



July 23, 2021

The Honorable Xavier Becerra
Secretary
U.S. Department of Health and Human Services
Hubert H. Humphrey Building
200 Independence Avenue, SW
Washington, D.C. 20201

RE: Comments in Response to Request for Information Regarding Reporting on Pharmacy Benefits and Prescription Drug Costs. File Code CMS-9905-NC

Dear Secretary Becerra,

The Cancer Support Community (CSC), an international nonprofit organization that provides support, education, and hope to cancer patients, survivors, and their loved ones, applauds your continued leadership and commitment to patients and caregivers. As the largest provider of social and emotional support services for people impacted by cancer, CSC has a unique understanding of the cancer patient experience. In addition to our direct services, our Research and Training Institute and Cancer Policy Institute are industry leaders in advancing the evidence base and promoting patient-centered public policies.

CSC appreciates the Administration's interest in promoting greater price transparency in health care as a means to promote competition and bring down overall costs. CSC supports and advocates for policies that improve access to and affordability of comprehensive, high-quality health care coverage that includes the ability of all cancer patients to obtain life-saving prescription drugs. It is vital that patients have access to the full range of treatment expenses and their potential out-of-pocket costs. To achieve this goal, we encourage the adoption and implementation of broad and comprehensive reporting requirements presented in patient-friendly language at appropriate reading levels and in a way patients can understand and interpret. This will help increase transparency and decrease patients' out-of-pocket expenses that can otherwise serve as a barrier to the most appropriate care and treatment. When describing the purpose of the reporting requirements, the *Request for Information Regarding Reporting on Pharmacy Benefits and Prescription Drug Costs* (RFI) provides that the Departments and Office of Personnel Management (OPM) are requesting input from the public regarding implementation of the data collection, the data elements to be collected, and the associated impact on plans and issuers. CSC appreciates the outreach to stakeholders but believes the primary use and focus of such data should be its impact on patient access and affordability to potentially life-saving prescription medications as compared to the associated

impact on plans and issuers. While the RFI provides that the Departments and OPM intend to publish the analysis in the required reports in a format that will enable plans and issuers to ultimately negotiate fairer rates and lower costs for participants, beneficiaries, and enrollees, we do not believe that the Departments and OPM's analysis of trends in overall spending on prescription drugs and other health care services by plans and issuers necessarily or accurately reflects the undue and often insurmountable financial burden imposed on patients..

Insurance plan designs are increasingly using utilization management (UM) tools such as prior authorization, step therapy, specialty formulary tiers, and high deductibles with the intent and effect of shifting and thus increasing more of the costs of prescription treatments onto patients to lower expenses paid by the plan. As high-cost prescription specialty medications with no generic alternatives increasingly offer the best treatment for cancer and other serious health conditions, many patients turn to and depend on manufacturer copay assistance to afford and access their medicine.

Much like the increased use of the UM tools mentioned above, plans are now increasingly implementing copay accumulator adjustment programs to shift more of the cost of specialty medications on to patients notwithstanding patients' need for copay assistance to access their medicine. Copay accumulator adjustment programs prevent any copayment assistance from counting toward a patient's deductible or maximum out-of-pocket requirements – thus negating the financial benefit to the patient of such assistance and potentially resulting in the patient being denied access to their medication with there being a direct correlation between patient out-of-pocket cost and treatment adherence. It is important to note that plans accept the patient's copay assistance and collect the high deductible and out-of-pocket maximum again from the patients and families struggling from the financial impacts of a life-threatening health condition. As plans collect from copay accumulator adjustment programs, some patients may abandon their potentially life-saving medication or experience financial toxicity in trying to access their medication while combating their cancer.

The lack of plan transparency regarding the use of copay accumulator adjustment programs adds to the burdens placed upon patients and their family members by these programs. The inconsistent and nondescript terminology used by plans to identify the existence of a copay accumulator adjustment program, as well as the non-pronounced and discreet locations where such programs are located within plan documents leave patients ill-prepared to address the unexpected and immediate need to produce potentially thousands of dollars to gain timely access for cancer treatment. These actions are counter to promoting greater price transparency in health care, especially as it relates to vulnerable patients.

In consideration of the above, CSC urges HHS to:

- Develop consistent, plain, and easy to understand terminology to describe copay accumulator adjustment programs and their impact/implications on enrollees' access to prescription drugs and their deductible and out-of-pocket maximum obligations;

- Require all plans and issuers to prominently display copay accumulator language in the plan documents, including the Summary of Benefits and Coverage available to all prospective plan enrollees, and the medication(s) subject to the copay accumulator adjustment program;
- Require plans to identify and account for the amount of all accepted copay assistance, the name of the medication(s) such copay assistance was accepted for, and the amount the plan thereafter required the patient to pay for the same medication, whether to meet the deductible and/or out-of-pocket maximum.

We appreciate HHS seeking and considering the input and perspectives of patients, caregivers, and those who advocate on their behalf. As the reporting requirements for health plans and issuers are developed and finalized, CSC urges HHS to make patients and their caregivers the primary focus of the implementation of the data collection and the data elements to be collected.

Thank you for the opportunity to comment on this important issue. Please reach out to me at kczubaruk@cancersupportcommunity.org if you have any questions or would like to discuss these comments in more detail.

Sincerely,



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