

Linking Newborn Screening Programs with Vital Records is Essential for Accurate Assessment of Screening Coverage

APHL POSITION STATEMENT | SUNSETS JULY 2030



Statement of Position

To optimize newborn screening (NBS) efforts, it is imperative NBS programs are integrated with vital records systems.

Background

NBS occurs within each US jurisdiction to identify and treat newborns at-risk for severe health disorders prior to symptom onset. NBS activities are time-sensitive and are recommended to occur within the first few days of life (see the [National Timeliness Guidelines](#)). As a public health program operating under jurisdictional mandates, NBS programs must be able to assess the extent to which screening occurs. The only way to measure this is through infant-level matching with birth certificates.

Birth certificates are a form of vital records that registers the birth of a child and documents important information such as full legal name, date and place of birth, parents' names, and other relevant demographic and medical data. These records are essential for legal, administrative, statistical and public health purposes. Vital records are typically maintained and managed by state government agencies that ensure the accuracy, confidentiality and accessibility of the records while adhering to legal and regulatory requirements related to data protection and privacy. Access to vital records—specifically birth certificates—by NBS programs may be subject to specific rules and procedures, depending on the jurisdiction and the type of record requested.

Integrating NBS Programs with Vital Records Systems Offers Multifaceted Benefits

Accurately Assesses Screening Coverage: Provides the percentage of newborns screened in each US jurisdiction and facilitates the identification of unscreened newborns by matching birth certificates to the NBS demographics. Matching and cross-referencing NBS records with birth certificates is the only available method to ascertain the number and percentage of babies screened. Without this capability, an accurate denominator is unattainable. Access to vital records information should be made available to NBS programs in a secure, automated and timely manner to maximize the benefits to the newborn and support screening activities impacting public health.

Improves Efficiency and Data Quality: Maximizes efficiency of public health systems by streamlining administrative processes and integration of otherwise siloed data systems. This enhances accuracy of NBS programs in capturing details relevant to screening that are collected via vital records (e.g., demographic details, medical history, etc.). Integrating vital record information with NBS systems allows for documentation and tracking of follow-up actions in a centralized system.

Supports Vital Record Activities: Infant-level matching mutually benefits vital records offices as it supports billing and various types of state-reporting activities. By collecting demographic and contact information on the dried blood spot card, NBS programs serve as a resource for vital record offices when the birth certificate cannot be found or if it was never filed, such as in instances of home births.

Mitigates Loss to Follow-up: Strengthens and supports time-sensitive NBS activities that must occur within the first few days of life. Specifically, linking to birth certificates improves the ability to identify unscreened newborns, determine if a newborn's specimen was lost in transit and ensure further evaluation of a newborn occurs after a screen-positive result. Linking can support improved timeliness of follow-up activities, which can result in better care for newborns and their families—including babies born or receiving care in a different state.

Recommended by: **APHL Newborn Screening Committee**
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APHL's Recommendations

APHL recommends that NBS programs partner with vital records offices to ensure all newborns receive a screen (or have a documented refusal) to improve quality care for all newborns. Specifically, NBS programs should have regular access to birth certificates in a timeframe shortly after birth such that a child who may have been missed during the screening process can be identified. To establish these linkages, it is necessary for public health departments to:

1. Have participation by all parties involved across the NBS system
2. Implement robust data governance, security and privacy protection measures as required by federal and state laws (e.g., data sharing agreements)
3. Invest in modern and flexible technological infrastructure, as well as staffing, to help ensure security, timeliness and data accuracy for both vital records and NBS systems.
4. Establish prompt and automated interoperability among disparate information systems through standardized data formats, terminology, interoperability standards and data-sharing protocols.

Resources

1. CLSI. *Newborn Screening Follow-up and Education*. 3rd ed. CLSI guideline NBS 02. Clinical and Laboratory Standards Institute; 2023.