

# Title V and Newborn Screening

## State Performance Measures and Long-Term Follow-Up

### Introduction

Each year, approximately four million infants are screened in the U.S. for a variety of serious or life-threatening heritable disorders and medical conditions. If these conditions are diagnosed in a timely manner, they can be successfully managed or treated to prevent severe and often life-long health consequences. Newborn screening saves or improves the lives of more than 20,000 babies each year.

Newborn screening is a coordinated system of efforts between birthing hospitals, state-based newborn screening programs, health care providers, and families. State newborn screening programs provide laboratory testing, short-term follow up, education for parents and physicians, and referrals for treatment. Depending on the infant's condition, clinical specialists (including metabolic geneticists, immunologists, and/or neurologists) direct the diagnosis, care, and management of newborn screening-identified infants. The majority of newborn screening conditions can be treated but not cured; thus, infants with special health care needs face a lifetime of care and clinical management.

The federal Newborn Screening Saves Lives Act outlines the role of three federal agencies in newborn screening. As outlined in Figure 1, the National Institutes of Health (NIH), the Centers for Disease Control and Prevention (CDC), and the Health Resources and Services Administration (HRSA) focus their efforts on different parts of the newborn screening system.

Additionally, states have used the federal Title V Maternal and Child Health (MCH) Services Block Grant, which is authorized by the Social Security Act, to support their newborn screening programs. The Title V MCH Block Grant is the only federal program of its kind devoted solely to improving the health of all women and children. The program plays a critical role in helping states implement systems of care for children and youth with special health care needs (CYSHCN). Historically, funding from this program supported not only newborn screening, but also the diagnosis, treatment, and follow-up care in some states. State CYSHCN directors are often members of state newborn screening advisory committees and also facilitate care coordination, ensure follow-up, and collect the data necessary to promote quality improvement.

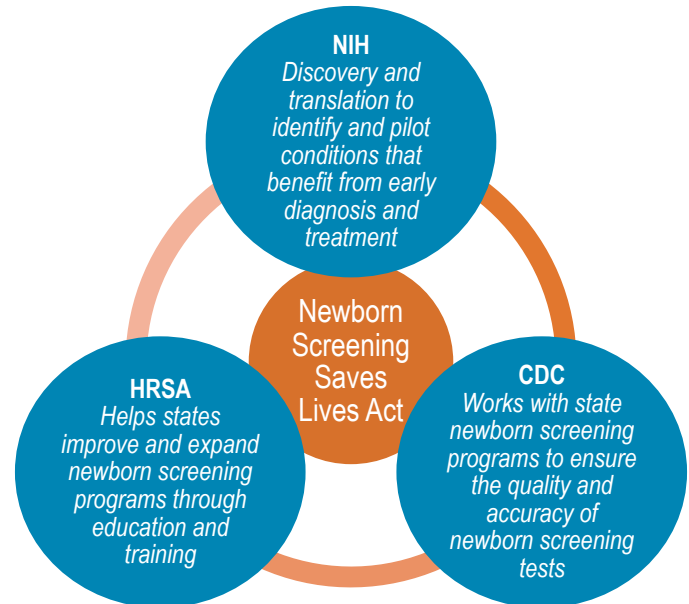


Figure 1: Federal agency roles are outlined in the Newborn Screening Saves Lives Act

## Environmental Scan of Title V Block Grant Applications: State Performance Measures and Long-Term Follow-Up

The Association of Maternal & Child Health Programs (AMCHP) reviewed the Title V Information System in the winter of 2017/2018 to identify states and jurisdictions (hereafter referred to as “states”) that adopted state performance measures related to newborn screening. AMCHP also conducted an environmental scan of newborn screening long-term follow-up activities documented in the fiscal year 2018 block grant applications. The goal of the environmental scan was to highlight ways that state Title V programs support newborn screening programs and systems.

### Title V and Newborn Screening: State Performance Measures

Title V requires each state to conduct a state-wide comprehensive needs assessment every five years to identify state-specific MCH priorities.<sup>1</sup> To ensure accountability for Title V-funded activities, states are required to report on national performance measures and national outcome measures that describe a specific MCH need that, when successfully addressed, can lead to a better health outcome within a designated time frame. Title V programs also set state performance measures that are instrumental in helping states address MCH priorities that are aligned with each state’s specific needs and capacity, which may fall outside the parameters of the national performance measure framework. This flexible state-federal partnership is a noteworthy feature of the Title V program.

In fiscal year (FY) 2018, seven Title V programs adopted at least one state performance measure<sup>ii</sup> related to newborn screening. Table 1 summarizes the state performance measures and their objectives/intent.

**Table 1: Title V State Performance Measures Related to Newborn Screening**

State	State Performance Measure	Objectives/Intent
Federated States of Micronesia	#4: Percent of infants screened for hearing	<ul style="list-style-type: none"> <li>• Increase the percent of newborns screened for hearing by one month.</li> <li>• Pilot tele-audiology in one of the federation’s states.</li> <li>• Increase the percent of children with hearing loss who receive early intervention.</li> </ul>
Louisiana	#1: Percent of infants born in Louisiana who screen positive for a condition mandated by Louisiana newborn screening statutes and receive timely diagnosis	<ul style="list-style-type: none"> <li>• Ensure at least 99% of newborns are screened for all conditions included in the Louisiana newborn screening panel annually.</li> <li>• Maintain 100% follow-up within 24 hours of lab report of children who screen positive for a genetic condition.</li> <li>• Reduce loss to follow-up of infants who fail newborn hearing screening.</li> </ul>
New Jersey	#3: Percentage of newborns who are discharged from New Jersey hospitals, reside in New Jersey, did not pass their newborn hearing screening, and who have outpatient audiological follow-up documented	<ul style="list-style-type: none"> <li>• Improve the number and percentage of infants that receive a timely diagnosis of hearing loss and timely enrollment in early intervention services.</li> </ul>

North Carolina	#1: Percent of infants with confirmed hearing loss who are enrolled for intervention services no later than the age of 6 months	<ul style="list-style-type: none"> <li>• Each year, 99% of newborn infants will be screened for genetic/metabolic disorders and will receive necessary follow-up.</li> <li>• Increase the percent of North Carolina infants who are screened for hearing disorders and who will receive expedited follow-up services.</li> </ul>
Ohio	#5: Number of performance measure benchmarks Ohio has reached toward improving Ohio's newborn screening system	<ul style="list-style-type: none"> <li>• Improve newborn screening data.</li> <li>• Improve pediatric primary care providers' (pediatricians and family practice physicians) knowledge of newborn screening and their role in newborn screening follow-up.</li> <li>• Improve messaging to parents about newborn screening.</li> </ul>
Pennsylvania	#3: Percent of newborn screening dried blood spot filter papers received at the contracted lab within 48 hours after collection	<ul style="list-style-type: none"> <li>• Increase the annual percentage of dried blood spot samples with a transit time to the contracted lab of less than 48 hours, in order to expedite diagnosis and treatment.</li> <li>• Implement a system where all newborns born in Pennsylvania are screened for all conditions listed on the Recommended Uniform Screening Panel.</li> </ul>
South Carolina	#4: Percentage of infants identified through newborn screening with sickle cell disease who receive care coordination services, through the CSHCN program.	<ul style="list-style-type: none"> <li>• Increase the percentage of infants identified through newborn screening with sickle cell disease who received care coordination services through the Department of Health and Environmental Control CSHCN program.</li> </ul>

## Long-term Follow-up Activities and Title V

As noted previously, once a newborn is diagnosed with a condition through newborn screening, he or she enters into the health care system for life-long management. The longitudinal collection of health information about these newborns is an important component of the newborn screening system. It is essential to not only track the health outcomes of these children, but to also perform long-term follow-up activities to assess the effectiveness of treatments and to ensure that children across different geographical locations have the same access to quality care. Key components of long-term follow-up include<sup>iii,iv</sup>:

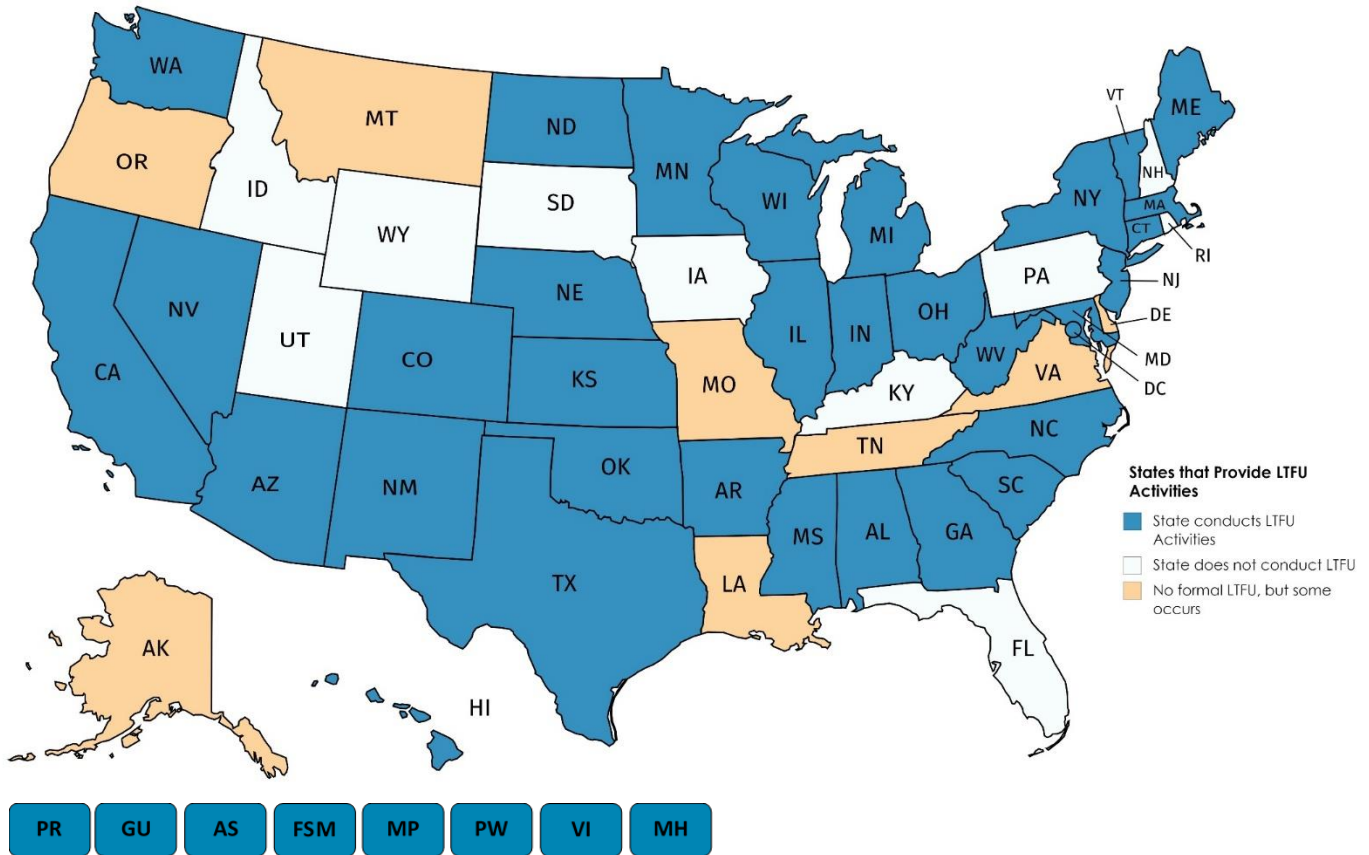
- **Care coordination through a medical home**
- **Evidence-based treatment**, which includes providing condition-specific therapy as well as connecting affected individuals with the most effective treatments or with clinical research trials
- **Ensuring that young adults transition to appropriate adult medical care**
- **Surveillance and evaluation of data related to care and outcomes**
- **Continuous quality improvement**
- **New knowledge discovery**, including research to evaluate the impact of interventions.

As part of their block grant applications, Title V programs are asked to describe their states' practices for monitoring infants with confirmed diagnoses, the type of information that is obtained, and the length of time infants are monitored. The application form describes long-term follow-up as the services provided after an infant is referred for treatment. The following results summarize the types of long-term follow-up activities reported by the 59 state and jurisdictional Title V programs in Form 4 of their FY 2018 applications.<sup>v</sup>



The majority of Title V programs report long-term follow-up activities for newborn screening: Forty-one Title V programs reported that their state conducts long-term follow-up activities. Of these, nine reported long-term follow-up activities for some conditions only (e.g., hearing loss, sickle cell, and certain metabolic disorders). Eighteen Title V programs reported that their state did not have a long-term follow-up program or policy. However, eight of those programs indicated that although they did not have a formal program or policy, some long-term follow-up activities do occur for certain conditions and/or the state provides the infrastructure to allow for long-term follow-up. (See Figure 2.)

**Figure 2: State Long-Term Follow-Up (LTFU) Activities for Newborn Screening**



Most of the Title V-reported long-time follow-up activities address medical home/care coordination, evidence-based treatment, and surveillance and evaluation.

- **Care coordination through a medical home:** Twenty-six states reported that their long-term follow-up care activities include care coordination through a medical home. These activities range from ensuring an infant is receiving care through a primary care provider and specialist to connecting the family with community resources to directly providing case management and care coordination services. Title V CYSHCN programs were most likely to provide care coordination and case management services. In some states, care coordination is provided by social workers or other state agencies (e.g., Medicaid, early intervention, special education). Primary care providers, specialists, and treatment centers/specialty clinics were most often reported as the leads for serving as the medical home.
- **Evidence-based treatment:** The majority of states (38) reported that their long-term follow-up activities included treatment and providing connections to appropriate treatments. Primary care providers, specialists, nurses, and nutritionists were the individuals most often reported as responsible for

providing long-term treatment. Many states fund specialty care clinics, metabolic clinics, and/or genetics clinics to provide treatment and services for infants and children. Some applications specified that the Title V program provides funding to clinics, whereas other applications broadly stated that public health funding was provided.

- **Surveillance and evaluation of data related to care and outcomes:** Nineteen states reported that they used long-term monitoring and data surveillance to evaluate and assess the outcomes of infants identified with a condition through newborn screening. Most states reported that these data were collected and monitored by the state newborn screening programs and/or CYSHCN program. The types of data tracked varied by state and within states by condition. Examples of the types of data collected include information on diagnosis and treatment plans, visits with primary care providers and specialists, frequency of hospitalizations and emergency room visits, health status, medical history, medication compliance, developmental milestones, service referrals and community resources provided, parent contact and referrals, and barriers and challenges to care (including housing and transportation).
- **Other reported long-term follow-up activities** included continuous quality improvement (CQI) and transitioning young adults into appropriate medical care. Three states noted quality improvement in activities such as identifying gaps in follow-up care, identifying opportunities for systems and policy improvement, and instituting CQI as a component of contracts to specialty providers for certain conditions identified through newborn screening. Three Title V programs noted specific activities related to transitioning to adult care, either as part of the long-term care coordination or through contracts with clinical or specialty centers to provide those services. It is important to note that many Title V programs address transition to adult care through their broader CYSHCN program. Many cited that infants are enrolled in their state CYSHCN programs as part of the long-term follow-up from newborn screening. Similarly, many Title V programs include CQI as part of their broader program approach and monitoring efforts. Therefore, the number of programs that address CQI and transitioning of young adults into appropriate medical care as part of long-term follow-up for infants is much higher than reported here.

## Discussion

Title V programs support newborn screening in their states in several ways. Title V programs may integrate newborn screening as strategies and activities in their action plans to address their states' priority MCH needs around timeliness and coordinated comprehensive systems; they also provide support for long-term follow-up after newborn screening. Title V programs were mostly likely to report they play a lead role in the long-term follow-up activities of medical home and care coordination; in ensuring the appropriate treatment of, and referral to services for, children diagnosed with a condition identified through newborn screening; and in ensuring ongoing surveillance and evaluation of outcomes. These findings have limitations as the environmental scan did not cover an exhaustive list of all activities reported in the Title V block grant applications. Additionally, Title V programs varied significantly in the level of detail and the way in which data on long-term follow-up activities were reported. The form did not require common reporting elements beyond a description of their states' practice for monitoring infants with confirmed diagnoses. The character limit for the long-term follow-up section on the form only allowed for brief responses; thus, states may not have reported all the details of their long-term follow-up activities. Still, this environmental scan does provide a broad picture of the role of Title V programs in supporting newborn screening programs and long-term follow-up activities for those infants identified with a condition. The information presented may be useful to Title V programs as they develop and implement strategies to build or improve newborn screening systems, and as they support coordinated systems of care for CYSHCN. This scan also provides examples of how Title V programs can partner with others engaged in efforts to deliver and improve newborn screening and services for children and families.





## More Information

For more information, visit [www.amchp.org/programsandtopics/CHILD-HEALTH/projects/newborn-screening](http://www.amchp.org/programsandtopics/CHILD-HEALTH/projects/newborn-screening).

## About AMCHP

The Association of Maternal & Child Health Programs is a national resource, partner, and advocate for state public health leaders and others working to improve the health of women, children, youth and families, including those with special health care needs. AMCHP's members come from the highest levels of state government and include directors of maternal and child health programs, directors of programs for children with special health care needs, and other public health leaders who work with and support state maternal and child health programs.

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## End Notes

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<sup>i</sup> Title V Maternal and Child Health (MCH) Services Block Grant to states program application/annual report guidance (Eighth Edition). Available from: <https://mchb.tvisdata.hrsa.gov/uploadedfiles/Documents/blockgrantguidance.pdf>.

<sup>ii</sup> Title V Information System: State performance measures. Available from: <https://mchb.tvisdata.hrsa.gov/PrioritiesAndMeasures/StatePerformanceMeasures>.

<sup>iii</sup> Kemper A.R., Boyle C.A., Aceves J., et al. (2008). Long-term follow-up after diagnosis resulting from newborn screening: Statement of the U.S. Secretary of Health and Human Services' Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children. *Genetics in Medicine*. 10:259-261. Available from: [www.nature.com/articles/gim200839](http://www.nature.com/articles/gim200839).

<sup>iv</sup> Association of Maternal & Child Health Programs. (2007). *Newborn screening long-term follow-up assessment*. Washington, DC. Available from: <http://www.amchp.org/programsandtopics/CHILD-HEALTH/resources/Documents/NBS-LTFU-Assessment.pdf>.

<sup>v</sup> *Form 4: Number and Percentage of Newborns and Others Screened, Cases Confirmed, and Treated*. From the Title V Maternal and Child Health (MCH) Services Block Grant to States program application/annual report guidance (Eighth Edition). Available from: <https://mchb.tvisdata.hrsa.gov/uploadedfiles/Documents/blockgrantguidance.pdf>.

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