

# Collaborating Across States to Improve Timeliness in NBS: An Overview of the CoIN Project

Yvonne Kellar-Guenther, PhD  
Colorado School of Public Health

*Funded through cooperative agreements from Genetic Services Branch of the Health Resources and Services Administration (HRSA)*

*NewSTEPS: APHL (#U22MC24078 - Ojodu)*

*NewSTEPS360: ColoradoSPH (#UC8MC28554 - Sontag)*



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# What is a CoIIN?

- CoIIN stands for Collaborative Improvement and Innovation Network
- Focus is on Quality Improvement vs Quality Assurance
- Learning collaborative
  - Shared lessons learned, ideas, and resources
  - Used technology to enable collaboration
  - Held monthly group webinars and meetings



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# What was the NBS Timeliness CoIN?

- 15 month Continuous Quality Improvement (CQI) project for 7 participating state NBS programs
- Teams were interdisciplinary including lab, follow-up, and hospital representative



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# Goal

Improve timeliness from **time of birth to reporting out** NBS results following the ACHDNC Recommendations:

1. Presumptive positive results for time-critical conditions should immediately be reported to the child's healthcare provider and no later than 5 days of life.
2. All presumptive positive results for time sensitive conditions should be reported to the healthcare provider as soon as possible but no later than 7 days of life.
3. All NBS results should be reported within 7 days of life (the "normal" screening results).



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# In order to achieve these goals:

- 1) Initial NBS specimens should be collected in the appropriate time frame for the baby's condition but no later than 48 hours after birth, and
- 2) NBS specimens should be received at the Laboratory as soon as possible; ideally within 24 hours of collection.



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# Measuring Progress

Data collected monthly in aggregate by states

- QI-5a - Birth to specimen collection
- QI-5b - Specimen collection to receipt by lab
- QI-5c - Specimen receipt to reporting out of complete results
- QI-5d - Birth to reporting out complete results



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# Progress & Lessons Learned

## *Specimen Collection Before 48 Hours of Life*

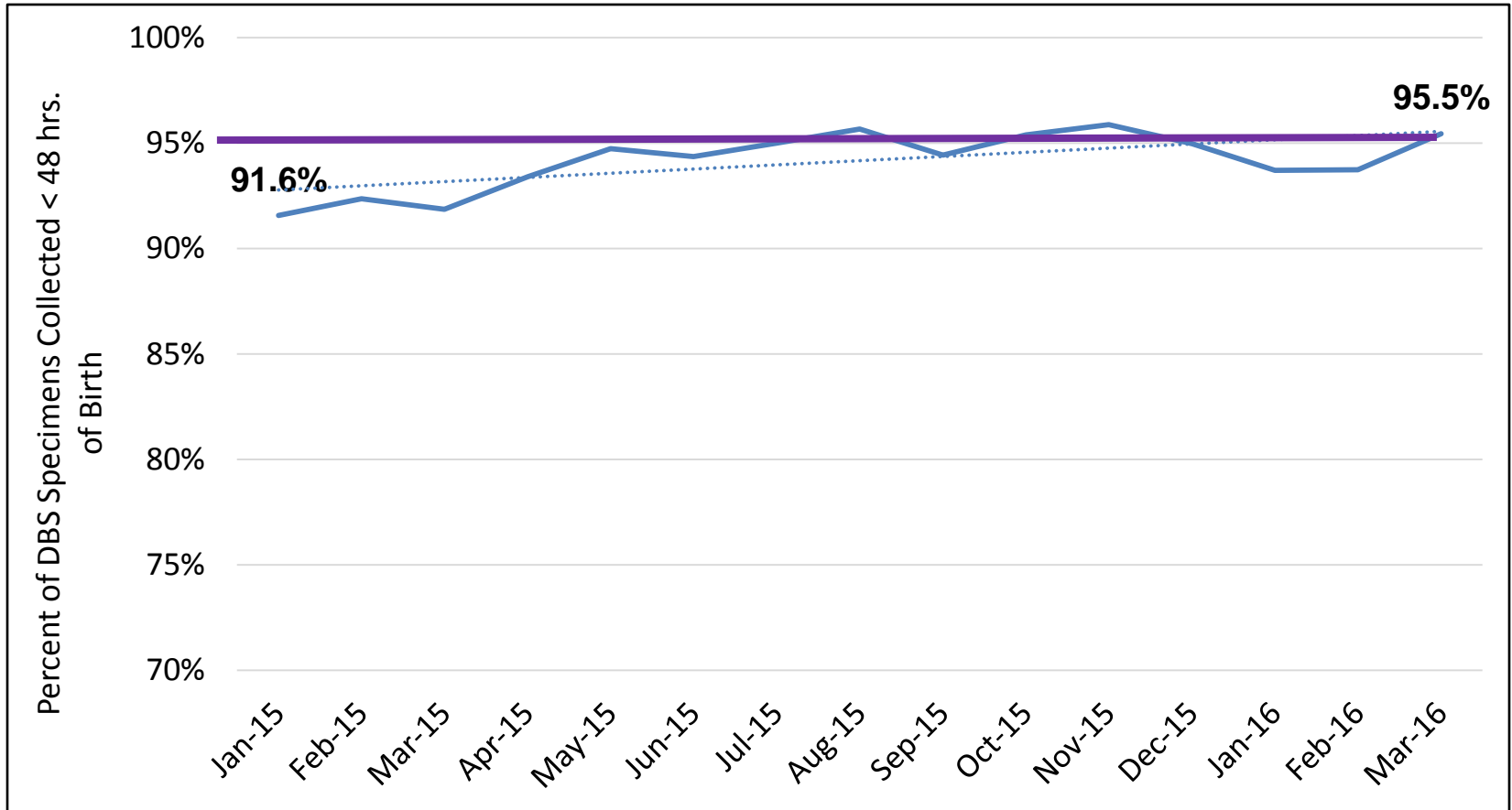


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# Specimen Collection Before 48 Hours of Life

## Progress of Whole Group (N=7)



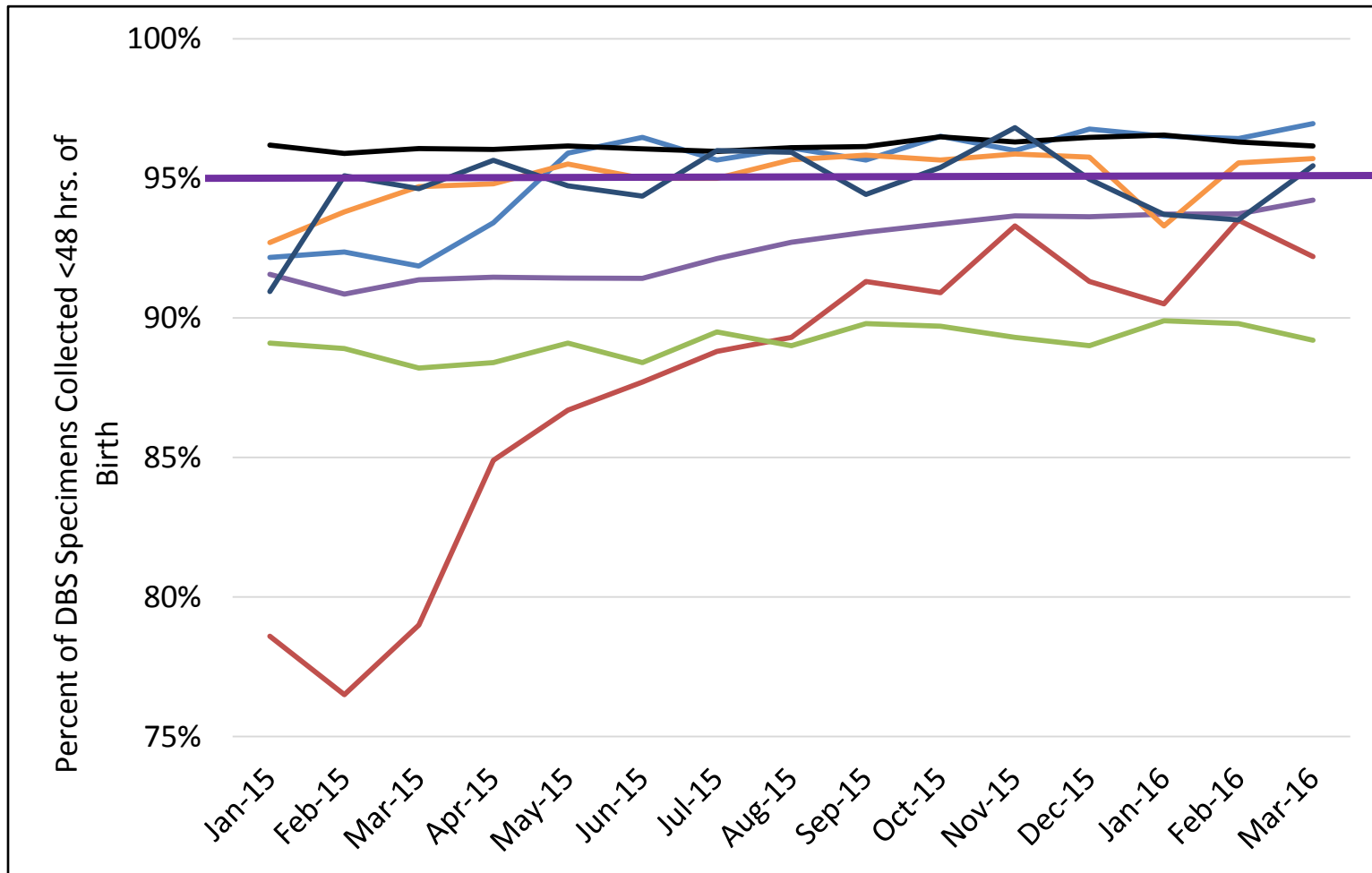
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# Specimen Collection Before 48 Hours of Life

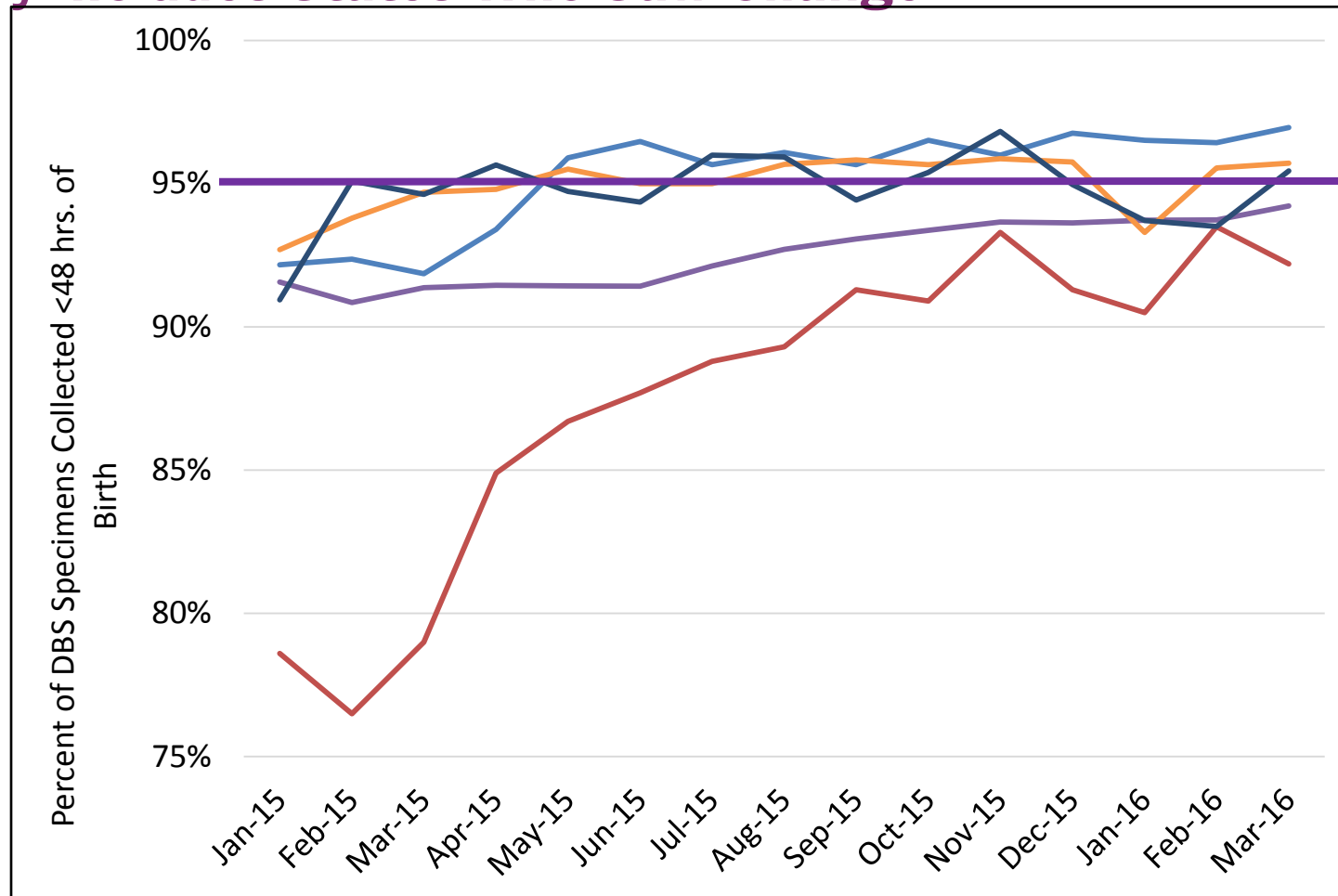
## Progress of Individual CoIN States



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# Specimen Collection Before 48 Hours of Life Only Includes States Who Saw Change



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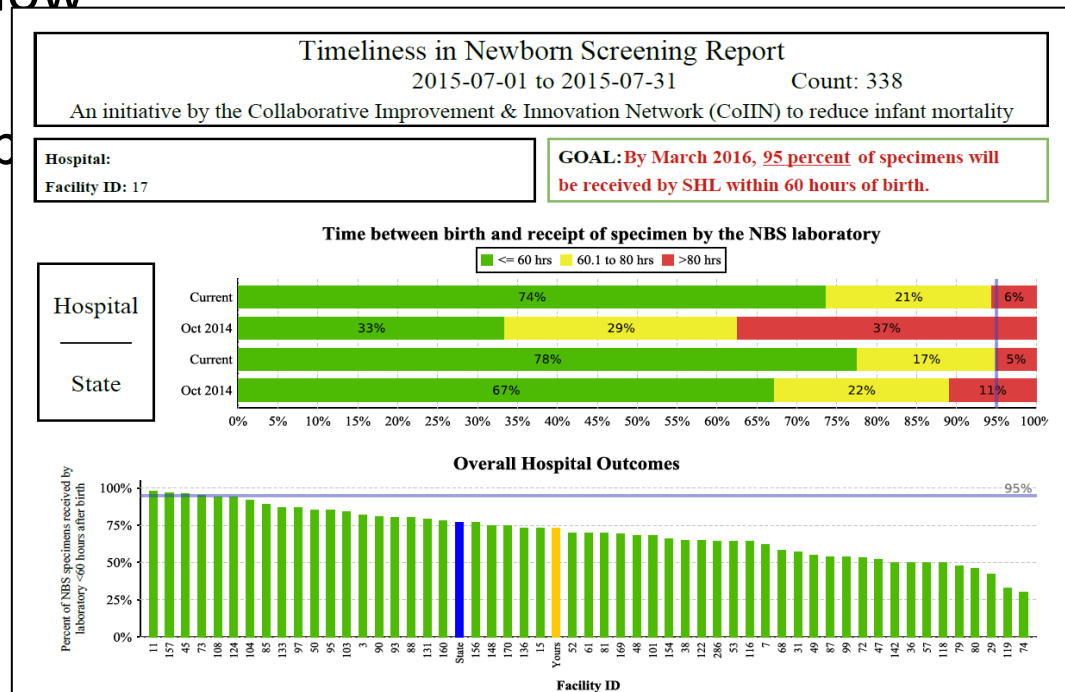
# Lessons Learned – Hospital Reports

## Barriers

- Hospitals do not know what they are aiming for or how well they are doing
- Report cards were not being shared with nursing or laboratory staff

## Solution

- Provide hospital reports



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# Lessons Learned – Education

## Barrier

- Only 36.2% recalled watching CLSI education video

## Solution

- Decided to use point-of-care educational messaging

Every time you fill out a Newborn Screening form you hold a baby's life in your hands.

Fill out the Newborn Screening form:

- ✓ *Accurately*
- ✓ *Completely*
- ✓ *Legibly*

This information could be a matter of life and death

In the event of a positive screening test, the information you provide is essential to locate the baby and provider



It's not just a form... It's a baby.



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# Lessons Learned – Education (Cont)

## Barrier

- State legislation allowed more time to collect first specimen which made it difficult to encourage hospitals to collect specimens earlier
  - *“shall have a blood specimen collected from the newborn between the second and sixth days of age.”*

## Solution

- Get legislation changed
  - *“This specimen collection shall occur after 12 hours but no later than 96 hours of age prior to discharge or transfer of the newborn . . .”*



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# Progress & Lessons Learned

*Specimens Received at NBS Lab within 48 hours of Collection*

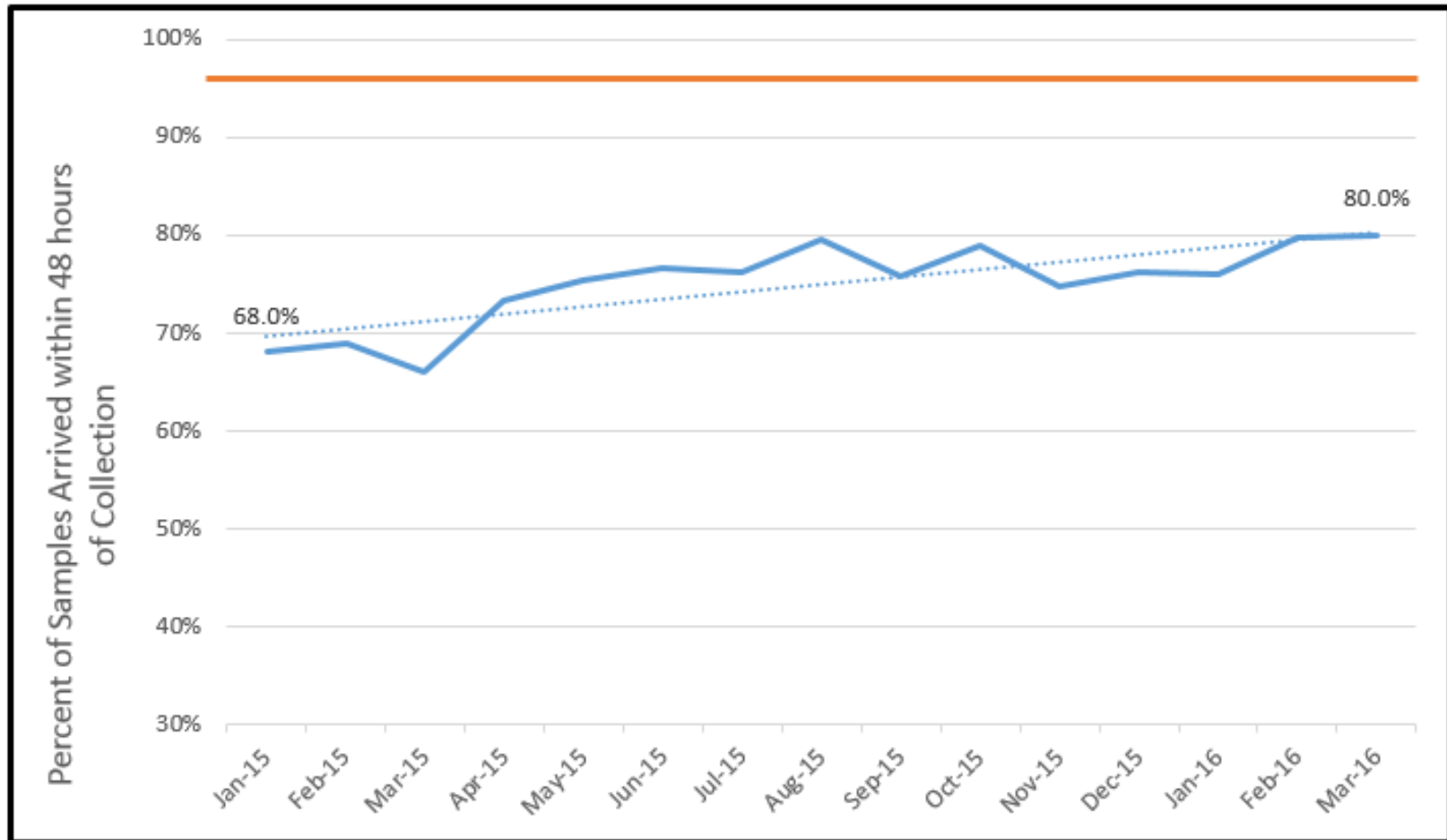


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# Specimens Received within 48 hours\* of Collection

## Progress of Whole Group (N=7)



NewSTEPS used a 48 hour benchmark.  
ACHDNC uses a 24 hour benchmark.

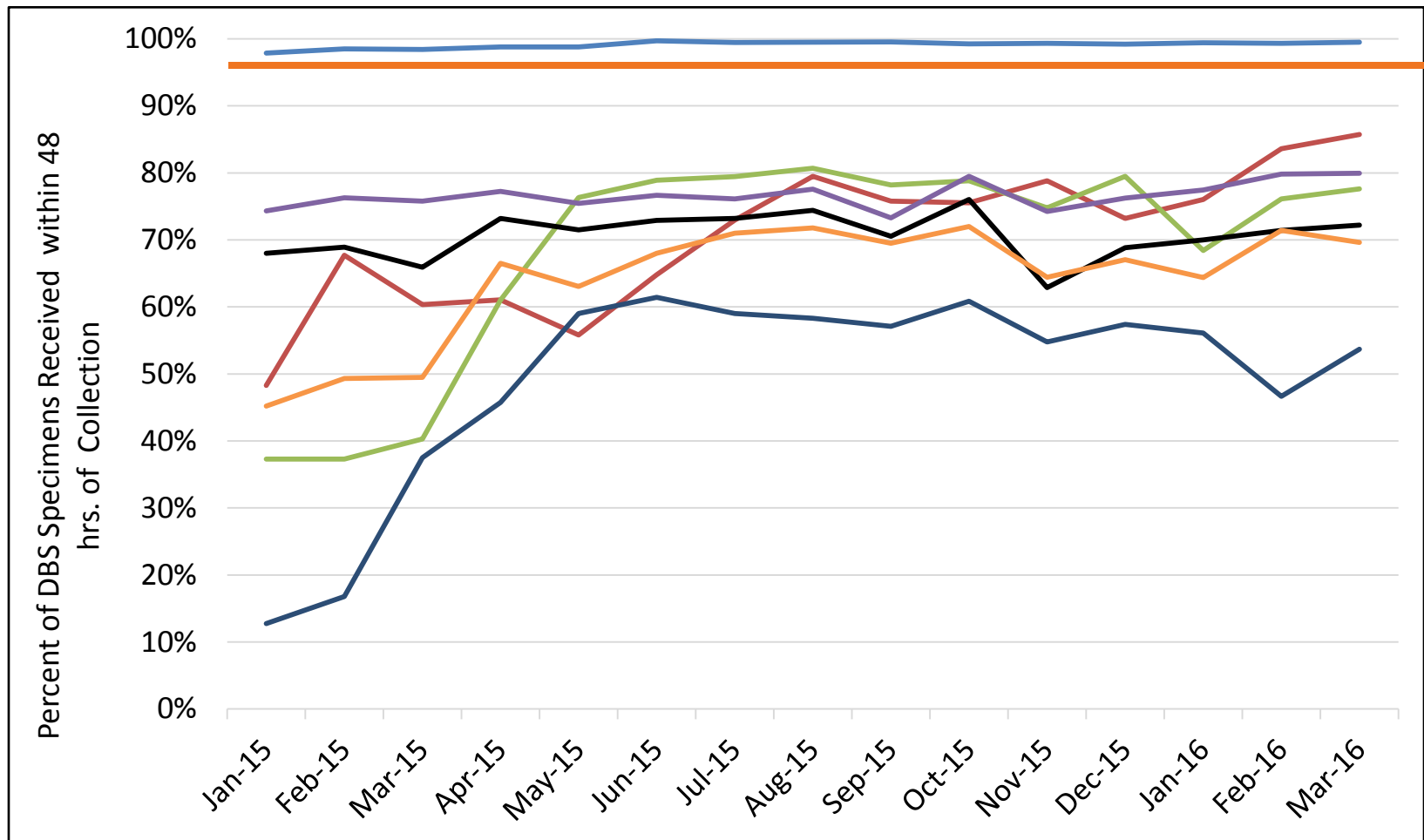


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# Specimens Received within 48 hours of Collection

## Progress of Individual COIN States



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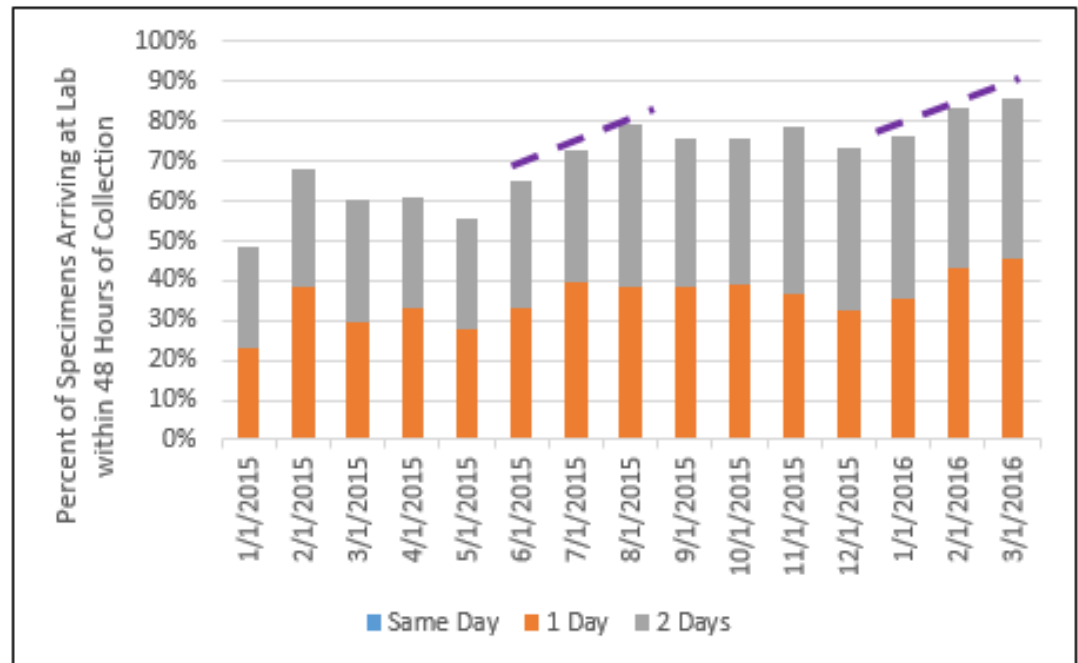
# Lessons Learned – Hospital Reports

## Barriers

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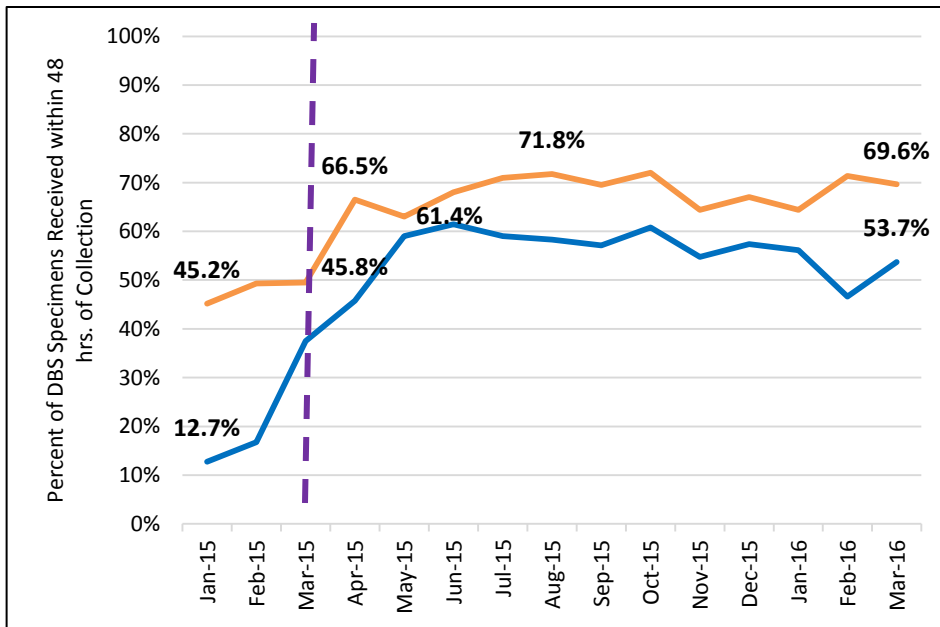
# Lessons Learned – Laboratory Hours

## Barriers

- Laboratories only open 5 days a week to receive or process specimens

## Solutions

- Increase the number of days the laboratory is open and processing specimens to 6 days a week

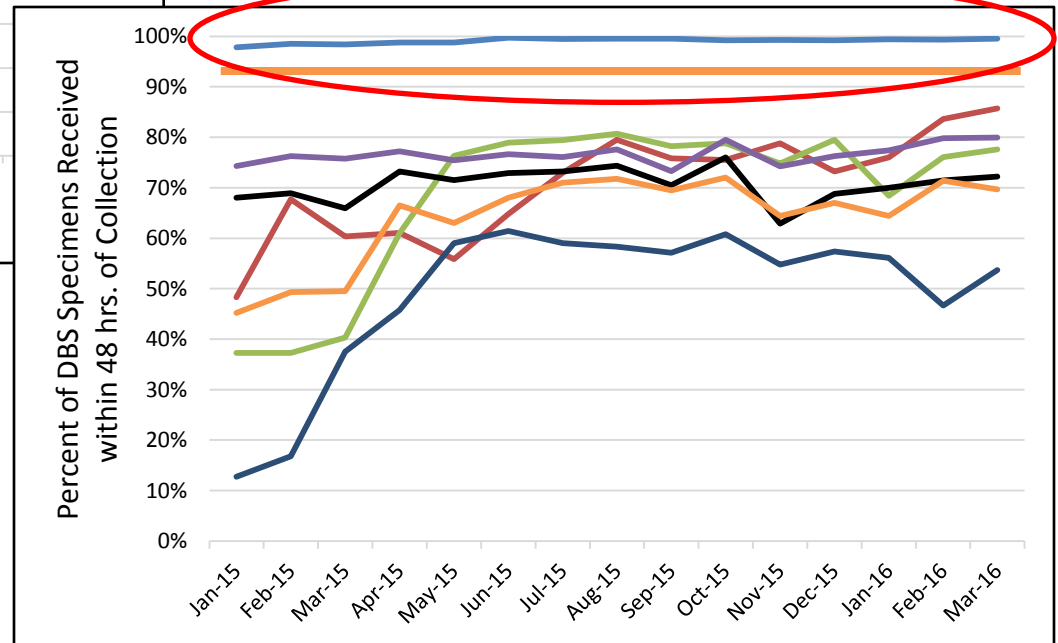
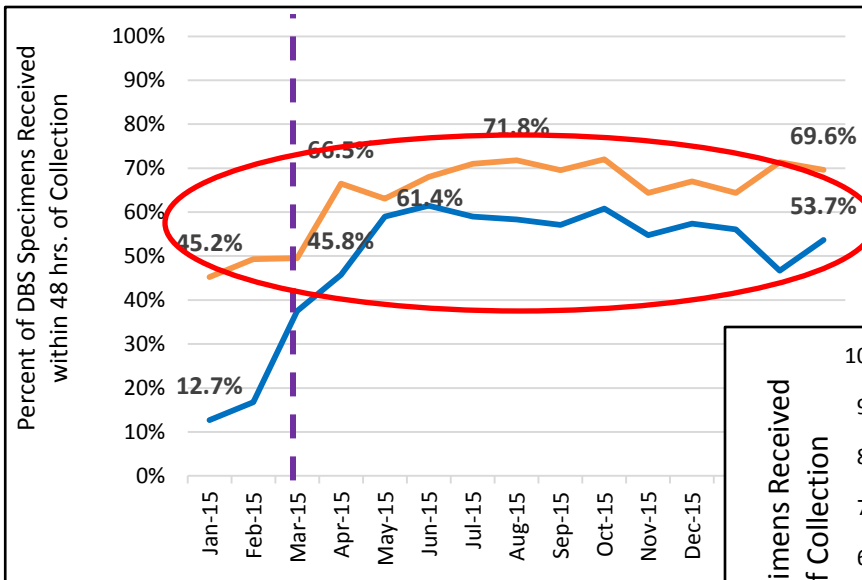


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# Lessons Learned – Laboratory Hours

Iowa's lab is open **7 days**  
a week, **24 hours** a day



Iowa was the only state to meet our goal of 95% of specimens received within 48 hours collection



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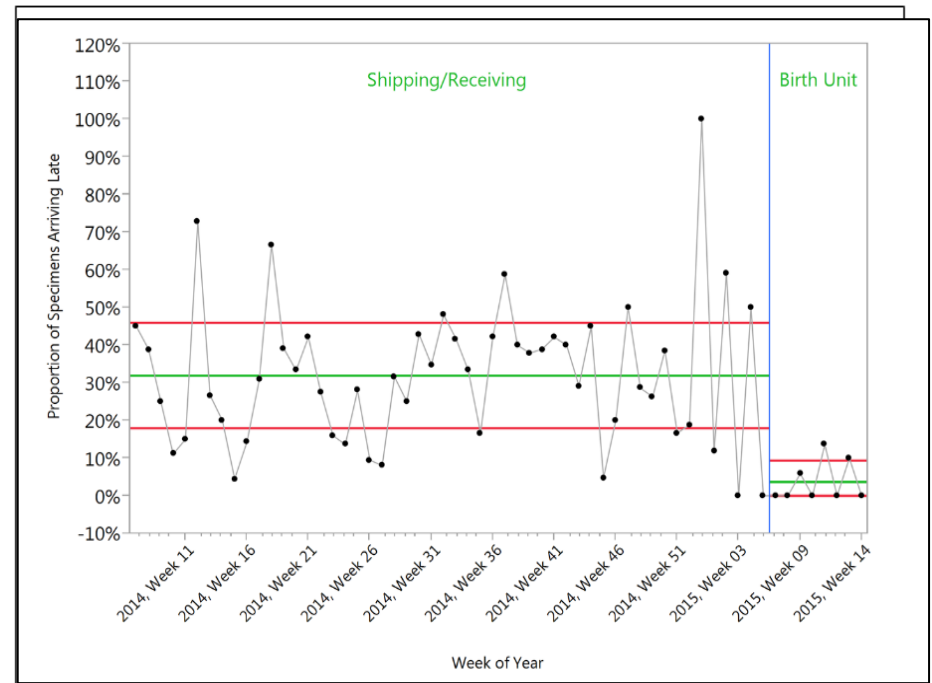
# Lessons Learned – Courier System

## Barrier

- Specimens spend too much time in transit
- Courier contracts not followed
- Hospital that is early on courier route cannot prepare specimens in time to meet 24 hour goal

## Solutions

- Introduce or increase courier system



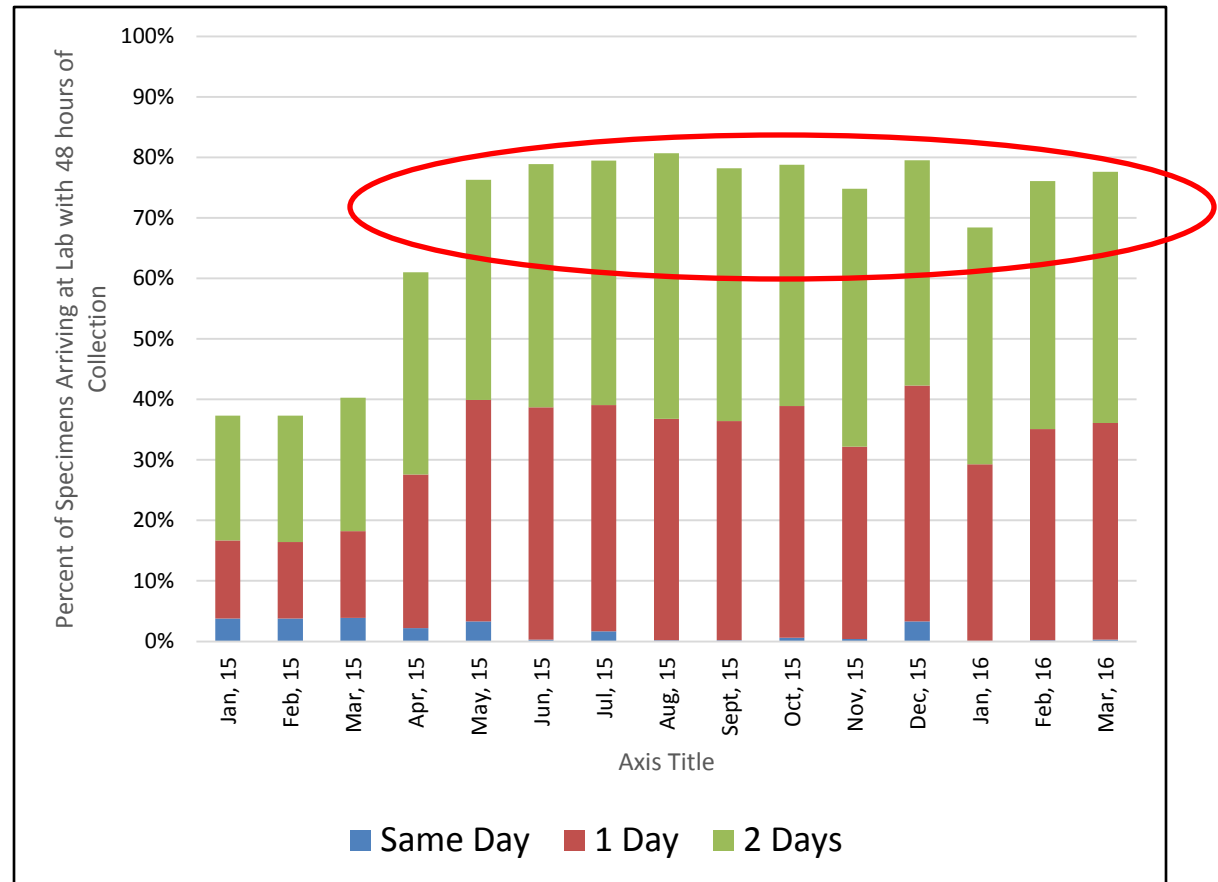
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# Lessons Learned – Courier System

Similar with the increase in laboratory hours, there is a plateau

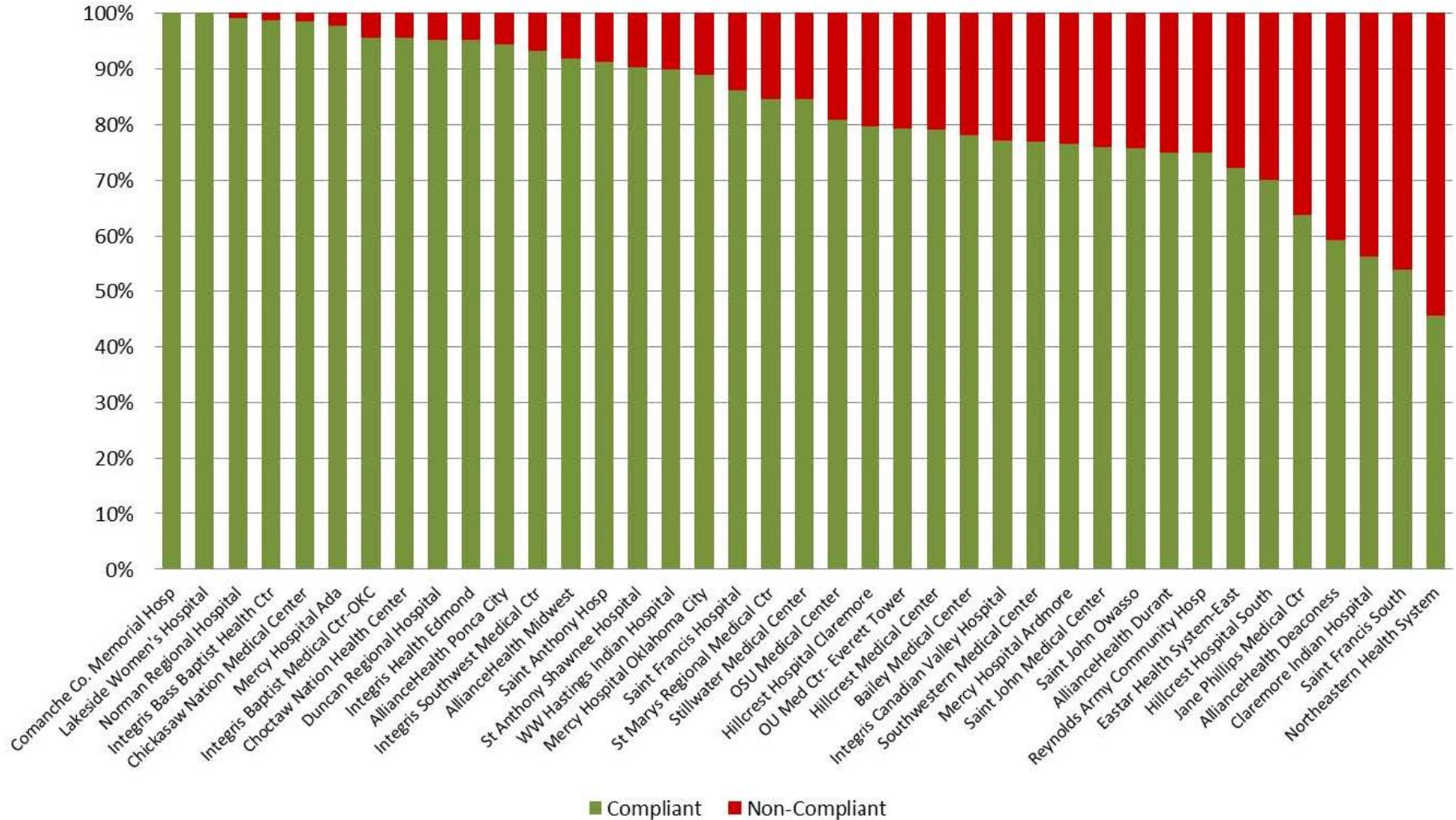
This state went from no courier to a 6 day a week courier. Could it become 7?



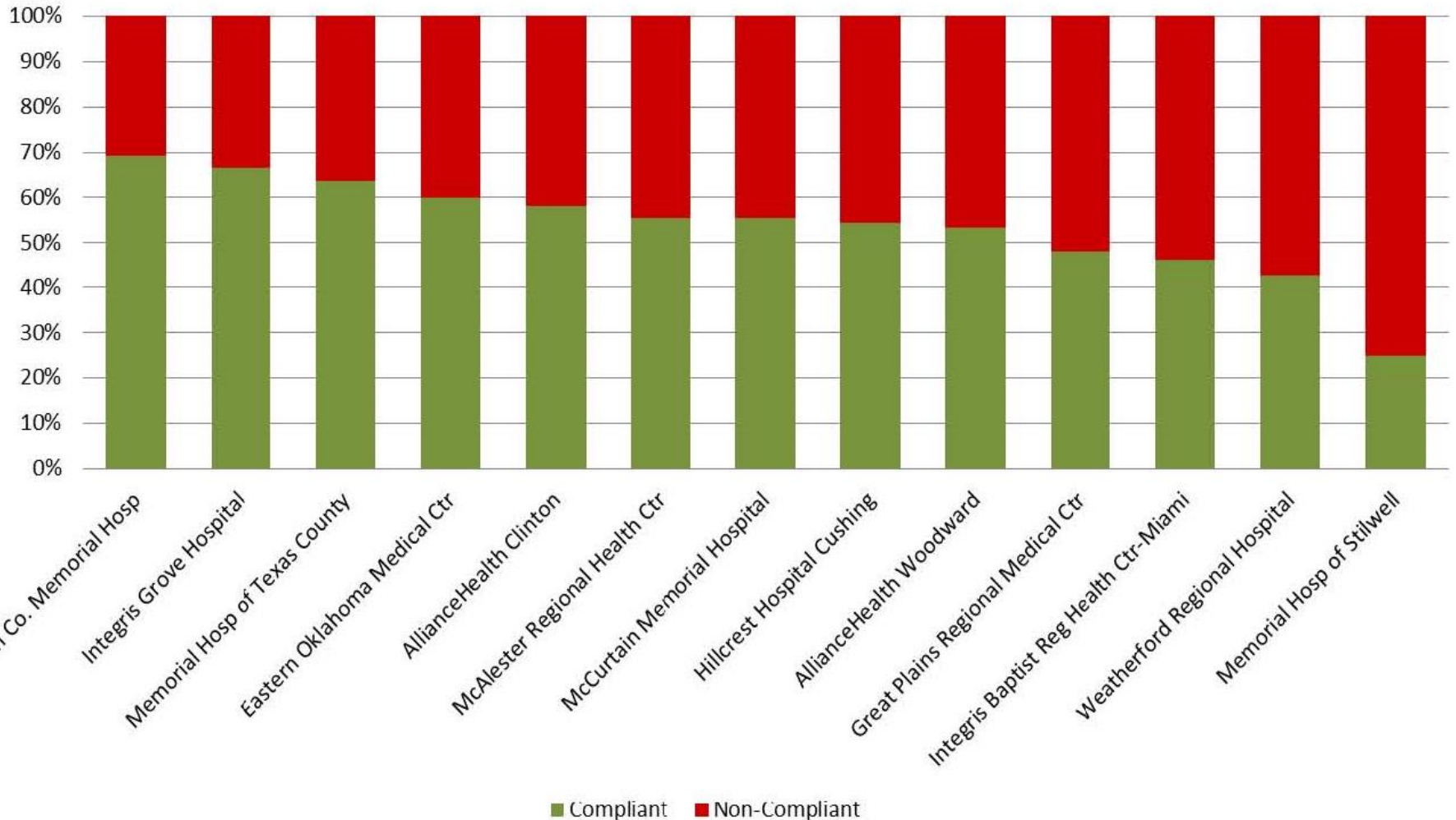
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## June 2016: % Compliance Ranking of Hospitals with 7-Day Courier Service



## June 2016: % Compliance Ranking of Hospitals with 5-Day Courier Service



# Progress & Lessons Learned

*Results Reported Out within 3 Days of Lab Receipt*

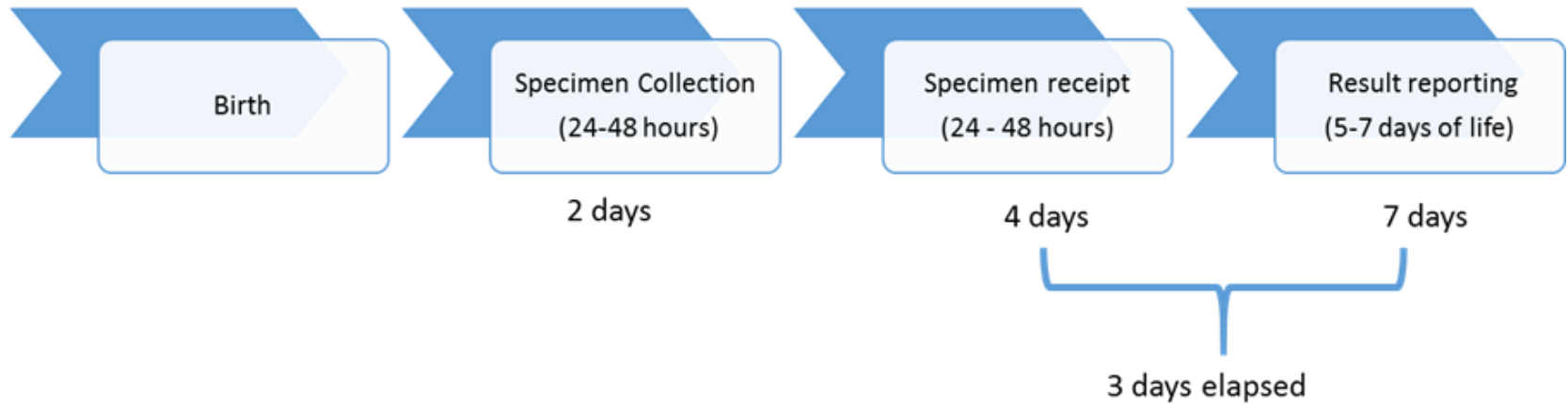


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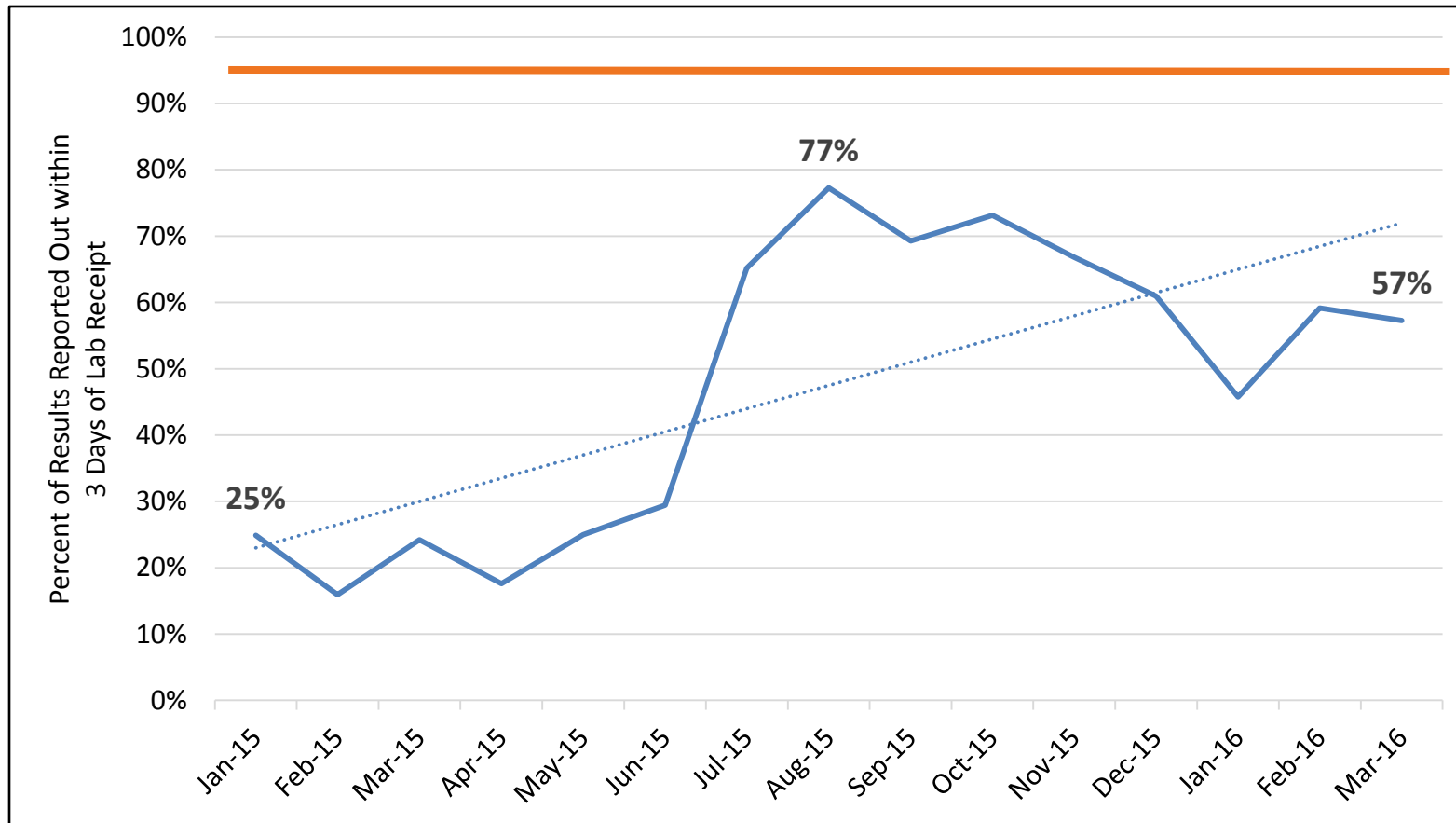
# Timeline of NBS Activities to Reporting Out Results, based on ACHDNC Recommendations



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# Results Reported Out within 3 Days of Receipt Progress of Group (N=4\*)



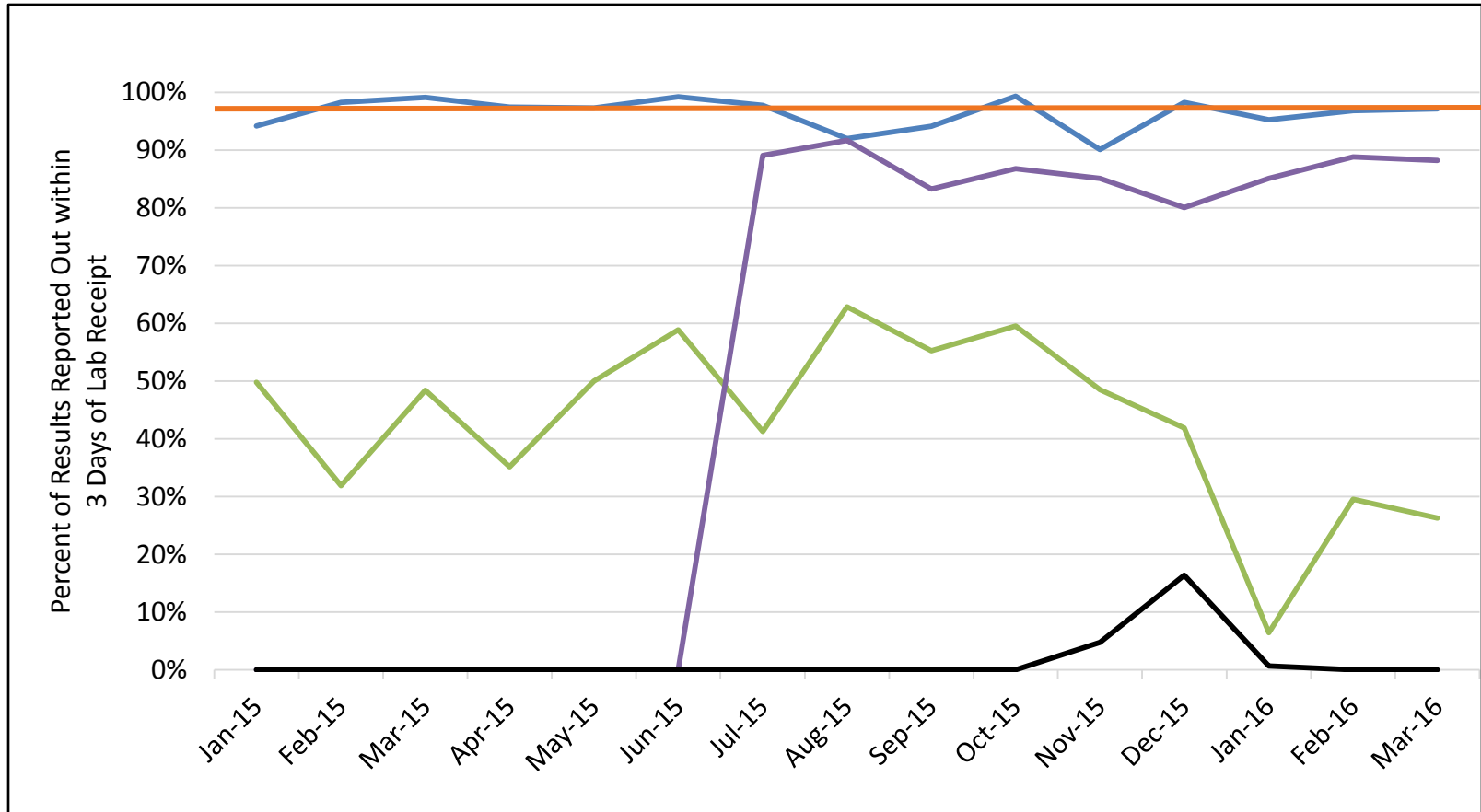
*\*Only 4 states could provide this data*



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# Results Reported Out within 3 Days of Receipt Progress of Individual COIN States



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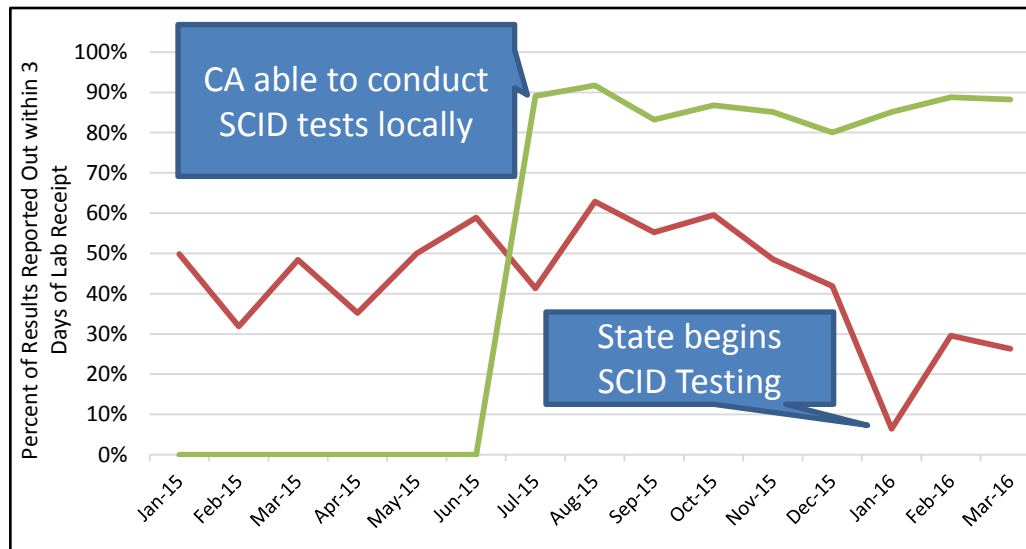
# Lessons Learned – Impact of Adding New Disorders

## Barriers

- Testing for new conditions introduces barriers like
  - Need for different staffing
  - Testing not able to be done in local labs so delay in when completed

## Solutions

- None yet—will learn more with the New Disorders Cooperative Agreement



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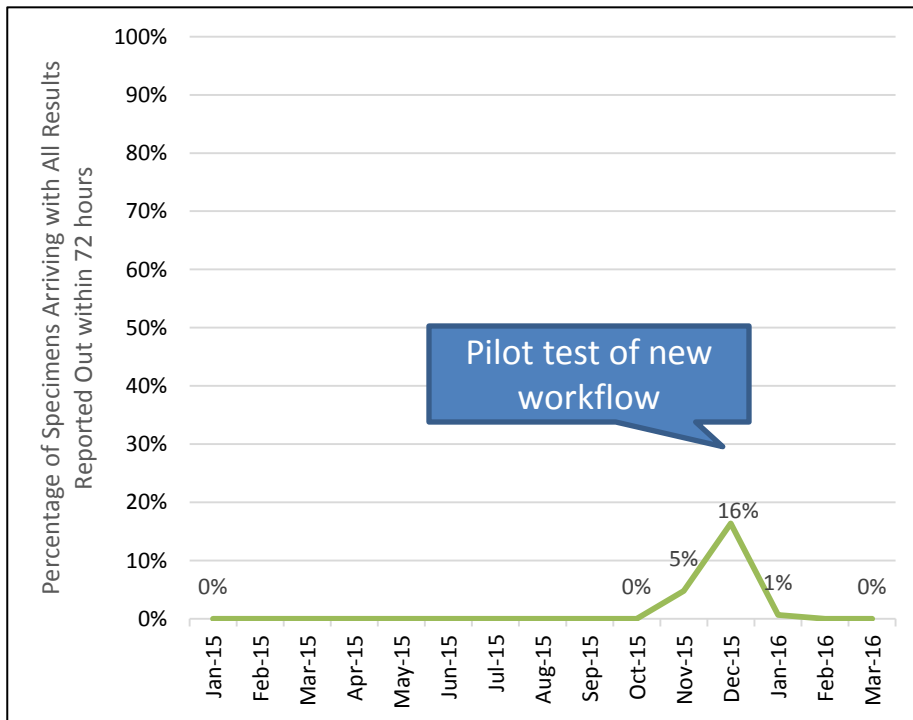
# Lessons Learned – Staffing and Workflow

## Barriers

- Staffing does not match when courier delivers samples

## Solutions

- Change lab operating hours
  - After CoIIN staff now come in closer to when first courier arrives and leaves after afternoon courier arrives.



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# Progress & Lessons Learned

*Results Reported Out within 7 Days of Birth*

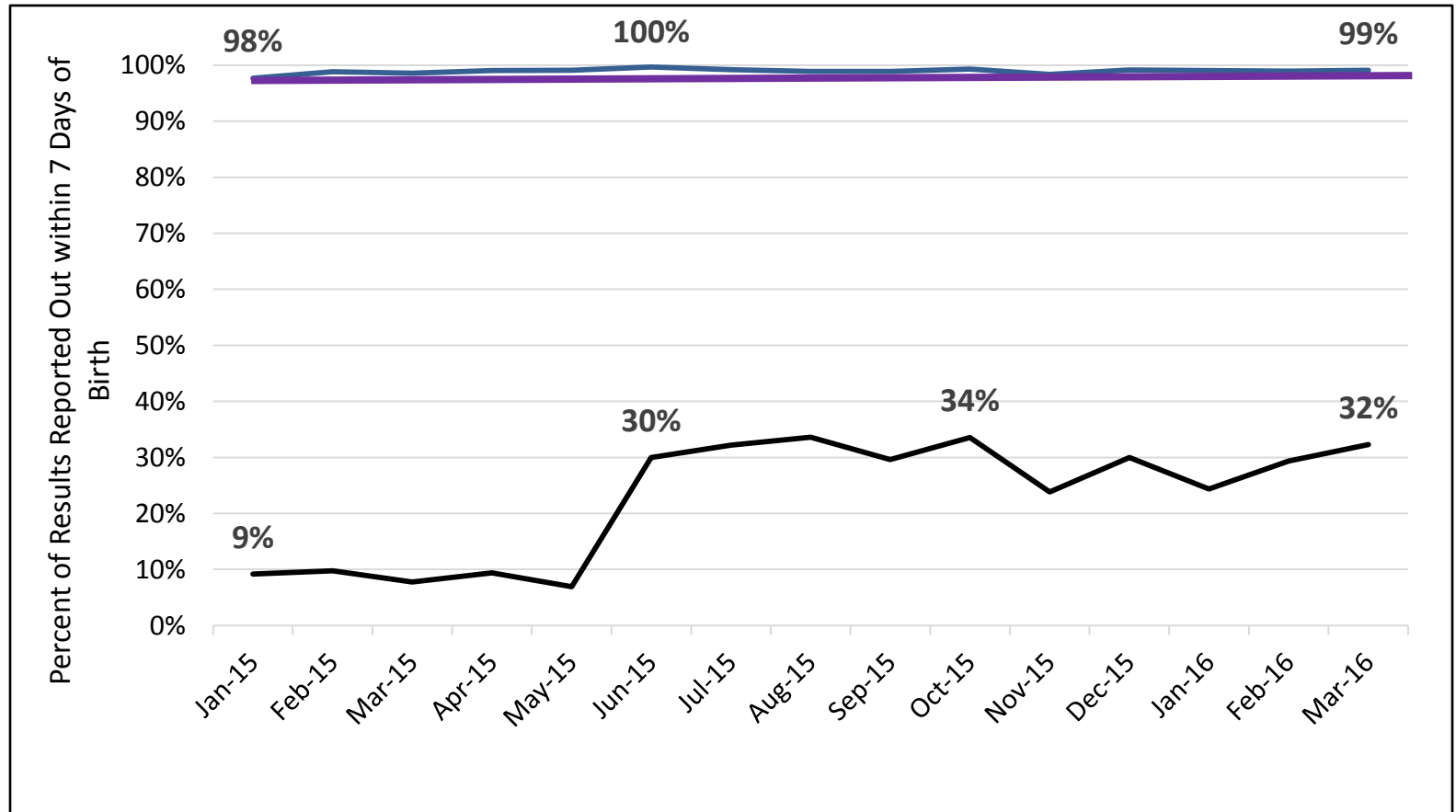


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# Results Reported Out within 7 Days of Birth

## Progress of Group (N=2\*)



*\*Only 2 states could provide this data*



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# Lessons Learned – Focus Efforts with ‘Poor Performers’

## Barrier

- Unable to meet goal despite education efforts
- State unable to provide courier service to all hospitals

## Solutions

- Focus on reaching out to hospitals with the greatest percent of delayed specimens, regardless of size
- Expand reach of courier service within state to help reach those “poor performers”.

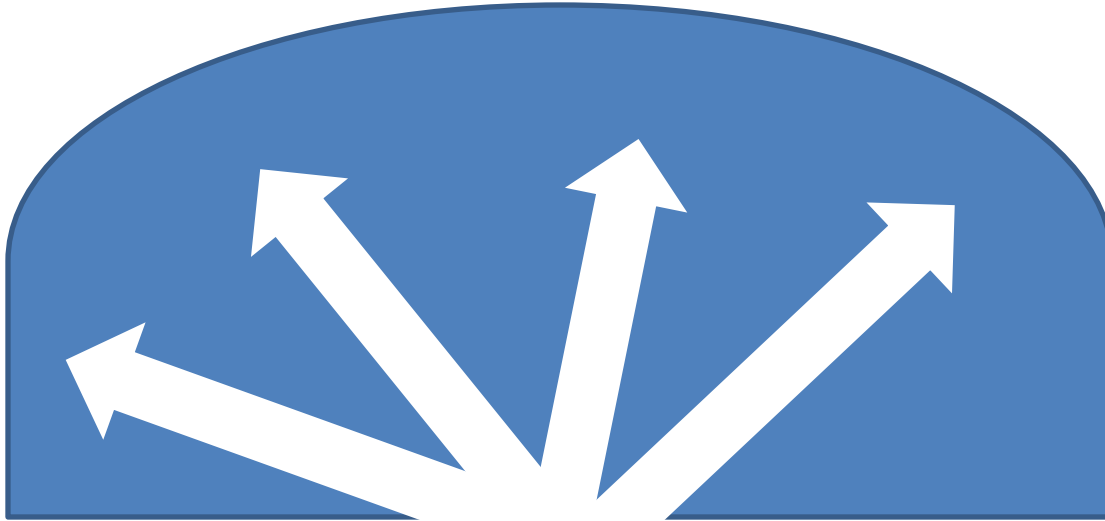


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# Impact of CoIN Activities



- All 7 states made progress.
- 3 met at least one of their goals.

So now what. . . .



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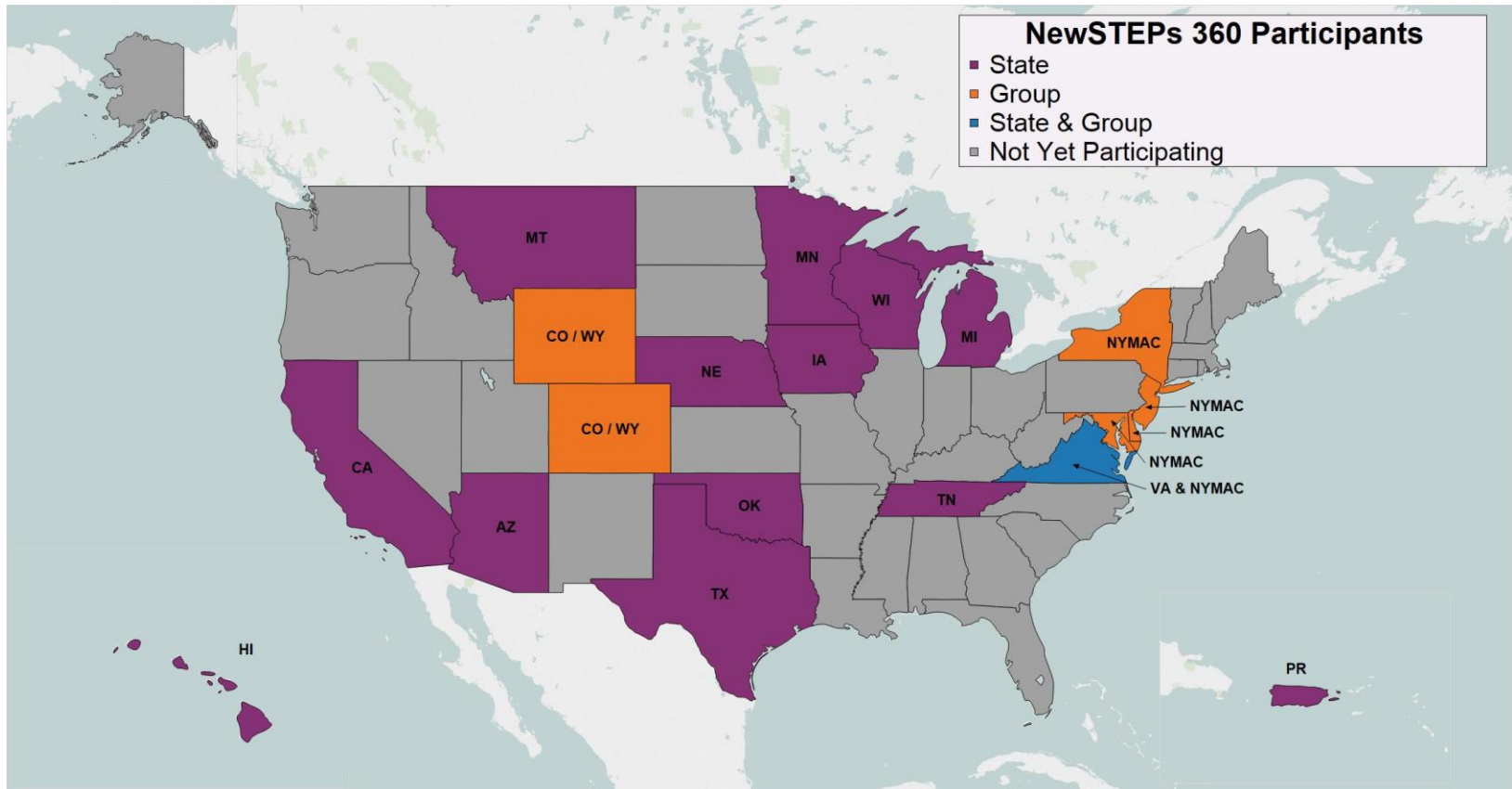


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and The Association of Public Health Laboratories™

# NewSTEPs 360: Year 1 States Funded



*\*Note: Currently reviewing applications to fund additional states starting in September 2016*

# Goal

To achieve timely reporting of results in 95% of newborns who receive dried-blood spot (DBS) newborn screening within each state participating in NewSTEPS 360 by August 30, 2018



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# Overview of NewSTEPS 360

- Awardees receive:
  - Financial assistance
  - Training on Continuous Quality Improvements (CQI) techniques
  - CQI coaching
  - Sharing resources
  - Monthly calls
  - Analysis of real time data
- For more details visit <https://www.newsteps.org/newsteps-360>



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# NewSTEP 360 Progress



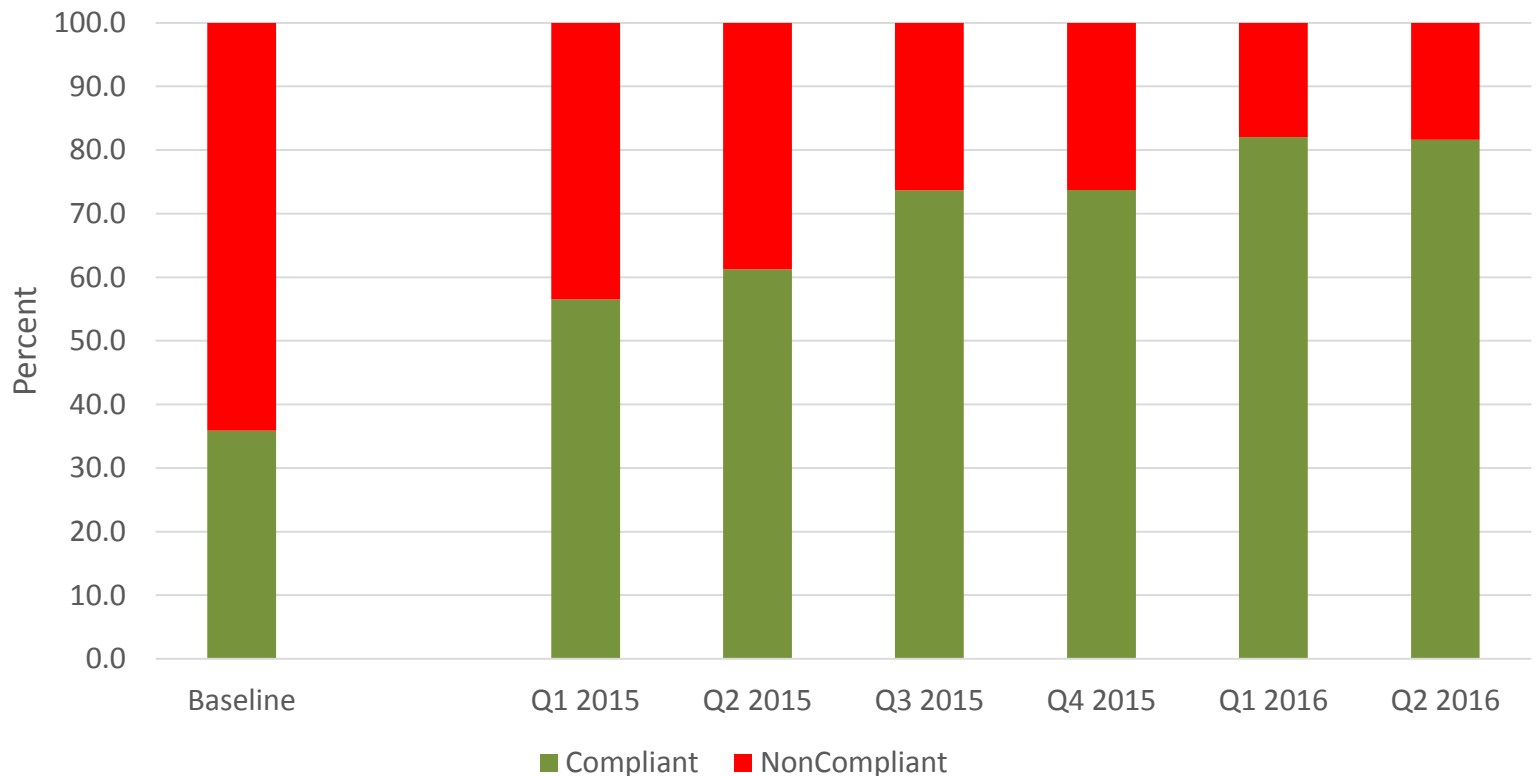
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# Focus on Decreasing Transit Time – Virginia and Oklahoma

- Oklahoma

- Made hospital report cards monthly



# Focus on Decreasing Transit Time – Virginia and Oklahoma

- Virginia
  - Added 15 hospitals to courier route (100% hospitals on courier)
  - Added Sunday to courier routes - so now 6 day pickup
  - Implemented quarterly report cards
  - Made site visits to 25 hospitals with the worst Transit time averages
  - Added announcements, information and comments about nonconformance or program changes to report cards
  - Implemented new LIMS so can now capture time of receipt as a discreet field, separate from date accessioned for testing.

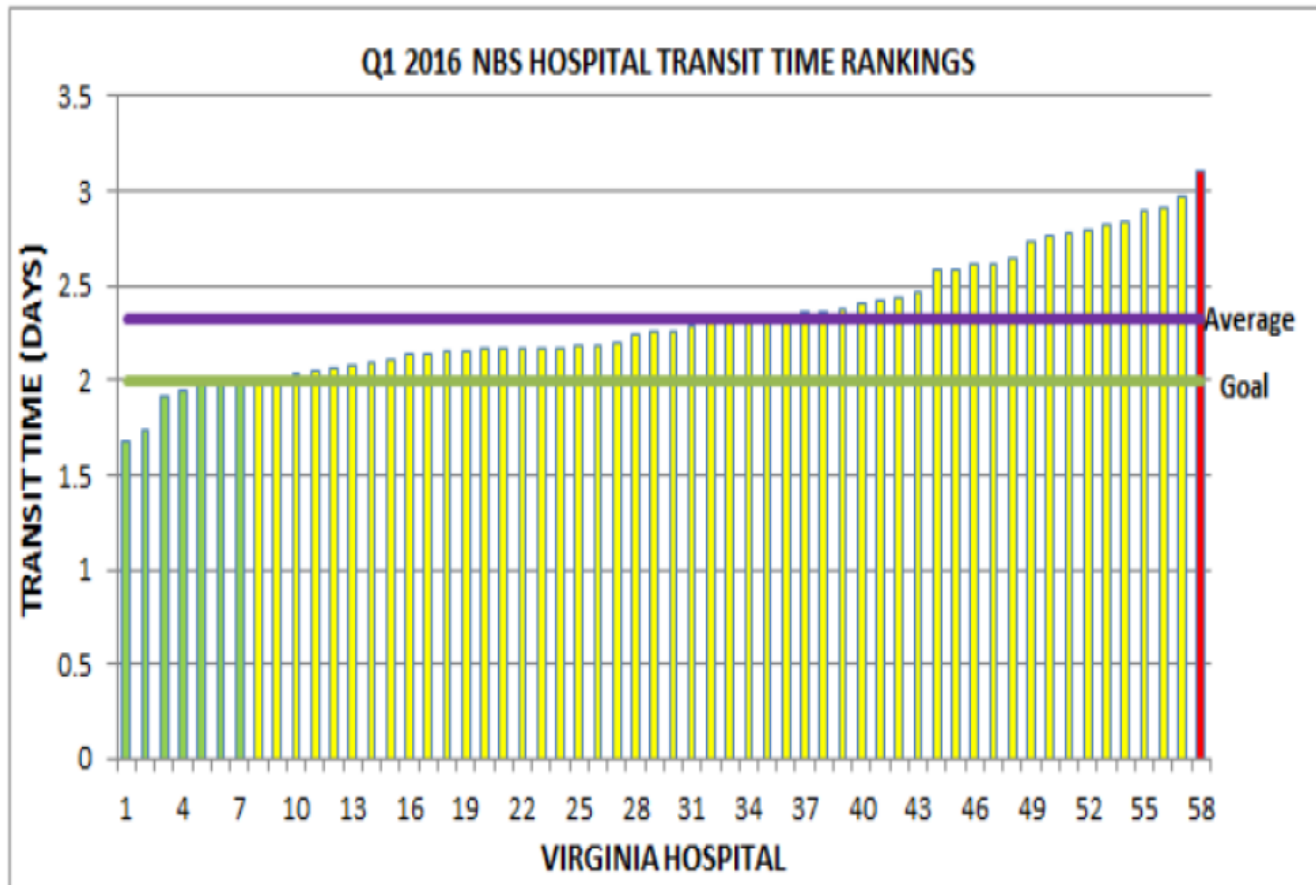


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# Virginia's Change in Time from Collection to Receipt by Laboratory



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# Decreasing Time It Takes Provider to Get The NBS Report - Wisconsin

Program is switching to faxing results to providers rather than mail

- Goal: To have fax capabilities for 80% of hospitals by December 31, 2016



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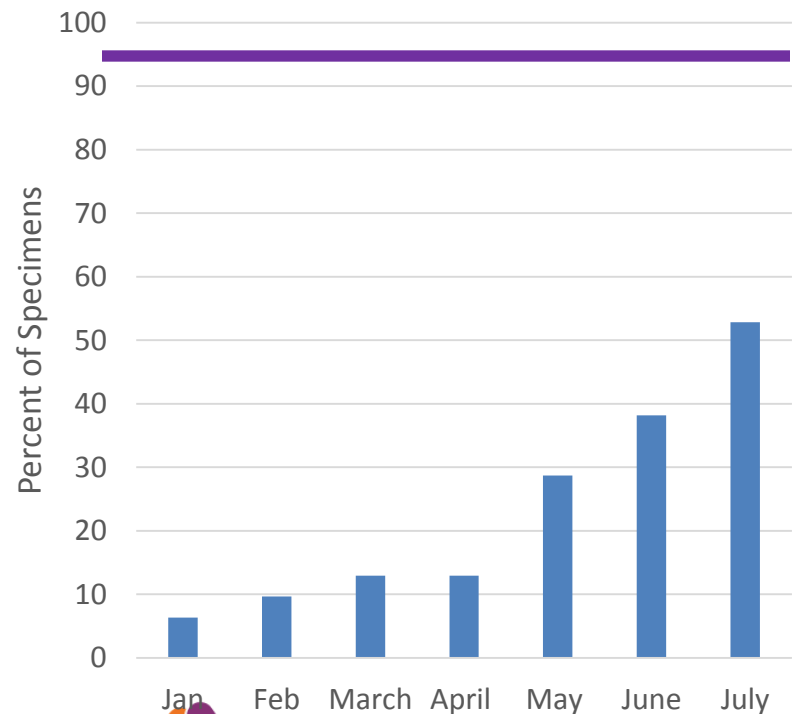
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# Wisconsin's improvement in time to result reporting

## Results reporting

- 95.7% of results are verified before 7 days of life
- Results have been mailed to PCPs historically
- Reduced mail and ship time from 2-3 days to <1 hour

Percent of Specimens Whose Results Were Reported within 7 Days



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# Understanding the knowledge and barriers related to newborn screening training and practices among nursing and midwifery groups

- Baby's First Test conducted a focus group during lunch at AWHONN
- Total of 14 people, 8 states represented



# Key Findings

- The heel prick (blood screening) has a lot of steps and is only one part of NBS; nurses are overwhelmed and do not receive updated training
- Disseminating information/recommendations is difficult, but making sure all staff (different shifts) understand or can implement those changes is harder
- Easy implementation = easy wins; needs to clearly fit in workflow
- Communication between staff, lab, and educators is key, but turnover is huge barrier
  - Establishing buy-in
  - Champions
  - Feedback
- Staff need to know the *why* of what they are doing; bringing newborn screening to a personal level

# Potential Next Steps

- Submitting abstract to AWHONN
- Short publication/perspective piece



# So Stay Tuned. . . . .



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# NewSTEPs and NewSTEPs 360 Team

Jelili Ojodu

Sikha Singh

Thalia Wood

Careema Yusuf

Guisou Zarbalian

Funke Akinsola

Sari Edelman

Marci Sontag

Yvonne Kellar-Guenther

Joshua Miller

Sarah McKasson

Ruthanne Salisbury

Laura Russell

Louise Guiliano



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# Thank you to our amazing **COLIN** **Teams!**

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California

Colorado/Wyoming

Iowa

New Hampshire

Tennessee

Texas



# Questions?



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