



600 13TH ST., NW, SUITE 500
WASHINGTON, DC 20005
p | 202-753-5500
f | 202-347-5147

16011 COLLEGE BLVD., SUITE 250
LENEXA, KS 66219
p | 913-262-1436
f | 913-262-1575

WWW.CHILDRENSHOSPITALS.ORG

August 16, 2024

The Honorable Cathy McMorris Rodgers
Chair
Energy and Commerce Committee
2125 Rayburn House Office Building
Washington, DC 20515

Dear Chair Rodgers,

On behalf of the nation's 200+ children's hospitals and the patients and families we serve, thank you for the opportunity to respond to your request for feedback on *Reforming the National Institutes of Health: A Framework for Discussion*. We appreciate your desire to ensure the National Institutes of Health (NIH) is modernized, well-funded, and strategically positioned to drive health care innovation that will improve the health of the nation and save lives. As you consider reforms to the NIH, **we urge you to prioritize the health care needs of children and the critical role NIH plays in supporting life-saving and innovative pediatric medical research, which is often conducted by highly specialized clinicians and researchers at children's hospitals.**

Children's hospitals are dedicated to the health and well-being of our nation's children. Children's hospitals serve the majority of children with serious, chronic, and complex conditions, providing 95% of all pediatric cancer care, and most major surgeries for children with complex medical conditions. Given the wide array of conditions treated at children's hospitals, especially those that are particularly rare or complex, children's hospitals are also hubs of pediatric medical research, exploring a wide range of issues in child development and children's health conditions, driving groundbreaking innovation in pediatric care.

Children's hospitals appreciate your longstanding commitment to strengthening the United States' position as a leader in biomedical research and health care innovation, including legislation like the 21st Century Cures Act. Further, we appreciate your recognition of the unique importance of pediatric medical research and the pediatric researchers who conduct this important work, including your strong support of the *Pediatricians Accelerate Childhood Therapies (PACT) Act*.

As you know well, children's hospitals are leaders in pediatric medical research and major grantees of the NIH especially through the National Institute of Child Health and Human Development (NICHD). As such, **children's hospitals are invested in ensuring that any reforms to the NIH consider the unique needs of children and the way pediatric health care is structured and delivered.** A medical research infrastructure that incorporates the needs of children is critical for developing treatments that improve their long-term health outcomes. As leaders in pediatric medical training and research, children's hospitals are eager to work with Congress to strengthen the pediatric medical research infrastructure, so that critically important pediatric-focused research advances and the pediatric medical research workforce grows.

We appreciate that the proposals within your framework acknowledge the need for all NIH institutes and centers to consider how age and stages of human development impact the discovery and delivery of effective treatments and broader health promoting interventions, such as studies to address nutrition or sleep disorders. Children's hospitals also agree with the need for better coordination across NIH institutes and centers on cross-cutting priorities and reducing silos that hinder collaborative research and innovation. We further appreciate your recognition of the need for additional funding to support pediatric research throughout the NIH. At the same time, we urge you to maintain the NICHD given its vital role in ensuring that pediatric research remains a priority at the NIH.

Champions for Children's Health

Safeguard the NICHD and its Focus on Children’s Health and Development

We oppose eliminating the NICHD—the sole NIH institute focused on child health and human development—or any consolidation with other institutes that would risk harm to its essential mission. Since it was established in 1962, the NICHD has played an essential role in expanding knowledge about human development, and the health conditions that impact children from birth and throughout their development. The NICHD supports critical research to improve the health of children and their families, including promoting healthy pregnancies, reducing infant deaths, and examining the challenges associated with birth defects, as well as intellectual and developmental disabilities. The work of the NICHD has translated to life-saving public health information and education, such as the *Safe to Sleep Campaign*—which provides education to parents, caregivers, and health care providers to prevent Sudden Infant Death Syndrome—and other sleep-related harms. **Pediatric medical conditions vary significantly throughout a child’s development, and only the NICHD is prepared to support a robust study design that can incorporate this dynamic time from fetus through adolescence.** The unique work of the NICHD remains absolutely vital and it should not be compromised through consolidation with other institutes or centers.

We certainly agree that all institutes and centers across the NIH should implement a life course approach to ensure their research portfolios are both inclusive of patients throughout the lifespan and facilitate the study of diseases unique to childhood. This is particularly critical to ensuring that treatments and interventions developed by NIH are also studied within pediatric patients—leading to safe, effective treatments for children. **Unfortunately, the inclusion of pediatric patients and pediatric researchers has not been prioritized across NIH institutes and centers, outside of NICHD. As a result, pediatrics receives fewer grants and too often has been omitted from cross-NIH initiatives.**¹ While children’s hospitals would like to see reforms that bolster the inclusion of pediatrics within all NIH institutes and centers, **we also strongly believe that the NICHD plays an irreplaceable role by prioritizing children’s health research, and it must continue as its own institute.**

Strengthen the Pediatric Research Workforce Pipeline

We were pleased to see the proposed framework recognizes the need for Congress and the NIH to better support early-career pediatric researchers and we urge you to support and bolster this talent pipeline as part of any NIH reform package. The disparities and additional challenges faced by pediatric researchers seeking grant funding not only result in fewer pediatric studies and delay the discovery of life-saving knowledge, but they also serve as a disincentive for scientists and physicians to pursue careers in pediatric medical research.

To that end, **we strongly support the bipartisan *PACT Act (H.R. 4714)***, which, as you know, would create a new training model focused explicitly on promising early-career researchers focusing on child health, including those from backgrounds under-represented in pediatric research. This bill would improve coordination of pediatric research by directing the NIH Pediatric Research Consortium to identify gaps and opportunities to support the development of new treatments and cures for children’s health conditions. Enacting this legislation would be a tangible way to infuse training dollars into child health research training programs, helping reverse declines that have occurred over the past several years.

Prioritize the Inclusion of Pediatric Patients and Investigators

We strongly encourage Congress to put in place measures that ensure the inclusion of pediatrics in cross-institute collaborative projects and NIH-wide initiatives. Inclusion of pediatric patients and pediatric specialties in cross-NIH

¹ [Name and Characteristics of National Institutes of Health R01-Funded Pediatric Physician-Scientists | PMC \(nih.gov\)](#)

projects has been inconsistent at best, with pediatrics too often being overlooked as initiatives are implemented. It is critical that the unique developmental and physiological needs of all children—including those living in rural and urban areas—are included in studies and clinical trials across the NIH.

One such initiative is the *All of Us Research Program* which aims to recruit participants into one of the most diverse health databases ever created, to enable researchers to study how our biology, lifestyle, and environment affect our health. For this database to be truly representative and to enable the study of health throughout the lifespan, the NIH must actively recruit all age groups, including children and adolescents. Unfortunately, decreases in funding for the *All of Us Research Program* have delayed pediatric recruitment into the program beyond an initial pilot. Failure to recruit children into the program in numbers that are proportional to the nation's population could lead to missed scientific opportunities, not only for children but for lifespan research.

We strongly recommend that Congress urge the NIH—and provide the needed funding in a timely manner—to finalize recruitment protocols for the *All of Us Research Program* to implement a multi-phase program geared to children. We recommend that Congress and NIH work with children's hospitals, given that they are regional centers for groundbreaking medical research into pediatric health conditions and life-saving treatments, on recruitment and other aspects of the child-focused components of *All of Us* and other NIH-wide initiatives that address pediatric research.

Thank you for this opportunity to provide feedback on *Reforming the National Institutes of Health: A Framework for Discussion*. The pediatric medical research supported by the NIH has driven the discovery of life-changing treatments and cures that positively impact children and their families. Further, decades of NIH research have produced public health knowledge that medical professionals, parents, caregivers, and communities leverage every day to mitigate health risks and promote healthy development in children.

We appreciate the underlying goals of this proposed NIH framework; however, we strongly encourage you to protect the expertise and integrity of NICHD and the critical work it does to promote and safeguard the health of America's children. As you and your colleagues continue to discuss reforms to the NIH, we strongly encourage a robust process that involves pediatric stakeholder input, public testimony, and an ongoing dialogue to prioritize the most urgently needed and effective changes to strengthen the NIH and prioritize the health needs of children. Children's hospitals stand ready to share our expertise with you as you consider next steps. Please contact [Cynthia Whitney](#) and [Natalie Torentinos](#) should you need additional information.

Sincerely,



Leah Evangelista
Chief Public Affairs Officer
Children's Hospital Association
Leah.Evangelista@childrenshospitals.org