American Cancer Society
Cancer Action Network
655 15th Street, NW
Suite 503
Washington, DC 20005
202.661.5700
www.fightcancer.org

September 28, 2022

National Academy of Sciences
500 Fifth Street NW
Washington, DC 20001

Re: National Academy of Sciences Federal Policies that Contribute to Racial and Ethnic Health Inequities Comments

Dear National Academy of Sciences:

The American Cancer Society Cancer Action Network (ACS CAN) appreciates the opportunity to comment on the National Academy of Sciences' request for federal policies that contribute to racial and ethnic health inequities. As the American Cancer Society's nonprofit, nonpartisan affiliate, 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.

In 2021, nearly two million people heard the words "you have cancer". That same year, over 600,000 of our family, friends, neighbors, and colleagues were projected to die from the disease.[1] Cancer is a disease that can affect anyone, but it does not affect everyone equally. Health care disparities can affect every step of cancer care — from prevention and screening, to financial hardship experienced, to the quality of life after cancer treatment — which means disparities in care can affect who develops cancer, who survives cancer and who dies from the disease.[2] Health disparities adversely affect groups of people who have systematically experienced greater social or economic obstacles to healthcare based on their racial or ethnic group, socioeconomic status, religion, gender, age, sexual orientation or gender identity; or other characteristics historically linked to discrimination or exclusion. The good news is that through investments in research, improvements in prevention and screening, the availability of new treatments, and expanded access to coverage, we are making progress in the fight against cancer. The following outlines the specific public policies ACS CAN believes will accelerate the changes needed to reduce racial and ethnic health inequities across the cancer care continuum.

Broaden and Diversify Access to Cancer Clinical Trials

Congress should enact the DIVERSE Trials Act (S2706/HR5030): While patient willingness to enroll in cancer clinical trials is high, some patients decline due to practical cost or convenience-related reasons which contributes to underrepresentation of some populations, including certain racial and ethnic

[1] American Cancer Society. *Cancer Facts & Figures 2022.* https://www.cancer.org/research/cancer-facts-statistics/all-cancer-facts-figures/cancer-facts-figures-2022.html
[2] American Cancer Society. *Cancer Facts & Figures for African Americans 2019-2021.* Atlanta, American Cancer Society, Inc.

groups in the U.S. For example, patients are frequently responsible for non-medical costs such as transportation and lodging associated with trial enrollment which can be a barrier to their participation. Some trial sponsors provide financial support for non-medical costs. Those that do not often cite concerns about running afoul of federal anti-kickback protections that could subject them to civil monetary or criminal penalties. To address this issue, Congress should pass the Diversifying Investigations Via Equitable Research Studies for Everyone (DIVERSE) Trials Act H.R. 5030/S. 2706 which creates safe harbors for sponsors to provide financial support to trial participants and the technology needed to participate in trials remotely. Additionally, the DIVERSE Trials Act requires the Department of Health and Human Services to issue guidance on how to conduct decentralized clinical trials to improve demographic diversity. Decentralized trials have the potential to reduce barriers to clinical trial participation. Techniques for conducting decentralized trials greatly increased during the pandemic, due in part to regulatory flexibilities offered during the public health emergency. In order for these flexibilities to continue after the pandemic ends, the Administration needs to issue guidance or regulations. ACS CAN has collected data on patient experience with these techniques through the Survivor Views and is poised to provide important insight and direction as the permanent policies are developed.

Prevent Cancer Across Populations

Advocating for Food and Drug Administration (FDA): The tobacco industry has specifically used menthol for decades to intentionally and aggressively target certain communities. As a result, African Americans consistently report the highest prevalence of menthol cigarette use. This problem was exacerbated when the landmark Family Smoking Tobacco Control Act passed in 2009, giving the FDA the authority to regulate tobacco products, prohibited flavors in cigarettes except for menthol and tobacco flavors.[3] In April 2022, the FDA released its proposed rules to prohibit menthol in cigarettes and all flavors in all cigars. The FDA should quickly finalize these proposed rules. Ending menthol flavoring in cigarettes and all flavors in cigars is a long overdue step forward in combating Big Tobacco's targeting of Black communities. Prohibiting menthol in cigarettes and all flavors in cigars will reduce youth tobacco initiation, help adults quit and reduce tobacco-related cancer in all communities.

Increase funding for CDC's Division of Cancer Prevention and Control (DCPC): DCPC provides key resources to states and communities to prevent cancer by ensuring that communities that are underserved or are of lower income, which disproportionately represent racial and ethnic minority communities, have access to vital cancer prevention programs. Programs include the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) and the Colorectal Cancer Control Program (CRCCP). The NBCCEDP provides timely access to breast and cervical cancer screening and diagnostic services to low-income, uninsured, and underinsured women in all 50 states, the District of Columbia, 6 U.S. territories, and 13 tribes. Additionally, it uses population-based approaches, such as public education, outreach, patient navigation, and care coordination, to increase screening and reach underserved populations. With more funding, NBCCEDP could serve more than 60,000 additional women a year, resulting in the detection of more than 600 breast cancers and 1,100 precancerous lesions. Due, in part, to funding challenges, the NBCCEDP cannot service all eligible individuals. According to most recent program data, among those eligible for the program, less than 1 in 10 received

[3] Jewett, Christina (2022). F.D.A. Moves to Ban Sales of Menthol Cigarettes - The New York Times (nytimes.com)

cervical cancer screenings (2015-2017) and less than 2 in 10 received breast cancer screenings (2016-2017).[4] For FY23 Congress should provide $462.5 million overall for the CDC's cancer programs, including $225 million for NBCCEDP, so that all Americans have access to lifesaving cancer screenings and prevention resources.

Improve Access to Care

Provide access to affordable health insurance coverage to the 2.2 million Americans who fall into the coverage gap: In 12 states, there are more than 2.2 million people who should be able to see a doctor but cannot because they fall into the Medicaid coverage gap – 60% of these uninsured are people of color, and the vast majority live in the American South, which disproportionately represents Black/African American populations. At the federal level, health insurance premiums should be affordable for individuals at all levels of income. Individuals with low and moderate incomes should have access to tax credits and subsidies to help them afford coverage, which includes premiums and cost-sharing. Congress should make the recently expand subsidies for premiums and cost-sharing in marketplace plans permanent so more Americans have access to quality and affordable health coverage. Congress should also close the coverage gap for lower income Americans who live in states that have not expanded Medicaid by providing comparable coverage with $0 premiums, very low cost-sharing, and benefits tailored to the low-income population. At the state level, all states should expand Medicaid eligibility up to 138% of the federal poverty level.

Increase access to quality cancer care among populations that are underserved through telehealth services and telemedicine: Federal regulations restrict Medicare coverage and reimbursement of telehealth services to a narrow framework which limits patient access to care. Current restrictions include limitations related to patient location, the types of practitioners who can provide telehealth services, and the types of services that can be furnished via telehealth. Telehealth provides cancer patients and survivors with a convenient means of accessing preventive, primary and cancer care – a particularly important option for individuals that have been marginalized, including racial and ethnic minority populations. During the COVID-19 pandemic the Centers for Medicare and Medicaid Services (CMS) issued temporary waivers around telehealth that are available so long as the state or federal COVID-19 PHE remains in effect. These waivers increased provider flexibility to furnish telehealth services and expanded patient access to care while reducing the risk of exposure to COVID-19, for example, under the temporary waivers, Medicare patients can receive telehealth services regardless of their location. Congress should enact legislation that makes it easier for patients to have permanent access to appropriate telehealth services.

[4] Centers for Disease Control and Prevention. National Breast and Cervical Cancer Early Detection Program: About the program.

Ensure complete and timely collection and publication of demographic data that help identify disparities: The Office of Management and Budget (OMB) categories for race and ethnicity are not homogenous. The U.S. population has continued to become more racially and ethnically diverse since OMB's last revision of the Standards for the Classification of Federal Data on Race and Ethnicity. Aggregating heterogenous racial and ethnic subpopulations in the collection of public health data can obscure health disparities. Disaggregated racial and ethnic information on certain groups would be helpful to target cancer prevention and control efforts and ensuring detailed race and ethnicity data are available, as well as accurate, objective, and impartial, is critical to evidence-based health equity work. OMB should add additional subgroups to the required minimum reporting categories which can provide opportunities for improved reporting of information pertaining to the health of the nation's diverse population.

Conclusion

On behalf of the American Cancer Society Cancer Action Network, we thank you for the opportunity to comment on federal policies that contribute to racial and ethnical health inequities across the cancer care continuum. If you have any questions, please feel free to contact me or have your staff contact Gladys Arias, Principal, Health Equity Policy Analysis & Legislative Support, at Gladys.Arias@cancer.org or (424) 702 - 4123.

Sincerely,

Lisa L. Lacasse
President
American Cancer Society Cancer Action Network