Standards for Public Health Data Exchange: Newborn Screening

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Why does the National HIT agenda include Newborn Screening?

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
The Vision for Clinical – Public Health Information Systems: Interoperability for Newborn Screening
Vision: Interoperability for Newborn Screening

Building interoperable information systems for public health will require working with:

- Public Health Community
- Clinicians
- Vendors
Vision: Interoperability for Newborn Screening

Working with Public Health Community to

- Understand interactions between public health data systems within a health department and across health departments
- Understand commonalities of data across public health data systems
- Define common public health needs in health information exchanges
Vision: Interoperability for Newborn Screening

Working with Clinicians to

- Define public health needs in information exchanges
- Understand interactions between clinical care and public health data systems
- Understand commonalities of data and data system architectures across clinical and public health data systems
Vision for Clinical – Public Health Information Systems
Interoperability for Newborn Screening

Working with Vendors
Clinicians and Software Developers
Working Together to Deliver Interoperable Health Information Systems

WWW.IHE.NET
IHE is a joint initiative

- Founded 1997 by Radiology (RSNA) and IT (HIMSS)
- Includes – among others
  - American College of Cardiology (ACC)
  - GMSIH, HPRIM, JAHIS (laboratory)
  - American Society of Ophthalmology
  - American College of Physicians (ACP)
  - American College of Clinical Engineering (ACCE)
  - Public Health Data Standards Consortium (PHDSC)
- International effort: IHE- Europe and IHE-Asia
What is IHE – Health IT Vendors

Leadership

Implementer

Supporter

Organizational Participants

Participants as of 11/20/06

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## IHE Standards - Technical Documents

- White Papers
- Technical Frameworks
- Integration Profiles
- Content Profiles
Public Health Activities at IHE

2007-2008

- Building a Roadmap for Health Information Systems Interoperability for Public Health – White Paper
- Cancer Pathology - Integration Profile
- Immunization - Demographics Profile

2008-2009

- Newborn Screening - White Paper
- Chronic Care (Diabetes Care) - White Paper
- Service-Oriented Architecture for Public Health - White Paper
IHE Quality, Research & Public Health Technical Committee White Paper 2009-2010

Newborn Screening (NBS and NHS/EHDI)

Supported by HRSA
IHE Newborn Screening White Paper

- Public Health Data Standards Consortium (PHDSC) (www.phdsc.org)
- IHE
  - Quality Research in Public Health Committee
  - Laboratory Committee: France, Germany, Austria
- With input from State Health Departments
  - Alaska, Iowa, Maryland, Texas
Our Purpose at IHE

- To maintain existing CDC and HRSA goals
  - For example CDC suggests that an individual hearing health record be maintained
    - That is individual
    - Can report the hearing status of every occurrent birth.

- To assure that EHDI programs QA /QI efforts could go forward as they exist now or perhaps better – but no worse.

- To maintain states’ jurisdictional autonomy
- To maintain flexibility
Purpose of This Presentation: EHDI

- Introduce “Functional Requirements” for Newborn Hearing Screening Systems
- Define “Actors”
- Review the simplified EHDI Use Case (scope) and Use Case Diagrams
- Review next steps
Functional Requirements

In this project, these included:

- Documentation of work processes at Hospital, by Public Health and by PCP/Medical Home
- Specification of Information
- Specification of how the Hospital EHR needed to function for EHDI
- Specification of EDI needed by Hospital EHR to communicate with Stakeholder systems.
Actors: People and Systems

- **Healthcare Providers**
  - Hospital
    - Attending Physician
    - Hearing Screener
    - Screening Supervisor (Birthing Facility’s or Contract Staff)
  - Primary Care Provider (PCP)/Medical Home

- **Public Health**
  - NHS / EHDI Program
    - Program Staff

- **Consumer**
  - Newborn;
  - Parent/Guardian

- Hospital Electronic Health Record System (**EHR-S**)
- Hearing Screening Device (**HS Device**)
- EHDI Information System (**NHS/EHDI-IS**)
- PCP’s **EHR-S**
- Personal Health Record System (**PHR-S**) (OUT OF SCOPE)
- Health Information Exchange (HIE)
Health Information Exchange

- Moves clinical information electronically among different systems while maintaining meaning of the information exchanged.
- Facilitates access and retrieval of clinical data for safer, more timely, efficient, effective, equitable, patient-centered care.
- Formal organizations are now emerging to provide both form and function for health information exchange efforts.
Interoperability

Birth Hospital

- Birth Record
- Newborn Bloodspot Screening Information
- Newborn Hearing Screening
- Immunization
- PCP/Medical Home

Public Health

- NBS Information Systems
- EHDI Information System
- Immunization Registry

Health Information Exchange
USE CASE DESCRIPTION

Use Case is a structured description of user activities and data generated/exchanged during these activities in the context of a particular clinical scenario.

NEWBORN HEARING SCREENING
Birth Screening
USE CASE – Birthing Facility

- **1.1 EHR** reminds **Hearing Screener** that Newborn is due for hearing screening
- **1.2 Hearing Screener** explains screening to **Parent**. Obtains Consent if needed
- **1.4 Hearing Screener** enters required information into **EHR** and/or **HS Device**
- **1.6 Hearing Screener** performs test using approved **HS Device**
USE CASE – Birthing Facility

- **2.1 HS Device** generates hearing screening results
- **2.2 HS Device** sends hearing results to **EHR**
- **2.3 HS Device** sends results to **EHDI-IS**
- **1.13 Hearing Screener** communicates results and provides information/education about follow-up care to **parent**
NHS/EHDI Program

- **3.1. EHDI-IS** receives notification of Newborn’s Birth

- **3.2. And** establishes Newborn’s record.

- **3.3. EHDI-IS** receives screening results from EHR or directly from HS Device

- **3.6 EHDI-IS** matches results to newborn’s record and calculates *outcome* for the Newborn including appropriate follow-up activities
NHS/EHDI Program

- **3.9 EHDI-IS** send newborn’s screening outcome to HIE
- **3.10 EHDI-IS** alerts **Program Staff** when follow-up is needed – as required
- **3.11 Staff** runs surveillance reports in periodically as required by jurisdiction
- **3.12 EHDI-IS** sends **Surveillance Reports** to HIE
4.1 Primary Care Provider receives Notification that Newborn’s records are available

4.3. PCP EHR downloads Newborn’s Hearing Outcome

4.4. If abnormal results, Primary Care Provider may be notified by NHS Program Staff for appropriate follow-up
NEWBORN HEARING SCREENING
USE CASE DIAGRAMS AND
WORKFLOW DIAGRAMS

- A way to depict user activities so vendors can select IT tools to support these activities

- UML: Unified Modeling Language
  - a standard for modeling information exchanges between participating information systems
Newborn Screening UML Use Case Diagrams

Use Case 2: Newborn Hearing Screening/Early Hearing Detection & Intervention (NHS/EHDI)

**Birthing Facility**

1.1 **EHR-S** presents a Reminder to Hearing Screener that Newborn is due for NHS

1.2 **Hearing Screener** explains test & obtains Consents or Consent Refusals from Guardian

1.3 **Hearing Screener** enters Consents or Consent Refusals into EHR-S

1.4 **Hearing Screener** enters HS data into EHR-S

1.5 **Hearing Screener** scans barcode or enters Newborn ID into HS Device

1.6 **Hearing Screener** performs the test using approved HS Device

1.7 **EHR-S** receives HS Results from the HS Device

1.8 **EHR-S** sends HS Results Report to NHS/EHDI-IS

1.9 **EHR-S** publishes HS Results Report into HIE

1.10 If abnormal, **EHR-S** notifies appropriate Clinicians

1.11 **EHR-S** receives Notification that NHS Outcome Reports are available in HIE

1.12 **Birthing Facility Staff** downloads NHS Outcome Reports from HIE into EHR-S

1.13 **Hearing Screener** communicates NHS Outcomes to Guardian

1.14 **EHR-S** receives Notification that NHS Surveillance Reports are available in HIE

1.15 **Birthing Facility Staff** downloads NHS Surveillance Reports from HIE into EHR-S
Newborn Screening UML Work Flow Diagrams

**EHDI Flow 1. Birthing Facility**

1. **Screening Reminder**
   - Birthing Facility
   - Hearing Screening Device
   - HIE
   - NHS/EHDI-IS
   - Primary Care Provider EHR-S

   1.1 Screen Reminder Care Management [PCC-7,8,9,10,11]
   1.2 Explain/Capture Consent
   1.3 XDS Provide & Register [ITI 15,41] BPPC
   1.4 Communicate Newborn Date to Device (PCD-?)
   1.5 Barcode (PCD-?)
   1.6 Perform Test
   1.7 Send Screening Results (PCD-?)
   1.8 Send Screening Results for Newborn, XDR ITI-41 XDS-SD,PCC-?
   1.9 XDS Provide & Register (XDR ITI-15,41) XDS-SD,PCC-?
   1.10 Abnormal Result Alert NAV? [Pending IHE Profile]
   1.11 Notification of Availability of Outcome Report [NAV ITI-25,26,27,25]
   1.12 XDS Query & Retrieve Outcome Report [ITI-18,17,43]
   1.13 Guardian Education
   1.14 Notification of Availability of HS Surveillance Report NAV [ITI-25,26,27,28]
   1.15 XDS Query/Retrieval HS Surveillance Report [ITI-18,17,43], XDS-SD?, PCC-?
   1.16 XDS Query/Retrieve Outcome Report [ITI-18,17,43] XDS-SD, PCC-?

Public Comment Period: June 8-July 7!

Review and send us your comments on the White Paper at <URL here>
Questions?