

NGA Public Health Leaders Call: Modernizing Data Systems & Infectious Disease Data Collection was the first session in a series facilitated by COVID Academy's **Margaret Bourdeaux, MD, MPH** and hosted by the NGA's **Brittney Roy, MPA**. These sessions aim to help state leaders craft public health system reforms by sharing lessons learned and emergent model practices so state public health systems can prevent and mitigate future public health crises.

The COVID-19 pandemic found U.S. public health data systems unprepared for the challenges of a global pandemic. Over the past two years states have undertaken Herculean efforts to repurpose, establish, and maintain systems to collect, integrate, and disseminate public health data to partners across levels of government and sectors of the economy. Governors can play a vital role in public health system modernization.

Considerations for governors include:

1. **Investing** in public health data systems modernization efforts with long-term sustainability in mind.
2. **Leveraging** existing and expanded federal funds for public health data modernization. Recognize that more than technological solutions are needed. Attend to data privacy, security, and equity considerations, as well as infrastructure and workforce needs.
3. **Cultivating** partnerships to capitalize on the policy moment, advocate for state involvement in national efforts.

The **Issues** and **Considerations** outlined below are based in part on the presentations of session discussants, **Keegan McCaffrey**, Epidemiology Manager, Influenza and COVID Surveillance, Utah Department of Public Health, **Rachelle Boulton, MSPH**, Health Informatics Program Manager, Utah Department of Public Health, **Vaneet Arora, PhD**, Director, Division of Laboratory Services, Kentucky Department of Public Health, Associate Professor of Pathology and Laboratory Medicine, **Suzanne Dorsey, PhD**, Executive, Maryland Department of the Environment, **Michelle Campbell**, Director, Data and Systems Modernization, Washington Department of Public Health, **Juliana Grant, MD, MPH**, Genomic Surveillance Specialist, Washington Department of Public Health, and **Donald McCormick**, Arkansas Department of Public Health.

This brief was written and edited by **Flavia Chen, MPH** and **Margaret Bourdeaux, MD, MPH**.

Issues

Recognition of the need to modernize public health data systems in the United States far predates the COVID-19 pandemic. Unlike clinical care systems, which benefitted from laws incentivizing and investing in health information technology transformation, public health has largely been left behind.

Early in the COVID pandemic, news articles cited the paradigmatic technology of public health – [the fax machine](#) – as a key relic hampering the nation's ability to respond. But outdated technologies represented a symptom rather than a root cause. Incomplete and siloed data, incomplete interoperability and data standards, personnel shortages, ambiguity in governing authorities, and persistent underfunding limited the U.S.' public health response.

The public health system is best understood as a vast and interdependent ecosystem comprised of local, state, territorial, tribal, and federal agencies interacting with individuals and populations across

geographies, public and private sector partners, and academia. The public health system has been described as a “[patchwork](#)”:

- 29 out of the 50 state public health agencies are independent, while 21 fall under an umbrella agency.
- Approximately two-thirds of state health officials are appointed by the governor, while the other one-third are appointed by either the secretary of the umbrella human services agency, state public health board, or other.
- Over 75% of local health departments (1887 out of 2459) are locally governed, while 404 are part of the state health department, and 168 have shared governance.

Public health data systems, therefore, need to be able to collect relevant data from disparate sources, integrate and synthesize data across relevant stakeholders and systems, and disseminate out reports to inform public health policymakers.

Data Collection

Effective public health response requires the collection of accurate, timely, and interoperable data. The siloed nature of public health programs across the country presents a major challenge to interagency and cross-jurisdiction solutions. Public health agencies and programs collect data from a multitude of sources and systems many of which were built to support individual programs (e.g. immunization databases, syndromic surveillance, vital records) without interoperability in mind.

Utah experience with COVID-19 provides an invaluable lesson in the importance of proactive investment in data collection systems. Their open source epidemiologic and disease surveillance system [EpiTrax](#) provides infrastructure for all communicable disease surveillance and reporting, and is used by all of Utah’s state and local health departments, as well as five tribal public health agencies, and a U.S. Air Force-based public health office. During COVID-19, Utah was able to configure EpiTrax to receive reports from new laboratories and novel data sources, highlighting both the opportunity and challenges posed by electronic laboratory and case reporting.

Utah found some data sources easier to integrate than others. Systems built specifically for COVID response, like wastewater surveillance, were easy to integrate. Legacy data streams, like hospital treatment data that existed before the pandemic, posed a much greater challenge to integrate. Many public health data sources are not designed with the specific uses to which they are ultimately put in mind. Utah’s experience highlights the importance of thinking proactively about existing and novel data sources and how to responsibly manage data across siloes.

Arkansas’s experience similarly highlights the importance of considering who is served by – or represented in – a particular data system. Arkansas’s rural areas were not being captured by municipal wastewater surveillance, for example, just as individuals without access to health care were left out of hospitals assessments of COVID impact. By thinking about who is or isn’t represented in their public health data systems, Arkansas was better able to bring resources to communities in need.

Bringing resources to communities in need was also the mission of the University of Kentucky’s mobile laboratory program. Building on a model of public health governance that places Department of Public Health Directors in field positions, the UKY mobile lab was able to leverage collaborations between academia and public health to not only define instrumentation needed for remote testing, but also bring rural communities COVID testing infrastructure they lacked.

Data Integration

Although Utah entered the COVID-19 pandemic on relatively strong footing with its EpiTrax system in place, integrating data from other Utah Department of Health-managed information systems and outside novel data sources presents an ongoing challenge. EpiTrax integration with EDEN, the Electronic Death Entry Network was completed in 2018, while integration with the Utah Immunization Information System, and School Enrollment systems were completed in early and late 2021 respectively.

Linking data across databases is one of the key challenges in data integration. Washington State noted the utility of a Master Patient Index in facilitating data management and minimizing the labor-intensive process of manually linking data sets and de-duplicating entries. When public health collects data it often intentionally omits collecting unique identifiers to protect confidentiality. Doing so however, means COVID case surveillance data cannot then be easily linked to COVID test reports or immunization records. Master Patient Indexes provide a mechanism to link disparate datasets. Washington's experience, like Utah's example above, highlights the challenge of leveraging data infrastructure built in a siloed fashion. Enabling legislation underlying disparate data sets are often different, resulting in cumbersome processes to allow data sharing even within a department or agency, let alone with external partners. Data sharing laws, policies, and regulations differ across local, state, tribal, territorial, and national jurisdictions, and the complexity of complying with regulations are often cited as significant barriers to data sharing.

Washington state recognized both the challenge – and need – to link epidemiological surveillance data and vaccination records and is pursuing a pilot program to implement EpiTrax with built-in Application Programming Interfaces (APIs) to link across multiple existing data systems, with the additional benefit of facilitating electronic case reporting.

Data Dissemination

It is insufficient to merely collect and integrate data. To provide benefit to public health, data must be analyzed, and results shared and used to guide policy.

Utah summarized the data dissemination challenge as analogous to finding the correct exit on a highway. On the highway, datasets are brought together, cleaned, and analyzed. Early challenges include how to assemble and analyze novel data sets while attending to data privacy and security considerations. Interpretation challenges inherent in data dissemination include how to present data in the most transparent, reproducible, digestible, and actionable way possible. Properly presented analyses and data can exit the superhighway at their targeted recipient. The highway has many on-ramps, such as the EpiTrax system, EDEN, USIIS, BRFSS, wastewater monitoring, etc. Off-ramps might include public health laboratory data linked to EpiTrax surveillance data. Successful data dissemination requires close collaboration between data providers, analysts, and users.

Washington State underscored the importance of collaboration in the data dissemination phase. As a “home rule” state, core public health functions reside with local and tribal health authorities. Operationally this requires cultivation of strong relationships between levels of government to both understand what is going on “on the ground” and to maximally support tribal data sovereignty from data collection through dissemination. COVID-19 has catalyzed work to establish appropriate data sharing agreements – an ongoing effort.

Maryland's example of leveraging municipal wastewater surveillance demonstrates the potential of public health data dissemination to empower the end user. Just as Arkansas's and Kentucky's early examples showed, access to COVID testing and environmental monitoring were not equitably distributed across the

state. A community in Maryland recognized the access gap and approached the Department of the Environment about establishing municipal sewage surveillance with community data access and control. Maryland's case highlights the ability to serve public health from an environmental – and not only clinical angle. In this case, a community impacted by environmental justice was empowered to catalyze public health action and cultivate trust.

Considerations for Governors

The interconnected and interdependent public health data systems discussed above requires investment and cultivation.

1. **Invest** in long-term public health data system modernizations efforts to enable benefits to accrue beyond the COVID-19 pandemic.
 - Focus on disease-agnostic interoperability, recognizing that data elements collected and needed vary across stakeholders. Aim to minimize siloes and redundant reporting requirements.
 - Build base infrastructure to move data, including computing capabilities, internet processing, server capacity, metadata standards, memory, and cloud computing.
 - Recognize that public health data system modernization requires a robust and resilient workforce.
 - Consult the [Data Exchange & Interoperability Resources](#) (APHL) to explore issues relevant to public health informatics.
2. **Leverage** existing and expanded federal funds for public health data modernization. Recognize that more than technological solutions are needed. Attend to data privacy, security, and equity considerations, as well as infrastructure and workforce needs.
 - Follow: [Data Modernization Initiative](#) (CDC)
 - Follow: [Data: Elemental to Health](#) campaign (APHL | ASTHO | Big Cities Health Coalition | CSTE | HIMSS | NACCHO | NAPHSIS)
3. **Cultivate** partnerships to capitalize on the policy moment, advocate for state involvement in national efforts.
 - Cybersecurity and risk management, privacy, data sovereignty, data security.
 - Cultivate community trust
 - Public health is inherently inter-jurisdictional – collaboration needed within and between states, with federal, territorial, and tribal partners
 - National standards for health data are needed.
 - July 2021 [Public Health Data Systems Task Force 2021](#) Report to the Health Information Technology Advisory Committee (HITAC)
 - October 2021 [Presidential COVID-19 Health Equity Task Force Proposed Implementation Plan and Accountability Framework](#)
 - October 2021 [Charting a Course for an Equity-Centered Data System: Recommendations from the National Commission to Transform Public Health Data Systems](#) (The Robert Wood Johnson Foundation).