

# NATIONAL QUALITY FORUM

## Measure Evaluation 4.1 December 2009

This form contains the measure information submitted by stewards. Blank fields indicate no information was provided. Attachments also may have been submitted and are provided to reviewers. The subcriteria and most of the footnotes from the [evaluation criteria](#) are provided in Word comments within the form and will appear if your cursor is over the highlighted area. Hyperlinks to the evaluation criteria and ratings are provided in each section.

**TAP/Workgroup** (if utilized): Complete all **yellow highlighted** areas of the form. Evaluate the extent to which each subcriterion is met. Based on your evaluation, summarize the strengths and weaknesses in each section.

**Note:** *If there is no TAP or workgroup, the SC also evaluates the subcriteria (yellow highlighted areas).*

**Steering Committee:** Complete all **pink** highlighted areas of the form. Review the workgroup/TAP assessment of the subcriteria, noting any areas of disagreement; then evaluate the extent to which each major criterion is met; and finally, indicate your recommendation for the endorsement. Provide the rationale for your ratings.

Evaluation ratings of the extent to which the criteria are met

C = Completely (unquestionably demonstrated to meet the criterion)

P = Partially (demonstrated to partially meet the criterion)

M = Minimally (addressed BUT demonstrated to only minimally meet the criterion)

N = Not at all (NOT addressed; OR incorrectly addressed; OR demonstrated to NOT meet the criterion)

NA = Not applicable (only an option for a few subcriteria as indicated)

(for NQF staff use) NQF Review #: 1351	NQF Project: Child Health Quality Measures 2010
MEASURE DESCRIPTIVE INFORMATION	
De.1 Measure Title: <a href="#">Proportion of infants covered by Newborn Bloodspot Screening (NBS)</a>	
De.2 Brief description of measure: <a href="#">What percentage of infants had bloodspot newborn screening performed as mandated by state of birth?</a>	
1.1-2 Type of Measure: <a href="#">Process</a>	
De.3 If included in a composite or paired with another measure, please identify composite or paired measure <a href="#">This measure is paired with other measures relevant to the monitoring and measurement of the early screening evaluation and intervention process.</a>	
De.4 National Priority Partners Priority Area: <a href="#">Population health</a>	
De.5 IOM Quality Domain: <a href="#">Effectiveness</a>	
De.6 Consumer Care Need: <a href="#">Living with illness</a>	

CONDITIONS FOR CONSIDERATION BY NQF	
Four conditions must be met before proposed measures may be considered and evaluated for suitability as voluntary consensus standards:	<b>NQF Staff</b>
<p>A. The measure is in the public domain or an intellectual property (<a href="#">measure steward agreement</a>) is signed. <i>Public domain only applies to governmental organizations. All non-government organizations must sign a measure steward agreement even if measures are made publicly and freely available.</i></p> <p>A.1 Do you attest that the measure steward holds intellectual property rights to the measure and the right to use aspects of the measure owned by another entity (e.g., risk model, code set)? <b>Yes</b></p> <p>A.2 Indicate if Proprietary Measure (as defined in measure steward agreement):</p> <p>A.3 Measure Steward Agreement: <a href="#">Government entity and in the public domain - no agreement necessary</a></p> <p>A.4 Measure Steward Agreement attached:</p>	<p>A</p> <p>Y <input type="checkbox"/></p> <p>N <input type="checkbox"/></p>
B. The measure owner/steward verifies there is an identified responsible entity and process to maintain and	<b>B</b>

update the measure on a schedule that is commensurate with the rate of clinical innovation, but at least every 3 years. <a href="#">Yes, information provided in contact section</a>	Y <input type="checkbox"/> N <input type="checkbox"/>
C. The intended use of the measure includes <u>both</u> public reporting <u>and</u> quality improvement. ► <b>Purpose:</b> <a href="#">Public reporting, Internal quality improvement</a> <a href="#">Accountability, Accreditation</a>	C Y <input type="checkbox"/> N <input type="checkbox"/>
D. The requested measure submission information is complete. Generally, measures should be fully developed and tested so that all the evaluation criteria have been addressed and information needed to evaluate the measure is provided. Measures that have not been tested are only potentially eligible for a time-limited endorsement and in that case, measure owners must verify that testing will be completed within 12 months of endorsement. D.1 <b>Testing:</b> <a href="#">No, testing will be completed within 12 months</a> D.2 <b>Have NQF-endorsed measures been reviewed to identify if there are similar or related measures?</b> <a href="#">Yes</a>	D Y <input type="checkbox"/> N <input type="checkbox"/>
<b>(for NQF staff use) Have all conditions for consideration been met?</b> Staff Notes to Steward (if submission returned):	Met Y <input type="checkbox"/> N <input type="checkbox"/>
Staff Notes to Reviewers (issues or questions regarding any criteria):	
Staff Reviewer Name(s):	

<b>TAP/Workgroup Reviewer Name:</b>	
<b>Steering Committee Reviewer Name:</b>	
<b>1. IMPORTANCE TO MEASURE AND REPORT</b>	
Extent to which the specific measure focus is important to making significant gains in health care quality (safety, timeliness, effectiveness, efficiency, equity, patient-centeredness) and improving health outcomes for a specific high impact aspect of healthcare where there is variation in or overall poor performance. <b>Measures must be judged to be important to measure and report in order to be evaluated against the remaining criteria.</b> ( <a href="#">evaluation criteria</a> ) 1a. High Impact	<a href="#">Eval Rating</a>
<b>(for NQF staff use) Specific NPP goal:</b>	
1a.1 <b>Demonstrated High Impact Aspect of Healthcare:</b> <a href="#">Affects large numbers, Frequently performed procedure, High resource use, Severity of illness, Patient/societal consequences of poor quality</a> 1a.2 1a.3 <b>Summary of Evidence of High Impact:</b> <a href="#">One in 800 infants born each year has a newborn screening detectable disorder, all of which can cause death or morbidity unless treated. U.S. Preventive Services Task Force. The USPSTF recommends screening for PKU, congenital hypothyroidism and sickle cell disease in all newborn infants. There is good evidence that NBS testing is highly accurate and leads to earlier identification and treatment of infants with these disorders. Good-quality evidence shows that early detection improves developmental and overall health outcomes.</a> <a href="http://www.uspreventiveservicestaskforce.org/uspstf/uspsspku.htm">http://www.uspreventiveservicestaskforce.org/uspstf/uspsspku.htm</a> <a href="http://www.uspreventiveservicestaskforce.org/uspstf/uspsscghy.htm">http://www.uspreventiveservicestaskforce.org/uspstf/uspsscghy.htm</a> <a href="http://www.uspreventiveservicestaskforce.org/uspstf/uspshemo.htm">http://www.uspreventiveservicestaskforce.org/uspstf/uspshemo.htm</a> 1a.4 <b>Citations for Evidence of High Impact:</b> <a href="#">ACMG Report- Newborn Screening Toward a Uniform Panel PEDIATRICS Vol. 106 No. 3 September 2000, pp. 595 - "The Importance of Newborn Screening" American Academy of Pediatrics NBS Task Force</a> <a href="http://www.uspreventiveservicestaskforce.org/uspstf/uspsspku.htm">http://www.uspreventiveservicestaskforce.org/uspstf/uspsspku.htm</a> <a href="http://www.uspreventiveservicestaskforce.org/uspstf/uspsscghy.htm">http://www.uspreventiveservicestaskforce.org/uspstf/uspsscghy.htm</a> <a href="http://www.uspreventiveservicestaskforce.org/uspstf/uspshemo.htm">http://www.uspreventiveservicestaskforce.org/uspstf/uspshemo.htm</a>	1a C <input type="checkbox"/> P <input type="checkbox"/> M <input type="checkbox"/> N <input type="checkbox"/>

<p><b>1b. Opportunity for Improvement</b></p> <p><b>1b.1 Benefits (improvements in quality) envisioned by use of this measure:</b> By using this measure, we will be able to document the proportion of infants screened by NBS, identify state programs with problems and assist them in making sure NBS is universally available and documented.</p> <p><b>1b.2 Summary of data demonstrating performance gap (variation or overall poor performance) across providers:</b> More than 10 states are unable to assess this measure, others range from 80% and some states have &gt;100% screened, which indicates lack of uniformity and reliability of current reporting.</p> <p><b>1b.3 Citations for data on performance gap:</b> <a href="http://nnsis.uthscsa.edu/xreports.aspx?XREPORTID=17&amp;FORMID=44&amp;FCLR=1">http://nnsis.uthscsa.edu/xreports.aspx?XREPORTID=17&amp;FORMID=44&amp;FCLR=1</a></p> <p><b>1b.4 Summary of Data on disparities by population group:</b> This is a national program and at this time, there is no specific information on disparities by population group.</p> <p><b>1b.5 Citations for data on Disparities:</b></p>	<p>1b C <input type="checkbox"/> P <input type="checkbox"/> M <input type="checkbox"/> N <input type="checkbox"/></p>
<p><b>1c. Outcome or Evidence to Support Measure Focus</b></p> <p><b>1c.1 Relationship to Outcomes (For non-outcome measures, briefly describe the relationship to desired outcome. For outcomes, describe why it is relevant to the target population):</b> If we cannot measure what percentage of infants are screened, we cannot address gaps in coverage of this public health program and infants could be dying from preventable disorders that have a reliable test and should be universally available.</p> <p><b>1c.2-3. Type of Evidence:</b> Cohort study, Evidence-based guideline, Expert opinion, Systematic synthesis of research</p> <p><b>1c.4 Summary of Evidence (as described in the criteria; for outcomes, summarize any evidence that healthcare services/care processes influence the outcome):</b> 95% of infants with PKU (detectable on NBS) will have mental retardation, seizures and brain changes if not started on treatment in first 2 weeks of life. 25% of infants with MCAD (NBS disorder) die with their first illness if not prospectively followed.</p> <p><b>1c.5 Rating of strength/quality of evidence (also provide narrative description of the rating and by whom):</b> Grade A: based on US Preventive Services Task Force</p> <p><b>1c.6 Method for rating evidence:</b> Based on USPSTF</p> <p><b>1c.7 Summary of Controversy/Contradictory Evidence:</b> There is limited evidence about the harms of screening, with conflicting research findings regarding anxiety associated with falsepositive test results. There is limited information about the harms of treatment</p> <p><b>1c.8 Citations for Evidence (other than guidelines):</b> Boles RG, Buck EA, Blitzer MG, Platt MS, Cowan TM, Martin SK, Yoon H, Madsen JA, Reyes-Mugica M, Rinaldo P. "Retrospective biochemical screening of fatty acid oxidation disorders in postmortem livers of 418 cases of sudden death in the first year of life", J Pediatr 1998; 132(6):924-33. Paine, RS. The variability in manifestations of untreated patients with phenylketonuria aciduria). Pediatrics 20:290-302, 1957.</p> <p><b>1c.9 Quote the Specific guideline recommendation (including guideline number and/or page number):</b> Screening for Phenylketonuria (PKU)- USPSTF Screening for Congenital Hypothyroidism - USPSTF Screening for Sickle Cell Disease in Newborns - USPSTF</p>	<p>1c C <input type="checkbox"/> P <input type="checkbox"/> M <input type="checkbox"/> N <input type="checkbox"/></p>

**1c.10 Clinical Practice Guideline Citation:** [Serving the Family From Birth to the Medical Home Newborn Screening: A Blueprint for the Future A Call for a National Agenda on State Newborn Screening Programs](#)

**1c.11 National Guideline Clearinghouse or other URL:**

**1c.12 Rating of strength of recommendation** *(also provide narrative description of the rating and by whom):*

The USPSTF recommends screening for phenylketonuria (PKU) in newborns; Congenital Hypothyroidism; Sickle Cell Disease. Grade: A Recommendation

**1c.13 Method for rating strength of recommendation** *(If different from [USPSTF system](#), also describe rating and how it relates to USPSTF):*

Rationale for PKU screening:

Importance: PKU is an inborn error of phenylalanine metabolism that occurs in from 1 per 13,500 to 1 per 19,000 newborns in the United States. In the absence of treatment during infancy, most persons with this disorder will develop severe mental retardation.<sup>1,2</sup>

Detection: Two approaches, fluorometry and tandem mass spectrometry, are in common use. The sensitivity and specificity of fluorometry are 100% and 51%, respectively, and of tandem mass spectrometry, 100% and 98%, respectively.<sup>3</sup>

Benefits of Detection and Early Treatment: There is good evidence that detection by neonatal screening and early treatment of PKU substantially improve neurodevelopmental outcomes for affected persons.

Harms of Detection and Early Treatment: False-positive tests could generate considerable parental anxiety Sickle Cell:

Rationale

Importance: Sickle cell anemia (hemoglobin SS) affects 1 in 375 African American newborns born in the United States and smaller proportions of children in other ethnic groups. Without prompt diagnosis and the initiation of prophylactic antibiotics and pneumococcal conjugate vaccination by 2 months of age, children with sickle cell anemia are vulnerable to life-threatening pneumococcal infections.<sup>1</sup>

Detection: In the United States, most state-based screening programs utilize thin-layer isoelectric focusing (IEF) or high performance liquid chromatography (HPLC) techniques performed on capillary blood collected from a heel stick and absorbed onto filter paper. The sensitivity and specificity of each of these tests approaches 100%.

Rationale for Congenital Hypothyroid:

Importance: Primary congenital hypothyroidism occurs in approximately 1 of every 3,000-4,000 newborns in the United States. In the absence of prompt diagnosis and treatment, most persons with this disorder will develop various degrees of neurological, motor and growth deficits, including irreversible mental retardation.

Detection: In the U.S., most state-based screening programs utilize serum thyroxine (T4) and/or thyroid-stimulating hormone (TSH) performed on capillary blood collected from a heel stick and adsorbed onto filter paper.

Benefits of Detection and Early Treatment: Early detection of CH by neonatal screening and appropriate treatment substantially improves neurodevelopmental outcomes for affected persons.

Harms of Detection and Early Treatment: Positive test results, whether true positive or false positive, cause anxiety in parents. For some parents, this anxiety may be considerable.

USPSTF Assessment: The USPSTF concludes that there is high certainty that the net benefit is substantial.

Benefits of detection and early intervention: There is good evidence that early detection of sickle cell anemia followed by prophylactic oral penicillin substantially reduces the risk of serious infections during the

<p>first few years of life. Additional benefits result from pneumococcal conjugate vaccination and parental education about early warning signs of infection. Finally, detection of sickle cell disease permits counseling for family members about disease management and future reproductive decisions.</p> <p>Harms of detection and early treatment: Incidental detection of sickle cell carrier status and hemoglobin disorders of questionable clinical significance has the potential to cause psychosocial harms, which may include exposure of non-paternity, stigma and discrimination, negative impact on self-esteem, and anxiety about future health.</p> <p>The USPSTF concludes that there is high certainty that the net benefit of screening for sickle cell disease in newborns is substantial</p> <p><b>1c.14 Rationale for using this guideline over others:</b>          These are the only USPSTF guideline related to newborn bloodspot screening and the only nationally recognized guidelines. Recently the Secretary of Health and Human Services endorsed the Uniform Screening Panel as put forward by the Secretary’s Advisory Committee on Heritable Disorders in Newborns and Children.</p>	
<p><b>TAP/Workgroup: What are the strengths and weaknesses in relation to the subcriteria for <i>Importance to Measure and Report</i>?</b></p>	<p>1</p>
<p><b>Steering Committee: Was the threshold criterion, <i>Importance to Measure and Report</i>, met? Rationale:</b></p>	<p>1          Y <input type="checkbox"/>          N <input type="checkbox"/></p>
<p style="text-align: center;"><b>2. SCIENTIFIC ACCEPTABILITY OF MEASURE PROPERTIES</b></p>	
<p>Extent to which the measure, <u>as specified</u>, produces consistent (reliable) and credible (valid) results about the quality of care when implemented. (<a href="#">evaluation criteria</a>)</p>	<p><a href="#">Eval Rating</a></p>
<p style="text-align: center;"><b>2a. MEASURE SPECIFICATIONS</b></p>	
<p><b>S.1 Do you have a web page where current detailed measure specifications can be obtained?</b>  <b>S.2 If yes, provide web page URL:</b></p> <p><b>2a. Precisely Specified</b></p>	
<p><b>2a.1 Numerator Statement (Brief, text description of the numerator - what is being measured about the target population, e.g. target condition, event, or outcome):</b>          The number of infants born in a state who have a valid newborn screen performed- in accordance with the state of birth mandated program specifications</p> <p><b>2a.2 Numerator Time Window (The time period in which cases are eligible for inclusion in the numerator):</b>          The time period varies upon needs of the particular user (e.g. calendar year, quarterly, monthly) but must be the same for both the numerator and denominator.</p> <p><b>2a.3 Numerator Details (All information required to collect/calculate the numerator, including all codes, logic, and definitions):</b>          Number of infants with newborn bloodspot screen performed as documented/collected by the state newborn screening program.</p>	
<p><b>2a.4 Denominator Statement (Brief, text description of the denominator - target population being measured):</b>          number of infants born in a state during the time period used in the numerator (same area used for numerator)</p> <p><b>2a.5 Target population gender: Female, Male</b>  <b>2a.6 Target population age range: birth to 2 weeks</b></p> <p><b>2a.7 Denominator Time Window (The time period in which cases are eligible for inclusion in the</b></p>	<p>2a-specs          C <input type="checkbox"/>          P <input type="checkbox"/>          M <input type="checkbox"/>          N <input type="checkbox"/></p>

<p><i>denominator</i>): The time period varies upon needs of the particular user (e.g. calendar year, quarterly, monthly) but must be the same for both the numerator and denominator.</p> <p><b>2a.8 Denominator Details</b> (All information required to collect/calculate the denominator - the target population being measured - including all codes, logic, and definitions): This should be information gathered by the state public health department by birth certificates or hospital birth records for matching with the numerator.</p>
<p><b>2a.9 Denominator Exclusions</b> (Brief text description of exclusions from the target population): infants who die prior to normal time frame for collection of newborn screen or infants who have a formal waiver signed by the parents/guardians refusing the state newborn screen</p> <p><b>2a.10 Denominator Exclusion Details</b> (All information required to collect exclusions to the denominator, including all codes, logic, and definitions): Joint Commission Discharge Disposition - Death Value Set (86986.v1) 1.3.6.1.4.1.33895.1.3.0.12. "Patient Deceased": Patient has expired.  LOINC# 54108-6 LA6644-4 C0580717 "Parental refusal"</p>
<p><b>2a.11 Stratification Details/Variables</b> (All information required to stratify the measure including the stratification variables, all codes, logic, and definitions): None because state mandates apply to all infants and do not stratify by NICU status, prematurity, geographic location, or insurance coverage. In the future we might explore health disparities, but current measures will be applied to all infants born in a state.</p>
<p><b>2a.12-13 Risk Adjustment Type:</b> No risk adjustment necessary</p>
<p><b>2a.14 Risk Adjustment Methodology/Variables</b> (List risk adjustment variables and describe conceptual models, statistical models, or other aspects of model or method):</p>
<p><b>2a.15-17 Detailed risk model available Web page URL or attachment:</b></p>
<p><b>2a.18-19 Type of Score:</b> Rate/proportion <b>2a.20 Interpretation of Score:</b> Better quality = Higher score <b>2a.21 Calculation Algorithm</b> (Describe the calculation of the measure as a flowchart or series of steps): (1) The time period for births included in the estimate is specified (see 2a.2, 2a.7). (2) All live births that occurred in a state during the time period are selected. (3) Result of step 2 is filtered to remove children who died prior to discharge (see 2a.9, 2a.10) or parental waiver. This result is saved The numerator is calculated using the following step: (4) Result of step 3 is further filtered to be limited to the subset with a NBS performed (see 2a.3) This result is saved as the numerator (see 2a.1). The denominator is: (5) Result of step (3)  Porportion calculated using the following step: (6) HRSA NBS measure is calculated by dividing the numerator (result of step 4) by the denominator (result of step 5).</p>
<p><b>2a.22 Describe the method for discriminating performance</b> (e.g., significance testing): chi squared comparison of porportions- Method to discriminate performance is based upon jurisdictionally based statistical measurement reflecting local and national variability.</p>
<p><b>2a.23 Sampling (Survey) Methodology</b> If measure is based on a sample (or survey), provide instructions for obtaining the sample, conducting the survey and guidance on minimum sample size (response rate): not applicable</p>
<p><b>2a.24 Data Source</b> (Check the source(s) for which the measure is specified and tested) Paper medical record/flow-sheet, Electronic administrative data/claims, Public health data/vital statistics, Electronic Health/Medical Record, Lab data</p>

<p><b>2a.25 Data source/data collection instrument</b> (<i>Identify the specific data source/data collection instrument, e.g. name of database, clinical registry, collection instrument, etc.</i>):                  Number of infants screened- NNSIS national newborn screening information system, collects the number of NBS performed in each state, will work to distinguish exact number of infants screened via tracking and linkage- need to distinguish between initial screens and repeat screens.                  number of infants born- state birth certificates and hospital discharge records</p> <p><b>2a.26-28 Data source/data collection instrument reference web page URL or attachment:</b> URL  <a href="http://nnsis.uthscsa.edu/xreports.aspx?XREPORTID=5">http://nnsis.uthscsa.edu/xreports.aspx?XREPORTID=5</a></p> <p><b>2a.29-31 Data dictionary/code table web page URL or attachment:</b> URL  <a href="http://nnsis.uthscsa.edu/NNSIS_User_Manual_V2.pdf">http://nnsis.uthscsa.edu/NNSIS_User_Manual_V2.pdf</a></p> <p><b>2a.32-35 Level of Measurement/Analysis</b> (<i>Check the level(s) for which the measure is specified and tested</i>)                  Facility/Agency, Population: states, Program: Other state newborn screening program</p> <p><b>2a.36-37 Care Settings</b> (<i>Check the setting(s) for which the measure is specified and tested</i>)                  Hospital, Ambulatory Care: Clinic</p> <p><b>2a.38-41 Clinical Services</b> (<i>Healthcare services being measured, check all that apply</i>)                  Laboratory, Other public health agency</p>	
<b>TESTING/ANALYSIS</b>	
<p><b>2b. Reliability testing</b></p> <p><b>2b.1 Data/sample</b> (<i>description of data/sample and size</i>): This is a population wide collection of data, gathered and assessed at the state level in the various state newborn screening programs. All states have a NBS program and collect data related to this program.</p> <p><b>2b.2 Analytic Method</b> (<i>type of reliability &amp; rationale, method for testing</i>):                  N/A - in the process of testing the methodology and determining reliability</p> <p><b>2b.3 Testing Results</b> (<i>reliability statistics, assessment of adequacy in the context of norms for the test conducted</i>):                  This should be a simple matter of matching births to newborn screening results. However, the numbers need to be verified and the matching needs to be done.</p>	2b C <input type="checkbox"/> P <input type="checkbox"/> M <input type="checkbox"/> N <input type="checkbox"/>
<p><b>2c. Validity testing</b></p> <p><b>2c.1 Data/sample</b> (<i>description of data/sample and size</i>): This is a population wide collection of data, gathered and assessed at the state level in the various state newborn screening programs.</p> <p><b>2c.2 Analytic Method</b> (<i>type of validity &amp; rationale, method for testing</i>):                  N/A - in the process of testing the methodology and determining reliability</p> <p><b>2c.3 Testing Results</b> (<i>statistical results, assessment of adequacy in the context of norms for the test conducted</i>):                  This should be a simple matter of matching births to newborn screening results. However, the numbers need to be verified and the matching needs to be done.</p>	2c C <input type="checkbox"/> P <input type="checkbox"/> M <input type="checkbox"/> N <input type="checkbox"/>
<p><b>2d. Exclusions Justified</b></p> <p><b>2d.1 Summary of Evidence supporting exclusion(s):</b>                  The exclusions only apply where legally mandated at the state level. Some states allow for exclusion based on a waiver, others do not. Some states all collect bloodspot screens on infant that expire prior to the mandated time frame for further evaluation if there is a question of a heritable disorder as causative.</p>	2d C <input type="checkbox"/> P <input type="checkbox"/> M <input type="checkbox"/> N <input type="checkbox"/> NA <input type="checkbox"/>

<p><b>2d.2 Citations for Evidence:</b>  <a href="http://genes-r-us.uthscsa.edu/resources/consumer/statemap.htm">http://genes-r-us.uthscsa.edu/resources/consumer/statemap.htm</a>                  This website can direct people to various states and their rules.</p> <p><b>2d.3 Data/sample</b> (<i>description of data/sample and size</i>):</p> <p><b>2d.4 Analytic Method</b> (<i>type analysis &amp; rationale</i>):</p> <p><b>2d.5 Testing Results</b> (<i>e.g., frequency, variability, sensitivity analyses</i>):</p>	
<p><b>2e. Risk Adjustment for Outcomes/ Resource Use Measures</b></p> <p><b>2e.1 Data/sample</b> (<i>description of data/sample and size</i>): N/A- at this time there is no risk adjustment needed</p> <p><b>2e.2 Analytic Method</b> (<i>type of risk adjustment, analysis, &amp; rationale</i>):</p> <p><b>2e.3 Testing Results</b> (<i>risk model performance metrics</i>):</p> <p><b>2e.4 If outcome or resource use measure is not risk adjusted, provide rationale:</b></p>	<p>2e                  C <input type="checkbox"/>                  P <input type="checkbox"/>                  M <input type="checkbox"/>                  N <input type="checkbox"/>                  NA <input type="checkbox"/></p>
<p><b>2f. Identification of Meaningful Differences in Performance</b></p> <p><b>2f.1 Data/sample from Testing or Current Use</b> (<i>description of data/sample and size</i>): At this time, cannot be determined</p> <p><b>2f.2 Methods to identify statistically significant and practically/meaningfully differences in performance</b> (<i>type of analysis &amp; rationale</i>):                  Will need to survey with good, reliable numbers in order to establish a baseline and then differentiate what are difference with impact. This is a state public health surveillance system, not a sampling system.</p> <p><b>2f.3 Provide Measure Scores from Testing or Current Use</b> (<i>description of scores, e.g., distribution by quartile, mean, median, SD, etc.; identification of statistically significant and meaningfully differences in performance</i>):</p>	<p>2f                  C <input type="checkbox"/>                  P <input type="checkbox"/>                  M <input type="checkbox"/>                  N <input type="checkbox"/></p>
<p><b>2g. Comparability of Multiple Data Sources/Methods</b></p> <p><b>2g.1 Data/sample</b> (<i>description of data/sample and size</i>): Will need to develop a method for linking and tracking in order to get reliable numbers of infants screened and infants born in the geographical area of interest.</p> <p><b>2g.2 Analytic Method</b> (<i>type of analysis &amp; rationale</i>):</p> <p><b>2g.3 Testing Results</b> (<i>e.g., correlation statistics, comparison of rankings</i>):</p>	<p>2g                  C <input type="checkbox"/>                  P <input type="checkbox"/>                  M <input type="checkbox"/>                  N <input type="checkbox"/>                  NA <input type="checkbox"/></p>
<p><b>2h. Disparities in Care</b></p> <p><b>2h.1 If measure is stratified, provide stratified results</b> (<i>scores by stratified categories/cohorts</i>): N/A at this time</p> <p><b>2h.2 If disparities have been reported/identified, but measure is not specified to detect disparities, provide follow-up plans:</b></p>	<p>2h                  C <input type="checkbox"/>                  P <input type="checkbox"/>                  M <input type="checkbox"/>                  N <input type="checkbox"/>                  NA <input type="checkbox"/></p>

<p><b>TAP/Workgroup: What are the strengths and weaknesses in relation to the subcriteria for <i>Scientific Acceptability of Measure Properties</i>?</b></p>	<p><b>2</b></p>
<p><b>Steering Committee: Overall, to what extent was the criterion, <i>Scientific Acceptability of Measure Properties</i>, met?</b>  <b>Rationale:</b></p>	<p><b>2</b>  C <input type="checkbox"/>  P <input type="checkbox"/>  M <input type="checkbox"/>  N <input type="checkbox"/></p>
<p><b>3. USABILITY</b></p>	
<p>Extent to which intended audiences (e.g., consumers, purchasers, providers, policy makers) can understand the results of the measure and are likely to find them useful for decision making. (<a href="#">evaluation criteria</a>)</p>	<p><a href="#">Eval Rating</a></p>
<p><b>3a. Meaningful, Understandable, and Useful Information</b></p> <p><b>3a.1 Current Use:</b> Testing not yet completed</p> <p><b>3a.2 Use in a public reporting initiative (disclosure of performance results to the public at large) (If used in a public reporting initiative, provide name of initiative(s), locations, Web page URL(s). If not publicly reported, state the plans to achieve public reporting within 3 years):</b>  At this time, a facsimile of the data is reported out by state on the <a href="http://genes-r-us.uthscsa.edu">http://genes-r-us.uthscsa.edu</a> website. However, at this time it is not verified and linked to insure that infants are not double entered does not occur, nor does linking to birth records or birth certificates. In the future, will be able to provide accurate aggregate data but the state specifics will be password protected and disseminated with their discretion.</p> <p>This was previously a Title V Block Grant Performance Measure and was tracked by the states. The decision was made to change the emphasis in the Block Grant to follow-up and so they changed the specific measure.</p> <p><b>3a.3 If used in other programs/initiatives (If used in quality improvement or other programs/initiatives, name of initiative(s), locations, Web page URL(s). If not used for QI, state the plans to achieve use for QI within 3 years):</b>  In the process of updating the information system this is reported in, working with various health informatics programs to provide automated linking and messaging systems, which will allow for less time intensive data entry and more reliable numbers. This will be incorporated into a NBS QI system at a national level with breakdowns by state. The Newborn Screening Saves Lives Act of 2008 also mandates reporting of quality indicators for newborn screening programs.</p> <p>A related measure proposed for Healthy People 2020 is: HP2020 Objective Text:  MICH HP2020-22: Increase appropriate newborn blood-spot screening and follow-up testing  a. Increase the number of states that verify, through linkage with vital records, that all newborns are screened shortly after birth for conditions mandated by their State-sponsored screening program.</p> <p><b>Testing of Interpretability (Testing that demonstrates the results are understood by the potential users for public reporting and quality improvement)</b></p> <p><b>3a.4 Data/sample (description of data/sample and size):</b> This is aggregate data to look at screening rates and evaluate the needs for further funding or programmatic assistance.</p> <p><b>3a.5 Methods (e.g., focus group, survey, QI project):</b>  QI project to cover full NBS system evaluation.</p> <p><b>3a.6 Results (qualitative and/or quantitative results and conclusions):</b></p>	
<p><b>3b/3c. Relation to other NQF-endorsed measures</b></p> <p><b>3b.1 NQF # and Title of similar or related measures:</b>  Proposed measures from NCQA for physician documentation of NBS results in patient record.</p>	
<p><b>(for NQF staff use) Notes on similar/related <a href="#">endorsed</a> or submitted measures:</b></p>	
<p><b>3b. Harmonization</b></p>	<p><b>3a</b>  C <input type="checkbox"/>  P <input type="checkbox"/>  M <input type="checkbox"/>  N <input type="checkbox"/></p> <p><b>3b</b></p>

<p>If this measure is related to measure(s) already <a href="#">endorsed by NQF</a> (e.g., same topic, but different target population/setting/data source <u>or</u> different topic but same target population):  <b>3b.2 Are the measure specifications harmonized? If not, why?</b>                  Yes.</p>	C <input type="checkbox"/> P <input type="checkbox"/> M <input type="checkbox"/> N <input type="checkbox"/> NA <input type="checkbox"/>
<p><b>3c. Distinctive or Additive Value</b>  <b>3c.1 Describe the distinctive, improved, or additive value this measure provides to existing NQF-endorsed measures:</b>                  This measure is aimed at the state NBS programs and accuracy of their ability to track the screened population. The NCQA measure is for physician documentation and records tracking.</p> <p><b>5.1 If this measure is similar to measure(s) already endorsed by NQF (i.e., on the same topic and the same target population), Describe why it is a more valid or efficient way to measure quality:</b>                  There is no competing measure that is population based rather than practice or hospital based and population data is required to measure this dimension of quality.</p>	3c C <input type="checkbox"/> P <input type="checkbox"/> M <input type="checkbox"/> N <input type="checkbox"/> NA <input type="checkbox"/>
<p><b>TAP/Workgroup: What are the strengths and weaknesses in relation to the subcriteria for <i>Usability</i>?</b></p>	3
<p><b>Steering Committee: Overall, to what extent was the criterion, <i>Usability</i>, met?</b>                  Rationale:</p>	3 C <input type="checkbox"/> P <input type="checkbox"/> M <input type="checkbox"/> N <input type="checkbox"/>
<p><b>4. FEASIBILITY</b></p>	
<p>Extent to which the required data are readily available, retrievable without undue burden, and can be implemented for performance measurement. (<a href="#">evaluation criteria</a>)</p>	<a href="#">Eval Rating</a>
<p><b>4a. Data Generated as a Byproduct of Care Processes</b></p> <p><b>4a.1-2 How are the data elements that are needed to compute measure scores generated?</b>                  Data generated as byproduct of care processes during care delivery (Data are generated and used by healthcare personnel during the provision of care, e.g., blood pressure, lab value, medical condition)</p>	4a C <input type="checkbox"/> P <input type="checkbox"/> M <input type="checkbox"/> N <input type="checkbox"/>
<p><b>4b. Electronic Sources</b></p> <p><b>4b.1 Are all the data elements available electronically?</b> (<i>elements that are needed to compute measure scores are in defined, computer-readable fields, e.g., electronic health record, electronic claims</i>)                  Yes</p> <p><b>4b.2 If not, specify the near-term path to achieve electronic capture by most providers.</b></p>	4b C <input type="checkbox"/> P <input type="checkbox"/> M <input type="checkbox"/> N <input type="checkbox"/>
<p><b>4c. Exclusions</b></p> <p><b>4c.1 Do the specified exclusions require additional data sources beyond what is required for the numerator and denominator specifications?</b>                  No</p> <p><b>4c.2 If yes, provide justification.</b></p>	4c C <input type="checkbox"/> P <input type="checkbox"/> M <input type="checkbox"/> N <input type="checkbox"/> NA <input type="checkbox"/>
<p><b>4d. Susceptibility to Inaccuracies, Errors, or Unintended Consequences</b></p> <p><b>4d.1 Identify susceptibility to inaccuracies, errors, or unintended consequences of the measure and describe how these potential problems could be audited. If audited, provide results.</b>                  Babies born in one state may get another screen in a second state that could result in double counting, however with good records linking and tracking this can be eliminated.</p>	4d C <input type="checkbox"/> P <input type="checkbox"/> M <input type="checkbox"/> N <input type="checkbox"/>
<p><b>4e. Data Collection Strategy/Implementation</b></p>	4e

<p><b>4e.1 Describe what you have learned/modified as a result of testing and/or operational use of the measure regarding data collection, availability of data/missing data, timing/frequency of data collection, patient confidentiality, time/cost of data collection, other feasibility/ implementation issues:</b>          Requires an accurate standardized denominator and numerator to successfully determine that all infants have been accounted for and received necessary screen. The limitation has been that states only report the number of screens performed, not tracking by individual infant.</p> <p><b>4e.2 Costs to implement the measure (costs of data collection, fees associated with proprietary measures):</b>          This is a measure calculated by public health and based on NBS lab reporting and matching with birth records and certificates. Public health information systems must be capable of having a specific NBS record on each infant and be capable of differentiating initial vs repeat screen. Such systems are in use in States. For other public health programs infrastructure may need to be strengthened and there will be a cost to this additional data collection.</p> <p><b>4e.3 Evidence for costs:</b></p> <p><b>4e.4 Business case documentation:</b></p>	<p>C <input type="checkbox"/>          P <input type="checkbox"/>          M <input type="checkbox"/>          N <input type="checkbox"/></p>
<p><b>TAP/Workgroup: What are the strengths and weaknesses in relation to the subcriteria for <i>Feasibility</i>?</b></p>	<p>4</p>
<p><b>Steering Committee: Overall, to what extent was the criterion, <i>Feasibility</i>, met?</b>  <b>Rationale:</b></p>	<p>4          C <input type="checkbox"/>          P <input type="checkbox"/>          M <input type="checkbox"/>          N <input type="checkbox"/></p>
<p><b>RECOMMENDATION</b></p>	
<p><b>(for NQF staff use) Check if measure is untested and only eligible for time-limited endorsement.</b></p>	<p>Time-limited  <input type="checkbox"/></p>
<p><b>Steering Committee: Do you recommend for endorsement?</b>  <b>Comments:</b></p>	<p>Y <input type="checkbox"/>          N <input type="checkbox"/>          A <input type="checkbox"/></p>
<p><b>CONTACT INFORMATION</b></p>	
<p><b>Co.1 Measure Steward (Intellectual Property Owner)</b>  <b>Co.1 Organization</b>          HRSA, 5600 Fishers Ln Rm 18A-19, Rockville, Maryland, 20857</p> <p><b>Co.2 Point of Contact</b>          Sara, Copeland, MD, scopeland@hrsa.gov, 301-443-8860-</p>	
<p><b>Measure Developer If different from Measure Steward</b>  <b>Co.3 Organization</b>          HRSA, 5600 Fishers Ln Rm 18A-19, Rockville, Maryland, 20857</p> <p><b>Co.4 Point of Contact</b>          Sara, Copeland, MD, scopeland@hrsa.gov, 301-443-8860-</p>	
<p><b>Co.5 Submitter If different from Measure Steward POC</b>          Sara, Copeland, MD, scopeland@hrsa.gov, 301-443-8860-, HRSA</p>	
<p><b>Co.6 Additional organizations that sponsored/participated in measure development</b></p>	

ADDITIONAL INFORMATION
<b>Workgroup/Expert Panel involved in measure development</b> <b>Ad.1</b> Provide a list of sponsoring organizations and workgroup/panel members' names and organizations. Describe the members' role in measure development. <a href="#">CDC Newborn Screening Quality Assessment Program, National Newborn Screening and Genetics Resource Center</a>
<b>Ad.2</b> If adapted, provide name of original measure: <b>Ad.3-5</b> If adapted, provide original specifications URL or attachment
<b>Measure Developer/Steward Updates and Ongoing Maintenance</b> <b>Ad.6</b> Year the measure was first released: 2010 <b>Ad.7</b> Month and Year of most recent revision: 2010 <b>Ad.8</b> What is your frequency for review/update of this measure? <a href="#">This is a new measure that will be released in Fall, 2010 and an annual review/update is planned</a> <b>Ad.9</b> When is the next scheduled review/update for this measure? 2011
<b>Ad.10</b> Copyright statement/disclaimers:
<b>Ad.11 -13</b> Additional Information web page URL or attachment: <a href="http://genes-r-us.uthscsa.edu">URL http://genes-r-us.uthscsa.edu</a>
<b>Date of Submission (MM/DD/YY):</b> <a href="#">08/30/2010</a>