****PRESS RELEASE****

Public Health Leaders Urge Federal Government to Incentivize State-led Health Data Management to Create a Stronger National Health Data Ecosystem

In a new report, leaders call for federal regulatory guidance to aid states in addressing inconsistent regulations, infrastructure, and governance across U.S. health data systems after post-pandemic progress stalls

- Weaknesses with health data pose multiple challenges for the United States, including issues with patient care coordination, administrative complexity, and gaps in the public health system.
- At least 10 reports have come out from think tanks, government agencies, and academics calling for a stronger nationwide health data ecosystem, but progress since the COVID-19 pandemic has stalled.
- A new report from leaders at the Ellison Institute of Technology, Association of State and Territorial Health Officials, Harvard T.H. Chan School of Public Health, and other organizations and institutions, takes a simple and pragmatic approach to solving this issue for the nation.
- Specifically, the report recommends the federal government incentivizes each state to establish a dedicated entity for health data management and to restructure digital health funding to support this goal.

LOS ANGELES, Calif., **Jan. 16, 2024** – Leaders at the **[Ellison Institute of Technology](#)**, the **[Association of State and Territorial Health Officials](#)**, the **[Harvard T.H. Chan School of Public Health](#)**, and others, published their recommendations in a new report, **"[Regulations and Funding to Create Enterprise Architecture for a Nationwide Health Data Ecosystem](#)"**, calling on the federal government to incentivize every state to have a single dedicated entity responsible for managing its health data, and to restructure digital health funding for states to help them achieve this goal.

The policy recommendations follow on the heels of the COVID-19 pandemic, which exposed long-standing weaknesses in the U.S.'s ability to efficiently collect, share, and use health data. While the federal government has since taken measures to bolster the nation's health data infrastructure, substantial challenges remain, from siloed public health systems and insufficient funding to a slow digitization of the healthcare sector.

To address these barriers, the proposal strongly encourages federal guidance and funding incentives to develop state-designated entities, which would be responsible for the collection, integration, and analysis of clinical, public health, social determinants of health, claims, administrative, and other relevant data. It also lays out recommendations for the federal government to develop the following:

- **A regulatory clearinghouse that highlights current laws, regulations, and governance** at the federal, state, or local level, identifying variances and opportunities for harmonization
- **Federal guidance, model legislation, and templated regulation** to help expedite regulatory development in states and avoid unnecessary divergence
- **Funding and incentives for enterprise architecture** across all relevant health data types via a state-designated entity.
- **Regulatory sandboxes that promote innovation** and enable states to experiment with services and technologies that have yet to be tested at a national level and generate the required evidence base for state policy.

The proposal also lays out the need for government-backed research focused on an economic model for investing in a nationwide health data ecosystem. This includes:

- **A retrospective analysis of previous efforts that studies the health, economic, and systems impacts of health data regulation** to provide evidence-based guidance for states on how to structure their health data and HIE laws.
- **Economic modeling of projected benefits**, drawing on point estimates of the benefits of standardizing the collection, sharing, and use of health data to project nationwide benefits.
- **Monitoring and evaluation of all future efforts** as federal and state governments take steps to improve the nation's health data infrastructure, with a cost-benefit analysis of these changes.

Gabriel Seidman, DrPH, Director of Policy, Ellison Institute of Technology said:
"To achieve our national objectives of improving patient health, including the Biden Administration's goal of ending cancer as we know it, we need to strengthen our health data infrastructure. This will require us to address significant gaps in our nation's health data ecosystem and shift our approach to how we collect, share, and use health data."

J.T. Lane, MPH, Senior Vice President, Population Health & Innovation, Association of State and Territorial Health Officials said:
"While states have long had the authority to collect health data, complex, jurisdiction-specific regulations, and a lack of stable, consistently funded infrastructure can hinder the safe, secure, exchange of the mission critical health data that guides public health responses to protect all Americans. Clear guidance and dedicated funding are major steps the federal government can take to better support state action to improve our nation's health and reduce healthcare costs."

Michelle A. Williams, ScD, Joan and Julius Jacobson Professor of Epidemiology and Public Health, Harvard T.H. Chan School of Public Health said:
"Data is driving the future of healthcare research. By developing a more robust nationwide health data ecosystem, we will be poised to unlock new insights and treatments that improve individual care and public health across the country."

Anne Zink, MD, Chief Medical Officer, State of Alaska said:
"As a physician, I understand how critical it is to respect patients' personal health information. As we generate more and more healthcare data, we must engage with federal leadership on how to store and share this data in ways that preserve patient privacy and security, while empowering patients to have their own data and sharing with their health care providers when they choose."

Paper Abstract:
The COVID-19 pandemic highlighted the United States' lack of a nationwide infrastructure for collecting, sharing, and using health data, especially for secondary uses (i.e., population health management and public health). The federal government is taking several important steps to upgrade the nation's health data ecosystem, notably, the CDC's Data Modernization Initiative and the ONC's Trusted Exchange Framework and Common Agreement. However, substantial barriers remain. Inconsistent regulations, infrastructure, and governance across federal and state levels and between states significantly impede the exchange and analysis of health data. Siloed systems and insufficient funding block effective integration of clinical, public health, and social determinants data within and between states. In this paper, we propose strategies to develop a nationwide health data ecosystem. We focus on providing federal guidance and incentives to develop state-designated entities responsible for the collection, integration, and analysis of clinical, public health, social determinants of health, claims, administrative, and other relevant data. These recommendations include the development of a regulatory clearinghouse, federal guidance, model legislation and templated regulation, funding to incentivize enterprise architecture, regulatory sandboxes, and a three-pronged research agenda.

About authors
Gabriel Seidman is the Director of Policy at the Ellison Institute of Technology. Ahmad AlKasir is a Policy Lead at the Ellison Institute of Technology. Kate Ricker is the CEO of Amelia Mayme Consulting. JT Lane is the Senior Vice President for Population Health and Innovation at the Association of State and Territorial Health Officials (ASTHO). Anne Zink is the Chief Medical Officer for the Alaska Department of Health and ASTHO's 80th President. Michelle A. Williams is the Joan and Julius Jacobson Professor of Epidemiology and Public Health at Harvard T.H. Chan School of Public Health.

# # #