# Legal Landscape of Public Health Data

A Scan of State Laws Governing Public Health Data Reporting, Surveillance, and Sharing

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# Introduction

Public health data modernization calls for improving the nation's surveillance and data infrastructure to facilitate timely detection of and response to public health threats. This transformation requires an evolution in technology used by public health as well as modernizing the laws and policies governing secure, timely data collection, exchange, and use.

A number of national initiatives seek to strengthen federal and state-level policies that would ensure the right public health data are available to decision-makers at the right time. Launched in 2020, CDC's Data Modernization Initiative includes a strategic priority of supporting and extending partnerships, in part, by advancing polices that support public health data exchange and use between CDC, state and local health departments, and other key partners.[1]

Released in 2021, the Executive Order on Ensuring a Data-Driven Response to COVID-19 and High-Consequence Public Health Threats also calls for efforts to facilitate the "gathering, sharing, and publication of COVID-19-related data" and a review of the "connectivity of public health data systems supporting detection and response to high-consequence public health threats."[2] An assessment of the legal landscape impacting public health data reporting, surveillance, and sharing is critical for these efforts.

To assist with federal initiatives, ASTHO, with support from HHS's Office of the National Coordinator for Health Information Technology (ONC), conducted a legal scan in 2021 to identify state statutes and regulations impacting public health data sharing. ASTHO's scan explored four key areas of public health data sharing: (1) immunization information, (2) case and laboratory reporting, (3) vital statistics, and (4) syndromic surveillance. This report includes background on each of these key domains of public health data and a summary of findings regarding the state laws governing reporting, surveillance, and sharing of these data.

# Background

## Immunization Information

Healthcare provider organizations, pharmacies, and health information systems report immunization administration information to public health departments through immunization information systems (IISs). These "confidential, population-based, computerized databases" are operated primarily by CDC-funded immunization programs in the states, territories and freely associated states, and select cities.[3] IISs offer healthcare providers consolidated immunization records that can be used to identify appropriate immunizations needed at the time of care or at a later date. At the population level, IISs also provide public health officials with aggregate information to support public health decision-making.

IISs emerged in the 1990s in response to a measles epidemic in the late 1980s and concerns over low childhood immunization rates.[4] Historically, IIS data capture of childhood immunizations has been more complete than for adult immunizations, though progress has been made in this space. Not all vaccine administrators are enrolled with their IIS, which also impacts the completeness of immunization data available to public health officials.

The COVID-19 pandemic increased national attention on immunization administration data and the systems that collect and house these records. Public health partners have called for a modernized immunization data infrastructure, noting the need for enhanced IIS technical capacity, improved data quality, standardization and system interoperability, and facilitation of cross-jurisdictional data sharing.[5]

## Case and Laboratory Reporting of Communicable Diseases

Detecting and preventing the spread of communicable diseases are critical public health functions. To prevent disease transmission, health departments require timely information about cases of infectious disease. Health departments gather information about each case, which may involve contact tracing to determine if other individuals could have been exposed to infection. From these investigations, health departments may set isolation or quarantine recommendations or requirements depending on the severity of the disease.

These public health activities are possible because providers and laboratories report infectious disease cases to state and local public health authorities. State and territorial laws requiring reporting of known cases of certain highly infectious diseases go back as far the mid-eighteenth century.[6] Current case reporting extends to infectious diseases such as tuberculous or measles, zoonotic diseases such as Lyme and West Nile, foodborne outbreaks including salmonella, and noninfectious conditions such as lead poisoning.[7]

Newly identified cases are primarily reported to state/territorial and local health departments. CDC maintains the National Notifiable Diseases Surveillance System (NNDSS) to monitor and track 120+ diseases and conditions at a national level.[8] While states and territories determine which diseases and conditions are reportable through their own statutes and regulations, CDC's list of notifiable diseases is established by the Council of State and Territorial Epidemiologists in collaboration with CDC experts. States and territories voluntarily share deidentified information with CDC about cases that fit established criteria.[9] CDC also provides health departments with funding to advance electronic laboratory reporting (ELR) and electronic case reporting (eCR), which supports the timely and secure movement of laboratory and case data to public health authorities.[10,11]

## Vital Statistics

State and territorial governments maintain and issue vital records—official records of births, deaths, and marriages. These records are often held by health departments and serve a key function in tracking population data. In the United States, laws requiring the recording of these significant events predate the country's formation, with the first law enacted in Virginia in 1632.[12]

A total of fifty-seven jurisdictions (all states, New York City, Washington D.C., Puerto Rico, the U.S. Virgin Islands, Guam, American Samoa, and the Commonwealth of the Northern Mariana Islands) collect vital records.[13] Whenever a significant event (e.g., birth, death or marriage) occurs, it is reported to the state or territory and subsequently used to create a national data source for population changes. While numbers are reported to the federal government, the vital records themselves are always held by the state or territory and are not considered to be federal records.[14] Nationally, these data are housed in two primary systems: the National Vital Statistic System (NVSS) and the National Death Index (NDI).[15]

There is already significant work underway to modernize the NVSS, with goals to improve health, reduce costs, strength national security, and increase resilience to outbreaks, disasters, and other emergencies.[16] Strengthening these systems leads to a better understanding of birth and death trends and can help public health authorities make more timely decisions on appropriate interventions.

## Syndromic Surveillance

Syndromic surveillance involves tracking symptoms of patients presenting at emergency departments to detect patterns of illness that may signal the need for further public health action.[17] First developed as an early detection method for large scale releases of biologic agents, syndromic surveillance is now used as an early warning system for many diseases.

The Public Health Security and Bioterrorism Preparedness and Response Act of 2002 established the initial syndromic surveillance platform, requiring the platform to permit for "timely sharing and discussion, in a secure manner, of essential information concerning bioterrorism or another public health emergency."[18] This program was expanded to the National Syndromic Surveillance Program (NSSP). Currently, many hospitals routinely collect and report on symptoms of potential disease outbreaks such as influenza, and syndromic surveillance has also been used to track non-infectious events (e.g., opioid overdoses and lung injuries associated with e-cigarette or vaping product use).[19]

Nationally, CDC manages the NSSP. Through this system, deidentified patient data, including primary complaint, ICD diagnosis codes, location, and patient demographics are collected from treatment providers and shared with health departments or health information exchanges (HIEs). From there, health departments and HIEs upload information into CDC's BioSense Platform to monitor public health and track emerging trends.[20]

# Statutes and Regulations Impacting Public Health Data Sharing

To assist with federal efforts to assess the nation's public health data systems under the 2021 Executive Order on Ensuring a Data-Driven Response to COVID-19 and High-Consequence Public Health Threats, ASTHO conducted a legal scan of the 50 states, Washington D.C., and Puerto Rico in 2021 to identify statutes and regulations governing reporting, surveillance and sharing of public health data. The scan covered the following domains: immunization information, case and laboratory reporting, vital statistics, and syndromic surveillance. Key components of the relevant laws were collected and noted, including but not limited to:

- Whether data reporting was mandatory or voluntary.
- Time requirements for reporting.
- Which individuals and entities were allowed access to data from the public health authority.
- Permitted conditions for data sharing and use.

Key findings from ASTHO's legal scan are summarized below. Findings were not validated with the state health agencies to determine completeness or accuracy of the laws discovered in the search. As such, there may be additional statutes or regulations, particularly around data privacy, that impact the collection or sharing of public health data that were not captured through this scan.

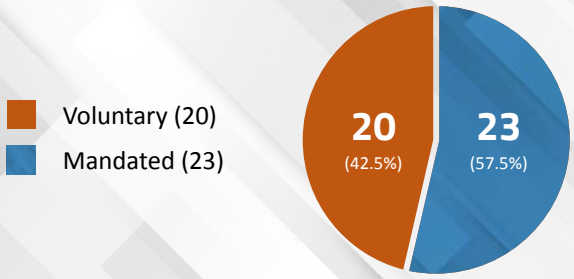
## Immunization Information

Of the 52 jurisdictions evaluated, 43 had established laws for IISs. Among those, jurisdictions were almost evenly split between some form of mandated reporting (23) to the IIS vs. voluntary reporting (20) (**Figure 1**).[i]

IIS information is considered confidential, but some sharing is allowed. Sixteen jurisdictions have laws specifically allowing IIS data to be shared with other jurisdictions—particularly with another jurisdiction's IIS—to complete patient records for individuals who have moved across state lines. Most of these jurisdictions require some form of written data-sharing agreement between the parties to ensure security and data confidentiality. Additionally, 31 jurisdictions specifically authorize their health departments to release information from the IIS to the individual patient or the patient's parent or legal guardian.

In addition to cross-jurisdictional sharing, 28 jurisdictions had laws explicitly allowing provider access to immunization data, although this number could be higher because some state laws do not denote whether providers are already considered authorized users of the IIS with their own log-in credentials for reporting immunizations to the system. The large number of jurisdictions that allow IIS data to be shared with providers for treatment and healthcare purposes could create additional avenues for data sharing with HIEs even if state laws do not explicitly include the HIE as an authorized user of the IIS.

**FIGURE 1: Number of Jurisdictions with Identified IIS Reporting Requirements, by Reporting Type, 2021[a]**




[a] Figure includes jurisdictions with established laws for IISs (n = 43).

[i] While the scan was conducted in 2021, beginning on January 1, 2022, Virginia's law mandating reporting to their IIS took effect, bringing the total number of jurisdictions with some form of mandated reporting to 24.

## Case and Laboratory Reporting

Healthcare providers are required to report communicable, infectious, or contagious diseases to their public health authority in all 52 jurisdictions reviewed (**Figure 2**). Of those jurisdictions, a significant majority (41) also explicitly require by statute that laboratories submit cases to the public health authority. Additionally, 17 jurisdictions require reporting by non-healthcare or laboratory professionals, such as school officials, correctional facility administrators, restaurant or food manufacturing managers, and even parents or individuals with knowledge of a case.

**FIGURE 2: Number of Jurisdictions with Required Communicable Disease Case Reporting, by Reporter Type, 2021**


Despite the broad mandates, only five jurisdictions have codified specific enforcement mechanisms for violations of case and laboratory reporting requirements. However, health departments often have some form of general enforcement authority for violations of public health laws and regulations, so enforcement mechanisms specific to case reporting may not be necessary.

Seventeen jurisdictions require case reports be made within 24 hours. Additionally, 17 jurisdictions have various reporting deadlines specific to the disease or condition. Providers may even need to report immediately to the public health authority via phone or fax if there are multiple sudden cases, more severe diseases, or novel diseases. Most jurisdictions maintain guidance documents on their health department website that list each specific disease and condition and the corresponding reporting time required.

Not all jurisdictions have codified the required elements to be reported for each individual case, but of those jurisdictions that have, 20 have included race and/or ethnicity as a required element. This finding should not convey that only twenty jurisdictions are collecting race in communicable disease case reports, as many states may have included it in electronic reporting guidance or as part of a form published for case reporting. Not all jurisdictions may have found it necessary to require it in their reporting laws if adequate reporting was already underway.

Jurisdictions were split between the confidentiality requirements and data sharing allowances for case reports. Twenty-two jurisdictions specifically prohibit the public health authority from disclosing communicable diseases reports[ii] (regardless of whether the report was received by a provider or laboratory), while other states allowed some forms of sharing with healthcare providers or with written authorizations by the patient. Six jurisdictions explicitly state reports may be shared with medical providers when it is necessary to treat the patient, whereas it may be implied in other jurisdictions by referring to sharing under the Health Insurance Portability and Accountability Act (HIPAA).[iii]

[ii] Jurisdictions may vary in how they interpret statutory language that deems data collected as "confidential." In some instances, this may allow for intra-agency sharing or the release of protected health information in accordance with the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule if the public health authority is also a covered entity. This legal scan did not capture jurisdictions' legal interpretations or potential applications of HIPAA standards.

[iii] HIPAA allows protected health information to be shared for treatment purposes. 45 C.F.R. § 164.502 (a)(1)(ii).

## Vital Statistics

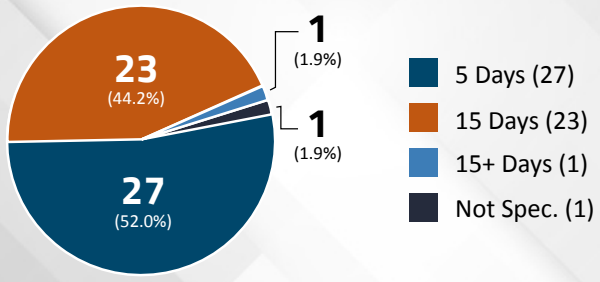
All 52 jurisdictions that were reviewed maintain a state registrar's office or state office of vital records. These offices collect information about births, deaths, marriages, and divorces and report to the NVSS. They also serve an important role of issuing official or certified copies of birth and death certificates. Each of the jurisdictions establish their requirements for reporting these events.

For births, almost every jurisdiction requires that a healthcare provider submit a form for issuance of a birth certificate within fifteen days of a child's birth. The remaining two jurisdictions still require a healthcare provider to submit the information to the registrar, but either do not specify a time or allow more than 15 days (**Figure 3**).

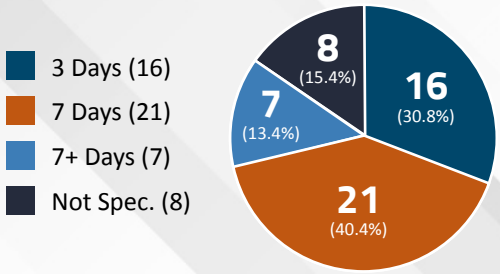
For deaths, there was slightly more variation among jurisdictions. The majority require a death certificate to be filed within seven days (**Figure 4**).

Of the 52 jurisdictions reviewed, 40 have specific laws dictating how identifiable information may be shared with other government agencies either within the jurisdiction, across other jurisdictions, or both. This information is used for a variety of purposes, from juror registry purges to child support enforcement.

### FIGURE 3: Number of Jurisdictions with Required Birth Record Reporting, by Reporting Timeframe, 2021




### FIGURE 4: Number of Jurisdictions with Required Death Certificate Reporting, by Reporting Timeframe, 2021




## Syndromic Surveillance

Though all 50 states have facilities (primarily hospitals) actively reporting syndromic surveillance data into NSSP, not all jurisdictions have established laws requiring participation. Laws that do exist were generally linked to the Medicare and Medicaid EHR Incentive Programs (now called the Medicare Promoting Interoperability Program[21]), which established an incentive program (generally known as meaningful use) through the Centers for Medicare and Medicaid Services (CMS) for eligible providers to adopt electronic health record (EHR) systems.[22] With large federal investments driving participation in syndromic surveillance, there has been less need to codify reporting requirements through state legislation. A few noteworthy findings from the 52 jurisdictions concerning syndromic surveillance policies include:

- Eleven jurisdictions require hospitals to participate in syndromic surveillance reporting. Of those, two also require other healthcare providers (e.g., EMS) to participate (**Figure 5**).
- Only three states have codified enforcement mechanisms.
- Six jurisdictions with either mandated or voluntary participation have established reporting deadlines.
- Four jurisdictions with either mandated or voluntary participation have codified what data should be reported.
- Eight jurisdictions have specific requirements for the use and disclosure of reported data.
- No jurisdictions were found to mandate reporting through an intermediary (e.g., hospital association).
- No jurisdictions were found to have patient opt out codified in their laws.

### FIGURE 5: Number of Jurisdictions with Required Syndromic Surveillance Reporting, by Provider Type, 2021

| Provider Type: | Hospitals | EMS/Other |
|---|---|---|
| Number of Jurisdictions: | 11 | 2 |

# Conclusion

The COVID-19 pandemic reinforced an already established need to modernize public health data systems. Public health data collection and sharing efforts are governed by a complex variety of laws. Federal initiatives focused on data modernization and interoperability will need to take state and territorials laws into account early in the process of establishing national standards, as not all jurisdictions are able to share data uniformly. Strong outreach to states and territories—with particular emphasis on gathering insights from their policy and legal experts—will be a cornerstone of advancing state reporting systems and structures.

In addition to federal initiatives, states and territories may also need to examine some of their public health laws to consider strategies for integration between health departments' own siloed data systems, other agencies, HIEs, and providers. Many state and territorial public health data laws pre-date the HIPAA privacy rule and do not establish broad exemptions for sharing protected health information with other public health authorities. As states and territories take steps toward updating their own laws and policies, a holistic approach will be needed to ensure privacy and security concerns are addressed without unnecessarily restricting data exchange.

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