

Newborn Screening Clearinghouse

Presentation to Secretary's Advisory Committee on
Heritable Disorders in Newborns and Children

January 21, 2010

Vision

- Connect parents and healthcare providers with resources and information
- Improve understanding and informed decision-making
- Facilitate information sharing
- Enable data transparency, integrated tools, technologies and education, and provide a basis for follow-up
- Provide information on federal funding for NBS

Consumers



HRSA/CDC EHDI Data

Newborn Screening Clearinghouse

NNSIS/HRSA

HL7

LOINC

National Center for Biomedical Communications/NIH

HRSA Genetics Collaboratives and Effective Follow-up Projects/HRSA

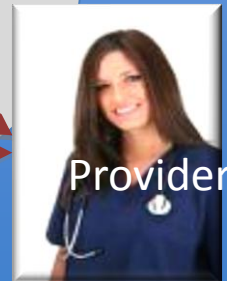
SNOMED

Education

- Trainings
- GARD
- APHL
- Current Tools
- New Development



NBS Translational Research Network/NIH



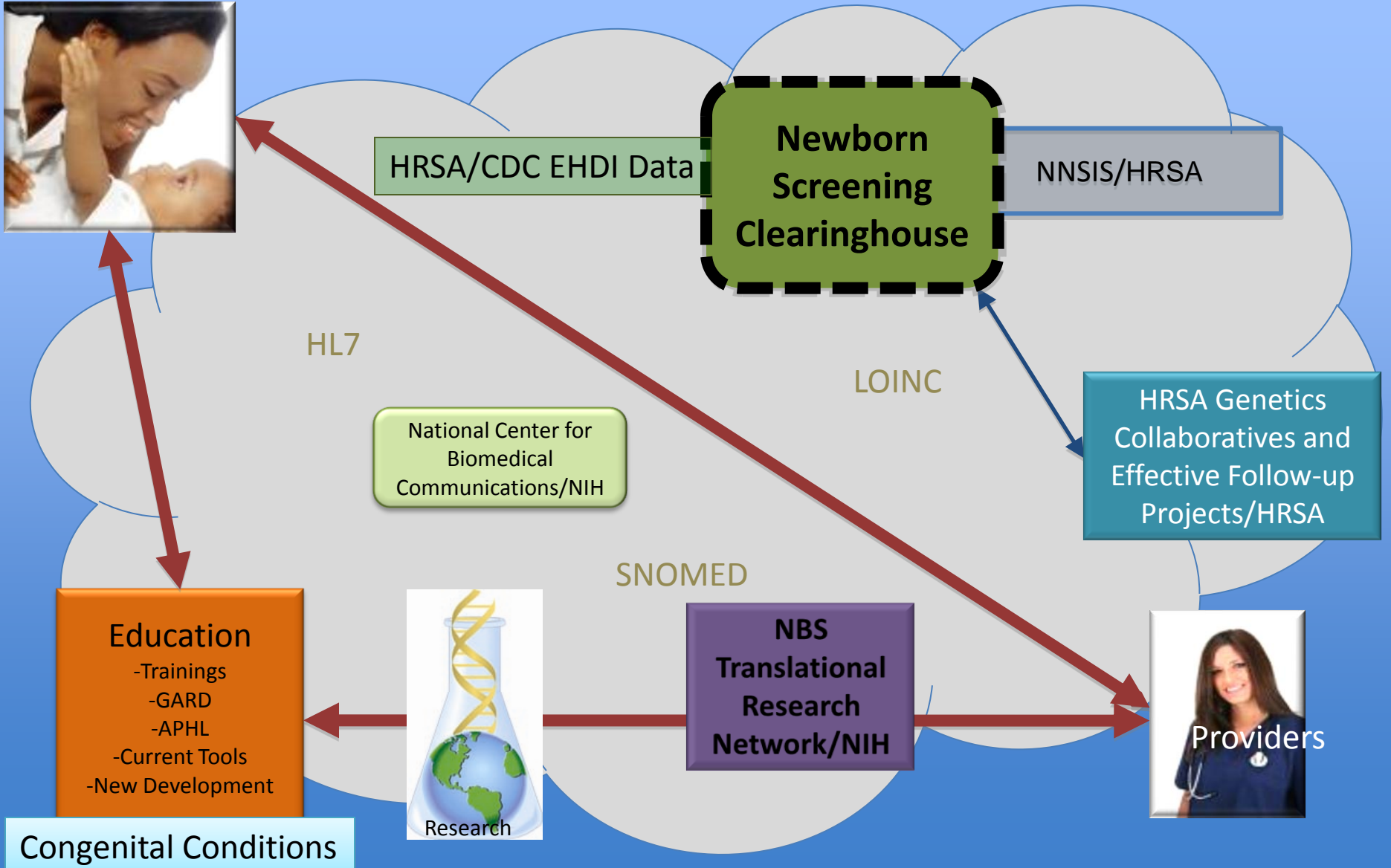
Providers

Congenital Conditions

HHS Secretary

Secretary's Advisory Committee for Heritable Disorders in Newborns and Children

Recommendations for data and data standards; grant activities



What the Act Requires

- Centralize and online
- Research-based information
- Information on each state
- Interactive forum
- Data
- Dissemination

What the **Guidance** Required

- Data, Information & Resources

Liquidity

- Meaningful Use
- Accuracy
- Access
- Information Flow
- Transparency

Data/Information/Resources Liquidity

Collection

Output

Linkages

Quality

Meaningful use

Accuracy

Access

Information flow

Transparency

facebook



BLOG



twitter

Activities for Year 1

- Landscape analysis of NBS materials (ongoing)
- Beta site (October 2009 • NBSC 0.9)
- Presentation to Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (January 2010)
- Workshop during Association of Public Health Laboratories Newborn Screening and Genetic Testing Symposium (May 2010)
- Construction of the NBSC 1.0, 2.0 and 2.x

NBS Clearinghouse: NAC Comments

- Prioritizing information / quality filters
- Roles: consumers, primary care providers
- Public Education / Interactive components
- HRSA Genetics Collaboratives
- Inclusion of international perspectives, issues

Beta Website