



TRACKING SILENT KILLERS —

Are State and Local Governments
Effectively Implementing Disease
Surveillance Systems?



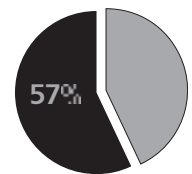
A Center for Digital Government survey finds states still have significant work to do.

Alongside traditional threats to public health, new threats have materialized with alarming frequency over the past year. From SARS to new strains of avian influenza to monkey pox, media coverage of disease outbreaks has raised public awareness about how easily and quickly a pathogen, whether naturally occurring or deliberately introduced, can surface and proliferate.

As public fears climb, state and local health departments undergo increasing scrutiny. Should an outbreak occur, how well could a state or local health department respond?

The Center for Digital Government recently examined that issue from a technology perspective. Recognizing that technology, when used appropriately and effectively, can substantially improve an agencies' ability to conduct fast and accurate disease surveillance and intervention, the Center for Digital Government surveyed 46 states and two large localities (Chicago and New York City) to determine to what degree they are effectively utilizing technology in public health preparedness efforts.

The study found that 57 percent of the jurisdictions surveyed either had a disease tracking and surveillance system in place or had begun implementing one. "That number is encouraging, but we hoped to see it higher," said Mark Struckman, vice president of research at the Center for Digital Government. "States that utilize technology will be better equipped to react and respond to an outbreak, whether it's a disease or a bioterrorism event."



Percentage of jurisdictions that had a system in place or had begun implementation.

A common problem with disease reporting and surveillance is the delay experienced from incident awareness, through laboratory testing and ultimately to public health investigation. "Effective outbreak and epidemic prevention or containment is about collapsing that cycle time," Struckman said. "And technology can do that."

COLLABORATION IS KEY

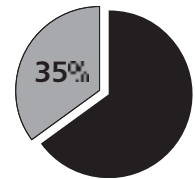
The Center for Digital Government's assessment of the importance of technology in disease tracking and surveillance concurs with a May 2003 report by the U.S. General Accounting Office. The report, "Information Technology Strategy Could Strengthen Federal Agencies' Abilities to Respond to Public Health



Emergencies,” goes on to say that technology can be more effective when state and local systems work together. “IT can more effectively facilitate emergency response if standards are developed and implemented that allow systems to be interoperable,” the report said.

In an effort to spur the development of a universal and interoperable system, the Centers for Disease Control and Prevention (CDC) began working on the National Electronic Disease Surveillance System (NEDSS) in 1999. NEDSS is a public health information architecture which stipulates data, communication and security standards needed to ensure the interoperability of related systems. The CDC offered grants to jurisdictions to cover implementing the NEDSS standards, and now requires all systems to comply with the standards. Aside from establishing the NEDSS standards, the CDC embarked on the development of a computerized system based on the NEDSS standards. The CDC-developed disease reporting and surveillance software system is known as the NEDSS Base System (NBS).

According to the Center for Digital Government survey, only 48 percent of the jurisdictions currently implementing a disease tracking and surveillance system are implementing the CDC’s NBS. The remaining states are implementing proprietary systems or pursuing other standalone system architectures that employ the NEDSS standards. Only 35 percent of those jurisdictions expect their systems to be able to collaborate with other states/jurisdictions.



Percentage of jurisdictions that expect their systems to collaborate with other jurisdictions.

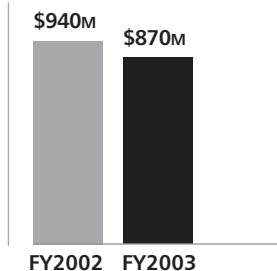
This lack of uniformity and collaboration creates roadblocks in states’ efforts to become more effective public health watchdogs. First, as echoed in the GAO report, a lack of interoperability can diminish the benefits of such systems, especially when cross-border issues are involved. According to the GAO, “Without a strategy to address the development and implementation of standards, agencies may not be well-positioned to take advantage of IT that could facilitate better preparation for and response to public health emergencies — including bioterrorism.”

Because diseases know no borders, the greater the number of diverse systems serving disease reporting and surveillance needs across the states, the more complex the national infrastructure for electronically sharing data between states. While there is currently no plan in place for a comprehensive, integrated, nationwide disease tracking and surveillance system, the better individual systems work together, the more capable public health organizations can become in handling widespread outbreaks, should they occur.



Secondly, the additional funding Congress appropriated to the CDC over the last two years may begin to dry up if states don't make significant in-roads into improved disease tracking and surveillance. Following September 11, Congress increased funding to the CDC in an effort to support state and local public health preparedness. The CDC was awarded \$940 million in FY 2002 and \$870 million in FY 2003. Yet a recent study by the Trust for America's Health found that, "despite the needed surge in federal funds, states are only modestly more prepared to respond to health emergencies than they were prior to 9/11."

Health departments have historically been grossly under-funded relative to their missions. The bioterrorism funding generated after 2001 changed that equation, but it didn't secure it permanently. Therefore, state and local government health departments must ask themselves if, as a collective universe, they are making the most effective use of bioterrorism funding to make next-generation disease reporting and surveillance a reality within the U.S.



"As a whole, state and large municipal health departments benefit financially when a limited number of best practice alternatives exist. States that transfer or acquire a best practice solution benefit from significant development cost avoidance," said Struckman. "Public health departments would be best served by looking to the few examples of well-developed and fully implemented solutions and leveraging that effort. States need to look at the resources and systems available from both the CDC and their peer states that could help get them there more quickly."

EMBRACING CHANGE

A disease tracking and surveillance system compliant with the NEDSS standards is a true enterprise-scale application. To effectively address this critical aspect of public health service, health departments and provider communities need to embrace the need for business process change. Properly preparing states and large municipalities for business process change requires a commitment to change as well as effective change leadership, training and outreach programs.

Furthermore, in order to respond to the dynamic realities of diseases and associated investigations, disease tracking and surveillance systems must be flexible and responsive to emerging diseases as well as evolving disease-based investigation questions. The ability to rapidly adapt to a surveillance system to meet the unique elements of an outbreak may mean the difference between a minor outbreak and a major one. Eighty-five percent of the respondents to the Center for Digital Government survey indicated a system's adaptability to accommodate emerging diseases and bio-agents



was important. Building computer systems that are highly responsive and adaptable to emerging diseases as well as evolving disease-based questions requires new approaches to collecting and entering data. To achieve this flexibility, changes in business processes are required and must be effectively communicated to and embraced by public health staff and point-of-care users, and information systems must be designed to support the dynamic nature of the public health environment.

According to the Center for Digital Government study, only 23 percent of jurisdictions surveyed planned to partner with external services providers to implement a disease tracking and surveillance system. Seventeen percent said they would use internal resources only. Yet, due to limited funding, many state health departments have only moderate in-house IT staff. In many cases, that staff has little experience with enterprise-class, Web-based systems development and implementation. Considering the complexity involved in such systems, acquiring the operational support, implementation expertise and maintenance abilities of a reputable management and technology consulting firm may prove to be critical.

Additionally, should a jurisdiction choose to pursue the CDC NBS, they may desire capabilities beyond what it offers. A management and technology consulting firm can customize the NBS to an extent that it more closely matches a jurisdiction's wants and needs.

Beyond the design and development of the information system are the business process redesign and change management components which have at least equal impact on the success of the implementation. External consultants also bring valuable expertise in these areas.

Information security is another critical component of any disease tracking and surveillance system. Disease tracking and surveillance systems are intended to be patient-centric systems and have the objective of capturing a patient's disease (case) history over time. Information stored in such a system requires careful attention to patient privacy and demands sophisticated computer security capabilities.

SETTING AN EXAMPLE

The Pennsylvania Department of Health (DOH) has set an excellent example of success in implementing a disease tracking and surveillance system. The DOH has taken advantage of the NEDSS standards, effectively leveraged federal bioterrorism funds and partnered with a management and technology consulting firm to implement a NEDSS system to meet their unique needs (see sidebar). The system the DOH built, Pennsylvania's National Electronic Disease Surveillance System (PA-NEDSS), electronically routes reportable disease data from health care providers directly to public health investigators throughout the state, who then quickly launch investigations into how a disease may have been contracted, what prevention methodology should be followed, who infected individuals came into contact with



and other critical information. PA-NEDSS allows ongoing, systematic collection of patient case data on all infectious diseases, vaccine-preventable diseases, sexually transmitted diseases (excluding HIV/AIDS), tuberculosis and lead poisoning.

In acknowledging the need for flexibility, PA-NEDSS also supports reporting and investigation processes for new disease types “on the fly.” The DOH can add to their investigator questionnaires in near real-time to gather additional information as an outbreak investigation proceeds. SARS reporting was online within hours after the state made the decision to add it to the reportable diseases list.

To implement PA-NEDSS effectively, the DOH partnered with Deloitte. Deloitte helped the DOH establish new reporting and investigations processes to monitor diseases and enhance the DOH’s ability to contain them. Deloitte also assisted the DOH staff during the business process reengineering effort, helping facilitate the requirements gathering as well as perform system design, development and implementation activities. Finally, the joint DOH/Deloitte team collaborated with the statewide healthcare community and public health investigators throughout the project to effectively plan for and manage the required process changes. PA-NEDSS is now used in all 67 counties of the Commonwealth.

PA-NEDSS includes many of the attributes state and local jurisdictions indicated were important in disease surveillance systems, as indicated by responses to the Center for Digital Government survey. In addition to adapting to emerging threats, PA-NEDSS includes point-of-care provider reporting capability (72 percent of respondents indicated this was important); integrated and cross-disease reporting and surveillance (81 percent of respondents indicated this was important) and electronic lab reporting (91 percent of respondents indicated this was important).

With PA-NEDSS, Pennsylvania has made significant progress in implementing the NEDSS standards. They have created a fully functional and fully integrated environment that’s NEDSS standard-compliant and integrated between local environments, state governments and the federal government.

In recognizing the value of their carefully designed system, the DOH, like the CDC, is offering PA-NEDSS free to other states interested in emulating their success. The DOH hopes that, by implementing a similar system, more states will be able to respond to outbreaks effectively, with more consistent data standards and improved collaboration on cross-border outbreaks.



SEEING THE BIG PICTURE

Despite the fact that states have emerging tools like the NBS and fully functional systems like PA-NEDSS available to them free, Struckman warns that state and local jurisdictions still need to consider and prepare for the implementation costs associated with such systems. “These are not easy applications to deploy,” he said. “States need to understand these solutions are bigger and require more operational support than states may be used to. There are broad categories of costs associated with acquisitions, implementation and maintenance.”

Yet it’s difficult to deny the benefits disease reporting and surveillance systems can bring when implemented correctly. According to the GAO report, “the use of emerging information technologies to support the public health infrastructure could help to improve agencies’ abilities to prepare for and respond to public health emergencies.” PA-NEDSS has already proven itself through the quick, effective identification of a recent Hepatitis A outbreak, which allowed the DOH to respond much more quickly than in the past. Thanks to PA-NEDSS, the DOH was not only able to track those people who came into contact with Hepatitis A at the restaurant, they were also able to track the people they in turn came into contact with, while mobilizing prevention and protection efforts overnight.

Yet, as indicated by the Center for Digital Government survey, most state and local public health departments still have a long way to go in implementing comprehensive, integrated systems that can give them big-picture views of what’s happening in their jurisdiction while helping them determine how best to respond.

“The use of technology will equate to increased public health reporting, better data accuracy and improved disease surveillance,” said Struckman. “But states need to have a sophisticated system in place that can add value to data and get it to the right people at the right time so it can have a greater impact on improving Public Health — ultimately saving lives.”

PA-NEDSS

a case study
by the Center for Digital Government

*PA-NEDSS (Pennsylvania-National Electronic Disease Surveillance System)
is improving Pennsylvania's ability to detect and respond to disease
outbreaks by demonstrating what's possible when public health officials exchange
information electronically.*

>> PA-NEDSS Case Study

> Saving Time and Saving Lives

PA-NEDSS is improving Pennsylvania's ability to detect and respond to disease outbreaks by demonstrating what's possible when public health officials exchange information electronically.

In early November 2003, an emergency department physician in a Pennsylvania hospital diagnosed multiple cases of Hepatitis A over a five-day period. Realizing that many cases over such a short time span was unusual, the physician notified the Pennsylvania Department of Health (DOH), which began an epidemiologic investigation.

Simultaneously, Joel Hersh noticed a disturbing trend develop before his eyes. As the director of Pennsylvania's Bureau of Epidemiology, it's up to Hersh and his staff to monitor incidences of diseases that, by law, must be reported to public health officials by doctors, hospitals and labs that encounter them. That same day, health department staff saw a sudden spike in electronic laboratory reports of the Hepatitis A virus. This highly infectious pathogen was turning up in many more emergency room patients in southwestern Pennsylvania, and Hersh knew that, unless something was done, the disease could spread rapidly.

Because he was tapped into Pennsylvania's National Electronic Disease Surveillance System (PA-NEDSS) and its instantaneous electronic reporting capabilities, Hersh was not only almost immediately aware of the outbreak; he and his team were able to respond much more quickly than in the past. Within hours, Pennsylvania public health officials had interviewed the initial patients and, as a result, tracked the disease back to a restaurant based in Monaca, PA. They were then able to notify restaurant inspectors and the owners of the establishment. Ultimately, the owners voluntarily closed the establishment.

"Had it not been for PA-NEDSS,
we couldn't have responded that quickly."

- Joel Hersh, director, Pennsylvania Bureau of Epidemiology

By the next day, the DOH had mobilized resources all over the state and set up an inoculation clinic for those who may have been exposed to the virus at the restaurant or through contact with individuals who had already become ill. Over 10,000 people were screened and over 9,000 inoculated during the following two days. "That allowed us to put a dent in the spread of the virus, as well as to prevent a number of people from becoming ill," said Michelle Davis, deputy secretary for Health Planning and Assessment at the DOH.

Ultimately, the Hepatitis A outbreak killed three people and infected more than 600. The disease was eventually traced back to contaminated green onions grown in Mexico, and has since sparked investigations into food handling practices in that country.

But Hersh believes the outbreak could potentially have been much more serious.

"Had it not been for PA-NEDSS, we couldn't have responded that quickly," he said. "PA-NEDSS has changed how we do business and how we're able to react to and manage outbreaks."

>> PA-NEDSS Case Study

> Seeing the Big Picture

PA-NEDSS is the first fully integrated disease surveillance system in the nation. It allows ongoing, systematic collection of patient case data on all infectious diseases, vaccine-preventable diseases, sexually transmitted diseases (excluding HIV/AIDS), tuberculosis and lead poisoning cases in real-time, providing a broad picture of possible outbreaks and facilitating responses. Whether it's a food-borne pathogen, a virus like influenza or a bioterrorism attack, PA-NEDSS is shedding light on what's possible when public health officials exchange information electronically.

Before PA-NEDSS, almost all disease reporting in Pennsylvania was done on paper. Health care providers mailed or faxed reports to local health departments. That information would then be forwarded to the state. It was a slow, labor-intensive process.

"The problem was the length of time it took to get something in the mail and get it to the right place for the right investigator to review it and act on it," said Hersh. "We'd get a report a week after the lab generated it. The report would then have to be sorted and sent out to one of our investigators in the state, so it would have to be faxed or re-mailed. It could be a couple of weeks before investigators could start checking out a situation."

"Ultimately it was a question of how we could reduce reporting time and, more importantly, reduce the time it takes to act on those reports, preventing diseases from spreading and potentially saving lives."

- Joel Hersh, *director, Pennsylvania Bureau of Epidemiology*

Often, that meant Pennsylvania health officials missed a critical window of opportunity to intervene. While investigators were waiting for reports to arrive via mail, deadly diseases had the opportunity to spread rapidly.

To improve the process, Hersh wanted to eliminate paper at the point of diagnosis. Led by Hersh, DOH officials decided to integrate several standalone, disparate data silos into one electronic disease surveillance and reporting system.

"Ultimately it was a question of how we could reduce reporting time and, more importantly, reduce the time it takes to act on those reports, preventing diseases from spreading and potentially saving lives," said Hersh.

Hersh also wanted to make the reporting process easier. Pennsylvania's complicated reporting structure often made it difficult for providers to determine where particular reports should go, further delaying the investigation process.

>> PA-NEDSS Case Study

“We received an incredible amount of push-back from provider organizations for years when it came to reportable diseases,” he said. “They basically said ‘if you’re complaining about under-reporting you’re right, because we can’t figure out to whom to report what.’”

Fortunately, the Centers for Disease Control and Prevention (CDC) had recently introduced the National Electronic Disease Surveillance System (NEDSS) — a blueprint for better integrating, modernizing and enhancing public health surveillance. Further, the CDC had embarked on the development of a computerized system based on the NEDSS standards. The CDC-developed disease reporting and surveillance software system is known as the NEDSS Base System.

The CDC was offering grants to states interested in using the CDC NEDSS standards as a base to build their own statewide systems. In 2001, Hersh and his team applied for and received a \$300,000 CDC grant to conduct a needs assessment and begin developing PA-NEDSS modules compliant with the CDC NEDSS standards.

While Hersh was pleased to have the funding, he was also interested in going beyond the CDC NEDSS Base System plans. “We didn’t see it as having a benefit to our providers — it was basi-

“It’s a dynamic application that is ultimately improving the accuracy of our data.”

- Mary Benner, CIO, Department of Health

cally a backroom system to improve the database and integrate the reports, but it still required providers to report to us on paper,” he said.

So the DOH applied for and received \$700,000 in e-commerce funds from then-Gov. Tom Ridge. The DOH would use those funds to build a secure Web-based entry system that would allow providers to report to the DOH electronically.

PA-NEDSS development was well under way when the country was stunned by the events of September 11. But those events, as well as the anthrax scare that followed, underscored the importance of systems like PA-NEDSS. As a result, the CDC increased financial support to states developing health and bioterrorism alert systems. Hersh and his team suddenly received a significant increase in funding, and by 2002 PA-NEDSS was up and running.

>> PA-NEDSS Case Study

> Single Stop Reporting

Today, PA-NEDSS is used in all 67 counties of the Commonwealth. Health care providers now make a single stop on the Internet to enter incidents of reportable diseases, providing the DOH data in near real-time.

Those reports are electronically routed to public health investigators throughout the state, who can quickly launch investigations into how the disease may have been contracted, what prevention methodology should be followed, who infected individuals came into contact with, etc.

“In short, it allows us much faster response to potentially dangerous situations,” said Mary Benner, CIO at the DOH.

The system is also much simpler than the previous process for reporting diseases.

“The CDC has over 100 different forms – one for each of the diseases,” said Benner. “When we started gathering those CDC data elements from the individual forms, we soon had over 6,000. The first task, then, was to boil those data elements down to a manageable number for busy health care providers.”

Limiting the amount of information health care providers have to report and providing drop-down menus instead of requiring information to be data entered textually has made PA-NEDSS easy to use. It’s also improved accuracy within the system. “It’s a dynamic application that is ultimately improving the accuracy of our data,” said Benner.

“They saw the value of what they were doing
and really put forth the effort.”

- **Mary Benner**, CIO, Department of Health

While there are minimal mandatory data entry fields for healthcare providers, the DOH has been pleasantly surprised by the voluntary entry of additional non-mandatory fields. More comprehensive disease incident reporting by healthcare providers helps avoid follow-up calls and saves public health investigators valuable time.

PA-NEDSS also features a case management tool that allows public health officials to track the cases investigators are working on and view the status of each investigation. “

>> PA-NEDSS Case Study

> Precautions and Stumbling Blocks

From the beginning, Hersh knew the idea of putting health information on the Web would make citizens uneasy, particularly public health disease reports, which can't be completely scrubbed of identifying data because of the need for follow-up. Therefore, security is a critical part of PA-NEDSS. The DOH staff provides a user ID and password to health care providers to access the system. Health care providers use the password to obtain a digital certificate through the PA-NEDSS website. The digital certificate must be installed on each computer from which a registered user accesses PA-NEDSS.

Like most large IT projects, PA-NEDSS has run up against its share of challenges.

Converting data from legacy systems was particularly difficult, according to David Andrews, PA-NEDSS project manager. "The amount of data that was collected by the old systems compared to what we collect in the new system is very different. Trying to map the data elements from the old applications to the new system was tricky," he said. "The landscape was always changing, so overall the project required flexibility and good project management processes."

Training was another critical component. Moving from a manual paper system to an online system was intimidating for many health care providers, according to Benner. "You can't just take a manual process and turn it into an automated system. You have to reengineer the business processes, and of course there is some resistance to that as well."

Benner said having a strong relationship with Deloitte, the consulting firm hired to develop and implement the system, was helpful. "They saw the value of what they were doing and really put forth the effort," she said.

The Deloitte team assisted DOH staff during the business process reengineering effort, helping facilitate the requirements gathering as well as perform system design, development and implementation activities. The joint DOH/Deloitte team collaborated with the statewide healthcare community and public health investigators throughout the project to effectively plan for and manage the required process changes.

Once the majority of the building and implementation hurdles were overcome, the challenge of getting health care providers to use the system remained. "That was difficult, particularly with physicians," said Andrews. "Physicians tend to see this as a burden more than anything else."

Andrews said the resistance primarily stems from the fact that private physicians are already over-burdened with paperwork and administrative tasks. Also, only certain types of physicians see patients with potentially reportable diseases. "Disease reporting by private physicians will always be a challenge for us," he said.

If a private physician does see a case, the information must be reported to the DOH. Therefore, to train physicians to use the system, the department is offering online training sessions and continuing medical education credit.

There are currently 285 hospitals and health clinics, 193 laboratories and 540 physicians registered with PA-NEDSS.

>> PA-NEDSS Case Study

> Sharing and Collaborating

Like the CDC, Pennsylvania is offering PA-NEDSS, a more comprehensive and advanced alternative to the CDC's NEDSS Base System, to other states at no cost. In the long run, said Davis, the more states that use the same system, the more effective they can all be in responding to threats. "If more states use PA-NEDSS we would have more consistent data standards and would be better able to collaborate on cross-boarder outbreaks," she said.

The restaurant involved in the Hepatitis A outbreak was located in southwestern Pennsylvania, near the border of Ohio and West Virginia. People who came across the border to eat were also affected by the virus.

"When SARS showed up in the U.S., specifically in Pennsylvania, we were ready. The SARS data elements were added to PA-NEDSS in a matter of hours."

- **Mary Benner**, CIO, Department of Health

"We had the information, and if we were able to share it electronically with Ohio and West Virginia, they would have been better able to manage the cases we identified," said Davis.

States that choose to use PA-NEDSS as a starting point for building their own statewide systems would also be able to more effectively leverage federal bioterrorism funds, according to Benner. "These types of systems need to be sustained, and if everyone is building something different then everyone needs to sustain a different system. But if dollars are put into one system, we as a whole would be better able to sustain it."

> Reaping Rewards

The struggles of implementing PA-NEDSS have not come without rewards. The DOH recently received an award for innovative use of technology from Government Computing News. PA-NEDSS was further recognized when the DOH was recently named one of 12 winners of the Grace Hopper Government Technology Leadership (Gracie) Award, from Government Executive magazine. Highlighting its significance to the nation's war on terrorism, PA-NEDSS was named the sole Gracie winner within the bioterrorism category.

But the true rewards lie in what the system has allowed the DOH to do: better control and manage outbreaks of disease, whether those diseases have existed for decades or have just made their debut.

“When SARS showed up in the U.S., specifically in Pennsylvania, we were ready. The SARS data elements were added to PA-NEDSS in a matter of hours,” said Benner.

PA-NEDSS was developed with a sophisticated user interface that enables the addition of new disease questions as well as the reporting of emergent diseases in a matter of hours. The dynamic user interface is highly responsive to the evolving characteristics of disease reporting and surveillance, saving valuable time and avoiding costly programming changes. “All we had to do was come up with the questions necessary to identify that disease and put them into the database. We were then able to immediately start tracking people affected by SARS and the people SARS patients had come into contact with,” added Benner.

In the end, whether it’s a Hepatitis A outbreak stemming from a food-related issue or a full-blown bioterrorism event, being able to collect and process information quickly, efficiently and effectively is critical to protecting public health.

“It’s hard to prove the negative — how many cases of disease we prevent — because we’ll never know that,” said Hersh. “What we do know is PA-NEDSS has allowed our investigators to get out in the field and investigate cases more quickly, and that speed is going to help us no matter what comes along.”

Pennsylvania has been able to rapidly and collaboratively develop a comprehensive surveillance and response system that brings clinical healthcare and public health closer together. And while the DOH had to overcome technical, organizational and funding challenges, the results have clearly been worth the effort.


The Center for Digital Government is a national research and advisory institute on information technology in state and local government. The Center specializes in custom research, reports, online resources and publications, surveying and advisory services.

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