August 18, 2018

Centers for Medicare & Medicaid Services
Department of Health and Human Services
P.O. Box 8016
Baltimore, MD 21244-8016

Re: Comments on the Section 1115 Demonstration Waiver for Kentucky HEALTH

To Whom It May Concern:

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 Section 1115 Demonstration Waiver request for the Kentucky HEALTH program. Our comments address our concerns with the proposed community engagement and employment initiative, lock-out periods, and increased enrollee cost-sharing that will ultimately limit access to care for low-income individuals in Kentucky living with cancer. For the reasons outlined in this letter, we are opposed to Kentucky’s 1115 waiver request and urge the Centers for Medicare and Medicaid Services (CMS) to reject it.

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 $40 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.

Cancer patients face a wide variety of barriers in access to quality and comprehensive care. Almost all patients report experiencing barriers in accessing care, regardless of their income-level, location, and health plan. Low-income cancer patients however are particularly at risk as they face obstacles in qualifying for, accessing, and maintaining health care coverage for essential services. Of the patients surveyed in the Access to Care in Cancer 2016 study conducted by CSC, only 4.8% had gained access to coverage through Medicaid. Of the patients
who reported being uninsured, 43% said they could not afford health insurance, and 31% said they were not eligible for Medicaid. In Kentucky, more than 428,000 patients gained access to coverage thanks to the expansion of Medicaid. Any additional barriers in access to care for cancer patients will set back progress and harm cancer patients and their families already facing significant difficulty in securing and maintaining coverage while undergoing difficult, life threatening, and time consuming treatment regimens.

I. Work Requirements do not meet the requirements for a Section 1115 Waiver

Federal law does not permit the implementation of work requirements or time limits in the Medicaid program, as the core mission of the Medicaid program is to provide comprehensive health coverage to people whose income and resources are “insufficient to meet the costs of necessary medical services”. Section 1115(a) of the Social Security Act was created to allow the Secretary of the Department of Health and Human Services to waive certain provisions of the Medicaid program as long as the initiative is “likely to assist in promoting the objectives of the program”. The Kentucky Health proposal does not fulfill the requirement as it will create significant access barriers for low-income Kentuckians.

The state proposal references a statement from CMS that “employment provides a sense of purpose, how we contribute to our community, and is associated with positive physical and mental health benefits.” The state is seeking to implement work requirements to promote employment, thereby attempting to improve the overall health and wellbeing of Kentuckians enrolled in the Medicaid program. However, according to a 2017 study by the Kaiser Family Foundation, 8 in 10 Medicaid recipients already live in working families and a majority are working themselves. The Medicaid program is designed to provide coverage for those that are unable for a variety of reasons, to find or maintain employment that can provide for their health care needs. Medicaid enrollees who are not working most often reported that the major impediments to their ability to work included illness, disability, or caregiving responsibilities. In a study done by The Ohio Department of Medicaid, it was reported that three-quarters of Medicaid beneficiaries who were looking for work said that Medicaid made it easier for them to do so. For those who were currently working, more than half said that Medicaid made it easier to keep their jobs.

Health care and the ability to maintain good health is itself critical to an individual’s ability to retain employment. A 2018 Kaiser Family Foundation study concluded that, “access to affordable health insurance has a positive effect on people’s ability to obtain and maintain employment, while lack of access to needed care, especially mental health care and substance abuse treatment, impedes employment.” It goes on to explain that low-income adult Medicaid enrollees have high rates of chronic conditions, and that these individuals are better able to hold a steady job if these conditions are treated or controlled, but work may become impossible if these conditions go untreated. Health setbacks often lead to job loss, which would lead to loss of access to health care and treatment, which would in turn make it more difficult for individuals to retain employment. The Kentucky HEALTH proposal operates under the assumption that steady employment is vital to health, but in reality, Kentuckians, particularly those impacted by cancer, absolutely need access to health care to maintain employment.
II. Vague exemption categories will harm individuals living with cancer

The Kentucky waiver would be disproportionately detrimental to cancer patients and their families. The application outlines 4 categories of enrollees that would be exempt from the requirements, none of which explicitly protect coverage for chronically ill patients or their caregivers. These exceptions are ill-defined and vague, likely leaving many patients unsure of whether they will qualify as exempt. Furthermore, to meet the work requirements, the proposal requires that “able-bodied adult members” must prove that they are employed, seeking work, enrolled as a student full-time, participating in unpaid community service, or a combination of those for 0-20 hours per week. Many individuals living with cancer are not classified as “severe” enough by the Medicaid program to qualify for a disability exemption, but are facing significant health problems that would make it extremely difficult or impossible to fulfill this requirement. Treatment for cancer may not always produce “severe physical or mental impairments” that will easily and explicitly qualify patients for disability, but can greatly impede their health and ability to maintain steady employment. Patients often face symptoms of their disease as well as difficult side effects of medications such as extreme nausea, fatigue, diarrhea or constipation, nerve damage, heart problems, pain, etc.

Cancer patients also depend on caregivers for help coordinating medical care, traveling to and from appointments and treatment, managing finances, and continuing with daily life. The National Alliance for Caregiving estimates that during any given year more than 65 million people in the U.S. spend about 20 hours each week caring for an ill, disabled, or aged family member or friend. These individuals are absolutely vital to the wellbeing of people with cancer, but are still expected to meet work requirements on top of a commitment to unpaid caregiving. Cancer patients, caregivers, and their families should not be subject to fear, uncertainty, and delays in care while attempting to comply with and apply for an exemption from these requirements.

III. Premiums, non-payment penalties, and lock-out periods will create further setbacks to enrollees health and independence

Kentucky’s proposal includes the addition of monthly premium payments of up to 4% of household income as a condition of eligibility. Enrolled adults with income below 100% FPL who are unable to pay their required premiums will be required to pay additional cost-sharing for healthcare services, and if the premiums are unpaid within 60 calendar days from the due date, enrollees face a six-month non-payment lock-out penalty. The increase in the cost-sharing burden placed on patients, coupled with the threat of loss of coverage, has the potential to harm the individuals that the program is intended to serve. A study from the Kaiser Family Foundation on the effects of premiums and cost-sharing on low-income populations (2017) found that premiums serve as a barrier to obtaining and maintaining Medicaid coverage among low-income populations.
individuals. The report goes on to explain that even small levels of cost sharing in the range of $1 to $5 are associated with a reduced use of necessary services, and increased rates of financial burden and uncontrolled disease. The research shows that these financial burdens often force families to cut back on necessities like food and housing in order to retain coverage. Furthermore, the projected savings to the state from the addition of premiums and cost-sharing is ultimately offset by individuals’ increased use of more expensive services, such as emergency room care, to manage unmet health needs.

The proposed cost-sharing increases, in addition to eligibility timelines and lock-out periods, will likely be harmful to individuals living with cancer. Cancer treatment duration can be a few weeks, months, or even years, depending on the individual patient, diagnosis, and treatment plan. Patients who do not qualify for an exemption and are also not able to meet program requirements will be locked out of coverage and unable to re-enroll before waiting six months, possibly interrupting lifesaving medical treatment. Enrollees are given the option to complete a “financial or health literacy course”, and pay the unpaid premiums, to re-join the program at any time, though this requirement is vague and likely unattainable for patients already unable to pay premiums. Further, some patients may be without access to transportation or the technology necessary to complete such a course. A program that was designed provide for the health care needs of low-income individuals without other options, should never be time limited or provisional.

We appreciate the opportunity to provide comments on the Kentucky Section 1115 Waiver Demonstration Request. For the reasons above, we urge the rejection of this proposal, to ensure that vulnerable populations retain access to necessary and affordable healthcare. Please reach out to me at efranklin@cancersupportcommunity.org if you would like to discuss any of the above in more detail.

Respectfully Submitted,

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