



# PUBLIC HEALTH FOR THE 21ST CENTURY: DATA MODERNIZATION AND PRIVACY PROTECTIONS



## LEGISLATIVE OVERVIEW SERIES: 2022 PUBLIC HEALTH SPOTLIGHT

### INTRODUCTION

The COVID-19 pandemic revealed the consequences of decades of underinvestment in public health, including limitations in public health data sharing and reliance on outdated technology and information systems. In 2019, CDC launched the Public Health Data Modernization Initiative (DMI) to create a modern, interoperable, and real-time public health data and surveillance infrastructure to support data-driven public health decision making.<sup>1,2</sup> DMI identified three primary focus areas: 1) automate data collection among state, territorial, local, and tribal partners and support multi-directional data flows; 2) improve CDC services by adopting enterprise-wide infrastructure and services capable of data linking, visualization, and sharing, and 3) develop new approaches to public health reporting, with real-world testing of new standards to access information in electronic health records.<sup>1</sup>

In Jan. 2021, President Biden issued an executive order calling for a data-driven response to the COVID-19 pandemic, which included a call to review existing public health data systems for their effectiveness, interoperability, and connectivity to support the detection and response to any future high-consequence public health threat.<sup>3</sup> While the federal government is enhancing its investment in modernizing public health information systems and data sharing, states and territories are enacting laws to better facilitate public health data collocation and data sharing while protecting people's privacy.



Under most state laws, private companies can use, share, or sell consumer data collected during the normal course of business—including health data—without notifying the consumer.<sup>8</sup>

During the 2021 legislative sessions, states enacted laws supporting greater data sharing throughout the healthcare and public health systems, including laws improving state Immunization Information Systems, Health Information Exchanges, and consumer data privacy protections.

### LEGISLATIVE TRENDS

#### IMMUNIZATION INFORMATION SYSTEMS

All states, territories, and Washington, D.C. maintain confidential, population-based electronic databases recording immunizations administered by participating providers known as Immunization Information Systems (IISs).<sup>4</sup> Each IIS is maintained within its jurisdiction, with state laws outlining the scope of the system and how information from the system can or cannot be shared. For IISs that are able to share data across jurisdictions, CDC developed the Immunization Gateway (IZ Gateway). The IZ Gateway enables data exchange between IISs, provider organizations, and consumer applications to support improved immunization data sharing, integration, and access across the nation.<sup>5</sup>

At least two states (Virginia and North Dakota) enacted laws relating to their IIS in 2021. Virginia's new law requires all healthcare providers report administered immunizations to the state's IIS. North Dakota's new law prohibits the state from using the IIS to create a machine-readable code or vaccine passport.

#### HEALTH INFORMATION EXCHANGES

Health Information Exchanges (HIEs) can support improved care quality and coordination by enabling healthcare providers to securely share and access appropriate patient data electronically.<sup>6</sup> In recent years, some states have endorsed a specific HIE to facilitate the secure information exchange of patient health data among providers in the state. In 2021, at least eight states (Delaware, Illinois, Maryland, North Carolina, Nebraska, Oklahoma, Rhode Island, and Wyoming) enacted laws relating to their statewide HIE.

Wyoming codified its HIE through its new law, authorizing the department of health to adopt rules and establish participation fees to recoup the costs of administering the HIE. The forthcoming rules will establish fees paid by healthcare entities that have a Participation Agreement with

the Wyoming Frontier Health Information Program, with the funds credited to a special revenue account for the health department. Nebraska's new law requires certain hospitals, clinics, pharmacies, and rehabilitation centers to participate in the designated state HIE to share clinical information.

North Carolina's new law requires the Department of Health and Human Services, Department of Information Technology, and other state agencies to support a statewide HIE network. The Illinois legislature extended a sunset provision in its HIE law, allowing the Illinois Health Information Exchange Authority to operate past 2022.

## CONSUMER PRIVACY PROTECTIONS

Many people in the United States are familiar with the healthcare privacy protections established under HIPAA, the federal healthcare privacy law that applies to healthcare providers, insurance plans, and certain business associates of covered entities.<sup>7</sup> In recent years, some states have enacted privacy protections for health data maintained by non-HIPAA covered entities as part of consumer protection legislation. For example, a new law in Oregon established restrictions and requirements on developing and implementing COVID-19 contact tracing applications and other technologies, limiting the storage of personal health data to 65 days.

Three states (California, Colorado, and Virginia) have enacted broad consumer privacy laws providing protections to consumer data, including healthcare data collected by commercial fitness trackers and other consumer-facing, health-related products.<sup>8</sup> In 2021, Colorado enacted its consumer privacy law, including protections to facilitate public health data sharing. California passed a law clarifying the intent of its consumer privacy act without altering the substance of the legislation.

## LOOKING AHEAD

ASTHO expects states to continue adopting laws to support public health data modernization efforts and enhance consumer privacy protections, including:

- State consumer privacy acts, ensuring that public health data can still be securely and appropriately shared.
- Laws designating a state HIE, empowering increased public health data sharing with existing

HIEs, and facilitating the types of information included in, and what providers have access to, the HIE.

- Enhancing state IIS laws, including requirements for providers to use the IIS and facilitating information sharing across state IISs.

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CDC's Data Modernization Initiative was allocated \$500 million in CARES Act funding to support public health infrastructure and improve data sharing.<sup>1</sup>

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