July 10, 2019

Secretary Alex Azar
U.S. Department of Health and Human Services
200 Independence Ave SW
Washington, DC 20201

Re: South Carolina 1115 Demonstration Waiver Application—South Carolina Medicaid Community Engagement

Dear Secretary Azar:

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 Community Engagement Section 1115 Waiver application. Our comments address our concerns with the proposed community engagement requirement that will ultimately limit access to care for low-income individuals in South Carolina living with cancer. For the reasons outlined in this letter, as well as previous comments submitted to the state, we have serious concerns with South Carolina’s 1115 waiver request and urge the state to withdraw 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. Any additional barriers in access to care for cancer patients will only serve to 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 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 South Carolina proposal does not fulfi l the requirement as it will create significant access barriers for low-income people in the state.

The state is seeking to implement community engagement requirements, citing a study that found, “Unemployment is generally harmful to health, and is correlated with numerous health challenges.” 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 fi nd 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.

II. Vague exemption categories will harm individuals living with cancer and their caregivers

The South Carolina waiver is likely to be extremely detrimental to cancer patients and their families. The application outlines 11 categories of enrollees that would be exempt from the 80 hour per month work requirements. These exceptions are ill-defined and vague, likely leaving many patients unsure of whether they will qualify as exempt. The proposal includes an exemption for disabled individuals, as well as individuals receiving treatment for cancer, but does not specify the process through which a patient must demonstrate this exemption. Every cancer patient is different and requires a different course of treatment as determined by their healthcare provider. This course of treatment may require a patient to go in and out of active treatment, leaving their ability to qualify for this exemption unclear. We are concerned that the exemptions regarding disabilities and those receiving treatment for cancer may not capture all individuals with a serious health condition that would prevent them from working. The proposal also cites an exemption for individuals living with “medically complex conditions that require multidisciplinary specialized care.” However, there is no further information provided about what is considered “medically complex” or “multidisciplinary”, nor the criteria for this determination. 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 fulfi l these requirements.
Treatment for cancer may not always produce “severe physical or mental impairments” that will easily and explicitly qualify patients for disability or medical frailty, 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.

III. Implementation will create significant administrative burdens and delays in care

South Carolina has suggested significant administrative changes that must be made to effectively implement these requirements, collect data from patients, declare eligibility, and administer care. Effective implementation of these requirements would be a significant burden and cost to the state’s existing Medicaid program, requiring new procedures, system changes, and appeals processes, in addition to the need for additional time and staff to screen, verify, and track compliance. All of these proposed changes require a considerable investment of time and funding to effectively implement and enforce. Lack of appropriate funds and resources in the implementation of this requirement will potentially cause serious delays in access to care and create a significant paperwork burden for both enrollees and the state as they work to satisfy the programs requirements. The state of Arkansas implemented a similar community engagement policy in the last year that required Medicaid enrollees to report their hours worked or document their exemption. During the first six months of implementation, the state terminated coverage for over 18,000 individuals. Furthermore, a recent study published in *The New England Journal of Medicine* from a team of Harvard led researchers found that Arkansas’s implementation of the nation’s first work requirements was associated with “significant losses in health insurance coverage in the policy’s initial six months but no significant change in employment.” An inability to navigate these complex administrative changes and a loss of coverage, even temporarily, could have serious, even deadly, consequences for people with cancer.

The revised waiver application also includes some changes in income levels for certain eligibility groups. Though the Cancer Support Community appreciates these efforts to expand Medicaid coverage, cancer patients would be better served if the state were to expand its Medicaid program to 138% of the federal poverty level ($17,236 for an individual in 2019) which would make coverage available to 240,000 low-income individuals in South Carolina.

IV. Conclusion

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 South Carolina proposal operates under the assumption that steady employment is vital to health, but in reality, low-income residents in South Carolina, particularly those impacted by cancer, absolutely need access to health care to maintain employment.

We appreciate the opportunity to provide comments on the South Carolina Community Engagement Application. For the reasons above, we urge that the state withdraw this proposal, to ensure that vulnerable populations retain access to necessary and affordable healthcare. A program that was designed provide for the health care needs of low-income individuals without other options, should never be provisional based on unattainable goals or detrimental to the health of its citizens. Please reach out to me at efranklin@cancersupportcommunity.org if you would like to discuss any of the above in more detail.

Respectfully Submitted,

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Cancer Support Community
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