



Secretary's Advisory Committee on Heritable Disorders in Newborns and Children

Health Information Technology Workgroup

Presentation by co-chairs

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Genetic Alliance and HIT Standards Committee

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Overview

- ❑ Workgroup Charge and Goals
- ❑ Workgroup Membership
- ❑ Relationship to SACHDNC subcommittees
- ❑ External events that have created immediate opportunities to deploy HIT in newborn screening
- ❑ Recommendation on monitoring the implementation of HL7 lab result messaging for NBS
- ❑ Prioritization of work program for the upcoming year

Charge to the Workgroup

- ❑ To advise the SACHDNC, and its subcommittees, on opportunities to use health information technology, systems, and standards to facilitate the exchange and use of newborn screening information.

Goals for the Workgroup

- The HIT Workgroup will bring recommendations and reports on best practices for implementing systems and standards in newborn screening for deliberation and approval by the SACHDNC and distribution to appropriate agencies and programs*.

* For example: state newborn screening programs, Newborn Screening Clearinghouse, Association of Public Health Laboratories, Newborn Screening Translational Research Network

Goals for the Workgroup (continued)

- ❑ The HIT Workgroup will ensure that the products from the SACHDNC subcommittees, workgroups, and special projects (i.e. NCQA measures) are in line with current HIT standards.
- ❑ The HIT Workgroup will, from time to time, monitor the adoption and implementation of those standards and their application to newborn screening.

Workgroup Logistics

- ❑ The workgroup will meet three times a year during the SACHDNC meetings (at a time that will NOT conflict with the subcommittees meetings)
- ❑ By phone on a monthly basis to prepare recommendations and reports.



Workgroup Membership

Chairs, Staff, Sub-Committee Liaisons

- ❑ Alan Zuckerman – NLM-HRSA
- ❑ Sharon Terry – HIT Standards Committee
- ❑ Alaina Harris - HRSA
- ❑ Natasha Bonhomme – Education Sub-Committee, Genetic Alliance
- ❑ Bob Bowman – Follow-up and Treatment Sub-Committee, Indiana DOH
- ❑ Harry Hannon - Lab Sub-Committee, CDC/Lab, NBSGRC

Workgroup Membership Federal Agencies

- ❑ Sara Copeland - HRSA/GSB
- ❑ Clement McDonald -NLM/LHNCBMC
- ❑ Rebecca Goodwin - NLM/LHNCBMC
- ❑ John Eichwald - CDC/EHDI
- ❑ Carla Cuthbert – CDC/Lab, Lab Standards Subcommittee, APHL NSGPH committee
- ❑ Barbara Daily – CMS
- ❑ Denise Dougherty – AHRQ
- ❑ Brandi Katman – NIH/NLM/NCBI
- ❑ Lee Stevens – ONC HIE

Workgroup Membership States and Professional Societies

- ❑ Christopher Kus – ASTHO, NY DOH
- ❑ Jane Getchell – APHL, Delaware DOH
- ❑ James Figge – HIT Policy Committee, NY DOH
- ❑ Michael Watson – ACMG
- ❑ Amy Brower – ACMG, NBSTRN
- ❑ Tim Geleske – AAP/Medical Home
- ❑ Christopher Lehmann – AAP/Child Health Informatics Center (CHIC)
- ❑ Lori Williamson - National Society of Genetic Counselors (NSGC)

Workgroup Membership

IT Standards Experts and Vendors

- ❑ Alex Kemper - Duke University
- ❑ Brad Therrell - NBSGRC, NNSIS
- ❑ Walter Reichert - Natus
- ❑ Ken Pool - Oz Systems
- ❑ Darren Hudach - Perkin Elmer
- ❑ Alan Hinman – PHII
- ❑ Michelle Meigs – APHL HIT Committee
- ❑ Dari Shirazi – Iowa State Public Health Laboratory University of Iowa
- ❑ TBA – National Institute of Standards and Technology NIST

Relationship to SACHDNC Sub-Committees

- ❑ The HIT Workgroup will assist the existing sub-committees by suggesting HIT methods to implement their work program
- ❑ The HIT Workgroup will meet at a separate time from the other sub-committee to avoid conflicts and maximize cross participation
- ❑ Some of the work of the HIT workgroup will fall outside of a sub-committee and relate directly to the mission of the SACHDNC

Requests From the SACHDNC Sub-Committees

- ❑ Laboratory Sub-committee
 - ❑ Need for expansion of vocabulary and coding guidance to include confirmatory testing
- ❑ Treatment and Follow-up Sub-committee
 - ❑ Need for a standard messaging and coding approach to capturing common and condition specific follow-up datasets
- ❑ Education Sub-committee
 - ❑ Need for education of primary care physicians about the value of HL7 NBS messages and including NBS in a lifetime medical record

Immediate HIT Opportunities and External Events

- ❑ Growth in HL7 Laboratory Results Messages supported by EHR certification criteria with convergence on common standards and use of LOINC codes
- ❑ CMS will develop quality measures for newborn screening for use in 2013 measures for Meaningful Use of EHR Regulations
- ❑ CMS and AHRQ: Model EHR Format for Children under CHIP-RA
- ❑ Nationwide Health Information Network including Project CONNECT NHIN, CONNECT direct, and funding for state HIE should include NBS
- ❑ ARRA/HITECH has increased attention to Public Health Informatics and Immunizations: attention to children and other vulnerable populations

HIT Workgroup Recommendation: Monitoring the Implementation of HL7 Lab Results Messages

- ❑ Monitor state use and compliance with the HRSA/NLM guidelines for coding, terminology and electronic messaging.
 - ❑ HL7 lab result messages are the standard for incorporating lab results into an EHR and NBS results should become part of a lifetime EHR
 - ❑ The states that implement HL7 messaging should request changes and additions as needed
 - ❑ The HIT workgroup should report back to the SACHDNC at its September meeting with a detailed proposal for data collection
 - ❑ The Secretary should recommend that beginning in the 2011 reporting year, the NNSIS should collect data on implementation of HL7 messages for NBS by the states

Examples of Monitoring Activities of the Implementation of HL7 Lab Results Messages

- ❑ State of readiness and implementation
- ❑ Statistics by percentage of hospitals and percent of live births included
- ❑ States sending results to Hospitals and to Practices
- ❑ States that receive orders for NBS
- ❑ States using LOINC codes
- ❑ States including quantitative results
- ❑ States reporting hearing screening results
- ❑ States using Web Portals
- ❑ Progress towards a uniform ordering dataset

Proposed Projects, Reports, or Recommendations for HIT Workgroup

- ❑ Develop a plan for monitoring the use of HL7 lab results messages for NBS and identify who is using standard codes, including to report quantitative data
- ❑ Expand coding and terminology to include screening for new conditions and confirmatory diagnostic testing
- ❑ Select a messaging or document format for the confirmed case report (LTFU enrollment form)
- ❑ Propose Automated Quality Measures for NBS in the 2013 Meaningful Use of EHR regulations
- ❑ Encourage integration of NBS with birth certificates
- ❑ Develop a report on getting providers to report results of short term follow-up for all screening to health departments



Additional Projects, Reports, or Recommendations for HIT Workgroup

- ❑ Prepare a report on newborn screening and HIE that includes Project CONNECT / NHIN
- ❑ Develop a recommendation on developing message conformance testing tools at NIST to test standard NBS lab reports
- ❑ Develop an education program for primary care physicians about NBS HIT
- ❑ Explore integration of NBS with immunization registries
- ❑ Develop a report on clinical decision support tools for newborn screening such as QRDA and RPE
- ❑ Disaster planning for NBS information technology



Topics for Discussion

- ❑ HIT Workgroup Charge, Goals, and Membership
- ❑ External events in HIT that create opportunities for newborn screening
- ❑ Recommendation on monitoring HL7 messaging implementation for NBS
- ❑ Priorities for Workgroup Activities