



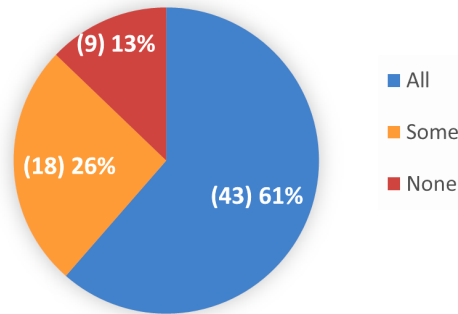
A quality initiative to increase awareness and screening of CCHD for all infants born in Kansas.

QI Project: Update for Birthing Facilities

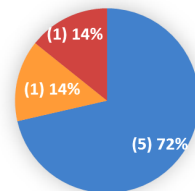
Fall 2016

Reporting CCHD results via the birth certificate supports KDHE staff in ensuring infants across the state are, in fact, being screened, and are receiving appropriate referrals and diagnostic testing. We need your help to make sure all CCHD results are reported.

September: Birthing Facilities Reporting CCHD



Midwives Reporting CCHD



Background: In 2013, the Kansas Newborn Screening (NBS) Program began a Quality Initiative to increase CCHD screening in Kansas. A CCHD Work Group was formed with KDHE, the American Heart Association, the Kansas Hospital Association, along with other organizations and passionate CCHD families across the state. Steps were taken in the implementation phase to improve awareness and screening of CCHD for all infants born in Kansas.

Current Status: The focus of the CCHD Work Group has expanded to include encouraging birth facilities to report their CCHD screening results. As of February 2016, facilities can now report screening results via the birth certificate, just like they currently do for hearing screenings. Unit clerks, nursing staff, and even midwives across the state are also able to report CCHD data via the birth certificate with a Kansas VRV Authorization Request Form.

Methods: The process for facilities should begin with the CCHD screening between 24-48 hours of age. Infants in special care nurseries (including intermediate care and neonatal intensive care, etc.) should be screened at 24-48 hours of age or when medically appropriate after 24 hours of age. In all cases, screening should occur prior to discharge from the hospital. Once results are documented, the Newborn Registrar (or other approved staff) enters the results of the final test into the electronic birth certificate (EBC). There is also an option to report if an infant was not screened due to various reasons. Infants who were reported as "Fail" or whose results do not fall into the state algorithm are immediately flagged for follow-up in the KDHE NBS Data System. KDHE staff will then contact birthing facilities to verify results and ensure proper follow-up has occurred.

Data Collected: NBS Follow-Up staff is currently tracking the number of infants with reported CCHD results in comparison to the total number of infants born in Kansas. Currently, 87% (n: 61) of facilities in Kansas are reporting at least some CCHD results (see above chart). Although only 13% (n: 9) of facilities in Kansas are not reporting any results, these facilities represent an average of approximately 32% of infants born per month¹ for whom Kansas still has no screening data. Reporting CCHD results via the birth certificate supports KDHE staff in ensuring infants across the state are, in fact, being screened, and are receiving appropriate referrals and diagnostic testing.

Next Steps: The CCHD Work Group will reach out to birthing facilities who are not currently reporting any CCHD data, and continue to address educational needs of facilities and midwives across the state. The goal is to encourage these entities to voluntarily report CCHD screening data.

KDHE Contact: For questions regarding the CCHD Work Group, reporting, or how to get more involved, contact Annie Gile, Newborn Screening Follow-Up Program Consultant/Educator, at (785)296-3617 or visit our website: http://www.kdheks.gov/newborn_screening/CCHD.htm



1. Out of 3,394 infants born in September 2016, 1076 (32%) were born at facilities not reporting CCHD.