Newborn Screening for Critical Congenital Heart Disease: CDC Activities

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Critical Congenital Heart Disease (CCHD) Stakeholders Meeting
February 27-28, 2014
Tasks Assigned to CDC by HHS Secretary, Kathleen Sebelius (2011)

- Evaluate state surveillance to monitor the effectiveness of CCHD newborn screening programs
- Conduct a cost-effectiveness analysis of newborn screening by pulse oximetry for the early identification of CCHD
- Leverage an electronic health record framework for congenital heart defects, including CCHD
Evaluate State Surveillance to Monitor the Effectiveness of CCHD Screening Programs

- Collaborated on a survey of state birth defects surveillance programs to assess programs’ potential roles, capabilities, and readiness to assist with newborn screening activities for CCHD (2011)
Evaluate State Surveillance to Monitor the Effectiveness of CCHD Screening Programs

- Worked with state birth defects surveillance programs, hospitals, and state health departments to understand how to implement and improve screening (2012)
  - Epi-Aid and Econ-Aid in New Jersey to evaluate the first three months of their state-mandated CCHD screening
  - Epi-Aid in Georgia to evaluate voluntary CCHD screening

Assess:
- Screening data flow and tracking at each facility
- Electronic health records (EHR) capabilities at each facility
- Process of communicating screening data to the state birth defects registry
Cost-Effectiveness Analysis of CCHD Screening by Pulse Oximetry (2013)

- CCHD screening appears to be cost effective
- Time-motion studies and resource utilization questionnaire to assess hospital cost burden
- Screening time ~9 minutes per newborn (including documentation and cleaning)
- Screening costs ~$14 per newborn
- In New Jersey
  - Hospital costs for CCHD screening were much lower among hospitals that used reusable screening equipment
  - Nursing staff reported that pulse oximetry was a familiar skill, and screening all newborns for CCHD was easily added to other routine tasks
Leverage an Electronic Health Record Framework for Congenital Heart Defects, Including CCHD

- CDC collaboration with the National Library of Medicine and the National Heart Lung and Blood Institute
- Mapping CCHD conditions to various coding systems
  - Highlight similarities and differences between codes
- Goal: Facilitate meaningful data exchange between stakeholders
Evaluation and Optimization of CCHD Screening Algorithms

- Goal: compare performance of CCHD screening algorithms and to design an optimal algorithm for CCHD using mathematical modeling
- Use existing data from healthcare systems that are already conducting CCHD screening and have available data (not prospectively collecting data)
  - CDC will serve as data repository
  - Participating sites will submit de-identified, individual-level data
Evaluation and Optimization of CCHD Screening Algorithms

- Data elements: age at screen, sex, race/ethnicity, saturation percentages, extremity tested, pass/fail, false or true positive, false or true negative
- Apply different algorithms to these data to identify how children would have performed using other screening algorithms
- Current/Tentative Timeline:
  - April 2014 to Summer – Hospitals/healthcare systems send data
  - Fall 2014-Winter 2014/2015 – Mathematical modeling, data analysis
  - Early 2015 – Results available
  - Spring 2015 – Publish results

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