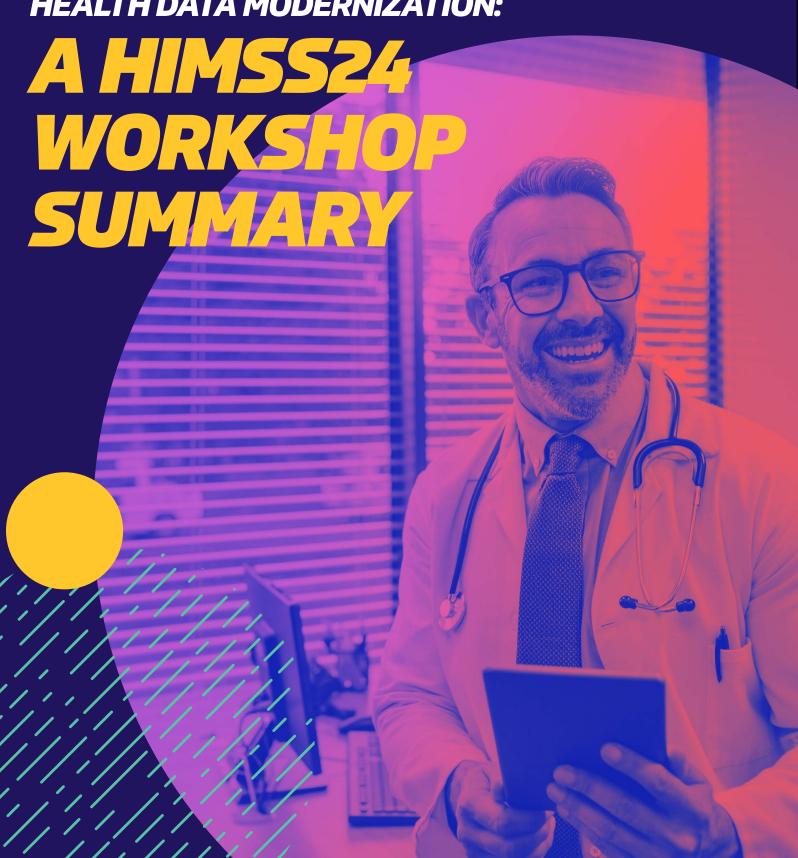


PERSPECTIVES ON PUBLIC HEALTH DATA MODERNIZATION:



Perspectives on Public Health Data Modernization:

A HIMSS24 Workshop Summary

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Executive Summary

IMSS, in partnership with the Electronic Health Record Association (EHRA), American Immunization Registry Association (AIRA), Association of State and Territorial Health Officials (ASTHO) and the Council of State and Territorial Epidemiologists (CSTE) held a Public Health Data Modernization Workshop at the 2024 HIMSS Global Health Conference and Exhibition (HIMSS24).

The objectives of the workshop were to:

- 1. Educate participants on the current state of public health data modernization
- Learn about participants' needs, challenges and priorities in this area
- Convene and forge connections within the public health community and between the public health, healthcare and IT supplier communities

Speakers presented on public health data modernization efforts, and participants shared their perspectives on partnerships between public health and healthcare communities, public policy and funding opportunities to support public health data modernization, as well as how the Trusted Exchange Framework and Common Agreement (TEFCA) can support public health information exchange.

Participants emphasized the importance of:

- Partnerships between the public health, healthcare and IT market supplier communities to enable information exchange and the need for this type of workshop to occur regularly to share insights across these communities
- Partnerships and coordination between public health associations to influence and provide technical assistance for public health data modernization
- Sustainable and predictable funding for public health data modernization
- Federal data sharing and quality standards, data element requirements and cross-jurisdictional exchange
- PHA's involvement with Data Modernization Implementation Center Program
- Comprehensive education on the implications and operations of TEFCA in public health
- A sustainable funding mechanism for public health's participation in TEFCA
- Change management processes for implementing TEFCA in PHAs and flexibility for TEFCA to adapt to public health needs
- PHAs involving their legal team to navigate statues and regulations in preparation for TEFCA implementation

Background

Public health is an important partner in the health system, from the local to global level. Public health agencies (PHAs) and tribal organizations rely on the exchange of health data to perform essential public health functions to prevent disease and improve overall health and wellbeing of the populations they serve. This community is being tasked with modernizing their antiquated data systems and processes. At the same time, progress is often limited due to low and unsustainable funding and workforce capacity challenges.

Given these limitations, HIMSS is calling for \$36.7 billion in data infrastructure and workforce investments to improve digitization, innovation and standards adoption. Moreover, HIMSS and its partners, EHRA, AIRA, ASTHO and CSTE, cohosted the Public Health Data Modernization Preconference Workshop, the first workshop of its kind to be held, at the 2024 HIMSS Global Health Conference and Exhibition (HIMSS24). This workshop was invitation-only and sponsored by HLN Consulting and Amazon Web Services (AWS). The objectives of the workshop were to:

- Educate participants on the current state of public health data modernization
- Learn about participants' needs, challenges and priorities in this area
- Convene and forge connections within the public health community and between the public health, healthcare and IT supplier communities

The workshop convened 140 participants. About 30% represented U.S. state and local PHAs and tribal organizations; 23% represented U.S. national and global nonprofit organizations; 20% represented ASTP/ONC and CDC; 17% represented health IT market suppliers such as EHR companies and consultants; 5% represented healthcare organizations and payers; 3% represented Canadian provincial governments; and 4% represented other categories such as academia. Participants were assigned to tables of seven based on their discussion topic selection. Each group was diverse by worksite and experience level to foster learning and cross-collaboration.

To begin the workshop, HIMSS, partners and sponsors shared the workshop objectives and how they are each supporting the public health data modernization community. A HIMSS representative presented on how PHAs can leverage HIMSS's digital health assessment solutions, and in particular, the Digital Health Indicator. Representatives from U.S. Department of





Health and Human Services, Centers for Disease Control and Prevention (CDC) Office of Public Health Data, Surveillance and Technology, and Assistant Secretary for Technology Policy and Office of the National Coordinator for Health Information Technology (ASTP/ONC) presented on crossagency efforts to improve public health and healthcare data interoperability as well as CDC's Data Modernization Initiative and on TEFCA. Lastly, senior leaders from Washington State Department of Health and Dallas County (Texas) Department of Health and Human Services presented their achievements and perspectives relating to TEFCA and data modernization. Following these presentations, participants engaged in breakout group discussions facilitated by planning partner representatives. Each group had the opportunity to report on their discussion points with all participants. The breakout discussions focused on:

- 1. Public Policy, Partnerships and Funding
- 2.TEFCA, Health Information Exchange and Public Health

The groups focused on public policy, partnerships and funding responded to the following questions:

- 1. How does public health interface with healthcare in your data modernization efforts? What challenges do you face in building connections between public health and healthcare and how do you overcome these challenges?
- 2. What are the public policy opportunities and barriers to public health data modernization and interoperability?
- 3. What are the challenges to effectively utilize modernization funding to support the adoption and upscaling of innovative technologies such as cloud solutions or the full implementation of electronic case reporting across multiple conditions?
- **4.** How can the public health and healthcare community advocate for funding and policies to support public health from Congress and jurisdictions?
- 5. How can partner organizations support you in these efforts? (e.g. dialogue/convening, identifying best practices, advocacy/influencing public policy/educating legislators, etc.)
- 6. Based on this discussion, what are your top three recommendations to advance public health data modernization?

The groups focused on TEFCA, Health Information Exchange and Public Health responded to the following questions:

- 1. What are important examples or use cases of how TEFCA can provide value to public health?
- 2. What are the success factors, challenges and considerations for TEFCA in public health? (Considerations include legal and policy, cost models and funding, onboarding and data

- validation, data quality monitoring, engaging with QHIN and signing on as participant or sub-participant, and the role of Health Data Utilities (HDUs) and/or Health Information Exchanges (HIEs))
- 3. How can public health play an effective role in the implementation of and ongoing data exchange using TEFCA?
- 4. How can partner organizations support you in these efforts? (e.g. dialogue/convening, identifying best practices, advocacy/influencing public policy/educating legislators, etc.)
- 5. Based on this discussion, what are your top three recommendations to advance public health data modernization relating to TEFCA? What messages would you bring to decision markers on public health and TEFCA?

Key Findings

Partnerships

Participants strongly advocated for maintaining partnerships between the public health, healthcare and EHR and other IT supplier communities and that these partnerships have improved information sharing and reduced duplication of efforts. They also shared that siloes exist within the public health community and that collaboration is crucial to connect the many data systems and agencies that impact public health. Participants shared best practices for partnerships among these communities should include the following:

- 1. Align on shared goals and priorities
- 2. Communicate the value and business case of the partnerships and of information exchange
- **3**. Simplify processes (e.g. simplify onboarding process for healthcare organizations to exchange information with public health)

Overcoming Partnership Challenges

Participants shared the following factors that challenge partnerships between public health, healthcare and IT suppliers:

Ineffective Communication

Participants shared that ineffective communication between partners can slow progress. Each partner's needs must be understood. Some participants felt that healthcare organizations may not always prioritize or understand public health information exchange needs. For example, a participant reported that when a rapid scale up of electronic case reporting (eCR) occurred between healthcare organizations and PHAs, it was not always clear if the data that the PHA received were meeting the agency's expectations or needs.





One participant provided an example of how miscommunication can hamper progress. Before the passage of the HITECH provisions in the American Recovery and Reinvestment Act of 2009, commonly known as Meaningful Use (MU), few providers were exchanging data electronically with immunization information systems (IIS). Initially, the public health community needed to educate and encourage healthcare providers to participate. When MU started, provider participation in data exchange with IIS surged, but public health was not fully prepared nor were they fully funded for the influx, resulting in a backlog of over 600 providers waiting to onboard to the jurisdiction's IIS.

Inclusion

Participants shared that entities, such as local health departments and tribal organizations, are not always included in data modernization discussions. Participants also shared that HIEs and HDUs at the state and regional levels are critical to include in strategic decision-making as well, due to their ability to convene and exchange information. Overall, it is important to evaluate which partners should be part of discussions and decision-making processes. This type of workshop held at HIMSS24 can continue to support this goal of collaboration.

Technology, Data Reporting and Standardization

Participants shared that information exchange between public health and healthcare settings are challenged by disparate exchange requirements, standards and methodologies, siloed data systems and PHAs and outdated technology. For example, participants identified data reporting errors as a challenge that could be due to disparate data exchange and quality requirements across jurisdictions. Variations in standards and specifications for data submission to public health agencies set by state and local laws and policies from national standards required for electronic health records create difficulties in connecting systems, affecting the overall quality and utilization of data.

Workforce

Workforce challenges can hamper partnerships, according to participants, who felt that high staff turnover in public health can sometimes lead to disruptions in continuity and expertise. The need for stability in staffing was underscored as vital for maintaining the momentum and trust necessary for successful partnerships and initiatives.

Incentives

Participants shared that business incentives to partner and exchange information between healthcare and public health can improve processes and partnerships. While regulations mandate certain levels of information sharing to ensure public health, limited resources can result in baseline compliance rather than proactive collaboration. Based on HIMSS member feedback, one type of business incentive for healthcare to

exchange information with public health is that realtime surveillance data from CDC reported to health systems during a crisis, such as a pandemic, can indicate a spike in cases, which drives preparedness for an influx of patients in health systems.

Public Policy

Participants identified public policy opportunities to support data modernization. Advocacy and education were emphasized as crucial for garnering support from Congress and legislatures at the jurisdictional levels. Advocacy, including data and stories, about the impacts of public health efforts can improve support for policies and funding. Partnerships and creating a unified voice between the public health, healthcare and IT supplier communities for advocacy were seen as best practice.

One discussion theme focused on implementing common data sharing and quality standards to improve information exchange across jurisdictions. Participants suggested that federal standards for different data types should be harmonized and implemented and certified products should be required to meet certain standards. They also suggested that creating a unified framework with common goals and strategies to standardize processes and data would be beneficial.

Additional policy opportunities identified included:

- 1. A common interpretation of data sharing policies
- A recommendation for standard data use agreements for PHA use
- **3.** Establish policy and guidance around race, ethnicity and other demographic data disaggregation
- 4. Allow for information sharing across jurisdictional borders
- 5. Address data sovereignty among tribal communities
- **6.** Improve reporting structures and policies to enable information exchange between healthcare and public health settings.

Funding

Challenges and Recommendations

A consensus recommendation involved ensuring the existence of sustainable, predictable funding for public health data modernization. COVID-19 offered significant resources, however, that funding is unsustainable and unpredictable in the outyears. Concerns exist that the public health funding levels will normalize and withhold or limit the resources needed for data modernization. Some participants suggested they prefer more, smaller installments of funding to jurisdictions over a longer time, instead of a single, larger investment with the requirement to spend it over a shorter time. Time limits on spending often lead to operational, maintenance and human resource challenges. Some jurisdictions rely exclusively on federal funding, making this recommendation even more critical. Participants also recommended removing or limiting siloed funding and instead employ an enterprise-wide approach,

considering hardware and software needs and workforce for modernization in all facets of public health, from chronic to infectious disease to environmental health.

Relating to sustainable funding, another recommendation was to invest in the recruitment, training and retention of a skilled public health workforce to ensure public health is a competitive sector for employment. Public health needs the ability to retain staff with critical skill sets to support data modernization, particularly health technologists, informaticians and economists. With short-term, unpredictable funding, some participants reported on the difficulty of hiring or retaining full-time employees, including with data expertise, and therefore PHAs often hire short-term contractors instead, which does not necessarily address the workforce skills needed in the long term.

TEFCA, Health Information Exchange and Public Health

Use Cases and Value of TEFCA and Roles for Public Health

As required by the 21st Century Cures Act, the ASTP/ONC and The Sequoia Project, designated as the Recognized Coordinating Entity (RCE), lead the development and implementation of TEFCA. The goals of TEFCA are to:

- Establish a universal governance, policy and technical floor for nationwide interoperability
- Simplify connectivity for organizations to securely exchange information to improve patient care, enhance the welfare of populations and generate health care value
- 3. Enable individuals to gather their health care information.

In August 2024, HIMSS published resources, including an eBook, on implications of TEFCA for the health IT community. According to The Sequoia Project, the benefits of TEFCA for public health and states, territories, localities and tribes (STLTs) are to improve:

- 1. Access to health data
- 2. Interoperable exchange for Medicaid
- Public health reporting and bidirectional exchange between healthcare providers and public health
- 4. Emergency preparedness and response
- State-level information exchange. This aligned with the participants' perspectives on TEFCA's value for public health.

When the workshop took place in March 2024, PHAs had not yet engaged in data exchange under TEFCA, but several "early demonstrators" planned to begin exchanging electronic case reporting data. As of July 2024, the CDC, ASTP/ONC, the Association of Public Health Laboratories, eHealth Exchange and Epic, along with several additional public health associations collaborated with "early demonstrator" PHAs to launch the first

two public health use cases for TEFCA: (1) the receiving of electronic case reports (eCR) from healthcare organizations in six states and (2) the ability of PHAs to query healthcare data through TEFCA for individuals in response to case investigations in three states. These early demonstrations mark a milestone for public health in TEFCA participation, but much work remains.

While the early demonstrations were focused on eCR, the public health community has been discussing potential future use cases for TEFCA. Workshop participants shared a variety of potential future public health use cases for TEFCA, such as:

- 1. Newborn screening for follow up and outcomes
- 2. Query of death information using vital records
- 3. Query for deidentified data, particularly around more sensitive data
- 4. Longitudinal condition tracking, where follow up is needed
- Integration of social determinants of health (SDOH) data with healthcare data
- 6. Chronic disease surveillance via bulk query

Call to Action

Partnerships

There is a critical need for public health, healthcare and EHR and other IT supplier communities to continue to partner, to communicate effectively and to exchange health information. Additionally, there is a need for public health to break down internal siloes and internally collaborate and exchange information. Finally, it is important to include all relevant entities in decision making, including local health departments and tribal organizations. Modernization of public health technology infrastructure, data reporting and standardization is necessary to support information exchange and partnerships overall.

Public health and healthcare associations should continue to coordinate their work to support PHAs and tribes by building an agile and sustainably funded, data-driven, interoperable public health system that supports the health of diverse communities. This coordination may occur through initiatives such as the Joint Public Health Informatics Taskforce (JPHIT), which consists of 14 public health, healthcare and health IT associations, as well as federal partners, aiming to optimize and advocate for the exchange of timely and accurate public health data to ensure actionable insights for public health decision-making.

Partnerships can provide a regular forum, such as workshops like this one for public health, healthcare and IT communities to collaborate and identify best practices.

PHAs can assess their digital health capacity using the HIMSS Digital Health Indicator and maturity models.

Public Policy and Funding

PHAs, healthcare systems, associations, IT market suppliers and others involved should continue educating policymakers, using data and stories, about the need for sustainable, predictable funding for public health data modernization. This is especially important to advocate for federal funding for jurisdictions that solely or mainly rely on federal funds and not on their jurisdictional funding. Sustainable funding can support critical workforce capacity and trainings as well as newer initiatives, such as TEFCA. HIMSS estimated a need for \$36.7 billion in funding for CDC and STLTs over the next 10 years and is prioritizing this advocacy through the Data: Elemental to Health Campaign.

More federal data sharing and quality standards, data element requirements when IT systems are enabled, and cross-jurisdictional exchange would be beneficial.

Organizations should provide technical assistance for public health on:

- 1. Available funding streams and eligibility for funding
- 2. Strategic planning to ensure wisely using limited resources
- Mandatory vs voluntary policies and model policies and practices to replicate

TEFCA, Health Information Exchange, and Public Health

Participants shared the following recommendations for the involvement of public health entities in TEFCA:

- ONC-ASTP, CDC, The Sequoia Project and other organizations and entities should continue to educate and provide technical assistance for the public health community on TEFCA's operations and potential impacts.
 - Questions remain around how STLT laws and regulations will be implemented and accommodated within the TEFCA framework, existing and future resources to aid STLTs in onboarding to QHINs, how to determine which QHIN(s) to join, the roles of HIEs and health data utilities

- (HDUs) in participating with QHINs and public health agencies, the impact on data quality and how PHAs, especially in lower resourced settings, will be supported to engage in TEFCA.
- Public health entities should be actively engaged in TEFCA, such as learning from and understanding how to replicate the public health use cases.
- PHAs may collaborate with and leverage the Data Modernization Implementation Centers, which will provide resources and support to PHAs for efforts that work toward adoption of latest health IT standards and in participation in data exchange networks, such as TEFCA.
- The public health, healthcare and IT supplier entities should partner with and share insights on the benefits and challenges of TEFCA participation.
- Federal agencies, such as CDC and ASTP/ONC, should ensure a sustainable funding mechanism for PHAs and tribes to participate in TEFCA. For example, workforce capacity needs to be supported to allow the public health community to exchange and use the large influx of data brought by TEFCA.
- Public health entities should be prepared for change management processes to use TEFCA and in turn, TEFCA should remain flexible to accommodate the needs of public health.
- PHAs should create a framework to navigate policy and legal issues and involve their legal team to navigate statutes and regulations.

Acknowledgements

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