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Modernizing Notifiable Disease Surveillance

August 7, 2014

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Seizing the opportunity provided by new technology and evolving data and exchange standards, CDC is now modernizing one of its most important public health surveillance systems: the [National Notifiable Diseases Surveillance System](#) (NNDSS). As part of the recently released [CDC Surveillance Strategy](#), the [NNDSS Modernization Initiative](#) (NMI) is underway to strengthen the system's surveillance capabilities to provide more comprehensive, timely, and higher quality data than ever before for public health decision making.

"NMI is a true CDC-wide effort because the modernization of NNDSS requires the collaboration of multiple CDC programs and their subject matter experts (SMEs)," stated Paula Yoon, ScD, MPH, division director, Division of Health Informatics and Surveillance (DHIS). "In addition, NNDSS represents a partnership across the whole public health enterprise, including CDC, public health jurisdictions, and partner organizations."

Within CDC, the NMI team in DHIS, Center for Surveillance, Epidemiology, and Laboratory Services (CSELS) is leading the development of the health information infrastructure needed to support NNDSS. Also, the NMI team currently is working hand-in-hand with SMEs in programs from the Office of Infectious Diseases (OID), who are leading the effort to develop disease-specific data elements for new Message Mapping Guides (MMGs) for disease case notification.

NMI also involves partners outside CDC. The NMI team is collaborating with the Council of State and Territorial Epidemiologists (CSTE) and the Association of Public Health Laboratories (APHL) to gain their expertise, insight, and assistance to implement MMGs in jurisdictions.

"Effective planning, collaboration, and communication among all stakeholders are crucial for the success of a project with the complexity and scope as large as NMI," stated Aaron Aranas, MPH, MBA, acting NMI program manager.

NMI is a multi-year initiative, and one of its main goals is to increase the robustness of the NNDSS technological infrastructure so that it is based on interoperable, standardized data and exchange mechanisms. The first major NMI milestone is that, by early 2015, CDC's STD, hepatitis, mumps, and pertussis programs are expected to receive timely, complete, and high-quality data from certain jurisdictions through the new CDC Platform (CDCP), a data and software platform that is the backbone of NMI. When this important milestone is achieved, CDC will increase the number of conditions and jurisdictions using the CDCP for NNDSS as well as develop new MMGs for case notifications.



CDC staff involved in the National Notifiable Diseases Surveillance System (NNDSS) Modernization Initiative (NMI) attended the 2014 Council of State and Territorial Epidemiologists Annual Meeting. Back row (l-r): Aaron Aranas, acting NNDSS program manager, DHIS; Ralph Coates, acting associate director for science, DHIS; Tonya Martin, senior advisor for informatics, OID. Front row (l-r): Paula Yoon, director, DHIS; Michele Hoover, NMI technical assistance lead, DHIS; Ruth Jajosky, Message Mapping Guide lead, DHIS.



Ruth Jajosky (c), Message Mapping Guide (MMG) lead, DHIS, provides an update on MMG developments at a recent National Notifiable Diseases Surveillance System Modernization Initiative biweekly coordination meeting with the Office of Infectious Diseases. Also pictured is Sandy Chapman (left), CDC

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"NNDSS is critically important to the national public health surveillance infrastructure, and its modernization will improve notifiable disease data collection, sharing, and analysis across the entire public health community," stated Sandra Roush, MT, MPH, surveillance officer, NCIRD. "The challenges around data collection, access, and management have been very significant, and the NNDSS Modernization Initiative is a welcome step forward in addressing those issues."

National Notifiable Diseases Surveillance System

In 1961, CDC assumed responsibility for collecting and publishing data concerning nationally notifiable diseases and began publishing the *Morbidity and Mortality Weekly Report (MMWR)* with notifiable diseases data on January 13, 1961. Launched several decades ago, the National Notifiable Diseases Surveillance System helps CDC to meet this responsibility.



NNDSS is a nationwide collaboration that enables all levels of public health (local, state, territorial, federal, and international) to share health information required to monitor, control, and prevent the occurrence and spread of state-reportable and nationally notifiable infectious and some noninfectious diseases and conditions.

NNDSS is a multifaceted program that includes the surveillance system for collection, analysis, and sharing of health data. It also includes policies, laws, electronic messaging standards, people, partners, information systems, processes, and resources at the local, state, and national levels. Many state, local, and territorial (SLT) health departments, CDC, academia, and partner organizations such as CSTE use NNDSS to:

- collect, manage, share, analyze, interpret, and disseminate health-related data for state-reportable and nationally notifiable diseases and conditions;
- develop and maintain national standards—such as consistent case definitions and electronic messaging standards;
- monitor regional and national trends in diseases and health conditions;
- work with other jurisdictions and partners to implement and assess prevention and control programs;
- designate certain diseases and conditions as nationally notifiable;
- submit data on nationally notifiable diseases to CDC; and
- maintain and publish the official national notifiable diseases statistics from 57 state, territorial, and local jurisdictions in *MMWR*.

CDC Surveillance Strategy

Because NNDSS provides such important surveillance data and services to health jurisdictions and to CDC programs, modernizing it is one of the initiatives outlined in the new CDC Surveillance Strategy. CDC launched the agency's surveillance strategy in February 2014 to improve the agency's activities in public health surveillance. The CDC Surveillance Strategy aims to improve CDC's overall surveillance capabilities and, by extension, those of the public health system at large. The strategy guides efforts to make essential surveillance systems more adaptable to the rapidly changing technology landscape, more versatile in meeting demands for expanding knowledge about evolving threats to health, and more able to meet the demands for timely and population-specific and geographic-specific surveillance information. The strategy will also facilitate work to consolidate systems, eliminate unnecessary redundancies in reporting, and reduce reporting burden. The three major goals of the CDC Surveillance Strategy are to

Platform lead, DHIS; and Robert Nelson, health scientist, Surveillance and Data Management Branch, Division of STD Prevention, NCHHSTP.

The Division of Health Informatics and Surveillance (DHIS) hosts biweekly NNDSS Modernization Initiative coordination meetings with SMEs in programs from OID. Back row (l-r): Aranas, acting NNDSS program manager, DHIS; Dan Morris, NMI logistical support; Tonya Martin, senior advisor for informatics, OID; Ralph Coates, acting associate director for science, DHIS. Front row (l-r): Ruth Jajosky, Message Mapping Guide lead, DHIS; Sandy Chapman, CDC platform lead, DHIS.



The National Notifiable Diseases Surveillance System Modernization Initiative (NMI) team works hand-in-hand with subject matter experts in programs from the Office of Infectious Diseases, who are leading the effort to develop disease-specific data elements for new Message Mapping Guides for disease case notification. (l-r): Ben Kupronis,

- | | |
|---|---|
| <ol style="list-style-type: none"> 1. enhance the accountability, resource use, workforce, and innovation for surveillance at CDC and in support of SLT agencies; 2. accelerate the utilization of emerging tools and approaches to improve the availability, quality, and timeliness of surveillance data; and 3. improve surveillance by addressing data availability, system usability, redundancies, and incorporation of new information technologies in major systems or activities. | epidemiologist, Epidemiology and Surveillance Branch, Division of Viral Hepatitis, NCHHSTP; Julie Zajac, NMI monitoring and evaluation lead, DHIS; Jason Hall, IT specialist, Scientific and Program Services Branch, Division of Preparedness and Emerging Infections, NCEZID; and Paula Yoon, director, DHIS. |
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NMI is one of four initiatives to address goal number three.

NMI Key Components

The initiative to modernize NNDSS began in January 2014 and is planned for five years with short-term deliverables in the first year and long-term activities in the following two to five years. NMI has three key components:

1. development of prioritized Message Mapping Guides for case notification;
2. development of the CDC Platform; and
3. technical assistance for implementation of MMGs in jurisdictions submitting case notifications to NNDSS.

Accelerate Standardization and Development of Message Mapping Guides

The DHIS NMI team is collaborating with SMEs from programs within OID and with jurisdiction partners and key stakeholders to accelerate the development and adoption of new-generation Message Mapping Guides for NNDSS case notifications.

CDC is developing new MMGs to support collection, transmission, and analysis of data needed at the national level for public health surveillance. In doing so, CDC is implementing messaging standards and vocabulary standards in case notifications. For some diseases and conditions, the epidemiology of the notifiable disease has changed over time and new data are needed about risk factors or new clinical information is needed, such as laboratory tests and results, vaccination information, and treatment information. For other nationally notifiable diseases, CDC previously received only generic data but now needs disease-specific data.

“With these guides, CDC will migrate from legacy messaging structures to the widely adopted Health Level Seven (HL7) standards and standardized vocabulary that provide content standardization and interoperable message exchange structures,” stated Ruth Jajosky, DMD, MPH, NMI MMG project lead. “In addition to providing core data elements and data exchange formats, these new MMGs will satisfy CDC program requests for disease-specific variables for notifiable conditions.”

The DHIS NMI team worked with SMEs in CDC programs to prioritize the following six MMGs for development and implementation in the first year of this initiative:

- 1) Generic Guide v2
- 2) STDs (syphilis, gonorrhea, chlamydia)
- 3) Hepatitis
- 4) Congenital Syphilis
- 5) Pertussis, and
- 6) Mumps

These disease areas were selected because they either cover a large volume of data in NNDSS or were identified as high-priority conditions.

“Data from NNDSS for public health decision making are critical for our center’s programs,” stated Hillard Weinstock, MD, branch chief, Surveillance and Data Management Branch, Division of STD Prevention, NCHHSTP. “During this first phase of NMI, implementation of MMGs for STDs is a priority as STDs make up more than 85 percent of all case reports to CDC. We hope that the data sent to CDC by jurisdictions who use these new MMGs will be more complete and of higher quality than ever before. We look forward to using these improved data to enhance our public health decision making.”

“The CDC Hepatitis Program has invested time and expertise with CSELS to co-develop the Message Mapping Guide for viral hepatitis case notifications,” stated Ben Kupronis, MPH, epidemiologist, Epidemiology and Surveillance Branch, Division of Viral Hepatitis, NCHHSTP.

"NMI is currently using industry-standard technologies to implement our guide. We look forward to the full implementation of the guide in all jurisdictions and the ability to analyze and report all the information we collect on our case report form. It will not happen overnight, but we realize that surveillance is a process and CDC is taking the long view to ensure that we are doing it right."

The NMI MMG team has posted draft versions of the priority six MMGs on the newly launched [NNDSS Draft Message Mapping Guides Web page](#). During each guide's six-week open comment period, SLT public health surveillance staff had an opportunity to review and comment on each MMG; now the guides are being reconciled according to the feedback received. As more draft guides are completed for review throughout the entirety of the NMI, the NMI MMG team will post them to the NNDSS Draft MMG Web page.

Develop the CDC Platform to Support the Electronic Exchange of Surveillance Data

CDC will replace the existing NNDSS messaging infrastructure with a state-of-the art standardized data and software platform—the [CDC Platform](#)—that facilitates the receipt and distribution of notifiable disease data.

"States will implement MMGs, and CDCP will support collection of data through these new guides and data exchange services, which will result in more comprehensive, more accurate, and timelier information than ever before provided to CDC programs," explained Sandy Chapman, BS, CDCP program manager.

The CDCP will be developed incrementally in five proposed phases. In Phase I of the CDCP effort, the CDCP Message Validation and Processing System (CDCP-MVPS), a component of the CDCP, will allow CDC programs to receive, process, and provision health-related data on a unified platform. In the United States today, many types of health data flow into a number of public health information systems. With multiple systems, health data entry, exchange, receipt, storage, and processing services and systems are often duplicated across the public health community. The CDCP-MVPS will help to alleviate this duplication.

Phase I of the CDCP development will be considered complete when messages within the priority disease lines (STDs, Hepatitis, Mumps, Pertussis, Generic, and Congenital Syphilis) are processed in the CDCP-MVPS and successfully provisioned to the appropriate CDC programs that use the data. The goal is to have Phase I completed by early 2015.

Phase II of the CDCP development will overlap with Phase I and is scheduled to be deployed in early 2015. Phase II will include a CDC-built and operated data and software platform that will run in a cloud-based environment that, once complete, is compliant with federal network security standards and certified by the Federal Risk and Authorization Management Program. Phase II will not focus on migrating to the cloud but will concentrate on developing a platform that will run in a cloud-based hosting environment at the end of Phase III.

The time frame for future phases will be determined as the work of Phase I and Phase II progresses.

Provide Technical Assistance and Support for Program Implementation

During the initial phase of NMI, CDC is partnering with CSTE and APHL to provide technical assistance to certain state and local jurisdictions to implement the initial six MMGs. Through this technical assistance, CDC and its partners will help jurisdictions adopt the MMGs and use them to send test case notification messages to the CDCP to ensure that these messages will be properly received, processed, and stored for analysis through this new platform.

"To help jurisdictions adopt the MMGs and successfully send notifiable disease data through the CDCP, CDC will collaborate with CSTE and APHL to provide direct technical assistance and training in the form of webinars, online technical guides, and other training materials to support implementation," stated Michele Hoover, MS, NMI technical assistance team lead.

"CSTE plays a major role in advancing public health policy and epidemiologic capacity by supporting systems such as NNDSS, which is critical to tracking nationally notifiable diseases and conditions," stated Jeff Engel, MD, executive director, CSTE.

"As NMI progresses, we look forward to collaborating with CDC and APHL to ensure that jurisdictions receive the technical assistance they need as they implement these new MMGs."

"We have a lot of exciting technical assistance activities, such as needs assessments and hands-on and virtual training, planned for NMI," stated Patina Zarcone, MPH, director of

informatics, APHL. "Our goal is to develop technical assistance solutions that can be reused across jurisdictions and to build jurisdictions' capacities to implement current and future MMGs."

DHIS also is collaborating with the Division of Scientific Education and Professional Development (DSEPD), CSELS, in two key areas. The Public Health Informatics Fellows Program in DSEPD is helping to plan and will support MMG implementation with the assistance of two informatics fellows. In addition, the Educational Design, Continuing Education, and Learning Services Branch in DSEPD provides expertise to NMI in developing training materials and online education for SLT agencies.

The DHIS NMI team is working with CDC programs and CSTE to identify the jurisdictions who will pilot the MMGs and technical assistance process. These jurisdictions will be selected on several criteria, including a jurisdiction's technical capability and readiness to participate and its scalability of solutions and lessons learned that can be used in other jurisdictions.

After the initial phase of NMI, all jurisdictions will be invited to adopt the MMGs and send case notification messages to CDC through the CDC Platform. CDC will measure its success in the NMI effort by the following NMI performance objective from the CDC Surveillance Strategy: By 2016, 90 percent of data reported through NNDSS will be by standard HL7 messages.

Julie Zajac, MPH, NMI monitoring and evaluation lead, will spearhead the evaluation of the NMI process to improve efficiencies and promote sustainability for CDC and SLT agencies in the long run. "As NMI progresses, we will identify lessons learned and best practices for both SLT agencies and CDC that will be applied to ongoing phases of this initiative," she stated.

The Way Ahead

In addition to the key NMI components mentioned above, longer term NMI activities to be accomplished in the next two–five years include the following:

- Continue development and implementation of MMGs.
- Implement and enhance the CDCP:
 - Continue to enhance the CDCP Message Validation and Processing System.
 - Initiate cloud implementation.
 - Develop and implement other services and components of the CDCP.
- Ensure standards and harmonization.
- Retire the National Electronic Telecommunications System for Surveillance.
- Determine the future direction of the National Electronic Disease Surveillance System Base System.

"NMI is an ambitious initiative with many facets, all designed to strengthen and enhance reporting and use of notifiable diseases data for jurisdictions and the public health programs that depend on these important data," stated Michael F. Iademarco, MD, MPH (CAPT, USPHS) director, CSELS. "This important initiative—and enhanced collaboration between CDC and its NNDSS partners—will pave the way for public health notifiable disease surveillance in the future."

This *Inside Story* by Lisa Bastin

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JoAna Stallworth says:

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