

15-EB-01

Committee: Executive Board**Title:** Common Data Structure for National Notifiable Diseases**I. Statement of the Problem:**

Over the past 10 years, jurisdictions contributing to the National Notifiable Disease Surveillance System (NNDSS), which include the 50 states, 5 territories, the District of Columbia and New York City, have been transitioning the information system used to notify the Centers for Disease Control and Prevention (CDC) from the National Electronic Telecommunications System for Surveillance (NETSS) to the National Electronic Disease Surveillance System (NEDSS). NEDSS, along with immunization, laboratory management systems and cancer registries, heralded the modern informatics age for the government public health sector including the use of interoperable platforms, electronic laboratory reporting (ELR) from clinical and public health laboratory information management systems (LIMS). These advances have led to the near replacement of paper reports of mandated reportable diseases in the jurisdictions with electronic reporting, analysis, visualization and management of the 71 infectious and 5 non-infectious conditions that make up the National Notifiable Diseases Surveillance System (NNDSS).

The CDC has provided technical and financial assistance to the jurisdictions through its Centers and the Epidemiology and Laboratory Capacity for Infectious Diseases (ELC) and Public Health Emergency Preparedness (PHEP) Cooperative Agreements. In the initial development phase of NEDSS, CDC provided the blueprint for NEDSS data structure, known as the Public Health Informatics Network (PHIN) message mapping guides and related system architecture. CDC developed, and still maintains, a government-off-the-shelf software product known as the NEDSS Based System (NBS) currently used by 22 jurisdictions. Other jurisdictions have opted for either commercial or home-grown NEDSS-compliant software. Regardless of the software used, because federal funding required PHIN standards for the platform, jurisdictions built their NEDSS and NEDSS-compliant systems accordingly. This should have led to a single, harmonized process of electronic notification from the jurisdictions to the CDC NNDSS.

Instead, the CDC receiving platform has not complied with its own PHIN standards. Adoption of national vocabulary standards and data transmission protocols (such as message mapping guides [MMGs]) are helpful only when all disease programs implement them uniformly and means for accessing the data once received at CDC are also supported. Programs in the CDC Centers still utilize legacy systems such that today CDC has 126 registered surveillance systems working independently, all contributing separately to NNDSS. Many CDC systems are only able to consume NETSS message transmissions. In addition, jurisdictions submitting case notifications are asked by various CDC programs to submit supplementary or duplicative data in a variety of formats (fax, SAS, XML, HL7, hard copy, excel, flat file, comma separated, web data entry), submission processes (email, fax, SAMS, web data entry, NETSS) and timelines (Immediately, Daily, Weekly, Monthly, Annually). Specific examples include, but are not limited to: paper submission for malaria, brucellosis, and *Vibrio*; Excel spreadsheet for animal rabies; and hand data entry for ArboNET and pediatric influenza mortality data. This has led to tremendous additional burden to the jurisdictional notification and data reconciliation processes, and represents a serious programmatic and technical flaw in national disease surveillance modernization.

The failure of CDC and the Department of Health and Human Services (HHS) to invest in advancing and harmonizing its surveillance systems impairs jurisdiction response to public health threats. Jurisdictions receive delayed information as a system and the inefficient transmission across CDC results in a weaker public health system. Utilizing IT support and the science of informatics to design system architecture could relieve jurisdiction and federal staff from routine activities that have no added value to epidemiology so that they can more effectively use their time to solve public health problems. 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 (1). Issues related to funding, and surveillance and informatics capacity at state, tribal, local, and territorial (STLT) levels were prominent, but the need for increased coordination among CDC programs, including use of common standards for surveillance including submission of case notifications was the most commonly identified priority issue otherwise¹. In September 2013, in response to clear calls for action from Congressional staff, state and local health officers and epidemiologists, the Council of State and Territorial Epidemiologists (CSTE), the Association of State and Territorial Health Officials (ASTHO), and other partner organizations, the CDC Director issued a directive to CDC leadership that called for a new surveillance strategy that encompassed four broad concepts:

1. Improve availability and timeliness of surveillance data to CDC programs, STLT agencies, and other stakeholders (public data)
2. Advance effective use of emerging information technology, including electronic health records, mobile technologies, and cloud computing
3. Identify and amend or retire ineffective or unnecessarily redundant CDC surveillance systems
4. Maximize the effectiveness of available agency resources devoted to surveillance and the performance and coordination of CDC surveillance systems.

In 2013, CDC reorganized the Office of Surveillance, Epidemiology and Laboratory Services (OSELs) into the Office of Public Health Scientific Services (OPHSS) under which are the National Center for Health Statistics (NCHS) and the newly created Center for Surveillance, Epidemiology and Laboratory Services (CSELS). OPHSS was charged to formulate, direct, and implement a CDC Surveillance Strategy, and in January 2014, the strategy was released internally at CDC. Importantly, the Strategy called for cross-cutting programmatic initiatives, one of which is the NNDSS Modernization Initiative (NMI). NMI seeks to achieve PHIN standards for the NNDSS within all CDC programs. CSELS redirected some of its funding in the CSTE Cooperative Agreement to begin work on the NMI and to prepare a PHIN-compliant CDC platform to receive jurisdictional notifications to the NNDSS. The original project plan with CSTE was to implement the 6 message mapping guides in 10 jurisdictions' NEDSS with regular and validated transmission to the CDC platform by January 2015. As this Position Statement is being written, the NMI project has been modified to implement 3 guides in 10 jurisdictions by December 2015.

The CDC/CSTE/Association of Public Health Laboratories (APHL) NMI project was discussed extensively at a surveillance and informatics pre-conference workshop at the CSTE Annual Conference in Nashville, TN in June 2014. At that meeting, CSTE subject matter experts (mainly surveillance and informatics epidemiologists) and CSELS technical monitors on the NMI agreed that alignment of the data structure (also known as harmonization) across all conditions in the NNDSS was ideal. CDC and the jurisdictions would save a good deal of time and money for change management of NEDSS if harmonization was done first with all message mapping guides rather than iteratively. Up front harmonization was emphasized in a letter to the OPHSS Director from the CSTE President and Executive Director in July 2014, to which CSTE has not yet received a response.

The NMI pilot project kicked off on June 13, 2014, and to date has been challenging and has already experienced significant slippage. The approach to the NMI has been iterative with only 6 MMGs, more than two have already experienced significant delays and there remains evidence of resistance from some CDC Offices, Centers, Institutes and programs to fully engage in the process. At this juncture, the CSTE Executive Board is very concerned that the current implementation path is at risk for failure because of the lack of support from all participating NNDSS programs. This joint project would greatly benefit from increased attention and resources. HHS and CDC need to prioritize the ongoing work of the modernization initiative and provide resources to accelerate the completion of the MMGs and data collection system, the implementation of the new systems and standards by states, and the retirement of the outdated legacy systems.

The lack of this action is inhibiting NNDSS modernization and the success of the CDC Surveillance Strategy, and continues to place a burden on STLT programs. It is now time for CDC Offices, Centers, Institutes, and programs to implement and adhere to PHIN standards.

II. Statement of the desired action(s) to be taken:

As a reasonable goal, CSTE asks that by the end of the Healthy People 2020 cycle, a single harmonized and standardized data structure, vocabulary, format and electronic transmission process will be implemented by CDC for all NNDs, and alternative file formats and submission processes will be eliminated and legacy systems retired. All actions possible within existing resources should be taken, and those actions requiring additional resources should be prioritized for future funding. CSTE asks CDC and HHS to prioritize funding for these efforts.

CSTE asks CDC to:

1. With all deliberate speed and with a date certain, the CDC director should direct all Offices, Centers and Institutes to develop and implement a common data structure, vocabulary, format and electronic transmission process for receiving case notifications from jurisdictions in the NNDSS.
2. Make substantive progress in the current NMI (3 MMGs implemented in 10 states by December 2015).
3. Develop message mapping guides (MMG) for remaining diseases and accommodate reporting of ancillary information in alternative file formats. Guides will be provided in a time window that gives STLTs ample opportunity to develop, test and implement the message. Up front harmonization should be prioritized and be applied across Centers.
4. Adopt funding guidelines and restrictions to take the “one message, one vocabulary, one portal” approach into account, thereby enhancing efficiency of workflow, reducing costs, and improving surveillance data quality. In parallel with the need to update STLT surveillance systems to comply with changes toward harmonization, CSTE recommends that CDC cover related costs through all future Cooperative Agreements that fund surveillance systems with STLT grantees.
5. Empower an intergovernmental working group that produces a document by January 2016 on the framework of agency-wide surveillance standardization and harmonization that includes management of control points requiring CDC check-off and approval (e.g. before submission of a new package to the Office of Management and Budget). This workgroup would also serve to review new surveillance requests in an effort to reduce development or propagation of new surveillance systems or case notifications. CSTE recommends two CSTE members (designated by the Executive Board) participate in the work group.
6. By January 2016, have a 4-year plan that schedules the retirement of all legacy surveillance systems and alternative file formats and submission processes for NND.
7. By January 2017, at the request of a jurisdiction, accept all routinely collected surveillance data for NNDs, including ancillary data requests, (e.g., web data entry, paper case report forms, Excel files) through the NNDSS portal. CDC will be responsible for transporting NND data to programs at CDC as needed.
8. Any forms used for data collection during emergency events or outbreaks would utilize existing and harmonized data elements.

III. Public health Impact:

Effective, efficient, and timely public health surveillance is the best foundation for protecting the public from threats to health and well-being. While advances in health information technology make possible advances in public health surveillance efficiency, these advances can only be fully realized through harmonization of data structure and flow within and across public health data systems.

The multiplicity of “siloes,” independent, non-interoperative CDC programs and their surveillance systems’ requirements for supplementary data unnecessarily divert surveillance resources at the STLT level. Because of the lack of alignment of data collection processes and structures among CDC programs, a common data use agreement (DUA) and data re-release guidelines cannot be developed and finalized between CDC and states (reference to 11-SI-01). Individual CDC program areas continue to work in siloes to establish their own data processing procedures for specific topics, with or without state input, resulting in states’ data being used and shared according to each particular program and subject area, rather than in one uniform fashion by CDC.

Data structure harmonization and improved interoperability require investment of additional resources in order to facilitate integration with the electronic medical record (EMR) Meaningful Use functionality and support public health case reporting from the EMR, which is one of the strategic priorities of the Office of the National Coordinator for Health Information Technology (ONC). Integration with the EMR Meaningful Use functionality is dependent on interoperability, so there is great potential for harmonized data in NNDSS to facilitate public health case reporting from the EMR. Additionally, adoption of national harmonized standards for case notifications would be transferrable to support electronic interstate reciprocal notification of diseases between STLTs.

Investment in up front harmonization at CDC, with fully interoperative surveillance systems, will free up STLT resources that are now used to maintain often duplicative, parallel direct and indirect communications with multiplicative data systems. It will also reduce opportunities for miscommunication and error. Additionally, STLT surveillance and informatics resources will be made available to improve receipt of data of public health import from the healthcare community (e.g. electronic case reporting, electronic laboratory reporting, etc.) Before and throughout the harmonization process, change management policies must be identified and maintained. CSTE understands that MMGs and/or message structures will need to be updated as part of harmonization, but CDC needs to be judicious about making non-critical changes to prevent extraneous costs due to frequent changes to STLT surveillance systems.

IV. References

1. Smith, Perry F. *Review of and Recommendations for the National Notifiable Disease Surveillance System: A State and Local Health Department Perspective*. Publication. Council of State and Territorial Epidemiologists, Apr. 2013. Web. <http://c.ymcdn.com/sites/www.cste.org/resource/resmgr/PDFs/NNDSS_Report.pdf>.
2. CSTE Letter to CDC Surveillance Leadership Board (to be *posted* online for citation)
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4. 00-EC-03: Need for Coordination of NEDSS, HAN, and Epi-X, 2011. <<http://c.ymcdn.com/sites/www.cste.org/resource/resmgr/PS/2000-EC-3.pdf>>
5. 97-EC-01: Implementation of National Public Health Surveillance System, 1997. <<http://c.ymcdn.com/sites/www.cste.org/resource/resmgr/PS/1997-ec-1.pdf>>

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