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STANDARDS CONSORTIUM**

The findings and conclusions in this presentation
have not been formally disseminated by the
Centers for Disease Control and Prevention and
should not be construed to represent any agency
determination or policy

EHDI HIT AS
RECOMMENDED BY
IHE, HITSP, AND
ONC





ALPHABET SOUP OR SOMETHING ELSE?

WHY NEWBORN SCREENING AS PART OF THE HIT CONVERSATION

- A first encounter between providers and public health
- As an encounter, communication becomes essential
- Communication is about interoperability between/among systems
- Interoperability has been elusive

HIT: THE GREAT ENABLER

Neal Halfon, M.D, MPH
UCLA

- ① Reduce Health Care Costs
- ① Reduce Errors
- ① Improve Quality
- ① Enhance Timeliness of Information
- ① Improve Access to Information

HIT: THE GREAT ENABLER

Neal Halfon, M.D, MPH
UCLA

- ⦿ Promote better service and system integration
- ⦿ Integrate personal and population health services

HIT MEETINGS INCLUDE

- Public Health Community (i.e., you guys)
- Clinicians
- Vendors

WHAT VENDORS FOR EXAMPLE?

Leadership

Logos of Leadership vendors: BlueWare, CERNER (All Together), CISCO, ECLIPSYS (The Outcomes Company), Lilly, GE Healthcare, genzyme, IBM, Initiate, MCKESSON (Empowering Healthcare), MISYS, Motion Computing, NDMA (National Digital Medical Archive), NOVARTIS, Pfizer, PHILIPS, QUOVADX (Integration Solutions), SAIC (From Science to Solutions), SIEMENS.

Implementer

Logos of Implementer vendors: AGFA, alert, ALLSCRIPTS (Inform. Connect. Transform.), AXOLOTL (HEALTHCARE CONNECTED), B. BRAUN (SHARING EXPERTISE), CapMed, CGI (CGI ITS), CPSI (Clear direction), digital Infuzion, Dräger medical (A Dräger and Siemens Company), Kodak, Epic, mie (MEDICAL INFORMATION EXCELLENCE), MediNotes (Deep Insights. Proven. Powerful. Peace of Mind.), MedQuist, NextGen (Healthcare Information Systems, Inc.), OUTCOME (POST-MARKETING EXCELLENCE), PHASE-FORWARD, PRACTICE PARTNER, QUADRAMEDY (Healthcare Information Systems), SAS (THE POWER TO KNOW), WelchAlllyn.

Supporter

Logos of Supporter vendors: BCE, XWAVE (A Division of Bell Allyn), CABLE MEANS BUSINESS, Canon, DAIRYLAND HEALTHCARE SOLUTIONS, Dynamic Imaging, eClinicalWorks (Whole. People. Care. Done.), EMAGEON, emdeon, GREENWAY (What Is Your Experience?), Sentillion, THOMSON MICROMEDEX, TOSHIBA, Healthvision.

Organizational Participants

Logos of Organizational Participants: ACCE, ANSI (American National Standards Institute), CAQH (Improving Healthcare Administration), CDISC, ISO, LiveData, MIDMARK (Diagnostic Group), IHL, INTERNET, LIBERTY ALLIANCE PROJECT, NIST (National Institute of Standards and Technology, Technology Administration, U.S. Department of Commerce).

Participants as of 11/20/06

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The Purpose of Today

ROLE OF PUBLIC HEALTH IN HEALTH TECHNOLOGY FOCUSED MEETINGS

ROLE OF PUBLIC HEALTH IN HIT STANDARDS

- ◎ To maintain existing CDC, HRSA goals
 - States know hearing status of each occurrent birth
 - States keep individual child hearing records

Its about verifiable data

ROLE OF PUBLIC HEALTH IN HIT STANDARDS

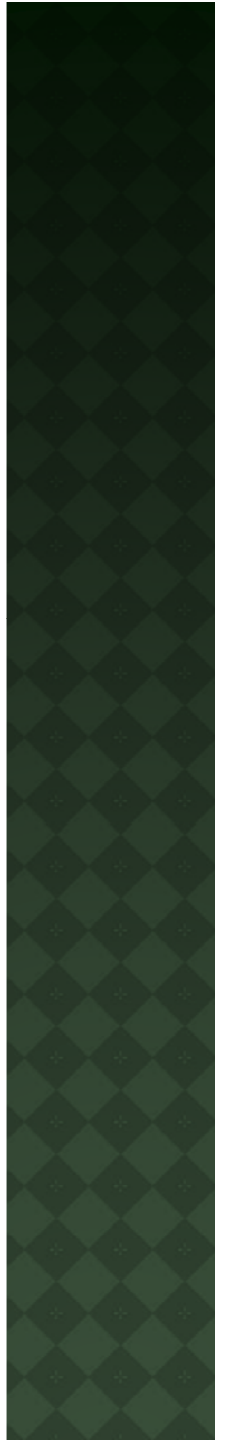
- ◎ To assure your QA efforts go forward as they exist now or better - but no worse
- ◎ To maintain public health's autonomy
 - AABR trumps OAE or not?
 - Certification and compliance by hospitals
- ◎ To maintain jurisdictional flexibility and control
 - Risk Factor requirements

ROLE OF PUBLIC HEALTH IN HIT STANDARDS

- ◎ So EHR vendors understand public health data requirements
- ◎ So EHR vendors understand communication requirements
- ◎ Understand data commonalities across public health states
- ◎ Define common public health needs in interoperability

The Purpose of Today

**REVIEW WHERE OUR
STANDARDS ARE RIGHT
NOW**



PUBLIC HEALTH ACTIVITIES

2008-2009

- Newborn Screening - White Paper
- Newborn Screening USE Case

2009-2010

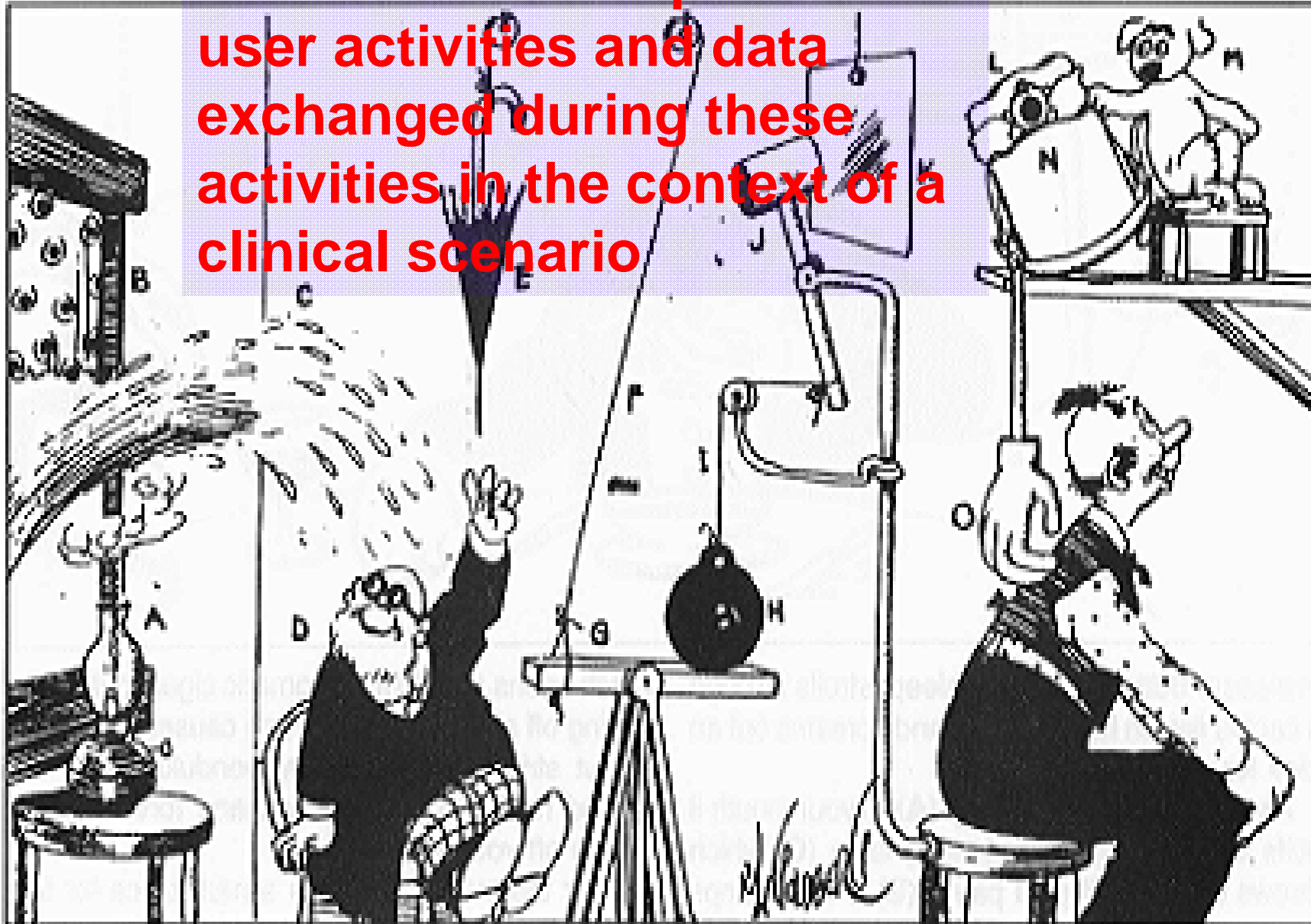
- Early and continuous hearing screening in the Medical Home - EHDI Profile

NEWBORN SCREENING WHITE PAPER AND USE CASES

- ◎ Public Health Data Standards Consortium (PHDSC)
- ◎ IHE
 - Quality Research in Public Health Committee
 - Laboratory Committee: France, Germany, Austria
- ◎ With input from State Health Departments
 - Alaska, Iowa, Maryland, Texas

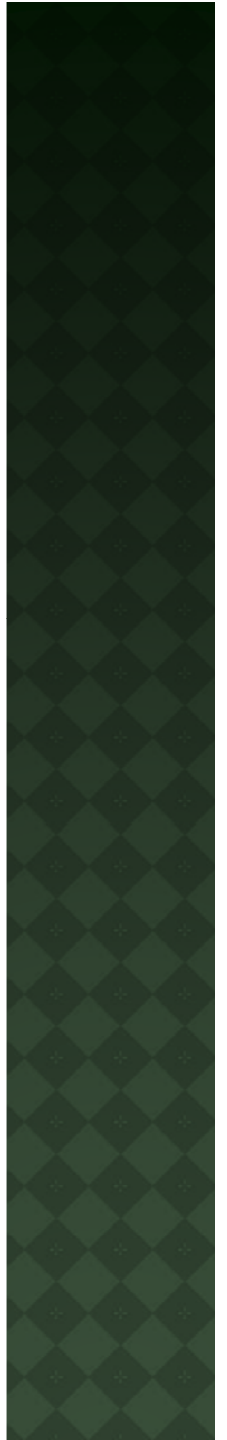
An Automatic Back Scratcher

Structured description of user activities and data exchanged during these activities in the context of a clinical scenario



The Purpose of Today

ADVOCATE NEXT STEPS
US VERSUS OTHER NATIONS IN
CHILD HEALTH



IT'S ABOUT HEALTH

- ◎ NBS is the child's first encounter between the health care system and public health
- ◎ Public Health programs like EHDI and NBS are the foundations for child health

HEALTH

- ① Health is developmental
- ① Health develops across life course
- ① Health development represented by health trajectories

PUBLIC HEALTH: improve
accountability and performance





Exchanging EHDI Data through Electronic Health Records

John Eichwald, MA FAAA
CDC EHDI Team Lead

and

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Public Health Data Standards Consortium

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Centers for Disease Control and Prevention
National Center on Birth Defects and Developmental Disabilities



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Health Information Technology Activities

- **American Recovery and Reinvestment Act (ARRA)**
- **Centers for Medicare & Medicaid Services (CMS)**
Proposed Rule
- **Department of Health and Human Services (HHS)**
Interim Final Rule
- **Logical Observation Identifiers Names and Codes (LOINC)**
- **Technology Standards Panel (HITSP)**
- **Integrating the Healthcare Enterprise (IHE)**



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**American Recovery and
Reinvestment Act
(ARRA) – Economic Stimulus
Package**



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ARRA Provisions

- Certified EHR for each person in the US by 2014
- Nationwide health information exchange infrastructure
- Technology to protect privacy and security for the electronic exchange of an individual's individually identifiable health information
- Electronic systems to ensure the comprehensive collection of patient demographic data
- Address needs of unique populations (e.g. children)
 - may include automated electronic enrollment



American Recovery and Reinvestment Act

TITLE IV — MEDICARE AND MEDICAID HEALTH INFORMATION TECHNOLOGY

Physicians and hospitals incentives for adoption and the “*meaningful use*” of certified EHR technology

TITLE XIII — HEALTH INFORMATION TECHNOLOGY

Health Information Technology for Economic and Clinical Health (HITECH) Act

- \$19 billion to ensure widespread adoption and use of interoperable health information technology



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ARRA Provisions

PROVIDER INCENTIVES

- Medicare & Medicaid authorizes loans to purchase EHR
- Increased physicians reimbursement with EHR

PROVIDER DISINCENTIVES

- Eligible hospitals that do not demonstrate meaningful use of certified EHR technology will receive less than 100% of the fee schedule beginning 10/1/2014
- This applies to eligible providers for their professional services beginning 1/1/2015



Proposed rule
Centers for Medicare & Medicaid
Services (CMS)
“Meaningful Use”



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EHR “Meaningful Use”

556 pages published 12/30/2009 - public comment period ends **3/15/2010**

Stage 1, CMS proposes objectives & measures for eligible providers and hospitals that must be met to be deemed a meaningful EHR user

** hospitals 10/1/2010 and providers 1/1/2011*

“Capability to provide electronic syndromic surveillance data to public health agencies and actual transmission according to applicable law and practice”



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EHR “Meaningful Use”

For Stage 2, which begins in 10/1/2012, CMS is considering expanding the clinical quality measure set to include:

Additional pediatrics measures such as
documentation of newborn screening

Committee on Heritable Disorders in Newborns and Children (ACHDNC) letter dated 1/22/10:

“The Committee strongly supports the inclusion of documentation of newborn screening as a quality measure for 2013”



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Interim Final Rule
Department of Health and Human
Services (HHS)



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HHS Interim Final Rule

Interim Final Rule: “Health Information Technology: Initial Set of Standards, Implementation Specifications, and Certification Criteria for Electronic Health Record Technology”

35 pages published 1/13/2010 - effective 2/13/2010

Part of the definition of EHR Module is “software program used to submit public health information to public health authorities”

Do EHDI data systems fit the definition of an EHR Module?



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EHDI
Logical Observation Identifiers
Names and Codes
(LOINC)

LOINC® Users' Guide©
Regenstrief Institute, Inc.



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New EHDI LOINC[®] Codes

Newborn Screening Coding and Terminology Guide

produced by:

Regenstrief Institute, the U.S. National Library of
Medicine, HITSP Population Perspective Technical
Committee, and the HHS Secretary's Advisory
Committee on Heritable Disorders in Newborns and
Children (ACHDNC)

<http://newbornscreeningcodes.nlm.nih.gov>



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U.S. National Library of Medicine

Newborn Screening Coding and Terminology Guide

Data Standards for Electronic Reporting

[Home](#) [Views](#) [Downloads](#) [HL7](#) [Resources](#) [Code Standards](#) [About](#) [Contact Us](#)

The goal of the Newborn Screening Coding and Terminology Guide is to promote and facilitate the use of electronic health data standards in recording and transmitting newborn screening test results. The Web site includes standard codes and terminology for newborn tests and the conditions for which they screen, and links to other related sites. The codes and vocabulary standards are provided in a series of tables that you can view on the Web and/or download for your own use. These tables cover conditions recommended for screening by the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) or by a state within the U.S.

Use of these standards can speed the delivery of newborn screening reports, facilitate the care and follow-up of infants with positive test results, enable the use (and comparison) of data from different laboratories, and support the development of strategies for improving the newborn screening process.

This website also includes [draft guidance for creating an HL7 version 2.x message using these codes](#) with examples. If you would like us to notify you about updates to this guidance and other new content, please [subscribe to the NBS-Announcements](#) e-mail list from the U.S. National Library of Medicine.

You can reach these various resources by picking a choice below.

Views: Generate customized Web views from the tables of conditions and analytes/measurements maintained by the U.S. National Library of Medicine (NLM®).

- **Conditions** — Conditions that are targeted by newborn screening
- **Analytes/Measurements** — Tests that are used as markers for newborn screening conditions
- **Tailored Views** — Specify subsets, or see relationships between conditions and analytes/measurements

Downloads: Download the tables of newborn screening conditions, of markers for these conditions and/or of mappings between conditions and their markers.

Resources: Find additional information about newborn screening and related codes and data standards, including the [Newborn Screening Draft Detailed Use Case](#) that was developed by the Office of the National Coordinator for Health Information Technology (ONC).



Newborn Screening Coding and Terminology Guide

Data Standards for Electronic Reporting

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Conditions View

The Conditions View presents the conditions you selected on a previous screen, and for each condition, the related Enzyme Commission code Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) Category, Online Mendelian Inheritance in Man (OMIM®) or Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) code.

Condition <i>Choose condition to view related measurements</i>	Abbreviation	ACHDNC Category	Enzyme Name	Enzyme Commission Number	OMIM ID	SNOMED CT Code
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Hearing Loss



Hearing Loss	HEAR	Core	N/A	N/A	N/A	15188001
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MS/MS (Tandem Mass Spectrometry) Measured Conditions

Amino Acid Disorders

Argininemia	ARG	Secondary	Arginase	3.5.3.1	207800	23501004
Argininosuccinic aciduria	ASA	Core	Argininosuccinate lyase	4.3.2.1	207900	41013004
Carbamoyltransferase deficiency	CPS	Other	Carbamoyltransferase I	6.3.4.16	237300	124380007
Citruillinemia type I	CIT-I	Core	Argininosuccinate synthetase	6.3.4.5	215700	398680004
Citruillinemia type II	CIT-II	Secondary	Aspartate glutamate carrier (citrin)	None	603471 605814	30529005
Dihydrolipoamide	E3	Core	Dihydrolipoamide	1.8.1.4	238331	29914000



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Newborn hearing screen method - Analyte/Measurement Details

LOINC® Long Common Name: Newborn hearing screen method of Ear

Analyte Short Name: Hear-Meth

LOINC Number: 54106-0

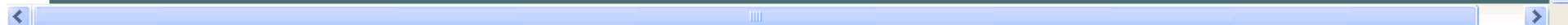
Answer List

The results of the measurement are expressed using the following answer list.

SNOMED Code	LOINC Answer ID	UMLS CUI	Answer Text
None	LA10387-1	None	Automated auditory brainstem response
None	LA10388-9	None	Auditory brain stem response
None	LA10389-7	None	Otoacoustic emissions
None	LA10390-5	None	Distortion product otoacoustic emissions
None	LA10391-3	None	Transient otoacoustic emissions
None	LA12406-7	None	Methodology unknown

Conditions

The analyte/measurement serves as a marker for the following conditions.



EHDI LOINC[®] Codes

LOINC#: Newborn hearing screen methods
54106-0

<u>Code</u>	<u>Answer</u>	<u>Answer ID</u>
AABR	Automated auditory brainstem response	LA10387-1
ABR	Auditory brainstem response	LA10388-9
OAE	Otoacoustic emissions	LA10389-7
DPOAE	Distortion product otoacoustic emissions	LA10390-5
TOAE	Transient otoacoustic emissions	LA10391-3
	Methodology unknown	LA12406-7



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EHDI LOINC[®] Codes

LOINC# 54109-4: Newborn hearing screen – right

LOINC# 54108-6: Newborn hearing screen – left

Answer	Answer ID
Pass	LA10392-1
Refer	LA10393-9
Parental refusal	LA6644-4
Attempted, but unsuccessful - technical fail	LA12408-3
Not performed	LA7304-4
Not performed, medical exclusion - not indicated	LA12409-1



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EHDI LOINC[®] Codes

LOINC# 58232-0: JCIH Risk Indicators

None	LA137-2
Caregiver concern about hearing	LA12667-4
Family Hx of hearing loss	LA12668-2
NICU stay > 5 days	LA12669-0
ECMO	LA12670-8
Assisted ventilation	LA12671-6
Ototoxic medication use	LA12672-4
Exchange transfusion for Hyperbilirubinemia	LA12673-2



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EHDI LOINC® Codes

LOINC# 58232-0: JCIH Risk Indicators (continued)

In utero infection(s)	LA12674-0
Craniofacial anomalies	LA12675-7
Physical findings of syndromes that include hearing loss	LA12681-5
Syndromes associated with hearing loss	LA12676-5
Neurodegenerative disorders	LA12677-3
Postnatal infections	LA12678-1
Head trauma	LA12679-9
Chemotherapy	LA6172-6



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Health Level 7 (HL7) Messaging Standard

Example of a potential EHCI HL7 message:

```
MSH|^~\&||NBS APP|HSPTL001|EHDI APP|1825  
CC|201001071230||ORU^R01^ORU_R01|CTRL-9876|P|2.4  
PID|||010-11-  
1111||Sully^Jake^^^^^^|20100106|M||White|1600 Clifton  
Road^^Atlanta^GA^30333|089|||English|||AC010111111|||90  
0-23-4567||DeKalb Medical  
Center|OBR|1|20100023456|10A1912102|54108-6^Hearing  
Loss NBS Panel  
^LOINC|Routine||201001070800|||||||||OBX|1|CE|54106-  
0^Newborn hearing screen method^LOINC|1|LA10388-  
9^ABR^LOINC |||||F|||20100107093015OBX|2|CE|54108-  
6^Newborn hearing screen - left^LOINC|1|LA10392-  
1^Pass^LOINC |||||F|||20100107093550OBX|3|CE|54109-  
4^Newborn hearing screen - right^LOINC|1|LA10393-  
9^Refer^LOINC |||||F|||20100107094001
```



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Health Level 7 (HL7) Messaging Standard

Example of a potential EHCI HL7 message:

```
MSH|^~\&||NBS APP|HSPTL001|EHDI APP|1825  
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6^Newborn hearing screen - left^LOINC|1|LA10392-  
1^Pass^LOINC |||||F|||20100107093550OBX|3|CE|54109-  
4^Newborn hearing screen - right^LOINC|1|LA10393-  
9^Refer^LOINC |||||F|||20100107094001
```



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Health Information Technology Standards Panel (HITSP)



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Newborn Screening Interoperability Specification (HITSP/IS92)

- Describes information flows, issues, and system capabilities supporting newborn screening (bloodspot and hearing) information exchanges among clinical care settings and public health
- 67 page document
- Public review and comment period 11/9/2009 – 12/4/2009
- On 1/25/2010 HITSP Panel approved the Newborn Screening Interoperability Specifications (IS92)



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Integrating the Healthcare Enterprise (IHE)



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Newborn Screening White Paper

- Developed by the IHE Quality, Research and Public Health (QRPH) Committee
- 49 pages published 1/9/2009
- Identified interoperable processes and data information exchange needs between public health and clinical information systems for Newborn Screening (bloodspot and hearing)
- Use Cases developed with the input from United States, France, Germany and Austria
- Proposed use of U.S. National Library of Medicine LOINC[®] Codes



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EHDI Integration Profile

Currently under development by the IHE QRPH Committee

Use Cases include:

- audiologic diagnosis
- referral to early intervention
- surveillance for delayed onset hearing loss

Timeline:

- January – May 2010: Profile development
- June 2010: Documents published for public comment
- July 2010: Public comment deadline
- August 2010: Documents published for trial implementation

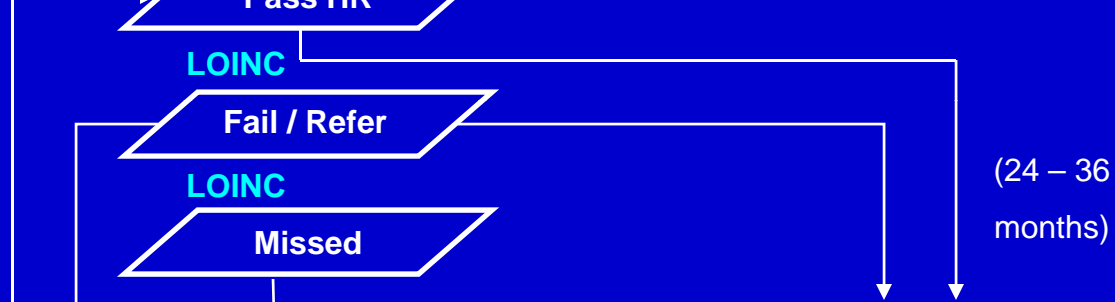
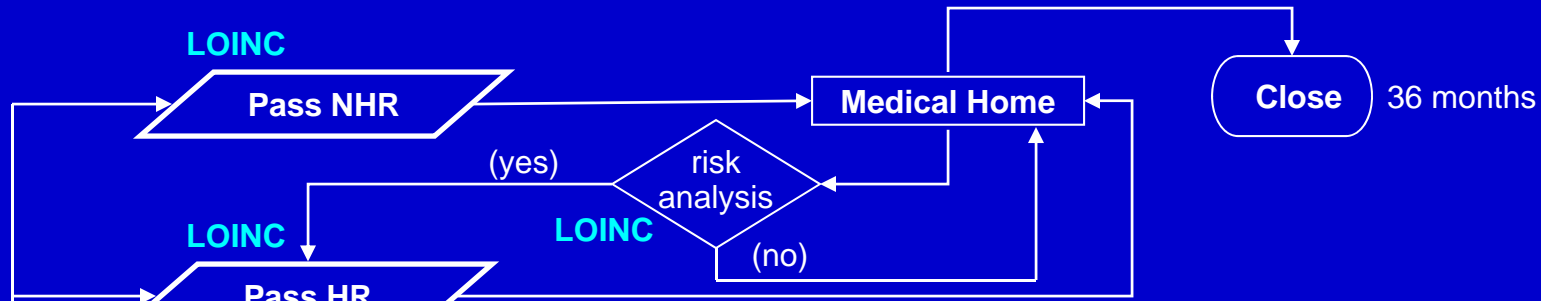


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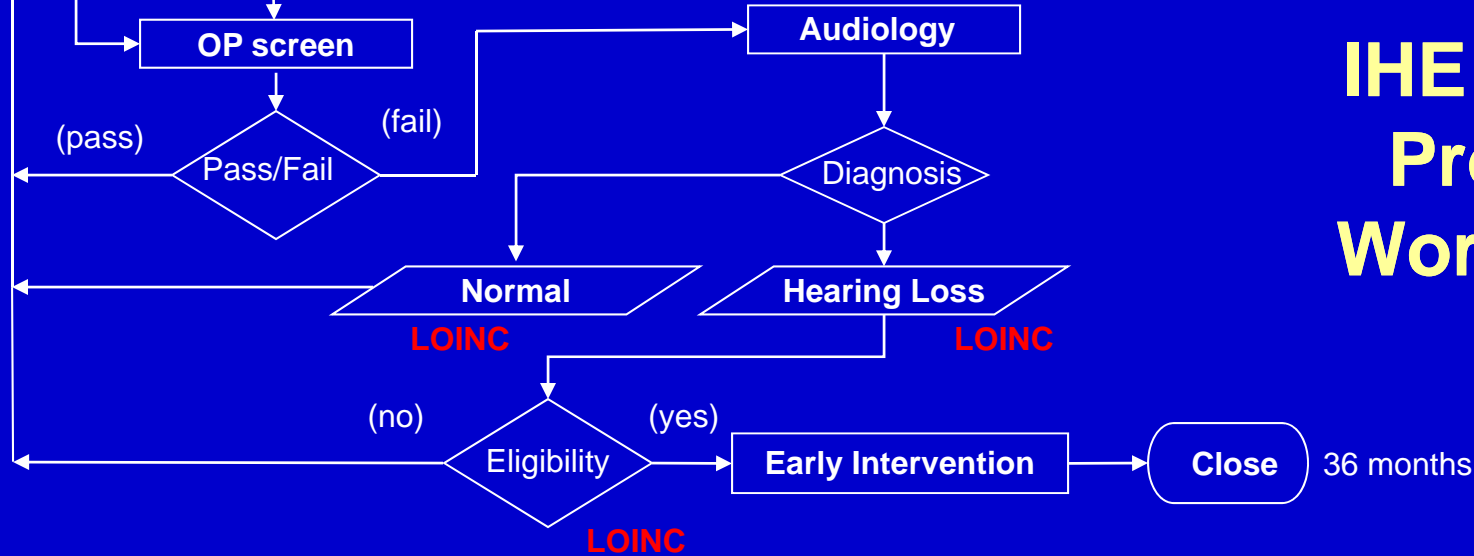
IHE NBS White Paper



(continuous monitoring)



IHE EHDI Profile Workflow





Questions?

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