

Key Components of Newborn Screening Follow-Up

APHL POSITION STATEMENT



Statement of Position

Timely, efficient, and integrated short-term follow-up programs that strive for continuous quality improvement are necessary components of successful newborn screening (NBS) systems.

Recommended by: **APHL NewSTEPS Short Term Follow-up Technical Assistance Workgroup**
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Background

NBS short-term follow-up accounts for activities that occur after an actionable result is identified by the NBS laboratory. Effective short-term follow-up reduces morbidity and mortality in infants by ensuring efficient diagnosis and timely intervention. Follow-up activities should be established, documented, and adhered to by all NBS programs to accomplish the goal of NBS systems.

Key components of NBS follow-up should include, but are not limited to:

- Timely notification of all actionable results
- Clear and concise verbal and written communication with healthcare providers
- Documented case management
- Regular review of performance and procedures and
- Education of internal and external partners.

The Clinical and Laboratory Standards Institute (CLSI) provides guidelines for NBS follow-up and educational activities and can serve as a resource for program development, implementation, and periodic reviews^a.

APHL Recommendations

Short Term Follow-up Newborn Screening Programs

It is recommended that all Short-Term Follow-up NBS Programs have, at a minimum, the following:

- Timely case management for infants with actionable NBS results until an outcome is obtained and recorded.
- Procedures for case evaluations that ensure the accuracy of diagnosis and case disposition assignments.
- Standard actions documented in an auditable case management system and reviewed annually to help ensure all actionable results receive follow-up.
- Routine assessment of performance metrics including, but not limited to timeliness, lost to follow-up rates, and final outcomes (intervention, diagnoses, false positives and negatives, etc.).
- Annual review and completion of staff competencies and evaluations.

^a Clinical and Laboratory Standards Institute (CLSI). Newborn Screening Follow-Up and Education. 3rd ed. CLSI guideline NBS02. Clinical and Laboratory Standards Institute, USA, 2020

- Regularly updated and disseminated educational and training materials for healthcare providers and families in collaboration with disease-specific experts.
- Established relationships with regional disease experts who can provide expertise on current and new disorders, algorithm and cutoff evaluations, genetic counseling, evaluation, and management of infants identified through NBS (if needed).
- Regular interaction and collaboration with other NBS programs.
- A continuity of operations plan (COOP) developed and disseminated to program leadership and stakeholders with annual activities including review, updates and practice.

US Health Resources and Services Administration

APHL recommends ongoing support from the US Health Resources and Services Administration (HRSA) to strengthen and expand NBS follow-up programs, particularly as new conditions are added to the Recommended Uniform Screening Panel (RUSP).

APHL recommends HRSA continue to provide dedicated funding to maintain, strengthen and expand a national technical assistance center that provides resources for follow-up programs in all states and territories (currently NewSTEPS).

Partner Organizations

APHL recommends partner agencies such as CLSI, Expecting Health, and the American College of Medical Genetics and Genomics support all state NBS follow-up programs by providing access to guidelines and educational materials designed to inform relevant NBS partners.

Association of Public Health Laboratories

APHL works to strengthen laboratory systems serving the public's health in the US and globally. APHL's member laboratories protect the public's health by monitoring and detecting infectious and foodborne diseases, environmental contaminants, terrorist agents, genetic disorders in newborns and other diverse health threats.