

# **Newborn Screening Web Portal Concept - Service-oriented Architecture**

**Constanze Coon, PhD  
Gregory Downing, DO, PhD**

**OS, Dept. Health and Human Services**

**September 25, 2009**

# 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:**

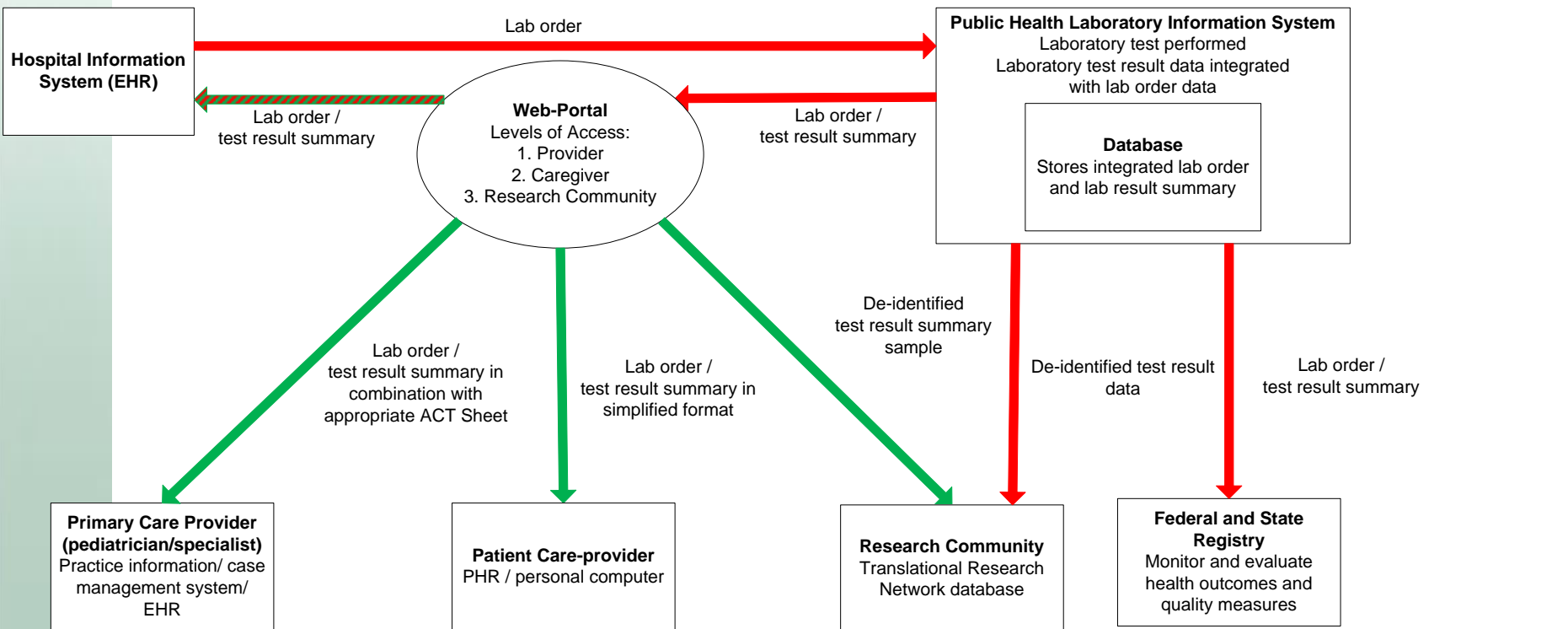
- Use of health information storage and exchange to support pediatric / lifelong care
- Communication among various elements of the health care system
- Integration of practice and public health information



**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.



 "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