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

Revisions

1. **Page 4: Added Birth Head Circumference and Birth Length to Patient Data**
2. **Page 9: Added First Date When Birth Weight Regained to Nutrition Data**
3. **Page 11: Added Disposition Head Circumference and Disposition Length to NICU Disposition Data**

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
4. Diagnoses and Treatments 12
    a. Respiratory 12
    b. Cardiovascular 14
    c. Central Nervous System 15
    d. Gastrointestinal 17
    e. Genitourinary 18
    f. Hematology 18
    g. Infectious Disease 19
    h. Miscellaneous 20
    i. Consults/Other Services 20

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; MM/DD/YYYY (e.g., 01/01/2004).
Birth Time	Enter the infant's time of birth; military time; (e.g., 00:01 = 12:01 AM).

Birth Weight	Enter the infant's birthweight in grams (integers < 10,000) use the weight from Labor & Delivery record; if unavailable or judged to be inaccurate then use the weight on admission to the neonatal unit or lastly, the weight obtained on autopsy (if the infant expired within 24 hours of birth).
Birth Head Circumference	Enter the infant's head circumference at birth to the nearest tenth of a centimeter, within the range 15.0 to 50.9. If using a tape measure that has only 0.5 cm gradations, note the measurement to the nearest 0.5 cm, within the range 15.0 to 50.5. Note: If the head circumference is not available in the birth record and the infant is more than 48 hours old upon admission, record as 99.9.
Birth Length	Enter the infant's length at birth to the nearest tenth of a centimeter, within the range 20.0 to 80.9. If using a tape measure that has only 0.5 cm gradations, note the measurement to the nearest 0.5 cm, within the range 20.0 to 80.5 If the length is not available in the birth record and the infant is more than 48 hours old upon admission, record as 99.9.
Sex	Enter infant's assigned gender select Male, Female, Unknown (ambiguous genitalia).
Plurality	Enter the total number of babies in **this pregnancy;** (e.g., twins=2, triplets=3 etc.).
Birth Order*	Enter the birth order for the infant you are entering; (e.g., 0=singleton, 1=first multiple, 2=second multiple etc.).
Cord pH	Check **Yes** if a Cord pH was obtained; check **No** if a Cord pH was not obtained.
Cord pH Value	Enter the Cord pH value; use real numbers with 2 decimal places; (e.g., 7.37; range 6.00 to 8.00).
Cord pH Type	Enter the type of sample drawn; UA (umbilical arterial) or UV (umbilical venous) or Not Assigned (if not known); if both types (UA/UV) were drawn within the first hour after birth, enter the UA (arterial value); if both were taken after one hour from birth, enter the first one drawn.
1 minute Apgar	Enter the Apgar score at one minute; use 1 or 2 digits (range 0 to 10); if not done, enter 11.
5 minute Apgar	Enter the Apgar score at 5 minutes; use 1 or 2 digits (range 0 to 10); if not done, enter 11 .
10 minute Apgar	Enter the Apgar score at 10 minutes; use 1 or 2 digits (range 0 to 10); if not done, enter 11; prompted for if 5 minute score is < 6.
Gestational Age Determined by:	**Select and record the BEST estimate of gestational age according to the following hierarchy, using the lowest applicable number:**

	1. Estimated Date of Confinement (EDC) determined by early ultrasound (prior to 24 weeks); 2. Last Menstrual Period (LMP) Date; 3. Physical Exam confirmed by physical criteria, neurologic examination, Ballard or Dubowitz, or examination of the lens. Computer will calculate gestational age based on the DATE filled in for either 1. (EDC) or 2. (LMP) or Enter integers for weeks and days based on Physical Exam. **Note: Complete both gestational age weeks and days – do not leave days field blank**
Delivery mode	Select mode of delivery: Vaginal (spontaneous or induced) C-section (elective or emergent)
Resuscitation at Birth	Check **Yes** or **No**; if yes, indicate type: **Oxygen** – any supplemental oxygen; **Bag/mask** – any positive pressure breaths with a bag and face mask; **Endotracheal tube ventilation** – any ventilation through an endotracheal tube (if an endotracheal tube was placed only for suctioning and assisted ventilation was not given through the tube do NOT check this box); **Epinephrine** – given via intravenous, intracardiac or intratracheal (through an endotracheal tube) routes; **Cardiac compressions** – external cardiac massage. **Responses to this item should be based on the initial resuscitation provided IMMEDIATELY after birth, regardless of where the resuscitation took place.**
Tracheal suctioning for Meconium Aspiration	Check **Yes, No** or **N/A.** Select **Yes** if tracheal suctioning through an endotracheal tube or suction catheter in the trachea was performed in an attempt to remove meconium; select **Yes** if suctioning was performed with no meconium recovery. Select **No** if meconium aspiration was present and tracheal suctioning was not attempted. Select **N/A** if no meconium was present.

You will be prompted for the following information on all admissions:

Hospital Medical Record Number	If inborn, this will prefill from previously entered data; if outborn, specify infant medical record number for your hospital.
Admission date	Enter admission date for the infant to the NICU; MM/DD/YYYY (e.g., 01/01/2004).
Admission time	Enter the time of admission for the infant to the NICU; military time (e.g., 00:01 = 12:01 AM).
Infant location prior to admission to your NICU	Check the location of infant prior to admission to your NICU: if inborn (born at your hospital), select L&D, Regular Nursery, ER;

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 24 hours after a dose); Check **Complete** if delivery occurred more than 24 hours after completion of at least a 48 hour course of corticosteroids.
Maternal History	Enter maternal history.

PATIENT ENCOUNTER DATA

INITIAL STATUS AFTER BIRTH DATA

Invasive Care	Check **Yes** if infant received any treatments to sustain life. Check **No** if the infant only received comfort care (no treatments to sustain life) or care is withdrawn within 4 hours after birth. **THIS VARIABLE NOT COLLECTED AFTER 12/31/2004; SEE CARE DEEMED FUTILE UNDER NICU DISPOSITION SECTION.**
DR (Delivery Room) Death (include all infants ≥400 grams)	Check **Yes** if infant dies in the delivery room or any other location in your hospital (i.e., in DR, L&D, or ER) prior to admission to the NICU and within 12 hours after birth [also respond to Care Deemed Futile in NICU Disposition section]. Check **No** if these criteria are not met.
Transport Death	Check **Yes** if NICU team alerted but infant expires en route to the NICU (include all infants ≥400 grams) [also respond to Care Deemed Futile in NICU Disposition section]. Check **No** if these criteria are not met.
Positive Pressure Mechanical Ventilation	Check **Yes** if infant received any type of mechanical positive pressure ventilation within 24 hours after birth. Check **No** if infant did not receive any type of mechanical positive pressure ventilation within 24 hours after birth.
MAP/PEEP (any device)	Enter mean airway pressure if mechanical ventilation or positive end-expiratory pressure if CPAP (e.g., 5.0; range 2.0 to 40.0).
FiO2	Enter FiO2 percent as decimal; (100%=1.00; range 0.21 to 1.00).
Assessment Date	Enter the date the above values were assessed; MM/DD/YYYY (e.g., 01/01/2004).
Assessment Time	Enter the time the above values were assessed; military time (e.g., 00:01 = 12:01 AM).
Initial Blood pH	Check **Yes** if a blood pH was obtained.

	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 -35 to **25**).
Draw Date	Enter the date the blood pH was drawn; MM/DD/YYYY (e.g., 01/01/2004).
Draw Time	Enter the time the blood pH was drawn; military time; (e.g., 00:01 = 12:01 AM).
Draw Type	Select the type of blood pH drawn; Arterial, Capillary, Venous.
Pressor Support: Volume Expansion	Check **Yes** if volume expansion pressor support was administered (e.g., normal saline). Check **No** if volume expansion pressor support was not administered.
Pressor Support: Pharmacologic	Check **Yes** if pharmacological pressor support was administered (e.g., dopamine). Check **No** if pharmacological pressor support was not administered.
First Measured Temperature in Nursery (°C.)	Enter the first measured temperature in nursery in degrees Centigrade; use real numbers with 1 decimal place, e.g., 37.1, and verify values outside the range 34.0 and 39.0.
Temperature Date	Enter the date when first measured temperature was taken MM/DD/YYYY (e.g., 01/01/2004).
Temperature Time	Enter the time the first measured temperature was taken; military time (e.g., 00:01 = 12:01 AM).

NUTRITION DATA

Enteral Feeding	Check **Yes** if enteral feedings were initiated Check **No** if enteral feeding were not initiated Enteral feedings may be provided by any method including breast, bottle, gavage tube, gastrostomy tube, feeding cup, etc.
Date of FIRST Enteral Feeding	**Enter the date of the first protein-containing feeding administered to the stomach or intestine by any route (e.g. - gavage, oral, G-tube). This definition excludes non-protein containing feedings, such as sterile water, used to stimulate GI function;** MM/DD/YYYY (e.g., 01/01/2004).
First Enteral Feeding Type	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 (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 (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 When Birth Weight Regained

Enter the date when the infant's birth weight was FIRST regained and sustained for 48 hours or more after having reached its lowpoint; MM/DD/YYYY (e.g., 07/01/2013). If the infant did not lose any weight after birth, enter the date of birth; if the infant did not regain birth weight at any time before being discharged, enter 00/00/0000; if the infant had FIRST regained birth weight prior to this admission, enter 99/99/9999.

OPHTHALMOLOGY DATA

Retinopathy of Prematurity (ROP)

Check **Yes, No, Not Assessed.**
Check **Yes** if results from an ophthalmologic examination indicate ROP in either eye.
Check **No** if results from an ophthalmologic examination do not indicate ROP in either eye.

Check **Not Assessed** if an ophthalmologic examination for ROP was not done even if one was not required.

If **Yes**, specify the **WORST** stage and zone documented for each eye; enter 0 for the eye in which ophthalmologic examination does not indicate ROP. Valid stages and zones include:

Stage 1= demarcation line
Stage 2= intraretinal ridge
Stage 3= ridge with extraretinal fibrovascular proliferation
Stage 4= retinal detachment
Stage 5= total retinal detachment

Zone 1= posterior pole or inner zone
Zone 2= middle area
Zone 3= outermost area
indicate Plus disease as "+" after stage

Cryotherapy/Laser Therapy

Check **Yes** if infant received laser therapy for ROP.
Check **No** if infant did not receive laser therapy treatment.

Cryotherapy/Laser Therapy Type

Check **unilateral** if the infant received laser therapy for one eye.
Check **bilateral** if the infant received laser therapy for both eyes.

NICU DISPOSITION DATA

NICU Disposition

MUST BE COMPLETED FOR ALL ADMISSIONS
Enter the initial disposition of the infant from your NICU. Select: Discharged Home (includes Foster Care), Transferred Out (to another hospital or location), Expired, or In-House Transfer.
Note: In House Transfer Disposition MUSTALSO BE COMPLETED FOR ALL IN-HOUSE TRANSFERS.

NOTE: *Initial Disposition* refers to the *first time* that the infant was discharged or transferred from your NICU. For centers with multiple in-house care sites (NICU, SCN, step-down unit, annex or satellite nurseries), please record the first time that the infant was transferred off the neonatology service to another inpatient service.

NICU Disposition Date

Enter the date the infant left your NICU; MM/DD/YYYY (e.g., 01/01/2004)

NICU Disposition Time

Enter the time the infant left your NICU; military time (e.g., 00:01 = 12:01 AM).

Transferred Out, Where

Indicate hospital name or other location where the infant was transferred.

Transferred Where Other

Specify infant transfer location if **Other than Hospital or Out of State.**

Transferred Out, Reason

Indicate reason for transfer.
Select from the following:
Back Transfer (reverse): infant is transferred for the provision of continuing care in preparation for eventual discharge home back to the hospital from which they originally came to your hospital ;

	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 provided.
In House Transfer, Location	Select In House transfer location: Normal Newborn Nursery, PICU, Pediatrics, Other.
In House Transfer Reason	Specify the reason for the In House transfer.
Disposition Weight	Enter the weight of the infant at NICU disposition in grams; integer < 10,000.
Disposition Head Circumference	**Enter the infant's head circumference at disposition to the nearest tenth of a centimeter, within the range 15.0 to 50.9. Note: if using a tape measure that has only 0.5 cm gradations, note the measurement to the nearest 0.5 cm, within the range 15.0 to 50.5.**
Disposition Length	**Enter the infant's length at disposition to the nearest tenth of a centimeter, within the range 20.0 to 80.9. Note: if using a tape measure that has only 0.5 cm gradations, note the measurement to the nearest 0.5 cm, within the range 20.0 to 80.5.**

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).

DIAGNOSES AND TREATMENTS BY SYSTEM

RESPIRATORY DATA

Anomaly - Diaphragmatic Hernia	Check if appropriate
Anomaly - Pulmonary Hypoplasia Secondary to	Check if appropriate, and select Pleural Effusion, Abdominal Defect, Oligohydramnios.
Anomaly - Other	Check if appropriate and specify (e.g., Cystic adenomatoid malformation).
Delayed Transition	Check if infant demonstrates slow adaptation to extrauterine life, requiring supplemental oxygen with no other diagnostic cause.
TTN (Transient Tachypnea)	Check if infant has tachypnea not due to other causes.
Meconium Aspiration	Check if appropriate. Check only if **all** the following criteria are satisfied:. 1. Presence of meconium stained amniotic fluid. 2. Respiratory distress (any of the following: tachypnea, grunting, nasal flaring, intercostals retractions) with onset within 1 hour of birth. 3. A PaO2<50 mmHg in room air, central cyanosis in room air or a requirement for supplemental oxygen to maintain PaO2 >50mmHg. 4. Abnormal chest x-ray compatible with the diagnosis of meconium aspiration. Findings may include coarse irregular or nodular pulmonary densities, areas of diminished aeration or consolidation alternating with areas of hyperinflation and generalized hyperinflation. 5. Absence of culture proven early onset bacterial sepsis or pneumonia. The diagnosis of culture proven early onset bacterial sepsis or pneumonia requires a positive blood culture obtained within 72 hours of birth.
PPHN (Persistent Pulmonary Hypertension)	Check if appropriate by echocardiographic and clinical evidence.
Pulmonary Air Leak Type	Check if appropriate, and specify type: Pulmonary Interstitial Emphysema (PIE), Pneumothorax (extrapleural air diagnosed by chest radiograph or needle aspiration, thoracentesis) Pneumopericardium Pneumomediastinum.
Respiratory Distress Syndrome/ Hyaline Membrane Disease	Check if infant has Respiratory Distress Syndrome (RDS) defined as: PaO2 < 50 mmHg in room air, central cyanosis in room air, or a requirement for supplemental oxygen to maintain PaO2 > 50 mmHg **AND** a chest radiograph with low lung volumes and reticulogranular appearance to lung fields, with or without air bronchograms. Infant must satisfy both criteria.

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 procedure and discontinued within 72 hours post surgery. Dates are reflective of the infant's stay in YOUR unit. If the infant is discharged or transferred with oxygen support, the end date is the NICU Disposition Date.

Nasal Cannula or Hood	Check if the infant received supplemental oxygen via nasal cannula or hood after leaving the delivery room. Enter the date(s) supplemental oxygen via nasal cannula or hood started and the date it ended. NOTE: If more than 4 occurrences, record on additional sheet. The NICU Module accommodates any number of entries.
CPAP	Check if the infant was given continuous positive airway pressure applied through the nose at any time after leaving the delivery room. Enter the date(s) CPAP applied through the nose started and the date it ended. NOTE: If more than 4 occurrences, record on additional sheet. The NICU Module accommodates any number of entries. Nasal IMV and nasal SIMV are both considered forms of nasal CPAP for the purpose of this definition. High flow nasal cannula oxygen is NOT considered nasal CPAP for the purpose of this definition.
CPAP Administered Prior to Positive Pressure Ventilation	Check **Yes** or **No.** Check **Yes** if the infant received continuous positive airway pressure applied through the nose without having previously received intermittent positive pressure breaths through an endotracheal tube using a mechanical ventilator or manually using a bag. Check **No** if the infant received intermittent positive pressure breaths through an endotracheal tube using a mechanical ventilator or manually using a bag before being given continuous positive pressure airway pressure applied through the nose.

- **The important point is whether the Nasal CPAP was given BEFORE or AFTER assisted positive pressure breaths through an endotracheal tube.**
- **If the infant was first treated with Nasal CPAP and later intubated and ventilated, the answer is "Yes".**
- **If the infant was first treated with Nasal CPAP and never intubated and ventilated, the answer is "Yes".**
- **If the infant was intubated and given positive pressure breaths through the endotracheal tube and later received Nasal CPAP, the answer is "No".**
- **Intubation in the Delivery Room solely for suctioning of meconium does not count as prior intubation. Thus, for an infant who was intubated for suctioning of meconium and the tube removed immediately after suctioning, who was later treated with Nasal CPAP, the answer is "Yes".**

Mechanical Ventilation	Check if the infant was given intermittent positive pressure ventilation at any time after leaving the delivery room. **Select the type:** IMV (conventional ventilator, IMV rate <240/min.); HIFI (HFOV, high frequency ventilator , IMV rate >= 240/min.); Jet.

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 Resulting in	Prostaglandins or Surgery 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 **select**:	Check if appropriate **even if above criteria are not met, and** **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).
Anomaly-Neural Tube Defect	Check if appropriate (e.g, spina bifida, meningocele, myelocele, myelomeningocele,myelocystocele, syringomyelocele, hydromeningocele, rachischisis).
Other	Check if appropriate, specify (e.g., acrania, anencephaly, hemianencephaly, amyelecephalus, hemicephaly, encephalocele, other CNS malformations, subarachnoid hemorrhage {SAH}).
Seizures	Check if there is clinical evidence of seizures and infant was treated with anticonvulsive medication.
Hypoxic-Ischemic Encephalopathy (HIE)	Check if infant was diagnosed with HIE as defined below: 1. The presence of a clinically recognized encephalopathy within 72 hours of birth. Encephalopathy is defined as the presence of **3 or more** of the following findings within 72 hours of birth: -- abnormal level of consciousness: hyperalertness, lethargy, stupor or coma -- abnormal muscle tone: hypertonia, hypotonia or flaccidity -- abnormal deep tendon reflexes: increased, depressed or absent -- seizures: subtle, multifocal or focal clonic

-- abnormal Moro reflex: exaggerated, incomplete or absent
-- abnormal suck: weak or absent
-- abnormal respiratory pattern: periodic, ataxic or apneic
-- oculomotor or pupillary abnormalities: skew deviation, absent or reduced Doll's eyes or fixed unreactive pupils

AND

2. Three or more supporting findings from the following list:
-- arterial cord pH<7.00
-- Apgar score at 5 minutes of 5 or less
-- evidence of multiorgan system dysfunction
-- evidence of fetal distress on antepartum monitoring: persistent late decelerations, reversal of end-diastolic flow on Doppler flow studies of the umbilical artery or a biophysical profile of 2 or less
-- evidence on CT, MRI, technetium or ultrasound brain scan performed within 7 days of birth of diffuse or multifocal ischemia or of cerebral edema
-- abnormal EEG: low amplitude and frequency, periodic, paroxysmal or isoelectric

AND

3. The absence of an infectious cause, a congenital malformation of the brain or an inborn error of metabolism, which could explain the encephalopathy.

Multiorgan system dysfunction requires evidence of dysfunction of one or more of the following systems within 72 hours of birth:
-- Renal: oliguria or acute renal failure
-- GI: necrotizing enterocolitis, hepatic dysfunction
-- Hematologic: thrombocytopenia, disseminated intravascular coagulapathy
-- Endocrine: hypoglycemia, hyperglycemia, hypercalcemia, syndrome of inappropriate ADH secretion (SIADH)
-- Pulmonary: persistent pulmonary hypertension
-- Cardiac: myocardial dysfunction, tricuspid insufficiency.

Indicate severity:
Mild Moderate Severe

IF HIE is checked indicate severity: if the infant was diagnosed with hypoxic-ischemic encephalopathy, record the worst stage observed during the first 7 days of life based on the infant's level of consciousness and response to arousal maneuvers such as persistent gentle shaking, pinching, shining a light or ringing a bell:

Select **mild** (normal to hyperalert) if infant was alert or hyperalert with either a normal or exaggerated response to arousal.

Select **moderate** (lethargy or mild stupor) if infant was arousable but had diminished response to arousal maneuvers.

Select **severe** (deep stupor or coma) if infant was not arousable in response to arousal maneuvers.

Indomethacin (prophylaxis)
<24 hours PNA

Check if infant received indomethacin prophylactically for IVH prevention.

Intraventricular Hemorrhage Assessed

Check if infant had at least one cranial ultrasound performed on or before day 28.

IVH Status	Select the most severe grade: None — No subependymal or intraventricular hemorrhage Grade I — Subependymal germinal matrix hemorrhage only Grade II — Intraventricular blood, no ventricular dilation Grade III — Intraventricular blood, ventricular dilation Grade IV — Intraparenchymal hemorrhage.
Hydrocephalus, post hemorrhage, shunt required	Check if infant was hydrocephalic post IVH and required a VP shunt.
PVL Assessed (before 3 Weeks of Age) PVL Imaging Date PVL Imaging Outcome	Check if appropriate. Enter the imaging date, MM/DD/YYYY (e.g., 01/01/2004). Specify results .
PVL Assessed (after 3 Weeks of Age) PVL Imaging Date PVL Imaging Outcome	Check if appropriate. Enter the imaging date, MM/DD/YYYY (e.g., 01/01/2004). Specify results.
PVL Confirmed	Check **Yes** or **No**; check **Yes** if infant has evidence of cystic periventricular leukomalacia on cranial ultrasound. Cranial ultrasound must identify multiple small periventricular cysts. Periventricular echogenicity without cysts and/or a porencephalic cyst in the area of previously identified intraparenchymal hemorrhage **should not** be considered PVL.

GASTROINTESTINAL DATA

Anomaly - Omphalocele/Gastroschisis	Check if appropriate.
Anomaly - Tracheo-Esophageal Fistula/ Esophageal Atresia	Check if appropriate. e.g., congenital fistula-esophagobronchial/esophagotracheal, imperforate esophagus, absent esophagus, webbed esophagus, stricture of the esophagus.
Other	Check if appropriate, specify e.g., imperforate anus/rectum, stricture of anus/rectum, other malformations of the gastrointestinal system.
Isolated Perforation	Check if infant had a single focal perforation (not due to NEC) with the remainder of the bowel appearing normal.
Necrotizing Enterocolitis (NEC):	Check if infant had NEC diagnosed at surgery, at postmortem examination or clinically and radiographically using the following criteria: 1. One or more of the following clinical signs present: -- bilious gastric aspirate or emesis -- abdominal distention -- occult or gross blood in stool (no fissure) **AND** 2. One or more of the following radiographic findings present: -- pneumatosis intestinalis -- hepato-biliary gas -- pneumoperitoneum. **Do not check if the infant does not satisfy the above definition.**

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 - <u>Suspected</u> Culture Negative, Treatment Discontinued	Check if early onset sepsis was suspected but cultures obtained from blood or cerebral spinal fluid **on or before day day 3 of life** were negative, treatment discontinued.

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 **on or before day 3 of life.** Enter date(s), time (s) culture obtained and select the identified organism(s). NOTE: If more than 5 occurrences, record on additional sheet. The NICU Module accommodates any number of entries.
Sepsis: Nosocomial - Culture Positive (cultures obtained after day 3 of life)	Check if nosocomial sepsis was confirmed with a positive culture obtained from blood or cerebral spinal fluid **after day 3 of life.** Enter date(s), time(s) culture obtained and select the identified organism(s). NOTE: If more than 5 occurrences, record on additional sheet. The NICU Module accommodates any number of entries.
	Note: For Coagulase Negative Staphylococcus or other potential skin contaminants, check and record the date IF the following is true: **Coagulase negative staphylococcus or other potential contaminant is recovered from a blood culture obtained from either a central line or peripheral blood sample, and/or is recovered from cerebrospinal fluid obtained by lumbar puncture, ventricular tap or ventricular drain;** **AND** **One or more signs appeared of generalized infection (such as apnea, temperature instability, feeding intolerance, worsening respiratory symptoms or hemodynamic instability);** **AND** **Treatment occurred with 5 or more days of intravenous antibiotics after the above cultures were obtained. (If the infant died, was discharged, or transferred prior to the completion of 5 days of intravenous antibiotics, this condition would still be met if the intention were to treat for 5 or more days.)**

MISCELLANEOUS DATA

Anomaly-Abnormal Appearance	Check if appropriate, and specify.
Anomaly-Chromosomal	Check if appropriate, specify known results of chromosomal testing and other details.
Anomaly-Ear Nose Throat	Check if appropriate, and specify (e.g., micrognathia, cleft lip/palate).
Anomaly-Musculoskeletal	Check if appropriate, and specify (e.g., club feet).

Birth Related Trauma	Check if appropriate (e.g., visceral hemorrhage, subgaleal hematoma, depressed skull fracture, Erb's palsy).
Hydrops: Immune	Check if appropriate.
Hydrops: Nonimmune	Check if appropriate.
Other Diagnosis	Check if appropriate, and specify (e.g., hyperbili, dehydration, IDM, IUGR).
Discharge Planning Details	Enter discharge planning details.

CONSULTS / OTHER SERVICES DATA

Check for all consults or services involved in the care of the infant:

Cardiology	Cardiothoracic Surgery	Endocrinology	Ear Nose & Throat
Genetics	Gastrointestinal	Genitourinary	Infectious Disease
Metabolic	Neurology	Neurosurgery	Ophthalmology
Orthopedic	Occupational/Physical Therapy	Pulmonary	Surgery

Other (specify) _____