August 16, 2024

The Honorable Cathy McMorris Rodgers
Chair, Energy and Commerce Committee
U.S. House of Representatives
Washington, DC 20515

Re: NIH Modernization Comments

Dear Chair Rodgers,

The American Cancer Society Cancer Action Network (ACS CAN), the nonprofit, nonpartisan advocacy affiliate of the American Cancer Society (the Society), supports evidence-based policy and legislative solutions designed to eliminate cancer as a major health problem. As the nation's leading advocate for public policies that are helping to defeat cancer, ACS CAN ensures that cancer patients, survivors, and their families have a voice in public policy matters at all levels of government. As the committee considers efforts to modernize the National Institutes of Health (NIH), ACS CAN is pleased to offer our perspective. Our primary engagement with NIH is with the National Cancer Institute (NCI), and our comments are largely through that lens.

The NCI has enjoyed bipartisan support over the decades in its mission to end cancer as we know it, and the support and funding that has come with it has helped lead to a one third reduction in death rate from cancer from 1991 to 2019[1]. There is significant evidence that research funding at NIH and NCI has played, and continues to play, a critical role in developing new therapies and improving outcomes for patients, and ACS CAN has been a strong supporter of these institutions. As Congress considers structural and policy reforms to NIH, it is imperative that patient benefit remain the north star, and that any changes be driven by scientific principles that do not jeopardize research progress. It is also critical to provide regular year-over-year increases in funding to continue progress.

Structural

The National Cancer Act of 1971 spelled out specific responsibilities and authorities for the National Cancer Institute (NCI) and we appreciate that in the proposed structural reorganization of NIH that NCI has been maintained as a distinct entity. While NCI houses the majority of the research that ACS CAN is focused on, tobacco and nicotine cessation research is also critical to reducing the burden of cancer, and research in this issue is spread throughout many other institutes and centers (ICs). There are many other examples of critical research efforts that are important to cancer patients and their families across the NIH and we urge you to ensure that the portfolio of research remains whole and is not diminished or deprioritized in any reorganization.

We are concerned about one aspect of the structural reorganization, namely the proposal to fold the newly formed ARPA-H along with other ICs into a new institute. ARPA-H has a unique mandate to tackle research gaps not currently addressed by either NIH-funded research or industry-funded research. The current affiliated structure is one that has created critical interactionswith the scientific community allowing ARPA-H to

demonstrate its unique approaches to catalyze breakthroughs in research and care. We urge the committee to retain the current affiliated structure to provide critical time to execute its approach before any consideration is made regarding its future.

NCI funds both basic research that drives deeper scientific understanding of cancer as well as clinical research which translates that understanding into new and improved treatments. Its successful role in driving clinical research is partly about supporting infrastructure uniquely required for clinical trials. NCI funds NCI-designated cancer centers and NCI Community Oncology Research Program (NCORP) sites. These grants provide the staff and infrastructure needed to conduct clinical research. While the focus of this infrastructure is to support NIH research, the expertise and capacity it facilitates also improves a site's ability to conduct clinical research from a wide variety of sponsors. NCI-funded sites, however, tend to be concentrated in urban areas and have a smaller footprint in rural areas. Our recent research showed a five-fold difference in trial enrollment between community cancer programs and NCI-designated cancer centers[2]. With relatively high enrollment already at NCI-designated cancer centers, moving the needle on overall trial enrollment will therefore only be possible by focusing on enrollment improvements in the community. We encourage future NCI funding increases be prioritized toward the decentalization of clinical trials by expanding clinical research infrastructure in rural and community settings, which in turn will increase access formany more people.

NCI also supports clinical research more directly by funding the national clinical trials network (NCTN) to conduct specific oncology clinical trials. These trials often test modifications or additions to standard of care to provide insight into ways to optimize existing therapies by changing dosing, timing of administration, combinations of therapies, or explore new indications for approved drugs. This is critical research that the biopharma industry may not have an incentive to conduct yet can have major impact on health outcomes. A recent review of the impacts of trials conducted by the Southwest Oncology Group (SWOG), one of the NCTN networks, found that SWOG trials had led to changes in care that resulted in 3.34 million life years saved at a research cost of only $125 per year saved[3]. Despite the incredible impact such research has on patient outcomes, funding for the NCTN and the associated patient enrollment capacity has remained essentially flat for years. Strategies to diversify support for this work is critical. As part of this we encourage future NCI funding increases be prioritized toward increasing the capacity of the NCTN to expand the geographic diversity and enrollment in clinical trials.

Policy

The proposal suggests reexamining and potentially limiting indirect costs associated with research, as well as increasing transparency of individual organizational indirect costs. Indirect costs are a real cost of doing research and are recognized and awarded by nearly every funding source, including the American Cancer Society. Indirect rates, however, vary substantially, both for institutions receiving grants and the allowable rates from granting institutions.A critical review and improved transparency in this space is merited. Any policy change, however, should only occur after an in-depth study to ensure any proposed policy changes continue to support the real costs of research at academic and community based institutions based on an equitable and evidence-based process.

Improving the lives of patients is the core mission of NIH, and to achieve that mission patients need to have a strong voice in governance and oversight of the ICs. Patients currently have roles as patient representatives throughout the NIH Institute and Centers structure and provided significant value; however, increased and more

meaningful numbers of patients and patient advocates on governing boards and bodies throughout all levels of the ICs will greatly benefit the work of the NIH and further elevate the patient voice. Within NCI, this would include the National Cancer Advisory Board and the Board of Scientific Advisors.

Conclusion

Thank you for the opportunity to comment on modernization of the NIH. Changes of the scope and scale included in the committee's proposal represent a significant disruption to the current research ecosystem. We encourage a transparent, bipartisan, and deliberate process with multiple opportunities to engage stakeholders as concrete proposals are developed. The American Cancer Society and the American Cancer Society Cancer Action Network have deep expertise in these critical issues and we would be eager to work with your office and stand ready to provide further input to ensure that our federal biomedical research investments benefit patients with cancer to the fullest extent possible. If you have any questions, please feel free to contact me or have your staff contact Julie Nickson (Julie.Nickson@cancer.org), Director, Federal Relations.

Sincerely,

Lisa A. Lacasse, MBA
President
American Cancer Society Cancer Action Network

1- American Cancer Society. Cancer Facts & Figures 2022. Atlanta: American Cancer Society; 2022. https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/annual-cancer-facts-and-figures/2022/2022-cancer-facts-and-figures.pdf
2- Unger JM, Shulman LN, Facktor MA, Nelson H, Fleury ME. National Estimates of the Participation of Patients With Cancer in Clinical Research Studies Based on Commission on Cancer Accreditation Data. J Clin Oncol. 2024 Apr 2:JCO2301030. doi: 10.1200/JCO.23.01030
3- Unger JM, LeBlanc M, Blanke CD. The Effect of Positive SWOG Treatment Trials on Survival of Patients With Cancer in the US Population. *JAMA Oncol.* 2017;3(10):1345–1351. doi:10.1001/jamaoncol.2017.0762