NewSTEPs Website Best Practices for Newborn Screening
Maryland Department of Health and Mental Hygiene
Critical Congenital Heart Disease (CCHD) Screening Implementation

Purpose: To capture model practices from within the newborn screening community, with the purpose of providing ready access through the NewSTEPs website.

Topic, Problem, Methods, Resolution

Critical Congenital Heart Disease (CCHD) Screening Implementation

Describe how you worked on the topic

An Expert Panel was mandated by legislation, convened and divided into 3 committees – education, clinical and feasibility, and quality assurance. A legislative report was developed which addressed the current state of the literature, potential benefits, costs and recommendations moving forward. The Expert Panel recommended that CCHD screening be standard of care rather than newborn screening, however once this screening was added to the Recommended Uniform Screening Panel (RUSP), Maryland was mandated to implement screening.

The Expert Panel then became the CCHD Implementation Advisory Committee, allowing for input from hospital staff, cardiologists and newborn screening experts into the process. Hospital nursery managers and administrators were notified of the implementation date, and modifications to our EHDI database were updated to include CCHD screening data collection. Educational webinars were developed utilizing some existing materials, such as the Baby's First Test video, and presented on 2 occasions to "train the trainers". A webpage with links to information for consumers and providers was developed. Our birth defects surveillance nurse assisted with setting up the CCHD screening program, and now our newborn screening follow up chief provides surveillance. We are currently working on analyzing data collected during the first year in order to evaluate the protocol in particular and the screening program in general.

Who was involved?

Our state Advisory Council on Hereditary and Congenital Disorders had been following the national activities around CCHD screening and was awaiting the Secretary's decision regarding adding it to the RUSP. Legislation resulted in the Expert Panel, the legislative report, and eventually implementation. The CCHD Implementation Advisory Committee consists of public health staff, hospital representatives including nurses, cardiologists and neonatologists. Our state has benefited from national discussions as well to inform the program.

WHAT ARE THE KEY THINGS YOU LEARNED FROM THIS PROCESS? WHAT WERE THE ELEMENTS THAT HELPED YOU TO SUCCEED?

The implementation of CCHD screening was successful in a large part because hospitals were very cooperative in the effort to implement screening. Several birth hospitals were already performing CCHD screening prior to the implementation date. Developing a method to electronically record pulse ox screenings in an existing database prior to implementation was very beneficial in obtaining results. By using an established database currently being used for the Early Hearing Detection and Intervention (EHDI) Program, hospital staff time to document results was minimally increased.

WHAT WOULD YOU DO DIFFERENTLY NEXT TIME? WHAT WERE THE BARRIERS OR CHALLENGES?

In our database, a category of "Physician Override" was given to allow for premature or sick infants who had an ECHO prior to screening . During implementation, it was determined that this category was too broad and the interpretation of when to use "physician override" was very inconsistent among different birth hospitals and even different individuals within the same birth hospital. In order to give us more specific information as to why a baby was not screened, database changes are now underway to provide more detailed information about babies who may not have been screened and for outcomes of infants who "failed" the screen.

A challenge to CCHD screening in our state has been screening of babies born at home or in birthing centers. Meetings with two of the birthing centers in the state have been conducted to educate them regarding the need for CCHD screening. Both of these centers are now working toward incorporating CCHD screening into their routine care. Unfortunately, it is difficult to determine in a timely manner when babies are being born out of the hospital or these two birthing centers in order to effectively screen the baby for CCHD prior to developing symptoms.

Education visits are currently being conducted with the birth hospitals to discuss documentation of CCHD screening outcomes. After completion of these site visits, focus needs to be placed on educational campaign directed at primary care providers in the community to help ensure babies have been screened for CCHD, especially those who have been born outside of the hospital.

The challenge of determining "false negatives", or babies not identified by screening, is being addressed by developing a relationship with one of the 3 major cardiac centers who provide care to Maryland babies if they are diagnosed after a passed CCHD screen and discharged from the hospital. Currently, working on developing relationships with the remaining 2 cardiac centers to determine the "false negative" rate.

WHAT ARE YOU ESPECIALLY PROUD OF IN HOW YOU MANAGED THIS PROCESS?

Creating the CCHD Implementation Advisory Committee was vital to managing the implementation process of CCHD screening in Maryland since this committee included hospital staff and cardiologists.

Birth hospitals were involved and remained well informed throughout the process which has helped facilitate the implementation of CCHD screening in Maryland.

PERTINENT RESOURCES

http://phpa.dhmh.maryland.gov/genetics/SitePages/CCHD_Program.aspx

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