November 17, 2018

The Honorable Alex Azar
Secretary
United States Department of Health and Human Services
Hubert H. Humphrey Building
200 Independence Avenue SW
Washington, DC 20201

Seema Verma
Administrator
Centers for Medicare and Medicaid Services
Hubert H. Humphrey Building
200 Independence Avenue SW
Washington, DC 20201

Re: Medicare and Medicaid Programs; Regulation to Require Drug Pricing Transparency [83 Fed Reg 52789]

Dear Secretary Azar and Administrator Verma:

On behalf of the Cancer Support Community (CSC), thank you for the opportunity to submit comments regarding Medicare and Medicaid Programs; Regulation to Require Drug Pricing Transparency.

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. Overall, we deliver more than $50 million in free, personalized services each year to individuals and families affected by cancer nationwide and internationally. Additionally, CSC is home to the Research and Training Institute the only entity of its kind focused solely on the experiences of cancer patients and their loved ones. The Research and Training Institute has contributed to the evidence base regarding the cancer patient experience through its Cancer Experience Registry, various publications and peer reviewed studies on distress screening, and the psychosocial impact of cancer and cancer survivorship.

The proposed rule seeks to improve the efficient administration of the Medicare and Medicaid programs by ensuring that beneficiaries are provided with relevant information about the costs of prescription drugs and biological products so they can make informed decisions that minimize not only their out-of-pocket costs, but also expenditures borne by Medicare and Medicaid, both of which are significant problems. The rule, if finalized, would revise the Federal Health
Insurance Programs for the Aged and Disabled by amending Medicare Parts A, B, C, and D, as well as Medicaid to require direct to consumer television advertisements of prescription drugs and biological products for which payment is available (directly or indirectly) through or under Medicare or Medicaid to include the Wholesale Acquisition Cost (WAC or “list price”) of that drug or biological product.

CSC supports the provision of information to patients that allows them to make informed decisions regarding their care and their out-of-pocket cost obligations. We appreciate HHS’ movement towards transparency but we believe that our health care system must become more transparent at every level. It is vital that patients have access to the full range of treatment expenses and potential out-of-pocket costs. This includes not only medication costs, but the costs of various treatment options (such as surgery and radiation in the case of oncology), the costs to obtain services at particular locations (such as large medical centers, community clinics, emergency centers, etc.), and the range of related expenses (such as transportation, supportive care, durable medical equipment, etc.). Further, patients deserve access to information regarding their options for assistance and alternatives. This information must be provided to patients at appropriate reading levels and in a way that they can understand and interpret. Our health care system is not adequately set up to help patients understand this information and take actionable steps, which makes a safety net of patient and financial navigators extraordinarily important.

The proposed rule falls short of providing meaningful and comprehensive information that allows patients to make informed decisions that are right for them. It is unlikely that many patients will be familiar with the role that list prices play in the overall pharmaceutical distribution and insurance chain. Further, many patients will not pay list price for their prescription medications. Patients need access to real world information regarding their anticipated out-of-pocket cost obligations as well as options to help them pay for their care. This is a more complex and nuanced approach than the one proposed by HHS. Ultimately, we are concerned that providing this limited information to patients may be misleading, cause distress, and deter them from seeking appropriate treatment.

Through CSC’s Open to Options decision support counseling program, we work one-on-one with patients to help prepare them for discussions with their health care team regarding what’s important to them. We also hear directly from patients through our affiliate network and our helpline regarding treatment decision-making and out-of-pocket spending. These conversations require far more time and information than can be included in a single DTC ad. For example, cancer treatment is often given in combination therapy. This proposal will not adequately address the complexity and nuance inherent in the treatment of and payment for complex diseases.

Cancer patients make careful treatment decisions in a shared decision making process with their health care team. The potential of a payment code to incentivize health care providers to dialogue with patients regarding their total cost of care would be a welcome development.

In conclusion, we encourage HHS to work with a range of stakeholders, including patient advocacy organizations like CSC, to determine how best to present more robust and nuanced information that will allow patients to make decisions about their care that is tailored to their...
values, needs, and preferences. We ask to serve as a resource to your work. I can be reached at efranklin@cancersupportcommunity.org or 202.650.5369. Thank you for the opportunity to submit these comments.

Sincerely,

[Signature]

Elizabeth F. Franklin, LGSW, ACSW
Executive Director, Cancer Policy Institute
Cancer Support Community Headquarters