16-SI-02

Committee: Surveillance

Title: Electronic Case Reporting (eCR)

I. Statement of the Problem:

Reporting individual cases of diseases and conditions by healthcare providers is a foundational component of public health surveillance (1). While timely and accurate reporting is mandated through jurisdictional laws, required case reports are often delayed, incomplete, or never submitted. Case reporting continues to be largely an entirely paper-based process, which consumes considerable human resources for both public health practitioners and health care providers. Additionally, it is fraught with numerous inherent opportunities for error, including data entry mistakes and confusion about what to report, what information to include in a report, when to report, and how to report. Moreover, the sluggish nature of the manual process, still in wide-spread use, has important downstream consequences, the most notable of which is delayed detection and response to public health threats, acute, chronic and emerging threats. A transition to electronic reporting has the potential to eliminate many of the problems inherent in paper-based reporting by digitizing the information sent from healthcare providers to public health. Vendors and reporters desire a unified approach. Implementing electronic case reporting (eCR) will advance public health surveillance into the 21st century by capitalizing on the advances in informatics and information technology (2).

What is Case Reporting and Electronic Case Reporting (eCR)?

- **Case reporting** –The process whereby healthcare providers submit (report) information *with personal identifiers* about patients (in compliance with legal mandates for reporting specific diseases and conditions) to a public health authority. Case reporting often occurs at the time illness is suspected prior to confirmation of illness and includes information beyond clinical laboratory results important for public health action (supplementing, not replacing electronic laboratory reporting). These reporters usually include healthcare providers and hospitals and exist today as a paper-based process. Case reporting is one of the foundational components of public health surveillance (1, 2).
    - **Note:** Case reporting is not the same as case notification although the two are often confused.
    - **Case notification** – The process of public health authorities voluntarily submitting *non-identified* nationally notifiable condition (NNC) data *to CDC* for summary at the national level. Without effective case reporting to public health authorities, case notification data are inadequate or non-existent; if a report is delayed or never received by a public health authority, the NNC data cannot be provided to CDC via the case notification process.
- **Electronic case reporting (eCR)** – eCR is the fully or semi-automated generation and electronic transmission of reports of potential cases of reportable diseases and conditions from an electronic health record (EHR) or health information technology (IT) system to appropriate public health authorities, replacing the historically paper-based process.

Benefits of eCR

eCR can dramatically improve reporting and public health surveillance effectiveness. Using interoperable technologies and a shared infrastructure for eCR can ensure critical case communications among patients, healthcare providers, public health authorities, and those at risk of illness. Additionally, eCR can significantly advance 2014 CDC Surveillance Strategy goals with particular impact on the Nationally Notifiable Diseases Surveillance System Modernization Initiative (NMI: http://www.cdc.gov/nmi/overview.html) (3). Modernization of State, Territorial, Local, and Tribal

(STLT) processes to receive better jurisdictional reportable disease and condition data will ultimately improve downstream nationally notifiable condition (NNC) data from STLT authorities to the CDC. The result will be more complete, accurate, and timely information for more robust public health surveillance and an acceleration of disease prevention.

If fully developed and properly used, the eCR infrastructure would benefit STLT public health authorities through modernized data exchange. Outcomes include:

- Improving morbidity and mortality surveillance data to protect the public's health.
- Obtaining more complete and accurate case data in near real time for action by public health officials.
- Identifying cases of disease, conditions of public health importance, and outbreaks more efficiently for action by public health officials.
- Responding to emerging threats and public health emergencies more quickly.
- Preventing disease through more timely implementation of public health interventions.
- Improving clinical efficiency and patient outcomes, by creating a new infrastructure and models of interaction between public health and clinical care to support the gathering of information for action and provision of feedback to providers.

eCR is challenging for public health and for reporters

The following challenges in implementation of eCR have been identified:

- Building consensus on a nationwide informatics infrastructure for eCR including, but not limited to, standardized terminologies and structures; standards that support heterogeneous reporting requirements and facilitate data exchange among disparate data systems, decision support processes, and informatics competencies.
- Ensuring adequate resources, including financial resources, for the adoption, use, and maintenance of technological solutions for case reporting, including workforce and financial resources.
- Determining the responsibility and ownership of shared infrastructure in the short and long term.
- Addressing the limited evidence to evaluate: legal and privacy concerns regarding where personal health information is stored, the positive predictive value (PPV) of disease and condition reporting through automated systems, and workforce knowledge gaps.
- Sustaining ongoing collaboration and coordination among public health, healthcare, and EHR system vendor communities on a complex series of technical solutions that have financial and legal implications.

Progress of eCR

Work by public health, public health partners, and other stakeholders has resulted in some foundational developments for eCR implementation. Over the last decade, the public health community has advocated for eCR, and CDC has played an integral and supportive role. For example, CDC has supported the exploration of shared infrastructure by funding the Public Health Community Platform (PHCP), developing tools to support eCR such as the Reportable Conditions Knowledge Management System (RCKMS), and developing an electronic initial case report (eICR) HL7 implementation guide. Additionally, CDC resources have supported eCR efforts through the Association of Public Health Laboratories (APHL), Association of State and Territorial Health Officials (ASTHO), the Public Health Informatics Institute (PHII), and CSTE cooperative agreements. Further examples of work activities by public health organizations with CDC support can be found in the Appendix. These efforts recognize the need to focus on activities that build local and state capacities to use eCR data obtained via improvements in health information technology (HIT) that will strengthen the effectiveness of public health services nationwide.

eCR is in Meaningful Use

The addition of eCR as a public health Meaningful Use measure provides an opportunity for public health authorities to leverage electronic case reporting capacity with federal assistance. Capacity gaps must be closed by 2018, when eCR is an optional measure for the Meaningful Use public health objective. The need to promulgate eCR standards and build eCR capacity to meet meaningful use timelines has increased the intensity and speed at which public health must address these challenges.

In its April 2014 Joint Explanatory Statement (Fiscal Year 2014), Congress expressed that, "The agreement notes that significant opportunities exist to create administrative and economic efficiencies in the reporting of public health data" (4). HIT resources are limited and there should be a focus on modernizing public health systems with the greatest potential for improved efficiencies and value to STLT public health authorities. Implementation of eCR to public health is one such efficiency.

CSTE's eCR vision

CSTE's vision is to have a national interoperable approach for eCR that enables timely sharing of information from healthcare provider to public health authorities and between jurisdictions. To achieve this vision, a flexible and scalable eCR infrastructure must be developed and implemented in a way that results in tangible, incremental, demonstrable and operational success. We propose the adoption of a framework for eCR that: 1) fosters standards–based interoperability; 2) limits the burden of implementation and ongoing electronic reporting for providers, hospitals, health care systems, and EHR vendors; 3) provides a method to ensure jurisdictional reporting mandates are met; and 4) establishes methods of data exchange that foster the evolution and longitudinal improvement of eCR.

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

Continued collaboration among public health organizations such as CSTE, the Association of State and Territorial Health Officials (ASTHO), the Association of Public Health Laboratories (APHL), the National Association of County and City Health Officials (NACCHO), the Office of the National Coordinator for Health Information Technology (ONC), the Public Health Informatics Institute (PHII), the International Society for Disease Surveillance (ISDS) the Joint Public Health Informatics Task Force (JPHIT), and CDC is needed to ensure successful implementation of eCR in jurisdictions across the United States and use of shared infrastructure by those jurisdictions. The collaboration and coordination will need to continue to evolve further engagement with the Robert Wood Johnson Foundation (RWJF), the Centers for Medicare and Medicaid Services (CMS), the Healthcare Information Management Systems Society (HIMSS), the American Medical Informatics Association (AMIA), the American Health Information Management Association (AHIMA), Health Level Seven International (HL7), the Electronic Health Record (EHR) system vendor community, Health Information Exchange (HIE) organizations, and the healthcare provider community.

Desired actions from CDC and CSTE collaborations:

1. **Leadership:** Continue to provide leadership and support for eCR across the public health community and engage the private sector healthcare enterprise by:
    a. Consider naming a leader for eCR-related work at both CDC and CSTE. This could be modeled after the successful NMI approach.
    b. Developing a companion document, or updated version 2.0 of the Surveillance Strategy: A Strategy for Improving the Centers for Disease Control and Prevention's Activities in Public Health Surveillance to specifically include eCR. (3)
2. **Financial resources:** Continue to provide financial resources and other support for STLT and, to the extent possible identify new resources. Continue to coordinate financial resources available to STLT

agencies through cooperative agreements including disease-specific cooperative agreements; to support the implementation and maintenance of eCR technical infrastructure, including participation in standards development; operations; and personnel. Ensure ongoing support and maintenance for eCR, once eCR is in production.

3. **Workforce:** Continue to collaborate with STLTs, CSTE, and other public health stakeholders and organizations to identify workforce training needs specifically to support eCR design, implementation, and operations, including public health informatics knowledge and skills.
4. **Standards development and harmonization:** Continue to support and expand support for standards development needed for eCR including:
    a. Continued support of enterprise-wide eCR efforts across the CDC centers and STLT programs to harmonize work in support of eCR.
    b. Support the use of a single eCR standard (rather than a multitude of disease specific standards) that aligns with the eICR HL7 implementation guide.
5. **eCR taskforce:** Assist with the establishment and support activities of an eCR taskforce, a partnership with other eCR stakeholders and partners. The eCR taskforce should address enterprise-wide establishment of eCR to develop a national eCR strategy. Identification of task force membership should occur by December 2016 and include representatives from:
    - STLT, CDC, and other public health stakeholders, organizations, and associations;
    - Provider organizations (e.g., hospitals and ambulatory clinics);
    - EHR system vendors and related associations;
    - ONC, and Standards Development Organizations (SDOs).

    The taskforce joint activities and decisions should include, but not be limited to:

    a. **Policy:** Determining policies for eCR that support STLT public health practice for surveillance, outbreak investigation, implementation of prevention and control measures, and response to emerging or critical conditions to assure eCR developments support STLT needs.

    b. **Coordination and governance:** Making recommendations to coordinate eCR efforts and identify the short and long term home of the eCR enterprise effort and help to answer the questions, “How should the eCR effort be coordinated overall?” and “Who is responsible for the overall eCR coordination effort?”

    c. **Communication and engagement:** Making recommendations for creating an eCR coordination plan and communication portal to provide information to public health partners about what is happening in the eCR landscape.
        Ideally, the communication portal should:
        - Build on the successes of existing communication strategies such as those used for the NNDSS Modernization Initiative (NMI).
        - Include communication to STLTs to provide updates and education about what activities are occurring related to eCR and activity timelines so that STLTs can better prepare for eCR.
        - Include an engagement and communication strategy regarding eCR to promote adoption of appropriate eCR infrastructure and operations across the eCR enterprise (healthcare community, STLT and CDC programs receiving nationally notifiable disease data from STLTs).

    d. **Shared services, infrastructure and harmonization:** Considering what shared services or infrastructure should be made available along with their supporting business requirements. Making recommendations regarding harmonized processes to receive eCRs in a standardized manner. Developing an operational plan to address responsibility, sustainability of the components of shared infrastructure and governance to support eCR that enables regular, periodic evolution of standards, tools, processes, and evaluation to enhance eCR performance and efficiency in a way that aligns with regulatory timelines.

- Describing the structure, process, and models of interaction between public health and reporters.
- Supporting standards development, a necessary requirement for the electronic sharing of information. Adopting standards in use by healthcare and public health will allow all partners to send and receive machine readable messages.
- Supporting development and adoption of unified national standards or other guidance necessary for enterprise-wide eCR adoption including by convening workgroups to collaborate on defining the content and processes for data to be shared (e.g., standards for value sets and rules).
- Supporting continuous quality improvement for eCR that includes evaluation of variation (between jurisdictions) in reporting rules for impact of this variation on the effectiveness of reporting, using metrics such as PPV, timeliness and sensitivity.

e. **Roadmap to progress:** Working with public health stakeholders and partners (including vendors), to establish guidance around "defining success" and benchmarks against which progress can be monitored. Recognizing that the system will be evolving and changing not only in response to the periodic evolution of standards, tools and processes, but also in response to the public health community's ability to fully integrate them into functional surveillance systems, a series of benchmarks will be established against which progress can be monitored.

f. **Resources and workforce development:** Identifying and prioritizing infrastructure and resources necessary to support the capability of *public health information systems* to conduct eCR.

III. Public Health Impact:

In supporting this position statement, the public health community unites in a commitment to eCR and support a unified approach to facilitate the implementation of eCR. This position statement is intended to be a definitive statement to public health partners (*e.g.,* health care providers, EHR vendors) calling for leadership and mobilization of resources in capitalizing on the opportunities HIT offers to improve population health. High-quality, actionable surveillance data is the foundation of public health. eCR is necessary to ensure public health is responsive to emerging health threats and emergency situations and is better prepared to confront and solve domestic and global risks to national health security. Full implementation of eCR will help close gaps in our ability to protect our nation's health by improving our capacity to better 1) identify public health problems, initiate investigations, and implement public health interventions, 2) characterize the burden of disease at the population-level, and 3) identify and describe the effectiveness of public health interventions.

IV. Revision History

V. References

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Appendices

I. History of Case Reporting in the United States

The long-standing history of case or disease and condition reporting in the United States serves as an example of effective federalism that has been refined over 135 years. Beginning in 1878, Congress authorized the U.S. Marine Hospital Service (forerunner of the Public Health Service or PHS) to collect reports from U.S. consuls overseas about local occurrences of diseases such as cholera, smallpox, plague, and yellow fever. This information was used to institute quarantine measures to prevent introducing or spreading these diseases in the United States. In 1879, Congress funded the collection and publishing of reports of these notifiable diseases and in 1893 expanded the authority for weekly reporting and publishing of these cases to include data from states and municipal authorities.

To improve data uniformity, Congress in 1902 directed the Surgeon General to provide specific forms for collecting and compiling these data and for publishing reports at the national level. In 1903, the PHS convened the first annual conference of state and territorial health officers to begin implementation of the congressional act, thus marking the dawn of national surveillance for communicable diseases of public health importance.

In 1950, a new federal agency, then named the Centers for Disease Control (now the Centers for Disease Control and Prevention or CDC), recognized the importance of state input in reporting communicable diseases, and asked the Association of State and Territorial Health Officials (ASTHO) to convene state epidemiologists and charge them with the responsibility of deciding which diseases should be reported nationally. A conference of state and territorial epidemiologists generated a fully documented list of nationally notifiable diseases.

Today, the Council of State and Territorial Epidemiologists (CSTE) works with CDC to determine the conditions which STLT members will voluntary transmit to the National Notifiable Diseases Surveillance System (NNDSS), a process called *case notification*. NNDSS is a multifaceted public health diseases and conditions surveillance system that gives public health officials powerful capabilities to monitor the occurrence and epidemiology of diseases and conditions of public health importance. Fifty-seven jurisdictions contribute to the NNDSS: the 50 states, New York City, the District of Columbia, and 5 territories including Guam, Commonwealth of Northern Mariana Islands, American Samoa, U.S. Virgin Islands and Puerto Rico.

II. Laws that Govern Case Reporting

Effective public health disease/condition/outbreak surveillance and control is a primary responsibility of STLT public health agencies. Mandatory disease/condition reporting of individual patients and public health access to corresponding health records with personally identifying information is governed by state and local laws, regulations and rules, which vary by jurisdiction. The Health Information Portability and Accountability Act (HIPAA) supports public health activities including identifying persons affected by diseases and conditions of concern, investigating reports received, and instituting control measures to halt transmission and reduce disease incidence. Public health agencies support national public health surveillance by voluntarily sending de-identified data received in case reports from healthcare providers to the CDC.

III. eCR parallels to ELR:

Laboratories also have to report test results that are associated with reportable conditions to the public health authorities. These reports by laboratories often serve as the initial ‘triggers’ to begin a public health case investigation. With the implementation of electronic laboratory reporting (ELR) public health agencies saw an increase in case identification; ELR helped to close the under-reporting gap. Since the early 2000’s, CDC has provided support through several funding mechanisms, and STLT public health

agencies have made great strides toward implementation of ELR. CDC-CSTE (and others) efforts have resulted in the adoption of a national standard for ELR based on HL7 v2 standards: the HL7 Version 2.5.1 Implementation Guide: Electronic Laboratory Reporting to Public Health, Release 1 (US Realm). This HL7 2.5.1 ELR standard has also been incorporated as the standard for public health reporting for ELR to meet meaningful use (MU) measures by laboratories based in MU eligible hospitals.

In many ways, the requirements for successful implementation of eCR parallel the efforts required for implementation of ELR: endorsement of a national standard, including terminology; support for reporters to include standards-based logic in their information systems; and the ability of public health systems to receive and use the reports.

IV. Example Ongoing Activities in Support of eCR Undertaken by Public Health Organizations and Entities, June 2015 – April 2016

Organization/Entity	Example Work or Activity
APHL	• Produced initial eCR triggers table for use in EHR systems • Providing ongoing support for health data coding • Maintains the AIMS Hub currently being leveraged for eCR pilot projects overseen by ASTHO
ASTHO	• Implemented eCR pilot projects through collaboration with EHR vendors and healthcare stakeholders (in progress) • Evaluating the legal considerations surrounding eCR • Initial work completed on the Public Health Community Platform (PHCP) • Oversight of Initial triggers table work conducted by APHL
CDC	• Providing funding for associations and organizations at the federal level • Collaborating with healthcare / EHR vendor communities supporting eCR • Educating and informing CDC Centers and Programs about eCR • Current work on the trigger code table • Ongoing support of data harmonization and standardization efforts including eICR
CSTE	• Development of Reportable Conditions Knowledge Management System (RCKMS) • Development of electronic Initial Case Report (eICR) minimum data elements • Development of eCR implementation tool kit for public health agencies
HL7 PHER Working Group	• Balloting and publishing of eICR Draft Implementation Guide (HL7 CDA R2 Implementation Guide: Public Health Case Report, Release 2) based on eICR developed by CSTE
JPHIT	• Ongoing support of eCR efforts – including a letter to CDC Director supporting eCR
NACCHO	• Support of eCR through JPHIT and public health community initiatives
ONC	• Sets criteria for Health IT certification required for meaningful use attestation by hospitals and eligible professionals • Authorizes Health IT testing laboratories, and certification bodies
PHII	• Partners with CDC Programs in developing an eCR implementation guide and trigger codes specific for STDs

V. Health Care Providers Are Critical Partners in Surveillance - Health care providers, including clinicians, laboratories, and other providers of care, are legally required to report to their jurisdiction's public health authorities when they reasonably suspect a patient of having a disease or condition of public

health concern. Health care facilities, including acute care hospitals, long-term care facilities, and outpatient facilities generally fall under mandated reporting requirements. Other individuals or entities might also be required to report events of potential public health concern. For example, in many jurisdictions, schools or restaurants must report when illnesses occur that could be associated with their establishments (such as influenza-like illness or gastrointestinal illness). For certain diseases or conditions, facilities and providers are required to report by phone upon immediate suspicion of such occurrences.

VI. **Variations in Public Health Authority Mandated Reporting -** The public health authority to which reports are sent might vary, but it is generally the state, county, or local public health authority in the jurisdiction where the patient resides, or sought care, or where the diagnosis was made or the lab test performed. There is variability in jurisdictional reporting requirements and complication result from patient travel, including travel to seek care, especially in areas where healthcare service areas cross jurisdictional boundaries. Jurisdictions have therefore established mechanisms to share reports with each other as appropriate and in compliance with reporting mandates. Public health officials determine what is reportable in their jurisdictions and jurisdiction-specific reportable diseases and conditions lists often differ from the list of nationally notifiable diseases and conditions. Jurisdiction-specific changes to mandated reporting lists are tailored to local or regional needs, such as the addition of "Valley Fever" or coccidioidomycosis which is caused by a fungus (*Coccidioides*) that has historically been endemic only to the Southwest region of the United States.