sults are based on data from 46 states and Puerto Rico. However, these areas represent approximately 91.2% of reported acquired immunodeficiency syndrome (AIDS) diagnoses in the United States and the dependent areas, and states with high proportions of Hispanics or Latinos were included. Second, data were adjusted for reporting delay but not incomplete reporting, and statistical adjustment of data might have introduced uncertainties into estimates of diagnoses of HIV infections or of the number of persons living with a diagnosis of HIV infection. Finally, birthplace data were missing for 16.4% of Hispanics or Latinos newly diagnosed with HIV infection in 2010. Additionally, birthplace does not indicate where a person became HIV infected.

The National HIV/AIDS Strategy calls for intensified HIV prevention efforts in communities where HIV infection is most heavily concentrated, including Hispanic or Latino communities.[9] The findings in this report suggest that HIV intervention efforts should be tailored to the characteristics and needs of the Hispanic or Latino population in different geographic areas. Regionally specific HIV prevention efforts should be used to increase early diagnosis and linkage to care for Hispanics or Latinos. CDC's high-impact prevention approach, a combination of scientifically proven, cost-effective, and scalable interventions (e.g., biomedical interventions, HIV testing and linkage to care, and individual and small group interventions), could be used in high-risk Hispanic or Latino populations, particularly injection-drug users in the Northeast and Puerto Rico, persons in rural areas, and recent immigrants to the South.

Acknowledgment

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9 Available.

*Hispanics or Latinos might be of any race.
†The five U.S. dependent areas are American Samoa, Guam, the Northern Mariana Islands, Puerto Rico, and the U.S. Virgin Islands.
§*Northeast*: Connecticut, Maine, New Hampshire, New Jersey, New York, Pennsylvania, and Rhode Island; *Midwest*: Illinois, Indiana, Iowa, Kansas, Michigan, Minnesota, Missouri, Nebraska, North Dakota, Ohio, South Dakota, and Wisconsin; *South*: Alabama, Arkansas, Delaware, Florida, Georgia, Kentucky, Louisiana, Mississippi, North Carolina, Oklahoma, South Carolina, Tennessee, Texas, Virginia, and West Virginia; *West*: Alaska, Arizona, California, Colorado, Idaho, Montana, Nevada, New Mexico, Oregon, Utah, Washington, and Wyoming.
¶Residents of metropolitan areas with ≥500,000 population.
**Residents of nonmetropolitan areas with <50,000 population.

Newborn Screening for Critical Congenital Heart Disease: Potential Roles of Birth Defects Surveillance Programs—United States, 2010–2011

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1 table omitted.

IN SEPTEMBER 2011, THE SECRETARY OF the U.S. Department of Health and Human Services (HHS) approved the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) 2010 recommendation that all newborns be screened for critical congenital heart disease (CCHD) using pulse oximetry, a noninvasive test of blood oxygenation, to prevent mortality and morbidity.[1] CDC partnered with the National Birth Defects Prevention Network (NBDPN) to conduct a survey designed to assess state birth defect surveillance programs' potential roles, capabilities, and readiness to assist with newborn screening activities for CCHD. States were surveyed in November 2010, after the initial SACHDNC recommendation, and again in November 2011, after the Secretary's approval. From 2010 to 2011, the number of birth defects surveillance programs involved in CCHD screening increased from one to 10. Barriers exist, such as the lack of legislative authority, staffing, funding, and informatics infrastructure. Sixty-seven percent of programs take an average of more than 12 months to collect complete data on birth defect cases, including congenital heart defects. An assessment of state birth defects programs' existing data and capability to lead the evaluation of screening for CCHD is warranted.

Universal newborn screening is the practice of screening every newborn for certain serious genetic, endocrine, and metabolic conditions, as well as functional disorders that are not apparent at birth. Through early identification and treatment, newborn screening provides an opportunity for reduction in infant morbidity and mortality.[2,3]

What is already known on this topic?

Universal newborn screening is the practice of screening every newborn for certain serious but inapparent conditions so that early intervention can reduce morbidity and save lives. Birth defects surveillance programs collect data that are useful for research, program planning, and program evaluation.

What is added by this report?

Many birth defects surveillance programs have the data and capabilities to lead the evaluation of newborn screening for critical congenital heart disease (CCHD). From 2010 to 2011, the number of birth defects surveillance programs involved in CCHD screening increased from one to 10. During that period, 13 of 43 birth defects surveillance programs reported the capability to evaluate all true and false-positive screening results. Thirteen of 43 programs also reported the capability to evaluate all false-negative screening results.

What are the implications for public health practice?

Newborn screening for CCHD provides a unique opportunity for synergy among state public health programs. States should evaluate infrastructure and resource needs before adoption of screening for CCHD to ensure a successful screening program.

SACHDNC provides national guidelines on newborn screening that are reviewed and endorsed by the HHS Secretary. The conditions for which screening is endorsed by SACHDNC, after a formal evidence review process, are known collectively as the Recommended Uniform Screening Panel (RUSP).[3] In 2012, a total of 31 conditions are included in RUSP. States use RUSP as guidance when establishing their state-specific screening panels.

The most recent addition to RUSP is CCHD.[1] Congenital heart disease occurs in approximately eight in every 1,000 live births. Of these cases, approximately one quarter are considered to be CCHD, defined as requiring cardiac surgery or catheterization before age 1 year.[4] Left undetected, infants with CCHD are at risk for the development of serious complications (e.g., end-organ damage, motor function impairments, and cognitive impairments) within the first few days or weeks of life. The seven CCHDs that are primary targets for screening are hypoplastic left heart syndrome, pulmonary atresia (with intact septum), transposition of the great arteries, truncus arteriosus, tricuspid atresia, tetralogy of Fallot, and total anomalous pulmonary venous return.[4] In September 2010, SACHDNC recommended that screening for CCHD by pulse oximetry be included in RUSP. This recommendation was endorsed by the HHS Secretary in September 2011.[1] Screening for CCHD is a point-of-care test that will occur in hospitals before an infant's discharge from the nursery, with results entered into the hospital medical record. State birth defects surveillance programs often draw from hospital medical records; therefore, these programs could assist in tracking and evaluating screening outcomes. Most state surveillance programs already collect data to calculate CCHD prevalence; however, differences exist across states in resources and case ascertainment methodologies that might affect how state programs can provide assistance with the implementation and evaluation of CCHD screening and follow-up.

To assess the differences between state birth defect surveillance programs, in October 2010, after the SACHDNC recommendation to add screening for CCHD to RUSP, CDC collaborated with the National Birth Defects Prevention Network, a national network of state and population-based programs for birth defects surveillance and research, to create and distribute an electronic survey to birth defects surveillance program primary contacts[6] in all 50 states, the District of Columbia, and Puerto Rico. The purpose of the survey was to assess state birth defect surveillance programs' potential roles, capabilities, and readiness to assist with newborn screening activities for CCHD to strengthen CCHD screening and follow-up. In November 2011, following the HHS Secretary's approval of the addition of screening for CCHD to RUSP, the survey was revised and redistributed to state programs, requesting confirmation or revision of the responses received in 2010. Nonresponders were contacted via e-mail and telephone. The 2010 and 2011 surveys were distributed to the same person in each program, with no changes in personnel occurring in the 1-year interval between the surveys. Multiple-choice and open-ended questions were asked to assess state CCHD screening activities, ways in which state birth defects surveillance programs could lead the evaluation of CCHD newborn screening, the confirmation of CCHD cases, and barriers to involvement with CCHD newborn screening.

The 2010 and 2011 surveys were completed in all 50 states, the District of Columbia, and Puerto Rico, for a response rate of 100%. In both surveys, 43 states responded that they had a birth defects surveillance program. CCHD activities increased from one state in 2010 to 10 states in 2011. State birth defects surveillance programs reported ways in which they could lead the evaluation of CCHD screening. In 2011, 28 states reported the ability to evaluate mortality associated with CCHD, 16 could evaluate morbidities associated with CCHD, and 11 could evaluate interventions associated with CCHD. States were asked to identify programs that might get involved in screening for CCHD, other than birth defects surveillance programs. Ten states identified their state's newborn screening program, and four identified children's medical services/Title V programs. Other responses included genetic services programs, hearing screening programs, and private pediatric hospitals. State birth defects surveillance programs reported varying relationships with state newborn screening programs, with five programs reporting they have no relationship with the state newborn screening program. Eight of the 10 states that reported being involved in CCHD screening activities in 2011 reported insufficient funds, nine reported inadequate staffing, and five reported lack of legislation or regulatory authority as barriers to involvement in newborn screening for CCHD. One of the 10 states reported legislatively mandated screening activities; nine were still in the planning stages. Sixty-seven percent of programs reported that it took ≥12 months to complete birth defects surveillance case records. Sixty-eight percent of programs did not have access to hospital point-of-care screening records.

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Editorial Note: State-level Title V maternal and child health programs and birth defects surveillance programs have potential roles in surveillance and evaluation of CCHD screening.[5] These state programs routinely conduct public education, train health-care providers, and support newborn screening programs and services for children with special health-care needs. Many birth defects surveillance programs have the data and capabilities to lead the evaluation of newborn screening for CCHD. In ad-

dition to monitoring CCHD prevalence, state birth defects programs could incorporate data collection to evaluate false-positive and false-negative screens, because neonatal medical records are one of the key data sources for birth defects surveillance. Collecting data to reveal factors associated with false-positive and false-negative results also could help refine the nationally recommended screening algorithm[5] and screening activities.

The findings in this report are subject to at least two limitations. First, although 100% of states completed the survey, participants were not required to respond to every survey question; therefore, data are incomplete for some survey items. Second, only state birth defects surveillance programs were surveyed; no information on the capabilities of other state public health programs to participate in CCHD screening activities was sought.

State birth defects surveillance programs reported that they can lead evaluation of CCHD screening by evaluating sensitivity and specificity, reporting mortality and comorbidities, assisting with economic evaluation, and reporting service utilization by children with CCHDs. However, most state programs also report major barriers to their involvement in newborn screening for CCHD. Many state birth defects surveillance programs indicate that inadequate staffing and insufficient funds would hinder involvement with screening for CCHD. Given that 67% of programs reported that it took ≥12 months to complete birth defects surveillance case records, timeliness of data collection will need to be addressed before birth defects surveillance can truly maximize its potential.

States should evaluate infrastructure and resource needs before adoption of CCHD screening to ensure a successful screening program. Legislative mandates for universal newborn screening for CCHD began in June 2011, with New Jersey being the first state to implement legislatively mandated screening.[7] Legislative activity increased in late 2011 and early 2012 (American Academy of Pediatrics, Division of State Government Affairs, unpublished data, 2012). Nineteen states reported that lack of legislative/public health authority required to obtain and collect CCHD screening data was a barrier to involvement with screening activities. Newborn screening for CCHD provides an opportunity for collaboration between state birth defects surveillance programs and state newborn screening programs.

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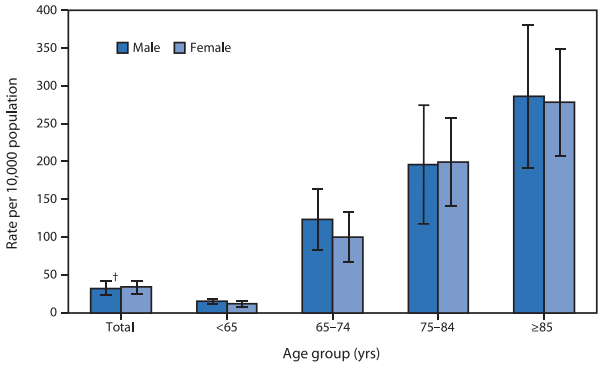
QuickStats

FROM THE NATIONAL CENTER FOR HEALTH STATISTICS

Rate* of Hospitalization for Stroke, by Sex and Age Group — National Hospital Discharge Survey, United States, 2010



* Per 10,000 population. Hospitalization for stroke (cerebrovascular disease) is defined as a first-listed diagnosis on the medical record of 430–438, as coded according to the *International Classification of Diseases, 9th Revision, Clinical Modification*. This includes hospitalizations for acute strokes, transient ischemic attack, and for late effects of stroke. Rates were calculated using U.S. Census Bureau 2000-based postcensal civilian population estimates.

† 95% confidence interval.

In 2010, hospitalization rates per 10,000 population for stroke for males and females increased with increasing patient age. For males, the rate per 10,000 ranged from 14.7 for those aged <65 years to 285.7 for those aged ≥85 years. For females, the rate ranged from 11.6 per 10,000 population for those aged <65 years to 277.4 for those aged ≥85 years. Within each age group, the rates for males and females were similar.

Sources: National Hospital Discharge Survey data (2010). Available at http://www.cdc.gov/nchs/nhds.htm.

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