



April 9, 2021

The Honorable Francis Collins, MD, PhD  
Director  
National Institutes of Health  
Building 1, One Center Drive  
Bethesda, MD 20892-2014

RE: Research Request for Information - Inviting Comments and Suggestions to Advance and Strengthen Racial Equity, Diversity, and Inclusion in Biomedical Research and Advance Health Disparities and Health Equity Research

Dear Dr. Collins:

On behalf of Nemours Children's Health System (Nemours), thank you for the opportunity to submit recommendations as the National Institutes of Health (NIH) works to support true health equity by addressing systemic challenges and barriers affecting the NIH workforce and NIH-supported biomedical community.

Nemours is an internationally recognized children's health system that owns and operates the Nemours/Alfred I. duPont Hospital for Children in Wilmington, Del., and Nemours Children's Hospital in Orlando, Fla., along with over 80 other care facilities in five states. Nemours delivers pediatric primary, specialty, and urgent care to children from all 50 states. In addition to clinical care, we provide research, education, advocacy, and prevention programs to benefit children everywhere. We are striving to create the healthiest generations of children.

## RECOMMENDATIONS

Below are specific recommendations for consideration under the *Research Areas* and *Further Ideas* categories included in the Request for Information (RFI).

### **Research Areas:**

Nemours urges NIH to consider addressing the research gaps and barriers below to advance the science of health disparities and health inequities research.

### **Using Big Data to Advance Research focused on Social Determinants of Health**

Nemours is encouraged by the public health community's increased focus on social determinants of health (SDOH) - the conditions in which people live, learn, work, play, and worship - and their impact on long-term health outcomes.<sup>1</sup> Growing research shows that SDOH are the root causes of health disparities and inequities, thus, advancing research focused on SDOH will help us to understand how we can improve the science of health disparities and health inequities research. Moreover, status quo structures and systems within society often create, perpetuate and exacerbate racial disparities.<sup>2</sup> As we continue to learn more about SDOH, we should also further examine how upstream SDOH factors such as limited

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<sup>1</sup> Braveman, P., & Gottlieb, L. (2014). The social determinants of health: it's time to consider the causes of the causes. *Public health reports*, 129(suppl2), 19-31.

<sup>2</sup> Yearby, R. (2020). Structural Racism: The Root Cause of the Social Determinants of Health. *Bill of Health*. <https://blog.petrieflom.law.harvard.edu/2020/09/22/structural-racism-social-determinant-of-health/>

educational attainment, low socioeconomic status, unemployment, discrimination and structural racism can impact downstream adverse health outcomes.<sup>3</sup>

Our health system is part of a growing cross-institution pediatric research network called PEDSnet, with data from eight children's health systems. This network provides our researchers with access to a unified dataset of 7.24 million de-identified pediatric records (from 2009-2021) primarily across 12 states. This represents a population of patients equivalent in size to over 9% of the US 2010 pediatric population.<sup>4</sup> Through PEDSnet, our institutions can gather enormous and previously inaccessible amounts of data to help design care that can save children's lives. A recently published retrospective cohort study in *JAMA Pediatrics* underscores the power of using large data sets to identify disparities.

Researchers in the study used PEDSnet data – electronic health records of 135,794 pediatric patients from Nemours and the six other participating children's health systems – to study the prevalence and impact of the coronavirus on children.<sup>5</sup> Though children are less likely to contract the SARS-CoV-2 virus, the study underscores disproportionately high rates of infection and worse health outcomes in children of Black, Hispanic, and Asian descent. This research corroborates other data that shows that people of color contract the virus and develop severe symptoms at a disproportionately higher rate, making up more than half of COVID-19 deaths in the United States.<sup>6</sup> **Nemours encourages NIH to make large data sets from NIH's many longitudinal cohorts readily available to the public. This will allow the research community to identify health disparities in the most at-risk populations, including children.**

**Nemours also urges NIH to fund longitudinal research studies that aim to increase understanding of how SDOH interventions in early childhood can impact long-term health outcomes and health care cost savings associated with such interventions.** We are now seeing growing evidence that interventions targeting SDOH such as education, housing, income, employment, etc., can reduce health disparities and health care costs.<sup>7</sup> For example, interventions aimed at providing quality education in early childhood and parenting support are cost effective and can yield long-term health outcomes for children and their families, such as improved health behaviors and decreased risk factors for cardiovascular disease.<sup>8</sup> These interventions have consistently proven to be successful with accrued health-related benefits into adulthood.<sup>9</sup> We need more research to understand the health impacts and cost-savings associated with interventions addressing SDOH, especially for children.

### **Prioritization of Health Disparities in Pediatrics**

As a children's health system, we have personally experienced the challenges of accurately capturing patients' demographic data. This data could help us to evaluate the underlying factors that drive health disparities – as these inequities may not manifest monolithically among one race or income level, for example. Inconsistent demographic data collection is an issue prevalent across the pediatric environment

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<sup>3</sup> Gray, D. M., Anyane-Yeboah, A., Balzora, S., Issaka, R. B., & May, F. P. (2020). COVID-19 and the other pandemic: populations made vulnerable by systemic inequity. *Nature Reviews Gastroenterology & Hepatology*, 17(9), 520-522.

<sup>4</sup> <https://www.census.gov/data/tables/time-series/demo/popest/2010s-national-detail.html>

<sup>5</sup> Bailey LC, Razzaghi H, Burrows EK, et al. Assessment of 135 794 Pediatric Patients Tested for Severe Acute Respiratory Syndrome Coronavirus 2 Across the United States. *JAMA Pediatrics*. Published online November 23, 2020. doi:10.1001/jamapediatrics.2020.5052

<sup>6</sup> Rodriguez, F., Solomon, N., de Lemos, J. A., Das, S. R., Morrow, D. A., Bradley, S. M., ... & Gupta, D. (2020). Racial and Ethnic Differences in Presentation and Outcomes for Patients Hospitalized with COVID-19: Findings from the American Heart Association's COVID-19 Cardiovascular Disease Registry. *Circulation*.

<sup>7</sup> Nichols, L. M., & Taylor, L. A. (2018). Social determinants as public goods: a new approach to financing key investments in healthy communities. *Health Affairs*, 37(8), 1223-1230.

<sup>8</sup> "The Effects Of Early Care And Education On Children's Health," *Health Affairs Health Policy Brief*, April 25, 2019. DOI: 10.1377/hpb20190325.519221

<sup>9</sup> Thornton, R. L., Glover, C. M., Cené, C. W., Glik, D. C., Henderson, J. A., & Williams, D. R. (2016). Evaluating strategies for reducing health disparities by addressing the social determinants of health. *Health Affairs*, 35(8), 1416-1423.

and hinders progress in pediatric research and treatment.<sup>10</sup> The lack of systematic standards or criteria in demographic data collection, and thus the lack of available demographic data, makes it difficult for pediatric research institutions like ours to see the full picture. This makes it challenging or impossible to identify the most at-risk populations for certain diseases and develop proactive treatments. Nemours is working to address this issue by conducting unconscious bias research to understand how to best train our employees to work through their implicit bias to capture demographic data. **Nemours encourages NIH to promptly address the barriers to demographic data science in pediatrics, more specifically, looking at what causes demographic data to be inaccurately captured (i.e. implicit bias) and what best practices can be adopted to address these barriers.**

Despite the reality of persistent health disparities, growing evidence shows that certain technologies can be effective in combatting them. For example, while rural populations face significant health disparities compared to urban populations, school-based telemedicine can improve control of symptoms and quality of life in cases of pediatric asthma and type I diabetes.<sup>11</sup> While much evidence demonstrates that asthma outcomes are poorer among Black and lower income populations, a number of technological interventions (including web-based health education, text messaging, etc.) have been associated with better health outcomes. However, access to broadband and/or mobile technology is not ubiquitous across rural, minority or lower-income populations.<sup>12</sup>

Pediatric type 1 diabetes is an area with substantive health disparities concerns. Among children with this condition, racial and ethnic minority groups along with lower-income populations often have higher blood levels of HbA1c, which can have profoundly negative effects on overall health.<sup>13</sup> Lower diabetes technology use has also been associated with lower socioeconomic status<sup>14</sup> – raising the question of whether broader access to diabetes technologies could improve outcomes among populations facing disparities in diabetes outcomes.<sup>15</sup> **Nemours calls on NIH to investigate barriers to the utilization of healthcare technology, particularly looking at how health disparities such as ethnicity and socioeconomic status can impact access to technology.**

### **Further Ideas:**

Nemours commends NIH for looking at approaches to implement bold and innovative measures to advance diversity, inclusion, and equity to promote research on health disparities. Below are two recommendations for your consideration.

### **Improving Diversity and Inclusion in Research Studies**

It is clear that health disparities continue to hinder health equity in the United States, and the burden of poorer health outcomes and treatment disproportionately affects people of color. However, despite significant evidence spanning multiple populations, conditions, and interventions, we must conduct more research to determine the causal direction driving these disparities. Many studies utilize small samples

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<sup>10</sup> Tan-McGrory, A., Bennett-AbuAyyash, C., Gee, S. *et al.* A patient and family data domain collection framework for identifying disparities in pediatrics: results from the pediatric health equity collaborative. *BMC Pediatr* **18**, 18 (2018). <https://doi.org/10.1186/s12887-018-0993-2>

<sup>11</sup> Marcin, J., Shaikh, U. & Steinhorn, R. Addressing health disparities in rural communities using telehealth. *Pediatr Res* **79**, 169–176 (2016). <https://doi.org/10.1038/pr.2015.192>

<sup>12</sup> Alan P. Baptist, Nishat Islam, Christine L.M. Joseph. Technology-Based Interventions for Asthma—Can They Help Decrease Health Disparities? *The Journal of Allergy and Clinical Immunology: In Practice*, **4**(6), 1135-1142 (2016). <https://doi.org/10.1016/j.jaip.2016.04.024>.

<sup>13</sup> Borschuk AP, Everhart RS. Health disparities among youth with type 1 diabetes: A systematic review of the current literature. *Fam Syst Health*. 2015 Sep;**33**(3):297-313. doi: 10.1037/fsh0000134. Epub 2015 May 18. PMID: 25984737.

<sup>14</sup> Addala A, Auzanneau M, Miller K, Maier W, Foster N, Kapellen T, Walker A, Rosenbauer J, Maahs DM, Holl RW. A Decade of Disparities in Diabetes Technology Use and HbA1c in Pediatric Type 1 Diabetes: A Transatlantic Comparison. *Diabetes Care*. 2021 Jan;**44**(1):133-140. doi: 10.2337/dc20-0257. Epub 2020 Sep 16. PMID: 32938745.

<sup>15</sup> Ravi SJ, Coakley A, Vigers T, Pyle L, Forlenza GP, Alonso T. Pediatric Medicaid Patients With Type 1 Diabetes Benefit From Continuous Glucose Monitor Technology. *J Diabetes Sci Technol*. 2020 Mar **14**:1932296820906214. doi: 10.1177/1932296820906214. Epub ahead of print. PMID: 32172603.

that do not represent the general population that they intend to study. To address the aforementioned issue, **Nemours encourages NIH to develop standard population sets, aggregated by disease, which the research community can reference when studying a specific population. This would enable further exchange of information and awareness about potential cohort bias and under representation of minority groups in research studies.** By gaining access to standard population sets, researchers can become more mindful of how the minority representation in their study compares to the overall population, helping to address inequities in research.

As biomedical research is a central pillar to the activity at NIH, we must acknowledge some of the barriers in research involving human participants. When evaluating health disparities, it is important to recruit and maintain a diverse sample population to understand how outcomes may differ based on demographics and experiences. Yet less than 3% of participants in published, genome-wide association studies are of African or Hispanic or Latin American backgrounds.<sup>16</sup> Additionally, white participants make up about 86% of adult clinical trial participants, and some evidence indicates pediatric clinical trials also have enrollment disparities among racial and ethnic groups<sup>17,18</sup> As a research community, we need to prioritize recruitment efforts to increase diversity in the populations we study.

Some evidence suggests that electronic health records (EHRs) can be effective in recruiting a diverse study population.<sup>19,20</sup> EHRs, paired with a team-based approach in which clinicians and researchers collaborate on efforts for clinical trial recruitment, could help to increase diversity in clinical trials.<sup>21</sup> Nemours recently updated our EHR system to incorporate criteria for active clinical trials. Through this update, our EHR system alerts physicians when patients qualify for certain clinical trials, enabling our physicians to work with their care team and researchers to address potential language and cultural barriers that could hinder trial enrollment. **Nemours respectfully requests that NIH conduct research on the effectiveness of EHRs in increasing diversity in clinical trial enrollment, and if proven effective, promote this as a technique for enhanced recruitment efforts.**

## CONCLUSION

Nemours stands ready to leverage our expertise and relevant experiences to assist NIH as it works to support diversity, equity and inclusion in the biomedicine research community. We look forward to continued collaboration. Thank you for your consideration of our recommendations. Please do not hesitate to reach out to me at [Daniella.Gratala@nemours.org](mailto:Daniella.Gratala@nemours.org) or to Vy Oxman at [Vy.Oxman@nemours.org](mailto:Vy.Oxman@nemours.org) with questions or for additional information.

Sincerely,



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<sup>16</sup> Knepper, T.C., and McLeod, H.L. (2018). When will clinical trials finally reflect diversity? *Nature* 557, 157–159.

<sup>17</sup> Mills, M.C., and Rahal, C. (2020). The GWAS Diversity Monitor tracks diversity by disease in real time. *Nat. Genet.* 52, 242–243.

<sup>18</sup> Factors Associated With Declining to Participate in a Pediatric Oncology Next-Generation Sequencing Study  
Katie M. Howard Sharp, Niki Jurbergs, Annastasia Ouma, Lynn Harrison, Elsie Gerhardt, Leslie Taylor, Kayla Hamilton, Rose B. McGee, Regina Nuccio, Emily Quinn, Stacy Hines-Dowell, Chimene Kesserwan, Anusha Sunkara, Jami S. Gattuso, Michelle Pritchard, Belinda Mandrell, Mary V. Relling, Cyrine E. Haidar, Guolian Kang, Liza-Marie Johnson, and Kim E. Nichols  
*JCO Precision Oncology* 2020 :4, 202-211

<sup>19</sup> Pfaff E, Lee A, Bradford R, Pae J, Potter C, Blue P, Knoepf P, Thompson K, Roumie CL, Crenshaw D, Servis R, DeWalt DA. Recruiting for a pragmatic trial using the electronic health record and patient portal: successes and lessons learned. *J Am Med Inform Assoc.* 2019 Jan 1;26(1):44-49. doi: 10.1093/jamia/ocy138. PMID: 30445631; PMCID: PMC6308009.

<sup>20</sup> *AMA J Ethics.* 2018;20(9):E873-880. doi: 10.1001/amajethics.2018.873.

<sup>21</sup> McHugh, K. R., Swamy, G. K., & Hernandez, A. F. (2018). Engaging patients throughout the health system: A landscape analysis of cold-call policies and recommendations for future policy change. *Journal of clinical and translational science*, 2(6), 384-392.



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