

# Arizona Newborn Screening Timeliness: A 5 Year Summary

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Presented To

*Advisory Committee on Heritable Disorders  
in Newborns and Children*

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*“The entire NBS system process, from sample collection through **transit**, testing and reporting, needs to be time-effective to meet the recommendations. NBS systems can use these goals for timeliness to achieve the best outcomes for affected newborns.”* ACHDNC



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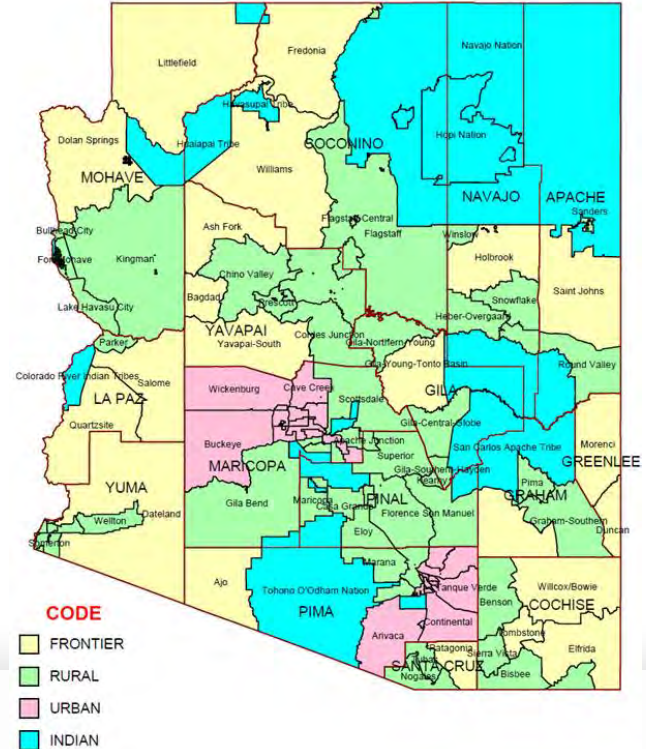
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[www.aznewborn.com](http://www.aznewborn.com)

# A Bit About Our State:

## Our Population is Widely Dispersed

- 6th largest land/water
- 6.5 million population
- 15 counties
- 47 birth hospitals
  - 43 send samples to lab
- ~85,000 births
- One state laboratory



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# We Didn't Realize The Magnitude of the Problem

A JOURNAL SENTINEL WATCHDOG REPORT

## Deadly Delays

The nation's newborn screening programs depend on speed and science to save babies from rare diseases. But thousands of hospitals fall short, deadly delays are ignored and failures are hidden from public view — while babies and their families suffer.

Published Nov. 16, 2013

**“Arizona has one of the worst track records in the country, with 17% of all newborn screening samples arriving at the state lab five or more days after collection in 2012.”**



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# A Plan was Established

## WHO



- ✓ Director set as agency priority
- ✓ Collaborated with Licensing Division; sent letters
- ✓ Announced a statewide goal
- ✓ Developed an intra-agency Transit Time taskforce
- ✓ Assigned executive sponsorship

## WHY

*“NBS specimens should be received at the laboratory as soon as possible; **ideally within 24 hours of collection.**”*

ACHDNC



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# Started with Hospitals; Identified Problems

1. Hospitals *batched* samples
2. Lack of *awareness* of urgency
3. *Courier limitations*—only ran Mon-Fri, some didn't realize it was free
4. *Restricted lab operating hours* (Mon-Fri), no holidays
5. *Lack of knowledge* about legal requirements
6. *High turnover*; inconsistent/deficient training at sites
7. Hospital *QA/QI* systems were often inadequate
8. *Performance reports* were not routinely provided



# Arizona Aimed High

*“Within six months (by July 1, 2014), 95% of newborn screening bloodspots (initial screens) will be received at the Arizona Public Health Laboratory within three days of collection.”* Director, Will Humble

## Applied the Methods

- Identified a need or issue
- Defined the current situation
- Analyzed the problem
- Developed action plan
- Made predictions

## and Reached that Goal

March Of Dimes Honors Arizona With First-Ever Newborn Screening Award

Arizona Health Director Honored for Reforms to Avoid Deadly Delays

CHANDLER, ARIZONA— Thursday, September 18, 2014



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# Maintained the Original Goal and Set a NEW one: 98% of Samples will be Received within 3 Days

## The Science of Improvement: Spread Change

- ❖ Lab Matters article
- ❖ APHL poster and presentation
- ❖ Regional collaborative webinars
- ❖ ASTHO article
- ❖ Participated in CoIIN Training
- ❖ Applied for and received **NewSTEPS 360** grant

*“All NBS tests should be completed within **seven days of life** with results reported to the healthcare provider as soon as possible.” ACHDNC*



# NewSTEPS 360 Partnership



## Year 3 Statement of Work

Based on quality indicator (QI) data reported to the NewSTEPS repository for March, 2017 on QI5c, *Time from specimen receipt to reporting out results, 60% of normal and out-of-range results took  $\geq 7$  days to be reported out in AZ.* Data entry and verification delays are the greatest contributing factor to this deficit and therefore directly impact timeliness. By reducing these delays our goal is to improve indicators QI5c & d—*Time from birth to reporting*—of the most significant delays (>7 days) for first, subsequent and second screens by August, 2018 by 50%.

“Presumptive positive results for all other conditions should be communicated to the newborn’s healthcare provider as soon as possible *but no later than seven days of life.*” ACHDNC





# Timeliness in AZ: Moving the Needle through a Series of Short and Intermediate Projects While Planning for Optical Character Recognition (OCR)

Authors: Sondi Aponte, Davina Benally, Okate Bilante, Sonal Bhakta—Office of Newborn Screening  
Sekhar Konanki, Rupal Mehta—Technology Services



### Challenges

- #1 • Too many samples arrive late
- #2 • The NBS program is chronically short-staffed
- #3 • Hemoglobin testing takes too much time (2-3 days)
- #4 • Manual demographic entry results in delays
- #5 • NBS Lab tests samples 5 days per week

### Measures of Success

- ✓ More midwives and high volume peds practices use **free** FedEx to ship samples
  - ✓ Staff is cross-trained for efficiency
  - ✓ More Lab Staff are hired
- ✓ Hemoglobin testing method is optimized to decrease sample wait times
- ✓ Manual card verification process is modified to reduce delays
- ✓ Contract is signed and planning OCR

### Lessons Learned

- ❑ Each division within NBS has an important role in improving timeliness
- ❑ Including IT in project planning ensures smoother implementation
- ❑ Look at internal opportunities to improve timeliness
- ❑ Find *Quick Wins* to stay motivated
- ❑ Discover ways to stay engaged through **BIG** projects

Learn more about *Optical Character Recognition* by attending the roundtable



### Methods



Observe Processes  
**GEMBA WALK**



Ask Questions  
**5 WHYS**



Develop Standards

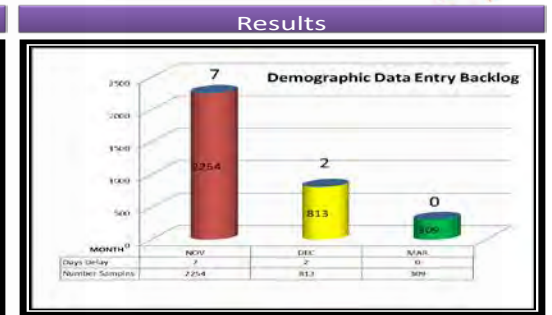
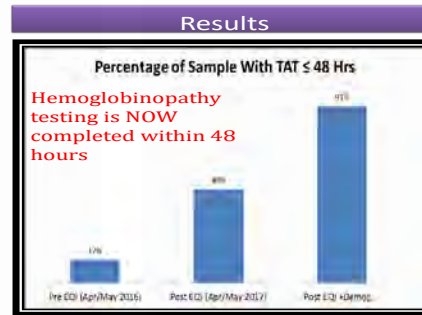


Conduct Training



Monitor Outcomes

← Continuous Quality Improvement →



This resource was developed by funding from the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number U22MC24078.

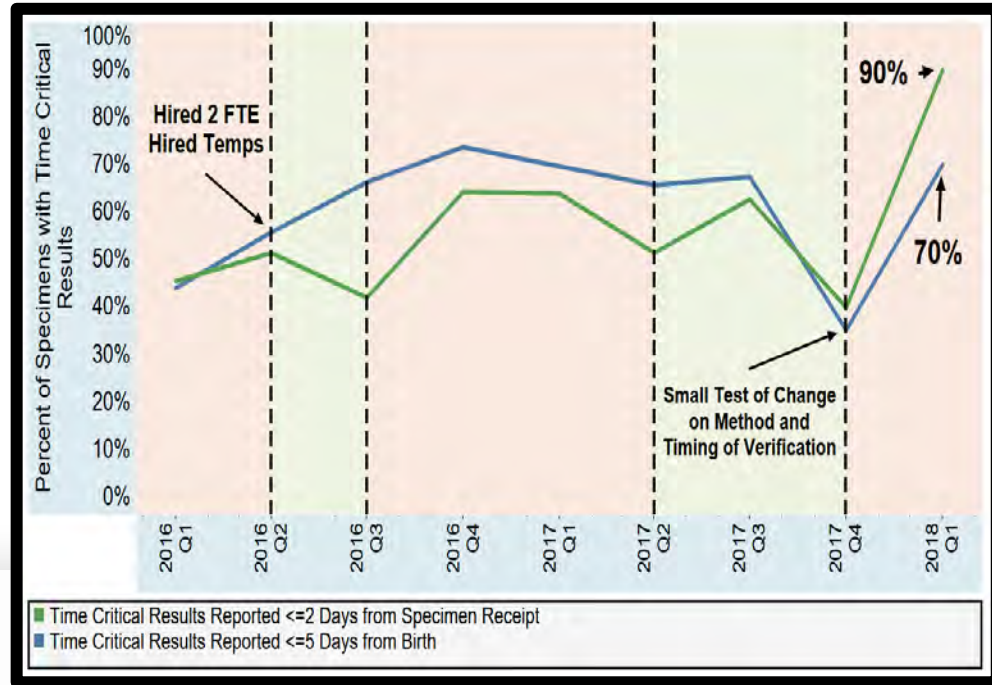
[AzNewborn.com](http://AzNewborn.com)

# Reporting out Time Critical Results

**Arizona:** Variance in the time to report time critical results depend heavily on lab processes. Change of methodology in the timing of data verification resulted in a significant increase to 70% of time critical results reported within 5 days of birth and 90% within 2 days of specimen receipt.

## Lesson #1

Achieving  
timeliness goals  
is directly tied to  
resource  
limitations and  
therefore  
requires  
innovation



# Overall *Lessons Learned*

- **Keep babies at the forefront**—talk to families and share their stories
- **Involve SME from each division of NBS in process improvement**  
Lab, Follow-up, QI, Education, & Demographics teams each contribute to success
- **Look for internal opportunities to improve timeliness**—  
Hemoglobinopathy testing and Demographic sight verification made a **BIG** difference
- **Find *Quick Wins* to stay motivated and *Move the Needle***
- **Utilize partner resources** and learn from other states
  - NewSTEPS 360 (APHL)
  - Baby's First Test
  - CO School of Public Health



# You get what you inspect, not what you expect.

American Management Association

“The entire NBS system process, from sample collection through transit, testing and reporting, needs to be *time-effective* to meet the recommendations. NBS systems can use these goals for timeliness to achieve the best outcomes for affected newborns.”

ACHDNC





# Questions?

## THANK YOU

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