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Electronic Notification to Improve Surveillance, Quality of NBS Pre-analytic Processes

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High quality newborn screening (NBS) depends upon the quality and timeliness of a series of pre-analytic activities, including collection of birth and other clinical information on the baby, collection of quality specimens and transport of the specimens with the relevant information to the laboratory. Rapid identification of presumptively affected infants requires effective monitoring of these pre-analytic activities and timely intervention when areas needing improvement are detected. However, it is challenging for NBS programs to assess effectiveness of many pre-analytic procedures due to various practical and logistical barriers, including the time intervals between baby birth, specimen collection and specimen arrival at the laboratory, and the different physical locations of the birth facilities and the NBS laboratory.

To explore ways to overcome these challenges and improve NBS pre-analytic processes, APHL, with funding from a cooperative agreement with CDC, awarded grants to the Indiana State Department of Health (ISDH) and the Montana Laboratory Services Bureau in 2014 to conduct proof of concept projects on testing the feasibility of establishing an electronic birth notification mechanism and the value of conducting surveillance on NBS pre-analytic processes to improve timeliness and quality.

The Indiana Project and Findings

The Indiana project expanded the use of their Newborn Admission Notification Information (NANI) system, which is a new health informatics system that collects standards-based electronic messages from the hospitals' electronic health records (EHR) and sends birth notification data to ISDH's NBS program. During the one year project period, the number of hospitals that implemented NANI increased from 8 to 12. ISDH conducted a comparison of the demographic data received electronically to that received on the filter paper card on 873

NBS specimens. In addition, over 8,000 NANI records were reviewed to determine the rate of linkage of a birth record to a specimen received in the NBS laboratory in order to detect missing NBS specimens. Significant findings include the following: 100% date of birth matching rate with an 81% match for the time of birth, 97% match for medical record numbers, 97% match for the mother's last name and a 57% match for addresses. The data inconsistencies were found to result from missing or incorrect data from either the filter paper cards or the NANI system.

Valuable post-analytic quality metrics were also found: approximately 4.1% of births at these facilities were not automatically linked to laboratory data, possibly due to data discrepancies that prevented a match or no newborn screening performed for these babies. These findings are currently being addressed with remedies to the system.

The Montana Project and Findings

The Montana project established birth notification data submission from a major hospital to the Montana Public Health Laboratory (MTPHL) by creating new IT interfaces, permitting MTPHL to collect baseline pre-analytic quality data at the end of the project. The average time from birth to NBS specimen collection was 2.5 days and from collection to receipt at the MTPHL 2.4 days, both comparable to the overall state averages (2.81 and 2.38 days respectively). The baseline rate of unsatisfactory specimens was 0.34% from this hospital, which was much lower than the state-wide average of 1.84% during the same time period. Nevertheless, these measures are expected to improve with the use of electronic birth notification. In addition, workflow analysis identified the need for several process changes both at the hospital and at the MTPHL for reporting and reviewing the birth notification data and future regular follow-up on babies with birth data but with no specimen received at the laboratory.



Sample collection for newborn screening testing

Conclusion and Next Steps

Both ISDH and MTPHL demonstrated the value of electronic birth notification for improving the quality and monitoring of NBS pre-analytic processes through their successful proof of concept projects. Meanwhile, both projects revealed significant challenges, including the complexity and time-consuming nature of establishing the electronic connectivity, the need to engage and motivate hospitals' participation, the training needs for hospital and NBS staff, and competing priorities for the hospitals and the NBS programs. Both programs have future goals to expand the data exchange to other hospitals, continue to receive and use birth notification data to improve NBS pre- and post-analytic quality metrics, and to implement improved workflow processes for continual process improvements.

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The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.