



NATIONAL HEALTH COUNCIL

August 16, 2024

The Honorable Cathy McMorris Rodgers
Chair
Committee on Energy and Commerce
U.S. House of Representatives
Washington, DC 20510

Dear Chair Rodgers:

The National Health Council (NHC) is pleased to respond to your Framework for Discussion (Framework) on reforming the National Institutes of Health (NIH). We appreciate the opportunity to provide input on how Congress can work to build on the long history of progress at NIH that has led to greater research into the causes of chronic diseases and disabilities and innovations in treatment.

Created by and for patient organizations more than 100 years ago, the NHC brings diverse organizations together to forge consensus and drive patient-centered health policy. We promote increased access to affordable, high-value, sustainable, equitable health care. Made up of more than 170 national health-related organizations and businesses, the NHC's core membership includes the nation's leading patient organizations. Other members include health-related associations and nonprofit organizations including the provider, research, and family caregiver communities; and businesses representing biopharmaceutical, device, diagnostic, generic drug, and payer organizations.

Consolidation of Institutes

The NHC agrees with the statements in the framework on the need to better coordinate research goals, agendas, and constituencies. However, the consolidation of Institutes and Centers (ICs) would not necessarily achieve this goal and could result in the deprioritization of certain research that patients have fought for years to have addressed such as on neglected diseases and populations. Part of the reason there are multiple ICs is that there were certain areas of research that were not prioritized in other ICs. For example, disability-specific research was not prioritized for years until advocates pushed for more research. Consolidated ICs could result in a constant reprioritization of areas of research, causing instability and uncertainty for researchers and patients. It could also result in competition within ICs to prioritize research into specific areas, therefore increasing gaps in research with some research areas being prioritized at the expense of others.

The NHC emphasizes that specific ICs were established to address gaps in research and ensure dedicated focus on various disabilities, diseases, and populations. For instance, the establishment of the National Institute on Deafness and Other

Communicative Disorders and the National Eye Institute was driven by the need to prioritize research in these critical areas. Combining ICs might dilute this focus, leading to potential neglect of less prominent but equally important research areas. Another example is that what was previously the National Institute on Aging would become the National Institute on Dementia under the proposal. While research into dementia is critically important, it is not the only age-related chronic disease, and the unique aspects of aging may be lost in other combined ICs.

Instead of the proposed consolidation, the NHC recommends focusing on incentivizing better coordination between ICs. This could take the form of new requirements for ICs to regularly exchange research agendas and encouraging research across ICs for areas of shared interest.

If Congress is indeed concerned about siloed work at NIH, increased guidance to the NIH Director to stimulate shared agendas and resources across ICs would be welcome.

Research into Specific Populations and Illnesses

In the introduction to the framework, there is a statement that the framework is intended to “eliminate the demographic or disease specific siloed nature of the current structure.” The NHC believes that there is a continued need for specific focuses on traditionally marginalized populations and diseases that would not get the same research attention if not incentivized within the NIH structure. Without specific ICs, some research into specific disabilities and diseases would have to compete against other interests to gain funding and prioritization within larger ICs and there is likely to be necessary, life-saving research that is lost in that process.

Historically, research on marginalized populations has often been underfunded and overlooked. For example, health disparities research, which examines differences in health outcomes among different population groups, has highlighted significant gaps in research and health care provision for people with disabilities, women, and racial and ethnic minorities. Without dedicated ICs to focus on these issues, research on such populations may not receive the necessary attention and resources, and they will continue to be left behind in the research agenda.

In addition, there is ample evidence that research addressing the specific needs of that is inclusive of marginalized populations has not historically been prioritized¹. Studies have shown that clinical trials often lack diversity, leading to findings that may not be applicable to all populations. For instance, the inclusion of people with disabilities, women, and minorities in clinical trials has been historically low, which can result in treatments that are less effective or have different side effects in these groups.

¹ [Carnethon MR, Kershaw KN, Kandula NR. Disparities Research, Disparities Researchers, and Health Equity. JAMA. 2020;323\(3\):211–212. doi:10.1001/jama.2019.19329](https://doi.org/10.1001/jama.2019.19329)

The establishment of specific ICs for areas like disability specific research, women's health, rare diseases, and minority health ensures that these critical areas receive focused attention and dedicated resources. The National Institute on Minority Health and Health Disparities (NIMHD), for example, plays a crucial role in leading scientific research to improve minority health and eliminate health disparities. Similarly, the National Institute of Nursing Research (NINR) focuses on the unique health needs of populations that may not be the primary focus of other ICs.

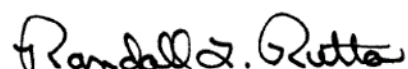
These specific population and disease-specific entities exist to assure attention and resources focused on areas that Congress and the research community have prioritized. The NHC recommends continuing the commitment to addressing specific needs.

Transparency

As mentioned above, greater transparency is a key to addressing many of the concerns raised in the framework. It is critical that Congress and the public have a clear line of sight into why, how, and to whom research funding is being allocated. However, any transparency that is required must come with context. It is particularly important that research funding continue to keep pace with patients' needs and priorities as well as research costs.

We appreciate the opportunity to provide additional input on these critical issues. Please do not hesitate to contact Eric Gascho, Senior Vice President of Policy and Government Affairs if you or your staff would like to discuss these issues in greater detail. He is reachable by phone at 202-973-0546 or via e-mail at egascho@nhcouncil.org.

Sincerely,



Randall L. Rutta
Chief Executive Officer