

Improving Quality Indicators Associated with Newborn Screening Specimen Collection and Transport

Scott M. Shone, PhD

Program Manager – NBS Laboratory

APHL Annual Meeting
May 19, 2015





Looking Back:
Making the
Past a Part of
Your Present

www.newlywedsurvival.com

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

1. Percent of unsatisfactory specimens due to improper collection
2. Percent of cards with all essential information
3. Frequency of condition detected at birth: First screen vs. Second screen
4. Rate of loss to follow-up: unsatisfactory & out-of range
5. Percent of parental refusals
6. Percent of eligible infants receiving valid newborn screening test
7. Average time:
 - a) From birth to specimen collection
 - b) From specimen collection to receipt by lab
 - c) From specimen receipt to reporting out results
 - d) From release of out-of-range results to notification of medical provider
 - e) From release of out-of-range results to medical intervention
 - f) From birth to diagnosis
8. Positive predictive value (PPV) of out-of-range screening results
9. Rate of out-of-range results, any referral to evaluation
10. Rate of missed cases (false negatives)

Welcome to the NewSTEPS Data Repository

The repository is now ready for data entry for basic state profiles, cases and quality indicators. We anticipate updates to occur on a quarterly basis, or sooner if needed. Please continue to check this page for announcements of new features. FAQs for the NewSTEPS Data Repository can be found linked [here](#). To consult the General User Guide please click [here](#). The State Administrators User Guide can be found [here](#).

What is Available Now?

Each state has the ability to review and revise basic state profile data, enter **cases** and **quality indicator data** through one designated state contact.

Reports

Sample Reports depicting fictional data summaries demonstrating the range of responses in quality indicators throughout newborn screening systems in the country while protecting the confidentiality of each state newborn screening program can be found linked here: [Sample Reports](#)

Quality Indicators

The 8 Quality Indicators that will be used to provide longitudinal comparisons within a program as well as comparisons to aggregate data across programs can be found linked here: [Quality Indicators](#) Worksheets demonstrating data that will be requested to populate the Quality Indicators can be found linked [here](#).

Current Activities

State Profile data can be entered prior to the ratification of the MOU. NewSTEPS has convened a series of **webinars** detailing the **Memorandums of Understanding (MOUs)** that will be entered into between APHL and newborn screening programs. NewSTEPS has contacted state representatives to help facilitate signatures. We request that all Quality Indicator and Infant level data entry be held until the MOUs are fully ratified.

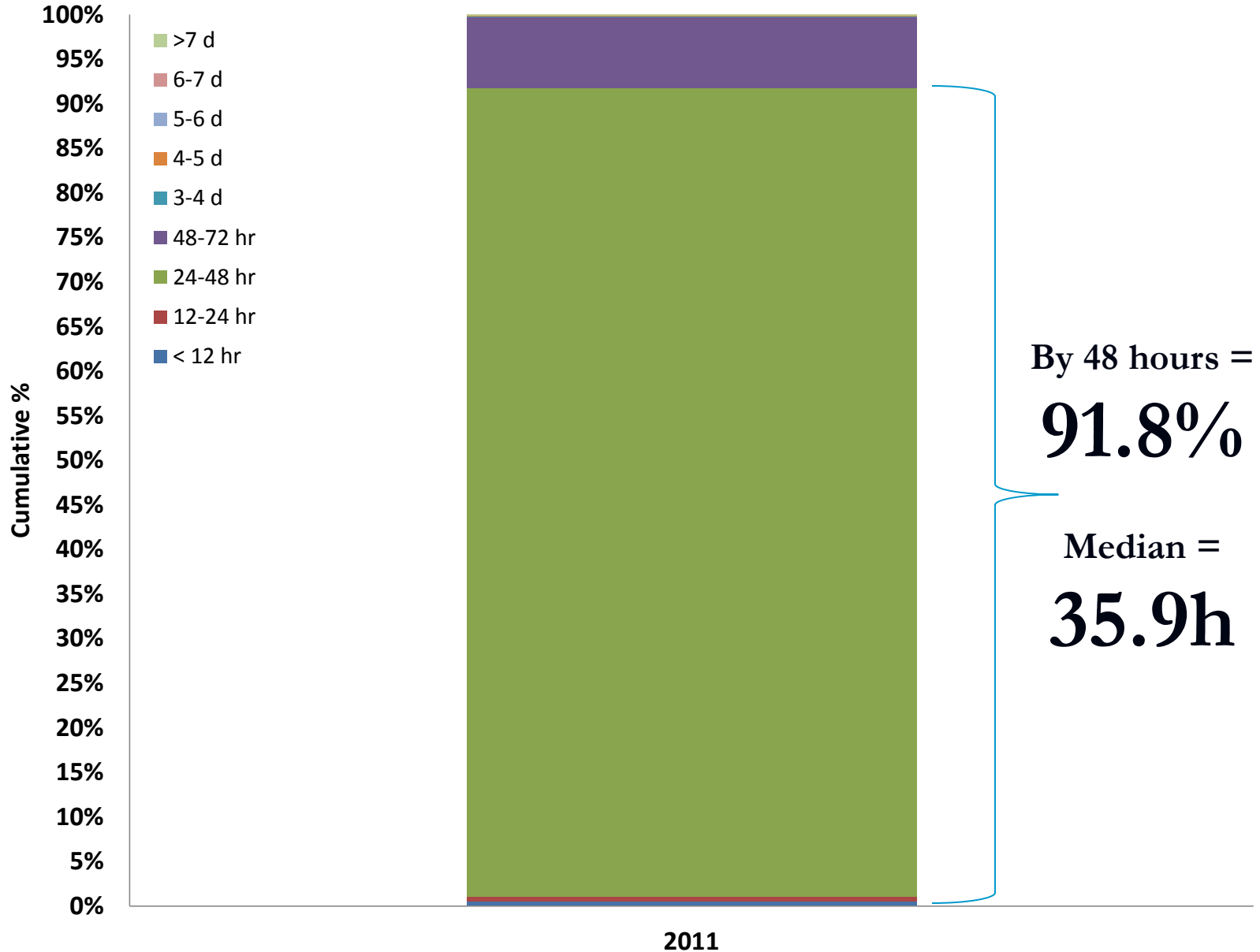
Pilot Study of Quality Indicators for the Next Generation of Data Collection into a National Newborn Screening Data Repository

1. Percent of unsatisfactory specimens due to improper collection
2. Percent of cards with all essential information
3. Frequency of condition detected at birth: First screen vs. Second screen
4. Rate of loss to follow-up: unsatisfactory & out-of range
5. Percent of parental refusals
6. Percent of eligible infants receiving valid newborn screening test
7. Average time:
 - a) From birth to specimen collection
 - b) From specimen collection to receipt by lab
 - c) From specimen receipt to reporting out results
 - d) From release of out-of-range results to notification of medical provider
 - e) From release of out-of-range results to medical intervention
 - f) From birth to diagnosis
8. Positive predictive value (PPV) of out-of-range screening results
9. Rate of out-of-range results, any referral to evaluation
10. Rate of missed cases (false negatives)

Specimen Collection and Submission

- N.J.A.C. 8:18-1.4(a)
 - Responsibilities of the chief executive officer
 - 9. Assure that specimens are taken before the infant is 48 hours old. If an infant is transferred or discharged from a facility prior to 48 hours of life, a specimen shall be collected prior to discharge unless there are medical reasons to prevent specimen collection

Time from Birth to Collection



Specimen Collection and Submission

- N.J.A.C. 8:18-1.4(a)
 - Responsibilities of the chief executive officer
 - 16. Assure that all specimens are forwarded to the testing laboratory within 24 hours of collection by next day delivery, or in the event service is unavailable with respect to Sundays and Federally designated holidays, then as soon thereafter as is practicable, using an account number the Department shall establish with an overnight package delivery service, which number the Department shall make available upon request

UPS CampusShip

The screenshot displays the UPS CampusShip web application interface. The browser title is "UPS CampusShip: Begin Your Shipment - Windows Internet Explorer provided by Department of Health". The address bar shows "https://www.campusship.ups.com/cship/create". The page features a navigation menu with "Shipping" and "Resources" tabs. A sidebar on the left lists options like "Create a Shipment", "Create a Return", and "View History". The main content area is titled "Create A Shipment" and includes a "Begin Your Shipment" section with a "Help" link. The form prompts the user to enter shipping information, with required fields marked with a diamond symbol. It is divided into three numbered sections: 1. "Where is this shipment going?" with an "Address Book" dropdown and links for "Enter New Address", "External Address Book", and "Corporate Address Book". 2. "Where is this shipment coming from?" with a "Ship From Address" field containing "New Jersey PHEAL-Newborn Screening" and "Irwin Margolin", a "Contact" field with "Irwin Margolin", and a "Return Address" dropdown set to "Same As Ship From". 3. "What are you shipping?" with a "Number of Packages" dropdown set to "1" and a "Use the same values for all packages?" checkbox set to "Yes".

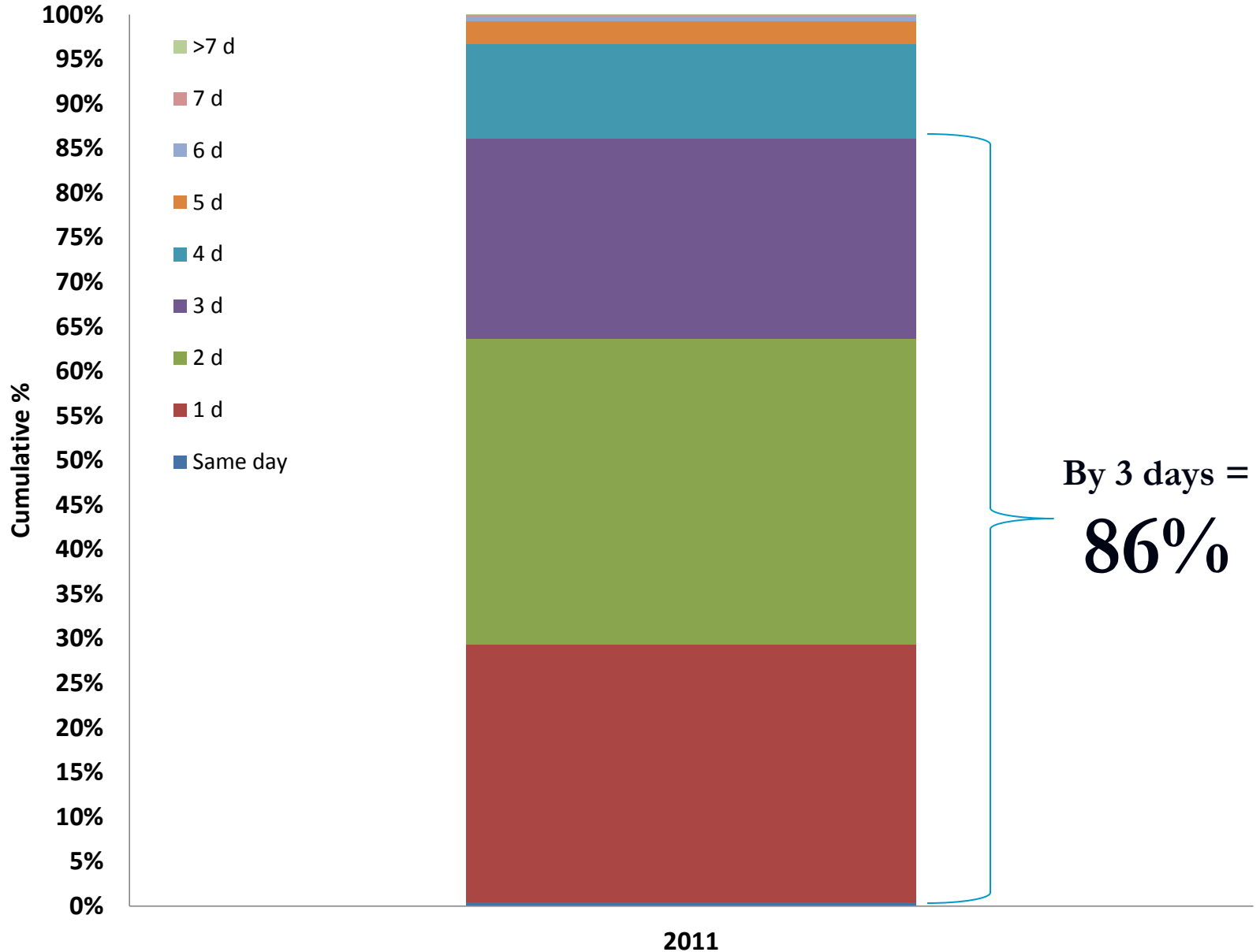
- Printing a shipping label
- Scheduling pickups
- Selecting Saturday delivery
- Tracking Packages

- The NJ NBS Laboratory is open Monday through Saturday and Holidays
 - Except New Year's Day, Memorial Day, Independence Day, Labor Day, Thanksgiving, and Christmas.
 - On Saturdays and Holiday, the most time sensitive procedures are performed with reduced staff.
 - Critical abnormal results are also reported on Saturdays and Holidays.

- The NJ NBS Laboratory works during all winter (and non-winter) states of emergency to ensure continuity of this critical testing service.

- Hospitals who do not follow these requirements are referred to HFE&L for investigation

Days from Collection to Receipt



Transmittal >3 days

| CODE | HOSPITAL | JAN | FEB | MAR | APR | MAY | JUN | JUL | AUG | SEP | OCT | NOV | DEC | TOTALS | % of all Transmittal |
|------|----------|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|--------|----------------------|
| XXX | A | 83 | 72 | 57 | 51 | | | | | | | | | 263 | 7.5% |
| | S | 46 | 58 | 123 | 27 | | | | | | | | | 254 | 7.2% |
| XXX | B | 81 | 39 | 51 | 57 | | | | | | | | | 228 | 6.5% |
| XXX | C | 59 | 36 | 43 | 49 | | | | | | | | | 187 | 5.3% |
| XXX | D | 38 | 38 | 36 | 21 | | | | | | | | | 133 | 3.8% |
| XXX | E | 53 | 27 | 21 | 31 | | | | | | | | | 132 | 3.8% |
| XXX | F | 46 | 38 | 25 | 20 | | | | | | | | | 129 | 3.7% |
| XXX | G | 29 | 26 | 30 | 41 | | | | | | | | | 126 | 3.6% |
| XXX | H | 36 | 2 | 29 | 33 | | | | | | | | | 100 | 2.8% |
| XXX | I | 18 | 18 | 34 | 19 | | | | | | | | | 89 | 2.5% |

Variety of Issues

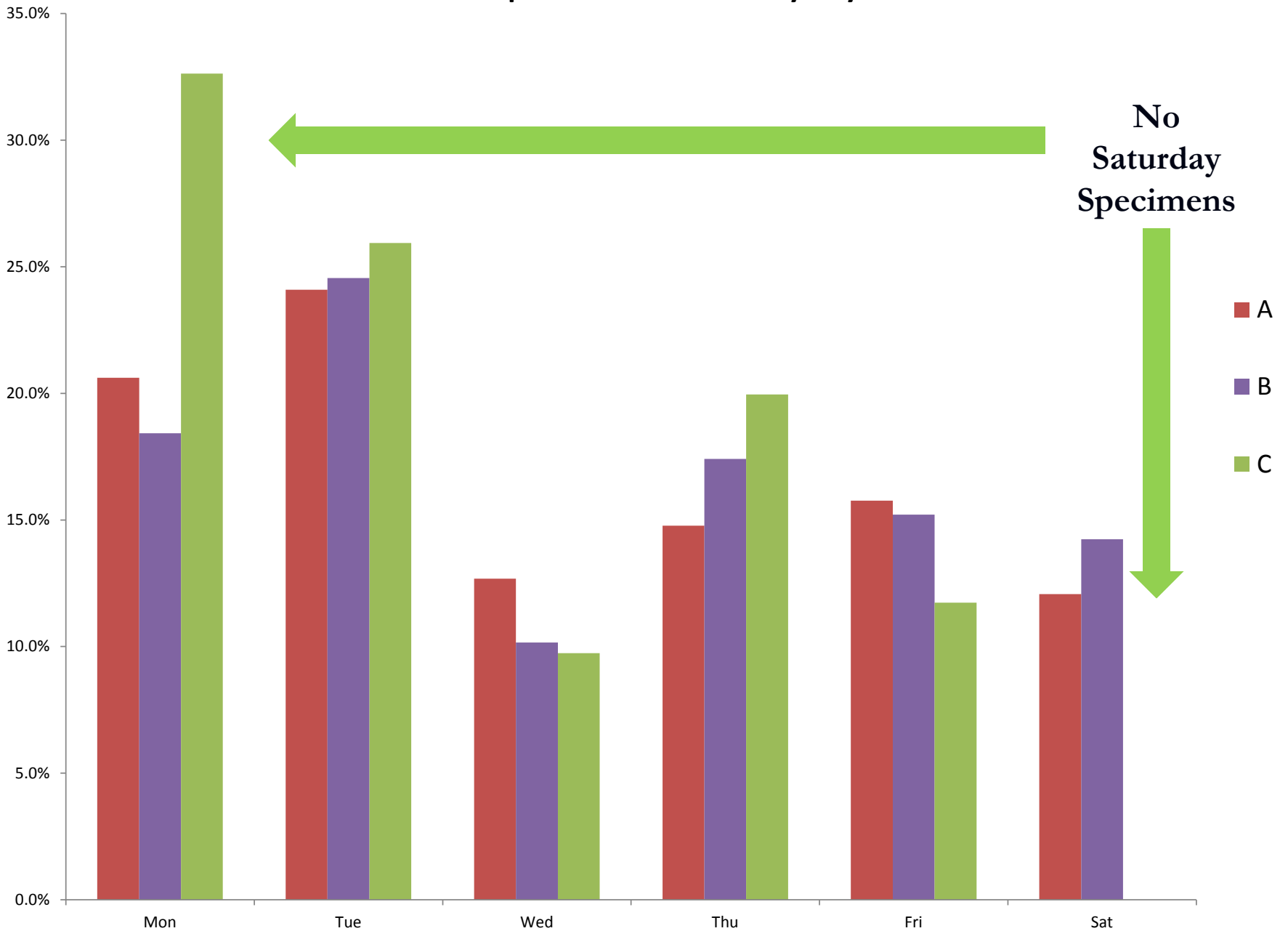
Collection

- Did not know
- Errors in reporting
- Medical issues
- Transferred

Transportation

- Saturday deliveries/Saturday pickups
- Batching specimens
- Timing of collection
- Incorrect use of UPS CampusShip system
- UPS delivery problem

Percent of Specimens Delivered by Day of the Week



Batching

10/1/2012



0

10/18/2012



10/2/2012



- 10/11/2012 - 6 days
- 10/10/2012 - 7 days
- 10/15/2012
- 10/17/2012
- 10/16/2012
- 10/15/2012
- 10/15/2012
- 10/15/2012
- 10/16/2012
- 10/16/2012
- 10/15/2012
- 10/15/2012
- 10/15/2012
- 10/14/2012
- 10/15/2012

- 9/19/2012
- 9/25/2012
- 9/25/2012
- 9/26/2012
- 9/25/2012
- 9/25/2012
- 9/25/2012
- 9/25/2012
- 9/19/2012
- 9/28/2012
- 9/27/2012
- 9/28/2012
- 9/28/2012
- 9/28/2012
- 9/28/2012
- 9/28/2012
- 9/27/2012
- 9/29/2012
- 9/29/2012
- 9/28/2012
- 9/29/2012

- 9/30/2012
- 9/30/2012
- 9/30/2012
- 9/25/2012
- 9/25/2012
- 9/30/2012

10-5-12
12299

10/19/12
12293

Give to Donna

Let Us Help You!

| CODE | HOSPITAL | JAN | FEB | MAR | APR | MAY | JUN | JUL | AUG | SEP | OCT | NOV | DEC | TOTALS |
|------|----------|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|--------|
| XXX | A | 11 | 14 | 13 | 12 | 14 | 14 | 10 | 8 | 3 | 4 | | | 103 |

- CLSI -Clinical and Laboratory Standards Institute
www.clsi.org
- LA04-A5 - Blood Collection on Filter Paper for Newborn Screening Programs; Approved Standard - Fifth Edition
- LA04-A5-DVD - Making a Difference Through Newborn Screening: Blood Collection on Filter Paper

LA4-A5
Vol. 27 No. 20
Replaces LA4-A4
Vol. 23 No. 21

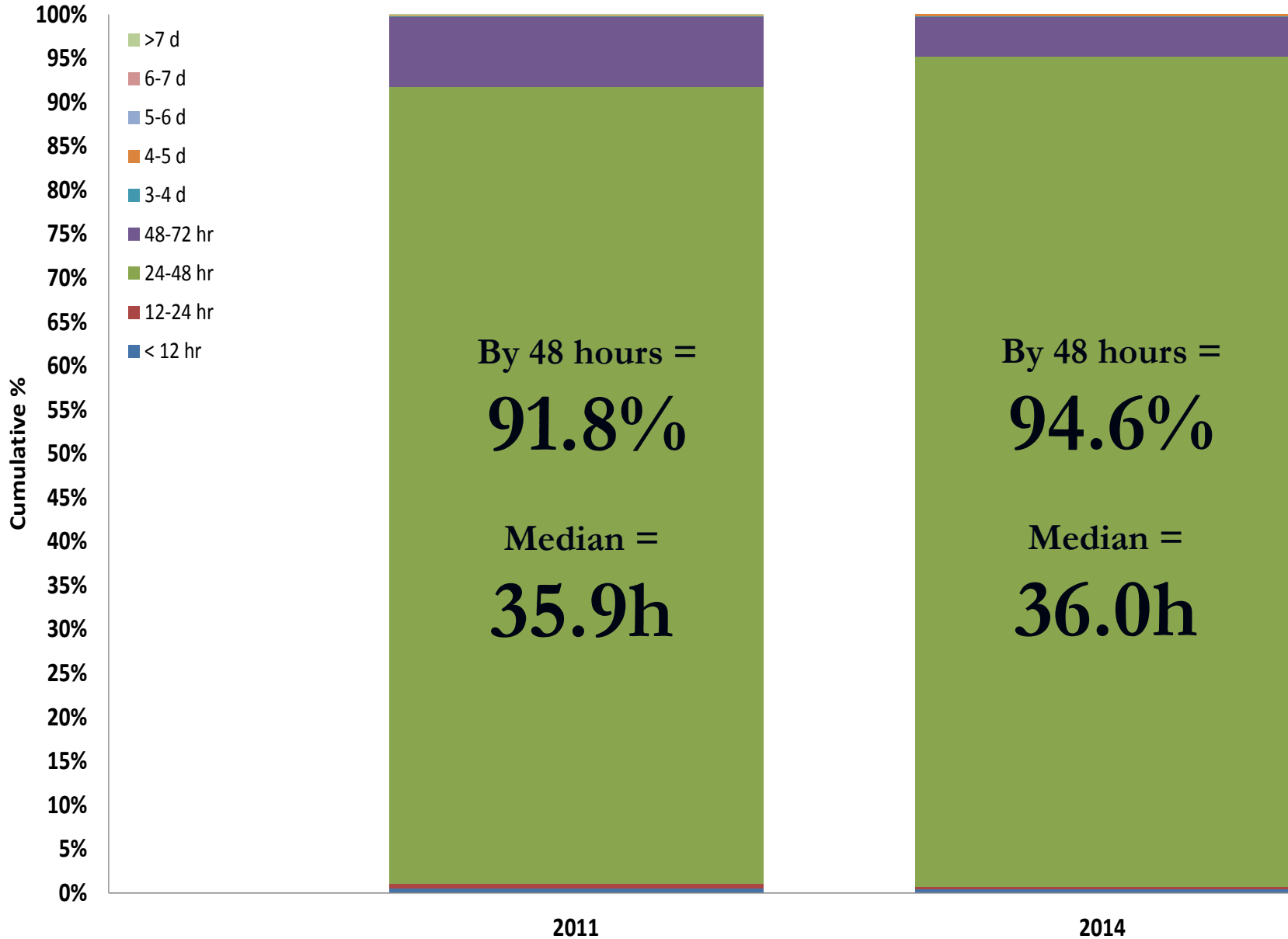
Blood Collection on Filter Paper for Newborn Screening Programs; Approved Standard—Fifth Edition

This document addresses the issues associated with specimen collection, the filter paper collection device, and the application of blood to filter paper, and provides uniform techniques for collecting the best possible specimen for use in newborn screening programs.

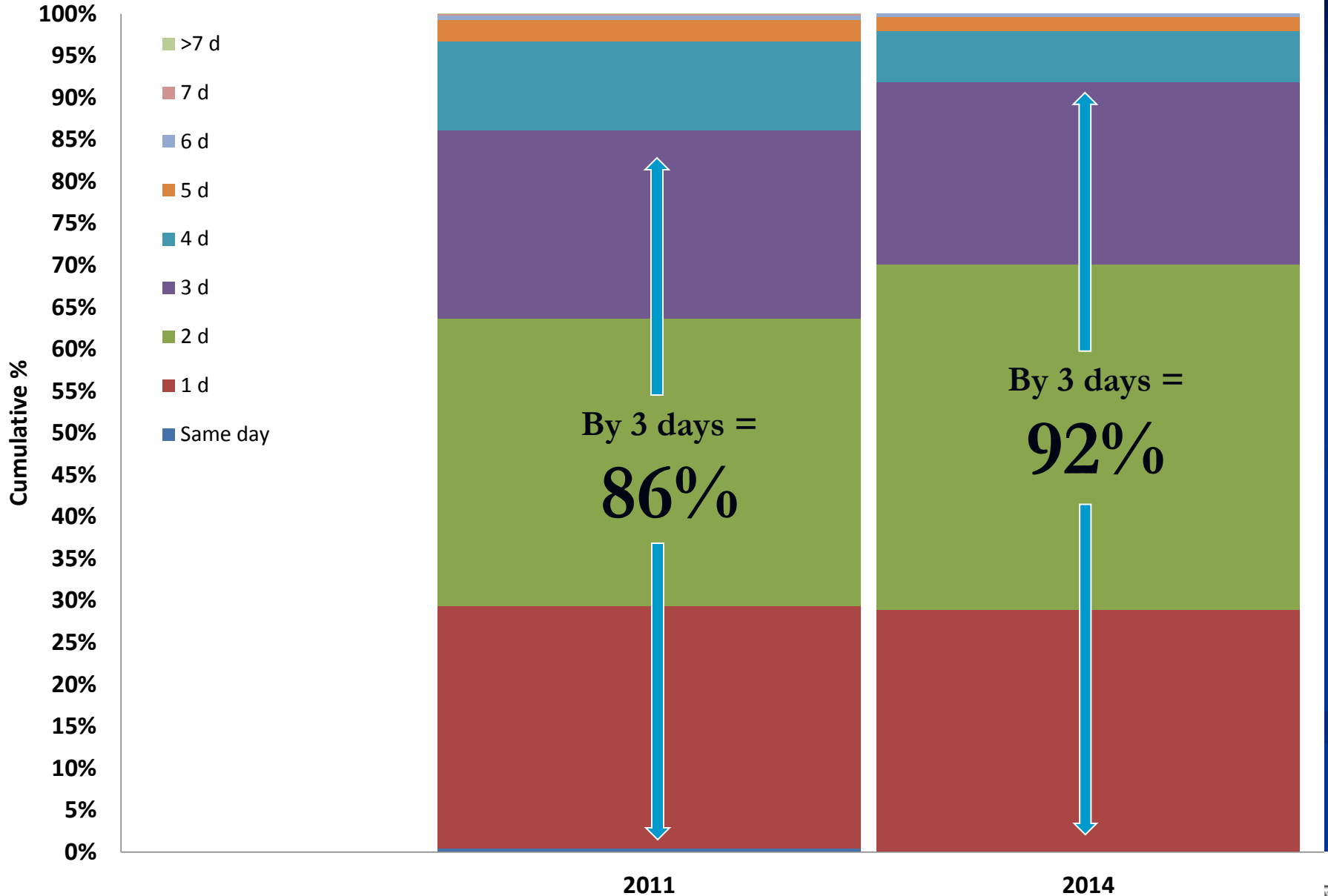
A standard for global application developed through the Clinical and Laboratory Standards Institute consensus process.



Time from Birth to Collection



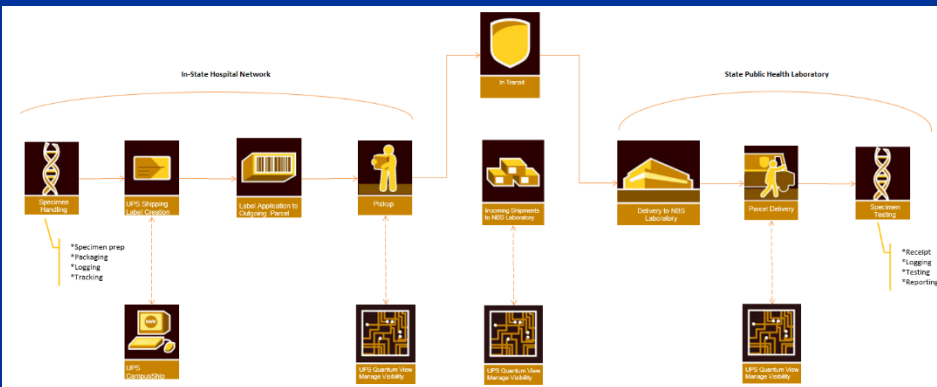
Days from Collection to Receipt




What's Next?

NJ NBS

NYMAC



QI 5f. Birth to confirmation of diagnosis



**Saving Babies
for 50 Years
1964 – 2014**

State of New Jersey
**NEWBORN
SCREENING**