-prolonging treatment. As an illness progresses, however, palliative therapies may increase as curative interventions decrease to coincide with the patient’s choices and preferences. Once a patient reaches a point at which the decision is made to forego life-prolonging therapies and instead focus on comfort at the end-of-life, hospice care is the form of palliative care provided.

**Figure 1**
**Conceptual Shift for Palliative Care[2]**



Importantly, regardless of when palliative care is initiated in the disease process, it is imperative that providers ensure that the goals and values of the patients and their families are jointly made, incorporated in all healthcare decisions, and fully documented in a plan of care. The palliative care plan should follow a patient throughout the illness and be updated regularly to ensure his or her needs and preferences continue to be met, as they may change over time. Doing so will foster a seamless palliative care experience for patients and their families.

## Access to Quality Palliative Care

Although multiple factors contribute to variability in access to high-quality palliative care, a primary barrier is the lack of healthcare professionals in the current workforce trained in core elements of palliative care. Current data suggest a significant shortage of palliative medicine specialists, with only one palliative specialist for every 31,000 people with serious advanced illness[3] compared to one cardiologist for every 71 heart attack victims.[4] Additionally, availability of palliative care services varies widely across states, making access even more difficult depending on where patients live. To counter this shortage, it is important to move toward a workforce of health professionals with basic competencies in palliative care and an increased number of specialists in this discipline.

Taking workforce issues a step further, it is essential that healthcare professionals are trained to deliver palliative care services in a culturally competent manner to address variation in use of palliative care and hospice services across ethnic and racial groups. In 2009, 80 percent of hospice patients were white (whites make up only 66 percent of the general population[5]), compared to 8.7 percent African American, and 1.9 percent Asian, Hawaiian, or Pacific Islander.[6] Patients' cultural or religious beliefs may prevent them from fully considering palliative care due to misperceptions about what it entails. Healthcare practitioners need to be able to discuss patients' religious faith and personal beliefs and values early in the disease process, taking into account their unique values and perspectives so they can make informed decisions about the initiation of palliative care and the extent of services to receive. In addition to sensitizing and educating providers to issues of cultural diversity, a more diverse workforce should be recruited.

It is important to acknowledge that the palliative care continuum applies to the pediatric patient population as well. Although the pediatric model of care inherently supports the provision of palliative care services through its support of the physical, developmental, emotional, and social needs of patients and their families, there is a greater lack of palliative care specialists for the pediatric population. The pediatric workforce also should have basic palliative care competencies and be able to access specialists when necessary, particularly to address the needs of children facing illnesses—which are inherently different from those of adults—as well as their parents due to the complexity and particularly sensitive nature of parental grief and bereavement.

## Community Partnerships

The needs of patients with complex illnesses and their family members are not just healthcare issues, but also community issues with far-reaching implications. To provide palliative care as outlined above—care that addresses physical, emotional, social, and spiritual needs of patients—supports outside of the traditional settings of the healthcare delivery system and within the broader community are necessary.

A convincing argument was made at the workshop that palliative care is a workplace issue for employees with chronic illness or for employees who are caregivers of patients, whether children, elderly parents, or other family members. With the average age of retirement climbing, more people in the workplace will be faced with a personal illness or need to care for a sick or aging loved one. This situation poses challenges for the employee, but also for the employer in terms of productivity and absenteeism. The challenge is to identify ways to incorporate these issues into corporate conversations. It was acknowledged that the workplace may not be the ideal setting for comprehensive discussions about serious illness or end-of-life care, but conversations can certainly start there. An employer can begin simply by building awareness around palliative care services and resources and then expand to include more specific offerings to support employees, such as coping mechanisms and skills to help in handling grief. Building palliative care into employee assistance programs can connect employees to available support services that may otherwise go untapped. Employers are recognizing that offering such resources—and relieving some of the burden on patients or caregivers—actually can benefit both the employee and the organization.

Collaborating with community-based organizations, such as churches or senior centers, offers another opportunity for developing partnerships to improve public health through an improved understanding of palliative care. Engaging leaders in the religious community and educating them about palliative care, for example, may encourage them to discuss such services openly when approached by a congregant facing an illness. Additionally, since many family caregivers seek the support of religious institutions and pastoral care, having well-educated staff and clergy offers an opportunity for open and informed conversations about palliative care and hospice care.

## III. DRIVERS OF CHANGE AND MOVING TOWARD ACTION

Informed by workshop presentations and the commissioned white paper, participants identified a set of action steps to be taken across stakeholder groups to improve access to high-quality palliative care. Participants focused on NPP's key drivers of change—payment, public reporting, performance measurement, and through a facilitated, iterative group process identified drivers and associated actions with the maximum potential to move toward desired outcomes. The following is a synopsis of the action plan formulated by the group. Appendix C provides a snapshot of the recommended action steps.

### Driver: Informed Consumer Decisionmaking

Patients and their families encountering the healthcare system often feel ill equipped to involve themselves actively in their own care. Patients in need of palliative care services are no exception and, due to their complex needs, may require even greater assistance. To make the best decisions about their care, patients and their families need a fundamental and accurate understanding of palliative care, access to information that helps them to select care providers, and encouragement to be actively engaged in making decisions about their care.

### *Communication*

Improving patient engagement and shared decisionmaking must start upstream by ensuring that the general public has a good understanding of palliative care. A multifaceted public education strategy must be developed that emphasizes the tenets of palliative care and its goals—from onset of illness through end-of-life care—and supports open communication between patients and their healthcare providers. Due to the sensitivities currently surrounding palliative care and end-of-life care issues, a campaign also would benefit from the stories of actual patients and caregivers who are often the strongest advocates for palliative care.

### *Public Reporting*

In addition to a basic understanding of palliative care, patients need timely access to performance information to make informed choices. Information on the quality of palliative care programs and services needs to be available and oriented so that the information is meaningful to patients and helpful in making decisions about their care. Comparisons of alternative settings and providers are crucial in supporting informed decisionmaking about where to receive care and from whom. Having data available about patient outcomes and/or experience with hospice services in the home versus at a hospice center, for example, may help patients and their families determine the care setting that is best for them. Coupling objective comparative data with qualitative stories of patient and family experience may provide the most comprehensive picture of an organization’s care practices and therefore offer the most valuable information for making informed decisions about care.

### *Shared Decisionmaking*

Finally, once patients have made a well-informed choice regarding their care provider, it is incumbent upon the healthcare professional to develop and maintain an open dialogue with the patient to ensure that all healthcare decisions are made together and with full knowledge of available options, including risks, benefits, and potential side effects. Working in partnership, the patient and provider establish and refine goals based on a mutual understanding of the trade-offs of more or less aggressive care as the disease progresses. Only with a full understanding of the anticipated outcomes can patients become actively engaged participants in selecting a preferred course of treatment and in making adjustments along the way.

## Driver: Payment Incentives and Performance Measurement

To fully integrate palliative care into the healthcare system, structures must be established to support providers in delivering this care. High-quality palliative care needs to be incentivized and rewarded through existing payment models and those emerging from health reform and the Affordable Care Act. For this to happen, palliative care performance measures must be included in payment and public reporting programs to drive toward high-quality patient-centered care.

### *Payment Incentives*

As new healthcare delivery and payment models take shape, integrating access to high-quality palliative care into new and existing models such as accountable care organizations (ACO) and patient-centered medical homes (PCMH) will be critical. These models can support the delivery of palliative care because of their emphasis on a multidisciplinary and multi-setting approach. Palliative care should be hardwired into payment programs, and performance metrics specific to palliative care incorporated into care delivery models. Importantly, the palliative care model offers key elements for consideration as requirements for the ACO and PCMH are further developed, including an uncompromising commitment to patient- and family-centered care, team-based care, and quality of life.

Additionally, there must be recognition of the value of shared decisionmaking and advance care planning, which are central to the palliative care model. Recent studies have shown that meaningful discussions between patients and providers on prognosis and patient goals demonstrably reduce costs and family burden.[7] The findings within this growing scientific evidence base need to be translated into emerging reimbursement structures and payment incentives. New and existing payment programs will need to support the necessary time and capacity required for health professionals to deliver this kind of care, which is inherently time-consuming but critical for the delivery of patient-centered care.

### *Performance Measurement*

Workshop participants agreed there is a need for general palliative care measures—not related to any particular condition or diagnosis or setting—to measure quality and effectiveness of care over time. Such measures would include process measures aligning with workflows, longitudinal measures of outcomes and cost, measures of shared decisionmaking, and composite measures that capture multiple aspects of care. They should address the continuum of the patient's care from screening and assessment to determine the need for and appropriateness of palliative care services to patient-reported outcomes such as functional status and health-related quality of life.

Participants recognized the importance of collecting patient-derived data throughout an episode of care, acknowledging that this can be a delicate undertaking, particularly when obtaining feedback from patients who are very near the end of life or from family members who have lost a loved one. These perceptions and experiences offer insightful feedback as has been demonstrated by the Family Evaluation of Hospice Care survey.[8] Such information will help paint a more complete picture of the patient's palliative and end-of-life care experience, and offer continued opportunities for learning and improvement.

## Driver: Accreditation, Certification, and Workforce Development

To provide high-quality palliative care to patients, a dedicated multidisciplinary team with an understanding of palliative care must be available and accessible. This team of health professionals must have the capacity to spend focused time with patients and family members to discuss the patient's values and preferences and then develop a comprehensive plan of care based on the stated needs and preferences. Developing such a plan would include offering clarity about the patient's diagnosis, setting realistic expectations regarding the disease process, ensuring shared and informed decisionmaking, and addressing any outstanding questions or concerns.

As noted earlier, there is a significant shortage of palliative medicine specialists as well as palliative care training programs—currently fellowship training for palliative medicine is unavailable in 20 states.[9] Outside of the palliative care community, many professionals within the healthcare industry do not fully understand palliative care, yet they are expected to initiate this care appropriately and make proper referrals. It is important to realize that addressing a shortage of this magnitude cannot be accomplished exclusively by expanding the number of palliative care specialists—it will require a two-pronged approach that promotes palliative competencies for all health professionals and provides incentives for specialty certification. For both basic and specialist training, it is critically important to develop innovative ways to reach mid-career professionals.

### *Specialized Training*

To support the provision of high-quality palliative care as well as ensure a talented pool of faculty to train the healthcare workforce, developing new ways to support the education and training of healthcare professionals is essential, particularly for those already practicing in the field. Creative approaches to mid-career training and more flexible ways of obtaining board certification need to be considered. An alternative pathway could include a parallel path to an executive MBA program—a program with flexibility in coursework structure and minimal disruption of a professional's current practice. Another way of supporting the education of practicing health professionals could be to increase the allocation of funds for continuing and graduate medical education focusing on palliative care. Offering medical and graduate school loan forgiveness for physicians, advance practice nurses, and clinical social workers who seek subspecialty training in palliative medicine also may be an effective tactic to encourage health professionals to consider further specialization.

### *Core Competencies*

With a persistent and severe shortage of palliative care specialists, developing a workforce with basic knowledge and competencies in palliative care will be necessary to impact access to palliative care in the near term. Increasing the number of fellowship programs and faculty to educate students and professionals about culturally competent palliative care is paramount. Employing a more business-like approach for faculty qualifications, such as years of experience in the palliative field in lieu of fellowship training, may offer an approach to increase the number of available faculty. In addition to incorporating core competencies into formal curricula, healthcare organizations can incorporate basic knowledge of palliative care into staff training and education programs, and professional organizations can offer programs on palliative care in their educational opportunities for their members.

### *Accreditation Programs*

An alternative approach to addressing workforce concerns more broadly is to develop and implement palliative care accreditation programs, which can offer a formal structure to reinforce the importance of these services through incentives and recognition. Accreditation in palliative care can be further promoted through health plan contracting and benefit design for preferred providers, and the pursuit and maintenance of accreditation would encourage organizations to ensure a well-trained staff that is competent to provide high-quality palliative care on a day-to-day basis.

## Driver: Research

In recent years, the research infrastructure has been growing and has demonstrated important links between palliative care and improved patient outcomes, improved patient and family experience of care, and reduced family burden and healthcare costs. Studies have shown that palliative care improves physical and psychosocial symptoms; family caregiver well-being; and patient, family, and physician satisfaction, while others illustrate that effective communication regarding prognosis and patient goals demonstrably reduces costs and family burden. More recent evidence even suggests that palliative care may be associated with a prolongation of life among certain patient populations.[10]

Despite these positive findings, inadequate funding is a major barrier to advancing this work and translating research into practice. Currently less than 1 percent of National Institute of Health funded grants focusing on cancer, dementia and diseases of the heart, lung, and kidney goes toward research related to palliative care.[11] Additional research funding would allow for the identification of approaches to address workforce and access issues; strategies for effective communication, messaging, and patient/family engagement; and approaches to integrating palliative care into new and existing care delivery models. The research community is an essential partner to further advance palliative care, particularly given the still relatively small number of health researchers dedicated to identifying effective and innovative ways to provide this care to diverse populations. Others in the healthcare community can support this effort through research grant funding, participating in clinical trials of new interventions, and serving as test sites for field studies.

Workshop participants cautioned against focusing only on quantitative research and stressed that qualitative research can contribute greatly to the evidence base. Health professionals may feel insensitive requesting a patient or family member to complete a survey on experience of care, particularly in a hospice setting, so gathering anecdotal feedback can help to fill those gaps. Storytelling by patients and their families as well as providers and health professionals can support the establishment of a strong, comprehensive evidence base. This information then can be used to educate consumers more broadly regarding palliative care and its benefits. As the evidence base supporting palliative care continues to grow, it is imperative to address barriers to translating proven approaches and methods into widely disseminated practice.

## IV. PATH FORWARD

As the Secretary of Health and Human Services finalizes the National Quality Strategy as required under the Affordable Care Act, NPP intends to offer its full support of the priorities and goals that will support the three aims to promote better care, affordable care, and healthy people/healthy communities. NPP’s Palliative Care and End-of-Life Care Workgroup recognizes the opportunity to support these three aims through improved access to high-quality palliative care, particularly given the demonstrated links between palliative care and improved patient outcomes and satisfaction; evidence of improved outcomes and better use of resources at end of life through a patient-centered approach to care; and opportunities for partnerships within communities to improve population health through care that is concordant with patient preferences and that emphasizes high quality of life.

The key drivers and associated actions presented in this report are offered as a starting point to improve provider-patient communications, relief of physical suffering, and psychological, social, and spiritual support for patients with chronic, advanced, and terminal illnesses. Opportunities exist to further align efforts with provisions put forth in the Affordable Care

Act, particularly in response to requirements to establish a value-based purchasing program pilot for hospices. Additional opportunities exist under ACA for the development and implementation of programs to educate and train healthcare professionals in pain care and to address cultural, linguistic, literacy, geographic, and other barriers to care in underserved populations.

The path forward will require further exploration and operationalization of the identified action steps to improve access to high-quality palliative care and end-of-life care. It is hoped, however, that any stakeholder group can identify an opportunity for implementation and subsequently take specific and immediate action.

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[1] National Priorities Partnership, *National Priorities and Goals: Aligning Our Efforts to Transform America's Healthcare,* Washington, DC: National Quality Forum; 2008.

[2] NHWG; Adapted from work of the Canadian Palliative Care Association and Frank Ferris, MD.

[3] Morrison RS, Dietrich, J and Meier DE. America's Care of Serious Illness: A State-by-State Report Card on Access to Palliative Care in Our Nation's Hospitals. Center to Advance Palliative Care: 2008. Available at: http://www.capc.org/reportcard/state-by-state-report-card.pdf. Last accessed December 2010.

[4] Ibid.

[5] US Census Bureau. Available at www.census.gov/newsroom/releases/archives/population/cb07-70.html. Last accessed January 2011.

[6] National Hospice and Palliative Care Organization Facts and Figures: Hospice Care in America; 2010. Available at www.nhpco.org/files/public/Statistics_Research/Hospice_Facts_Figures_Oct-2010.pdf. Last accessed January 2011.

[7] Zhang B, Wright AA, Huskamp HA, et al. Health care costs in the last week of life: associations with end-of-life conversations. Arch Intern Med. Mar 9 2009;169(5):480-488.

Wright AA, Zhang B, Ray A, et al. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. Jama. Oct 8 2008;300(14):1665-1673.

[8] FEHC

[9] Morrison RS, Dietrich, J and Meier DE.

[10] Temel J, Greer J, Muzikansky A, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. N Engl J Med. Aug 2010;363(8):733-742.

[11] Gelfman LP, Morrison RS. Research funding for palliative medicine. J Palliat Med. Jan-Feb 2008;11(1):36-43.

# APPENDIX A
# NATIONAL PRIORITIES PARTNERSHIP

## PALLIATIVE CARE AND END-OF-LIFE CARE CONVENING MEETING ATTENDEES
## NOVEMBER 2010

# NATIONAL PRIORITIES PARTNERSHIP
## *Convened by the National Quality Forum*

## PALLIATIVE CARE AND END-OF-LIFE CARE CONVENING MEETING

### INVITED PARTICIPANTS

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# APPENDIX B
# NATIONAL PRIORITIES PARTNERSHIP

## *Improving Healthcare Quality through Increased Access to Palliative Care and Hospice*

*Diane Meier, MD*

# IMPROVING HEALTHCARE QUALITY THROUGH INCREASED ACCESS TO PALLIATIVE CARE AND HOSPICE SERVICES

Diane E. Meier, MD

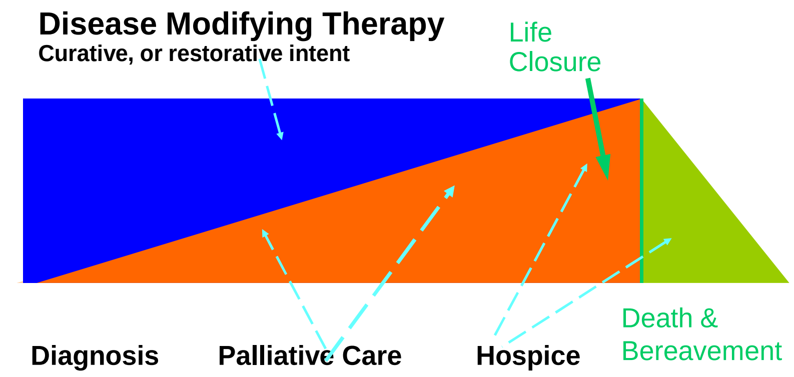
## I. Purpose

In its 2008 report, *National Priorities and Goals- Aligning Our Efforts to Transform America's Healthcare,*[1] [2] the National Priorities Partnership (NPP) identified six national priorities that if addressed, would significantly improve the quality of healthcare delivered to Americans. In recognition of evidence of poor health care quality despite high expenditure among patients with multiple chronic conditions, functional impairment, and serious and life threatening illness, the NPP identified palliative care as one of its six priority areas, reflecting the impact of both palliative care and hospice services on improving key patient-centered, population health, and utilization outcomes. This paper was developed as a background piece for a meeting of the National Priority Partnership's Palliative and End-of-Life Care workgroup with an aim of identifying the steps necessary to match medical treatment to patient and family goals through improved access to quality palliative care and hospice services.

## II. Background

***What is palliative care?*** Palliative care focuses on relieving suffering and achieving the best possible quality of life for patients and their family caregivers. It involves the assessment and treatment of symptoms; support for decision-making and assistance in matching treatments to informed patient and family goals; practical aid for patients and their family caregivers; mobilization of community resources to ensure a safe and secure living environment; and collaborative and seamless models of care across a range of care settings (i.e., hospital, home, and nursing home). Palliative care is provided both by a hospice (hospice palliative care) and outside it (nonhospice palliative care). Nonhospice palliative care is offered simultaneously with life prolonging and curative therapies for persons living with serious, complex, and life threatening illness. Hospice palliative care services, often reimbursed by a distinct insurance benefit (Medicare, Medicaid and other payers) is largely, but not exclusively restricted to patients with a prognosis of 6 months or less, if the disease follows its natural course, who agree to forego therapies with curative intent. Hospice is designed to provide comprehensive interdisciplinary team-based palliative care, mostly in a place the patient calls home, for dying patients with an identifiably short prognosis. Hospice palliative care becomes appropriate when patients and their families decide to forego curative therapies in order to focus on maximizing comfort and quality of life, when curative treatments are no longer beneficial, when the burdens of these treatments outweigh their benefits, or when patients are entering the last weeks to months of life.[3-5] Hospice supports the family caregiver throughout the care process and provides bereavement services to family members after the death of the patient.

**Figure 1**
**Conceptual Shift for Palliative Care[3]**



NHWG; Adapted from work of the Canadian Palliative Care Association & Frank Ferris, MD

***Why do we need palliative care?*** Despite enormous expenditures, studies demonstrate that patients with serious illness and their families receive poor quality medical care, characterized by untreated symptoms, unmet psychosocial and personal care needs, high caregiver burden, and low patient and family satisfaction.[6-10] Of the $491 billion spent by Medicare in 2009, 27 percent ($132.5 billion) was spent on acute care (hospital) services and a small proportion—10 percent--of the sickest Medicare beneficiaries accounted for about 57 percent of total program spending, at more than $44,220 per capita per year.[9] [11] The costliest beneficiaries include those using hospital services, those with multiple chronic conditions, functional dependencies, dual eligibility for Medicare and Medicaid, and those who are in their last year of life-- all of whom could benefit from palliative care and hospice services.[12]

***How do palliative care and hospice improve quality?*** Palliative care and hospice programs improve physical and psychosocial symptoms, family caregiver well-being, bereavement outcomes, and patient, family, and physician satisfaction.[13] [14] [15] [16] [17] [18] [19] [20] [21] [22] [23] [24] [25] [26] [10] [27] [28] [29] [30] [31] Employing interdisciplinary teams of physicians, nurses, social workers, spiritual counselors, pharmacists, aides, and additional personnel as needed (physical therapists, psychologists, others), palliative care and hospice teams identify and rapidly treat distressing symptoms which have been independently shown to increase medical complications and hospitalization.[26] [25] [18] [32] Palliative care and hospice teams meet extensively with patients and their families to establish appropriate and realistic goals, support families in crisis, and plan for safe transitions out of hospitals to more supportive settings (home care, home hospice, nursing home care with hospice, or inpatient hospice care). Communication about prognosis and patient goals by a dedicated team with time and expertise leads to better informed decision making, clarity of the care plan, and consistent follow through. Such discussions demonstrably reduce costs and family burden[30 31] and improve family satisfaction and bereavement outcomes.[27 30] Finally, and contrary to widely-held assumptions, several recent studies demonstrate that both nonhospice palliative care and hospice care may be associated with significant *prolongation* of life among selected patient populations.[14 33-35]

### *Essential elements of quality palliative care and hospice*

As outlined by the National Quality Forum Framework and Preferred Practices for Hospice and Palliative Care[4] and the National Consensus Project for Quality Palliative Care,[3] the essential structural elements of palliative care include:

- Interdisciplinary team of clinical staff (MD, RN, SW, spiritual counselor, pharmacist, aide, volunteers)
- Staffing ratios determined by nature and size of population to be served
- Staff trained, credentialed and/or certified in palliative care
- Access and responsiveness 24 hours per day, 7 days per week

The NQF Guidelines include 38 preferred structure and quality practices (see Appendix A) that have been utilized to develop quality metrics for hospital palliative care services in the U.S..[36-40]

Examples of preferred practice measures include determination and documentation of patient and family goals for care through advance care planning using, for example, the Medical or Physician Orders for Life Sustaining Treatment (MOLST or POLST, see www.polst.org) or the Respecting Choices paradigm, both of which have been shown to increase the likelihood that care actually received is concordant with patient goals.

***What do we know about quality of palliative care?*** Information on quality of palliative care and hospice programs is limited. Standardized empirical quality metrics usable for either internal or external quality reporting and pay-for-performance methods are needed. The NQF Framework and Preferred Practices identified 38 preferred practices in 8 domains that inform the relevant structure and process measures, but their correlation with relevant outcomes (symptom burden, caregiver burden, satisfaction, transitions, cost) is not known. Brown University investigators along with the National

Hospice and Palliative Care Organization (NHPCO) developed a post-death hospice family evaluation of care survey (the Family Evaluation of Hospice Care or FEHC),[10] which is now NQF endorsed.[41] The survey measures the quality of hospice interventions directed toward the family as well as the family's perspective of the quality of care received by the patient. Results of these surveys are not publicly available. While the perspective of the family is obviously a central component of quality, it may not fully reflect the patient's actual experience. For example, in studies that compare family and patient ratings of symptom intensity, families rate pain higher than patients do, and patients rate family distress higher than family members do.[42 43] Given the advanced stage of illness of these patients, there are inherent difficulties fashioning an empirical tool that is feasible, actionable, and patient-centered to directly assess the patient's perceptions of hospice or palliative care. CMS does not currently require quality reporting from hospice, unlike other major Medicare provider groups (nursing homes, rehabilitation facilities, hospitals, certified home health agencies), though conduct of a Quality Assessment and Performance Improvement (QAPI) program has been required as a hospice condition of participation in Medicare since 2008.

Through contracts with its QIOs, CMS has initiated several projects to develop and field test a series of hospice and palliative care measures (PEACE Project),[44] both as part of the CARE[45] instrument validation and as stand-alone measures. The 2010 Affordable Care Act (H.R. 3590 Section 3004) requires hospice to report to CMS on quality measures[46] or face a 2 percent reduction in their market basket update. Measures are to be endorsed by a "quality measure consensus-based entity" and must be published no later than October 1, 2012 for reporting to CMS beginning October 1, 2013.

Nonhospice palliative care programs also have no current external quality reporting requirements. The American Hospital Association annual survey contains a yes/no question on presence of a hospital palliative care program, but does not ask for further information. The Center to Advance Palliative Care[47] launched a program registry in 2009 for voluntary reporting of nonhospice palliative care structure and process measures derived from the NQF Framework and Preferred Practices. Data from the Registry are not currently publicly available. A series of consensus guidelines on structure and process measures for hospital consultation and inpatient unit programs, derived from the NQF Framework, were developed and published from the Center to Advance Palliative Care[37-40] in 2008-2010 but these have neither been field tested nor validated against patient level and efficiency outcomes. The Department of Veterans Affairs has developed measures that evaluate the incidence of goals discussions, chaplain visits, and advance directives. These are quality measures on which palliative care teams in VA hospitals are being evaluated.[48 49] The Joint Commission has developed and field tested a voluntary certificate program derived from the NQF Framework for palliative care but as of September 2010 the program had not been released. A new NQF call for hospice and palliative care measures is expected in 2011 under a contract from CMS as required by the Affordable Care Act (H.R. 3590 Section 3004).

As with other clinical outcome measures, it is critical that quality metrics developed for palliative care and hospice demonstrate a clear link between structure and process and the relevant clinical and patient-centered outcomes, and that the measures represent areas demonstrably improvable by providers.

***How do palliative care and hospice improve healthcare value?*** The seriously ill and those with multiple chronic conditions and functional impairment constitute about 5-10 percent of all patients in the U.S., but account for well over half of the nation's healthcare costs. In the Medicare program roughly half of beneficiaries have chronic conditions combined with functional limitations and this group accounts for 70 percent of program spending.[12] Palliative care programs targeting this patient population in hospitals are a rapidly diffusing innovation[50] and have been shown to both improve quality and reduce costs of care for America's sickest and most complex patients.[10 23 27 30 51-57 14] Medicare-certified hospices serve over 1.5 million dying Americans each year (about 41 percent of all Medicare deaths in 2009[44 58]) and hospice care is also associated with demonstrable improvements in quality and reductions in total health care spending.[5 33 59-61] Palliative care and hospice programs, therefore, are an important solution to the quality and cost crisis facing our healthcare system.

Palliative care and hospice programs promote the delivery of coordinated, communicated, and patient-centered care by targeting the drivers of increased utilization of hospitals, specialists, and procedures. These drivers include financial incentives for quantity and fragmentation of care, lack of training in management of patients with complex or multiple chronic conditions, lack of a strong primary care infrastructure, and the financial and structural disconnects between the acute and the post-acute care settings for healthcare. By addressing pain and symptoms that might otherwise increase hospital complications and lengths of stay, meeting with patients and families to establish clear care goals, tailoring treatments to those goals in consultation with the patients and their families, and by developing comprehensive discharge plans, hospital and community based palliative care and hospice programs reduce preventable hospitalizations, readmissions, and emergency department visits.[14 53 62-64 65] Patients are able to remain in their homes as a consequence of better family support, care coordination, and home care and hospice referrals; more admissions go directly to the palliative care service or hospice program instead of a high cost ICU bed; patients not benefiting from an ICU setting are transferred to more supportive settings; and non-beneficial or futile imaging, laboratory, specialty consultation, and procedures are avoided. Controlled trials in Europe[26 66]and the U.S.,[14 35] and multi-site studies in the U.S. suggest that the ability of palliative care and hospice programs to help patients avoid hospitalization can be substantial.[51 52 23 53 54 55 27 30 56 61 67-70 27 14]

***Impact of palliative care and hospice on annual health care spending.*** Based on recent data,[53] the per patient net costs saved by hospital palliative care consultation are $2,659. Approximately 2 percent of all 30,181,406 annual hospitalizations in the U.S. end in death.[71] Assuming that palliative care programs should be seeing most patients who die in hospital, plus the approximately triple this number of hospitalized patients with advanced and complex chronic illness who are discharged alive, at scale, palliative care programs should be seeing approximately 5-8 percent of all hospital discharges (patients who die and very sick patients discharged alive). At present (2008 data) palliative care programs are reported at 58.5 percent of U.S. hospitals with more than 50 beds,[50 72] and penetration reaches approximately 1.5 percent of all discharges.

Hospice care has also been shown to reduce total health care costs among the majority (70 percent) of Medicare beneficiaries.[61 73] Using propensity score analysis to control for selection bias, an estimated $2,300 is saved per beneficiary on average. Extrapolating this average savings across the number of hospice patients served each year yields overall savings of more than $3.5 billion a year (1,560,000 patients x $2,300 = $3.5 billion). Maximum savings occurred with a length of hospice use of approximately 7 weeks, leading to reduced Medicare costs of $7,000 among cancer patients, and $3,500 for others. The savings attributed to hospice patients persisted through 233 days of hospice care for cancer patients and 154 days of care for non cancer patients.[61] In addition, recent analyses have found that the costs of care for patients with cancer who disenrolled from hospice were nearly five times higher than for patients who remained with hospice. Patients who disenroll from hospice are far more likely to use emergency department care and be hospitalized.[74]

These studies generally have found that Medicare spending for hospice enrollees across settings is less than that for nonenrollees in the last several months before death, but that these savings diminish as hospice stays increase in length beyond 180 days.[75] The dramatic rise in access to hospice in long term care settings has resulted in a rise in average (but not median) length of stay, primarily because of growth in the number of very long stay (the top 10th percentile of lengths of stay) beneficiaries. Since hospice care is paid on a per diem basis, these long stays along with growth in the number of chronically ill Americans receiving hospice has resulted in a quadrupling of government expenditures on hospice in the last 8 years.[44] Despite data pointing to overall Medicare savings in association with use of hospice,[76] this observation has led to a review of the Medicare Hospice Benefit, as currently defined, in the large population of Medicare beneficiaries with multiple chronic conditions and functional impairment who are not (imminently) dying and may survive beyond the initial 6-month prognostic eligibility criteria set in statute.[44]

### *III. Barriers to Palliative Care and Hospice*

The primary barriers to receipt of quality palliative care and hospice are variability in access by geographic and other characteristics; inadequate workforce and workforce pipeline to meet the needs of patients and their families; inadequate research evidence base to guide quality care; and lack of public knowledge of, and demand for, the benefits of palliative care and hospice.

#### *1. Access to palliative care and hospice*

Until recently, palliative care services were typically available only to patients enrolled in hospice.[3] Now, palliative care programs are found increasingly in hospitals – the main site of care for the seriously ill and site of death for 50 percent of adults on average nation-wide, as well as in other settings. As of 2008, 58.5 percent of U.S hospitals (with at least 50 beds) and 81 percent of hospitals with more than 300 beds reported the presence of a palliative care program – an increase of 125 percent from 2000.[77] [50] [72]

The 47 percent growth in number of hospice programs and 74 percent increase in number of persons served by hospice in the U.S. in the last 10 years have been equally dramatic.[44] [58] [78] As of 2009, there were 3,400 programs (93.0 percent of which are Medicare-certified) serving approximately 1.56 million Americans, primarily in their homes (56 percent of days), nursing home (29 percent of days) or assisted living facility (10.9 percent of days). In 2009 over 40 percent of Medicare decedents utilized hospice at some point in their care, an increase from 23 percent in 2000.[58] [44] More than

New CMS Definition of Palliative Care *Does Not Mention Prognosis:*

***Palliative care** means patient and family-centered care that optimizes quality of life* by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice.

*73 FR 32204, June 5, 2008*
*Medicare Hospice Conditions of Participation—Final Rule*

80 percent of hospice beneficiaries are over age 65 and more than a third are over 85 years of age. In tandem with the aging of the hospice and U.S. population, patterns of diagnosis have changed. Ten years ago the majority (53 percent) of hospice patients died from cancer while by 2008 only 31 percent had cancer and 69 percent died from chronic debilitating diseases such as frailty, atherosclerotic and respiratory disease, and dementia for whom the art and science of predicting prognosis is considerably more uncertain.[44 79] These shifts in diagnoses reflect a pattern of hospice utilization increasingly correlated with the leading causes of death (cancer accounts for fewer than 25 percent of deaths in the U.S.), suggesting that hospice providers are responding to the needs of Medicare beneficiaries.

In both nonhospice and hospice palliative care delivery models, access to palliative care and hospice programs is highly variable across the country. For-profit, southern U.S. and small and safety-net hospitals (under 100 beds) are less likely to report hospital palliative care programs[72 80] as compared to not-for-profit hospitals, hospitals outside the South, and larger hospitals. Even in settings in which a palliative care program is available, there is a great deal of variability in the services to which patients have access, ranging (for example) from a 0.5 FTE RN to a full interdisciplinary palliative care team. Hospice penetration is also highly variable, from a low of 6.7 percent of all deaths in Alaska, to a high of 44.7 percent in Arizona, based on 2006 data.[81] Reasons for this variation in utilization of hospice are unclear as it does not appear to be related to differences in availability of hospice capacity across the states.[44] Approaches to standardization of access to quality palliative care are listed in Tables 1 and 2 in Appendix B.

### *2. Workforce*

An inadequate medical and nursing workforce with expertise in palliative care is among the most important barriers to access. A report commissioned by HRSA in 2002 projected significant shortfalls in the nation’s number of palliative medicine specialists and[82] called for policy focused on increased education and training in palliative medicine across all clinical specialties serving patients with chronic and eventually fatal illness; expanded funding and reimbursement to attract young physicians into the field; and examination of the appropriate role of non physician professionals (such as nurse practitioners, clinical social workers, and physician assistants) in strengthening access to palliative care across health care settings. Another physician-specific workforce study commissioned by the AAHPM in 2010[83] conservatively estimated a shortfall of at least 2,787 FTE (or approximately 6,000 palliative medicine physicians given the frequency of part-time participation in the field).[83]

This workforce shortage has had a dramatic impact on the hospice community. Growth in the number of programs (and patients served) has rapidly outstripped growth in the number of trained professionals. More recently, the CMS requirement of face-to-face visits by physicians or nurse practitioners for recertifications for hospice services[44 75 78] has heightened the mismatch between workforce capacity and clinical need.

Several Institute of Medicine reports have also called for policy changes aimed at strengthening the palliative care workforce[6] In part as a response to these concerns, in 2006 Hospice and Palliative Medicine became an American Board of Medical Specialties-approved subspecialty with 10 parent boards.[84] Subsequently, the Accreditation Council for Graduate Medical Education (ACGME) has certified[85] the first 63 post graduate fellowship training programs to develop the workforce necessary to meet the nation's needs.[87-91]

A continuing barrier to physician specialty training in palliative medicine is the cap on Graduate Medical Education (GME) slots within teaching hospitals.[92] Despite a 30 percent growth in the U.S. population and a doubling of the number of Americans over age 65 since 1997, the total number of Medicare-funded graduate medical education training slots has been capped at 110,000 since the passage of the Balanced Budget Act in 1997.[93] Distribution of GME slots, at present, are entirely within the purview of each teaching hospital, and are not federally mandated.[112] A new subspecialty such as palliative medicine has little power to secure GME-funded slots from longstanding and preexisting training programs and as a result specialty training in palliative medicine is largely dependent on private sector philanthropy. In recognition of the need for data to inform federal training priorities, the August 2010, U.S. Senate Appropriations Committee report for the Departments of Labor, Health and Human Services, and Education for FY 2011 included language in its section on Health Professions Workforce Information and Analysis calling for HRSA-sponsored studies on adequacy of the palliative care workforce:

> *The (U.S. Senate Appropriations) Committee is aware that hospice and palliative medicine [HPM] improves quality, controls cost and enhances patient/family satisfaction for the rapidly expanding population of patients with serious or life-threatening illness. Therefore, the Committee encourages HRSA to study workforce trends, training capacity and need for HPM physicians, physician assistants and nurse practitioners in our Nation's academic medical centers, hospice organizations and palliative care programs.*[113]

### *3. Lack of research on palliative care and hospice*

Investment in research on palliative care and hospice is necessary to assure that care is based on reliable evidence and to test promising delivery models in a range of patient populations and settings. Despite the fact that the U.S. population is aging and that persons with multiple chronic conditions and functional impairment drive well over two-thirds of health care spending,[12] a recent study found that[4] less than 1 percent of total NIH extramural funding between 2003 and 2005 went to palliative care-related research.[9] With rare exceptions,[95] not-for-profits and charitable foundations do not invest in research, placing additional pressure on federal funding sources to fill the gaps. Reflecting awareness of this problem, the August 2010 U.S. Senate Appropriations Committee report for the Departments of Labor, Health and Human Services, and Education for FY 2011 included report language[114] in its section on the National Institutes of Health calling for a trans-Institute strategy aimed at increasing funding for palliative care research:

> *Palliative Care – The (Senate Appropriations) Committee strongly urges the NIH to develop a trans-Institute strategy for increasing funded research in palliative care for persons living with chronic and advanced illness. Research is needed on: treatment of pain and common non-pain symptoms across all chronic disease categories, which should include cancer, heart, renal and liver failure, lung disease, Alzheimer's disease and related dementias; methods to improve communication about goals of care and treatment options between providers, patients, and caregivers; care models that maximize the likelihood that treatment delivered is consistent with patient wishes; and care models that improve coordination, transitions, caregiver support, and strengthen the likelihood of remaining at home.*[114]

In summary, the key barriers to assuring access to quality palliative care for all Americans with advanced or serious illness include:

- Need for regulatory and accreditation requirements to redress variability in access to palliative care and hospice services based on geographic location, hospital size, and ownership among other variables;[50] [96] [97]
- Need for both primary and specialist-level physician, nursing, social work, and pharmacy palliative care education and training;[98] [99] [100] [101]
- Need for adequate compensation and loan forgiveness opportunities to attract professionals into the field;
- Need for financial incentives encouraging workforce development and organizational commitment;
- Need for investment in adequate research to develop an evidence base guiding quality care; [94] and
- Need for public outreach and education on the value of palliative care and hospice.

### *IV. Palliative Care and Hospice in the Affordable Care Act of 2010*

Although many provision related to access to quality palliative care were ultimately removed from the original health reform bills (S.1150 Advance Care Planning and Compassionate Care Act [102] and Life Sustaining Treatment Preference Act[103]) several provisions directly relevant to palliative care and hospice were enacted into law with the passage of the Affordable Care Act (ACA). These provisions[104] focus exclusively on hospice[105] and include:

- Market basket cuts and productivity adjustments for hospice (Sec. 3132);
- Hospice Payment Reform—requires increased data collection, and provides that no earlier than October 1, 2013, the Secretary of HHS shall undertake a new payment methodology for hospice;
- Hospice reforms—implements a face-to-face recertification of hospice patients by an MD or nurse practitioner prior to the 180 day recertification period and for each subsequent 60-day recertification period (Sec. 3132);
- Medicare Concurrent Care Demonstration—allows study of simultaneous hospice and life prolonging treatments under Medicare in 15 sites (Sec. 3140);
- Concurrent (Curative and Palliative) Care for Children in Medicaid and CHIP—effective immediately on passage (Sec. 2302);
- Tests of Value-Based Purchasing for Hospice—implementation October 2016 (Sec. 3006); and
- Quality Reporting mandate to be preceded by hospice and palliative care measure endorsement before October 2012, for implementation October 2013 (Sec. 3004).

The ACA does afford opportunities for integration and participation of palliative care and hospice programs as a component of the new delivery and payment models including Accountable Care Organizations (ACOs), Patient Centered Medical Homes (PCMHs), also known as Health Homes, and bundling of payments for a single episode of health care. Each of these models aims to improve quality and control cost for high-need patient populations by focusing on patient-centered, goal-driven, and intensive care coordination; identification and treatment of problems before crises prompt preventable Emergency Department visits or hospitalizations; and shifting provider incentives from fee-for-service drivers of quantity to payment based on quality (see Table 3—Opportunities for Palliative Care in the Affordable Care Act in Appendix B).

- **Accountable Care Organizations:** ACOs are groups of providers receiving set fees to deliver coordinated quality care to a select group of patients. Sec. 3022 of the ACA, (Medicare Shared Savings Program) allows providers organized as

ACOs that voluntarily meet quality thresholds to share in the cost savings they achieve for the Medicare program. To qualify as an ACO, organizations must agree to be fully accountable for the overall care of their Medicare beneficiaries, have adequate participation of primary care and specialist physicians, define processes to promote evidence-based medicine, report on quality and costs, and coordinate care. ACO incentives are aligned to maximize quality and minimize cost and are an important vehicle for improving access to palliative care and hospice for-high risk, high-need patient populations.

- **Patient Centered Medical Homes/Health Homes:** The PCMH is defined as "an approach to providing comprehensive primary care that facilitates partnerships between individual patients, and their personal providers, and when appropriate, the patient's family." The CMS Medicare demonstration[106] provides a care management fee to physician practices serving "high need" patients, who must use health assessment, integrated care plans, tracking of tests and providers, review of all medications, and tracking of referrals (Tier 1), and should develop an Electronic Health Record, coordinate care across settings, and employ performance metrics and reporting (Tier 2).[107] The ACA Section 2703 provides for a new State option of a Medicaid Health Home for enrollees with at least 2 chronic conditions or 1 chronic condition and risk of another or at least one serious and persistent mental illness. The provision permits a team of health professionals to provide comprehensive medical management, health promotion, and care coordination services in return for an enhanced (90 percent) FMAP. The "high need" target populations for the medical and health home models are patients best served by palliative care and, when eligible, hospice programs- both have demonstrated effectiveness in improving quality and length of life in high-risk, high-need patient populations, as well as reducing unnecessary acute care spending.
- **Bundled Payments:** Provisions for both Medicare and Medicaid beneficiaries establish pilots to develop and evaluate paying a single bundled payment (Sec. 3023) for all acute inpatient hospital services, physician services, outpatient hospital services, and post-acute home care services for an episode of care that begins three days prior to a hospitalization and spans 30 days following discharge. If the pilot program achieves stated goals of improving or not reducing quality and reducing spending, a plan is to be developed for its expansion. Success with payment bundling is critically dependent upon reliable and high quality services outside the hospital for the complex and seriously ill patient populations at high risk for readmission- again, such patients are

demonstrably best served by palliative care and hospice teams with expertise in caring for "high need" patients (and their family and paid caregivers) across community settings (home, nursing home, assisted living).[108]

A major challenge to the success and scaling of these new delivery and payment models is the fact that the skills necessary to accomplish their goals for high-risk high-need patient populations with serious and advanced illness, multimorbidity and functional dependency are not widely available among healthcare providers in the U.S. This is due both to lack of training in care for the seriously and chronically ill, as well as long practice experience of mid-career professionals with the current fee-for-service incentives for acute and specialist level care. These skills are, however, available in the staff of the nation's 1,500 palliative care and 3,400 hospice programs. The rapid growth of non hospice palliative care programs in the last decade is a hospital and health professional response to the unmet needs of a seriously and chronically ill patient population with significant care needs that are not predictably dying and are therefore ineligible for hospice care. As a consequence, over 80 percent of large hospitals and 55 percent of mid to large-size hospitals in the U.S. already have palliative care teams with relevant skills.[72] Similarly, the growth in numbers and utilization of hospice over the last decade has resulted in a national workforce trained and experienced in the care of the targeted high-need patient population. Linkage of palliative care and hospice teams to implementation of new delivery models may increase their likelihood of achieving their quality and healthcare value objectives.[109] Metrics for quality palliative care and hospice necessary to include them in the specifications for the new delivery and payment models aimed at improving care value for this patient population will be available by October 2012 as required in the Affordable Care Act (Sec. 3004).

## *V. Solutions and Drivers of Change*

***Scaling palliative care by assuring access for all Americans in need.*** To assure access to high quality palliative and hospice care for all Americans who might benefit requires that providers are trained to deliver this kind of care; that an evidence base exists to assure quality; that health care organizations have the capacity to provide it; and that the public understands palliative care and hospice and demand such care from their providers. Policies aimed at increasing access to quality palliative care in the U.S. therefore fall into four major categories:

1. Workforce training and development necessary to meet patient's needs;
2. Research to build the evidence base necessary for quality care;

3. Financial and regulatory incentives for health care organizations and providers across the continuum to develop and sustain access to quality palliative care and hospice services; and
4. Public outreach and education campaigns to improve awareness of and demand for the benefits of palliative care and hospice.

The Senate Appropriations Committee Report for 2011 calls for government attention to both the palliative care workforce and research priorities. The new delivery and payment models encouraged by the ACA and aimed at a high risk high need target population should also strengthen recognition of the value of palliative care and hospice services in the acute, the post acute, and long term care settings. Alignment of government efforts with existing and future private sector commitments is necessary. Private sector actions to date include individual hospital and nursing home commitments to palliative care as a core component of quality, health care organization recognition of and awards for quality palliative care (such as the American Medical Association's nationally disseminated physician education initiative *Education for Physicians in End-of-Life Care* or EPEC, and the American Hospital Association's annual *Circle of Life* awards for quality palliative care programs), medical and nursing school incorporation of palliative care content into training and competency requirements, health plan creativity with, for example, access to simultaneous hospice and curative therapies as well as intensive care coordination,[110] [111] and the enormous investment in development of the field over the last 20 years by philanthropy. The combined and sustained commitment of both sectors is needed to bring the palliative care innovation to scale in the U.S. in the near future. Palliative care and hospice care teams advance the NPP priorities among America's highest risk and highest need patient populations, addressing care coordination, patient and family engagement, safety and population health (through prevention of wrong care such as risky and unnecessary tests and procedures), and associated reductions in overuse. Infrastructure investment in the workforce, the evidence base, information technology, and valid and actionable quality measures are needed to bring this innovation to scale. These and other opportunities to increase access to quality palliative care for all Americans are summarized in Tables 1-3 in Appendix B.

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# Appendix A

## A National Framework and Preferred Practices for Palliative and Hospice Care Quality: A National Quality Forum (NQF) Consensus Report

The National Quality Forum identified palliative care and hospice care as national priority areas for healthcare quality improvement. This report provides a framework and set of NQF-endorsedTM preferred practices that focus on improving palliative care and hospice care across the Institute of Medicine's six dimensions of quality – safe, effective, timely, patient-centered, efficient, and equitable. The preferred practices mark a crucial step in the standardization of palliative care and hospice.

**Preferred Practices***

1. Provide palliative and hospice care by an **interdisciplinary team** of skilled palliative care professionals, including, for example, physicians, nurses, social workers, pharmacists, spiritual care counselors, and others who collaborate with primary healthcare professional(s).
2. Provide access to palliative and hospice care that is responsive to the patient and family **24 hours a day, 7 days a week**.
3. Provide **continuing education** to all healthcare professionals on the domains of palliative care and hospice care.
4. Provide adequate t**raining and clinical support** to assure that professional staff is confident in their ability to provide palliative care for patients.
5. Hospice care and specialized palliative care professionals should be appropriately **trained, credentialed, and/or certified** in their area of expertise.
6. Formulate, utilize, and regularly review a **timely care plan** based on a comprehensive interdisciplinary assessment of the values, preferences, goals, and needs of the patient and family and, to the extent that existing privacy laws permit, ensure that the plan is broadly disseminated, both internally and externally, to all professionals involved in the patient's care.
7. Ensure that upon transfer between healthcare settings, there is timely and thorough communication of the patient's goals, preferences, values, and clinical information so that **continuity of care and seamless follow-up** are assured.
8. Healthcare professionals should present **hospice as an option** to all patients and families when death within a year would not be surprising and should reintroduce the hospice option as the patient declines.
9. Patients and caregivers should be asked by palliative and hospice care programs to assess physicians'/healthcare **professionals' ability to discuss hospice** as an option.
10. **Enable patients to make informed decisions** about their care by educating them on the process of their disease, prognosis, and the benefits and burdens of potential interventions.
11. Provide **education and support to families** and unlicensed caregivers based on the patient's individualized care plan to assure safe and appropriate care for the patient.
12. Measure and **document pain, dyspnea, constipation, and other symptoms** using available standardized scales.
13. Assess and **manage symptoms and side effects** in a timely, safe, and effective manner to a level that is acceptable to the patient and family.
14. Measure and **document anxiety, depression, delirium, behavioral disturbances,** and other common psychological symptoms using available standardized scales.

15. **Manage anxiety, depression, delirium, behavioral disturbances,** and other common psychological symptoms in a timely, safe, and effective manner to a level that is acceptable to the patient and family.
16. Assess and **manage the psychological reactions** of patients and families (including stress, anticipatory grief, and coping) in a regular, ongoing fashion in order to address emotional and functional impairment and loss.
17. Develop and offer a **grief and bereavement care plan** to provide services to patients and families prior to and for at least 13 months after the death of the patient.
18. Conduct regular **patient and family care conferences** with physicians and other appropriate members of the interdisciplinary team to provide information, to discuss goals of care, disease prognosis, and advance care planning, and to offer support.
19. Develop and implement a comprehensive **social care plan** that addresses the social, practical, and legal needs of the patient and caregivers, including but not limited to relationships, communication, existing social and cultural networks, decision making, work and school settings, finances, sexuality/intimacy, caregiver availability/stress, and access to medicines and equipment.
20. Develop and document a plan based on an assessment of **religious, spiritual, and existential concerns** using a structured instrument, and integrate the information obtained from the assessment into the palliative care plan.
21. Provide information about the **availability of spiritual care services,** and make spiritual care available either through organizational spiritual care counseling or through the patient's own clergy relationships.
22. Specialized palliative and hospice care teams should **include spiritual care professionals** appropriately trained and certified in palliative care.
23. Specialized palliative and hospice spiritual care professionals should build **partnerships with community clergy** and provide education and counseling related to end-of-life care.
24. Incorporate **cultural assessment** as a component of comprehensive palliative and hospice care assessment, including but not limited to locus of decision making, preferences regarding disclosure of information, truth telling and decision making, dietary preferences, language, family communication, desire for support measures such as palliative therapies and complementary and alternative medicine, perspectives on death, suffering, and grieving, and funeral/burial rituals.
25. Provide professional **interpreter services** and culturally sensitive materials in the patient's and family's preferred language.
26. Recognize and **document the transition to the active dying phase,** and communicate to the patient, family, and staff the expectation of imminent death.
27. **Educate the family on a timely basis regarding the signs and symptoms of imminent death** in an age-appropriate, developmentally appropriate, and culturally appropriate manner.
28. As part of the ongoing care planning process, routinely ascertain and **document patient and family wishes** about the care setting for the site of death, and fulfill patient and family preferences when possible.
29. Provide **adequate dosage of analgesics and sedatives** as appropriate to achieve patient comfort during the active dying phase, and address concerns and fears about using narcotics and of analgesics hastening death.
30. **Treat the body after death with respect** according to the cultural and religious practices of the family and in accordance with local law.

31. Facilitate effective grieving by implementing in a timely manner a **bereavement care plan** after the patient's death, when the family remains the focus of care.
32. **Document the designated surrogate/decision maker** in accordance with state law for every patient in primary, acute, and long-term care and in palliative and hospice care.
33. **Document the patient/surrogate preferences for goals of care,** treatment options, and setting of care at first assessment and at frequent intervals as conditions change.
34. **Convert the patient treatment goals into medical orders,** and ensure that the information is transferable and applicable across care settings, including long-term care, emergency medical services, and hospital care, through a program such as the Physician Orders for Life-Sustaining Treatment (POLST) program.
35. **Make advance directives and surrogacy designations available across care settings,** while protecting patient privacy and adherence to HIPAA regulations, for example, by using Internet-based registries or electronic personal health records.
36. Develop healthcare and community collaborations to **promote advance care planning** and the completion of advance directives for all individuals, for example, the Respecting Choices and Community Conversations on Compassionate Care programs.
37. Establish or have access to **ethics committees or ethics consultation** across care settings to address ethical conflicts at the end of life.
38. **For minors with decision making capacity, document the child's views and preferences** for medical care, including assent for treatment, and give them appropriate weight in decision making. Make appropriate professional staff members available to both the child and the adult decision maker for consultation and intervention when the child's wishes differ from those of the adult decision maker.

**Order a copy of the NQF Consensus Report online at www.qualityforum.org/publications/reports**
*The Center to Advance Palliative Care has created and distributed this document courtesy of the National Consensus Project. *Bolding has been added by the Center to Advance Palliative Care.

# Appendix B

## Table 1
## Considerations for Strengthening Access to Quality Palliative Care and Hospice

| Stakeholder Category | Suggested Actions |
|---|---|
| **Quality Improvement Organizations** | 1. Identify and measure timely access to palliative care and hospice services as a key marker of quality across all settings.<br>2. Encourage and incent adherence to NQF Preferred Practices and (when available) certificate criteria as a means of assuring quality and standardizing program operations across the country. |
| **Consumer Organizations** | 1. Increase consumer awareness, education and access to palliative care and hospice program information through dissemination of consumer education resources, articles and linking organizational websites to caringinfo.org and getpalliativecare.org.<br>2. Identify special topics related to palliative care and hospice that are of interest to their constituency, strengthen editorial content and feature pieces, and support data collection by survey and focus group techniques to aid in development of requests and recommendations.<br>3. Establish an internal task force or committee to identify high leverage activities.<br>4. Where appropriate, support policy initiatives that will improve access and quality of palliative care and hospice, such as enhanced workforce, research funding, and regulatory requirements. |
| **Accreditation and Certification Organizations** | **Education**<br>1. Promote palliative care and hospice certificate program to hospitals, home care, and NFs.<br>2. Exempt ACGME approved Palliative Medicine fellowship training from the GME funding cap.<br>3. Encourage adherence to NQF Preferred Practices and participation in palliative care and hospice certificate programs in the review process for hospitals. Review, recognize and reward hospitals, home care and NFs that receive certification.<br>4. ABMS's new subspecialty certification in Hospice and Palliative Medicine needs to establish and promote standards for medical practice in a broad range of specialties.<br>**Measurement & Reporting**<br>5. Develop claims-based measure of competency in # of referrals to palliative care and hospice.<br>6. Implement measures of utilization of services including days in ED, ICU, and hospital at end of life and number of days in hospice care.<br>7. Develop measures of institutional capacity for high-quality palliative and hospice care.<br>8. Develop composite measure of symptoms assessment (pain, dyspnea, constipation, HRQoL) that is harmonized across all settings.<br>9. Develop a standard measure of hospital and NF mortality that distinguishes preventable deaths from expected deaths.<br>10. Adapt Family Evaluation of Hospice Care (FEHC) survey to multiple settings. |
| **Purchasers/ Businesses/ Health Plans** | 1. Require presence of a quality palliative care and hospice program as a condition of preferred provider status<br>2. Sponsor and encourage research and demonstration projects or pilots that support concurrent palliative care in hospital and home settings including provision for collaboration with hospice providers.<br>3. Increase employee awareness, education and access to palliative care and hospice program information through company website and linking to nhpco.org, caringinfo.org, getpalliativecare.org, and palliativedoctors.org. |

| Stakeholder Category | Suggested Actions |
|---|---|
| | 4. Assist employers to educate employees and dependents on opportunities to choose high quality palliative care and hospice (such as NBGH's work). |
| **Payers** | **Payment for Services**<br>1. Reimbursement for non-physician interdisciplinary team members in the acute care setting.<br>2. Develop appropriate compensation by Medicare and private insurance to assure provision of time-intensive expert palliative and hospice care of complex, seriously ill patients.<br>3. Develop a reimbursable code for family and goals of care and care coordination conferences that do not require face-to-face patient presence.<br>4. Implement pay for performance programs which reward hospitals offering palliative care consultation and/or hospice referral for patients with complex, multiple co-morbidity and end stage disease (measurable via claims and DRG data).<br>5. Utilize robust data analytic approaches to determine appropriate changes in hospice reimbursement mechanisms including implications for access to care.<br>6. Access to quality palliative care and hospice programs for appropriate patient groups as a condition of participation in Medicare and Medicaid.<br>7. Encourage and support cross-state consistency and enhancement of Medicaid coverage for palliative care and hospice.<br>8. Include palliative care and hospice as essential insurance benefits. Educate consumers to select plans covering palliative and hospice care and link sites to getpalliativecare.org, palliativedoctors.org, and nhpco.org.<br>9. Sponsor and encourage research, demonstrations or pilots that support concurrent palliative care activities in hospital, nursing facilities, and home settings including provision for collaboration with hospice providers.<br>10. Include palliative care and hospice as a regular topic in all health plan quality committee meetings.<br>**Payment for Education**<br>11. Medical and graduate school loan forgiveness for physicians, advance practice nurses, and clinical social workers who seek subspecialty training in palliative medicine.<br>12. Provide special cap-exempt Graduate Medical Education funds to support GME for ACGME accredited palliative medicine fellowship training programs.<br>13. Increase GME/IME payments and hospital budgets for palliative medicine training programs for ACGME accredited palliative medicine fellowship programs. |
| **Health Professional Organizations/ Providers** | **1.** Develop a reimbursable code for family conferences that does not require face-to-face patient presence.<br>**2.** Develop a CPT code for palliative care associated with reimbursement commensurate with the time intensity, team approach, and complexity of palliative care services.<br>**3.** Improve access to education and certification opportunities for physicians, nurses, chaplains, and social workers.<br>**4.** Include prognosis, symptom, transitions, and communication competencies for serious and advanced illnesses as a routine part of undergraduate, and graduate medical and nursing training, CME and CE. |
| **Research and Workforce Organizations** | 1. Commit resources to the palliative care and hospice research priorities established by NIH State of the Science conference and the three IOM reports.<br>2. Increase funding for palliative care and hospice research to 2% of total NIH-AHRQ budget (up from 0.5%).<br>3. Offer palliative care and hospice research fellowships and career development awards annually. |

| Stakeholder Category | Suggested Actions |
|---|---|
| | 4. Conduct research on clinical treatments and organizational approaches to delivering palliative care and hospice, including prospective studies of palliative care and hospice concurrent with disease-specific treatment across disease types and treatment settings.<br>5. Establish an NIH-AHRQ Palliative Care and Hospice Study Section for purposes of quality peer review.<br>6. Establish cross-Institute NIH strategy to increase research funding in palliative care and hospice, as called for by the U.S. Senate Appropriations Committee report for the Departments of Labor, Health and Human Services, and Education for FY 2011.<br>7. Conduct a study of workforce trends, training capacity, and needs for hospice and palliative care workforce for the nation's medical centers, hospices, and outpatient and long term care settings, as called for by the U.S. Senate Appropriations Committee report for the Departments of Labor, Health and Human Services, and Education for FY 2011. |

**Note**: Recommended Actions for NQF Stakeholders in Support of Palliative Care and Hospice Quality and Access in the U.S.

## Table 2
## Policies to Improve Access to and Quality of Palliative and Hospice Care

| **ACCESS: Improve Access to Palliative Care and Hospice Services** |
|---|
| **1. Workforce**<br>**Physician workforce capacity**<br>o Assure post graduate training (fellowship) opportunities for masters-prepared nurses, social workers, and for physicians via exemption to (or increase in) the cap on Graduate Medical Education slots for this area of workforce shortage.<br>o Distribute currently unused GME slots to ACGME-accredited palliative medicine fellowship training programs.<br>**Educational and training capacity (Reynolds 2008)**<br>o Support young medical, nursing, and social work faculty entering the field through HRSA Title VII-supported career development awards (similar to Title VII Geriatric Health Professions Training Programs).<br>o Incent entry into the field through educational loan forgiveness for physicians and advance practice nurses. |
| **2. Financial and regulatory incentives for delivery of palliative care services for hospitals, nursing homes, and all providers receiving Medicare or Medicaid payments.**<br>o Payment increment to hospitals and nursing homes providing quality palliative care and hospice services to patients in high-need categories; followed after several years by financial penalties for failure to provide.<br>o Require access to quality non-hospice and hospice palliative care services for eligible beneficiaries in all proposed models of payment reform (including bundled payments, Accountable Care Organizations, and the Patient Centered Medical Home/Health Homes).<br>o Direct deemed regulatory bodies to develop an (initially) voluntary, and later a required certificate or accreditation program for quality palliative care programs.<br>o Palliative care services meeting quality guidelines as a condition of accreditation and payment as a regulatory requirement for health care organizations receiving Medicare and Medicaid financing. |
| **QUALITY: Improve Quality of Palliative Care and Hospice Services** |
| **1. Health professional training and certification (Macy 2008; Weissman, Blust 2005; Weissman et al 2007)**<br>o Assure adequate numbers of palliative care teaching faculty in the nation's nursing, social work, chaplaincy, and medical schools through faculty career development awards.<br>o Mandate demonstration of core palliative care competencies at both undergraduate and post-graduate medical, social work, and nursing education levels as a condition of accreditation. |
| **2. Research to strengthen the evidence base (Institute of Medicine 2001; Field, Cassel 1997; Field and Behrman 2003; NIH 2004)**<br>o Designated funding for the NIH, AHRQ and the VA for conduct of research on prevention and relief of pain and other symptoms, and to improve communication, decision support, and care transitions in advanced illness.<br>o Designated funding for Career Development Awards in palliative and hospice care in all appropriate government research funding agencies.<br>o Direct government research funding agencies to develop research Centers of Excellence in Palliative and Hospice Care.<br>o Direct Comparative Effectiveness Research (CER) funding to evaluate palliative care and hospice delivery models, alternative approaches to pain and symptom management, and effective means of communication, decision-support, and transitional care coordination for seriously ill and multiple chronic condition patient populations and their families. |

- Direct the Secretary of Health and Human services to conduct demonstrations and pilot projects testing hospital-, nursing home-, and community-based non hospice and hospice palliative care programs for patients with multiple chronic conditions, functional decline, and/or serious illnesses.
- Direct the DHHS to conduct research and analyses of actual costs of hospice delivery (including travel time, volunteer support, telephone care coordination, and bereavement services) in order to accurately inform payment for the Medicare Hospice Benefit (NHPCO 2010).

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## Table 3
## Opportunities to Strengthen Access to Quality Palliative Care and Hospice in the Affordable Care Act of 2010

| Palliative Care and Hospice Opportunities | Affordable Care Act Provision |
|---|---|
| **Hospice-specific provisions** | 1. Section 3132- Market basket cuts and productivity adjustments for hospice<br>2. Section 3132- Hospice Payment Reform; requires data collection, face-to-face recertification of hospice patients by an MD or nurse practitioner prior to the 180 day limit<br>3. Section 3140- Medicare Concurrent Care Demonstration, allows study of simultaneous hospice and life prolonging treatments under Medicare; 15 sites<br>4. Section 3202- Concurrent (Curative and Palliative) Care for Children in Medicaid and CHIP; October 2013<br>5. Section 3006- Tests of Value-Based Purchasing for Hospice; implementation October 2016<br>6. Section 3004- Quality Reporting mandate to be preceded by hospice and palliative care measure endorsement before October 2012, for implementation October 2013. |
| **Value-Based Purchasing and Pay for Performance** | 7. Section 3001- Establishes VBP for hospital payment based on performance on quality measures.<br>8. Section 3008- Provides for payment penalties for hospital acquired conditions<br>9. Section 3025- Provides for payment penalties for risk adjusted readmission rate<br>10. Section 3005- Establishes VBP for prospective-payment-exempt cancer hospitals.<br>11. Section 3006- Provides for transition to VBP for home health agencies, SNF, ambulatory surgery. |
| **Delivery System Reforms and Coordinated Care** | 12. Section 3022- Medicare Shared savings and Accountable Care Organizations, promote accountability for overall care of a population of patients and incents care processes and coordination focused on quality and efficiency.<br>13. Section 3023- Payment Bundling Pilot, tests impact on quality and cost of a single 'bundled' payment for all aspects of an episode of care. Encourages coordinated community care services and aligns incentives to reduce use of the most expensive setting for care.<br>14. Section 3024- Independence at Home demonstration tests bringing care to the home for the homebound, aligns incentives to coordinate and deliver all care needed, rewards coordination, quality, and maintaining beneficiaries in their homes.<br>15. Section 3026– Community Based Care Transitions, supports payment for care coordination and safe transitions to the community.<br>16. Section 3502- Community Health Teams to Support the Patient-Centered Medical Home. |
| **Innovation/ Cost Control** | 17. Section 3021- Center for Medicare and Medicaid Innovation at CMS, provides capacity to test an array of delivery and payment models designed to strengthen quality and control cost. Successful pilots can be expanded nationwide.<br>18. Section 3403- Independent Medicare Advisory Board, establishes a 15-member group charged with development of legislative proposals to reduce excess Medicare spending and improve quality. |
| **Workforce** | 19. Section 5101- National Health Care Workforce Commission, establishes authority to evaluate adequacy of health workforce; to coordinate Federal, state and local workforce initiatives, and to prioritize workforce investments based on population needs.<br>20. Sections 5201, 5202, 5203- provides for loan repayment and student loan supports. |
| **Quality** | 21. Section 6301- Patient-Centered Outcomes Research<br>22. Section 3011- National Health Care Quality Strategy<br>23. Section 3014- Quality Measurement |

**Note**: Legislative provisions relevant to palliative care and hospice services.

# APPENDIX C
# NATIONAL PRIORITIES PARTNERSHIP

# PALLIATIVE CARE AND END-OF-LIFE CARE DRIVERS AND ACTIONS

# National Priorities Partnership
# Palliative Care and End-of-Life Care Workgroup Draft Action Plan

| | Drivers | | | | |
|---|---|---|---|---|---|
| | **Informed Consumer Decisionmaking** | **Payment Incentives** | **Performance Measurement** | **Accreditation, Certification, and Workforce Development** | **Research** |
| **Recommended Actions** | Increase consumer awareness, education, and access to palliative care and hospice program information through the dissemination resources that better equip patients to be actively involved in their care.<br>Increase consumer awareness to dispel myth that death panels are included in the Affordable Care Act.<br>Formulate comparative information across alternative settings that is available to the public (e.g., quality of palliative care across home health, hospital, nursing home).<br>Tailor public reporting to be more actionable for patient decisionmaking.<br>Target inconsistent messaging to stress that palliative care:<br>» emphasizes the matching of treatment to patient goals;<br>» is not only limited to those who are dying; and<br>» is a continuum that includes, but is not limited to end-of-life care.<br>Create an outlet for the sharing of patient and family experience stories and lessons learned. | Align payment incentives with accountable care organization (ACO) and patient-centered medical home (PCMH) requirements for the capacity to deliver quality palliative care and end-of-life care.<br>Create incentives for the development of advance care planning that is shared and honored across settings (i.e., advance care planning is not another legal document but rather a plan that is jointly developed, and shared and honored across settings).<br>Align payment incentives to ensure completion of advance care planning (e.g., failure to execute advanced care planning should be seen as an error).<br>Promote the formation and support of collaborative and strategic public-private partnerships between providers, health plans, employers, and others. | Advise all stakeholders on which measures most salient to palliative care and end-of-life care should be integrated into ACOs, PCMHs, and bundled payment models.<br>Emphasize the collection of health-related qulaity of life (HRQoL) and functional status data from patients, clinicians and health systems and couple electronic health records (EHR) that contain provider-reported data with patient-generated data on HRQoL and experience.<br>Develop a balanced set of metrics along a continuum that includes:<br>» screening, assessment, care planning, monitoring, and outcomes;<br>» longitudinal measures;<br>» composites (roll up and drill down);<br>» process measures concordant with workflows; and<br>» monitoring of unintended consequences of simplifying a complex interaction.<br>Link process (assessment) and outcome (improvement) measures, e.g., routine pain assessment not associated with higher quality management. | Increase the hospice care and palliative care workforce across settings, (e.g., medical centers, hospices, and long term care settings) to address extremely low patient:provider ratios (1 palliative care medicine specialist per 31,000 people with life limiting illness).<br>Establish alternate pathways for mid-career physicians and allow board certification pathways to be more flexible (e.g., parallel path to executive MBA program).<br>Direct graduate medical education funding to support palliative care training.<br>Establish medical and graduate school loan forgiveness for physicians, advance practice nurses, and clinical social workers who seek subspecialty training in palliative care medicine.<br>Develop expectations of basic palliative care skills for all clinicians (e.g., through maintenance of certification and upstream training). | Increase proportion of National Institutes of Health (NIH) and Agency for Healthcare Research and Quality (AHRQ) funding for palliative care and hospice research (e.g., increase from current 1 percent NIH funding).<br>Conduct translational research to move research into practice.<br>Develop tools and incentives to enable and encourage individuals to have in- depth conversations about their care (e.g., What are triggers for palliative care or hospice care? When should an in-depth conversation take place? Who should initiate it?). |
| **Implementers** | Consumer groups<br>Healthcare professionals and providers<br>Health plans<br>Public and private purchasers | Employers<br>Large provider organizations and hospitals<br>Consumer groups<br>Health plans<br>Public and private purchasers<br>Federal, state, and local government agencies | Measure developers<br>Specialty societies<br>Research community accreditors<br>NQF<br>Public and private funders<br>Quality alliances | Communities and public health agencies<br>Healthcare professionals and providers<br>Health plans<br>Public and private purchasers<br>Policymakers<br>Universities | Communities and public health agencies<br>Consumer groups<br>Healthcare professionals and providers<br>Health plans<br>Public and private purchasers<br>Policymakers |