Improving Quality Indicators Associated with Newborn Screening Specimen Collection and Transport

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APHL Annual Meeting
May 19, 2015
Looking Back: Making the Past a Part of Your Present

www.newlywedsurvival.com
RESULTS

Q1. Percent of Unsatisfactory Results Due to Imperior Collection

Results include all initial and repeat specimens. A test result is unsatisfactory if there is no way to currently differentiate. Red bars indicate percent of specimens rejected per CLSI guidelines.

Q2. Percent of Specimens Lacking Essential Information

Results include all initial and repeat specimens that were received missing essential demographic information and even if the data was ultimately provided. The red bars indicate percent of specimens lacking essential information.

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

• The shows the number and frequency of detection on first screen divided by total number.

Q4. Rate of Loss to Follow-up

• Overall, average time is not as useful as graphs of distribution.

Q5. Percent of Parent Refusals

Unable to calculate as this is currently monitored by the hospitals and physicians and not by the State Program.

Q6. Percent of Eligible Infants Receiving Valid NBS

• Table shows number of births reported to the State’s electronic birth certificate (EBC) system for the 3rd quarter of 2011, the number of 1st specimens received by the laboratory, the number of unsatisfactory 1st specimens, the number of “valid” 1st specimens (i.e. specimens unsuppressed), and percent of births screened.

• First specimens include initial specimens, repeat specimens with no previous specimens in the laboratory information system (LIS), and out of state births. In addition, actual patient data is not matched between the EBC and LIS. Therefore, this is the best available approximation of the QI measure.

• Overall, average time is not as useful as graphs of distribution.

Q7: Time from X to Y

• Chart A shows the time from birth to specimen collected for initial specimens and repeat unsatisfactory specimens from the 1st quarter in 2011.

• Some protocol dictates that specimens should be collected between 24 and 48 hours of life. 52.0% of initial specimens are collected in this time frame. This “>7d” spike in collection of repeat specimens is a likely result of the State’s (NJK) protocol.

• Figures C and D show in bars, therefore, all data in chart B is presented in days.

• These charts depict that specimens must be transmitted to the NBS Laboratory within 24 hours of collection. In addition, for initial specimens, States provides overnight delivery services. Transmitted times greater than 3 days for initial specimens suggests the potential holding of specimens or the hospitals and indicates a need for continued education.

• Repeat specimens sent to physicians are often transmitted via UPS, which is likely contributed to these times. The 7% “>7d” spike in collection of repeat specimens is a result of the State’s (NJK) protocol.

• This chart includes both borderline cases (mailed letter) and presumptive cases (phone call). The >7d spike in collection of repeat specimens is a likely result of the State’s (NJK) protocol.

• This chart includes both borderline cases (mailed letter) and presumptive cases (phone call). The >7d spike in collection of repeat specimens is a likely result of the State’s (NJK) protocol.

• This chart shows the initial and repeat specimens that were received missing essential demographic information and even if the data was ultimately provided. The red bars indicate percent of specimens lacking essential information.

METHODS

The New Jersey Newborn Screening Program routinely monitors several quality indicators (QIs) as part of Divisional quality improvement initiatives as well as Governor Christie’s statewide program to track the operations and performance of each department state government. QIs monitored include workload, specimen quality, demographics data collection quality, and time for specimen transmission from submitter to laboratory.

The New Jersey Newborn Screening Program is responsible for the next generation of data collection into a National Newborn Screening Data Repository. The repository is a collection of information from中山医学实验室, Natus Medical Inc., San Carlos, CA) was operated using a variety of built-in and user-defined data filters and queries.

Data were processed using Microsoft Excel, Microsoft Access, and Crystal Reports (Inaguate Tech, Southfield, MI).
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.

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.

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

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

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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

By 48 hours = 91.8%
Median = 35.9h
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

- Printing a shipping label
- Scheduling pickups
- Selecting Saturday delivery
- Tracking Packages
■ The NJ NBS Laboratory is open Monday through Saturday and Holidays
  ■ 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

By 3 days = 86%
## Transmittal >3 days

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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

No Saturday Specimens

- A
- B
- C
Batching
Let Us Help You!

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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

By 48 hours = 91.8%
Median = 35.9h

By 48 hours = 94.6%
Median = 36.0h
Days from Collection to Receipt

By 3 days = 86%

By 3 days = 92%
What’s Next?

NJ NBS

NYMAC

QI 5f. Birth to confirmation of diagnosis