Newborn Screening Web Portal Concept - Service-oriented Architecture

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Agenda

• Overview of current state of newborn screening electronic information exchange

• Value proposition of newborn screening electronic information exchange

• Proposal of approach to promote state information exchange adoption: Newborn Screening Web-Portal
Newborn Screening Health IT Overview

**Purpose**
- To improve quality of care for newborns by enabling early detection of and intervention for heritable disorders.

**Special considerations and challenges**
- Public health screening in conjunction with primary care delivery
- Continuity of care from birth center to primary care and follow-up care.
- Pediatric and maternal health – integration of pre-natal, post-natal and infant healthcare

**Resources available to initiate electronic information exchange of NBS data**
- Use Case
- Coding and Terminology Guide
- Information Package
- Privacy and Security Policy Guidance
Current Limitations for Electronic Information Exchange in Newborn Screening

- Public health information exchange systems are nascent (NHIN etc.).
- Overall limited capability to exchange lab orders and results – progress in some states (i.e. Iowa, Texas, Delaware and New York)

**However:**

- Provides opportunity for connecting Newborn Screening with (i.e. immunization to build comprehensive EHR).
- Presents a case of transfer of care (birth center to primary care provider) and could serve as a template for other scenarios.
- Supports population health activities including research and program evaluation.
- Supported by massive federal investment (HITECH) in infrastructure and adoption.
Rationale and Proposal for Newborn Screening Web Portal

Web-portal based information exchange addresses both the importance of Newborn Screening as well as electronic information exchange opportunities.

- an area of public health importance.
- mandated by all states.
- a ‘leading edge’ area for clinical application of genetic knowledge.

An effective electronic communication strategy would both improve NBS-based care and potentially serve as a model for:

- Use of health information storage and exchange to support pediatric / lifelong care
- Communication among various elements of the health care system
- Integration of practice and public health information

Electronic storage and distribution of NBS data would also:

- Provide new resources for research
- Lay a foundation for use of genetic information in clinical care
- Expand consumer access to information and medical decision-making
Newborn Screening Web Portal Concept

Web-portal concept based on service-oriented architecture to support NBS information exchange.

- **Hospital Information System (EHR)**
- **Public Health Laboratory Information System**
  - Laboratory test performed
  - Laboratory test result data integrated with lab order data
- **Database**
  - Stores integrated lab order and lab result summary
- **Web-Portal**
  - Levels of Access:
    1. Provider
    2. Caregiver
    3. Research Community
- **Primary Care Provider (pediatrician/specialist)**
  - Practice information/case management system/EHR
- **Patient Care-provider**
  - PHR/personal computer
- **Research Community**
  - Translational Research Network database
- **Federal and State Registry**
  - Monitor and evaluate health outcomes and quality measures

**Levels of Access**

1. Provider
2. Caregiver
3. Research Community

**Lab order / test result summary**

**Lab order / test result summary in combination with appropriate ACT Sheet**

**De-identified test result summary sample**

**De-identified test result data**

- **“PUSH” information is provided by the source**
- **“PULL” information provided following a query**
Expected Outcomes and Benefits

**Benefits to Patients and Parents:**
- Availability of complete newborn screening information
- Portability of patient record
- Improved coordination of care
- Improved child safety (adverse event avoidance)
- Reduced loss to follow-up

**Benefits to Primary Care Providers:**
- Actionable information for primary care providers, public health and specialists
- Reduced time and effort entering data manually
- Improved timely and appropriate data sharing to support follow-up care and treatment.
- Non-duplication of services

**Benefits to State Health Department / Public Health Laboratory:**
- Preserve the systems that healthcare professionals already use
- Reduced cost of specimen processing due to more effective recording and reporting.
- Connect local systems into regional network
- Provide a centralized data exchange
- Deliver benefits to users early in the deployment process
- Reduced cost and deployment time compared to fully integrated HIE
Next Steps

• Identification of community-based coalitions including state(s) or regional collaboratives to lead demonstration project

• Funding resources available for web-portal development
  - ARRA/HITECH Section 3013
  - ARRA/HITECH Section 3011
  - CMS Medicaid Incentive Payments