January 14, 2013

Submitted via www.regulations.gov
Health Information Technology Policy Committee
Office of the National Coordinator for Health Information Technology
Department of Health and Human Services
Patriots Plaza III
355 E Street SW
Washington, DC 20201

> RE: Request for Comment, Stage 3 Meaningful Use, published November 26, 2012 at 77
> Federal Register 70444. Docket ID: HHS-OS-2012-0007

Dear Health Information Technology Policy Committee:

The undersigned member organizations of the National Coalition for Hospice and Palliative Care (NCHPC) appreciate the opportunity to comment on the Policy Committee's proposed recommendations for Meaningful Use Stage 3. The NCHPC is a consortium of the leading hospice and palliative care organizations dedicated to advancing care of patients and families living with chronic, debilitating, and serious or life-threatening illnesses.

Palliative Care is a patient-centered practice focused on providing patients with relief from the symptoms, pain, and stress of a serious illness - whatever the diagnosis and whatever the stage of treatment. Palliative care programs, principles, and approaches have repeatedly been demonstrated to improve quality of care, survival, and quality of life, and to markedly reduce costs. 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.   Current EHR technology and its usage are not optimized to adequately prompt and facilitate these aspects of care. Therefore, in consonance with the HITPC's laudable recommendation that stage 3 be the time to begin to transition from a setting-specific focus to a collaborative, patient- and family- centric approach, NCHPC makes the following comments.

General Comments:

Before addressing specific query numbers, NCHPC would like to make several general comments about utilization of the EHR from the perspective of palliative care providers, and for the benefit of those with serious illness. We note that some of these recommendations, like those regarding advance directives, are appropriate for all adult patients. For others, like goals of care, the fields may be most appropriate only for those with serious illness. To facilitate targeting of the most apt recipients of palliative care, we suggest the possibility of a new objective: Use clinically relevant information stored within the CEHRT to identify patients who should receive palliative care services.

> ➤ In order to utilize EHRs to prevent medical crises through transitions, and to provide better quality *patient* care:

- o **Protocol for handling pain and symptoms**. The EHR must include information on the treatment of the patient's pain and symptoms, and how each provider can help the patient in case of worsening pain. This is particularly important for facilitating successful care transitions. Often, patients are readmitted to the hospital for unmanaged pain because no instructions were communicated to the care team for how to properly handle pain and symptoms.

- o **Contact information in case of crisis**. For patients, leaving the hospital is frightening because once they have left the hospital, neither they nor their community providers may be able to get in contact with the physician who was managing their pain and symptoms. This information must be included in the EHR to ensure proper coordination across settings.

➢ In order to better utilize the EHR to engage patients in their care, and to ensure that patients' wishes are being honored, we make the following recommendations:

- o **Prognosis**. The EHR should contain information about prognosis and what was communicated to the patient regarding prognosis. Providers often fail to record this crucial aspect of treatment, and indeed frequently fail to communicate prognoses to either the patient or the care team. Insisting that this be recorded will greatly enhance communication between providers and facilitate communication with patients. We suggest that the Committee consider the importance of structured data here to facilitate future measurement of communication.

- o **Advance Care Planning Documents**. The EHR should contain all necessary legal documentation of a patient's preferences. This must contain, at a minimum, the identity and contact information of a patient's authorized healthcare decision-maker, any advance directives, and any POLST/ MOLST forms where applicable and available.

- o **Worthy of an alert prompt**. Though we are sensitive to 'alert fatigue' advance care planning represents a basic aspect of proper informed consent, and should be considered a priority in triaging prompting alerts.

- o **Flag of crucial information**. If a healthcare decision-maker has been activated, this should be flagged and highly visible on the homepage of the EHR. If this is not immediately visible, patient safety can be compromised due to confusion regarding consent, and patients may suffer delays in treatment as well as superfluous care transitions.

- o **Goals for care.** Goals for care is an extremely important part of care planning for those with serious illness. Goals of care discussions begin with a question such as "what is most important to you" and focus on patient-centered goals like relief of pain or ability to interact with loved ones. The EHR must be equipped with a space to record what was said in these goals of care conversations and what the agreed upon goals are. This will tremendously aid communication between providers, and its benefit to patients is obvious: a care team that is working together towards a goal—an outcome: high-quality care, as defined by the patient.

  - ▪ The crucial information to be captured in goals of care include:

    - • Did a goals of care discussion occur?

- With whom were the goals of care discussed?
- What providers were present?
- What was discussed?
- What decisions were made?
- What is the care plan in light of those decisions?

- Goals of care can and should be captured as **structured data** so that future measures can be developed related to goals of care that will not require laborious chart abstraction. A measure concept of importance is whether the treatment provided to the patient was in alignment with the stated goals of care, and this measure concept will never be feasible without the necessary EHR infrastructure. To help imagine what this might look like, we cite the below example from an eMOLST[1] form. MOLST forms are only appropriate for those very ill individuals with very poor prognoses, but we cite the below as illustrative of what is possible for goals of care generally. Indeed, forward-thinking health systems are, in concert with their CEHRT vendors, actively developing EHRs that can record goals of care. The meaningful use program should include objectives for health systems who are not so forward-thinking in leveraging EHRs in this way.

Discuss values and beliefs with the person who will make the decision

Review what the patient/family knows and wants to know about the patient's condition/prognosis. Provide new information about the patient's condition/prognosis. Explore common understanding and differences. Determine next steps needed to resolve any differences.

You can identify core patient values and beliefs by asking the patient: "What makes life worth living?" and "What really matters to the person?" Examples of responses include *(Check all that apply)*:

- [ ] Participation in meaningful relationships
- [ ] Not to be a burden to loved ones
- [x] Avoidance of severe discomfort
- [x] Relief of suffering
- [ ] Improvement or maintenance of quality of life
- [ ] Maintenance of personhood
- [x] Achieve a good death
- [x] Support for families and loved ones
- [ ] Other: *Please document additional patient values and beliefs in the box below.*

1. This eMOLST includes a guided and progressive system to draw out the patient's values and goals. This has been developed for a MOLST registry and program in New York State. To learn more about this program, contact Patricia Bomba M.D., at Patricia.Bomba@lifethc.com.

Discuss goals for care with the person who will make the decision

The degree to which the patient is meeting their core values generally determines their goal for care that in turn guides the patient's choice of treatments. Broad categories of goals for care include *Check **one***:

○ Longevity: "Do what is necessary to keep me alive."

○ Functional preservation: "Being independent is most important to me. I want to do as much as I can for myself for as long as I can."

● Comfort care: "I am currently not meeting my core values and have a poor quality of life. Focus solely on my comfort. Longevity at this point may increase my suffering."

○ Other: *Please document additional goals for care in the box below.*

Briefly summarize pertinent content of the discussion.

Mr. Doe's health care agent (his daughter, Nancy) knows that her father would want to be comfortable and ensure his children and grandchildren are supported through the dying process. Nancy wants to make sure her dad has his family around him when he dies.

Specific Comments:

❖ **SGRP 104: Demographics**

  o Committee's Recommendation: To retire current demographic objectives (language, sex, race, ethnicity, DOB) because it is topped out. Add the following objectives: occupation and industry, sexual orientation and gender identity, and disability status.

  o NCHPC comment: We suggest adding several aspects of demographic information that will both have operative value and value for measurement.

    ▪ The patient's authorized healthcare decision maker and contact information.
    ▪ The patient's living situation (i.e. nursing home, independent at home, with family)
    ▪ The family members that are active in the patient's care
    ▪ Insurance status

❖ **SGRP 112: Advance Directive**

  o Committee's Recommendation: the advance directive menu objective/ measure be available to Eligible Providers, and that this be a core measure for eligible hospitals.

  o NCHPC Comment: We strongly support this expansion of the advance directive objective, but note several deficiencies of this objective:

    ▪ It is little use to know that a patient has an advance directive if the advance directive cannot be accessed at the point of care. This objective should include a copy of the advance directive and any other care planning documents, including POLST/ MOLST forms where applicable and available. These legal and care planning documents represent a very low bar for ensuring that providers are informed of patients' care preferences, yet they are absent from most patient health records.

- It is worth explicitly noting that this "advance directive" should include the identity and contact information of a patient's healthcare decision-maker.

- As a final note, it is appropriate for **all adults** to have an advance directive and designation of healthcare proxy on file in the EHR. Because individuals could lose cognitive function at any time and for a number of reasons, it is appropriate for all adults to plan ahead. Thus any measure for this objective should not be restricted to those over age 65.

❖ **SGRP 204B: Patient-generated information.**

o Committee's Recommendation: Provide 10% of patients with the ability to submit patient-generated health information.

o NCHPC Comment: We endorse this objective, and encourage the evidence-based implementation of this functionality, including the use of psychometrically validated instruments, timely reminders, and appropriate recall periods. Patient reported information is critical to assessment and monitoring in palliative care and more widely. The listed objective uses examples of patient-reported data that are qualitative, like recording patient goals and advance directives, but this functionality should also encompass quantitative data such as pain scales, etc. Patient-reported outcomes (PROs) are used increasingly in cancer research and experiences within the research domain can serve as a guide for wider implementation of PROs in everyday patient care. While the research community utilizes some PRO standards tailored specifically for research, there are a number of standards and tools commonly used in oncology that could be used in clinical care including Edmonton Symptom Assessment Scale (ESAS), Patient Care Monitor (PCM), Linear Analog Self-Assessment (LASA) and the MD Anderson Symptom Inventory (MDASI). It is critical that meta-data be attached to any patient-reported data in order to identify the source of the data including, where relevant the tools used for collection.

o Further, though we are unsure of the precise definition of "patient-generated" as used here, we suggest that care planning is a highly interactive process that may be appropriate for this objective. For example, advance directives can be executed electronically by a patient and uploaded directly to the patient's EHR.

❖ **SGRP 304: Care Transitions**

o We strongly support the Committee's proposal on this objective. We comment on the list as follows:

- Medical diagnosis and stages
- Functional status, including ADLs
  - *We also support specific inclusion of cognitive status. This can be a simple check box of yes/no for "cognitive impairment." The recording of presence of cognitive impairment is critical to activation of the surrogate decision maker and alters risks and benefits of a number of medical interventions and decisions. Most people with dementia have no notation of the diagnosis on their medical record in part because physicians are poorly trained in*

> *dementia diagnosis and are loath to discuss the possibility with patient and family because it can be difficult and time consuming conversation.*

- ▪ Relevant social and financial information
  - • *This should include the members of the patient's family or close circle who have been active in his or her care, relevant spiritual beliefs, and insurance status.*
- ▪ Relevant environmental factors impacting patient's health
- ▪ Most likely course of illness or condition, in broad terms
  - • *Should also include what has been communicated to the patient regarding this prognosis.*
- ▪ Cross-setting care team member list, including the primary contact from each active provider setting, including primary care, relevant specialists, and caregiver
  - • *We are particularly supportive of the Committee's inclusion of the patient's caregiver.*
- ▪ The patient's long-term goal(s) for care, including time frame (not specific to setting) and initial steps toward meeting these goals.
  - • *We have noted the importance of this element above, and suggest that the committee consider the value of semi-structured data here.*
- ▪ Specific advance care plan (Physician Orders for Life-Sustaining Treatment (POLST) and the care setting in which it was executed.
- ▪ Notes for additional elements:
  - • *We suggest that code orders from previous hospitalizations be included on this list.*
  - • *For effective transitions, especially those from the hospital to a community or long term care setting, it is essential that providers are informed about how to handle the patient's pain and symptoms, as noted above in our general comments. Often, uncertainty in this area can lead to crises and to needless readmissions.*

- ❖ **SGRP 308: E-Notification of Significant Healthcare Event**
  - o Committee Recommendation: That the EH/CAH will send electronic notification of a significant healthcare event to key members of the patient's care team.

  - o NCHPC comment: The activation of a healthcare decision-maker should be considered a significant healthcare event for this objective.

- ❖ **QMWG16: High priority measure domains**

  - o The EHR is not currently optimized for measuring patient engagement in care, shared decision making, and effective management or relief of pain and symptoms. We hope that effective EHR design will enable measuring whether patient care was concordant with treatment preferences, and whether providers effectively communicated with patients regarding prognoses and patient-centered goals of care.
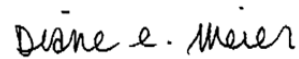
- ❖ **QMWG18: Innovation Track**

o We strongly support allowing health systems, ACOs and other provider networks to utilize the quality measures they have generated locally in lieu of formal MU requirements. The most effective and meaningful measures (and indeed, EHRs) are those that are built by providers for providers. In the integrated care context, there is tremendous incentive to provide high quality episodes of care while reducing wasteful expenditures and these providers are thus developing data and measurement tools to reach those goals. We suspect this is particularly true in the areas of care coordination and shared decision making, as the NQF endorsement process, with its emphasis on setting- and population-specific measures, is not particularly well positioned to handle these new needs for measurement.

We appreciate your consideration of these comments. Should you have questions about these comments, which are endorsed by the signatory organizations listed below, please contact Dale Lupu, PhD, Senior Project Manager, National Coalition for Hospice & Palliative Care, at 301-439-8001 or dlupu@daleviewassociates.com.

Sincerely,

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