Infographics and Outreach Used to Improve Newborn Screening Timeliness

Ashley Comer
Newborn Screening Quality Improvement Coordinator
State Hygienic Laboratory at The University of Iowa
Disclosure

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NewSTEPs
A Partnership between The Colorado School of Public Health and The Association of Public Health Laboratories™
Goal of newborn screening is to identify at-risk babies before the onset of symptoms to reduce the chance of disability, morbidity and mortality.

- Iowa NBS program must have structures in place to adequately address the time critical conditions on NBS panel.

- Everyone involved in the process (birth facilities, midwives, PCPs and office staff, parents, etc.) need to be aware of their roles(s) and how the newborn screening process works in Iowa.
Reality then and now

Babies born with time critical conditions detected by newborn screening can be born on any day of the week in any part of the state.

Do our current structures (receiving samples by mail and testing 6 days a week) allow us to reach our goal?

What changes could align our efforts with our goal?
Iowa NBS program must have structures in place to adequately address the time critical conditions on NBS panel

- Dedicated same day courier service picks up samples and delivers to NBS lab SAME DAY 365 days/year
- NBS lab staff receive samples
- Begin testing and data entry when samples arrive at night
- Dayshift finishes testing and report abnormals.
- Notify STFU of critical results via web portal and phone call 365 days/year.
- Communicate results with provider and/or specialist 365 days/year
- Make recommendations for intervention to PCP

So that: Every baby has the same opportunity for a healthy life regardless of which day or where they are born in Iowa.
Challenge

• Making sure everyone in the newborn screening system understands the importance of his/her role.

• Utilize the available infrastructures as effectively as possible to maximize the benefits of “Timeliness” for all newborns in Iowa.
Then there was CoNN

Plan of attack

- Infographic
- Facility Education
- Technical assistance

Goal: Receive 95% of initial samples at newborn screening lab within 60–65 hours or less from birth.
Timeliness in Newborn Screening Report
2015-01-01 to 2015-03-31  Count: 919
A project of the Iowa Collaborative Improvement & Innovation Network (CoIIN) to improve timeliness in newborn screening

GOAL: By January 2017, 95 percent of specimens will be received by SHL within 65 hours of birth.

Time between birth and receipt of specimen by the NBS laboratory

<table>
<thead>
<tr>
<th></th>
<th></th>
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<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;= 65 hrs</td>
<td>45%</td>
<td>77%</td>
<td>79%</td>
</tr>
<tr>
<td>65.1 to 80 hrs</td>
<td>21%</td>
<td>11%</td>
<td>10%</td>
</tr>
<tr>
<td>&gt;80 hrs</td>
<td>34%</td>
<td>10%</td>
<td>10%</td>
</tr>
</tbody>
</table>

Overall Hospital Outcomes

- 95%
65 hours or less from birth???

- SMART goal? Are you sure that’s an attainable goal?
65 hours or less from birth???

- **SMART goal?**
  Are you sure that’s a attainable goal?

**Case Study:**
Baby was born about 2.5 hours from newborn screening lab

<table>
<thead>
<tr>
<th>Day of the week</th>
<th>Date</th>
<th>Time</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>Thursday</td>
<td>6/11/2015</td>
<td>1653</td>
<td>Baby born</td>
</tr>
<tr>
<td>Friday</td>
<td>6/12/2015</td>
<td>1733</td>
<td>NBS collected (24.5hrs after birth)</td>
</tr>
<tr>
<td>Saturday</td>
<td>6/13/2015</td>
<td>2200</td>
<td>NBS received at newborn screening lab (54.5 hrs from birth)</td>
</tr>
<tr>
<td>Sunday</td>
<td>6/14/2015</td>
<td>0850</td>
<td>Abnormal TMS result communicated to Follow-up (65 hrs from birth)</td>
</tr>
<tr>
<td>Tuesday</td>
<td>6/14/2015</td>
<td>0945</td>
<td>PCP contact made with recommendations (<strong>66 hrs from birth</strong>). Baby already symptomatic (low blood sugars-PCP was not sure why yet)</td>
</tr>
<tr>
<td>Wednesday</td>
<td>6/17/2015</td>
<td>1040</td>
<td>Confirmation testing came BACK confirming LCHAD (baby is on day 6 of life-not quite 6 whole days old)</td>
</tr>
</tbody>
</table>
Facility Education

Webinar to kick off timeliness project statewide

- Goal of newborn screening and WHY timeliness matters
- Overview of Iowa’s infrastructure and their role in the process
- Tools and reports available to use to monitor performance
Facility Education cont.

- Partnerships

![Iowa’s Statewide Perinatal Care Program](image)

- Visited >20 facilities with representation from different departments (lab, M/B, NICU, etc.) in person or via Zoom.

- Monthly/quarterly emails with CoiIN infographic and feedback
Houston, we have a problem!

• “We see we have 20% outside of the goal. Can you tell us what patients fell out?”

• “I have all these hospitals calling requesting courier pick up time changes”
Web portal resources

Facilities are able to log into the State Hygienic Web portal and view their turnaround time metrics.
Percent of samples received by newborn screening lab in 65 hours or less from birth

<table>
<thead>
<tr>
<th>Date</th>
<th>Count</th>
<th>≤65 hours</th>
</tr>
</thead>
<tbody>
<tr>
<td>Oct-Dec 2014</td>
<td>9586</td>
<td>79%</td>
</tr>
<tr>
<td>May-Aug 2017</td>
<td>10190</td>
<td>96%</td>
</tr>
</tbody>
</table>

Show me the data
Then and Now

1st monthly report sent to facilities: January 2015

Monthly report sent to facilities: July 2017
Then and Now

1st Quarterly report sent to facilities: Jan-March 2015

Quarterly report: May 22nd-August 22nd, 2015

Overall Hospital Outcomes

Percent of NBS specimens received by laboratory in <65 hours after birth.
Eyes on the Prize

ACHDNC recommendation: newborn screen results for time critical conditions should be available within 5 days of life
Eyes on the Prize

Q15d.i: Percent of first dried blood spot specimens with out-of-range results for time critical disorders requiring clinical diagnostic workup by an appropriate medical professional reported out in the specified time categories from birth.

<table>
<thead>
<tr>
<th>Month</th>
<th>&lt;= Day 2</th>
<th>Day 3</th>
<th>Day 4</th>
<th>Day 5</th>
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<tbody>
<tr>
<td>1</td>
<td>68.8%</td>
<td>96.9%</td>
<td>100.0%</td>
<td>100.0%</td>
</tr>
<tr>
<td>2</td>
<td>47.2%</td>
<td>94.4%</td>
<td>97.2%</td>
<td>100.0%</td>
</tr>
<tr>
<td>3</td>
<td>50.0%</td>
<td>86.4%</td>
<td>95.5%</td>
<td>100.0%</td>
</tr>
<tr>
<td>4</td>
<td>60.0%</td>
<td>96.7%</td>
<td>100.0%</td>
<td>100.0%</td>
</tr>
<tr>
<td>5</td>
<td>50.0%</td>
<td>90.0%</td>
<td>96.7%</td>
<td>100.0%</td>
</tr>
<tr>
<td>6</td>
<td>67.9%</td>
<td>92.9%</td>
<td>92.9%</td>
<td>100.0%</td>
</tr>
<tr>
<td>7</td>
<td>61.8%</td>
<td>94.1%</td>
<td>100.0%</td>
<td>100.0%</td>
</tr>
<tr>
<td>Grand Total</td>
<td>55.3%</td>
<td>93.3%</td>
<td>98.0%</td>
<td>100.0%</td>
</tr>
</tbody>
</table>
What Makes a Good Infographic?

DATA
- underachieving
- invisible
- potential

DESIGN
- boring
- amateur
- damaging
- embarrassing
- popular
- message solutions

SHAREABILITY
- visibility
- SEO
- location
- social

STORY
- reliably
- timely
- content

The diagram illustrates the key elements that contribute to creating a good infographic.
Team Effort

NBS CoiIN Team

NBS Program staff
Kim Piper, RN, BS, CPH, CPHG - Iowa Department of Public Health
Carol Johnson - University of Iowa Stead Family Children’s Hospital
Stan Berberich, PhD - State Hygienic Laboratory at the University of Iowa

Hospital Partners
Kristen Ernsperger, MSN - Mercy Medical Center - DSM
Kim Vonahsen, MHA, MLS, SLS - Unity Point Iowa Methodist Medical Center

SHL IT
Matt Bielicke
Dari Shirazi (now with APHL)

NewSteps360
Ruthanne Sheller, MPH - QI Coach