June 25, 2018

Ms. Seema Verma  
Administrator  
Centers for Medicare and Medicaid Services  
Department of Health and Human Services  
Attention: CMS-1694-P  
P.O. Box 8013  
Baltimore, MD 21244-8013

Re: Docket No. CMS-1694-P: Medicare Program; Hospital Inpatient Prospective Payment Systems for Acute Care Hospitals and the Long Term Care Hospital Prospective Payment System and Proposed Policy Changes and Fiscal Year 2019 Rates; Proposed Quality Reporting Requirements for Specific Providers; Proposed Medicare and Medicaid Electronic Health Record (EHR) Incentive Programs (Promoting Interoperability Programs) Requirements

Dear Administrator Verma,

On behalf of the Cancer Support Community (CSC), an international nonprofit organization that provides support, education, and hope to cancer patients, survivors, and their loved ones, we appreciate the opportunity to provide comments on the Centers for Medicare & Medicaid Services’ Medicare Program; Hospital Inpatient Prospective Payment Systems for Acute Care Hospitals and the Long Term Care Hospital Prospective Payment System and Proposed Policy Changes and Fiscal Year 2019 Rates; Proposed Quality Reporting Requirements for Specific Providers; Proposed Medicare and Medicaid Electronic Health Record (EHR) Incentive Programs (Promoting Interoperability Programs) Requirements.

As the largest direct provider of social and emotional support services for people impacted by cancer, and the largest nonprofit employer of psychosocial oncology professionals in the United States, CSC has a unique understanding of the cancer patient experience. Each year, CSC serves more than one million people affected by cancer through its network of over 40 licensed affiliates, more than 120 satellite locations, and a dynamic online community of individuals receiving social support services. Overall, we deliver more than $40 million in free, personalized services each year to individuals and families affected by cancer nationwide and internationally. The following comments reflect what we have learned from this frontline experience and captured scientifically through our Cancer Experience Registry, which serves as the cornerstone of our research efforts. Our Registry of over 13,000 individuals allows us to measure what
matters most to patients and caregivers so that we can translate these findings into policy recommendations.

**Background**
The social and emotional impact of cancer is well-documented and CSC supports a comprehensive Medicare program that provides services to evaluate and address the psychosocial aspects of the disease. Nearly half of all cancer patients experience moderate levels of distress (Institute of Medicine, 2008) which has been defined as emotional, social, spiritual, or physical pain or suffering (National Cancer Institute, n.d.). “Cancer patients may have trouble coping with their diagnosis, physical symptoms, or treatment” (National Cancer Institute, n.d., pp. 1) ultimately leading to such distress.

CSC has found that when patients experience distress that interrupts their work, family, or school life, they have an 86% probability of developing a clinical diagnosis of depression (Miller et al., 2016). Patients with depression can have lower rates of treatment adherence (Buzaglo et al., 2014), higher health care utilization rates, and higher annual health care costs (Jeffrey et al., 2011).

Studies have shown that breast cancer patients who were engaged in social and emotional interventions had significant psychological and physiological benefits over those who did not, including survival advantages (1.5 years), reduced risk of recurrence (45%), as well as decreases in anxiety, and fewer symptoms and toxicities from cancer treatment (Andersen et al., 2010, 2008, 2004). This proposed rule provides an opportunity for CMS to include new measures that evaluate whether cancer patients are being screened for distress or receiving a psychosocial assessment and referred to follow-up services.

CSC is pleased to submit comments on the following areas:

*CMS should engage patients in the process of updating measures*
CSC supports CMS’ practice of evaluating existing measures to determine whether some should be retired and others should be added to improve patient-care and provider efficiency and workload. To do so in a meaningful way, CSC recommends that CMS engage patients in the process by surveying patients on which measures are meaningful as well as what aspects of care patients feel should be measured to improve care delivery and patient outcomes. CSC offers ourselves as a resource to aid CMS in surveying patients to identify which types of measures are most meaningful to measuring the patient experience.

*Patient benefit should be prioritized over the cost of measures*
While CSC acknowledges that CMS and the Medicare Program are concerned about costs associated with collecting and reporting data for the program measures, CSC would like CMS to have a stronger emphasis on the outcomes and benefits associated with the measures. CSC supports the addition of measures that will improve patient outcomes as well as those that improve the patient experience and patient quality of life. We encourage CMS to explore the
addition of measures that more accurately touch on the patient experience such as those that measure patient distress for reasons mentioned above.

**Proposed New Quality Measure Beginning With the FY 2021 Program Year: 30-Day Unplanned Readmissions for Cancer Patients (NQF #3188)**

The CSC is supportive of CMS adopting the proposed new measure of 30-Day Unplanned Readmissions for Cancer Patients. The data presented in the Federal Register outlined the reasons why adopting this measure is appropriate for the cancer patient population. Just as with other diagnoses, cancer patients do not want to be in the hospital if they do not need to be and there are steps that health care providers and hospital systems can take to prevent cancer patients from coming back into the hospital following discharge.

As stated in the Federal Register notice, preventing readmissions improves the quality of care for patients: “Unnecessary hospital readmissions also negatively impact cancer patients by compromising their quality of life, placing them at risk for health-acquired infections, and increasing the costs of their care. Furthermore, unplanned readmissions during treatment can delay treatment completion and, potentially, worsen patient prognosis” (p. 20504). Providing and paying for comprehensive, patient-centered care will improve outcomes that matter to patients. The Federal Register notice suggests that if patients are discharged at the appropriate time with meaningful discharge summaries, and with adequate outpatient support to assist them with any issues that may arise (symptom management to address issues such as dehydration as well as social and emotional support services), they will be less likely to be readmitted to the hospital which will improve quality of life for the patient as well as reduce costs to the system (p. 20504).

**PPS-Exempt Cancer Hospital Quality Reporting (PCHQR) Program**

CSC supports empowering patients to use available data to inform decisions about their health care and we recognize that programs such as the PPS-Exempt Cancer Hospital Quality Reporting Program create an infrastructure to collect meaningful data to help patients make such decisions. It is essential that the patient be central to the decisions that CMS is making about what measures to retire and what new measures to adopt. In regards to Factor 8, the proposed additional measure removal factor, CSC would like to know whose benefit is being considered when evaluating whether “the costs associated with the measure outweigh the benefit of its continued use in the program” (p. 20501). There is considerable focus on the cost of the measure but a transparent process must be put in place to weigh the patient benefit against the cost of the measure. CSC appreciates that CMS will propose removing measures based on Factor 8 on a case-by-case basis and we strongly encourage CMS to survey patients to understand whether or not they feel the measures are beneficial. CSC again offers ourselves as a resource to CMS to query patients.
**Possible New Quality Measure Topics for Future Years**

There are many valuable and meaningful measures that are currently being used yet there remains to be a gap in measures that are evaluating the patient experience. As mentioned above, CSC encourages CMS to adopt measures that document whether providers have assessed patients for distress or other measures that comprehensively evaluate the patient experience.

**Possible New Quality Measure Topics for Future Years:**

*Shared Decision-Making Process (NQF #2962)*

Patients should have the opportunity to engage in a shared-decision making process with their provider, other health care professionals, and loved ones. Because treatment decisions are highly personalized, CSC asks that CMS include a measure as to whether or not providers refer patients to use other shared decision making tools such as CSC’s [Open to Options](#) decision support tool to develop a set of personalized questions based on what each individual patient values most (as opposed to the four standard questions in the proposed rule).

*Future Measurement Topic Areas:*

There are some additional measurement areas that would greatly improve general cancer care versus those for cancer-specific clinical conditions. One such area would be a measure around end-of-life conversations. Because cancer patients who are hospitalized tend to have advanced disease, complications, or a very aggressive cancer, it is incredibly important that cancer patients are provided with the tools and resources to engage in shared decision-making around end-of-life decisions. To ensure that patients receive high quality, appropriate care throughout the trajectory of their cancer journey it is essential that they have conversations with their care team and loved ones about what type of care they would like to receive, what they value, and when they would like to transition into hospice or only receive supportive care rather than curative therapy. These conversations are often difficult for providers to have with patients and family members but are essential in providing individualized, high-quality care.

*Requirements for Hospitals to Make Public a List of Their Standard Charges via the Internet*

Patients should have access to information such as standard costs of services that will help them choose where to have their care delivered (should they have the luxury of deciding between different hospitals). CSC is supportive of increased transparency in the health care system to include the costs of services as well as the out-of-pocket costs that patients will be responsible for. Because patient preferences differ, CSC would recommend a measure of asking patients if they would like to speak with their provider about the out-of-pocket costs before receiving a service. In addition to asking a patient if they would like to have this information, CSC also encourages CMS to develop a measure as to whether or not providers have referred patients to external organizations, or connected patients to resources such as those that are offered by CSC.
to help patients better understand their out-of-pocket responsibility and how to include that information in their treatment decision making process.

In addition, CSC would like CMS to adopt a measure of informing patients of their admission status when admitted into the hospital. When patients are admitted for a “short stay,” their out-of-pocket drug costs will be considerably higher once discharged as they will be charged to Medicare Part D rather than their hospital medical benefit.

In summary, CSC would like CMS to consider measures that better evaluate the full patient experience such as distress screening measures and other measure to better understand the social and emotional experiences of the patient. CSC stands ready to assist the agency in identifying measures that meaningfully measure benefits that are valuable to patients.

Sincerely,

Kristen Cox Santiago
Sr. Director, Policy & Advocacy
Cancer Support Community
References


