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An update on the use of health information technology in newborn screening

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ABSTRACT

Newborn screening (NBS) has high-stakes health implications and requires rapid and effective communication between many people and organizations. Multiple NBS stakeholders worked together to create national guidance for reporting NBS results with HL7 (Health Level 7) messages that contain LOINC (Logical Observation Identifiers Names and Codes) and SNOMED-CT (Systematized Nomenclature of Medicine–Clinical Terms) codes, report quantitative test results, and use standardized computer-readable UCUM units of measure. This guidance (a LOINC panel and an example annotated HL7 message) enables standard HL7 v2.5.1 laboratory messages to carry the information required for reporting NBS results. Other efforts include HL7 implementation guides for reporting point-of-care (POC) NBS results as well as standardizing follow-up of patients diagnosed with conditions identified through NBS. If the guidance is used nationally, regional and national registries can aggregate results from state programs to facilitate research and quality assurance and help ensure continuity of operations following a disaster situation.

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Introduction

Newborn screening (NBS) is a complex system of public health laboratories and follow-up programs, hospitals, clinicians, courier services, and families with newborns. The information flow and communication network involved in NBS combined with the growing adoption of electronic health records (EHRs) and electronic exchange of laboratory test results, created an opportunity to develop consensus-based standard vocabularies that would enable NBS health information exchange (HIE) as well as provide a foundation for establishing research and quality measures.[1–3] In 2009, Downing et al.[3] described the potential benefits of using health information technology (HIT) for NBS and the initial

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steps that had been taken to enable the use of HIT. In this update, we summarize the efforts over the last 5 years to make HIT use for NBS a reality.

Background

Members of multiple government agencies, NBS programs, and laboratories worked together to develop standardized guidance for electronic reporting of NBS results[4] using nationally accepted vocabulary[5,6] and electronic messaging standards: (1) LOINC (Logical Observation Identifiers Names and Codes) contains standard codes for identifying laboratory tests and other clinical measures; (2) SNOMED CT (Systematized Nomenclature of Medicine—Clinical Terms) is an international terminology standard for systematically specifying symptoms and diagnoses; (3) UCUM (Unified Code for Units of Measure) specifies the units for a given test or measure in a standard, machine-readable format; and (4) HL7 (Health Level 7) specifies the standards for electronic messaging. The guidance includes a comprehensive LOINC panel and an example annotated HL7 message that states can use as a template to develop their specifications for transmitting electronic NBS result messages.[7] The National Library of Medicine (NLM) has continued to refine and add to this guidance, as new conditions are added to NBS.

Other efforts in the area of NBS HIT include publication of implementation guides for NBS dried blood spot (DBS) orders[8] and results[9] reporting and balloting of HL7 implementation guides for point-of-care (POC) critical congenital heart disease (CCHD)[10] and infant hearing[11] screening. A 2013 survey conducted by the Association of Public Health Laboratories (APHL), which is described in more detail below, assessed different state NBS programs' progress in implementing HIT systems for NBS. This HIT work is also evolving beyond NBS, to short- and long-term follow-up, because the infant NBS is only the first step in a long continuum of care.

HRSA/NLM HIT guidance for NBS

In 2009, the NLM and the Health Resources and Services Administration (HRSA) created a LOINC panel that covered all of the conditions stated on the Secretary of Health and Human Services' Advisory Committee on Heritable Disorders in Newborns and Children's (SACHDNC) Recommended Uniform Screening Panel (RUSP)[12] as well as other conditions that were screened by any U.S. NBS program.[13] It included amino acid, acylcarnitine, endocrine, and hemoglobin disorders, as well as infant hearing screening. The NLM/HRSA guidance also included an example HL7 NBS result message with detailed annotations that was meant to be a primer on electronic messaging and data standards. The NLM worked closely with several state NBS programs, reviewed their early test HL7 messages, and refined the LOINC panel and HL7 messaging guidance based on their feedback. This work was reviewed by the SACHDNC Laboratory Standards and Procedures Subcommittee and first published on the NLM NBS website (http://newbornscreeningcodes.nlm.nih.gov) in September 2009.

The messaging guidance included help for transitioning from local codes to standard codes or, for the systems that need to continue using local codes, for incorporating both into their HL7 messages. For example, the HL7 message can include both the standard LOINC code and test name (in italics for illustrative purposes) and the local code and test name (underlined, also for illustrative purposes) for the third field (observation ID) of the observation (OBX) segment:

OBX|4|NM|*59407-7^Oxygen saturation in Blood Preductal by Pulse oximetry^LN*^Pre-SaO2^Preductal O2 saturation^L||99|%|>95|N|||F

The fifth field of the OBX segment can carry both a standard SNOMED CT code and name (in italics) and either a LOINC answer (LA) code and name or a local code and name (underlined) for the NBS condition:

OBX|4|CE|57131-5^Newborn conditions with positive markers [Identifier] in Dried blood spot^LN|1|**128596003**^*Medium-chain acyl-coenzyme A dehydrogenase deficiency^SCT*^ MCAD^Med-chain acyl-coenzyme A dehydro def^L|||A|||F

Since the original LOINC panel and HL7 example message were published, NLM has been continuously refining the guidance based on feedback from NBS programs and other stakeholders. As an example, the original LOINC panel included a method for reporting hemoglobin screening results that was based on hemoglobin patterns, which was unsustainable, as the number of hemoglobin variants that states could identify continued to grow. The NLM worked with hemoglobin and NBS experts from multiple federal and state agencies and NBS programs to devise a new method for reporting hemoglobin screening results based on reporting the individual hemoglobin variants suspected rather than the pattern or peaks observed. The NLM and the Regenstrief Institute created a LOINC panel containing five LOINC codes for reporting up to five suspected hemoglobins in a specimen in terms of their relative concentrations (Table 1). Depending on the number of hemoglobins suspected in a given sample, one to all the five codes can be used in separate HL7 message segments. For example, the following three HL7 OBX segments together represent the three hemoglobin types suspected (F, A, and S) in the order of decreasing concentration in a single NBS specimen:

OBX|1|CE|64117-5^ Most predominant hemoglobin ^LN^^^ |1| LA16208-3^Hb F^LN ||||||F||| 2009071414 5203
OBX|2|CE|64118-3^Second most predominant hemoglobin^LN^^^ |1|LA11112-2^Hb A^LN ||||||F||| 20090714145203
OBX|3|CE|64119-1^Third most predominant hemoglobin ^LN^^^ |1| LA13007-2^Hb S^LN ||||||F||| 20090714145203

The new method is easy to understand and complies with HL7 messaging standards, while remaining straightforward to implement using LOINC codes.

In May 2011, the SACHDNC Laboratory Standards and Procedures Subcommittee suggested that the NLM review

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