An Initial Report on the Quality Improvement Project for Tracking of Collection of Expanded Newborn Screens in Children < 31 Days of Age and Follow-up of Abnormal Results

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Children’s Mercy Hospitals and Clinics (CMH) serves as a major referral center for newborn screening (NBS) in the state of Missouri. With the implementation of expanded newborn screening and recent mandate to implement screening for selected lysosomal storage diseases in Missouri, a committee of CMH experts was formed to (1) address barriers associated with communication and documentation of NBS collection and (2) appropriate and timely follow-up NBS results within CMH facilities.

Objectives:
1. Ensure that every child < 31 days who comes to any CMH location has a NBS collected, specifically including the emergency room and urgent care centers (ER / UCC), primary care clinics and the intensive care nursery (NICU).
2. Ensure that any child who comes to any CMH location with an abnormal NBS test result is followed up on appropriately.
3. Facilitate communication with primary care providers in the greater Kansas City area.
4. Ensure that any child who has a moderate, repeat borderline, high or presumptive positive NBS result receives appropriate and timely follow-up and that the result and all follow-up is charted in the child’s electronic medical record (EMR).
5. Ensure that once a child receives a diagnosis based upon NBS results that long-term follow-up for these conditions occurs per standard of care guidelines.

The committee included members from general pediatrics, neonatology, emergency medicine, laboratory medicine, information system and each subspecialty involved in NBS follow-up. Significant changes were made to the electronic medical records (EMR) system, as well as revisions to the hospital policy to ensure better tracking. See Figure 1 for an overview of the revised process.

Our changes included the addition of electronic prompts at check-in and admission as well as at discharge for all children < 31 days of age regarding screen collection at CMH locations. A report is generated daily, extracting patient data from the electronic forms regarding NBS collection. The NBS Database Coordinator then collaborates with Missouri and Kansas to ensure that a NBS has been collected. If a screen was previously collected elsewhere, then CMH requests a copy of the report from the appropriate state, which is then scanned into the child’s EMR. If it is determined that a NBS has not been collected then the CMH primary care clinics assume responsibility for ensuring that a NBS is collected. Any abnormal NBS result is referred to the CMH primary care clinics for additional follow-up. In case of moderate and high risk case, in addition to contacting primary care physician, the state laboratory contacts CMH genetics center for follow-up for confirmation and treatment.
Figure 1: Flowchart describes our revised, routine NBS procedures
Finally, any child that is referred to CMH referral centers with a high risk result has a medical record number assigned. All follow-up activities regarding the abnormal NBS is charted in the child’s EMR.

Data collected during February 1st through April 6th, 2010 is summarized below.

- 1504 children < 31 days were seen at a CMH facility
- Of those, there were 2392 visits
- Of those, 392 were referred to the NBS follow-up report because (1) parents reported no NBS performed (2) unknown whether NBS was collected or (3) the parents knew that one had not been performed.

Chart 1 summarizes the major departments from where the samples for NBS were collected.

Thus far this project has demonstrated process improvement and that no child’s initial collection has been missed. Tracking of follow-up is on-going.

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