Public Health Informatics Transforms the Notifiable Condition System

The science of informatics brings Washington public health practice into the 21st century.

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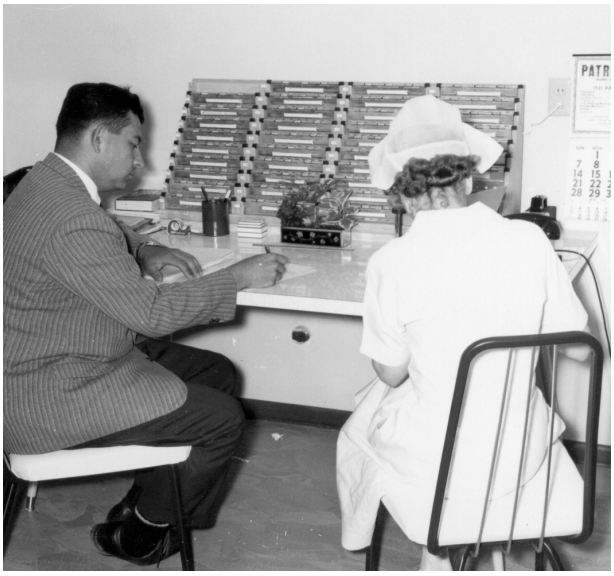
The notifiable condition surveillance system is the foundation of disease control and prevention in the United States. This system was founded more than one hundred years ago, when states first made tuberculosis reportable to public health authorities. Today, the practice of surveillance is not much different than it was in the last century. Health care providers diagnose a patient with a disease of public health interest. The providers contact local public health officials by telephone or mail and relay specific information about the patient and the case. Local health officials follow-up, contacting other individuals who may be at risk and taking actions to protect the general public. Local health agencies transmit relevant information about the case to the state health agency, which aggregates all information from the local level and identifies inter-jurisdictional trends. Finally, state agencies send aggregated information to the Centers for Disease Control and Prevention (CDC) to enable identification of national patterns and provide input into development of national disease prevention policies.

This system has proven to be generally effective, but is by no means perfect. It has grown more complex, with more conditions being added to mandatory reporting regulations and more public health agencies requiring direct reporting from both health care providers and laboratories. At the same time, the clinical health care system, where the majority of disease reports originate, has also gained complexity. Managed care has changed the way health care providers see patients and diagnose disease. Increasingly restrictive payment systems have made it more difficult for providers to find time to comply with disease-reporting requirements. Health care has also become regionalized, with patients crossing jurisdictional boundaries to receive care.



Reviewing lab data on communicable disease, Seattle, c. 1953.

A closer look at Washington's notifiable condition surveillance system illustrates this complexity. Much of the information received by local health agencies comes from clinical laboratories. In Washington, a clinical laboratory must understand the notifiable condition regulations and know the appropriate state or local health program for submitting a report. Laboratories may send a disease report to the most convenient health department, such as the one for the county where the laboratory is located. Consequently, large county health departments often must sort incoming disease reports and forward them to the appropriate county. Reports can fall through the cracks or be significantly delayed in reaching their destination.

Once a local health agency or state program has received a report, it must be entered into that agency's information system. If the report needs to be forwarded to another program or agency, it may need to be reformatted to meet the requirements of the new information system. Since different programs and agencies have different information systems, aggregating or comparing data across programs or agencies takes time and effort.

Technology's Role in Notifiable Condition Surveillance

Information technology offers hope for making existing systems function more effectively. Ideally, laboratories or physicians would automatically generate disease reports directly from their information system and send them securely and electronically to the appropriate destination. The recipient organization would incorporate the information directly into its information system. The information would be easily transmissible to other public health programs, including programs

outside categorical boundaries, and could be aggregated at the local, state, or national level. But public health officials are faced with a difficult question. How can mutually compatible information technology be implemented across a complex, interdependent yet functionally autonomous heath care and public health system?

The answer lies in informatics, the scientific field that deals with the storage, retrieval, sharing, and use of data, information, and knowledge. Over the last decade, informatics specialists have begun shaping a unified framework for information technology through the development and advocacy of standards.

Although standards offer the potential for organizations to use common approaches to information technology, the complexity and proliferation of standards makes their application difficult. As many informatics specialists say, "Standards are wonderful because there are so many to choose from." Fortunately, public health informatics specialists are focusing on the application of informatics to the particular needs of public health (*see sidebar on this page.*)

Washington's Informatics Approach

For more than five years, Washington has been developing an integrated notifiable condition surveillance system, following the principles of informatics. The effort began at the state level with a push at the state Department of Health (DOH) to map out all of the agency's key business functions and identify the information flow associated with them. We recognized that information systems in our agency should support common business practices, such as disease surveillance or case management, using common information technology design and data standards. In this way, we could develop systems for use by multiple agency programs. Further, we realized that these common business practices are not unique to the state health agency. Local health agencies have many similar processes and operational needs. We concluded that we must consider the entire notifiable condition surveillance framework—the health care industry and local, state, and federal health agencies—as a system, with a system-wide approach to planning. Consequently local health agencies and the CDC have joined forces with DOH to develop a comprehensive, holistic information technology approach to notifiable conditions.

This planning has led to the formation of the Washington Electronic Disease Surveillance System (WEDSS) project. The WEDSS project is modular; each of its projects (*see table on p. 16 and figure on p. 17*) addresses a specific component of the notifiable condition surveillance system:

1. Reporting of data from the clinical health care system to the appropriate public health agency and among public health agencies;
2. Management of case information;
3. Management of aggregated surveillance information
4. Analysis and dissemination of information

WEDSS also includes a technology infrastructure project to enable all of this information exchange to take place in a secure electronic environment. The WEDSS work is funded in part through the CDC's National Electronic Disease Surveillance System program and is consistent with that national direction, which is beginning to establish information technology standards for public health.

Principles of Public Health Informatics

Four principles, flowing directly from the scope and nature of public health, distinguish it from other specialty areas.

1. The primary focus of public health informatics should be applications of information science and technology that promote the **health of populations** as opposed to the health of specific individuals.
2. The primary focus of public health informatics should be applications of information science and technology that **prevent disease and injury** by altering the conditions or the environment that put populations of individuals at risk.
3. Public health informatics should explore the potential for prevention at **all vulnerable points in the causal chains** leading to disease, injury, or disability; applications should not be restricted to particular social, behavioral, or environmental contexts.
4. As a discipline, public health informatics should reflect the **governmental context** in which public health is practiced.

The nature of public health defines a special set of informatics challenges. For example, to assess a population's health and risk status, data must be obtained from multiple sources, such as hospitals, social service agencies, police, departments of labor and industry, population surveys, and on-site inspections. Data about particular individuals from these various sources must be accurately combined, and then individual-level data must be compiled into usable, aggregate forms at the population level. This information must be presented in clear and compelling ways to legislators and other policy makers, scientists, advocacy groups, and the general public, while ensuring that the confidentiality of the health information of specific individuals is not compromised.

From: Yasnoff WA, O'Carroll PW, Koo D, et al: Public health informatics: Improving and transforming public health in the information age. J Pub Health Management Practice, *in press.*

A modular, yet coordinated approach to information system planning has many advantages. Smaller projects have a better chance of actually getting completed. Multiple funding sources can be used, each directed at a single project or a combination of projects. If a single project fails or is delayed, the rest of the projects are not jeopardized. Common technology solutions, such as secure networks or database servers, can be identified and implemented to support multiple projects. As the long-term vision is refined, individual projects can be modified to reflect the changed direction without adversely affecting the entire system.

A look at one of the WEDSS projects—the Electronic Laboratory Reporting system (ELR)—illustrates the application of public health informatics. In the new ELR system clinical laboratories generate a data file from their laboratory information management system to send to DOH. The data file is in a health care industry standard format, called HL7, using nationally recognized codes for data elements such as patient demographics, analytical method, and test result. Because national standards are being used, the laboratory does not have to construct a data file unique to DOH. The same kinds of files can be sent to other data-trading partners, such as insurance companies and hospitals. The files are sent via a secure Internet connection to a single location, DOH. The use of a common industry platform, the Internet, is critical to this system's success. Laboratories will not have to develop custom connections for different public health agencies, and so are more likely to participate.

DOH is establishing a mechanism to automatically receive reports from laboratories, determine which local health agency or DOH program each report should go to, and forward the report appropriately. In an interim process, the mechanism will also translate the file from HL7 into the format appropriate for the end-recipient's database. As other WEDSS projects progress, so that databases and software in public health agencies around the state are using the same standards, there will be less need for customization. Local health agencies participating in a pilot of this system are receiving laboratory reports more quickly than under the traditional reporting system. Also, the reports are more complete, both in data content (more information in each report) and quantity (more reports are being received).

What changes have to be made in public health agencies to implement a system such as electronic laboratory reporting? Health departments must be willing to adopt the national data and information technology standards in use or being considered by the health care industry. National movement toward standardization has been accelerated by regulations adopted under the 1996 Health Insurance Portability and Accountability Act (HIPAA) that require health care organizations to use standards for any electronic data transaction.

Another necessary change is in the area of security. Notifiable condition reporting requires transmission of identifiable health information, sometimes of a very sensitive nature. We have to be absolutely sure that any mechanism we use is secure. For this reason, we are implementing electronic laboratory reporting in tandem with a security infrastructure enhancement project. The security project is using a variety of technologies to enable safe transmission of information via the Internet. These include firewalls (electronic barriers that prevent unauthorized access to a network) at each participating organization, authentication of users through the use of digital certificates, "tunneling" software to protect the information during transmission, and high-level encryption. This work is being done as part of the state's implementation of the Health Alert Network, a component of the CDC's bioterrorism preparedness initiative.

Table 1. WEDSS Projects

WEDSS Component Projects

Electronic Laboratory Reporting (ELR)	Secure electronic transfer of notifiable condition data from laboratories, centralized to simplify process. Automatic, rapid dissemination of data to appropriate local health agency.
Web-Based Public Health Issue Management System (PHIMS)	Case management tool for local health agencies, with standardized processes to simplify receipt and distribution of electronic case notifications, create a mechanism for workload management, and improve quality of case investigations.
Disease Condition Database (DCD)	Integrated data repository to replace existing communicable disease database and improve ability to share and compare data. Based on national Public Health Conceptual Data Model.
Epidemiologic Query and Mapping System (EpiQMS)	Browser-based interface for conducting standard statistical analyses, geo-spatial analyses, mapping, and report generation.
Health Alert Network (HAN)/ Perimeter Security Enhancement Project	Creates an infrastructure using the backbone of the Washington Intergovernmental Network to allow for secure transmission of identifiable disease information between local health agencies, DOH, and major partners.

A third significant change is in the area of information flow. For the majority of notifiable conditions in Washington, the local health agency bears responsibility for collecting reports, conducting follow-up, and performing interventions. Historically the notifiable condition regulations (WAC 246-101) have reflected this responsibility and required laboratories and clinicians to submit reports directly to the appropriate local health agency. In the interest of efficiency, electronic laboratory reporting is changing this information flow. Reports from laboratories will go to the state health agency, then be routed immediately to the appropriate local health agency. Local health agencies are willing to accept this change in information flow, provided it does not affect their ability to receive reports in a timely manner. As part of the pilot testing of the new ELR system, we are developing evaluation methods for each laboratory that submits reports, so that local health agencies have an opportunity to verify that the new system is working as well as or better than the traditional reporting system. This process is needed not only to test the efficiency of the system but also to build trust in the new information flow and in the technology.

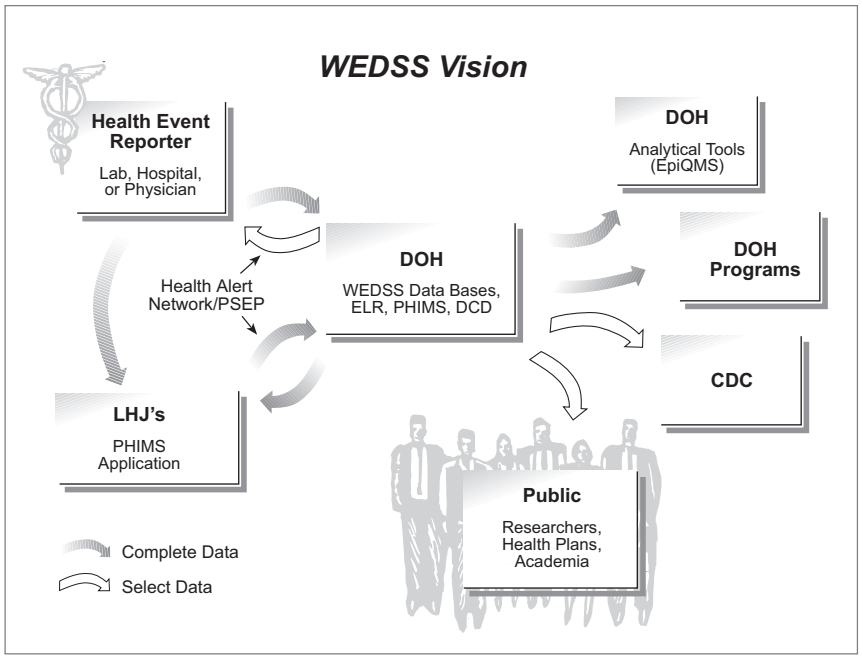


Fig. 1. Ideal data flow in the public health reporting sytem.

Lessons Learned

Over the course of the last five years, we have learned a number of lessons that may be helpful to other agencies looking to implement integrated information systems.

Cultural change is as important as technological change. Although public health practitioners often focus on technology when implementing integrated information systems, the cultural change that must come about in an organization is far more difficult to accomplish. Organization or system-wide planning requires people to adopt new behaviors—collaborating with others outside their immediate program area, changing internal business processes to align with external practices, and giving up short-term internal gains for long-term system-wide benefit. Change agents need to be sensitive to these issues and be prepared to address them.

Communication is critical. Communication with all participants should begin early and continue throughout the planning and implementation process. Individuals and groups who will not immediately be affected but are likely to be involved in the future should also be included in the communication loop. This can help reduce anxiety over potential changes and ensure that specific program needs are met.

Privacy and confidentiality issues must be handled aggressively, through strong security practices. Electronic exchange of information and integrated information systems raise the public's and health officials' concern over loss of privacy and confidentiality. To build and maintain trust in the integration efforts, planners must actively pursue strong security measures and must test those measures to ensure they are effective.

Training is essential. Not only do staff in public health agencies need training in how to use new technology, background training in informatics is essential. This provides staff with a basic understanding of why integration is necessary and how it works. That understanding helps promote the necessary cultural change.

The scope of change envisioned for the notifiable condition surveillance system can be intimidating, but there will never be a better time to begin than now. In the public health system and across the health care industry, the national direction is toward standardization and organized system planning. Funding opportunities are available now that may not be available in the future. Increasingly limited resources are forcing public agencies to be more thoughtful in how they implement information technology solutions. Public health officials understand the need to make more effective use of surveillance information. With a comprehensive planning approach that is well-grounded in public health informatics, we anticipate a transformation of the notifiable condition surveillance system over the next five years that will significantly improve Washington's ability to detect and prevent disease.

Recommended Reading

Yasnoff WA, O'Carroll PW, Koo D, et al: Public health informatics: Improving and transforming public health in the information age. *J Pub Health Management Practice, in press.*

HL7 information:
www.hl7.org/

HIPAA information:
aspe.os.dhhs.gov/admnsimp/

Health Alert Network information:
www.phppo.cdc.gov/han/

NEDSS Information:
www.cdc.gov/od/hissb/docs.htm

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