

Attachment—Additional Questions for the Record

Subcommittee on Health Hearing on “Empowered by Data: Legislation to Advance Equity and Public Health” June 24, 2021

Kara Odom Walker, M.D., M.P.H., M.S.H.S.
Executive Vice President and Chief Population Health Officer
Nemours Children’s Health

The Honorable Gus Bilirakis (R-FL)

1. As Co-Chair of the Rare Disease Caucus, I would like to focus some time on the disparity of care in sickle cell disease. The Trump Administration made great progress, including increased NIH research, and the approval of two novel therapies. I was also proud to support the enactment of the Sickle Cell Disease Research Surveillance Prevention and Treatment Act in 2018. But disparities in care remain — I am told of the 100,000 Americans suffering from Sickle Cell Disease — the great majority of whom are Black— only 30 percent of these 100,000 Americans receive any form of medical treatment despite its widespread availability.
 - a. What can Congress and the Administration do to break through and build on the Trump Administration’s progress in sickle cell disease, all the more important now that novel therapies have been approved with even more on the horizon?

Thank you for your work supporting Sickle Cell Disease (SCD) research and treatment activities that benefit patients and families nationwide.

As you mention, there are disparities in access to quality SCD care and health outcomes. The COVID-19 pandemic has worsened these disparities, as people of color have been disproportionately impacted by the health impact of the COVID-19 virus. One of several reasons behind this disparity is higher incidence of underlying comorbid conditions that increase risk of contracting COVID-19 and experiencing worse outcomes. SCD is one of the conditions identified by the Centers for Disease Control and Prevention (CDC) known to increase risk of severe illness from COVID-19.

Governmental support is critical to advancing SCD treatment and closing the disparities you have highlighted.

Nemours Children’s Health participates in a number of research, clinical and advocacy networks engaging in a spectrum of activities aimed at supporting individuals,

particularly children, with SCD. In 2020, Nemours received a \$10.5 million research grant from the National Institutes of Health (NIH) Center of Biomedical Research Excellence (COBRE) Phase II to establish and run the [Delaware Comprehensive Sickle Cell Research Center](#). The multidisciplinary Center works to strengthen early career investigator mentoring while further advancing biomedical research infrastructure for sickle cell disease research. The specific aims of the grant are: 1) Develop and oversee expert mentoring of early career investigators in research methods, research program development, and academic independence across an array of disciplines involved in the study of sickle cell disease; 2) Establish a diverse and inclusive grants program to promote the development of the next generation of sickle cell researchers in Delaware; and 3) Maintain administrative oversight that ensures strategic planning and development, compliance with all local and federal reporting requirements, and effective stewardship of resources to lead to the sustainable success of the Delaware Sickle Cell Research Center. The target projects included in the COBRE grant will explore the interactions of racism, stigma, and pain in sickle cell disease while evaluating ways to improve adherence to crucial disease modifying therapies. There is a particular focus on the adolescent/young adult population who are navigating the transition from pediatric to adult health care settings, a period of vulnerability marked by increased risk of morbidity and mortality. This research brings together our pediatric and adult health care systems to create comprehensive care addressing disparities across the lifespan. We would be happy to keep you updated on key findings from our work.

In addition, through our partnership with the American Society of Hematology (ASH), we support a legislative proposal to establish a Medicaid demonstration project to create a Medicaid delivery and payment model for SCD care. Such a demonstration would test models that aim to improve access to comprehensive, high quality outpatient care, including recommended clinical, mental health, ancillary, and support services, for individuals living with SCD who are enrolled in Medicaid, with an emphasis on targeting young adults and pregnant women with SCD.

A Centers for Medicare and Medicaid Services (CMS) report found that approximately 50% of the U.S. SCD population are covered by Medicaid. A second report found that almost 12,000 are covered by Medicare and of those, more than 8,000 are dual eligible for Medicare and Medicaid. We would welcome the opportunity to discuss this proposal with you and your team.

Congress should authorize a demonstration model that would allow states to apply for funding and test approaches to comprehensive care for individuals living with SCD, especially young adults and pregnant women.

The Honorable Richard Hudson (R-NC)

1. A number of public and non-profit safety net hospitals who serve large populations of low income and diverse patients who are challenged by numerous social risk factors have come together to share and innovate best practices. One major identified need is data platforms that track both medical and social conditions and facilitate access to services that respond to these needs. Another is support for “learning laboratories” that will advance identification and dissemination of promising innovations to improve care to these aforementioned populations.
 - a. Would you agree that investments into entities working to help advance best practices related to social determinants of health could drive progress in improving health inequity?

Investing in approaches to address individual and population-level social drivers of health (SDOH), including data platforms and sharing of best practices, would help drive progress in improving health equity.

With respect to data platforms, we support investments in community care coordination systems that provide tools to improve health outcomes by allowing bi-directional information sharing and referrals between health care providers and a full range of community-based service providers. Often referred to as “closed loop referral systems,” these data platforms can support the identification of social needs, referrals to services and feedback when the service is procured. Various Electronic Health Records (EHR) providers and technology companies have built referral systems for use across health care providers, community-based organizations, government agencies, and others.

However, we also recognize numerous challenges in the current ecosystem of closed loop referral systems. Interoperability is perhaps one of the most significant concerns. The simultaneous growth of numerous referral systems is already creating challenges. For example, when a major health system invests in a specific closed loop referral system, other health systems in the region are left with a difficult decision to either pay the fees associated with the closed loop referral system or choose to utilize a different system altogether, thereby contributing to a disjointed referral network. Community-based organizations find this especially problematic given their existing resource constraints and the challenges of managing multiple referral sources.

Some states are taking the lead in addressing this challenge. For example, North Carolina’s NCCARE360 is the first statewide coordinated care network to electronically connect those with identified needs to community resources and allow for a feedback loop on the outcome of that connection. NCCARE360 is made possible because of a public-private partnership between the North Carolina Department of Health and Human Services and the Foundation for Health Leadership and Innovation (FHLI). **This type of unified platform could be an emerging best**

practice that Congress could support through passage of the LINC to Address Social Needs Act of 2021 (S.509), which would establish statewide or regional partnerships to better coordinate health care and social services. We appreciate your leadership in working to introduce similar legislation in the House. Through public-private partnerships, states could leverage local expertise and technology to overcome longstanding challenges, helping to connect people to community resources to address social needs such as food, housing, child development, job training and transportation.

Furthermore, Congress could direct the Centers for Medicare and Medicaid Services (CMS) to highlight innovations like NCCARE360 and share best practices for their development and use with other states. CMS should also solicit feedback on ways to incentivize interoperability across these closed loop referral systems. The historical and ongoing challenges with EHR interoperability present a compelling case for federal government action in this increasingly competitive sector.

More broadly, Nemours Children's agrees that investments to advance best practices related to SDOH, whether through learning labs or other approaches, could have a positive impact on health inequity. Since 2017, Nemours Children's has supported 27 community networks via Learning Labs and we have found the approach to be promising. Participants from our Learning Lab project noted that their collaboration in the project helped to accelerate their work in their home communities, enabling them to achieve and exceed their community health goals. We found that a critical enabler of our Learning Labs was direct technical assistance to help advance their goals. Further, participants reported the benefits of the Learning Lab to be the creation of a safe space - a laboratory - to test ideas and approaches towards shared population health goals. **We encourage Congress to further explore learning laboratories as an approach to advance and improve outcomes.**

- b. What do you consider to be the investment of most immediate need in ensuring that health care, social risk, and other data are being collected on vulnerable populations and what do you see as the best steps for coordination among stakeholders on these efforts?

Nemours Children's considers investments in promulgating social drivers of health (SDOH) identification, collection of best practices and measurement to be the most immediate needs to ensure that health, social risk, and other data are being consistently and responsibly collected on vulnerable populations with their consent and engagement. Greater consistency across the country on how we capture and measure SDOH, with input and consent from patients and families, would provide an opportunity for authentic data to be utilized to help improve health.

Congress could help support and incentivize states and regions to identify and invest in a shared social needs platform for gathering that data. This would help to eliminate undue stress on our community programs from having to respond to multiple platforms and would make identifying social needs more efficient. Deidentified, aggregated social needs data can shed light on where the greatest inequities exist so that community partners and residents can work together to address root causes at the individual and population level. Coordination among stakeholders is a critical component for implementation of such efforts.

Additionally, we need consistent measurement of the impact of social drivers in federal payment programs. There are currently no approved social drivers measures in any Centers for Medicare and Medicaid Services (CMS) programs. CMS has included the first social drivers measures – focused on screening patients for food insecurity, housing instability, transportation, utility needs, and interpersonal safety – in its “measures under consideration” list. If approved, this would be a promising step forward, and we urge continued focus in this area.

Congress could support this work by encouraging CMS to advance the social drivers measures under consideration.