Session 5 – Health Information Technology

Tuesday, Oct. 28, 3:30pm-5:00pm

Moderators – Robin Thomas, RN, California Department of Public Health and Patricia Scott, MT(BT), Delaware Public Health Laboratory

Newborn Screening for CCHD – The First Six Months of Data Reporting in Michigan Using Multiple Electronic Options
K. Andruszewski, J. Bach, M. Kleyn, K. Urquhart, K. Tomasko, J. Ehrhardt and B. Young, Michigan Department of Community Health, Lansing, MI

Abstract

In 2011, pulse oximetry was recommended by the U.S. Department of Health and Human Services SACHDNC as an important screening tool for detection of critical congenital heart disease (CCHD) in asymptomatic newborns.

In 2012, the Michigan Department of Community Health (MDCH) implemented a HRSA-funded CCHD Newborn Screening (NBS) Demonstration Program to: 1) increase the number of Michigan newborns screened for CCHD using a validated screening protocol; and 2) develop state infrastructure for collection of CCHD screening data through electronic health information exchange. Effective April 1, 2014, MDCH has implemented mandated screening of all Michigan newborns for CCHD using pulse oximetry with electronic reporting of screening results to the state NBS Program.

MDCH is collecting individual-level CCHD screening data on all babies. Three primary reporting mechanisms are available to hospitals, with an additional paper format for home births. Hospitals can report CCHD screening data to MDCH by: 1) using an online individual entry module called eReports; 2) creating a report from data entered into their electronic medical records and submitted securely to the MDCH FTP site; or 3) HL7 messaging. The data collected includes pulse oximetry readings, individual screening results and demographic information on the newborns. These data will allow MDCH to track the number of newborns being screened as well as follow up on missed and failed screens. The analysis of data will allow MDCH to determine compliance with screening protocols, assess errors in reporting, and evaluate the Michigan CCHD screening algorithm.

We will be presenting on the first six months of screening data for Michigan including: an overview of the reporting methods selected by hospitals and midwives, total number of infants screened, number of failed screens, number of and reasons for missed screens, and screening performance metrics (false positive rate and positive predictive value).

Presenter: Kristy Tomasko, BS, Michigan Department of Community Health, Lansing, MI, Phone: 517.335.8532, Email: tomaskok@michigan.gov

**Summary**

In 2011, pulse oximetry screening was recommended by the Secretary of Health and Human Services as an important screening tool for detection of critical congenital heart disease (CCHD) in asymptomatic newborns.¹

In 2012, the Michigan Department of Community Health (MDCH) implemented a Health Resources and Services Administration (HRSA) funded CCHD Newborn Screening (NBS) Demonstration Program to: 1) increase the number of Michigan newborns screened for CCHD using a validated screening protocol; and 2) develop state infrastructure for collection of CCHD screening data through electronic health information exchange. Effective April 1, 2014, MDCH has implemented mandated screening of all Michigan newborns for CCHD using pulse oximetry with electronic reporting of screening results to the state NBS Program.

MDCH is collecting individual-level CCHD screening data on all babies. Three primary reporting mechanisms are available to hospitals for the pulse oximetry screenings, with an additional paper format for home births. Hospitals can report CCHD screening data to MDCH by: 1) using an online individual entry module called PerkinElmer’s eReports; 2) creating a report from data entered into their electronic health records (EHR) and submitted securely to the MDCH file transfer protocol (FTP) site; or 3) HL7 messaging. The data collected includes pulse oximetry readings, individual screening results and demographic information on the newborns.

**Pulse Oximetry Data Elements**

<table>
<thead>
<tr>
<th>Baby’s Demographics</th>
<th>Additional follow-up data elements</th>
</tr>
</thead>
<tbody>
<tr>
<td>NBS kit number</td>
<td>Clinical Exam</td>
</tr>
<tr>
<td>Date of screen</td>
<td>Date/Time</td>
</tr>
<tr>
<td>Time of screen</td>
<td>Findings</td>
</tr>
<tr>
<td>Right Hand Saturation</td>
<td>Echocardiogram</td>
</tr>
<tr>
<td>Foot Saturation</td>
<td>Date/location</td>
</tr>
<tr>
<td>Difference</td>
<td>Findings</td>
</tr>
<tr>
<td>Outcome</td>
<td>Case Report</td>
</tr>
<tr>
<td>Reason screening was not done</td>
<td>Antenatal ultrasound?</td>
</tr>
<tr>
<td></td>
<td>How CCHD was first suspected?</td>
</tr>
<tr>
<td></td>
<td>Surgery date/hospital</td>
</tr>
<tr>
<td></td>
<td>Catheterization</td>
</tr>
<tr>
<td></td>
<td>Diagnosis</td>
</tr>
</tbody>
</table>

The first method of reporting clinical data is PerkinElmer’s eReports. This is a web-based module which is accessible through Michigan’s Single-sign-on application and customized for pulse oximetry. Data is entered at the hospital facility by various clinical staff, matches to data in the PerkinElmer Laboratory information and follow-up management system via a linkage algorithm and made accessible to MDCH NBS follow-up staff. eReports also holds the follow-up modules for clinical exam, echocardiogram and case reports for failed screens. This is the only reporting method where this follow-up information can be collected.

The second method of reporting is data submission by FTP site through the Data Exchange Gateway. This allows the birthing hospitals to extract a daily or weekly data file of required data elements from the electronic health record (EHR) to create a batched file for upload to a secure state FTP site. This
method requires the hospital to obtain authorizations to connect to the server. The file is downloaded to the eReports pulse oximetry holding table where it links with the NBS blood spot card information.

The final method for reporting is by HL7 messaging. This method requires a hospital to build the CCHD pulse oximetry reporting fields into its EHR. Once data is entered into these fields, the messages are sent nearly instantaneously from the hospital EHR to MDCH via the MDCH Data Hub into PerkinElmer’s eReports database. Data reporting and message flow in Michigan requires connectivity to MiHIN, the Michigan Health Information Network. MiHIN serves as the Statewide Shared Services system to transfer data from the State to organizations and vice versa. For the purposes of CCHD pulse oximetry, birthing hospitals interested in sending these messages via HL7 must be part of a sub-state Health Information Exchange that has an arrangement with MiHIN in order to send the data to the MDCH Data Hub which then puts the information into the eReports database. Infrastructure development was needed to design the HL7 message. The NBS program collaborated with the MDCH Office of Medicaid Health Information Technology and the Department of Technology, Management and Budget to access Medicaid Meaningful Use funding for implementation of HL7 messaging for CCHD. Development included a project charter, requirements gathering and an Implementation Guide specific to Michigan’s needs, based on a national draft reference guide. The Implementation Guide provided detailed specifications for mapping to receive the hospital messages into the NBS database, and ways to handle errors in the data and messages.

Each pulse oximetry reporting method provides different pros and cons for a hospital system. While eReports is the cheapest option for hospitals in terms of IT costs, it requires the most unit staff time. FTP transfers incur some costs for modifying the hospital EHR but the data can be transmitted semi-automatically. Lastly, HL7 requires the largest upfront expenditure for hospital systems in modifying and developing the HL7 message but once development is complete, minimal hospital staff time is required. It should be noted that future plans are for the NBS card demographic fields to be sent by HL7 messaging in addition to the CCHD message. This incentive will save significant staff time and is currently helping promote the use of HL7 messaging. While most of our efforts have been focused on hospital submissions, we have also worked with midwives caring for the homebirth population to offer two reporting options: paper forms and eReports. Michigan midwives have been using both methods to submit data.

The individual-level pulse oximetry data enables MDCH to track the number of newborns screened and to follow-up on missed and failed screens. The analysis of data will allow MDCH to determine compliance with screening protocols, assess errors in reporting, and evaluate the Michigan CCHD screening algorithm.

After excluding births from hospitals implementing HL7 messaging, 68% of newborns with a NBS blood spot card submitted to MDCH had pulse oximetry results reported and linked to the blood spot data in the first six months following statewide implementation. Due to problems with data quality, more pulse oximetry results have been reported but have not been successfully linked to a NBS blood spot record. Therefore, these are not considered to be a successfully reported result. MDCH set an initial goal that 90% of infants with a blood spot screen also have a pulse oximetry result reported. In the first six

months, 21 of 76 regular nursery units met this goal (excluding units submitting via HL-7, Special Care Nurseries, and Neonatal Intensive Care Units).

From April through September, 2014, 34,864 newborns had some pulse oximetry data reported. Of the 34,248 newborns screened for CCHD, 34,089 passed, 141 needed a rescreen and 18 failed. The median age at initial screen for these newborns was 25 hours. A total of 616 newborns were reported as not screened; reasons included transfer, prenatal diagnosis or missed.

Errors in following the screening algorithm have been identified when MDCH staff followed up on the 18 “failed” screens. Examples of these errors include newborns being screened while in distress and newborns failing the initial screen but receiving a passing rescreen instead of obtaining a clinical exam as recommended by the algorithm. Five failed screens had the pulse oximetry values recorded incorrectly by hospital staff and should not have been reported as failed screens. Three newborns with failed screens were moved to the NICU, received further follow up and were diagnosed with the following conditions: mild restrictive Patent Ductus Arteriosis, pulmonary hypertension and congenital pneumonia.

The first six months of data has helped MDCH identify areas that require further education for hospitals such as appropriately following the algorithm and the importance of accurate data reporting. After more data are collected, the CCHD screening performance metrics will be calculated. NBS staff will continue to monitor and evaluate the pulse oximetry CCHD screening program, particularly focusing on evaluating the MDCH screening algorithm.

References:

CCHD Screening: Screening Interpretation and Data Sharing Between Providers and Public Health to Improve Outcomes
A. Saarinen\(^1\), L. Daussat\(^2\);
\(^1\)Newborn Foundation | Coalition, St. Paul, MN, \(^2\)OZ Systems, Arlington, TX

Abstract

This session will highlight a recent retrospective review of newborn CCHD screening in Minnesota, and will review the challenges in implementing a new point of care screening, complexity of algorithm interpretation and follow up, and feasibility of data reporting. A review of pilot screening data for nearly 8,000 newborns in the well-baby nursery showed provider misinterpretation of screening results in more than 35 cases.

The session will provide public health leaders and pediatric health care providers and administrators with the latest information, strategies and tools to fully leverage the role of health information technology and screening implementations, including how data in timely, quality newborn intervention and follow up. Participants will walk through the steps how screening is done, hurdles with algorithm interpretation, and how information is collected and communicated in a robust data sharing framework. A clinician, newborn screening program expert, health IT expert and policy/advocacy representative will

discuss real world examples of how health data and information exchange can reduce disparities, improve care and outcomes.

Attendees will also learn how clarifications (technical and non-technical) around screening protocols, electronic data collection, analysis and interoperability through established frameworks supporting:
- Patient Safety and Quality through open, streamlined communications
- Efficiency: Improving provider staff workflow
- Improved Surveillance and Quality: allows local, state or federal public health programs to monitor performance and intervene/support when appropriate

**Presenters:** Annamarie Saarinen, Newborn Foundation | Coalition, St. Paul, MN, Phone: 612.964.6728, Email: annamarie@newborncoalition.org and Lura Daussat, OZ Systems, 2001 NE Green Oaks Blvd., Suite 100, Arlington, TX 76006, Phone: 469.867.1826, Email: ldaussat@oz-systems.com

**Summary**

This session will highlight a retrospective review of newborn CCHD screening in Minnesota, and will review the challenges in implementing a new point of care screening, complexity of algorithm interpretation and follow up, and feasibility of data reporting. The session will provide a policy and public health IT perspective of newborn CCHD screening, and a review of pilot screening data for nearly 8,000 newborns in the well-baby nursery showed provider misinterpretation of screening results in more than 35 cases.

As CCHD is a relatively new point of care screening program, data collection is integral to program evaluation and protocol review over time. As with many states, as Minnesota began screening, data collection was included to capture a variety of data elements related to CCHD screening. In addition to recording oxygen saturation values for both extremities and the difference between the two, hospital screeners collect the perfusion index and pulse rate. While those specific data elements are recorded, they are also able to capture the overall interpretation of the screening and later review those results.

For statewide implementation, Minnesota began using the New Jersey protocol which differs slightly from the Kemper protocol and requires both the hand and the foot be greater than 95%. By using a decision support tool for reporting of CCHD results, it helps the hospitals with their interpretation and allows the state to evaluate the interpretation of screeners, thus helping with quality assurance and quality control.

Timing is critical to data collection for CCHD. Both public health staff and clinicians are busy, so direct reporting can help streamline data collection. It can help avoid inaccurate data collection or problems with algorithm interpretation. The goal of direct results reporting in the Minnesota program is to streamline efforts among screeners, improve data integrity and identify screening issues among hospitals, particularly as they are implementing something new into their standards of care. This implementation involved working with nursery screeners and program managers and collecting information directly from the device. While direct results reporting can be a challenge, data can be streamed directly from the device into a software that reports directly to public health. One challenge is that not all devices stream data, so some manual data entry of results had to be allowed.

While interoperability between devices and public health is a goal, it is often a challenge in real implementation. Hospital bio-med staff are often burdened with a variety of projects, thus putting...
CCHD direct results reporting lower on the list of projects. However, once it is implemented, it does exchange results directly from the device, thus enhancing the quality and quantity of data that public health receives. This results in a better way to review the data and identify opportunities for improvement in CCHD screening.

The Minnesota program aims to show how electronic data collection can also help ensure children with abnormal screens receive the recommended follow-up in the recommended timelines. It also ensures hospital reporting compliance and that standards of care are truly standard. When the collection of raw data is mandated, the degrees to which screening supports CCHD can be defined. This level of data proficiency also supports valuable birth defect monitoring and aggregate research as it can verify what screening values are associated with which heart defects or other secondary conditions. It can also help identify which hospitals may be struggling with implementation, equipment issues or problems with reporting, followup diagnostics testing or referrals. Direct results reporting may also allow for more accurate understanding of false negatives and positive and sets the tone for other point of care screenings.

Improving Short- and Long-term Follow-up Efficiency Through Implementation of an Internet Case Management System
B. Vogel, M. Caggana and J. Orsini, New York State Department of Health, Albany, NY

Abstract

Objectives: To describe the impact of an internet case management system on short- and long-term follow-up in NYS.

Methods: An internet case management system (iCMS) was developed by Neometrics in response to Program specifications, which includes online diagnosis forms for cystic fibrosis and SCID, image upload capability, fillable long-term follow-up forms, remote entry of case notes by stakeholders, viewing whether the case is open or closed and new physician information. Hospital of birth newborn coordinators (n=37), local health officers (n=15), and cystic fibrosis specialty care centers (n=11), were trained to use the tool.

Results: From August 2013 to April 2014, 427 case notes and images were entered by birth hospitals, local health officers and specialty care centers. The use of the system allowed the newborn screening program staff to cancel pending follow-up letters, close cases and address problematic cases sooner. By report, the system also improved internal communications within the birth hospitals by allowing newborn screening coordinators to track case status and facilitate case closure.

Conclusions: In this limited pilot study, the use of iCMS improved the efficiency of follow-up by providing real time communication between external stakeholders and NBS Program follow-up staff. The NBS Program staff learned that hospitals, specialty care centers and local health officers were often making phone calls and sending letters to parents for cases that were already resolved. Plans to expand the system include building additional short- and long-term follow-up forms for all disorders and engaging the remaining 50 local health officers, 100 birth hospitals and 70 specialty care centers.

Presenter: Beth Vogel, MS, New York State Department of Health, Wadsworth Center, Newborn Screening, Albany, NY, Phone: 518.474.7945, Email: bmh06@health.state.ny.us
Summary

In 2011, the New York State Newborn Screening Program coordinated with physicians from specialty care centers and the software vendor, Natus to develop an internet-based case management application for short- and long-term follow-up. Predicted benefits of the system were an increased ability to interact with providers, enhanced provider access to newborn screening results, and bi-directional electronic health information exchange.

The system was developed in response to Program specifications, and includes online diagnosis forms for cystic fibrosis and SCID, image upload capability, fillable long-term follow-up forms, remote entry of case notes by stakeholders, viewing whether the case is open or closed and new physician information.

Implementation of the case management application began in August 2013. Hospital of birth newborn coordinators (n= 60), local health officers (n=15), and cystic fibrosis specialty care centers (n=11), were trained to use the tool.

From January 2014 to August 2014, 1,187 case notes and images were entered by birth hospitals, local health officers and specialty care centers. The use of the system allowed the newborn screening program staff to cancel pending follow-up letters, close cases and address problematic cases sooner. Each image or notebook entered generates a reminder for newborn screening staff to review the case.

The hospital of birth newborn screening coordinators are frequently using the system and each notebook they enter typically eliminates scheduled follow-up calls or letters. The newborn screening coordinators are responsible for obtaining repeat specimens when requested by the laboratory. Sample notebooks and follow-up actions include:

- Notebook: The baby has expired.
  Follow-up action: The case is closed and all follow-up actions are cancelled

- Notebook: A repeat specimen has been collected.
  Follow-up action: All letter and call actions are cancelled. A case review action is entered for one week after the specimen was collected. The review action automatically cancels when the repeat sample is received.

- Notebook: The primary care provider was notified of the need for a repeat sample.
  Follow-up action: The due date of scheduled letters informing the hospital of birth and primary medical doctor that a repeat is required is delayed.

- Notebook: The family was notified of the need for a repeat specimen
  Follow-up action: The due date of scheduled letters informing the parents of the need for a repeat sample is delayed.

- Notebook: The family cannot be contacted
  Follow-up action: If needed, additional case management is done including checking the NYS Immunization Registry, birth certificate records and contacting the county health officer. If all other follow-up has been exhausted, the case is closed lost to follow-up.

- Notebook: The infant is in the NICU on total parenteral nutrition
  Follow-up action: The due date of scheduled calls and letters is delayed

- Image: Diagnosis forms or follow-up lab results
  Follow-up action: The case is typically closed.

- Image: Letter sent to the mother of the baby

Follow-up action: The due date of letters to be sent to the mother is delayed and the mother’s address and the baby’s name are verified. Another name for the baby is frequently obtained from these letters.

- Image: Letters sent to the primary care provider
- Follow-up action: The due date of the scheduled letter to the primary medical doctor and the hospital of birth is delayed. The demographic information and PMD information is updated, if needed.

In addition to entering case updates and documents, the hospital of birth newborn screening coordinators are able to view case status and closing diagnosis. By report, the system improved internal communications within the birth hospitals by allowing newborn screening coordinators to track case status and facilitate case closure. For example, often when a repeat sample is requested for a borderline screen for congenital hypothyroidism, the PMD chooses to order thyroid function testing instead. The newborn screening coordinator can view the case status to stop follow-up efforts when the case status changes to closed.

The Cystic Fibrosis Specialty Care Centers use the application and it has improved communication with our Program. The system maintains a list of open cases, which are removed from a referral landing grid when an online diagnosis form is completed. Previously newborn screening follow-up staff compiled open case lists for Centers as part of their follow-up efforts. This system has removed the need to manually maintain these lists. The specialists also enter case notes when an appointment is scheduled for a sweat test. Follow-up letters and calls can be delayed until after the scheduled appointment, removing the need to for at least one letter and phone call per case. The Centers also enter a note when they are unable to confirm the PMD and when the parents miss their scheduled appointment. Both of these updates prompt immediate additional follow-up by Newborn Screening Program staff.

Local health officers receive a letter if a repeat specimen has not been obtained four weeks after the initial request. The local health officers are able to view the case status and enter case notes to summarize their follow-up efforts. Their use of system has eliminated follow-up staff time spent providing updates and documenting efforts. The system has also improved communication between the health officers and hospital of birth staff preventing redundant calls to the primary care provider and to the mother of the baby.

Through use of this system, the NBS Program staff learned that follow-up efforts were often duplicated by the stakeholders and the Program. Plans to expand the system include building additional short- and long-term follow-up forms for all disorders and engaging the remaining 50 local health officers, 77 birth hospitals and 70 specialty care centers. Once the system is fully implemented, it will allow the NBS Program to focus follow-up efforts on cases that are not being followed by another stakeholder.
Performance Feedback and Proactive Alerts from the BORN Ontario Registry Have Contributed to More Comprehensive and Timely Newborn Screening

J. Milburn\textsuperscript{1,2}, S. Dougan\textsuperscript{2}, C. McRoberts\textsuperscript{1}, J. Marcadier\textsuperscript{2}, A. Sprague\textsuperscript{1}, P. Chakraborty\textsuperscript{1,2}; \textsuperscript{1}Better Outcomes and Registry and Network (BORN) Ontario, Ottawa, ON, Canada, \textsuperscript{2}Newborn Screening Ontario, Ottawa ON, Canada

Abstract

The Better Outcomes Registry and Network (BORN Ontario) is the authoritative source for maternal/child information in Ontario. BORN captures information across the continuum of care; from the initial prenatal screening result, through labour and birth, postpartum, and all newborn screening results and follow-up investigations and diagnoses. Through comprehensive data collection, BORN helps identify trends and gaps in provision of care, and informs appropriate updates to screening algorithms and processes. With almost 100 birthing hospitals and over 80 midwifery practices submitting about 145000 newborn screening samples each year, there is measurable variation in practice across the province.

BORN’s Maternal Newborn Dashboard (MND), which launched in November 2012, is a data feedback mechanism with the goal to promote change, decrease practice variation and encourage best practices by alerting users to their organizations’ performance status across a set of key performance indicators (KPI). The newborn screening unsatisfactory sample rate has been included as one KPI in the BORN MND. Before the MND, the overall unsatisfactory sample rate was 2.6%. One year later, the provincial unsatisfactory rate was 1.5%. This dramatic improvement may be due to hospitals’ awareness of the KPI coupled with Newborn Screening Ontario’s (NSO) education initiatives and support of change at the submitter level.

Newborn screening data is also linked with provincial birth records in BORN to identify infants who do not have a newborn screening record by 14 days of age, and NSO is notified daily of all potential missed screens. NSO contacts care providers to determine if the newborn screen was obtained, declined, or planned, and monitors the case until the family is notified or a sample is obtained. Between February 2012 and April 2014 there have been 1250 potential missed screen alerts made to NSO for follow up. Analysis has identified common reasons for delayed or missed samples, allowing NSO to target education and implement processes to mitigate the risk.

These two examples demonstrate the utility of the BORN Registry and Network to identify gaps and variability in preanalytical practices and allow submitters and NSO to implement corrective actions for more comprehensive and timely newborn screening.

Presenter: Jennifer Milburn, MHA, Newborn Screening Ontario, Ottawa ON, Canada, Phone: 613.302.9094, Email: jmilburn@cheo.on.ca

Summary

The Better Outcomes Registry & Network (BORN Ontario) is Ontario’s prescribed pregnancy, birth and childhood registry. Established to collect, share and rigorously protect critical data about each child born in the province, BORN Ontario manages an advanced database that delivers reliable, secure and comprehensive information on maternal and child care. Through comprehensive data collection across
the continuum of care, BORN helps identify trends and gaps in provision of care, as well as inform appropriate updates to algorithms and processes.

Newborn Screening Ontario (NSO) is the largest newborn screening program in Canada and strives to ensure every newborn receives the highest quality screening and care. With almost 100 birthing hospitals and over 80 midwifery practices submitting about 145000 newborn screening samples each year, there is measurable variation in practice across the province. With a goal to have better integrated data to inform practice and support better outcomes, NSO was a founding partner of BORN, and has contributed almost 400,000 records since BORN go-live in January 2012.

Performance Feedback via the Maternal Newborn Dashboard

BORN’s Maternal Newborn Dashboard (MND) (Figure 1), which became available to hospitals in November 2012, is a data feedback mechanism with the goal to “promote change, decrease practice variation and encourage best practices” (JOGC 2013;35(1):29-38) by alerting users to their organizations’ performance status across a set of key performance indicators (KPI). Due to the inherent risks when an infant’s sample is deemed unsatisfactory for testing, and because the process is amenable to improvement, the “unsatisfactory sample rate” has been included as one KPI in the BORN MND. At the time the MND was implemented, the overall unsatisfactory sample rate was 2.6%. One year later, the provincial unsatisfactory rate was 1.5% (Figure 2,3). This dramatic improvement in sampling may be due to hospitals’ awareness of the KPI coupled with Newborn Screening Ontario’s (NSO) education initiatives and support of change at the submitter level.

Proactive Alerts of Potential Missed Screens

One of BORN’s key mandates as a prescribed registry is to facilitate and improve care, which is clearly demonstrated through the partnership with NSO in identifying newborns who have not had dried blood spot screening in a timely fashion. In the past if a newborn was missed, there was no mechanism to identify this oversight and offer screening for the 29 diseases on the panel. Through BORN’s comprehensive data set, it is also now possible to link newborn screening data with provincial birth records to identify infants who did not receive a newborn screen. This facilitates an alerting process whereby NSO is notified on a daily basis of all infants where a birth has been recorded in BORN, but no newborn screening record has been matched to the same patient by 14 days of age. NSO contacts the care providers to determine if the newborn screen was obtained, declined, or if there is a plan in place to complete testing, and monitors the case until the family is notified or a sample is obtained. Since BORN went live in January 2012, over 1300 missed screen alerts have been followed-up by NSO. Analysis has identified common reasons for delayed or missed samples, allowing NSO to target education and implement processes to mitigate the risk.

Figure 4 shows the distribution of reasons for the missed screens identified in 2013. In almost a quarter of all cases, there is no apparent reason for the missed screen and it is noted as not taken in error. In addition, a further 5% of alerts occurred in patients transferred between hospitals or between units, where neither unit did the screen. Prior to BORN’s implementation, these infants may have ‘fallen through the cracks’ and never have received a newborn screen. In 23% of cases, it appears that late sampling, batching at the hospital or delays in transportation result in the alert occurring before the sample has been received. NSO can further investigate these cases to identify issues with sample flow in certain institutions or areas of the province, and intervene with education or corrective actions where necessary. Positive impacts have been noted from these interventions. Between 2013 and 2014, there has been a 13% decline in the average monthly total of missed screen alerts requiring follow up.
These two examples demonstrate the utility of the BORN Registry and Network to identify gaps and variability in preanalytical practices and allow submitters and NSO to implement corrective actions for more comprehensive and timely newborn screening.

**Figure 1:**

Date report run: 7-Mar-2013 (allow 1 month lag in February for data acknowledgement)

Maternal Newborn Dashboard - Home Page

<table>
<thead>
<tr>
<th>Key Performance Indicators</th>
<th>Rate (%)</th>
<th>Status</th>
<th>Benchmark rates (%)</th>
<th>Comparator rates (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Target (green)</td>
<td>Warning (yellow)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>&lt;2.0</td>
<td>2.0-3.0</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>&lt;13.0</td>
<td>13.0-17.0</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>&lt;20.0</td>
<td>20.0-25.0</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>&lt;11.0</td>
<td>11.0-15.0</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>&gt;94.0</td>
<td>&gt;94.0</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>&lt;5.0</td>
<td>5.0-10.0</td>
</tr>
</tbody>
</table>

Data source: BORN Ontario, 2012-2013

Notes:

1. Rates and status are based on the three prior months of data that have been acknowledged for submission, allowing for a one month lag.
2. Grey status indicates incomplete month end acknowledgement for key performance indicators. Please ensure month end acknowledgement is complete for each of the three months in the reporting period. If a key performance indicator has a grey status, no comparator data for that indicator will be shown.
3. Comparator data is represented as the rate from a minimum of three or more hospitals who have acknowledged their data for the three month reporting period, within a given comparator category. The comparator rates for other same level of care hospitals and other similar birth volume hospitals exclude the reporting hospital, whereas the rates for Ontario include the reporting hospital.
4. Neonatal Level of Care was chosen for comparator data as maternal Level of Care designations were created by the Provincial Council for Maternal and Child Health (PCMCH) in 2011 and were not available prior to this date.
**Figure 2. Proportion of newborn screening samples that were unsatisfactory for testing by Local Health Integration Network (LHIN) (%) 01-Apr-2012 and 31-Dec-2013**

| Benchmark rates (%) | 
|---------------------|---------------------|---------------------|---------------------|---------------------|---------------------|---------------------|---------------------|---------------------|---------------------|---------------------|---------------------|---------------------|---------------------|
| Target | Warning | Alert |
| <2.0 | 2.0-3.0 | >3.0 |
| LHIN 2 - South West | 5.8 | 4.2 | 4.0 | 3.1 | 1.8 | 1.1 | 1.0 | 4.8 |
| LHIN 6 - Mississauga/Halton | 3.3 | 2.8 | 4.9 | 2.5 | 0.6 | 0.7 | 0.7 | 2.6 |
| LHIN 12 - North Simcoe Muskoka | 3.9 | 2.0 | 2.5 | 1.1 | 1.4 | 1.2 | 1.8 | 2.1 |
| LHIN 9 - Central East | 3.1 | 1.7 | 1.5 | 1.7 | 1.5 | 0.8 | 1.2 | 1.9 |
| LHIN 5 - Central West | 3.2 | 3.9 | 3.9 | 4.5 | 2.3 | 1.7 | 1.3 | 1.7 |
| LHIN 7 - Toronto Central | 3.8 | 2.3 | 3.5 | 2.4 | 1.5 | 2.0 | 2.1 | 1.7 |
| LHIN 4 - Hamilton Niagara Haldimand Brant | 2.6 | 1.3 | 1.9 | 2.0 | 1.1 | 0.8 | 1.1 | 1.5 |
| LHIN 10 - South East | 3.3 | 3.6 | 3.5 | 2.9 | 1.6 | 0.9 | 2.2 | 1.1 |
| LHIN 11 - Champlain | 1.9 | 1.0 | 0.8 | 1.2 | 0.5 | 0.4 | 1.0 | 0.9 |
| LHIN 8 - Central | 2.4 | 1.4 | 1.8 | 1.7 | 1.5 | 1.0 | 1.7 | 0.7 |
| LHIN 14 - North West | 4.3 | 2.0 | 5.7 | 4.4 | 2.5 | 1.8 | 3.6 | 0.7 |
| LHIN 11 - Erie St. Clair | 1.0 | 0.8 | 0.7 | 1.2 | 1.3 | 0.7 | 0.4 | 0.6 |
| LHIN 3 - Waterloo Wellington | 0.9 | 0.7 | 0.8 | 0.7 | 0.5 | 0.4 | 1.2 | -0.3 |
| LHIN 13 - North East | 3.4 | 2.9 | 3.4 | 4.0 | 4.0 | 2.7 | 3.8 | -0.4 |
| Ontario | 3.0 | 2.1 | 2.6 | 2.2 | 1.4 | 1.1 | 1.5 | 1.5 |

**Data source**
BORN Ontario, 2012-2014

**Definition of indicator**
The number of newborn screening samples that are unsatisfactory for testing, expressed as a percentage of the total number of newborn screening samples submitted to Newborn Screening Ontario (NSO) from a given organization (as noted on the newborn screening requisition as the ‘Submitting Health Care Provider’).

**Notes**
The BORN Maternal Newborn Dashboard became available November 19, 2012.
Figure 3. Proportion of newborn screening samples that were unsatisfactory for testing by level of care (%), 01-Apr-2012 and 31-Dec-2013

<table>
<thead>
<tr>
<th>Benchmark rates (%)</th>
<th>Target</th>
<th>Warning</th>
<th>Alert</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>&lt;2.0</td>
<td>2.0-3.0</td>
<td>&gt;3.0</td>
</tr>
<tr>
<td>Apr 2012 - Jun 2012</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>Jul 2012 - Sep 2012</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>Oct 2012 - Dec 2012</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>Jan 2013 - Mar 2013</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>Apr 2013 - Jun 2013</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>Jul 2013 - Sep 2013</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>Oct 2013 - Dec 2013</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
</tbody>
</table>

Data source: BORN Ontario, 2012-2014
Definition of indicator: The number of newborn screening samples that are unsatisfactory for testing, expressed as a percentage of the total number of newborn screening samples submitted to Newborn Screening Ontario (NSO) from a given organization (as noted on the newborn screening requisition as the ‘Submitting Health Care Provider’).
Notes: The BORN Maternal Newborn Dashboard became available November 19, 2012

Figure 4. Distribution of missed screens by reason

Data source: Newborn Screening Ontario Jan-Dec 2013
**NewSTEPs Data Repository: A Resource for the Newborn Screening Community**

C. Yusuf and S. Singh, NewSTEPs, Association of Public Health Laboratories, Silver Spring, MD

**Abstract**

**Background:** The success of state newborn screening (NBS) programs is largely measured through internal metrics. NBS programs can benefit by utilizing comparative data from other programs and developing activities to support changes in their own programs.

**Objective:** To develop a robust data repository to enable NBS programs to benchmark their own programs and implement quality improvement activities.

**Methods:** NewSTEPs engaged a workgroup of experts from the NBS community to inform the development of the repository. The NewSTEPs Data Repository collects three tiers of data:

1. **State Profiles:** State profile information is accessible to the public and includes demographic, disorder specific, policy and other programmatic information. Reports depicting fees, disorders screened, and dried blood spot retention time are available via the NewSTEPs website. Changes can be made to State Profiles on a real time basis.

2. **Quality Indicators:** Quality Indicators have undergone careful evaluation by stakeholders to assure agreement on definitions. These will be used to provide longitudinal comparisons within a program as well as comparisons to aggregate data across programs.

3. **Case Definitions:** Standard surveillance case definitions developed via Health Resources and Services Administration (HRSA)-led expert review groups allow for determination of the frequency of disorders, as well as for comparisons across states.

**Results:** The NewSTEPs data repository is web-based, meeting stringent security standards, and can be accessed by authorized users. The design of the repository allows each NBS program to securely explore data to meet program needs. State profile data, and aggregate and de-identified case level reports are publicly available and accessible through the repository. NBS programs can generate standardized reports and run queries in real time to support development of local and regional quality improvement initiatives. NewSTEPs provides reports with data summaries at the state, regional, and national levels. Public requests for data will be considered by a Data Review Subcommittee, functioning under the purview of the NewSTEPs Steering Committee.

**Conclusion:** The NewSTEPs data repository allows for robust comparisons of NBS program practices, disorder frequencies, and quality practices across states.

**Presenter:** Careema Yusuf, MPH, NewSTEPs, Association of Public Health Laboratories, Silver Spring, MD, Phone: 240.485.2721, Email: careema.yusuf@aphl.org

**Summary**

The NewSTEPs data repository collects data on a variety of components of the newborn screening (NBS) system with the goal of providing comparative data to NBS programs. The NewSTEPs data repository is web-based, meeting stringent security standards, and can be accessed by authorized users from anywhere, allowing each NBS program to securely explore data to meet local program needs. The NewSTEPs Data Repository houses and manages 3 sets of data: State Profiles; Cases; Quality Indicators.
NewSTEPs provides comprehensive, customized usable data reports to inform NBS program daily activities.

Currently data entry into the NewSTEPs data repository is manual. In the near future there will be an option to electronically transfer data into the repository. NewSTEPs is working with the main information system vendors (PerkinElmer, Natus/Neometrics, StarLIMS and OZ Systems) to create data queries for their information systems that will generate reports and/or information on the Quality Indicators and case data.

State NBS programs are in control of the data they wish to send to the NewSTEPs data repository. They can generate the reports via the queries within their information systems, review the information and then upload the information into the NewSTEPs data repository.

Technical assistance resources for implementation of Health Information Technology (HIT):

• The APHL/ NewSTEPs NBS HIT workgroup is made up of representatives from state NBS programs, HIT vendors and federal partners. This workgroup develops and hosts national educational webinars on HIT topics determined by the NBS community.

• NewSTEPs is committed to facilitating implementation of industry standards such as Health Level 7 (HL7), within Laboratory Information Management Systems (LIMS) to improve quality and best data practices while reducing time and resources required for sharing data across healthcare entities. NewSTEPs will collaborate with APHL’s Informatics program to evaluate NBS laboratories for their current HIT capabilities.

• NewSTEPs will facilitate technical assistance for NBS programs that are in the process of developing their HL7 messages and mapping their local variables to federally endorsed clinical data standards. Specifically, NewSTEPs will evaluate and leverage the existing Public Health Informatics Institute (PHII) HL7 implementation guidelines available for newborn screening.

The NewSTEPs data repository allows for robust comparisons of NBS program practices, disorder frequencies, and quality practices across states.