Implementing Recommended Screening for Critical Congenital Heart Disease

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BACKGROUND AND OBJECTIVE: Critical congenital heart disease (CCHD) is endorsed by the US Secretary of Health and Human Services as part of the recommended uniform screening panel for newborns. Although initial recommendations for implementation exist, as states and hospitals have moved forward with implementation of screening, new challenges and areas for additional focus have been identified. The objective of this study was to develop recommendations to address current challenges and areas of focus surrounding CCHD newborn screening.

METHODS: A workgroup of experts and stakeholders was convened in Washington, District of Columbia, for a 1-day meeting in February 2012. At the beginning of the meeting, the stakeholders held a brainstorming session to identify areas of main priority based on their experience. After this, stakeholders broke into small groups to refine recommendations, which were then finalized by consensus.

RESULTS: Recommendations to address selection of screening equipment, standards for reporting of screening outcomes to stakeholders, training of health care providers and educating families, future research priorities, payment for screening, follow-up diagnostic testing, and public health oversight, and advocacy to facilitate effective and comprehensive screening were proposed. Suggestions for future work were developed.

CONCLUSIONS: Screening for CCHD presents novel challenges and opportunities; however, addressing these will strengthen newborn screening and newborn care networks, and ultimately improve health outcomes. Pediatrics 2013;132:e185–e192

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In October 2010, the US Health and Human Services Secretary’s Advisory Committee on Heritable Disorders in Newborns and Children recommended that screening for critical congenital heart disease (CCHD) using pulse oximetry be added to the recommended uniform screening panel (RUSP). After this, the Secretary’s Advisory Committee on Heritable Disorders in Newborns and Children collaborated with the American College of Cardiology (ACC), the American Academy of Pediatrics (AAP), and the American Heart Association (AHA) to convene a workgroup to discuss and describe strategies related to implementation. These approaches were later outlined in the article “Strategies for Implementing Screening for Critical Congenital Heart Disease,” published in Pediatrics, and have been used to facilitate the implementation of screening programs throughout the country.

In September 2011, Secretary Sebelius endorsed the addition of CCHD newborn screening to the RUSP. In addition, she supported the development of screening standards, infrastructure for point-of-service testing, educational materials by the Health Resources and Services Administration (HRSA), additional research conducted by the National Institutes of Health (NIH), and surveillance and cost-effectiveness research by the Centers for Disease Control and Prevention (CDC). Each state is responsible for determining best practice for CCHD screening, and state health departments have been actively engaged and typically serve as the central administrative leader for this initiative. Not unusually this involves educational and advisory responsibilities that differ from other newborn screening.

As states and hospitals began planning for and implementing CCHD screening, many important challenges were identified that will be addressed in detail. These challenges include the following: (1) selection of screening equipment; (2) standards for reporting of screening outcomes to stakeholders; (3) training of health care providers and educating families; (4) future research priorities; (5) payment for screening, follow-up diagnostic testing, and public health oversight; and (6) advocacy to facilitate effective and comprehensive screening. To develop strategies to address these challenges, an expert panel was convened in Washington, District of Columbia, in February 2012. In attendance were key stakeholders (see Appendix), including primary care providers, specialists (pediatric cardiologists and neonatologists), sonographers, nurses, researchers, industry representatives, parent advocates, an advocacy group (Genetic Alliance), professional organizations (AAP, ACC, AHA, American College of Medical Genetics), state public health officials, and representatives from federal agencies (CDC, HRSA, NIH, Food and Drug Administration [FDA]). This report summarizes the consensus recommendations from this meeting and provides clarification of outstanding issues not addressed in the article “Strategies for Implementing Screening for Critical Congenital Heart Disease,” published in Pediatrics.

### Equipment Selection

Oximeters used for screening for CCHD must be approved by the FDA for measuring arterial oxygen saturation. This approval is based on the accuracy assessed by studies performed in adults exposed to a range of oxygen concentrations. The FDA has not tested the performance of pulse oximeters in CCHD screening protocols and considers this screening only as “practice of medicine” use of the device. As such, interpretation of pulse oximetry results in newborns must take into account the clinical situation, and requires clinician judgment, interpretation, and decision-making to determine what, if any, diagnostic or therapeutic actions are appropriate. The FDA has no specific approval process for using pulse oximetry for the detection of CCHD. The expert panel developed a list of criteria for pulse oximeters to be used for CCHD screening (Table 1) to help those who are now adopting screening.

There are opportunities to improve pulse oximetry technology used for screening for CCHD. Because neonatal oximeters are approved based on adult data, it will be helpful to provide data from CCHD screening to the FDA as additional evidence of suitability of oximeters for neonates. In particular, by tracking results of screening using a uniform protocol, differences in oximeter characteristics, including sensitivity and specificity, can be evaluated. Incorporating CCHD screening algorithms and tools to facilitate accurate interpretation of the screening results into the software for the device or as a separate device would decrease potential error in the screening process. Because many congenital defects, including those that do not produce cyanosis, result in low perfusion, improvements in detecting low perfusion by pulse oximetry might improve the sensitivity of screening.

<table>
<thead>
<tr>
<th>TABLE 1 Recommendations for Pulse Oximetry Equipment for Newborn Screening</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Meet the International Organization for Standardization standard and be cleared by the FDA for hospital use in neonates.</td>
</tr>
<tr>
<td>2. Have adequate performance under normal circumstances and tolerant of motion.</td>
</tr>
<tr>
<td>3. Use a sensor indicated for use on neonatal extremities and not require a fixation method that can affect skin integrity. Adult sensors should not be used on neonates.</td>
</tr>
<tr>
<td>4. Include systems to ensure that only the proper sensors are used with the device.</td>
</tr>
</tbody>
</table>

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**Note:** The content is a summary and does not include all the details and references from the original text.
REPORTING STANDARDS

Public health monitoring is critical to ensure the effectiveness of the screening activities. Reporting of results is complex because there are a number of different entities that either screen or require the screening results. These entities include the birth facilities, primary care providers, specialty care providers, and state public health programs, including the newborn screening program and birth defects registries. Each entity has different data requirements to ensure that effective screening and evaluation and validation of the screening program can be accomplished. Table 2 presents minimum data recommendations and considerations for data exchange for reporting.

TRAINING OF HEALTH CARE PROVIDERS AND EDUCATING FAMILIES

Education of health care providers and families is important to the successful implementation of CCHD screening programs. At the first stakeholder meeting, it was recommended that the benefits and limitations of CCHD screening using pulse oximetry be the primary focus of educational materials. This remains the underlying theme of educational efforts targeted to both providers and families. Additional issues that should be addressed include identification of providers responsible for teaching, recommended components and key messages of educational programs, ensuring that educational materials are culturally competent and available in languages to meet the needs of a multilingual population, provider and parent education on new technology associated with CCHD screening (ie, pulse oximetry devices, electronic health exchange systems), community education, access to and dissemination of educational materials, and creation of regional networks for educational collaborations.

Educational materials for both parents and providers should provide background and significance of CCHD screening and information on CHD and CCHD appropriate to either population according to the intended use of the materials. Parents should be provided information on limitations of pulse oximetry for detection of CCHD, what they should expect if results are positive, information on CHD resources, and signs and symptoms of CHD. In addition, materials for parents should be suitable for a diverse audience and comprehensible at an appropriate reading level as determined by the organization responsible for creating the materials. Last, materials for parents should address issues of consent where required, as well as how results will be recorded and reported.

Information for provider groups will depend on the role of the provider. In addition to providing information on background and significance of CCHD screening, educational materials should provide information on communication strategies with parents across the spectrum of care and details related to screening protocols and processes. The response to positive screens should be outlined, including the need for echocardiographic evaluation. Advice on care coordination with parents/families and supportive measures for positive screens should be provided, appropriate to the level of the provider. Providers should be given guidance on reporting and documenting results as well as quality assurance measures. The technological limitations of CCHD screening should be reviewed, as well as the use of data reported to public health. All providers should understand that a negative screen does not rule out the presence of all forms of CHD in a given patient.

To make appropriate and safe recommendations for the concerns previously described, to avoid duplication of efforts, and to provide guidance on developing and

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TABLE 2 Minimum Data Recommendations and Considerations for Data Exchange for Reporting of CCHD Screening Results

<table>
<thead>
<tr>
<th>Birth Facility Data</th>
<th>Public Health Program Data</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Patient-level data:</td>
<td>1. Will vary according to the legislative or executive mandate of each state.</td>
</tr>
<tr>
<td>Patient identification data that allows validation that all infants had a valid screen and results</td>
<td>2. Aggregate or individual data may be specified to be provided to and tracked by public health programs</td>
</tr>
<tr>
<td>Age in hours at time of screening, All oximetry saturations reported (initial screen and any subsequent screens)</td>
<td>3. Birthing facilities required to report to public health programs should provide data sufficient to determine whether all eligible infants were screened and, in the case of positive screens, information about the evaluation performed.</td>
</tr>
<tr>
<td>Final screening result</td>
<td>4. Ideal for positive screens: Final diagnosis should be tracked as well as interventions that follow. Should include whether infants required transport for evaluation and treatment or had evaluation at the birthing facility and what treatment entailed.</td>
</tr>
<tr>
<td>Obstacles encountered during screening process (ie, obstacles with the infant/family, staff, equipment)</td>
<td>5. Ideal for negative screens: Subsequent identification of congenital heart defects (ie, false-negative screens) could be linked within the NBS programs.</td>
</tr>
<tr>
<td>Diagnostic results</td>
<td>6. Summary statistics should be provided by health departments and NBS programs to stakeholders.</td>
</tr>
<tr>
<td>2. Screening program data:</td>
<td></td>
</tr>
<tr>
<td>Screening protocol being used</td>
<td></td>
</tr>
<tr>
<td>Type of pulse oximeter used for screening</td>
<td></td>
</tr>
</tbody>
</table>

NBS, newborn screening program.
FUTURE RESEARCH PRIORITIES

Outcomes of Screening for CCHD

The goal of screening is to decrease morbidity and mortality from unrecognized CCHD. To verify that this goal is met, the extent to which mortality is decreased through screening, and whether serious morbidity, including end-organ damage, is prevented will need to be determined. This is difficult to assess because screening is only 1 aspect of care that affects outcome and outcomes overall have improved over time because of better care.

In evaluating outcomes, it will be important to specify the time frame of interest. The initial focus should be on outcomes in the first few weeks of life, often the most risky time period for patients with CCHD. However, newborn screening research is increasingly focused on longer-term outcomes, including neurodevelopmental outcomes, and it will be appropriate to take this approach in evaluating screening for CCHD.

Screening for CCHD should also be considered in the context of screening that already occurs, such as screening using fetal ultrasound. Routine fetal ultrasound is performed in most pregnancies in the United States and can identify several of the malformations that come under the rubric of CCHD. This leads to referral for fetal echocardiography, which may lead to the detection of up to 60% of CCHD prenatally. Postnatal screening using pulse oximetry may not be applied in cases in which there is a known prenatal diagnosis. Therefore, short- and intermediate-term outcomes should be evaluated on the basis of all forms of screening for CCHD.

Other Outcomes

Screening with pulse oximetry will identify conditions other than CCHD, including noncritical CHD and non-cardiac conditions, such as pulmonary disease, sepsis, and metabolic disease. In addition, screening may be associated with psychosocial consequences for families, particularly in the setting of false-positive screens. To obtain a complete picture of screening for CCHD, it will be essential to capture these and other secondary outcomes. In addition, nationwide screening for CCHD should increase the awareness of CHD, and it would be useful to evaluate this phenomenon.

Screening Process

The efficiency of screening for CCHD will vary across facilities and individuals. It is clear from the quality improvement literature that almost any process can be improved by studying its components. It should be possible to improve the efficiency of screening by using the natural experiments that may arise as states implement different screening processes. As experience with CCHD screening increases, it is also likely that process research questions will be identified that can be pursued using a variety of study designs.

In addition to evaluating the process of screening, it will be useful to consider evaluating potential alternatives to pulse oximetry screening, such as new technologies or other measures. Such technologies and measures could include the peripheral perfusion index, biomarkers, or advanced echocardiographic techniques to obtain data that can be collected without the need for skilled technologists and are read remotely.

Pulse Oximetry Equipment

Some pulse oximetry equipment may be better than others for screening under certain circumstances. For example, most pulse oximeters have not been validated extensively at the lower oxygen saturations associated with CCHD. One strategy for resolving this gap is through the ACC-funded Improving Pediatric and Adult Congenital Treatment registry of pediatric cardiac catheterization procedures. During such procedures, simultaneous direct measurements of oxygen saturation and pulse oximetry readings are recorded, making the registry an important source of data to evaluate pulse oximetry equipment.

Immediate Next Steps

A number of programs are currently working to address existing research questions surrounding CCHD screening. The immediate next step is to compile a summary of the information available from existing programs and data sources, and then use this information to identify specific strategies to address the 5 research

TABLE 3 Responsibilities of Proposed Collaborative to Address Education Surrounding CCHD Screening

| 1. Review and assess existing materials. |
| 2. Identify gaps in existing materials. |
| 3. Determine/identify best practices for educational materials and methods. |
| 4. Pilot and evaluate educational materials when necessary. |
| 5. Determine best practices, stakeholders, partners, and outlets for dissemination of guidelines. Strategies could include public awareness campaigns, long distance strategies (telemedicine), social media, academic education/curriculums, state public health education. |
| 6. Identify funding sources. |
analyses should be performed after

Additional cost and cost-effectiveness

the issue of who bears the costs.

medical costs with health outcomes at

letter. Such analyses compare direct

system mandate that similar assess-

payments by health plans or govern-

sensors, paying for the time required

and causing or arranging for

follow-up evaluations in the case of

issues of who is responsible for bearing those costs and

and government entities need to be addressed. In

providing public health oversight of

Costs of screening include developing

educational materials for screeners and

and families, training screeners,
purchasing and maintaining calibration

of pulse oximeters, purchasing

screening is being prepared by CDC as

for CCHD is being prepared by CDC as

ment of cost per life-year saved has not

yet been published. In addition, the dif-

ferences inherent in the US health care

system mandate that similar assess-

ments be undertaken here. A formal

cost-effectiveness analysis of screening

for CCHD is being prepared by CDC as

part of its response to Secretary Sibelius’

letter. Such analyses compare direct

medical costs with health outcomes at

the level of society but do not address

the issue of who bears the costs.

Additional cost and cost-effectiveness

analyses should be performed after

more experience has been gained by

various states with screening. Such

experience can be expected to de-

crease the time required to screen,

communicate with families, and ar-

range for any follow-up care that is

needed and result in more stable
cost estimates. In addition, it would

be helpful to assess the costs of

screening incurred by different stake-

holders, including hospitals and birth

centers.

PAYMENT FOR SCREENING,
FOLLOW-UP DIAGNOSTIC TESTING,
AND PUBLIC HEALTH OVERSIGHT

Advocacy to Facilitate
Effective and Comprehensive
Screening

Although CCHD was added to the RUSP
by Secretary Sebelius in September
2011, work continues at the state level
toward uniform adoption of screening
for CCHD. Because adoption of the
complete RUSP is not required by all
states, individual state action may be
required, either through legislation
or executive action, to mandate or
promote the adoption by health fac-

ities and providers of screening.

Working at the state level, health care

provider leaders and advocates have

educated state legislators and de-

partments of health on the benefits

of screening. Each state has presented
different challenges; for example,
determining thresholds for high-
alitute screening in the mountain

states. Through different models of

legislation, regulation, or as a standard
of care, the ad hoc coalition of physi-
cians, nurses, parents, and other advo-
cates has succeeded in the adoption
of CCHD screening through a variety of
mechanisms. Indiana was the first state
to pass legislation, quickly followed by
Maryland, New Jersey, New Hampshire,
West Virginia, Connecticut, and Cal-
fornia. Several states, including Ala-
bama, Utah, Georgia, Michigan, Ohio,
and Pennsylvania, have taken or are
in the process of taking a regulatory
route to implementation. Arkansas and

North Carolina are in the process of
a legislative approach to approval and
work continues as a general effort in
Wisconsin and Maine. There are ex-
pected to be continued efforts in the
2013 legislative session. With contin-
ued education and advocacy, some
states that were initially hesitant to
adopt legislation may continue to
move forward.

Local support can be developed
through engagement with a variety of
stakeholders (ie, state AAP Chapters,
the March of Dimes, the AHA, regional
CHD advocates, parent advocacy
groups, the Congenital Heart Public
Health Consortium, local state medi-
cal societies) and by offering model
legislation or regulatory language.

Another important partner in the ef-
fort is the state chapter of the
American Hospital Association, as
many hospitals view screening as an
unfunded mandate as seen in the
subcommittee debate in California.

Resolving concerns among advocates
and articulating clearly the benefits
of CCHD before attempting to secure
legislative or regulatory require-
mnts to screen is advised.

At the state level, model legislation
can mandate a regulatory approach
or the screening itself. Legislation can
define birthing facilities, specify CCHD
screening, and call on the department
of health to develop regulations
to implement, track, and report
screening in the state. At the federal
level, 6 states or groups of states (MI,
New England [ME, NH, VT, RI, and CT],
NJ, UT, VA, and WI) were awarded
grants from HRSA to help implement
and evaluate programs. Funding to
better standardize reporting and
tracking is still needed. Other long-
term federal efforts include adding
CCHD screening to the National
Quality Forum–approved measures
and continued engagement of reg-
ulatory agencies (ie, the Joint
Commission) in adopting CCHD screening as a standard. Eventually, CCHD screening results should be an element imbedded in each hospital’s electronic health record with a decision support tool assisting the physicians and nurses in assessing the patient and in reporting the results.

The New Jersey Experience

On June 2, 2011, Governor Christie of New Jersey signed legislation mandating newborn pulse oximetry screening. The law went into effect 90 days later on August 31, 2011, making New Jersey the first state in the nation to implement mandatory screening for CCHD. As such, critical review of the New Jersey experience can provide important lessons for other states implementing or planning to implement statewide CCHD screening. The New Jersey Department of Health (NJDOH) led the implementation efforts and established the New Jersey Critical Congenital Heart Disease Screening Working Group, which includes neonatologists, cardiologists, nurses, nurse midwives, pediatricians, parents, NJDOH staff from the New Jersey Birth Defects Registry, the newborn screening program, and newborn hearing screening program, as well as representatives from the NJDOH Division of Health Facilities Evaluation and Licensing, the AAP New Jersey Chapter, Maternal and Child Health Consortia, and the New Jersey Hospital Association. The NJDOH, with input from members of the CCHD Screening Working Group, developed a recommended screening protocol, trained hospital providers, and instituted a 2-pronged approach to data collection. Challenges to implementation identified in the New Jersey experience were the short implementation period, the unfunded mandate, and barriers associated with initiation of a new surveillance system.

CONCLUSIONS

CCHD newborn screening presents new challenges and opportunities to health care providers, families, hospitals, and state and federal health agencies. Addressing the challenges and acknowledging the opportunities for further work provides an opportunity to strengthen screening and newborn care networks in ways that should benefit children born with CCHD.

APPENDIX

The following is a list of work group members and the agencies or organizations they represented at the meeting (being listed as a work group member does not imply that the members or the organization that they represent endorse all aspects of this report):

Swapna Abhyankar, MD; National Institutes of Health, National Library of Medicine
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Jeff Bialick; Newborn Coalition
Ulf Borg; Covidien
Elizabeth Bradshaw Mikula, MSN, RN, CPN; Children’s National Medical Center
Waldemar (Wally) Carlo, MD; American Academy of Pediatrics, Section on Perinatal Pediatrics
Lynn Colegrove; American Academy of Pediatrics
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Sheri Crow, MD, MS; Mayo Clinic
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Olivia Easley, MD; Bless Her Heart
James Fasules, MD; American College of Cardiology
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Scott Grosse, PhD; Centers for Disease Control and Prevention
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Lazaros Kochilas, MD; University of Minnesota
Praveen Kumar, MD; American Academy of Pediatrics; Northwestern University Feinberg School of Medicine
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Jody Lemacks; Mended Little Hearts
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Jeannette Lowe; March of Dimes, National Office of Government Affairs
William Mahle, MD, FACC, American Heart Association

Appendix
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Kristine Brite McCormick; It’s My Heart, Inc.
Clement McDonald, MD; National Institutes of Health, National Library of Medicine
Stephanie Mitchell; American College of Cardiology
Cynthia Moore, MD, PhD; Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities
Sue Nelson; American Heart Association
Richard Olney, MD, MPH; Centers for Disease Control and Prevention
Michael O’Reilly, MD, MS; Masimo Corporation
Matt Oster, MD, MPH; March of Dimes; Children’s Healthcare of Atlanta; Centers for Disease Control and Prevention
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Ken Pool, MD; OZ Systems, Inc
Melissa Benish Putman; March of Dimes National, Office of Government Affairs
Guyan Randall; Masimo Corporation
Jeffrey Ranous; American Heart Association
Annamarie Saarinen, MA; Newborn Coalition, 1in100
Kenneth Shaffer, MD, FACC, FAAP; Pediatrix Cardiology
Jill Shuger, ScM; Health Resources and Services Administration
Elizabeth Stark, MS, CGC; Genetic Alliance
Trisha Stewart, PA-C; Covidien/Nellcor
Bonnie Strickland, PhD; Health Resources and Services Administration
Barry Thompson, MD; American College of Medical Genetics
Sandy Weininger, PhD; Food and Drug Administration, Center for Devices & Radiological Health
Josh Zets; PerkinElmer
Diane Zook, BS; MultiCare Health System: Tacoma General Hospital, Mary Bridge Children’s Hospital, Good Samaritan Hospital, MultiCare Institute for Research & Innovation
Alan Zuckerman, MD; National Library of Medicine

ACKNOWLEDGMENTS
We thank Sara Copeland, MD, Health Resources Services Administration/ Maternal and Child Health Bureau, John Laschinger, MD, Food and Drug Administration, and Scott D. Grosse, PhD, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, for their participation on the expert panel and for their contributions to this manuscript.

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(Continued from first page)

The findings and conclusions in this article are those of the authors and do not necessarily represent the official positions of the Centers for Disease Control and Prevention, the National Heart, Lung, and Blood Institute/National Institutes of Health, the Food and Drug Administration, or the New Jersey Department of Health. The federal and state authors are not involved in the advocacy activities discussed herein.

www.pediatrics.org/cgi/doi/10.1542/peds.2012-3926
doi:10.1542/peds.2012-3926

Accepted for publication Mar 27, 2013

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FINANCIAL DISCLOSURE: The authors have indicated they have no financial relationships relevant to this article to disclose.

FUNDING: No external funding.
Implementing Recommended Screening for Critical Congenital Heart Disease

Pediatrics originally published online June 17, 2013;

Updated Information & Services
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http://pediatrics.aappublications.org/content/early/2013/06/12/peds.2012-3926

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*Pediatrics* originally published online June 17, 2013;

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