

COUNCIL OF STATE AND TERRITORIAL EPIDEMIOLOGISTS

Review of and  
Recommendations for  
the National Notifiable Disease  
Surveillance System:  
A State and Local Health Department Perspective



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## Executive Summary

The National Notifiable Diseases Surveillance System (NNDSS) is complex. It involves reporting of state and locally mandated conditions by health care providers and clinical laboratories to health departments. Health departments, in turn, process and use the information for public health purposes and notify the Centers for Disease Control and Prevention (CDC) of conditions that are designated “notifiable” by the Council of State and Territorial Epidemiologists (CSTE).

In 2011, the Division of Notifiable Diseases and Healthcare Information at CDC began funding an external review of NNDSS. A report on the first phase of the review, issued in December 2011, focused on NNDSS processes within CDC. The second phase of the review addressed the needs and perspectives of state and local health departments about infectious disease surveillance within NNDSS, and its findings are presented in this report.

Information for the second phase was collected from state and local health department staff by the following methods: discussions at a preconference NNDSS workshop at the June 2012 CSTE Annual Conference in Omaha, Nebraska; responses to the 2012 CSTE National Electronic Disease Surveillance System (NEDSS) Assessment Survey; input from a guidance team of 15 surveillance experts; and in-depth reviews of the notifiable disease surveillance systems in Kansas, Massachusetts, Missouri, New Hampshire, New York, and Tennessee.

Health departments use various systems for notifiable disease surveillance, including custom-built systems, commercially available systems (including 1 open-source system), and the NEDSS Base System (NBS) built and supported by CDC. Of the 51 respondents (50 states and the District of Columbia) to the 2012 CSTE Assessment Survey, 17 use custom-built systems, 15 use commercial systems (7 Massachusetts Virtual Epidemiologic Network, 4 Scientific Technologies Corporation, 2 Atlas, and 2 Trisano), and 19 use NBS.

State and local health department staff identified the following main findings relating to notifiable disease surveillance:

- The vast majority of states are satisfied or very satisfied with their NEDSS solutions and do not plan to switch to new solutions in the near future.
- The most often mentioned “most important issue” among states is the need to address gaps in public health informatics capabilities.
- The second and third most mentioned issues were insufficient resources for surveillance and the need for increased coordination among CDC programs including their use of common standards for surveillance.
- Message mapping guides are urgently needed for all notifiable conditions, so that the National Electronic Telecommunications System for Surveillance (NETSS) can be retired.
- Implementing Health Level 7 format and electronic laboratory and health record reporting is technically challenging and requires considerable resources and expertise. Surveillance staff need more informatics training.
- NBS has become a successful, essential tool for many health departments that now depend on it for their surveillance work.
- State and local surveillance staff often are unable to explain to data reporters why CDC requests certain surveillance information. This knowledge gap undermines compliance with reporting and data quality.

- Surveillance workflow processes at the state and local levels should be considered in the successful design of electronic systems. Without more input from jurisdictions, CDC is not well positioned to appreciate local surveillance workflow and system needs.
- More transparent handling of state and local surveillance data within CDC and better data feedback loops are needed if state and local reporters are to work effectively with CDC staff to improve data quality.
- No mechanism currently exists to enable CDC and state and local health departments to rapidly institute national, standards-based data collection systems in response to national outbreaks. Rapidly developed ad hoc systems are cumbersome and have persisted long after the emergency passed.
- No national standards exist for electronically sharing case information with or “transferring” cases to another jurisdiction.
- CDC’s communications with state and local health departments about CDC’s surveillance system planning are frequently incomplete or untimely. Improved CDC communications and long-term commitment to stated plans would greatly aid state and local planning.

The following recommendations reflect the consensus of the state and local participants in this review:

1. For the development and ongoing maintenance of CDC surveillance systems, CDC should implement a better change-control process, including increased communications with its surveillance partners about system plans.
2. CDC should improve its mechanism for gathering input from all state and local health departments about the development and maintenance of surveillance systems.
3. CSTE and CDC should work together to develop standards for the interjurisdictional secure sharing of case information among state, territorial, and local jurisdictions.
4. CDC program staff should clarify the purpose for collecting all requested data elements by explaining how they will be used and should periodically weigh their need against the burden of collecting the information.
5. CDC should ensure a minimum level of informatics knowledge, perhaps through an informatics tutorial, for all of its epidemiology, program, and leadership staff.
6. CDC, in collaboration with state and local health departments, should develop a standard capability to respond quickly to the need to collect surveillance information when new national outbreaks occur.
7. CDC should continue to support the NEDSS Base System.
8. CDC programs should adhere to Public Health Information Network standards.
9. The legacy NETSS format should be discontinued as soon as possible.
10. Systems for handling notifiable conditions data should be designed to promote high-quality usable information.
11. CDC should provide increased, reliable, and less categorical funding to state, territorial, and local jurisdictions to support surveillance, especially for technical support.
12. CDC and CSTE should maintain their commitment to and leadership in helping public health surveillance meet the challenges posed by modern information technology and the use of electronic health records.
13. CSTE and CDC should consider convening a group of state, local, territorial, and federal surveillance experts to develop a strategic vision for notifiable disease surveillance for the next 5 years and to clarify terminology.

## Introduction

The National Notifiable Diseases Surveillance System (NNDSS) is complex. It involves reporting of state and locally mandated conditions by health care providers and clinical laboratories to state and local health departments. Health departments, in turn, process this information; use it to track health conditions, control disease through case management, partner notification, and response to outbreaks; generate reports; and notify the Centers for Disease Control and Prevention (CDC) of conditions that are designated “notifiable” by the Council of State and Territorial Epidemiologists (CSTE).

Coordinating and maintaining such a system is challenging. Current influences that affect public health surveillance—including technologic advances in information exchange, the need for more rapid information by greater numbers of stakeholders, health care reform that is making electronic information more available from clinical settings, and tighter constraints on public funding—are increasing the complexity and challenges of surveillance.

In 2011, CDC’s Division of Notifiable Diseases and Healthcare Information, Public Health Surveillance Program Office, Office of Surveillance, Epidemiology, and Laboratory Services (OSELs), began funding an external review of NNDSS. The first phase of the review focused on NNDSS processes within CDC and resulted in a report in December 2011 that presented several recommendations for improving CDC’s NNDSS operations. One recommendation was that the “NNDSS enterprise should undergo further collaborative review by its stakeholders...at local, state and territorial health departments who were not included in the current evaluation.” This current report describes this subsequent review to address the needs and perspectives of state and local health departments.

The goals of this review were to gather input from state and local health departments about NNDSS and to develop recommendations for improving its operation over the next 5 years.

Specific objectives were to

- Describe current state and local surveillance processes and their rationale.
- Develop a list of electronic system functionalities used at the state and local levels that support efficient case-based surveillance, including both reportable (cases required to be reported locally but not necessarily to CDC) and notifiable (cases for which CDC also receives notification) case reporting.
- Describe current electronic system solutions that state and local health departments are using.
- Identify the major challenges that interfere with successful and efficient case-based surveillance, as well as future challenges that are likely to arise from technologic advances.
- Identify recommended solutions to address these challenges, including defining how CDC and CSTE may be most supportive of state and local health departments.

## Methods

Information for the review was collected from state and local health department staff. These staff were asked to comment on current NNDSS processes, problems, and successes and to suggest improvements or recommendations for NNDSS. Information was collected by the following methods:

- Discussions at a preconference NNDSS workshop at the June 2012 CSTE Annual Conference in Omaha, Nebraska, to identify major issues related to NNDSS.
- Responses to the 2012 CSTE National Electronic Disease Surveillance System (NEDSS) Assessment Survey by the District of Columbia and the 50 state health departments. Among other questions, respondents were asked about their type of NEDSS, how satisfied they were with the functional capacity of their system, whether they planned to replace their system, and to “describe two leading NNDSS issues...and why they are important to sustaining NNDSS at the state and local level over the next 5 years.”
- Input from a guidance team of 15 surveillance experts (see Acknowledgements) chosen in consultation with CSTE, CDC, and the National Association of County and City Health Officials; the Guidance Team met periodically by conference call throughout the evaluation.
- In-depth reviews of 6 states' conduct of national notifiable disease surveillance. The states—Kansas, Massachusetts, Missouri, New Hampshire, New York, and Tennessee—were selected to include a variety of electronic surveillance systems, varying population sizes and resources, geographic diversity, and staff availability. Information was collected by interviewing state and local health department staff in each state, usually during a 1-day site visit to the state, and by state and local health department responses to a written questionnaire. The questionnaire asked about desirable surveillance system functionality, costs, ways in which data are sent to CDC, barriers to and recommendations for surveillance, terminology, and cloud technology. Six state and 2 local health departments (from within 2 of the 6 selected states) answered the questionnaire.

To help limit the review to a manageable scope, respondents were asked to focus on NNDSS issues and core electronic system functions relevant to infectious disease surveillance and to not address noninfectious disease case reporting, surveillance governance, confidentiality/privacy of data, data sharing agreements among government users of surveillance data, and development of specific technical system solutions.

## Findings

### Overview of National Notifiable Diseases Surveillance

Preliminary results from the 2012 CSTE NEDSS Assessment Survey provide information about current use of surveillance systems and issues that are important to the state health departments. Health departments use various systems for infectious disease surveillance; they include custom-built systems, several commercially available systems (including 1 open-source system), and the NEDSS Base System (NBS) built and supported by CDC. Of the 51 survey respondents (50 states and the District of Columbia), 17 use custom-built systems, 15 use commercial systems (7 Massachusetts Virtual Epidemiologic Network [MAVEN], 4 Scientific Technologies Corporation, 2 Atlas, and 2 Trisano), and 19 use NBS. Well over 90% of respondents reported being “very satisfied” or “somewhat satisfied” with their current system and were not planning to replace their system within the next 3 years.

The NEDSS Assessment Survey also asked respondents to describe 2 leading NNDSS issues that they believed this evaluation should address and why these issues are important to sustaining NNDSS at the state and local levels over the next 5 years. The most mentioned issue was the need to address gaps in public health informatics capabilities, especially involving the urgent need for message mapping guides for all notifiable conditions, the technical challenges surrounding the implementation of Health

Level 7 (HL7), electronic laboratory reporting (ELR), and electronic health record (EHR) reporting. The second and third most mentioned issues were insufficient resources for surveillance and the need for increased coordination among CDC programs including their use of common standards for surveillance. (See Appendix 1 for a complete list of the issues identified.)

## **Summary of Findings from State and Local Health Departments in the 6 Selected States**

### *State Surveillance Systems*

The 6 selected states provided summaries of their core surveillance systems, including system development and functionalities and reasons particular systems were selected (see Appendix 2). Also, a composite of the comments from state and local health departments in the 6 states on desired functionality for NEDSS, in response to question 1 of the 6-state questionnaire, is presented in Appendix 3. Respondents considered most of the functions as important but varied in regard to whether they should be integrated or interoperable with an NEDSS solution.

### *Primary Issues Identified*

This section describes the major issues raised during the 6 state reviews (in alphabetical order).

#### Barriers and Important Messages for CDC

Responses to the 6-state questionnaire mentioned the same barriers as were raised on the national NEDSS Assessment Survey. They included problems with CDC's processing of data sent by states, lack of or poor communication by CDC, multiple schedules and standards for sending data to CDC, slow development and challenges of implementing message mapping guides (MMGs), need for better feedback loops on submitted data to increase data quality, lack of resources, need for more CDC appreciation of local surveillance workflow processes, and need for better standardized state-to-state data exchange. (See the full list of responses in Appendix 3: question 5 lists barriers identified; question 8 lists what states and local health departments identified as needing from CDC and CSTE; and question 10 lists other comments.)

Respondents to the questionnaire raised the following points as important messages for CDC:

- CDC should standardize its surveillance systems, including vocabulary, message structure and content, and transmission methods.
- CDC should provide stable funding for state and local surveillance, including support for system user groups that is not tied to individual programs or diseases.
- NBS is a successful, cost effective system and should continue to be supported.
- CDC could improve its communications with state and local health departments and be more inclusive in surveillance planning. Improved CDC communications and long-term commitment to stated plans would greatly aid state and local planning.
- CDC's explanation of how all surveillance data are used would help the surveillance process and data quality. Reducing the complexity of data requested, where possible, also would help.
- MMGs are helpful, but their design needs more input from individual CDC programs.
- State and local health departments collect surveillance data for disease control and prevention and programmatic purposes and are not driven by CDC data requirements.

(See Appendix 3, question 7, for a full list of responses.)

### Cloud Technology

Responses to question 9 about cloud technology were mixed. Some respondents indicated that they need to know more about the technology, some responded that cloud technology was not a good solution for many of the problems they face in surveillance, and others were positive about its use. Many had concerns about data security and confidentiality. (See Appendix 3 for a full list of responses.)

### Costs and Resources

Respondents had considerable difficulty estimating costs because surveillance systems are built in continuous, multiyear stages; are often part of larger information systems within health departments; and involve staff whose time is spent on other projects. Only 3 states attempted to quantify costs; these responses are summarized here. One estimated the initial implementation cost to be about \$1.46 million with an annual maintenance cost of about \$280,500. The 2 other states gave annual maintenance costs of \$350,000–\$450,000. One state with fairly good technical capability estimated that an HL7 version change would take about 2 months, with another month needed to test it.

Staff in every state and local health department mentioned the challenge of inadequate resources to meet all their surveillance needs or even their basic needs. Their impression is that state leadership does not perceive supporting surveillance infrastructure as a priority. One state reported that about 93% of its state infectious disease surveillance staff are federally funded. Another receives no state support for surveillance. State and local health departments look to CDC for dedicated funding to support surveillance. Some CDC programs provide more surveillance support than others, with the HIV/AIDS program a prime example of strong support. However, even when federal support is available, it does not cover all costs. Maintaining sophisticated systems is expensive, requiring highly trained technical staff who are often not supported by categorical CDC program funding. Assisting surveillance staff in the use of these sophisticated systems and managing user accounts add to the costs. In 1 state, simply creating and maintaining user accounts takes approximately 25% of the help desk staff time.

Lack of sufficient, dedicated federal surveillance funding presents challenges to state and local health departments. Some federal funding (e.g., Epidemiology and Laboratory Capacity [ELC] and Public Health Emergency Preparedness [PHEP] cooperative agreement funds) is not restricted to specific diseases and may be used to develop general surveillance infrastructure. However, such federal funding has been decreasing. Furthermore, some states have cut their local support of surveillance because they assume that ELC or PHEP is covering that need. Most other federal funding is categorical by disease area and does not fit state and local surveillance practices, which are often integrated across diseases, not categorical. Wherever possible, CDC funding guidelines and restrictions should take this into account, thereby enhancing efficiency of workflow, reducing costs, and improving surveillance data quality.

### Data Quality

To ensure the best information for public health action and disease tracking, notifiable disease surveillance data must be accurate, timely, and complete. Increasingly, CDC's programmatic funding to states is tied to surveillance performance, which means that data accuracy is doubly important. Generally, subject-matter experts in the specific disease programs at CDC, working with state and local health department staff, are best equipped to monitor data quality and correct data problems, which requires teamwork between CDC and the reporters of the information and requires that staff understand any transformations in the data as processed by CDC.

An example of difficult data validation occurred in early 2012. One state began entering arboviral diseases cases into its core surveillance system. The system generates notifications in HL7 v2.5 messages to OSELS, which in turn generates a file that is sent to CDC's arboviral diseases program in Ft. Collins, Colorado. Lack of consistent documentation and Fort Collins' staff involvement has made it difficult to validate data among the state, OSELS, and Fort Collins.

The CDC tuberculosis (TB) program appears to have a good system for monitoring data quality. After state-provided TB case data are uploaded to OSELS's data mart, the CDC TB program places the data in its own National TB Surveillance System, which allows state staff and CDC TB program staff to work from the same data set, resolve data issues, and ensure data accuracy.

For some program areas, the main method of monitoring data quality is to compare aggregate numbers of reported cases meeting the case definition and to respond to specific data problems that CDC may recognize. This type of data checking can miss many errors.

### Emerging Infections Program

The Emerging Infections Program (EIP) has developed a dependable surveillance system with accurate transmission of data from participating states directly to the CDC programs through a number of systems. The systems are maintained through supplemental funding under cooperative agreements. However, there is little integration of case notification under EIP with routine case notification, aggravating the complicated notification process mentioned earlier. Following is a list of data sent from 1 EIP state to CDC ("NEDSS" refers here to the state's core surveillance system).

- NEDSS FoodNet data are sent to both OSELS and the CDC FoodNet Program:
  - NEDSS→OSELS.
  - NEDSS extract→flat file→FoodNet Access database via Public Health Information Network (PHIN) Messaging System (PHINMS).
  - Hemolytic uremic syndrome hospital discharge data→Access database→CDC FoodNet (PHINMS).
- NEDSS Active Bacterial Core Surveillance (ABC) data are sent to both OSELS and ABC Programs:
  - NEDSS→OSELS.
  - ABC data→data re-entered into an Access database→CDC ABC programs.
- Methicillin-resistant *Staphylococcus aureus* and *Candida*→Access database→CDC ABC (file transfer protocol).
- Human papillomavirus data→CDC (Web-based system).
- *Clostridium difficile* data from 1 county is extracted from NEDSS and re-entered into another database→CDC.
- Antimicrobial resistance→data entered into an Access database→CDC.

Special data feeds for EIP projects make extra work for states. Also, when FoodNet variables are added to NBS, they are added for all NBS-using states (unless they are created as locally defined fields), not just the EIP states, which create additional click-through screens for the non-EIP states. EIP does not provide any funding for technical support. Substantial overlap often exists between what is being requested in EIP data sets and what is already collected and reported to CDC.

### Importance of Surveillance Work Processes in Developing Surveillance Systems

A good surveillance system does much more than simply report to CDC. Public health surveillance and response involve a wide variety of tasks that should contribute to the design of electronic systems for collecting and managing surveillance information. State and local surveillance workflow determines how electronic surveillance systems are used and how they can be most helpful to surveillance staff. A careful analysis of surveillance workflow has already been studied and is available.<sup>1</sup>

Some state and local staff provided the following examples of some typical surveillance tasks that well-designed electronic systems can facilitate:

- Generation of standard management reports, with appropriate staff access, to assist with coordinating work assignments, tracking staff performance, and monitoring data quality. For example, such reports could include documentation of report receipt (who, date/time stamps), investigator assignments (who, date/time stamps), time of investigation start, work load of investigators, monitoring which cases are part of clusters, documenting transfers to other jurisdictions (who, date/time stamps), ensuring follow-up of all appropriate laboratory results, time of instituting public health control measures, and monitoring activity on both old and new cases (e.g., which cases have been opened and which have been edited recently).
- Cleaning of incoming laboratory reports (e.g., deletion of proficiency test results, standardization), which is needed before they can be used for surveillance.
- Sampling 20% of laboratory reports of suspected cases of high-volume diseases, such as Lyme disease, for full investigation and then extrapolating the total number of confirmed cases from the sample. Sampling can be extremely helpful and efficient, but 1 local health department pointed out the need for a system change to sample more efficiently based on its workflow. This health department prefers to print out laboratory reports for field investigation. However, the system allows only for printing 100% of laboratory reports, not the 20% sample, a poorly planned function that wastes staff time and paper.
- Automating electronic printing of prepopulated case report forms based on information from laboratory reports of suspect reportable diseases. This function is increasingly used to streamline local surveillance. The forms can be mailed to the ordering physicians, who complete and fax them back to the health department, where the information can be scanned, verified, and uploaded to the surveillance system.

A brief case study of 1 state's challenges with meeting the needs of surveillance through its data systems is described in Appendix 4.

The Enhanced HIV/AIDS Reporting System (eHARS) illustrates a well-designed data management and reporting system but one that has limited functionality for meeting states' needs. It allows for very limited (or no) analysis or tracking of services and workflow. Some states have developed their own HIV tracking systems to fill the need. In addition to uploading data into eHARS, these systems perform such tasks as acceptance of electronic provider and laboratory reports, data cleaning, matching to other data sources (e.g., sexually transmitted disease [STD] and hepatitis case reports, Medicaid files, death files), tracking of HIV reported cases for partner notification, and provision of HIV services. (See Appendix 5 for additional detailed comments on eHARS.)

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<sup>1</sup> Public Health Informatics Institute. Redesigning public health surveillance in an eHealth world. June 2012. Available at [www.phii.org/resources/view/1186/Redesigning%20Public%20Health%20Surveillance%20in%20an%20eHealth%20World](http://www.phii.org/resources/view/1186/Redesigning%20Public%20Health%20Surveillance%20in%20an%20eHealth%20World). Accessed January 14, 2013.

A carefully designed system can improve programmatic outcomes. For example, the number of identified cases of pregnant women with hepatitis B increased in 1 state partly as a result of better prompting for case information, such as pregnancy status. Such a system also can improve work efficiencies by tracking work to be done by role and by person. It also can prioritize case investigations and pending work tasks.

Optimal design of state and local surveillance systems requires an understanding of state and local needs. Because CDC staff are often not familiar with state and local surveillance workflow and because CDC's primary surveillance responsibility is to receive and manage national-level data, CDC is not well positioned to design systems that are optimally functional for state and local health departments. This situation has several implications for CDC's design of such systems:

- Because the needs of state and local health departments vary, 1 inflexible system will not meet the needs of all localities.
- CDC must continue to ensure some built-in flexibility in CDC-built systems to enable states to use the systems to meet their needs, not just the needs of national surveillance reporting.
- The use of common standards by all localities and CDC becomes even more important with the different systems and functions involved in surveillance.

#### Message Mapping Guides and National Electronic Telecommunications System for Surveillance

The use of MMGs for selected conditions has improved the accuracy and ease of submitting surveillance data to CDC. However, MMGs for all the remaining conditions urgently need to be completed to correct some of the ongoing loss of information transmitted to CDC and to simplify the complicated and varied notification processes. For example, states still use the National Electronic Telecommunications System for Surveillance (NETSS) to notify CDC of notifiable conditions that lack MMGs. Because NETSS has not been upgraded for many years, the coding for notifiable conditions has not been changed to reflect current needs. For example, NETSS codes only for the pertussis whole-cell vaccine and not the pertussis acellular vaccine; when state pertussis case information is submitted to CDC and transformed into NETSS format, acellular vaccination information is lost.

CDC should clarify its MMG plans for states as soon as possible; without this information, states find planning and budgeting for surveillance enhancements difficult. Also, in developing and implementing MMGs, CDC has not always been clear about which variables are required and which are optional, an ambiguity that has created confusion and expense. For example, after the TB and varicella MMGs were developed and implemented in 1 state, CDC surveillance staff changed some variables from "optional" to "required," which created problems and expense for the vendor building the state's system.

#### NEDSS Base System

There was general consensus that NBS is a good, proven system and should be maintained and supported by CDC. The use of NBS by 19 states has the added advantage of encouraging CDC programs to use national standards and build systems that interoperate with NBS.

NBS enables continuing improvements in integration and interoperability of surveillance systems and activities (see Appendix 2 with the description of the Tennessee system). For example, after the discontinuation of the Tuberculosis Information Management System, several states worked with CDC to develop a page in NBS to record and track cases of latent TB infection using Page Builder in NBS. This was accomplished with little cost and added functionality to NBS for TB surveillance. Similarly,

CDC's STD and NBS staff are doing a gap analysis to determine what functions are missing in NBS for STD surveillance and control (e.g., case management and contact tracing), with the plan to develop the missing functions by using Page Builder.

### Reason to Collect Data

Whether or how CDC uses all the information collected about notifiable conditions was not clear to most of the interviewed state and local surveillance staff. Surveillance staff find it difficult to justify collecting data that are not used locally or by CDC, at least as apparent in national reports. They gave the following examples of requested information that they found difficult to explain to data reporters:

- Extensive behavioral information about HIV case-patients.
- Month/day/year when a TB case-patient started smoking.
- Month/day/year of diagnosis for TB.
- Whether TB cases occurred “within city limits.”
- Immigration status of TB case-patients.

State and local surveillance staff need to understand why CDC asks for each piece of information so that they gather accurate information and can explain the purpose to those who report to public health. The inability of public health staff to explain why selected information is collected leads to a “cry wolf” phenomenon with poor cooperation from reporters, which jeopardizes the collection of critical information when it is most urgently needed. Poor understanding of the reasons for collecting information also can lead to poor state compliance with CDC requests for data. Staff from 1 state reported that they do not send some supplemental data to CDC because CDC staff do not seem to miss it. They questioned the need to collect it, especially because collecting and entering some supplemental data is overwhelming.

Understanding the urgency for obtaining surveillance information is also helpful to surveillance staff so they can prioritize tasks. Some data are needed for immediate disease control interventions; other data are routine—for example, data to track person–place–time characteristics of disease in populations—and then some are not acutely time dependent, such as special surveillance evaluation projects.

The optimal foundation for surveillance includes explicit communication about the need for each piece of information. If the information is not justified by its importance to public health, then collecting it should be discontinued, as was done recently when CDC decreased the amount of data collected on West Nile virus cases, which enabled elimination of the West Nile virus case supplemental forms in ArboNET.

### Standards

CDC programs are not following PHIN standards or using uniform coding and messaging. Updating data in 1 disease registry with information from a different registry is made more difficult by CDC programs using different coding of variables. For example, CDC's HIV, hepatitis, and STD surveillance programs code behavioral risk factors differently, which limits the ability to translate risks from 1 registry to another. Furthermore, vocabulary standards and MMGs are most helpful only when all CDC programs implement them uniformly.

Responses to the fourth question about how data are sent to CDC varied widely among the 6 states. This variation in responses illustrates the variation in messaging currently used for sending NNDSS reports to CDC (see Appendix 3 for a summary of responses).

Standards are especially needed for developing emergency surveillance systems in response to national outbreaks. During the emergence of the West Nile virus and the 2009 influenza A(H1N1) outbreak, for example, CDC programs developed ad hoc nonstandardized systems to collect national data. Such systems are cumbersome (e.g., double data entry, manual data transmissions to CDC, poor analysis functions) and often persist long after the emergency has passed. CDC is still using a separate influenza pediatric death reporting system started during the A(H1N1) pandemic. CDC and state and local health departments need to develop the capability to rapidly institute national, standards-based data collection systems. If CDC provided state and local health departments with the standards for reporting surveillance information during emergencies, health departments would be better able to incorporate new data into their existing systems and electronically transmit the data to CDC. This approach would provide some flexibility at the state and local levels while meeting national surveillance needs.

Also, more standardization of surveillance information and messaging is needed so that public health can realize the benefits of faster, more reliable and complete reporting that EHRs make feasible. All of public health needs to agree on uniform standards for physician and laboratory reporting. The same is true for states reporting to CDC. As 1 state person said about CDC notifications: “One message; One vocabulary; and One portal.”

### Terminology

One question asked whether terms and concepts, such as PHIN, NEDSS, and NNDSS, were clear or whether they should be revised. Responses showed confusion about terminology. The answers ranged from “I don’t know what these terms mean” and “I can’t really define their differences” to “Yes, I have a clear idea what they mean.” However, it became clear that staff may believe they have a common understanding of the terms, when in fact they do not. During a group discussion in 1 state, staff first indicated agreeing about what the terms meant, but when asked to define them, they disagreed on definitions and concepts. There was considerable confusion between “NEDSS” and “NNDSS.” Confusion is aggravated by repeated CDC reorganization and changes in “brand names.” For example, 1 person asked the difference between “PHIN” and “PHI” and noted that many people think that NEDSS and NBS are the same. One local health department staff member said that understanding these terms is irrelevant to local-level surveillance; the terms were more important for national conceptual planning. A state person suggested that consistent terminology should be developed to integrate with the Office of the National Coordinator for Health Information Technology terminology and meaningful-use requirements. Another noted that “NNDSS” should be “NNCSS” to account for “Conditions” rather than “Diseases” in the acronym. The need for clarification between the terms “nationally notifiable” and “under national surveillance” was also mentioned.

Thus, considerable confusion exists over terminology. Some respondents favored revising terminology to make it more precise, distinct, and clear to all, including upper level management that controls funding and support for surveillance.

### Training

Because of rapid turnover of local staff, continuing training by the state for local staff is needed to keep them knowledgeable about the systems used. Training can be a challenge because of state staff shortages. Insufficient staff training can adversely affect the quality of data sent to CDC. Comprehensive manuals for standardizing the recording and entering of data into a state’s surveillance system are especially helpful.

## Recommendations

**Note:** Although the following recommendations were developed in response to the findings of this review of notifiable *infectious disease* surveillance, they also can be applied to noninfectious notifiable diseases, such as lead poisoning and cancer surveillance.

- 1. For the development and ongoing maintenance of CDC surveillance systems, CDC should implement a better change-control process, including increased communications with its surveillance partners about system plans.** A good change-control process would track all requests and plans for changes to existing systems and standards. This process would ideally include dedicated CDC staffing and a group of federal, state, and locally vested partners in reviewing and prioritizing proposed changes (see Recommendation 2 below). CDC needs to monitor the timing of system and standards upgrades by states so that CDC knows when most states are capable of implementing a proposed change. This information avoids CDC trying to implement new systems or standards when most states are not ready. The change-control process also should establish a national source of reliable information for state and local health departments about proposed and planned changes, with anticipated timetables for implementation. What happens when upgrades to existing CDC systems are requested often is not clear, and states find it difficult to plan and implement their own systems without knowing CDC's plans. CDC could be more responsive to state and local needs by increasing communications about upgrades, how they are prioritized, and ideally speeding up needed system changes.
- 2. CDC should improve its mechanism for gathering input from all state and local health departments about the development and maintenance of surveillance systems.** State and local health departments can provide important input into system development and the need for and prioritization of upgrades. This type of planning should include consideration of the functionality needed to accommodate state and local workflow, in addition to messaging to CDC. For example, CDC should ensure that data entry screens are clear and user-friendly to promote efficient workflow at the state and local levels. Also, NBS could be improved by incorporating better means to manage workflow and staff assignments.
- 3. CSTE and CDC should work together to develop standards for the interjurisdictional secure sharing of case information among state, territorial, and local jurisdictions.** No national standard exists for sharing case information with or "transferring" cases to another jurisdiction.
- 4. CDC program staff should clarify the purpose for collecting all requested data elements by explaining how they will be used and should periodically weigh their need against the burden of collecting the information.** Clarity of purpose for each data element helps to justify the data requested to reporters, to ensure good data quality, and to meet review requirements of the Office of Management and Budget. Collecting low priority surveillance information is wasteful because it diverts resources from higher priorities. Clarifying the purpose of data elements should include clear definitions of data elements in an operational data dictionary.
- 5. CDC should ensure a minimum level of informatics knowledge, perhaps through an informatics tutorial, for all of its epidemiology, program, and leadership staff.** Maintaining and updating this knowledge may require periodic training. Training state and local health department staff in basic informatics skills would also benefit surveillance.

6. **CDC, in collaboration with state and local health departments, should develop a standard capability to respond quickly to the need to collect surveillance information when new national outbreaks occur.** Such a rapid-response surveillance system should be flexible; interoperate with the various state and local NEDSS solutions in current use; and include analysis, visualization, and reporting (AVR) capability. Previously, when new outbreaks have occurred, CDC has developed ad hoc surveillance systems, which have sometimes been maintained over years and led to more stand-alone systems that prove inefficient for state and local surveillance.
7. **CDC should continue to support the NEDSS Base System.** Decisions on its future direction, support, and architecture (for example, moving to a centralized cloud-based database) should be thoroughly vetted by the NBS User Group and an expert visioning group, as recommended in #13 below.
8. **CDC programs should adhere to Public Health Information Network standards.** For example, they should all use standard PHIN vocabulary coding. Updating data in 1 disease registry with information from a different registry is made more difficult by nonuniform coding of variables among programs. Vocabulary standards and MMGs are helpful only when all disease programs implement them uniformly. Furthermore, meaningful-use requirements for EHRs will require public health programs to standardize their data needs.
9. **The legacy NETSS format should be discontinued as soon as possible.** It does not meet current PHIN standards and interferes with accurate, complete transmission of surveillance information to CDC. Its discontinuation will require comparing and standardizing, where possible, all variables for the nationally notifiable conditions and development of an MMG for the remainder of notifiable conditions currently lacking one. Such a comprehensive MMG should be developed as soon as possible and submitted in 1 coordinated request to the Office of Management and Budget for approval. Achieving this requires CDC, state, local, and territorial staff to make this task a high priority.
10. **Systems for handling notifiable conditions data should be designed to promote high-quality usable information.** The following steps should be taken to improve the notifiable disease data sent to CDC: a) CDC should ensure that all routine surveillance data received from states, cities, and territories are available to appropriate CDC program staff in timely, accurate, and usable format; b) CDC program staff should ensure that all data elements collected are regularly reviewed and used; and c) CDC should continue to standardize and simplify the messaging of notifiable disease information to CDC. Meanwhile, CDC should make any transformations of data within CDC very clear and transparent to the jurisdictions sending the information and to the CDC disease program staff so they are better able to work together to review data and ensure their quality.
11. **CDC should provide increased, reliable, and less categorical funding to state, territorial, and local jurisdictions to support surveillance, especially for technical support.** Restricting surveillance funding to designated diseases or to nontechnical support should be avoided where possible because such restrictions can result in inefficient use of funds at the state and local levels.
12. **CDC and CSTE should maintain their commitment to and leadership in helping public health surveillance meet the challenges posed by modern information technology and the use of electronic health records.** CDC and CSTE have been especially effective by playing an active role in the Standards and Interoperability Initiative and by providing staff support to develop the

Reportable Conditions Knowledgebase Management System. These projects are critical for the future success of surveillance, and state and local health departments often lack the time, staff, or expertise to lead these efforts. Specific areas where CDC and CSTE can be helpful include a) ensuring that knowledgeable public health people are included when decisions are being made that impact surveillance, such as developing requirements for meaningful use and systems that meet those requirements; b) anticipating ways to strategically position public health to take advantage of the opportunities from technologic advances; and c) helping to identify where more technical training of public health practitioners is needed and making it available.

13. **CSTE and CDC should consider convening a group of state, local, territorial, and federal surveillance experts to develop a strategic vision for notifiable disease surveillance for the next 5 years and to clarify terminology.** Questions exist about the optimal system structure for national surveillance (e.g., the role and feasibility of cloud technology; variable state surveillance system solutions and ways to maintain them; and ways to use EHR) and confusion over terms, such as PHIN, NEDSS, and NNDSS. Explicit discussion of these issues should be directed to developing a road map for future system design and clarification of terms. This strategic planning should comprise noninfectious, as well as infectious, notifiable conditions, such as cancer, silicosis, and pesticide and lead poisoning.

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- Massachusetts.
- Missouri.
- New Hampshire.
- New York.
- Tennessee.

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**Note:** Much of the information in this report was collected from a relatively small number of state and local health departments and therefore does not represent all health departments' views. In addition, the recommendations and conclusions are the general consensus of the participants and may not represent individual participants' opinions.

## List of Acronyms and Abbreviations

ABC	Active Bacterial Core Surveillance
ABLES	Adult Blood Lead Epidemiology and Surveillance
APHL	Association of Public Health Laboratories
AVR	Analysis, Visualization, and Reporting
CDC	US Centers for Disease Control and Prevention
CDESS	Communicable Disease Electronic Surveillance System (New York)
CSI	Collaborative Software Initiative
CSTE	Council of State and Territorial Epidemiologists
ECLRS	Electronic Clinical Laboratory Reporting System (New York)
EDI	Electronic Data Interchange
eHARS	Enhanced HIV/AIDS Reporting System
EHR	Electronic Health Record
EIP	Emerging Infections Program
ELC	Epidemiology and Laboratory Capacity
ELR	Electronic Laboratory Reporting
eRVCT	Electronic Report of Verified Case of Tuberculosis
ESP	Enhanced Support for Public Health Practice Initiative (Massachusetts)
HIPAA	Health Insurance Portability and Accountability Act of 1996
HL7	Health Level 7
IT	Information Technology
KDHE	Kansas Department of Health and Environment
KS-EDSS	Kansas Electronic Disease Surveillance System
LHD	Local Health Department
LOINC	Logical Observations Identifiers Names and Codes
MAVEN	Massachusetts Virtual Epidemiologic Network
MDPH	Massachusetts Department of Public Health
MMG	Message Mapping Guide
NBS	NEDSS Base System
NEDSS	National Electronic Disease Surveillance System
NETSS	National Electronic Telecommunications System for Surveillance
NHEDSS	New Hampshire Electronic Disease Surveillance System
NNDSS	National Notifiable Diseases Surveillance System
NYCDHMH	New York City Department of Health and Mental Hygiene
NYSDOH	New York State Department of Health
OSELS	Office of Surveillance, Epidemiology, and Laboratory Services, CDC
PHEP	Public Health Emergency Preparedness
PHIN	Public Health Information Network
PHINMS	PHIN Messaging System
PRISM	Patient Reporting Investigation Surveillance Manager
PTBMIS	Patient Tracking and Billing Management Information System (Tennessee)
SDN	Secure Data Network
SFTP	Secure File Transfer Protocol
SNOMED	Systematized Nomenclature of Medicine
STC	Scientific Technologies Corporation
STD	Sexually Transmitted Disease
STDNIS	STD Management Information System

STELLAR	Systematic Tracking of Elevated Lead Levels and Remediation
TB	Tuberculosis
TDH	Tennessee Department of Health
WIC	Women, Infants, and Children Program
XML	Extensible Markup Language

## Appendix 1: Responses from the 2012 NEDSS Assessment Survey

Following are the responses by the 50 states and the District of Columbia to the request, “Please describe two leading NNDSS issues that you believe should be addressed in this evaluation and why they are important to sustaining NNDSS at the state and local level over the next 5 years.” The responses are grouped under several theme headings below.

### **Public Health Informatics Gaps** (24 comments)

#### Message Mapping Guides (MMGs) (11 comments)

- MMG's need to be accurate and involve participation from program areas at CDC. In addition, program areas should review all forms, needs, gaps, required elements, where creating the guides and be able to consume all the data prior to its release. The inability of this leads to confusion and additional work for states.
- Interstate notifications for HL7 messaging-need a message mapping guide.
- Timeliness of approving/publishing nationally notifiable diseases messaging guides.
- Generic 2.0—We have been waiting a long time for this and because this is delayed we are still doing double data entry.
- The lack of messaging guides needs to be addressed.
- Availability of message mapping guides needs to be addressed. These guides need to be published in a more timely manner and need to be available for all programs for which states are charged with submitting case notifications, regardless of program area and consuming system (meaning should include HIV and STD).
- ELR and proper coding, whose responsibility and how can it be enforced?
- The core data variables collected in the system and then made available to CDC programs—quicker turnaround time with MMGs.
- Not being notified of changes in MMGs. Delayed response from CDC concerning implementation. Timeliness of publishing MMGs.
- CDC program bureaucratic hurdles preventing states from MMG adoption and use.
- Message mapping and reporting to CDC needs to move more quickly to 1 HL7 solution so all data are sent in 1 format.

#### HL7 (6 comments)

- Developing tool to assess HL7 messages for defects.
- HL7 messaging—still working on sending NEDSS files via our new system.
- Support for transition to HL7 case notifications.
- Understanding HL7 messaging.
- Standardized vocabulary for HL7 messaging.
- The CDC case notification guides are going to be very difficult to implement, especially if the optional fields become mandatory at some point. Will be very labor-intensive on our end because of the HL7. If they were not HL7, Epi staff could create periodic extracts with the desired extended data (using our data analysis tools) without requiring months of IT [information technology] involvement.

#### Electronic Laboratory Reporting (5 comments)

- Receipt of electronic laboratory reports.
- Lack of standard LOINC [Logical Observations Identifiers Names and Codes] and SNOMED [Systematized Nomenclature of Medicine] codes affect implementation of ELR.
- Improving the legislative requirement for electronic laboratory reporting. Model legislation that can be shared with project areas.
- Duplicate reporting from ordering facilities (hospitals that do not perform their own lab tests) and performing facilities (labs and reference labs that perform the lab tests yielding reportable results). In a paper-based world, it was common for an expectation that anyone and everyone with knowledge of a reportable lab result report that result to public health. If this is carried forward into electronic reporting, we are maximizing and institutionalizing duplicated data that could exponentially increase reporting volumes as well as require additional costly effort on both sides of the data exchange to handle these duplicate records—all for zero benefit if there is an assurance that all reportable lab results are getting reported. This assurance is the tricky part. Public health should be pursuing efficiencies that maximize benefits and minimize costs and effort.
- CDC laboratory send electronic laboratory reports to jurisdictions.

#### Electronic Case Reporting (2 comments)

- How we move from ELR only to full electronic case reporting.
- Electronic case reporting from electronic health records and exchange of lab and case reports between public health agencies (i.e., other states and cities).

## **Resources** (19 comments)

- Ways to provide funding that has longer-term stability than 1-year grant cycles.
- Sustainable funding.
- Future funding streams.
- Funding equity for those states that have partnered with CDC and adopted the NBS...by continuing the funding for the NBS. CDC needs to recognize the NBS for the success it is and strongly support!
- Funding! Every change costs us with our vendor and we never have enough. In addition, CDC sees our vendor in the contracting line and always guts that funding, even though its license and maintenance costs for the system.
- Grant funding is decreasing, our maintenance budget has been cut by more than half, because grants are more likely to fund new projects or upgrades and less likely to fund maintenance costs.
- Shortage of staff resources have been a major barrier in most areas.
- Tied to grants, we are expected to collect additional information with no additional funding.
- Limited resources for state/local to obtain data from health care providers.
- Interoperability of electronic systems is a priority, but more resources, and guidance is needed to accomplish.
- Better options and support for sending data to CDC.
- Consistent funding for maintaining our surveillance systems.
- Funding maintenance to support federal initiatives (e.g., meaningful use).
- Continuing development of NBS—We don't have capacity to develop and maintain own system.
- More lead time from CDC to implement changes and funding to do so. As state systems have become more integrated, the time necessary to implement changes has expanded to make sure new functionality doesn't negatively impact existing functionality.
- Standardization support from CDC for COTS [commercial off the shelf] solutions.
- Funding.
- Sustained funding.
- Most critical—need for more public health informatician resources to improve data exchange.

### **Need for Increased CDC Program Coordination (15 comments)**

- CDC doesn't seem to coordinate between and within disease programs with reporting data. This makes things very difficult to maintain. Separate projects tied to special funds while at the same time try to interact with things that are already established.
- Data provisioning from NNDSS to CDC program areas.
- Lack of standardization between data systems also needs to be addressed.
- Standard messaging solutions should be used to communicate data with CDC and not require the use of separate, proprietary formats. The existing HL7 case notification 2.5 message format should be used for all notifications. Adopting different and/or additional formats for communicating notifications should not be permitted as it would require states to implement yet again another solution that is not permitted to come to fruition and succeed.
- Standard messaging: there are too many disease-specific case notification messaging guides for state/local to implement.
- We need to streamline our messaging to CDC, e.g., develop a standard HL7 message for all CDC programs. Currently we're sending a bunch of various outputs to various CDC programs.
- True integration of surveillance systems with support by CDC programs.
- CDC should look toward supporting the inclusion of duplicitous [sic] systems (i.e., ArboNET, eHARS).
- CDC programs need to be coordinated and consistent in their participation.
- Consolidate reporting to CDC, and make all reporting electronic and bi-directional. Need more collaboration among CDC programs.
- Establishing consistent message standards and formats so that there are no more moving targets. Establishing consistent PHIN/grant requirements.
- Coordinated CDC approach across program areas; now we have multiple program areas asking us all for the same data.
- May want to ask about how often states send state surveillance extracts to other branches of CDC. We already send data sets with additional information on botulism, rickettsial diseases, *Listeria*, etc.
- CDC needs a unified approach with NNDSS across programmatic areas and needs to standardize the information collected.
- Program areas at CDC cannot access the data sent by states—this results in additional programmatic requests of states and for data to be re-sent in different, nonstandardized formats.

### **Other Topics** (15 comments)

- A long-term vision, with milestones and goals, should be developed and discussed with the states. States are partners with CDC in collecting, analyzing, and disseminating information.
- Incorporating HIV/AIDS surveillance into NBS.
- Interoperability—would give us access to more complete data.
- Enhanced data analyzing tools—allow us to better respond and detect.
- Legal backing for data exchange and protection in public health agencies.
- Local-level training.
- Ability for CDC common data store to successfully function.
- We experience extreme difficulty in pulling out our own data for reporting purposes.
- Case definitions changes and additions. Increasing number of reportable diseases places burden on states to update surveillance systems to comply.
- Adequate technical training and support of NBS—staff turnover has led to a knowledge void that prevents us from using NBS to its full capacity.
- Implementing nationwide HIE [Health Information Exchange] standards so vendors will make updates to their software and be marketable to all states without charging states individually for the functionality.
- Acceptability. States are asked to collect a lot of information and not sure it is all needed.
- Utility and amount of information required to be collected. We collect the information, and we would like to see who uses it and what is it used for.
- Electronic interstate notification of reportable condition standards and mechanics.
- Interoperability with other public health data systems and integration with other data sets to support public health decision making.

## Appendix 2: Summaries of State Surveillance Systems

### Overview of Kansas' Core Surveillance System

Kansas has a population of 2.9 million, with 105 counties served by 100 local health departments (LHDs). Each is independent and responsible for surveillance within its jurisdiction except for HIV/AIDS and STDs, which are conducted by state staff. Notifiable diseases are reported in several ways. Provider reports are generally sent to the county health departments, which enter them into EpiTrax, Kansas' NEDSS solution (see below). Occasionally, provider reports are sent directly to the state, which then enters them. Laboratory reports are mostly faxed to the state, which enters them into EpiTrax where counties can access their own reports on line. Currently, EpiTrax provides staff access to all conditions under surveillance within their jurisdiction. EpiTrax will be upgraded to allow access rights to select groups of diseases for different staff based on their work needs. Currently, Kansas restricts access rights based on work needs by creating specialized jurisdictions that only authorized staff can access. STD program data have an additional level of security. STD data are classified as "sensitive" and cannot be seen in system searches by users who do not have access privileges for STD. EpiTrax sends data to CDC in 2 formats: NETSS and HL7. HIV surveillance data are housed separately in eHARS and sent to CDC in XML [Extensible Markup Language] format.

The Kansas Department of Health and Environment (KDHE) began implementing a new electronic disease surveillance system, Collaborative Software Initiative's (CSI) TriSano, named EpiTrax in Kansas, in August 2011 to replace a number of independent systems—Kansas Electronic Disease Surveillance System (KS-EDSS) for general communicable diseases and TB, STD Management Information System (STD-MIS) for STDs, and Systematic Tracking of Elevated Lead Levels and Remediation (STELLAR) and Adult Blood Lead Epidemiology and Surveillance (ABLES) for blood lead surveillance. The STD Program conducted user training in December 2011 and went live with EpiTrax in January 2012. A data migration from STD-MIS was completed at this time too. The general communicable disease and TB programs went live in March 2012. KDHE uses CDC's eRVCT electronic entry forms. The blood lead program switched to EpiTrax in September 2012. Data migration is still pending from KS-EDSS, STELLAR, and ABLES.

This implementation has been very rapid and successful, although it was not conducted completely without issues. The largest barriers have been problems with system performance when large forms are attached to a case; some difficulty with availability of data and ease of use of the data AVR feature in EpiTrax (Pentaho business intelligence system); and data migration from legacy systems. CSI has been working with KDHE to resolve the first 2 issues. Data migration was originally planned to be performed by KDHE information technology staff; however, there have been significant challenges, and data migration has not been completed to date.

KDHE provided the following comments on TriSano:

CSI was founded in 2007 with the collaborative approach to building and deploying software products at a low cost as the foundation of the business model. CSI uses a community approach to engage community members, customers, subject-matter experts, and partners to develop open-source software, available with commercial support for a low-cost annual subscription fee. TriSano was developed through a collaborative effort with the Utah Department of Health and deployed in 2009. It is HIPAA [Health Insurance Portability and Accountability Act of 1996] Security compliant, Web-based software that is both event-centric and patient-centric.

## Pros

- Highly configurable:
  - Form Builder allows for building of disease-specific fields through the system administrator.
  - Core customizer allows for core fields to be hidden on events that would not require the data.
- Outbreak management built into system.
- Dashboard home screen:
  - Tasks.
  - Alerts.
- Tasks, alerts, and workflows are built into user roles for better investigation completeness and case management.
- Case management:
  - Hepatitis B perinatal tracking built into system.
- Contact management:
  - Automatically upgrade a contact to a case
- Google Maps Premier geographic information system
  - Address verification.
  - Mapping.
- AVR data warehouse:
  - All data are exportable.
  - Configurable to dump data to AVR as often as possible.
  - Includes metrics reports.
  - Create user specific dashboards.
- Online Help wiki in system.
- ELR ready.
- PHIN compliant:
  - NETSS export built in.
  - HL7 message mapping ready.
- Import case capability.
- Professional documentation and training in Enterprise Edition.
- Strong collaborative community:
  - Improvements developed in open-source community available for all users.
- Low-cost annual fee for Enterprise Edition.
- Available as Software as a Service (SaaS) for lost cost.
- Rapid deployment models.
- Globalization feature allows for language translation, such as American Spanish.

## Cons

- TriSano is a very new product from a young company.
- Lacks administrative capabilities, such as user tracking and reports.

- Unclear if it will work with our centralized patient registry.
- Non-human cases not addressed as separate function.

#### Reason for Selecting CSI's Trisano:

KDHE selected CSI's Trisano after a comprehensive review of all available systems. The evaluation showed that all available systems could meet the functionality needs for the state that the previous system did not meet. Therefore, when selecting TriSano, the costs of implementation and long-term maintenance became major factors. TriSano met the basic system functionality and surveillance needs, as well as more specialized needs, such as analysis, outbreak management and case management (so that TB and STD could be included) that some of the other cost-effective options did not include. Additionally, the option for Software as a Service was a big plus when choosing TriSano because Kansas had to be mindful of its very scarce IT resources, and the cost savings were appealing. The timeframe for implementation was also a major factor; Kansas was using a failing system that needed to be rapidly replaced due to lost functionality and concerns about stability. However, Kansas was aware that it did not want to sacrifice functionality or user satisfaction just to bring a new system on quickly. Kansas was very mindful of the burden that changing systems put on the LHD users and also made sure to address the very real concerns users had about replacing the existing system with an equally difficult one. TriSano was selected only after a trial evaluation period and many meetings with stakeholders to ensure everyone felt their needs would be met.

## Overview of Massachusetts' Core Surveillance System

Massachusetts has a population of 6.5 million, serviced by 351 town/city health departments (no county health infrastructure). The Massachusetts Department of Public Health (MDPH) provides 24/7 response and coordinates surveillance with the local boards of health. In 2004, the MDPH created the Office of Integrated Surveillance and Informatics Services, which now has a staff of 25–30 epidemiologists, informaticists, and research analysts. They collaborate closely with the department's information technology staff and the Bureau of Infectious Disease staff and provide a single point of contact for disease reporting.

Before 2004, Massachusetts had separate disease systems that involved duplicate data entry at local and state health offices. The MDPH conducted competitive bidding and chose Consilience with the plan of integrating diseases into 1 system (currently, HIV and STDs are not integrated). Massachusetts has pooled resources across cooperative agreements (ELC, PHEP, Immunization, STD, HIV, Refugee/Immigration, TB) and state funding to create this statewide system. The concept was to use the Consilience software platform to implement national standards for epidemiologic, surveillance and laboratory data; create a single point of contact for disease reporting for laboratories, hospitals, and other public health providers; automate triage of information to increase efficiency; implement standardized quality assurance/control measures; and coordinate data exchange. The system, the Massachusetts Virtual Epidemiologic Network (MAVEN), can generate both “canned” reports and ad hoc reports. It also enables disease-specific decision making and access. Specific goals included

- PHIN-compliant, Web-based disease surveillance and case management.
- Data security and confidentiality.
- Single integrated person-based system.
- Capture of all data elements required for surveillance and case management.
- Disease-specific question packages.
- Responsiveness to programmatic needs.
- Interface with ELR and EHRs for timely and electronic notification of reports.
- Role-based access.
- Real-time information sharing.
- Streamlined business processes.
- Workflow management (e.g., investigation prioritization and contact investigations).
- Outbreak response.
- Easy and timely analytical extracts.
- Full data extracts.
- CDC reporting.

The MDPH has been implementing MAVEN in a phased approach and has enhanced programmatic functionality with the addition of new workflows, reports, and variables since its initial deployment. Epidemiology and Immunization were the first modules implemented in 2006. Additional features and models to support TB, outbreak management, rabies exposures, Refugee and Immigrant Health, on-call response, hepatitis C medical management, and ESP (see below) have now been developed. The addition of STDs is in progress.

MAVEN is very easy to update or change. The MDPH can make changes without calling Consilience. Partly because of this, MAVEN is less expensive to maintain for MDPH than Scientific Technologies Corporation (STC) would have been. There are 4 levels of technical complexity for making changes:

1) simple user-instituted changes (tailoring a data collection form to an outbreak); 2) writing simple MAVEN code such as SQL [Structured Query Language] and model management enhancements, by Office of Integrated Surveillance and Informatics Services staff; 3) complex code writing, such as Java Server Pages and complex model management development work, by the MDPH IT staff, and 4) core product enhancements, which are conducted by Consilience. However, the ease with which changes can be made has raised the question of oversight/management regarding who is allowed to make changes. Changes to MAVEN are prioritized internally and also discussed at quarterly governance meetings with the LHDs. MDPH maintains a statewide help desk for MAVEN, which receives about 30–50 calls per day.

The MDPH now has 70 commercial and private laboratories and hospitals transmitting electronic laboratory reports. Only 4 clinical laboratories and 3 major national laboratories (Quest, ARUP, and LabCorp) still report on paper. The Massachusetts Bureau of Laboratory Sciences shares the same ELR system for receiving remote order entries and reporting results. Each laboratory reports in a standard format (either HL7 2.3.1 or 2.5.1) using its own local codes. MDPH then translates the messages into HL7 2.5.1 (if needed) and the codes into standardized codes (>9,500 LOINC and SNOMED combinations), using its “Diagnosis One” system. Then this information is uploaded into MAVEN, automatically creating or appending to disease events. The ELR system was certified as meeting meaningful use in February 2012 and processes over 1.5 million lines of laboratory data annually.

The MDPH received CDC funding for a Center of Excellence in Public Health Informatics in collaboration with the Harvard Medical School and the Boston Children’s Hospital Informatics Program. The Enhanced Support for Public Health Practice (ESP) initiative has developed automated disease detection and reporting for public health from electronic medical records. The system detects cases (based on CSTE case definitions) and reports them to the MDPH with patient demographics; clinician information; basis for detection of the condition; and supplemental information, such as treatment and pregnancy status, if needed and available. ESP has resulted in large increases in the number of cases detected; for example, reported gonorrhea cases increased 53%.

#### Reason for Selecting MAVEN:

Massachusetts was the first jurisdiction to use MAVEN and worked jointly with Consilience to develop much of the initial core public health infectious disease surveillance functionality. Considerations in making the decision included the specific goals listed above.

## Overview of Missouri's Core Surveillance System

Missouri has a decentralized public health system, with a population of 6 million and 115 public health jurisdictions (both counties and cities), each with its own employees. The state has staff in regional offices, but does not staff the local jurisdictions.

Missouri's NEDSS solution, called "WebSurv," is a component of the Missouri Health Strategic Architecture and Information Cooperative (MOHSAIC). WebSurv is a centralized, integrated, Web-based system that allows the Department of Health and Senior Services and local public health agency staff to enter and/or update case report information and respond to disease threats. The application includes electronic forms corresponding to the Disease Case Report form, with continuing development of disease specific case reporting forms in accordance with CDC program data needs. WebSurv data are stored nightly in a data warehouse that enables use of predefined, prompted reports and creation of complex, individualized reports. These data can be accessed by using a variety of tools (e.g., Microsoft Access, SAS, Crystal Reports). WebSurv includes all the reportable general communicable diseases, STDs, and TB, but not HIV. It went live in June 2009 and is being implemented over time. The most recent addition was the STDs in November 2011. WebSurv enables the LHDs to transfer case assignments and case management (for example, follow-up of a case of latent TB infection) to another LHD within Missouri but not to another state.

Weekly transmission of core data elements from nationally notifiable diseases/conditions to CDC occurs through NETSS. A coded file is created using an automated procedure created and managed by Information Technology Support Division staff. This file is then transmitted by the State Reporter, located in the Bureau of Communicable Disease Control and Prevention, through the Secure Data Network (SDN). In addition, some conditions are transmitted to CDC through HL7 messaging. Missouri is PHIN certified in TB, varicella, and the generic case notification messaging process.

For ELR, Missouri has only 2 national laboratories in production so far. However, state public health staff currently print out the electronic laboratory reports and re-enter them into WebSurv.

### Reason for Selecting a Custom-Built System:

Before deciding to custom-build its own system, Missouri saw demonstrations of existing systems, but none met its needs as well as a system that could be developed in-house. Also, Missouri's application could be built less expensively. Additionally, a system developed in-house would be much easier and more cost effective for future updates and enhancements.

## Overview of New Hampshire's Core Surveillance System

New Hampshire has a population of 1.3 million and a centralized public health system with only 2 full-service LHDs (in Manchester and Nashua). The Bureau of Infectious Disease Control oversees surveillance and public health services for infectious disease in the state, including full childhood immunization coverage. Manchester and Nashua conduct surveillance for all communicable diseases in their jurisdictions except for STDs, HIV, and Lyme disease, which are covered by state health department staff. The state also conducts surveillance for all diseases for all other cities and towns in the state.

The City of Nashua, Division of Public Health and Community Services, covers a population of 86,000; surveillance is overseen by an epidemiologist with a staff of 5 public health nurses. The Division provides many services, including immunizations, TB and lead poisoning screenings, community outreach and health education, tobacco prevention and control, and environmental health services and houses the city welfare office. Nashua borders Massachusetts, and more than 49 languages are spoken by students in the school district.

The Manchester Health Department services a population of 109,000. Surveillance is conducted by a staff of 4 community health nurses. Manchester is a major refugee resettlement site, with about 250–300 new refugees per year. The local poverty rate and need for health services are increasing. The health department provides immunization, dental, lead poisoning, TB, HIV, and refugee health services.

The most frequently reported infectious diseases are *Chlamydia* infections (2,484 cases in 2010) and Lyme disease (1,342 in 2010). Additionally, enteric diseases (infections from *Salmonella*, *Campylobacter*, *Giardia*, Shiga toxin-producing *Escherichia coli*, *Listeria*,) also account for a major proportion of infectious disease burden in New Hampshire as a group, with more than 500 cases reported each year. Reportable diseases are tracked in 6 different surveillance systems. New Hampshire continues to work toward more automated electronic disease reporting and integration of data systems to improve the overall reportable disease network for disease tracking, reporting, and response.

New Hampshire retained STC to implement the New Hampshire Electronic Disease Surveillance System (NHEDSS) in 2006. NHEDSS is much better than the paper system with NETSS file transmissions to CDC that existed before. In 2009, the Manchester and Nashua health departments got access to NHEDSS. They enter cases directly into NHEDSS. NHEDSS is used for all reportable infectious diseases except STDs, TB, and HIV/AIDS.

The NHEDSS application is only 1 of several key surveillance applications in use in New Hampshire to meet the PHIN initiatives and to support national efforts to detect emerging infections and track morbidity and mortality. Since 2002, New Hampshire has used various funding vehicles and staff to build PHIN-compatible systems, with several systems achieving PHIN certification. New Hampshire has achieved PHIN certification in varicella, eRVCT for TB, generic MMG, and Communicator!NXT for direct alerting. It has also deployed STD-MIS and eHARS and uses ArboNET for the reporting of arboviral diseases and the Laboratory Response Network Results Messenger for reporting both biological and chemical results to CDC using national standards for message content, structure, and transmission.

New Hampshire has begun implementing ELR, currently with reporting from LabCorp and Mayo in production in NHEDSS and eHARS. (The Association of Public Health Laboratories [APHL]/CDC ELR technical assistance was very helpful in achieving ELR for eHARS). New Hampshire is currently working toward implementing ELR with STD\*MIS and has been approved to receive technical assistance for this initiative as well. In the future, New Hampshire hopes to implement a new STD surveillance system (ideally integrated with NHEDSS) but has not identified funds for this project.

NHEDSS has some rudimentary data checks programmed into the system. The New Hampshire staff also perform annual, manual quality assurance checking of surveillance data.

The NHEDSS system at times is slow and is “down” a lot, most often because of state server and network configuration issues rather than the application itself. Entering Supplemental Form data takes a long time and is cumbersome. Overall, however, NHEDSS seems to be working “pretty well”; however, based on conversations with Massachusetts public health staff, the staff believe that Consilience’s MAVEN has more functionality.

#### Reason for Selecting STC:

In 2003, New Hampshire used PHEP funds to purchase its STC system by using the Direct Assistance mechanism, which required the selected vendor to be registered with General Services Administration. New Hampshire put out a competitive Request For Proposals and selected STC. The initial NHEDSS was implemented in 2006. The system did not have all of the required functionality at that time, and New Hampshire considered pursuing a different system. However, New Hampshire had invested considerably in the system and continued to work with STC to make NHEDSS function as intended. New Hampshire would like NHEDSS to have additional functionality but currently does not have funds to support enhancements.

## **Overview of New York State's Core Surveillance System**

New York State has a population of nearly 20 million, served by 57 local health departments (LHDs) and the New York City Department of Health and Mental Hygiene (NYCDHMH), which have primary responsibility for disease control and surveillance. The 57 LHDs report to the New York State Department of Health (NYSDOH), which sends notifications to CDC, whereas the NYCDHMH sends notifications directly to CDC. This description covers the NYSDOH's, and not the NYCDOH's, surveillance system.

### Electronic Clinical Laboratory Reporting System

The Electronic Clinical Laboratory Reporting System (ECLRS) provides all clinical laboratories with a single point for the secure and rapid transmission of disease reports, including STDs and other communicable diseases, TB, HIV, cancer, lead information, and congenital malformations test results to the NYSDOH, LHDs, and the NYCDHMH. Laboratories send reports through the use of an ASCII or HL7 file or online data entry for reportable conditions and the use of LOINC and SNOMED coding schemes. These reports are then automatically distributed to the appropriate public health authorities in the NYSDOH, LHDs, and NYCDOHMH. In July 2007, the Governor signed into law a requirement that all clinical labs and blood banks must report electronically within 1 year.

Since implementation of the ECLRS in 2001, there have been 552 reporting laboratories. The number of labs using the HL7 standard is 115 for communicable diseases, 37 for lead, 39 for HIV, and 42 for cancer. A total of 113 labs use the LOINC/SNOMED coding scheme, and 215 labs use New York's Universal Public Health Node (UPHN)MS for data transport.

### Communicable Disease Electronic Surveillance System

The Communicable Disease Electronic Surveillance System (CDESS) is a single, secure application for the 57 upstate New York LHDs, hospital infection control programs, and NYSDOH staff to collect, integrate, analyze, and report data from heterogeneous sources for infectious disease surveillance. The CDESS was designed to integrate with ECLRS so that laboratory reports of general communicable diseases, STDs, and TB data can trigger public health case investigations. CDESS also provides LHDs the capability to forward a case to another county to investigate as appropriate. The CDESS eliminates redundant data entry; has a person-centric, flexible architecture; and provides tracking and case management functions for hepatitis, STD, and other selected diseases. The CDESS provides contact tracing for TB, hepatitis, vaccine-preventable diseases, and pandemic influenza.

New York was one of the first states to build a system to replace the Tuberculosis Information Management System, with a module in CDESS for TB. Since there is an approved TB message mapping guide, TB cases are sent to OSELS at CDC from CDESS in HL7 through PHINMS.

The functions of the old CDC STD MIS have been replaced by a CDESS module for case management and partner services, which is currently accessible only by central office staff. The plan is to make it accessible to all the counties/regions for data entry and tracking. However, because use of the system requires staff training and because the STD intervention staff do not have the time for data entry, intensive training of clerical staff in the counties/regions is needed before they can use the system. Because STD does not yet have an MMG, the STD cases in CDESS are transformed into NETSS format before being sent to CDC through SDN.

**Reason for Selecting a Custom-Built System:**

CDESS was custom-built before any commercial software programs were available. New York wanted it to handle general communicable diseases, STDs, and TB and to run on its state platform.

## Overview of Tennessee's Core Surveillance System

### Surveillance

Tennessee has a population of 6.4 million and a decentralized, LHD-based surveillance system. Reports of nationally notifiable and state reportable conditions and events are received by the local, state, and regional health offices (13 public health regions). The Tennessee Department of Health (TDH) uses the NBS as its NEDSS solution for integrated disease surveillance of general communicable diseases, including TB and arboviral diseases (starting in spring 2012), as well as for the collection of Emerging Infections Program–specific data (e.g., FoodNet, Hepatitis, ABC). STD-MIS was replaced with the Patient Reporting Investigation Surveillance Manager (PRISM) System in April 2010. HIV surveillance uses eHARS. Reports received by TDH are entered into the appropriate surveillance systems.

NBS does not contain an outbreak module. Different programs use different methods for tracking outbreaks, such as paper, spreadsheets, Epi Info, and foodborne diseases outbreak software.

### Electronic Laboratory Reporting

Electronic laboratory reports are received in the form of an HL7 message following either the HL7 2.3.1 or 2.5.1 Implementation Guides for ELR to Public Health. Three national labs are currently sending electronic laboratory reports in production (LabCorp, Mayo, and ARUP); ARUP was moved into production in the late spring of 2012. Quest is engaged with TDH to begin ELR testing. TDH is actively engaged with eligible hospital meaningful-use trading partners across the state, including 3 hospital systems that are expected to move to production by the end of 2012. One of these hospital systems was actually moved into production, sending electronic laboratory reports following the HL7 2.5.1 Implementation Guide in winter 2011 but was removed because of unexpected changes to vocabulary. ELR messages are transmitted to TDH by using either secure file transfer protocol (SFTP) or PHINMS and received by TDH's communicable disease electronic data interchange (EDI) engine, Orion's Rhapsody. Messages are validated, translated (if necessary), and routed to consuming systems, including NBS, PRISM, eHARS, the Blood Lead program, and the State of Alabama (bidirectional). Work is under way to document functional and technical requirements for implementation of both NwHIN [Nationwide Health Information Network] Direct and SOAP [Simple Object Access Protocol].

The Tennessee public health laboratory uses StarLIMS v. 9 and is working with epidemiology to develop electronic laboratory reporting for surveillance and for electronic test ordering. Test results from the public health laboratory have to be manually entered into NBS and other surveillance systems (e.g., PRISM and eHARS) because the public health laboratory is still working on implementing ELR.

### Electronic Case Reporting and Notification

In addition to ELR, the NBS also provides the function that enables electronic case reporting between public health jurisdictions. This function is available as of NBS General Availability release 4.3. This infrastructure will be leveraged to support electronic case reporting from clinical reporters, as national interoperability specifications for electronic case reporting are developed. Once Tennessee has upgraded to at least General Availability release 4.3, TDH will begin exchanging case reports electronically with the Alabama Department of Health.

For conditions reported to NBS, the associated case notifications are being sent to CDC using the NEDSS Master Message or, for TB cases, varicella-associated deaths, and arboviral diseases cases, by using the HL7 2.5 message following the MMGs. As CDC publishes additional MMGs, TDH will

standardize surveillance and case notifications from NBS. Anticipated guides include those for hepatitis, STD surveillance, vaccine-preventable conditions, and the Generic Version 2 (and associated Generic Version 2 plus) guides. Case notifications from both PRISM and eHARS are submitted in NETSS format. TDH is committed to the NEDSS initiatives by adopting a more integrated approach to surveillance and plans eventually to migrate the other categorical program areas to the NBS to further integrate disease surveillance initiatives.

#### Integration and Interoperability

Tennessee continues to move toward integration and interoperability of systems. Examples of integration and interoperability with public health systems include

- Adoption of arboviral diseases surveillance within the NBS (replaced feed to Fort Collins with standard case notification message).
- Inclusion of integrated disease surveillance within TDH's Next Generation PTBMIS project (patient tracking and billing for TDH).
- Working toward implementation of a standards-based case management system that programs like integrated disease surveillance (using NBS) and the Women, Infants, and Children (WIC) program could both use within the Next Generation PTBMIS.
- Incorporating more case management into NBS. The Tennessee WIC system is integrated (will become interoperable) with the Immunization Registry to provide up-to-date immunization information to WIC personnel and for scheduling. Although the current NBS has a rudimentary contact tracing module, it lacks specific case management functionality. Future releases of the application are expected to have refined contact tracing functionality that can be made specific to conditions through the use of Page Builder technology in the application and include some basic case management functionality that is being driven by the possible inclusion of STD surveillance within the system. These are expected in 2013.

#### Reason for Selecting NBS:

1. The possibility of eventual interoperability with other public health systems.
2. Cost and support.
3. The belief that a CDC system would implement national interoperability standards and CDC requirements.
4. The opportunity to participate in the design of the system, thus maximizing the expected value to Tennessee.

## Appendix 3: Summary of Responses to the 6-State Questionnaire

1. “NEDSS Functionality: Please identify which of the following functionalities are most essential for integration into an electronic disease information surveillance system for local/state health departments to conduct *communicable disease surveillance* (including STD, TB, and HIV), those which are desirable but not essential for integration, and those that should be available in an interoperable, independent system.”

**NOTE:** Respondents varied in the way they approached this question. Some based their choices on whether they considered a particular function “Essential,” “Desirable,” or “Not Important”; others based their choices primarily on whether each function should be “Integrated” or “Interoperable.”

Functionality	Choose One			Comments
	Essential and Should be Integrated within System	Desirable, but not Essential, to be Integrated within System	Not Important to Integrate within System but to Have Available in an Interoperable Independent System	
Receive Electronic Lab Report Messages in HL7	5 States 1 LHD		1 State 1 LHD	<ol style="list-style-type: none"> <li>1. Electronic data interchange should be interoperable. Receiving app should be able to consume HL7 natively, regardless of sender.</li> <li>2. We maintain an independent ELR system that also transfers EHR information into our surveillance system.</li> <li>3. HL7 part okay to be integrated, but the system must consume electronic laboratory reports.</li> </ol>
Crosswalk Proprietary Lab Codes into Standardized Codes	2 States 1 LHD	1 State	3 States	<ol style="list-style-type: none"> <li>1. If not, then extra cost for laboratories.</li> <li>2. Should not be receiving proprietary codes.</li> <li>3. We do not do this currently for ELR and do not have plans to add the functionality at this time. Facilities that participate in ELR are expected to map to LOINC.</li> <li>4. ELR system translates local codes to LOINC and SNOMED and then sends data to surveillance system.</li> </ol>
Receive Electronic Health Record Messages in HL7	2 States 1 LHD	2 States	2 States	<ol style="list-style-type: none"> <li>1. EHR may be in CDA [clinical document architecture] format, which states are not ready to receive.</li> <li>2. EDI should be interoperable. Receiving app should be able to consume HL7 natively, regardless of sender.</li> <li>3. Though this is not something that is currently essential, it will become essential as the technology develops.</li> </ol>

Browser-based Web Data Entry	6 States 1 LHD			1. In pilot.
Remote Data Entry from Field Locations	3 States 1 LHD	2 States 1 LHD	1 State	1. Not applicable if it is Web based?
Master Patient Index to Allow De-duplication and Linking of Patient Reports	2 States 2 LHDs	1 State	3 States	1. Too expensive. 2. Use the broadest MPI [master patient index] available covering all public health functions. Do not set up an MPI for surveillance alone.
Analysis, Visualization, and Reporting	3 States 1 LHD	2 States	1 State 1 LHD	
Case Management (Specific to Disease Conditions)	5 States 1 LHD		1 State 1 LHD	1. Categorical programs should not have case management functionality; it should be interoperable, with a broad public health based case management system. Case management should not be specific by program area.
Partner/Contact Management and Notification	5 States 1 LHD	1 State	1 LHD	
Outbreak Management	3 States 1 LHD	2 States	1 State 1 LHD	1. During outbreaks, we do not have the capability to rapidly update systems to collect additional data. So, it is difficult to get LHD staff to collect supplemental outbreak case data. They use extra spreadsheets, which add work for the state staff trying to collate outbreak information.
Interoperability with Other Surveillance Systems (e.g., to match patients with co-infections such as HIV and TB)	2 States 1 LHD	2 States	2 States 1 LHD	1. HIV confidentiality doesn't allow other systems to integrate with HIV system. 2. Prefer to be fully integrated on 1 platform.
Inclusion of Business Logic (data validation, code mapping)	5 States 1 LHD			1. Can be internal or external to system. 2. When this is not integrated, it makes the entire process more difficult.
Geocoding	1 State	3 States 1 LHD	2 States 1 LHD	1. It would be nice to be a service for all systems to use.
Secure Data Transfer to CDC	6 States 1 LHD			1. Depends on infrastructure and specification.
Secure Inter-jurisdictional Data Transfer	2 States 2 LHDs	1 State	1 State	1. Do not have this capability yet.
Other? Sampling for sentinel surveillance	1 LHD			
Other? Communication with EHR, Immunization registry.			1 State	
Other? Form Building	1 State			1. It is essential to be able to have flexibility to add/remove questions from forms w/out vendor intervention.

4. “Please fill out the spreadsheet below to show all the types of information that your department sends to CDC for notifiable infectious disease case reports and summary data. You may add additional conditions or types of reports, if needed.”

<b>Disease Condition or Category of Report</b>	<b>System (e.g., NBS, Maven)</b>	<b>File Type (e.g., NETSS, HL7)</b>	<b>Transport Method</b>	<b>Transport Frequency</b>	<b>Sent to Which CDC Office?</b>	<b>Case or Summary Data</b>
Various NNDSS Conditions	CDESS (NY), MAVEN, NBS, NHEDSS (STC), Trisano, Websurv (MO)	HL7, SAS, NETSS, eHARS (XML), Hard Copy, Verbal by Telephone, ArboNET, Excel, Flat File, NBS Master Message, Web Entry on SDN, Comma Separated, eRVCT, Text	PHINMS, Filezilla, Postal Mail, Telephone, Web, sFTP, Secure File Upload through SDN, Email, FAX	Immediately, Daily, Weekly, Monthly, Annually	OSELS and Various Program Offices	Mostly Case Reports, but Some Summary Reports

5. “What are the major barriers in your current notifiable disease reporting system that prevent efficient receiving and sending of public health data between the different levels of public health? What design change (system, work process, workflow, etc.) could improve or remove these barriers?”

#### State Health Perspective

- Multiple data sets must be sent to different CDC programs on varying schedules.
- The data sets sent via NETSS can differ from data sets sent directly to programs.
- Implementing CDC message mapping guides requires state resources, and becoming certified by CDC is time consuming.
- Data submitted to CDC often do not make their way to program areas, and if they do, they are often not timely, accurate, or in a usable format. This results in requiring separate data feeds from states to fulfill notification & submission requirements.
- System decisions being made for perception and not to further functionality. For example: NBS is being enhanced to consume natively an HL7 2.5.1 ELR message so it can say that it is ready for meaningful-use purposes. However, because meaningful-use standards do not include HL7 2.3.1, backwards compatibility is not being included. So now states that will receive an overwhelming majority of their messages in HL7 2.3.1 will have to convert all of those messages to 2.5.1 for the sake of being able to consume a few 2.5.1 messages from hospitals. HL7 V 2 is backwards compatible, not upwards compatible. Converting a 2.3.1 to 2.5.1 is in violation of the standard. However, maintaining the ability to consume both would allow the system to remain compliant and conformant.
- Lack of timeliness and reliability of message mapping guides that states can implement to standardize messaging to CDC and program areas is a barrier. States are converting much of their data into NETSS, which loses rich, valuable information that is requested by CDC programs. Also, the OMB [Office of Management and Budget] process is inappropriately long. Combined with the time to develop a message mapping guide, the whole process can take 2 years or longer. If states decide to move forward prior to CDC publishing the guide, then states run the very likely risk that they will have to do the work twice, or send multiple file formats; either is unacceptable.
- Another barrier is the lack of change-control procedures by CDC program areas (constantly adding new fields without taking stock of what is already in systems such as NBS).
- Poor communication with states is a problem. For example: 1) CDC program areas not aware that states are receiving ELR; actions and messages are not always consistent; hepatitis pregnancy status problem: the CDC program area moved forward with a solution without addressing it with ELR community; 2) frequent changes in direction in informatics solutions that are poorly communicated to program areas.
- Categorical disease program staff bypassing NEDSS implementers is a major barrier. Example: Hepatitis and the pregnancy indicator.
- No useful feedback loop to quickly see what we have sent to CDC and what is missing at the individual case level—just a summary file, which is almost never an accurate count until the end of the year cleaning due to duplicates that cannot easily be identified and resolved.
- The HL7 messaging process is very slow and labor intensive on our end. No clear roadmap so that we feel comfortable committing resources (Generic 1 was replaced by Generic 2, then Generic 2 disappeared and we are being encouraged to do Generic 1). We certainly do not want to end up maintaining numerous disease-specific HL7 exports, but we cannot build it into non-NBS systems until CDC decides what it is doing.
- Currently, information requested on the many CDC programs’ forms (e.g. Rickettsial diseases, bioterrorism diseases) is not transmittable to CDC electronically.

- Knowledgebase, informatics and IT resources to build HL7 messages are very scarce in our state.
- Exchanging data between states electronically is difficult.
- eHARS does not have the ability to import HL7 messages; requires processing/maintenance in outside system.
- Data requirements from CDC can change frequently. As updates to our database cannot take place overnight, we require notification of changes as quickly as possible so that additional requirements can be planned for the next release of our database.
- Our system currently cannot process electronic reporting directly into the application. It makes it extremely inefficient since we do have a few laboratories reporting electronically, and we still have to print out the reports and enter them manually. We are working on developing a tool to manage electronic reporting, but funding and other issues have slowed that process down.
- eHARS is a document-based surveillance system, whereas all other communicable diseases housed in our system are case-based. We would like to incorporate HIV into our system, but the document-based HIV system makes this difficult to do while still meeting CDC requirements for reporting, data collection, etc.
- Multiple and incomplete streams of data are sent to CDC from multiple local systems in multiple formats.
- Often need to re-enter information in spreadsheets to upload to CDC.
- Programs unable to access necessary data and contact states for additional information.
- Metadata are not consistent across CDC.
- Categorical funding.
- For reporting to CDC, there are not enough message mapping guides available to allow for sharing of all of the supplemental data that we collect. We are often required to fax supplemental forms (*Listeria*, *Vibrio*, tickborne and rickettsial, etc).
- For reporting between states, it would be helpful to have a standard message mapping guide and then also to explore the possibility of CDC serving as a central repository for interstate notifications so that each state does not need to set up connections with 50–60 other jurisdictions. Instead, CDC could establish connections with each jurisdiction, and then we can send our interstate notifications to CDC who in turn routes the message to the appropriate state (like a post office).

#### Local Health Perspective

- Transferring information from the ELR system to the case surveillance system can be onerous.
- Duplication of investigation activities or questions asked amongst different program areas (no coordination) and the use of separate HIV and STD systems.
- Lack of understanding of the local public health business and how resources are utilized and shared across program areas makes it difficult to leverage resources. Many programs at federal and state levels operate based on funding source; but locals do not have this luxury, and surveillance is no exception.

7. “What are the most important messages/recommendations that this evaluation report should include for CDC?”

- CDC should simplify its surveillance system and its program requirements for states.
- CDC should provide stable funding support for states to maintain surveillance systems.
- NBS is cost effective and provides 1 solution for 19 states.
- Constantly changing directions and not letting solutions continue until completion is not the way to go. Long-term commitments that can be counted on by states in CDC’s planning are of great value to states, especially when looking at resource procurements and allocation.
- Continue support for the NEDSS, NBS, MSS [NEDSS message subscription services], PHINMS [PHIN messaging system]....user groups by providing administrative resources, programs when appropriate, and requiring participation on the part of the contractors.
- Be more inclusive of engagement, as opposed to less.
- Standardization! One clear method for reporting that is not complicated or resource heavy to implement on the states end is needed. (Is that asking a lot? ☺)
- CDC and state health departments must find ways to support LHDs with communicable disease surveillance.
- CDC needs to provide us with information about how the data we collect are used. Enhanced variables for STD do not appear in any reports that are disseminated for our use.
- It would be helpful to have better defined variables that are used for analysis by CDC. In some program areas we receive items, such as “additional epidemiology data,” as a variable that is reviewed for completeness for national reports. This is a rather ambiguous variable and makes it difficult for us to ensure that we are providing the complete data they are looking for.
- It would be very helpful to know that the different programs/branches are being included in the discussions for the message mapping guides for PHIN certification. We have experienced issues in the past where we thought we were providing the required elements according to the guide, and then the program denied our attempt at certification because the variables they wanted as required were not marked that way in the guide. This puts a great deal of pressure on limited time and resources to have to redo items that were thought to be completed.
- State and local health departments collect surveillance data for disease control and prevention and programmatic purposes and are not driven by CDC data requirements.
- CDC funding is inconsistent across programmatic areas and is too categorical in nature. This impedes attainment of a sustainable surveillance infrastructure.
- CDC programs share data collection elements and are not as unique in nature as depicted. Silo’d programs impede effective and rapid public health response and reduce analytic capability.
- See more of the data that we submit analyzed and used by CDC.
- Reduce length and complexity of supplemental forms to minimum necessary.
- Help states move forward with electronic interstate notifications by developing a message mapping guide and also consider serving as a central repository.
- Continue to develop message mapping guides.
- If public health surveillance is seen as a core public health service, it would be great if funding reflected this concept, since currently there are few funding sources specifically targeted to surveillance. The HIV Surveillance Grant is the only grant that is specifically targeted for surveillance, and having these funds is very helpful to maintain our core HIV surveillance activities. In stark contrast, there is no funding specifically for STD surveillance (higher disease burden), and we must take away funds intended for prevention in order to maintain STD surveillance. In the past we have relied heavily on PHEP funds to support surveillance, but with

funding cuts, this is no longer feasible. More recently, we have received ELC and ELC ACA [Patient Protection and Affordable Care Act of 2010] funds that help support public health surveillance (NEDSS position, ELR, critical messaging infrastructure, etc.); but these funds do not allow for maintenance or enhancement of our current NEDSS or other surveillance systems (TB, STD).

8. “What do you need most **from CDC** to improve surveillance practice and surveillance systems?”

- Stable and regular communications with states.
- Funding support for states to maintain integrated or interoperable surveillance systems.
- Standardization, consistency between messages and actions, support, and their commitment to get the data to the program areas without asking states to send yet another file. This is for all programs areas, including EIP, HIV/AIDS, STD, and “other” programs. CDC should make a commitment to educate its program areas in informatics so they can appropriately be a part of the discussions affecting their programs and the provided solutions. There needs to be better communication amongst the CDC program areas and widespread understanding of state’s necessity to utilize resources to solve more than 1 program area’s problems.
- We need informatics resources or knowledge base guidance to help us get up and running with HL7.
- We need deliberate, clear plans of what CDC is doing.
- A recommendation for how an LHD’s communicable disease surveillance program should be organized (i.e., for a population of 500,000, how many communicable disease investigators and epidemiologists are recommended) and funding to support these recommendations.
- Additional funding support for general communicable diseases would be very beneficial. There are some very specific programs that receive funding, but several of the nationally notifiable conditions do not receive any [or receive] very little financial support for collection and reporting of data.
- Clear cut standards for collection of core data elements are essential. The message mapping guides are assisting with this, but programs must be included in development of these guides for states’ use.
- Improved communication across CDC centers.
- Utilization of national standards to support message transport and vocabularies.
- Consistent metadata across diseases where appropriate (for example, collect race/ethnicity in the same way).
- Hearing from state and locals (similar to the recent NCHHSTP [National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention] consultation meeting).
- Consistent CDC direction and strategy.
- Technical assistance. For example, the recent CDC/APHL ELR technical assistance was very successful, efficient, and helpful.
- There are some key enhancements we would like to make to our NEDSS, such as incorporating STD and TB to really improve investigations and increase efficiencies, but we have no funds to do this work. It would be great if all of the states could receive funding to get all states functioning at least at minimum capability.

**“From CSTE?”**

- Be more independent.
- Consolidation of work groups.
- Solicitation of members to participate. It seems like the same people are always the ones participating on all the calls.
- Promote HL7 and SDOs.
- Support public health activities when working with external organizations like ONC [Office of the National Coordinator for Health Information Technology] and CMS [Centers for Medicare and Medicaid Services].

- CSTE could be very helpful with standardization and increasing communication between diverse programs.
- Training, mentoring, and fellowships specifically for LHD epidemiologists. It is hard for us to grow in our careers when we are the only epidemiologist in the agency. I also think this would give us more credibility with our peers at the LHD level.
- Continued advocacy on the part of states when issues arise that need to be communicated to CDC. It is very helpful to have a source for states to present concerns/issues to and have those be passed along to the appropriate staff at CDC.
- This evaluation is good start.
- CSTE could serve as a communications bridge between the centers.
- Write a position statement to support standards-based reporting across CDC programmatic areas.
- Continue to advocate for states, and explore, develop, and share best practices.

9. “Please comment on whether you consider ‘cloud technology’ to be a viable national tool for storing, managing, and sharing surveillance information for your state or county.”

- Cloud technology is new to us. I’m not sure about its security. I would like to wait and see.
- Not at this time, no. Putting data in a cloud just changes its location; it doesn’t necessarily solve the problems. Cloud technology is a technological solution to what may not be a technological problem. Depending on a jurisdiction’s IT infrastructure and requirements, cloud environments and open-source solutions may not be feasible.
- Yes! We are using cloud technology to host our NEDSS system.
- I definitely think it is.
- Our state moved the STD data servers to the state IT office and now use cloud technology to access it. Cloud technology has major cost advantages. They implemented stringent security policies. However, the epidemiology staff have major security and ownership concerns about cloud technology for storing state data at the national level. They also believe that the entire concept is not well understood by many, and it has different meanings for different people. Until reasonably clear vision is articulated to the states, it will be difficult for our state to pledge participation. The legal foundation for such a data transfer out of state will also require major consideration and review.
- Sure—but it won’t improve surveillance practice or data unless the aforementioned issues are resolved.
- We have concerns about security and confidentiality of the data. It would require further exploration and consultation with our IT staff and HIPAA Security Officer.

10. “Please add any other comments that you believe are important for improving notifiable disease surveillance at the state/local levels.”

- Mandatory training for local health staff on a state’s NEDSS system is important.
- Informatics education.
- The system/process needs to be easy for health care providers to notify their local or state health departments.
- Building a QA [quality assurance] process that can be used by LHDs to ensure we are entering data correctly into NEDSS and investigating cases appropriately. QA processes that are built into the NEDSS system would also be helpful. For example, if a case has been open in NEDSS for a prolonged period of time, it should get “flagged” or somehow brought to attention of the staff.
- Streamlining, as much as possible, all the various types of databases that get used for tracking infectious diseases into 1 database. Creating functionality to include outbreaks into NEDSS would assist with the maintenance of data and reporting features of outbreaks.
- Although the need to enter data from the field into NEDSS is not needed for normal day-to-day activities, expanding this function may be beneficial if there is a large public health incident, such as an anthrax outbreak with large-scale illness where this feature would be useful.
- If NEDSS were expanded to include outbreak investigations, geocoding would be a nice feature to have so that the locations of patients could be mapped.

## Appendix 4: Description of 1 State's Surveillance Challenges

It is instructive to understand 1 state's challenges with surveillance processes in some detail, challenges that are common to many states.

This state has a core surveillance system that falls short of meeting many staff needs. The state would like to allow some reporters (e.g., infection control nurses in hospitals) to enter case information into their system. However, as currently configured, the system allows the original reporter to see all subsequently added case information, regardless of its origin. Such access to information presents confidentiality concerns. Adding non-public health reporters to the system would require reprogramming the system. Another limitation is that their system does not have outbreak management capability. Outbreaks are currently managed on paper. Despite the use of a core system, this state still has reportable diseases tracked in 6 different surveillance systems (its core system, eRVCT, STD-MIS, eHARS, ArboNET, and another system for direct alerting) and reported to CDC through 4 mechanisms (exports of data uploaded to SDN, data entry into CDC Web applications, HL7 messaging from eRVCT, and HL7 messaging from NEDSS for those conditions meeting the CDC MMGs for Generic v 1.0 and varicella).

To gather case information about the high volume laboratory reports for Lyme disease and chlamydia, the state surveillance office generates "Dear Doctor" letters to request the needed information for surveillance. The letters are generated using MS Access and Word through mail merge, which is a cumbersome manual process. The state lacks the resources to change to an electronic, automated process.

The state uses 3 data systems for TB case management and information: 1) eRVCT, where cases are keyed into the system and sent to CDC through an automated process in HL7 format; 2) NEDSS, where case assignments, management, and notes are maintained; and 3) Access database, where information about TB contacts and latent TB infection cases is kept. Although the system vendor has developed a functional TB program area module, it is too costly for this state.

The state is using CDC's STD-MIS, which has shortcomings; for example, it does not send all the HIV partner services contact information to CDC, and electronic laboratory reports must be hand entered.

HIV/AIDS data are maintained in eHARS and sent to CDC monthly through SDN. Only about one third of HIV/AIDS lab reports come in electronically; the other two thirds are paper-based and hand entered into eHARS. However, even the electronic reports are uploaded through a manual, multistage upload process into eHARS.

## Appendix 5: eHARS Comments

States reported that eHARS was a robust system that generally does a good job in managing HIV/AIDS data and providing notifications to CDC. A major problem with the system is the long time (e.g., years) that it takes CDC to upgrade the system. The following were some of the states' comments regarding needed eHARS upgrades:

- Calculated variables listed on the bottom of the Person View page should be updated for EVERY document entered, not just those initially entered to create the Adult or Pediatric Case report Form.
- Updates to eHARS seem to occur much too slowly to keep up with data demands from the Health Resources and Services Administration and new CDC cooperative agreements; this may be the result of this surveillance system trying to be “all things for all people.” It may be time to reevaluate exactly what CDC should be using this database for and keep major additions of variables to a minimum.
- The “Presumed Heterosexual” category for females has been discussed and approved for some time, although this is not reflected in eHARS in how exposure category is calculated.
- eHARS lacks upload functionality for pediatric cases. States with large numbers of pediatric cases have the significant burden of re-entering these cases into eHARS. A pediatric upload function has been requested for years.
- eHARS and the STD system need to be interoperable, if not integrated. Often cases are entered into multiple systems, taking up valuable field staff time and potentially causing data errors.