

Attachment—Additional Questions for the Record

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

Ms. Beth Blauer, Executive Director, Johns Hopkins University Centers for Civic Impact

The Honorable Kathy Castor (D-FL)

1. Ms. Blauer, you also mention that H.R. 976 could be strengthened by requiring public health data reporting for states moving forward. What would be the benefit of requiring states to report data? Do you have any recommendations on the type of data that should be reported – especially to address equity?

There are a number of reasons why structuring state reporting of public health data could provide benefit. Here are the two most significant:

1. **Expose opportunities to reform.** The first and most essential reason why collecting public health data regularly from the states is the capacity for this data to reveal the opportunities for the public health system to cure generational flaws that have created massive inequities in access to care, solid public health information, and meeting basic public health needs. If COVID-19 is the example, we have learned that in the face of a public health emergencies, our public health system is ill-equipped and vulnerable. Significant inequalities emerged in who has access to testing, vaccination, and solid public information. These inequities contribute to disproportionate death and hospitalization in black and brown communities.
2. **Standardization of Data.** Structuring the state data would allow the federal government to provide much needed guidance to the states on how to define core demographic and programmatic categories in their data collection efforts. This alignment would make it easier for policy makers to understand what works, where there are specific needs, and how to be strategic with investments. The absence of this consistency leads to limited visibility into strategies that deliver results, creates disparities, and exacerbates some of the worst outcomes. To start these standards could focus on uniform demographic categories for:
 - a. Standard age bands
 - b. Inclusive gender categories
 - c. Ethnicity

d. Race

Having uniform demographic categories across programs will allow policy makers to have a full understanding of the impact of investment across the population.

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?

Yes, having medical records with social data is ideal. This must be approached with care. We need to prioritize and ensure privacy and safe handling of data—which is not impossible. This requires people who know how to use the data to drive systems change. There are also a number of federally funded initiatives that have created data collections that should be linked. For example, when the Department of Education funded Race to the Top, there was significant investment across the states to launch longitudinal data systems that track students from cradle to profession. There is rich data that is collected as part of these systems that could deeply inform health policy. Before creating another platform to collect this data we should inventory all the systems that are currently collecting population level data and understand how they could potentially be linked or leveraged.

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?

To start, we should not just focus on vulnerable populations. We need a health care system that looks at whole people. This includes social factors for all people. It’s important to track this data over time so we can use the data and identify tipping points or early warning signs that economic or social distress is setting in. Both have significant impact on health. As a first step, before a dollar is spent on technology, we should be focusing on intergovernmental data governance. We need to bring people together from across all levels of government to oversee how we are investing the collection of population level data. This governance should draw from program level

experts, front line delivery perspectives, policy makers, and technical teams. Governance should focus on collection standards, ethics, data needs and technology challenges. Governance can be instrumental in prioritization and safeguarding current and future investments from confusion, fraud and waste. Organizations that focus on governance first, spend less money on data collection and derive a much more significant benefit.