U.S. Newborn Screening System: NewSTEPs Summary

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Colorado School of Public Health

On behalf of the Newborn Screening Community

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**NewSTEPs Vision**
Dynamic newborn screening systems have access to and utilize accurate, relevant information to achieve and maintain excellence through continuous quality improvement.

**NewSTEPs Mission**
To achieve the highest quality for newborn screening systems by providing relevant, accurate tools and resources and to facilitate collaboration between state programs and other newborn screening partners.
NewSTEPs: Data to Support NBS
National Data Repository for NBS

**Purpose:** Provide tools to state newborn screening systems to adequately evaluate, analyze, and benchmark the performance of their tests and the quality of their newborn screening programs
Select a state to view profile information.
Data Collection and Confirmation

• Data Repository
• Interviews with and training of each NBS program
• Data entry from NBS programs
• Confirmation of data via printed summary reports
• Iterative process
Newborn Screening System Partners

- Hospitals
- Clinics
- Insurance
- Specimen Acquisition
- Demographic Entry
- Reporting
- Medicaid Regulations
- Stakeholder Groups
- Private Laboratory
- Advisory Committees
- Laboratory Testing
- Laboratory
- Case Management
- Customer Service
- Parents
- Policy Makers
- Physicians
- Information Technology
- Military
- Medical Consultants
- Nurses
- QA

Slide Courtesy of Susan Tanksley, PhD
Pre-Analytic

- Birth
  - Consent
  - Storage
  - Timing
- DBS Collection
  - Shipping/Couriers
- DBS Shipment
  - Operating hours
  - Staff
- Arrival at Lab
  - LIMS systems
  - Required Data
- Data Entry/Confirmation

NewSTEPs
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Number of Annual Births in the U.S.

States (each bar is one state)

Number of Births/year

Median – 52,200

NewSTEPs
A Program of the Association of Public Health Laboratories™
Number of Annual Births in the U.S.

- Number of Births/year
- States (each bar is one state)

50% of states
21,000 – 87,000
Number of Annual Births in the U.S.
Birth rates vary between states

- The number of live births per 1,000 population varies
- May point to different needs

http://kff.org/other/state-indicator/birth-rate-per-1000/#map
What do we know about our newborn screening systems in the U.S.?

- 52 newborn screening programs
- 36 newborn screening labs
- Geographically diverse states
  - 663,000 Square Miles to 1,212 square miles
Pre-Analytic

Birth

DBS Collection
- Consent
- Storage
- Timing

Shipping/Couriers

Arrival at Lab
- Operating hours
- Staff

LIMS systems
- Required Data

Data Entry/Confirmation

NewSTEPs
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States practices on parental refusal of newborn screening

• Consent is implied in most states; Most states allow parents to opt-out of newborn screening (religious, other)

<table>
<thead>
<tr>
<th>Refusal provision</th>
<th>No State Form</th>
<th>Optional State Form</th>
<th>Required State Form</th>
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<tr>
<td></td>
<td>n</td>
<td>%</td>
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<td>Refuse for any reason</td>
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<td>10%</td>
<td>6</td>
<td>12%</td>
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<tr>
<td>Refuse for religious reasons</td>
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<td>24%</td>
<td>14</td>
<td>27%</td>
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<td>No provision for refusals</td>
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<td>6%</td>
<td>0</td>
<td>0%</td>
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<tr>
<td>Total</td>
<td>20</td>
<td>39%</td>
<td>12</td>
<td>24%</td>
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Report for the Heartland Genetic Services Collaborative, April, 2015
https://drive.google.com/file/d/0BwP8F0nwpufqMFpib0o5VWhIYm8/view
Storing Samples and Storing Data
Data Storage Periods

Normal Specimen Data Storage Period
- 2 years or less
- 3-5 years
- 6-10 years
- 20 years or more
- No data retention policy
- Not Provided

Abnormal Specimen Data Storage Policy
- 2 years or less
- 3-5 years
- 6-10 years
- 20 years or more
- No data retention policy
- Not Provided

Summary Count
- 2 years or less
- 3-5 years
- 6-10 years
- 20 years or more
- No data retention policy
- Not Provided

NewSTEPs
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Informed Consent for NBS Research and Storage of Dried Blood Spots
NBSSLA Research Amendment

- Federally funded research on NBS blood spots is considered research on human subjects, regardless of whether the specimens are identifiable.
- Eliminates the ability of an IRB to approve alterations or waivers of informed consent.
- Applies to samples collected 90 days after enacted date.
- Secretary must promulgate proposed revisions to Federal Policy for the Protection of Human Subjects within six months and final regulations within two years.
Which States Use Dried Blood Spots for Research?

Residual Dried Blood Spot Used for Research:
- Used for Research
- Not Used for Research
- Not Provided

*The state labels on the map indicate whether or not residual dried blood spot specimens are consented for research.

NewSTEPs
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Timeliness
ACHDNC Timeliness Recommendations

In order to achieve the best outcomes for babies:

A. Presumptive positive results for time-critical conditions should be communicated immediately to the child’s healthcare provider but no later than 5 days of life.

B. Presumptive positive results for all other conditions should be communicated to the child’s healthcare provider as soon as possible but no later than 7 days of life.

C. All NBS tests should be completed within 7 days of life.
ACHDNC Timeliness Recommendations

In order to achieve these goals and reduce delays in newborn screening:

D. Initial NBS specimens should be collected in the appropriate time frame for the baby’s condition but no later than 48 hours after birth.

E. NBS specimens should be received at the Laboratory as soon as possible; ideally within 24 hours of collection.
Specimen collection

- NewSTEPs Data
  - Cases with disorders diagnosed by NBS
  - States with signed MOUs
  - Not all disorders
State variation in Specimen Collection
Pre-Analytic

- Birth
- DBS Collection
  - Consent
  - Storage
  - Timing
- DBS Shipment
- Arrival at Lab
  - Operating hours
  - Staff
- Shipping/Couriers
- LIMS systems
- Required Data
- Data Entry/Confirmation

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States are changing policies for delivery of samples

“To get nearer the [recommended] time frame, the state last week deployed a new courier service that will pick up and shuttle hospitals' newborn screening specimens on a quicker, more consistent schedule.”
Weekend Operating Status

State Labs Open/Closed Weekends

Weekend Lab Status
- Open Saturday and Sunday
- Open Saturday
- Closed Weekends

Number of State Labs Open/Closed Weekends

Follow-up Programs Open/Closed Weekends

Weekend Follow-up Status
- Open Saturday and Sunday
- Open Saturday
- Closed Weekends

Number of Follow-up Programs Open/Closed Weekends

NewSTEPs
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“Gillim-Ross [laboratory director at the Colorado Department of Public Health and Environment] says the state is taking other steps to speed test results. It’s made a courier service available to hospitals to deliver blood tests to the lab in Denver. And its working with the Colorado Hospital Association to educate medical professionals on taking the blood samples promptly and correctly.”
Pre-Analytic

Birth

DBS Collection
- Consent
- Storage
- Timing

DBS Shipment

Shipping/Couriers

Arrival at Lab
- Operating hours
- Staff

Data Entry/Confirmation
- LIMS
- Systems
- Required
- Data

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Maps and Reports

- **Screened Conditions Report** - Report of screened condition counts
- **Conditions By Query Report** - Query for screened condition details
- **NBS Fees Report** - Provides information on the NBS fees each state NBS program is charging
- **DBS Retention Report** - Provides information on the dried blood spot specimen storage/retrieval times and storage conditions for each state NBS program
- **Courier System Report** - Provides information on the Courier system each state NBS program is using
- **LIMS System Report** - Provides information on the LIMS system each state NBS program is using
- **Data Retention Report** - Provides information on NBS data retention periods for each state NBS program
### LIMS System Summary

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<th>LIMS System</th>
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<tr>
<td>Internally Developed</td>
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<tr>
<td>Neometrics/ Natus</td>
<td>14</td>
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<tr>
<td>Other</td>
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<tr>
<td>PerkinElmer</td>
<td>15</td>
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<td>StarLims</td>
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<td>Unanswered</td>
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### LIMS System by State

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<tr>
<th>State NBS Program</th>
<th>LIMS System</th>
<th>Other LIMS Specified</th>
<th>Follow-up System</th>
<th>Other Follow-up System Specified</th>
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<td>Neometrics/ Natus</td>
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<td>Arizona</td>
<td>PerkinElmer</td>
<td>Neometrics/ Natus</td>
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<td>Arkansas</td>
<td>Unanswered</td>
<td>Unanswered</td>
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<tr>
<td>California</td>
<td>PerkinElmer</td>
<td>Internally Developed</td>
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<tr>
<td>Colorado</td>
<td>PerkinElmer</td>
<td>Internally Developed</td>
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<tr>
<td>Connecticut</td>
<td>StarLims</td>
<td>StarLims</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Delaware</td>
<td>Neometrics/ Natus</td>
<td>Neometrics/ Natus</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Screening Practices in States
NBS Process Model

Pre-analytic NBS
- Birth
  - DBS Collection
    - Consent
    - Storage
    - Timing
  - Shipping/Couriers
  - DBS Shipment
  - Arrival at Lab
    - Operating hours
    - Staff
  - Data Entry/Confirmation

Analytic -> Post-analytic NBS
- Lab Processing/Testing
  - QA/QC
  - Algorithms
  - Assays
  - Confirmation
- Critical Results
  - Communicate results
- Non-Critical Results
  - Communicate results
- All Results
  - Communicate results
- Intervention Initiated
  - Evaluate newborn
- Diagnosis Confirmed

NewSTEPs
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Number of screens (1 vs. 2 Screen States)
Single newborn screen or routine second screening for primary congenital hypothyroidism

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b Wisconsin State Laboratory of Hygiene, University of Wisconsin, Madison, WI, USA
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Race and ethnicity
Routine second screen

ABSTRACT
Routine second screening of most newborns at 8–14 days of life for a panel of newborn conditions occurs in 12 U.S. states, while newborns in the other states typically undergo only a single routine newborn screen. The study objective was to evaluate screening consequences for primary congenital hypothyroidism (CH) in one- and two-screen states according to laboratory practices and medical or biochemical characteristics of screen-positive cases. Individual-level medical and biochemical data were retrospectively collected and analyzed for 2251 primary CH cases in one-screen (CA, WI) and two-screen (AL, DE, MD, OR, TX) states. Aggregate data were collected and analyzed for medical and biochemical characteristics of all screened newborns in the states. Among the states evaluated in this study, the detection rate of primary CH was higher in the one-screen states. In the two-screen states, 11.5% of cases were detected on the second screen. In multivariate analyses, only race/ethnicity was a significant predictor of cases identified on the first versus second screen, which likely reflects a physiologic difference in primary CH presentation. Newborn screening programs must heed the potential for newborns with CH not being detected by a single screen, particularly newborns of certain races/ethnicities. If the two-screen states converted to a single screen using their current algorithms, newborns currently identified on the routine second screen would presumably not be detected, resulting in probable delayed diagnosis and treatment. However, based on the one-screen state experiences, with appropriate modifications in screening method and algorithm, the two-screen states might convert to single screen operation for CH without loss in performance.

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Newborn Screening Fees

Initial Newborn Screening Fee

$0.00 - $157.54

Map showing the initial newborn screening fees across the United States. States are color-coded to indicate the fee range.
What is covered by the newborn screening fees?

- Program administration
- Laboratory tests (includes salaries of laboratory personnel, supplies, instruments and equipment maintenance)
- Information technology support (lab and general)
- Short-term follow-up services (includes salaries and educational materials)
- Courier services
- Long-term follow-up services
- Bio-bank program
- Metabolic foods and formula
State Practices: Screening for Disorders

• Recommended Uniform Screening Panel
• Counting the Disorders
  – Core
  – Secondary
  – Other
• Screening for disorders on the Recommended Uniform Screening Panel
<table>
<thead>
<tr>
<th>ACMG Code</th>
<th>Core Condition</th>
<th>Metabolic Disorder</th>
<th>Endocrine Disorder</th>
<th>Hemoglobin Disorder</th>
<th>Other Disorder</th>
</tr>
</thead>
<tbody>
<tr>
<td>PROP</td>
<td>Propionic Acidemia</td>
<td>Organic acid condition</td>
<td>Fatty acid oxidation disorder</td>
<td>Amino acid disorder</td>
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<tr>
<td>MUT</td>
<td>Methylmalonic Acidemia (methylmalonyl-CoA mutase)</td>
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<td>X</td>
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<tr>
<td>Cbl A,B</td>
<td>Methylmalonic Acidemia (Cobalamin disorders)</td>
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<tr>
<td>IVA</td>
<td>Isovaleric Acidemia</td>
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<td>3-MCC</td>
<td>3-Methylcrotonyl-CoA Carboxylase Deficiency</td>
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<td>HMG</td>
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<tr>
<td>MCD</td>
<td>Holocarboxylase Synthase Deficiency</td>
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<td>βKT</td>
<td>β-Ketothiolase Deficiency</td>
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<tr>
<td>GA1</td>
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<tr>
<td>CUD</td>
<td>Carnitine Uptake Defect/Carnitine Transport Defect</td>
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<td>MCAD</td>
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<td>CH</td>
<td>Primary Congenital Hypothyroidism</td>
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<td>S,S Disease (Sickle Cell Anemia)</td>
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<td>Organic acid condition</td>
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<td>MISCHAD</td>
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<td>GA2</td>
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<td>Medium-chain ketoacyl-CoA thiolase deficiency</td>
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<td>2,4 Dienoyl-CoA reductase deficiency</td>
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<td>Citrullinemia, type II</td>
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<td>MET</td>
<td>Hypermethioninemia</td>
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<td>Benign hyperphenylalaninemia</td>
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<td>BIOPT (BS)</td>
<td>Biopoterin defect in cofactor biosynthesis</td>
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<td>BIOPT (REG)</td>
<td>Biopoterin defect in cofactor regeneration</td>
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<tr>
<td>TYR II</td>
<td>Tyrosinemia, type II</td>
<td></td>
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</tr>
<tr>
<td>TYR III</td>
<td>Tyrosinemia, type III</td>
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<tr>
<td>Var Hb</td>
<td>Various other hemoglobinopathies</td>
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<tr>
<td>GALE</td>
<td>Galactoepimerase deficiency</td>
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<tr>
<td>GALK</td>
<td>Galactokinase deficiency</td>
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<tr>
<td></td>
<td>T-cell related lymphocyte deficiencies</td>
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</table>

1. Selection of conditions based upon "Newborn Screening: Towards a Uniform Screening Panel and System." Genetic Med. 2006; 8(5) Suppl: S12-S252 as authored by the American College of Medical Genetics (ACMG) and commissioned by the Health Resources and Services Administration (HRSA).
2. Disorders that can be detected in the differential diagnosis of a core disorder.
Secondary Disorders

“Disorders that can be detected in the differential diagnosis of a core disorder.”
Screening of the 32 Core Disorders

* Screening is on the state panel and fully implemented in the state

NewSTEPs
A Program of the Association of Public Health Laboratories™
Other disorders screened in the U.S.

Universally Screened:
- Ethylmalonic encephalopathy – EME (4)
- Hyperornithinemia with Gyrate Deficiency - Hyper ORN (5)
- Ornithine transcarbamylase deficiency – OTC (5)
- Prolinemia Type I/ Type II – PRO (1)
- Nonketotic Hyperglycinemia – NKH (5)
- Carbamoyl phosphate synthetase I deficiency – CPS (8)
- Krabbe (1)
- Fabry (2)
- Gaucher (2)
- Niemann Pick (1)
- Mucopolysaccharidosis I - MPS I (2)
- Glucose-6-phosphate dehydrogenase deficiency - G6PDD/G6PD (2)
- Hyperornithinemia-hyperammonemia-homocitrullinemia syndrome – HHH (10)
- Pyroglutamic acidemia - 5-OXO (3)
- Congenital Toxoplasmosis – TOXO (5)
- Human Immunodeficiency Virus - HIV Exposure (1)
- X-linked Adrenoleukodystrophy (1)
## Screened Conditions Report

### Organic Acid Disorders
- **Ethylmalonic encephalopathy - EME**
  - Universally Offered: 4
  - Likely Detected: 1

### Amino Acid Disorders
- **Hyperornithinemia with Gyrate Deficiency - Hyper ORN**
  - Universally Offered: 5
- **Ornithine transcarbamylase deficiency - OTC**
  - Universally Offered: 5
  - Likely Detected: 1
- **Prolinemia Type I / Type II - PRO**
  - Universally Offered: 1
- **Nonketotic Hyperglycinemia - NKH**
  - Universally Offered: 5
  - Likely Detected: 1
- **Carbamoyl phosphate synthetase I deficiency - CPS**
  - Universally Offered: 8
  - Likely Detected: 1

### Lysosomal Storage Disorders
- **Krabbe Disease**
  - Universally Offered: 1
  - Likely Detected: 4
  - Pilot Tested: 1
- **Pompe**
  - Universally Offered: 1
  - Likely Detected: 1
- **Fabry**
  - Universally Offered: 2
  - Likely Detected: 1
- **Gaucher**
  - Universally Offered: 2
  - Likely Detected: 1
- **Niemann Pick**
  - Universally Offered: 1
  - Likely Detected: 1
- **Mucopolysaccharidosis I - MPS I**
  - Universally Offered: 2
  - Likely Detected: 2
### Screened Condition Details

**Condition:**
- Mucopolysaccharidosis I - MPS I

**Screening Status:**
Universally required by Law or Rule and fully implemented

**States:**
- Illinois
- Missouri

<table>
<thead>
<tr>
<th>Condition</th>
<th>Req Not Implemented</th>
<th>Likely Detected</th>
<th>Pilot Tested</th>
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<td>Organic Acid Disorders</td>
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<tr>
<td>Ethylmalonic encephalopathy - EME</td>
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<td>Amino Acid Disorders</td>
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<td>Hyperornithinemia with Gyrat Deficiency - Hyperornithinemia</td>
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<tr>
<td>Ornithine transcarbamylase deficiency - OTC</td>
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<td>Prolinemia Type I / Type II - PRO</td>
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</tr>
<tr>
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<td>1</td>
<td>4</td>
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<tr>
<td>Pompe</td>
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<td>1</td>
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<tr>
<td>Niemann Pick</td>
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<td>1</td>
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</tr>
<tr>
<td>Mucopolysaccharidosis I</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Decision making, policies

- Advisory committees, board of health, commissioner of health
- Legislators
Advisory committees across the U.S.
Composition of advisory committees

- Consumers or parents of patients affected by screened conditions
- Laboratory representatives of pathology and chemistry
- Pediatric, neonatology, and family practitioners
- Pediatric subspecialists (e.g., Endocrine, Hematology, Metabolic etc.)
- Metabolic nutritionists
- Hospital association representative
- March of Dimes representative
- Medical ethicist
- NBS program (management, follow-up and lab) representatives
Timeliness outcomes in infants diagnosed with disorders

- Birth to Receipt by lab
- Birth to Report of Results
- Birth to Intervention
- Birth to Diagnosis
Time to Release of Out of Range Results
Time to Confirmed Diagnosis

Days

NewSTEPs
A Program of the Association of Public Health Laboratories™
Time to Receipt by Lab by Disorder
Time to Release of Out of Range Results by Disorder
Time to Intervention by Disorder
Time to Confirmed Diagnosis by Disorder
Cystic Fibrosis
Cystic Fibrosis
Time to Release of Out of Range Results

Days

State 1
State 2
State 3
State 4
State 5

NewSTEPs
A Program of the Association of Public Health Laboratories™
Cystic Fibrosis

Time to Intervention by State

NewSTEPs
A Program of the Association of Public Health Laboratories®
Cystic Fibrosis

Time to Confirmed Diagnosis by State
Congenital Hypothyroidism
Congenital Hypothyroidism
Time to Release of Out of Range Results

Days

State 1  State 2  State 3  State 4  State 5  State 6  State 7  State 8

NewSTEPs
A Program of the Association of Public Health Laboratories®
Congenital Hypothyroidism
Time to Intervention by State
Congenital Hypothyroidism
Time to Confirmed Diagnosis by State

NewSTEPs
A Program of the Association of Public Health Laboratories®
Quality Indicators
Quality Indicator Data

• Overview of indicators
• Challenges in data collection. States pull data from different sources.
• Partnering with LIMS vendors
  – Efforts to ensure data are consistent
  – Differences in local collection
• Data collection is deliberate – and will result in high quality data
Conversations with Vendors

- Partnering with PerkinElmer and Natus to develop queries that will collect data in a systematic way from all states
- Will expand to other vendors and states with locally-developed systems
Challenges Uncovered in Data Collection

– Example: QI 1a: **Percent of invalid dried blood spot specimens/cards due to improper collection**: Number of dried blood spot specimens/cards on which labs cannot report a complete newborn screening panel due to improper collection errors [occurring pre-analytic] divided by number of specimens submitted, multiplied by 100.
Colorado’s adaptation of the LIMS system

– Potential reasons for unsatisfactory due to collection
  • No blood applied
  • No blotter with slip
  • Incorrect form
  • Clots or uneven
  • Serum separation
  • Contaminated
  • Multiple application
  • Incomplete submission
  • Quantity not sufficient
Next steps

• Timelines
• Where do we go from here with the data
  – Natus
  – PerkinElmer
  – Others...not all states are covered by these LIMS vendors. How do we extend the lessons learned?
Analytic -> Post-analytic NBS

Lab Processing/Testing

- QA/QC
- Algorithms
- Assays
- Confirmation

Critical Results
- Communicate results

Non-Critical Results
- Communicate results

All Results
- Communicate results

Intervention Initiated
- Evaluate newborn
- Diagnosis Confirmed
Newborn level data collected within NewSTEPs

Purpose

“To provide an accurate characterization of the frequency of newborn screening disorders in the U.S., along with timing of screening and diagnostic activities”

Systematic definitions helpful at local AND national levels
Cystic Fibrosis Example

- Newborn with abnormal newborn screen:
  - IRT 105 ng/ml (normal range < 60 ng/ml)
  - NBS DNA analysis revealed F508/R117H; 7T/9T
  - Referred to CF Center for Sweat Test
  - Sweat test results: 25 mmol/L (diagnostic > 60mmol/L)
CF Diagnosis can vary by clinician

• Dr. Smith: Baby likely has CF. Follow monthly and repeat sweat test; tell family baby has CF.

• Dr. Jones: Baby has CRMS (Cystic Fibrosis Related Metabolic Syndrome). Not CF, we should follow this baby every 6 months to see if baby develops CF symptoms.

• Dr. Garcia: Baby is fine, no CF, no CRMS. No diagnosis, baby does not need to be seen.
Surveillance case definitions

• This newborn would be classified as CRMS using the case definitions

• The burden of CRMS in the U.S. is not well understood
Two Cases from the Repository

• Case 1
  – Elevated IRT
  – 2 mutations known to be disease causing on NBS
  – Sweat test >60mmol/L
  – Repeat sweat test 30-59mmol/L
  – No repeat DNA test

• Diagnosed as CRMS

• Case 2
  – Elevated IRT
  – 2 mutations known to be disease causing on NBS
  – Sweat test 30-59mmol/L
  – Repeat sweat test quantity not sufficient
  – No repeat DNA test

• Diagnosed as CF
Challenges and Solutions

• Culture change
  – Time commitment
  – Developing communication avenues

• Case Definition Implementation Workgroup
  – Marketing
  – Communication

• New Disorders on RUSP
  – CCHD
  – SCID
  – Pompe
  – MPSI

• Manuscript in preparation
Efforts to Support NBS Programs and Timeliness
Collaborative Improvement and Innovation Network: CoIIIN

• Eight states participating in continuous quality improvement activities to address challenges in timeliness:
  – Arizona, California, Colorado, Iowa, New Hampshire, Tennessee, Texas, Wyoming

• Fifteen-month project, teams of 5 individuals from states, comprised of laboratory, follow-up, hospital staff

• Sharing ideas and collaborating to find solutions
• Funding starting September 1
• Will support at least 20 state newborn screening programs to improve timeliness over three years
• Build on success of CoILN
• Competitive funding opportunity
Project Instant Gratification (PIGs)

• Giving tools back to states that help them to do their jobs
  – Did You Know E-mails
  – Run Charts
  – Personalized QI Reports
Did you know...

That the following real-time queries are now available on the NewSTEPs website to answer your questions about newborn screening programs?

- **Screened Conditions Report** - the status of NBS conditions that are screened in each state.
- **Conditions By Query Report** - details (e.g., equipment used) on the screened NBS conditions.
- **NBS Fees Report** - the NBS fees charged by each state.
- **DBS Retention Report** - the dried blood spot (DBS) specimen storage/retention times and storage conditions for each state NBS program.
- **Courier System Report** - the courier system used by each state NBS program.
Tennessee: Tracking improvement in timeliness

Receipt by Lab: Displayed by Time Frames

Percent of Specimens

Baseline (Jan-Jul 14)

GOAL

Sept, 15

Aug, 15

Jul, 15

Jun, 15

May, 15

Apr, 15

Mar, 15

Feb, 15

Jan, 15

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Same Day 1 Day 2 Days 3 Days 4 Days 5 Days 6 Days >= 7 Days
Partnerships and Collaborations

• Steering Committee and Workgroups
• Newborn Screening Programs
• Regional Collaboratives
• Federal Partners
• Private Partners
• Vendors
What have we learned? Where do we go from here?

• NewSTEPs is partnering with state newborn screening programs to develop solutions for strengthening the NBS System
  – Quality data
  – Technical assistance
  – Bringing people together to share ideas and expertise
NewSTEPs Team

- Jelili Ojodu, MPH
- Sikha Singh, MHS, PMP
- Careema Yusuf, MPH
- Thalia Wood, MPH
- Ruthanne Salsbury
- Guisou Pineyro, MPH

Colorado School of Public Health

- Marci Sontag, PhD
- Yvonne Kellar-Guenther, PhD
- Joshua Miller, MPH
MPS-I Screening Status