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January 17, 2019

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

**Re: SoonerCare 1115(a) Research and Demonstration Waiver Amendment Request  
Project Number: 11-W-00048/6**

Dear Secretary Azar:

The American Cancer Society Cancer Action Network (ACS CAN) appreciates the opportunity to comment on Oklahoma's SoonerCare Section 1115 research and demonstration waiver amendment request. ACS CAN is making cancer a top priority for public officials and candidates at the federal, state, and local levels. ACS CAN empowers advocates across the country to make their voices heard and influence evidence-based public policy change as well as legislative and regulatory solutions that will reduce the cancer burden. As the American Cancer Society's nonprofit, nonpartisan advocacy affiliate, ACS CAN is critical to the fight for a world without cancer.

ACS CAN supports Oklahoma's goal to improve health outcomes for Medicaid beneficiaries in the Parent or Caretaker Relative (POCR) SoonerCare program. Unfortunately, we believe the proposed work and community engagement requirement could negatively impact the adult Medicaid POCR population, particularly cancer patients, survivors, and those who will be diagnosed with cancer in their lifetime. Over 20,500 Oklahomans are expected to be diagnosed with cancer in 2019<sup>1</sup> and there are over 189,500 cancer survivors in the state<sup>2</sup> – many of whom will receive health care coverage through the SoonerCare program. ACS CAN wants to ensure that cancer patients and survivors in Oklahoma will have adequate access and coverage under the Medicaid program, and that specific requirements do not create barriers to care for low-income cancer patients, survivors, and those who will be diagnosed with cancer.

The proposed Medicaid work and community engagement requirement could limit eligibility and access to care for some of the most vulnerable Oklahomans, including those with cancer, cancer survivors, and those who will be diagnosed with the disease. We strongly urge the Centers for Medicare and Medicaid Services (CMS) address the concerns that we and other stakeholders have or reject this waiver in its current form.

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<sup>1</sup> American Cancer Society. *Cancer Facts & Figures 2019*. Atlanta, GA: American Cancer Society; 2019.

<sup>2</sup> American Cancer Society. *Cancer Treatment & Survivorship Facts & Figures 2016-2017*. Atlanta, GA: American Cancer Society; 2018.

The following are our specific comments on the Oklahoma Health Care Authority's ("OHCA") SoonerCare 1115 waiver amendment request:

### **Community Engagement Requirement**

Oklahoma's waiver includes the requirement that all "able-bodied" adults aged 19 through 50 years must be employed or participating in job search/training or community service activities for 80 hours per month to maintain eligibility or enrollment in the Medicaid program. This policy could unintentionally disadvantage patients with serious illnesses, such as cancer. While we understand the intent of the proposal is to "increase employment and community engagement" among Medicaid enrollees, many cancer patients in active treatment are often unable to work or require significant work modifications due to their treatment.<sup>3,4,5</sup>

ACS CAN opposes tying access to affordable health care for lower income persons to work or community engagement requirements, because cancer patients, survivors, and those who will be diagnosed with the disease – as well as those with other complex chronic conditions – could be seriously disadvantaged and find themselves without Medicaid coverage because they are physically unable to comply. Research suggests that between 40 and 85 percent of cancer patients stop working while receiving cancer treatment, with absences from work ranging from 45 days to six months depending on the treatment.<sup>6</sup> Recent cancer survivors often require frequent follow-up visits and maintenance medications to prevent recurrence,<sup>7</sup> and suffer from multiple comorbidities linked to their cancer treatments.<sup>8,9</sup> Cancer survivors are often unable to work or are limited in the amount or kind of work they can participate in because of health problems related to their cancer diagnosis.<sup>10,11,12,13</sup> If work and/or participation in community engagement activities is required as a condition of eligibility, many cancer patients, recent survivors, and those with other chronic illnesses could become ineligible for the lifesaving treatment

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<sup>3</sup> Whitney RL, Bell JF, Reed SC, Lash R, Bold RJ, Kim KK, et al. Predictors of financial difficulties and work modifications among cancer survivors in the United States. *J Cancer Surviv.* 2016; 10:241. doi: 10.1007/s11764-015-0470-y.

<sup>4</sup> de Boer AG, Taskila T, Tamminga SJ, et al. Interventions to enhance return to work for cancer patients. *Cochrane Database Syst Rev.* 2011; 16(2): CD007569. doi: 10.1002/14651858.CD007569.pub2.

<sup>5</sup> Stergiou-Kita M, Pritlove C, van Eerd D, Holness LD, Kirsh B, Duncan A, Jones J. The provision of workplace accommodations following cancer: survivor, provider, and employer perspectives. *J Cancer Surviv.* 2016; 10:480. doi:10.1007/s11764-015-0492-5.

<sup>6</sup> Ramsey SD, Blough DK, Kirchoff AC, et al. Washington State Cancer Patients Found to be at Greater Risk for Bankruptcy than People Without a Cancer Diagnosis," *Health Affairs*, 32, no. 6, (2013): 1143-1152.

<sup>7</sup> National Cancer Institute. *Coping with cancer: Survivorship, follow-up medical care.* Accessed December 2018. <https://www.cancer.gov/about-cancer/coping/survivorship/follow-up-care>.

<sup>8</sup> Mehta LS, Watson KE, Barac A, Beckie TM, Bittner V, Cruz-Flores S, et al. Cardiovascular disease and breast cancer: Where these entities intersect: A scientific statement from the American Heart Association. *Circulation.* 2018; 137(7): CIR.0000000000000556.

<sup>9</sup> Dowling E, Yabroff R, Mariotto A, et al. Burden of illness in adult survivors of childhood cancers: Findings from a population-based national sample. *Cancer.* 2010; 116:3712-21.

<sup>10</sup> Ibid.

<sup>11</sup> Guy GP Jr, Berkowitz Z, Ekwueme DU, Rim SH, Yabroff R. Annual economic burden of productivity losses among adult survivors of childhood cancers. *Pediatrics.* 2016; 138(s1):e20154268.

<sup>12</sup> Zheng Z, Yabroff KR, Guy GP Jr, et al. Annual medical expenditures and productivity loss among colorectal, female breast, and prostate cancer survivors in the United States. *JNCI J Natl Cancer Inst.* 2016; 108(5):djv382.

<sup>13</sup> Kent EE, Davidoff A, de Moor JS, et al. Impact of sociodemographic characteristics on underemployment in a longitudinal, nationally representative study of cancer survivors: Evidence for the importance of gender and marital status. *J Psychosoc Oncol.* 2018; 36(3):287-303.

services provided through Medicaid. We also note that imposing work or community engagement requirements on lower income individuals as a condition of coverage could impede individuals' access to preventive care, including cancer screenings.

We appreciate the State's acknowledgement that not all people are able to work and the decision to include several exemption categories and "good cause" exemptions from the community engagement requirement and associated termination from the program. However, we are concerned that the waiver does not go far enough to protect vulnerable individuals, including cancer patients, recent cancer survivors, those with conditions that put them at risk for cancer, and other serious chronic diseases often linked to cancer treatments.<sup>14,15</sup> SoonerCare's eligibility is restricted to parents or caretakers at or below 45 percent of the poverty line, or \$779 per month for a family of three.<sup>16</sup> Requiring POCR enrollees to work 80 hours per month could result in a number of individuals earning an income that exceeds the SoonerCare income eligibility requirements, but not qualify for subsidies for insurance coverage through the individual insurance market. This could cause POCR enrollees that are able to comply with the community engagement requirement to be disenrolled from the SoonerCare program and find themselves without access to affordable health care coverage. While we appreciate that the State clarified that enrollees whose income increases over 100 percent of the FPL but is less than 185 percent of the FPL may qualify for Transitional Medical Assistance (TMA), eligibility for TMA is not guaranteed and individuals and their families could still find themselves without affordable health care coverage. The increase in administrative requirements for enrollees to attest to their working status and exemptions on a monthly basis would likely decrease the number of individuals with Medicaid coverage, regardless of whether they are exempt.<sup>17</sup>

As an example, in the sixth month of implementation of the *Arkansas Works* work requirement (November 2018) only 14 percent of the over 9,800 Medicaid enrollees, who did not declare an exemption, were able to navigate the complex reporting system and satisfy the state's reporting requirement.<sup>18</sup> As of January 7, 2019 (the seventh month of implementation), an additional 1,232 *Arkansas Works* enrollees were locked out of coverage through the end of the calendar year due to noncompliance with the work requirement.<sup>19</sup> The number is in addition to the 16,932 individuals the state removed from the program in the last four months, totaling 18,164 Arkansans losing coverage

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<sup>14</sup> Dowling E, Yabroff R, Mariotto A, et al. Burden of illness in adult survivors of childhood cancers: Findings from a population-based national sample. *Cancer*. 2010; 116:3712-21.

<sup>15</sup> Mehta LS, Watson KE, Barac A, Beckie TM, Bittner V, Cruz-Flores S, et al. Cardiovascular disease and breast cancer: Where these entities intersect: A scientific statement from the American Heart Association. *Circulation*. 2018; 137(7): CIR.0000000000000556.

<sup>16</sup> Henry J Kaiser Family Foundation. Medicaid income eligibility limits for adults as a percent of the federal poverty level. Published January 1, 2018. Accessed December 2018. <https://www.kff.org/health-reform/state-indicator/medicaid-income-eligibility-limits-for-adults-as-a-percent-of-the-federal-poverty-level/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D#note-11>.

<sup>17</sup> Garfield R, Rudowitz R, Musumeci M. Implications of a Medicaid work requirements: National estimates of potential coverage losses. Kaiser Family Foundation. Published June 2018. Accessed December 2018. <http://files.kff.org/attachment/Issue-Brief-Implications-of-a-Medicaid-Work-Requirement-National-Estimates-of-Potential-Coverage-Losses>.

<sup>18</sup> Arkansas Department of Human Services. Arkansas Works Program: November 2018 Report. Accessed December 2018. [https://humanservices.arkansas.gov/images/uploads/newsroom/181217\\_AWreport.pdf](https://humanservices.arkansas.gov/images/uploads/newsroom/181217_AWreport.pdf).

<sup>19</sup> Arkansas Department of Human Services. Arkansas Works Program: December 2018 Report. Accessed January 2019. [https://humanservices.arkansas.gov/images/uploads/011519\\_AWReport.pdf](https://humanservices.arkansas.gov/images/uploads/011519_AWReport.pdf).

since September 2018. Some of these individuals may have been eligible for an exemption but did not realize they were exempt or were unable to successfully navigate Arkansas' reporting system. Given the experience with Arkansas' work requirement, CMS should consider the number of Oklahomans whose health could be negatively impacted and the coverage losses that could occur due to this proposal.

#### *Termination or Suspension from Medicaid Program*

We are deeply concerned about the proposed Medicaid coverage termination or suspension period for non-compliance with the work requirement. The OHCA offers a compliance grace period of 90 days for enrollees before terminating coverage for at least a 30-day period. Beneficiaries may reapply for Medicaid after the 30-day lockout period if they comply with community engagement activities for the specified number of hours in the State's phased-in approach or prove an exemption status. The OHCA offers individuals who have failed to participate in the requirement a fair hearing to appeal a denial or termination of Medicaid benefits, but it is unclear how long the appeals process would take and whether the beneficiary would lose health coverage during the process. If individuals are locked out of coverage for the 30-day period or during any appeals process they will likely have no access to affordable health care coverage, making it difficult or impossible for a cancer patient or recent survivor to continue treatment or pay for their maintenance medication until they come into compliance with the requirement or they are determined to be exempt. This is particularly problematic for cancer survivors who require frequent follow-up visits and maintenance medications as part of their survivorship care plan to prevent recurrence<sup>20</sup> and who suffer from multiple comorbidities linked to their cancer treatments.<sup>21</sup> It may also be a problem for individuals in active cancer treatment who may not realize they are exempt. Being denied access to one's cancer care team could be a matter of life or death for a cancer survivor and the financial toll that the termination or suspension would have on individuals and their families could be devastating.

#### *Workforce Engagement Requirement Does Not Meet CMS Criteria*

We note that the OHCA failed to provide coverage loss estimates in the waiver, stating that they are still analyzing how many beneficiaries would be impacted by the waiver. Federal rules for the state public notice process for 1115 waivers require states to include, "an estimate of the estimated increase or decrease in annual enrollment" and expenditures for the demonstration requested by the State.<sup>22</sup> This allows stakeholders and CMS to adequately assess the impact the demonstration waiver may have on state residents. Therefore, we strongly urge CMS to require the State to include these projections, as required by federal law, so that the public has an opportunity to comment on the impact of the proposed waiver demonstration with adequate information.

#### **Conclusion**

We appreciate the opportunity to provide comments on Oklahoma's SoonerCare Section 1115 demonstration waiver application. The preservation of eligibility and coverage through Medicaid remains critically important for many low-income Oklahomans who depend on the program for cancer

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<sup>20</sup> National Cancer Institute. *Coping with cancer: Survivorship, follow-up medical care*. Accessed January 2019. <https://www.cancer.gov/about-cancer/coping/survivorship/follow-up-care>.

<sup>21</sup> Mehta LS, Watson KE, Barac A, Beckie TM, Bittner V, Cruz-Flores S, et al. Cardiovascular disease and breast cancer: Where these entities intersect: A scientific statement from the American Heart Association. *Circulation*. 2018; 137(7): CIR.0000000000000556.

<sup>22</sup> 42 CFR 431.408 (a)(1)(i)(C).

prevention, early detection, diagnostic, and treatment services. We ask CMS to weigh the impact that this policy proposal may have on access to lifesaving health care coverage, particularly for those individuals with cancer, cancer survivors, and those who will be diagnosed with cancer during their lifetime.

Our comments include numerous citations to supporting research, including direct links to the research for the benefit of CMS in reviewing our comments. We direct CMS to each of the studies cited (please see attached addendum) and we request that the full text of each of the studies cited, along with the full text of our comments be considered part of the administrative record in this matter for purposes of the Administrative Procedure Act.

Maintaining access to quality, affordable, accessible, and comprehensive health care coverage and services is a matter of life and survivorship for thousands of low-income cancer patients and survivors, and we look forward to working with the Administration to ensure that all Americans are positioned to win the fight against cancer. If you have any questions, please feel free to contact me or have your staff contact Michelle DeFavero of our policy team at [Michelle.DeFavero@cancer.org](mailto:Michelle.DeFavero@cancer.org) or 202-585-3266.

Sincerely,

A handwritten signature in black ink, appearing to read "Lisa Lacasse". The signature is written in a cursive, flowing style.

Lisa Lacasse  
Senior Vice President, ACS CAN Strategy & Operations