

Incorporating State Newborn Screening Program Input on Quality Indicators

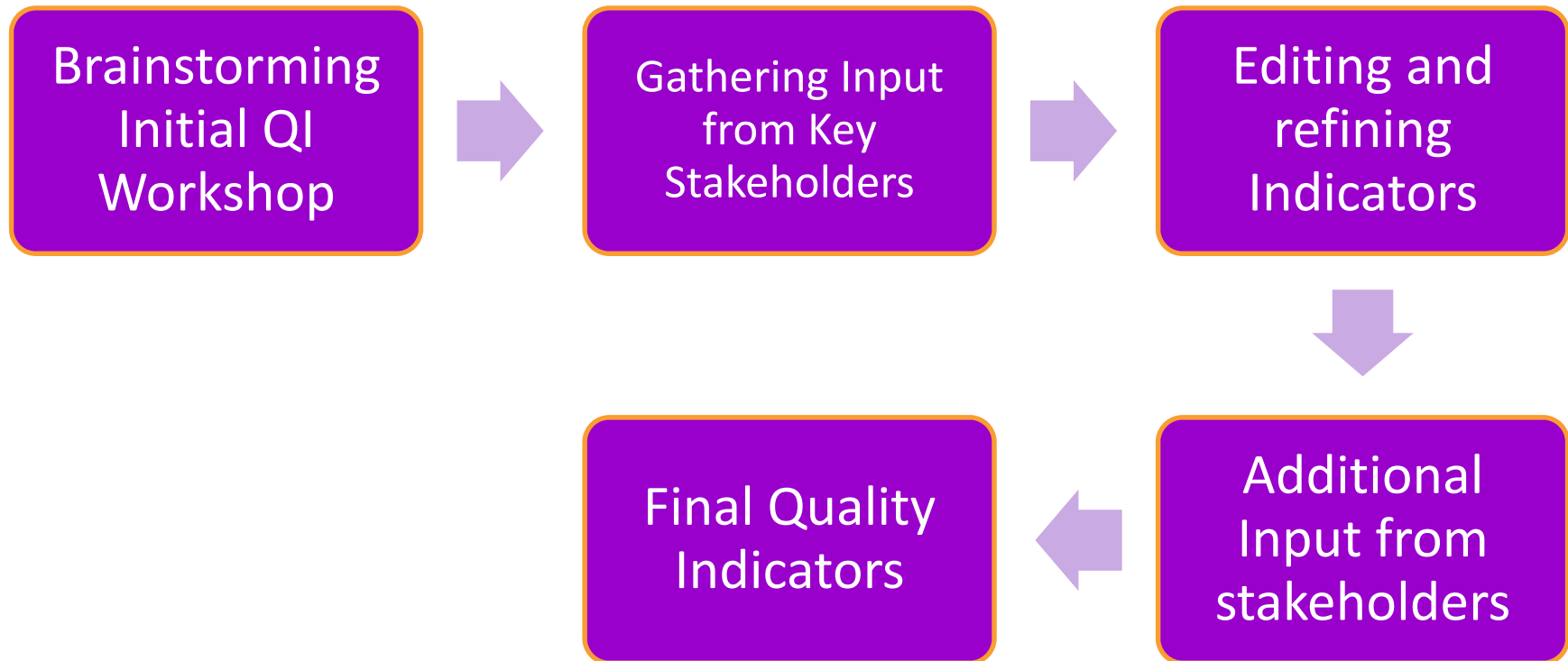
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The journey of a quality indicator



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2011 Workshop: Goals and Objectives

1. Identify and categorize current quality indicators.
2. Harmonize definitions of current QIs.
3. Summarize utility of current QIs and begin to identify QIs.
4. Select key QIs voluntarily collected by all states.
5. Define key QIs including common standards regarding operational and outcome-based processes.



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2011 Workshop to Develop QIs

Participants

Swapna Abhyankar
Natasha Bonhomme
Bob Bowman
Michele Caggana
Sara Copeland
Carla Cuthbert
Roger Eaton
Leslie Gafney
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Judi Tuerck
Sharon Vaz
Sheila Weiss
Donna Williams
Bill Young
Alan Zuckerman

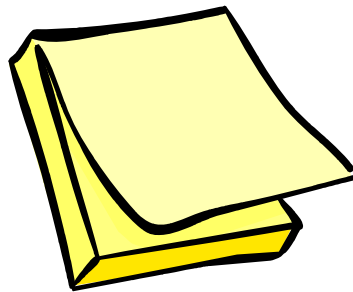


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Initial Quality Indicators Developed

- Two day process of facilitated discussions
- Definitions developed through sub-groups, cross-talk between sub-groups and intricate voting system
- Resulted in a list of 10 quality indicators and definitions for state newborn screening programs




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New Jersey Pilot Tested the QIs

- Used 2011 data to evaluate test the QIs
- Presented the findings at NBSGTS 2011



Pilot Study of Quality Indicators for the Next Generation of Data Collection into a National Newborn Screening Data Repository

Scott Shone, PhD, Evelyn Margalit, Suzanne Karabin, MS, CGC; Donna McCourt, Lori Garg, MD, MPH and Martha Smith
Newborn Screening Program, New Jersey Department of Health and Senior Services, Trenton, New Jersey



ABSTRACT


In June 2011, the Association of Public Health Laboratories (APHL) convened a Quality Indicators (QIs) Working Group consisting of individuals from four newborn screening (NBS) Programs, the APHL, the Health Resources and Services Administration (HRSA), the Centers for Disease Control and Prevention, the National Library of Medicine, and the American Society for Human Genetics. The goal of the working group was to identify, define, and evaluate quality indicators that could be used to assess the quality of newborn screening data collection and reporting. The group identified 10 QIs that were used to evaluate the pilot study of the National Newborn Screening Performance Program (NBSGTS) in 2011. The group also identified 10 QIs that were used to evaluate the pilot study of the National Newborn Screening Performance Program (NBSGTS) in 2011. The group also identified 10 QIs that were used to evaluate the pilot study of the National Newborn Screening Performance Program (NBSGTS) in 2011. The group also identified 10 QIs that were used to evaluate the pilot study of the National Newborn Screening Performance Program (NBSGTS) in 2011.

INTRODUCTION

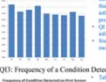
The New Jersey Newborn Screening Program recently received national quality certification (CCL) as part of the national quality improvement program for newborn screening (NBS) in the United States. The program is a national effort to improve the quality of newborn screening data collection and reporting. The program is a national effort to improve the quality of newborn screening data collection and reporting. The program is a national effort to improve the quality of newborn screening data collection and reporting.

RESULTS


Q1: Percent of Unsatisfactory Specimens Due to Improper Collection



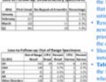
Q2: Percent of Specimens Lacking Essential Information




Q3: Frequency of a Condition Detected at Birth, 1st Screen vs. 2nd Screen




Q4: Rate of Loss to Follow-up




Q5: Unavailability of Out of Range




Q6: Percent of Parent Refusals




Q7: Time from X to Y



Q8: Percent of High Infant Receiving Valid NBS



Q9: Average (costs)



Q10: Positive Predictive Value for Out of Range Results

Q11: Rate of Out of Range Results

Q12: Rate of Missed Cases

CONCLUSIONS

The pilot study of the National Newborn Screening Performance Program (NBSGTS) in 2011 demonstrated that the use of quality indicators (QIs) can improve the quality of newborn screening data collection and reporting. The program is a national effort to improve the quality of newborn screening data collection and reporting. The program is a national effort to improve the quality of newborn screening data collection and reporting.



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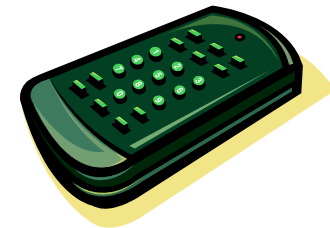
Transparency!
Pull back that curtain!



Slide courtesy of Scott Shone, PhD

Broadening the Scope – Getting feedback from States

- Goals and Objectives
 - To get state experts' opinions on each indicator
 - Importance
 - Appropriate Definition
 - Feasibility
 - Qualitative Feedback
 - Used 'clickers' to vote
- Incorporated feedback from states



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2012 QI Workshop

Participants

Swapna Abhyankar

Cindy Ashley

Becky Bailey

Lou Bartoshesky

Linda Beischel

Stan Berberich

Natasha Bonhomme

Bob Bowman

Amy Brower

Michele Caggana

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Roger Eaton

Lisa Feuchtbaum

Bryant Fortner

Lucy Fossen

Debra Freedenberg

Michael Glass

Aaron Goldenberg

Art Hagar

Alaina Harris

Kathryn Hassel

Cindy Hinton

Amy Hoffman

Philis Hoggatt

Patrick Hopkins

Cindy Ingham

Ward Jacox

Carol Johnson

Jamey Kendall

Janice Kong

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Sharon Linard

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Mark McCann

Susan Oliver

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Kupper Wintergerst

Alan Zuckerman



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Additional Feedback and Refinement 2012 - 2013

- Workgroup of experts from state newborn screening programs
- Met via Webinar
- Discussed the QIs and definitions and suggested additional modifications



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QI Workgroup Members

- Michele Caggana
- Stanton L. Berberich
- Debra Freedenberg
- Ward B. Jacox
- Jamey Kendall
- Sharon Linard
- Jennifer Macdonald
- Lois Taylor
- Inderneel Sahai



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Final Product: 8 Quality Indicators

- A set of 8 quality indicators have been developed in cooperation with newborn screening program experts
- The intent of these indicators is to provide tools to states to identify areas of strength or improvement while providing a snapshot of national trends
- QIs 1 and 2 focus on collection and information gathering for dried blood spots
- QIs 3 – 8 are intended for all NBS conditions



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Quality Indicators

- QI 1. Percent of invalid dried blood spot specimens due to improper collection and/or transport
- QI 2. Percent of dried blood spot specimens missing essential information
- QI 3. Percent of eligible infants not receiving valid newborn screening test, stratified by dried blood spot or point of care test(s).
- QI 4. Percent of loss to follow-up
- QI 5. Time elapsed from birth to screening, follow-up testing, confirmed diagnosis
- QI 6. Percent of out of range results
- QI 7. Frequency of condition detected by newborn screening for each disorder
- QI 8. Percent of missed cases (false negatives), stratified by disorder



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Definitions and Examples



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QI 5. Time elapsed from birth to screening, follow-up testing, confirmed diagnosis

- a. Birth to specimen collection, data collected in aggregate by state, with proportions of screens indicated in the following categories:
 - For initial screen: less than 12 hrs, 12 to 24 hrs, greater than 24 to 48 hrs, greater than 48 to 72 hrs, 4 days, 5 days, 6 days, 7 days, and greater than 7 days
 - For subsequent screen : less than 7 days, 7-10 days, greater than 10 to 14 days, greater than 14 to 21 days, greater than 21 days.



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Feedback on QI 5 – Time from birth to screening

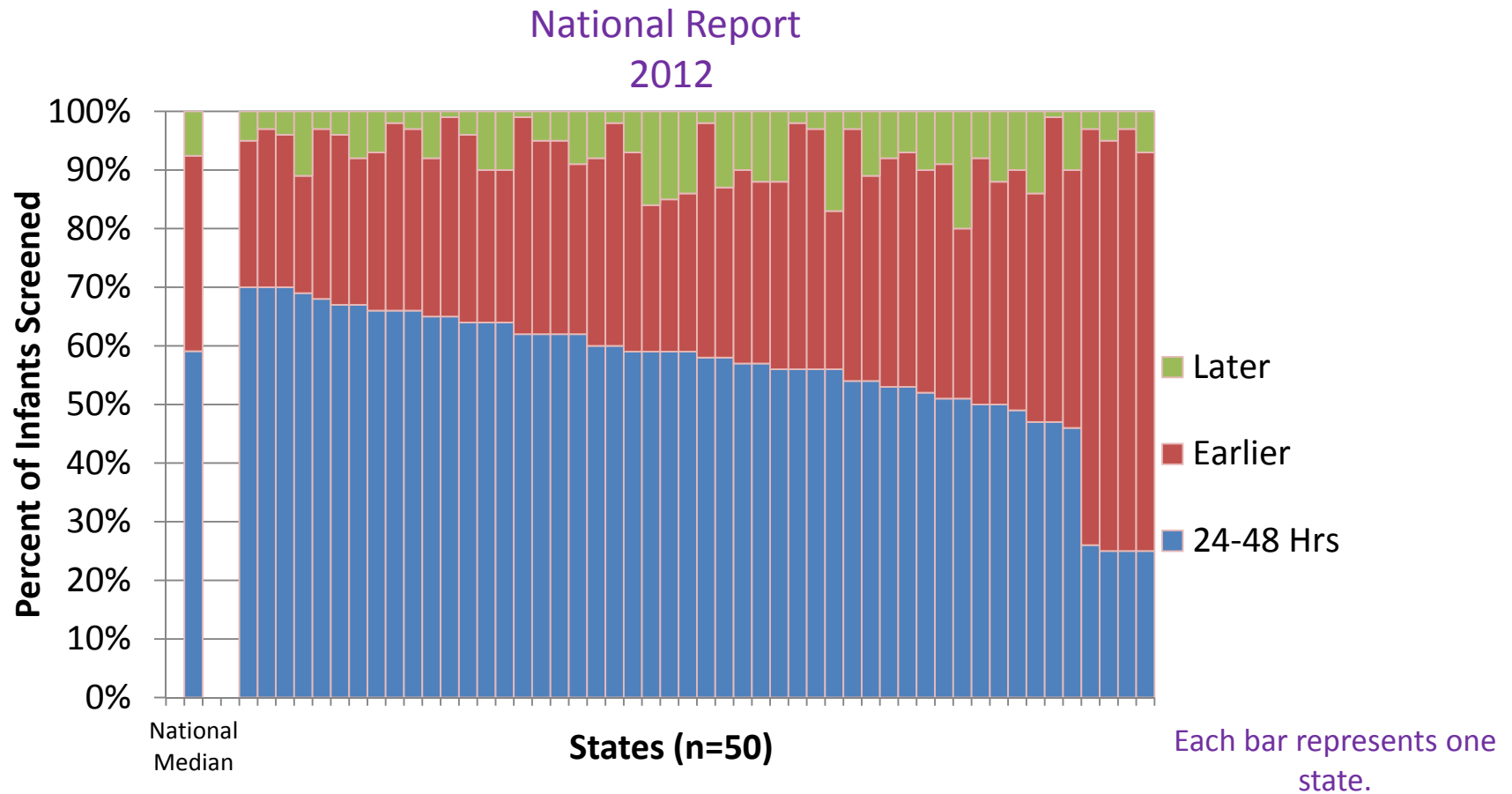
- Ratings from state newborn screening experts:
 - 98% felt it was important/somewhat important
 - 50% felt it required some adjustment in definition
- Further feedback:
 - “There are too many buckets”



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QI 5 - Percent of infants receiving screening in specified time intervals



All data portrayed in this sample report are fictitious. Data do not represent actual outcomes from any newborn screening program. Any resemblance to real data from a real newborn screening program is completely coincidental.

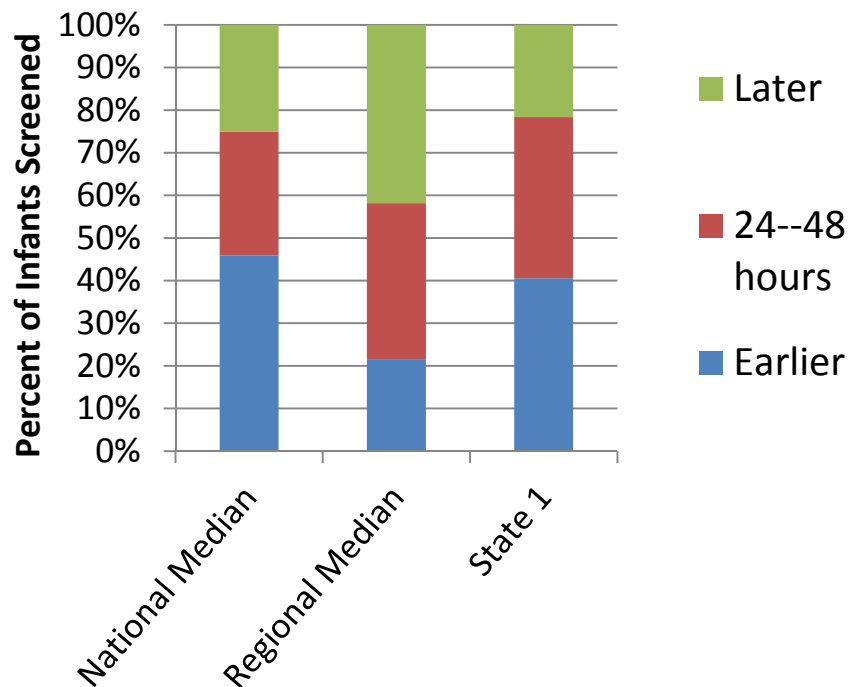


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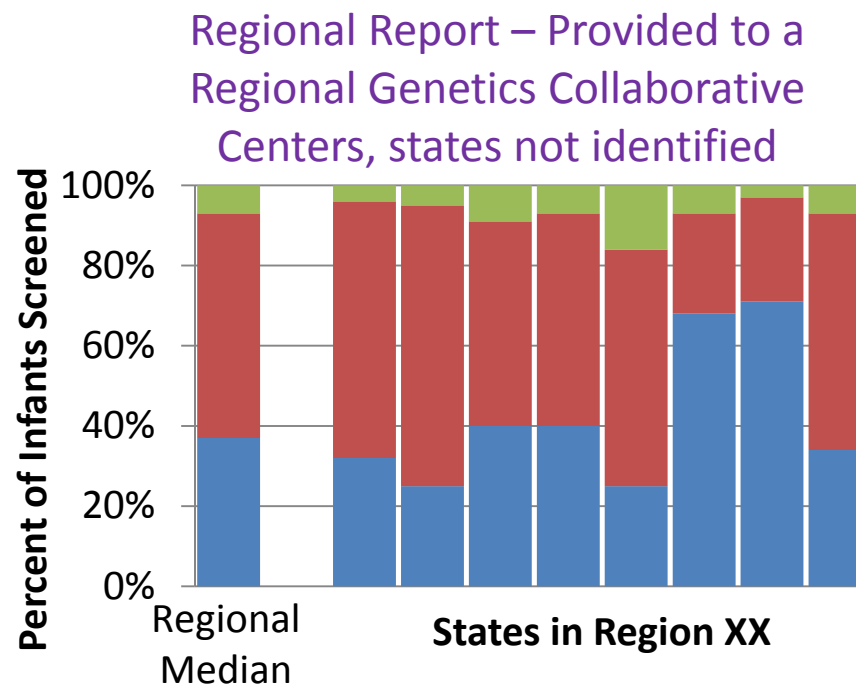
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QI 5 - Percent of infants receiving screening in specified time intervals

State and Regional Reports



State Report – Provided confidentially to a state with regional and national data for comparison



Regional Report – Provided to a Regional Genetics Collaborative Centers, states not identified

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QI 1. Percent of invalid dried blood spot specimens due to improper collection and/or transport

- **Percent of invalid dried blood spot specimens due to improper collection and/or transport**
- **Definition:** Number of specimens on which labs cannot *report* a complete newborn screening panel due to errors [occurring pre-analytic] divided by number of specimens submitted, multiplied by 100.



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Feedback on QI 1 – Percent of invalid dried blood spot specimens

- Important/Somewhat Important: 100%/0%
- Initial definition requiring at least some change: 95%
- Challenges getting the data: 67%

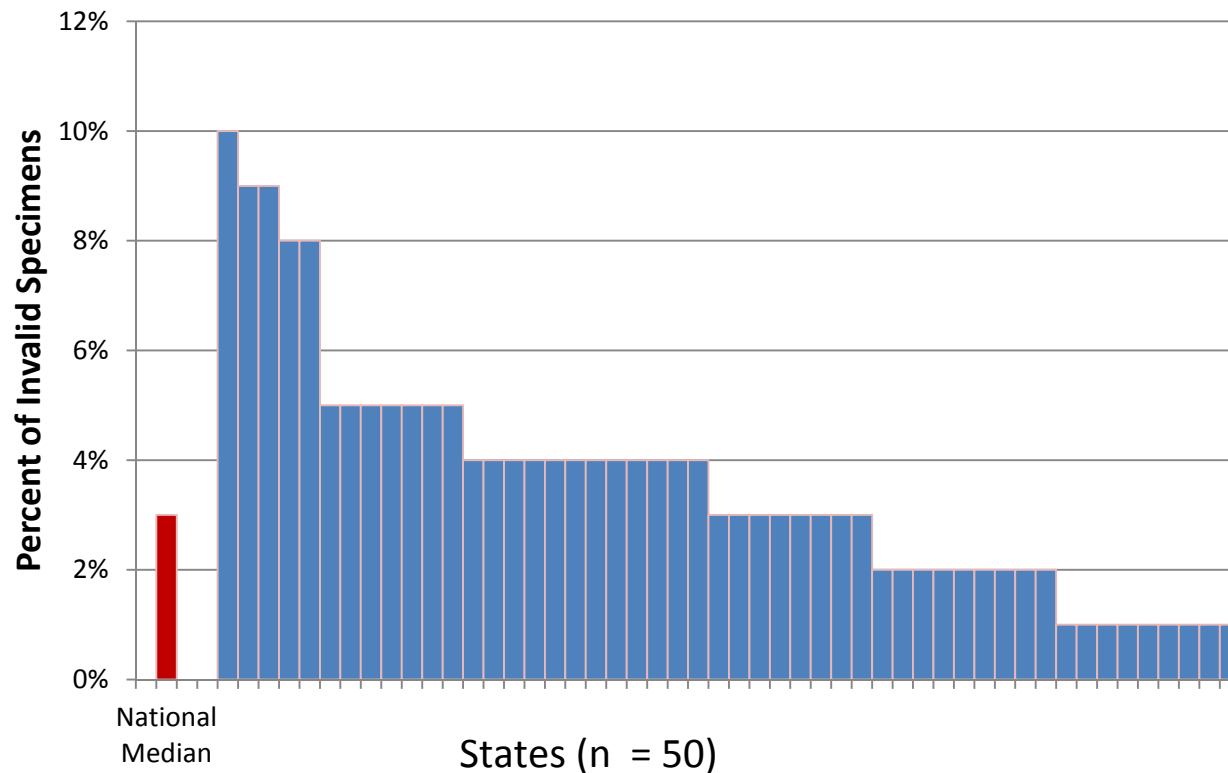


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QI 1. Percent of invalid dried blood spot specimens due to improper collection and/or transport

National Report
2012



Each bar represents one state.

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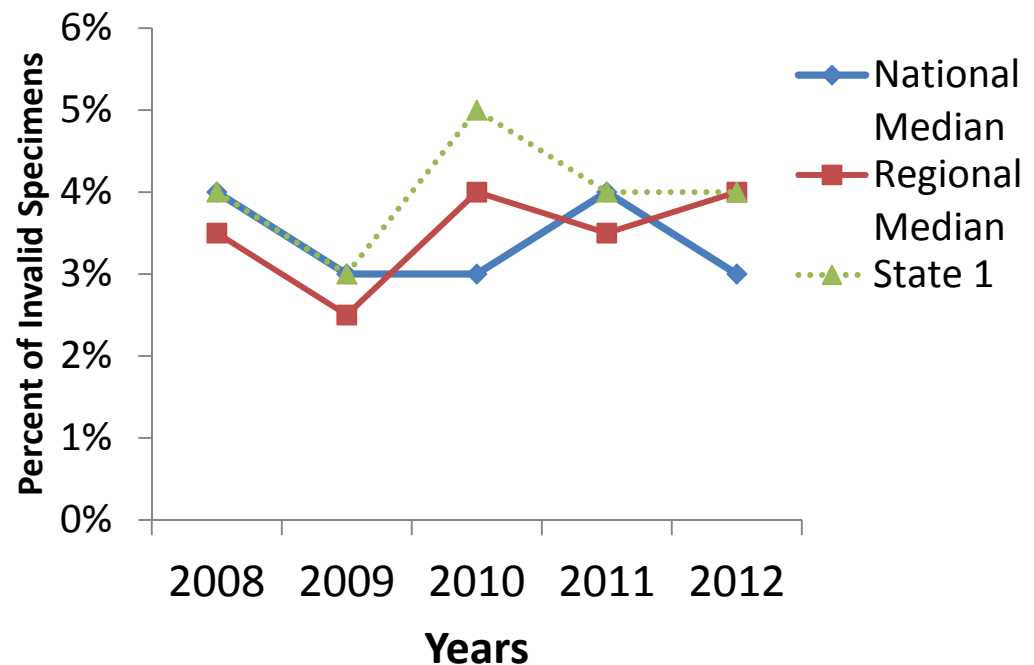


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QI 1. Percent of invalid dried blood spot specimens due to improper collection and/or transport

Longitudinal Trends



State Report – Provided confidentially to a state with regional and national data for comparison

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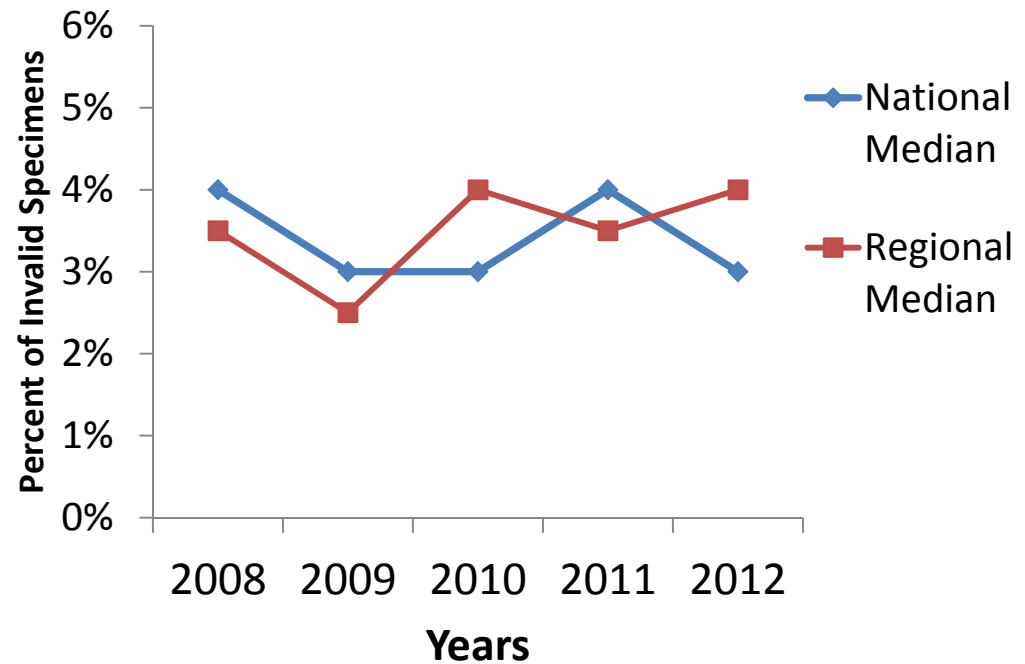
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Longitudinal Trends

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Conclusion

- 8 quality indicators have been developed by state newborn screening programs
- Indicators will be incorporated into NewSTEPS data repository
- Tracking of QIs will be used to support and strengthen NBS programs – sample reports available at www.newsteps.org
- We are seeking input from states and regions to help develop reports that will be useful



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Thank you

- Newborn screening community for providing insight and feedback
- Students in Colorado School of Public Health, Public Health Genetics Class
- Cooperative Agreement # U22MC24078 from the Health Resources and Services Administration (HRSA).



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|-------------------|----------------------|--------------------|---------------------|--------------------|
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| Susan Tanksley | William Mahle | Becky Bailey | Patricia Terry | |

THANK YOU



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Questions?

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