

# Update on the Data Linkage Assessment Project

Presentation to the  
Heartland Regional Genetics and  
Newborn Screening Collaborative

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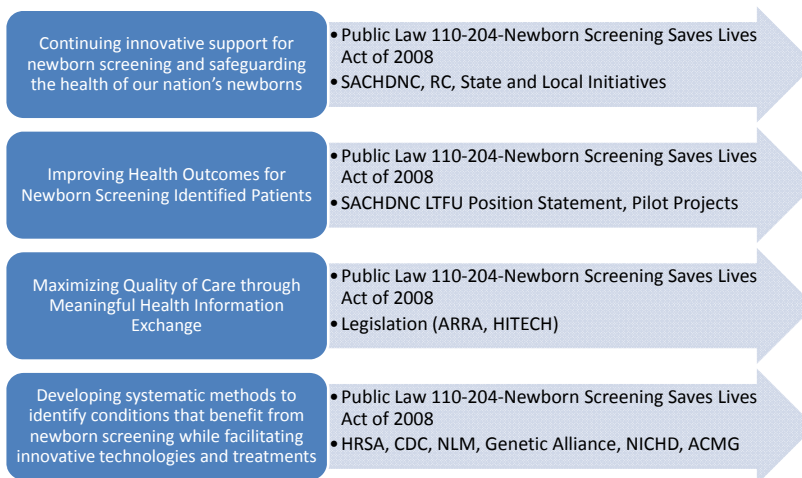
## Presentation Outline

- Project Conception
- Data Linkage Project
  - Goals and Deliverables
  - Methodology
  - Assessment
  - State Summaries
  - Disseminate to Key Partners
  - Summary Report
- Next Steps
- Q & A

## Project Conception

- Heartland Newborn Screening Workgroup
- Key Drivers
  - National Initiatives in Health Information Exchange
  - Increased Emphasis on Health Outcomes and Performance Measures
  - Publication of Newborn Screening Use Case
  - Development of Coding and Terminology Guidelines
  - Newborn Screening Initiatives
- Demonstration of Need within the Heartland

## Overarching Drivers



## Key Driver - National Initiatives in Health Information Exchange

- American Recovery & Reinvestment Act (ARRA) of 2009
  - Created new office to promote the development of a nationwide interoperable Health IT infrastructure
  - Established Health IT Policy and Standards Committees
  - Provides financial incentives
- Health Information Technology for Economic and Clinical Health (HITECH) Act
  - Grant programs to support States in establishing health information exchange (HIE) capability among healthcare providers and hospitals in their jurisdictions.

### Over \$750M in Grants Awarded to Promote Adoption and Meaningful Use of Health IT

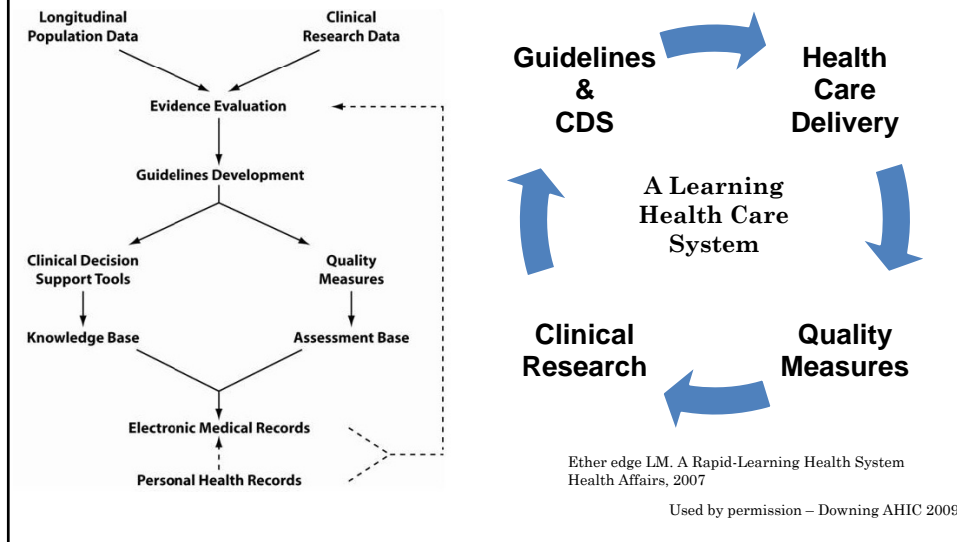


On February 12th, HHS Secretary Kathleen Sebelius announced over \$750 million in grant awards as part of a federal initiative to build capacity to enable widespread meaningful use of health IT. Funding is being distributed through two Cooperative Agreement Programs: the [State Health Information Exchange Cooperative Agreement Program \(HIE\)](#) and the [Health Information Technology Extension Program \(HECs\)](#).

## Key Driver – National Initiatives in Health Information Exchange

- Enhancing the Quality and Efficiency of Newborn Screening Programs through the Use of Health Information Technology – Downing GJ, Zuckerman AE, Coon C, Lloyd-Puryear M.
  - Information infrastructure in development
  - Technical capabilities of EHR systems being enhanced
  - Financial incentives available
  - Decision support tools in development

## Key Driver - National Initiatives in Health Information Exchange



## Key Driver - Focus on Health Outcomes and Performance Measures

- SACHDNC Position Statement on LTFU
  - Care coordination through a medical home
  - Evidence-based treatment
  - Continuous quality improvement
  - New knowledge discovery
- NCQA and SACHDNC Subcommittee efforts
- HRSA supported demonstration and pilot projects
- CDC supported projects

## Key Driver - Newborn Screening Use Case

- Focused on the electronic exchange of information related to newborn screening among ordering clinicians, pediatric clinicians, consumers, Public Health, testing laboratories, and audiology service providers.
- Scope
  - The ability to communicate initial screening results, confirmatory testing orders, and results and information specific to referral and management of the patient
  - The ability to report newborn screening information to Public Health.
- <http://www.hhs.gov/healthit/usecases/nbs.html>

## Key Driver – Coding Guide

- National Library of Medicine
  - Newborn Screening Coding and Terminology Guide (<http://newbornscreeningcodes.nlm.nih.gov>)
  - Standard codes and terminology for newborn tests
  - The overall goal is to promote and facilitate the use of electronic health data standards in recording and transmitting newborn screening test results.



U.S. National Library of Medicine  
**Newborn Screening Coding and Terminology Guide**

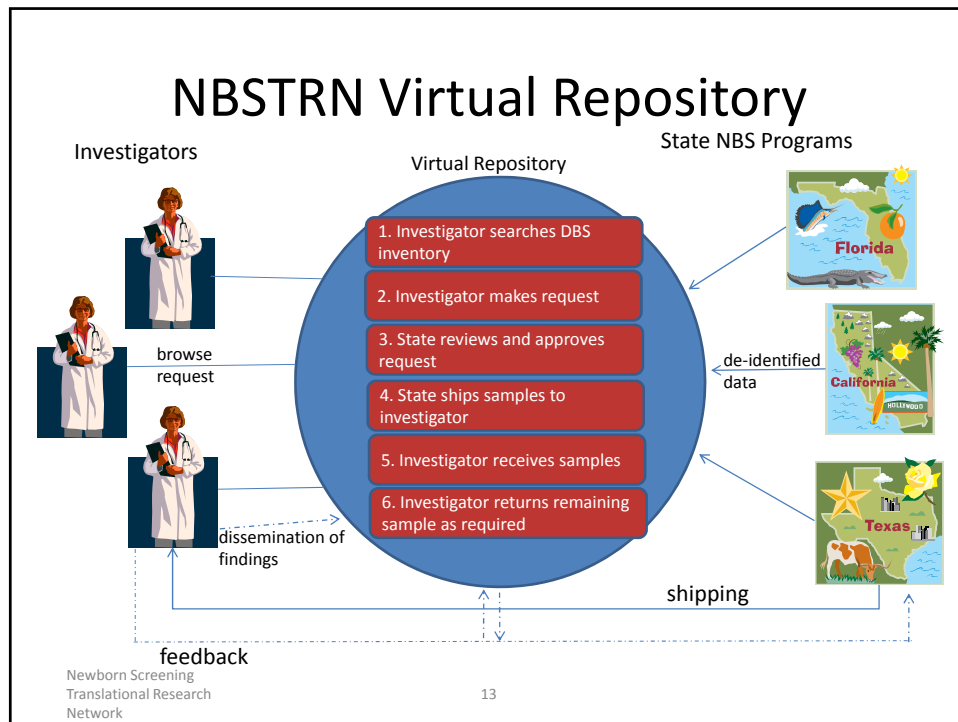
Data Standards for Electronic Reporting

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# Newborn Screening Initiatives

- HRSA Efforts
  - Regional Collaborative Efforts
  - Pilot Projects
  - Clearinghouse
- NICHD Efforts
  - Natural History
  - Pilot Projects
  - NBSTRN

The screenshot displays the website for the National Birth Defects Prevention Center's Newborn Screening Clearinghouse. The browser window shows the URL <http://www.nbsclearinghouse.org/>. The page header includes the NBSC logo and navigation links: Home, Blog, F.A.Q., Contact, and Login. A sidebar on the left provides quick links to various resources such as 'About the Clearinghouse', 'General Newborn Screening Information', and 'NIH Research Portfolio Online Reporting Tool (RePort)'. The main content area features a 'Featured Resources' section with a detailed description of the RePort tool, which aggregates data from multiple sources to improve the quality of newborn screening information. Below this, there are sections for '@BabysFirstTest Updates', 'Recent blog posts', and 'Newborn Screening News'.



## Demonstration of Need

- Seven of eight states report not having sufficient information sharing and data linkage systems
- All states report awareness of focus on health outcomes and performance measurements

## Data Linkage Project

- Goal
- Work Plan
- Methodology
- Assessment
- State Summaries
- Disseminate to Key Partners
- Summary Report

## Goal

- Conduct a multilevel, multisource assessment of the exchange of information related to newborn screen identified individuals for each state in the Heartland Region



## Work Plan

- Determine methodology
- Engage states
- Conduct state assessments
- Draft state reports
- Share report with states
- Update based on feedback
- Disseminate to key partners
- Summary report to Heartland

## Methodology

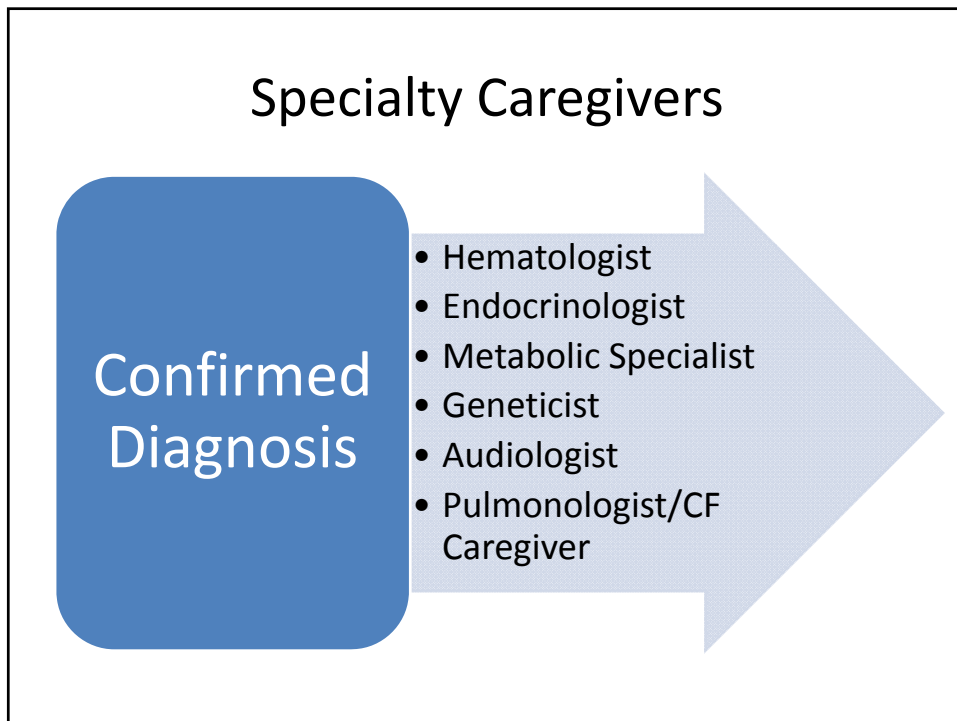
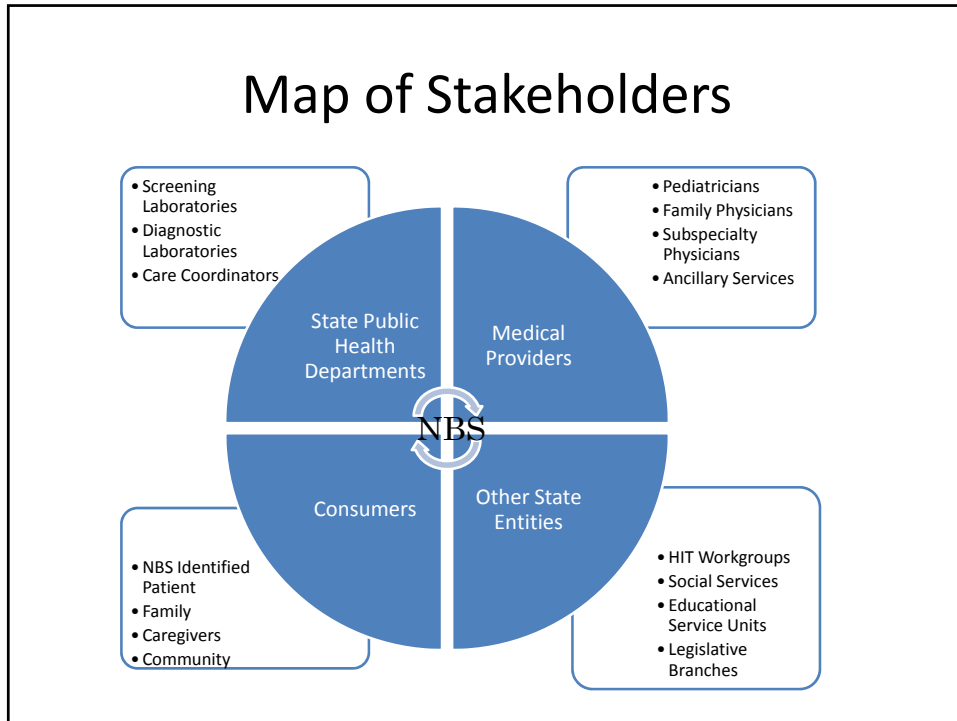
- Evaluation Toolkit for Integrated Health Information Systems published by Public Health Informatics Institute
  - 39 evaluation tools and guides
    - Gather credible evidence
    - Focus assessment design
    - Describe the program
    - Engage stakeholders
    - Justify conclusions
    - Ensure use, share lessons learned
  - 3 utilized
    - AHRQ: National Resource Center for Health Information Technology Evaluation Toolkit Version 3
    - HRSA: Program Evaluation and Assessment Scheme (PEAS)
    - PHII: Integration of NBS and Genetic Services Systems with other MCH Systems: *A Tool for Assessment and Planning*

## Methodology

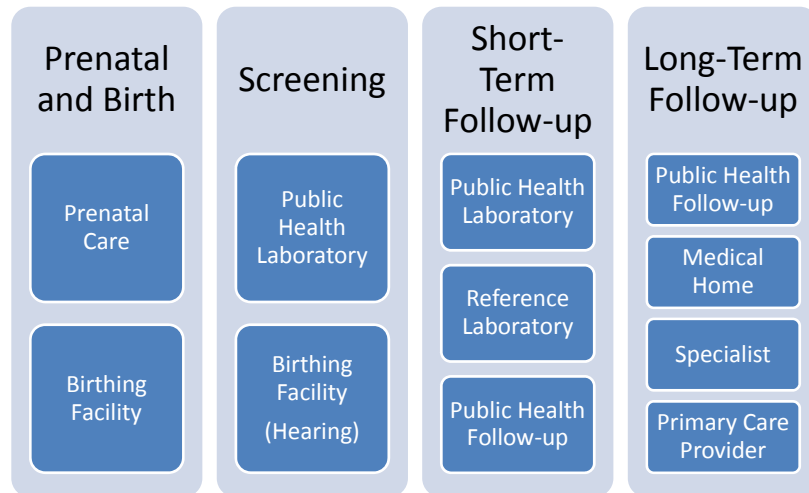
- Semi-structured interviews
- Focus group sessions
- Include unique State characteristics and considerations

## Engage States

- Lead contact for each state
- Introductory conference call
- Written project introduction
- Background presentation and literature exchange
- Timing of state visit
- Identify special circumstances



## Locations of Information Exchange



## Assessment

- Flow of information
- Status of data linkage
- Climate within health department
- Available resources
- Future plans

## Assessment Stakeholder Groups

- In Scope
  - Newborn Screening Program
  - Department of Public Health
  - Hearing Loss Program
  - Pediatric Specialists
  - Primary Care Providers
  - Consumers and Parents
- Out of Scope
  - Prenatal Caregivers
  - Birthing Facility Caregivers
  - Educational Providers
  - Department of Health Caseworkers

## State Visits

- Preparation
  - Project introduction to State Leads
  - Engage stakeholders
  - Determine visit type
  - Develop agenda
  - Provide background materials and/or present background
- Visit
- Follow-up Action Items

## Sample Assessments

### Coding and Message Structure

Defined Elements	Screening	Diagnosis	STFU	LTFU	Transition
LOINC	Screening	Diagnosis	STFU	LTFU	Transition
SNOMED	Screening	Diagnosis	STFU	LTFU	Transition
ICD9	Screening	Diagnosis	STFU	LTFU	Transition
NLM Guide	Screening	Diagnosis	STFU	NA	NA
HL7	Screening	Diagnosis	STFU	LTFU	Transition

## Sample Assessments

### Long-Term Follow-Up

Care Coordination	Screening	Diagnosis	STFU	LTFU	Transition
Evidence Based Treatment	Screening	Diagnosis	STFU	LTFU	Transition
Quality Improvement	Screening	Diagnosis	STFU	LTFU	Transition
New Knowledge Discovery	Screening	Diagnosis	STFU	LTFU	Transition
Other	Screening	Diagnosis	STFU	LTFU	Transition
Other	Screening	Diagnosis	STFU	LTFU	Transition

## Sample Interview Questions

- What is your agency's role in the NBS program?
- How is NBS information transmitted to primary care providers? Subspecialists?
- What is the system/process for confirmatory testing? Referrals to subspecialists?
- What is your role and responsibilities for follow-up?
- When do your responsibilities for follow-up begin and end?
- How do you define short-term follow-up and long-term follow-up?

## Preliminary Findings

- Electronic Linkage
- Information Access
- Information Sharing
- Health Information Exchange
- Long-Term Follow-Up
- Barriers and Enablers

## Electronic Linkage

Program	Percentage of States Linked to Newborn Screening Program
	n/N(%)
Vital Records	4/8 (50%)
Hearing Loss	4/8 (50%)
Birth Defects	2/8 (25%)
Immunization	3/8 (37.5%)
Other	4/8 (50%)

## Information Access

User	Percentage of States Allowing Access (%)	
	Without Consent	With Consent
PCP	0/0 (0%)	8/8 (100%)
Hospitals	4/8 (50%)	8/8 (100%)
Social Services Agencies	0/0 (0%)	8/8 (100%)
Schools	0/0 (0%)	0/0 (0%)
Families	0/0 (0%)	0/0 (0%)



## Information Sharing Method

Method	Percentage of States (%)
Mail	8/8 (100%)
Telephone	8/8 (100%)
Fax	8/8 (100%)
Email	6/8 (75%)
EHR	2/8 (25%)
Web-based	4/8 (50%)

## Health Information Exchange

Code/Structure	Percentage of States (%)
LOINC	1/8 (12.5%)
SNOMED	0/8 (0%)
ICD9	0/8 (0%)
HL7	4/8 (50%)
Other	4/8 (50%)

## Long-Term Follow-Up

Component	Percentage of States (%)
Care Coordination	8/8 (100%)
Evidence Based Treatment	2/8 (25%)
Quality Improvement	8/8 (100%)
New Knowledge Discovery	2/8 (25%)

## Barriers and Enablers

- Laws and Regulations
  - 2/8 (25%) have laws or regulations that facilitate
    - Birth Defects Monitoring System expanded existing authority for active surveillance
    - State statute mandates long-term follow-up to age 21
- State based Initiatives
  - 1/8 (12.5%) report DOH developing strategic plan for HIE and including newborn screening program

## Next Steps

- State Summaries
- Disseminate to Key Partners
- Summary Report

## Acknowledgements

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# Q & A

