



April 11, 2016

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NQF Palliative and End-of-Life Care Project Team
1030 15th Street, NW Suite 800
Washington DC 20005
Submitted via email: palliative@qualityforum.org

Re: Pre-Meeting Comments on NQF's Palliative and End-of-Life Care Project

Dear Ms. Johnson:

On behalf of the palliative care community, we thank the National Quality Forum for convening its Palliative and End-of-Life Care 2015-2016 Project and for the opportunity to provide preliminary feedback on the palliative and end-of-life care measures that will soon be evaluated by the project's Standing Committee.

The American Academy of Hospice and Palliative Medicine (AAHPM) is the professional organization for physicians specializing in hospice and palliative medicine, and our membership also includes nurses and other health and spiritual care providers committed to improving quality of life for seriously ill patients and their families. We support the pursuit of interdisciplinary, team-based palliative care and its emphasis on care coordination, pain and symptom management, shared decision making, and patient-centered goal-setting. The provision of palliative care has been shown to improve patient experience and satisfaction,ⁱ reduce caregiver burden,ⁱⁱ and increase survivalⁱⁱⁱ; it has also been shown to reduce needless hospital admissions and readmissions through effective care coordination and symptom management^{iv}; and through these gains in quality, it reduces costs.^v

While we do not, at this time, view any of the measures under consideration as particularly controversial, their limited scope reflects the critical ongoing gaps related to palliative and end-of-life care measurement and highlights the unique challenges that have contributed to those gaps. For example, the current set of measures under consideration is largely limited to cancer or hospice settings. These measures employ a narrow denominator (e.g., *hospice* patients rather than *dying* patients). This is certainly a good start, but measuring only hospice patients in order to improve the quality of end-of-life care is like searching for a lost dollar bill only where the light is good. It will not move the needle to the extent that we need it to. The National Hospice and Palliative Care Organization (NHPCO) reports in its *2011 Facts and Figures* that only 42% of those who died in 2010 were enrolled in hospice. How do we measure the quality of end-of-life care for the majority of patients who die in hospitals, skilled nursing facilities, and homes without the benefit of hospice care? These are questions we have not yet been able to answer.

The fact that the current set of measures under consideration by the NQF only includes one new measure (i.e., the Hospice CAHPS) also illustrates that the standard default pathways for measure development, testing, and endorsement are not working for the patients, providers and researchers in our field. Patient and family preferences and experience of care are critical elements of quality palliative care, and ongoing funding, data analysis and personnel are required to develop these kinds of measures and keep them endorsed and in use. For example, the current NQF requirement for measure developers to test survey instrument data elements in addition to the measures themselves (double testing) poses a barrier to advancing the field. While the process of submitting the PEACE measures from the University of North Carolina has gone well because of RTI's support and the national data coming from the Hospice Item Set (HIS), the process that the NQF requires to submit measures is not feasible for the majority of the palliative care field. The absence of a national sample or 100 testing sites should not stand in the way of progress.

Another challenge our field continues to face is the perpetuation of silos in our healthcare delivery system. Since hospitals are designed to treat acute, potentially-reversible problems, they report post-discharge, patient-rated satisfaction surveys that completely miss the experience of the many patients who die during their stay. Likewise, skilled nursing facilities are viewed as places for rehabilitation, so federal reporting mandates focus only on restoration of function, even though many patients languish and die there. Since hospice is the place for dying, that is where the federal government mandates reporting of end-of-life quality measures, but again, that is not going to improve the quality of dying where most of it happens.

We have worked together with other organizations and independently to wade through numerous existing quality measures. Throughout these efforts, we have been struck by how difficult it is to design really good measures that capture the quality of palliative and end-of-life care. We are dismayed by the tendency to pursue and require "measures of convenience" in national reporting programs instead of focusing on fewer measures that really matter to patients. We continue to emphasize that more funding is needed for measure development in our field, as well as assistance from organizations like the NQF to shine a spotlight on measure gaps and encourage collaboration from various stakeholders, such as what's occurring in the NQF's measure incubator project. We encourage the NQF to help advocate for CMS to use the \$75 million allocated by MACRA to invest in activities to fill critical measure gaps in our field and to collaborate with organizations such as ours that can provide appropriate clinical expertise to guide such work.

In late 2013, AAHPM and the Hospice and Palliative Nurses Association (HPNA) – in consultation with the Center to Advance Palliative Care (CAPC), NHPCO, The Joint Commission, the U.S. Department of Veterans Affairs and numerous other stakeholders – initiated the Measuring What Matters (MWM) project, which set forth to produce a consensus recommendation for a portfolio of performance measures that all hospice and palliative care programs could use for program improvement. The goal of MWM was to sort through all relevant published measures and select a concise set that would matter most for patients with palliative care needs across all settings. The belief is that voluntary adoption of these measures broadly in hospice and palliative care could lay the groundwork for benchmarking and meaningful comparison. We are now sorting through and prioritizing what will constitute Phase 2 of the project, which we hope will include more complex tasks, such as creating e-specifications and patient-reported outcome

measures, field-testing altered, expanded and untested measures, and developing a common palliative care denominator.

Given the value of palliative care and our nation's rapidly aging population, there is an urgent need to focus attention on the quality and availability of palliative care services – both for acutely ill patients and older adults with life-limiting diseases. AAHPM continues to highlight the need for a common denominator that comprehensively captures the patient population appropriate for palliative care. No measure currently used under federal quality reporting programs, or recommended for future years, focuses on this population exclusively. For example, there are currently no measures in the PQRS program that specifically address the broad category of palliative care for patients of any age, without being disease-specific. This puts palliative care providers (or really any provider who cares for seriously ill patients across settings) in the difficult position of either having to report on measures that are not clinically relevant, or being subject to CMS review and possible negative payment adjustments despite the high quality of care they provide.

For many years, experts have tried to develop a common denominator that will enable the field to target patients who are most likely to benefit from palliative care. Doing so involves striking the right balance between number and/or type of chronic conditions, extent of functional and cognitive impairments, and overarching quality of life. AAHPM is committed to the goal of transitioning from basic to more meaningful measures that focus on this broader population, important outcomes, care coordination, and patient experience. We have worked with relevant stakeholders to identify a priority list of measures and broader measure concepts that are either not quite ready for accountability purposes or are not necessarily as robust as NQF and CMS request (e.g. process vs. outcomes measures or not grounded in Grade A evidence). However, with some guidance, collaboration, and funded technical assistance, we believe these could evolve into more meaningful and useful measures and help to close the gap in measures that target the palliative care patient population specifically.

We know that NQF is increasingly emphasizing that measures developed from electronic data sources such as electronic health records (EHRs) and Qualified Clinical Data Registries (QCDRs) draw from a rich set of clinical data and can reduce data collection and reporting burden while supporting more timely performance feedback to physicians and other clinicians than is possible through traditional claims- or paper-based measures. While AAHPM agrees with this observation, our specialty has faced challenges in regards to electronic data collection and measure specifications.

The Institute of Medicine's (IOM) 2014 report titled *Dying in America*, recognized that in order to better understand and improve the care received by those at the end-of-life, we need better information about dying and about those with serious illness—not just about the demographic characteristics and health conditions of those who die, but also about their quality of life as they cope with declining health, the quality of the health care provided to them during this time, and the quality of their death. The ability to better capture this data would serve many other specialties, beyond Hospice and Palliative Medicine, and could drive patient-centered and family-oriented quality care. However, most EHRs still do not capture much of what is needed to measure palliative care quality. Processes and programs to develop standardized data elements and corresponding quality measures in partnership with large electronic medical record vendors

(EPIC, Cerner) and other government agencies would spur this development.

We understand that it is not the responsibility of the NQF to solve these broader policy challenges. However, the NQF does have substantial influence over the type and scope of measures ultimately selected for both public and private payer reporting programs and seems to be playing an increasingly larger role in measure “incubation.” We hope that as it continues down those paths that it keep in mind the critical need to accelerate the development and testing of new palliative care and end-of-life care measures that align with the goals of our organizations.

We are also working with the National Coalition for Hospice and Palliative Care (NCHPC) and other organizations in our field on issues and challenges related to measure development. Both the Hospice and Palliative Nurses Association (HPNA) and the Center to Advance Palliative Care (CAPC) endorse these comments at this time.

Thank you again for the opportunity to submit these comments. Please do not hesitate to contact Katherine Ast, AAHPM’s Director of Quality and Research (kast@aahpm.org), if we can provide any additional detail or assistance.

Sincerely,



Christian T. Sinclair, MD, FAAHPM
President
American Academy of Hospice and Palliative Medicine

ⁱ See e.g. MO Delgado-Guay et al. *Symptom distress, interventions, and outcomes of intensive care unit cancer patients referred to a palliative care consult team*, 115(2) *Cancer* 437-45 (2009); David Casarett et al., *Do Palliative Consultations Improve Patient Outcomes?* 56 *J Am Geriatric Soc’y* 593, 597-98 (2008) (discussing results indicating that palliative care improves quality of end of life care).

ⁱⁱ See Laura P. Gelfman et al., *Does Palliative Care Improve Quality? A Survey of Bereaved Family Members*, 36 *J Pain Symptom Manag* 22, 25 (2008) (explaining results showing palliative care consultation services improve family-centered outcomes); P Hudson et al. *Reducing the psychological distress of family caregivers of home-based palliative care patients: short-term effects from a randomized controlled trial*, *Psycho-Oncology* (2013)(Advance online publication. doi: 10.1002/pon.3242) (finding that short palliative interventions can augment caregivers’ feelings of preparedness and competence in supporting a dying relative).

ⁱⁱⁱ See Jennifer S. Temel et al., *Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer*, 363 *New Eng J Med* 733, 739 (2010) (finding that palliative care prolonged survival of cancer patients).

^{iv} See C Nelson et al., *Inpatient palliative care consults and the probability of hospital readmission*, 15(2) *Perm J* 48-51 (2011) (finding that palliative care consultations reduced six month readmissions from 1.15 admissions per patient to 0.7); S Enguidanos et al., *30-day readmissions among seriously ill older adults*. 15(12) *J Palliat Med* 1356-61 (2012) (finding that receipt of palliative care following hospital discharge was an important factor in reducing 30-day hospital readmissions); L Lukas et al., *Hospital outcomes for a home-based palliative medicine consulting service*, 16(2) *J Palliat Med* 179-84 (2013) (finding that total hospitalizations, total hospital days, total and variable costs,

and probability of a 30-day readmission were significantly reduced after enrollment in a home based palliative care program).

^v See R. Sean Morrison et al., *Cost Savings Associated with US Hospital Palliative Care Consultation Programs*, 168 Arch Intern Med 1783, 1785 (2008) (stating "patients receiving palliative care consultation had significantly lower costs" than usual patients who did not); Joan D. Penrod et al., *Hospital-Based Palliative Care Consultation: Effects on Hospital Cost*, 13 J Palliat Med 973, 976 (2010) (finding "palliative care during hospitalizations was associated with significantly lower direct hospital costs."); R. Sean Morrison et al., *Palliative Care Consultation Teams Cut Hospital Costs for Medicaid Beneficiaries*, 30 Health Aff. 454, 457 (2011) (finding overall results show patients who received palliative care had significantly lower costs than patients who did not).