

Expert Meeting on Legal and Ethical Issues in Syndromic Surveillance

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OBJECTIVES

The International Society for Disease Surveillance will convene a group of experts to: (1) share experience with privacy, confidentiality, and other legal and ethical issues in syndromic surveillance; (2) clarify the research, practice, legal, and ethical issues that enable and restrict data sharing; and (3) identify approaches to overcoming barriers in a way that protects privacy and confidentiality while maximizing the usefulness of syndromic and related surveillance systems.

BACKGROUND

For syndromic and related surveillance systems to be effective public health tools, state and local health departments and CDC need access to a variety of types of health data. However, since the development and implementation of syndromic surveillance systems began in recent years, experience in gaining access to personal health data has been mixed. Although some have argued that the HIPAA Privacy Rule permits data owners to disclose protected health information to public health authorities, covered entities have cited HIPAA in refusing to provide data to researchers and health departments. In addition to HIPAA, a variety of federal, state, and local public health laws enable, restrict, and otherwise influence the ability to share data for public health surveillance purposes. Concerns about protecting proprietary data also influence data sharing for public health purposes. It is in the national interest to clarify the conditions under which data can be shared, balancing privacy and confidentiality with the ability of public health agencies at all levels of jurisdiction to access information needed to protect the public from disease. As the practice of syndromic surveillance evolves, it is equally important to assure that data are collected and used ethically as well as legally. The methods and uses of syndromic surveillance pose challenging questions regarding the interpretation and future development of ethical and legal standards for public health practice and research. The discussion will not be confined to the legal and ethical issues surrounding the release of data but will also address these issues as they concern the subsequent transmission, storage, replication, and display of health data by local, state, and federal public health users, including how the information is used for both early event detection and situational awareness functions.

METHODS

A group of 15 to 20 individuals with experience in the practice and science of syndromic and other public health surveillance and related legal and ethical issues, drawn from federal, state, and local public health agencies, hospitals and other "data suppliers," academic institutions, and other groups active in syndromic surveillance and related activities will meet for one and a half days in Washington DC in September 2007.

Following a preliminary discussion of practice issues such as surveillance data needs, barriers to data sharing, and strategies that have been used to overcome such problems, the experts will address the following issues:

What are the legal authorities that enable syndromic surveillance at the local, state, and federal level? Is more specific authority needed?

What does the HIPAA Privacy Rule actually imply for syndromic surveillance? In what circumstances does the public health practice clause allow syndromic surveillance? Is specific legal authority necessary? Are data use agreements (DUA) necessary? Is personal health information (PHI) that is "de-identified" according to HIPAA standards useful for syndromic surveillance?

How do other federal, state and local laws and regulations enable, restrict, and otherwise influence the ability to share data for public health surveillance purposes?

How does the application of the HIPAA privacy rule and other laws and regulations depend on whether data are being used for research as opposed to public health practice? In this context, how are distinctions made between research, practice, and evaluation of public health practice? Is some new form of ethical review called for?

If syndromic surveillance data are shared with law enforcement and intelligence agencies, or used for other non-public health purposes (or perceived by the public as being used for these purposes), how with that affect the public's confidence in public health and public health's ability to function?

Further Information:

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