# THE CANADIAN NEONATAL NETWORK<sup>TM</sup>

# LE RÉSEAU NÉONATAL CANADIEN<sup>TM</sup>



# Abstractor's Manual

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# CHAPTER ONE: INTRODUCTION TO THE CNN

#### What is the Canadian Neonatal Network?

The Canadian Neonatal Network (CNN) is a group of multi-disciplinary Canadian researchers who collaborate on research issues relating to neonatal care. The Network was founded in 1995 by Shoo Lee, MBBS, FRCPC, PhD and now includes members from 29 hospitals and 17 universities across Canada. The Network maintains a standardized neonatal intensive care unit (NICU) database and provides a unique opportunity for researchers to participate in collaborative projects on a national and international scale. Health care professionals, health services researchers and health administrators participate actively in clinical and epidemiological outcomes, health services, health policy and informatics research aimed at improving the efficacy and efficiency of neonatal care. Research results are published in Network reports and in peer-reviewed journals.

#### Mission Statement of the CNN

"To be a network of Canadian researchers who conduct leading multi-disciplinary, collaborative research dedicated to the improvement of neonatal-prenatal health and health care in Canada and internationally".

# Specific Goals

- Establish a national network of multi-disciplinary Canadian researchers interested in neonatal-perinatal research
- 2) Establish and maintain a truly national neonatal-perinatal database and provide the infrastructure to facilitate collaborative research
- 3) Longitudinally study outcomes and variation in medical care that increases costs but does not improve outcomes. This is important because NICU care is one of the largest components of child health expenditures and exhibits large variations in mortality, morbidity and costs.
- 4) Develop innovative research methods that can lead to improvement in health and quality of healthcare.

#### Database

- 1) <u>Core Database</u>: The Network will maintain a core Network database. Institutional representatives and the Steering Committee decide policy concerning content and use of the database.
- 2) <u>Project Database</u>: Research projects may request utilization of the Network data acquisition system to collect project related data. Such requests will be approved by the Steering Committee. Access to such data will be limited to members of the research project. Expenses relating to such data acquisition will be the responsibility of the project researchers concerned.

# **CHAPTER TWO: BACKGROUND**

#### **Neonatal Intensive Care**

Newborn intensive care is a rapidly evolving area of medicine in which advancing technology and new treatment techniques have proven very effective in improving infant outcomes. There is constant innovation and introduction of new treatments, equipment and procedures. Despite this rapid progress, there remains a significant mortality and complication rate, particularly for extremely premature infants. It has become evident that there are marked differences in outcome between different Neonatal Intensive Care Units (NICUs). Furthermore, neonatal care is extremely costly, amounting to thousands of dollars spent for each day in the NICU. Due to wide variations in care outcomes, and to the extremely high cost of care it is crucial that both established and novel medical treatments for newborn infants be analyzed for effectiveness and cost-efficiency.

# **Evaluating Practices**

The effectiveness of many individual treatments (respirators, drugs, formulas, etc.) has been proven in clinical trials. However, when used in combinations, on different populations, or by less skilled clinicians, the effectiveness of these treatments in actual practice may vary. These variations in effectiveness or quality of care may be responsible for the observed variations in outcomes. If true, this presents an important opportunity to improve care, by identifying ineffective care practices.

One method for identifying the most effective practices is to compare the outcomes of patients who undergo different treatment strategies. This approach depends on comparing equivalent patients. For example, if two NICUs use different treatment strategies on babies with the same medical condition, but some babies started out sicker than others, there is no way to accurately assess whether the treatments were used effectively, and which of the treatments was most effective. To permit fair comparisons, it is essential to have an objective way to measure severity of illness.

#### The SNAP Score

SNAP (*Score for Neonatal Acute Physiology*) is an illness severity scoring system which sums up the worst physiological derangement in each organ system in the first 12 hours of admission to the NICU. This scoring system has been shown to be highly predictive of neonatal mortality and to be correlated with other indicators of illness severity including therapeutic intensity, physician estimates of mortality risk, length of stay, and nursing workload. SNAP provides a numeric score that reflects how sick each infant is. This scoring system is modeled after similar adult and pediatric scores, which are already widely in use.

#### The TRIPS Score

The *Transport Risk Index of Physiological Stability* (TRIPS) is an index which is used to assess changes in patient condition as a result of the transport process. TRIPS looks at four empirically weighed items: temperature, blood pressure, respiratory status and response to age appropriate stimuli. These items are compared just prior to transport, upon admission to the receiving NICU, and twelve hours following admission. TRIPS has been found to be a good predictor of NICU mortality and severe IVH risk. TRIPS is also important in that it can be used to help explain causes for a patient's change in status during transportation and from this new procedures to improve patient care during transport can be identified.

#### The NTISS Score

The *Neonatal Therapeutic Intervention Scoring System (NTISS)* is an index used to assess therapeutic interventions a patient is receiving at any time point during day 1 and day 3 of admission. It covers a wide range of pharmacological and non-pharmacological interventions provided during stay in the NICUs. NTISS has been found to be a good tool for identifying resource utilization and illness severity of patients. Because of data collection on TRIPS and SNAP scores, collection of NTISS is optional in this version of the CNN database.

# **CHAPTER THREE: DATA COLLECTION**

#### Data Collection

Data collection will be conducted by either medical chart review or prospectively collecting in real-time. Data collection should occur at the bedside both to maximize the amount of information obtainable (that is, having the ability to clarify confusing or incomplete chart entries by asking attending clinicians), and to save the time involved in tracking down medical records once the patient has left the hospital. In addition, the data collected will be entered directly into computers. Direct data collection combines the steps of data collection and data entry into one task, saving time and reducing the risk of human error in obtaining the data. The requirements for the new CNN application are as follows:

#### Software requirements:

- 1) Windows XP SP2 or later (Windows 2000 is not supported)
- 2) Access 2000/2003 or higher
- 3).NET Framework 3.5 SP1 (Freely downloadable software at http://tinyurl.com/5m4j75).

#### **Hardware Requirements:**

- 1) CPU speed of 2.0 Ghz or higher (Pentium 4, Core2Duo or AMD similar class CPU)
- 2) 512 MB Memory (1GB recommended)
- 3) Screen Resolution of 1024 x 768

#### Which Babies to Abstract

Abstractors are responsible for abstracting every eligible admission to the NICU. Eligible babies are babies who stay in the NICU for at least 24 hours OR who die/are transferred to another level 2 or 3 facility within 24 hours and all delivery room deaths of infants  $\geq$ 22 weeks gestational age. (Note: For purposes of this database, time of admission is defined as the time of the first set of recorded vital signs.) Once a baby has been admitted to your NICU, you will have ultimate responsibility for the data collection on that baby, regardless of outcomes or transfers. Please note once you identify an infant as Delivery Room Death on the first page in the field "CASE TYPE" you will only be required to complete a very small subset of information (Admission, Mother and Resuscitation screens only) before you will be able to validate the case successfully..

# Admission Tracking

Abstractors should check NICU admission log books and delivery room records daily for new admissions. It is crucial that every eligible baby be abstracted (see "Which Babies to Abstract" above). In order to not miss eligible babies it is best to stay current in your abstraction. It is important to stay on top of your abstracting because: 1) If something is unclear or confusing, you can ask the NICU staff questions and they are likely to know the information. If you wait too long after the baby's discharge, they may not have accurate recall of the needed information. 2) Tracking down medical records once the baby leaves the unit can be time consuming and difficult. It also runs the risk that records may be lost. You may try to arrange with your Institutional Representative to have your NICU staff hold charts of discharged babies for an extra day thus giving you the opportunity to obtain the discharge data before chart removal. If this is arranged, you should check for charts of discharged babies first thing each day to minimize the delay in chart removal.

#### Data Content

Data collection consists of five major categories of information.

- 1) **Registration Information:** Background information such as birth weight, gender, gestational age and obstetric variable will be recorded on admission to the NICU.
- 2) Illness Severity: Illness severity will be recorded using SNAP, a physiology based measure.
- 3) **Transport Information:** Transport details and physiological details as a result of transport situations will be recorded after 12 hours of admission.
- 4) **Diagnosis and Procedures:** Details about various diagnoses and procedures patients underwent during their stay in NICU.
- 5) **Discharge Abstract:** At discharge, abstractors will record a number of outcome variables including discharge date and place and support.

# General features and use of the new CNN application

Compared to the old CNN application, the new CNN application has numerous unique features to facilitate data entry and enhance abstractors' productivity. Some of the major improvements are listed below:

- 1) Brand new, more user-friendly data entry interface
  - Intuitive side navigation panel for more efficient data access and updates
  - Dropdown menus and toolbar for easier menu access
- 2) Improved Search Engine
  - New easily accessible search panel with more search fields as criteria
  - Patient list view for browsing search results
- 3) Improved data entry validation
  - Calendar popup date entry, masked edit boxes used to prevent errors at point of entry
  - Floating error message balloons for unobtrusive field validation
  - Validate Case screen with easily understandable error messages
- 4) Record Activation / Deactivation feature
  - Activate / re-activate records instead of using the free-text Comments field
- 5) Unlock record / Log out user feature
  - User can unlock the locked cases and log out users if the application exits suddenly due to PC/application crash
- 6) Improved Upload/Update functions
  - More user-friendly database upload and application updates
- 7) Integrated Help system
  - The CNN manual is now integrated with the CNN application and is automatically updated with new manual revisions during application updates

The following are two examples of the general data entry workflow, one for creating a new case and the other for searching and updating an existing case.

#### **Creating a new CNN case:**

- 1) Go to File-New Case or click on the New Case toolbar icon
- 2) Enter the hospital record number and admission date/time.
- 3) User enters admission info in the admission screen that opens up
- 4) Browse through the screens using the left navigation menu (Mother, Resuscitation, Transport...etc) and enter the information required
- 5) Tick the Reviewed checkbox once all the fields have been reviewed by the user
- 6) Go to Validate Case screen to validate the whole CNN case and its status will change to Validated if successful

#### **Searching and Updating existing cases:**

- 1) Go to the search panel, enter the search criteria and click Search
- 2) Select the record you want to update by double-clicking on the row in the patient list search results box
- 3) Update the fields as required on the admission screen that opened up
- 4) Browse to any of the other screens to do any updates required
- 5) If the update for the current case is done, select another case to update in the patient list search results box or perform a new search

# Scoring Periods

**SNAP:** SNAP is scored on the day of admission for the first 12 hours following admission. Where the time of admission is defined as the time the first vital signs are recorded in the NICU.

Day 28: Day 28 data should be recorded as the first data noted after midnight on day 28 of life to 23:59 (24 hours).

Week 36: Week 36 is 36 weeks post conception (gestational age plus weeks of life). It is computed using the gestational age that is calculated from the best available information on the first page. Please note that if the baby is born at 32 weeks gestational age, the week 36 data will be identical to the day 28 data. Therefore, this data should not be collected if the gestational age is 32 weeks or more, or if the patient dies or is transferred to a level 1 nursery prior to week 36. Data should be recorded by using the first value noted after midnight on the first day of week 36 to 23:59 (24 hours).

# Missing SNAP Scores

If you are missing information from the scoring period either because a flow sheet is missing or because the baby was transferred out, or died during the scoring period complete the SNAP screen using the information that is available, leaving the rest of the fields blank.

#### Deaths

For all babies who are admitted to the NICU and die you will need to verify the cause of death by a) asking the attending physician and b) checking the death certificate to see what is listed. Note that the autopsy report may not be completed for several weeks. If a baby dies during the SNAP scoring period you should abstract the score regardless of how many hours of the scoring period the baby lived. Please make a note in the comments box for these cases indicating the length of time the score was based on. You should also talk to your Site Investigator about getting a log of all *delivery room deaths of babies greater than or equal to 22 weeks gestational age (live born babies only)* from delivery room or Pathology. These include babies who die in the resuscitation room or are born following induction of labour for termination purposes and then die in other places in the hospital shortly after birth. Intrauterine deaths or stillbirths are not included. Please enter these infants in the database. We need only basic information for such patients.

# Rounding

Most numeric entries need not be rounded (head circ, temp, pH can all be entered as a decimal). However, some numeric entries that need to be rounded for entry should be rounded as follows: 2.4 and smaller should be rounded to 2;

2.5 and larger should be rounded to 3. Generally, if values are listed as "<", as in "<2", score as one less than what is written, e.g. <2 would become 1 (or 1.9 in the case where an integer is not required).

#### Readmissions

For those sites just beginning data collection; a "readmission" on the patient log/admission screen can only be scored if this patient has been entered previously in the database. Therefore, any patient who is readmitted to your unit and whose initial admission is prior to the data collection start date would be scored as either inborn or outborn AND not a readmission (given that their initial visit was not recorded in the database) and their case type set to "3 – Readmission from 2009".

For all readmissions use the same record number (hospital chart number) and indicate which readmission number it is. This is different from the old application where "a" or "b", "c"..etc was appended to the record number for readmissions.

# Patient Unique Identifier (Patient UI)

Since the CNN sites have separate local databases, the patient Unique Identifier field was created to uniquely identify a patient in CNN when the baby moves across different sites. That ID will be used to link the different admission records entered in the separate local site databases when they are consolidated.

When a new admission is created, there is a unique id generated under the Patient UI field. The following is the workflow that all site abstractors MUST FOLLOW to make sure that the patient UI number remains consistent across all the sites.

- 1) A baby is born at CNN site X and gets admitted to CNN with an autogenerated patient UI number A
- 2) The baby then gets admitted to CNN site Y and a patient UI number B is automatically assigned.

The abstractor at site X will need to let the abstractor at site Y know of the patient UI number A and the latter should update the baby's patient UI from B to A.

The guideline is that the hospital with the first CNN admission is the one which propagates the originally created baby patient UI to the subsequent sites and the abstractor at the transferring site should inform the other abstractor within a reasonable amount of time (for example, within a couple of days to a week maximum) for the patient UI update to take place.

If you are entering a baby who was entered in the previous CNN database and who is now being re-admitted, select Case Type #3 on the admission screen, and please enter the patient UI from the previous database into the appropriate field in the current program.

# Multiple Births (Twins, Triplets...)

For cases where a mother has multiple babies, when the second baby is entered into the application, there is a feature to autofill the mother information automatically since they have the same mother. If the "Births this pregnancy" value is more than 1, the ">1 Births" button will appear. When you click on it, a popup window will appear and you can type in the record number of the first baby admission already in the database. The case id, name and date of birth information for the existing baby record for the multiple birth case will be displayed for verification purposes. When you click on OK button, the mother information of the current baby will be autofilled. The retrieved record will be displayed if the "Birth This Pregnancy" field value matches the current baby record. The Date Of Birth retrieved will be in red if it does not match the current baby record to alert the abstractor that the baby from which the mother info is going to be autofilled may be incorrect. Please refer to the "Birth This Pregnancy" field below in the Admission Screen section for a screenshot of the popup.

# Missing Values

Note that you need not record something for each data item when asked, except when mandatory to case validation. If the information asked for is unavailable please leave the associated field blank or indicate that it is unknown. In previous versions of this application missing values such as "99 or 999 etc." were noted, but this has now been replaced with "unknown" and "N/A" options.

#### Data Grids

The new CNN application employs the use of data grids throughout the screens (Diagnosis/Procedures; Cultures/Transfusions; Medications). If errors in entry are made, rows can be deleted in their entirety by clicking on the grey area to the left of the first column of the entry you wish to delete. Once selected, pressing "Delete" on your keyboard will clear the row from the dataset and move remaining entries up.

## Glossary

THE MEDICAL GLOSSARY IN THIS VERSION OF THE CNN MANUAL HAS BEEN REMOVED. PLEASE REFER TO ONLINE MEDICAL DICTIONARIES (SUCH AS <a href="http://www.nlm.nih.gov/medlineplus/mplusdictionary.html">http://www.nlm.nih.gov/medlineplus/mplusdictionary.html</a>) IF YOU HAVE QUESTIONS ABOUT MEDICAL DEFINITIONS.

# **CHAPTER FOUR: ERROR CHECKING**

# Computer data checks

The computer program has several error checking systems in place. At a primary level, the program performs error checks during data entry, to help ensure accurate data capture. For instance, there are checks for "reasonableness". For example, if you entered '66:66' as a value for time, the computer will generate an immediate error message prompting you that this is not a valid entry, and will require you to change this value before proceeding. At a secondary level, once you have completed an entire patient file and wish to submit your data a final error check (validation) will be run. A third error check occurs after your data has been submitted to the Coordinating Centre (CC), in which you may be contacted by the CNN Coordinator to confirm any unusual entries. If you enter something unusual, please write an explanation in the "comments" section to save the time of rechecking the chart. If you receive an error message that is not self-explanatory, contact the CC for advice.

#### Abstractor checks

Some data items are not easily checked by the computer. It is crucial that everything you enter into your computer makes sense to you. If it doesn't, please ask questions of the NICU staff to protect the data integrity. In addition, please read through each data screen before closing it to make sure you have filled in all the information correctly.

#### Record Deactivation

In the old CNN, whenever an admission record was entered wrongly or was invalid, abstractors wrote "To Delete", "To Filter", "Pls Ignore" or similar notes under the Comments field. This made identification of those invalid cases (for annual data cleanup and CNN annual report generation) difficult as the Comments field is free-text.

A new "Record Deactivation" feature has been added in the new CNN application to deactivate admission records that are invalid.

Please **DO NOT** enter "To Delete", "To Filter", "Pls Ignore" or similar words under the Comments field for the new CNN application, use the Record Deactivation feature instead.

# Abstractor organization

It is important for data abstractors to be organized to help alleviate errors and missed or overlooked data. In order for the CC to determine the difference between missing data that is unavailable from the chart versus data that may simply have been overlooked by the abstractor it is crucial that the abstractor enter appropriate values. Whenever possible, a blank space should be left any time a data field cannot be completed because the information is not directly noted or cannot be inferred from information anywhere in the patient's complete chart. Abstractors are also advised to keep a separate excel file to keep track of which patient records are complete (following discharge) and which records are still missing information and need to be followed up on. The excel file can also be a way to record which infants have had name changes in order to avoid confusion or duplicate entries. Please note that when babies are transferred to other hospitals it is the responsibility of the first hospital's data abstractor to provide the UI to subsequent hospital's data abstractor in a timely fashion (within 3 weeks of transfer to a subsequent facility) so that information on a patient can be linked appropriately. In the Help menu there is a link to the CNN website where you will be able to find list of abstractors and site investigators and their contact details. There is also a listing of site investigators in Appendix VII. Please use these tools to contact the correct person. If you need to talk to the CNN Coordinator or Database Programmer for computer related issues, their contact details are also provided on the CNN website.

# Customizability of the CNN Application

The new CNN application allows users to select from various settings in order to personalize the application environment. To access the settings dialogue window, go to the Tools menu on the upper border of the application and select "Settings...". Here you can customize the Patient Chart, the Search settings, the default Inborn and Outborn Hospital and the database file location. The Patient Chart customization allows you to change the colours of the Patient Chart grid and to personalize the vertical highlight bar. You can customize default search settings by selecting Date to reflect either Date of Admission or Date of Entry Creation, customize how far back to search, and the status of the cases that will be retrieved. By default, the database file location is the application installation folder, which you may choose to change depending on your local organizational needs. You can restore default settings on all tabs by clicking on the "Clear All" button at the bottom of the Settings window. For more information on these features go to General Database Use on page 12.

# CHAPTER FIVE: CONFIDENTIALITY AND PROFESSIONALISM

# Confidentiality

There are several levels of confidentiality that must be maintained. Firstly, the data in the computer represents personal information about patients. To maintain full confidentiality, the computer will encode all information from the medical chart that identifies the patient before it is transmitted to the Coordinating Centre (CC). The CC will be able to identify patients by their CNN Case ID number, but only the Data Abstractor at individual sites will be able to match that number to a specific patient. Secondly, the SNAP can be used to compute a risk of death. However, the predictive accuracy of this estimate has never been tested. Finally, please ensure that the Research Ethics Board of your institute has approved the CNN data collection. Feel free, however, to answer any questions parents or clinicians may have about the general purpose of the data collection.

For data confidentiality and accountability, for the new application, each abstractor will be issued a user id and password, only known to him/her to log in to the application. Every record created or updated using a given user id will be marked in the backend database with that user id and the created/updated date. This audit trail information can be used for security purposes as well as for improving CNN data entry and data quality. This is different from the old CNN application, where one database password was used and shared by all.

Please also note that the mothers P.H.N. will only be kept on your local datasets and will not be transferred to the CNN Coordinating Centre upon upload.

#### Professionalism

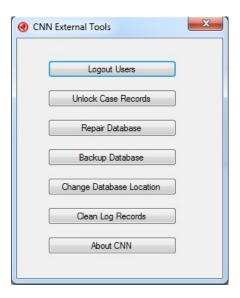
It is important that you maintain a professional image while working in the NICU. This includes making sure you are not disruptive of parents visiting their sick babies, of clinicians caring for the babies, or of any other NICU routines. Your dress should be professional and your appearance neat at all times you are working, even when working evening or weekend hours. In addition, please try to keep your voice low and your behaviour calm so as not to disturb any sensitive babies.

#### NICU staff interactions

The NICU staff is often very busy caring for the babies. They are also an excellent resource for information on specific babies or specific medical terminology. In your interactions with the staff, it is important to ask the bedside nurses before using the medical chart, to keep the chart in the immediate area and to make sure the nurses know where to locate the chart if they need it. In addition, be sure that your presence is not interfering with the nurses' care of patients.

# **CHAPTER SIX: CNN Application - External Tools**

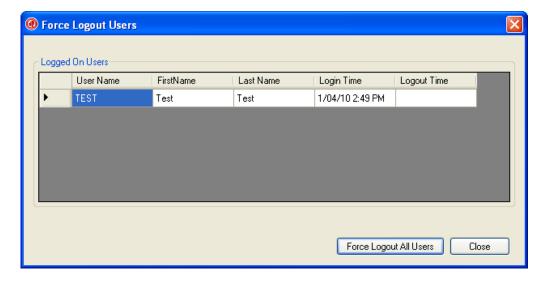
The CNN Application has two tools that are used outside of the application itself. The two tools are "Logout Users" and "Unlock Case Records".



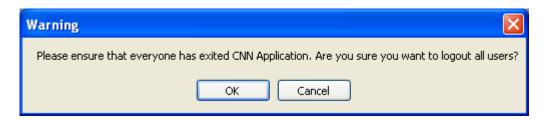
#### **Logout Users**

The "Logout Users" external tool is used when a user continues to be logged in to the CNN Application despite the application having been closed. This normally occurs when the application is closed abruptly due to a power failure or an application crash.

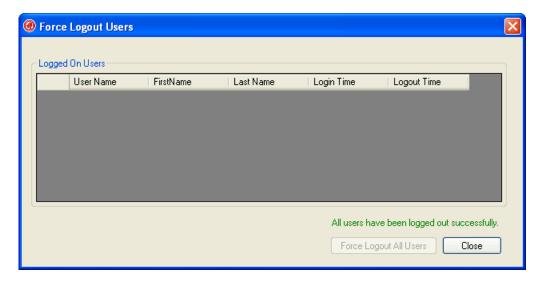
1. Click on the "Force Logout All Users" button.



2. Make sure that the CNN Application is not running and click on the "OK" button.



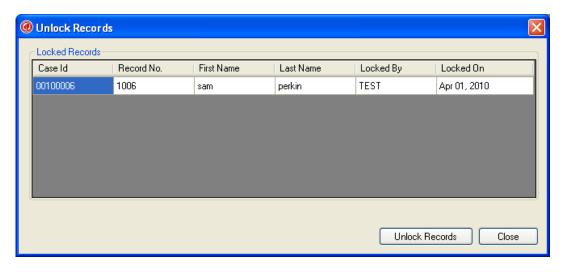
3. A message will appear stating that the users have been successfully logged out. Click the "Close" button to exit the tool.



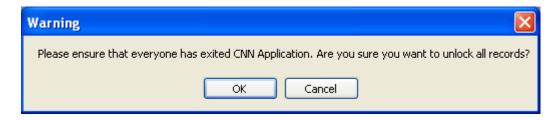
#### **Unlock Case Records**

A patient case is normally locked for other users when one user is currently accessing it. This is done to prevent two users from editing the same record and potential clashing. This tool is used when a patient case continues to stay locked despite the fact that no user is accessing the case. This normally occurs when the application is closed abruptly due to a power failure or an application crash.

1. Click on the "Unlock Records" button.



2. Make sure that the CNN Application is not running and click on the "OK" button.



3. A message will appear stating that the users have been successfully logged out. Click the "Close" button to exit the tool.

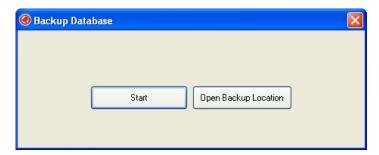


#### Repair Database

Database files can grow quickly as you use them, sometimes they would impede performance. They can also occasionally become corrupted or damaged. You can use the **Repair Database** in CNN External Tools to prevent or fix these problems. Please make sure no user is logon to the CNN application before use this feature.

#### **Backup Databse**

The "Backup Database" tool is used to back up the database. Click on "Backup Database" button to open up a new window where you can "Start" the back up process or find the location of the back up file with "Open Backup Location".

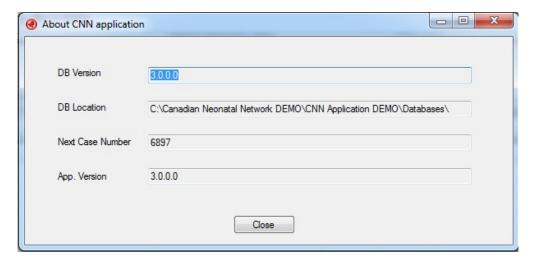


#### **Change Database Location**

Select this tool to change location of the database when the database file path is changed

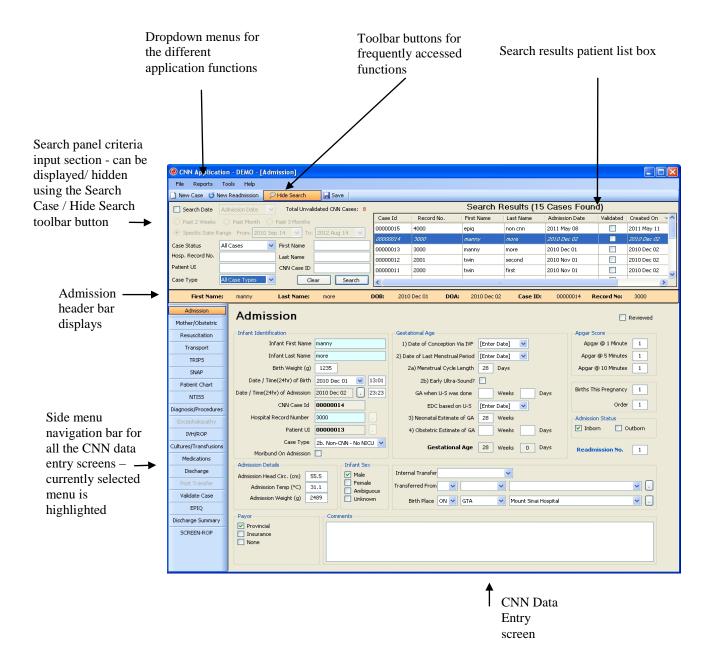


# **About CNN Application**



# **GENERAL DATABASE USE**

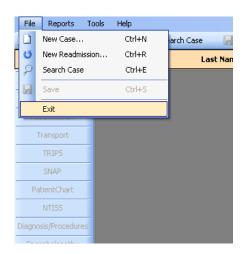
#### Overview of new CNN user interface

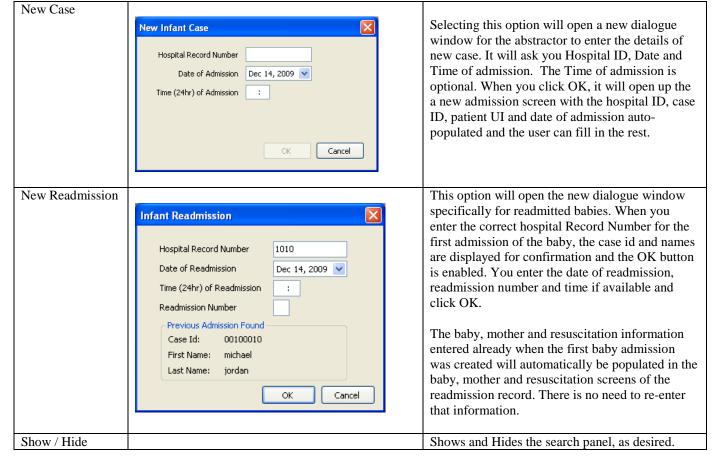


#### Application Menu Items



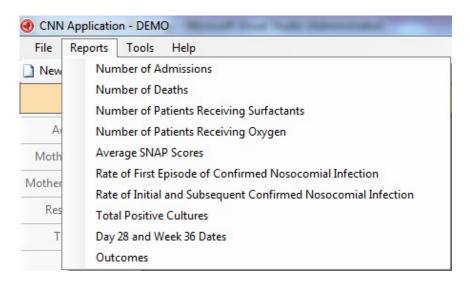
#### **File**





Search	You can hide the search panel to have a larger viewing area for the screens without the need to scroll.
Save	Select this option to save your input.
Exit	Select this option to exit the system. Exiting the application will automatically save any entered data.

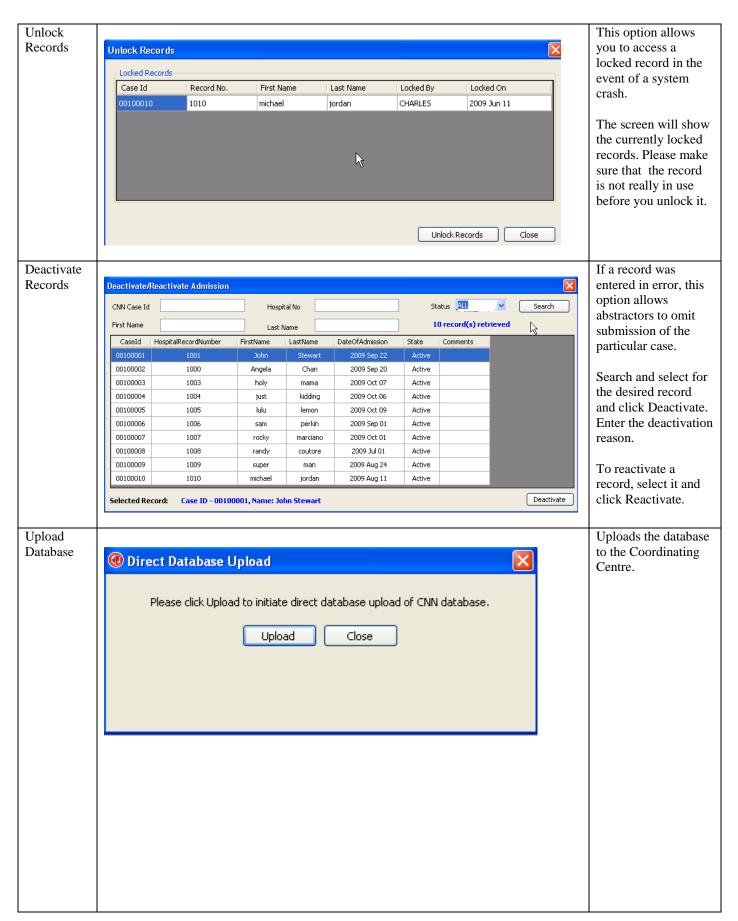
# Reports

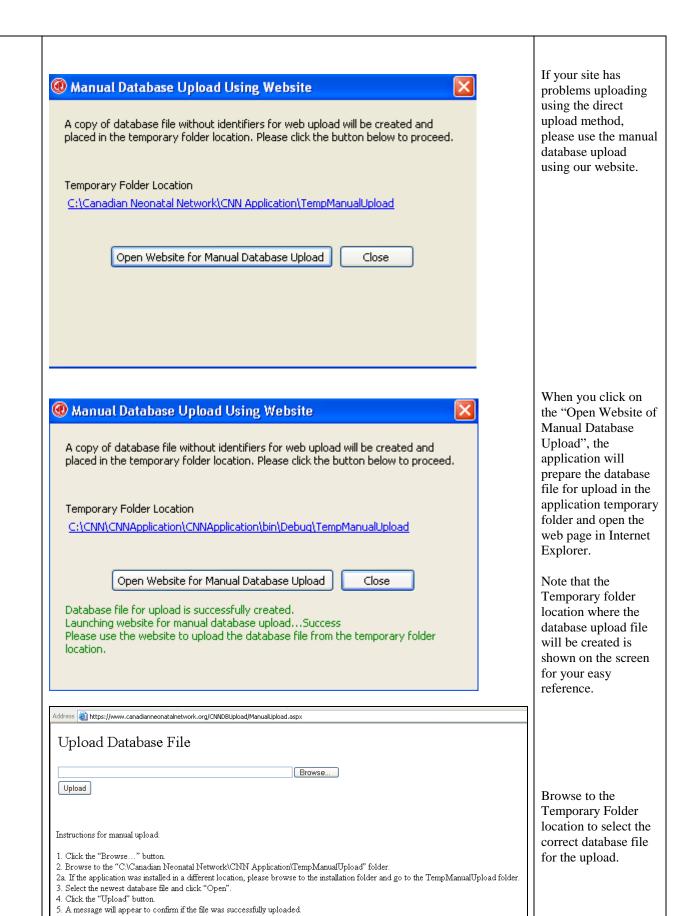


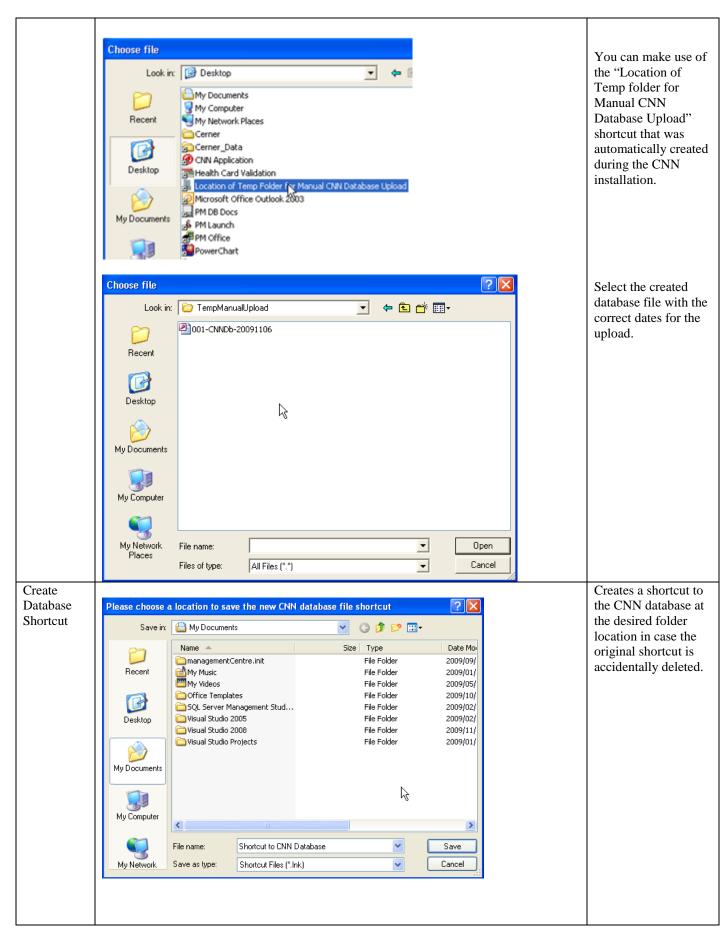
Number of Admissions	Includes Validation Status; report output includes
	hospital record number
Number of Deaths	
Number of Patients Receiving Surfactants	Measures time from date of birth
Number of Patients Receiving Oxygen	
Average SNAP-II and SNAPPE-II Scores for Patients	
Rate of first episode of confirmed nosocomial infection in	
a given time period	
Rate of initial and subsequent confirmed nosocomial	
infection in a given time period	
Total Positive Cultures	
Day 28 and Week 36 Dates	
Outcomes	Query all babies in the database with mortality or
	major morbidities for two calendar years. Report
	is based on local data only and without taking
	transfers into account.

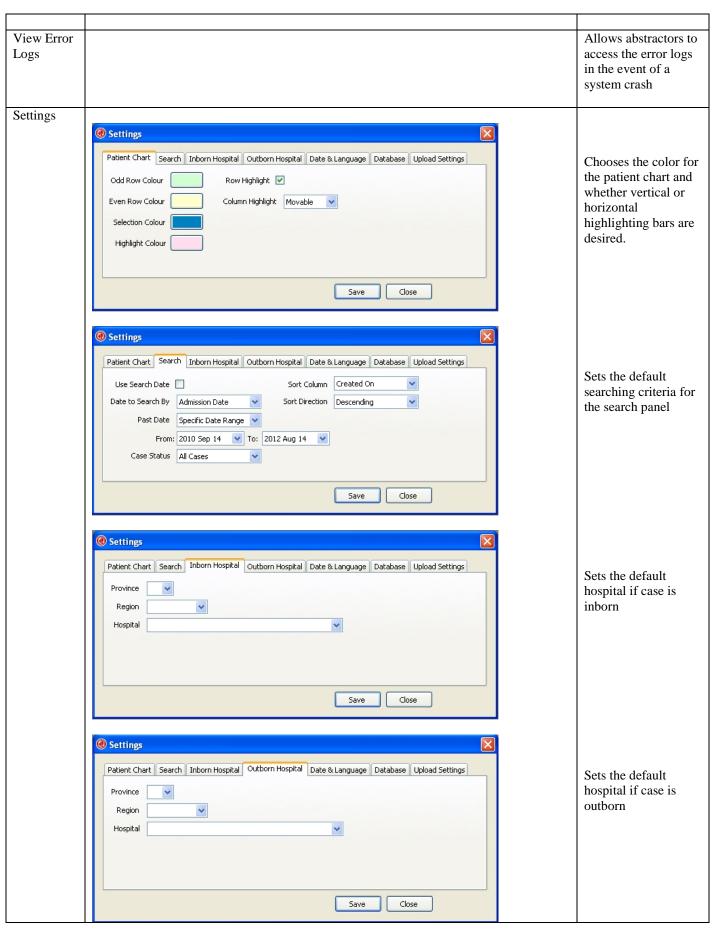
# Tools

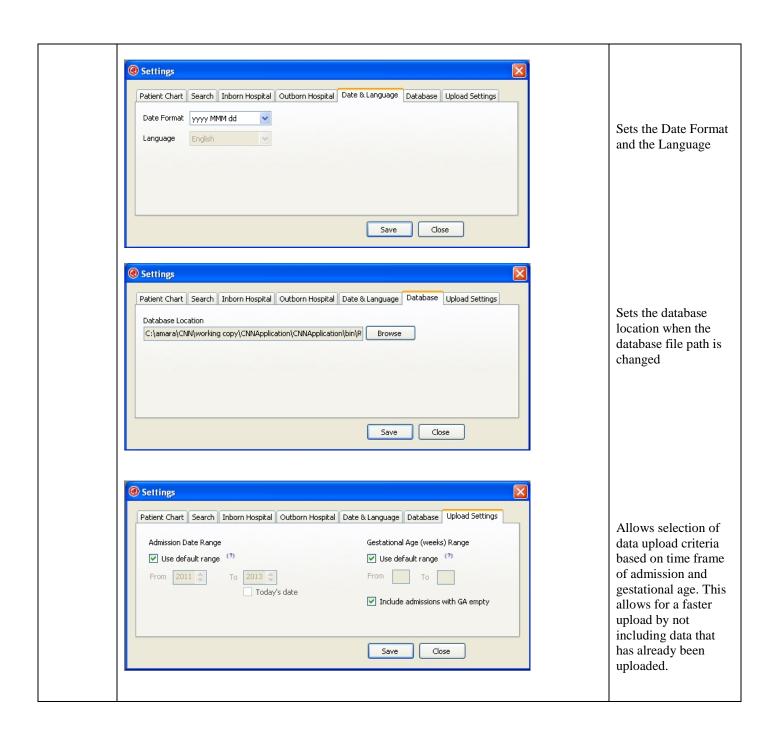


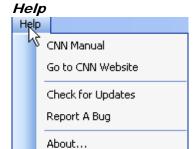






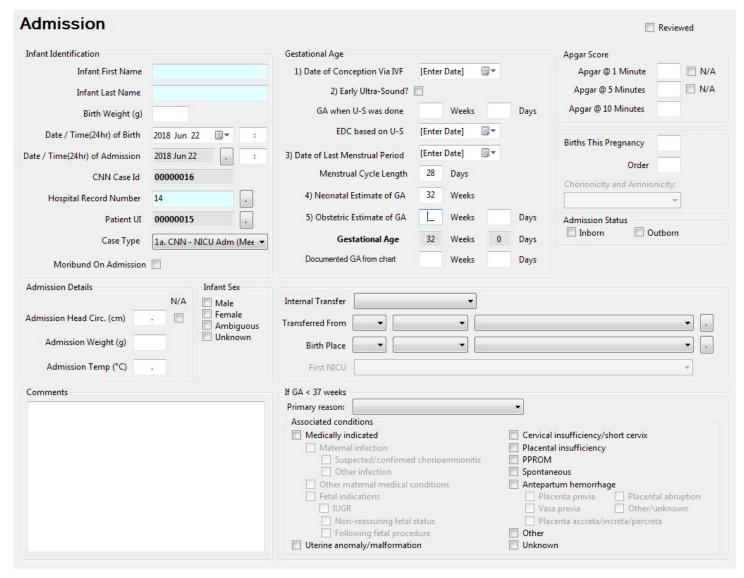






CNN Manual	Access the CNN Manual for reference (section
	anchors pending)
Go To CNN	Access the Canadian Neonatal Network TM website
Website	for reference
Check For	Go to CNN Website Updates download page
Updates	
Report A Bug	Go to CNN Bug Reporting / Feedback website
About	Allows users to view information about the
	application version

#### **SCREEN 1: ADMISSION SCREEN DEFINITIONS**



Abstractors are responsible for abstracting every eligible admission to the NICU. Eligible babies are infants who stay in the NICU for at least 24 hours, who die/are transferred to another level 2 or 3 facility within 24 hours, and delivery room deaths of infants  $\geq$ 22 weeks gestational age. (Note: For purposes of this database, time of admission is defined as the time of the first set of recorded vital signs). Please include data occurring in the resuscitation room provided that the infant is afterwards ADMITTED TO THE NICU.

Record only patient data relating to the specified admission to your NICU. You are not to record treatments/ resolved diagnosis provided at another hospital unless specific services that are not provided at your institute such as surfactant administration, PDA ligation, ROP Surgery for which infant was temporarily transferred to another facility and returns back in a reasonable period of time depending upon procedure (this should be individualized as to the procedure – PDA ligation baby if stays for <48 hours, ROP surgery <24 hours, Surfactant administration <24 hours etc.) Please use your discretion as to whether patient stayed longer than expected and how likely is that the other NICU will initiate data collection during the period infant was in other NICU.

#### **INFANT IDENTIFICATION**

Infant First Name	First name(s) of infant as recorded on the medical record. Do <i>not</i> type in "Baby" "Boy" or "Girl" or their
	abbreviations. If the infant is not given a first name upon admission to the NICU leave this field blank, you
	can come back to it and enter it later. If the infant has still not been given a first name upon discharge, simply
	leave this field blank.
Infant Last Name	Family name of infant as recorded on the medical record. If hyphenated or double name, record both. <i>If the</i>

	baby has a change of last name, do not record the change here or in the comments box. However, you may want to note the change for yourself elsewhere for future reference.
Birth weight	Weight in <i>grams</i> at birth as recorded in birth hospital. If birth weight is unavailable, use the first weight taken
	up to 24 hours of life. If birth weight is only listed as an estimate, record the estimate. If weight was recorded
	after 24 hours and an estimate was used during first 24 hours, please record estimate (mandatory field)
Date of Birth /	Date of birth according to obstetric and/or admitting records. Enter by selecting from the calendar displayed
Time of Birth	or by typing in the date in the format YYYYMMDD. If date of birth is unknown leave the field blank. Enter
	time of birth in <i>military time</i> (24 hour clock). If infant is born at midnight, record as 00:00 (where midnight
	(00:00) is the first minute of a new day; for example: 23:59 on Jan 3 <sup>rd</sup> and 00:00 on Jan 4 <sup>th</sup> is 1 minute later).
Date of Admit /	Date of admission to the study NICU. This may be different than date of birth for late admissions or out-born
Time of Admit	babies. Auto-populated from initial screen and should not be changed carelessly as this will clear the patient
	chart. Time of admission is defined as the time of first vital signs (at least one vital sign) recorded in the
	NICU. Do not include time in transport for out-born infants, or time in the delivery room for inborn infants.
	Write time of admission in military time. If time of admission is midnight record as 00:00 (mandatory field).
CNN Case ID	This is an auto-generated Case Identification number. It uniquely identifies a baby admission record in CNN.
	You do not need to enter any data in this field. <i>All screens are linked via this number</i> (mandatory field).
Hospital Record	Medical record number of the infant at the study hospital. When a patient is <i>readmitted</i> simply use the same
Number	record number and indicate the readmission number in the field that is displayed on the right hand side. To
	change this number from the one previously entered, click the button on the right of the field and proceed as
	instructed (mandatory field).
Patient UI	Patient Unique identifier (UI) number is assigned automatically by the program. No data entry required. It is
	the unique identifier for a patient and is used when transferring patients between hospitals. To change this
	number from the one previously assigned, click the button on the right of the field and proceed as instructed. Patient UI can be reset to its original value, if necessary.
Case Type	There are four types of patients collected under this screen. (1a) CNN / NICU admission – which will be the
case Type	commonest and default regular option (1b) delivery room death - delivery room deaths of babies greater than
	or equal to 22 weeks gestational age (live born babies only). These include babies who die in the
	resuscitation room or are born following induction of labour for termination purposes and then die in other
	places in the hospital shortly after birth. Intrauterine deaths and stillbirths are not included. (2a) Non-CNN /
	NICU admission not meeting CNN criteria - Certain sites collect babies in the database who are not eligible
	for CNN, such as short stay babies; (2b) Non-CNN / non-NICU admission – admitted to other hospital unit;
	(2c) Non-CNN / non-NICU admission – not admitted to our hospital; (3) Readmission from 2009
	(mandatory field)
Moribund on	A patient will be classified as moribund at admission if patient is receiving only comfort care, without
admission	intubation, mechanical ventilation, pressor treatment, or cardiac compressions (mandatory field).

#### **GESTATIONAL AGE (APPEAR IN ORDER OF ACCURACY)**

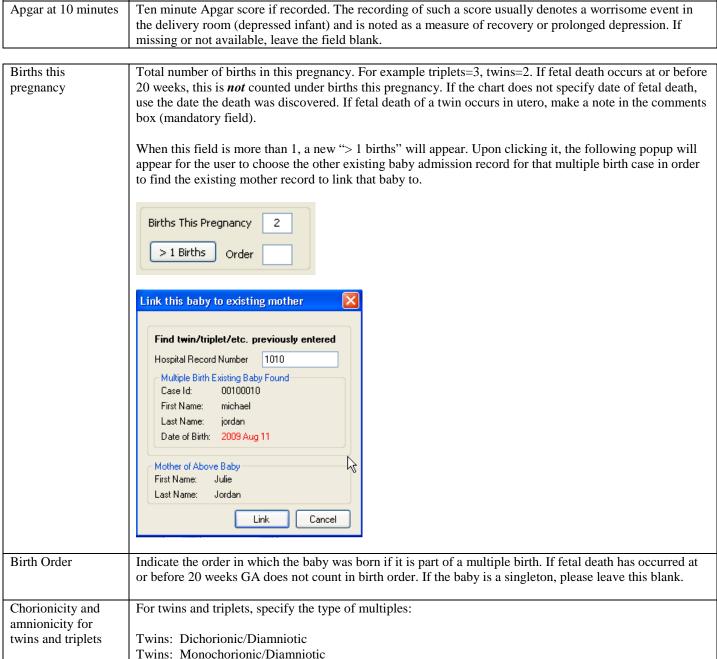
Note that this is a change from the previous CNN application. This program is set in such a way that it will calculate GA based on the best information that is available. Abstractor will complete as **much information available from charts as** they can, even if the dates or values in the chart are estimates. Please leave field blank if information is not available. If the Neonatal and Obstetrical estimated GA is reported as weeks + then just report weeks and leave days as zero. If Neonatal estimation spans more than one week enter earlier estimate (i.e. if GA is estimated as 30-31 weeks enter 30 weeks and zero days). GA refers to gestational age at BIRTH - and NOT the Corrected GA

Date of conception	If the date of conception is available in cases of in-vitro fertilization (IVF) pregnancy, enter the date in this
via IVF	field.
Date of last	Enter from maternal chart or history the date of last menstrual period.
menstrual period	
Menstrual cycle	Enter if this information is available. This field will contain the default entry of 28 days.
length	
Early Ultrasound	Click this field if mother had early ultrasound done. Early is defined as any ultrasound prior to 24 weeks.
GA when US was	If there was an early ultrasound examination recorded, enter what was the estimated gestational age based
done	on such an early ultrasound examination.
EDC based on US	Enter estimated date of confinement (delivery) based on the early ultrasound mentioned above. Note that
	this field is <b>not</b> Estimated Date of Conception.
Neonatal estimate of	Enter the estimate based on neonatal assessment as to how many weeks gestational age infant appears,
GA	generally by the Ballard or Modified Ballard examination. If there is no Neonatal estimate listed in the

	chart but the baby is referred to as a 'term baby', enter 40 weeks. (In weeks only)
Obstetric estimate of	Enter obstetric estimate of GA here in weeks and days.
GA	
Gestational Age	This field will be automatically populated based on input from the other fields. You do not need to enter any
	data here. Check that the value generated in this field is within a reasonable range of the best estimate of the
	infant's gestational age according to the patients chart. If there is a discrepancy, recheck data entry above.
Documented GA	Enter the gestational age as documented from chart.
from chart	

#### **APGAR SCORE**

Apgar at 1 minute	One minute Apgar score. Select "N/A" if the value is missing or not available. Mandatory field unless "N/A" is checked.
Apgar at 5 minutes	Five minute Apgar score. Select "N/A" if the value is missing or not available. Mandatory field unless "N/A" is checked.
Apgar at 10 minutes	Ten minute Apgar score if recorded. The recording of such a score usually denotes a worrisome event in the delivery room (depressed infant) and is noted as a measure of recovery or prolonged depression. If missing or not available, leave the field blank.



Twins: Monochorionic/Monoamniotic Twins: Unknown or other type
Triplets: Trichorionic/Triamniotic triplets Triplets: Monochorionic/Diamniotic twins pair with 'singleton' (also Dichorionic/Triamniotic) Triplets: Monochorionic/Monoamniotic twins pair with 'singleton' Triplets: Unknown or other type
Chorionicity/amnionicity information is not collected for higher order multiples. This field is enabled only if the number of births for this pregnancy is 2 or 3.

# **ADMISSION DETAILS**

Admission status at the study hospital. Score as inborn or out-born (transferred in). If out-born, specify the external transfer location in the "transferred from" field. If a patient is born at your hospital, discharged home a couple of days later (without admission to the NICU) then admitted to the NICU from home this is considered an " <i>inborn late admission</i> ". Score simply as inborn.
If a patient is discharged to another hospital for 24 hours or less for surgery or other medical treatments not provided at your hospital, then this does <i>not</i> count as a readmission. For patients transferred out longer than 24 hours, you will need to begin a new data set and consider this now a readmission (mandatory field).
The first Occipito-Frontal Circumference (OFC) (Head Circumference) measured after admission, as noted in the physician or nursing notes. Record in cm. If discrepancy between two measurements, select the measurement made by the nurse. Select "N/A" if the first recorded head circumference is after the first 72 hours of admission, or if value is not available. Mandatory field unless "N/A" is checked.
Body temperature in Celsius as recorded at admission to the study NICU. <i>Record the first temperature listed within five hours of admission</i> . If the first recorded temperature is after 5 hours of admission leave the field blank. For readmissions, record the temperature at the time of this second admission to the study NICU. Use axillary or rectal, but not skin probe temperatures (temperature of the baby taken by the incubator). If the temperature is recorded as "<36" score as 35.9.
Weight in grams as recorded at admission to the study NICU. When no admission weight is recorded – take birth weight as admission weight if baby was admitted on the first day after birth AND if baby was admitted after the first day and not weighed on admission, take weight measured in the first 24 hours after admission. If no weight is taken in the 24 hours following admission enter estimated weight on which treatment is based (mandatory field).
Record sex of infant. If sex is listed as ambiguous, enter it as such; however, if later baby was identified as Male or Female, correct it before final submission. If not listed or unknown, select "unknown" (mandatory field).
Indicate from which department within your hospital the baby was transferred, if applicable. This field is optional and should only be used by sites that wish to have this data. The list of selectable items are the following.
<ol> <li>PICU/PCCU (Pediatric Intensive Care Unit / Pediatric Critical Care Unit)</li> <li>L2N/SCN (Level 2 Nursery / Special Care Nursery)</li> <li>Operating Room</li> <li>Outpatient Clinic</li> <li>Emergency Department</li> </ol>
<ul> <li>6. CCU/CCCU (Critical Care Unit / Comprehensive Cardiac Care Unit)</li> <li>7. Labor &amp; Delivery</li> <li>8. Mother/Baby Unit</li> <li>9. Pediatric Ward</li> <li>10. Others</li> <li>11. Unknown</li> </ul>

Transferred From	Record the name of the facility ( <b>outside your hospital</b> ) the infant was transferred from <i>most recently</i> . Do <i>not</i> complete this item for inborn late admissions from home or from any other area within your hospital. If an
	infant was admitted from home (because born at home), score as an out-born and enter OT > Others > "non-medical facility" here (this is NOT considered an inborn late admission from home).
	For non-hospital areas or non-Canadian hospitals, you will be able to choose from the following:  1. Non-medical facility (home, school, mall, taxi, trucketc)  2. Non-hospital medical facility  3. US Hospital  4. Non-US Hospital Outside Canada
	If a baby is transferred from a community hospital (or home) to your hospital emergency department which then assesses the baby condition and decides to transfer the baby to your NICU, the transferred from field refers to the <b>external place</b> from which the baby comes from when it first reached the hospital.
	For those types of cases, DO NOT enter the transport data in the transport screen since there was no direct transfer and admission to your NICU.
	For inborn cases where baby is born and then directly transferred to the NICU in the same hospital stay, leave the field empty.
Birth Place	If baby was inborn, your hospital will automatically appear here if the Settings are set appropriately (refer to page 11, "Customizability of CNN Application"). The list of selectable items is the same as for the "Transferred From" field, and will include an Unknown option (mandatory field).
First NICU	For outborn babies, what was the first CNN hospital of admission? Select from list. Default is your own hospital.
Comments	Please enter comments for the CC here (maximum 255 characters). Do not record notes to yourself in this box. Use this item sparingly, it is not necessary to note additional maternal/obstetric information not required on the maternal screen. If you are unsure of the classification of a given congenital anomaly, diagnosis, or have a question regarding data collection please contact the CC for advice, <b>do <u>not</u> enter your question here.</b>
	To indicate a record is invalid or erroneous, DO NOT enter "To Delete", "To Filter", "Please Ignore" or similar comments here. Use the new Deactivation feature available to deactivate invalid cases.

# **GA <37** WEEKS - REASONS FOR PRETERM BIRTH

This section is enabled when the calculated GA on Admission Screen is < 37 weeks.

If GA < 37 weeks	Select the <b>primary reason</b> for THIS preterm birth. (Select only one from list)
<ul> <li>Primary reason</li> </ul>	Consult the local MFM/OB Site Investigator if the primary reason for this preterm birth was not documented.
	Multiple pregnancy
	Select if multiple pregnancy was the primary reason for this preterm birth.
	Sold of the programmy was and primary rounds from order
	Medically indicated
	Maternal hypertension/preeclampsia/eclampsia: Includes HTN, PIH, HELLP and PET.
	Maternal infection:
	i. Suspected/confirmed chorioamnionitis: Chorioamnionitis is defined as inflammation of the
	<u> </u>
	chorion and amnion. Select this option if either suspected chorioamnionitis or pathology confirmed
	chorioamnionitis was the primary reason for this preterm birth.
	ii. Other maternal infection: Score this if any other type of systemic infection was found in mother
	during peri-partum period. These include, but not limited to, urinary tract infection, pneumonia,
	septicemia etc.
	Other maternal medical conditions: Score this if the chart has documented any other maternal medical
	condition which was the primary reason for the preterm birth.
	Fetal indications:
	Only score the affected fetus for preterm delivery of multiples.
	i. IUGR: Intrauterine growth restriction, which will also appear as fetal growth restriction. This
	includes suspected IUGR as documented in chart.
	ii. Non-reassuring fetal status or compromised fetal status: Includes non-reassuring fetal heart rate
	tracing, non-reassuring biophysical profile or other such as Doppler, or evidence of fetal compromise.
	iii. Following fetal procedure: If preterm birth occurred within 72 hours after fetal procedures such as

transfusion, laser, shunt placement, amnioreduction, surgery, catheterization, fetal reduction etc.

#### Uterine anomaly/malformation

Includes Müllerian abnormality, Unicornuate uterus, Uterus didelphys (also uterus didelphis), Bicornuate uterus, Septated uterus.

#### Cervical insufficiency/short cervix

Includes cervical insufficiency, cervical incompetence and short cervix. Cervical insufficiency might also be written as: "silent cervical dilation", "painless cervical dilation", or "bulging membranes without contractions". If any intervention was applied for cervical insufficiency, such as cervical suture or pessary, they would be documented on the Mother/Obstetric screens.

#### **Placental insufficiency**

Select if placental insufficiency was the primary reason for this preterm birth.

#### **PPROM**

Score if Preterm Premature Rupture of Membranes was the primary reason for this preterm birth. This includes prelabour rupture of membranes that occurred before 37 weeks gestation. Do not score if membranes were ruptured artificially by health care provider prior to birth.

#### **Spontaneous**

Score this if spontaneous preterm labour was documented as the primary reason for this preterm birth.

## Antepartum hemorrhage

Select if antepartum hemorrhage was the primary indication for this preterm birth and the cause of antepartum hemorrhage was classified as any of the below. This information can usually be found in the chart/antenatal record, operative note or delivery note. Do NOT score this variable if the mother has any of placenta previa, vasa previa, or placenta accreta/increta/percreta but does not hemorrhage. Do NOT include chronic abruption bleed that occurs early in pregnancy but "resolves" or no longer bleeding around time of birth.

- **i. Placenta previa:** Information can be found under "Preoperative Diagnosis", "Indication for cesarean section" or operative note.
- **ii. Vasa previa:** Information can be found under "Preoperative Diagnosis", "Indication for cesarean section" or operative note.
- **iii. Placenta accreta/increta/percreta:** Information can be found under "Preoperative Diagnosis", "Indication for cesarean section" or operative note.
- **iv. Placental abruption:** Information can be found in maternal chart close to time of delivery as abruption or marginal abruption.
- v. Other/unknown antepartum hemorrhage: Antepartum hemorrhage not otherwise specified by one of the above. Score this if the chart has documented any other type of antepartum hemorrhage which was the primary reason for the preterm birth. Score this if reason for antepartum hemorrhage is unknown.

#### **Other**

Select this if the primary reason for this preterm birth was documented but cannot be classified into any of the above.

#### **Unknown**

Select if the primary reason for this preterm birth could not be determined despite consultation with the local MFM/OB Site Investigator.

# If GA < 37 weeks - Associated conditions

Select all conditions mentioned in the chart that were or may be associated with THIS preterm birth. Exclude if these events occurred only in the past and in another pregnancy. (Select all that apply)

#### **Medically indicated**

#### **Maternal infection:**

- **i.** Suspected/confirmed chorioamnionitis: *Chorioamnionitis* is defined as inflammation of the chorion and amnion. Score if suspected chorioamnionitis was mentioned in the chart, or if pathology report confirmed chorioamnionitis.
- **ii. Other maternal infection:** Score this if any other type of systemic infection was found in mother during peri-partum period. These include, but not limited to, urinary tract infection, pneumonia, septicemia etc.

**Other maternal medical conditions:** Score this if the chart has documented any other maternal medical conditions which may be associated with the preterm birth.

#### **Fetal indications:**

Only score the affected fetus for preterm delivery of multiples.

- **i. IUGR:** Intrauterine growth restriction, which will also appear as fetal growth restriction. This includes suspected IUGR as documented in chart.
- **ii. Non-reassuring fetal status** or compromised fetal status: Includes non-reassuring fetal heart rate tracing, non-reassuring biophysical profile or other such as Doppler, or evidence of fetal compromise.
- **iii. Following fetal procedure:** If preterm birth occurred within 72 hours after fetal procedures such as transfusion, laser, shunt placement, amnioreduction, surgery, catheterization, fetal reduction etc.

#### Uterine anomaly/malformation

Includes Müllerian abnormality, Unicornuate uterus, Uterus didelphys (also uterus didelphis), Bicornuate uterus, Septated uterus.

#### Cervical insufficiency/short cervix

Check this if "cervical insufficiency", "cervical incompetence" or "short cervix" is documented in the chart. "Cervical insufficiency" might also be written as: "silent cervical dilation", "painless cervical dilation", or "bulging membranes without contractions". If any intervention was applied for cervical insufficiency, such as cervical suture or pessary, they would be documented on the Mother/Obstetric screens.

#### **Placental insufficiency**

Check this if documented in chart of having "placental insufficiency". Usually this is associated with fetal growth restriction or IUGR particularly when associated with oligohydramnios.

#### **PPROM**

Preterm Premature Rupture of Membranes: Score this if prelabour rupture of membranes occurred before 37 weeks gestation. Do not score if membranes were ruptured artificially by health care provider prior to birth.

#### **Spontaneous**

Score this if spontaneous preterm labour was documented.

#### Antepartum hemorrhage

Select if the cause of antepartum hemorrhage is classified as any of the below. This information can usually be found in the chart/antenatal record, operative note or delivery note. Do NOT score this variable if the mother has any of placenta previa, vasa previa, or placenta accreta/increta/percreta but does not hemorrhage. Do NOT include chronic abruption bleed that occurs early in pregnancy but "resolves" or no longer bleeding around time of birth.

- i. **Placenta previa:** Information can be found under "Preoperative Diagnosis", "Indication for cesarean section" or operative note.
- ii. **Vasa previa:** Information can be found under "Preoperative Diagnosis", "Indication for cesarean section" or operative note.
- iii. **Placenta accreta/increta/percreta:** Information can be found under "Preoperative Diagnosis", "Indication for cesarean section" or operative note.
- iv. **Placental abruption:** Information can be found in maternal chart close to time of delivery as abruption or marginal abruption.
- v. **Other/unknown antepartum hemorrhage:** Antepartum hemorrhage not otherwise specified by one of the above. Score this if the chart has documented any other type of antepartum hemorrhage which may be associated with preterm birth. Score this if reason for antepartum hemorrhage is unknown.

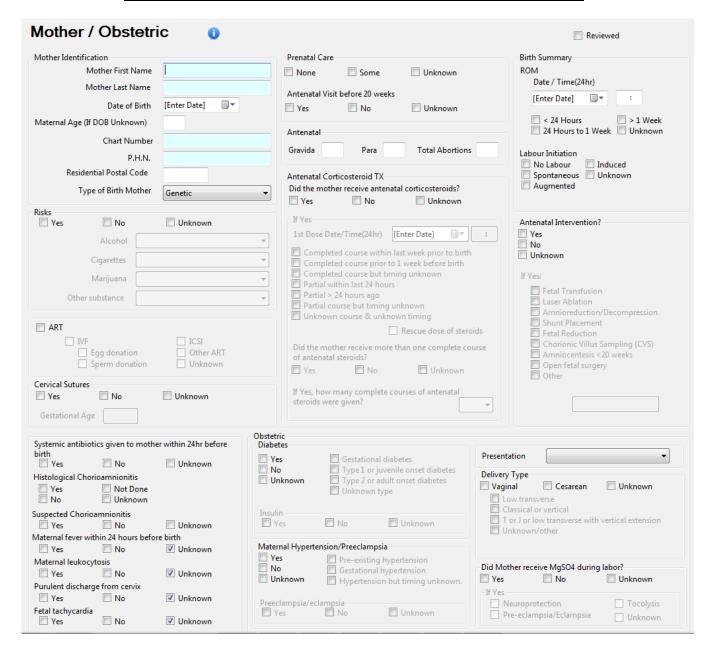
#### **Other**

Select this if any other conditions were documented to be associated with preterm birth.

#### Unknown

Select if information is not available.

# **SCREEN 2: MOTHER/OBSTETRIC SCREEN DEFINITIONS**



Record information on this screen according to the birth mother's information. If an infant is placed in foster care, DO NOT record details regarding the foster family here.

## **MOTHER IDENTIFICATION**

Mother First Name	First name of mother as recorded on medical records. Do not enter abbreviations. Leave blank if unknown.
Mother Last Name	Family name of mother as recorded on the medical records.
Date of Birth	Mother's date of birth. If date of birth or age is unknown leave the field blank.
Maternal Age	Enter maternal age if known.
Date of Admit	Mother's date of admission to <i>birth</i> hospital. If date of admission is unknown leave the field blank.
Chart Number	Mother's hospital record number for all inborn infants. For out-born infants leave the field blank.
P.H.N.	Mother's personal health number if mother has provincial coverage. If mother does not have provincial

	coverage or PHN is unknown leave the field blank (this information is kept locally, not transferred to CNN).
Lone Parent	Record whether the child is cared for by a lone parent (mandatory field).
	If a spouse (irrespective of sex) is regularly (i.e. daily) involved in the social care of this child (not
	financial), score "no".
	If no one other than the mother fits this description, score "yes".
	If this is unclear, score "unknown".
Residential Postal	Postal Code of mother's primary residence. Record the 6 digit number/letter code in the correct sequence
Code	(eg A1A 1A1). This should be completed for all babies, including out-born. If unknown, leave the field
	blank.
Type of birth mother	Record the type of birth mother: Genetic, Non-genetic, Surrogate, or Unknown. Default is "Genetic".

#### RISKS

#### Risks

- Alcohol
- Cigarette
- Marijuana
- Other substance

Indicate whether or not the mother used alcohol, cigarettes (include e-cigarettes), marijuana/cannabis or other substances *during this pregnancy*. Do not score if the mother used these substances prior to this conception or during a previous pregnancy. Include all routes of administration (e.g. smoked, vaporized, oral, topical etc.). Also include both legal and illegal use.

**Other substance**s include all recreational drugs (i.e. cocaine, heroin, etc.) as well as abused prescription drugs known to do damage to a developing fetus (i.e. opioids, codeine, methadone etc.).

Select the "Yes" checkbox if the mother had exposure to alcohol, cigarette, marijuana/cannabis or other substances during this pregnancy. Also score "yes" if the mother had "suspected exposure" and test was not done or unavailable. Then select from the dropdown menu for each of the four categories.

Select the "No" checkbox if the mother had no exposure to alcohol, cigarette, marijuana/cannabis or other substances during this pregnancy. The dropdown menus for the four categories below would be disabled and defaulted to "No".

Select the "Unknown" checkbox if it was unclear whether mother had any exposure for alcohol, cigarette, marijuana/cannabis or other substances during this pregnancy. The dropdown menus for the four categories below would be disabled and defaulted to "Unknown if exposed".

If the "Yes" checkbox was selected, enter the usage information for each of the four categories: Score "No" if the mother did not use the substance during this pregnancy.

Score "Yes, but quit during pregnancy" if the mother used the substance but quitted once she became aware of this pregnancy. As this option does not define quantity, **do** record substance use even if described as social use only.

Score "Yes, and use is ongoing" if there was ongoing use of the substance, or if mother quitted and restarted, during this pregnancy. As this option does not define quantity, **do** record substance use even if described as social use only.

Score "Yes, but timing is unknown" if the mother used the substance during this pregnancy but usage information is not available.

Score "Unknown if exposed" if it was unclear whether the mother had exposure to the substance during this pregnancy or information was not available.

#### **OBSTETRIC / ANTENATAL HISTORY**

Assisted Reproductive Technology (ART) Score if Assisted Reproductive Technology was used in this pregnancy. If yes, select the type.

**IVF:** *In Vitro* Fertilization – Select if IVF was used in this pregnancy. If yes, then select egg or sperm donation as applicable. Leave blank if information regarding egg donation and sperm donation is unknown.

**ICSI:** Intracytoplasmic Sperm Injection

**Other ART:** This includes Intrauterine Insemination (IUI), embryo donation, surrogates, gestational carriers, ovulation induction with Clomid or other fertility drugs

**Unknown ART**: Score this when Assisted Reproductive Technology was used but technique unknown.

Cervical Sutures	Was cervical suture in place? Select yes, no or unknown. If yes, enter the fetus GA in completed weeks at the time of suture. If more than one suture was placed, record the first. GA ranges between 8 to 36 weeks. Do not round up GA for incomplete weeks. Leave blank if GA is unknown.
Systemic antibiotics given to mother within 24hr before birth	Record whether systemic antibiotics were given to the mother <i>within 24 hours before birth</i> . This includes antibiotics given only enterally or parentally, not topical antibiotics. If unknown check the unknown box (mandatory field).
Maternal fever	Score yes if any of these conditions existed within the 24 hours before birth. Reason for fever would not be a factor in this determination.  1. Any maternal fever of ≥39.0 °C recorded one or more times.  2. Any maternal fever of >38.0 °C recorded twice at least 30 minutes apart.
Maternal leukocytosis	Maternal white cell count >15000/mm <sup>3</sup> (or sometimes recorded as >15) for blood sample collected within the 24 hours before birth, regardless if mom was in labour.
Purulent discharge from cervix	Definite purulent discharge within the 24 hours before birth, as documented in chart or intrapartum notes. It might be written as discharge that is 'yellow', 'green', 'foul-smelling' or 'malodourous'.
Fetal tachycardia	Documented fetal tachycardia with fetal heart rate >160 bpm within the 24 hours before birth. Abnormal fetal heart rate may be documented on maternal partogram charting of fetal heart rate and intrapartum progress notes. Score if "fetal tachycardia" is documented in chart, even when the fetal heart rate is not available.
Chorioamnionitis	<ul> <li>Histological Chorioamnionitis: Chorioamnionitis is defined as inflammation of the chorion and amnion.</li> <li>Yes – placental pathology/histological report indicates positive for chorioamnionitis</li> <li>No – placental pathology/histological report indicates negative for chorioamnionitis</li> <li>Not Done – placental pathology/histological investigation was not done</li> <li>Unknown – placental pathology/histological report was not available, report inconclusive, or unknown if report was done</li> <li>Suspected chorioamnionitis: Was "chorioamnionitis" or "suspected chorioamnionitis" documented in the chart? (regardless of other indicators)</li> <li>Yes – select if chorioamnionitis or suspected chorioamnionitis was documented in chart</li> <li>No – select if chorioamnionitis or suspected chorioamnionitis was not documented in chart</li> <li>Unknown - information not available</li> </ul>
Prenatal Care	If the mother had <i>at least one</i> prenatal care visit prior to hospital admission during which delivery occurred, score as 'some'. Otherwise, score as 'none'. If a pregnancy is dated by ultrasound (U/S) (other than on this admission) or if the notes indicate the mother had prenatal screens (rubella immune or hepatitis status) assume that there was some prenatal care. If there are no obstetric records, select "unknown" (mandatory field).
Antenatal Visits before 20 weeks	Check the box if mother had prenatal visit before 20 weeks of gestational age. If mother had first trimester screen, nuchal translucency measured, anatomy scan performed, or screening for genetic anomaly performed (triple screen) then score "yes" (mandatory field).
Gravida	The number of times a woman has been pregnant, including all abortions, live and still births. Note that this number includes the current pregnancy, therefore if this is the mother's first pregnancy enter '1'.
Para Total Abortions	The number of viable offspring in previous pregnancies. If a mother has had twins, her para is 2.  The total number of both spontaneous (miscarriages including stillbirths) and therapeutic (planned) abortions of mother to date.

Antenatal	Antenatal corticosteroid treatment given to mother prior to delivery (mandatory field). These include any of
Corticosteroid TX	the following: betamethasone, beta celestone, dexamethasone, cortisone, dihydrocortisone, but <i>not</i>
	prednisone
	If Yes: score as below  a. Complete course within last week prior to birth [defined as receipt of at least two doses of corticosteroids 24 hours or more but within one week of birth]  b. Complete course before 1 week of birth (defined as receipt of at least two doses of corticosteroids initiated more than one week prior to birth)  c. Complete course but timing unknown (If no dates of administration are given, but the chart refers to "complete" or if chart specifies two doses were given)  d. Partial course within last 24 hours (defined as any dose given less than 24 hours prior to birth)  e. Partial course within last 24 hours (defined as one dose given >24 hours ago and was not repeated")  f. Partial course but timing unknown (If no dates of administration are given, but the chart refers to "partial" or if chart specifies that only one dose was given)  g. Course and timing unknown (select if antenatal corticosteroid was given but no other details were available. I.e. Complete vs partial course and timing were unknown.  Long course of corticosteroid for mother: For Mothers who received systemic (oral or parenteral) corticosteroids for indications other than for lung maturity (e.g. fetal heart block, suspected congenital adrenal hyperplasia or for maternal indication etc.) for a prolonged period of time (>2 weeks), score the appropriate "Completed course" option and enter the Number of Courses as "10". If steroid was continued until the date of delivery, enter "Completed course within last week prior to birth". If it was stopped 1 week prior to birth, then enter "Completed course before 1 week of birth". Please enter the detailed reason for
	multiple steroid administrations in the comment box on the Admission Screen.
First dose of antenatal steroid	If antenatal steroids were given to mother, select "Yes" and provide date/time of first dose.  Also, do complete other information under Antenatal Corticosteroid Treatment such as complete/partial courses.  Information may be available on maternal charts.
Rescue dose of steroids	This field is enabled only if "complete course" is selected above.  The practice of giving a rescue dose of steroid is adopted in some units. This means that mother has received a complete course of steroid >1 week ago when she presented with threatened preterm birth.  However, she settled and did not deliver at that time. She then presented with another episode of threatened preterm birth and rather than repeating a course of steroid, practitioner gave a single dose of steroid as rescue dose prior to current preterm birth. Usually this is a single dose within 12 hours of birth.
Number of Courses	If mother has received multiple complete courses (at least one complete and more) mark yes and indicate the number of antenatal corticosteroid courses given to mother prior to delivery. If not mentioned or unknown, select unknown. If mother has received complete and partial courses in the past, only enter courses that were complete (as defined above) and ignore partial courses.

# **BIRTH SUMMARY (TOP RIGHT-HAND CORNER)**

Rupture of	Rupture of maternal membranes (ROM), either artificial or natural, releasing the amniotic fluid and
membranes (ROM)	indicating the onset of labour.
	Enter the date and time when rupture of membranes occurred. There is no further need to classify the timing below if the date/time is available.
	If exact timing is unknown but information is available to classify the time between rupture of membranes and time of birth, select from the 3 groups below: <24 hours; 24 hours to 1 week; >1 week
	Mark unknown if information is not available. (mandatory field)
Labour Initiation	Type of labour initiation, whether none, spontaneous, augmented (speeding up labour), or induced (getting labour started). If unknown record as such. Augmentation is defined as medications given to increase the

strength and/or speed of contractions (mandatory field).

#### **ANTENATAL INTERVENTION**

Antenatal	Indicate if there were any interventions during this pregnancy to treat a fetal condition. If "Yes" was
Intervention?	selected, indicate which intervention was performed.
	Amniocentesis and Chorionic Villus Sampling are performed to rule out chromosomal abnormalities and
	other genetic disorders (e.g. Down Syndrome and neural tube defects). Shunt placement includes
	pleuroamniotic shunt, vesicoamniotic shunt, antenatal placement of shunt for reduction of hydrocephalus, or
	shunt anywhere in the body to drain fluid collection. If there was only tapping of fluid from cavity and no
	shunt was placed, mention it in the "Other" category. If the intervention is not listed, click "Other" and free
	text the intervention (maximum 50 characters).

# **OBSTETRIC (BOTTOM RIGHT-HAND CORNER)**

Diabetes and Type	Answer yes, no or unknown regarding mother's status as a diabetic. This includes both gestational diabetes as well as previous maternal diabetes (i.e. prior to conception). Impaired Glucose Tolerance is not included. (Mandatory field).  If Yes, select the type:  1. Gestational diabetes: Diabetes which was first time diagnosed during this pregnancy 2. Type 1 diabetes or juvenile onset diabetes: Diabetes diagnosed at younger age 3. Type 2 diabetes or adult onset: Diabetes diagnosed during adulthood 4. Unknown type: Reported as diabetes but type is unknown.
Insulin	Answer yes, no or unknown regarding whether or not mom received insulin for the treatment of diabetes.
Maternal Hypertension	Record whether maternal hypertension is present or not, or whether this information is unknown. If obstetric information is noted, but maternal hypertension is not mentioned, select "no." If there is no obstetric data in the chart, select "unknown." Common abbreviations for this include: HTN, PIH, HELLP and PET. "Questionable HTN," "question of HELLP syndrome" or "rule out PET" without more information should be scored as unknown (mandatory field).
	If Yes, select type:  1. Pre-existing hypertension: Hypertension that was preexisting before current pregnancy 2. Gestational hypertension: Hypertension diagnosed first time during this pregnancy. It may have been reported in previous pregnancy but mother was not hypertensive in between pregnancies.  3. Hypertension but timing unknown: Reported as hypertension but timing unknown
Preeclampsia/ Eclampsia	Record whether preeclampsia or eclampsia is present or not, or whether this information is unknown.
Maternal MgSO4	Enter YES if MgSO4 is given at any time during gestation when mom had threatened preterm labour. This includes previous MgSO4 given weeks before actual birth when mother might have been admitted for threatened preterm labour but not given birth.
	If Yes, select the reason.  Neuroprotection: Administration of MgSO4 for prevention of cerebral palsy in infants. This is given when mother is admitted in threatened preterm labour. MgSO4 given for neuroprotection in all previous admissions for threatened preterm labour should be included. Check this if MgSO4 is intended for neuroprotection, irrespective of maternal conditions. Under most circumstances this is given for up to 24 hours in the event of suspected or threatened preterm labour, and stopped if mother does not progress to labour.  Pre-eclampsia/Eclampsia: Administration of MgSO4 for the treatment of maternal pre-eclampsia or
	eclampsia. This treatment can last for longer than 24 hours and should be mentioned as a reason in maternal charts.  Tocolysis: Administration of MgSO4 for the purpose of relaxing the uterus when mother presents with
	contractions and threatened preterm birth.  Unknown: When reason cannot be determined, identified or not known.

Presentation	Fetal presentation at birth (mandatory field). This should be recorded as:  *VERTEX:* Head first, includes OP (occiput posterior), hand presentation with head coming with hand, or *BREECH*: All types - footling, frank, etc.; or *OTHER*: Includes shoulder, transverse, brow, face, oblique vertex, and compound (not vertex or breech but has other more than one parts as presenting parts) presentations.  If there is no mention of presentation select "unknown." If a baby was converted to vertex presentation for delivery by c-section, *score the initial position of the baby*. If vertex presentation can be inferred (e.g. "tried vacuum extraction"), score vertex.
Delivery Type	Record whether the delivery was vaginal or by cesarean section (mandatory field). If obstetric information is noted, but delivery type is not mentioned, "vaginal" may be assumed. If vaginal can be inferred (e.g. "vacuum extraction"), score vaginal. If there are no obstetric records, select "unknown."  Type of uterine incisions  The following options are enabled when cesarean delivery is selected:  1. Low transverse  2. Classical or vertical  3. "T" or "J" or low transverse with vertical extension  4. Unknown/other – if information is not available  Information may be found in operative records.
A	The following screen will pop up to display the list of babies for this mother's current pregnancy.
	List of babies for this mother's pregnancy
	First Name   Last Name   Hospital Record No.
	super man 1009
	michael jordan 1010

# **SCREEN 3: MOTHER / OBSTETRIC (G) SCREEN DEFINITIONS**

	Partner					
Naternal ducation (Highest level of education completed)	# Previous D & C			Partner Education (Highest level of education completed)		
- Completely	# Previous D & E					
Antonial Francisco and Status				Dartner Frankeyment Status		
Maternal Employment Status	# Previous preterm births			Partner Employment Status		
☐ Employed ☐ Unemployed	# Previous live b	irths		Employed Unemplo		
Student	# Previous stillbirths			Student Student		
☐ Full-time homemaker ☐ Unknown	# Previous pregr	nancies with multip	ples	☐ Full-time homemaker ☐ Unknown ☐ Other		
Other	Previous Cone/L	FED/LIFT7				
	Yes	No No	Unknown			
				Partner Age		
Severe Pre-existing Maternal Medical conditions	Pre-pregnancy o	r early antenatal w	veight	Obstetric		
Exclude Diabetes and Hypertension)	Pounds	Kilos	Unknown		n measured <24 w	eeks
☐ Yes ☐ No ☐ Unknown ☐ Severe Cardiovascular Disease	. (lb)	· (kg)		☐ Yes	□ No	Unknown
Severe Renal Disease	Mother's weight before birth		Shortest le	ngth (	mm)	
Severe Nervous System Disorder	Pounds	Kilos	Unknown	Route		_
Severe Rheumatological Disease	. (lb)	· (kg)				
Other Severe Maternal Conditions	Height		Was the cervix open (dilated) before <24 weeks?			
Maternal mental health condition during pregnancy	Feet/Inches	Centimeters	Unknown	₩as the cervix	No	Unknown
None		(cm)				E OHKHOWH
Anxiety		(CIII)		Tocolytics		
Depression	Dre-pregnancy o	or early antenatal E	RMI	Yes	□ No	Unknown
Bipolar disorder Schizophrenia	Fie-pregnancy c	r carry antenatal E		If Yes		
Other	Fetal fibronectin				ycerin patch	MgSO4
Unknown	Yes	□ No	Unknown		oine - Adalat	Other
	If Yes			Indocid	d	Unknown
Progesterone	Vaginal Pessary			Severe Matern	al Outcome	
Ses, started at or after 16 weeks GA	Yes Yes	No	Unknown	☐ Yes	□ No	Unknown
Yes, started before 16 weeks GA	Daily Aspirin			Require	e higher level of ca	ire
Yes, unknown timing No	Yes	No	Unknown	Transfu	usion ≥4 units	
Unknown				Septic		
				Require	e operation	

Record information on this screen according to the birth mother's information. This screen is enabled for babies with GA < 29 weeks.

## **MATERNAL**

Maternal Education	Record the highest level of education completed by the mother.	
	Choose from: Less than high school, Completed high school, Some college, CÉGEP or university, Completed college, CÉGEP or university, Post-graduate training, Unknown	
	If the mother has completed CÉGEP and some university, please select "Some college, CÉGEP or university".	
	If mother has completed some high school but not finished high school, select "Less than high school". If mother has not completed any high school, select "Less than high school".	

	If mother has taken any courses or completed any level of post-graduate training (including Master's or PhD), select "Post-Graduate Training".
Maternal Employment Status	Record the mother's employment status.  Employed: Select if employed full- or part-time or if self-employed.  Unemployed: Select if mother is available to work but does not have paid employment. If mother is not available for work due to childcare and other household responsibility, select Full-time Homemaker. If mother is not available for work due to injury or disability, select Other.  Student: Select if mother spends most of the time attending classes or works part-time while attending full-time classes. However, if mother works full-time but attends night classes, select Employed.  Full-time Homemaker: Select if mother is not available for paid employment due to childcare and household responsibilities.  Unknown: Select if employment status cannot be determined or unknown.  Other: Score this if none of the above applies. Specify in free text field.
Severe pre-existing maternal medical conditions (exclude diabetes and	Record whether or not the mother had pre-existing medical conditions NOT including diabetes and hypertension.  Select "Unknown" if this information was not documented.
hypertension)	If "Yes", select the appropriate condition(s) if they were documented.  Severe Cardiovascular Disease includes Left Ventricular dysfunction "LV" dysfunction, Ejection Fraction or EF <45%, "Heart Failure" or "NYHA class >II", Complex Congenital Heart Disease (NOT repaired Atrial Septal Defect (ASD) or repaired Ventricular Septal Defect (VSD); would include Cyanosis or cyanotic, Tetralogy of Fallot, Transposition of the Great Arteries, "Eisenmenger's ", Pulmonary Hypertension, Ventricular Fibrillation, Ventricular Tachycardia, or other severe (e.g. angina or heart attack) Myocardial Infarction, MI, Mechanical Valve, Aortic Root Dilation >45 mm, cardiac transplant, cardiac ablation).
	<b>Severe Renal Disease</b> includes "dialysis", renal failure (acute or chronic), pyelonephritis during the current pregnancy, or other severe transplant (e.g. renal/kidney).
	<b>Severe Nervous System Disorder</b> includes epilepsy ("not well controlled", "poorly controlled", frequent seizures during pregnancy), stroke during the current pregnancy (Cerebrovascular Accident (CVA), "Brain Haemorrhage"), Transient Ischemic Attack (TIA), brain tumour diagnosed in pregnancy or intracranial hemorrhage.
	<b>Severe Rheumatological Disease</b> includes severe lupus (SLE), severe rheumatoid arthritis (RA) or any other severe type of rheumatologic disease. Do not include any type of mild, well controlled, controlled or stable conditions, regardless of medications used.
	Other Severe Maternal Condition(s) include cystic fibrosis, severe asthma requiring hospitalization during pregnancy, ulcerative colitis on medications but poorly controlled, Crohn's on or off medications but poorly controlled, cancers, endocrine disorders (e.g. thyroid storm, prolactinoma), haematological disorders (e.g. anemic sickle cell).  Do not include hyperemesis gravidarum requiring hospitalization in "Other severe maternal condition".
Maternal mental health conditions during pregnancy	Indicate the maternal mental health conditions that are ongoing problems during current pregnancy. Include pre-existing or pregnancy-related mental health conditions of the mother that occurred during this pregnancy only.
	Do not include previous postpartum depression or risk of postpartum depression as they are not "ongoing".
	Select from anxiety, depression, bipolar disorder and schizophrenia.  Select "other" for maternal mental health condition not otherwise specified by one of the above.  Select "unknown" if information is not available.
Number of previous D & C	Indicate the number of previous first trimester dilation and curettage (D&C) procedures either for termination or miscarriage. The first trimester/term of pregnancy is considered to be up to and including 13 weeks gestation. If the timing of D&C was not documented and the procedure was done less than or equal to 13 weeks gestation, score as D&C. Score under D&C if the mother had a previous D&C or D&E, but the

	infant's GA is unknown.
	Leave blank if information is not available or unknown. This field is auto-populated with "zero" when Gravida=1.
Number of previous D & E	Indicate the number of previous second trimester dilation and evacuation (D&E) procedures either for termination or miscarriage. Include D&E done between 13 weeks + 1 day and 24 weeks gestation (including 24 weeks).  If the timing of D&E was not documented and the procedure was done was on or after 13 weeks + 1 day gestation, score as D&E. Score under D&C if the mother had a previous D&C or D&E, but the infant's GA is unknown.  Leave blank if information is not available or unknown. This field is auto-populated with "zero" when Gravida=1.
Number of previous Preterm Births	Preterm refers to birth before 37+0 weeks gestation; therefore, the gestational age of previous children must be < 36+6 weeks to be included here.
	Leave blank if information is not available or unknown. This field is auto-populated with "zero" when Gravida=1.
Number of previous live births	Record the total number of previous live births, both term and preterm.  Exclude the baby who is being abstracted. A live birth is the complete expulsion or extraction from the mother after at least 20 completed weeks gestation or after attaining a weight of at least 500 grams, or a product of conception in which, after the expulsion or extraction, there IS breathing, beating of heart, pulsation of umbilical cord or unmistakable movement of voluntary muscle.
	Leave blank if information is not available or unknown. This field is auto-populated with "zero" when Gravida=1.
Number of previous stillbirths	Death prior to the complete expulsion or extraction from the mother of a product of conception, irrespective of the duration of pregnancy; the death is indicated by the fact that after such separation the fetus does not breathe or show any other evidence of life, such as beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles. Only fetal deaths where the product of conception has a birth weight of 500 grams or more or the duration of pregnancy is 20 weeks or longer are registered in Canada.
Number of previous pregnancies with multiples	Record the number of previous pregnancies with multiples, irrespective of livebirth or stillborn. This is not the number of children, but the number of pregnancies with multiples.
muniples	Leave blank if information is not available or unknown. This field is auto-populated with "zero" when Gravida=1.
Previous Cone/LEEP/LLETZ	Answer "Yes", "No", or "Unknown" regarding whether mother had previous Cone/LEEP/LLETZ.
Colle/LEEF/LEE1Z	Cold Knife Cone (CKC): Surgical procedure which removes a cone-shaped piece of cervical tissue containing abnormal cells using a scalpel or laser. It is not a biopsy of the cervix Loop of Electrosurgical Excision Procedure (LEEP): Surgical procedure which also removes a large portion of cervical tissue containing abnormal cells using cautery. LEEP can also be referred to as the Large Loop Excision of the Transformation Zone (LLETZ)
Pre-pregnancy or early antenatal weight	Record the pre-pregnancy weight of the mother or weight measured at the first antenatal visit (if <13 weeks gestation) using either the imperial or metric system.  Imperial system range: 30 lbs to 500 lbs (if more than 500lbs, then enter 500).  Metric system range: 20 kg to 250 kg (if more than 250Kg, enter 250 kg)
	If pre-pregnancy weight was not documented and mother's weight before 13 weeks gestation was not measured or documented, select "Unknown".
Mother's weight before birth	Record the mother's weight last measured before this current birth, using either the imperial or metric system. Timing between measurement and delivery was irrelevant. Record the weight measured closest to birth, irrespective of where it was measured.

	Imperial system range: 30 lbs to 500 lbs (if more than 500lbs, then enter 500).  Metric system range: 20 kg to 250 kg (if more than 250Kg, enter 250 kg)  If pre-delivery weight was not documented, select "Unknown".
Maternal height	Record the height of the mother using either the imperial or metric system.  Imperial system range: 3 feet to 7 feet (if more than 7 feet, enter 7 feet)  Metric system range: 90 cm to 210 cm (if more than 210cm, enter 210cm)  If maternal height was not documented, select "Unknown".
Pre-pregnancy or early antenatal Body Mass Index (BMI)	Record the pre-pregnancy BMI of the mother or BMI documented at the first antenatal visit (if <13 weeks gestation). Leave field blank if pre-pregnancy/early antenatal weight AND height were both entered. Leave blank if not documented or unknown.

Fetal fibronectin test	Fetal fibronectin (FFN) is a fibronectin protein produced by fetal cells. It is tested with a maternal vaginal swab and it is a screen for preterm birth.
	Record whether or not the mother received a Fetal Fibronectin Test. Select "Unknown" if information was not documented.
	If "Yes" was selected, indicate whether the result of the test was "positive", "negative", or "unknown".
	If more than 1 FFN swab was done, record the last result.
	Information may be available in lab reports or maternal charts (under admitting plan if admitted for threatened preterm labour).
Progesterone	Progesterone intake including oral, per vagina (pv), or intramuscular.
	Record whether or not progesterone was given and timing. Select "unknown" if information was not available or unknown.
Vaginal Pessary	Vaginal Pessary: A ring-shaped device inserted in the vagina, to change the angle of the cervix with the uterus, to prevent preterm birth (See image below). Does not include pessary for urinary incontinence or for prolapsed uterus.
Daily Aspirin	Record if mother was given daily aspirin during pregnancy for prevention of preeclampsia, SGA/IUGR, or other conditions. This does not include the use of aspirin for headache or other pain/inflammation management. The usual dosing is either 80 mg or 160 mg daily.
	This information can usually be found in antenatal record, under Medications and also on an initial consult under Medications or in the Plan/Recommendation and/or the admission history for birth, under Medications.

## **PARTNER**

Record the highest level of education completed by the partner. The partner is the person whom the mother
I Decord the highest level of education completed by the norther. The norther is the norsen whem the mother
T NECORD THE HIGHEST LEVEL OF EDUCATION COMDIESED BY THE DATMEL. THE DATMEL IS THE DEISON WHOM THE MOMEN

	has identified in the antenatal record. Leave blank if partner was not identified or information was not available.
	Choose from: Less than high school, Completed high school, Some college, CÉGEP or university, Completed college, CÉGEP or university, Post-graduate training, Unknown
	If the partner has completed CÉGEP and some university, please select "Some college, CÉGEP or university".
Partner's Employment Status	Record the partner's employment status. The partner is the person whom the mother has identified in the antenatal record. Leave blank if partner was not identified or information was not available.
	Employed: Employed full- or part-time or if self-employed.  Unemployed: Partner is available to work but does not have paid employment. If partner is not available for work due to childcare and other household responsibility, select Full-time Homemaker. If partner is not available for work due to injury or disability, select Other.  Student: Partner spends most of time attending classes or works part-time while attending full-time classes. However, if works full-time but attends night classes, select Employed.  Full-time Homemaker: Partner is not available for paid employment due to childcare and household responsibilities.  Unknown: Employment status cannot be determined or unknown.  Other: Score this if none of the above applies. Specify in free text field.
Partner's Age	Enter partner's age. The partner is the person whom the mother has identified in the antenatal record. Leave blank if information is not available or unknown.

# **OBSTETRIC**

Cervical length measured before 24	Indicate whether the mother's cervical length was measured before 24 weeks gestation.
weeks gestation	If "Yes", record the shortest length in millimeters. Range is set between 1 and 60 mm. Enter 60 mm if the measurement is >60mm. Leave blank if length was not available or unknown.
	Select "No" if cervical length was not measured before 24 weeks gestation.
	Select "Unknown" if it was not documented whether measurement was made.
	If "Yes", indicate the method used to measure cervical length. Select transvaginal ultrasound, transabdominal ultrasound, or transperineal ultrasound.
Cervix open before 24 weeks gestation	Indicate whether the mother's cervix opened/dilated before 24 weeks gestation, regardless of size of dilation. This information might also be written in the chart as "bulging membranes". If this cannot be determined or unknown, then select "Unknown". Information may be found in maternal charts.
Tocolytic agents prior to birth	During this admission, indicate whether or not mother received tocolytic treatment in an attempt to delay or halt labour.  If this cannot be determined or unknown, then select "Unknown".  If "Yes", indicate the type of tocolytics.  a) NTG patch (nitroglycerin patch)  b) Ca-channel blocker (Nifedipine=Adalat)  c) Indomethacin (Indocid)  d) MgSO4  e) Other (Ritodrine; Terbutaline, Salbutamol)  f) Unknown type  Record if a dose of Indocid was given following placement of cervical suture.

# Severe maternal outcome

Indicate whether there was severe maternal morbidity or mortality within 4 weeks postpartum, regardless of the location of these events. Collect information during the birth admission and any readmissions due to pregnancy-related complications. Information can usually be found in discharge summary.

## If Yes,

- a. Required higher level of care including Intensive Care (ICU) and High Dependency Unit (HDU): Include transfer of the mother to another institution that provides higher level of maternal care.
- Transfusion  $\geq 4$  units of any blood products
- c. Septic shock
- d. Required operation: mother returned to operating room post C-section or required operation after vaginal birth.
- e. Maternal Death: Exclude accidentals

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# SCREEN 4: RESUSCITATION / STABILIZATION / TRANSITION SCREEN DEFINITIONS

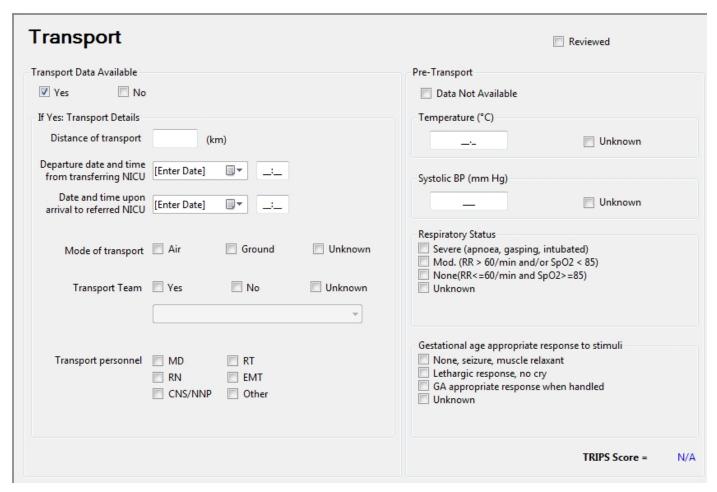
Resuscitation / Stabilization /	Transition Reviewed
Date of Birth: N/A Time of Birth: N/A	Date/Time 30 Minutes After Birth: N/A
Please record if the following occurred in the first 30 minutes	s of birth
Resuscitation Details  No active resuscitation needed Unknown Suction and/or mild stimulation and/or free flow CPAP PPV via bag and mask or T Piece PPV via ET tube Chest compression >= 30 seconds Epinephrine (ET or IV) Palliative care or DNR order  If Palliative Care or DNR Order Extreme immaturity Major malformation Other	If Resuscitation provided Initial gas provided for resuscitation  Air/oxygen = 21% Supplemental Oxygen > 21% 100% Oxygen Unknown  Maximum of oxygen in % provided during resuscitation  Discontinuation of all resuscitation measures due to no or poor response (time in minutes)
Delayed Cord Clamping attempted?  Yes No Unknown  Umbilical cord milking Yes No Unknown	

Record information on this screen according to the first 30 minutes of birth. At least one checkbox under Resuscitation Details must be selected for validation to be complete. You do not have to fill this information out for readmissions, but do for all outborns.

Resuscitation	Provide resuscitation details that the infant received in the first 30 minutes after birth irrespective of location
Details	of resuscitation. Note all that apply i.e. if infant required suction, stimulation, bag and mask and intubation;
	mark all items for the infant (mandatory field).
	1. No active resuscitation needed: Infant did not require any resuscitation. These are typically
	babies with Apgar scores higher than 8.
	2. Unknown: If the details of resuscitation are completely unknown. If the infant is intubated at birth,
	then infer intubation rather than unknown even if details of resuscitation before intubation are
	unknown. "Unknown" categories are to be used for infants for whom no details are known and
	cannot be inferred from available information.
	3. Suction and/or mild stimulation and/or free flow: If infant required orpharyngeal or nasal

	suction or free flow oxygen or stimulation then code here. Typically all infants who require
	resuscitation beyond this stage have this stage completed except babies with meconium stained
	liquor.  4. CPAP: Charle this have if the infant is given CPAP without antificial inflations on positive pressure.
	4. <b>CPAP:</b> Check this box if the infant is given CPAP without artificial inflations or positive pressure
	ventilation.
	5. <b>PPV via bag and mask or T piece:</b> Check this box if positive pressure ventilation is performed,
	including artificial inflations, using bag and mask or T piece.
	6. <b>PPV via ET tube:</b> Check this box if positive pressure ventilation is performed on an infant who
	received endotracheal intubation. Note that ETT insertion for the purpose of suction of meconium
	is excluded and should not be marked here. However, if the same infant after suction requires
	intubation and receives positive pressure ventilation, then such infants would classify as yes in this
	category.
	7. Chest compression for ≥30 seconds: For chest compressions provided for <30 seconds, do not
	check box. If duration is unknown and can not be inferred from supplemental information such as
	need for multiple doses of epinephrine etc; leave this unchecked. Compressions for <30 seconds
	are not collected.
	8. <b>Epinephrine (ET or IV):</b> If the baby received epinephrine via ETT or PIV or umbilical catheter,
	then check this box.
	9. <b>Palliative care or DNR order:</b> If the infant was planned to have palliative care after birth due to
	life limiting diagnoses and no active resuscitation was planned because of extreme prematurity or
	any other causes, check this box. Distinguish this clearly from first category where infant does not
	need resuscitation (maximum 50 characters in "Other" category).
If resuscitation	If the infant received any form of active resuscitation, you would indicate what was the initial gas used
provided	during resuscitation (air, supplemental oxygen or 100% oxygen). This would be the amount of oxygen the
provided	infant received at first attempt of resuscitation. Only enter value that was used during initiation irrespective
	whether it was increased within a few seconds or not. Usually your unit policy should clearly indicate this.
24 :	For Supplemental Oxygen > 21%, enter a value between 22 – 99%.
Maximum oxygen	Indicate what was the maximum concentration of oxygen used during resuscitation (only during
in % provided	resuscitation). If initial gas provided during resuscitation is 100%, this field will be automatically populated
during resuscitation	indicating that maximum concentration was 100%. If any other concentration was used, you need to indicate
(note resuscitation	maximum oxygen given during resuscitation. If it is unknown, leave the field blank.
may last <30	Choose the highest known FiO2 during the time period. Ignore times when the FiO2 is unknown.
minutes)	
Discontinuation of	For some unfortunate infants, resuscitative measures are not successful and at times resuscitation is
resuscitation due to	discontinued. Note after how many minutes of resuscitation these measures were discontinued (note that this
no or poor response	may be longer than 30 minutes).
Delayed cord	Indicate whether delayed cord clamping was attempted.
clamping	If yes, enter the duration of the delay in seconds. Valid range from 5 to 300 seconds.
	Enter 300 if duration was longer than 300 seconds.
	Enter the lowest number if a range was given.
	Leave blank if timing is unknown. (Duration is an optional field)
Umbilical cord	Umbilical cord milking is defined as milking of the cord 3-5 times from placenta towards the baby at a rate
milking	of 5-10cm/second. Record "yes" if it is documented as cord milking was performed irrespective of number
	of times and rate of milking.
•	-

# **SCREEN 5: TRANSPORT SCREEN DEFINITIONS**



Complete the Transport Sheet for all outborn or readmitted infants transported into the study NICU from another hospital.

Do *not* complete, but select "No" for Transport Data Available and check "Data not available", for:

- inborn late admissions (see definition under Admission Status, pg. 22)
- patients transported between wards within your hospital
- patients admitted for the first time from home
- those born at home and transported to the hospital by ambulance
- infants transported out of your hospital
- cases admitted via emergency department or other internal departments.

Transport Data	Indicate whether or not any data to complete this screen is available for the infant. The rest of the fields will			
Available	be activated only if the selection is "yes" (mandatory field).			
Distance of	Refers to the distance <i>between</i> the referring (departing) hospital and the destination (arriving) hospital, <i>one</i>			
transport	way, entered in km. If distance is unavailable, approximate the distance for both ground and air transport.			
Departure date	Date of transport from the transferring NICU. If transport occurred over midnight (i.e. two days) record the			
/Departure time	date that transport began Also record the time at which the transport team left the departing hospital. Do <i>not</i>			
from transferring	record the time at which the transport team first arrived at the departing hospital. Note: the time at which the			
NICU	transport team first begins recording vitals is NOT necessarily the departure time. If at midnight, record as			
	00:00 (where midnight (00:00) is the first minute of a new day; for example: 23:59 on Jan 3 <sup>rd</sup> and 00:00 on			
	Jan 4 <sup>th</sup> is 1 minute later). If unknown leave blank.			
Date of transport /	Date of transport into the study NICU and the time at which the transport team arrives at the receiving			
Arrival time	hospital and vitals are being taken by your study hospital. This time is often analogous to the admission time.			
Mode of transport	Record mode of transport as air or ground. Indicate both methods of transport by checking both boxes if			
	applicable. Select unknown if information is not available.			
Transport Team	Score "yes" if there was clear use of a critical care transport team to transport the patient on arrival to your			

	NICU for admission.			
	If "yes", select the name of transport team from the dropdown menu.			
	Score "no" if personnel in attendance were not part of a specific critical care transport team. Critical Care Transport teams often have dedicated staff and specific transport team documentation forms. Do not use these fields for any critical care transport team used on departure of the patient from your NICU.			
	Score "unknown" if information was not available.			
Team Personnel	Record personnel in attendance throughout transport. MD (Doctor), RN (Registered Nurse), RT (Respiratory Therapist) EMT (Emergency Medical Technician; paramedic), Clinical Nurse Specialist/Neonatal Nurse Practitioner (CNS/NNP), other or unknown. Indicate multiple types of personnel in attendance by checking multiple boxes. Select "other" if the personnel category did not fit into any of the available options. Select "unknown" if information about personnel was not available or unclear.			

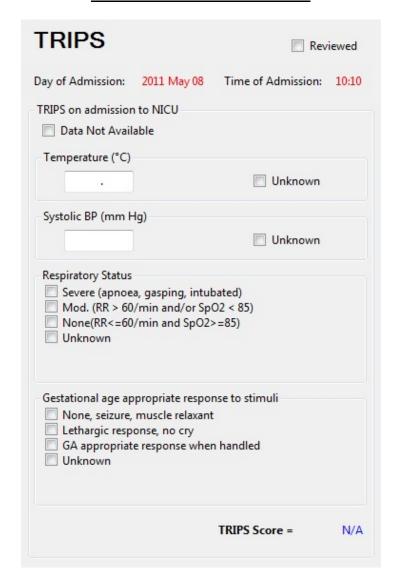
#### PRE-TRANSPORT

Refers to the outcomes on arrival of the transport team to the referring (departing) hospital (i.e. the condition in which the team finds the infant on arrival). If, for some reason, the transport team does not assess the patient for a particular item, use measurements taken from the referring hospital within two hours of the team's arrival. If no measurement within two hours is available for a particular item, check "unknown". A TRIPS score will be generated after all necessary information has been entered (i.e. no "unknown") and you click the Save button. If baby was not transported, select "Data Not Available" (mandatory field) in the first box. Select "unknown" for all fields if baby was transported but information is not found.

Temperature	Body temperature in Celsius. Range valid from 25°C to 45°C. Use axillary or rectal, but not skin probe (temperature of the baby taken by the incubator). If no appropriate recording select unknown (mandatory field).
Systolic BP	Systolic blood pressure in mm Hg. Range valid from 5 mm Hg to 300 mm Hg. Arterial line pressures and cuff pressures should be weighted equally. If more than one blood pressure is recorded, score the average blood pressure. If no appropriate recording is available select unknown (mandatory field).
Respiratory Status: Severe	Record if infant is intubated and receiving mechanical ventilation. Also record if the infant is not intubated, but suffers from apneic spells or gasping or if the infant is being bagged.
Respiratory Status: Moderate	Record if respiratory rate is <i>greater than</i> 60 resps per minute <i>OR</i> oxygen saturation recording (SPO2) is <i>less than</i> 85 regardless of mode of ventilation (i.e. CPAP or oxygen treatment). Therefore, a patient breathing less than or equal to 60 resps per minute but who is actually on CPAP will be scored as 'respiratory status-none'. This is because we are looking to capture changes in patient condition as opposed to severity of the condition itself. If both severe and moderate symptoms are displayed, score as severe (the higher of the two).
Respiratory Status: None	Record if respiratory rate is <i>less than</i> or equal to 60 breaths per minute <i>AND</i> oxygen saturation recording (SPO2) is <i>greater than</i> or equal to 85 regardless of mode of ventilation (i.e. CPAP or oxygen treatment). Therefore, a patient breathing less than 60 resps per minute but who is actually on CPAP will be scored as 'respiratory status-none'. This is because we are looking to capture changes in patient condition as opposed to severity of the condition itself.
Respiratory Status: Unknown	Record if respiratory rate is missing. Selecting one field in Respiratory Status is mandatory.
Gestational age appropriate response to stimulus: None	Record if infant shows no gestationally appropriate response to stimulus. <i>Also record</i> if the infant has had <i>seizures</i> or been given <i>muscle relaxants</i> (i.e. pancuronium) within the last few hours of the scoring time.
Gestational age appropriate response to stimulus: Lethargic response, no cry	Record if infant has a lethargic gestationally appropriate response (i.e. slow to respond, no crying, reduced activity, poor response to painful stimuli such as heel prick or venepuncture, etc.) when exposed to a stimulus.
Gestational age appropriate response to stimulus: GA appropriate	Record if infant shows a normal gestationally appropriate response when exposed to a stimulus.

response when	
handled	
Gestational age	Record if a gestationally appropriate response to stimulus is missing.
appropriate response	
to stimulus:	Selecting one field in Gestational age appropriate response to stimulus is mandatory.
Unknown	Score the most intense response demonstrated or documented.

# **S**CREEN 6: TRIPS SCREEN



TRIPS score data are mandatory collection for all inborn and outborn infants.

#### TRIPS on admission to NICU

- (a) Data are collected upon arrival to your NICU for outborn infants, and from first set of vitals collected after stabilization and admission to NICU for inborn infants.
- (b) For each of the four items, *use the first available measurement within two hours of admission*. The four items may be obtained from different time points, but must be within two hours of admission.
- E.g. If baby is admitted at 0800 hr to your NICU, use the measurements taken as close to 0800 hr as possible. Include measurements taken up to and including 1000 hr.
- (c) If measurement is not available within two hours of admission for a particular item, check "unknown".

The same four items are recorded here as in pre-transport on the transport sheet: temperature, systolic blood pressure, respiratory status and response to a gestational age appropriate stimulus.

Refer to the definitions listed under the Transport Screen for these items, but remember to record them in the appropriate scoring time period. The TRIPS scores will be generated automatically after all necessary information has been entered (i.e. no "unknown" selections) and you click the Save button or go to another screen.

# SCREEN 7: SNAP SCREEN DEFINITIONS

nsferred/Died within 12										
the first 12 hours of adr	mission		Arterial Blood	Gases			If Low Flow			
	Highest	Lowest			FiO2	pO2	FiO2 Flow			
ean Blood Pressure			With Lowest p	002						
eart Rate			With Highest	MAWP						
the first 12 hours of adr	mission		With Highest	FiO2						
			Umbilical Cor	d Gases						
west Temperature					рН	pCO2	pO2	HCO3	Base Deficit	Base Excess
west Serum pH			UA	■ N/A						
rst Lactate			UV	□ N/A						
rine (cc)			Unspecified	■ N/A						
izures										
None Sin	ale	Multiple								

SNAP data on day one should be scored from the time of admission (defined as the time of first vitals in the NICU) for twelve (12) hours. Values occurring during an operation should be included. If you are missing information from the scoring period either because a flow sheet is missing, because the baby was transferred out, or died during the scoring period, complete the following screen using the information that is available. The SNAPII and SNAPIIPE scores are generated automatically once appropriate information is entered and the user clicks Save or moves to another screen. If the baby is transferred/died within the 12 hours, tick the checkbox at the top of the screen accordingly. If it is ticked, the SNAP score will not be calculated since it is based on twelve hours only.

#### Vital Signs:

Vital signs recorded while a baby is in the most stable condition possible. Score only non-zero values recorded in the chart for babies who are dying (i.e. do NOT score the low heart rate as zero for babies who die during a scoring period).

Values listed as a range should be scored as the midpoint. Values listed as "< a certain value" should be scored as point one (0.1) less than the value listed (e.g. a low temp of <34 should be scored as 33.9). Similarly, values listed as "> a certain value" should be scored as point one (0.1) more than the value listed.

#### Lab Values:

Lab values should be included in the scoring period if they are *drawn during the scoring period*. Time of draw should be taken from the flow sheet when this is explicitly recorded. If the time of the draw is not explicitly recorded on the flow sheet, assume the time the lab received the samples is within 15 minutes of the draw (in other words, include values listed as occurring within 15 minutes of the end of the scoring period).

Computer values should generally be considered more accurate than flow sheet/progress note values unless they are clearly being discounted by the clinicians. Lab values discounted by clinicians should not be recorded on SNAP. Hemolyzed values are acceptable. Pathology blood draws, cord specimens and other non-blood draws (CSF, urine) should *not* be scored on SNAP. Do not score "diluted" lab values or samples that are contaminated.

Transferred / Died within 12 hours	If this applies to the patient, check the box
Mean Blood Pressure: Low	Lowest mean arterial pressure (MAP), also called mean blood pressure (MBP), during the <i>time period</i> , as recorded in the nursing flow sheet. Arterial line pressures and cuff pressures should be weighted equally. If these values are very different, ask a staff member in the NICU or contact the CC for advice. If only systolic and diastolic pressures are recorded, assume <i>mean blood pressure = diastolic + 1/3 (systolic - diastolic)</i> . E.g. 55/43: MBP = 43 + 1/3 (55-43) = 47. If only one blood pressure is recorded during the scoring period, enter this value as both the high and low value. <i>Do NOT score the low blood pressure as 0 for babies who die during a scoring period</i> .
Heart Rate: High	Highest heart rate during the <i>time period</i> sustained for more than one minute continuously. Do not include transient heart rate values that reflect bradycardia associated with apnea/desats. If only one heart rate is recorded during the scoring period, enter this value as both the high and low value.
Heart Rate: Low	Lowest heart rate during the <i>time period</i> sustained for more than one minute continuously. Do not include transient heart rate values that reflect bradycardia associated with apnea/desats. If only one heart rate is taken during the scoring period, enter this value as both the high and low value. <i>Do NOT score the low heart rate as zero</i> (0) <i>for babies who die during a scoring period</i> .
Lowest Temperature	Lowest body temperature during the time period (axillary or rectal but not skin probe, which is the baby's temperature recorded through the isolette) recorded in Celsius.
Lowest Serum pH	Lowest pH during the <i>time period</i> . This may be obtained by arterial (ABG), capillary (CBG) or venous (VBG) blood gases.
First Lactate	Record the first lactate or lactic acid value reported from baby's blood. It could be venous, capillary or arterial. Do not include cord blood values.
Urine CCs	Total CCs of urine output during the <i>time period</i> . Do <i>not</i> divide by birth weight. <i>If notes indicate that</i> 20% or more of the total output for the time period was lost/unmeasured (recorded as mixed with stool, "VOID", or overflow) then leave the field blank. To calculate whether 20% was lost, if all urine output values list specific numbers, determine whether the uncertain values (CCs recorded as mixed with stool or overflow) make up 20% of the total CCs. If some values are not recorded at all (recorded as "VOID") then determine whether the uncertain values (unmeasured diapers) make up 20% of the total number of diapers.
Seizures	If only one seizure was confirmed, score as "single." If more than one seizure was confirmed, score as "multiple." Otherwise, check "none." Confirmed is defined as witnessed by two (2) or more clinicians or diagnosed by EEG or amplitude integrated EEG. Use of antiepileptics (phenobarbital) ALONE is not enough evidence for diagnosis. However, if antiepileptics are ordered by one clinician, and seizure is observed by a DIFFERENT clinician, assume the seizure is confirmed.

# **ARTERIAL BLOOD GASES**

Record only **arterial** blood gases, if there are no arterial blood gases recorded during the scoring period then leave this entire section blank. If there is only one arterial blood gas, enter the information required in the first line of blood gas with lowest pO2, and leave the remaining lines blank. When two values are available for blood gases (original and corrected for body temperature), use the corrected values.

Arterial Blood Gas with lowest pO2	Select the <i>arterial</i> blood gas (ABG) with the lowest pO2. If there are several blood gases at the same lowest pO2, record the one occurring first. Record the FiO2 (21% - 100%) at the time blood was drawn, and the PO2 from this blood gas.
	<i>FiO2</i> should be left blank if the baby was on blow-by oxygen at the time of the draw or if the FiO2 is unavailable. If the baby was on room air, record FiO2 as 21. FiO2s listed while "bagging" should be recorded.
	If the baby is on low flow oxygen during SNAP scoring period, please enter the value of the flow of additional gas in ml/min in the last column. At the same time you will need to enter how much oxygen concentration is given to the baby in the flow mixture.
	Examples:  1. If baby is getting 20 cc of low flow air - enter 20 cc in the last column and 21% in the FiO2 column.  2. If baby is getting 20 cc of low flow oxygen - enter 20 cc in the last column and 100% in FiO2 column.

	3. If baby is getting 20 cc of air and 50% oxygen mixture - enter 20 cc in the last column and 50% in FiO2 column.
Arterial Blood Gas with highest MAWP	Select the <i>arterial</i> blood gas with the highest mean airway pressure. If this is the same gas recorded above in the lowest PO2 row, select the gas with the next highest MAWP instead. If there are several blood gases at the same highest MAWP, record the one with the lowest PO2. If there are several gases with the same highest MAWP <i>and</i> the same lowest PO2, record the gas occurring first. If MAWP is '0' for the entire scoring period because the baby was never on assisted ventilation or no MAWPs are available, leave this row blank.  Record the FiO2 (21% - 100%) at the time blood was drawn, and the PO2 from this blood gas.
	FiO2 should be left blank if the baby was on blow-by oxygen at the time of the draw or if the FiO2 is unavailable. FiO2s listed while "bagging" should be recorded.  If the baby is on low flow oxygen during SNAP scoring period, please enter the value of the flow of additional gas in ml/min in the last column. At the same time you will need to enter how much oxygen concentration is given to the baby in the flow mixture.  Examples:  1. If baby is getting 20 cc of low flow air - enter 20 cc in the last column and 21% in the FiO2 column.  2. If baby is getting 20 cc of low flow oxygen - enter 20 cc in the last column and 100% in FiO2 column.  3. If baby is getting 20 cc of air and 50% oxygen mixture - enter 20 cc in the last column and 50% in FiO2 column.
Arterial Blood Gas with highest FiO2	Select the <i>arterial</i> blood gas with the highest FiO2. If this is the same gas recorded above in the lowest PO2 row OR in the highest MAWP row, select the gas with the next highest FiO2 instead. If there are several blood gases with the same highest FiO2, select the one with the lowest PO2. If there are several gases with the same highest FiO2 <i>AND</i> the same lowest PO2, select the gas occurring first.  Record the FiO2 (21% - 100%) at the time blood was drawn, and the PO2 from this blood gas. <i>FiO2</i> should be left blank if the baby was on blow-by oxygen at the time of the draw or if the FiO2 is unavailable. FiO2s listed while "bagging" should be recorded.  If the baby is on nasal canula or oxygen hood during SNAP scoring period, please enter the value of the flow of additional gas in ml/min in the last column. At the same time you will need to enter how much oxygen concentration is given to the baby in the flow mixture.  Examples:
	1. If baby is getting 20 cc of low flow air - enter 20 cc in the last column and 21% in the FiO2 column.

- 1. If baby is getting 20 cc of low flow air enter 20 cc in the last column and 21% in the FiO2 column.
- 2. If baby is getting 20 cc of low flow oxygen enter 20 cc in the last column and 100% in FiO2 column.
- 3. If baby is getting 20 cc of air and 50% oxygen mixture enter 20 cc in the last column and 50% in FiO2 column.

#### **UMBILICAL CORD GASES**

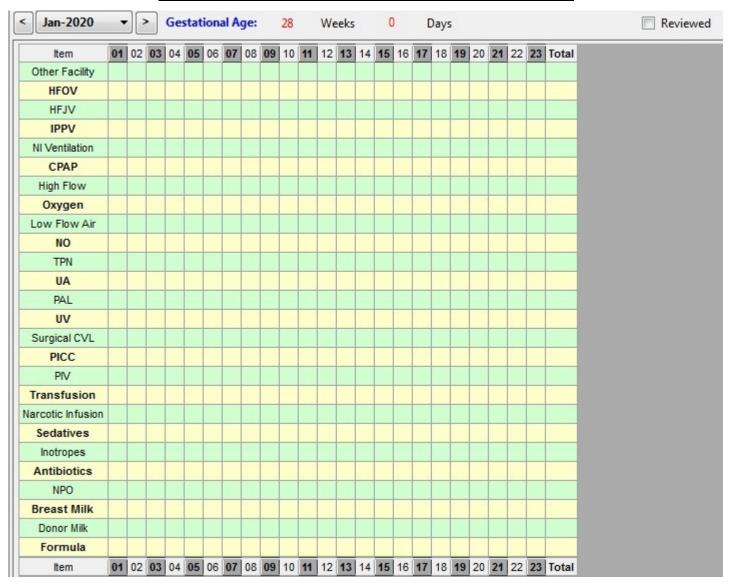
Record umbilical cord gases values from venous and arterial samplings. Cord gases values are auto-populated for readmissions of each baby. Select N/A if information is not available.

UA: Umbilical Arterial UV: Umbilical Venous

**Unspecified:** Unspecified source

**Base Excess / Base Deficit:** Record either Base Excess *or* Base Deficit as found on the lab report, and leave the other field blank. Each centre should be consistently reporting one of these two variables. Valid range from -30.0 to 30.0.

# **S**CREEN 8: PATIENT CHART SCREEN DEFINITIONS



This chart describes daily resource utilization by individual patients (absolute calendar day value. Day is considered from 00:00 hours to 23:59 hours on that calendar date). Resuscitation details which occur in the first 30 minutes after birth should be recorded in the Resuscitation Screen.

You need to click only boxes that apply to your patient. The chart will start from the date of admission and can be moved forward or backward as needed in terms of time. Until you submit the data this chart is editable. You can easily correct mistakes made in data entry. A group of respiratory support variables are included. Please read the explanation carefully as we would like to collect only the highest support received to a patient on a particular day. The chart is customizable for colour of row and column highlight as well as day to start and complete database. Please note that you can select multiple consecutive days by clicking on the start date, pressing and holding down the "Shift" key, and clicking again on the end date to automatically select all in between. *Therapies administered during an operation should be included*.

Item	Standard list of treatment items to select if patient is on item on a given day. Up to four additional items can be added for an individual site's own data collection upon request to CC.
	Day on which an item is administered.
	If the selected month is the admission month, the first day column displayed will be the admission day.
	If the selected month is the current month and baby is not discharged, the last day column shown will be today.
Day column	If the selected month is the current month and the baby is discharged already, the last day column shown will be the discharge day.
	This is the absolute calendar day value. Day is considered from 00:00 hours to 23:59 hours on that calendar date.
	The Day Of Admission and Day Name can be displayed if you hover over the header cell.
Total	Total number of days during the entire patient stay that a certain item was administered.
Total	This value is updated dynamically when cells are checked/unchecked.

Below are details and explanation of what should be included in each grid of data collection. Note that for respiratory support, you will have to select the highest support received by infant on a particular day and not all types of support that the patient received.

#	Item	Description of Item and Selection	n Criteria		
1	Other facility	If patient has gone to other facility for >a majority of part your facility click this box. Do not use this box if patient and is not expected/not returned within 24 hours. This box have left your unit temporarily and are likely to return or within 24 hours.	is discharged from your hospital x is only for those patients who		
2	HFOV (High frequency oscillatory ventilation)	For patient chart days in 2020 and onwards, select HFOV or HFJV where it applies.	These items are indicative of respiratory support. <b>Only one</b>		
3	HFJV (High frequency jet ventilation)	Only one of HFOV and HFJV can be selected for any given day on the patient chart.	of these items should be checked for a particular day. The highest support received		
4	IPPV	Intermittent positive pressure ventilation (IPPV): This includes all forms of mechanical ventilation with endotracheal tube (except HFOV and HFJV), as well as Neurally Adjusted Ventilatory Assist (NAVA), Synchronized Intermittent Positive Pressure (SIMV), Pressure Support Ventilation (PSV) and Volume Guarantee (VG).	by an infant should be checked for each day. Please do not include bagging for the treatment of apnea.  The hierarchy would be HFV/HFOV/HFJV followed by		
5	NI Ventilation	Non invasive ventilation: This includes all forms of non-invasive positive pressure support such as nIPPV, SNIPPV (synchronized nasal intermittent positive pressure ventilation), where on the ventilator machine the respiratory rate is set. NIHFOV (non-invasive high frequency oscillation ventilation) and non-invasive NAVA (Neurally Adjusted Ventilatory Assist) are included.	IPPV, followed by NI Ventilation, followed by CPAP and then High Flow. Enter the maximum support even if baby did not respond to the highest support.		
6	СРАР	Continuous positive airway pressure (CPAP): Includes bubble CPAP, infant flow driver CPAP, BiPAP (Biphasic positive airway pressure), SiPAP (Sigh-positive airway pressure). Please note that in SiPAP mode of ventilation, the rate set is for cycling between two levels of CPAP and not rate of ventilation. CPAP is scored regardless of route administered. CPAP can be scored if it is administered via any of: tracheostomy, endotracheal tube or prongs.			
7	High Flow	Click this if the infant is receiving oxygen or air at a			

	rate >1.5 litres/minute. Also score if infant is getting humidified air at >1.5 litres/minute but in room air (e.g. AIRVO).
Oxygen	Click this if infant is receiving oxygen higher than 21% at any given time of day. This is irrespective of whether patient is receiving mechanical ventilatory support or not. This includes if patient is receiving oxygen only for suctioning or while bottle feeding etc. This will also capture low flow oxygen as only this box will be checked. Also score if infant is getting additional oxygen (higher than 21%) via connected flow (e.g. AIRVO).
Low Flow Air	Click this if infant is receiving low flow air via nasal cannula and not oxygen. Low flow air can be selected only if the patient is on low flow air without oxygen and is not receiving any of items 2-6 (HFV, IPPV, NI ventilation, CPAP, or High Flow) at any time during the 24 hour period.
NO	Use of nitric oxide on that day
TPN	Use of total parenteral nutrition (aminoacids with or without lipids) on that day
UA	Umbilical arterial catheter on that day. Only report if it was being used in NICU.
	Peripheral arterial catheter on that day. Only report if it was being used on that day.
	Patients with two catheters on same day will be marked once only.
UV	Umbilical venous catheter on that day. Only report if it was being used on that day. Mark even if it is only saline locked or heparin locked. Patients with two catheters on same day will be marked once only.
Surgical CVL	Central venous catheter other than umbilical venous catheter inserted surgically or by cutdown. This includes surgically placed catheters, broviac lines, HICKMAN <sup>TM</sup> catheters, central portacath etc. Only report if it was being used on that day. Patients with two catheters on same day will be marked once only. This also includes PICC lines inserted via "cut down" in the NICU or OR.
	Peripherally inserted central catheter typically placed in the NICU. It may be placed by image guided therapy by a radiologist. Only report if it was being used on that day. Mark even if it is only saline locked or heparin locked. Patients with two catheters on same day will be marked once only.
PIV	Peripheral intravenous catheter (including intraosseous line) on that day. Only report if it was being used on that day. Mark even if it is only saline locked or heparin locked. Patients with two catheters on same day will be marked once only.
NPO	Days when infant is not fed anything orally over entire 24 hour period. If infant is receiving any oral feeds, including sham feeds, do not score this item.
Transfusions	Click the day when blood or platelet transfusion was initiated. Do not include any other blood products. <i>Only click the day of initiation</i> . Do not click subsequent day(s) when the transfusion spanned over multiple days.
	Note: The total number of transfusions is collected in the Cultures/Transfusion Screen.
	Packed red blood cells – yes Whole blood (regardless of reason) – yes Platelets – yes
	Fresh Frozen Plasma - no
	Cryoprecipitate - no Albumin - no
	Immunoglobulin – no
Narcotic Infusion	Days when infant is receiving narcotic infusion. This includes morphine, fentanyl,
	alfentanyl and newer narcotics. Continuous infusion and not bolus infusion.  Do not include epidural given post-operatively and epidural Fentanyl.
Sedatives	Days when infant is receiving sedatives such as midazolam, chloral hydrate,
	dexmedetomidine etc. This could be oral or parenteral, and intermittent or infusion.
Inotropes	Days when infant is receiving dopamine, dobutamine, epinephrine, norepinephrine, milrinone and phenylephrine. Use of epinephrine for resuscitation does not count in this
	Low Flow Air  NO TPN UA PAL UV  Surgical CVL  PICC  PIV  NPO Transfusions  Narcotic Infusion  Sedatives

		field.	
23	Antibiotics	Days when infant is receiving treatment doses of systemic antibiotics. This includes antibiotics used in pre- and post-surgery, and antibiotics for Congenital Toxoplasmosis.  Excludes: topical antibiotics, antibiotics used for other conditions (such as Trimethoprim for reflux, UTI prophylaxis, Fluconazole prophylaxis for antifungal). In Patient Chart Screen, DO NOT score antibiotics given for prophylactic interventions.	
24	Breast Milk	Use of biological mother's breast milk $\geq$ 0.5 ml given enterally irrespective of frequency during a given day. Do not include Oral Immune Therapy.	
25	Donor Milk	Use of donor human breast milk $\geq$ 0.5 ml (including that from non-biological mother) given enterally irrespective of frequency during a given day.	
26	Formula	Use of formula $\geq$ 0.5 ml given enterally irrespective of frequency during a given day.	

Note: For items 20-23, please indicate the days on which medication was actually administered.

# SCREEN 9: DIAGNOSIS/PROCEDURES SCREEN DEFINITIONS

Diagnosis / Procedures					Reviewed
Prophylactic Interventions	PDA			Any Time	
Indomethacin Antifungal Probiotics Other  CNS Seizures None Suspected Definite Treated Yes No	Yes No Unknown	If Yes:  Treated Not  If Treated:  Acetaminophen  Ibuprofen  Indomethacin  Ligation  [Enter Date]  Surgical  Device Closure	Treated Diagnosed By Clinical Echo	Operations/Procedure ECMO Laparotomy Thoracotomy Reservoir/Drain Gastro-Intestinal Perfo None NEC Related Spontaneous Unknown	<ul><li>□ VP Shunt</li><li>□ Ostomy</li><li>□ Other CNS surgery</li><li>□ Others</li></ul>
HIE None Stage II Not Available Stage III Unknown Stage Stage I	Thrombosis  Yes  If Yes  Arterial	No Unk	Location	NEC Stage 2 or Higher Yes If Yes NEC Date (First episo	No
Lungs Oxygen Reduction Test Yes No Unknown  RDS None Uncertain Definite NA / Unknown	Aortic Renal Cerebral Other Unknown	Cerebral venous  Other  Unknown	Method of	[Enter Date]	Autopsy/Biopsy Clinical X-Ray Ultrasound Unknown
Pneumothorax  Pneumothorax  If Yes  Pneumothorax Date  [Enter Date]  Treatment  Observation  Chest Tube	Catheter (line) removal Standard Heparin		diagnosis Clinical Imaging Unknown	Were there multiple	
☐ Needle Paracentesis				Exchange Transfus	ion
Congenital Anomalies Other Diagnosis					
Congenital Anomaly Type			System		
*					

Score all major diagnoses and procedures that that you are aware for the infant on this screen. If a baby is transferred into your NICU, score only issues pertaining to the baby at the time of transfer into your NICU. If the initial diagnosis of a current issue occurred at the transferring hospital, use the admission date to your NICU as the diagnosis date.

Likewise for readmission records, you are not required to record diagnoses that have already been resolved in the initial admission. Note that only ongoing and new issues pertinent to this particular (readmission) visit need be recorded. Do *not* score questionable diagnoses except where the data item has an uncertain/suspected category (i.e. RDS, seizures). *If there are conflicting diagnoses, where available use autopsy findings as they are more reliable than diagnostic tests*.

Prophylactic	Check off any applicable interventions that have been given to the patient. These interventions have to be
Interventions	given for prophylactic purposes only. They have to be administered before a relevant diagnosis is ascertained. These interventions are usually given in the first 24-36 hours after birth. For interventions not listed, select "other" and write the intervention in the free text box (maximum 50 characters).
Indomethacin	Check this if indomethacin was used within the first 24 hours of life and was not used for the purpose of PDA treatment. There would have been a unit policy to give indomethacin for the prevention of IVH.
Probiotics	Check this if infant was started on any form of probiotics for prevention of NEC and/or sepsis.
Antifungal	Administration of antifungal agent e.g. Fluconazole, Nystatin or other antifungal agent from birth or immediately after birth with explicit interest of <b>prevention</b> of fungal infection. Initiation of antifungal agent for suspected fungal infection should <i>not</i> be counted here. This is usually based on unit policy.
Other	If infant was commenced on any other intervention that were reported to be of prophylactic nature.
CNS: Seizures	Occurrence of seizures at any time during the hospital stay.  Score "None" if there were no seizures or seizure-like movements mentioned during the hospital stay.
	<ul> <li>Score "Suspected" if:</li> <li>observed by only one clinician</li> <li>there were movements of uncertain significance observed by more than one person. Descriptions of seizure like movements should be considered movements of uncertain significance when not</li> </ul>
	accompanied by a diagnosis of seizures or administration of phenobarbital.  Score "Definite" if:  witnessed by 2 or more clinicians  diagnosed by EEG or a-EEG  there is one clinical observation of seizure like movements coupled with administration of phenobarbital or with a diagnosis of seizures by a different clinician. The use of antiepileptics/anticonvulsants (i.e. phenobarbital) is not alone evidence of definitive diagnosis, but can be
	considered as confirmation if prescribed by a second clinician.  When an EEG is normal and contradicts a seizure diagnosis, score according to attending physician/neurologist diagnosis made <i>after</i> reviewing the EEG results.
	Indicate whether the seizure was treated by checking the appropriate box to the right.
CNS: Hypoxic-	Score this section <i>only</i> if all of the following preliminary conditions are met
Ischemic encephalopathy (HIE)	1. Documented evidence of an acute perinatal event such as fetal distress, cord prolapse, uterine rupture, reduced fetal movements, abruption, antepartum hemorrhage or emergency cesarean section due to fetal distress
()	<ul> <li>2. Evidence of intrapartum hypoxia: at least one of:</li> <li>a. Apgar score of ≤5 at 10 minutes;</li> <li>b. Mechanical ventilation or resuscitation within 10 minutes;</li> </ul>
	<ul> <li>c. Cord pH &lt; 7.00 (venous or arterial), or an infant arterial pH &lt; 7.00 or base deficit ≥ 12 within 60 minutes of birth</li> <li>Record data for encephalopathy if the above criteria are met.</li> </ul>
	Record data for encephanopathy if the above criteria are met.
	1. <b>None:</b> either baby does not meet entry criteria, or baby meets <u>some</u> criteria but has <u>no</u> evidence of encephalopathy
	<ul> <li>2. Not available: baby died before a diagnosis could be made or data is unavailable</li> <li>3. Unknown Stage: (either of)</li> <li>a. baby meets entry criteria but data on staging could not be ascertained</li> </ul>
	<ul> <li>b. baby did not meet entry criteria but hypothermia treatment initiated</li> <li>4. If the chart mentions staging of encephalopathy, use the highest grade at any time during the stay in NICU (Stage I = Mild; Stage II = Moderate and Stage III = Severe)</li> </ul>
	<ul> <li>5. If seizures are present, record as Stage II or Moderate encephalopathy</li> <li>6. If the chart is unclear about staging, check for data on neurological examination and record</li> <li>a. Stage I or Mild: irritability, jitteriness, hyperalertness</li> </ul>
	b. Stage II or Moderate: lethargy, hyper-reflexia, miosis, bradycardia, seizures, abnormal tone, weak suck, incomplete Moro reflex, decreased activity, distal flexion, complete extension, hypotonia (focal or general), constricted pupils and periodic breathing
	c. Stage III or Severe: stupor, coma, flaccidity, deviated, dilated or small to mid-position pupils which react poorly to light, decreased stretch reflexes, hypothermia, absence of Moro reflex and sucking, decerebrate posture, variable heart rate and apnea
	The Encephalopathy screen will activate only when Mild, Moderate, Severe, or Unknown Stage is selected.
PDA	First question would be whether infant has PDA or not, or if it is unknown.

If infant has no clinical suspicion of PDA – enter no. If infant received treatment for PDA – enter yes. If infant had clinical or echocardiographic suspicion of PDA – enter yes. Do not score PDA if the ductus arteriosus is artificially kept open due to critical cardiac defect, which is done by giving Prostaglandin/Alprostadil/Prostin. In such scenario, PDA is not an anomaly. It happens when the patient has duct dependent cardiac malformation such as Transposition of great vessels, Hypoplastic left heart, and condition associated with single ventricle physiology. If PDA was detected, then was it treated? yes or no If it was treated – how? (select all that applies) 1. Acetaminophen 2. Ibuprofen 3. Indomethacin 4. Ligation & date (also score as Operations/Procedures "Others") If PDA ligation was performed, select one of the following: 1. Surgical closure 2. Device closure - A device was inserted by cardiac catheterization for ductal occlusion. Indicate how PDA was diagnosed – clinical or via echocardiography. Do not score only for the fact that infant had an echocardiogram, but score if PDA was diagnosed by this route. You can select both options if applicable. Oxygen Reduction Many units have adopted conducting oxygen reduction test at 36 weeks of GA for neonates who are in <30% Test oxygen and not on either CPAP or other positive pressure support. Based on the results of this test, they identify baby as having BPD or not. Please record "yes" if the baby had this test irrespective of whether baby was classified as "pass" or "fail". **RDS Respiratory distress syndrome (RDS)**, sometimes called hyaline membrane disease (HMD), should be diagnosed within the first two days after birth (ie on day 1 or 2). The classical signs of RDS are less commonly seen today because of the use of exogenous surfactants for RDS prophylaxis and early rescue. RDS most commonly occurs in preterm babies but can occur in term babies. RDS is recorded by clinical certainty and not by severity. There is a hierarchy to the identification of a baby with RDS: firstly, the chest x-ray report from day 1 or 2; secondly according to physician diagnosis; and thirdly, if there is surfactant administration after 2 hours of age (on day 1 or 2). This hierarchy is to be used when there are conflicting diagnoses. However, if any one of the sources is definite, and the others are not, score RDS according to what definite information you have. If the evidence is conflicting, you may seek clarification from an involved physician. Score "Definite" if: (1) a chest x-ray report from day 1 or 2 reports definite RDS, Hyaline membrane disease (HMD) OR (2) clinicians specify definite RDS based on typical symptoms and signs (grunting and retractions and/or oxygen requirement), and/or a typical chest x-ray (diffuse granularity, "ground glass"), OR (3) exogenous surfactant is administered beyond 2 hours of age (on day 1 or 2) but not for meconium aspiration syndrome or pneumonia or pulmonary hemorrhage. If the CXR expresses doubt about the diagnosis, review the physician diagnosis with attention to dates of diagnoses as compared with x-ray dates, and find out if surfactant was given. Score "None" if:

- (1) the clinicians describe "respiratory distress" without a specific diagnosis of RDS, no X-ray confirmation, and no administration of surfactant, OR
- (2) there is a confirmed alternative pulmonary condition (for example "transient tachypnea of the newborn", "meconium aspiration syndrome", "congenital pneumonia") and no RDS according to any of the three definitions, OR
- (3) if there is no respiratory distress and none of the three definitions are satisfied.

	Score "Uncertain" if:
	(1) there was respiratory distress in the first 2 days of age but the clinicians recorded doubt about the diagnosis of RDS, OR (2) surfactant was given in the first 2 hours after birth and there was no subsequent confirmation of diagnosis
	of RDS by CXR or clinically, and no further treatment with surfactant.
	Do not score uncertain if you are unsure about what the clinicians are saying. In this case, investigate further in the chart, or ask one of the clinicians in the NICU about RDS.
	Score "Unknown/NA" if the baby died shortly after birth and no diagnosis of RDS was made.
Pneumothorax	Occurrence of pneumothorax, as diagnosed by chest x-ray, thoracentesis with documented removal of air or autopsy report. While placement of a chest tube is a common response, it is not necessary for diagnosis. This field does not include pulmonary interstitial emphysema (PIE).
Pneumothorax date and treatment	Date of occurrence of the <i>first definite</i> pneumothorax by chest x-ray, documented needle aspiration <i>or autopsy report. If the first time a pneumothorax is diagnosed is by autopsy report, score the date of death (not the date of autopsy) as the pneumothorax date.</i> If the baby is transferred in with a pneumothorax, record the pneumothorax date as the admission date and record the date <i>of the first pneumothorax diagnosed</i> at the transferring hospital in the comments box, if available. If date of first pneumothorax is unknown, leave the field blank. If no pneumothorax during this hospital visit, leave blank.  Treatment of pneumothorax:  1. Observation (No intervention was performed)  2. Needle paracentesis or needle thoracentesis: This means draining air from pleural space with a needle and syringe and not leaving any permanent drainage.  3. Chest tube placement: This means placing a tube in chest wall and draining air via negative pressure suction.
Neonatal	Yes, no or unknown
Thrombosis	
- Location	The report should clearly mention about the presence of a thrombus. Presence of infarct, necrosis or ischemia does not necessarily mean that there was a thrombus. Please review the report completely for the reporting of "thrombus" or "clot".
	If Yes, select location (multiple selections are permissible):
	1. Arterial 2. Venous
	2. Venous 3. Cardiac
	4. Location unknown
	For Arterial, select from the following options where appropriate (multiple selections are permissible):  1. Aortic 2. Renal
	3. Cerebral (includes anterior, middle, posterior cerebral arteries etc.)
	<ul><li>4. Other: (includes carotid, brachial, femoral arteries etc.)</li><li>5. Unknown</li></ul>
	For Venous, select from the following options where appropriate (multiple selections are permissible):  1. Umbilical venous
	2. Portal 3. Renal
	4. Cerebral Venus
	<ul><li>5. Other (includes brachiocephalic, axillary, femoral, common iliac veins etc.)</li><li>6. Unknown</li></ul>
Neonatal	Select from (multiple selections are permissible):
Thrombosis - Method of	1. Clinical (signs and symptoms include loss of pulsation, change in color, palpation of clot in the vessel and other symptoms depending upon location of thrombus)
Diagnosis	<ol> <li>Imaging (includes but not limited to ultrasonography, angiography, Doppler, CT scan or MRI etc.)</li> <li>Unknown</li> </ol>
Neonatal	Select from (multiple selections are permissible):

Thrombosis	Conservative (includes elevation of limb, compresses and careful observation etc.)
- Treatment	2. Catheter (line) removal (includes removal of catheter after diagnosis of clot)
	3. Standard Heparin (unfractionated heparin usually used as continuous infusion, DO NOT include
	prophylactic use of heparin to prevent thrombus)
	4. Low molecular weight heparin (This includes Enoxaparin, Dalteparin, Tinzaparin, Nadroparin,
	Bemiparin, Centoparin, Nadroparin, Parmaparin or Reviparin etc.)
	5. Other anticoagulants (This includes Warfarin or other thrombolytic therapy such as urokinase)
	6. Other treatment (This includes surgical removal of thrombus, or image guided therapy to snare
	thrombus and any other method specifically designed to remove or dissolve thrombus not specified
	above)
	7. Unknown

#### **OPERATIONS / PROCEDURES**

\*Record operations that occurred at any time during infant's stay. Some operations may not have been performed in your hospital (such as PDA ligation or ROP surgery). These should be documented in patient charts as for some of them an infant may go to another hospital for less than 24 hours and the data may not be captured. If relevant make a note of these instances in the comments box. If multiple operations were performed under the same anesthesia episode, include them all.

ECMO	On extra corporeal membrane oxygenation (ECMO) at any time during the hospital stay. ECMO given as part of an operation should be scored here, but a note should also be made in the comments box that ECMO was given as part of an operation and not as a procedure unto itself.
Laparotomy	Laparotomy ( <i>abdominal exploration</i> ) for surgical resolution of a variety of problems, excluding laparoscopy. For a complete list of procedures included under laparotomy, see appendix II.
Thoracotomy	Thoracotomy ( <i>chest exploration</i> ) for surgical resolution of a variety of reasons, excluding thorascopy. For a complete list of procedures included under thoracotomy, see appendix II.
VP shunt	Placement of reservoir or shunt for drainage of cerebro-spinal fluid (CSF).
Reservoir/Drain	Reservoir/Drain includes any type of CSF drainage procedure other than VP shunt. It includes ventriculostomy.
Ostomy	Score this if ostomy was performed at any time during the hospital stay (include ileostomy or colostomy, but not tracheostomy or gastrostomy). Score regardless of where the original ostomy surgery occurred. Ostomy at time of discharge/transfer is also collected under the Discharge Screen.
Other CNS Surgery	Other CNS surgery includes myelomeingeocele repair or spina bifida related surgeries.
Others	Check box for any other operation. You can score operations such as BAS, surgically placed catheters, gastrostomy tube insertions, hernia repairs, rectal biopsies, PDA ligations and ROP therapies.  Refer to appendix II for a list of operations that can be included in Others.
Gastro-Intestinal Perforation	Presence of free air under diaphragm or aspiration of intestinal contents from abdominal cavity suggest intestinal perforation. Possible causes are  1. NEC related: Perforation in a patient who is also diagnosed as having NEC (see below)  2. Spontaneous: In a patient who does not show evidence of NEC. Typically this occurs in the first week after birth.  3. Unknown: If the type is not identified then select unknown.  This also includes gastric perforation.  SIP Date and Treatment is enabled when "Spontaneous" is checked above.  Spontaneous Intestinal Perforation (SIP): Approximately 50% of neonates who are diagnosed with intestinal perforation are now classified as SIP. This means that on further clinical, sonographic and operative assessment revealed no signs of ischemia or inflammation in baby diagnosed with perforation.
	This entity is termed as SIP. Treatment for this is similar to NEC related perforation with peritoneal drainage alone, surgery alone or peritoneal drainage followed by surgery (3 options available).

NEC Stage 2 or Higher	Necrotizing enterocolitis (NEC) according to Bell's criteria, stage 2 or higher (mandatory field). If there is definite pneumatosis (air in the bowel wall) or portal/hepatic air (air in the liver) diagnosed by x-ray or other imaging techniques, or if there is a surgical or autopsy diagnosis of NEC. If surgical/autopsy diagnosis conflicts with x-ray diagnosis, the surgical/autopsy diagnosis takes priority. X-rays showing free air WITHOUT pneumatosis do NOT count as NEC diagnoses. Bloody stools without pneumatosis may lead to
	a suspected diagnosis and treatment, but is <i>not</i> counted as NEC diagnosis. <i>Score "No" if:</i> there was no NEC diagnosed according to our definition during the hospital stay.
	If yes, mention stages:  1. Stage II: medical suspicion confirmed by pneumatosis  2. Stage III: Perforation
	3. Unknown: If it is not known whether to call stage II or III.
NEC Date	Date of the first definitive diagnosis of NEC (pneumatosis diagnosed by x-ray, other imaging techniques or by surgery). Record as YYYYMMDD. If pneumatosis is suspected on medical imaging and then NEC is diagnosed definitively by surgery/autopsy, score the date of onset of NEC as the date of the first medical imaging that showed a suspicion of pneumatosis. If unknown, leave the field blank.
NEC Diagnosed By	If pneumatosis was found, record whether it was diagnosed by autopsy/biopsy, clinical, x-ray or ultrasound. Select all that apply. Select unknown if information is not available.
NEC Treatment	Record if patient required surgical treatment or peritoneal drainage. Surgical treatment includes laparotomy.  Peritoneal drainage alone is not considered surgical treatment. However, if your unit practices "minilaparaotomy" it should be included under surgical treatment and operations. You will be able to select both if patient initially had peritoneal drainage and later went for surgery.
Multiple Episodes	Indicate if more than one episode of NEC occurred prior to discharge.
Acquired Stricture	If patient was later diagnosed as stricture possibly related to NEC, mention it here. Patients may or may not have stage 2 or stage 3 NEC diagnosis in the early period (mandatory field).
Exchange transfusion	Check if patient received single volume or double volume or partial <b>exchange transfusion</b> (mandatory field).

## **CONGENITAL ANOMALIES / OTHER DIAGNOSIS**

Congenital	Record all diagnosed congenital anomalies of a patient. Record only confirmed anomalies, anomalies that are				
Anomaly Type	"questionable" or "pending" should <i>not</i> be recorded. Do not enter if a baby returns for readmissions and the				
	anomaly was fully repaired <u>prior</u> to this readmission.				
	Anomalies are grouped under the systems they relate to and then listed alphabetically. Selecting the				
	appropriate system from the system scroll down list will limit the anomalies that appear in the type scroll				
	down list. If you cannot find a specific anomaly listed here check appendix IV for additional help in				
	identifying how a given anomaly is recorded in the database. If you think a major anomaly is not listed, or if				
	it requires specification, contact the CC for advice.				
Other Diagnosis	Record additional major diagnoses included in the scroll down list provided. Record only confirmed				
	diagnoses, diagnoses that are "questionable" or "pending" should <i>not</i> be recorded. Note that some diagnoses				
	may be worded differently at various hospitals. For example a diagnosis of "hypoglycemia" is listed on the				
	scroll down list as "hypoglycaemia". If you cannot find a given diagnosis in the list, check appendix III for				
	additional help in identifying how a given diagnosis may be recorded in the database.				
	Optional: For any diagnoses that are not listed in the "Diagnosis Type" scroll down menu, "Other" may be				
	chosen and a free text field (maximum characters=100) for "Other Diagnosis Description" may be entered.				

# **SCREEN 10: ENCEPHALOPATHY SCREEN DEFINITIONS**

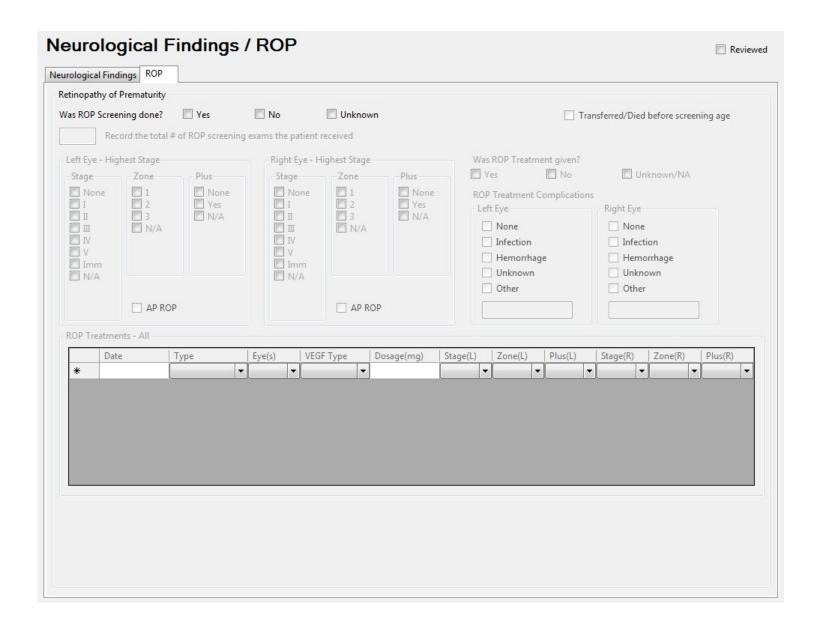
Yes	Encephalopathy		Reviewed
Selective Head   Sele			
Selective Head   Body Cooling	If yes		
Body Cooling			
Target temperature (°C)	Initiation		Death
Target temperature (*C)	Temperature		
Highest recorded temperature during hypothermia (°C) N/A  Clinical Status  At initiation of hypothermia At completion of hypothermia Hypotension requiring treatment Yes No Thrombocytopenia requiring treatment Yes No Cagulopathy HIE Stage I	Target tempe		
At initiation of hypothermia Encephalopathy HIE Stage I			
At initiation of hypothermia Encephalopathy HIE Stage I	Clinical Status	Side effects during hypothermia	If No: Reasons
HIE Stage II		Hypotension requiring treatment Yes No	Chromosomal anomaly
HIE Stage II	The state of the s	Thrombocytopenia requiring treatment Yes No	
HIE Stage III		Coagulopathy requiring intervention 🔲 Yes 🔲 No	Extreme condition
Normal  Normal  Normal  Normal  Normal  Any other side effects  Unit policy Health care team preference Delayed transfer Parental request Unknown  Other Complications of Asphyxia  Yes No Unknown  If yes No Unknown  If yes No Unknown  If yes No Unknown  If yes Date of first imaging [Enter Date] Normal Discontinuous Iso electric Normal Was attes Epilepticus Other  Was attes Epilepticus Other  Was attes Epilepticus Other  Was attes Epilepticus Other Other Other Other Other Cardiac dysfunction Other		Persistent metabolic acidosis 🔲 Yes 🔃 No	Head trauma or intracranial hemorrhage
Health care team preference   Delayed transfer   Parental request   Unknown		Any other side effects	
Delayed transfer   Parental request   Unknown	Normal		
Parental request	Science		
Investigations  Was Full Channel EEG performed?  Yes No Unknown  If yes Normal Burst suppression Discontinuous Iso electric Low amplitude Unknown Status Epilepticus Other  Was aeEEG performed?  Yes No Unknown  If yes Date of first imaging [Enter Date] Normal Watershed injury / white matter Basal ganglia / thalamic injury / grey matter Porencephalic cyst Diffusion changes Spectroscopic changes Hemorrhage Unknown Other Unknown Other	Seizures		
Was Full Channel EEG performed?  Yes No Unknown  If yes Normal Burst suppression Discontinuous Iso electric Dother Channel Basal ganglia / thalamic injury / grey matter Porencephalic cyst Diffusion changes Spectroscopic changes Hemorrhage Unknown  If yes Unknown  Other Complications of Asphyxia PPHN Renal failure DIC Hepatic dysfunction Cardiac dysfunction Cardiac dysfunction Unknown Other Other Other Complications of Asphyxia			
Was Full Channel EEG performed?  Yes No Unknown  If yes  Normal Burst suppression Discontinuous Iso electric Low amplitude Unknown  Status Epilepticus Other  Was aeeg performed?  Was neuroimaging (MRI/MRS) performed?  Yes No Unknown  If yes  Date of first imaging [Enter Date]  Normal Watershed injury / white matter Basal ganglia / thalamic injury / grey matter Porencephalic cyst Diffusion changes Spectroscopic changes Hemorrhage Unknown Other  Other Complications of Asphyxia  PPHN Renal failure DIC Cardiac dysfunction Cardiac dysfunction  Cardiac dysfunction Other  Other Complications of Asphyxia			Onkriown
Yes		w · · · Amphana) · · · In	al a h : 5. l :
If yes    Normal			
Normal			
Discontinuous Iso electric Normal Watershed injury / white matter  Status Epilepticus Other  Basal ganglia / thalamic injury / grey matter  Porencephalic cyst  Diffusion changes  Spectroscopic changes  Spectroscopic changes  Hemorrhage  Unknown  If yes  Unknown  Other  Other  Other  Watershed injury / white matter  Porencephalic cyst  Diffusion changes  Spectroscopic changes  Unknown  Other  Other  Other			
Low amplitude Unknown Watershed injury / white matter Status Epilepticus Other  Basal ganglia / thalamic injury / grey matter Porencephalic cyst Diffusion changes Spectroscopic changes Spectroscopic changes Hemorrhage Unknown Unknown Other  Unknown Other  Mild abnormality Iso electric Moderate abnormality Seizures			
Status Epilepticus Other Basal ganglia / thalamic injury / grey matter Porencephalic cyst Diffusion changes Spectroscopic changes Spectroscopic changes Hemorrhage Unknown Unknown Other Other Status Epilepticus Other Other Other Other Other Spectroscopic changes Other Other Other			
Basal ganglia / thalamic injury / grey matter   Porencephalic cyst   Diffusion changes   Spectroscopic changes   Spectroscopic changes   Hemorrhage   Unknown   Unknown   Unknown   Other   Other   Mild abnormality   Iso electric   Moderate abnormality   Seizures			
Was aEEG performed?  Yes No Unknown  If yes  Normal Burst suppression  Mild abnormality Iso electric  Moderate abnormality Seizures			tter
Was aEEG performed?  Yes No Unknown  Hemorrhage  Unknown  Unknown  Other  Mild abnormality Iso electric  Moderate abnormality Seizures			
Tyes No Unknown Hemorrhage  If yes Unknown  Normal Burst suppression  Mild abnormality Iso electric  Moderate abnormality Seizures			
If yes Unknown  Normal Burst suppression  Mild abnormality Iso electric  Moderate abnormality Seizures			
Normal Burst suppression Other  Mild abnormality Iso electric  Moderate abnormality Seizures			
Mild abnormality Iso electric Moderate abnormality Seizures			
Moderate abnormality Seizures		ession	
Other			
	Onknown Other		

This screen will be activated if in the "Diagnosis / Procedures" screen it was recorded that baby has any degree of encephalopathy except for none. You need to complete this screen if it is activated in order to complete the case.

Hypothermia treatment	Mention here whether patient received hypothermia treatment or not. If patient has received hypothermia further screen detailing treatment will be activated. Hypothermia treatment is defined as active attempts to maintain temperature below 35.5°C after HIE was diagnosed (mandatory field).
Method of Hypothermia	If hypothermia was given mention method of hypothermia. This usually confines to standard method used in your unit and very rarely changes between patients.
Timing	Enter timings for initiation of active/passive hypothermia and when warming was initiated. In the event of baby's death whilst receiving hypothermia, please enter time of death as the time of rewarming.
Temperature	Select target temperature range that was planned. This will again conform to your unit policy and would be constant in your unit. From continuous monitoring of patient, enter the lowest and the highest recorded temperature during hypothermia treatment.
Clinical Status	From clinical records, enter HIE staging before (within 6 hours of initiation of hypothermia) and after hypothermia (6 hours after completion of hypothermia). Document if patient had seizures within 6 hours of initiation of hypothermia. If the clinical status is unknown, mention unknown or if it is normal, check normal.
Side Effects	<ol> <li>If patient developed any side effect during hypothermia record it here.</li> <li>Hypotension requiring treatment: Treatment could be in the form of fluid or inotropes.</li> <li>Thrombocytopenia requiring treatment: Treatment would be in the form of platelet transfusion.</li> <li>Coagulopathy requiring intervention: Intervention could be in the form of FFP, Plasma or blood transfusion.</li> <li>Persistent metabolic acidosis: Defined as pH &lt;7.0 on two consecutive samples obtained at least 6 hours apart after initiation of hypothermia</li> <li>Any other complication / side effect not mentioned above can be free-texted (maximum 50 characters). Bradycardia should not be included in this as it is a known effect.</li> </ol>
Was hypothermia discontinued before 72 hours of treatment?	Indicate whether hypothermia was discontinued before 72 hours by choosing "yes" or "no". If yes, please identify the reason for discontinuation of hypothermia from the list provided.
Reasons if No	If hypothermia was not provided please identify reason.
Investigations: EEG	Indicate if full channel EEG (12 or 16 channels/electrodes placed and full EEG tracing taken) was performed and classify findings of background activity as indicated. This refers to background activity only (mandatory field).
Investigations: aEEG/CFM	Amplitude-integrated EEG (aEEG) is a method for electrocortical monitoring, whereas Cerebral Function Monitor (CFM) refers to the device for trend monitoring of changes in the amplitude of the electroencephalogram.  Select if aEEG or CFM was performed. If it was performed, indicate the worst result during recording. If seizures were detected during aEEG/CFM, record it here as well (mandatory field).
Investigations: MRI	If neuroimaging in the form of MRI or MRS was performed indicate the results and date of scan. Note that some of the results collected are broad (diffusion changes, restriction changes etc). In the initial period of data collection, this will be kept like this (mandatory field). The "Other" field can hold a maximum of 50 characters.
Other complications of asphyxia	<ol> <li>Complications of asphyxia should be mentioned here. You can choose multiple options.</li> <li>PPHN: Diagnosis will ideally require echocardiographic evidence; however, it may not be practical at every site and we will take any definition used in the chart.</li> <li>Renal failure: Urine output &lt;0.5 ml/kg/hr OR rising creatinine &gt;100 mmol/l at any time within first 72 hours</li> <li>DIC: Evidence of Coagulopathy for which no explanation could be provided.</li> <li>Hepatic dysfunction: AST or ALT &gt;100 IU at any time in the first 7 days after birth Cardiac dysfunction: Need for inotrope to support BP or echocardiographic evidence of cardiac dysfunction.</li> </ol>

# Screen 11: NEUROLOGICAL FINDINGS / ROP SCREEN DEFINITIONS





Score the Neurological Findings portion of the screen based on all head ultrasounds, CT scans and MRIs done during this NICU admission and taken during the appropriate time periods. If you come across any serious outcomes, which are not included on the Neurological Findings & ROP screen mention them in "other" section. The following should not be scored here: "possible" or "questionable" diagnoses, subarachnoid hemorrhages, subdural hemorrhages, tentorial bleeds, fluid collections in the brain, arachnoid cysts, caudothalmic groove cysts, choroid plexus cysts, subependymal cysts or cysts other than those found in the brain parenchyma (the brain itself). If there are conflicting diagnoses, where available use autopsy findings as they are more reliable than diagnostic tests. Also note that MRI findings should be used over Ultrasound findings.

See appendix III to confirm hemorrhages that are to be included under 'other diagnosis' on the diagnosis/procedures screen. Record only "congenital cerebral cysts" (found in the brain parenchyma) under congenital anomalies (nervous cyst); other cysts not mentioned below need not be scored.

## **NEUROLOGICAL / AUTOPSY FINDINGS**

- ❖ Score "questionable" and "possible" as None
- Score "suggestive of..." and "most likely..." as Suspected

Brain Lesions (Ultrasound and/or	Was any neuroimaging performed during infant's stay in NICU? Mark yes, no or unknown. Mark yes if you have report from autopsy of brain (mandatory field).
MRI)	
If Yes (both left and right brain)	If it was performed, you will be asked to provide a report for both sides. If you report that it was abnormal, then the following explanation will help you to fulfill appropriate boxes.

We are interested mainly in 5 types of cerebral ultrasound/CT scan/MRI abnormalities, and any or all of these may be present at different times so you need to review all reports during the stay of an infant in the NICU and report any or all of these lesions if present at any time during the hospital stay.

	T
Blood in germinal matrix	Evidence of blood in the germinal matrix or "germinal layer/matrix hemorrhage", "subependymal hemorrhage", "grade I intraventricular hemorrhage (IVH) (according to Papile)". This is usually seen in the first 7 days of life. It is recorded as "present", "suspected", "none", or "unknown" irrespective of the presence of other lesions.
Blood in ventricles	Evidence of blood in the ventricles or in the lining of the ventricles, also known as "intraventricular blood", "intraventricular hemorrhage", "grade II intraventricular hemorrhage (IVH) (according to Papile)". This is usually seen in the first 7 days of life. It is recorded as "present", "suspected", "none", or "unknown" irrespective of the presence of other lesions.
Intraparenchymal lesions	Evidence of focal intraparenchymal lesions (echodense or echolucent) in the white or grey matter (with or without intraventricular hemorrhage) also known as "parenchymal lesion", "parenchymal echodensity or echolucency", "focal infarction", "venous infarction", "intraparenchymal hemorrhage", "grade IV IVH (according to Papile)". Remember to indicate whether there is blood in the ventricles or ventricular enlargement if you document a focal lesion. This is usually seen in the first 14 days. A single "porencephalic cyst", or "cystic change" within a focal lesion also falls in this category – this should be distinguished from "cystic leukomalacia" which is more extensive, occurs later in age, is usually bilateral, and usually consists of multiple cysts.
Ventricular enlargement	Ventricular enlargement is collected at two time points: within 1 <sup>st</sup> week of life and after 1 <sup>st</sup> week of life. The infant's date of birth must be available for the ventricular enlargement fields to open. The computer will calculate dates and display them on the screen if Birth Date and Admission Date are entered on Admission Screen. Complete both time frames using the definitions described below.
	Before entering these measures, please note:  a. If you have more than one of these measures reported, please enter as many as you can. If the measurement was recorded on imaging reports from the specified time period, select the tick box and enter the highest value recorded. Measurements do not have to come from the same report. If the measurement was not done, leave the tick box unchecked.  b. Please note that the highest measures are most likely before any procedures such as shunt placement, or ventricular drainage procedure is carried out.  c. If ventricular enlargement/dilatation is reported but none of the measurement types are incorporated in report, please select Yes for Ventricular dilatation and make appropriate selection in "Descriptor" section.  d. If there are measurements provided and there is no mention of ventricular dilation/enlargement, please enter the highest measurements and select a descriptor as defined in #8 below.  e. All measurements are reported between 0.1 and 99.9 to one decimal place. Ventricular size, Anterior horn width and Ventricular index are entered in millimeters. If the imaging report details are in centimeters, convert to millimeters.  f. Take care to ensure numbers less than 10.0 are entered correctly. Data accuracy will be improved if you enter numbers less than 10.0 with a leading zero. E.g. entering "087" will equal 8.7 but if you enter just "87" or "8.7" it will be accepted as "87.0".  g. If a measurement is recorded but the report does not state which side, please do not enter.  Description:  1. Imaging Available – includes ultrasounds, MRI or CT scanning
	a. Yes = brain imaging was done during this time period

- b. No = no brain imaging done during this time period
- c. Unknown = it is uncertain if brain imaging was done during this time period choose this also if date of admission is after one week of age. For section on after one week of age, choose this if baby was discharged before one week of age.
- 2. Ventricular dilatation also known as "hydrocephalus", "ventriculomegaly", or "ventricular enlargement"
  - a. Yes = ventricular dilatation / enlargement (of any degree or certainty) was noted by a physician or radiologist during this time period
  - b. No = ventricular dilatation / enlargement was NOT noted by a physician or radiologist during this admission
  - c. Unknown = it is uncertain whether ventricular dilatation / enlargement was present or not during this admission
- 3. **Ventricular size** (**highest**): enter the highest reported measurement in millimeter at any level. The measurement should be clearly one of the following: frontal, occipital or temporal horn. Enter the largest number of ventricular size in the time period. If unclear what area is being measured, see #7 below.
- 4. **Anterior horn width (AHW):** This is typically measured on the more dilated lateral ventricle at the widest point at oblique plane at the level of foramen of Monro. It is reported in millimeter. The measurement should be clearly labeled as "anterior horn width". See figure below for reference. Enter the largest number of AHW in the time period. If unclear what area is being measured, see #7 below.



Image 1: VI = Ventricular index, AHW = Anterior horn width

- 5. **Ventricular index (VI)**: Ventricular index is the distance between the midline and the most lateral point of the lateral ventricle in millimeters. It is measured in the coronal plane at the level of foramen of Monro. It is reported in mm. The measurement should be clearly labeled as "ventricular index". Enter the largest number of VI in the time period. See figure above for reference. If unclear what area is being measured, see #7 below.
- 6. Frontal and Temporal Horn Ratio (FTHR): This is the average of the frontal and temporal horn width divided by the interparietal diameter at the level foramen of Monro. It is reported as a ratio. It does not have a unit because it is a ratio. The measurement should be clearly labeled as "FTHR". Enter the largest number of FTHR in the time period. If unclear what area is being measured, see #7 below.



**Image 2**: Frontal and Temporal Horn Ratio, FTHR = A+B/2C

7. **Measurement of Unknown Type:** If there is any other measurement type than what is described above, then enter it here. If there is a measurement with no label or the label/ description does not fit

	with the above options, then enter it here. Enter the largest number of unknown measurement in the time period.  8. <b>Descriptor:</b> Enter qualitative descriptions for ventricular enlargement using <i>normal</i> , <i>mild</i> , <i>moderate or severe</i> . Choose the worst descriptor in the time period. If a qualitative description is mild/moderate, then enter as moderate. If a qualitative description is moderate/severe, then enter as severe. Enter "suspected" as "mild".  If measurements were available but a descriptor was not provided on the radiological report, select the descriptor based on the highest measurement as follows:  a. "Normal": Measurement is <7 mm at any level section of lateral ventricle.  b. "Mild": Measurement is 7 to 10 mm at any level of the larger lateral ventricle on sagittal scan.  d. "Severe": Measurement >15 mm at any level of the larger lateral ventricle on a sagittal scan.
	Previous Intraventricular Hemorrhage Reported:  a) Yes = intraventricular hemorrhage noted before ventricular dilatation started. This includes intraventricular hemorrhage noted in previous admission (s) or at other institutions prior to this admission  b) No = intraventricular hemorrhage noted but NOT before ventricular dilatation started  c) Not Applicable = NO intraventricular hemorrhage noted at any time in current or previous admission (s) or at other institutions prior to this admission  d) Unknown = it is not known or unclear if intraventricular hemorrhage was noted before ventricular dilatation started.
Periventricular leukomalacia	Evidence of diffuse brain lesions (usually echodense) in the white matter consistent with periventricular leukomalacia (PVL) or "white matter injury". To be "present" these may be confirmed by noticing development of multiple cysts on MRI or ultrasound ("cystic periventricular leukomalacia").
Other lesions	Mention any other lesions that were identified in the imaging or autopsy. Co-natal cyst is a term used for cystic lesions in the front of the lateral ventricles (frontal horn). The "Other" field can hold a maximum of 25 characters.
Resolved before discharge	These fields only become activated when corresponding indications are checked in previous selections (i.e. when Ventricular dilatation = yes, or when Descriptor = Mild, Moderate or Severe).  If from last imaging it is determined that there was resolution of abnormalities detected before, indicate here. If it is not known, leave boxes unchecked.

# RETINOPATHY OF PREMATURITY (HIGHEST STAGE)

Was Screening	Mark yes, no or unknown. Patient may have been transferred to another facility before complete
Done	vascularization is noted. If one screen was performed in your hospital – mark it yes.
	If you select "no" or "unknown", a question will appear whether the reason for no is because patient died or
	was transferred to another facility prior to discharge (mandatory field).
	Do not record eye exams completed for purposes other than ROP Screening. You will know if the eye
	examination was performed for ROP Screening because the chart mentions any of the following (at least 1
	of, however, it is rare to see 1 without another): a) ROP, b) Zone, c) Stage, d) Plus Disease
Total # of ROP	Enter a numeric value greater than or equal to 1 (whole numbers only, two characters only).
Screening exams	Enter a value which represents a count or sum of the number of ROP Screening exams the patient
the patient	experienced while in your NICU. If a baby had two distinctly separate ROP Screening eye exams on the
received	same day, count each one. Count each ROP Screening exam as one event regardless of the number of eyes
	examined.
Left/Right Eye:	Selecting N/A in any field generates a default N/A selection for the other two. These selections, however, can
Stage	be changed if desired. Maximum stage of retinopathy of prematurity (ROP) in left/right eye as defined by the
	International Committee on Retinopathy of Prematurity (ICROP). Score according to the grade of ROP
	assigned on an eye exam done by an ophthalmologist. If there is no explicit grade listed, then score according
	to the descriptions given by the ICROP:
	-None denotes that there are no indications of an immature retina or ROP from the eye exam.
	-Stage 1 is characterized by a demarcation line between the normal retina near the optic nerve and the non-

	vascularized retina more peripherally.  -Stage 2 ROP has a ridge of scar tissue and new vessels in place of the demarcation line. The white line now has width and height, and occupies some volume. It may take on a pink color as it becomes more vascularized. Small tufts of new vessels ("popcorn vessels") may appear posterior to the ridge.  -Stage 3 ROP shows an increased size of the vascular ridge, with growth of fibro-vascular tissue on the ridge and extending out into the vitreous. Fibrous scar tissue is beginning to form in this stage, with attachments between the vitreous gel and the ridge.  -Stage 4 refers to a partial retinal detachment. The scar tissue associated with the fibrovascular ridge contracts, pulling the retina away from the wall of the eye. There may also be an exudation of fluid under the retina, contributing to the detachment.  -Stage 5 ROP implies a complete retinal detachment, usually with the retina pulled into a funnel-shaped configuration by the fibrovascular scar tissue. Eyes with stage 5 ROP usually have no useful vision, even if surgery is performed to repair the detachment.  -Imm is the abbreviation for 'immature' retina. If a patient's eye exam states "imm" or "immature" look to see if this progresses further into a stage of ROP. If not, then score as 'imm'.  - Score "N/A" if there is no eye exam during this hospital stay.
Left/Right Eye: Zone	Record location of ROP in left/right eye by zone. Score according to eye exam having the greatest degree of ROP severity. Disease severity is worst in Zone 1 (optic disk to macula), very serious in Zone 2, (macula to periphery) and worrisome in Zone 3 (peripheral vision). If there is no eye exam or if stage is scored as "none", score as "N/A".
Left/Right Eye:	Presence of plus disease at any stage of ROP in the left/right eyes. Plus disease is indicated by extreme
Plus	tortuosity and redness of vessels, often accompanied by rapid progression of ROP disease. If an eye exam was completed, but there is no eye exam results available, score as "N/A".
Aggressive	This is a severe form of ROP that does not progress through the classic stages of ROP from stage 1-3. It is
Posterior ROP (APROP)	commonly observed in zone 1, but may also occur in zone 2. These patients usually require immediate treatment. Score only if APROP is mentioned in ophthalmologist's note.
Was ROP	Mark yes, no or unknown. If yes, complete the following sections about ROP treatment.
Treatment given?	yyyyyyyy
ROP Treatment	Record any complications associated with ROP Treatment.
Complications	None: Check this if no complication is recorded.
Complications	•
	• <b>Infection:</b> Record any ocular infection that occurred within 2 weeks of ROP treatment. e.g. conjunctivitis, chorioretinitis, ophthalmitis etc.
	Hemorrhage: Record any intra-ocular haemorrhage that occurred within 2 weeks of ROP treatment. i.e. conjunctival, retinal, vitreal etc.
	• Unknown: Check this if data is not available or not known.
	• Other: Check this if a complication arose within 2 weeks of ROP treatment that is a result of the
	ROP treatment. Specify the complication using the free text box.
ROP Treatment(s)	ROP Treatment(s) should also be scored as Operations/Procedures > "Others" on the Diagnosis/Procedures screen.
POP Treatment	<b>Date</b> – Please enter the date on which the ROP treatment occurred. Enter by selecting from the calendar
ROP Treatment	
Details	displayed or by typing in the date in the format YYYYMMDD. If the patient had ROP treatment on two different dates (example two different types of treatment or different days), use a different
	different dates (example two different types of treatment or different eyes on different days), use a different line for each treatment date.
	Type – Record the type of treatment using the drop down selections as follows:
	• Laser - Laser surgery for ROP (also known as diode laser or argon laser)
	VEGF Blocker - VEGF Blockers for ROP (also known as anti-VEGF, VEGF Inhibitors, Macugen c
	[Pegaptanib Sodium], Lucentis c [Ranibizumab], and Avastin c [Bevacizumab])
	Other Surgery - Retinal detachment surgery (seen on the operative record notes)
	• Unknown
	Eye(s) – Select the eye or eyes on which the ROP treatment occurred. Record "Right" or "Left", or record
	"Both" if both eyes treated with the same type of treatment and, if VEGF, the same type and dose of
	medication administered. If both eyes were treated on the same day with different treatment types and/or
	different type or dose of VEGF blockers, use more than one line and record the treatments separately. If one or both eyes were treated more than once in one calendar day, use more than one line to record all treatments.
VEGF Details	<b>Type</b> – Specify the type of VEGF Blocker used for ROP. These are also known as anti-VEGF or VEGF Inhibitors. If both eyes were treated with a different type of VEGF blocker on the same day, then use one line
	to record the left eye and one line to record the right eye noting the correct VEGF blocker type for each

#### treatment.

- Avastin © [Bevacizumab]
- Lucentis © [Ranibizumab]
- Macugen © [Pegaptanib Sodium]
- Other
- Unknown

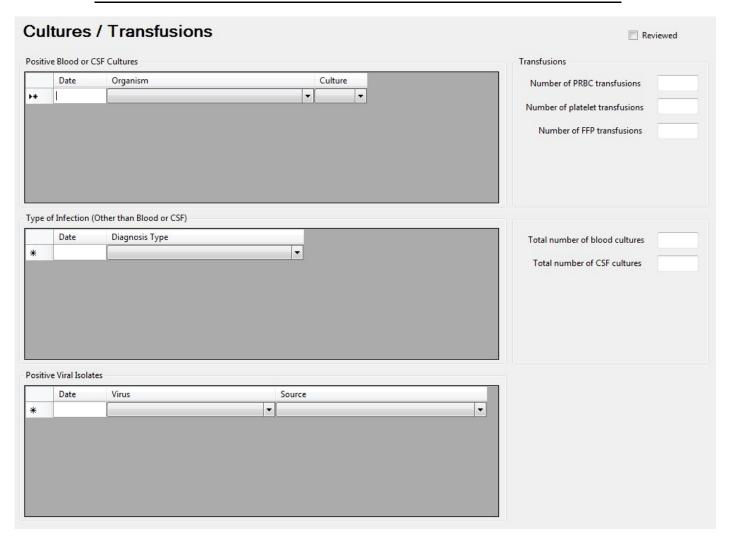
**Dosage (mg)** – Specify the dosage of the VEGF blocker used in milligrams (mg). If the dosage is unknown record 0.0 mg. If both eyes were treated with VEGF blockers on the same day with the same drug but with a different dosage in each eye, then use one line to record the left eye and one line to record the right eye noting the correct dosage for each treatment.

## Left/Right Eye: Last Exam Result before Treatment

Record the last ROP screening result available from the most recent exam just before this ROP treatment regardless of if it was the worst or not the worst reported eye result. The results of this eye exam often lead to the decision to treat the patient. Record the Left and the Right eye exam result using the Stage, Zone and Plus results.

- *Left/Right Stage* Record severity of ROP in left/right eye by stage.
- *Left/Right Zone* Record location of ROP in left/right eye by zone.
- *Left/Right Plus* Record the presence of plus disease at any stage ROP.

# **SCREEN 12: CULTURES/TRANSFUSIONS SCREEN DEFINITIONS**



#### **POSITIVE BLOOD OR CSF CULTURES**

- Record only positive cultures that occur at your study hospital. If a blood culture is drawn at another hospital prior to this admission visit, it should *not* be recorded. However, if this culture is positive AND the baby is considered to have an infection at the time of arrival to your hospital, this should be recorded as an infection episode under Type of Infection (given that this is an ongoing concern of the patient). In this instance, record the infection type according to the definitions of infection diagnosis listed in appendix V, and make a note in the comments box regarding the details of the positive culture including the organism discovered.
- ❖ If patient is transferred in your hospital from a non-CNN hospital with a positive culture, record it as "Admitted with infection from other hospital" under "Type of Infection".
- \* Enter positive blood cultures found on autopsy here, and enter date of death as date of the blood or CSF draw.
- ❖ Admissions to NICU from your ER Department: Include positive cultures drawn in the emergency department of your hospital immediately prior to admission to NICU. Record the appropriate date of the culture (this may be the day before your admission date for those who are admitted after midnight.) These should also be counted in the "Total # of blood cultures" and "Total # of CSF cultures".

Date	For each positive blood or CSF culture, record the date of the blood draw, NOT the date the culture was found to be positive. Only positive cultures are listed in detail. Negative cultures are to be included in counting the total number of blood/CSF cultures, but are not listed in detail. Enter the date using the pull-down calendar. If date unknown leave the field blank.
Organism	See Appendix VI for the list of pathogenic organisms in alphabetical order with their coded abbreviations.  Contact the Coordinating Centre for organisms that do not appear on the list.  For each positive culture, please check the duration of antibiotics use alongside the same timeline of positive

	culture.
	If multiple organisms are found in the same culture, enter each organism separately on a new line in the table.
	Only record the organisms if:  1. Organism is listed in Appendix VI; <u>AND</u> one of the following  2. Infant receives 5 or more days of antibiotics; OR  3. Infant dies within 5 days of positive culture
	Do not record repeat cultures that are considered part of the same infection. Therefore, a second positive blood culture containing the same organism (repeat culture) is NOT included if the culture date is within 10 days of the initial positive blood culture. However, when a positive CSF culture OR a positive blood culture containing a new organism is identified, even if the culture date is within 10 days of the initial positive blood culture, it should be added as new infection separately following the same criteria as described above (for antibiotic duration). Any positive culture drawn after 10 days is considered a new episode of infection and should be included (regardless of the type of organism) separately following the same criteria as described above (for antibiotic duration).
	For calculation of 10 days, count day of infection as "day 1".
	If patients are transferred to your hospital from a non-CNN hospital with a positive culture, do not record here, but record it as "Admitted with infection from other hospital" under "Type of Infection".
	Do not record information about resistance to antibiotics.
Code	An organism code is automatically entered once an organism has been selected. It has been included to easily identify contaminants. A <i>contaminant</i> is defined as isolation of organism which is either considered to be non-pathogenic or for which antibiotics were prescribed for less than 5 days (unless baby dies within 5 days of isolation of organism).
Culture	Source of positive culture. Choose from <i>blood or CSF</i> (cerebrospinal fluid).

#### **TRANSFUSIONS**

Include transfusions that took place in the Operating Room.

Number of PRBC	Include total number of Packed Red Blood Cell transfusions during infant stay. Does NOT include whole
Transfusions	blood transfusions. Enter zero if none occurred. Leave the field blank only if the answer is unknown.
Number of platelet	Include number of platelet transfusions during infant stay. Enter zero if none occurred. Leave the field blank
transfusions	only if the answer is unknown.
Number of FFP	Include number of Fresh Frozen Plasma transfusion during infant stay. Enter zero if none occurred. Leave the
transfusions	field blank only if the answer is unknown.

#### TYPE OF INFECTION (OTHER THAN BLOOD OR CSF)

An "episode" of infection is defined as any event where infection is suspected and as a result begins with:

- (a) bacteriological or viral samples taken; OR
- (b) antibiotics are initiated; OR
- (c) a diagnosis of infection is made.

If samples are taken: an "episode" of infection includes all cultures drawn within 10 days of the initial positive culture, except in the following circumstances (which indicate then a new infection episode):

- 1) A new organism is found in a repeat culture within 10 days of the initial culture draw date.
- 2) The same (or new) organism is found in a *new type* of culture within 10 days of the initial culture draw date.

After 10 days, any persistent infection should be considered a new infection episode. However, any repeat culture after 10 days that proves to be negative should be excluded entirely as it is neither the start of a new episode nor part of the previous episode (as it is beyond the 10 day limit).

For calculation of 10 days, count day of infection as "day 1".

**CENTRAL NERVOUS SYSTEM INFECTION:** Includes meningitis, ventriculitis, spinal abscess without meningitis and brain abscess (ie. epidural abscess).

Meningitis or ventriculitis must meet the following criterion:

a) A pathogen must be isolated from or detected in CSF.

PRIMARY BLOODSTREAM INFECTION: Includes laboratory-confirmed bloodstream infection and clinical sepsis.

Laboratory-confirmed bloodstream infection must meet one of the following criteria:

- 1. Recognized pathogen isolated from a blood culture *where* pathogen is not related to infection at another site. <sup>1</sup>
- 2. One of the following: fever (>38°C), chills, or hypotension *and* any of the following:
  - a) Common skin contaminant<sup>2</sup> isolated from 2 blood cultures drawn on separate occasions and where the organism is not related to infection at another site<sup>1</sup>
  - b) Common skin contaminant isolated from patient's blood culture with intravascular access device and physician institutes appropriate antimicrobial therapy for at least 5 days
  - c) Common skin contaminant isolated from patient's blood culture and physician institutes appropriate antimicrobial therapy for at least 5 days
  - d) Positive antigen test on blood<sup>3</sup> and organism is not related to infection at another site
- 3. Patient is less than or equal to 12 months of age and has one of the following: fever (>38°C), hypothermia (<37°C), apnea, or bradycardia *and* any of the following:
  - a) Common skin contaminant<sup>2</sup> isolated from 2 blood cultures drawn on separate occasions and where the organism is not related to infection at another site<sup>1</sup>
  - b) Common skin contaminant isolated from patient's blood culture with intravascular access device and physician institutes appropriate antimicrobial therapy for at least 5 days
  - e) Common skin contaminant isolated from patient's blood culture and physician institutes appropriate antimicrobial therapy for at least 5 days

Positive antigen test on blood<sup>3</sup> and organism is not related to infection at another site

Date	Enter the date using the pull-down calendar. If the date of diagnosis is unknown, please record the date when treatment began (i.e. when antibiotic was initiated). If the start date of treatment is unknown and the patient was admitted with infection from another hospital, then enter the date of admission. Date of diagnosis of infection could be before date of admission. Leave the field blank if information is not available.		
Diagnosis Type	Select the diagnosis type for each episode of infection from the scroll down list according to the descriptors of infection types given in appendix V.		
Total # of blood	Total count of all blood culture draws (regardless of whether culture is positive or negative) received by the		
cultures	clinical laboratory during this NICU admission. Two blood cultures taken at the same time from different		
	sites (2 blood draws) count as two blood cultures. Two bottle aerobic/anaerobic combination count as 1		
	culture (1 blood draw). Also include blood cultures drawn in the ER if the patient is then admitted to the		
	NICU. Includes blood cultures drawn for serology only.		
Total # of CSF	Total number of CSF culture draws (regardless of whether culture is positive or negative) received by the		
cultures	clinical laboratory during this NICU admission. If CSF is obtained without culture, do not include. Also		
	include CSF cultures drawn in the ER if the patient is then admitted to the NICU.		

<sup>&</sup>lt;sup>1</sup> When an organism isolated from a blood culture is compatible with a related nosocomial infection at another site, the bloodstream infection is classified as a secondary bloodstream infection. Exceptions to this are intravascular device-associated bloodstream infections, all of which are classified as primary even if localized signs of infection are present at the access site.

<sup>&</sup>lt;sup>2</sup> Organisms that are normal skin flora (eg. diphtheroids, Bacillus sp., Propionibacterium sp., coagulase-negative staphylococci, or micrococci).

<sup>&</sup>lt;sup>3</sup> Detection of bacterial, fungal, or viral antigen (eg. *Candida sp.,herpes simplex, varicella zoster, Haemophilus influenzae, streptococcus pneumoniae, Neisseria meningitidis, group B strptococci*) by rapid diagnostic test (eg. counterimmunoelectrophoresis, coagulation, or latex agglutination)

### **POSITIVE VIRAL ISOLATES**

- ❖ If a culture of secretion, body fluid, surface swab or any other tissue material is found to be positive for virus, or if molecular test (e.g. PCR) is positive for virus, then enter the date when the specimen was taken, the organism isolated and the source of specimen.
- \* Record only positive viral isolates that occur at your study hospital. If a specimen is taken at another hospital prior to this admission visit, and it is positive AND the baby is considered to have an infection at the time of arrival to your hospital, this should be recorded as an infection episode under "Type of Infection" (given that this is an ongoing concern of the patient). In this instance, record the infection type according to the definitions of infection diagnosis listed in appendix V, and make a note in the comments box regarding the details of the positive culture including the organism discovered.
- ❖ If patient is transferred to your hospital from a non-CNN hospital with a positive viral isolate, record it as "Admitted with infection from other hospital" under "Type of Infection".
- ❖ Include positive viral isolates found on **autopsy**, and enter date of death as date of the viral isolation.
- ❖ Admissions to NICU from your Emergency Department: Include positive viral isolations done in the emergency department of your hospital immediately prior to admission to NICU. Record the appropriate date of the specimen (this may be the day before your admission date for those who are admitted after midnight.)

Virus	See Appendix VII for the list of pathogenic viruses to include. Only enter confirmed cases. Do not include suspected cases.		
	If multiple viruses are found in the same specimen, enter each virus separately on a new line in the table.		
	If the same virus was found in more than one specimen and isolated from <i>the same source</i> during the same admission, only enter it once.		
	If the same virus was found in more than one specimen and isolated from <i>different sources</i> during the same admission, enter them on separate lines.		
	Enterovirus: examples include Coxsackie virus, echovirus		
Source	Identify the source of specimen for isolation.		
	Choose from bronchoalveolar lavage ("bronchioalveolar washing"), endotracheal aspirate, nasopharyngeal swab/nasopharyngeal wash, throat swab, rectal swab/stool, urine, surface swab (including skin blisters) and other body fluid/tissue.		
Date	For each positive viral isolate, record the date when the specimen was taken, NOT the date the culture was found to be positive. Enter the date using the pull-down calendar. Leave the field blank if the date is unknown.		

# **Screen 13: Medications Screen definitions**



**Refer to appendix I for a complete list of drugs** and the categories they are classified under. If you are unsure what category a medication should be classified under contact the CC for advice. Record each complete course of a particular medication as a single line. Therefore if Dexamethasone is given for 11 days but only given every other day, this would be scored as 1 'course', and each day need **not** be scored separately on a new line. Generally if a medication is stopped for more than 48 hours and restarted, this is considered the start of a new 'course'..

*If a patient is transferred in* on a particular medication, record the date of admission to your unit as the start date. *If a patient is transferred out* while still receiving a particular medication, record the discharge date as the end date.

#### **POST-NATAL STEROIDS**

Туре	Select from the scroll down list the type of post-natal steroid administered. Common steroids include: <i>dexamethasone, budesonide, hydrocortisone and beclamethasone</i> . If a steroid is not included in the list, select "Other"	
Indication	Select indication from the list. Select "other" when an indication is not in the list and "unknown" when not specified. The list of relevant items will be displayed for the given selected steroid type.	
Route	Select route of administration from the pull-down list. If the route is IM, select "parenteral".	
Start Date	First date of administration of all post-natal steroids given during this hospital admission. Record regardless of method of administration (i.e. bolus or infusion). <i>Do NOT score steroids given to the mother prior to the infant's birth.</i> Enter the date using the pull-down calendar.	
End Date	Last date of administration of the listed steroid. Enter the date using the pull-down calendar. <i>If a medication is only given for 1 day score that day as both the start and end date.</i>	

### **SURFACTANT**

Here you will enter date, time and type of surfactant administration.

Once you enter details of first dose, a second row will be populated which will allow you to enter subsequent doses if patient has received. Note that date of second dose could not be prior to first dose.

Date of administration	Enter the calendar date in which the dose of surfactant was given (regardless of whether the dose was given while the infant was admitted to your NICU or not). The default date of the calendar will be set to the birth date, however if this is not correct, you will need to edit this date. If the date on which surfactant is given is unavailable, leave the field blank.	
Time of Dose	Record the time in <i>military time</i> (24 hr clock) at which the dose of the particular surfactant was given (should correspond to the date listed above). Record midnight as 00:00 (and the first minute of a new day; for example: 23:59 on Jan 3 <sup>rd</sup> and 00:00 on Jan 4 <sup>th</sup> is 1 minute later). If the time at which surfactant is given is unavailable, leave blank.	
Туре	Score all surfactants (i.e. BLES, Survanta, Exosurf, Curosurf etc.) given to a patient using the pull-dow menu. Score regardless of whether given at your hospital or at a different transferring/birth hospital. I surfactant was given at a previous hospital, record all the information below if available.	
Method	Select the method of surfactant administration from options:  1. Endotracheal  2. LISA  3. Other  4. Unknown  Score regardless of whether the surfactant was given at your hospital or at a different transferring/birth hospital. If surfactant was given at a previous hospital, record all the information if available.  Less Invasive Surfactant Administration (LISA) includes administration of surfactant with the use of thin catheter (special catheter, intravenous cannula or NG tube). Also include Minimally Invasive Surfactant Treatment (MIST) under this option.  Other includes aerosol surfactant.	

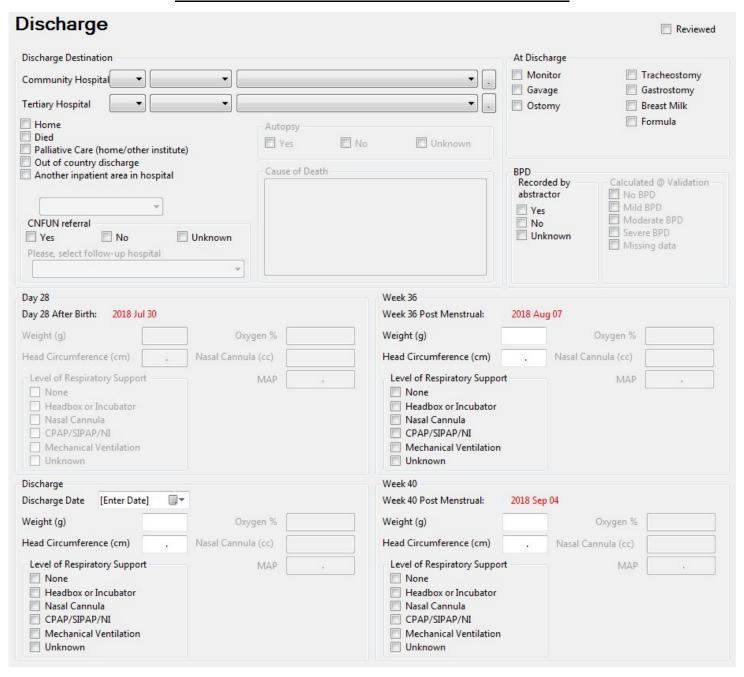
## **CAFFEINE**

Start and End Dates	Enter the start date and final stop date of caffeine administration using the pull-down calendar. <i>DO NOT</i>		
	enter the dates when caffeine was intermittently stopped and restarted. Do not enter theophylline or		
	aminophylline here. If caffeine was only given for 1 day, score that day as both the start and end date.		

## PDA TREATMENT

Treatment	Select the type of treatment from scroll down list. Options include Acetaminophen, Ibuprofen and Indomethacin.	
Start Date	First date of administration of the PDA treatment during this hospital admission. Enter the date using the pull-down calendar.	
End Date	Last date of administration of the PDA treatment. Enter the date using the pull-down calendar. If the medication is only given for 1 day score that day as both the start and end date.	

# **SCREEN 14: DISCHARGE SCREEN DEFINITIONS**



Complete this screen for all patients that are discharged from your NICU, regardless of whether or not they are transferred out of your hospital or to another ward/nursery within your hospital. If a patient is transferred within your hospital enter your hospital name and the nursery name under the appropriate level of care received there. If a patient is discharged to another hospital for less than 24 hours for either surgical or medical care that can not be given at your hospital, you need not count them as a discharged patient. Mention "other facility" in Patient Chart screen and continue data collection for the rest of the patient's hospital stay in the current data set. If however the patient is discharged for more than 24 hours, complete the discharge information and record their return as a readmission, entering the remainder of the hospital stay in the new 'readmission' data set.

Discharge	Indicate the destination on discharge from your NICU.
Destination	
	Select "Community Hospital" if: the baby was transferred to any term (level 1/level II/regular/healthy
	baby) nursery/ community hospital. Select from drop-down list (in which case you should follow up on this
	baby with the post-transfer screen, if possible).

**Score "Tertiary Hospital" if:** the baby was transferred to one of the other study sites (in which case you should follow up on this baby with the post-transfer screen) or to another tertiary care centre. Select from drop-down list.

**Score** "Home" if: the baby was discharged home (or into home foster care) from your NICU. If the baby is discharged into foster care it is **not** necessary to make a note in the comments box. We are only interested in the type of care the baby is to receive, i.e. home care versus hospital care. However, if the infant is discharged home on palliative care, record this as palliative care.

Score "Died" if: the baby died during this hospital stay.

Score "Palliative Care" if: Patient was discharged to home or other institution for palliative care.

Score "Out of Country discharge" if: Patient was discharged to a facility outside of Canada or home outside of Canada

*Score "Another inpatient area in hospital" if:* Patient was discharged to an inpatient area within your hospital. Selection of this field will activate the Post Transfer screen. The list of places are as follows:

- 1. PICU/PCCU
- 2. L2N/SCN
- 3. Operation Room
- 4. CCU/CCCU
- 5. Labor & Delivery
- 6. Mother/Baby unit
- 7. Pediatric Ward
- 8. Others
- 9. Unknown

*If the baby was transferred to the OR*, and does not return to the NICU (i.e. discharged from the NICU on the way to the OR), enter as OR (at your hospital), but do not score this operation on the diagnosis and procedures screen.

### **SUPPORT AT DISCHARGE**

If the infant was not on any of the supports listed below at the time of discharge or transfer, leave this section blank. *Do NOT mark anything in this column if the baby died.* 

Monitor	Score this if the patient is receiving continuous cardiac or apnea monitoring <i>at the time of discharge/transfer</i> . If the chart does not specify and discharge is to a level 2 or 3 community hospital, score monitor at discharge. If the chart does not specify and discharge is to the routine (level 1) nursery, do not score. If discharged home there must be clear evidence of plans for home monitoring to score this item.	
Gavage	Score this if the patient received gavage feeding (any PG or NG feeds) at any time in the 24 hours prior to discharge/transfer. If you are already scoring gastrostomy at discharge, do not score gavage at discharge as well.	
Ostomy	Score this if the patient has any ostomy (ileostomy or colostomy, <i>but not</i> tracheostomy or gastrostomy) <i>at the time of discharge/transfer</i> .	
Tracheostomy	Score this if the patient has a tracheostomy in place at the time of discharge/transfer.	
Gastrostomy	Score this if the patient has a gastrostomy in place at the time of discharge/transfer.	
Breast Milk	Record if patient was receiving any breast milk in the previous 24 hours of discharge. If only powder supplements are being added to breast milk and there are no liquid supplements (other than those who use the Similac version of HMF which is liquid), then it should be classified as breast milk.	
Formula	Record if patient was receiving any formula in the previous 24 hours of discharge	

### DAY 28 / WEEK 36 / WEEK 40 / DISCHARGE

The scoring period for "day 28" data should be from 00:00 hr on day 28 of life to 23:59 hr (24 hours). For your convenience the calendar date of day 28 has been calculated and is listed in red. If you are missing part of the day 28 flow sheet and you can get accurate information from other sources (i.e. progress notes), then score based on these other sources. Otherwise, you should use the closest complete 24 hour scoring period (it is okay to adjust times of day), but it should not be more than 48 hours off from day 28.

The scoring period for "week 36" data should be from 00:00 hr on day one of **week 36** to 23:59 hr (24 hours). Otherwise, you should use the closest complete 24 hour scoring period (it is okay to adjust times of the day). For your convenience, the calendar date of the first day of week 36 has been calculated where appropriate and is displayed in red on the right upper corner of this screen.

The scoring period for "week 40" data should be from 00:00 hr on day one of **week 40** to 23:59 hr (24 hours). Otherwise, you should use the closest complete 24 hour scoring period (it is okay to adjust times of the day). For your convenience, the calendar date of the first day of week 40 has been calculated where appropriate and is displayed in red on the right upper corner of this screen.

Week 36 and week 40 data need never be collected if the gestational age (see above for which gestational age to use) is 33 weeks or more. Week 36 and week 40 also need not be collected if the baby is discharged home, to a level 1 nursery, or if the patient dies before 36 or 40 weeks. In these instances, the week 36 and week 40 weights and head circumferences will be grayed out and you will not need to enter anything under this section. If a baby is transferred to another level 2 or level 3 hospital before week 36 where available, score according to the receiving hospital's records.

Day 28, week 36 and week 40 data are auto-populated for readmissions of each baby.

Date	These dates will be automatically calculated from the admission screen (mandatory field).			
Discharge Date	Record the infant's date of discharge.			
Weight	Record infant's weight nearest day 28, week 36, week 40 and discharge (within 2 days). If not weighed or data not available, leave the field blank.			
Head circumference	Record infant's head circumference nearest day 28, week 36, week 40 and at discharge (within 7 days). If the information is unavailable, or if head circumference is not measured within 7 days, leave the field blank.			
Level of	Score "None" if no respiratory support was being used or if the baby was only receiving humidity for			
Respiratory	tracheostomy patients at day 28, week 36 or week 40 as appropriate.			
Support	Score "Headbox or Incubator" if the baby is receiving oxygen via headbox or incubator, without Nasal			
	Cannula, at day 28, week 36 or week 40 as appropriate and at discharge/transfer.			
	Score "Nasal cannula" if the baby is receiving air and/or oxygen via nasal cannula, at day 28, week 36 or			
	week 40 as appropriate and at discharge/transfer. This also includes "High Flow Nasal Prongs (HFNP)" (item			
	#6) and "Low Flow Air" (item #8) as defined on the Patient Chart screen.			
	Score "CPAP/SiPAP/NI" if the baby is on CPAP, SiPAP or Non Invasive Ventilation – items #4 or #5 on the			
	Patient Chart Screen, at day 28, week 36 or week 40 as appropriate and at discharge/transfer.			
	Score "Mechanical Ventilation" if baby was receiving mechanical ventilation as defined on the Patient Chart			
	Screen as "HFV (item #2) or "IPPV" (item #3), at day 28, week 36 or week 40 as appropriate and at			
	discharge/transfer. Route must be endotracheal tube or tracheostomy tube.			
Oxygen %	Record the level of oxygen percentage on day 28, week 36 or week 40 as appropriate and at discharge. Please			
	enter maximum oxygen percentage given on that day between 21 and 100. Enter 100 if patient is on oxygen			
	via nasal cannula.			
Nasal Cannula	Record the flow of gas in cc per minute given via the nasal cannula on day 28, week 36 or week 40 as			
(cc)	appropriate and at discharge. (maximum value 10,000 cc)			
MAP	Record the highest mean airway pressure given on day 28, week 36 or week 40 as appropriate and at discharge.			
	If baby is on CPAP record the CPAP level as MAP. If baby is on NIPPV, enter Expiratory positive airway pressure (EPAP) as MAP.			

### **A**UTOPSY

If the death is selected as disposition of the infant during this admission, then the following screen will be activated and require completion.

Autopsy	Record whether autopsy consent was obtained. This information will be used to recall charts later to verify	
	causes of death.	
Cause of death	Record the principle cause of death as stated by the attending physician or autopsy findings (maximum 255	
	characters). Where there is a discrepancy, ask the physician to verify the cause of death. <i>Use underlying</i>	
	diagnoses, NOT terminal events like "cardiac arrest." Field is only activated if "Died" was selected from the	
	Discharge Destination field and it becomes mandatory in this case.	

### **CNFUN REFERRAL**

CNFUN Referral	Complete this section regardless of whether or not your site participates in CNFUN. Select yes if baby was	
	referred to a CNFUN hospital for neurodevelopmental assessment. This field is applicable to babies less than	
	29 weeks GA and for the purpose of linking to CNFUN babies only.	

### BRONCHOPULMONARY DYSPLASIA (BPD) / CHRONIC LUNG DISEASE (CLD)

Applicable for babies  $\leq 32$  weeks GA

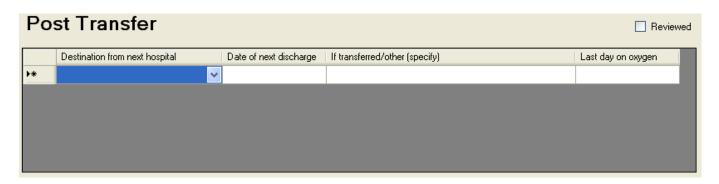
# BPD/CLD There are two displays of BPD/CLD in the CNN database:

- 1. Manually entered by selecting yes, no or unknown based on clinician's notes.
  - Completion of this field is optional.
  - Yes Clinical notes describe BPD <u>OR</u> there is use of "oxygen" and/or "invasive or non-invasive ventilatory support" and/or "high flow air" when infant reaches 36 weeks of postmenstrual age or at the time of discharge to Level 2 hospital, whichever is earlier.
  - No
- There is no use of "oxygen" and/or "invasive or non-invasive ventilatory support" and/or "high flow air" <u>OR</u>
- There is use of "oxygen" and/or "invasive or non-invasive ventilatory support" and/or "high flow air" <u>BUT</u> there is a confirmed explanation for such requirement like an acute event such as surgical procedures, postoperative care, or congenital central hypoventilation syndrome at 36 weeks CGA or at discharge. The infant prior to this acute event was in room air for prolonged period of time.
- **Unknown** Score this if diagnosis of BPD is unknown or not available.
- 2. Upon validation (when the "Validate Case" button is clicked on the Validate Case Screen), a calculated value is displayed based on other data entries using the following algorithm:

BPD	Oxygen	Mode of delivery of oxygen	Flow rate
No BPD	21%	None	-
Mild BPD	>21%	Headbox or Incubator	Any amount
	100%	Nasal cannula	<100cc/min
	≥21-99%	Nasal cannula blended air/oxygen	< 1.5 L/min
Moderate	100%	Nasal cannula	≥100 cc/min
BPD	≥21-29%	Nasal cannula blended air/oxygen	≥ 1.5 L/min
	≥21-29%	CPAP, SIPAP, NIPPV, NIHFV	
Severe	<u>&gt;</u> 30%	Nasal cannula blended oxygen	≥ 1.5 L/min
BPD	<u>&gt;</u> 30%	CPAP, SIPAP, NIPPV, NIHFV	
	≥21-100%	Mechanical ventilation (Intubated)	

The manually entered BPD value will NOT override the calculated value. In case of discrepancies between the two values, the CNN Site Investigator will advise the coordinating centre with respect to the final call of BPD for reporting purposes.

# **SCREEN 15: POST TRANSFER SCREEN DEFINITIONS (OPTIONAL)**



Complete this screen only for patients that are discharged to another level 2 or level 3 nursery from your NICU. If patients are discharged home or to a level 1 nursery from your NICU leave this screen blank. Once a patient has been classified as being included under 'post-transfer' then you should continue to complete this screen for each time there is a transfer, until the patient is finally discharged home or to a level 1 nursery. If the information for certain items will never be available (e.g. the baby has been discharged from the next hospital and they do not have the oxygen information anymore), score these items as "unknown" or leave the field blank where appropriate.

Destination from next hospital	Record destination on discharge from second hospital here. If second discharge is to another hospital or the baby died at the subsequent location <i>score</i> "other" and record the destination/death in the "if transferred/other (specify)" box. If second discharge is unknown score as "unknown or N/A". If baby has died, select "Death".
Date of next discharge	Record the date of discharge from the subsequent location. If that discharge was to a destination other than home, record the next discharge information again in the box that pops up below.
If transferred/other, specify	If discharge destination is other than home, record destination from second hospital here.
Last day on oxygen at hospital	If the infant was still on oxygen at the time of the primary discharge, attempt to ascertain from the receiving hospital what day supplemental oxygen was finally discontinued. If the baby did not receive O2 at the receiving hospital, leave blank. If the baby went home or to another hospital/nursery on O2 and last day on O2 is unknown, use the date of discharge.

# **SCREEN 16: VALIDATE CASE SCREEN DEFINITIONS**



Here you can enter any notes that you did not have enough room previously to enter (maximum characters=255). Press "Validate Case" for an error report that will highlight missing, inaccurate or conflicting data and dates, or an acknowledgement of a correctly entered case.

You can print off a status report if you so desire by selecting the "Print Status" link to the upper right of the "Validate Case" button.

# **SCREEN 17: RESPIRATORY CARE SCREEN DEFINITIONS**

\*To be completed by sites participating in the NIPPV vs CPAP study\*

Respiratory Care (GA	( < 29 weeks)			
reening of all patients and confirmation of	eligibility			
Was patient intubated?		NRS support mode following first	t extubation	
Yes No		CPAP NIPPV	Other	
Extubated for withdrawal of treatment?		Was initial post-extubation CPAP  Yes No	use in "BiPhasic" form?	
Date/Time(24hr) of Initial Extubation		Was initial post-extubation NIPP\	V use in "NIV-NAVA" for	m?
[Enter Date] □▼ :		Yes No		
ssess transitions (if any) from CPAP within fi	irst 7 days post-initial extubation			
Remained on CPAP only or any combinat	ion of CPAP/HFNC/LFNC/BiPhasic CPAP	Changed (escalated) to anoth	ner mode from CPAP	
or room air		NIPPV	Date/Time	(24hr) when changed
Maximum PEEP on CPAP or MAP on BiPh	nasic CPAP cmH2O	☐ NIHFV ☐ NIV-NAVA		Date] 🖳 :
If Maximum PEEP/MAP >12 cmH20		☐ Intubation		
Date/Time(24hr) when exceeded	Enter Date] ■▼ :	Other	-	BiPhasic prior to change
Date/Time(24hr) when exceeded	Enter Datej □▼ :	Other	PEEP/MAP	cmH2O
Date/Time(24hr) when exceeded [I		Other	-	
BiPhasic CPAP used at any time within fire	st 7 days post-extubation	Other	PEEP/MAP	
BiPhasic CPAP used at any time within fire	st 7 days post-extubation  first 7 days post-initial extubation	Other	PEEP/MAP	
BiPhasic CPAP used at any time within first	st 7 days post-extubation  first 7 days post-initial extubation	<ul> <li>Other</li> <li>Changed (escalated) to anoth</li> </ul>	PEEP/MAP FiO2	
BiPhasic CPAP used at any time within fire	st 7 days post-extubation  first 7 days post-initial extubation		PEEP/MAP FiO2 ner mode from NIPPV	
BiPhasic CPAP used at any time within first ssess transitions (if any) from NIPPV within f Remained on NIPPV only or combination LFNC or room air	st 7 days post-extubation  first 7 days post-initial extubation	Changed (escalated) to anoth	PEEP/MAP FiO2  ner mode from NIPPV Date/Time	cmH2O
BiPhasic CPAP used at any time within first ssess transitions (if any) from NIPPV within f Remained on NIPPV only or combination LFNC or room air	st 7 days post-extubation  first 7 days post-initial extubation  of NIPPV/ CPAP <= 10cmH2O/ HFNC/	Changed (escalated) to anoth CPAP >10 cmH2O PEEP on CPAP NIHFV	PEEP/MAP FiO2  ner mode from NIPPV  Date/Time cmH2O [Enter	cmH2O e(24hr) when changed Date]
BiPhasic CPAP used at any time within first ssess transitions (if any) from NIPPV within f Remained on NIPPV only or combination LFNC or room air  Maximum PEEP on NIPPV  If Maximum PEEP > 10 cmH2O	st 7 days post-extubation  first 7 days post-initial extubation  of NIPPV/ CPAP <= 10cmH2O/ HFNC/	Changed (escalated) to anoth CPAP >10 cmH2O PEEP on CPAP NIHFV NIV-NAVA	PEEP/MAP FiO2  ner mode from NIPPV  Date/Time cmH2O [Enter	cmH2O
BiPhasic CPAP used at any time within first seess transitions (if any) from NIPPV within first Remained on NIPPV only or combination LFNC or room air  Maximum PEEP on NIPPV cr  If Maximum PEEP > 10 cmH2O	st 7 days post-extubation  first 7 days post-initial extubation  of NIPPV/ CPAP <= 10cmH2O/ HFNC/  mH2O	Changed (escalated) to anoth CPAP >10 cmH2O PEEP on CPAP NIHFV NIV-NAVA Intubation	PEEP/MAP FiO2  ner mode from NIPPV  Date/Time cmH2O [Enter	cmH2O e(24hr) when changed Date]
BiPhasic CPAP used at any time within fire ssess transitions (if any) from NIPPV within f Remained on NIPPV only or combination LFNC or room air Maximum PEEP on NIPPV  If Maximum PEEP >10 cmH2O Date/Time(24hr) when exceeded	st 7 days post-extubation  first 7 days post-initial extubation  of NIPPV/ CPAP <= 10cmH2O/ HFNC/  mH2O	Changed (escalated) to anoth CPAP >10 cmH2O PEEP on CPAP NIHFV NIV-NAVA	PEEP/MAP FiO2  ner mode from NIPPV  Date/Time cmH2O [Enter	e(24hr) when changed Date]  The state of the
BiPhasic CPAP used at any time within fire ssess transitions (if any) from NIPPV within f Remained on NIPPV only or combination LFNC or room air Maximum PEEP on NIPPV  If Maximum PEEP >10 cmH2O Date/Time(24hr) when exceeded	st 7 days post-extubation  first 7 days post-initial extubation  of NIPPV/ CPAP <= 10cmH2O/ HFNC/  mH2O  Enter Date]	Changed (escalated) to anoth CPAP >10 cmH2O PEEP on CPAP NIHFV NIV-NAVA Intubation	PEEP/MAP FiO2  ner mode from NIPPV Date/Time cmH2O [Enter Settings of PIP PEEP	cmH2O  (24hr) when changed  Date]
BiPhasic CPAP used at any time within first ssess transitions (if any) from NIPPV within first Remained on NIPPV only or combination LFNC or room air  Maximum PEEP on NIPPV  If Maximum PEEP >10 cmH2O Date/Time(24hr) when exceeded  Maximum PIP on NIPPV  If Maximum PIP >24 cmH2O	st 7 days post-extubation  first 7 days post-initial extubation  of NIPPV/ CPAP <= 10cmH2O/ HFNC/  mH2O  Enter Date]	Changed (escalated) to anoth CPAP >10 cmH2O PEEP on CPAP NIHFV NIV-NAVA Intubation	PEEP/MAP FiO2  ner mode from NIPPV Date/Time cmH2O [Enter Settings or PIP PEEP Rate	cmH2O  e(24hr) when changed Date]
BiPhasic CPAP used at any time within first ssess transitions (if any) from NIPPV within first Remained on NIPPV only or combination LFNC or room air  Maximum PEEP on NIPPV  If Maximum PEEP >10 cmH2O Date/Time(24hr) when exceeded  Maximum PIP on NIPPV  If Maximum PIP >24 cmH2O	st 7 days post-extubation  first 7 days post-initial extubation  of NIPPV/ CPAP <= 10cmH2O/ HFNC/  mH2O  Enter Date]	Changed (escalated) to anoth CPAP >10 cmH2O PEEP on CPAP NIHFV NIV-NAVA Intubation	PEEP/MAP FiO2  ner mode from NIPPV Date/Time cmH2O [Enter Settings of PIP PEEP	cmH2O  (24hr) when changed  Date]
BiPhasic CPAP used at any time within first ssess transitions (if any) from NIPPV within first Remained on NIPPV only or combination LFNC or room air  Maximum PEEP on NIPPV  If Maximum PEEP >10 cmH2O Date/Time(24hr) when exceeded  Maximum PIP on NIPPV  If Maximum PIP > 24 cmH2O Date/Time(24hr) when exceeded	st 7 days post-extubation  first 7 days post-initial extubation  of NIPPV/ CPAP <= 10cmH2O/ HFNC/  mH2O  Enter Date]	Changed (escalated) to anoth CPAP >10 cmH2O PEEP on CPAP NIHFV NIV-NAVA Intubation	PEEP/MAP FiO2  ner mode from NIPPV Date/Time cmH2O [Enter Settings or PIP PEEP Rate	cmH2O  cmH2O  cmH2O  cmH2O  cmH2O  cmH2O  bpm
BiPhasic CPAP used at any time within first ssess transitions (if any) from NIPPV within first Remained on NIPPV only or combination LFNC or room air  Maximum PEEP on NIPPV  If Maximum PEEP >10 cmH2O Date/Time(24hr) when exceeded  Maximum PIP on NIPPV  If Maximum PIP > 24 cmH2O Date/Time(24hr) when exceeded	st 7 days post-extubation  first 7 days post-initial extubation  of NIPPV/ CPAP <= 10cmH2O/ HFNC/  mH2O  Enter Date]	Changed (escalated) to anoth CPAP >10 cmH2O PEEP on CPAP NIHFV NIV-NAVA Intubation	PEEP/MAP FiO2  ner mode from NIPPV Date/Time cmH2O [Enter Settings of PIP PEEP Rate i-Time	cmH2O  cmH2O  cmH2O  cmH2O  cmH2O  cmH2O  bpm

# Screening of all patients and confirmation of eligibility

Was patient intubated?	Select Yes or No. Screen is disabled if "No" is selected.
Extubated for withdrawal of treatment	Check yes if infant was extubated due to palliation, withdrawal of life-sustaining treatment, or redirection of care. Remaining screen is disabled when yes is selected.
Date/Time (24hr) of Initial Extubation	Enter the date and time of the <i>initial</i> extubation (regardless of postmenstrual age/chronological age at time of extubation). This includes unplanned extubation where decision was made to leave the infant unintubated and includes extubation as part of INSURE.  However, only count extubation if not re-intubated within 1 hour. If re-intubated within 1 hour, ignore this attempt, and look for next extubation.
NRS support mode following the first extubation	<ol> <li>Select the Non-invasive Respiratory Support (NRS) mode utilized following the first extubation.</li> <li>CPAP: Check this box if the infant received CPAP (including "Biphasic CPAP" – see below) following the first extubation.</li> <li>NIPPV: Check this box if the infant received NIPPV following the first extubation. Note: "NIV-NAVA" is included in this NIPPV arm. Other labels for NIPPV may include "NIMV", "NIV-PC" or "NIV-PS". In rare instances, the term "NIV" by itself may be used to refer to NIPPV.</li> <li>Other: Check this box if the infant received NRS other than CPAP or NIPPV following the first extubation. This may include, but not limited to, NIHFV (which may also be labeled as nHFOV or NIHFOV); HFNC (which may also be labeled as HHHFNC or HHFNC); and LFNC.</li> </ol>
Was initial post- extubation CPAP use in "BiPhasic" form?	Indicate whether <i>initial</i> post-extubation CPAP was utilized in "Biphasic" form by choosing "yes" or "no". <b>Note</b> : Biphasic CPAP offers two levels of CPAP and may be labeled as any of the following: "Biphasic CPAP", "Bi-level CPAP", "Duo-PAP", "SiPAP", or "BiPAP".
Was initial post- extubation NIPPV use in "NIV- NAVA" form?	Indicate whether initial post-extubation NIPPV was utilized in "NIV-NAVA" form by choosing "yes" or "no".

# <u>CPAP arm - Assessment of respiratory support following *initial* extubation</u> This section is enabled when CPAP is selected as the NRS support mode utilized.

Remained on CPAP only or any combination of CPAP/HFNC/LFNC /BiPhasic CPAP or	Select this box if the infant remained on CPAP only, a combination of CPAP/HFNC/LFNC/BiPhasic CPAP or room air for the first 7 days post- <i>initial</i> extubation. The end point refers to the end of 7 24-hour periods. This end point (date/time) is displayed on the screen when the date/time of initial extubation is entered above.
room air	If selected, indicate the maximum value (cmH <sub>2</sub> O) of PEEP on CPAP or MAP on BiPhasic CPAP used over the first 7 days post-initial extubation.
	If the maximum PEEP or MAP on BiPhasic >12 cmH <sub>2</sub> O, enter the date and time when it exceeded the suggested maximum. This value only needs to be recorded for the <i>first event</i> in which PEEP was exceeded.
BiPhasic CPAP	Score if BiPhasic CPAP was used at any time within first 7 days post-initial extubation.  Note: Biphasic CPAP offers two levels of CPAP and may be labeled as any of the following: "Biphasic CPAP", "Bi-level CPAP", "Duo-PAP", "SiPAP", or "BiPAP".
Changed (escalated)	If the infant was changed (or escalated) to another mode from CPAP within the first 7 days post-initial
to another mode	extubation, select the new mode used. Record the first event only.
from CPAP	1. NIPPV
	2. NIHFV
	3. NIV-NAVA
	4. Intubation

#### 5. Other

If selected, record the date and time when the mode was changed from CPAP to another mode. Record the *first event* only.

Also enter the settings on CPAP or BiPhasic prior to switching modes. Include the value of PEEP or MAP respectively in cmH<sub>2</sub>O and FiO2.

### NIPPV arm - Assessment of respiratory support following initial extubation

This section is enabled when NIPPV is selected as the NRS support mode utilized.

### Remained on NIPPV only or combination of NIPPV/HFNC/LFN C or room air

Select this box if the infant remained on NIPPV only, a combination of NIPPV/HFNC/LFNC or room air for the first 7 days post-initial extubation. The end point refers to the end of 7 24-hour periods. This end point (date/time) is displayed on the screen when the date/time of initial extubation is entered above.

If selected, enter the following:

- 1. The maximum value of PEEP on NIPPV within the first 7 days post-initial extubation.
  - ➤ If the maximum PEEP >10 cmH<sub>2</sub>O, record the date and time when it exceeded the suggested maximum \*
- 2. The maximum value of PIP on NIPPV within the first 7 days post-initial extubation.
  - If the maximum PIP >24 cmH2O, record the date and time when it exceeded the suggested maximum.\*
- 3. The maximum set rate on NIPPV in bpm within the first 7 days post-initial extubation.
  - If the maximum rate on NIPPV >60 bpm, record the date and time when it exceeded the suggested maximum.\*

\*Only record the first event out of the three and no need to look beyond.

# Changed (escalated) to another mode from NIPPV

If the patient was changed (or escalated) to another mode from NIPPV within the first 7 days post-initial extubation, select the new mode used. Record the first event only.

- 1. CPAP > 10 cm H2O
  - If the patient was switched to CPAP from NIPPV, record the PEEP level.
- 2. NIHFV
- 3. NIV- NAVA
- 4. Intubation
- 5. Other

If selected, record the date and time when the mode was changed from NIPPV to another mode. Record the *first event* only.

Also enter the settings on NIPPV prior to switching modes. Include the values of PIP and PEEP in  $cmH_2O$ , NIPPV rate in bpm, i-Time in seconds and FiO2.

## APPENDIX I

# MEDICATION CLASSIFICATION LIST

CNN medications include only those drugs classified as: nitric oxide, narcotics, sedatives, inotropes, caffeine, antibiotics, post-natal steroids, surfactant.

DRUG NAME	CLASSIFICATION	Other information
A CETTA MINOPHENI (T. 1. 1)	on Patient Chart Screen	
ACETAMINOPHEN (Tylenol)	ANALGESIC, PDA TREATMENT	Do not score analgesic use.  If used for PDA treatment, score on
	TDA IREATMENT	Medications Screen and
		Diagnosis/Procedures Screen.
ACYCLOVIR	ANTIVIRAL	Score as Antibiotic on Patient Chart
		Screen. If given prophylactically, score on
		Diagnosis/Procedure Screen under
		Prophylactic Interventions.
ALFENTANYL	NARCOTIC INFUSION	
ALPROSTADIL	PROSTAGLANDIN E1	Do not score.
		This drug is usually given for keeping the
		ductus arteriosus open in neonates with
		critical cardiac condition.
		Do not score that the baby had a PDA if this medication was used to artificially
		keep the ductus arteriosus open.
AMIKACIN	ANTIBIOTIC	neep the ductus diteriosus open
AMOXICILLIN (same as	ANTIBIOTIC	
Amoxil)		
AMPHOTEROCIN B	ANTIBIOTIC	
AMPICILLIN	ANTIBIOTIC	
ANCEF	ANTIBIOTIC	
ATIVAN (same as Lorazepam)	SEDATIVE, ANTICONVULSANT	Score as Sedative on Patient Chart Screen
•		if used as sedative and not as
		anticonvulsant.
		Do not score if the reason is unclear.
		Score as seizure treatment if applicable.
AVASTIN (Bevacizumab)	VEGF BLOCKER	If given intraocularly, score on the ROP screen under ROP treatment
AZT (same as Retrovir and	ANTIVIRAL	Score as Antibiotic on Patient Chart
Zidovudine)		Screen. If given prophylactically, score on
		Diagnosis/Procedure Screen under
DACTDIM ( C	ANTIBIOTIC	Prophylactic Interventions.
BACTRIM (same as Septra)	ANTIBIOTIC	Score as Antibiotic on Patient Chart Screen only if given daily to treat infection.
		Do not score on Patient Chart Screen if
		given for prophylaxis.
		Score prophylactic use on
		Diagnosis/Procedure Screen in Other
		Prophylactic Interventions.
BECLOMETHASONE	POST-NATAL STEROID	Score on Medications Screen
BECLOVENT PUFFS	POST-NATAL STEROID	Score on Medications Screen
BEMIPARIN	ANTICOAGULANT	Score on Diagnosis/Procedure screen under
		Neonatal Thrombosis Treatment if given
		for treatment.
DETAMETHACONE	DOCT NATAL CEEDOLD	Do not score if given prophylactically.
BETAMETHASONE	POST-NATAL STEROID,	Score on Medications Screen if given to baby.
	ANTENATAL CORTICOSTEROID	Score on Mother/Obstetrics Screen if given

BEVACIZUMAB (Avastin)	VEGF BLOCKER	If given intraocularly, score on the ROP screen under ROP treatment
BIAXIN (same as Clarithromycin)	ANTIBIOTIC	
BIOGAIA	PROBIOTICS	Score prophylactic use on Diagnosis/Procedure Screen
BLES	SURFACTANT	Score on Medications Screen
BUDESONIDE (inhaled)	POST-NATAL STEROID	Score on Medications Screen
CAFFEINE	CAFFEINE	Score on Medications Screen – first and last dose only
CEFAZOLIN	ANTIBIOTIC	
CEFIXIME	ANTIBIOTIC	
CEFOTAXIME (same as Claforan)	ANTIBIOTIC	
CEFOXITIN	ANTIBIOTIC	
CEFTAZIDIME	ANTIBIOTIC	
CEFTRIAXONE	ANTIBIOTIC	
CEFUROXIME	ANTIBIOTIC	
CELESTONE	POST-NATAL STEROID,	Score on Medications Screen if given to
	ANTENATAL CORTICOSTEROID	baby. Score on Mother/Obstetrics Screen if given to mother prior to delivery.
CENTOPARIN	ANTICOAGULANT	Score on Diagnosis/Procedure screen under Neonatal Thrombosis Treatment if given for treatment. Do not score if given prophylactically.
CEPHALEXIN	ANTIBIOTIC	
CHLORAL HYDRATE	SEDATIVE	
CHLORAMPHENICOL	ANTIBIOTIC	
CIPROFLOXACIN (CIPRO)	ANTIBIOTIC	
CLAFORAN (same as Cefotaxime)	ANTIBIOTIC	
CLARITHROMYCIN (same as Biaxin)	ANTIBIOTIC	
CLINDAMYCIN	ANTIBIOTIC	
CLOXACILLIN	ANTIBIOTIC	
CODEINE	NARCOTIC INFUSION	
CORTISONE	POSTNATAL STEROID,	Score on Medications Screen if given to
	ANTENATAL CORTICOSTEROID	baby. Score on Mother/Obstetrics Screen if given to mother prior to delivery.
COSYNTROPIN	POST-NATAL STEROID	Score on Medications Screen
CO-TRIMOXAZOLE (same as Septra)	ANTIBIOTIC	Score as Antibiotic on Patient Chart Screen only if given daily to treat infection. Do not score on Patient Chart Screen if given for prophylaxis. Score prophylactic use on Diagnosis/Procedure Screen in Other Prophylactic Interventions.
CUROSURF	SURFACTANT	Score on Medications Screen
DALTEPARIN	ANTICOAGULANT	Score on Diagnosis/Procedure screen under Neonatal Thrombosis Treatment if given for treatment.  Do not score if given prophylactically.
DECADRON	POST-NATAL STEROID	Score on Medications Screen
DEXAMETHASONE	POST-NATAL STEROID,	Score on Medications Screen if given to

		baby.
	ANTENATAL CORTICOSTEROID	Score on Mother/Obstetrics Screen if given to mother prior to delivery.
DEXMEDETOMIDINE	SEDATIVE	
DIAZEPAM (same as Valium)	SEDATIVE, ANTICONVULSANT	Score as Sedative on Patient Chart Screen if used as sedative and not as anticonvulsant.  Do not score if the reason is unclear.  Score as seizure treatment if applicable.
DIHYDROCORTISONE	POSTNATAL STEROID	Score on medication screen if given to baby.
DILANTIN (same as Phenytoin)	ANTICONVULSANT	Score as seizure treatment if applicable
DOBUTAMINE	INOTROPES	
DOPAMINE	INOTROPES	
ENOXAPARIN	ANTICOAGULANT	Score on Diagnosis/Procedure screen under Neonatal Thrombosis Treatment if given for treatment.  Do not score if given prophylactically.
EPINEPHRINE (EPI DRIP)	INOTROPES	
ERYTHROMYCIN	ANTIBIOTIC	
EXOSURF	SURFACTANT	Score on Medications Screen
FENTANYL	NARCOTIC INFUSION	
FLAGYL (same as Metronidazole)	ANTIBIOTIC	
FLORABABY	PROBIOTICS	Score prophylactic use on Diagnosis/Procedure Screen
FLORINEF	POST-NATAL STEROID	Score on Medications Screen
FLOVENT (Inhaled, same as flonase, fluticasone)	POST-NATAL STEROID	Score on Medications Screen
FLUCONAZOLE	ANTIBIOTIC	Score as Antibiotic on Patient Chart Screen only if given daily to treat infection.  Do not score on Patient Chart Screen if given for prophylaxis.  If used as Antifungal agent, score under Prophylactic Interventions on Diagnosis/Procedure Screen.
FLUCYTOSINE	ANTIBIOTIC	
FLUDROCORTISONE	POST-NATAL STEROID	Score on Medications Screen
FLUTICASONE	POST-NATAL STEROID	Score on Medications Screen
GANCYCLOVIR	ANTIVIRAL	Score as Antibiotic on Patient Chart Screen. If given prophylactically, score on Diagnosis/Procedure Screen under Prophylactic Interventions.
GENTAMYCIN	ANTIBIOTIC	
HEPARIN	ANTICOAGULANT	Score on Diagnosis/Procedure screen under Neonatal Thrombosis Treatment if given for treatment. Do not score if given prophylactically.
HYDROCORTISONE	POST-NATAL STEROID	Score on Medications Screen.  Do not score if only given topically as Hydrocortisone cream.
IBUPROFEN	ANTI-INFLAMMATORY, PDA TREATMENT	If used for PDA treatment, score on Medications Screen and Diagnosis/Procedures Screen.

INDOMETHACIN, INDOCIN, INDOCID	PDA TREATMENT,	If used for PDA treatment, score on Medications Screen and Diagnosis/Procedures Screen.
	IVH PROPHYLAXIS	If used prophylactically for prevention of neurological injury, score <i>only</i> on Diagnosis/Procedures Screen under Prophylactic Interventions.
INFASURF	SURFACTANT	Score on Medications Screen
INHALED STEROIDS	POST-NATAL STEROID	Score on Medications Screen
ISONIAZID	ANTIBIOTIC	
KEFLEX	ANTIBIOTIC	
KEFZOL	ANTIBIOTIC	
KETAMINE (Anesthetic)	SEDATIVE	
KETOCONAZOLE	ANTIFUNGAL	Score as Antibiotic on Patient Chart Screen
LINEZOLID	ANTIBIOTIC	
LORAZEPAM (same as Ativan)	SEDATIVE, ANTICONVULSANT	Score as Sedative on Patient Chart Screen if used as sedative and not as anticonvulsant.  Do not score if the reason is unclear. Score as seizure treatment if applicable.
LUCENTIS (Ranibizumab)	VEGF BLOCKER	If given intraocularly, score on the ROP screen under ROP treatment
MACUGEN (Pegaptanib Sodium)	VEGF BLOCKER	If given intraocularly, score on the ROP screen under ROP treatment
MEPERIDINE	NARCOTIC INFUSION	
MEROPENEM	ANTIBIOTIC	
METHADONE	NARCOTIC INFUSION	
METHYLPREDNISOLONE, METHYLPREDNISONE	POST-NATAL STEROID	Score on Medications Screen
METICILLIN	ANTIBIOTIC	
METRONIDAZOLE (same as Flagyl)	ANTIBIOTIC	
MIDAZOLAM	SEDATIVE	
MILRINONE	INOTROPES	
MORPHINE	NARCOTIC INFUSION	
MORPHINE SULFATE (same as MSO4)	NARCOTIC INFUSION	
MUPIROCIN (same as Bactroban)	NOT SCORED (topical antibiotic)	
MYCOSTATIN (same as Nystatin)	See Nystatin (oral vs. topical)	
NADROPARIN	ANTICOAGULANT	Score on Diagnosis/Procedure screen under Neonatal Thrombosis Treatment if given for treatment. Do not score if given prophylactically.
NAFCILLIN	ANTIBIOTIC	
NETILMICIN	ANTIBIOTIC	
NEVIRAPINE	ANTIVIRAL	Score as Antibiotic on Patient Chart Screen. If given prophylactically, score on Diagnosis/Procedure Screen under Prophylactic Interventions.
NITRIC OXIDE (iNO)	NITRIC OXIDE	
NYSTATIN ORAL SUSPENSION	ANTIBIOTIC	Score as Antibiotic on Patient Chart Screen <i>only if</i> given daily to treat infection.  Do not score on Patient Chart Screen if

		given for prophylaxis. If used as Prophylactic Antifungal agent,
		score under Prophylactic Interventions on Diagnosis/Procedure Screen.
OXACILLIN	ANTIBIOTIC	Diagnosis/110ccdare Screen.
PARMAPARIN	ANTICOAGULANT	Score on Diagnosis/Procedure screen under Neonatal Thrombosis Treatment if given for treatment. Do not score if given prophylactically.
PEDIAPRED	POST-NATAL STEROID	Score on Medications Screen
PEGAPTANIB SODIUM (Macugen)	VEGF BLOCKER	If given intraocularly, score on the ROP screen under ROP treatment
PENICILLIN G	ANTIBIOTIC	
PENTOBARBITAL	SEDATIVE	
PHENOBARBITAL	SEDATIVE, ANTICONVULSANT	Score as Sedative on Patient Chart Screen if used as sedative and not as anticonvulsant.  Score as seizure treatment if applicable.  Do not score if the reason is unclear.  Do not score if given as treatment for cholestasis or other uses.
PHENYLEPHRINE	INOTROPES	
PHENYLEPHRINE EYE DROPS	NOT SCORED	
PHENYTOIN (same as Dilantin)	ANTICONVULSANT	Score as seizure treatment if applicable
PIPERACILLIN	ANTIBIOTIC	
POLYSPORIN	NOT SCORED (topical)	Topical or ophthalmic ointments are not scored
PREDNISOLONE	POST-NATAL STEROID	Score on Medications Screen
PREDNISONE	POST-NATAL STEROID	Score on Medications Screen
PROBIOTICS	PROBIOTICS	Score prophylactic use on Diagnosis/Procedures Screen
PROPOFOL	SEDATIVE	
PROSTIN	PROSTAGLANDIN E1	Do not score.  This drug is usually given for keeping the ductus arteriosus open in neonates with critical cardiac condition.  Do not score that the baby had a PDA if this medication was used to artificially keep the ductus arteriosus open.
PROSTAGLANDIN E1	PROSTAGLANDIN E1	Do not score. This drug is usually given for keeping the ductus arteriosus open in neonates with critical cardiac condition. Do not score that the baby had a PDA if this medication was used to artificially keep the ductus arteriosus open.
PULMICORT	POST-NATAL STEROID	Score on Medications Screen
RANIBIZUMAB (Lucentis)		If given intraocularly, score on the ROP screen under ROP treatment
RETROVIR (same as Zidovudine and AZT)	ANTIVIRAL	Score as Antibiotic on Patient Chart Screen. If given prophylactically, score on Diagnosis/Procedure Screen under Prophylactic Interventions.
REVIPARIN	ANTICOAGULANT	Score on Diagnosis/Procedure screen under Neonatal Thrombosis Treatment if given for treatment. Do not score if given prophylactically.

RIFAMPIN	ANTIBIOTIC	
RIVOTRIL	ANTICONVULSANT	Score as seizure treatment if applicable
SEPTRA (same as Bactrim or Co-Trimoxazole)	ANTIBIOTIC	Score as Antibiotic on Patient Chart Screen only if given daily to treat infection.  Do not score on Patient Chart Screen if given for prophylaxis.  Score prophylactic use on  Diagnosis/Procedure Screen in Other  Prophylactic Interventions.
SOLUCORTEF	POST-NATAL STEROID	Score on Medications Screen
SOLUMEDROL, SOLU-MEDROL	POST-NATAL STEROID	Score on Medications Screen
STREPTOMYCIN	ANTIBIOTIC	
SUFENTA	NARCOTIC INFUSION	
SURVANTA	SURFACTANT	Score on Medications Screen
TAZOCIN	ANTIBIOTIC	
TINZAPARIN	ANTICOAGULANT	Score on Diagnosis/Procedure screen under Neonatal Thrombosis Treatment if given for treatment. Do not score if given prophylactically.
TOBRAMYCIN	ANTIBIOTIC	
TRIMETHOPRIM	ANTIBIOTIC	
UROKINASE	ANTICOAGULANT	Score on Diagnosis/Procedure screen under Neonatal Thrombosis Treatment if given for treatment. Do not score if given prophylactically.
VALIUM (same as Diazepam)	SEDATIVE, ANTICONVULSANT	Score as Sedative on Patient Chart Screen if used as sedative and not as anticonvulsant.  Do not score if the reason is unclear.  Score as seizure treatment if applicable.
VALPROIC ACID	ANTICONVULSANT	Score as seizure treatment if applicable
VANCOMYCIN	ANTIBIOTIC	
VIGABATRIN	ANTICONVULSANT	Score as seizure treatment if applicable
WARFARIN	ANTICOAGULANT	Score on Diagnosis/Procedure screen under Neonatal Thrombosis Treatment if given for treatment. Do not score if given prophylactically.
ZIDOVUDINE (same as Retrovir and AZT)	ANTIVIRAL	Score as Antibiotic on Patient Chart Screen. If given prophylactically, score on Diagnosis/Procedure Screen under Prophylactic Interventions - OTHER.

# **CLASSIFICATION OF OPERATIONS**

Score all operations/procedures performed in the operating room and/or requiring anaesthesia. If multiple operations were performed under the same anesthesia episode, include them all.

LAPAROTOMY (MAJOR)	THORACOTOMY (MAJOR)
Abdominal omphalocele, repair of Aneurysm in right internal iliac artery, removal of Bladder rupture, closure of	ASD closure BTS for tricuspid atresia Coarctation repair
Bowel, re-section of	
correction of atresia	Cystic adenomatoid malformation, correction of Cystic hygroma
Colostomy	Diaphragmatic hernia repair (from above the diaphragm)
revision of prolapsing colostomy	Esophageal atresia (laparo- or thoro- as per location)
Corkscrew duodenum, release of	Lobectomy
Dermoid Cyst, removal of	Lung biopsy (open chest)
(laparo- or thora- depending on site)	Pacemaker, insertion of (permanent)
Diaphragmatic hernia repair (from under the diaphragm)	Pneumonectomy
Duodenojejunostomy	Pulmonary artery banding
Fundoplication	Pulmonary artery plasty (Blalock-Tassug shunt placed)
Enterotomy (for removal of meconium)	Tracheoesophageal fistula (TEF), repair
Epispadias repair	Vascular ring operation
Gastroschisis defect, closure of	
Ileostomy	
closure/reversal of ileostomy	
resection ileum & formation ileostomy/mucus-fistula	
closure of ileostomy & mucus fistula	
NEC	
Nephrectomy	
Omphalocele, closure or re-section of	
Omphalomesenteric duct fistula, repair of	
Orchidectomy	
Pyloromyotomy (for pyloric stenosis)	
Pyloroplasty	
Urinary ascites w/ bladder rupture, repair	
Vesicostomy, closure/revision of	
Volvulus correction	ECMO (MA IOR)
VP SHUNT (MAJOR)	ECMO (MAJOR)
RESERVOIR/DRAIN (MAJOR)	OSTOMY (MAJOR)
OTHER CNS SURGERY (MAJOR)	
Myelomeingeocele repair	
Spina bifida related surgeries	

OTHER/MINOR	OTHER / MINOR
Amputation, below the knee	Nephrostomy (tube placement)
Angiogram	Nerve biopsy (under general anaesthesia)
Anoplasty	Occipital encephalocele, re-section of
Ballon dilations of the esophagus (also of pulm. valve)	Orchiopexy
Ballon Septostomy	Osteomyletis, drainage of left tibial
Bone marrow biopsy	Pacemaker insertion of (if put in intracardiac)
Bronchoscopy	PDA ligation/closure (even if a thoracotomy is required)
Catheters, surgically placed	PDA closed during cardiac catheterization with device
arterial (cardiac) catheterization	Penrose drain insertion
CVL placement (in OR or w/anaesthesia)	for spontaneous intestinal perforation
Elecath pacing catheter placement	for NEC (with or without general anaesthesia)
IVC catheter	Posterior laryngeal cleft, repair of through a laryngeal
peritoneal drainage catheter	fissure approach
Choanal atresia repair	Rectal biopsy
Circumcision	Right femoral artery, resection of w/ proximal
Craniotomy to drain subdural hematoma	thrombectomy & w/ a 4-compartment fasciotomy of
closure/re-section of	lower leg
Cryo/Laser treatment (for ROP)	Right forearm fasciotomy, both dorsal & volar
Cytoscopy	compartments
Embolization	Right groin wound, debridement & repair of
Esophagoscopy	ROP therapy
Examination under anaesthesia (i.e.)	Scalp wound debridement (with formation of multiple
Eye surgery to re-attach cornea (with or without banding)	flaps & skin grafts
Gastroscopy	Septum pellucidum fenestration for
Gastrostomy	hydrocephalus
G-tube insertion under general anaesthesia	Silo placement for gastroschisis
G-tube replacement (with general anaesthesia)	Skin grafting
Hepatic cyst drainage (in radiology under U/S guidance)	Stint Placement (even if only lidocaine applied)
Hernia repair	Subperiosteal release for mouth
Herniorrhaphy	Tethered cord, release of with operating
HICKMAN <sup>TM</sup> catheter line, placement of (if to superior	microscope
vena cava)	Tongue adhesion to palate, release of
Iridectomy	Tongue lip adhesion
Laparoscopic fundoplication	Tracheostomy (on Diagnosis/Procedures screen only)
Laryngoscopy	cricoid split
Laryngo-bronchoscopy	Tracheotomy
Lensectomy	Ventricular taps, multiple frontal
Lung biopsy (if by puncture)	ventricular drain insertion (if w/ general anaesthesia)
Myeloschisis, closure of	Vitrectomy
Myringotomy tubes	

 $HICKMAN^{\text{\tiny{IM}}} \textit{ is a trademark of C.R. Bard Inc. and its related company, BCR, Inc.}$ 

NO SCORE	NO SCORE
Ballon catheter in lung	Peripheral arterial line (PAL) placement
(with fentanyl & pavulon but not anaesthesia)	Skin biopsy
Chest tube placement	Thora/paracentesis
Cutdown venous access	Tooth extraction under local anaesthetic
CVL removal (or any line, unless sent to OR	Tracheostomy (only counts on Diagnosis/Procedures
specifically for removal)	screen)
Extra digit removal	UAL or UVL placement
10 French thoracotomy tube placement	Ventricular drain insertion
G-Tube replacement (without anaesthesia)	(with fentanyl but not general anaesthesia)
Lumbar puncture	Ventriculopuncture (through a previously implanted
Pacemaker insertion via esophageal lead	catheter)

# APPENDIX III

# CLASSIFICATION OF OTHER DIAGNOSIS LIST

Name	Number	Description	
Anemia of prematurity	P61.2	Anaemia due to no identified cause or other causes in preterm infant	
Apnea of prematurity	P28.4	Apnoea due to no other reason in a preterm infant	
Arrhythmia	P29.1	Cardiac rhythm disturbances	
Aspiration of amniotic fluid and mucus	P24.1	Amniotic fluid aspiration	
Aspiration of meconium	P24.0	Meconium aspiration syndrome	
Aspiration of milk and regurgitated food	P24.3	Milk aspiration	
Birth injury, intracranial hemorrhage	P10.1	Intracranial hemorrhage due to birth injury	
Birth injury, subarachnoid hemorrhage	P10.3	Subarachnoid haemorrhage due to birth injury	
Birth injury, subdural hemorrhage	P10.0	Subdural haemorrhage due to birth injury	
Birth injury, unspecified and other	P15.9	Trauma during birth	
Cardiomyopathy	I42	Cardiomyopathy	
Coagulopathy but not DIC	P61.6	Coagulation abnormalities not meeting diagnosis of DIC, Transient coagulation disorder	
Coagulopathy due to Disseminated intravascular coagulation	P60	DIC	
Congenital cytomegalovirus infection	P35.1	Congenital CMV infection	
Congenital herpes viral [herpes simplex] infection	P35.2	Congenital herpes viral [herpes simplex] infection	
Congenital rubella syndrome	P35.0	Congenital rubella infection	
Congenital toxoplasmosis	P37.1	Congenital toxoplasmosis	
Dehydration	P74.1	Dehydration	
Fetal blood loss, other	P50.8	Other foetal blood loss	
Fever	P81.9	Pyrexia	
Gastroesophageal reflux disease	K21	GERD	
Hemolytic disease due to ABO incompatibility	P55.1	ABO incompatibility	
Hemolytic disease due to Rh incompatibility	P55.0	Blood group Rh incompatibility	
Hemolytic diseases of fetus and newborn, other	P55.8	Other haemolytic diseases of foetus and newborn	
Hemorrhage into co-twin	P50.3	Feto-fetal hemorrhage	
Hemorrhage into maternal circulation	P50.4	Feto-maternal hemorrhage	
Hemorrhagic disease due	P54	Neonatal hemorrhage	

to cause other than			
Vitamin K Deficiency			
Hemorrhagic disease due to Vitamin K deficiency	P53	HDNB	
Hydrocele	P83.5	Scrotal swelling	
Hydrops fetalis due to isoimmunization	P56.0	Hydrops fetalis due to isoimmunization	
Hydrops fetalis due to other and unspecified haemolytic disease	P56.9	Hydrops fetalis due to other and unspecified haemolytic disease	
Hyperglycemia	R73.9	Hyperglycemia	
Hyperkalemia	P74.31	Hyperkalaemia	
Hypernatremia	P74.21	Hypernatraemia	
Hypertension	P29.2	High blood pressure	
Hypertonia	P94.1	Increasead tone	
Hypoglycaemia	P70.4	Neonatal hypoglycaemia	
Hypokalemia	P74.30	Hypokalaemia	
Hyponatremia	P74.20	Hyponatraemia	
Hypotension	R03.1	Low blood pressure, refractory hypotension	
Hypothermia	P81	Hypothermia not as part of therapy	
Hypotonia	P94.2	Congenital hypotonia	
Inguinal hernia	K40.9	Hernia, inguinal	
Intestinal obstruction	P76.9	Bowel obstruction, unspecified includes atresia	
Meconium ileus	P75	Meconium ileus, meconium plug	
Neonatal abstinence syndrome (NAS) due to maternal use of addictive substances	P96.1	Withdrawal symptoms from maternal use of drugs in newborn	
Neonatal abstinence syndrome (NAS) due to neonatal use of addictive substances	P96.2	Withdrawal symptoms from therapeutic use of drugs in newborn	
Neutropenia	P61.5	Transient neonatal neutropenia	
Osteopenia of prematurity	M85.9	Metabolic bone disease of prematurity	
Persistent pulmonary hypertension (PPHN)	P99.9	Persistent pulmonary hypertension or PPHT	
Pneumomediastinum	P25.2	Pneumomediastinum	
Pneumopericardium	P25.3	Pneumopericardium	
Pulmonary edema	J81	Pulmonary edema	
Pulmonary haemorrhage	P26.8	Pulmonary haemorrhage	
Pulmonary Interstitial Emphysema	P.25.0	Interstitial emphysema originating in the perinatal period	

Renal failure	P96.0	Renal failure	
Respiratory distress, unspecified (not RDS)	P22.9	Respiratory distress (excluding RDS)	
Thrombocytopenia	P.61.0	Transient neonatal thrombocytopenia due to:  •exchange transfusion  •idiopathic maternal thrombocytopenia  •isoimmunization	
Transient myocardial ischemia	P29.4	Transient myocardial ischemia	
Transient tachypnea of newborn	P22.1	TTN	
Twin-to-twin transfusion syndrome	P02.3	Twin-to-twin transfusion syndrome (TTTS – donor) Twin-to-twin transfusion syndrome (TTTS – recipient) Twin-to-twin transfusion syndrome (TTTS – donor/recipient status unknown)"  TTTS may be treated antenatally which could prevent the presentation of TTTS at birth. Please record treated/resolved and untreated cases.	
Umbilical hernia	K42.9	Hernia, Umbilical but not omphalocele	
Vocal cord palsy	J38.0	Paralysis of vocal cords and larynx	
Wilson-Mikity syndrome	P27.0	Wilson-Mikity syndrome	
Other	O00.0	Optional: "Other" may be chosen to enter any diagnoses that are not listed in the scroll down menu. A free text field (maximum characters=100) for "Other Diagnosis Description" will display.	

# APPENDIX IV

# **CLASSIFICATION OF CONGENITAL ANOMALIES**

System	Name	ICD10	Comments
Cardiac Chambers And	Atrial Septal Defect	Q21.1	
Circulation		Q21.1	
Cardiac Chambers And Circulation	Atrioventricular Septal Defect	Q21.2	
Cardiac Chambers And Circulation	Coarctation Of The Aorta	Q25.1	
Cardiac Chambers And Circulation	Congenital Absence And Hypoplasia Of The Umbilical Artery (Single Umbilical Artery)	Q27.0	
Cardiac Chambers And Circulation	Congenital Heart Block	Q24.6	
Cardiac Chambers And Circulation	Double Outlet Right Ventricle	Q20.1	
Cardiac Chambers And Circulation	Hypoplastic Left Heart Syndrome	Q23.4	
Cardiac Chambers And Circulation	Other Congenital Malformations Of The Circulatory System	Q28	
Cardiac Chambers And Circulation	Other Congenital Malformations Of The Heart	Q24	This includes dextrocardia, cor triatrium, pulmonary infundibular stenosis, subaortic stenosis
Cardiac Chambers And Circulation	Pulmonary Valve Stenosis	Q22.1	
Cardiac Chambers And Circulation	Tetralogy Of Fallot	Q21.3	
Cardiac Chambers And Circulation	Total Anomalous Pulmonary Venous Connection	Q26.2	
Cardiac Chambers And Circulation	Transposition Of The Great Vessels (Tgv)	Q20.3	
Cardiac Chambers And Circulation	Ventricular Septal Defect	Q21	
Chromosomal Abnormalities	Balanced Rearrangements And Structural Markers Not Elsewhere Classified	Q95	
Chromosomal Abnormalities	Down's Syndrome	Q90	
Chromosomal Abnormalities	Edwards' Syndrome Or Trisomy 18	Q91.3	
Chromosomal Abnormalities	Monosomies And Deletions From The Autosomes Not Elsewhereclassified	Q93	
Chromosomal Abnormalities	Other Sex Chromosome Abnormalities, Female Phenotype Not Elsewhere Classified	Q97	
Chromosomal Abnormalities	Other Sex Chromosome Abnormalities, Male Phenotype Not Elsewhere Classified	Q98	
Chromosomal Abnormalities	Other Trisomies And Parial Trisomies Of The Autosomes Not Elsewhere Classified	Q92	
Chromosomal Abnormalities	Patau Syndrome Or Trisomy 13	Q91.7	
Chromosomal	Turner'S Syndrome	Q96	

Abnormalities			
Digestive	Atresia Of Oesophagus With Tracheo-Oesophageal Fistula	Q39.1	
Digestive	Atresia Of Oesophagus Without Fistula	Q39.0	
Digestive	Atresis Of The Bile Ducts	Q44.2	
Digestive	Congenital Absence, Atresia And Stenosis Of The Anus (Imperforate Anus)	Q42.3	
Digestive	Congenital Absence, Atresia And Stenosis Of The Duodenum	Q41.0	
Digestive	Congenital Absence, Atresia And Stenosis Of The Jejunum	Q41.1	
Digestive	Congenital Absence, Atresia And Stenosis Of The Small Intestine	Q41	
Digestive	Congenital Hypertrophic Pyloric Stenosis	Q40.0	
Digestive	Congenital Malformations Of The Esophagus	Q39	
Digestive	Congenital Malformations Of The Gallbladder, Bile Ducts And Liver	Q44	
Digestive	Congenital Malformations Of The Tongue, Mouth, Pharynx	Q38	
Digestive	Other Congenital Malformations Of The Digestive System	Q45	
Digestive	Other Congenital Malformations Of The Intestine	Q43	This includes meckel's diverticulum, Hirschprung's disease, ECTOPIC ANUS, COLACAL ANOMALY
Ear	Congenital Malformations Of The Ear Causing Impairment Of Hearing	Q16	This includes anomalies of auditory canal, eustachian tube, ossicles
Ear	Other Congenital Malformations Of The Ear	Q17	This includes small ear, large ear, misplaced ear, accessory auricle
Eye	Anophthalomos, Microphthalmos And Macrophthalmos	Q11	
Eye	Congenital Lens Malformations	Q12	This included congenital cataract, lens abnormalities
Eye	Congenital Malformations Of Eyelid,Lacrimal Apparatus And Orbit	Q10	
Eye	Congenital Malformations Of The Anterior Segment Of The Eye	Q13	This includes abnormalities of iris, cornea
Eye	Congenital Malformations Of The Posterior Segment Of The Eye	Q14	This includes abnormalities of vitreous, retina, optic disc, chroid
Eye	Other Congenital Malformations Of The Eye	Q15	
Face And Neck	Congenital Anomalies Of Neck Region	Q18	This includes sinus, cycst, fistula, webbing of neck region
Genital	Congenital Malformations Of Ovaries, Fallopian Tubes And Broad Ligiaments	Q50	
Genital	Congenital Malformations Of	Q51	

	The Uterus And Cervix		
Genital	Hypospadias	Q54.0	
Genital	Indeterminate Sex And Pseudohermaphroditism	Q56	
Genital	Other Congenital Malformations Of The Female Genitals	Q52	
Genital	Other Congenital Malformations Of The Male Organs	Q55	
Genital	Undescended Testicle, Bilateral	Q53.2	
Genital	Undescended Testicle, Unilateral	Q53.1	
Musculoskeletal	Congenital Deformities Of The Feet	Q66	This includes talipes, varus and valgus deformities
Musculoskeletal	Congenital Deformities Of The Hip	Q65	
Musculoskeletal	Congenital Diaphragmatic Hernia	Q79.0	
Musculoskeletal	Congenital Malformations Of The Musculoskeletal System, Not Elsewhere Classified	Q79	
Musculoskeletal	Congenital Malformations Of The Spine And Bony Thorax	Q76	
Musculoskeletal	Congenital Musculoskeletal Deformities Of Arm, Leg, Long Bones	Q68	
Musculoskeletal	Congenital Musculoskeletal Deformities Of Head, Face, Spine And Chest	Q67	
Musculoskeletal	Craniosynostosis	Q75.0	
Musculoskeletal	Exomphalos	Q79.2	
Musculoskeletal	Gastroschisis	Q79.3	
Musculoskeletal	Other Congenital Malformations Of Limbs (Shoulder Girdle, Knee, Arthrogryposis)	Q74	
Musculoskeletal	Other Congenital Malformations Of The Skull And Face Bones	Q75	
Musculoskeletal	Polydactyly	Q69	
Musculoskeletal	Reduction Defects Of The Lower Limb	Q72	
Musculoskeletal	Reduction Defects Of The Upper Limb	Q71	
Musculoskeletal	Reduction Defects Of Unspecified Limb	Q73	
Musculoskeletal	Syndactyly	Q70	
Nervous	Anencephaly	Q00	
Nervous	Congenital Hydrocephalus	Q03	
Nervous	Encephalocele	Q01	
Nervous	Microcephaly	Q02	
Nervous	Other Congenital Malformations Of The Brain	Q04	This includes malformation of corpus callosum, holoprosencephaly, reduction anomaly of brain, cerebellar anomaly
Nervous	Other Congenital Malformations Of The Nervous System	Q07	This includes any other malformations of central nervous sytem not mentioned above

Nervous	Spina Bifida	Q05	
Nervous	Spinal Cord Anomaly Other Than Spina Bifida	Q06	
Other Congenital Malformations	Congenital Ichthyosis	Q80	
Other Congenital Malformations	Congenital Malformations Of The Breast	Q83	
Other Congenital Malformations	Congenital Malformations Syndromes Due To Known Exogenous Causes Not Elsewhere Classified	Q86	This includes fetal alcohol syndrome, fetal hydantoin
Other Congenital Malformations	Epidermolysis Bullosa	Q81	
Other Congenital Malformations	Fetal Alcohol Syndrome (Dysmorphic)	Q86.0	
Other Congenital Malformations	Neurocutaneous Syndromes	Q85	This includes neurofibromatosis, tuberous sclerosis)
Other Congenital Malformations	Other Congenital Malformations Of Skin Appendages Such As Nail, Hair	Q84	This includes hair and nail abnormalities
Other Congenital Malformations	Other Congenital Malformations Of The Skin	Q82	This includes incontinentia pigmenti, mastocytosis, xeroderma, heriditary lymphoedema)
Other Congenital Malformations	Other Congenital Malformations, Not Elsewhere Classified	Q89	This includes malformations of spleen, adrenal, endocrine glands, conjoint twins
Other Congenital Malformations	Other Specified Congenital Malformation Syndromes Affecting Multiple Systems	Q87	
Other Congenital Malformations	Situs Inversus	Q89.3	
Respiratory	Cleft Lip	Q36	
Respiratory	Cleft Palate	Q35	
Respiratory	Cleft Palate With Lip	Q37	
Respiratory	Congenital Cystic Lung	Q33.0	
Respiratory	Congenital Malformations Of The Larynx	Q31	
Respiratory	Congenital Malformations Of The Lung	Q33	This includes agenesis, ectopic, hypoplastic and dysplastic lung
Respiratory	Congenital Malformations Of The Nose	Q30	
Respiratory	Congenital Malformations Of The Trachea And Bronchus	Q32	
Respiratory	Sequestration of The Lung	Q33.2	
Urinary	Congenital Hydronephrosis	Q62.0	
Urinary	Congenital Posterior Urethral Valves	Q64.2	
Urinary	Congenital Renal Cystic Diseases	Q61	
Urinary	Other Congenital Malformations Of The Urinary System	Q64	This includes epispadias, exstrophy of bladder, stricture of meatus
Urinary	Renal Agenesis And Other Defects Of The Kidney	Q60	This includes renal agenesis, hypoplasia, Potter's syndrome

### APPENDIX V

### **DEFINITIONS OF TYPE OF INFECTION**

When confirming a diagnosis for a given infection episode, look first for a positive culture, then for the administration of appropriate antibiotic therapy and finally look for the clinical signs listed below to infer the appropriate diagnosis type for a particular infection.

### Admitted with infection from other hospital:

Select this if a patient is admitted to your hospital from a **non-CNN hospital** with a culture proven diagnosis of infection. Also select this if a patient is admitted to your hospital after culture was taken at a non-CNN hospital and later was confirmed to be positive. If a patient is admitted from another CNN hospital and later identified to be positive for blood or CSF culture, then please contact the original CNN hospital to code in their discharge.

### Lower respiratory tract (pneumonia) must meet the following criterion:

- 1. Patient is less than or equal to 12 months of age and has chest x-ray changes consistent with 'pneumonia', 'consolidation' or 'infiltrates' *and*
- 2. Worsening respiratory signs (increased respiratory distress or oxygen or ventilation requirements in the previous 24 hours (ie. temp. instability, apnea, bradycardia, etc.) and
- 3. Isolation of pathogenic organism from ETT culture or broncheoalveolar lavage and
- 4. Treatment with antimicrobial for at least 5 days

### *Clinical sepsis* must meet the following criterion:

- 1. Patient is less than or equal to 12 months of age and has one of the following clinical signs or symptoms with no other recognized cause: fever (>38°C), hypothermia (<37°C), apnea, or bradycardia *and all* of the following:
  - a) Blood culture not done or no organism or antigen detected in blood
  - b) No apparent infection at another site
  - c) Physician institutes (or intends) appropriate antimicrobial therapy for sepsis for at least 5 days

**Skin and Soft Tissue Infection:** Includes skin infection (other than an incisional wound infection), soft tissue infection, decubitus ulcer infection, burn infection, breast abscess or mastitis, omphalitis, infant pustulosis, and newborn circumcision infection **AND must meet any of the following criteria:** 

- 1. Purulent drainage, pustules, vesicles, or boils, necrotizing fasciitis, infectious gangrene, necrotizing cellulitis, infectious myositis, lymphadenitis, or lymphangitis
- 2. Two of the following at affected site: localized pain or tenderness, swelling, redness, or heat and any of the following:
  a) Organism isolated from culture of aspirate or drainage from affected site; if organism is normal skin flora, must be a pure culture of a single organism
- 3. Physician institutes (or intends) appropriate antimicrobial therapy for at least 5 days

Surgical Site Infection (SSI): SSI can be superficial infections involving the skin only. Other SSI can involve tissues under the skin or organs. Score if there was infection of the surgical site diagnosed within 30 days of surgery and physician institutes (or intends) at least 5 days of antibiotics treatment. The surface swab/fluid/pus from the site needs to be positive for pathogenic bacteria. This category includes wound infection or abscess at surgical site.

*Urinary Tract Infection:* Includes symptomatic urinary tract infection, asymptomatic bacteriuria, as well as other infections of the urinary tract.

### Symptomatic urinary tract infection must meet either of the following criteria:

- 1. Patient is less than or equal to 12 months of age and has one of the following: fever (>38°C), hypothermia (<37°C), apnea, bradycardia, dysuria, lethargy, or vomiting *and* a urine culture of  $\geq$ 10² colonies/ml of urine with no more than 2 species of organisms in a catheter specimen or bladder tap.
- 2. Physician institutes (or intends) appropriate antimicrobial therapy for at least 5 days

## POSITIVE CULTURES - ORGANISM LIST

Organism
Acinetobacter Baumannii
Acinetobacter Lwoffii
Actinomyces Acremonium Species
Actinomyces Species
Adenovirus
Aggregatibacter Species
Alpha Streptococcus
Anaerobic Gram Negative Rod(s)
Aspergillus Species
Astrovirus
Bacillus Cereus
Bacillus Species
Bacteroides Species
Bifidobacterium Species
Bordetella Pertussis
Campylobacter Jejuni
Candida Albicans
Candida Glabrata
Candida Guilliermondii
Candida Lusitaniae
Candida Parapsilosis
Candida Species (unspecified)
Candida Tropicalis
Chlamydia Trachomatis
Citrobacter Freundii
Citrobacter Koseri
Clostridium Botulinum Toxin
Coronavirus
Corynebacterium Species
Cronobacter Sakazakii
Cytomegalovirus
Dengue
EBV, Epstein Barr Virus
Eikenella Species
Elizabethkingia Species
Enteric Streptococcus
Enterobacter Cloacae or Enterobacter Asburiae
Enterococcus Avium
Enterococcus Faecalis
Enterococcus Faecium
Enterococcus Gallinarum
Enterococcus Species
Enterovirus or Coxsackievirus or Echovirus
Escherichia Coli
Eubacterium Species
Gram Negative Bacteria

Gram Negative Rod(s) (includes coliform)
Gram Positive Bacteria
Gram Positive Coccus (Cocci)
Gram Positive Rods
Group B Streptococcus or Streptococcus Agalactiae
Haemophilus Influenzae
Hepatitis A Virus
Hepatitis B Virus
Herpes Simplex Virus Type 1
Herpes Simplex Virus Type 2
HIV
Human Herpes Virus 6
Human Metapneumovirus
Influenza A Virus
Influenza B Virus
Klebsiella
Klebsiella Aerogenes
Klebsiella Oxytoca
Klebsiella Pneumoniae
Lactobacillus Species
Lactococcus Lactis
Listeria Monocytogenes
Malassezia Furfur
Measles Virus
Moraxella Species
Morganella Morganii
Mycobacterium Species
Mycobacterium Tuberculosis
Mycoplasma / Mycoplasma Hominis
Neisseria Gonorrhoeae
Neisseria Meningitidis
Neisseria Species
Norovirus
Other Organism
Paenibacillus Pabuli
Pantoea Agglomerans
Parainfluenza
Parechovirus
Parvovirus
Pasteurella Aerogenes
Peptostreptococcus Species
Plasmodium Species or Malaria
Prevotella Species
Proteus Mirabilis
Proteus Species
Proteus Vulgaris
Providencia Species
Pseudomonas Aeruginosa
Pseudomonas Alcaligenes
Pseudomonas Fluorescens Group
· · r

D 1 D 1 C
Pseudomonas Putida Group
Respiratory Syncytial Virus
Rhinovirus
Rhodotorula Rubra
Rotavirus
Salmonella Species
Salmonella Typhimurium
Sapovirus
Serratia Marcescens
Shigella Species
Staphylococcus Aureus Coagulase Positive
Staphylococcus Capitis
Staphylococcus Coagulase Negative
Staphylococcus Epidermidis
Staphylococcus Haemolyticus
Staphylococcus Hominis
Staphylococcus Lugdunensis
Staphylococcus Species
Staphylococcus Warneri
Stenotrophomonas Maltophilia
Streptococcus Anginosus
Streptococcus Bovis
Streptococcus Milleri
Streptococcus Pneumoniae
Streptococcus Pyogenes or Group A Streptococcus
Streptococcus Viridans Group
Streptococcus Zooepidermidis
Toxoplasma Gondii
Treponema Pallidum or Syphilis
Ureaplasma Species
Varicella Zoster Virus
Yeast

# APPENDIX VII

## POSITIVE VIRAL ISOLATES - ORGANISM LIST

Organism
Adenovirus
Coronavirus
Cytomegalovirus
Enterovirus
Herpesvirus - Herpes Simplex virus I or II
Influenza virus
Norovirus/Norwalk virus
Parainfluenza virus
Respiratory Syncytial Virus
Rhinovirus
Rotavirus
Other virus

### APPENDIX VIII

### CANADIAN NEONATAL NETWORK SITES AND CONTACT INFORMATION

HOSPITAL SITE INVESTIGATOR

BC Children's Hospital Dr. Joseph Ting
Children's Hospital of Eastern Ontario Dr. Brigitte Lemyre

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Dr. Everett Chalmers Hospital Dr. Hala Makary

Foothills Medical Centre Dr. Ayman Abou Mehram
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Hamilton Health Sciences Centre Dr. Amit Mukerji
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Health Sciences Centre Dr. Molly Seshia

Hôpital Sainte-Justine Dr. Keith Barrington & Dr. Anie Lapointe

IWK Health CentreDr. Jehier AfifiJaneway Children's Health and Rehabilitation CentreDr. Julie EmberleyJewish General HospitalDr. Ermelinda PelausaKingston General HospitalDr. Faiza Khurshid

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Dr. Michael Dunn

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For a detailed listing of abstractors and their up-to-date contact information, please go to the CNN website at <a href="https://www.canadianneonatalnetwork.org">www.canadianneonatalnetwork.org</a>