



NewSTEPS

A Program of the Association of Public Health Laboratories™

NewSTEPS Data Repository Data Elements

1. Case Level Data

- **Demographics:** State Unique ID; Date of Birth*; Gestational Age; Birth Weight; Biological Sex, Race, Ethnicity
- **Screening information:** Was prenatal testing done; Which newborn screen result indicated this infant was at risk for the disorder; Was this individual diagnosed later in life (not identified by newborn screening); Screening dates* (initial/subsequent) – date of specimen collection, receipt by lab, release of out of range results; Date of intervention by appropriate medical provider; Date of confirmation of diagnosis
- **Case definition information:** diagnostic information (post newborn screen) – varies by disorder. Please see the [case definition worksheets](#) for more details

2. Quality Indicators (QIs)

- Aggregate data for 8 QIs that are described in the [quality indicators document](#)
- Data elements – please see the [quality indicators worksheet](#) for more details

3. State Profiles

- State Demographics
 - Number of births, by Race, Ethnicity, Sex
 - Number of birthing centers
 - Number of infants screened
 - Number of dried blood spot specimens received
- Disorders Screened
 - Year (and month) disorder was screened at the population level
 - Dried Blood Spot (DBS) collection card image
 - Testing methodology – 1st screen, 2nd screen
 - Testing equipment
 - Target(s) screened
 - Where is testing performed?
- Newborn Screening (NBS) Policies on:
 - Recommended age at initial screening and second screening
 - Consent
 - Follow-up services
 - Missed cases
 - Birth Matching
 - Storage of specimens

Case Definitions Worksheets: <https://newsteps.org/sites/default/files/Case%20Definitions%20Master.pdf>

Quality Indicators Worksheet:

<https://newsteps.org/sites/default/files/QI%20Worksheet%20September%202013.pdf>

Quality Indicators Description:

<https://newsteps.org/sites/default/files/Quality%20Indicators%20August%20Final.pdf>



NewSTEPS

A Program of the Association of Public Health Laboratories™

- Storage of data
- Sharing of specimens
- Collaborating or providing support to other NBS programs during emergencies
- Adding new disorders to a state screening panel
- NBS Fees:
 - How is screening paid for?
 - Fees for screens
 - How are fees are collected
 - What the fees pay for
- NBS Program Structure
 - Organizational chart (PDF)
 - Hours of operation: lab, follow-up
 - Weekend hours?
 - NBS program information brochures (PDF)
 - Contact information: lab, follow-up, CCHD, EHDI, HIT
 - NBS Advisory Committee
 - Make up
 - Charge/ by-laws
 - URL to site (if applicable)
- Information Technology & Lab Systems
 - Applications in use in the lab? Follow-up?
 - Continuity of Operations Plans (COOP)
- Health Information Technology Elements
 - Data integration and exchange policies and procedures

* Please note that dates are collected only in the browser for the purpose of calculating differences in dates (i.e., days elapsed between birth and screening) – aside from birth year, no date is stored in the system

Case Definitions Worksheets: <https://newsteps.org/sites/default/files/Case%20Definitions%20Master.pdf>

Quality Indicators Worksheet:

<https://newsteps.org/sites/default/files/QI%20Worksheet%20September%202013.pdf>

Quality Indicators Description:

<https://newsteps.org/sites/default/files/Quality%20Indicators%20August%20Final.pdf>