Research Protocol for Public Health Departments and State Patient Confidentiality Laws

Prepared by Sarah Hexem, JD

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I. **Scope**

The research team created a research design and methodology that endeavored to answer the following questions for each state:

1. Do communicable diseases have to be reported to a health department?
2. To which part of the health department are communicable diseases reported?
3. When can personally identifiable information (PII) collected by a health department be released?
4. How can PII collected by a health department be used by the department?

II. **Data Collection**

To answer these questions, the Public Health Management Corporation (PHMC) research team conducted a review of laws pertaining to the confidentiality of information collected and held by health departments across all 50 states and the District of Columbia (hereinafter “states” unless otherwise noted) and an additional nine cities eligible for direct HIV prevention funding from the CDC. From the initial four questions, the research team created 42 variables, which are all documented in the Public Health Departments and State Patient Confidentiality Laws Codebook. The codebook also presents the research questions used throughout the project alongside the questions used to present the dataset on the Public Health Departments and State Patient Confidentiality Laws Map.

The sources of data for this project included state- and city-level reporting and confidentiality statutes and regulations (hereinafter “laws” unless otherwise noted) governing health departments and states' Reportable Disease Lists.¹ For the nine additional cities, the research team reviewed the equivalent of these materials at the city ordinance and policy-level. The state laws were identified using the WestlawNext search engine and, when not found in the laws, Reportable Disease Lists were found on the websites of state health departments. City laws were identified using tools provided on the city health department websites, where applicable.

¹ No other areas of law and/or policy outside of these sources were reviewed, analyzed, or coded. However, based on consultation with the PCSI sites, the research team predicts that county level laws and informal departmental policies may affect decisions regarding the collection, release, and use of personally identifiable information. Neither sources of law were included in this research. Further, this research did not consider any sources of case law, administrative procedures, nor judicial review of agency actions.
If an answer to a question required two pieces of law to be read together, all the sources that were utilized to determine the answer were recorded. A common example of this is when a statute or regulation uses a term in one part of the law, and defines it in another.

The research team developed the final research protocol (see Appendix B) through an iterative process, which included consultation with national public health experts. As the protocol developed, the team repeated research on states previously reviewed using the working protocol. All states were reviewed using the final protocol. As part of the process, the team created operational definitions to establish uniform research and coding methods.

III. Coding
Codes for the variables were created to answer these questions. Parent questions were coded in a binary format. Child questions were multivariate. Codes for child questions regarding the release and use of PII focused on whether release of PII is permitted for the following purposes: treatment, research, public health, outbreak response, disease investigation, disease prevention and control, coordination of care, intra-agency exchange, partner notification and tracking, and implementation of public health laws. Purposes that were not coded in our research included: disclosure for quality assurance purposes, court proceedings, health emergencies, testing of emergency medical workers, quarantine procedures, adjudicative orders, and more.

A final research protocol and a codebook were developed to achieve replicable search results. For more information on the collection of laws, operational definitions, and precise rules for the coding of variables, please see the Public Health Departments and State Patient Confidentiality Laws Essential Information and the Codebook.

IV. Quality Assurance
The team implemented quality control measures to ensure research integrity. The policy associate conducted initial legal research. The legal intern updated the policy associate’s earlier research as the protocol developed, and the lawyer reviewed one-third of the states and all the cities. Quality assurance focused on early research to establish a reliable methodology and operational protocols and coding. The lawyer also reviewed any states about which the policy associate or legal intern raised questions.

After completing the coding, the lawyer reassessed the codes and met with other public health lawyers to review answers requiring advanced interpretation.