



HEALTH INFORMATION AND DATA SHARING

Fact Sheet

Improving Local Public Health Access to Public Health Data: Illinois Out in Front

Background

Local health departments are the boots on the ground—interfacing with the public and tackling public health challenges, such as COVID and the opioid crisis, head on. Yet, while in many cases the action takes place on the local level, public health *data*—the lifeblood of public health practice—is typically routed to state agencies. Unfortunately, these state agencies often face legal barriers, both actual and perceived, to sharing that data back to local health departments. Without timely public health data, local health departments are hamstrung in their ability to detect disease outbreaks, reduce adverse pregnancy outcomes, devise effective strategies to reduce overdose deaths, and implement other public health interventions.


Illinois is a state with decentralized public health governance, with no fewer than 97 local health departments conducting public health surveillance, investigations, and interventions at the local level. Yet, despite these important public health activities at the local level, most public health data, such as hospital discharge and prescription drug monitoring data, is routed to Illinois *state* agencies.

The Illinois legislature recently passed a sweeping law, effective January 1, 2024, transforming access to public health data by local health departments in the state. This factsheet takes a deep dive into Illinois's new [Access to Public Health Data Act \(the Act\)](#) and other provisions of [House Bill \(HB\) 2039](#) to explore how this new law may transform local public health access to key data.

Access to Public Health Data Act

At the heart of the Illinois Access to Public Health Data Act is the following provision:

Notwithstanding any other provision of State law to the contrary, the Department of Public Health, the Department of Human Services, and the Department of Healthcare and Family Services shall, at the request of a certified local health department in this State, make any and all public health data related to residents



of that certified local health department's jurisdiction available to that certified local health department for the purposes of preventing or controlling disease, injury, or disability. The commissioner, executive director, chief operating officer, chief medical officer, or equivalent executive leader of a certified local health department has express authority to request and receive such data.

410 Ill. Comp. Stat. Ann. 501/10(a)

As discussed below, this and other provisions within HB 2039 create a legal framework that is aimed at preserving data privacy and security while increasing local public health access to public health data.

Key Provisions to Ensure Local Public Health Access to Public Health Data

Public Health Data Defined

The Act defines the data subject to mandatory release under the Act to include “birth and death certificate data, hospital discharge data, adverse pregnancy outcomes reporting system (APORS) data, cancer registry data, syndromic surveillance data, and prescription monitoring program (PMP) data.” However, it does not limit public health data to these categories.

Calling out these specific datasets is significant, as each is of particular value to public health practice. For example, [Illinois' Controlled Substances Act](#) requires every dispenser of controlled substances to transmit information to the state's PMP repository on every controlled substance dispensed. Although amended on January 1, 2023, to allow for sharing data with local public health administrators for limited purposes, prior to that date the Controlled Substances Act allowed for sharing of data with *law enforcement* under certain circumstances, but not local public health. The new Act opens the door to full access for local health departments to this and other data.

Notwithstanding any other provision

The Act makes clear that despite any other provision of Illinois law that may say otherwise, this law requires data sharing from three state agencies to local health departments. This “notwithstanding any other provision” phrase is significant because other provisions of law may have thus far expressly or impliedly prohibited sharing of certain data with local health departments or may have been silent, ambiguous, or subject to misinterpretation regarding data sharing. The [Illinois Vital Records Act](#), for example, permits any “municipal, county, multi-county, public health district or regional health officer... [to] examine vital records.” However, terminology such as “examin[ing] vital records,” may suggest a focus on paper records and could be interpreted too narrowly to limit or bar release of datasets to local public health departments. This is particularly so when compared to another provision in the same law that allows the state registrar to “disclose, or authorize disclosure of, data contained in the vital records... for research.” The new Act overcomes any such potential misinterpretations or overly narrow readings of other data-related laws by requiring the release of public health data when consistent with the Act, regardless of any other provision in Illinois law to the contrary.

What's more, the public health data to be released under the Act is described to include “any and all public health data related to the residents of that certified local health department's jurisdiction.” This phrase removes any ambiguity about the scope of data subject to disclosure, further limiting any discretion by the state agency to limit the data subject to disclosure.



Mandatory, not permissive, disclosures

The new law uses mandatory, rather than permissive, language. The Act states three state agencies “*shall*, at the request of a certified local health department in this State, make... public health data... available to [the] certified local health department” (emphasis added). Any discretion on whether to act is thus vested, not in the state agency, but in the local health department. Further vesting the local health department with discretion, and divesting the state agency of any discretion, the Act states the local public health “commissioner, chief medical officer, or other equivalent executive” shall have the “express authority to request *and* receive such data” (emphasis added). The state agency does not, therefore, have discretion to decline the request, or limit types of data available, when all conditions are met.

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Application to certified local health department only

The Illinois Administrative Code creates certification for local boards of health ([Ill. Admin. Code tit. 77, Part 600](#)). The code recognizes that public health services are best delivered by local health departments and allows the state to recognize a local health department that “carries out the core functions of public health, assessment, [and] policy development.” By limiting data sharing under the Act to certified local health departments, which meet eligibility requirements and achieve certain practice standards, the Act bolsters privacy and security of the data subject to release under the Act.

Appropriate safeguards


Mirroring the language of the Health Insurance Portability and Accountability Act (HIPAA) and other privacy laws, the Act requires appropriate “administrative, physical and technical safeguards to ensure the privacy and security of the data and protect the data from unauthorized access, use, or disclosure.” These administrative safeguards, such as security awareness training; physical safeguards, such as facility access controls; and technical safeguards, such as unique user identification, protect the data and reduce the risk of a data breach once the data has left the state agency.

Minimum necessary data on a need-to-know basis

The Act limits access to the public health data to the minimum needed, stating “[a] certified local health department shall apply appropriate controls to ensure that access to data under this Act is provided on a minimum, necessary basis.” The Act further limits access “only to those persons whose public health duties and responsibilities require such access.” This language, which also mirrors HIPAA’s minimum necessary rule, places appropriate controls around the data by limiting the (1) data subject to release to that which is necessary and (2) individuals who may access the information at the local health department to those who require such access to perform their duties.

Current data in a timely manner

To make the best use of public health data, the data must be current. Mortality data, for example, can provide a valuable window into the public health, by identifying leading causes of death. However, older mortality data



from years past may have particularly limited utility, such as when combatting the opioid crisis or COVID-19. [Provisional data, typically available before final mortality data, can provide early insights on shifts in causes of death and guide public health interventions to reduce mortality.](#)

The Act expressly states that the state agencies required to release data “must provide the latest available data for each certified local health department within 120 business days after completion of [a] data use agreement, except to the extent prohibited by current technology.” Such provision may prove key to accessing *timely* current data that will be of greatest utility to local health departments.

Data Use Agreements

To prevent inappropriate use of data, the Act requires that each disclosing state agency and requesting local health department execute a master data use agreement (DUA). Specifically, the DUA is intended to promote the “appropriate, effective and efficient use of the data.” However, the Act also makes clear that the DUA may not unnecessarily “impede certified local health department access to any public health data available.” And, recognizing limitations on government agencies’ authority to indemnify third parties under Illinois law, the Act clarifies that the state agency may not condition release of public health data on inclusion of an indemnification provision in the DUA.

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The DUA provision, therefore, adds important protections around public health data subject to release under the Act. Time will show whether the need for separate master DUAs with potentially 97 local health departments proves practical or impractical.

Non-discoverability and FOIA exemption

Two key provisions in HB 2039 protect identifiable public health data from disclosure in connection with litigation and in responses to public records requests. First, the Act expressly states that all data obtained pursuant to the Act and in the hands of a local health department “shall be exempt from inspection and copying under... the [Illinois] [Freedom of Information Act](#)” and “shall not be admissible as evidence nor discoverable in any action of any kind in any court or before any tribunal, board, agency, or person.” This language mirrors similar provisions in Illinois law upon which public agencies rely to withhold sensitive public health data from discovery in legal proceedings and in response to public records requests, such as the [AIDS Confidentiality Act](#) (exempting HIV test results and HIV-related information from release under FOIA or from disclosure in any proceeding) and the [Sexually Transmissible Disease Control Act](#) (similarly, exempting information relating to cases of sexually transmissible infections from disclosure under FOIA or in any proceeding).

Second, HB 2039 amends the Illinois Freedom of Information Act to add an exemption for “[i]nformation obtained by a certified local health department under the Access to Public Health Data Act.” The Freedom of Information Act creates a presumption that all records in the custody of a public agency are public records subject to release ([5 Ill. Comp. Stat. 140/1.2](#)), and this exemption means that public health data obtained pursuant to the Access to Public Health Data Act are not subject to release in response to a FOIA request.



Conclusion

Timely access to public health data is key to targeting public health interventions to have the maximum impact, while also making the most of limited public health funding. However, the law is often presented as a barrier, whether actual or perceived, to sharing data with local health departments. The Illinois Access to Public Health Data Act provides a template for other states who wish to enhance access to public health data to support local public health. The law includes key provisions designed to mandate data sharing in appropriate circumstances while maintaining the privacy, integrity, and security of public health data. A key feature of the new Act—one that will hopefully not get lost in the flurry of data requests that may result—is that it removes from the three state agencies discretion to decline requests for data that otherwise comply with the new law. Other key provisions include limiting data access to the minimum necessary and requiring access controls and a data use agreement. Not only is the law a model for jurisdictions seeking to share data with local health departments, but similar laws could be conceived to increase data sharing with the Centers for Disease Control and Prevention (CDC), Tribal governments and Tribal Epidemiology Centers (TECs).

Join the Local Privacy Officer Peer Group

The Network's Local Privacy Officer Peer Group provides support, resources, and learning opportunities to privacy officers at local public health agencies. Members participate in quarterly webinars and are included in a directory of local privacy officers. Members are also included in a local privacy officer listserv through which they may connect directly with other local privacy officers around the country.

To join the Local Privacy Officer Peer group at no cost, contact [Jeffrey Allen](mailto:jallen@networkforphl.org), Program Coordinator, jallen@networkforphl.org.

This document was developed by Stephen Murphy, J.D., Deputy Director, Mid States Region. The Network for Public Health Law provides information and technical assistance on issues related to public health. The legal information and assistance provided in this document does not constitute legal advice or legal representation. For legal advice, please consult specific legal counsel.

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