What Identifying Information Is Collected On Reportable Disease Forms and How Is It Used?

All 50 states plus the District of Columbia mandate that physicians and laboratories (and typically a variety of other health care providers and institutions) report cases of certain reportable diseases and conditions to the state and/or local health department. Reports of disease are often made after someone with a reportable illness or health condition seeks treatment with a physician or hospital, or when a laboratory evaluation of a patient sample confirms the presence of a particular disease. The physician, hospital, or laboratory does not need patient consent to submit disease reports to state and local health agencies because that disclosure is permissible under HIPAA's exceptions for public health practice and disclosures required by law.

Each state has reportable disease statutes and regulations setting out what information reporting entities must provide to the health department. Although this information varies from state to state, several pieces of personal identifying information are typically required, including:

- Patient's name
- Patient's address
- Patient's contact information
- Patient's date of birth
- Patient's sex
- Disease being reported
- Name and contact information for the reporting entity (e.g., physician, laboratory)

This information is transmitted to health departments in a number of ways. Although several states now require entry of disease reports into an electronic statewide database, other state and local health departments obtain this information through paper reporting forms submitted by email, fax, or regular mail. For diseases that present a significant public health threat, notification to the health department is most often required to be provided by phone directly, with paper or computerized reports filed later.

Once health departments have obtained patient information through a disease report, state law protects use and disclosure of this information at varying levels. All states consider disease reports to be strictly confidential and exclude reportable disease reports from state freedom of information requests. However, laws in all states permit state and local public health agencies to use this information to conduct disease investigations, which is particularly important in cases of communicable disease. (Note, however, that most states also have special rules for the sharing and use of information pertaining to HIV/AIDS.) Beyond the public health agency that collected the data, state laws vary regarding the use and disclosure of personally identifying reportable disease data. States frequently allow disclosure, to varying degrees and with various restrictions, to emergency health workers, other state, local and federal health agencies, schools and employers, and law enforcement. After the information has been de-identified, almost all states permit the use and disclosure of aggregate reportable disease data for purposes beyond disease investigation, such as public health research.

For more information on state and federal laws related to privacy, see www.healthinfolaw.org/topics/63. For more information about HIPAA, see www.healthinfolaw.org/federal-law/HIPAA.

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