American Cancer Society

American Cancer Society Cancer Action Network

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Dr. Bhattacharya:

The American Cancer Society (ACS) and the American Cancer Society Cancer Action Network (ACS CAN) appreciate the opportunity to comment on the Request for Information (RFI) on the National Institutes of Health (NIH)-Wide Strategic Plan for FY27-FY31 (NOT-OD-26-047). The ACS mission is to improve the lives of people with cancer and their families through advocacy, research, and patient support, to ensure everyone has an opportunity to prevent, detect, treat, and survive cancer. ACS, operating throughout the United States (US), is the largest voluntary health organization in the country. ACS CAN is making cancer a top priority for public officials and candidates at the federal, state, and local levels. ACS CAN is the nonprofit, nonpartisan advocacy affiliate of ACS, advocating for evidence-based public policies to reduce the cancer burden for everyone. 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.

The RFI seeks input on three priorities: research areas, research capacity, and research operations. Below we lay out our suggestions for developing the strategic plan for each of the priorities.

Priority 1: Research Areas

Advancing the foundational knowledge of health and disease has always been a core mission of NIH and should continue to be a primary goal. Basic research facilitates discoveries that can ultimately transform human health, but this type of research typically has such a long timeline and low percentage yield in terms of developing commercially viable products that industry is not willing to fund it. NIH funding has filled this gap, providing early funding for basic or applied research supporting 354 of 356 drugs (99.4%) approved from 2010 to 2019[i]. This demonstrates that NIH-funded foundational research leads to improved therapies for patients.

Preventing or detecting cancer at earlier stages reduces unnecessary suffering, death and costs while improving quality of life. For example, at least 40% of cancer deaths in the United States are potentially preventable[ii]. Factors such as tobacco use, diet, weight, and exposure to cancer-causing environmental factors and infections can significantly increase cancer risk.

Prevention often involves interventions to change individual behaviors or exposures and access to some types of preventive services is not consistently covered by insurance, while treating disease typically relies on therapeutic interventions that are covered by healthcare insurance. This distinction has important implications for financial incentives which tend to drive private investment in research toward more profitable efforts. Although prevention research may offer fewer commercial incentives, the potential public health, health care and economic benefits are substantial, underscoring the importance of federal investment through NIH.

While basic research will always be a primary mission of NIH, it is critically important that discoveries be translated into meaningful interventions. While industry investments often drive translational research, they naturally target research with the highest financial returns. There is much work in the translational and optimization spaces that can be impactful for human health, but for which the returns are either nonexistent, uncertain, involve long timelines, or are too small to attract private capital. Examples include rare diseases, such as childhood cancer where markets for any developed therapies are small, work on comparing efficacy between treatment options, supporting early phase translational research (e.g. through SBIR programs), and developing new indications for existing drugs that have little or no patent protection. NIH should continue to develop and maintain mechanisms to fund these critical categories of research.

Another important area of research is palliative/supportive care, which is specialized medical care for people living with serious illness that focuses on treating the discomfort, symptoms, and stress of such illness. Research to date has shown that palliative care can improve patient care, patient-clinician communication, and patient-centered outcomes while decreasing unwanted and/or burdensome treatments and enhancing quality of life for people with serious illness, their loved ones, and their care partners[iii]. We urge building upon existing knowledge through multi-center coordination aimed at a wide variety of palliative care research, training, dissemination, and implementation of projects to intensify the strategic coordination of palliative care research efforts. Lastly, as more survivors live longer, survivorship research is critical to ensuring quality of life.

Priority 2: Research Capacity

NIH has long played a key role in training and launching researchers and this mission continues to be essential to both improving outcomes for patients and continuing American leadership in the biomedical innovation ecosystem in the face of rising international competition. The research workforce is composed of multiple roles from clinicians to bench scientists, to data analysts and clinical research coordinators. Formal career development programs like the R35 or K awards, as well as R01 grant support of graduate student lab workers, are vital components in developing skilled, innovative researchers. While NIH support is geared toward generating new PhD and MD scientists who can become principal investigators, their ability to develop and conduct independent research is affected by the limited supply of academic positions and low federal funding success rates. By offering levels of funding to support as many new grants as possible, and maintaining infrastructure support for research facilities, NIH can restore emerging researchers' trust and enthusiasm, while ensuring continued scientific and clinical advances and ongoing American leadership.

At the same time, there is a shortage of research nurses and research coordinators who perform the majority of frontline work in the context of clinical trials. Nationwide, for every experienced clinical research coordinator seeking work, there are seven jobs posted. For clinical research nurses, the ratio is 1:10 and, for regulatory affairs professionals, 1:35[iv]. These staff shortages have been frequently cited for the inability to activate and conduct research in the U.S., contributing to the erosion of American dominance in biomedical research. These elements of the research workforce have been neglected and have become a limiting step in clinical trial success. NIH should perform a needs analysis within the research ecosystem and develop programs to address identified staffing needs to enhance the formation of more research coordinators and nurses.

While NIH is one of the largest direct funders of research, its impact on research goes beyond funded grants. NIH creates and maintains critical infrastructure that benefits the entire biomedical research ecosystem. Examples include data resources like PubMedCentral and ClinicalTrials.gov; materials like tissue and cell lines; and infrastructure like research center grants that build research capacity. In the field of cancer research, cancer center and NCI Community Oncology Research Program (NCORP) grants provide sites with funding to build out necessary clinical trial infrastructure.

With a goal of improving human health, it is appropriate for NIH's investments to serve as a catalyst for impacts beyond NIH-funded projects. The U.S. is steadily losing its share of global clinical trials, and if we are to reverse that decline, we must invest in additional underlying clinical trial capacity that can be leveraged by all sponsors. This means expanding programs like NCORP to create new infrastructure in locations beyond existing large, urban academic sites so that a greater share of Americans have access to local clinical trial opportunities.

Priority 3: Research Operations

While peer-review scoring and institute leadership priorities have always been combined to make grant decisions, the recent changes to increase the role of political appointees and deemphasize peer review in making awards have led to confusion and concern. While researchers may be willing to shift their efforts toward administration priorities, the ability to understand those priorities is limited. Typically, NIH goals to fund targeted proposals within a specific research area would be facilitated by Notice of Funding Opportunity (NOFO) announcements detailing the type of research desired. However, the number of NOFOs has been reduced by nearly 90%[v], limiting a key tool for communicating administration priorities. In the absence of NOFOs, NIH should provide clear guidance for grant seekers regarding the research areas currently emphasized and likely to be funded.

Moreover, whether as formalized policy or de facto outcome, many areas of valid scientific research related to health disparities are currently blocked from NIH funding. While we know that all Americans are at risk for disease, whether that be cancer, Alzheimer's, diabetes, or heart failure, everyone does not experience these diseases in the same way. There are often profound differences in incidence, morbidity, and mortality between demographic groups for the same disease. In cancer, for example, Black women are less likely to be diagnosed with breast cancer, but more likely to be diagnosed with triple-negative breast cancer, one of the deadliest forms, and are more likely to die from any breast cancer diagnosis than White women[vi]. Hispanic individuals are nearly twice as likely to be diagnosed with liver cancer than White people.[vii]Disparities are geographic as well, with rural Americans 20% more likely to develop colon cancer and 40% more likely to die from lung cancer than those living in urban areas[viii]. These disparities are real and lead to unnecessary death and suffering. A better understanding of the basis of these differences is key to improving outcomes for everyone. NIH must not only acknowledge the existence of health disparities, but also actively fund research to identify and address root causes.

Patients and members of the public are the ultimate beneficiaries of the advances made possible by NIH research, and accordingly they should play an important role in governance and priority setting. The use of advisory committees has recently been significantly curtailed across all agencies, reducing opportunities for external input. In some cases where the use of committees has continued, they have been entirely reconstructed, often bypassing typical nomination procedures and important conflict of interest vetting processes. Because transparency and public trust depend on accepting and acting on external input, following formal and rules-based processes, and empowering patients with more than token roles, NIH must take action to ensure that a range of voices, including patients', are incorporated into a transparent and unbiased advisory committee review process.

Conclusion

Thank you for the opportunity to comment on NIH's next strategic plan. NIH has helped propel nearly every major advancement in medicine, and further progress depends on continued robust funding for NIH as well as a clear strategic vision. NIH should continue to drive basic discovery, while also funding the infrastructure—including workforce and institutions—needed to maintain America's leadership in biomedical research. NIH serves a foundational role in funding research critical to our public health, which includes disparities, prevention, and rare and neglected diseases research. We look forward to continued engagement in support of NIH. If you have any questions, please feel free to have your staff contact Alex Sutton, Director, Federal Advocacy, at Alex.Sutton@cancer.org.

Sincerely,

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

William Dahut, MD
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[i] https://jamanetwork.com/journals/jama-health-forum/fullarticle/2804378

[ii] https://acsjournals.onlinelibrary.wiley.com/doi/full/10.1002/cncr.35577

[iii] https://ascopubs.org/doi/10.1200/JCO.2016.70.1474

[iv] https://myscrs.org/resources/sites-now/exploring-the-current-clinical-workforce/

[v] https://www.nature.com/articles/d41586-026-00823-2

[vi] https://acsjournals.onlinelibrary.wiley.com/doi/pdf/10.3322/caac.21754

[vii] https://www.cdc.gov/cancer/health-equity/hispanic-latino.html

[viii] https://academic.oup.com/jnci/advance-article-abstract/doi/10.1093/jnci/djag047/8527796?login=false