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January 13, 2020

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

Re: Nebraska Medicaid Section 1115 Heritage Health Adult Expansion Demonstration

Dear Secretary Azar:

The American Cancer Society Cancer Action Network (ACS CAN) appreciates the opportunity to comment on Nebraska's Medicaid Section 1115 "Heritage Health Adult" (HHA) Expansion Demonstration. 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.

We strongly support Nebraska's expansion of their Medicaid program. Access to health care is paramount for persons with cancer and survivors. An estimated 10,560 Nebraskans are expected to be diagnosed with cancer this year,¹ and there are nearly 108,500 cancer survivors in the state² – many of whom rely on Medicaid or will greatly benefit from receiving their health care through the expansion of the program. ACS CAN wants to ensure that cancer patients and survivors in Nebraska 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.

However, the proposed beneficiary engagement requirements, including the wellness initiative, personal responsibility activities, and community engagement activities, for the adult expansion group could limit – rather than expand – eligibility and access to care for some of the most vulnerable Nebraskans, 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) reconsider moving forward with the current waiver until stakeholder concerns are addressed.

¹ American Cancer Society. *Cancer Facts & Figures 2020*. Atlanta, GA: American Cancer Society; 2020.

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

The following are our specific concerns with the Nebraska's Medicaid section 1115 demonstration waiver application:

Community Engagement Activities

Nebraska's waiver application would establish a two-tiered benefit package for the HHA population: Tier 1 - a "Basic" benefits package which would include medical, behavior health, and prescription drug coverage; and Tier 2 - the "Prime" benefits package which would include the basic benefits plus vision, dental, and over-the-counter medication. How beneficiaries comply with specific requirements, including community engagement requirements, would determine which package they receive.

For example, in order to be eligible for the Prime benefits package, adult enrollees over the age of 20 must either be employed or volunteer 80 hours per month. Some exemptions would be available. Although we appreciate that enrollees would not lose eligibility for Medicaid and would retain Basic benefit coverage, this requirement could still unintentionally disadvantage Medicaid enrollees with complex chronic conditions like cancer, who may need the additional services offered under Prime coverage. Many cancer patients in active treatment are often unable to work or require significant work modifications due to their treatment.^{3,4,5} 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.⁶ Recent cancer survivors often require frequent follow-up visits⁷ and suffer from multiple comorbidities linked to their cancer treatments.^{8,9} 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.^{10,11} If work and community engagement is required as a condition of eligibility for the Prime benefits package, many recent cancer survivors and those with other chronic illnesses could find that they are ineligible for critical benefits and services that can improve their quality of life and improve the timeliness and effectiveness of their treatment. We also

³ 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.

⁴ 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.

⁵ 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.

⁶ 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.

⁷ National Cancer Institute. *Coping with cancer: Survivorship, follow-up medical care.* Accessed January 2020. <https://www.cancer.gov/about-cancer/coping/survivorship/follow-up-care>.

⁸ 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.

⁹ 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.

¹⁰ Ibid.

¹¹ 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; 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; and 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.

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.

Therefore, ACS CAN opposes tying access to comprehensive 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 necessary Medicaid coverage because they are physically unable to comply.

Further, increased administrative reporting requirements for enrollees to attest to their work or exemption status would likely reduce the number of individuals with Prime Medicaid coverage, regardless of whether they are exempt.^{12,13} While we appreciate the state using as many automated tools as possible to determine compliance and exemptions for the work requirements, the state cannot ensure without a doubt that automated tools will catch all eligible enrollees; therefore, individuals will likely fall through the cracks and lose access to important vision and dental coverage.

Given the recent experience with Arkansas' work requirement, where uninsured rates were driven up and employment actually declined in the state after the work requirement went into effect,¹⁴ CMS and the state must consider the number of state residents whose health could be negatively impacted due to this proposal. Additionally, it is clear from the 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. Therefore, CMS should consider the negative impact that the community engagement requirements could have on Nebraska residents before accepting this waiver proposal.

Wellness Initiative Requirements

To comply with the wellness initiative requirements, a non-exempt beneficiary "must actively participate in case and care management; attend an annual health visit; and choose a primary care provider."¹⁵ If the beneficiary does not engage in these activities, they will not gain the Prime benefits package and will remain in the Basic benefits package for the subsequent two, six-month benefit periods, with the possibility to gain the Prime benefits after the second six month benefit tier review. In other words, if the beneficiary does not comply with the wellness initiative requirements, he/she could be locked out of Prime benefits for at least a year.

Case and Care Management Activities

ACS CAN supports Nebraska's goal of improving health outcomes of its residents through the wellness initiative requirements; however, the state is proposing a mandatory, outcomes-based program that would require adult expansion beneficiaries to complete an annual health risk screening, an annual

¹² 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 January 2020. <http://files.kff.org/attachment/Issue-Brief-Implications-of-a-Medicaid-Work-Requirement-National-Estimates-of-Potential-Coverage-Losses>.

¹³ Sommers BD, Goldman AL, Blendon RJ, et al. Medicaid work requirements – Results from the first year in Arkansas. *NEJM*. 2019. DOI: 10.1056/NEJMSr1901772.

¹⁴ Ibid.

¹⁵ See Waiver Application pg. 4.

social determinants of health assessment, and fill medications routinely (on top of all of the other requirements) as a condition of receiving the Prime benefits package.

Research indicates that penalizing enrollees for non-compliance or failing to meet outcomes dictated by the state will not likely generate cost savings or improve the health of low-income Medicaid enrollees.¹⁶ Nebraska's wellness initiatives also appear to focus on administrative activities, like completion of health risk screenings and social determinants of health assessments (which rely heavily on availability of office appointments by the managed care plan), rather than evidence-based quality improvement programs. We believe state residents would be better served by a comprehensive, evidence-based participatory wellness initiative based on incentives that provides adequate and comprehensive coverage of preventive services (including tobacco cessation, weight loss, and cancer screenings) and emphasize evidence-based interventions to educate, promote, and encourage patients to participate in prevention, early detection, and wellness. Evidence shows that unhealthy behaviors can be changed or modified by modest incentives, rather than penalties, as long as they are combined with adequate medical services and health promotion programs.¹⁷ Providing enrollees incentives could lead to a change in behavior whereas penalties do little to improve health and could reduce access to necessary health care services. Therefore, we urge CMS to deny the state's request to require a wellness initiative, unless they change their wellness initiative to an optional, evidence-based incentive program that focuses on activities that can improve health, rather than just administrative hoops that beneficiaries must go through to gain Prime benefits or prevent from losing Prime benefits.

Annual Health Visit and Primary Care Provider Selection

We support Nebraska's proposal for HHA beneficiaries to have an annual health visit and choose a primary care provider. Having a usual source of care increases the likelihood that individuals receive recommended preventive services, including cancer screenings.^{18,19} However, we cautioned the state against making the annual health visit a requirement in order to receive or prevent losing Prime benefits. As mentioned above, research indicates that penalizing enrollees for non-compliance or failing to meet outcomes dictated by the state will not likely generate cost savings or improve the health of low-income Medicaid enrollees.²⁰ Instead, we urged the Department to consider incentivizing enrollees to attend an annual health visit to better increase participation and health outcomes in the long term. We urge CMS to deny the request, unless the state changes the requirement to an optional, evidence-based incentive program.

¹⁶ Consensus statement of the Health Enhancement Research Organization, American College of Occupational and Environmental Medicine, American Cancer Society and American Cancer Society Cancer Action network, American Diabetes Association, and American Heart Association. Guidance for a reasonably designed, employer-sponsored wellness program using outcomes-based incentives. *JOEM*. 2012; 54(7): 889-96.

¹⁷ *Ibid*.

¹⁸ Blewett LA, Johnson PJ, Lee B, Scal PB. When a usual source of care and usual provider matter: adult prevention and screening services. *J Gen Intern Med*. 2008; 23(9): 1354-60.

¹⁹ O'Malley AS, Mandelblatt J, Gold K, Cagney KA, Kerner J. Continuity of care and the use of breast and cervical cancer screening services in a multiethnic community. *Arch Intern Med*. 1997; 157(13): 1462-70.

²⁰ Consensus statement of the Health Enhancement Research Organization, American College of Occupational and Environmental Medicine, American Cancer Society and American Cancer Society Cancer Action network, American Diabetes Association, and American Heart Association. Guidance for a reasonably designed, employer-sponsored wellness program using outcomes-based incentives. *JOEM*. 2012; 54(7): 889-96.

Personal Responsibility Requirements

To comply with the personal responsibility requirements, a non-exempt beneficiary “must avoid missing three or more scheduled provider appointments in a benefit period; maintain employer-sponsored health coverage if it is available; and provide timely notification to the State of any change in status that will impact the beneficiary’s Medicaid eligibility or benefit tier.”²¹ If the beneficiary does not engage in these activities, they will be locked out of Prime coverage for a year with the possibility to gain the Prime benefits after the second six month benefit tier review.

Attending Appointments

We appreciate the state wanting Medicaid beneficiaries to keep scheduled medical appointments. No show appointments not only cost physicians time and income but penalize other patients who could have used the appointment. At the same time, many low-income individuals frequently have issues with reliable transportation,²² flexible work hours,²³ and childcare.²⁴ We urged the state to consider these challenges and to take them into account when defining what constitutes a “reasonable notice of a cancellation.” We urge CMS to require the state to consider these concerns before allowing them to move forward with this proposal.

Maintaining Commercial Coverage

We appreciate Nebraska wanting individuals with employer-sponsored insurance (ESI) to use their ESI rather than Medicaid, but ESI is not always an affordable option. Many of these plans have higher out-of-pocket costs which decrease the likelihood that a lower income person would seek health care services, including preventive screenings.^{25,26,27} Cancers that are found at an early stage through screening are less expensive to treat and lead to greater survival.²⁸ Uninsured and underinsured individuals already have lower screening rates resulting in a greater risk of being diagnosed at a later, more advanced stage of disease.²⁹ Proposals that place greater financial burden on the lowest income residents create barriers to care and could negatively impact Medicaid enrollees – particularly those individuals who are high service utilizers with complex medical conditions.

Moving cancer patients and survivors out of the more robust Medicaid program and into ESI could result in reduced benefits and a significant increase in out-of-pocket cost sharing - making coverage less

²¹ See Waiver Application pg. 4.

²² Syed ST, Gerber BS, Sharp LK. Traveling towards disease: Transportation barriers to health care access. *J Community Health*. 2013; 38(5): 976-93.

²³ Henly JR, Lambert SJ. Unpredictable work timing in retail jobs: Implications for employee work-life conflict. *ILR Review*. 2014; 67(3):986-1016.

²⁴ The Lewin Group, Inc. Indiana HIP 2.0: Evaluation of non-emergency medical transportation (NEMT) waiver. Updated March 11, 2016. Accessed January 2020. <https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/downloads/in/Healthy-Indiana-Plan-2/in-healthy-indiana-plan-support-20-nemt-eval-03112016.pdf>.

²⁵ 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.

²⁶ 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.

²⁷ Trivedi AN, Rakowski W, Ayanian JA. Effect of cost sharing on screening mammography in Medicare health plans. *N Eng J Med*. 2008; 358: 375-83.

²⁸ American Cancer Society. *Cancer prevention & early detection facts & figures 2019-2020*. Atlanta: American Cancer Society; 2019.

²⁹ Ibid.

comprehensive and unaffordable. We are concerned that the proposal would leave individuals exposed to significant cost-sharing, beyond what is permitted under current federal requirements.

Premiums and cost sharing above the five percent of family income maximum for Medicaid enrollees would be particularly burdensome for a high-utilizer of health care services, such as an individual in active cancer treatment or a recent survivor. Cancer patients in active treatment require many services shortly after diagnosis and thus incur a significant portion of cost sharing over a relatively short period of time.³⁰ It can be challenging for an individual – particularly an individual with limited means – to be able to afford their cost-sharing requirements. Likewise, a recent survivor may require frequent follow-up visits to prevent cancer recurrence. Having to pay the full cost up front would likely result in many cancer patients and survivors delaying their treatment and could result in them forgoing their treatment or follow-up visits altogether. We strongly urge CMS to deny the proposal to require low-income individuals to maintain commercial coverage.

Waiving Retroactive Eligibility

Medicaid currently allows retroactive coverage if: 1) an individual was unaware of his or her eligibility for coverage at the time a service was delivered; or 2) during the period prospective enrollees were preparing the required documentation and Medicaid enrollment application. Policies that would reduce or eliminate retroactive eligibility could place a substantial financial burden on enrollees and cause significant disruptions in care, particularly for individuals battling cancer. Therefore, we are concerned about the state's proposal to waive retroactive eligibility, as it would also apply to non-expansion populations, including women enrolled in Medicaid through the state's Every Woman Matters Screening & Diagnostic Program.

Many uninsured or underinsured individuals who are newly diagnosed with a chronic condition already do not receive recommended services and follow-up care because of cost.^{31,32} In 2018, 45 percent of uninsured nonelderly adults went without care because of cost.³³ Waiving retroactive eligibility could mean even more people are unable to afford care and forgo necessary care due to cost.

Safety net hospitals and providers also rely on retroactive eligibility for reimbursement of provided services, allowing these facilities to keep the doors open. For example, the Emergency Medical Treatment and Labor Act (EMTALA) requires hospitals to stabilize and treat individuals in their emergency room, regardless of their insurance status or ability to pay.³⁴ Retroactive eligibility allows hospitals to be reimbursed if the individual treated is eligible for Medicaid coverage. Likewise, Federally

³⁰ American Cancer Society Cancer Action Network. *The costs of cancer: Addressing patient costs*. Washington, DC: American Cancer Society Cancer Action Network: 2017.

³¹ Hadley J. Insurance coverage, medical care use, and short-term health changes following an unintentional injury or the onset of a chronic condition. *JAMA*. 2007; 297(10): 1073-84.

³² Foutz J, Damico A, Squires E, Garfield R. The uninsured: A primer – Key facts about health insurance and the uninsured under the Affordable Care Act. *The Henry J Kaiser Family Foundation*. Published January 25, 2019. Accessed January 2020. <https://www.kff.org/report-section/the-uninsured-a-primer-key-facts-about-health-insurance-and-the-uninsured-under-the-affordable-care-act-how-does-lack-of-insurance-affect-access-to-health-care/>.

³³ The Henry J. Kaiser Family Foundation. Key facts about the uninsured population. Updated December 13, 2019. Accessed January 2020. <https://www.kff.org/uninsured/fact-sheet/key-facts-about-the-uninsured-population/>.

³⁴ Centers for Medicare & Medicaid Services. Emergency medical treatment & labor act (EMTALA). Updated March 2012. Accessed January 2020. <https://www.cms.gov/regulations-and-guidance/legislation/emtala/>.

Qualified Health Centers (FQHCs) offer services to all persons, regardless of that person's ability to pay or insurance status.³⁵ Community health centers also play a large role in ensuring low-income individuals receive cancer screenings, helping to save the state of Nebraska from the high costs of later stage cancer diagnosis and treatment. Therefore, we urge CMS to consider these providers and their contribution to Nebraska's safety net, as well as the patients who rely on Medicaid for health care coverage, before approving Nebraska's request to waive retroactive eligibility for its Medicaid beneficiaries.

Conclusion

We appreciate the opportunity to provide comments on Nebraska's Medicaid 1115 HHA Expansion Demonstration. Expanding eligibility and coverage through the Medicaid program is critically important for many low-income Nebraskans who could greatly benefit from the program for cancer prevention, early detection, diagnostic, and treatment services. However, the proposed policies included in the 1115 waiver could negatively impact Nebraska residents. We ask CMS to weigh the potential impact the proposed policies could have on low-income Nebraskans' access to lifesaving health care coverage, particularly 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 and made available to the agency through active hyperlinks, 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 CMS 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 DeFavero of our policy team at Michelle.DeFavero@cancer.org or 202-585-3266.

Sincerely,



Lisa A. Lacasse, MBA
President

³⁵ National Association of Community Health Centers. Maine health center fact sheet. Published March 2017. Accessed January 2020. http://www.nachc.org/wp-content/uploads/2016/03/ME_17.pdf.