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June 22, 2015

Senator Orin Hatch  
Chairman, Senate Committee on Finance  
United States Senate  
219 Dirksen Senate Office Building  
Washington, D.C. 20510

Senator Ron Wyden  
Ranking Member, Senate Committee on  
Finance  
United States Senate  
219 Dirksen Senate Office Building  
Washington, D.C. 20510

Senator Johnny Isakson  
Co-Chair, Chronic Care Working Group  
131 Russell Senate Office Building  
Washington, DC 20510

Senator Mark Warner  
Co-Chair, Chronic Care Working Group  
475 Russell Senate Office Building  
Washington, DC 20510

Re: Request for Comments on Ways to Improve Outcomes for Medicare Patients with Chronic Conditions

Dear Chairman Hatch, Ranking Member Wyden, Senator Isakson and Senator Warren:

On behalf of the Cancer Support Community (CSC), an international nonprofit organization that provides support, education and hope to over 1 million people affected by cancer each year, we appreciate the opportunity to respond to your request for comments on ways to improve outcomes for Medicare patients with chronic conditions. We applaud your attempt to achieve bipartisan legislation that will improve the quality of care for Medicare beneficiaries suffering from chronic conditions and to enhance the efficiency of care delivery in Medicare.

The Cancer Support Community respectfully submits the following ideas for your consideration. Our comments detailed below are applicable to the issue areas specified in your request for comment letter. These areas include Medicare fee-for-service reform, Medicare Shared Savings ACO Program modifications, and options for empowering Medicare patients to play a greater role in managing their health care. We believe that there are five components to any policy designed to improve disease management, streamline care coordination, improve quality and reduce Medicare costs.

## **Implementing a Distress Screening Protocol to Improve Psychosocial Assessment**

Psychosocial distress screening is vital to quality health care, yet rarely assessed systematically. Preliminary findings suggest that distress screening with appropriate follow-up care can lead to positive patient-centered outcomes, including improved access to community-based psychosocial services.

According to the Institute of Medicine (IOM), there are more than 14 million cancer survivors in the U.S. today, and at least 50 percent of those suffer from late treatment-related side effects, including physical, psychosocial, cognitive and sexual abnormalities, as well as concerns regarding recurrence and/or the development of new malignancies. Survivors also face issues involving lack of appropriate health maintenance counseling, increased unemployment rate and workplace discrimination. Studies show that the same effects of distress are observed in patients with other chronic illnesses such as diabetes, arthritis and heart conditions, among others. Research shows that distress can negatively affect medical and psychological outcomes and obstruct advancement into long-term survivorship. Screening for psychosocial distress helps people identify their concerns and worries, and voice them with their health care team; it also provides personalized information and support to address each person's specific concerns.

As a fundamental element of comprehensive, quality care, screening for psychosocial distress, referral and follow-up care should be a required component of routine chronic care management as well as a reimbursed service. CSC recommends the implementation of a validated protocol to routinely screen Medicare patients for psychosocial distress and link them with appropriate professional and community resources. The evidence regarding psychosocial intervention on improved patient outcomes and decreased overall costs underscore our recommendation and support total integration of psychosocial distress screening into the overall patient care continuum.

## **Engaging Patients through Long-term Care Planning**

As care becomes more complex with patients living longer with chronic conditions, written care plans should be established at the earliest point in their diagnosis and continue throughout their lives. Care plans should be based on goals of therapy; document treatments received and identify their short-term and long-term patient care needs.

Specifically, cancer research indicates that people who have completed treatment often feel ill-equipped to deal with an array of issues including emotional health, sexual health and understanding their risk for recurrence. In 2005, the Institute of Medicine (IOM) released a seminal report, *From Cancer Patient to Cancer Survivor: Lost in Translation*, which calls for the implementation of survivorship care planning by health care providers that must include intervention for consequences of cancer and its treatment. However, in a recent survey of Commission on Cancer programs (Birken, S., et al., 2014), it was found that fewer than 50 percent of survivors and their primary care providers received a survivorship care plan. The overall lack of implementation of survivorship care planning leaves high risk individuals particularly vulnerable.

The Cancer Support Community believes that a multi-faceted survivorship program for Medicare patients suffering from chronic conditions and their caregivers must be implemented. This program should educate patients and their caregivers about the disease progression, tools to manage one's health post-treatment—including a survivorship care plan, resources available to help cope with the social, emotional and physical impact of the disease and how to communicate and partner with their post-treatment health care team. The goal of a survivorship program is to educate and empower patients to continue to take an active role in their health and survivorship plan as well as to improve coordination of care between specialists and primary care providers to ensure that all of the survivor's health needs are met.

In order to incentivize health care providers to improve care coordination for patients living with chronic conditions it is fundamental to reform Medicare's current fee-for-service program and to offer reimbursement for survivorship planning, as well as consultative time to meet with the patient and caregivers. Survivor care plans are a valuable part of care and deserve to be recognized as such by payers.

### **Engaging Patients in Data Collection to Improve Health Outcomes**

The benefit of psychosocial support as a part of comprehensive cancer care has been well known and documented. Most notably, the Institute of Medicine 2008 report *Cancer Care for the Whole Patient* specifically states, "Today, it is not possible to deliver good quality cancer care without using existing approaches, tools, and resources to address patients' psychosocial health needs."

The current approval process for drugs and medical devices is a very effective way in which to meet this mandate through the incorporation of patient quality of life tools and patient reported outcome measures. Specifically, by integrating routine screening for psychosocial distress into the clinical trial process and required elements for data collection, researchers, patients and policymakers will be able to understand key elements of the patient experience directly related to the clinical approval decision at hand. Moreover, collection and reporting of this data over time will provide the community at large with information that could be used to benefit future clinical trial design.

Research has shown that nearly 50 percent of patients with cancer experience psychological, social, or economic distress, and that this form of distress can have a significant negative effect on the patient's ability to complete a course of therapy. In a clinical trial context, a patient's personal distress level can have a profound effect on the patient's ability to participate in all protocol-mandated visits, tests, treatments and follow-up appointments. Each time a patient is unable to adhere to the requirements of the study, or fails altogether to complete the study, the overall quality and statistical power of the study is weakened. Given that patients have significantly better health outcomes when screened and treated for distress, we believe that distress screening and supportive care will lead to a more efficient use of clinical trial resources and have a positive impact on patient outcomes.

A true focus on patient-centered needs and concerns and the application of evidence-based interventions would dramatically improve participation, outcomes and satisfaction. Therefore, in order to maximize health care outcomes for patients living with chronic conditions, we must do a

far better job of recruiting and retaining patients in clinical trials. This type of intervention would ensure that we are proactively assessing components of care for the whole patient that are often not a part of biomedical assessments, yet have considerable impact on the overall experience.

### **Supporting Shared Decision-Making to Maximize Health Care Outcomes**

As the care for chronic conditions becomes more advanced, decisions faced by patients and families become more complex and often have significant trade-off considerations including efficacy, tolerability, cost and impact to overall quality of life, to name a few. We know from the Cancer Experience Registry—the only Registry of its kind to map the patient experience with cancer—that patients often feel unprepared to make treatment decisions yet they are left to manage the long-term effects of their cancer experience.

Shared decision-making (SDM) is a collaborative process receiving increased attention as providers, policymakers, and consumers explore opportunities to integrate patient-centered concepts into standards of care. SDM is a process that engages patients in a dialogue with their providers to help them select health care options that conform to their values, preferences and financial abilities. SDM honors the patient participation in decisions and is a promising tool for improving quality, reducing unwarranted variation in care, and improving patient satisfaction. Research shows that SDM can reduce over-diagnosis and over-treatment and thereby reduce health care costs.

Our suggestion is to implement a validated tool for shared decision-making into the care process, to ensure that patients have the support and information they need to make the best individualized care decisions, while allowing health care providers to feel confident in the care they prescribe. At the same time, affordability and other access limitations must be minimized in support of patient adherence to the best care plan for him/her. Hence, decisions should be based on evidence specific to the patient's individual clinical, biological and social profile, input from the patient regarding his or her goals of therapy and full disclosure and agreement about the cost implications.

There are a number of elements of the shared decision-making process that can be used as measurable indicators to evaluate the outcomes of the process. These include outcome of a decision, readiness to make a decision and decision quality.

We believe that patients and their providers make health care decisions together. Taking into account the best scientific evidence available, as well as the patient's values and preferences, is a fundamental step to achieve the goals of meaningfully engaging patients with their health care teams, empowering patients to play a greater role in managing their health, and maximizing health care outcomes for Medicare patients living with chronic conditions.

### **Improving Quality of Life through Access to Palliative Care**

The goal of palliative care is to improve the quality of life of patients suffering from chronic conditions, their family members and/or caregivers, by managing all aspects of patients' physical symptoms and psychosocial distress.

Research shows that palliative care improves the quality of care for cancer patients. A 2010 study (Temel, J.S., et al.) comparing individuals with metastatic non-small-cell lung cancer who received palliative care services early after diagnosis, shows that fewer patients who received palliative care developed signs of depression, and the median survival rate was longer for those individuals who received palliative care services.

The use of palliative care has also been shown to reduce health care costs. A 2011 study (Morrison, R.S., et al.) found that Medicaid patients at four New York hospitals, Individuals' whose care is managed by palliative care professionals have reduced re-hospitalizations, spent less time in intensive care, and were less likely to die in the ICU.

Given that palliative care has been shown to improve the quality of care and to reduce health care costs, palliative care should be provided alongside traditional medical care, as needed, from the moment of diagnosis through the remainder of the patient's disease journey by a multidisciplinary health care team. Additionally, palliative care services should be reimbursed at the same payment level as other medical care.

### **Conclusion**

CSC strongly supports access to patient-centered, high quality, comprehensive care for all people. Public policies and health care delivery models should support the patient-physician dialogue and shared decision-making to arrive at evidence-based care plans that incorporate patients' values and preferences. Patients should have access to all treatments deemed appropriate and necessary following an informed, evidence-based dialogue between the physician and the patient that incorporates consideration of the patient's definition of value and the impact of the care plan on the overall patient experience.

We appreciate the opportunity to share our suggestions and look forward to working with you on this important effort.

Sincerely,

A handwritten signature in blue ink that reads "Linda House". The signature is written in a cursive, flowing style.

Linda House, MSM, BSN, RN  
President

## References

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