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Via Electronic Submission:
<https://jira.oncprojectracking.org/browse/PCQM>

Re: **Comments on “Access to Quality Advance Directive Care Plans” Electronic Clinical Quality Measure**

Dear Ms. Ward:

Thank you for the opportunity to submit comments on the new measure, “Access to Quality Advance Care Plans”.

The Center to Advance Palliative Care (CAPC) is a national organization dedicated to ensuring that all persons with serious illness have access to quality palliative care, regardless of diagnosis, setting of treatment, or state of the disease. 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. Palliative care is an interdisciplinary, team-based model of care that emphasizes 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

We appreciate that CMS recognizes the importance of advance care planning (ACP) and applaud the steps taken to ensure that these conversations are documented in the electronic health record (EHR). Meaningful Use has driven incremental progress towards the integration of ACP documents in the EHR – specifically the ability to check whether a patient has an advance directive (AD) in Stages 1 & 2 and the ability to store an advance care plan and/or provide a link to an external location

where the document resides in Stage 3. This new proposed measure appears intended to take EHR capability one step further by requiring that providers caring for patients in their last few months of life review the existing ACP documentation in the EHR, confirm the selection of a surrogate, and either make necessary changes or fill remaining gaps in care preferences. Our experience caring for patients with serious illness and their families confirms that proper care planning requires ongoing discussions, since goals of care and treatment preferences often change as patients move along the disease trajectory. Given this, we understand CMS's decision to use hospitalization as a trigger to review ACP documents and make sure they continue to reflect the patients' wishes.

That being said, we have the following concerns about the proposed measure specifications:

The operational definition of "Serious Illness" is problematic, and creates unnecessary confusion in the denominator. The field of palliative care currently uses the term "serious illness" to describe medical diseases and processes that are either life-threatening, life-limiting, or associated with long-term morbidity and impairments of quality life. We take great care to disassociate this phrase from end-of-life, as palliative care is appropriate for any person with serious illness regardless of prognosis. Therefore, **we strongly oppose** the proposed definition of serious illness as one that will "likely cause death and has no or limited effective treatments to reverse the disease course and/or manage disease symptoms". As described, the "Access to Quality Advance Care Plans" measure applies to patients who are far downstream in their disease course with conditions that 1) cannot be treated and 2) will result in the patients' death. **Given this, we urge CMS to change the measure denominator/description to "Terminal Illness"**. This will help clarify the target population for the measure, and reduce confusion for providers who do more upstream care planning.

We also want to highlight that while this downstream measure may serve as a useful trigger for providers to clarify and/or confirm patients' preferences as they enter the last stage of illness, we have reservations that it will yield many of the benefits typically associated with ACP (e.g., fewer hospitalizations, less intensive treatments, more hospice use, reduced costs).^{vi} The measure specifically targets patients who are hospitalized, by design missing the opportunity to develop a care plan that could potentially prevent a number of these hospitalizations in the first place. Furthermore, the measure seems predicated on the fact that a significant portion of the target population will already have some sort of ACP documentation completed and available in the EHR; however, this is not currently the case. **Therefore, we recommend that CMS consider developing a complementary measure that would trigger**

true care planning earlier in the disease course, and be programmed to apply to all patients with serious illness (e.g., patients with multiple chronic conditions, functional and/or cognitive impairment). At a minimum, these conversations should include the following components:

1. What to expect regarding the likely evolution of the patient's disease(s), particularly for patients with debility and dementia;
2. The different treatment options as health changes occur, including their benefits and drawbacks; and
3. Whether the patient would want primarily comfort care, or care focused on prolongation of life under circumstances *when the patient is unable to recognize or interact with loved ones and is not expected to recover.*

Finally, while we understand that the intent of this measure is to make ACP conversations part of the standard of care for patients with terminal illness, it is critical to note that this is still a checkbox measure. By completing the measure in the EHR, providers are asserting that they know who the decision-maker is and whether they have reviewed the paperwork. However, our experience has shown that many providers are more likely to check off the boxes based on answers to a few quick questions, rather than engage in meaningful conversations about the patients' preferences as the disease progresses. **Therefore, we encourage CMS to think about how to better incentivize these conversations and increase EHR capacity to capture the content of ACP discussions.**

Thank you again for the opportunity to submit these comments. Please do not hesitate to contact us or Stacie Sinclair, Policy Manager at Stacie.Sinclair@mssm.edu if we can provide any additional detail or assistance.

Sincerely,



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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).

^{vi} See Silveira MJ, Kim SY, Langa KM. *Advance directives and outcomes of surrogate decision making before death*. *N Engl J Med*. Apr 1 2010;362(13):1211-1218