NEW YORK STATE DEPARTMENT OF HEALTH

Statewide Perinatal Data System
Neonatal Intensive Care Unit (NICU)
High Risk Module

User's Guide for Data Collection

Revised June 2013

Table of Contents

1. Patient Data 2
    a. Add a New Patient 2
    b. Patient Data 3
2. Mother/Demographic Data 5
3. Patient Encounter Data 6
    a. Initial Status After Birth Data 6
    b. Nutrition Data 7
    c. Ophthalmology Data 8
    d. NICU Disposition Data 9
    e. Referral Data 10
    f. Home Nursing Data 11

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ADD A NEW PATIENT

This section reflects the first of the NICU module's on-line data entry screens to be encountered.

Fields marked with an asterisk also appear in the next section, PATIENT DATA.

Fill in as much information HERE as you have available.

When it is entered on-line, it will be transferred automatically onto the PATIENT DATA screen.

You MUST enter at least LAST NAME, DATE OF BIRTH, and BIRTH ORDER to create a new record on-line.

NOTE: If the infant was born at your hospital and your hospital is NOT located in NYC, you will be able to import some of the patient and birth related data from the Statewide Perinatal Data System (SPDS) Core Module.

Last Name*	Enter infant's last name on admission to the NICU. Do NOT enter birth order designator such as “A”, “B” etc. Enter a generation designation with a space between each letter to retain uppercase status. (i.e., John Smith I I I). If there is a name change, do NOT change the original name. Add the new name in parentheses after the original name.
First Name*	Enter infant's first name on admission to the NICU.
Date of Birth*	Enter infant’s date of birth; MM/DD/YYYY (e.g., 01/01/2004).
Birth Order*	Enter birth order for the infant. (e.g., 0=singleton, 1=first multiple, 2=second multiple, etc.).
Birth Hospital Medical Record #*	Enter infant's medical record number at the BIRTH hospital or first hospital infant is admitted to if not born at a hospital.
Place/Hospital of Birth*	Enter or select the location of infant's birth from drop-down list; may also be Clinic, Home Delivery , Out of State Hospital, Outside of Hospital (e.g., ambulance, parking lot, car etc.), Physician’s Office.
Admission Post Discharge	Select for infants admitted after discharge from their birth hospitalization.

PATIENT DATA

Last Name*	Enter infant's last name on admission to your NICU.
First Name*	Enter infant's first name on admission to your NICU.
Birth Hospital Medical Record #*	Enter the birth hospital medical record number for the infant (up to 17 characters); include all digits and letters.
Birth Hospital Name*	Select the infant’s birth hospital from the drop-down list.
Birth Date*	Enter the infant’s date of birth;

	if outborn (born at home, another non-NICU hospital or other location), select Other Location (outborn); if the infant was transferred from another NICU, select Another NICU.
If the patient came to you from another NICU,	Enter the NICU hospital name.
Was the patient admitted to that hospital's NICU?	Enter Yes or No.
	For infants admitted after discharge from their birth hospitalization: if infant was born at your hospital, select Home (inborn) or Other (inborn) noting from where (i.e. correctional facility); if infant was not born at your hospital, check Home (outborn) or Other (outborn) noting from where (i.e. correctional facility).

MOTHER / DEMOGRAPHIC DATA

Mother's Last Name	Enter mother's last name at the time of the infant's admission to NICU.
Mother's First Name	Enter mother's first name at the time of the infant's admission to NICU.
Mother's Maiden Name	Enter the mother's maiden last name.
Mother's SSN	Enter the mother's SSN; 999-99-9999 (e.g., 123-45-6789).
Mother's Date of Birth	Enter mother's date of birth; MM/DD/YYYY (e.g., 01/01/1960).
Street Address	Enter street address of mother's residence at time of infant's admission to NICU.
City	Enter city of mother's residence at time of infant's admission to NICU.
State	Enter state of mother's residence at time of infant's admission to NICU; defaults to New York.
Zip Code	Enter zip code of mother's residence at time of infant's admission to NICU; 5 or 9 digits.
County	Select county of mother's residence at time of infant's admission to NICU from listing; select 'Out of State' if outside New York State.
Telephone	Enter mother's telephone number at the time of infant's admission to NICU; (area code) 999-9999 (e.g., (315) 470-7000).
Maternal Transfer	Check Yes if mother transferred from another hospital or location (prior to giving birth) to your hospital. Check No if not transferred from another hospital or location.
If YES, transferred from	Select the hospital name or location from which the mother was transferred from the drop-down list.
Referring Hosp Medical Record #	Enter the mother's medical record number from the transferring hospital.

Tocolysis	Check Yes if mother received tocolysis at any time during this pregnancy; check No if she did not receive tocolysis during this pregnancy.
Antenatal Steroids	Check Yes if the mother received corticosteroids via IM or IV any time during this pregnancy prior to delivery. Check No if the mother did not receive corticosteroids via IM or IV any time during this pregnancy prior to delivery.
Dose	Check Incomplete if delivery occurred before completion of a 48 hour course of corticosteroids (i.e., less than 2

	Check No if a blood pH was not obtained.
Initial Blood pH Value	Enter the value of the blood pH use real numbers with 2 decimal places; (e.g., 7.37; range 6.00 to 8.00).
Base Excess / Deficit	Enter the base excess or deficit corresponding to the above blood pH use real numbers with one decimal point; (e.g., -2.1; range -

	Breast Milk Only (Exclusive breast milk feeding): Infant has been fed ONLY breast milk... Breast milk feeding includes expressed mother's milk as well as donor human milk, both of which may be fed to the infant by means other than suckling at the breast. Breast milk feeding also includes added human milk fortifier in either powdered or liquid form. Formula Only: Infant has been fed formula (any amount). Formula includes all standard newborn formulas, premature formulas, and special formulas. Infant has NOT been fed any breast milk, and may or may not have been fed other liquids, such as water or glucose water. Both Breast Milk and Formula: Infant has been fed BOTH breast milk (any amount) AND formula, water, glucose water and/or other liquids (any amount).
FIRST Date Without IV Nutrition	Enter the first date (full 24 hours) on which infant no longer received intravenous nutrition; MM/DD/YYYY (e.g., 01/01/2004).
First Enteral Feeding Type without IV	Check the type of feeding the infant received: Breast, Formula, or Both Breast Milk and Formula. At this point during the period between birth and discharge from the hospital, indicate whether the infant has been fed breast milk exclusively, infant formula, a combination of both breast milk and formula, or other. Breast Milk Only

Check Not Assessed

	Chronic Care: infant is transferred to an institution for long term chronic care; **Growth & Discharge Planning**: infant is transferred to another hospital for the provision of continuing care in preparation for eventual discharge home; **Parental Request**: infant is transferred to another hospital due to parental request; **Surgery**: infant is transferred to another hospital specifically for surgery even if surgery is not actually performed after the transfer; **Medical/Diagnostic Services**: infant is transferred to another hospital to receive medical care or diagnostic tests which are not available at your hospital (even such diagnostic tests result in surgery, the reason for transfer is still Medical/Diagnostic Services); **Other (specify)**: if the reason for transfer does not meet any of the above criteria.
Transferred Reason Other	Specify reason for transfer in not available in dropdown list.
If Expired, Consent for Autopsy	Check **Yes** if parents consented to an autopsy. Check **No** if parents did not consent to an autopsy.
If Expired (including DR or Transport Death), Care Deemed Futile	Check **Yes** if care deemed futile before or by Level III evaluation. Check **No** if care not deemed futile.
If **Yes**, Where	Specify whether care was deemed futile before evaluation by Level III staff or by staff in Level III NICU.
Care Deemed Futile, Reason	Indicate reason why care deemed futile. Select from: **No Support, poor prognosis** to indicate non-intervention or withheld support based on a poor prognosis; **No Support, lethal anomaly** to indicate non-intervention or withheld support based on determination of a lethal anomaly; **Support withdrawn, lethal anomaly** to indicate intervention withdrawn based on determination of a lethal anomaly; **Support withdrawn, poor neurological prognosis** to indicate intervention withdrawn based on a poor neurological prognosis; or **Progressive failure despite support** to indicate progressive body system failure despite intervention; including "DNR" order after any intervention prov32 Tw ;R[(•Tc 0 Tw 1.181 8-9(a)-8(t)L(.17 0 Td( )Tj/TT1 1 EM

O2 Support	Check Yes if infant left the NICU on supplemental oxygen. Check No if infant did not require supplemental oxygen after leaving the NICU.
Cardiac-Apnea Monitor	Check Yes if infant left the NICU on a cardiac-apnea monitor. Check No if infant did not require a cardiac-apnea monitor after leaving the NICU.
Hearing screen	Check the result of the hearing screening test: Passed or Didn't Pass. If the screening was not performed check Not Done.
Date Rescreen Scheduled	Enter the rescreen date for the hearing test if one was scheduled; MM/DD/YYYY (e.g., 01/01/2004).
Primary Care Physician/Group	Enter the first and last name physician or group responsible for infant's care after disposition from your unit.
Feeding Type at Disposition	Check the type of feeding the infant was receiving at NICU disposition: Breast Milk Only, Formula Only, Both Breast Milk and Formula or None. At the time of discharge from the hospital, indicate whether the infant is being fed breast milk exclusively, infant formula, a combination of both breast milk and formula, or none. Breast Milk Only (Exclusive breast milk feeding): Infant has been fed ONLY breast milk. Breast milk feeding includes expressed mother's milk as well as donor human milk, both of which may be fed to the infant by means other than suckling at the breast. Breast milk feeding also includes added human milk fortifier in either powdered or liquid form. Formula Only: Infant has been fed formula (any amount). Is NOT being fed any breast milk. Has or has not been fed other liquids, such as water or glucose water. Both Breast Milk and Formula: Infant has been fed BOTH breast milk (any amount) AND formula, water, glucose water and/or other liquids (any amount). None: Infant has NOT beeen fed any breast milk or formula. This response is rare; it will include infants who have required intravenous feeding.
In House Transfer Disposition	MUST BE COMPLETED FOR ALL IN HOUSE TRANSFERS Enter the Disposition of the infant following In House Transfer Select: Discharged Home, Transferred Out (to another hospital or location), Expired, Readmit to NICU. Note: In House Transfer Disposition MUST BE COMPLETED FOR ALL IN-HOUSE TRANSFERS.
In House Transfer Disposition Date	Enter the date of the disposition; MM/DD/YYYY (e.g., 01/01/2004).
In House Transfer Disposition Time	Enter the time of the disposition, military time; (e.g., 00:01 = 12:01 AM).

REFERRAL DATA

On the following referral items check Yes if the infant was referred for service(s) or Check No if there was no referral for the specific service. All items will default to No and must be changed to Yes if infant is referred.

County Public Health Nurse	Yes or No
Early Intervention	Yes or No
Developmental Testing (hospital based or other)	Yes or No
Other (specify)	Enter text as appropriate.

HOME NURSING DATA

Home Nursing for Chronic Care	Check if infant requires Home Nursing for Chronic Care.
Provided by:	Check the type of agency providing Home Nursing Services: Certified Home Health Agency Public Health Nurse Hospital Based Agency Other (specify).

Other (Respiratory Diagnosis)	Check and specify if infant has any other respiratory diagnosis not listed above (e.g., Birth Depression (slow adaptation to extrauterine life of a neurological nature), distress due to anomaly of another system).

RESPIRATORY SUPPORT (After Leaving the Delivery Room)

No Respiratory Support/ Room Air Only	Check if the infant did not receive supplemental oxygen at any time after leaving the delivery room.

There may be multiple start and end dates for the various types of Respiratory Support. Do not enter end date if the duration of the change is <12 hours and results in a return to the previous mode of support. Do not check mechanical ventilation if initiated only for surgical e inot riaul not che0 TdsDc(a)5(d)]T 11.03(uk(i)5()-1(es)-4(o)4(f)2(Res)-7

Enter the date(s) the mechanical ventilation started and ended. NOTE: If more than 4 occurrences, record on additional sheet. The NICU Module accommodates any number of entries.

If the type of mechanical ventilation changes, select a new type and enter start and end dates.
Do not check mechanical ventilation if given for OR only.

RESPIRATORY TREATMENT

Surfactant	Check if exogenous surfactant was administered to the infant.
First Dose at	Check when first dose of surfactant was administered: **<1/2 hr postnatal age** – select if the first dose of surfactant was given in the first 30 minutes of life . **> 1/2 hr postnatal age** -- select if the first dose of surfactant was given after the first 30 minutes of life.
Total Number of Doses	Enter an integer value of for the total number of surfactant doses given (range 1-9).
Systemic Steroids for Lung Disease	Check if corticosteroids were used after birth to treat or prevent bronchopulmonary dysplasia or chronic lung disease. Enter start and end dates. NOTE: If more than 3 occurrences, record on additional sheet. The NICU Module accommodates any number of entries.
Nitric Oxide	Check if Nitric Oxide was administered to the infant. Enter start and end dates. NOTE: If more than 2 occurrences, record on additional sheet. The NICU Module accommodates any number of entries.
ECMO (Extracorporeal Membrane	Check if the infant was treated with ECMO / ECLS; Oxygenation/ECLS). Enter start and end date. NOTE: If more than 1 occurrence, record on additional sheet. The NICU Module accommodates any number of entries.
Chest Tube	Check if a chest tube was inserted (for e.g., pneumothorax, pulmonary hemorrhage).
Other (Respiratory Treatment)	Check and specify any significant treatments not captured above.

CARDIOVASCULAR DATA

Anomaly-Congenital Heart Disease	Check if appropriate for e.g., transposition of great vessels, tetralogy of Fallot, endocardial cushion defect, anomalies of pulmonary valve, tricuspid atresia and stenosis, stenosis and insufficiency of aortic valve, common atrium / AV canal / truncus defect, dextrocardia, cor biloculare, ectopia cordis, Ebstein's anomaly, hypoplastic left heart syndrome, pericardial defect, single ventricle, VSD, ASD, PFO, coarctation of aorta, double outlet right ventricle, Pentology of Cantrell, SVT, PPS. And indicate whether:
Treated with	Prostaglandins or Surgery
Resulting in	Congestive Heart Failure

Hypertension	Check if the infant was hypertensive and treated with antihypertensive medication.
Hypotension	Check if the infant was hypotensive and treated with volume and/or pressors.
Patent Ductus Arteriosus	Check if infant had clinical evidence of left to right PDA shunt documented by continuous murmur, hyperdynamic precordium, bounding pulses, wide pulse pressure, congestive heart failure, increased pulmonary vasculature or cardiomegaly by CXR, and/or increased oxygen requirement or ECHO evidence of PDA with documentation of left to right ductal shunting. Do not check if the infant does not satisfy the above definition.
Intervention type	Check if appropriate even if above criteria are not met, and
select:	**Ligation** – select if surgical ligation of the ductus arteriosus was attempted in the OR or NICU **Indomethacin** – select if Indomethacin was administered **Other Pharmacologic** – select if other pharmacologics were administered.
Other	Check if appropriate and specify other malformations of circulatory system not listed above.

CENTRAL NERVOUS SYSTEM DATA

Anomaly-Congenital Hydrocephalus	Check if appropriate.
Anomaly-Microcephaly	Check if appropriate (e.g., microcephaly, hydromicrocephaly, microencephalon)sm H0 [illegible] l

Details	Specify one of the following means of diagnosis: Surgically Confirmed (Treated) Clinically Suspected (Pneumatosis/portal air) Diagnosed by PostMortem Examination only.
:	Note: Spontaneous intestinal perforation (SIP) occurs most commonly in VLBW neonates as a single intestinal perforation that is typically found at the terminal ileum. SIP is a separate clinical entity from necrotizing enterocolitis and should not be included here.
Cholestatic Jaundice	Check if appropriate; Total Parenteral Nutrition (TPN)-associated increase in direct bilirubin level.

GENITOURINARY/RENAL DATA

Renal Agenesis	Check if appropriate (e.g., Potter's syndrome, atrophy of kidney, hypoplasia of kidney).
Renal Failure	Check if appropriate (only if infant’s creatinine >2).
Other	Check if appropriate, and specify (e.g., hydronephrosis, hypospadias, other malformations of genitourinary system).

HEMATOLOGY DATA

Coombs Positive	Check if appropriate.
Direct Bilirubin > 3 mg/dl	Check if appropriate.
Exchange Transfusion	Check if infant received a blood exchange transfusion . Select either Partial or Complete.
RBC Transfusion	Check if infant received an RBC transfusion . Select either Single or Multiple.
Recombinant Erythropoietin	Check if infant received recombinant Erythropoietin (EPO). Enter start and end dates.
Other	Check if appropriate, and specify.

INFECTIOUS DISEASE DATA

Anomaly - Confirmed Congenital Infection (TORCH)	Check if appropriate.
Type:	Select Toxoplasmosis, Rubella, CMV, Herpes, Syphilis, Parvovirus, Other (specify).
Early Onset Sepsis	

Early Onset Sepsis - Suspected Culture Negative, Treatment Continued	Check if early onset sepsis was suspected, cultures obtained from blood or cerebral spinal fluid on or before day 3 of life were negative but treatment continued for full course.
Early Onset Sepsis - Confirmed Culture Positive (cultures obtained on or before day 3 of life)	Check if early onset sepsis was confirmed with a positive culture obtained from blood or cerebral spinal fluid o n o r b e

Birth Related Trauma	Check if appropriate (e.g., visceral hemorrhage, subgaleal hematoma,