"Data Management for EHDI: Helpful Friend, Not Dreaded Foe"

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

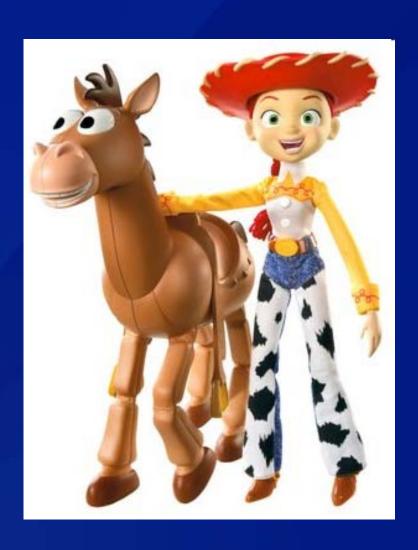
IFSC/Pediatric Audiology Symposium/SE Regional EHDI Conference
October, 2011
Raleigh, NC



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)

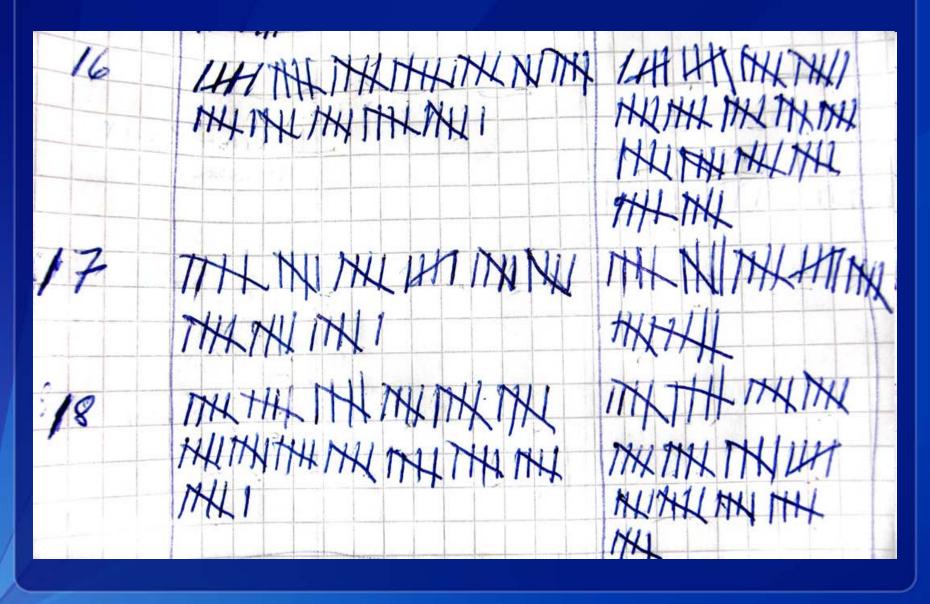
Why is Data a Helpful Friend?

- 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!)

Isthisdata?



Isthisdata?

	А	В	С	D	Е	F	G	Н	I .	J	K	L	M
1	99	16	94	88	76	25	86	5	9	63	35	89	30
2	79	11	69	60	89	92	6	14	98	56	20	36	69
3	93	97	17	56	39	74	22	91	26	83	32	24	33
4	68	10	51	25	62	89	22	92	79	79	88	100	42
5	5	68	79	36	46	73	12	45	95	49	98	2	26
6	67	86	61	8	82	8	14	81	14	2	60	9	58
7	73	98	64	70	25	89	62	66	46	28	46	90	15
8	72	52	99	30	82	91	87	23	48	11	27	72	92
9	86	7	89	62	61	31	33	23	16	26	2	41	26
10	73	51	3	34	35	16	9	97	62	0	7	13	25
11	92	25	78	94	63	13	84	14	78	99	32	19	91
12	37	34	18	96	34	54	65	96	66	21	59	82	80
13	97	53	70	99	27	77	4	50	56	10	28	6	75
14	14	34	43	67	16	85	42	61	20	48	93	75	69
15	75	36	34	11	18	7	29	61	5	22	13	56	25
16	23	40	37	93	74	99	20	11	49	95	18	79	96
17	18	4	23	54	89	59	34	1	31	33	47	40	12
18	13	39	81	73	6	59	67	83	6	54	5	90	59
19	40	55	61	71	5	100	35	15	69	60	47	48	59
20	94	9	3	7	74	80	18	79	33	94	36	87	69
21	9	86	84	68	75	97	41	89	43	18	31	83	23
22	19	16	95	45	29	72	67	86	67	21	16	30	37
23	58	76	61	20	60	1	25	35	58	16	27	38	3
24	78	95	57	47	91	17	11	10	93	66	27	17	71
25	9	5	83	23	85	5	29	13	10	11	76	87	42

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)

Interpretation

Truth

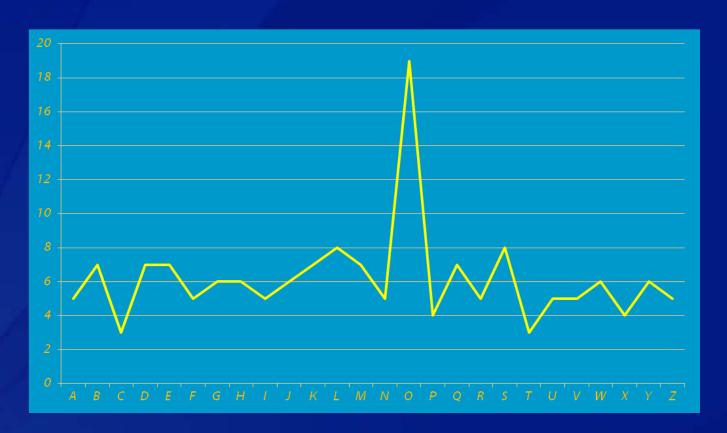
Facts

Information

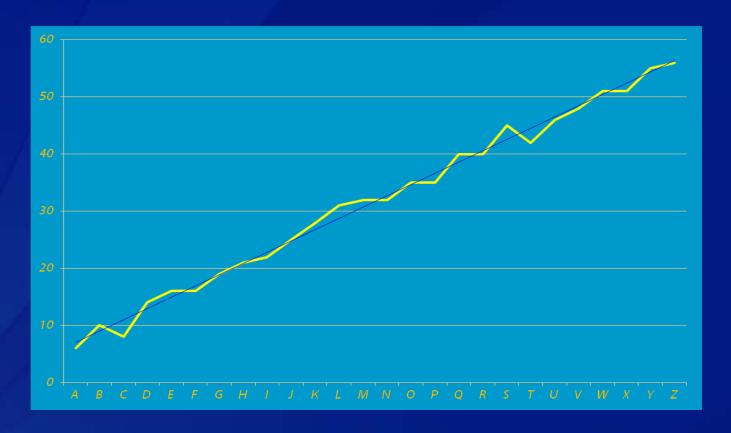
Data

Foundation is based upon valid and verifiable, individual and unduplicated data

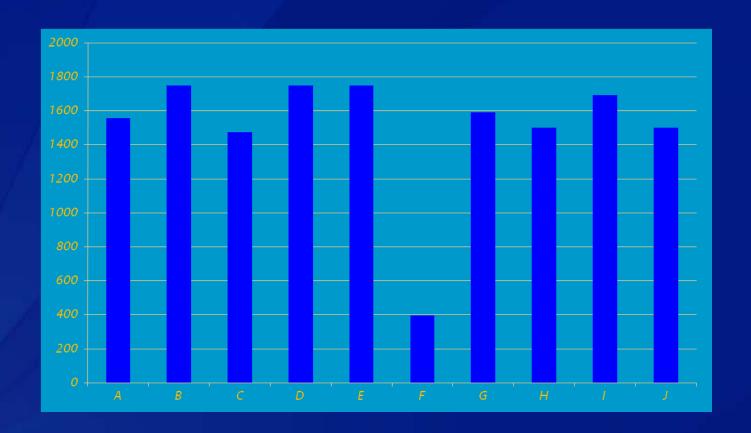
• provides a snapshot of the overall success of your program activities at any given point in time



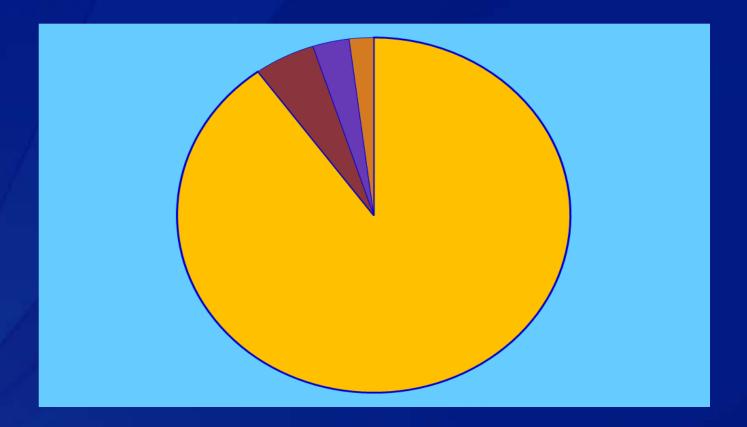
• ensures that you have a track record how you are progressing



• gives you an idea of where you need to concentrate your efforts



• provides transparent accountability for stakeholders

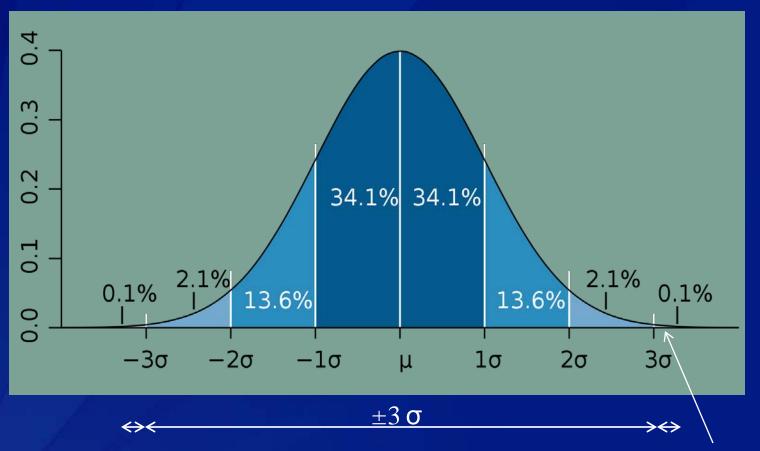


Turning Data into Information

Statistical Significance

Aggregation Bias

Statistical Significance



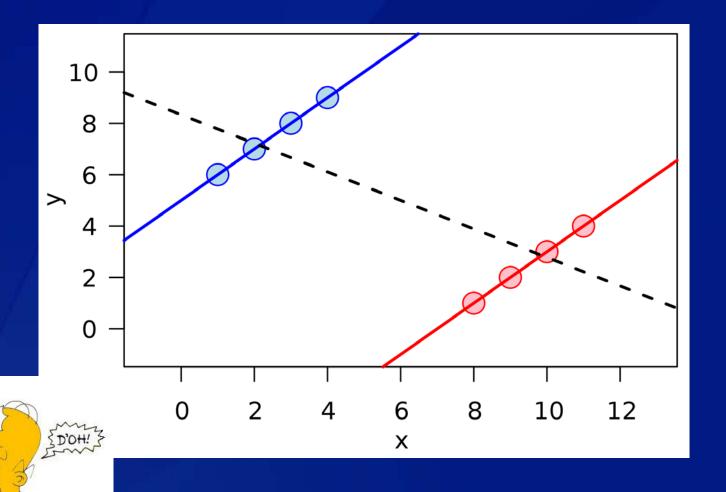
"Stuff" happens out here!

0.004 of 4,000,000 births = 16,000 babies!

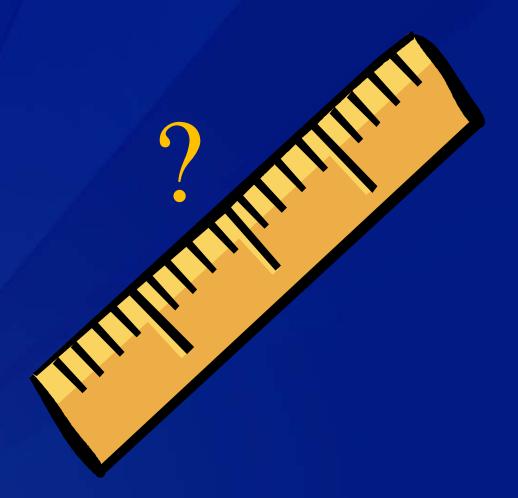
Why Individual Not Aggregate Data?

- 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

Smpson'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.



com DilbertCartoonist@gmail.co

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 <u>draft guidance for creating an HL7 version 2.x message using these codes</u> with examples. If you would like us to notify you about updates to this guidance and other new content, please <u>subscribe to the NBS-Announcements</u> e-mail list from the U.S. National Library of Medicine.

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

<u>Views</u>: 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
- o Analytes/Measurements Tests that are used as markers for newborn screening conditions
- Tailored Views Specify subsets, or see relationships between conditions and analytes/measurements

<u>Downloads</u>: 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).



Condition

Newborn Screening Coding and Terminology Guide

Data Standards for Electronic Reporting

Abbreviation

ACHDNC

Downloads | HL7 | Resources | Code Standards | About | Contact Us

Enzyme

OMIM

SNOMED CT

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

Enzyme

	Choose condition to view related measurements		Category	Name	Commission Number	ID	Code
Hea	aring Loss						
	Hearing Loss	HEAR	Core	N/A	N/A	N/A	15188001
MS	/MS (Tandem Ma	ass Spectro	metry) M	easured Conditi	ons		
An	nino Acid Disorders						
	<u>Argininemia</u>	ARG	Secondary	Arginase	3.5.3.1	207800	23501004
	Argininosuccinic aciduria	ASA	Core	Argininosuccinate lyase	4.3.2.1	207900	41013004
	<u>Carbamoyltransferase</u> <u>deficiency</u>	CPS	Other	Carbamoyltransferase I	6.3.4.16	237300	124380007
	Citrullinemia type I	CIT-I	Core	Argininosuccinate synthetase	6.3.4.5	215700	398680004
	Citrullinemia type II	CIT-II	Secondary	Aspartate glutamate carrier (citrin)	None	603471 605814	30529005
	Dihydrolipoamide	E3	Core	Dihydrolipoamide	1.8.1.4	238331	29914000



Newborn Screening Coding and **Terminology Guide**

Data Standards for Electronic Reporting

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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 emisions
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.





Newborn Screening Coding and Terminology Guide

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Newborn hearing screen - left - Analyte/Measurement Details

LOINC® Long Common Name: Newborn hearing screen - left

Hear-L Analyte Short Name:

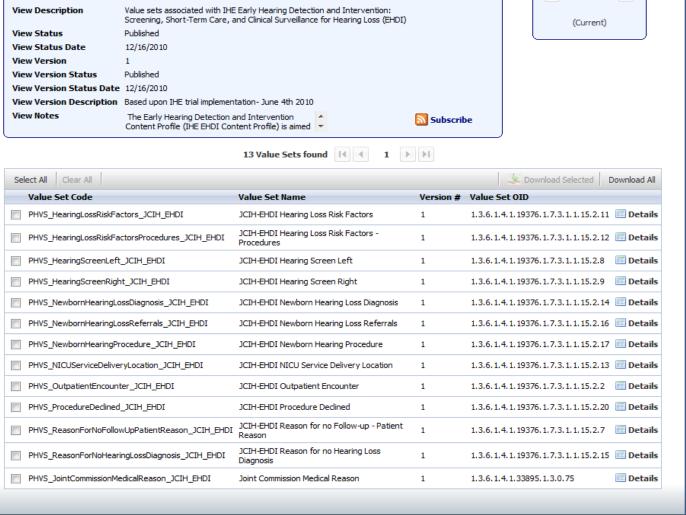
LOINC Number: 54108-6

Answer List

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

SNOMED Code	LOINC Answer ID	UMLS CUI	Answer Text
None	LA10392-1	C0437470	Pass
None	LA10393-9	C0580715	Refer
None	LA6644-4	C0580717	Parental refusal
None	LA12408-3	C0522770	Attempted, but unsuccessful - technical fail
None	LA7304-4	C0445106	Not performed
None	LA12409-1	C1444655	Not performed, medical exclusion - not indicated

The PHIN Vocabulary Access and Distribution System (VADS) RCMT Search Results Search Home Ouick Search View Information Version History IHE EHDI: Screening, Short-Term Care, and Clinical Surveillance for Hearing 🗽 Download View View Name VADS Navigation Menu View Description Value sets associated with IHE Early Hearing Detection and Intervention: Screening, Short-Term Care, and Clinical Surveillance for Hearing Loss (EHDI) View Status Published **View Status Date** 12/16/2010 View Version View Version Status Published View Version Status Date 12/16/2010



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Version 1

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Value Set Information

Value Set Code PHVS_HearingLossRiskFactors_JCIH_EHDI

Value Set Name JCIH-EHDI Hearing Loss Risk Factors

1.3.6.1.4.1.19376.1.7.3.1.1.15.2.11 Value Set OID

Value Set Description To Reflect the Risk Factors associated with hearing loss using SNOMED-CT Finding and

Situation concepts







Subscribe



Value Set Concepts | Value Set Details

13 Value Set Concepts found





Se	lect All Clear A			Dov.	vnload Selected	Download All
	Concept Code	Concept Name	Preferred Concept Name	Code System	Value Set	
	276687002	Conjugated hyperbilirubinemia in infancy (disorder)	Conjugated hyperbilirubinemia in infancy (disorder)	SNOMED-CT	JCIH-EHDI Hearing Loss Risk Factors	■ Details
	80690008	Degenerative disease of the central nervous system (disorder)	Degenerative disease of the central nervous system (disorder)	SNOMED-CT	JCIH-EHDI Hearing Loss Risk Factors	■ Details
	439750006	Family history of hearing loss (situation)	Family history of hearing loss (situation)	SNOMED-CT	JCIH-EHDI Hearing Loss Risk Factors	■ Details
	206005002	Fetus or neonate affected by maternal infection (disorder)	Fetus or neonate affected by maternal infection (disorder)	SNOMED-CT	JCIH-EHDI Hearing Loss Risk Factors	■ Details
	161653008	History of - chemotherapy (situation)	History of - chemotherapy (situation)	SNOMED-CT	JCIH-EHDI Hearing Loss Risk Factors	■ Details
	441899004	History of therapy with ototoxic medication (situation)	History of therapy with ototoxic medication (situation)	SNOMED-CT	JCIH-EHDI Hearing Loss Risk Factors	■ Details
	206331005	Infections specific to perinatal period (disorder)	Infections specific to perinatal period (disorder)	SNOMED-CT	JCIH-EHDI Hearing Loss Risk Factors	■ Details

Value Set Information Value Set Code PHVS_NewbornHearingLossDiagnosis_JCIH_EHDI ▲ Download Value Set 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



Value Set Concepts | Value Set Details

16 Value Set Concepts found



L <u>2</u>



Se	lect All Clear A	JI .		₩ D	ownload Selected	Download All
	Concept Code	Concept Name	Preferred Concept Name	Code System	Value Set	
	443805006	Auditory neuropathy spectrum disorder (disorder)	Auditory neuropathy spectrum disorder (disorder)	SNOMED-CT	JCIH-EHDI Newborn Hearing Loss Diagnosis	■ Details
	95820000	Bilateral hearing loss (disorder)	Bilateral hearing loss (disorder)	SNOMED-CT	JCIH-EHDI Newborn Hearing Loss Diagnosis	■ Details
	44057004	Conductive hearing loss (disorder)	Conductive hearing loss (disorder)	SNOMED-CT	JCIH-EHDI Newborn Hearing Loss Diagnosis	■ Details
	18647004	Mild (severity modifier) (qualifier value)	Mild (severity modifier) (qualifier value)	SNOMED-CT	JCIH-EHDI Newborn Hearing Loss Diagnosis	■ Details
	255605001	Minimal (qualifier value)	Minimal (qualifier value)	SNOMED-CT	JCIH-EHDI Newborn Hearing Loss Diagnosis	■ Details
	77507001	Mixed conductive AND sensorineural hearing loss (disorder)	Mixed conductive AND sensorineural hearing loss (disorder)	SNOMED-CT	JCIH-EHDI Newborn Hearing Loss Diagnosis	■ Details
	6736007	Moderate (severity modifier) (qualifier value)	Moderate (severity modifier) (qualifier value)	SNOMED-CT	JCIH-EHDI Newborn Hearing Loss Diagnosis	■ Details

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 | Value Set Details

4 Value Set Concepts found



.



Se	elect All Clear A	All			Nownload Selected	Download All
	Concept Code	Concept Name	Preferred Concept Name	Code System	Value Set	
	1039-7	Neonatal critical care unit [Level II/III]	Neonatal Critical Care(Level II/III)	Healthcare Service Location (HL7)	JCIH-EHDI NICU Service Delivery Location	⊞ Details
	1040-5	Neonatal critical care unit [Level III]	Neonatal Critical Care (Level III)	Healthcare Service Location (HL7)	JCIH-EHDI NICU Service Delivery Location	Details
	1037-1	Neonatal unit	Neonatal unit	Healthcare Service Location (HL7)	JCIH-EHDI NICU Service Delivery Location	Details
	1041-3	Step down neonatal ICU [Level II]	Step down Neonatal ICU (Level II)	Healthcare Service Location (HL7)	JCIH-EHDI NICU Service Delivery Location	■ Details

https://phinvads.cdc.gov

Go





Search USHIK

Advancing Excellence in Health Care

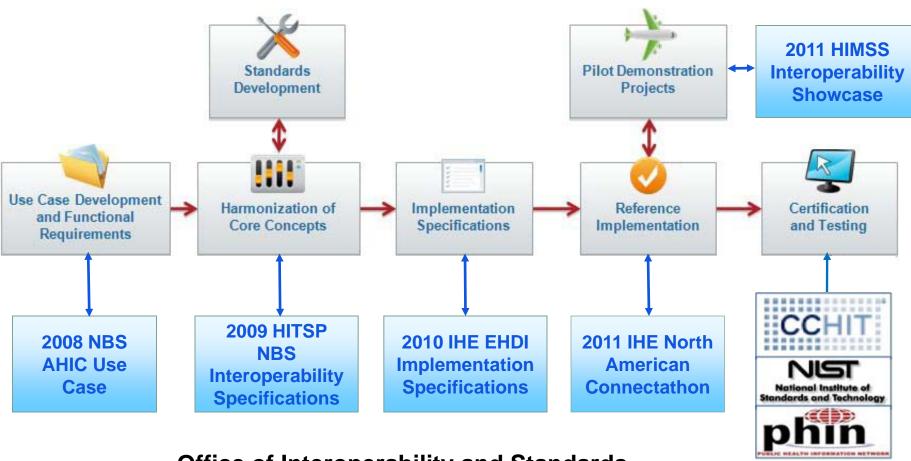
www.ahrq.gov

Advancing Excellence in Health	F Gal E		<u>www.anrq.gov</u>						
US	USHIK Home Frequently Asked Questions Contact Us Site Map What's New About								
Data Elements		Value Domain Details							
Data Element Concepts	These metadata attributes in	nclude the Registration Authority's spec	ification and may contain						
Value Domains	blanks for information which hasn't been provided to USHIK.								
Constraints	Newborn Screening Results – Observation and Findings V								
Functional Groups	[Identifying and Definitional	Set [Relational and Representational	[Administrative						
Conceptual Domains	Attributes]	Attributes]	Attributes]						
Contexts	Identifying and Definitional	Attributes:							
	Name:	Newborn Screening Re	sults – Observation and						
Vocabularies		Findings Value Set							
Representational	Abbreviation:								
Classes	Alternative Name:								
Measures	Definition:	From the LOINC® databa	ase, Newborn Screening						
Forms		Results – Observation an							
Views		Developed in-conjunction							
Information Models	Context:	C154 HITSP Data Diction	nary Component						
momation woders	Registration Authority:	Health Information Techn	ology Standards Panel						
Organizations	USHIK Value Domain ID:	00000051.86787.v1							
Data Agreements	OID:	1.3.6.1.4.1.12009.10.2.1							
Collections	URI:	http://newbornscreeningo	odes.nlm.nih.gov/nb/sc						

United States Health Information Knowledgebase (USHIK)

Exchanging Newborn Hearing Screening Data Through Electronic Health Record Interoperability

Standards & Interoperability Framework Functions



Office of Interoperability and Standards
Office National Coordinator for Health Information Technology

EHDI IHE®Integration Profile

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

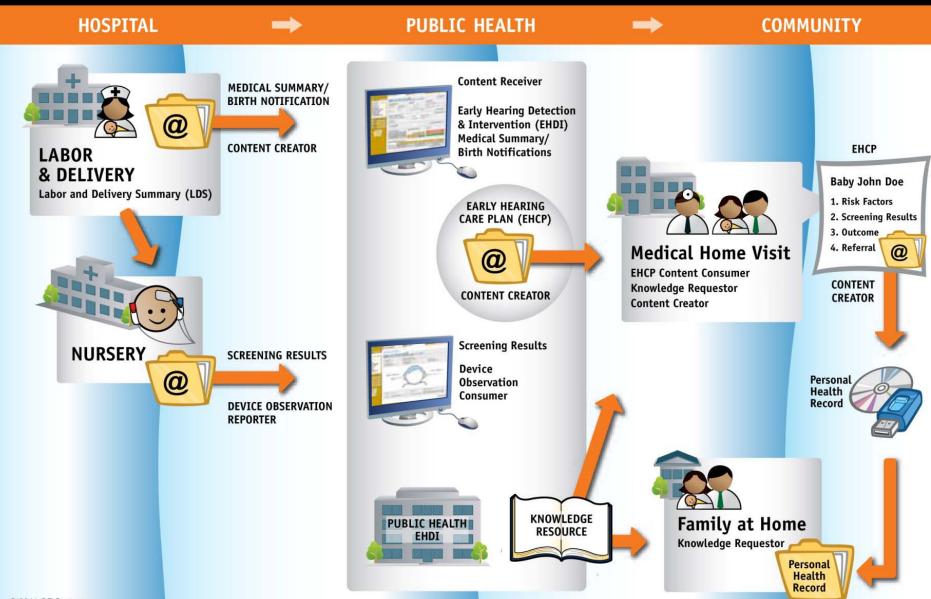
Profile also includes:

- Early Hearing Care Plan (EHCP)
- identified LOINC®&SNOMED-CT®coding terminology
- quality measurement indicators

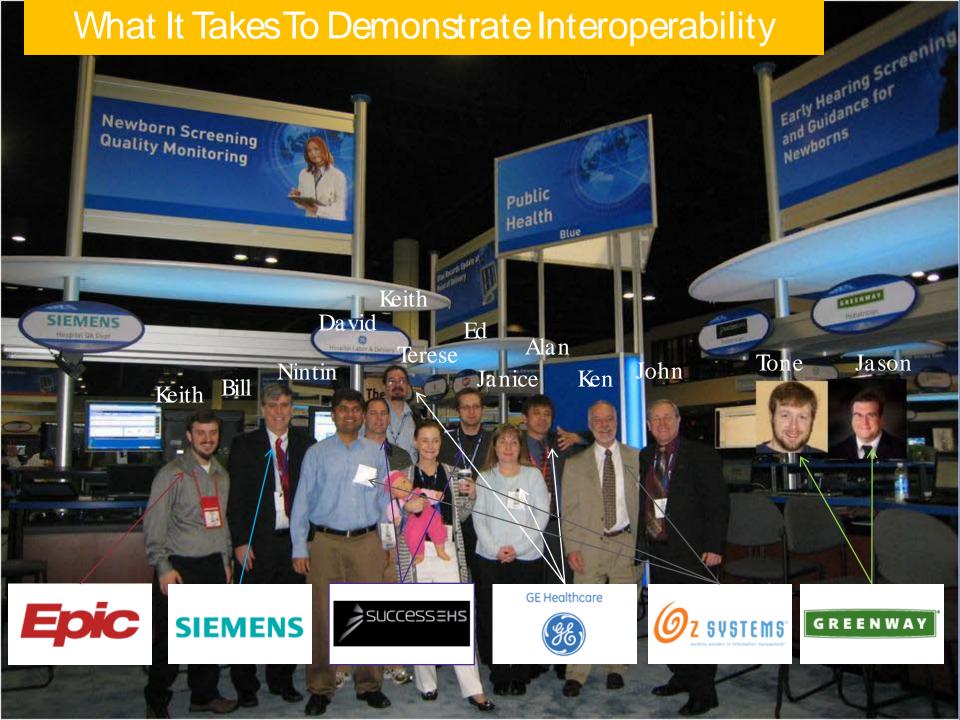


EARLY HEARING DETECTION & INTERVENTION

FROM THE SCREENING DEVICE AT THE HOSPITAL TO PUBLIC HEALTH TO THE COMMUNITY

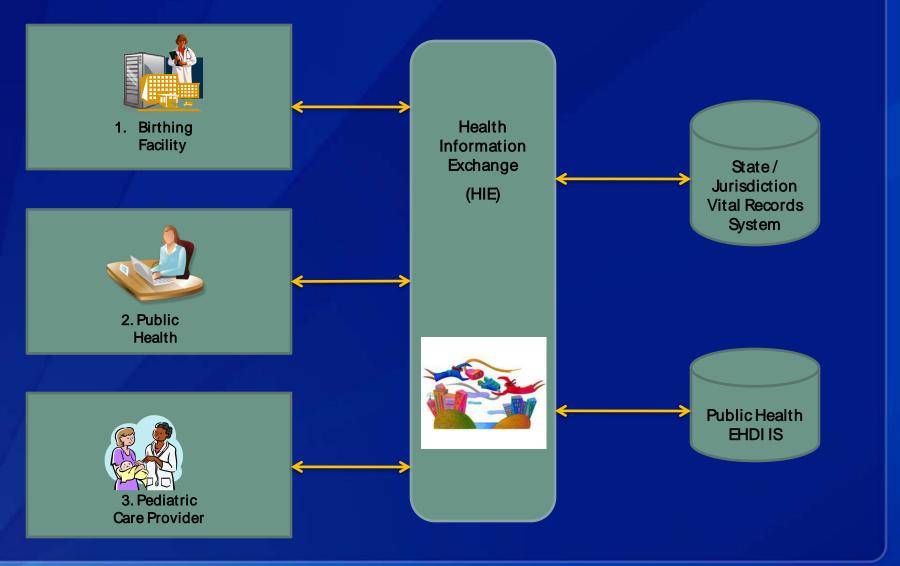






PHI 2011 Interoperability Showcase

Vital Registration and Care Coordination for Newborn Hearing Screening



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

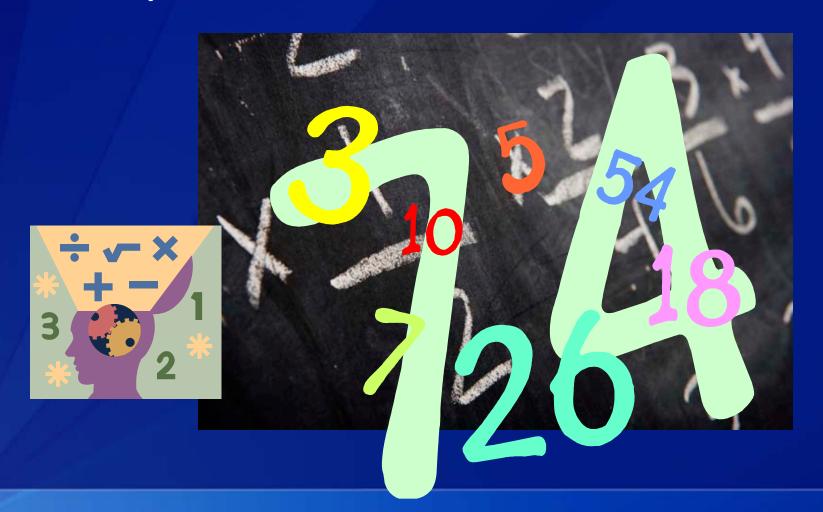
 Documented Passed and Not Passed the final (last or most recent) screen

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)

- "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

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

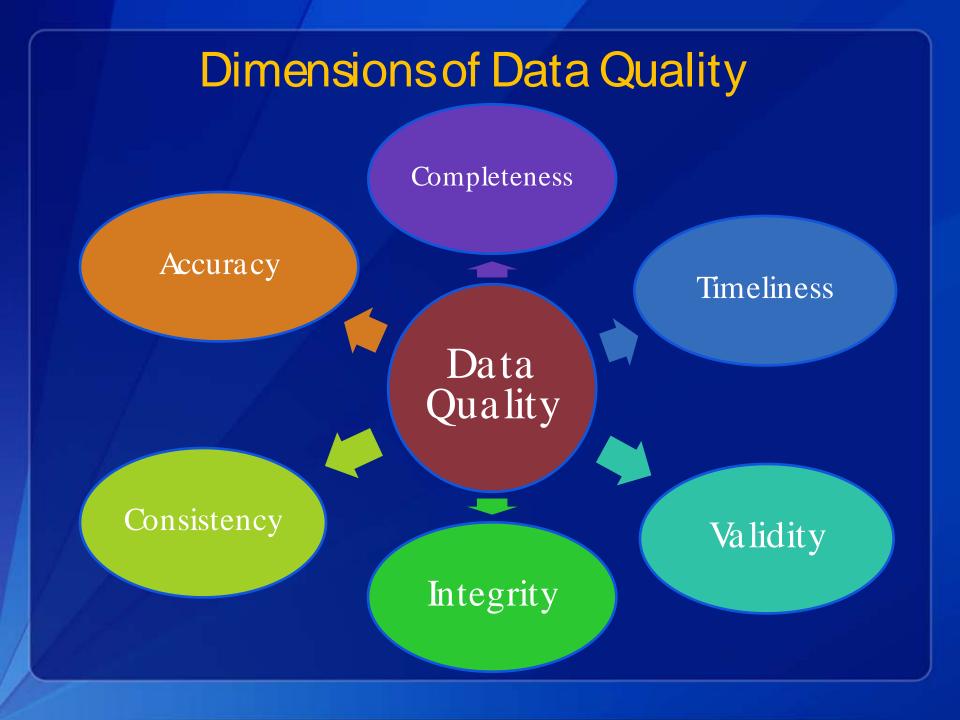
Denominator Exclusion Details

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)

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)



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.

