Structured Information Sharing in Disease Surveillance Systems

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Introduction

The practice of real-time disease surveillance, sometimes called syndromic surveillance, is widespread at local, state, and national levels. Diseases ignore legal boundaries, so situations frequently arise where it is important to share surveillance information between public health jurisdictions. There are currently two fundamental ways for systems to share public health data and information related to disease outbreaks: sharing data, or sharing information. Data refers to patient level and aggregate counts of patients, and can be difficult to share legally because of privacy issues. Information refers to summaries, opinions or conclusions about data. There are few if any legal barriers to sharing information, and by definition it includes interpretation of data by knowledgeable local personnel which is vital during outbreak investigation. Currently most shared information is unstructured text, and this format makes it difficult for computers to use the information in any meaningful way. The only thing a system can do with this unstructured information is allow users to read each message.

Objectives

Alternate methods are needed to facilitate communication between jurisdictions during potential disease outbreaks. One alternative is to share structured information. Defined at the appropriate level, information sharing can avoid traditional data sharing barriers while capturing valuable local knowledge. The key is to identify the types of surveillance information that are neither so highly interpreted as to lose their value nor so loosely interpreted as to face traditional data sharing barriers. The objective of this work is to identify the level at which surveillance information sharing can be both feasible and beneficial, and to create a vocabulary standard that supports the exchange of structured information between diverse surveillance systems.

Methods

Research is ongoing in three areas: defining the message structure; identifying appropriate technology; and developing a prototype system. The message structure should allow public health officials from different communities to share information that describes the current conditions of health in their communities. The structured message should take advantage of existing standards such as ICD9, SNOMED, geographical definitions, age groups, etc. A variety of potentially useful technologies are available. Sharing information over secure technologies such as PHIN-MS, secure ftp, secure socket layers (SSL), and other technologies will be investigated. Moving the information from producer to consumer through web services also provides a standard interface to submit or review information from any type of application. This allows the system to be integrated with stand alone applications, current disease surveillance systems, or centralized information sharing web portals. The prototype will have easy to use input screens and visualization techniques that take advantage of the structured aspect of the information. These visualizations will make heavy use of GIS maps to provide a national or international situation awareness perspective to the users.

The system developed from this project will be demonstrated in a working proof-of-concept prototype. Initial qualitative analyses of its epidemiological utility will be performed using the National Capital Region (NCR) Public Health Surveillance Network, which can currently exchange patient level data between multiple jurisdictions.

Results

Work on this project is ongoing. The new message format will be described and examples provided of its use in key use cases. A prototype of the input and output visualizations will be presented with a description of any outstanding technical issues.

Conclusions

Sharing raw disease surveillance data from electronic surveillance systems between multiple jurisdictions is difficult and sometimes impossible because of confidentiality issues and regional laws. Sharing information eliminates the privacy issues, providing useful knowledge to other jurisdictions while retaining local interpretation that is so necessary during investigation of an event. By sharing that information in a structured way, systems can use the shared information to populate maps, run information-specific algorithms, and compare their situation with that in other communities automatically.

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