Disease Surveillance: The Need for Interactive Data Networks

EXECUTIVE SUMMARY In a brief two-year span, 911, anthrax and SARS have irrevocably changed many basic assumptions about American life. As a result, the need for a nationally integrated healthcare information network has become essential to any first response strategy. In the case of fast-moving epidemics or bioterrorist events, communication among hospitals, physicians, laboratories, police and other emergency personnel will require robust, interactive and secure data networks that enable identification and sharing of epidemiological information as quickly as possible.

Given healthcare's inability to automate even basic processes like sharing of medical records between physicians, it's no surprise that we're still a long way from building national or even regional data networks that link all providers and emergency response professionals. However, the ripple effect of 9/11 and ensuing threats like anthrax and SARS is fueling initiatives to build community health networks across the country. This is especially true in the case of automated disease-surveillance networks, the primary tool in detecting deadly pathogen outbreaks in the population.

The technology to link multiple players in the community in order to detect disease patterns—a process called syndromic surveillance—is available. The most difficult part of disease surveillance is coordinating those players and introducing the technology into existing work flow. In some cases ER physicians are taking the lead, perfectly positioned by their natural front-line roles.

In this report we interview two ER physicians who are pioneering efforts to automate disease surveillance on a regional and national basis, a firm providing software tools for disease surveillance to the Centers for Disease Control and a dean of a graduate school of public health who has redesigned the school's curriculum to address bioterrorism. The commonality among all: the need for an interactive communications network for early detection of disease outbreaks and the narrowness of the conventional public-health model that looks at such outbreaks retrospectively rather than in real time.

Improving Healthcare Performance Through Information Management and Process Improvement

A broader view of surveillance

"SARS was a fire drill for a system that needs to be put in place," says Ed Barthell, MD, executive VP and CIO of Infinity Healthcare, an ER staffing firm in Milwaukee. Barthell, a practicing ER physician, says that 9/11, the anthrax threat and SARS have all combined to demonstrate the need for an effective disease surveillance system in this country to provide early detection of threats.

"We need an ongoing assessment and management tool, even if it's to calm people that there is no disease breakout," he says. "Our vision of surveillance is broader than the old view of just reporting data. We need an interactive, real-time surveillance model," says Barthell, an activist for better disease surveillance among ER physicians.

The new interactive model allows for collecting data in real time and feeding the information back to providers so they can react as situations evolve. "That's the paradigm shift—it's not just passive reporting," he says.

The technical tools for such a system are available but just haven't been implemented. The challenge is getting consensus, overcoming political barriers and developing a mindset of cooperation and then implementing the tools in such a way that they become a seamless part of the workflow.

Ambulances to epidemics

Barthell has joined forces with Brian Keaton, MD, another ER physician who is on the board of the American College of Emergency Physicians, to create the Frontlines of Medicine project which lays out a vision of how emergency departments can contribute to national surveillance. (See www.frontlinesmed.org, which includes a link to a paper on the topic published by the Annals of Emergency Medicine.) The group's aim is to foster standards that can be used to enable EDs to report data real-time to public health agencies.

Infinity Healthcare is betting that disease surveillance's time has come, having developed a subsidiary, EMSystem (www.emsystem.com) that sets up Web-based disease-surveillance systems. Originally designed to manage ambulance diversions from overcrowded ERs to less busy ones, Infinity Healthcare found that EMSystem was a great way for ERs to report on the kinds of symptoms and complaints with which patients were coming in.

The EMSystem is now up and running in 28 cities and in two state-wide applications, covering about 18% of the country, according to Barthell.

This summer the company was involved in a surveillance project in Milwaukee during Major League Baseball's All Star Game in which ERs used the EMSystem to report patient counts every 24 hours to establish a baseline and monitor the event.

More recently, Chicago conducted its TOPOFF exercise to test emergency response to bioterrorism and disease outbreaks. "They were frantically trying to fax information. It was a good example of why we need a disease-surveillance network in place," says Barthell.

Arrivals and departures

Using EMSystem, each hospital can update its capacity and display its available resources on a secure shared site that can be viewed by other emergency providers, public health and other authorized users. This "situational awareness" is similar to flight-schedule monitors at airports. But the system also has e-messaging capability that allows interaction with other entities like the public health department.

ERs seem like perfect nodes in an early warning system: they're ubiquitous and open 24 hours a day, seven days a week and 365 days a year. Clinics on the other hand only track weekday activity. "So many people have trouble getting in to see their regular physician" that they go to the ER when they're alarmed by symptoms, Barthell says, adding that ERs aren't the only types of surveillance sources. Other indicators can be absentee rates at work and school or illness patterns at nursing homes.

While no surveillance system is perfect, the lack of one can effectively blind a community to biological threats. Milwaukee found that out in the early 1990s when its water supply became infected by a parasite. Hospitals, physicians and public health officials were oblivious to the problem until a couple of pharmacists noticed that all the Immodium was flying off their shelves. "That experience is now used as a model. It showed an absence of good surveillance," notes Barthell.

Industry response to disease-surveillance initiatives has been varied, according to Barthell. "Some physicians are too busy. Some are very interested. It's not always easy to do. There are all the classic difficulties with change management and the need to inspire a willingness to collaborate." In the end the change may happen as a result of the government requiring it. He estimates that at a cost of only $15 million a year the country could install a first-phase communication capability for disease surveillance. "All you need is a PC connected to the Internet with MS Internet Explorer." A more comprehensive system that tracks every encounter entering emergency departments, similar to the Frontlines of Medicine vision, would cost "a lot more," says Barthell.

Too busy to check

"The best disease surveillance systems are ones built into the existing work flow," says Keaton, who, besides serving on ACEP's board, is an ER physician at Summa Health System in Akron, Ohio, and director of the Summa Center for Emergency Medical Informatics. A lesson learned from the SARS outbreak, he says, is that even simple tasks like checking "yes" or "no" to a patient's temperature above 100.4°, respiratory complaints and having traveled recently—all factors pointing to SARS—proved to be too burdensome to harried nurses and physicians in a busy ER. Such a system routinely failed to capture the sickest, highest-risk patients, those who arrived by ambulance and bypassed ambulatory triage procedures.

The ideal solution will be to incorporate surveillance tools into electronic medical records (EMRs). With increasing penetration of EMRs into care, automated disease surveillance will become more easily integrated into the work flow—without adding tasks. "Once you have a functional EMR,

you can repurpose the data collected in the process of care, with appropriate confidentiality provisions, into surveillance data. That's where the future is," says Keaton.

Brian Keaton, MD, Emergency Medical Informatics Director, Summa Health System, Akron, Ohio

"I don't think any surveillance system will catch the first case. Early detection will always be the job of the astute clinician. However, syndromic surveillance will both prompt public health officials and clinicians to look for the cause of unexpected syndromic trends and, hopefully, lead to earlier discovery and management of a public health problem. The surveillance tools will also provide a means of tracking and alerting health officials to possible outbreaks and disease spread," he says. For example, such a tool would have identified a spike in ER visits for diarrhea, the use of anti-diarrhea medications and increased school absences which occurred in Milwaukee when its water supply was compromised. "It helps you connect the dots," says Keaton.

Ideally, such a system also has two-way communication so that when the public health department receives real-time data, staff can message back to the ER to conduct, for example, specific tests on the next 30 people who come in with high fevers. "There are a lot of things from a messaging standpoint that can be done. We're at the drive-thru banking stage and we want to get to the ATM or online commerce stage," Keaton says, adding that he fully expects to get there—someday.

"When I started 20 years ago we'd wait two to three hours to get a chart from medical records for a patient discharged the day before. Now my partners get upset if they have to wait nanoseconds."

Louisville slugger

That a new era of disease surveillance has dawned is clear at places like the University of Louisville, whose School of Public Health and Information Sciences has reorganized to address new issues like bioterrorism.

"Traditional disease surveillance meant public health departments covered 50 to 75 communicable diseases in a reactive manner," says Peter Walton, MD, acting associate dean at the school and associate director of the university's Center for Deterrence of Biowarfare and Bioterrorism. "That approach doesn't help with the new threats like SARS and the West Nile Virus because they're new pathogens. We're looking at new ways of early detection," he says.

Peter L. Walton, MD, Associate Dean for Health Information Sciences, University of Louisville, Louisville, KY

Louisville's school of public health is involved with several surveillance initiatives. The first grew out of an alliance between the university, private industry and the county-wide metropolitan health department to develop an immunization-management system that incorporates guidelines from the CDC. The aim was to eliminate the need for busy practitioners to remember protocols.

That initiative expanded to include case management and tackled inventory management of vaccines and finally morphed into an electronic public-health management system covering disease surveillance, case management, immunization management and other tasks like epidemiological investigation using a geographical information system.

Warehouse of data

Because reporting requirements under such a system can be burdensome for the infection-control nurse, who must notify the public health department on disease patterns, Web-based reporting was installed to make it easier.

A second initiative involved building of a Health Research Data system, which is used to collect "any and all" electronic clinical data from hospitals and clinic systems and prepare it for research purposes. This clinical data warehouse (not a repository, which is used for care) stores de-identified, retrospective patient data whose vocabulary has been standardized.

The system's advantages include the fact that it gives academic institutions access to clinical data for research without having to secure IRB approval.

A third initiative, made possible by a CDC grant, combines the first two to enable analysis of the data as it arrives in real time. For example, officials will be able to track blood tests to see if hepatitis A, B and C symptoms are reoccurring. Walton likens such "pre-diagnosis" tracking to the leading economic indicators. The occurrence of chest x-rays might also tip officials off to an outbreak.

Studying traffic jams

Finally, another CDC-funded initiative—more bleeding edge—focuses on "a-causal" or indirect signals for early detection of bioterrorism and epidemics. The theory is that causal indicators like over-the-counter medication purchases or school absences may lag other seemingly unrelated indicators such as the number of cars backed up at a stoplight at a certain time of day or a spike in the number of telephone calls.

Such "social network analysis," as it's called, has been used for years in military and crime intelligence to determine the presence of armies or mobsters in an area, but is just beginning to be applied to disease surveillance.

"The earlier you can get on the first leg, the better," says Walton, who cites SARS as a good example of an outbreak that could have been completely contained had such early indicators been followed up on.

emergint Given the increasing availability of electronic clinical data and the promulgation of safeguards like HIPAA to protect patient privacy and confidentiality, companies like Louisville, Ky.-based Emergint Technologies Inc. are establishing themselves as information brokers for academic medical centers, federal agencies and pharmaceutical firms.

"Everybody's interested in data," says Gil Delgado, president and CEO of Emergint, which provides software and services for processing and 'optimizing' data for surveillance purposes. "They want to mine it for potential epidemics, adverse drug reactions and bioterrorism. They all have a common need: better surveillance is what ties them all together."

moving from data-driven to knowledge and workflow-driven systems including an overview of their recent publication on this topic.

October 29, "Nursing Time and Attendance: Automation ROI." Carol Ann Cavouras and ChrysMarie Suby, Labor Management Institute, share their research data and client case studies that demonstrate how information technology in Nursing Operations management can measurably reduce overtime and traveler expenses. Time and Attendance systems can provide direct benefit in returning nurses to the bedside and in reducing potential fraud and abuse. While respecting nurses, managers can still measure productivity and outcomes using proven systems and with a clear ROI.

October 30, "A Case Study in Supply Chain Efficiency." Dan Eckert, President and COO of Neoforma (www.neoforma.com), and John Russell, Director of Materials Management at Phoebe Putney Memorial Hospital (www.phoebe putney.com), Albany GA, present and discuss the critical role that Supply Chain Management plays in cost containment, including why healthcare requires technology solutions specifically for providers. John will also discuss the evolving role of materials managers, moving beyond pricing to one of a financial officer role requiring strategic analysis. He

will also provide insight on how Phoebe Putney was able to reduce costs and paper-based processes across many departments, and conserve one of their most valuable commodities—time.

November 3, "Scottsdale Institute/Leapfrog Group Survey Results Review." David Classen, MD, VP, First Consulting Group (www.fcg.com), reviews results from an SI member survey designed to uncover barriers and success factors in implementing the Leapfrog Group recommended Patient Safety practices of CPOE and Intensivist Staffing. Dr. Classen shares his own views about what he sees in the marketplace and facilitates an open discussion.

November 5, "SNOMED: How and Why to Adopt." Debra Konicek, RN, BSN, BC, Terminology Manager, SNOMED® International, a division of the College of American Pathologists, provides an update on the recent HHS licensure of SNOMED®, and the resulting availability to all health systems and vendors. Learn how to integrate this important tool into your systems planning and quality improvement efforts, as well as what you can expect from your vendors in the next year.

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Leveling towers of Babel

Optimizing data means first understanding the myriad specialized vocabularies and coding systems—SNOMED, LOINC, MEDRA, MESH and others—used in every care environment, whether it's laboratories, radiology departments, or medicine and nursing units. Emergint looks across each of these settings and uses a proprietary method for normalizing those disparate vocabularies to build a "semantic network" with consistent meaning.

Once the data is optimized, it can be customized for clients. Emergint can partner with providers and help them repurpose de-identified data that's a byproduct of their clinical processes. That information can also be provided to federal agencies or drug firms. "We call ourselves data brokers but we add a lot of value to the data," says Delgado.

For example, it's possible to scrutinize data for heart attacks, angioplasties or any number of events or syndromes and correlate it according to patient age, gender and medical history. For disease surveillance, the information can be as detailed as blood-cell counts.

The approach seems to be working. The CDC announced this month that it would license Emergint's technology for its BioSense bioterrorism preparedness initiative. The system will take data from lots of different sources across the country—clinical sites, insurance companies, and over-the-counter pharmacies, to name a few—and run it through Emergint's software for early detection of bioterrorist threats.

Delgado acknowledges that as a nation we're still only making first steps and that a national electronic healthcare infrastructure is a necessary part of the disease-surveillance vision. Like Barthell, he says we're years away from such a network, but the country's new focus on preparedness and early detection as opposed to response is the first critical ingredient for success.

Conclusion

Disease surveillance is an information-management issue if it is anything. "Especially with bioterroism, the best defense is early detection and quarantine/containment—and then vaccination," says Louisville's Walton. "The answer is not massive, preemptive immunizations, which can risk lots of deaths, disability and expense for an unknown scope of occurrences. Surveillance has to be on the micro-level," he says.

The technology for the interactive data networks required for such surveillance is available today. The real challenge is to generate the will to collaborate among providers, public health departments and state and local governments to implement automated disease surveillance in an era when the economy is bad, state budgets are in shambles and Washington is preoccupied with a war. But with the threat of bioterrorism and new pathogens escalating, investment in such an important public health surveillance tool could provide enormous national security and public health benefits. In this case an ounce of prevention is truly worth a pound of cure.

SURVEILLANCE RESOURCES

(Courtesy of Edward Barthell, MD, and Brian Keaton, MD)

1. Centers for Disease Control and Prevention, www.cdc.gov

2. US Dept of Homeland Security, http://www.dhs.gov/dhspublic/

3. US Dept of Health and Human Services, http://www.hhs.gov/disasters/index.shtml

4. American Public Health Association (APHA), www.apha.org

5. National Association of City and County Health Officials (NACCHO), www.naccho.org

6. Project ER One, www.ER1.org

7. EMSystem, www.emsystem.com

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21. Annotated Bibliography on Syndromic Surveillance Now available on the CDC/Epidemiology Program Office/Division of Public Health Surveillance and Informatics Internet Website: http://www.cdc.gov/epo/dphsi/syndromic/index.htm

22. Also available through the CDC Public Health Emergency Preparedness and Response Website: http://www.bt.cdc.gov/episurv/index.asp

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