American Cancer Society
Cancer Action Network
555 11th Street, NW
Suite 300
Washington, DC 20004
202.661.5700
www.fightcancer.org

September 3, 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: Utah 1115 Demonstration Waiver Application: Per Capita Cap

Dear Secretary Azar:

The American Cancer Society Cancer Action Network (ACS CAN) appreciates the opportunity to comment on Utah's 1115 Demonstration Per Capita Cap Application. 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 appreciates Utah's goal of lowering the rate of uninsured low-income Utah residents, but there are several proposals included in the current waiver – as well as their previous waiver – that cause us serious concern. Over 11,600 people in Utah are expected to be diagnosed with cancer this year[1] and there are nearly 116,000 cancer survivors in the state[2] – many of whom rely on Medicaid or would greatly benefit from receiving their health care through a full expansion of the program. ACS CAN wants to ensure that cancer patients and survivors have adequate access and coverage and that specific requirements do not create barriers to care for low-income cancer patients, survivors, and those who will be diagnosed with cancer. Therefore, we strongly urge the Centers for Medicare and Medicaid Services (CMS) reconsider moving forward with the previous accepted and currently proposed waivers until stakeholder concerns are addressed.

We reiterate our concerns with recently adopted proposals, including the enrollment limits, community engagement requirements, and the employer sponsored insurance (ESI) proposal highlighted below and how these proposals will interact with the policy proposals at issue under the current proposed waiver:

[1] American Cancer Society. Cancer Facts & Figures: 2019. Atlanta: American Cancer Society, 2019.
[2] American Cancer Society. *Cancer Treatment & Survivorship Facts & Figures 2019-2021*. Atlanta, GA: American Cancer Society; 2019.

Enrollment Limits for the Limited Expansion Group

We remain concerned with the establishment of an enrollment limit on the Adult Expansion demonstration group. An enrollment limit could adversely impact providers and prevent eligible individuals, such as cancer patients and survivors, from receiving critical health care and treatment services. For instance, it is unclear how an enrollment limit would work with retroactive eligibility, which allows hospitals and providers to retroactively enroll eligible low-income, uninsured individuals into the Medicaid program. Instead of being cost effective for the State, enrollment limits could instead increase uncompensated care, as individuals would assume they are eligible for Medicaid, but are not given coverage.

Community Engagement through a Self Sufficiency Requirement

ACS CAN opposes tying access to affordable health care for lower income persons to work or community engagement requirements because cancer patients, survivors, 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 shows 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.[3] Recent cancer survivors often require frequent follow-up visits and maintenance medications to prevent recurrence,[4] and suffer from multiple comorbidities linked to their cancer treatments.[5,6] Some 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.[7,8,9,10] If work and community engagement is required as a condition of eligibility, many cancer patients, recent survivors, and those with other chronic illnesses could find that they are ineligible for the lifesaving care and treatment services provided through the state's Medicaid program. We also note that imposing work or community engagement requirements on lower income individuals as a condition of coverage could impede rather than improve 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 lock-out period. However, the waiver does not go far enough to protect

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[3] Ramsey SD, Blough DK, Kirchhoff AC, et al. Washington State Cancer Patients Found to be at Greater Risk for Bankruptcy then People Without a Cancer Diagnosis," Health Affairs, 32, no. 6, (2013): 1143-1152.

[4] National Cancer Institute. *Coping with cancer: Survivorship, follow-up medical care*. Accessed August 2019. https://www.cancer.gov/about-cancer/coping/survivorship/follow-up-care.

[5] 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.

[6] 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.

[7] Ibid.

[8] 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.

[9] 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.

[10] 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.

vulnerable individuals, including recent cancer survivors and other serious chronic diseases often linked to cancer treatments.[11,12] Additionally, the increase in administrative requirements for enrollees to attest to their work or exemption status would likely decrease the number of individuals with Medicaid coverage even more, regardless of whether they are exempt.[13,14]

There are lessons to be learned from the Arkansas work requirement which resulted in uninsured rates being driven up and employment actually declining in the state.[15] CMS should carefully analyze the data from Arkansas and consider the number of Utahans whose health could be negatively impacted, and coverage lost due to the Utah work requirement proposal. Additionally, it is clear from this preliminary data from Arkansas that the work requirements are not meeting the state's goal of incentivizing employment and increasing the number of employed Arkansas Works beneficiaries. A goal that Utah also states in their waiver.

Lock-out Period
We oppose the proposed lock-out period for non-compliance with the work or community engagement requirement. The Utah Department of Health ("the Department") offers individuals who have failed to participate in the requirement "good cause" exemptions, but it is unclear how long the appeals process would take and whether the beneficiary would lose health coverage during the process. This could be devastating to the health outcomes of a person in active cancer treatment.

Those with acute and chronic health care conditions who apply for an exemption to avoid the lock-out period will still have to verify their exemption and undertake a burdensome documentation process. This could lead to instances where those who should be able to maintain coverage are disenrolled, jeopardizing access to life-saving treatment. If individuals are locked out of coverage, 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[16] and who suffer from multiple comorbidities linked to their cancer treatments.[17] It may also be a problem for individuals in active cancer treatment who may

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[11] 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.
[12] 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.
[13] 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 August 2019. http://files.kff.org/attachment/Issue-Brief-Implications-of-a-Medicaid-Work-Requirement-National-Estimates-of-Potential-Coverage-Losses.
[14] Sommers BD, Goldman AL, Blendon RJ, et al. Medicaid work requirements – Results from the first year in Arkansas. *NEJM*. 2019. DOI: 10.1056/NEJMsr1901772.
[15] Ibid.
[16] National Cancer Institute. *Coping with cancer: Survivorship, follow-up medical care*. Accessed August 2019. https://www.cancer.gov/about-cancer/coping/survivorship/follow-up-care.
[17] 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.

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 patient or survivor; additionally, the financial toll that the lock-out would have on individuals and their families could be devastating.

Employer Sponsored Insurance

In our comments on the initial proposal, we commended the State for offering individuals in the demonstration group premium reimbursement and wrap-around coverage for their ESI. But we had several clarifying questions about the requirement that individuals enroll in their ESI or be ineligible for Medicaid. These questions were not fully answered in the State's responses to stakeholders. Therefore, it was premature for CMS to approve this proposal until stakeholder questions were answered. We urge CMS to consider stakeholder comments, particularly since the state now estimates that approximately 10,000 to 14,000 individuals would be impacted by this proposal.[18]

Current Proposals

We are extremely concerned with the proposals discussed in the current 1115 waiver application and how these proposals will interact with the ones previously approved by CMS in March.

Per Capita Cap for Low-income Adult Populations

We strongly urge CMS to reject the per capita cap proposal for the partial expansion adults with dependent children, partial expansion adults without dependent children, and the targeted adult populations, which would reportedly impact over 80,000 partial expansion adults. This proposal would fundamentally alter the Medicaid program in Utah, shifting the funding from a percentage match, wherein the program's funding adjusts automatically to account for the number of enrollees and rising health care costs, to one where funding could be capped on a per enrollment group member month basis. This change could significantly reduce low-income cancer patients, survivors, and their families' access to affordable, comprehensive health care in the state.

Per Capita Caps Unable to Respond to Unexpected Medical Cost Growth

Per capita caps are based on *historical* spending per enrollee and a pre-determined growth rate (Utah has chosen the Medical Consumer Price Index (CPI-M)). Per capita caps would likely favor higher-income states that tend to spend more Medicaid dollars, leaving lower-income states to pay for a greater portion of program costs than under the federal match.[19] This would include Utah, which spends less on Medicaid than other high-income states. Additionally, if projected costs are more than estimated in the prior year – even if CMS were to approve the receipt of the state's traditional FMAP for expenditures more than the total per capita cap – the state could be left paying a greater portion of the bill than they would under a federal match, putting pressure on already tight state budgets. This could, over time, negatively impact the federal budget as states struggle to pay their share. In 2017, the non-partisan Congressional Budget Office (CBO) estimated that applying per capita caps would significantly reduce revenues to states and lead to an estimated three quarters of people losing Medicaid coverage.[20]

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[18] See page 12 of the waiver request.

[19] Holahan J, Buettgens M. Block grants and per capita caps: The problem of funding disparities among states. Urban Institute. Published September 8, 2016. Accessed August 2019. http://www.urban.org/research/publication/block-grants-and-capita-caps.

[20] Congressional Budget Office. *Impose caps on federal spending for Medicaid. Budget Options*. Published December 8, 2016. Accessed August 2019. https://www.cbo.gov/budget-options /2016/ 52229.

Health care costs are often greater than projected, as increases in medical expenses and health coverage needs are difficult to predict in advance. For example, a new breakthrough drug, an exciting new cancer treatment, or an unexpected health care emergency could cause health care costs to increase significantly, leaving states with a larger share of unanticipated Medicaid costs. Additionally, economic downturns or major state disasters could create greater need for Medicaid coverage among state residents. Currently, when these unexpected incidents occur the federal match automatically adjusts to cover additional state spending to meet state beneficiary enrollment and needs. If CMS decides to accept the per capita cap, but not the state's requested exclusion of expenditures in the case of public health emergencies, natural disasters, or major economic events from the cap, Utah could find themselves even further in debt due to a significant decrease of federal funds coming in from the Medicaid program. The state's ability to rebase the cap in year two of the demonstration if actual spending is five percent above the per capita amounts for any of the enrollment groups could still leave the state taking on a large portion of health care costs in year one, causing the state to be further in debt than they would under a full federal match. Therefore, CMS should consider the impact a per capita cap could have on the state's budget, which could negatively impact its residents and local health care facilities, as well as the federal budget in the long term.

Per Capita Caps Mean Reduced Federal Funds for Hospitals, Providers, and Health Centers
Greatly reducing federal funding levels in Medicaid and increasing state flexibility to determine eligibility levels would not necessarily reduce underlying program costs. Instead, it is likely that reduced federal financial support through a per capita cap would result in a shift of additional costs to Utah hospitals, health systems, providers, and enrollees through increased uncompensated care. Many public hospitals, children's hospitals, rural providers, and federally qualified health centers (FQHC) make up the safety net for low-income individuals and families, including those battling cancer. These health systems greatly rely on Medicaid revenue to provide services. There are 13 community health centers in Utah[21] that serve 16 percent of Medicaid beneficiaries in the state and 52 percent of the state's uninsured.[22] Without current federal and state funding levels, hospital systems, FQHCs, and providers may have to limit the number of Medicaid or uninsured patients they treat, due to lower reimbursement rates and higher uncompensated care costs. Not only would this mean reduced access for Medicaid beneficiaries and the uninsured, but it could also hinder efforts to improve health outcomes in the state and lower the uninsured rate of low income Utahns – two goals the Department mentions they hope to achieve through the waiver. Again, CMS should consider the impact this type of proposal would have on Utah residents, Medicaid beneficiaries, and health care systems in Utah.

Per Capita Caps Could Restrict Eligibility, Enrollment, or Benefits Guaranteed by Medicaid
The Department suggests that per capita caps provide states greater flexibility in administering state Medicaid programs. Unfortunately, this flexibility with reduced federal funding will likely result in restrictions in eligibility, enrollment, and/or benefits and services for Medicaid enrollees in Utah. This is antithetical to the purpose of the Medicaid program, which is to provide comprehensive health coverage to low-income individuals that need it. Because the state may see a significant reduction in overall federal funding under a per capita cap, the Department may be forced to use other cost-saving

[21] Ibid.
[22] The Henry J Kaiser Family Foundation. Community health center patients by payor source: 2017. Published March 2019. Accessed August 2019. http://kff.org/other/state-indicator/fqhc-revenue-by-source/?currentTimeframe=0.

measures that are otherwise prohibited by the current Medicaid program, including enrollment freezes, waiting lists, withholding certain medical benefits, and increased cost sharing for impacted beneficiaries. Multiple studies have shown that individuals are less likely to seek health services, including life-saving preventive screenings (e.g., mammograms and colonoscopies), when they must pay for those services out-of-pocket.[23,24,25] Deterring a low-income person from care could result in higher costs later, which the state may have to bear and which could negatively impact the federal government in the long term.

For a person with cancer, enrollment freezes, waiting lists, and out-of-pocket cost sharing could mean a later-stage diagnosis when treatment costs are higher, and survival is less likely. Ultimately, capping Medicaid reimbursement costs per enrollment group, per month raises serious issues about the program's ability to offer low-income Utahns quality, affordable, and comprehensive health care coverage, particularly for those suffering from cancer. Therefore, we strongly urge CMS to consider the impact this proposal could have on low-income cancer patients and survivors who need health care coverage to fight and hopefully survive their disease and reject this harmful proposal.

Lockout for Adult Expansion Population for Intentional Program Violation

The state is requesting authority to apply a six-month lockout on individuals determined by the Department to have committed an intentional program violation (IPV) to become or remain eligible for Medicaid. While we appreciate the state's attempt to prevent fraud and abuse in the Medicaid program, it is critical that the Department ensure that the 500 individuals per year it anticipates will lose eligibility for six months have an effective and swift appeal process in place to ensure individuals do not lose access to critical health care coverage due to an administrative mistake made by the state.

While we appreciate the state's intent to include an appeals system for those accused of having committed an IPV, we are concerned that the proposal would require enrollees to repay the cost of coverage if found to be in violation. This potential result could have the unintended consequence of deterring individuals who are not engaged in fraudulent activity from enrolling in the program. Therefore, we request that CMS ensure that the state have an efficient and effective appeal process in place before allowing the state to move forward with this type of proposal.

Twelve Month Continuous Medicaid Eligibility

The state seeks to provide 12-months of continuous eligibility for the adult expansion population, with some exceptions, including failing to comply with the community engagement requirement during the three-month participation period or failing to enroll in employer-sponsored insurance.

In general, we are supportive of this request, as it will help with churn that occurs in the Medicaid program and ensure some continuity of care as individuals transition out of Medicaid and into the Marketplace (as they become eligible for subsidies) or into employer sponsored insurance. However, we remain concerned that individuals and families making between 100 and 138 percent of the federal

[23] Solanki G, Schauffler HH, Miller LS. The direct and indirect effects of cost sharing on the use of preventive services. *Health Services Research.* 2000; 34: 1331-50.
[24] Wharam JF, Graves AJ, Landon BE, Zhang F, Soumerai SB, Ross-Degnan D. Two-year trends in colorectal cancer screening after switch to a high-deductible health plan. *Med Care.* 2011; 49: 865-71.
[25] Trivedi AN, Rakowsi W, Ayanian JA. Effect of cost sharing on screening mammography in Medicare health plans. *N Eng J Med.* 2008; 358: 375-83.

poverty level ($12,140 to 17,236 for an individual in 2019)[26] may not be able to afford Marketplace coverage (even with the subsidies) or employer sponsored insurance (which can significantly vary in cost, even with the help of state dollars to help pay some of the individuals cost sharing).

Waiving Presumptive Eligibility for Low-Income Adults

Patients rely on presumptive eligibility to qualify for affordable health care, particularly if they did not realize they were eligible for affordable coverage through Medicaid. Safety net hospitals and providers also rely on presumptive eligibility for reimbursement of provided services, allowing these facilities to keep the doors open.[27,28] Waiving presumptive eligibility, along with the already approved enrollment limit and the possibility of a per-capita-cap, could result in either an individual facing significant out-of-pocket expenses for care that they believed would be covered by their presumed eligibility or a provider being responsible for the cost of the provided services – should the patient be unable to pay for them. The state anticipates that approximately 300-400 individuals per month will no longer receive eligibility through presumptive eligibility, solidifying our concern that less individuals will receive health insurance coverage. Therefore, we urge CMS to reject this request, as it could negatively impact patients, hospitals, and providers in the state.

Flexibility for Providing Managed Care

In general, we are supportive of Utah's decision to provide health care coverage to the expansion population through managed care. However, we request that CMS require that the Department provide a guarantee that they will incorporate continuity of care provisions that would ensure that individuals in active treatment for life-threatening illnesses, such as cancer, not face significant care disruptions. For an individual undergoing cancer treatment, timely and uninterrupted access to services is critical. When cancer treatment is delayed or disrupted, the effectiveness of the treatment could be jeopardized, and the individual's chance of survival can be significantly reduced. Failure to consider the care delivery and/or treatment regimen of patients, especially those managing a complex, chronic condition like cancer, could have devastating effects on patients, their families, and providers. Additionally, we recommend that CMS require the Department to establish a clearly defined process through which a Medicaid enrollee can inform the state that they are in active treatment. These actions will allow cancer patients to maintain their cancer care treatment regimen and continue to see their providers in the same health care systems through the end of their treatment.

ACS CAN also urges CMS to require the Department to provide clarification on how it intends to ensure that health plan networks include an adequate number of specialists to guarantee that enrollees have access to the specialists necessary to treat their medical conditions, especially oncologists, cancer surgeons, and radiologists.

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[26] U.S. Department of Health and Human Services, Office of The Assistant Secretary for Planning and Evaluation, 2019 Poverty Guidelines. Available at: https://aspe.hhs.gov/poverty-guidelines.
[27] Centers for Medicare & Medicaid Services. Emergency medical treatment & labor act (EMTALA). Updated March 2012. Accessed February 2018. https://www.cms.gov/regulations-and-guidance/legislation/emtala/.
[28] National Association of Community Health Centers. Maine health center fact sheet. Published March 2017. Accessed August 2019. http://www.nachc.org/wp-content/uploads/2016/03/ME_17.pdf.

Conclusion

We appreciate the opportunity to provide comments on Utah's 1115 waiver amendment. Expanding eligibility and coverage through the Medicaid program is critically important for many low-income Utahns who could greatly benefit from the program for cancer prevention, early detection, diagnostic, and treatment services. However, the currently proposed changes in this 1115 waiver could negatively impact Utah residents. It is important for CMS to also take into consideration that the people of Utah voted to expand the Medicaid program in November 2018 in order to increase access to health care coverage. No waiver should undercut this outcome. We ask CMS to weigh the potential impact the previously accepted waiver proposals (community engagement requirements, lock-out periods, and limited enrollment) along with the current 1115 proposed changes could have on low-income Utahn's access to lifesaving health care coverage, particularly those individuals with cancer, cancer survivors, and those who will be diagnosed with cancer during their lifetime.

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 people 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 DelFavero of our policy team at Michelle.DelFavero@cancer.org or 202-585-3266.

Sincerely,

Lisa A. Lacasse, MBA
President