COMMITTEE ON
ENERGY & COMMERCE
CHAIRMAN FRANK PALLONE, JR.

MEMORANDUM

June 22, 2021

To: Subcommittee on Health Members and Staff

Fr: Committee on Energy and Commerce Staff

Re: Legislative Hearing on "Empowered by Data: Legislation to Advance Equity and Public Health"

On **Thursday, June 24, 2021, at 10:30 a.m. (EDT) in the John D. Dingell Room, 2123 of the Rayburn House Office Building, and via Cisco WebEx online video conferencing**, the Subcommittee on Health will hold a legislative hearing entitled, "Empowered by Data: Legislation to Advance Equity and Public Health."

I. BACKGROUND

In 2009, the Health Information Technology for Economic and Clinical Health (HITECH) Act spurred the digital transformation of the health care industry information systems in the United States[1], shifting health information technology (IT) systems from paper to electronic health records (EHRs).[2] Unfortunately, robust funding for public health IT systems in the United States to make a similar transition has been lacking. As such, public health data and IT systems have not kept pace with rapid technological advancements in data collection in clinical health settings.[3] Underfunding and decentralized implementation of public health IT systems has resulted in fragmented public health data infrastructure that is unable to adequately capture the information needed to maintain optimum, equitable public health surveillance.[4]

The gap in technological and administrative advancement was underscored during the coronavirus disease of 2019 (COVID-19) pandemic as public health officials, policy leaders, and the public faced barriers to collecting and accessing timely data.[5] The COVID-19 pandemic

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[1] Health Affairs, *Our Progress in Digitizing Health Care* (Sept. 29, 2016) (www.healthaffairs.org/do/10.1377/hblog20160929.056792/full/).

[2] *Id.*

[3] de Beaumont Foundation, Driving Public Health in the Fast Lane (debeaumont.org/wp-content/uploads/2019/09/DSI-White-Paper_v15-Spreads.pdf) (accessed June 14, 2021).

[4] *Id.*

[5] *'Our top headache': How data collection is posing new challenges in the Covid-19 vaccination effort*, STAT News (Jan. 29, 2021) (www.statnews.com/2021/01/29/covid19-vaccination-data-tracking-disparities/).

revealed a number of failures including: inadequate data governance and data sharing policies; lack of public health data standards; low levels of interoperability; an inability to collect high quality data on demographic information, social determinants of health, and other factors that drive health disparities; and an understaffed public health workforce in the field of data and informatics.[6]

Legislative efforts to address deficiencies in public health data and technology fall across four key domains: (i) developing a strategic action plan, data standards, and advancing data sharing policies; (ii) capturing data that reveals the drivers of health disparities such as race/ethnicity, sexual orientation/gender identity, and social determinants of health; (iii) creating the public health data/technology infrastructure needed to deploy essential interventions such as testing, contact tracing, vaccination distribution, and resource management; and (iv) public health informatics workforce development.

A. Public Health Data and Informatics

Public health is foundational to the health of our communities and has been essential in extending the lifespans of Americans across the 19th and 20th centuries.[7] Large amounts of complex data are needed for our public health systems to work effectively.[8] This data includes: (i) vital records of births, deaths, and maternal outcomes; (ii) environmental data on water quality and air pollution; (iii) use of preventative services such as vaccinations and cancer screening; (iv) health behaviors like tobacco, alcohol, and drug use, as well as physical activity, and nutrition; (v) social determinants of health; and (v) exposure to infectious diseases such as HIV, Hepatitis, and COVID-19.[9]

Public health has received only a fraction of the federal investments that are made in the healthcare system despite its essential role in keeping our country healthy and the high complexity and volume of data.[10]

The COVID-19 pandemic also demonstrated the difficulty of building new, large-scale data systems and simultaneously training the public health workforce on these new systems

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[6] Health Information Technology Advisory Committee, *Public Health System Performance During Covid-19, Thomas Frieden, MD, MPH, Resolve to Save Lives* (May 13, 2021) (www.healthit.gov/sites/default/files/facas/2021-05-13_Tom_Frieden.pdf).

[7] Centers for Disease Control and Prevention, *Morbidity and Mortality Weekly Report (MMWR): Ten Great Public Health Achievements – United States, 1900-1999* (www.cdc.gov/mmwr/preview/mmwrhtml/00056796.htm) (accessed June 14, 2021).

[8] Trust for America's Health, *The Impact of Chronic Underfunding on America's Public Health Data: Trends, Risks, and Recommendations, 2020* (www.tfah.org/wp-content/uploads/2020/04/TFAH2020PublicHealthFunding.pdf) (accessed June 17, 2017).

[9] American Public Health Association, What is Public Health? (www.apha.org/what-is-public-health) (accessed June 14, 2021)

[10] *See* note 3.

during an emergency.[11] Systems that were able to function best during COVID-19 were those that were used every day and could be easily expanded to meet the demands of the emergency.[12] Creating these types of scalable systems requires long-term planning and upfront investments for development, as well as long-term funding for maintenance and updates.[13]

B. Social Determinants of Health

Social determinants of health impact the quality of everyone's life and are the primary drivers of health outcomes.[14,15] Generally, social determinants of health are defined as the medical, economic, educational, environmental, and social conditions affecting individuals as they live and age.[16] Examples of social determinants of health include income, housing, transportation, safety, literacy, language, hunger, access to clean water and nutritional food, civic engagement, and access to and quality of health care.[17] Although these markers are the most important indictors of health-related risks, individual-level social determinants of health are not routinely collected or systematically used by healthcare providers to allocate resources or supports to individuals most in need.[18]

Discrimination based on race, ethnicity, gender identity, and sexual orientation is a key social determinant of health and a significant factor in underlying health inequities.[19] For example, Black men consistently had the lowest life expectancy – 71.8 years – from 2006-2015, compared to non-Hispanic white and Hispanic men and women.[20] Across all measures of age,

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[11] The Council for State and Territorial Epidemiologists, Data Modernization (www.cste.org/page/DM-2021) (accessed June 14, 2021).

[12] *Id*.

[13] *Id*.

[14] Health.gov, *Social Determinants of Health* (health.gov/healthypeople/objectives-and-data/social-determinants-health) (accessed June 11, 2021).

[15] Kaiser Family Foundation, *Beyond Healthcare: The Role of Social Determinants* (May 10, 2018) (www.kff.org/racial-equity-and-health-policy/issue-brief/beyond-health-care-the-role-of-social-determinants-in-promoting-health-and-health-equity/).

[16] *See* note 3.

[17] *See* note 7.

[18] Centers for Disease Control and Prevention, Agency for Toxic Substances and Disease Registry, Fact Sheet: What is Social Vulnerability? (/www.atsdr.cdc.gov/placeandhealth/svi/fact_sheet/fact_sheet.html) (accessed June 14, 2021).

[19] American Public Health Association, *Structural Racism is a Public Health Crisis: Impact on the Black Community* (Oct. 24, 2020) (www.apha.org/policies-and-advocacy/public-health-policy-statements/policy-database/2021/01/13/structural-racism-is-a-public-health-crisis).

[20] The American Academy of Family Physicians, *Advancing Health Equity by Addressing the Social Determinants of Health in Family Medicine (Position Paper)*

socioeconomic status, and educational attainment, infant mortality rates are highest among children born to Black mothers.[21] Lesbian, gay, bisexual, and transgender (LGBT) individuals are more like to delay care due to cost than heterosexual individuals and experience higher levels of violence and discrimination.[22] Public health information systems are unable to fully capture the data describing these key demographics with adequate fidelity to effectively inform interventions designed to advance health equity.[23,24]

C. Data Sharing and Governance

There is a lack of key standards for public health data particularly in the domains of data quality, storage, and data sharing.[25] Under the Biden Administration, the Office of the National Coordinator (ONC) Health Information Technology Advisory Committee (HITAC) task force on public health data systems has started to discuss gaps in public health data standards to assist with data interoperability and data sharing, with a final report scheduled to be released mid-July of 2021.[26] New policies also need to be implemented to ensure that this data is secured and protected as an essential asset.[27]

D. Congressional Action

In the response to the COVID-19 pandemic, Congress made significant investments for public data modernization. The Coronavirus Aid, Relief, and Economic Security (CARES) Act, which was signed into law on March 27, 2020, provided $500 million to the Centers for Disease Control and Prevention (CDC) for public health data surveillance and analytics infrastructure

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(www.aafp.org/about/policies/all/social-determinants-health-family-medicine.html) (accessed June 14, 2021).

[21] *Id.*

[22] *Id.*

[23] American Journal of Public Health, *Sexual Orientation and Gender Identity Data Collection: Clinical and Public Health Importance* (July 2020) (ajph.aphapublications.org/doi/10.2105/AJPH.2020.305722).

[24] Elissa V Klinger, et. al., *Accuracy of race, ethnicity, and language preference in an electronic health record*, Journal of General Internal Medicine (June 2015) (pubmed.ncbi.nlm.nih.gov/25527336/).

[25] *See* note 3.

[26] Office of the National Coordinator, Public Health Data Systems Task Force 2021 (www.healthit.gov/hitac/committees/public-health-data-systems-task-force-2021) (accessed June 14, 2021).

[27] Health Information Technology Advisory Committee, *Annual Report for Fiscal Year 2020* (Feb. 10, 2021) (www.healthit.gov/sites/default/files/page/2021-03/HITAC%20Annual%20Report%20for%20FY20_508_0.pdf).

modernization.[28] The Consolidated Appropriations Act, 2021, which provided the annual appropriations for fiscal year (FY) 2021 and approximately $900 million for COVID relief, was signed into law on December 27, 2020. The bill included $100 million for CDC public health data modernization and interoperability.[29] The American Rescue Plan Act of 2021, signed into law on March 11, 2021, invested an additional $500 million for CDC public health data infrastructure improvements and enhancements to the United States disease warning system, including academic and public health workforce and data collection systems.[30]

In addition to funding, Congress took action to require the Department of Health and Human Services (HHS) to expand, enhance, and improve public health data systems used by CDC and to support modernization of public health data systems within public health departments. Enacted as a part of the Consolidated Appropriations Act, 2021, HHS is directed to award grants to State, local, Tribal, or territorial public health departments for the modernization of public health data systems in order to assist public health departments in assessing current data infrastructure capabilities and gaps; to improve secure public health data collection, transmission, exchange, maintenance, and analysis; to enhance the interoperability of public health data systems; to support and train related personnel; to support earlier disease and health condition detection; and to develop and disseminate related information and improved electronic case reporting. HHS is also required to develop and submit to Congress a coordinated strategy and accompanying implementation plan that identifies and demonstrates measures utilized to carry out such activities, and requires HHS to consult with State, local, Tribal, and territorial health departments and other appropriate public or private entities regarding the plan and grant program to modernize public health data systems pursuant to this section.

II. LEGISLATION

A. H.R. 379, the "Improving Social Determinants of Health Act of 2021"

H.R. 379, the "Improving Social Determinants of Health Act of 2021", introduced by Rep. Barragán (D-CA) and 30 original cosponsors, authorizes the Director of the Centers for Disease Control and Prevention (CDC) to carry out a Social Determinants of Health program to improve health outcomes and reduce health inequities and improve the capacity of public health agencies and community organizations to address social determinants of health. Such activities shall include awarding grants to address social determinants of health and provides priority to grant awardees who collect quantifiable health data regarding the most significant gaps in health-promoting social, economic, and environmental needs. The bill also would award grants to nonprofit organizations and institutions of higher education to conduct research and outreach related to best practices to improve social determinants of health, and provide technical assistance and training to grantees.

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[28] Centers for Disease Control and Prevention, *Public Health Data Modernization Initiative: An Urgent Need to Modernize* (www.cdc.gov/budget/documents/covid-19/COVID-19-Data-Modernization-Initiative-Fact-Sheet.pdf) (accessed June 17, 2021).

[29] Consolidated Appropriations Act, 2021, Pub. L. No. 116-260.

[30] American Rescue Plan Act of 2021, Pub. L. No. 117-7.

B. H.R. 666, the "Anti-Racism in Public Health Act of 2021"

H.R. 666, the "Anti-Racism in Public Health Act of 2021", introduced by Rep. Pressley (D-MA) and 39 original cosponsors, establishes a National Center on Antiracism and Health within the CDC and a law enforcement violence prevention program. This Center would be directed to collect and analyze data on the public health impacts of structural racism and effectiveness of intervention strategies, administer research and grant programs to address the public health impacts of structural racism, establish regional centers of excellence, establish a clearinghouse for the collection and storage of data, and coordinate within CDC scientific and programmatic activities to consider structural racism, among other activities. Further, the bill would require the National Center for Injury Prevention and Control at CDC a law enforcement violence prevention program.

C. H.R. 778, the "Secure Data and Privacy for Contact Tracing Act of 2021"

H.R. 778, the "Secure Data and Privacy for Contact Tracing Act of 2021", introduced by Rep. Speier (D-CA) and seven original cosponsors, authorizes CDC to award grants to State, Tribal, and territorial public health departments to incorporate digital contact tracing technology in COVID-19 contact tracing programs. Use of digital contact tracing would be required to be voluntary for users, ensure that consent not be a condition of receipt of government benefits or employment, and allow for the deletion or de-identification of data, among other conditions. Public health departments would be required to develop and make publicly available a plan for how to incorporate digital contact tracing, and to establish procedures for completing or obtaining an independent security assessment. The bill also prohibits data derived from contact tracing technology to be used in legal proceedings or for immigration enforcement.

D. H.R. 791, the "Tracking COVID-19 Variants Act"

H.R. 791, the "Tracking COVID-19 Variants Act", introduced by Rep. Bera (D-CA) and 11 original cosponsors provides funding to expand and enhance genomic sequencing, analytics, and disease surveillance activities, including through partnerships with academic research institutions. The bill also directs the National Center for Health Statistics (NCHS) to carry out a demonstration program to expand an existing program that links different federal data sets for statistical public health research, including food insecurity, housing instability, and other social determinants of health. The program must support linkages with the National Death Index, a database of death records maintained by the NCHS and maintain a publicly accessible website detailing information about the demonstration program. Additionally, CDC is required to issue guidance related to the sharing of specimens obtained from patients, securing sharing of information about such specimens, and the appropriate use of viral sequence data.

E. H.R. 831, the "Health Standards To Advance Transparency, Integrity, Science, Technology Infrastructure, and Confidential Statistics Act of 2021" or the "Health STATISTICS Act of 2021"

H.R. 831, the "Health STATISTICS Act of 2021", introduced by Reps. Peters (D-CA), Eshoo (D-CA), Fitzpatrick (R-PA), McBath (D-GA), and Craig (D-MN), directs CDC to develop uniform public health data standards for State and local health departments when reporting data to federal centers and agencies. The bill establishes a working group to make recommendations on an ongoing basis to establish comprehensive common standards across appropriate health care, public health, environmental, and public assistance data systems. The bill also requires that CDC establish COVID-19 high priority standards related to therapeutic interventions, treatment settings and associated outcomes, and provide epidemiological surveillance grants to public health reporting entities. In addition, NCHS may award grants or cooperative agreements to public health reporting entities to establish protocols and acquire technologies to implement the standards and required reporting. NCHS would also be required to carry out a demonstration program to assess the availability of data sets among Federal, state, local, and non-federal entities that may be useful for focusing on social determinants of health and link data when relevant.

F. H.R. 925, the "Data to Save Moms Act"

H.R. 925, the "Data to Save Moms Act", introduced by Rep. Davids (D-KS) and 34 original cosponsors, expands data collection and research on maternal morbidity and mortality among minority populations through additional funding for maternal mortality review committees (MMRCs) in order to promote representative community engagement and develop initiatives to conduct outreach and community engagement efforts on the work of MMRCs. Additionally, H.R. 925 requires the Secretary of HHS to consult with relevant stakeholders to review existing maternal health data collection processes and measures and make recommendations on ways to improve such processes and measures. The legislation also requires the Indian Health Service (IHS) to conduct a comprehensive study on maternal mortality and severe maternal morbidity in the populations of American Indian and Alaska Native individuals and report to Congress on its findings. Finally, the legislation also establishes a grant program to award grants to research centers, health professions schools and programs, and other entities at minority-serving institutions to study specific aspects of the maternal health crisis among pregnant and postpartum individuals from racial and ethnic minority groups.

G. H.R. 943, the "Social Determinants for Moms Act"

H.R. 943, the "Social Determinants for Moms Act", introduced by Rep. McBath and 33 original cosponsors, directs HHS to convene a task force to develop a strategy and coordinate federal efforts to understand and address social determinants of maternal health with respect to pregnant and postpartum individuals. The bill also provides grants through the Department of Housing and Urban Development (HUD) to assist pregnant and postpartum individuals with access to housing; requires the Department of Transportation (DOT) to research transportation barriers for pregnant and postpartum individuals seeking medical care; extends nutrition programs under the Department of Agriculture, including the Special Supplemental Nutrition Program for Women, Infant, and Children to 24 months postpartum; and engages the National Academies to assist the Environmental Protection Agency (EPA) in better understanding the environmental conditions that impact maternal and infant health. Finally, the legislation also establishes a grant program to award eligible organizations with funding to provide pregnant and

postpartum individuals with free and accessible drop-in child care services during prenatal and postpartum appointments, as well as grants to eligible entities to address social determinant of maternal health for pregnant and postpartum individuals.

H. H.R. 976, the "Ensuring Transparent Honest Information on COVID-19 Act" or the "ETHIC Act"

H.R. 976, the "ETHIC Act", introduced by Reps. Castor (D-FL) and Underwood (D-IL), requires State, local, Tribal, and territorial governments to report to the CDC on COVID-19 data as a condition of receipt of certain COVID-19 funding and to make certain data publicly available on a website of the CDC. In addition, the bill requires HHS to contract with the National Academies of Science, Engineering, and Medicine (National Academies) to conduct a study to review the current system for public health data infrastructures and reporting and provide recommendation on needed data and system improvements for ongoing public health needs.

I. H.R. 2125, the "Quit Because of Covid-19 Act"

H.R. 2125, the "Quit Because of Covid-19 Act", introduced by Rep. Blunt Rochester (D-DE) and 12 original cosponsors, would require state Medicaid programs to cover comprehensive tobacco cessation services including access to pharmacotherapy without cost for Medicaid and CHIP beneficiaries.

J. H.R. 2503 "Social Determinants Accelerator Act of 2021"

H.R 2503, the "Social Determinants Accelerator Act of 2021", introduced by Rep. Bustos (D-IL) and 22 original cosponsors, directs the Secretary of HHS in coordination with the Centers for Medicare and Medicaid Services (CMS) to establish an interagency council on social determinants of health to improve the coordination of federal programs and funding, and to provide grants to State, local, and Tribal health agencies to create and implement social determinants accelerator plans that are designed to advance the health and well-being of individuals at-risk for poor health outcomes secondary to adverse social determinants of health.

K. H.R. 3894, the "Collecting and Analyzing Resources Integral and Necessary for Guidance for Social Determinants Act of 2021" or the "CARING Act of 2021"

H.R. 3894, the "CARING Act of 2021", introduced by Rep. Blunt Rochester, requires the Secretary of HHS to provide guidance and technical assistance to states on how to address social determinants of health through Medicaid and CHIP. It requires that the guidance be updated every three years.

L. H.R. 3969, To amend title XXVII of the Public Health Service Act to include activities to address social determinants of health in the calculation of medical loss ratios.

H.R. 3969, introduced by Reps. Curtis (R-UT) and Cárdenas (D-CA), would include spending on activities related to social determinants of health in the calculation of private health insurance plans' medical loss ratio.

M. H.R. ____, the "Social Determinants of Health Data Analysis Act of 2021"

H.R. ____, the "Social Determinants of Health Data Analysis Act of 2021", introduced by Rep. Burgess (R-TX), requires the Comptroller General of the United States to submit to Congress within two years of enactment a report on the actions taken by the Secretary of HHS to address social determinants of health. The report shall include: an analysis of how data collection undertaken by HHS complies with Federal and state privacy laws and regulations, a description of any coordination by HHS with other relevant Federal, State, and local agencies, an identification of any potential for duplication or any barriers, and recommendations on how to foster public-private partnerships and leverage private sector to address social determinants of health.

III. WITNESSES

Romilla Batra, M.D., M.B.A.
Chief Medical Officer
SCAN Health Plan

Beth Blauer
Executive Director
Johns Hopkins University Centers for Civic Impact

Karen DeSalvo, M.D., M.P.H, M.Sc.
Chief Health Officer
Google Health

Faisel Syed, M.D.
National Director of Primary Care
ChenMed

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