

**STATEWIDE PERINATAL DATA SYSTEM  
NICU High Risk Module**

**User's Guide for Data Collection**

[Revised: September 2008](#)

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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.

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.)
Hospital of Birth*	Enter 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.), Physicians Office
Birth Hospital Medical Record #*	Enter infant's medical record number at BIRTH hospital or first hospital infant is admitted to if not born at a hospital
Admission Post Discharge	Select for infants admitted after discharge from their birth hospitalization
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 hospital or other location), select Other Location (outborn).  <u>For infants admitted after discharge from their birth hospitalization:</u> 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)
If infant is from another NICU, indicate NICU hospital name	Select the name of the referring NICU from the drop-down list

## 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).
Sex	Enter infant's assigned gender select Male, Female, Unknown (ambiguous genitalia)
Plurality	Enter the total number of babies in <b>this pregnancy</b> ; (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 <b>Yes</b> if a Cord pH was obtained; check <b>No</b> 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:

estimate of gestational age  
 applicable number):

Select and record the **BEST**  
 from the hierarchy below (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 EDC or LMP  
 or  
 Enter integers for weeks and days based on Physical Exam

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)

## 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.

### 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 Check **Yes** if infant dies in the delivery room or any other location in  
(include all infants  $\geq 400$  grams) 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  $\geq 400$  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 enteral feeding; MM/DD/YYYY (e.g., 01/01/2004)

First Enteral Feeding Type

Check the type of feeding the infant received:

**Breast, Formula, or Both**

Formula includes all standard newborn formulas, premature formulas, and special formulas

FIRST Date Without IV Nutrition

Enter the first date (full 24 hours) on which infant no longer required intravenous nutrition; MM/DD/YYYY (e.g., 01/01/2004)

Full Enteral Feeding Type

Check the type of feeding the infant received:

**Breast, Formula, or Both**

Formula includes all standard newborn formulas, premature formulas, and special formulas

#### 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 NICU Disposition of the infant  
 Select: Discharged Home, Transferred Out (to another hospital or location), Expired, In House Transfer

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 not available in dropdown list

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

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, Formula, Both** or **None**.

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



## 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 <b>all</b> the following criteria are satisfied. <ol style="list-style-type: none"><li>1. Presence of meconium stained amniotic fluid.</li><li>2. Respiratory distress (any of the following: tachypnea, grunting, nasal flaring, intercostals retractions) with onset within 1 hour of birth.</li><li>3. A PaO<sub>2</sub>&lt;50 mmHg in room air, central cyanosis in room air or a requirement for supplemental oxygen to maintain PaO<sub>2</sub> &gt;50mmHg.</li><li>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.</li><li>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.</li></ol>
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/  
 (RDS) Check if infant has Respiratory Distress Syndrome  
 Hyaline Membrane Disease defined as:  
 PaO<sub>2</sub> < 50 mmHg in room air, central cyanosis in  
 room air,  
 or a requirement for supplemental oxygen to maintain  
 PaO<sub>2</sub> > 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.

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.

Nasal IMV's 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/minute)  
HIFI (HFOV, high frequency ventilator IMV rate >= 240/minute)  
Jet

Enter the date(s) the mechanical ventilation started and ended.  
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

Nitric Oxide

Check if Nitric Oxide was administered to the infant  
Enter start and end dates

ECMO (Extracorporeal Membrane Oxygenation/ECLS)

Check if the infant was treated with ECMO / ECLS;  
Enter start and end date

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

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)
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, hemiccephaly, 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)	<p style="text-align: center;">Check if infant was diagnosed with HIE as defined below:</p> <ol style="list-style-type: none"> <li>1. The presence of a clinically recognized encephalopathy within 72 hours of birth. Encephalopathy is defined as the presence of <b>3 or more</b> of the following findings within 72 hours of birth: <ul style="list-style-type: none"> <li>-- abnormal level of consciousness: hyperalertness, lethargy, stupor or coma</li> <li>-- abnormal muscle tone: hypertonia, hypotonia or flaccidity</li> <li>-- abnormal deep tendon reflexes: increased, depressed or absent</li> <li>-- seizures: subtle, multifocal or focal clonic</li> <li>-- abnormal Moro reflex: exaggerated, incomplete or absent</li> <li>-- abnormal suck: weak or absent</li> <li>-- abnormal respiratory pattern: periodic, ataxic or apneic</li> <li>-- oculomotor or pupillary abnormalities: skew deviation, absent or reduced Doll's eyes or fixed unreactive pupils</li> </ul> <p style="text-align: center;"><b>AND</b></p> </li> <li>2. Three or more supporting findings from the following list: <ul style="list-style-type: none"> <li>-- arterial cord pH &lt; 7.00</li> <li>-- Apgar score at 5 minutes of 5 or less</li> <li>-- evidence of multiorgan system dysfunction</li> <li>-- 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</li> <li>-- evidence on CT, MRI, technetium or ultrasound brain scan performed within 7 days of birth of diffuse or multifocal ischemia or of cerebral edema</li> <li>-- abnormal EEG: low amplitude and frequency, periodic, paroxysmal or isoelectric</li> </ul> <p style="text-align: center;"><b>AND</b></p> </li> <li>3. The absence of an infectious cause, a congenital malformation of the brain or an inborn error of metabolism, which could explain the encephalopathy.</li> </ol> <p>Multiorgan system dysfunction requires evidence of dysfunction of one or more of the following systems within 72 hours of birth:</p> <ul style="list-style-type: none"> <li>-- Renal: oliguria or acute renal failure</li> <li>-- GI: necrotizing enterocolitis, hepatic dysfunction</li> <li>-- Hematologic: thrombocytopenia, disseminated intravascular coagulopathy</li> </ul>

- 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

Check if appropriate

Fistula/ Esophageal Atresia 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 Surgically Confirmed (Treated)  
Clinically Suspected (Pneumatosis/portal air)  
Diagnosed by PostMortem Examination only

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) Type:	Check if appropriate  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 <b>on or before day 3 of life</b> were negative, treatment discontinued
Early Onset Sepsis - <u>Suspected</u> Culture Negative, Treatment Continued	Check if early onset sepsis was suspected, cultures obtained from blood or cerebral spinal fluid <b>on or before day 3 of life</b> were negative but <b>treatment continued for full course</b>
Early Onset Sepsis - <u>Confirmed</u> 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 <b>on or before day 3 of life</b>  Enter date(s), time (s) culture obtained and select the identified organism(s)
Sepsis: <u>Nosocomial</u> - 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 <b>after day 3 of life</b>  Enter date(s), time(s) culture obtained and select the identified organism(s)

## 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)	_____		