

**Joint NCC/RC LTFU and NBSTRN Clinical Centers Workgroup
Newborn Screening Long Term Follow-up Uniform Data Set
9/22/09 – updated 2/23/10**

KEY	
Disease specific items to be added	√ indicates 50% or greater surveyed identified
Data fields to be expanded upon	this domain for this item

DOMAIN OF INTEREST

Data Field	Surveillance	Public Health	Patient Care	Knowledge Generation
ENROLLMENT DATA				
DEMOGRAPHICS				
Unique identifier (with or without data in the number- no HIPAA identifiers)	√	√	√	√
Consent (yes/no)			√	√
Permission to contact			√	√
Mother's maiden name	√	√		
Follow-up status	√	√	√	√
Followed by 1+ center	√	√	√	√
Permission to share data between centers	√		√	√
If deceased, age at death	√	√	√	√
How far away is pt from nearest subspecialty center?		√	√	
SES				
Maternal education (linked from birth certificate)		√		√
Paternal education (linked from birth certificate)		√		√
Maternal age at birth	√	√		√
Patient Hispanic	√	√		√
Marital status at birth	√	√		√
Primary insurance at birth	√	√		
Family constellation		√	√	
FAMILY HISTORY				
Consanguinity (yes/no)		√	√	√
Affected parents	√	√	√	√
Birth order	√	√		
Affected sibling(s)	√	√	√	√
Affected sibling data			√	√
PRENATAL HISTORY				
Prenatal testing done? (yes, no, offered but not accepted)	√	√	√	√
Disease specific maternal exposure/history	√	√	√	√
Pregnancy complications/risk factors	√	√	√	√
Assisted reproductive technology		√	√	√
NEONATAL HISTORY				
Need something here	√	√	√	√
MEASUREMENTS				
Birth weight	√	√	√	√
Birth length			√	√
Head circumference	√		√	√
NEWBORN SCREENING				

Data Field	Surveillance	Public Health	Patient Care	Knowledge Generation
Days of age first referral to subspecialty	√	√	√	√
Disease specific NBS values	√	√	√	√
State NBS serial number	√	√		
NEWBORN HEARING SCREENING				
Pass/Fail	√	√	√	√
Referred for diagnostic testing	√	√	√	
PHL identified (unilateral/bilateral)	√	√	√	
Amplification (hearing aid/cochlear implant)	√	√	√	√
Referred for EI	√	√	√	√
DIAGNOSTIC TESTING				
Disease specific confirmatory labs: ACP level and normal/not normal or % of normal activity	√	√	√	√
Laboratory where diagnostic testing performed	√		√	
Genotype data	√	√	√	√
Genotype data concordant w/ NBS results?	√	√	√	√
PAST HEALTH HISTORY				
Hospitalizations prior to enrollment	√	√	√	√
Symptoms prior to enrollment	√	√	√	√
Age at first intervention	√	√	√	√
Genetic counseling	√	√	√	
EMERGENCY MANAGEMENT				
Family was given emergency contact information		√	√	
INTERVAL DATA				
DEMOGRAPHICS				
Identification of Medical Home	√	√	√	
Follow-up status	√	√	√	√
Followed by 1+ center	√	√	√	√
If deceased, age of death	√	√	√	√
How far away is pt from nearest subspecialty center?	√	√	√	
SES				
Current insurance status	√	√	√	√
Marital status	√	√		
Family constellation		√	√	
MEASUREMENTS				
Weight	√	√	√	√
Height	√	√	√	√
Head circumference	√	√	√	√
INTERVAL HEALTH HISTORY – since last visit				
Anesthesia			√	√
Surgeries			√	√
Transplants/major medical procedures	√		√	√
EMERGENCY MANAGEMENT				
Family was given emergency contact information		√	√	
Number urgent office visits	√	√	√	√
Number ER visits	√		√	√
Number ER visits – disease related	√	√	√	√
Number hospital days – disease related	√	√	√	√
Number ICU days	√	√	√	√
ICD-9 codes for hospitalizations	√	√	√	√
Number missed visits	√	√	√	√
Number phone calls			√	
CARE COORDINATION				

Data Field	Surveillance	Public Health	Patient Care	Knowledge Generation
Other services received (define symptomatic vs. preventative for all checked)		√	√	√
Community resources received		√	√	
Other providers seen at this visit			√	
DEVELOPMENTAL ASSESSMENT				
Developmental assessment done at this visit	√	√	√	√
Developmentally normal or abnormal (or mild, moderate, severe delay)	√	√	√	√
If not normal, was something done	√	√	√	√
EDUCATION				
Special education received	√	√	√	√
HOME MONITORING				
Home monitoring done		√	√	√
Type of home monitoring done (disease specific)		√	√	√
LABORATORY STUDIES				
Disease specific assays done and values	√		√	√
Genotype data	√		√	√
Is genotype data concordant w/ NBS results?	√	√	√	√
IMAGING STUDIES				
Imaging done – details to be discussed			√	√
PHARMACO THERAPY				
Disease specific med questions			√	√
OTC meds/vitamins/homeopathic			√	√
NUTRITION				
Disease specific nutrition questions		√	√	√

√ indicates 50% or greater surveyed identified this domain

Suggested Additional Fields:

- Patient status when NBS sample was obtained: sick/well
- Maternal prenatal drug exposure
- Race/Ethnicity (beyond Hispanic)
- Was kindred expanded by genetic counseling (yes/no)
- Specific ethnicity data; language(s) spoken at home
- Congenital Abnormalities
- Recording immunization status (type and if up-to-date).
- Cause of death