“Data Management for EHDI: Helpful Friend, Not Dreaded Foe”

John Eichwald, Team Lead
Early Hearing Detection and Intervention (EHDI)

IFSC/Pediatric Audiology Symposium/SE Regional EHDI Conference
October, 2011
Raleigh, NC
Learning Objectives

• Differentiate the dimensions of data quality
• Propose data collection activities to track program effectiveness
• Develop actions to ensure effective data use
What is a friend?
A friend is someone who:

• you like and enjoy being with
• helps or supports someone or something
• has a strong liking for and trust in another
• is not an enemy (not a “foe”)
• aids or favors something

(www.merriam-webster.com)
Why is Data a Helpful Friend?

- When something gets measured, it gets done;
- When those doing it receive feedback about its measurement, it gets done better; and
- When those doing it well get rewarded, it gets repeated
Why do I need Quality Data?

- To improve services to families
- To find problems, recognize impact, take action
- To analyze and disseminate information to shape ongoing development
- To inform partners and stakeholders of the program’s successes and challenges
- To reward top performers
- To fill out CDC national survey (last!)
Is this data?
Is this data?

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</table>
Definition of DATA

1. factual information, as measurements or statistics, used as a basis for reasoning, discussion, or calculation

2. information output by a sensing device or organ that includes both useful and irrelevant or redundant information and must be processed to be meaningful

3. information in numerical form that can be digitally transmitted or processed

(www.merriam-webster.com)
Foundation is based upon valid and verifiable, individual and unduplicated data
Data collection

• provides a snapshot of the overall success of your program activities at any given point in time
Data collection

• ensures that you have a track record how you are progressing
Data collection

- gives you an idea of where you need to concentrate your efforts
Data collection

• provides transparent accountability for stakeholders
Turning Data into Information

Statistical Significance

Aggregation Bias
Statistical Significance

“Stuff” happens out here!

0.004 of 4,000,000 births = 16,000 babies!
Why Individual Not Aggregate Data?

• When data from individuals are grouped, there is a loss of information (aggregation bias)

• With grouped data, inferences made about individuals can be wrong

• Conclusions about individuals are in general only weakly supported by group data
Simpson’s Paradox
What Temperature is it?
National Data Standards
National Data Standards

STANDARDS MEETING

EACH OF YOU HAS BEEN CHOSEN TO REPRESENT THE INTERESTS OF YOUR RESPECTIVE COMPANIES.
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 (NLMinfo).

- **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).
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®) classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) code.

### Hearing Loss

<table>
<thead>
<tr>
<th>Condition</th>
<th>Abbreviation</th>
<th>ACHDNC Category</th>
<th>Enzyme Name</th>
<th>Enzyme Commission Number</th>
<th>OMIM ID</th>
<th>SNOMED CT Code</th>
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</thead>
<tbody>
<tr>
<td>Hearing Loss</td>
<td>HEAR</td>
<td>Core</td>
<td>N/A</td>
<td>N/A</td>
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### MS/MS (Tandem Mass Spectrometry) Measured Conditions

#### Amino Acid Disorders

<table>
<thead>
<tr>
<th>Condition</th>
<th>Abbreviation</th>
<th>Category</th>
<th>Enzyme Name</th>
<th>Enzyme Commission Number</th>
<th>OMIM ID</th>
<th>SNOMED CT Code</th>
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<td>Argininemia</td>
<td>ARG</td>
<td>Secondary</td>
<td>Arginase</td>
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<td>23501004</td>
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<td>Argininosuccinic aciduria</td>
<td>ASA</td>
<td>Core</td>
<td>Argininosuccinate lyase</td>
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<td>41013004</td>
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<td>Carbamoyltransferase deficiency</td>
<td>CPS</td>
<td>Other</td>
<td>Carbamoyltransferase I</td>
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<td>Citrullinemia type I</td>
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<td>Core</td>
<td>Argininosuccinate synthetase</td>
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<td>Citrullinemia type II</td>
<td>CIT-II</td>
<td>Secondary</td>
<td>Aspartate glutamate carrier (citrin)</td>
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<td>Dihydrolipoamide</td>
<td>E3</td>
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<td>Dihydrolipoamide</td>
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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.

<table>
<thead>
<tr>
<th>SNO MED Code</th>
<th>LOINC Answer ID</th>
<th>UMLS CUI</th>
<th>Answer Text</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>LA10387-1</td>
<td>None</td>
<td>Automated auditory brainstem response</td>
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<tr>
<td>None</td>
<td>LA10388-9</td>
<td>None</td>
<td>Auditory brain stem response</td>
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<td>None</td>
<td>LA10389-7</td>
<td>None</td>
<td>Otoacoustic emissions</td>
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<td>None</td>
<td>LA10390-5</td>
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<td>Distortion product otoacoustic emissions</td>
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<td>None</td>
<td>LA10391-3</td>
<td>None</td>
<td>Transient otoacoustic emissions</td>
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<td>None</td>
<td>LA12406-7</td>
<td>None</td>
<td>Methodology unknown</td>
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</table>

Conditions

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

Newborn hearing screen - left - Analyte/Measurement Details

**LOINC® Long Common Name:** Newborn hearing screen - left

**Analyte Short Name:** Hear-L

**LOINC Number:** 54108-6

**Answer List**

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

<table>
<thead>
<tr>
<th>SNOMED Code</th>
<th>LOINC Answer ID</th>
<th>UMLSCUI</th>
<th>Answer Text</th>
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</thead>
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<tr>
<td>None</td>
<td>LA10392-1</td>
<td>C0437470</td>
<td>Pass</td>
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<td>None</td>
<td>LA10393-9</td>
<td>C0580715</td>
<td>Refer</td>
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<td>None</td>
<td>LA6644-4</td>
<td>C0580717</td>
<td>Parental refusal</td>
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<td>None</td>
<td>LA12408-3</td>
<td>C0522770</td>
<td>Attempted, but unsuccessful - technical fail</td>
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<td>None</td>
<td>LA7304-4</td>
<td>C0445106</td>
<td>Not performed</td>
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<td>None</td>
<td>LA12409-1</td>
<td>C1444655</td>
<td>Not performed, medical exclusion - not indicated</td>
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### Value Set Concepts

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<tr>
<th>Concept Code</th>
<th>Concept Name</th>
<th>Preferred Concept Name</th>
<th>Code System</th>
<th>Value Set</th>
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<tbody>
<tr>
<td>276687002</td>
<td>Conjugated hyperbilirubinemia in infancy (disorder)</td>
<td>Conjugated hyperbilirubinemia in infancy (disorder)</td>
<td>SNOMED-CT</td>
<td>JCIH-EHDI Hearing Loss Risk Factors</td>
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<td>806900008</td>
<td>Degenerative disease of the central nervous system (disorder)</td>
<td>Degenerative disease of the central nervous system (disorder)</td>
<td>SNOMED-CT</td>
<td>JCIH-EHDI Hearing Loss Risk Factors</td>
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<td>439750006</td>
<td>Family history of hearing loss (situation)</td>
<td>Family history of hearing loss (situation)</td>
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<td>JCIH-EHDI Hearing Loss Risk Factors</td>
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<td>206005002</td>
<td>Fetus or neonate affected by maternal infection (disorder)</td>
<td>Fetus or neonate affected by maternal infection (disorder)</td>
<td>SNOMED-CT</td>
<td>JCIH-EHDI Hearing Loss Risk Factors</td>
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<td>161653008</td>
<td>History of - chemotherapy (situation)</td>
<td>History of - chemotherapy (situation)</td>
<td>SNOMED-CT</td>
<td>JCIH-EHDI Hearing Loss Risk Factors</td>
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<td>441899004</td>
<td>History of therapy with ototoxic medication (situation)</td>
<td>History of therapy with ototoxic medication (situation)</td>
<td>SNOMED-CT</td>
<td>JCIH-EHDI Hearing Loss Risk Factors</td>
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<td>206331005</td>
<td>Infections specific to perinatal period (disorder)</td>
<td>Infections specific to perinatal period (disorder)</td>
<td>SNOMED-CT</td>
<td>JCIH-EHDI Hearing Loss Risk Factors</td>
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**Value Set Information**

- **Value Set Code**: PHVS_NewbornHearingLossDiagnosis_JCIH_EHDI
- **Value Set Name**: JCIH-EHDI Newborn Hearing Loss Diagnosis
- **Value Set OID**: 1.3.6.1.4.1.19376.1.7.3.1.1.15.2.14
- **Value Set Description**: To Reflect EHDI hearing loss diagnosis coded with SNOMED-CT on the problem list

**Version History**

- (Current)

**Value Set Concepts**

16 Value Set Concepts found

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<tr>
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<th>Code System</th>
<th>Value Set</th>
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<td>443805006</td>
<td>Auditory neuropathy spectrum disorder (disorder)</td>
<td>Auditory neuropathy spectrum disorder (disorder)</td>
<td>SNOMED-CT</td>
<td>JCIH-EHDI Newborn Hearing Loss Diagnosis</td>
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<td>95820000</td>
<td>Bilateral hearing loss (disorder)</td>
<td>Bilateral hearing loss (disorder)</td>
<td>SNOMED-CT</td>
<td>JCIH-EHDI Newborn Hearing Loss Diagnosis</td>
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<td>44057004</td>
<td>Conductive hearing loss (disorder)</td>
<td>Conductive hearing loss (disorder)</td>
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<td>JCIH-EHDI Newborn Hearing Loss Diagnosis</td>
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<td>Mild (severity modifier) (qualifier value)</td>
<td>Mild (severity modifier) (qualifier value)</td>
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<td>JCIH-EHDI Newborn Hearing Loss Diagnosis</td>
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<td>255605001</td>
<td>Minimal (qualifier value)</td>
<td>Minimal (qualifier value)</td>
<td>SNOMED-CT</td>
<td>JCIH-EHDI Newborn Hearing Loss Diagnosis</td>
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<td>77507001</td>
<td>Mixed conductive AND sensorineural hearing loss (disorder)</td>
<td>Mixed conductive AND sensorineural hearing loss (disorder)</td>
<td>SNOMED-CT</td>
<td>JCIH-EHDI Newborn Hearing Loss Diagnosis</td>
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<tr>
<td>6736007</td>
<td>Moderate (severity modifier) (qualifier value)</td>
<td>Moderate (severity modifier) (qualifier value)</td>
<td>SNOMED-CT</td>
<td>JCIH-EHDI Newborn Hearing Loss Diagnosis</td>
</tr>
</tbody>
</table>
### Value Set Information

**Value Set Code**: PHVS_NICUServiceDeliveryLocation_JCIH_EHDI

**Value Set Name**: JCIH-EHDI NICU Service Delivery Location

**Value Set OID**: 1.3.6.1.4.1.19376.1.7.3.1.1.15.2.13

**Value Set Description**: To reflect that the newborn was treated in the NICU reflecting hearing loss risk

### Value Set Concepts

4 Value Set Concepts found

<table>
<thead>
<tr>
<th>Concept Code</th>
<th>Concept Name</th>
<th>Preferred Concept Name</th>
<th>Code System</th>
<th>Value Set</th>
</tr>
</thead>
<tbody>
<tr>
<td>1039-7</td>
<td>Neonatal critical care unit [Level II/III]</td>
<td>Neonatal Critical Care (Level II/III)</td>
<td>Healthcare Service Location (HL7)</td>
<td>JCIH-EHDI NICU Service Delivery Location</td>
</tr>
<tr>
<td>1040-5</td>
<td>Neonatal critical care unit [Level III]</td>
<td>Neonatal Critical Care (Level III)</td>
<td>Healthcare Service Location (HL7)</td>
<td>JCIH-EHDI NICU Service Delivery Location</td>
</tr>
<tr>
<td>1037-1</td>
<td>Neonatal unit</td>
<td>Neonatal unit</td>
<td>Healthcare Service Location (HL7)</td>
<td>JCIH-EHDI NICU Service Delivery Location</td>
</tr>
<tr>
<td>1041-3</td>
<td>Step down neonatal ICU [Level II]</td>
<td>Step down Neonatal ICU (Level II)</td>
<td>Healthcare Service Location (HL7)</td>
<td>JCIH-EHDI NICU Service Delivery Location</td>
</tr>
</tbody>
</table>

https://phinvads.cdc.gov
Value Domain Details

These metadata attributes include the Registration Authority's specification and may contain blanks for information which hasn't been provided to USHIK.

Newborn Screening Results – Observation and Findings Value Set

[Identifying and Definitional Attributes]  [Relational and Representational Attributes]  [Administrative Attributes]

Identifying and Definitional Attributes:
Name: Newborn Screening Results – Observation and Findings Value Set

Abbreviation:

Alternative Name:

Definition:
From the LOINC® database, Newborn Screening Results – Observation and Findings concepts. Developed in-conjunction with NLM

Context:
C154 HITSP Data Dictionary Component

Registration Authority:
Health Information Technology Standards Panel

USHIK Value Domain ID:
00000051.86787.v1

OID:
1.3.6.1.4.1.12009.10.2.1

URI:
http://newbornscreeningcodes.nlm.nih.gov/nb/sc
Exchanging Newborn Hearing Screening Data Through Electronic Health Record Interoperability
Published by the IHE Quality, Research and Public Health (QRPH) Committee (September 2010)

5 Use Cases include:

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

Profile also includes:

- Early Hearing Care Plan (EHCP)
- identified LOINC® & SNOMED-CT® coding terminology
- quality measurement indicators
EARLY HEARING DETECTION & INTERVENTION
FROM THE SCREENING DEVICE AT THE HOSPITAL TO PUBLIC HEALTH TO THE COMMUNITY

HOSPITAL

LABOR & DELIVERY
Labor and Delivery Summary (LDS)

NURSERY

PUBLIC HEALTH

CONTENT CREATOR
MEDICAL SUMMARY/BIRTH NOTIFICATION

Content Receiver
Early Hearing Detection & Intervention (EHDI)
Medical Summary/Birth Notifications

EARLY HEARING CARE PLAN (EHCP)

Screening Results
Device Observation Consumer

CONTENT CREATOR

Family at Home
Knowledge Requestor

COMMUNITY

EHCP
Baby John Doe
1. Risk Factors
2. Screening Results
3. Outcome
4. Referral

CONTENT CREATOR

Medical Home Visit
EHCP Content Consumer
Knowledge Requestor
Content Creator

PERSONAL HEALTH RECORD

© 2011 OZ Systems
PHI 2011 Interoperability Showcase
Vital Registration and Care Coordination for Newborn Hearing Screening

1. Birthing Facility
2. Public Health
3. Pediatric Care Provider

Health Information Exchange (HIE)

State / Jurisdiction Vital Records System
Public Health EHDI IS
Data Comparisons

- What are you comparing?
National Data Measures
It’s as easy as “1 – 3 – 6”?

JCIH Quality Indicator for Screening
• Percentage of all newborn infants who complete screening by 1 month of age

Healthy People 2020 Objective:
• Screening for hearing loss no later than age 1 month

MCHB Performance Measure #12:
• Percentage of newborns who have been screened for hearing before hospital discharge.

CDC Hearing Screening and Follow-up Survey
• Documented Passed and Not Passed the final (last or most recent) screen
It’s as easy as “1 – 3 – 6”?  

- Not screened at hospital  
  - missed, equipment failures, home births  
- Fail initial screen with no documented 2nd screen  
  - protocol driven, 1 stage/2 stage, closed cases vs. lost  
  - fail final (most recent) screen with no documented audiological diagnosis  
- Diagnosis not completed due to multiple visits  
  - OME complications, sedation issues  
- Identified infant with hearing loss to intervention  
  - referral or enrolled
Caveat!

- Know your numerators and denominators:
National Quality Forum (NQF)

NQF is a nonprofit organization whose mission includes the endorsement of national consensus standards for measurement and public performance reporting. Membership includes consumer organizations, public and private purchasers, physicians, nurses, hospitals, accrediting and certifying bodies, supporting industries, and healthcare research and quality improvement organizations (AAO-HNS, AAP, CDC, HRSA).
National Quality Forum (NQF)

Measure specifications include:

- numerator statement, time window and details*
  - to identify and calculate cases
- denominator statement, time window and details*
  - to identify and calculate the target
- denominator exclusion details
- calculation algorithm/measure logic

*definitions, codes with descriptors, and/or specific data collection items/responses
National Quality Forum

• #1402: Newborn hearing screening (NCQA)
• #1354: Hearing screening prior to hospital discharge (CDC)
• #1357: Outpatient hearing screening of infants who did not complete screening before hospital discharge* (CDC)
• #1360: Audiological evaluation no later than 3 months of age (CDC)
• #1361: Intervention no later than 6 months of age (CDC)

Full Endorsement August 10, 2011
*Time limited endorsement
NQF screening prior to hospital discharge

- “Numerator contains all live births during the measurement time period born at a facility and screened for hearing loss prior to discharge”
- “Denominator contains all live births during the measurement time period born at a facility and discharged without being screened OR screened prior to discharge”
- “The measurement time period varies upon needs of the particular user (e.g. calendar year, quarterly, monthly) but must be the same for both the numerator and denominator

Full Endorsement August 10, 2011
NQF screening prior to hospital discharge

Denominator Details

- Total number of newborns discharged:
  
  Joint Commission National Quality Core Measures -
  Discharge Status OR
  
  with "Hearing Screening Performed": evidence of hearing
  screening performed. (LOINC# 54109-4: Newborn
  hearing screen – right = Pass LA10392-1 OR Refer
  LA10393-9 AND LOINC# 54108-6: Newborn hearing
  screen – left= Pass LA10392-1 OR Refer LA10393-9)

Full Endorsement August 10, 2011
NQF screening prior to hospital discharge

Denominator Exclusion Details

Joint Commission Discharge Disposition - Death Value Set
(86986.v1) 1.3.6.1.4.1.33895.1.3.0.12. "Patient Deceased": Patient has expired

LOINC# 54109-4: Newborn hearing screen – right OR
LOINC# 54108-6: Newborn hearing screen – left includes “Parental refusal” (LA6644-4) OR Not performed, medical exclusion - not indicated (LA12409-1)

Full Endorsement August 10, 2011
NQF screening prior to hospital discharge

Calculation Algorithm

1. The time period for births included in the estimate is specified
2. All live births that occurred at a facility during the time period are selected
3. Result of step 2 is filtered to remove children who died prior to discharge and without being screened, whose parent(s) refused, or children who were not screened due to medical reasons
4. Result of step 3 is filtered to be limited to the subset that received a screen prior to discharge
5. Result of step 3 is filtered to be limited to the subset that (a) has been discharged, AND (b) did not receive a screen
6. Result of step 4 (i.e., the numerator) is added to the result of step 5
7. Measure is calculated by dividing the numerator (result of step 4) by the denominator (result of step 6)
Dimensions of Data Quality

- Completeness
- Timeliness
- Validity
- Integrity
- Consistency
- Accuracy
Thank you!

Questions?
jeichwald@cdc.gov

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.