STATEMENT FROM THE NATIONAL COALITION FOR HOSPICE AND PALLIATIVE CARE
TO THE
INSTITUTE OF MEDICINE (IOM) IN SUPPORT OF RECOMMENDATIONS IN
DYING IN AMERICA: IMPROVING QUALITY AND HONORING PREFERENCES NEAR THE
END OF LIFE

MAY 23, 2016

The National Coalition for Hospice and Palliative Care (Coalition) is strongly committed to working with stakeholders in support of the recommendations contained in the IOM Report: Dying in America: Improving Quality and Honoring Preferences Near the End of Life. The Coalition is composed of the leading national hospice and palliative care organizations dedicated to advancing care of patients and families living with serious and often chronic conditions, as well as those facing the end of life. The organizations that form the Coalition represent more than 4,000 physicians, 11,000 nurses, 5,000 professional chaplains, more than 5,000 social workers, researchers, 1,600 palliative care programs, and over 5,300 hospice programs and related personnel, caring for millions of Medicare beneficiaries. Our combined membership represents the interdisciplinary hospice and palliative care team which is patient and family-centered.

The Coalition commends the IOM for hosting this meeting and the upcoming Roundtable on Quality of Care for People with Advanced Illness and continuing to tackle this critically important issue which impacts, or will impact every person in our society. Guaranteeing and honoring one’s individual goals of care near the end of life should be a right, not a privilege, for all. The research and data presented in the IOM’s seminal report indicate that for millions of Americans their needs near the end of life are not being met. The report recommends transformative changes related to societal views of mortality as well as specific recommendations regarding increasing and improving access to both palliative care and hospice.

The Coalition believes that the message that “early provision of specialty palliative care improves quality of life, lowers spending and helps clarify treatment preferences and goals of care” resonates with key health care decision makers and key opinion leaders.¹ Our Coalition continues to strongly encourage wide dissemination of the IOM Report and recommends action on the recommendations through a variety of legislative and regulatory opportunities. The Coalition has spent the past 18 months working to promote the overarching recommendation that “high quality compassionate, cost effective, person and family centered care should be accessible to anyone with a serious, advanced illness or near the end of life”.² Our first effort was to host a free webinar shortly after publication of the IOM Report for hospice and palliative care providers. Over 1,000 hospice and palliative care providers, including physicians, nurses, chaplains and social workers


² Ibid.
participated and had the opportunity to dialogue with experts in the field, including members of the IOM Committee which drafted this report. The Coalition continues to cite this report in our communications to Congress and in response to various opportunities for public comment to the Department of Health and Human Services, Centers for Medicare and Medicaid Services (CMS) and the National Quality Forum (NQF).

Sample of Current Efforts

Clinician Patient Communication and Advance Care Planning (ACP)
The Coalition was pleased to see that after the release of the IOM Report, and considerable advocacy from the provider and beneficiary community, including our Coalition, CMS began reimbursing for advance care planning services through the Medicare Physician Fee Schedule. Through public comment and other efforts, we continue to advocate that ACP should be conducted through a series of conversations between the health care team and the patient and family, and that these conversations should occur throughout one's life, not just at the end of life. We are currently developing recommendations regarding the need for appropriate training to properly conduct these conversations.

Policies and Payment Systems
The Coalition supports efforts to increase transparency and accountability through public reporting of aggregate quality and cost measures for all aspects of the health care system. Recently, the National Quality Forum (NQF) selected seven of the Coalition’s nominees to serve on the NQF Palliative and End of Life Care Committee, and we will work with this Standing Committee to evaluate new and previously endorsed measures related to palliative and end-of-life care.

Potential Barriers/Opportunities

Lack of Strong Palliative Care Quality Measures
The IOM and the NQF has cited palliative care as a high-leverage measure gap that needs to be addressed through the development and implementation of relevant quality measures. Developing feasible, valid, reliable and actionable quality measures in palliative and end-of-life care is extremely difficult for this complex patient population. However, it is imperative for CMS and other health care entities to support the development of such measures, and ensure that these measures are tested and validated across patient populations and care settings. Critical measure concepts include: occurrence and documentation of patient and family communication about goals of care; occurrence and documentation of a comprehensive symptom assessment; occurrence and documentation of family caregiver needs; and rate of referral to and length of stay in hospice for beneficiaries who die. CMS should focus some of its measure development resources in this area and other funding sources need to be identified and cultivated with a sense of urgency.

Limited Access to Home and Community Based Palliative Care
The Coalition, and our Members, are committed to using the IOM Report to make the case that it is a national call to action to increase access to palliative care and hospice for anyone potentially experiencing a serious advanced illness. With the exception of the Medicare Hospice Benefit, current Medicare and Medicaid infrastructure does not easily provide or pay for palliative care in the community. Hospice and palliative care offer a team-based approach to care through the use of physicians, nurses, social workers and chaplains and other health care professionals as needed. However, only physicians and other qualified health care personnel, such as advanced practice nurses, are reimbursed in Medicare FFS. This means that institutions that provide true interdisciplinary care must find other ways to pay for non-physician providers, generally through a mix of hospital funding and philanthropic support. This can be extremely difficult for community-

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based palliative care programs, but it is critical as many seriously ill patients with multiple chronic conditions do not have adequate support once they leave the hospital, putting them at risk for avoidable crises and readmissions. Expanding early access to palliative care and hospice for Medicare and Medicaid beneficiaries across settings – particularly outpatient clinics, long term care facilities, and the home – will address this gap by increasing care coordination among individual providers, and thus improving outcomes for patients with serious advanced illness. The Coalition will continue to recommend that Congress and CMS consider policy options which would expand reimbursement to include non-physician providers across care settings.

**Future Plans/Priorities**
The Coalition is committed to using the IOM Report as the basis and rationale for numerous public policy positions. We will continue to recommend that policymakers consider options which would provide earlier access to hospice and palliative care for all Medicare and Medicaid beneficiaries with serious illness across all CMS programs.

**Regulatory Opportunities**
CMS recently released a number of proposed rules on programs that present a significant opportunity to further integrate hospice and palliative care into services provided for seriously ill patients (e.g., Hospice, Skilled Nursing Facilities, and Long Term Care Hospitals, Quality Reporting Programs, and MACRA-Medicare Access and CHIP Reauthorization Act). The Coalition will use these comment opportunities to describe the benefits of hospice and palliative care and push for the inclusion of appropriate quality measures in the various quality reporting programs.

**Senate Finance Committee Chronic Care Workgroup**
The establishment of the Senate Finance Committee Chronic Care Workgroup represents an opportunity to improve care for those with multiple chronic conditions, the seriously ill and those at the end of life. As part of our written comments and in-person discussion with the Committee’s staff, we strongly recommended that they utilize the excellent research and recommendations contained in the IOM Report. We especially noted that the lack of access to early hospice and palliative care often leads to burdensome, unnecessary and costly health care transitions for the most vulnerable Medicare beneficiaries. We will continue to monitor the activities of this committee, and advocate for increased access to hospice and palliative care as appropriate.

**Palliative Care and Hospice Education and Training Act (PCHETA)**
The Coalition will continue to communicate the benefits of palliative care to various policymakers such as Congress, CMS, NQF and others. In June, the Patient Quality of Life Coalition will host a joint advocacy day in support of the PCHETA (H.R. 3119/S. 2748). This advocacy day will bring nearly two dozen provider and patient groups to Capitol Hill to advocate for increased access and training of hospice and palliative care providers, increased research focus and priority at the NIH and support for a national awareness campaign for palliative care in multiple settings.

**Conclusion**
The National Coalition for Hospice and Palliative Care, and our member organizations, thank the IOM for your leadership and willingness to engage with the broad stakeholder community and for your dedication to improving the health of those with serious illness and at the end of life. We look forward to future stakeholder engagement opportunities with the IOM, such as the upcoming Roundtable. If you have any questions, please do not hesitate to contact Amy Melnick, Executive Director of the Coalition at amyam@nationalcoalitionhpc.org or 202.306.3590.
ORGANIZATIONS IN COALITION

American Academy of Hospice and Palliative Care (AAHPM)
Association of Professional Chaplains
Center to Advance Palliative Care
Health Care Chaplaincy Network
Hospice and Palliative Nurses Association (HPNA)
National Hospice and Palliative Care Organizations (NHPCO)
National Palliative Care Research Center
Social Work Hospice and Palliative Network (SWPHN)

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