

A NEW DATA AGENCY FOR THE PROTECTION OF PUBLIC HEALTH

AN EARLY WARNING SYSTEM FOR INFECTIOUS DISEASE, PROPOSED BY U.S. SENATOR MITT ROMNEY.

The Center for Public Health Data (CPHD) would be a new data agency whose mission is to improve access to impartial and objective public health data in real time and bolster our infectious disease intelligence and preparedness. This data already exists in electronic forms across laboratories, clinics, and hospitals, but is incomplete and fragmented across the Department of Health and Human Services (HHS) and is not shared quickly enough to drive decision making.

→ CPHD, as a data science agency, would provide de-identified public health data that is:

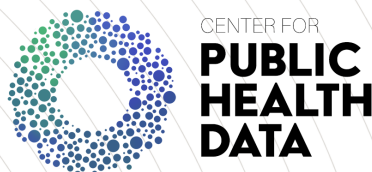
- Consistent and in real-time to quickly identify threats as they unfold;
- Accessible to all levels of government, hospitals, researchers, and the public—not just the CDC or federal agencies;
- De-politicized, objective, and separate from regulatory and policy decisions, like mask mandates; and
- Aligned with privacy and security standards.

BACKGROUND ON PUBLIC HEALTH DATA COLLECTION

The early 2000s saw the 9/11 terrorist attacks, Hurricane Katrina, anthrax attacks, concerns of increasing bioterrorism, and a new strain of Avian Flu. As a result, in 2006, Congress instructed HHS to develop capabilities for real time nationwide public health data aggregation for situational awareness that would lead to pandemic prevention and preparedness, electronically.

Since then, HHS has failed to prioritize and deliver consistent, timely public health data for situational awareness, in part because HHS has failed to establish a lead agency to manage, oversee, and govern such a data system. This failure has resulted in miscommunication among hospital systems and public health officials, contributed to the continued rise in public mistrust of our public health institutions, and weakened our nationwide public health awareness for COVID-19 and it also continues to play out in the limited nationally available monkeypox data.

The CDC's prolonged failures to provide the public with real-time data in recent years has proven that we need a new dedicated agency focused on delivering reliable, timely public health data.



THE CENTER FOR PUBLIC HEALTH DATA

The Center for Public Health Data (CPHD) would be a modern data agency, focused exclusively on aggregating comprehensive, de-identified public health data from diverse sources, including local, state, and federal public health units; state health data utilities and exchanges; hospital systems; public and commercial laboratories; and academic and research institutions.

CPHD will be structured as an independent data subagency inside the Department of Health and Human Services (HHS), and led by a Chief Data Engineer. It will serve as an open and transparent repository of information to provide the public, academics, and policymakers objective, unbiased data in real time. A clear picture of the state of public health and disease spread will help policymakers develop and implement informed and proactive policy solutions.

THE CENTER FOR PUBLIC HEALTH DATA WOULD:

- **Reform existing, but disconnected, public health data streams with a single system of community acquired infectious disease health data** to better protect and empower individuals and decision makers.
 - Streamline fragmented and duplicative data management efforts that exist across HHS;
 - Aggregate already-collected, de-identified data from diverse sources, including hospitals and laboratories, to provide a full, clear picture of the status of public health;
 - Provide open access to real-time, de-identified data for public health situational awareness and analysis on an electronic platform. "Real-time" is defined as 24 hours from collection to release.
- **Maintain strict confidentiality, privacy, and objectivity** of information collected.
- **Report daily and publicly on public health data in the United States** to enable rapid response policymaking. Rapidly sharing community acquired infectious disease information, such as monkeypox, COVID-19, or influenza outbreaks and forecasting hotspots, will support better health outcomes.
- **Partner with states, localities, and public and private entities to modernize public health data infrastructure**, improve interoperability, and support information sharing.
- **Let high-quality, real-time data stand on their own.** The agency would be required only to collect and disseminate high-quality data, with clear and accessible graphics, and would be prohibited from making public health recommendations.

WHAT THE CENTER FOR PUBLIC HEALTH DATA COULD NOT DO:

- **It could NOT collect personally identifiable information.** Information is required to be de-identified from the source, like a hospital or lab, before it is sent to CPHD.
- **It could NOT collect information beyond community acquired infectious disease information based on ICD codes.** This information already exists, but the government's fragmented approach to reporting and aggregation renders it unactionable.
- **It could NOT provide any public health or policy recommendations.** For example, it could not recommend isolation or quarantine guidance, use of personal protective equipment, or declare a public health emergency.
- **It could NOT enact public health mandates.** CPHD is a data collection, aggregation, and dissemination agency—it is not a regulatory body. For example, it could not recommend mask or vaccine mandates.



CENTER FOR
**PUBLIC
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