CDC Healthcare Information Management Systems Society 2012 White Paper

CDC Connecting to Healthcare through Interoperability

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Overview

The Centers for Disease Control and Prevention (CDC) plays an integral role in increasing interoperability between healthcare and public health information systems. This effort has gained momentum in the past few years with the enactment of the Health Information Technology for Economic and Clinical Health (HITECH) Act that supports the Meaningful Use (MU) of Electronic Health Records (EHRs). EHR MU is led by the Centers for Medicare and Medicaid Services (CMS) and the Office of the National Coordinator for Health IT (ONC). CMS and ONC collaborate with CDC to ensure that EHR MU not only benefits healthcare by improving the quality, safety, and efficiency of healthcare delivery, but also benefits public health by promoting the use of EHR systems to:

- Improve the completeness and efficiency of case reporting through electronic laboratory reporting (ELR),
- Protect against vaccine preventable diseases through timely data transfer to immunization information systems (IIS), and
- Detect and respond to outbreaks through near real-time data transfer to syndromic surveillance (SS) systems.

The three public health domains selected for Stage 1 MU (ELR, IIS, and SS) represent just a few of several types of ongoing information exchange between clinical providers and public health agencies that occur on an ongoing basis. CDC develops and facilitates the development of initiatives and tools that help foster interoperability between healthcare and public health information systems for information exchange in a variety of public health domains.

Standards and Interoperability (S&I) Framework Public Health Reporting Initiative

CDC, ONC and a number of public health partners participate in the Standards and Interoperability (S&I) Public Health Reporting Initiative. This initiative is part of the larger S&I Framework to create a robust, repeatable process based on federal best practices that will enable ONC to execute initiatives that will help improve interoperability and adoption of standards and health information technology. The S&I Framework Public Health Reporting Initiative seeks to develop and implement a standardized approach to electronic public health reporting from EHR systems to local, state and federal public health programs that address the needs of several different reporting use cases. The long-term goal is to reduce the difficulty, experienced by both providers and public health agencies, of implementing electronic versions of the broad spectrum of public health reporting.

Public Health Information Network (PHIN)

The Public Health Information Network (PHIN) is a national initiative to increase the capacity of public health to exchange data and information electronically across organizational and jurisdictional boundaries. This is achieved by promoting the use of standards and defining

functional and technical requirements. PHIN establishes and supports shared policies, standards, practices, and services that facilitate efficient public health information access, exchange, use, and collaboration among public health agencies and with their clinical and other partners. The vision of PHIN is an integrated healthcare and public health system using information effectively to advance population health and well-being. Please visit http://www.cdc.gov/phin for more information.

Public Health Information Network (PHIN) Vocabulary Access and Distribution System (VADS) and Reportable Condition Mapping Table (RCMT)

In 2004, CDC developed a Web-based enterprise vocabulary system called PHIN Vocabulary Access and Distribution System (VADS) to access, search, and distribute value sets used within PHIN. The public health community uses PHIN VADS to obtain the value sets associated with the various Health Level Seven (HL7) implementation guides based on HL7 2.x, V3 and Clinical Data Architecture (CDA). As a complement to PHIN VADS, the Reportable Condition Mapping Table (RCMT) was made available on July 1, 2011. The RCMT provides mappings between reportable conditions and their associated Logical Observation Identifiers Names and Codes (LOINC) laboratory tests and Systematized Nomenclature of Medicine (SNOMED) results. It also does the following: 1) helps identify HL7 ELR messages received by public health agencies that are related to reportable conditions and also facilitates the routing of ELR messages to appropriate public health programs (e.g., tuberculosis and malaria); 2) facilitates the mapping of local laboratory test and result codes related to reportable conditions to standard vocabulary codes, which also helps to achieve semantic interoperability; and 3) helps to identify patients from hospital EHR decision support systems who have reportable conditions, that trigger public health case reporting and ELR. Please visit http://www.cdc.gov/phin/tools/PHINvads/index.html and http://www.cdc.gov/EHRmeaningfuluse/rcmt.html for more information.

Public Health Information Network (PHIN) Message Quality Framework (MQF)

PHIN Message Quality Framework (MQF) is an automated testing tool that ensures messages adhere to standards defined in the messaging guides by: 1) validating the structure of the message, 2) validating that the messages are following the business rules defined for the message, and 3) verifying that the vocabulary defined for the message is utilized. PHIN MQF can be used to test MU-compliant ELR, IIS and SS messages as well as other HL7 messages. Please visit http://www.cdc.gov/phin/resources/certification/MQFtool-overview.html for more information.

Electronic Laboratory Reporting (ELR) Translation Tool

As CDC worked with stakeholders to implement EHR MU (which specifies the use of HL7 2.5.1), the need was identified for a mechanism to translate HL7 Unsolicited Observation Message (ORU_R01) Version 2.3.1 messages into HL7 ORU_R01 Version 2.5.1 messages used for ELR. There was also a need to develop a mechanism to translate HL7 Unsolicited Observation Message (ORU_R01) Version 2.5.1 messages into HL7 ORU_R01 Version 2.3.1 messages. The ELR Translation Tool was completed in November 2011 by CDC with the

assistance of the CDC/CSTE ELR Taskforce Standards Workgroup. Through collaboration with HL7, HL7 members can download this tool from the HL7 website. The ELR Translation Tool was developed using the Orion™ Health Symphonia Messaging and Mapping Tool and is available for distribution to HL7 members. To become an official member of HL7, please visit http://www.HL7.org.

 To download the tool, login to the HL7 website and paste the following link into your Internet browser http://www.hl7.org/documentcenter/private/standards/V2XML/ELR.zip. You will be prompted to review the Licensing Agreement Reminder, then click Begin Download button to download the tool.

Public Health Information eXchange (PHIX)

To better understand the challenges and opportunities of developing solutions to link public health with clinical care stakeholders, a comprehensive standards-based solution for advancing the exchange of data the Public Health Information eXchange (PHIX) was created. To make this solution readily available to public health organizations and health care providers and to further expand the capabilities of the information exchange, the PHIX team launched an open source community portal as part of the CDC Informatics Research and Development Laboratory portal. This project transcends public health practice, moving directly into the realm of healthcare to build a single product that enables data exchange among public health and clinical care providers in support of the EHR MU Stage 1 objectives and incentives as defined for public health. This portal community will focus on further development and deployment of PHIX.

PHIX has identified five use case scenarios, listed below, which are brokered through the product and connect public health laboratories (PHLs), clinical care stakeholders, and state and public health departments, all of whom are participants in the PHL Interoperability Affinity Domain.

Scenario 1 – Reporting of Notifiable Laboratory Results
Scenario 2 – EHR to PHL Test Order & Result Reporting
Scenario 3 – PHL to PHL Test Order & Result Reporting
Scenario 4 – Send Unsolicited Admit Discharge and Transfer (ADT) Messages (SS)
Scenario 5 – Send Unsolicited Vaccination Messages

PHIX was designed with a set of features to support interoperable data exchange across healthcare. These features include message transformation, vocabulary validation and translation, configuration and routing based on appropriate business rules and organizational requirements, and message component analysis of incoming data streams for specific conditions of interest. The solution architecture utilizes a wide range of application standards

defined by HL7, Integrating the Healthcare Enterprise (IHE) Frameworks and Healthcare Information Technology Standards Panel (HITSP) Interoperability Specifications including:

- HITSP Electronic Health Records Laboratory Results Reporting Interoperability Specification (IS01) – HL7 2.5.1 ORU
- Immunization Registry Content (IRC)
- HITSP Biosurveillance Interoperability Specification (IS02)
- IHE Laboratory Technical Framework
- Public Health Laboratory Interoperability Project (PHLIP) Electronic Test Order & Result (ETOR) HL7 v2.6 Lab Order for Multiple Orders (OML^O33)

CDC has selected Nationwide Health Information Network (NwHIN) Direct as the message transport for a production pilot of PHIX at HealthBridge, a functioning Health Information Exchange (HIE) in Cincinnati, Ohio. HealthBridge has been selected as a Beacon Community and a Regional Extension Center by ONC. The live demonstration would showcase an immunization report directed from an ambulatory provider in the University of Cincinnati Health system to the Health Bridge HIE housing PHIX. The architecture utilizes a range of standards defined by HL7, IHE and HITSP Interoperability Specifications. This process would demonstrate validation, transformation and routing of the immunization report at PHIX, deployed at HealthBridge. It would be sent via NwHIN Direct to an Immunization Registry at a State Public Health Agency in Kentucky, Indiana or Ohio. NwHIN Direct is currently operational at HealthBridge and supports the Beacon HIT interventions for transitions of care and EHR interoperability for MU. Please visit http://Phix.phiresearchlab.org for more information.

The potential for EHRs to benefit public health goes far beyond ELR, IIS, and SS. This white paper highlights three CDC programs that continue to benefit from the interoperability between healthcare and public health information systems.

National Program of Cancer Registries

Description of Program

The National Program of Cancer Registries (NPCR) is funded and managed by CDC's Cancer Surveillance Branch (CSB) in the Division of Cancer Prevention and Control (DCPC). NPCR provides funds and technical assistance to 48 central cancer registries (CCRs) to improve cancer registration and cancer surveillance throughout the United States. CDC builds state and national capacity through support of the NPCR to monitor the burden of cancer, including disparities among various population subgroups, and provides data for research, evaluation of cancer control activities, and planning for future health care needs.

Cancer surveillance is a complex system that captures longitudinal data from multiple and varying data sources using a variety of methods. The cancer surveillance infrastructure consists of a complex network of hospitals, physician's offices, treatment centers, clinics, laboratories, health departments, non-governmental organizations, and government agencies. In addition to

recording the occurrence of each reportable cancer (or tumor), the reporters provide information on the diagnosis, treatment and outcomes.

These data are used for surveillance and development of comprehensive cancer control programs and health care planning and interventions. Improved accuracy of cancer surveillance impacts all areas of public health interventions. Data also provide baseline and performance measures for all cancer-related interventions designed to reduce cancer incidence or improve early detection. Identification of disparities in access to treatment or in treatment received can inform interventions to reduce these disparities and reduce the cancer morbidity and mortality in special populations.

Cancer surveillance presents several challenges, including delay in availability of data, limited resources for collecting data, completeness of reporting, lack of standardized data exchange for non-cancer registry data sources, and limited data sets. To help address these needs, the CSB supports the NPCR Advancing E-cancer Reporting and Registry Operations (NPCR-AERRO) project, which develops best practices, guidelines, and recommendations for an ideal cancer surveillance informatics infrastructure by using emerging health information technology and national and international standards. NPCR-AERRO uses a collaborative framework to construct a comprehensive model to demonstrate the potential of electronic cancer registry reporting and automated registration to grantees and partners.

NPCR-AERRO works with hospitals, CCRs, national programs, and data sources (such as pathology laboratories, hospital registries, and physician offices) to help meet these goals in the context of the emerging development and use of the Electronic Medical Record (EMR), EHR, Personal Health Record (PHR) and HIE systems.

NPCR-AERRO has established the following goals to address the challenges of collecting accurate and complete cancer surveillance data:

- Improve completeness, timeliness, and quality of data.
- Reduce costs for registries and data providers.
- Develop a national plan or “blueprint” to identify priorities that make better use of cancer surveillance resources.
- Provide guidance for development of standards based systems for cancer registries.
- Improve data exchange between systems by using industry standards.

Interoperability with Healthcare

Data collection standards for reporting cancer data from hospital cancer registries to CCRs and then to the national cancer programs have existed for many years. Similar standards for anatomic pathology (AP) laboratory reporting have been developed more recently, and NPCR has helped several national reference laboratories implement these standards. Until NPCR-AERRO began working on it in 2010, there were no standards specifically designed for physician reporting to CCRs. NPCR-AERRO relies on national/international Health Information HIT standards to help establish interoperability with these disparate healthcare data sources, and addresses the following problems:

- Delay in the availability of data.

- Limited resources for collecting data.
- Lack of completeness of reporting.
- Lack of standardized data exchange for non-cancer registry data sources.
- Limited data sets.

One way NPCR-AERRO has addressed these issues is to develop and implement IHE profiles for reporting cancer data from AP laboratories and physician offices to CCRs. IHE promotes the coordinated use of established standards such as DICOM (Digital Imaging and Communications in Medicine) and HL7 to address specific clinical needs in support of optimal patient care.[1]

Interoperability with Anatomic Pathology (AP) Laboratories

CCRs collect data on cancers or premalignant conditions diagnosed in AP laboratories. The NPCR developed the IHE Anatomic Pathology Reporting to Public Health (ARPH) integration profile as a way to transmit AP reports from AP laboratories to CCRs, screening organizations, and other public health organizations and it is intended for international use. The HL7 AP work group worked closely with the North American Association of Central Cancer Registries (NAACCR) E-Path Working Group on this profile to ensure consistency with the HL7 standards.

CCRs in the United States and Canada have extensive experience using HL7 Version 2.x standards in the electronic reporting process and the IHE ARPH integration profile is based on the *NAACCR Standards for Cancer Registries Volume V: Pathology Laboratory Electronic Reporting*, Version 3.0 (NAACCR Volume V). It specifies transmission of an HL7 Version 2.5.1 Observation Result (ORU) message from AP laboratories to the appropriate CCRs. The NPCR-AERRO project tested the IHE ARPH profile at the 2010 and 2011 IHE North-American Connectathons and successfully demonstrated the ability to send electronic pathology laboratory reports from a pathology laboratory information system to a central cancer registry according to the profile. The demonstration used the CDC NPCR-developed software eMaRC Plus (electronic Mapping, Reporting and Coding) to enable CCRs to receive and process the data.

The IHE ARPH profile defines the actors and transactions involved in AP reporting to public health organizations. This integration profile will make it easier for AP laboratories, public health agencies, and software vendors to adopt a uniform method to report, transmit, and process data. It will facilitate international electronic reporting of AP data in the public health domain.

NPCR-AERRO is currently exploring options for expanding laboratory reporting related to cancer to include the reporting of biomarker/molecular test results from laboratories. This includes a review of existing clinical genomics implementation guides for reporting DNA based genetic test results and the possible use of the *NAACCR Volume V* standard for reporting of other biomarker/molecular test results. Once the appropriate HL7 2.x standard is identified, NPCR-AERRO will begin working with laboratories to pilot test and implement reporting of these tests to CCRs.

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[1] Twombly R. Medicare cost containment strategy targets several oncology drugs. J Natl Cancer Inst. 2004; 96(17):1268-1270.

Interoperability with Clinics and Physician Offices

Complete and high quality cancer data reporting has traditionally relied primarily on data from hospitals and pathology laboratories. Advances in medicine and changes in the healthcare delivery system now allow patients to obtain their care outside the acute care hospital setting. Private oncology clinics deliver 80% of all cancer care.[2] Data collection systems from other sources such as these physician offices/clinics and radiation therapy centers, however, are not as consistent or complete with reporting. This leads to under-reporting of certain types of cancers, especially those now diagnosed and treated outside of hospitals, such as in dermatology, urology and hematology. Both melanomas and prostate cancers, for example, have been shown to be under-reported when central registries rely only on hospital reporting. One study estimated that over 1,000 prostate and bladder cancer cases were not reported in single year to a single CCR, or up to 54,000 additional prostate and bladder cancer cases per year nationally.[3]

Additionally, information such as patient's occupation, industry, and birthplace are more difficult to collect. Physician offices also have the potential to provide CCRs with more complete treatment and biomarker data. When reporting from these non-hospital data sources does occur, it may be through a manual process of identifying reportable cases and submitting paper copies of the medical record or sending certified tumor registrars (CTR) employed by the CCR into physicians' offices to manually abstract the information from the paper-based medical records. These processes are very resource intensive, time-consuming, and vulnerable to errors in transcription. The need to access the data contained in physician offices with limited resources is driving the need to develop an automated electronic process for accessing and utilizing the physicians' EHR/ EMR to identify and report cancer cases. The use of EMR systems and technology will increase awareness and knowledge of physicians about the need to report cancer cases to the registries, and provide them with an efficient means of doing so.

Related to these efforts to establish electronic reporting from EMRs, NPCR has worked on efforts to establish cancer reporting from physicians to registries as a criterion for MU. The ONC HIT Policy Committee of has recommended that cancer reporting from physician offices to CCRs be included as a criterion in Stage 2. The recommendation states: "Eligible Provider: Submit reportable cancer conditions (attest to at least one) in accordance with applicable law and practice." The HIT Policy Committee also recommended to the HIT Standards Committee "possible use of IHE cancer reporting profile" for this criterion.

The IHE cancer reporting profile, called Physician Reporting to Public Health-Cancer Registries (PRPH-Ca), was based on work conducted by an NPCR-AERRO workgroup made up of stakeholders from CCRs, NAACCR, physician offices, professional organizations, other national standards setting organizations, and NPCR. The workgroup used the Clinical Oncology Requirements for the EHR (CORE) document developed by the American Society of Clinical

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[2] Twombly R. Medicare cost containment strategy targets several oncology drugs. J Natl Cancer Inst. 2004; 96(17):1268-1270

[3] Penberthy et al. Impact of Automated Data Collection from Urology Offices: Improving Incidence and Treatment Reporting in Urologic Cancers. J Registry Manag. 2010 Winter; 37(4): 141-7

Oncology (ASCO) and National Cancer Institute (NCI) as the foundation for identification of data elements to include in the cancer report. The profile, developed in collaboration with IHE, provides a single, consistent format for electronic physician reporting to CCRs. EMR vendors have participated with NPCR at IHE Connectathon and Healthcare Information and Management Systems Society (HIMSS) Showcases to test and demonstrate implementation of the PRPH-Ca profile for electronic data exchange.

The PRPH-Ca profile defines the actors and transactions involved in physician reporting to CCRs. This HL7 CDA content profile uses several IHE constructs to facilitate the secure exchange of clinical data from physician EMRs to CCRs. The IHE constructs used to support the PRPH-Ca profile include: 1) IHE Retrieve Form for Data Capture (RFD), which allow the EMRs used in physician offices to automatically populate a standard form with relevant clinical data that can be reported to CCRs with no additional burden to the physician; 2) IHE Cross Enterprise Document Sharing (XDS) for direct exchange of the document; 3) IHE Medical Document Specification, which defines the base set of constraints to be used for this profile; 4) HL7 Continuity of Care Document (CCD) as basis for CDA content modules.

Collaboration with Health Information Exchanges (HIEs)

HIEs also play an important role in the EMR implementation process. HIEs can provide the bridge between physician offices, EMR vendors, and public health for testing and implementation of anatomic pathology laboratory and physician office cancer reporting. NPCR is in the process of engaging with HIEs to explore potential collaborations. HIEs may provide various functions in the two cancer scenarios, such as supporting the transport mechanisms for laboratory reports and/or physician reports, such as NwHIN Connect, NwHIN Direct, or PHIN Messaging System (MS). They could also provide services such as filtering reports based on case reporting criteria, routing reports to the appropriate public health program, converting different file formats to the standard HL7 2.x or CDA format, and Master Patient Index functions.

Benefit to Patient Care and Impact on Public Health Practice

The ARPH and PRPH-Ca profiles make it easier for anatomic pathology laboratories, clinics, physician offices, public health organizations, and software vendors to adopt a uniform method for reporting, transmitting, receiving and processing data. Implementation of these profiles will improve the ability of laboratories, physician offices, specialty providers (e.g., dermatology, urology, hematology, and oncology), and other non-hospital facilities to identify and send cancer registry related information and for CCRs to receive data for cancers diagnosed outside the hospital systems.

Improved interoperability with all cancer surveillance data sources can provide:

- Improved capture of treatment data, leading to improved recommendations and interventions.
- Better risk factor data to inform and improve patient care.
- Bi-directional exchange of data between EHRs and CCRs for decision support and improved patient care.
- More targeted health interventions, leading to improved patient and population health.

- Improved timeliness, completeness, and quality of cancer case reporting to CCRs, which will ultimately improve survivorship, patient care, and quality of care.
- Reduction in the amount of manual data entry that CCRs currently have to perform.
- Facilitation of real-time reporting from physician offices to CCRs funded by NPCR.
- More accurate identification of disparities in cancer incidence.
- More accurate cancer incidence data overall for the United States and by state and possibly contribute to clinical quality control indicators.
- Improved capability to assess disparities in cancer treatment and access to care.
- Improved capability to investigate and intervene on rare cancers and special populations.

In the long term, development and improvement of interoperability between clinical healthcare and public health systems, will establish the infrastructure and means for electronic data exchange between health care providers and public health, helping to meet ONC's goals of bidirectional electronic exchange of public health and medical information as well as support the ONC efforts towards regional health information exchange. By automating systems and utilizing EMRs/EHRs, implementation will ultimately lead to reduced health care costs as case reporting functions are modernized, automated, and streamlined. These efforts will contribute to the strengthening of public health systems and seamlessly connect them to clinical healthcare systems, and ultimately to improved cancer surveillance and public health.

National Vital Statistics System

Description of Program

The National Vital Statistics System is a CDC program managed by the National Center for Health Statistics (NCHS) which requires contributions from many organizations and individuals responsible for responding to vital events occurring in the United States. Two main goals of the Vital Records community are to:

- Efficiently create certificates of birth and death, and reports of fetal deaths that are accurate and available quickly to meet the needs of families experiencing these vital events.
- Produce timely, accurate, high quality data based on birth and death certificates, and fetal death reports to inform public health at the local, state and national levels.

For more than a century, these vital events have been registered annually by registration areas [currently, 50 states, two cities (New York and Washington DC), and 5 United States Territories (American Samoa, Guam, the Northern Mariana Islands, Puerto Rico, and the United States Virgin Islands)] from information captured by individuals located throughout the country in accordance with state and jurisdictional laws. Detailed data on all events are transmitted to the NCHS for processing and dissemination and for NCHS to meet its legal obligation to produce national multipurpose statistics. Annually, over 6 million vital event records, including statistical information (demographic, medical, and geographic) are derived from over 4 million birth certificates and from about 2.4 million death certificates and fetal death reports. NCHS closely

collaborates with individual states within the United States and jurisdictions, the National Association for Public Health Statistics and Information Systems (NAPHSIS), and the World Health Organization on standardization. NCHS, state, and NAPHSIS work focuses on developing standard certificates and reports for data collection and administrative purposes, as well as standardized procedures for data preparation and processing to promote a uniform national database.

Impact on Public Health Practice

Vital statistics data (e.g., teen childbearing, prenatal care, cesarean, preterm and low birth weight rates, infant and maternal mortality) are essential for key national health and healthcare-related policy decisions and also influence programmatic and policy decisions for state agencies. The data are used to measure progress toward national and state health objectives, such as Healthy People 2020 goals and are the basis for information relevant to the health of the public and for aiding decision makers in setting policies, directing resources, managing problems, and identifying emerging health trends. A few recent examples of important public trends identified and causes elucidated via vital statistics data are:

- The dramatic rise in national multiple birth rate, the greater risk of morbidity and mortality of multiples births and the impact of the rise in multiple births on key measures of national maternal and infant health such as preterm and low birth weight rates.
- The decline and then rise in the cesarean delivery rate in the United States, and estimates of non-medically indicated cesarean deliveries. Important differences in these rates across states, regions and hospitals.
- The rise in the preterm birth rate, especially in infants born late preterm (34-36 weeks of gestation). The greater risk of infants born late preterm compared with those born at full-term and the impact of management of labor and delivery on rising preterm birth rates. The March of Dimes “Prematurity Campaign,” launched in 2003, uses vital statistics gestational age data to track progress in efforts to lower the level of preterm births, and issues an annual “premature birth report card” in which vital statistics data are used to award grades to the nation and each state based on their preterm birth rate.
- Long term decline in maternal mortality and peaked interest in the nature of observed increases in recent years. Methodological changes are important factors accounting for the increases.
- The increase in Sudden Infant Death and Sudden Unexplained Infant Death Syndromes (SIDS/SUIDS) and then the decline in these deaths coincident with the dispersion of public health messages.
- The trend for life expectancy. In the 1980’s, HIV and homicide patterns had an impact on black male life expectancy and there is concern about the potential implications of increasing obesity in the general population for the future life expectancy statistics.

Connection to Electronic Health Records

Many data items required by birth and death certificates and fetal death reports are captured in medical records. For example, the mother’s and infant’s medical records are recommended by

NCHS and NAPHSIS to serve as the source for more than one-half of all data items collected on the 2003 United States Standard Certificate of Live Birth and the United States Standard Report of Fetal Death. Currently, these data typically are gathered by hospital personnel from the hospital's medical records using paper worksheets. However, the vital statistics community has been collaborating on standards setting to build upon more than a century's effort in standardization and to encourage EHRs to capture the common items in a way that vital statistics can use and reduce duplicative entry by hospital and other medical personnel.

There is considerable debate about the use of electronic health records data as a source for Vital Records information. The benefits of this approach have yet to be demonstrated. That is, will the quality and timeliness of vital records data improve? Will the data collection become more or less standardized? Will it lead to a reduction in the redundancy of data entry and ultimately lower costs for both the hospital and states? While the research on these questions continues, the vital records community recognizes the potential integration of EHRs with electronic vital records systems and the importance of laying a solid foundation for standardized transmission of certain vital records information for this purpose. This includes activities to support the development of interoperability specifications and to identify existing gaps that need to be addressed to support data exchange and interoperability of vital records information.

NCHS has been collaborating with NAPHSIS and other vital records stakeholders to develop vital records standards that are supported by the standards development organization (SDO), HL7 and the standards organization, IHE. HL7 is one of several American National Standards Institute (ANSI) http://www.ansi.org/ accredited SDOs operating in the healthcare arena to produce clinical and administrative data standards for the healthcare domain.[4] IHE promotes the coordinated use of established standards such as DICOM (Digital Imaging and Communications in Medicine) and HL7 to address specific clinical needs in support of optimal patient care.[5]

NCHS sponsored a project that was approved and supported by the HL7 Public Health and Emergency Response Work Group (PHER WG) to develop an HL7 Vital Records Domain Analysis Model (VR DAM). The VR DAM identifies and describes the activities and data required for processing birth, death and fetal death records in compliance with the 2003 Revision of the United States Standard Certificates of Birth and Death, and the 2003 Revision of the United States Standard Report of Fetal Death. The model depicts vital records stakeholders who are involved in exchanging data within the context of each activity. The model also includes descriptions of each of the data elements required for vital registration as defined by the national standard. The VR DAM was published as an HL7 standard in April 2011. The model is serving as a framework to guide additional design and implementation efforts to standardize electronic vital records exchange.

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[4] Health Level Seven International. Retrieved from http://www.hl7.org/ .

[5] Integrating the Healthcare Enterprise. Retrieved from http://www.ihe.net/

Building on this collaborative relationship, NCHS, NAPHSIS and other vital records stakeholders developed an HL7 Electronic Health Record System (EHR-S) Vital Records Functional Profile (VRFP). This activity was supported by the HL7 Electronic Health Records Work Group. The VRFP was derived from the HL7 EHR-S Functional Model (FM), which provides a reference list of functions that may be present in an EHR system. Functional profiles are a subset of the EHR-S FM that provide a standardized description and common understanding of the functions that are needed or required for a specific care setting or subject area. The VRFP profile defines the functional requirements needed to capture vital records data at the point of contact or care with a patient and supports messaging between EHR systems and states, local registrars, and federal agencies. The VRFP is intended to ultimately serve as a reference for potential certification of EHR systems that include functionality to support vital records requirements. The profile is slated to be published as an HL7 standard by early 2012.

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Recent NCHS standards activities, in partnership with other vital records stakeholders, have been focused on developing HL7 technical messaging implementation guides as draft standards for trial use (DSTU) for birth, death and fetal death reporting that are based on the HL7 Version 2.5.1 standard. An HL7 V2.5.1 IG: Reporting Death Information from the EHR to Vital Records, R1 was balloted and approved for publishing in October 2011. Current work is in progress to develop an HL7 V2.5.1 IG: Reporting Birth and Fetal Death Information from the EHR to Vital Records, R1. The development of these guides represents an initial effort to provide implementation guides for transmitting live birth, fetal death and death related medical and health information from a clinical setting to the vital records electronic registration systems.

Standards activities for vital records within IHE have been supported by the IHE Quality, Research and Public Health (QRPH) Committee. NCHS collaborated with QRPH to modify the IHE Maternal and Child Health (MCH) Technical Framework Supplement. The MCH Technical Supplement describes the content to be used in automating the data captured for vital records purposes such as for the United States Standard Certificate of Live Birth and the United States Standard Report of Fetal Death. The IHE MCH technical supplement describes how select information may pre-populate the vital records systems and potentially other stakeholder information systems for birth and fetal death events via the mechanism provided by the Request Form for Data Capture (RFD) integration profile. The MCH profile uses transactions and content modules defined in other IHE profiles to provide interoperable data exchange. Additionally, NCHS facilitated the development of the IHE Birth and Fetal Death Reporting (BFDrpt) Profile that describes the content and format to be used within the pre-population data part of the Retrieve Form Request transaction from the RFD Integration Profile. This profile describes the content to be used in automating the data captured for vital records while adhering to the Birth Edit Specifications for the 2003 Revision of the United States Standard Certificate of Birth and the Fetal Death Edit Specifications for the 2003 Revision of the United States Standard Report of Fetal Death. Based on the availability of fiscal year 2012 funding, NCHS is planning to pilot test in several states interoperability between EHR and Vital Record systems utilizing these HL7 and IHE developing standards.

Benefit to Patient Care

Vital statistics birth and fetal death or stillbirth information has the greatest implications for women and families in their reproductive years. These data guide pre-pregnancy planning and pregnancy management, and inform appropriate interventions. Standardization of vital records data within the EHR could improve the timeliness and accuracy of these and other valuable data for improved patient care. The information collected serves as baseline measurements for a lifetime exposure to patient care. Mortality data serve as the concluding documentation on the lifetime interaction with patient care. For that person's family, the information is part of the surviving family's medical history. For the broader patient population, capturing standard data will help identify issues for which patient care needs to improve through the continuum from the beginnings of life, a successful birth, and finally, the conclusion of life with death.

Early Hearing Detection and Intervention

The Early Hearing Detection and Intervention (EHDI) Team is housed in CDC's National Center on Birth Defects and Developmental Disabilities. The EHDI Team's focus is to provide support and technical assistance to state and territorial based EHDI programs as they develop surveillance and data systems to meet the needs of their stakeholders.

Description of Program

Hearing loss identified in the newborn period has been referred to as a neuro-developmental emergency. Congenital hearing loss affects two to three infants per 1,000 live births. Congenital and delayed onset hearing loss in infants is linked with speech and language delay and lifelong social-emotional and cognitive challenges.

The United States Preventive Services Task Force (USPSTF) recommends screening for congenital hearing loss in all newborn infants because there is good evidence that screening is highly accurate and leads to earlier identification and treatment of infants with hearing loss. According to data submitted to the CDC more than 95% of over the 4 million infants born each year in the United States are screened for hearing loss.

The national goals for EHDI programs are 1) all infants should be screened no later than 1 month of age 2) all infants who do not pass the hearing screening should have a diagnostic audiological (hearing) evaluation no later than 3 months of age and 3) all infants with hearing loss should receive early intervention services no later than 6 months of age (medical, audiological, educational and coordinated healthcare services).

Since the organized collection of newborn hearing screening data started in 2000 (for year 1999) demonstrated progress has been made in increasing the number of infants screened for hearing loss. Now more than 95% of United States infants can be documented as having their hearing screened; yet the most recent data suggest 45% of infants needing care following screening may still not receive it.[6] It is assumed that follow up were obtained for a segment of

[6] Summary of 2009 National CDC Data. Retrieved from http://www.cdc.gov/ncbddd/hearingloss/2009-Data/2009_EHDI_HSFS_Summary_508_OK.pdf

this group, however existing surveillance tools makes tracking these services problematic at present.

Impact on Public Health Practice

Newborn screening (both for hearing and bloodspot) is one of the first interactions between clinical care and public health that involve information exchanges. To ensure the delivery of necessary and timely services, information needs to flow among birthing facilities, various health care providers, and the public health community. Without an electronic exchange, newborn data typically rely on busy hospital or laboratory staff entering data, often multiple times, and reporting the same information to multiple entities.

Newborn screening can create an electronic information exchange among hospitals, providers and public health establishing one of the first meaningful interoperability opportunities in an individual's lifetime and providing an opportunity to lay the foundation for a public health role in EHR clinical information exchanges. Working towards bidirectional electronic information exchange between interoperable systems improves the ability of public health EHDI programs to ensure that all newborns in their jurisdiction receive timely and appropriate services.

Connection to Electronic Health Records

Electronic health information exchanges in the EHDI domain have already been tested through IHE 2011 Connectathon published interoperability profiles and demonstrated at both the 2011 HIMSS and the 2011 Public Heath Informatics Conference Interoperability Showcases. This proof of concept included the transmission of patient level newborn and maternal demographics, as well as hearing screening results, from hospital EHR systems to the jurisdictional public health authority. Although these demographic data were only a subset of the public health information usually obtained through less automated means, they illustrated how maternal and newborn information data entered once in a clinical setting can be used to pre-populate and transmit information for multiple uses in other public health programs, such as vital records, immunizations (HepB) and newborn bloodspot screening.

Clinical decision support through the transmission of best clinical practice guidelines from the Public Health EHDI program to ambulatory clinical EHR systems was included in the IHE Connectathon testing and HIMSS demonstration. Additionally, IHE and HIMSS provided the platform that demonstrated how population level electronic health measures (eMeasures), specifically developed for EHDI and endorsed this summer by the National Quality Forum (NQF), could be captured, processed and displayed. These eMeasure benchmarks may be used to trigger hospital or jurisdictional public health compliance activities, such as re-writing of procedural guidelines or re-training of screening staff.

National standard newborn screening codes were developed in collaboration with the ONC through content published in the 2008 American Health Information Community (AHIC) Newborn Screening Detailed Use Case. The selection process of these harmonized standards was conducted by the HITSP Population Perspective Technical Committee. In 2010 HITSP released the Newborn Screening Interoperability Specification (IS 92) for implementation which

describes the information flows, issues, and system capabilities supporting newborn screening reporting and information exchanges among clinical care settings and public health.

The creation of standardized LOINC® codes for newborn screening and their acceptance by the United States Department of Health and Human Services (HHS) Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) provides a technical framework for interoperability among hospital and clinical practice EHRs, device manufacturers, public health laboratories and public health EHDI information systems. The United States National Library of Medicine (NLM) published the Newborn Screening Coding and Terminology guide to promote and facilitate the use of standard LOINC and Systematized Nomenclature of Medicine — Clinical Terms (SNOMED CT®) codes as well as draft guidance for incorporating these codes in the creation of HL7 messages. The United States Health Information Knowledgebase (USHIK) metadata registry of healthcare-related data standards, hosted by the Agency for Healthcare Research and Quality (AHRQ), includes this Newborn Screening Order Value Set (HITSP.86785.v1). Additionally the CDC PHIN VADS provides web-based access to these value sets as well as those associated with IHE EHDI Profile, including the transmission of Joint Committee of Infant Hearing (JCIH) risk indicators for use in clinical surveillance of children at risk for delayed onset or progressive hearing loss within the Medical Home.

As part of its final rule for the EHR Incentive Program, the CMS reported “newborn screening, both as a clinical quality measure, and from a data standards perspective, is a prime candidate for inclusion in the Stage 2 definition of meaningful use.” Through new Integration Profiles, Integration Statements, and Technical Framework documents, the Quality, Research and Public Health (QRPH) Planning and Technical IHE Committees continue to address the infrastructure and content necessary in standardizing the approach to electronic public health reporting between EHR systems and public health EHDI information systems. This includes future testing at the 2012 IHE Connectathon and demonstration at the 2012 HIMSS Interoperability Showcase. In collaboration with the CDC, the Public Health Data Standards Consortium (PHDSC) is working to develop testing methods and tools for HIT products supporting electronic health information exchanges in the EHDI domain.

Benefit to Patient Care

Electronic data exchange between clinical care providers and public health EHDI programs offers many advantages as information can be consistently and reliably communicated to health care providers. Current inefficiencies and labor-intensive manual data entry processes can be removed, decreasing the likelihood of time delays and poor quality health information. With the realization of interoperability between EHR systems and EHDI-IS, state EHDI programs will be better able to provide guidance and recommendations to service providers in their jurisdiction. As a primary benefit to patient care, providers will now have ready access to timely clinical and diagnostic guidance to assist in care coordination for their infant patients with suspected hearing loss.

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

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Glossary of Acronyms

ACHDNC	Advisory Committee on Heritable Disorders in Newborns and Children
ADT	Admit, Discharge, Transfer
AERRO	Advancing E-cancer Reporting and Registry Operations
AHIC	American Health Information Community
AHRQ	Agency for Healthcare Research and Quality
ANSI	American National Standards Institute
AP	Anatomic Pathology
ARPH	Anatomic Pathology Reporting to Public Health
ASCO	American Society of Clinical Oncology
BFDrpt	Birth and Fetal Death reporting
CCD	Continuity of Care Document
CCR	Central Cancer Registry
CDA	Clinical Document Architecture
CDC	Centers for Disease Control and Prevention
CMS	Centers for Medicare and Medicaid Services
CORE	Clinical Oncology Requirements for the Electronic Health Record
CSB	Cancer Surveillance Branch
CTR	Certified Tumor Registrars
DCPC	Division of Cancer Prevention and Control
DHHS	Department of Health and Human Services
DICOM	Digital Imaging and Communications in Medicine
DSTU	Draft Standards for Trial Use
EHDI	Early Hearing Detection and Intervention

EHR	Electronic Health Record
EHR-S	Electronic Health Record System
EHR-S FM	Electronic Health Record System Functional Model
EHR-SVRFP	Electronic Health Record System Vital Records Functional Profile
ELR	Electronic Laboratory Reporting
e-MaRC	electronic Mapping, Reporting and Coding
EMR	Electronic Medical Record
ETOR	Electronic Test Order and Result
FM	Functional Model
HIE	Health Information Exchange
HIMSS	Healthcare Information and Management Systems Society
HIT	Health Information Technology
HITECH	Health Information Technology for Economic and Clinical Health
HITSP	Healthcare Information Technology Standards Panel
HL7	Health Level 7
IHE	Integrating the Healthcare Enterprise
IIS	Immunization Information System
IRC	Immunization Registry Content
IS01	Electronic Health Records Laboratory Results Reporting Interoperability Specification
IS02	Biosurveillance Interoperability Specification
JCIH	Joint Committee of Infant Hearing
LOINC	Logical Observation Identifiers Names and Codes
MCH	Material and Child Health
MU	Meaningful Use
NAACCR	North American Association of CCRs

NAPHSIS	National Association for Public Health Statistics and Information Systems
NCHS	National Center for Health Statistics
NLM	United States National Library of Medicine
NPCR	National Center of Cancer Registries
NQF	National Quality Forum
NwHIN	Nationwide Health Information Network
OML	Lab Order for Multiple Orders
ONC	Office of the National Coordinator for Health Information Technology
ORU	Observation Results
PHDSC	Public Health Data Standards Consortium
PHER WG	Public Health and Emergency Response Work Group
PHIN MS	Public Health Information Network Messaging System
PHIN	Public Health Information Network
PHIN MQF	Public Health Information Network Message Quality Framework
PHIN VADS	Public Health Information Network Vocabulary Access and Distribution System
PHIX	Public Health Information eXchange
PHL	Public Health Laboratory
PHLIP	Public Health Laboratory Interoperability Project
PHR	Personal Health Record
PRPH-Ca	Physician Reporting to Public Health-Cancer Registries
QRPH	Quality Research and Public Health
RCMT	Reportable Condition Mapping Table
RFD	Request Form for Data capture
RFD	Retrieve Form for Data capture

S & I	Standards and Interoperability
SDO	Standards Development Organization
SNOMED	Systematized Nomenclature of Medicine
SNOMED CT	Systematized Nomenclature of Medicine-Clinical Terms
SS	Syndromic Surveillance
USHIK	United States Health Information Knowledgebase
USPSTF	U.S. Preventive Services Task Force
VR DAM	Vital Records Domain Analysis Model
VRFP	Vital Records Functional Profile
XDS	Cross Enterprise Document Sharing