



Illinois Department of

PUBLIC HEALTH

Improving public health, one community at a time

2009

Illinois – National Electronic Disease Surveillance System (I-NEDSS)

**Category:
Business Continuity and
Disaster Recovery**

**NASCIO
Recognition Award
Submission**

Executive Summary

Illinois National Electronic Disease Surveillance System (I-NEDSS) is part of a national electronic disease reporting system that not only links health care providers, state and local public health agencies within Illinois, but also provides data to the Centers for Disease Control and Prevention (CDC). The Illinois state public health director (IDPH), Dr. Damon T. Arnold quoted; "Through this state-of-the-art system, we are gathering and analyzing data quickly and accurately. I-NEDSS is improving our ability to identify and track infectious diseases and detect clinical patterns that might signal an emergency situation, whether it be naturally occurring or a terrorist attack." I-NEDSS is a key part of IDPH's response to bio-terrorism providing both rapid detection and intensive investigative capabilities.

IDPH developed the I-NEDSS application to improve the ability of public health agencies to identify, track and respond to emerging infectious disease outbreaks and bioterrorism threats. The first release of I-NEDSS in 2004 was a secure and real-time communication link available to state and local health departments. It included the reporting of ten foodborne diseases. Today I-NEDSS allows for the entry of 77 reportable diseases with the ability to add more as regulations and requirements dictate. The addition of the electronic reporting functionality allowed health care providers to enter data into the I-NEDSS system, which increased both the timeliness and quality of information provided and decreased the reporting burden in the provision of information. The implementation of iDetect (the framework that allows adding new questions on the fly in the I-NEDSS production system) and the program user-controlled administration functionality, has given I-NEDSS the ability to quickly respond to the ever changing needs of public health. Currently there are 114 IDPH and 657 Local Health Departments (LHD) registered users, three major reference laboratories transmitting electronic data and approximately 500 health care professionals entering electronic provider reports into the I-NEDSS system.

I-NEDSS provides tremendous efficiency over paper-based routing, because it facilitates electronic transfer of lab results from state and private laboratories, and case reports from health care providers (such as hospitals, clinics and private physicians) to the corresponding local health department for investigation. Through I-NEDSS, the volume of cases handled is running approximately twice what was handled compared to a paper based system. A centralized repository used by I-NEDSS ensures that LHDs and IDPH have immediate access to data whether entered manually or electronically. I-NEDSS has provided Illinois a way to successfully identify disease outbreaks earlier which leads to improved disease prevention, greater community awareness, and a faster response to outbreaks.

In conclusion, Public health professionals are continually seeking essential tools capable of addressing and meeting the ever changing needs of the public health community. I-NEDSS has become the core of Illinois public health, by providing functionality that ensures public health professionals have real-time access to health care and health related data. In the event of a disaster, be it man-made such as a bioterrorism event or natural like a disease outbreak or pandemic, the above mentioned functionality in I-NEDSS and the ability to react quickly and respond, is critical in implementing effective community based interventions, and thereby reducing mortality and morbidity.

Description of the Business Problem and Solution

The Illinois Department of Public Health (IDPH) is responsible for protecting the public health of Illinois' 12.4 million residents, as well as countless visitors, through the prevention and control of disease and injury. The Division of Infectious Disease (DID) within IDPH is responsible for the surveillance of communicable, vaccine preventable and sexually transmitted diseases, as well as tuberculosis and HIV/AIDS. Prior to the implementation of I-NEDSS, each section within DID responded to the needs of its public health community through the use of multiple CDC-provided distributed desktop systems, which were used by the Local Health Departments (LHDs) in Illinois to capture surveillance data. In 2000, the Centers for Disease Control and Prevention (CDC) released its National Electronic Disease Surveillance System (NEDSS), and required that all states implement this system or develop an in-house system that met CDC reporting requirements.

Problem statement: Prior to I-NEDSS, the various disparate systems in use did not meet the reporting requirements of Homeland Security and the Illinois Preparedness Initiative, in managing bioterrorism and pandemic events. In 2000, IDPH was relying on health care providers to report cases via paper copy, fax, and phone call to the appropriate LHD for investigation. These reports then had to be manually entered by LHD staff in multiple systems and forwarded to IDPH. Because IDPH only received information periodically, collection and quality assurance efforts during each reporting period required enormous effort on the part of DID staff. In addition, the information was not timely, and therefore early outbreak identification was unattainable at the state level. Additionally, the CDC's Class 1a and 1b diseases had stricter reporting requirements, such as notification within 3 to 24 hours of the disease report, which was unmanageable through the various desktop systems. These legacy systems were not available 24 hours a day/7 days a week, and backup and recovery could not be centrally managed. These systems did not allow for direct data entry by health care organizations such as hospitals and laboratories, thereby further reducing the timeliness of Bioterrorism disease and pandemic event reporting. In conclusion, these systems were not flexible and adaptable to the changing needs of the public health community in bioterrorism, disease and outbreak management.

Barriers and Challenges: The first major challenge in implementing a new system was to identify and meet all of the disparate business needs of the 95 local health departments as well as the IDPH Central Office. In addition, the system had to meet all the day-to-day disease surveillance and reporting requirements of each Program Area within DID, as well as the constantly changing reporting requirements of the CDC. IDPH also had to implement outreach programs for the Infection Control Practitioners (ICPs) at hospitals and clinics to encourage their participation in a new web-based reporting system. Also, in order to receive electronic reports from laboratories, each laboratory's unique coding system had to be converted into a common coding system, without violating the regulations of the Clinical Laboratory Improvements Amendment (CLIA). The Health Insurance Portability and Accountability Act (HIPAA) required IDPH to protect the confidentiality of patient health information. The new system also had to meet the newly established reporting

requirements of Department of Homeland Security (DHS) and Department of Health and Human Services (HHS) for management of bioterrorism and pandemic events.

Assessment and Decision Process: Following are 3 options assessed by IDPH:

- Purchase third party software: It was discovered that all available products were very limited in capability and none could provide the needed flexibility to react quickly to an outbreak or bioterrorism threat.
- Adopt the free CDC software (NEDSS): This option limited IDPH to track only diseases that CDC declared reportable. The problem here was that IDPH and the LHDs would be reliant on CDC to publish new versions of the software and any state modifications would have to be re-implemented with each publication.
- Develop in-house solution: This option would provide IDPH the most control in creating an application that would meet all of the specified requirements that DID identified, right from data collection through CDC reporting.

Approved Solution: IDPH chose to develop the in-house solution, the Illinois National Electronic Disease Surveillance System (I-NEDSS); a web-based application that establishes a secure and real-time communication link between hospitals, laboratories and health care providers with state and local health department staff for the purposes of reporting and managing infectious disease information. The core component of I-NEDSS is a LHD and IDPH surveillance system. Electronic reporting is a key to the success of I-NEDSS with provider reporting and Electronic Laboratory Reporting (ELR) functionalities. The system has role based security, 128 bit Secure Sockets Layer (SSL) encryption and supports an ad-hoc reporting system.

Project Management Approach: Using an iterative approach, the I-NEDSS project was divided into multiple phases scheduled for implementation over a period of years. The project phases were structured to meet the most immediate needs of the IDPH staff while implementing the infectious disease and bioterrorism reporting system. I-NEDSS change management process provides IDPH with the opportunity to submit change requests as well as review all requests for system impact and cost benefit effectiveness.

Architecture and Innovative technology: The custom built iDetect portion of the I-NEDSS is a page-builder system that allows IDPH to customize or build new modules to suit the CDC reporting requirements for each event, pandemic or outbreak within a short timeframe and without a deployment. I-NEDSS provides administrative functionality which allows IDPH administrative staff to implement on-the-fly changes in disease reporting without relying on IT staff to implement the changes as the situation dictates.

Transferability: The I-NEDSS system complies with all the infectious disease reporting requirements of the CDC. Therefore, it is completely transferrable to other states. IDPH has been approached for reuse of the system by the CDC and other states.

Communication: IDPH has been able to encourage and increase the use of I-NEDSS through presentation at various public health conferences and one-on-one discussions with hospitals, laboratories, and clinics.

Significance to the Improvement of the Operation of Government

IDPH had set four primary goals for the I-NEDSS system. The I-NEDSS system has significantly improved IDPH's ability to protect the public's health in Illinois and in the nation through coordination with the CDC in response to disease outbreaks. I-NEDSS provides information to CDC and the Office of Preparedness and Response (OPR) in their efforts to manage resources, identify hot spots, and organize state and national response to a bioterrorism or pandemic event.

Goal #1: "improve the timeliness and accuracy of information regarding threats to the public's health through early event detection and in real-time, to appropriate staff on a need to know basis". This goal was attained by the implementation of a centralized repository utilized by local health departments, health care providers, laboratories and IDPH staff. Since health care provider reports and laboratory reports are stored in the same repository as I-NEDSS surveillance data, the routing of provider and laboratory reports is instantaneous to the investigating LHD. In addition, IDPH is able to respond to the movement of patients throughout the state by instantaneously transferring identified cases to new jurisdictions. Because of the multiple entry points for data collection, IDPH is able to cast a wide net across the health system infrastructure, to obtain information early in the life cycle of a reportable threat. Furthermore, a centralized repository reduces errors inherent in manual data entry from paper, fax or phone calls.

Goal #2: "quickly responding to the ever changing needs of public health". I-NEDSS is completely customizable and configurable to any situation without requiring a deployment. I-NEDSS also contains many administrative functions to minimize the number of deployments required for disease changes, adding new laboratories to its ELR reporting system, making modifications in response to changes at an existing laboratory and changes to the health care provider reporting through the I-NEDSS system. Automated and as needed scheduling features are available for the Hepatitis C auto-close as well as CDC reporting, allowing IDPH to quickly respond to CDC reporting requirements.

Goal #3: "decrease the time to identify causes, risk factors, and appropriate interventions for those affected by threats to the public's health". I-NEDSS contains an Analysis, Visualization and Reporting (AVR) tool based on a data warehouse structure, which receives all I-NEDSS surveillance within 30 seconds. This tool, Business Objects, also contains an alert system which can be customized to any event monitoring, as well as ad-hoc reporting. The AVR allows IDPH staff to data-mine all surveillance data, discover risk factors not readily apparent, and establish cause and effect relationships. The data collected in I-NEDSS is used as a source of information communicated to the general public through various messaging systems at IDPH. In addition, this information has also been used to manage the National Strategic Stockpile of vaccine based on the threat characteristics.

Goal #4: "increase the use of disease surveillance and early event detection systems". I-NEDSS contains a feature to advise health care providers and LHDs when a disease requires more immediate reporting, such as the Class 1a and 1b disease reporting requirements. IDPH maintains and posts I-NEDSS procedure

manuals and quick-tip documents to the web for easy reference by health care providers.

Benefit of the Project

I-NEDSS has been a key component of Illinois' pandemic planning and preparedness initiative since 2006. The Novel Influenza and Pediatric Flu Death modules were added to I-NEDSS, specifically to address the management of pandemic flu events. Each of these modules can be customized to a specific outbreak or pandemic situation including any combination of diseases, risk factors, countermeasures or specific laboratory testing requirements. The ability to completely customize I-NEDSS to an event is extremely useful in identifying risk factors quickly, containing outbreaks and thereby reducing morbidity and mortality in the state. This ability has also been used by the State of Illinois in its preparedness initiative for handling biological events such as Anthrax. This is a key part of the mission of federal agencies such as DHS and HHS. Due to its customizability, I-NEDSS is able to handle all of the biological event requirements of DHS and HHS. The return on investment can be calculated by the state's ability to respond to man-made or natural disasters, bioterrorism attacks, and pandemic or disease outbreaks at any time without advanced warning.

In September 2008, the configurability of I-NEDSS was put to the test. In response to a Rabies vaccine shortage, the CDC asked states to track the number of doses approved weekly by public health. Five questions relating to vaccination information for Rabies were added to the Rabies module, and within 24 hours the LHDs were able to start collecting the information. The ability to immediately begin collecting this data allowed the CDC to effectively manage the vaccine shortage. This configurability will continue to benefit IDPH in managing future outbreaks and other events.

The constant and continual efforts to increase I-NEDSS' electronic data interchanges has decreased the burden on LHDs to manually input paper, faxed or phone call disease reports. Prior to I-NEDSS, IDPH manually entered an average of 12,000 cases per year in multiple systems. I-NEDSS rate of growth between 2004 and 2008 was 76.33% with 22,470 cases reported in 2008. Since I-NEDSS electronic data interchange began in 2005, the percentage of cases created from lab & provider reports has increased from 46.55% to 84.16%, a rate of growth of over 62%. I-NEDSS provider reporting is currently being used by 84% of Illinois hospitals that maintain more than 100 licensed beds. Electronic reporting also aligns with the Green IT, budget and cost control and security priorities of Illinois' state CIO by reducing the amount of paper and office materials needed as well as securing patient health information. An additional benefit of ELR is an improvement in the timeliness of disease reporting since LHDs will receive laboratory reports within the same timeframe as the patient's physician. And, since its implementation in March, 2007, specialized ELR import filters have removed from I-NEDSS laboratory reports that do not support case definition for reportable diseases, resulting in a 33% decrease in the LHDs workload. The ELR import process also provides automatic disease mapping of laboratory reports and automated routing to the investigating LHD. The de-duplication and merge process prevent duplicate patients and cases

from being created, allowing for more accurate disease reporting, along with a reduction in data entry and case closure activities for the LHDs and IDPH.

With the implementation of I-NEDSS, and by utilizing its centralized repository, accessible by IDPH and LHD staff, health care providers and the ELR import, IDPH feels it has recognized more than a 50% cost saving in resources and time. Between 2004 and 2008 there were a total of 120,306 cases reported in I-NEDSS; approximately 66% were received electronically; 22% were entered by health care providers, 44% were reported through ELR messages. 34% were manually entered by LHD or IDPH staff. There has been a good progress in timeliness: 'LHD received date' to 'Date opened' in I-NEDSS was reduced to zero days (mode) and two days (median). To accomplish these benefits, I-NEDSS was made available on a twenty-four hour by seven day basis, three hundred sixty-five days a year, which will continue to provide maximum availability to IDPH and LHD staff during any type of surveillance situation.

Based on a recent survey conducted by the IDPH Office of Health Protection, Division of Infectious Diseases, with I-NEDSS users, the majority of users reported that "there has been an overall improvement in data accuracy and completeness than when using other reporting methods in the past".

New functionality was implemented to automatically close Hepatitis C cases that do not violate any business rule, and where all data is complete and accurate. The system will automatically determine the correct case status and disposition to close the case and report to CDC. The Hepatitis auto-close function accurately closes approximately 90% of Hepatitis C cases. In 2007, IDPH staff spent as much as 159.3 person days completing and closing Hepatitis C cases. With the implementation of the auto-close, that effort was reduced by 91% to 13.3 person days in 2008, and the auto-close will continue to be of benefit in future years despite the expected increase in case reporting.

The reporting (AVR) system within I-NEDSS enables the users to schedule reports that run automatically and alert users about emerging outbreaks, without the need for manual monitoring.

Summary

The I-NEDSS application provides a centralized and common interface for LHDs, IDPH, and health care providers, to enter, investigate and monitor bioterrorism events and infectious diseases in the State of Illinois. It decreases the time to identify causes and risk factors; it decreases the time needed to detect and report chemical, biological and radiological agents in tissue, food or environmental samples that cause threats to public health; and it improves the timeliness and accuracy of communications regarding threats to public health. I-NEDSS fulfills all the goals and objectives of a bioterrorism, event and disease surveillance system.