

# The Role of Law in Sociodemographic Data Collection for Disease Surveillance

A decorative background consisting of numerous small, colorful squares in various colors (blue, green, orange, purple, red, yellow, brown, pink) scattered across the page, creating a vibrant, abstract pattern.

**S**ociodemographic data reporting – that is, reporting of individual characteristics such as age, race, sex, education, employment, and income – allows public health departments to recognize how diseases affect diverse populations.<sup>1</sup> Accurate reporting of sociodemographic data as part of public health surveillance enables public health agencies to respond to health inequities more effectively by identifying groups that are disproportionately affected by certain diseases. Laws and policies are used to set uniform baseline standards and create norms for reporting across the field of public health. By understanding the role of the law in disease surveillance, public health practitioners can use the law to improve sociodemographic data collection, which in turn enables public health agencies to provide better services to the diverse communities they serve.

This resource illustrates how laws influence sociodemographic data collection during public health surveillance. Typically, providers or laboratories send information about cases of **reportable** diseases or conditions to local and state health departments.<sup>2</sup> State health departments send case data on **notifiable** diseases to the Centers for Disease Control and Prevention (CDC).<sup>3</sup> Diseases and conditions that are reportable are determined by state and local laws. Diseases and conditions that are notifiable are determined by CDC and the Council of State and Territorial Epidemiologists.<sup>4</sup> The information sent to CDC is defined by state and federal laws and policies as well as requirements laid out in data use agreements<sup>5</sup> and in sub-regulatory guidance from government agencies. State laws may require, permit, or prohibit sending data to CDC. These laws may differ, depending on the sensitivity of the data.

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State, tribal, local, or territorial (STLT) jurisdictions can enact laws that address what types of demographic information must be collected for case reports on diseases and conditions. A 2021 study of disease-reporting laws in all 50 states found that 48 states had at least some laws that required sociodemographic reporting for at least one disease or condition.<sup>6</sup> The law may play an important role in what data are collected for disease surveillance.

## The Disease Surveillance Process

**STEP 1:** A patient goes to their health care provider.

**STEP 2:** The health care provider diagnoses – or laboratory tests confirm – a disease that is reportable by state law to a STLT public health department. The provider or the laboratory sends the report to the STLT public health department.

**STEP 3:** The public health department receives disease data and uses that information to identify and control disease outbreaks and ensure that the patient is treated effectively to limit spread.

**STEP 4:** The public health department sends information about national notifiable diseases to CDC and may also receive data from CDC to inform disease control efforts.

CDC collects national notifiable disease data in the National Notifiable Diseases Surveillance System and provides these data to disease-specific programs across the agency. CDC programs use disease-specific data to respond to and monitor disease outbreaks. CDC programs also send data back to STLT public health departments to use in disease control and prevention activities. This resource highlights a few of the laws that influence sociodemographic data collection practices as part of public health surveillance.



## STEP 1

### A patient goes to their health care provider.

At the first step of the disease-reporting process, many laws are associated with data collection, including laws that establish disease-reporting mechanisms, authorize health departments to collect disease-related data, and address patient privacy and the confidentiality of health information.<sup>7</sup> There may be opportunities within these laws to expand the sociodemographic data elements that are collected. These laws are balanced against laws ensuring patient privacy, which are foundational to patients' trust in the health care system and are important at every step of the public health surveillance process.<sup>8,9</sup> Typically, privacy laws include exceptions that allow public health surveillance efforts.<sup>10</sup>



## STEP 2

### A health care provider or laboratory confirms the presence of a reportable disease and sends the information to the appropriate STLT public health department.

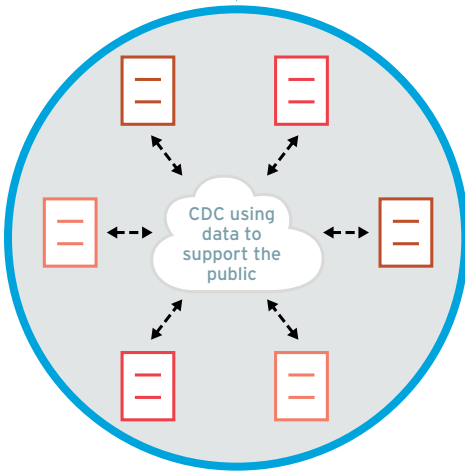
As the health care provider or lab gathers information for a diagnosis and then sends the information to the appropriate public health agency, many laws guide these activities, including laws that authorize health care providers and laboratories to collect disease information and report it to public health agencies, as well as laws that establish what data must be collected. Federal laws or policies can encourage or require reporters to include specific data elements in their reports.<sup>11</sup> Similarly, state laws that address which diseases must be reported to the state public health department typically include requirements for inclusion of specific data elements.<sup>12,13</sup>



## STEP 3

The public health department receives disease data and uses them to identify and control disease outbreaks and ensure that the patient is effectively treated to limit spread.

It is important to ensure that individuals' privacy is protected and that medical information is kept confidential as jurisdictions collect sociodemographic data. State and federal laws and policies can set important security and confidentiality requirements for public health data, to increase public trust and encourage sharing. State and federal agencies have also developed guidance to address how public health and other agencies should collect and share sociodemographic data.<sup>14,15,16</sup>



## STEP 4

The public health department sends information about national notifiable diseases to CDC and may also receive data from CDC to inform disease control efforts.

At this stage of the process, the laws that govern data exchange are incorporated into data use agreements that are executed by state and federal public health agencies. CDC programs use disease-specific data to support recognition of disease outbreaks; monitor shifts in disease patterns; and evaluate and fund disease control activities. CDC programs also analyze the data and share the results of their analysis with STLT health departments to inform decisions about disease prevention activities. By analyzing data from partners across the country and sharing that information as appropriate, CDC can facilitate cross-jurisdictional coordination and response.

# Conclusion

There is no national standard for reporting of sociodemographic data for public health, and there is also a lack of consistency among requirements under state laws.<sup>17</sup> This variability makes it difficult to identify disparities in infection and death rates caused by the spread of disease. Laws and policies are the primary mechanism through which we create uniformity across fields. Laws that promote robust collection of sociodemographic information allow public health professionals to gather a more complete picture of the burdens of disease and injury across populations and enable public health agencies to connect with communities and respond to health inequities more effectively.

Ultimately, though, laws alone are not enough. In addition to incorporating sociodemographic data collection into law and policy, jurisdictions need to clearly articulate its value through public health messaging and demonstrate its efficacy through practices that protect patient privacy and respond to community need in culturally appropriate ways.

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ChangeLab Solutions is a nonprofit organization that provides legal information on matters relating to public health. The legal information in this document does not constitute legal advice or legal representation. For legal advice, readers should consult a lawyer in their state.

# Notes

- 1 Weber SB, Moreland A, Hulkower R, Holiday TR. Examining sociodemographic data reporting requirements in state disease surveillance systems. *Saint Louis University J Health Law Policy*. 2021;14(2):572-573. [scholarship.law.slu.edu/jhlp/vol14/iss2/16](https://scholarship.law.slu.edu/jhlp/vol14/iss2/16). Accessed October 19, 2023.
- 2 Centers for Disease Control and Prevention (CDC). *National Notifiable Diseases Surveillance System*. [cdc.gov/nndss/docs/NDSS-Overview-Fact-Sheet-508.pdf](https://cdc.gov/nndss/docs/NDSS-Overview-Fact-Sheet-508.pdf). Accessed October 19, 2023.
- 3 CDC, *Notifiable Diseases*.
- 4 CDC, *Notifiable Diseases*.
- 5 Data use agreement. National Library of Medicine website: [nmlm.gov/guides/data-glossary/data-use-agreement](https://nmlm.gov/guides/data-glossary/data-use-agreement). Accessed October 19, 2023.
- 6 Weber et al., Sociodemographic data reporting requirements, 574.
- 7 Holt JD, Ghosh SN, Black JR. Legal considerations. In: Rasmussen SA, Goodman RA, eds. *The CDC Field Epidemiology Manual*. 4th ed. Oxford University Press; 2019:263-279.
- 8 Privacy and confidentiality have different implications for different populations. Some Black patients or patients who are immigrants may fear revealing their demographic data because they believe they may receive inferior care. Other patients may fear that their data will make them a target of state action – for example, in states with laws that criminalize HIV-positive status. Still other people may think that sociodemographic categories are irrelevant or inappropriate. See, e.g., Iott BE, Campos-Castillo C, Anthony DL. Trust and privacy: how patient trust in providers is related to privacy behaviors and attitudes. *AMIA Annu Symp Proc*. 2020 Mar 4;2019:487-493. Accessed October 24, 2023.
- 9 Examples of laws that protect individuals' privacy include the Health Insurance Portability and Accountability Act, Pub. L. No. 104-191; and the Virginia Consumer Data Protection Act, Va. Code Ann. § 59.1-576 (C)(1).
- 10 45 C.F.R. § 164.512(b).
- 11 Interim Final Rule (IFC), CMS-3401-IFC.
- 12 W.A.C. 246-101-011.
- 13 H.B. 3159, 2021 Reg. Sess. (Or. 2021).
- 14 H.B. 22-1157, 2022 Reg. Sess. (Colo. 2022).
- 15 Jinadasa D, Okada B. *Implementation Guide: Part 1, Data Collection on Race and Ethnicity: A Tool to Advance Health Equity in Utah*. Office of Health Equity, Utah Department of Health and Human Services; 2022. [healthequity.utah.gov/wp-content/uploads/Implementation-Guide.pdf](https://healthequity.utah.gov/wp-content/uploads/Implementation-Guide.pdf). Accessed October 19, 2023.
- 16 Connecticut Department of Public Health. *Connecticut Department of Public Health Policy and Procedures for Collecting Sociodemographic Data - Users' Guide*. Updated May 2019. [portal.ct.gov/-/media/DPH/Office-of-Health-Equity/Main-Page/Policy-and-Procedures/SD-Data-Collect-Users-Guide-6719-FINAL.pdf](https://portal.ct.gov/-/media/DPH/Office-of-Health-Equity/Main-Page/Policy-and-Procedures/SD-Data-Collect-Users-Guide-6719-FINAL.pdf). Accessed October 19, 2023.
- 17 Weber et al., Sociodemographic data reporting requirements, 580.