Long-Term Follow-Up in Newborn Screening: An Update on ACMG’s Work on the NBSTRN and NCC

Amy Brower, PhD
Program Manager, NBSTRN and NCC
Presentation Overview

• Background
• ACMG Coordinating Centers
• Current Efforts
• Case Studies
• Discussion
Goal of Newborn Screening

- Early detection, diagnosis, and intervention can prevent death or disability and enable children to reach their full potential.
- Lifelong treatment in most cases.
- Today’s focus is on long-term follow-up.

Prenatal Education

Screening

Diagnosis and Short-Term Follow-Up

Clinical Care and Long-Term Follow-Up
H.R. 1281 (113th): Newborn Screening Saves Lives Reauthorization of 2014

- Section 3: Extends through FY2019 a grant program to evaluate the effectiveness of screening, counseling, or health care services in reducing the morbidity and mortality caused by heritable disorders in newborns and children. Expands the program to include evaluation of health outcomes through adolescence and best practices for timely screening of newborns.

- Section 9: Authorizes the Secretary to expand the Hunter Kelly Newborn Screening Research Program to: (1) provide research and data for newborn conditions under review by the Advisory Committee to be added to the Recommended Uniform Screening Panel, and (2) conduct pilot studies on conditions recommended by the Advisory Committee to ensure that screenings are ready for nationwide implementation.
Advisory Committee on Heritable Disorders in Newborns and Children

- Provides guidance to reduce the morbidity and mortality associated with heritable disorders, with a special emphasis on those conditions detectable through newborn screening.
- Identified key features and defined the major overarching questions to be answered to assure newborn screening is meeting its goal of achieving the best quality outcome for the affected children and families.

Long-term follow-up after diagnosis resulting from newborn screening: Statement of the US Secretary of Health and Human Services’ Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children

Alex R. Kemper, MD, MPH, Colleen A. Boyle, PhD, Javier Aceves, MD, Denise Dougherty, PhD, James Figge, MD, MBA, Jill L. Fisch, Alan R. Hsuan, MD, MPH, Carol L. Greene, MD, Christopher A. Kus, MD, MPH, Julie Miller, BS, Derek Robertson, MBA, JD, Brad Therrell, PhD, Michelle Lloyd-Puryear, MD, PhD, Peter C. van Dyck, MD, MPH, and Rodney Howell, MD

What questions should newborn screening long-term follow-up be able to answer? A statement of the US Secretary for Health and Human Services’ Advisory Committee on Heritable Disorders in Newborns and Children

Cynthia F. Hinton, PhD, MPH, Lisa Feuchthbaum, DrPH, MPH, Christopher A. Kus, MD, MPH, Alex R. Kemper, MD, MPH, Susan A. Barry, MD, Jill Levy-Fisch, BA, Julie Ludikke, BS, Celia Kaye, MD, PhD, and Colleen A. Boyle, PhD, MS

Abstract: The US Secretary of Health and Human Services’ Advisory Committee on Heritable Disorders in Newborns and Children provides guidance on reducing the morbidity and mortality associated with heritable disorders detectable through newborn screening. Efforts to systematically evaluate health outcomes, beyond long-term survival, with a few exceptions, are just beginning. To facilitate these nascent efforts, the US Secretary of Health and Human Services’ Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) initiated a project to define the major overarching questions to

Key Words: neonatal screening, comprehensive health care, guideline
Statement on Long-Term Follow-Up

Assure the best possible outcome for individuals with disorders identified through newborn screening

<table>
<thead>
<tr>
<th>Key Features</th>
<th>Central Components</th>
</tr>
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<tbody>
<tr>
<td>Quality chronic disease management</td>
<td>Evidence-based treatment</td>
</tr>
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<td>Condition-specific treatment</td>
<td>Continuous quality improvement</td>
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<tr>
<td>Age-appropriate preventive care throughout the lifespan</td>
<td>New knowledge discovery</td>
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<tr>
<td>Care coordination through a medical home</td>
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ACMG
### Overarching Questions

**Care Coordination**
- Is the family/child prepared for transition to adolescent or adult system of care?
- How is my child doing clinically?
- Is up-to-date information on treatment made available to families?
- Is my child able to enroll in clinical research?

**Evidence-based Txt**

**Quality Improvement**
- Percentage with an individual care plan that is updated at regular intervals.
- Are best practices used appropriately in treatment?
- Annual review of best practices and care plan?
- Percentage of children enrolled in clinical research.

**New Knowledge**
- How many children are lost to follow-up?
- What are developmental, physical, and mental outcomes among affected children?
- Is there ongoing evaluation of the effectiveness of various treatment protocols/regimens?
- Do states use national standards to collect data and link systems?

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**Families**

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**State/Nation**

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• Background
• **ACMG Coordinating Centers**
• Current Efforts
• Case Studies
• Discussion
ACMG Coordinating Centers

**NBSTRN**
- NICHD Contract – Established 2009
- Current Funding 5 Years – Through 2018
- Improve the health outcomes of newborns with genetic or congenital disorders by means of an infrastructure that allows investigators access to robust resources for newborn screening research.

**NCC**
- HRSA – Established 2004
- Current Funding 2 Years – Through 2017
- Strengthen and support the genetics and newborn screening capacity of the states, to improve the availability, accessibility, and quality of genetic services and resources for individuals having, or at risk for, genetic conditions and their families across the lifespan.
Key Considerations in Newborn Screening

Bridging Between Diverse Stakeholders

- State Public Health
- Investigators
- Clinical Service Providers
- Industry
- Patients
- Federal Partners

Begins in State Public Health Newborn Screening Programs

- Controlled through State Departments of Health
- Requires working with 50+ independent entities
- Chronic conditions requiring life-long medical care
- Care received in diverse settings
- Majority are rare or very rare
- Lack of natural history studies
- Incomplete understanding of genomic contributions
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# Development of LTFU Tools

## Joint Committee
- Common Data Elements (CDEs)
- RUSP Conditions
- Subject Matter Experts
- Applicable for Research and Public Health

## NBSTRN
- Informatics Infrastructure
- Disease Specific and Candidate Conditions CDEs
- Clinical Integration Workgroup
- Pilots and Grantees

## NCC
- Public Health Focus
- Leveraging the Regional Genetics Collaboratives
- NCC/RC LTFU Data Workgroup
- Pilots
Development of LTFU Tools

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Makeup of Joint Committee

- **NCC LTFU Data Workgroup**
  - 14 Members
  - 2 Per RC

- **NBSTRN Clinical Centers Workgroup**
  - 22 Members
  - 72% MDs

- Priority Projects
- Effective Follow-Up Projects
- Centers for Disease Control and Prevention
- National Library of Medicine
- NBSTRN Pilots
- NBSTRN Data Capture Tool
- Office of Rare Disease Research
Key Components

Objectives

• Enable investigators and public health teams to systematically collect, analyze and share data across the research community

Resource

• Information system using consensus standardized data sets, case report forms, secure data collection, sharing and management
Potential Uses of Data Sets

- National Data Set
- Research
- Public Health
- NQF

- Natural History
- Hypothesis Driven & Generating
- Surveillance, Outcomes, Quality Assurance & Improvement
- Benchmarks
Use Cases

Investigator – New & Existing Technologies, Novel Treatment & Management Strategies

• Enable Novel Statistically Robust Proposals

Grantee – New & Existing Technologies, Novel Treatment & Management Strategies

• Accelerate & Facilitate Research

Public Health Partner – Service Delivery & Quality Assurance/Improvement

• Implement Technologies & Assess Health Outcomes for Novel Treatments

Describe the clinical course of NBS identified conditions in which patients are asymptomatic.

What is the relationship between CFTR genotypes and lung function in adolescence for newborn screen identified cystic fibrosis patients?

Describe the relationship between service delivery and treatment methods to define optimal follow-up care plans for children with MCAD.
Scope of Work

- Recommended Uniform Panel (RUSP)
- Evidence Review Process
- Long-Term Follow-Up Statement
- Newborn Screening Saves Lives Act

Key Drivers

- 32 Core Components
- 26 Secondary Components
- New Conditions

Management & Outcomes
Common Data Elements (CDEs)

NBS Conditions

RUSP
- Development
- Consensus
- Grantee

Candidates
- Grantee
- Consensus

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Current Efforts

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Facilitating Newborn Screening Research

• The NBSTRN is an NICHD funded contract awarded to ACMG (September 2013 - September 2018)

• The NBSTRN will develop, maintain, administer and enhance resources to support investigators with projects related to newborn screening for:
  – New technologies
  – New Conditions
  – New treatments and management approaches
NBSTRN Tools

VRDBS

- The **Virtual Repository of Dried Blood Spots (VRDBS)** is an open-source, web-based tool that enables NBS researchers to search over 2.9 million DBS from participating states.

R4S

- The **Region 4 Stork** tool is a web-based application for the collection and reporting of analytical results. It has been widely adopted into the routine practice of newborn screening laboratories worldwide.

LPDR

- The **Longitudinal Pediatric Data Resource (LPDR)** is a secure informatics system designed to enable enhanced data collection, sharing, management and analysis for conditions identified as part of newborn screening or for conditions that may benefit from newborn screening.

ELSI Advantage

- The **ELSI Advantage** is an ethical, legal and social issues resource for NBS researchers. Information on IRBs, NBS related FAQs and templates to customize your own consent forms.
Longitudinal Pediatric Data Resource (LPDR) Mission

• The majority of NBS conditions are rare and translating new discoveries into clinical practice requires prospective collection, aggregation and sharing of health information

• To facilitate this translation the NBSTRN developed the Longitudinal Pediatric Data Resource which includes:
  – Data Sets
  – Data Almanac
  – Informatics System
  – Discovery Interface
Welcome

The Longitudinal Pediatric Data Resource (LPDR) is a suite of information technology tools to support newborn screening researchers. The LPDR enables longitudinal collection of clinical and research information within a secure environment that provides permission-based access and data sharing to research teams. Leading clinicians and public health professionals have created a series of questions and answers organized into common data elements (CDEs) to capture important information about each of the conditions that are part of routine newborn screening, the Recommended Uniform Screening Panel (RUSP), or are candidates for newborn screening.

Learn More  Privacy Policy
### Saved CDE's

- **Form:** Demographics
- **Section:** Condition
- **Condition Category:** Amino acid disorders
- **Condition:** Medium-chain acyl-CoA dehydrogenase deficiency
- **Variable Type:** Core
- **Keyword:**
- **Sources:** Select a Source
- **Sites:** Select a Site

**Visit Lab Studies**

- **Renal Labs**
  - u_ren_24_cr
  - u_ren_24_cr_r_range
  - u_ren_24_cr_units
  - u_ren_24_cr_values
  - u_ren_gfr
  - u_ren_gfr_r_range
  - u_ren_gfr_units
  - u_ren_gfr_values
  - u_ren_oth_com
  - u_ren_oth_r_range
  - u_ren_oth_units
  - u_ren_oth_values
  - u_ren_oth
  - u_renal_labs
  - u_ren_oth_name
  - u_ren_cr
  - u_ren_cr_r_range
  - u_ren_cr_units
  - u_ren_cr_values

**Chemistry Labs**

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4 CDEs from search criteria

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# Current Conditions and Cohorts

<table>
<thead>
<tr>
<th>Consensus</th>
<th>Draft</th>
<th>Development</th>
<th>Future</th>
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</thead>
<tbody>
<tr>
<td>N = 46</td>
<td>N = 7</td>
<td>N = 12</td>
<td>N = 3+</td>
</tr>
<tr>
<td>14 RUSP AA</td>
<td>4 Hemoglobinopathies</td>
<td>SMA</td>
<td>Duchenne Muscular Dystrophy</td>
</tr>
<tr>
<td>15 RUSP OA</td>
<td>2 Endocrinopathies</td>
<td>7 LSDs</td>
<td>Krabbe</td>
</tr>
<tr>
<td>13 RUSP FA</td>
<td>Hearing Loss</td>
<td>NICU</td>
<td>Public Health</td>
</tr>
<tr>
<td>1 RUSP Biotinidase</td>
<td></td>
<td>Healthy Cohort</td>
<td></td>
</tr>
<tr>
<td>3 RUSP Galactosemia</td>
<td></td>
<td>2 SCID</td>
<td></td>
</tr>
</tbody>
</table>

**Public Health**
Current Consensus and Grantee CDEs

Total 10,216

- Metabolic 6136
- SMA 1637
- LSD 1201
- PCH 348
- NICU 405 to 836
- NSIGHT 1702

Intake
- Demographics
- Family History
- Newborn Screening
- Initial Testing
- Past Health History

Visit
- Demographics and Family History
- Health History
- Lab Studies
- Findings
- Management and Treatment – Nutrition
- Management and Treatment – Pharmacotherapy
- Other Studies

Other
- Study Status
- Pregnancy
- Dialysis
- Transplant
REDCap™ Case Report Forms

Subject | Longitudinal Care Record

- Intake
- Visit
- Study Status

<table>
<thead>
<tr>
<th>Demographics</th>
<th>Initial Testing</th>
<th>Health History</th>
<th>Treatment</th>
<th>Studies</th>
<th>Study Status</th>
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<tbody>
<tr>
<td>Consent</td>
<td>NBS</td>
<td>Immunizations</td>
<td>Pharmacotherapy</td>
<td>Labs</td>
<td>Pulmonary</td>
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<tr>
<td>Diagnosis</td>
<td>Genotype</td>
<td>Sick Visits</td>
<td>Nutrition</td>
<td>Home Monitoring</td>
<td>PT</td>
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<tr>
<td>Race</td>
<td></td>
<td>Procedures</td>
<td>Therapy</td>
<td>Imaging</td>
<td>Neurology</td>
</tr>
</tbody>
</table>

Family History
- Parents
- Siblings

Health History
- Prenatal
- Neonatal

Exam
- Growth
- Development

Ancillary
- Care Coordination
- Education
- Emergency Management

Pulmonary

PT

Neurology
Secure Informatics Infrastructure

Level 1
- Public Resources – Low Restriction
- VRDBS Search
- LPDR Index
- Data Almanac - CDEs
- Case Report Forms

Level 2
- Highly Restricted
- Grantee Controlled Data
- Grantee Generated Published Data
- Case Level Data
Current Efforts

Joint Committee

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- Informatics Infrastructure
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NCC

- Public Health Focus
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- Pilots
The ideal implementation of LTFU in state NBS programs residing in state health departments requires the adoption of a common set of questions and answers that will be collected across all conditions.

A set of common data elements (CDEs) enables the aggregation, analysis, sharing and reporting of information across conditions and state NBS programs.
Public Health Focus

**Goals**

- Coordinate and accelerate LTFU efforts within public health
- Develop CDEs for public health
- Pilot public health data set
- Identify barriers

**Tool**

- Consensus Questions
- LPDR Overlay
- Overarching Questions

**Pilot**

- LPDR Public Health
- Recruit within RCs
- Identify implementation issues
- Inform future efforts
Consensus Questions

1. Is the disorder on the newborn panel?
2. What percent of children with disorders remain in care between the ages of one and five years old?
3. What percent become lost to follow-up?
4. What percent of parents refuse treatment?
5. What percent died due to problems associated with this disorder?
6. What percent were determined not to need ongoing treatment?
7. What percent of children (combined or by specific type of disease) had age appropriate developmental status with respect to speech, physical development, mental/cognitive development, gross motor and fine motor development?
8. What percent of children were severely delayed with respect to any of the developmental measures and what year of life did the delays become apparent?
9. What percent of patients experienced symptoms associated with their disorder and at what age did the symptoms become apparent?
10. In any given year, what percent of children experienced the loss of skills they had previously acquired?
11. What percent of children had no hospitalizations or emergency room visits in the previous year of life?
12. What disorders are associated with the greatest number of hospitalizations and emergency room visits due to disorder-related complications?
13. What disorders are associated with the highest utilization of metabolic center visits?
14. What percent of children are receiving a multidisciplinary team of services, including nutritional counseling, health education and social services?
LPDR Overlay

~1200 - 6500

~200

30

CDEs
Uniform
Public Health
Source of Desired Information

- Prenatal Education
- Screening
- Diagnosis and Short-Term Follow-Up
- Clinical Care and Long-Term Follow-Up
Presentation Overview

- Background
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- **Case Studies**
- Discussion
Case Studies

- Clinical Heterogeneity
- Diagnoses
- Follow-Up

SCID

Genomics
- NICU
- Health Population
Case Studies

SCID
- Clinical Heterogeneity
- Diagnoses
- Follow-Up

Genomics
- NICU
- Health Population
Severe Combined Immune Deficiency

• SCID and related T-cell lymphocyte deficiencies are a group of disorders
• Characterized by lack of functioning immune system
• Classic SCID is universally fatal in the first two years without immune reconstitution
• Early diagnosis is essential for lifesaving treatment
• Recommended to the RUSP January 2010
• Adopted to the RUSP May 2010
• Currently ~70% of newborns screened
Utilization of NBSTRN Tools

Core
- Coordinate meetings of SCID experts in NBS, diagnosis, and management
- Translate findings to state programs, clinicians and other stakeholders
- Host monthly stakeholder calls and webinars

VRDBS
- Mechanism to make screen positive samples available to researchers
- Samples = 173
- Clinical diagnoses = 6

LPDR
- Clinical case report forms and system to collect information
- Diagnosis categories for screen positive
- Screened = 3,030,083  Cases = 52

R4S
- Analytical and clinical validation of screening technology
- Data elements captured = 28
- Submitters = 83   Cases = 177
Report of 11 Programs

• Objectives
  – To present data from a spectrum of SCID newborn screening programs, establish population-based incidence for SCID and other conditions with T-cell lymphopenia, and document early institution of effective treatments.

• Results
  – Screening detected 52 cases of typical SCID, leaky SCID, and Omenn syndrome, affecting 1 in 58,000 infants.
  – Survival of SCID-affected infants through their diagnosis and immune reconstitution was 87%(45/52), 92%(45/49) for infants who received transplantation, enzyme replacement, and/or gene therapy

• Conclusions
  – Newborn screening in 11 programs in the United States identified SCID in 1 in 58,000 infants, with high survival. The usefulness of detection of non-SCID T-cell lymphopenias by the same screening remains to be determined.
Current Case Studies

- SCID
  - Clinical Heterogeneity
  - Diagnoses
  - Follow-Up

- Genomics
  - NICU
  - Health Population
“Genomic sequencing has potential to diagnose a vast array of disorders and conditions at the very start of life. But the ability to decipher an individual’s genetic code rapidly also brings with it a host of clinical and ethical issues, which is why it is important that this program explores the trio of technical, clinical, and ethical aspects of genomics research in the newborn period.”

Alan Guttmacher, MD, Director of NICHD
Four Pilot Projects

Brigham and Women’s Hospital and Boston Children’s Hospital
- Impact and usefulness of genomic data throughout infancy and childhood

Children’s Mercy Hospital, Kansas City
- Benefits and risks of using genomic information in the NICU

University of California, San Francisco
- Exome sequencing for RUSP and candidate conditions

University of North Carolina at Chapel Hill
- Examine exomes of infants with known genetic conditions and determine best way to return results to doctors and parents
Goals of Collecting CDEs

• Types of research
  – Gene discovery
  – Phenotype spectrum of rare variants
  – Modifying genes for metabolic conditions
  – PGx studies

• Research across NSIGHT
  – Across all groups
  – Between 2 or 3 groups

• Research across NBSTRN

• Contribute to other efforts – ClinGen/ClinVar
4 Different Study Designs

- **BWH/BCH/BCM**
  - NICU population
  - Healthy newborns

- **Children’s Mercy**
  - NICU population

- **UNC**
  - Affected cohort with diagnosed metabolic conditions
  - Healthy newborns

- **USF**
  - De-identified newborn blood spots linked to clinical data
  - Patients suspected of having a primary immunodeficiency not identified by newborn screening
Approach to CDE Sharing

- “Above and below the line” approach to identify CDEs
  - Shared with NBSTRN LPDR
  - Shared among NSIGHT Teams
  - NSIGHT Team only
Case Studies Highlight Keys to LTFU

Assure the best possible outcome for individuals with disorders identified through newborn screening

Key Features
- Quality chronic disease management
- Condition-specific treatment
- Age-appropriate preventive care throughout the lifespan

Central Components
- Care coordination through a medical home
- Evidence-based treatment
- Continuous quality improvement
- New knowledge discovery
Acknowledgements

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