

# 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**  
Approved by Board of Directors: **April 2023**  
Approved by Membership: **June 2023**  
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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 review.<sup>a</sup>

### Implementation

1. APHL will support information dissemination to short-term follow-up personnel through quarterly national webinars on topics of interest.
2. APHL will convene roundtables at the APHL Newborn Symposium to enhance communication and collaboration among follow-up staff from different programs.
3. APHL will organize in-person trainings and meetings for short-term follow-up.
4. APHL will, upon request from newborn screening (NBS) programs, coordinate site reviews and engage experts from the NBS community. Site reviews will include a thorough assessment of short-term follow-up accompanied by recommendations for improvement.
5. APHL will continue to update the NewSTEPS website to ensure timely educational materials are available as a resource to NBS programs.
6. APHL will provide a platform for data entry and analysis pertinent to short-term follow-up with the goal of assisting programs in related quality improvement efforts. Data collected will include, but is not limited to, disease-specific times to diagnosis and treatment and number of cases lost to follow-up.

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

## 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.
- 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.