07-EC-02

Committee: Executive

Title: CSTE official list of Nationally Notifiable Conditions

Statement of the Problem:

The federal American Health Information Community (AHIC) Biosurveillance Workgroup (now re-titled Population Health & Clinical Care Connections Workgroup) was charged with developing recommendations "to implement the informational tools and business operation to support real-time nationwide public health event monitoring and rapid response management". In early 2007, the workgroup and AHIC adopted case-reporting recommendations which included:

- *Recommendation 2.0* By April 30, 2007, CSTE, in collaboration with CDC, should define an on-going process to be used in establishing a common list of nationally notifiable conditions to be reported to all levels of public health and their associated standardized case definitions including the data elements to be reported.

- *Recommendation 2.1* By August 1, 2007, CSTE, in collaboration with CDC, should provide to HHS the common list of nationally notifiable conditions and the first set of case definitions including the list of common and disease specific data elements to be reported. Subsequent sets of case definitions will be delivered on a scheduled basis as defined by the process resulting from Recommendation 2.0 above.

The National Notifiable Diseases Surveillance System is described by CDC as follows (http://www.cdc.gov/epo/dphsi/nndsshis.htm):

- In 1878, Congress authorized the U.S. Marine Hospital Service (i.e., the forerunner of the Public Health Service [PHS]) to collect morbidity reports regarding cholera, smallpox, plague, and yellow fever from U.S. consuls overseas; this information was to be used for instituting quarantine measures to prevent the introduction and spread of these diseases into the United States. In 1879, a specific Congressional appropriation was made for the collection and publication of reports of these notifiable diseases. The authority for weekly reporting and publication of these reports was expanded by Congress in 1893 to include data from states and municipal authorities. To increase the uniformity of the data, Congress enacted a law in 1902 directing the Surgeon General to provide forms for the collection and compilation of data and for the publication of reports at the national level. In 1912, state and territorial health authorities--in conjunction with PHS--recommended immediate telegraphic reporting of five infectious diseases and the monthly reporting, by letter, of 10 additional diseases. The first annual summary of The Notifiable Diseases in 1912 included reports of 10 diseases from 19 states, the District of Columbia, and Hawaii. By 1928, all states, the District of Columbia, Hawaii, and Puerto Rico were participating in national reporting of 29 specified diseases. At their annual meeting in 1950, the State and Territorial Health Officers authorized a conference of state and territorial epidemiologists whose purpose was to determine which diseases should be reported to PHS. In 1961, CDC assumed responsibility for the collection and publication of data concerning nationally notifiable diseases.

- The list of nationally notifiable diseases is revised periodically. For example, a disease may be added to the list as a new pathogen emerges, or a disease may be deleted as its incidence declines. Public health officials at state health departments and CDC continue to collaborate in determining which diseases should be nationally notifiable; CSTE, with input from CDC, makes recommendations annually for additions and deletions to the list of nationally notifiable diseases. However, reporting of nationally notifiable diseases to CDC by the states is voluntary. Reporting is currently mandated (i.e., by state legislation or regulation) only at the state level. The list of diseases that are considered notifiable, therefore, varies slightly by state.

In October 1990, in collaboration with CSTE, CDC published *Case Definitions for Public Health Surveillance*, which, for the first time, provided uniform criteria for reporting cases, and included infectious diseases and non-infectious conditions. This report was revised in 1997 and published as *Case Definitions for Infectious Conditions Under Public Health Surveillance*. The CDC NNDSS program currently maintains a list of "Nationally Notifiable Infectious Diseases" (http://www.cdc.gov/epo/dphsi/phs/infdis.htm), although the collection of case definitions includes archived non-infectious conditions (http://www.cdc.gov/epo/dphsi/casedef/case_definitions.htm).

In 2001, CSTE adopted the position statement "Standardizing the structure of public health case definitions for diseases and conditions placed under the National Public Health Surveillance System (NPHSS)."

CSTE has surveyed state epidemiologists on reporting requirements periodically, roughly every other year in the current decade. In order to aid production of its weekly tables in MMWR and the annual publication Summary of notifiable diseases, NNDSS has conducted annual surveys of reporting requirements. In November 2007, CSTE and CDC plan to initiate a joint annual survey.

In 2006, CSTE and CDC began planning for the next generation of information systems for reporting requirements, the Notifiable Conditions Knowledge-base (NC-Kb), which will "provide a central, up-to-date listing of reportable Public Health conditions by jurisdiction". NC-Kb will be an authoritative real-time centralized listing of all reportable conditions in each reporting jurisdiction, for healthcare providers, laboratories, hospitals, and other entities that require this information. Manufacturers of administrative software systems for physician offices could use information in the centralized repository to automate case-reporting to states, when a diagnosis of a reportable condition is made. NC-Kb information could also be used by healthcare and laboratory information systems to facilitate automated case-reporting to public health. The NC-Kb will be accessible through webpage query, as are the current CSTE survey results, and also available for machine-to-machine automated data exchange. We anticipate that the information in the NC-Kb will be maintained using CDC resources for security and for back-up of the data, and that the established procedures will enable modification access limited to authorized state health agency staff.

In announcing in December 2006 that the U.S. would adopt the new WHO International Health Regulations, DHHS Secretary Leavitt stated that the nation "accepted the IHRs with the reservation that it will implement them in line with U.S. principles of federalism." This explicit statement reiterates the principles which have served as a foundation for the state-federal relationship responsible for the existing National Notifiable Diseases Surveillance System.

An official list of nationally-notifiable conditions must achieve a balance between two contradictory objectives:

- to include conditions which are currently explicitly included under existing state law/regulation in all jurisdictions
- to include all conditions which have been recommended to be nationally notifiable by CSTE, regardless of whether they are currently explicitly included under existing state law/regulation in every jurisdiction.

A list which meets only the former objective will be shorter, while a list which meets only the latter objective will be longer. State and territorial laws and regulations often do not include explicit mention of certain specific low-incidence conditions on the rationale that their rules include “rare diseases of public health importance”, or similar language. In this circumstance, traditional reporters (clinicians. labs, hospitals) are expected to report because the rules mandate such reporting. However, with the development of electronic automated case-reporting capacity, a list of notifiable conditions which omits some conditions can result in under-reporting. Conversely, a more comprehensive list of notifiable conditions can result in over-reporting in some jurisdictions: sending of case reports to public health authorities in the absence of legal authority for the sender to do so (e.g., a violation of HIPAA). Further, in some jurisdictions, certain specific high-incidence conditions are omitted from the list of notifiable conditions because the governmental health agency lacks the resources to conduct individual case investigations. In that circumstance, a more comprehensive list of notifiable conditions could result in over-reporting in some jurisdictions that would result in a flood of case reports which the agency would find difficult to manage. In addition, the more comprehensive list of notifiable conditions includes some conditions of special regional significance, which are not a substantial problem equally in all regions.

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

CSTE requests:

1. The assistance of CDC in establishing and maintaining the CSTE official list of Nationally Notifiable Conditions.

2. That CDC, in collaboration with CSTE, develop, implement and maintain notifiable conditions standardized reporting definitions which comply with the AHIC recommendations for standardization to support “automated case reporting from electronic health records or other clinical care information systems” and have been adopted by CSTE. At a minimum, this is expected to include common and disease-specific reportable data elements, regardless of whether data elements are specified in the relevant CSTE position statement.

3. That CDC continue its valuable collaboration with CSTE on development and implementation of the joint CDC-CSTE Notifiable Conditions Knowledge-base (NC-Kb), which will be the authoritative real-time centralized listing of all notifiable conditions in each reporting jurisdiction. NC-Kb should also document reporting definitions and disease-specific data elements. The NC-Kb should be accessible through webpage query, and also available for machine-to-machine automated data exchange. The information in the NC-Kb should be maintained securely by CDC, with modification access limited to authorized state health agency staff. CSTE will establish a mechanism for identification of the specific authorized individuals for each jurisdiction.

4. That the CDC National Notifiable Diseases Surveillance System (NNDSS) implement CSTE position statements which call for national surveillance of specified non-infectious conditions using case ascertainment conducted by the sending of individual case data to the state health agency by clinicians, laboratories or hospital facilities. This includes maintaining case definitions for these non-infectious conditions on the existing CDC case definition website. Implementation steps for listing all Nationally Notifiable Conditions can be accomplished by either establishment of a new list of Nationally Notifiable Non-Infectious Conditions, or by modification of the existing list of Nationally Notifiable Infectious Diseases to become a unified list of Nationally Notifiable Conditions. The latter option would mirror the list of Nationally Notifiable Conditions maintained by CSTE.

Public Health Impact:
This establishment and maintenance of the CSTE official list of Nationally Notifiable Conditions, along with standardized reporting definitions, will help CSTE and CDC partners to achieve more complete and timely reporting of potential notifiable condition cases through expanded use of

automated electronic case reporting. Public health not only has a responsibility to keep laboratories, hospitals, and healthcare providers serving the population of one state informed of their reporting requirements, public health also has a responsibility to keep laboratories and hospitals serving the needs of multiple states informed of those states' reporting requirements.

References:

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