Shot in the Arm for Public Health: Weak Systems Require Reinforcement at All Levels

by Claire Dixon Lee, PhD, RHIA

Bioterrorism has become a real threat in the US and around the world. Is our public health system robust enough to handle the surveillance and reporting activities needed to protect citizens? Today, the answer is no. But efforts already in progress at local and national levels may be able to change that.

Remember the headlines last year? Anthrax and West Nile virus dominated news reports in 2002, creating anxiety about the dangers of public transportation and mosquitoes. Meanwhile, public health departments across the country were working to collect and disseminate timely and accurate information to the public and the providers responsible for recognizing and treating these outbreaks.

Public health programs within the United States have a long history working behind the scenes of our healthcare delivery system. Physicians, nurses, epidemiologists, clerical staff, information technologists, and officials support a network of local, county, and state public health agencies and laboratories that communicate to the Centers for Disease Control and Prevention (CDC). Over the years, public health services in the US have sought to eradicate diseases such as measles, small pox, and typhoid fever through childhood vaccine programs. In addition, they have labored to reduce health risks from HIV/AIDS to influenza outbreaks, to ensure our drinking water is pure, inspect our food service system, and many other services that may go unnoticed. Much of this work is under funded and understaffed. It took the events of September 2001 and subsequent threats of bioterrorism to bring this vast network to our nation's attention.

A new approach to public health reporting and disease surveillance is needed to ensure the usefulness of public health departments' data collection efforts and the safety of the public. Until actions on the international to the local level are united with industry and nonprofit initiatives and government support, nothing will change. In this article, we'll examine ongoing efforts to shore up public health and where shortfalls still exist.

Surveillance Efforts Hindered on Many Levels

In the past year, both public health programs and the public have recognized the limitations of current public health surveillance programs. The information public health programs receive and the communication links they have to healthcare providers, physicians, and the laboratory networks cannot meet the needs of true public health surveillance. As HIM professionals know, most public health reporting is based on standard criteria, confirmed diagnoses, and providers' attention to public health reporting. However, a shortage of staff and technology in public health departments can hinder this process. For example, some public health agencies at the local level may have as few as one or two staff members to process information generated from numerous sources and for varied purposes. Further, the majority of information is retrospectively collected by telephone, fax, and on paper. Manual data entry increases the risk of error-prone surveillance data and can lead to results so old that they can only provide analytical perspectives for past trending. For example, the information routinely provided to public health services may be older and less detailed than MEDPAR (Medical Provider Analysis and Review) data.

True public health disease surveillance information is time-sensitive. It requires a direct link to the source of information in order to view, trend, and analyze it to detect the presence of an unusual health event or bioterrorism threat. Too often, epidemiologists must rely on subsets of data, piecemeal reports, phone calls, and faxes. The bulk of their work today is based on "passive reporting," once a condition is officially confirmed. Unfortunately, by the time a patient is symptomatic, results and treatment options may be limited.

For decades, the US public health system has relied on weekly reporting of morbidity and mortality statistics, but various sources indicate that public health agencies don't know what percent of infections actually go unreported. To effectively conduct concurrent surveillance for infections, bio-incident reporting, and even realistic chronic disease trending, a paradigm shift is needed. The pressure is on public health to develop an early-warning, early-response tracking system for bio-incident reporting, as well as a user-friendly, efficient, cost-effective means for routine provider submission of chief complaints, diagnostic, and laboratory information. Whether the goal is to identify single cases (covert), large populations (overt), or emergency department cases in the context of major events (syndromic surveillance), the current system offers little more than disconnected, multi-data sources like clinical, pharmacies, laboratories, 911 calls, and suspicious absenteeism reports.

Having released major funding in 2002 and additional funding in 2003 directed toward demonstration projects and grants to expand technology and data linkages, the Bush administration is providing initial leverage to seek improvements in the field. But from the CDC down to the local public health departments, officials may be overlooking some fundamental aspects of healthcare data, collected for one purpose while needed for others.

Data Collection Needs Help Worldwide, at Home

Beginning on an international level, the World Health Organization provides several key public health programs, including Communicable Disease Surveillance and Response (CSR) and the Training in Epidemiology for Public Health Intervention Network (TEPHINET), which provides training and intervention initiatives. Through these programs, there are defined principles of surveillance, forensic data, outbreak response logistics, and funding. Worldwide data collection on morbidity and mortality rates of AIDS, anthrax, cholera, hepatitis, influenza, plague, and many other diseases assist in targeting world relief funding and medical services. Further, today's terrorist threats on numerous nations as well as American citizens in the military, traveling, or working abroad also emphasize the need for international cooperation for improvements in disease surveillance systems. Given the disparity of routine international data collection and the plight of third-world countries, even data on confirmed cases can be difficult to collect. While the use of ICD-10 on a global level meets its international classification purpose, many gaps exist in the uniformity and regularity of the actual reporting.

In the US, the CDC has several programs focused on the following three-step model:

1. Surveillance (problem identification)
2. Risk factor identification (response)
3. Intervention and evaluation (implementation)

With cooperation from local and state public health departments and the National Association of County and City Health Officials (NACCHO), the CDC created the Health Alert Network (HAN), which is designed to provide resources for building information technology capacity within our local public health system. To begin this process, the National Electronic Disease Surveillance System (NEDSS) automated technology application was released in summer 2002. NEDSS represents an attempt at standardized data elements fundamental to support public health database development and epidemiological population and person analysis. The system of data elements is HL7 compliant and would populate the public health conceptual data model.

The long-term goals are:

- automatically gather health data from various sources on a real-time basis
- assist in the ongoing analysis of trends and detection of emerging public health problems
- facilitate the monitoring of the health of communities
- provide information for setting public health policy

The core of the data set relies on person identification (legal under HHS/HIPAA privacy regulations), chief complaints, physician orders, and microbiology results. The state of Nebraska is currently testing the feasibility of a NEDSS-based system, but has already noted a breakdown in routine communications between public health labs and public health authorities within the state. They have realized that laboratory information systems do not lend themselves to data mining functionality, but only to basic functional summary reports consisting of proprietary, proscriptive data sets.

The shortcomings of the NEDSS first release include:

- **reliance on manual copies** of lab reports, emergency room information, and physician reporting with manual data entry and no obvious means to expedite communication of this information in any systematic manner
- the accepted **minimum uniform hospital discharge data set** (UHDDS) and various data sets for other healthcare levels do not match element for element the contents of NEDSS, which makes it difficult to tap into existing health information systems
- the need to **examine the HIPAA electronic data transaction standards** against the NEDSS dataset
- large-scale acceptance of NEDSS relies on a **wide variety of commercial interface capabilities** to connect to the many existing proprietary healthcare databases
- the lack of a uniform national patient identifier

Of greater concern is the development of this system outside the context of the provider sector of healthcare delivery. There is no doubt that an accepted public health data model for electronic transmission across local, state, and national public health networks is imperative and would greatly improve the analytical power of public health services and the CDC to measure and project disease and wellness among US populations. But unless federal legislation requires universal compliance to the NEDSS dataset, the usefulness of this system for routine bio-incident surveillance remains in question, and the US is still at risk.

Uniformity in symptom description as well as confirmed diagnoses, and the context in which such evidence of potential disease states has occurred, add another dimension to specific bio-incident reporting. The most efficient method of communication would be the Internet, but privacy, confidentiality, and encryption of transmitted files need to be considered. Compatibility with healthcare information systems initially, and post-implementation will involve issues of system upgrades and periodic maintenance issues. Healthcare organizations' senior management will need to allocate resources to the process, address economic concerns, and provide for large-scale staff training.

States Push Forward

Within many states, demonstration projects are in process. The **Florida** public health system has been using the Merlin system, which is fed by lab results, patient profiles, and some claims data. The system facilitates data sharing among county health departments and Florida hopes to add a new "outbreak" module. The system has two shortcomings: it relies on coded data and confirmed diagnoses and it is a legacy system, which is easy to use but generally inefficient for bio-incident surveillance purposes.

Wisconsin is experimenting with Web-based communications and a bioterrorism supplement to its Health Alert Network (HAN). The demonstration model includes a component for distance education and training to reach local communities on both routine and emergency public health issues.

The **Utah** public health services were tested during preparations for the 2002 Olympics. The public health department relied on several national resources including the National Pharmaceutical Stockpile Plan and the National Smallpox Readiness Plan. Additionally, the public health department worked with emergency departments to clarify syndromic definitions for routine data collection such as respiratory infections, GI bleeding, febrile with rash, sepsis, botulism-like symptoms, and more during the Paralympic games. This required the public health staff to go on site to manually review emergency room logs, pull charts, and search for identifiable chief complaints matching the syndromic definitions. This was a time-consuming manual process for which the hospital staff training, automated alerts, and a systematic information transmission process could have expedited more efficient data collection.

Turn Attention to Local Levels

As a nation, there is no lack of experimental projects and varied initiatives in support of an improved public health system. Renewed funding for 2003 will continue to be directed to demonstration projects. For example, Harvard was awarded a $1.2 million dollar grant to design a national reporting system across all 50 states. However, action is needed at the local level through awareness in our own healthcare facilities, overall coordination, active cooperation between providers and community health departments, and financial resources to support connectivity at the local hospital level. Sporadic funding has attempted to strengthen the effectiveness of community health departments, but many of these suffer from inadequate staffing and lack Internet access, computers, and in some cases, fax machines. There are variations among states in what is considered

"conditions under surveillance," multiple, disparate sources of data, and inefficient communications from local to state public health levels.

Tracking diseases is becoming a surveillance activity rather than a reporting activity and requires the shift to concurrent methods of information transfer. Yet several questions remain unanswered: will all of these new systems communicate with each other? Should we have a universal patient identifier to effectively recognize and link incidents? How can local health departments access and conduct the surveillance processes that bio-incident reporting requires? As HIM professionals, awareness is the first step in recognition of the data needs external to our healthcare organizations and critical to the health and welfare of our nation.

In addition, as efforts to shore up technologies to assist epidemiological surveillance and analysis increase, information technology experts are finding new positions in local and state public health agencies. HIM professionals are needed within the ranks of those who are directly involved in demonstration projects, system design, and general public health statistical analysis and data mining. There has never been a more urgent need and better time for HIM professionals to step forward, educate themselves, and become involved.

The Joint Commission on Accreditation of Healthcare Organizations already requires facilities to plan and rehearse for medical emergencies. In addition, a routine, real-time process to submit clinical data is needed for vital surveillance information. This, in turn, can prevent an act of bioterrorism and save lives.

An effective disease surveillance program relies on the following developments:

- an **early warning system** with links from providers to local, state, and national public health entities
- an additional **link between our healthcare network and US intelligence agencies** is fundamental to national surveillance
- **training at all levels** within our healthcare network in early detection, alerts, and treatment response
- unambiguous **definitions of specific trigger conditions** beyond those traditionally considered "notifiable, confirmed diseases"
- **policies to guide public health authorities** when outbreaks do occur, in the fundamental issues of privacy, confidentiality, and security coupled with the public need to know

HIM professionals have a real responsibility to demonstrate and share our expertise in building an improved US public health system. It's time to get involved, identify the demonstration projects in your community and state, volunteer your advice and expertise, educate those around you, and assist physicians and emergency room personnel in understanding the developments within your state. HIM professionals know the best sources of crucial intake information within the organization and can help to improve the process that ultimately may save lives.

References

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Movement on the Nonprofit Front

Several nonprofit healthcare organizations are mobilizing to strengthen the public health surveillance system. Two major forces are:

- The Public-Private Sector Collaboration for Public Health: The eHealth Initiative and its Foundation have launched a collaborative effort with the CDC, state and local health departments, NACCHO, NAHDO (National Association for Health Data Organizations), the Centers for Medicare & Medicaid Services and many others to improve the public health infrastructure.
- RAND: This institution provides research, panels, private grant funding, research, and policy creation. Through a series of conferences, research papers, visibility, and spokespersons, RAND has supported efforts by states and local groups to develop approaches to improve information surveillance and overall public health preparedness activities. A recent example includes collaborative efforts with the University of Pittsburgh's Realtime Outbreak Detection System, Carnegie-Mellon, Pennsylvania's Department of Health, and others to create the BioMedical Security Institute (BMSI) to develop a research base on issues of preparedness, surveillance, and response methodologies. For more information about BMSI, go to www.rand.org/nsrd/terrpanel/WatsonAug01.pdf.

How Has Public Health Changed Since September 11, 2001?

After the September 11, 2001, terrorist attacks, the American Public Health Association (APHA) released "Guiding Principles for a Public Health Response to Terrorism," a set of 12 guidelines for terrorism preparedness. To assess the progress the US has made in response to these guidelines, APHA issued a report card, "One Year After the Terrorist Attacks: Is Public Health Prepared?," which details US government and international actions in this arena. For more information, visit www.apha.org/united/reportcardfile.htm.

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