Newborn Screening Codes & Terminology and an Approach to a Standard Report Payload

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Outline of presentation

- Goals
- Work done so far
  - Standardization of content
  - Standardization of messaging format
  - Demonstration of new website
- Work ahead

Goals

- To promote and facilitate the use of electronic health data standards in recording and transmitting newborn screening test results
- Benefits:
  - 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
  - support the development of strategies for improving the newborn screening process

Prerequisites for standardized electronic reporting

- Content
  - Standard codes for test names, analytes, conditions screened and other categorical answers
- Messaging format
  - Standard messaging format to convey the content electronically

Use of national and international code standards

- A coding and terminology framework is essential to standardizing laboratory reporting and enabling interoperability of information exchange across Electronic Health Record (EHR) platforms
- Coding standards used:
  - LOINC
  - SNOMED CT
  - ICD-9-CM, ICD-10-CM
  - Enzyme codes
  - OMIM codes

LOINC

- Logical Observation Identifiers Name and Codes
- Supported by NLM and Regenstrief Foundation (Indianapolis)
- Universal code for identifying measurement (e.g. laboratory tests) and results in HL7 messages
- Used widely in U.S. and internationally
- No cost license in perpetuity

Lots of languages - translations of glucose

LOINC_NUM	LANGUAGE_NAME	COMPONENT
2349-9	Brazilian Portuguese	Glucose
2349-9	Estonian	Glükoos
2349-9	French	glucose
2349-9	German	Glukose
2349-9	Italian	glucosio
2349-9	Korean	포도당
2349-9	Simplified Chinese	葡萄糖
2349-9	Spanish	glucosa

LOINC Web site –download everything

SNOMED CT

- Systematized Nomenclature of Medicine – Clinical Terms
- Originally developed by the College of American Pathologists
  - ownership transferred to the International Health Terminology Standards Development Organisation (IHTSDO)
  - 12 member countries including US, Canada, UK, Australia, Netherlands, Sweden and Spain.
- Emergent international clinical terminology standard

SNOMED CT

- Very comprehensive – over 300,000 concepts
- multilingual clinical health care terminology designed for use in Electronic Health Record systems and in health data exchange
- available free of charge in IHTSDO member countries, including the U.S., in low-income countries as defined by the World Bank, and for qualified research projects in any country.

ICD-9-CM

- International Classification of Diseases, Ninth Revision, Clinical Modification
- the official system of assigning codes to diagnoses associated with hospital utilization and public health reporting in the U.S.
- One of the Health Insurance Portability and Accountability Act (HIPAA) code sets
- Planned transition to ICD-10-CM by 2013

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Other code standards

- Enzyme codes:
  - List of Recommended Names for Enzymes recommended by the Nomenclature Committee of the International Union of Biochemistry and Molecular Biology (NC-IUBMB) in consultation with the IUPAC-IUBMB Joint Commission on Biochemical Nomenclature (JCBN) Enzyme Nomenclature
  - freely available for use
- OMIM codes
  - Online Mendelian Inheritance in Man is a comprehensive, authoritative, and timely compendium of human genes and genetic phenotypes

The UMLS

- The Unified Medical Language System
- Developed by NLM
- The UMLS Metathesaurus incorporates over 100 biomedical terminologies, classifications and coding systems
- Contents organized by meaning
  - Terms that mean the same thing are grouped together and given a common and permanent code (Concept Unique Identifier CUI)
  - A bridge between different coding standards

What NLM has done

- Collect the lists of tests, analytes, conditions and categorical answers, some of them are already mapped to standard coding systems
- Fill in gaps where standard codes exist, add UMLS CUIs
- Make these lists available on an NLM website (http://newbornscreeningcodes.nlm.nih.gov), together with guidance and rationale for their use produced by the AHIC Committee on Newborn Screening, and other useful links
- Maintain these lists and guidance as they are revised over time

Messaging standard

- Encourage the use of HL7 as the standard for reporting of Newborn Screening results
- Facilitate the development of a standard specification for the payload part of the message that uses the codes and approaches proposed by the AHIC committee

HL7

- Health Level Seven is an international messaging standard for the healthcare domain
- HL7 version 2 - almost universally available in large practices, laboratories, hospitals
- Federal government requires HL7 vs. 2.5 for laboratory reporting
- Used widely internationally as well - Germany, Netherlands, France, Japan, etc

HL7 basics

- An HL7 message is composed of segments, each segment conveys a specific type of information e.g.
  - MSH – message header segment
  - PID – patient identification and demographic information
  - OBR – information about observation requests (e.g. laboratory and radiology orders)
  - OBX – information about observations (e.g. laboratory results)

HL7 basics

- Each type of message has specified syntax so that information can be sent and received unambiguously
- HL7 also has pre-defined data types e.g.
  - DT – Date e.g. CCYYMMDD
  - PN - Person name e.g. Last name ^ first name ^ middle ^ suffix
  - CE – Coded e.g. Code1 ^ print text ^ Code system

Coded data type

- A coded data element has three parts:
  - Code e.g. 54084-9
  - Print text e.g. Galactosemia [Mass/volume] in Blood dot
  - Code system e.g. LOINC
- Can include 2 codes for a given purpose- e.g. Universal LOINC code and individual laboratory's internal code

OBX segment

- The important fields:
  - OBX-3 is the question (e.g. serum glucose) - always a coded item
  - OBX-5 is the answer
    - May be numeric (e.g. 150 mg/dl)
    - May be coded (e.g. 80394007^Hyperglycemia^SNOMED)
    - May be other data types

Put it all together for hemogram report – Red-> measurement, Orange -> value

Patient level

PID|||0999999^6^M10||TEST^PATIENT^||19920225|F||B|4050 SW WAYWARD BLVD |

Order/report level

-OBR|||H9759-0^REG_LAB|20725^Hemogram^LOINC

- Discrete Results

OBX|2|NM||789- 8^RBC^LN||4.9|M/mm3| 4.0-5.4

OBX|3|NM|718-7^HGB^LN||12.4|g/dL|12.0 5.0||||F|

OBX|4|NM||20570-8^HCT^LN||50|%|35-49|H|||F|

OBX|5|NM||30428-7^MCV^LN||81|fL|80-94||||F|b

Proposed "Rules of engagement"

- NBS Labs would report quantitative and categorical results labeled with the appropriate LOINC code from the NBS LOINC catalogue .
- They would report quantitative measures numbers with the agreed upon units specified in the NBS LOINC catalogue
- The categorical results (e.g. S-Beta thalassemia from hemoglobin electrophoresis studies) would be reported as SNOMED CT codes

A mock-up HL7 message for NBS

- It is based on real but completely de-identified message data from Georgia
- Message structure
  - The wrapper segments (MSH, PID etc.)
  - The payload
    - The OBX segments are grouped and indented below the OBRs e.g. Acylcarnitine tests
    - Includes both interpretations and quantitative measures
    - Each discrete interpretation/measurement is reported in a separate OBX and identified by a LOINC code

Galactosemia panel

- **OBR|1|2001178109|10A1912102|54079-9^Galactosemia Newborn Screening Panel^LOINC|… y**
  - **OBX|1|ST|46737-3^ Galactosemia interp^ LOINC|1|Test for enzyme defect: INCONCLUSIVE|| |*|||F|||20090714143552**
  - **OBX|2|ST|54084-9^Galactose [Mass/volume] in Blood dot (filter paper)^LOINC|1| 1.6|mg/dL|<11||||F|||20090714143552**

Customizing test names

- Regarding names in reports
  - The test names are LOINC long common names
  - These could be revised per a consensus of NBS labs
  - HL7 has option for including laboratory's code and names in addition to the universal LOINC codes and names

NLM's NBS web site – Launched 9/16

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Newborn Screening Coding and Terminology Guide

Data Standards for Electronic Reporting

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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.

Work is underway on guidance for creating an HL7 version 2.x message using these codes with examples, which will appear on this website in the future. If you would like us to notify you about this 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).

Code and Terminology Standards: View terms of use and other information about codes and terminologies listed and referenced on this Web site, including Logical Observation Identifiers Names and Codes (LOINC®), Systematized Nomenclature of Medicine — Clinical Terms (SNOMED CT®), and others.

About Us: Learn about the National Library of Medicine Lister Hill National Center for Biomedical Communications (LHNCBC) and gather more information about the Newborn Screening Coding and Terminology Guide.

Your questions and comments are welcome. Contact Us.

Web site functions

- Down load the AHIC tables
- Customized reports of table contents
- Links to related documents and resources

Download tables

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Downloads

You can download the full tables of conditions, markers, and the relationships between them. These comma-separated-values ("csv") files can be opened with spreadsheet software, such as Microsoft Excel or OpenOffice.org Calc.

- **Conditions.csv** — tabular data for conditions and their attributes, including standard data codes from multiple clinical medical terminologies.
- **Analytes.csv** — tabular data for analytes/measurements that serve as markers for conditions of interest to newborn screening. Each row includes the analyte name, short name, Logical Observation Identifiers Names and Codes (LOINC) code, units of measure, and LOINC long common name. Within the proposed framework, the LOINC codes identify the individual measures and groups of measures delivered in Health Level 7 (HL7) order and report messages.
- **Mappings.csv** — tabular data that maps the associations between conditions and their markers.
- **Answer-lists.csv** — tabular data containing the answer lists for categorical (non numeric) newborn screening measures, such as Hemoglobin electrophoresis. Each row contains the LOINC measure code to which the answer list applies, the answer text, a LOINC answer code (as a place holder), a sequence defining the order of presention, and a Systematic Nomenclature of Medicine Clinical Terms (SNOMED CT®) code for the answer.

If you load all four of these tables into an appropriately defined local database, you can re-create the database the U.S. National Library of Medicine (NLM®) uses to generate views on the Web site.

Customized views of tables

- Four different views:
  - Conditions only
  - Analytes (and measurements) only
  - Conditions linked to analytes
  - Analytes linked to conditions
- Additional filters:
  - Conditions
    - Condition categories e.g. hearing loss, amino acid disorders
    - ACHDNC core or secondary conditions
  - Analytes
    - Analyte categories e.g. amino acid, organic acid
    - Derived measures

Four different views

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Views

Select the subject matter for your view from one of the four following choices. You will be able to customize your choice fur page.

Step 1. Choose a view:

- **Condition or analytes only**
  - Conditions — Lists the conditions that are targeted by newborn screening and their associated genetic and
  - Analytes/Measurements — Lists the tests (analytes/measurements) that are used as markers for newborn s Logical Observation Identifiers Names and Codes (LOINC®) name, codes and units of measure or answer lis
- **Conditions or analytes along with relationships between them**
  - Conditions *and* the Analytes/Measurements that serve as markers — Lists the conditions that are targe each condition the analytes or measurements used as markers
  - Analytes/Measurements *and* the Conditions they signal — Lists the analytes/measurements that may be *and* for each analyte/measure the conditions that it can signal

Conditions view

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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 (when applicable), the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) Category, Online Mendelian Inheritance in Man (OMIM®) code, and International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) code.

Condition *Choose condition to view related measurements*	Abbreviation	ACHDNC Category	Enzyme Name	Enzyme Commission Number	OMIM ID	SNOMED CT Code	ICD-9-CM Code	ICD-10-CM Code
Hearing Loss								
Hearing Loss	HEAR	Core	N/A	N/A	N/A	15188001	389.9	H91.9
MS/MS (Tandem Mass Spectrometry) Measured Conditions								
Amino Acid Disorders								
Argininemia	ARG	Secondary	Arginase	3.5.3.1	207800	23501004	270.6	E72.21
Argininosuccinic aciduria	ASA	Core	Argininosuccinate lyase	4.3.2.1	207900	41013004	270.6	E72.22
Carbamoyltransferase deficiency	CPS	Other	Carbamoyltransferase I	6.3.4.16	237300	124380007	270.6	E72.20
Citrullinemia type I	CIT-I	Core	Argininosuccinate synthetase	6.3.4.5	215700	398680004	270.6	E72.23
Citrullinemia type II	CIT-II	Secondary	Aspartate glutamate carrier (citrin)	None	603471 605814	30529005	270.6	E72.23
Dihydrolipoamide dehydrogenase deficiency	E3	Core	Dihydrolipoamide dehydrogenase	1.8.1.4	238331	29914000	270.3	E71.0
Disorders of biopterin biosynthesis	BIOPT-BS	Secondary	6-Pyruvoyltetrahydropterin synthase	4.2.3.12	261640	237914002	270.1	E70.1
Disorders of biopterin regeneration	BIOPT-REG	Secondary	Dihydropteridine reductase	1.5.1.34	261630	58256000	270.1	E70.1

Analytes/measurements view

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Analytes/Measurements View

The Analytes/Measurements View lists the analytes (chemical entities) and the hearing measurements that serve as markers for newborn screening conditions. This view includes the analytes you selected on a previous screen, a short name, and a Logical Observation Identifiers Names and Codes (LOINC®) Number that may be used in electronic laboratory reports. Click on an analyte name to view related conditions, or to see answer lists for measurements with categorical values. For measurements with numeric values, the view also includes the units of measurement.

Analyte Name *Choose analyte to view related conditions*	Analyte Short Name	LOINC Number	Units
Hearing			
Newborn hearing screen method	Hear-Meth	54106-0	Answer list
Newborn hearing screen of Ear - bilateral	Hear-Both	54107-8	Answer list
Newborn hearing screen of Ear - left	Hear-L	54108-6	Answer list
Newborn hearing screen of Ear - right	Hear-R	54109-4	Answer list
Hearing loss newborn screen interpretation		46770-4	
MS/MS			
Acyl-Carnitine			
Octenoylcarnitine (C8:1)	C8:1	53174-9	umol/L
Amino Acid			
5-Oxoproline+Pipecolate	OXOPRO + PIPA	53232-5	umol/L
5-Oxoproline+Pipecolate/Phenylalanine	[OXOPRO + PIPA] / PHE	53394-3	N/A
Alanine+Beta Alanine+Sarcosine	ALA + BALA + SARC	53150-9	umol/L
Alloisoleucine+Isoleucine+Leucine+Hydroxyproline	AILE + ILE + LEU + OHPRO	53152-5	umol/L

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Conditions linked to analytes view

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Condition to Analyte/Measurement Mapping View

The Condition to Analyte/Measurement Mapping View displays the conditions you selected on a previous screen along with the markers that signal these conditions.

Condition	Abbreviation *and primary and secondary analytes or laboratory measures*	ACHDNC Category
MS/MS (Tandem Mass Spectrometry) Measured Conditions		
Amino Acid Disorders		
Argininemia	ARG Primary Markers (LOINC Number : LOINC Long Common Name) • 47562-4 : Arginine [Moles/volume] in Dried blood spot • 53398-4 : Arginine/Phenylalanine [Molar ratio] in Dried blood spot	Secondary
Argininosuccinic aciduria	ASA Primary Markers (LOINC Number : LOINC Long Common Name) • 53062-6 : Argininosuccinate [Moles/volume] in Dried blood spot • 53200-2 : Argininosuccinate/Arginine [Molar ratio] in Dried blood spot • 42892-0 : Citrulline [Moles/volume] in Dried blood spot • 54092-2 : Citrulline/Arginine [Molar ratio] in Dried blood spot • 53157-4 : Citrulline/Phenylalanine [Molar ratio] in Dried blood spot Secondary Markers (LOINC Number : LOINC Long Common Name) • 53399-2 : Citrulline/Tyrosine [Molar ratio] in Dried blood spot	Core
Carbamoyltransferase deficiency	CPS Secondary Markers (LOINC Number : LOINC Long Common Name)	Other

Analytes linked to conditions view

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Analyte/Measurement to Condition Mapping View

The Analyte/Measurement to Condition Mapping View displays the analytes/measurements matching the categories you selected on a previous screen, along with the conditions for which they serve as markers. Each measurement is shown with its Logical Observation Identifiers Names and Codes (LOINC®) Number, Analyte Short Name, and LOINC Long Common Name, which is derived from its formal name by using conventional names for analytes and procedures. The long common name eliminates the parts of the formal name that are not needed to distinguish the test from related tests.

Analyte Short Name	LOINC Number	LOINC Long Common Name *and conditions or disorders that positive results may signal*
MS/MS		
Acyl-Carnitine		
C8:1	53174-9	Octenoylcarnitine (C8:1) [Moles/volume] in Dried blood spot Secondary marker for: • MCKAT : Medium-chain ketoacyl-CoA thiolase deficiency
Amino Acid		
OXOPRO + PIPA	53232-5	5-Oxoproline+Pipecolate [Moles/volume] in Dried blood spot Primary marker for: • 5-OXO : Pyroglutamic acidemia
[OXOPRO + PIPA] / PHE	53394-3	5-Oxoproline+Pipecolate/Phenylalanine [Molar ratio] in Dried blood spot Primary marker for: • 5-OXO : Pyroglutamic acidemia
ALA + BALA + SARC	53150-9	Alanine+Beta Alanine+Sarcosine [Moles/volume] in Dried blood spot Secondary marker for: • E3 : Dihydrolipoamide dehydrogenase deficiency

Filters for conditions

Tailoring your Conditions

Legend

Step 2. Select general condition categories of interest:

Use the checkboxes on the right to select some or all of the conditions listed. If you pick "Amino Acid Disorders" and "Thyroid Disorders", for example, your view will only show information about conditions listed within those two categories.

Step 2. Select general condition categories of interest:

Select All | Clear All

- ☑ Hearing Loss
- ☑ MS/MS (Tandem Mass Spectrometry) Measured Conditions
  - ☑ Amino Acid Disorders
  - ☑ Fatty Acid Oxidase Disorders
  - ☑ Organic Acid Disorders
- ☑ Non MS/MS Measured Conditions
  - ☑ Cystic Fibrosis
  - ☑ Endocrine Disorders
    - ☑ Adrenal Hyperplasia
    - ☑ Thyroid Disorders
  - ☑ Hemoglobin Disorders
    - ☑ Hemoglobinopathies
    - ☑ Hemoglobinopathy Traits
  - ☑ Infectious Diseases
  - ☑ Biotinidase
  - ☑ Galactose Disorders
  - ☑ Other Disorders

Step 3. Limit view to ACHDNC core, secondary or other conditions:

You can restrict your view to any combination of Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) core, secondary or other conditions by checking the corresponding boxes to the right.

- Core conditions — those that the ACHDNC recommends be included in all newborn

Step 3. Limit view to ACHDNC core, secondary or other conditions:

Select All | Clear All

- ☑ ACHDNC Recommended Uniform Screening Panel
  - ☑ Core Conditions
  - ☑ Secondary Target Conditions
- ☑ Other Conditions (Screened by Some States)

Generate View >>

Filters for analytes/measurements

Tailoring your Analytes/Measurements

Legend

Step 2. Select tests/measurements:

Use the checkboxes to select some or all of the tests/measurements listed to the right.

Most newborn screening tests are done with a blood sample taken 24 to 48 hours after a baby is born. The tests then measure the amounts of chemicals (known as analytes).

MS/MS refers to tests that are analyzed using a technique called tandem mass spectrometry. Non-MS/MS analyses use other techniques.

The hearing test uses a soft earphone or other instrument that is placed in the baby's ear.

Step 3. Include or exclude derived measures:

Some of the markers listed in these tables are direct measures of a particular chemical substance and some are derived as sums and/or ratios from two or more direct measures.

Step 2. Select tests/measurements:

Select All | Clear All

- ☑ Hearing
- ☑ MS/MS
  - ☑ Acyl-Carnitine
  - ☑ Amino Acid
  - ☑ Fatty Acid Oxidase
  - ☑ Fatty Acid Oxidase-Organic Acid
  - ☑ Organic Acid
- ☑ Non-MS/MS
  - ☑ Biotinidase
  - ☑ Cystic Fibrosis
  - ☑ Endocrine Disorders
  - ☑ Galactosemia
  - ☑ Hemoglobin Disorders
  - ☑ Infectious Diseases
  - ☑ Other

Step 3. Include or exclude derived measures:

- ◉ Include derived measures
- ○ Exclude derived measures

Generate View >>

Link to other resources

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Resources

These resources provide additional information about newborn screening and related codes and data standards.

What is Newborn Screening?

- Genetics Home Reference™ (LHNCBC/NLM)

  Genetics Home Reference (GHR) is the National Library of Medicine (NLM®) Web site for consumer information about genetic conditions and the genes or chromosomes related to those conditions. This resource offers consumer-friendly summaries of all 29 health conditions recommended for newborn screening in the HRSA/ACMG report.

- National Newborn Screening and Genetics Resource Center (NNSGRC)

  The NNSGRC provides information about newborn screening and genetics to benefit health professionals, the public health community, consumers, and government officials.

- MedlinePlus® Health Topic on newborn screening (NLM)

  This consumer resource from the National Library of Medicine provides links to a variety of reputable sources of information about newborn screening.

- HRSA/ACMG report on newborn screening (HRSA)

  This report from the Health Resources and Services Administration (HRSA) and American College of Medical Genetics (ACMG) outlines the standardization of outcomes and guidelines for state newborn screening programs and defines responsibilities for collecting and evaluating outcome data, including a recommended uniform panel of conditions to include in state newborn screening programs.

- Genetic Alliance

  Genetic Alliance is a health advocacy organization that connects members of parent and family groups, community organizations, disease-specific advocacy organizations, professional societies, educational institutions, corporations, and government agencies to create novel partnerships. It engages in improving access to information for individuals, families and communities, while supporting the translation of research into services.

Information on code standards

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Code Standards

A coding and terminology framework is essential to standardizing laboratory reporting and enabling interoperability of information exchange across Electronic Health Record (EHR) platforms. Some of the code standards include:

LOINC®

Logical Observation Identifiers Names and Codes (LOINC) is a US standard for identification of laboratory tests and other measurements. It is available free of charge in a database that carries universal codes and names, and other attributes, for laboratory and other kinds of tests, clinical reports, measurements, survey instruments and other observations. It was developed to enable the exchange and pooling of clinical results for clinical care, outcomes management, and research by providing a set of universal codes and names to identify laboratory tests and other clinical observations. The LOINC terminology was developed by the LOINC Committee and Regenstrief Institute and is maintained by the Regenstrief Institute, Inc., a non-profit medical research organization associated with Indiana University. You can download the database and a browser program (also no cost) from http://loinc.org/downloads. The LOINC and Regenstrief LOINC Mapping Assistant (RELMA®) Terms of Use are available at: http://loinc.org/terms-of-use.

SNOMED CT®

Systematized Nomenclature of Medicine — Clinical Terms (SNOMED CT) is a comprehensive, multilingual clinical health care terminology designed for use in electronic health record systems and in health data exchange. SNOMED CT aims to facilitate communication and interoperability in electronic health data exchange. Originally created by the College of American Pathologists (CAP) in cooperation with the UK National Health Service, SNOMED CT is now owned, maintained, and distributed by the International Health Terminology Standards Development Organisation (IHTSDO), a not-for-profit association in Denmark, with contract assistance from the CAP. It is available free of charge in IHTSDO member countries, including the U.S., in low-income countries as defined by the World Bank, and for qualified research projects in any country. The National Library of Medicine is the US Member of the IHTSDO. Information about obtaining SNOMED CT (in multiple formats) is available at http://www.nlm.nih.gov/research/umls/licensedcontent/snomedctfiles.html. A free Unified Medical Language System® (UMLS®) Metathesaurus license (which includes the IHTSDO Affiliate license) is required. It can be obtained via the same site.

ICD-9-CM

International Classification of Diseases, Ninth Revision, Clinical Modification, vols. 1-2, based on the World Health Organization's Ninth Revision, International Classification of Diseases (ICD-9), is the official system of assigning codes to diagnoses associated with hospital utilization and public health reporting in the U.S. ICD-9-CM is a required standard for use in administrative transactions subject to the Health Insurance Portability and Accountability Act of 1996 (HIPAA). The National Center for Health Statistics (NCHS), part of the Centers for Disease Control and Prevention, and the Centers for Medicare & Medicaid Services are the U.S. governmental agencies responsible for overseeing all changes and modifications to the

Work in progress…..

Card variables

- Additional information collected about the baby e.g. birth weight, transfusion history
- Some may be covered in other HL7 segments e.g. PID segment
- Others will be sent in OBX segments
- Will need additional LOINC panel and observation codes – but first have to agree upon a core set of data elements

Use of special HL7 functionalities

- Hide function of OBX-13
  - Can flag some results to be hidden from routine clinical care displays
  - Results will still be available for management and research purposes
- Delivery of a printed image of the report
  - HL7 can deliver a full formatted report within an OBX segment
  - Specific LOINC codes will be assigned to each kind of report

Other work

- Build a more complete example and guide of HL7 messaging
- Get agreement on requirement of additional interpretation variables