In Collaboration with

Incorporating State Newborn Screening Program Input on Quality Indicators

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The journey of a quality indicator

1. Brainstorming Initial QI Workshop
2. Gathering Input from Key Stakeholders
3. Editing and refining Indicators
4. Final Quality Indicators
5. Additional Input from stakeholders
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.
2011 Workshop to Develop QIs
Participants

Swapna Abhyankar
Natasha Bonhomme
Bob Bowman
Michele Caggana
Sara Copeland
Carla Cuthbert
Roger Eaton
Leslie Gafney
Karim George
Jane Getchell
Michael Glass
Rebecca Goodwin
Alaina Harris
Cheryl Hermerath
Patrick Hopkins
Ward Jacox
Christelle Larose
Mark McCann
Joanne Mei
Jelili Ojodu
Michele Puryear
Deborah Rodriguez
Debi Sarkar
Scott Shone
Marci Sontag
Sharon Terry
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
New Jersey Pilot Tested the QIs

- Used 2011 data to evaluate test the QIs
- Presented the findings at NBSGTS 2011
Transparency!
Pull back that curtain!
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
2012 QI Workshop Participants

Swapna Abhyankar
Cindy Ashley
Becky Bailey
Lou Bartoshesky
Linda Beischel
Stan Berberich
Natasha Bonhomme
Bob Bowman
Amy Brower
Michele Caggana
Colleen Clarke
Anne Comeau
Sara Copeland
William Cramer
Hank Dorkin
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
Michelle Lewis
Sharon Linard

Jennifer Macdonald
Mark McCann
Susan Oliver
Richard Parad
Melissa Parisi
Julie Raburn-Miller
Deborah Rodriguez
Inderneel Sahai
Scott Shone
Susan Tanksley
Laura Taylor
Lois Taylor
Patricia Terry
Tiina Urv
Sheila Weiss
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
QI Workgroup Members

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

All data portrayed in this sample report are fictitious data. 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.
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.
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%
QI 1. Percent of invalid dried blood spot specimens due to improper collection and/or transport

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

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

All data portrayed in this sample report are fictitious data. 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.
QI 1. Percent of invalid dried blood spot specimens due to improper collection and/or transport

Longitudinal Trends

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

All data portrayed in this sample report are fictitious data. 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.
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
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).
THANK YOU
Questions?

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