June 26, 2020

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

Re: Oklahoma SoonerCare 2.0 Application

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 SoonerCare 2.0 Section 1115 Demonstration Application. While we support Oklahoma’s proposal to expand coverage to low-income adults, including thousands of people impacted by cancer, we urge CMS to reject the SoonerCare 2.0 Demonstration.

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.

CSC is also 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.

Additionally, the CSC Cancer Policy Institute (CPI) brings together patient advocates and policy experts to ensure that the voices of cancer patients and their loved ones play a central role in federal and state legislative, regulatory, and executive policy making. We work in partnership with patient advocates, the CSC affiliate network and RTI, and numerous allied health care and oncology organizations to work towards a future where 15.5 million cancer survivors have access to comprehensive, high-quality, timely, and affordable medical, social, and emotional care.

This proposal would create a capped funding structure which has the potential to reduce patients’ access to critical benefits and services, as well as add administrative and financial barriers to the
Medicaid program. Cancer patients already 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 nearly 900 patients surveyed in the Access to Care in Cancer 2016 study conducted by CSC, 4.8% had health insurance 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.

It is especially dangerous to move forward with this proposal during the current COVID-19 pandemic, as the virus has already put an enormous burden on our nation’s healthcare system, including the Medicaid program. The Kaiser Family Foundation reports that like in past economic downturns, as more individuals lose jobs and income, enrollment and spending in Medicaid grows. COVID-19 is likely to increase the need for Medicaid coverage long-term as well. For the reasons outlined in the comments below, we urge CMS not to approve this SoonerCare 2.0 Demonstration.

Work Requirements

Under the application, individuals between the ages of 19 and 60 be required to prove that they work up to 80 hours per month or meet exemptions. 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 Oklahoma proposal does not fulfil the requirement as it will create significant access barriers for low-income people in the state.

The proposal has failed to address the increased administrative burden on individuals in the Medicaid program. Increasing administrative requirements will likely be a significant burden and cost to Oklahoma’s Medicaid program, as it has the potential to 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 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. Cancer patients who rely on Medicaid for their live saving treatment cannot afford delays in care due to month’s long administrative processes when attempting to comply, or submitting exceptions requests and appeals for a program that they rely on for their health care.
Per Capita Cap

Oklahoma requests to use per capita caps for the expansion populations, however without additional details, it is virtually impossible to offer full, meaningful comment on the many possible impacts of a per capita cap on people impacted by cancer. The proposal provides almost no information about the funding transformation the State seeks and does not explain how the transformation will affect stakeholders from enrollees to health care providers.

As we outlined in our March Statement, CSC opposes Medicaid Block Grants. We are concerned that states, like Oklahoma, will cut coverage completely for certain treatments or impose additional barriers to crucial services—making it more difficult for cancer patients to access the care and medications that they need. For instance, as the gap between the block grant and actual costs of care increases over time, states may feel increasing pressure to implement cost saving measures such as freezing enrollment and/or creating waiting lists, reducing benefits, or increasing cost-sharing for patients.

Retroactive Coverage

Oklahoma proposes eliminating retroactive coverage for enrollees in the Medicaid expansion population, a policy that prevents gaps in coverage by covering individuals for up to 90 days prior to the month of application, assuming the individual is eligible for Medicaid coverage during that timeframe. It is common that individuals are unaware they are eligible for Medicaid until a medical event or diagnosis occurs. Retroactive eligibility allows patients who have been diagnosed with a serious illness, such as cancer, to begin treatment without being burdened by medical debt prior to their official eligibility determination.

Waiving retroactive coverage poses substantial harm for both enrollees and health care providers. People with serious conditions like cancer may have an emergency hospitalization or require other services before they learn they are eligible for, and have had a chance to enroll in, Medicaid expansion. Eliminating that coverage exposes many people to the financial burden of those initial treatment costs.

Premiums and Prescription Drug Access

Oklahoma proposes Medicaid expansion premiums. Under the application, individuals with incomes above 42 percent of the federal poverty level (FPL) would have to pay premiums ranging from $5 ($7.50 for families) to $10 per month ($15 for families). Importantly, individuals could not enroll in coverage or access benefits until they pay their first premium and could lose their coverage after a 90-day grace period if they are unable to pay future premiums. The State also requests flexibility to impose premiums up to 5% of household income – up to $120/month for a family of three at 133% FPL – without requesting an additional amendment to its project.
The premiums can create a major enrollment barrier for individuals who are unable to or do not know how to pay the initial premium. Others could lose coverage due to nonpayment after they enroll. Research has repeatedly confirmed that premiums deter and reduce enrollment among low-income individuals (Artiga, et al., 2017). As noted above, Oklahoma itself predicts that premiums and work requirements will depress enrollment by at least five percent. Recent evidence from states that have enacted similar premium structures indicates the coverage losses would be much higher. For example, when Indiana implemented required premium payments for individuals and households above 100% FPL, 23% of otherwise eligible individuals who were required to pay an initial premium to begin coverage did not pay it, and as a result, did not enroll in coverage (The Lewin Group, 2017). The same study found that another 7% of those who successfully enrolled and had to pay premiums to stay eligible later lost coverage for failing to pay subsequent premiums. In short, we know and have seen that premiums simply reduce enrollment, which is not consistent with the objectives of the Medicaid Act.

Oklahoma’s proposal also requests the flexibility to impose a commercial-style closed formulary on its Medicaid expansion population with only “advance notice procedures”. CSC is concerned that the creation of a limited formulary will severely limit the ability of providers to make the best medical decisions for their patients, based on the patient’s individual needs. A formulary that may only cover one or two drugs in a class could harm patients and potentially raise medical costs as patients do not react, or react poorly, to the limited medications that can be prescribed to them. This is particularly true for cancer patients who often receive personalized or combination therapy. Rather, providers should be prescribing based on clinical guidelines and a shared decision-making process with the patient. The closed formulary has the potential to create delays in appropriate care, cause patients to forgo care completely, increase patient distress, and ultimately even contributing to higher health care costs. In the CSC Access study (2016) referenced above, we found that 25% of patients experience delays in accessing needed care (due to policy barriers such as prior authorization or step therapy), with Medicaid patients experiencing the greatest care delivery delays. We are concerned that the proposed exceptions process outlined in the waiver amendment simply cannot ensure uninterrupted access to needed drugs, particularly for patients living with cancer or other life-threatening diseases.

Medicaid Benefits

Oklahoma’s application also jeopardizes access to vital services for those served by the Medicaid program, particularly those with serious and chronic diseases like cancer.

Oklahoma proposes to exclude coverage of non-emergency medical transportation (NEMT) for the Medicaid expansion population. NEMT is essential for many individuals enrolled in the Medicaid program. Transportation barriers pose a significant problem for many low-income individuals and families, particularly people with disabilities. Research shows that NEMT significantly improves access to health care and is cost-effective for states (Hughes-Cromwick et al, 2008). Transportation barriers are often associated with reduced medication adherence (Welty et al, 2010), and studies demonstrate that enrollees with chronic conditions are more likely to participate in care-management visits when they have access to reliable transportation (Kim et al., 2009). In addition, by reducing costly hospitalizations and emergency department visits due
to delayed or foregone care, NEMT can actually save states money (Hughes-Cromwick et al, 2008).

Data from Iowa has shown that individuals have missed medically necessary appointments or reported unmet health needs due to transportation barriers (Bentler et al, 2016). Notably, people in relatively poorer health with multiple physical ailments were all much more likely to report unmet transportation needs (Bentler et al, 2016). Women, people of color, and younger enrollees were also significantly more likely to face these barriers. We are concerned that eliminating NEMT in Oklahoma has the potential to lead to unmet care needs and to exacerbate health disparities in the state.

Additionally, Oklahoma proposes to waive Early and Periodic Screening, Diagnosis and Treatment (EPSDT) services for individuals in the expansion population aged 19 and 20. Congress included EPSDT in the Medicaid program to provide comprehensive coverage of screening, diagnosis and treatment services for individuals under the age of 21. EPSDT provides an opportunity to identify significant health conditions, allows for early intervention, and can dramatically improve health outcomes. Eliminating EPSDT may lead to unmet care needs, leaving young adults without necessary screening and treatment services that could help prevent more serious and costly conditions as they age.

**Conclusion**

Simply put, the core objective of the Medicaid program is to furnish healthcare to people living with limited incomes and this demonstration undercuts this goal. We are concerned that the demonstration application will jeopardize beneficiaries’ access to care. For the reasons we outlined above we urge CMS not to approve this SoonerCare 2.0 Demonstration.

Access to quality, comprehensive, and affordable healthcare is critically important for Oklahomans living with cancer, and we strongly continue to support Medicaid expansion in Oklahoma. However, a program that was designed to 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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References


