

## **Some Lessons Learned from Early Hearing Detection and Intervention (EHDI) that may be applicable to Critical Congenital Heart Disease (CCHD) Screening**

### Background

EHDI and CCHD Programs both represent point-of-care (POC) screening efforts that occur in the birthing facility before the infant is discharged. Hearing screening and CCHD screening are quite different in their timelines for follow-up. Hearing screening follow-up occurs as an outpatient while CCHD screening necessitates follow-up in the hospital because delay may result in severe morbidity or death of the infant. Still, we have learned some lessons from the experience of EHDI that are applicable to CCHD screening. These lessons may also be applicable to other POC screening.

### What can be learned from the EHDI experience that may be applicable to CCHD screening?

- State EHDI and Newborn Bloodspot screening programs are often not well integrated with each other. Public Health Newborn Screening Programs should strive to better integrate their various components.

Bloodspot screening and POC screening are often handled by different parts of health departments. Therefore, one part of a health department may not be aware of the existence of a patient who has not been screened for a particular condition(s) but who is known to another screening program. Data integration is essential for collecting complete and accurate data on all infants, including those who were not screened and reasons screening was not performed such as neonatal death or severe illness. It would also allow information that is discovered about a patient by one part of a health department, such as name changes, contact information, or clinical status, to be immediately shared with others who are following the same patient.

Integration of newborn bloodspot and POC data will help with overall reporting and with child health data integration efforts. Clinicians wish to view all newborn screening results on a single report and to consult a single source to see if there are any tasks that are still required to complete the screening process. In addition, integrating the data would allow all newborn screening information to be transferred as a whole to the medical home and would expedite coordination of care with specialists when a patient moves between practices. Some states have already begun to integrate newborn screening results with their immunization registry so that providers can access key child health data using a single system with one set of access credentials. Some states have integrated EHDI and Newborn Bloodspot screening, and/or Birth Defects tracking programs.

- The State Health Department should play a leadership role in implementing electronic data systems that utilize standards-based messaging to reduce errors and enhance timeliness in data reporting.

State Health Departments have a critical and essential role in current and future Health Information Technology (HIT) deployment and adoption. States are leveraging Electronic Health Record (EHR) HIT infrastructure and state/regional level Health Information Exchange (HIE) initiatives to improve services among multiple clinical care providers and public health programs. Several public health program areas including: vital records, laboratory, infectious disease, immunization and cancer registries have promulgated nationally recognized data and messaging transmission standards. This includes the National Library of Medicine (NLM) publication of the Newborn Screening Coding and Terminology Guide to promote and facilitate the adoption of electronic health data standards in recording and transmitting newborn screening test results.

The most efficient, accurate, and timely transfer of information between systems occurs when it is part of routine workflow and operations and does not require separate and duplicative efforts by staff. One of the most important features of interoperable information systems is that information can be entered once, or captured automatically from instrumentation without the possibility of human error, and then filed in multiple locations and systems. For example, the Newborn Admission Notification Information message (NANI) can be configured once by a hospital EHR and demographic information submitted to multiple newborn public health programs. NANI, which provides an accurate denominator of hospital births, was produced by the Quality Research and Public Health Committee for Integrating the Health Care Enterprise.

The State of Texas has implemented NANI for its EHDI program. Maryland is leveraging the State HIE to send NANI messages from birthing facilities to the State's integrated child information system for EHDI, CCHD and Birth Defects tracking programs. Such novel implementations create challenges and require collaboration among diverse entities. Once these are addressed the interoperable tool facilitates the flow of information from EHRs to public health.

Both EHDI and CCHD represent functional conditions (hearing loss or hypoxemia caused by critical heart disease) that are caused by a variety of diseases, many of which are heritable. Standards for disease coding and terminology will allow capture of the specific diagnosis that may indicate the need for genetic testing or counseling and allow appropriate comparisons of long term outcomes and identification of cases which were not found through newborn screening.

The use of standards-based messaging can enable capture of detailed data about the screening process on both in-range and out-of-range screens, which can then

be used to improve the screening process and reduce the number of false positive and false negative screens without requiring additional staff time to record results and transmit them to the health department for population-based analysis.

EHDI has served as a model in the area of electronic information exchange between clinical care and public health programs. National data element standards developed in collaboration with the EHDI program have been accepted and published by the CDC, NLM and the Agency for Healthcare Research and Quality (AHRQ). In 2011 the CDC EHDI program was identified as the Measure Steward for four child health quality measures endorsed by the National Quality Forum (NQF). In 2012 the Centers for Medicare and Medicaid Services (CMS) included one of these NQF-endorsed EHDI measures in their Stage 2 criteria for the EHR Incentive Program. In 2012 the Health Level Seven (HL7) International included EHDI with Vital Records and Cancer Registries as specific public health-clinical information collection, management and exchanges.

State programs would be advised to leverage the extensive work currently underway to facilitate the electronic exchange of newborn screening results. These efforts include the HL7 Draft Standard for Trial Use (DSTU) guides to capture, store and transmit newborn screening results (hearing and pulse oximetry) from devices to clinical EHR systems or public health programs. Integrating the Healthcare Enterprise (IHE) has produced profiles defining how to apply public health data standards and EHR conformance criteria. One of these profiles includes using structured data capture which has been used in pilot projects for Vital Registration and recently EHDI.

In a CDC-funded pilot project with Oregon EHDI, a public health structured data form appeared inside the participating hospital EHR and it was prepopulated with available information about each baby. The hospital staff completed data entry and submitted the form. There was no need for data entry into a separate public health information system to complete reporting. At that point the hospital's work was complete. Behind the scenes, a forms manager system transmitted the newborn screening results to public health. Such a pilot project highlights the collaborative challenges demanded of these efforts since the hospital EHR vendor and hospital IT participated with the public health forms vendor, the public health IT vendor and hospital and state program staff. State Public Health should be aware of such efforts and evaluate their feasibility on an ongoing basis.

- Screening programs should require child level data for quality improvement efforts.

Newborn bloodspot screening laboratories have verifiable results that can be analyzed and replicated. EHDI and CCHD Programs should encourage hospitals to report verifiable, individualized screening results. A verifiable result is one that comes directly from a screening device and reduces the potential for data entry error. Individual results for each baby allow public health to recognize who needs more care. That is, to identify babies whose screening was not completed as well as identify babies who failed screening.

Individual rather than aggregate data are essential to support quality improvement initiatives and assure completion of the entire screening process with adherence to all protocols and reporting of all evaluation and referral activities. Current hearing screening programs are concerned that many of the unknown outcomes of out-of-range screens represent loss to documentation rather than true loss to follow-up. Individual data can be used to improve the screening process as well as to locate infants whose screening was not completed prior to hospital discharge. Individual data can be aggregated to produce institutional and population level reports, but aggregate data alone cannot be used to identify and improve specific barriers or track individual patients.

- Appropriate financial support (federal and state) will be needed to develop, implement and maintain the CCHD screening system.

Funds will be needed to modify existing data systems in use for hearing screening or dried blood spot screening in order to include pulse oximetry screening for CCHD. When it is not feasible to modify existing systems, the goal would be to link all newborn screening data through interoperable screening systems with a common point of access such as an immunization registry or health information exchange. This would create a virtual child health record that would support management of all screening and prevention activities that providers could access with a single sign-on.

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