

## **Public Health Surveillance Case Definitions for Newborn Screening**

**Purpose:** The public health surveillance case definitions will be used to provide an estimate of the true birth prevalence of disorders identified by newborn screening. State programs can use the case definitions tables and data collected on the [case definitions worksheets](#) to classify cases in a uniform manner. This will allow for comparisons of data between states, comparison between years within a state and for a state to have consistent definitions for infants diagnosed at different tertiary care centers.

### **What are newborn screening surveillance case definitions?**

- An infant identified by newborn screening at risk for a disorder screened for on that state's newborn screening panel has his/her diagnosis confirmed by a clinical specialist. Most diagnoses are straightforward and the same diagnosis would be made by clinicians in different centers. However, many screened disorders need to undergo a differential diagnosis. Public health surveillance case definitions for newborn screening allow comparisons of disorder frequency and timing of diagnoses across newborn screening programs, between clinical centers in the same state, and show trends across time. These data will help to inform policy and to make state and regional level decisions (e.g., resource allocation).
- Case definitions have been developed by clinical experts to be utilized by newborn screening short-term follow-up programs across the United States.
- The case definitions are recommended to be used by the newborn screening short-term follow-up programs to resolve cases within the first year after birth.

### **Why should we use them in our state newborn screening program?**

- Public health surveillance case definitions for newborn screening will help state newborn screening programs by providing consistent diagnoses for newborn screening across all states (i.e., states can compare themselves with other states for quality and benchmarking purposes without the danger of comparing apples to oranges). These definitions can be used for:
  - o Consistent closing out of open newborn screening cases.
  - o Describing trends of disorders identified by newborn screening from year to year, even with changing clinical interpretations and clinical staff.
  - o Creating consistent public health diagnoses between different tertiary care centers and clinicians.

### **How do we use the case definitions?**

- NewSTEPS has developed worksheets for state newborn screening programs to use to collect information from the clinical specialist who make the diagnoses.
- Once the information is collected within the NewSTEPS Data Repository, a series of reports will be developed to illustrate birth prevalence of disorders as identified by newborn screening. The certainty of case diagnoses can be evaluated to ensure uniform comparisons are made. These reports will be produced by state, region and nationally.

**What is the retention policy for case data?**

- Case data is de-identified within the Data Repository; all dates and times entered are NOT saved. They are simply used to calculate date and time differences and then erased.
- What is saved are the Calculated Age at Screening Specimen Collected (or performed in the case of point of service testing), Age at Diagnosis, Age at Screening Results Reported
- De-identified data will be saved indefinitely within the NewSTEPS repository. No link will be able to be made from the NewSTEPS data repository and other data sources. Data within the NewSTEPS data repository cannot be linked to data in any other data source (i.e., no link can possibly be generated which allows NewSTEPS data repository data to be matched to any other data source).
- The State NBS Program may request retroactive withdrawal of any State data previously entered into the Data Repository by submitting a written notice to APHL requesting this retroactive withdrawal.