



EHM NCCC Data Dictionary

The purpose of the Data Dictionary is to develop consistency in data entry. The Data Dictionary refers to elements visible when the reporting forms are printed.

Patients enrolled in the EHM NCCC data system will require provider input at enrollment, discharge and for all shifts that the infant is hospitalized through 28 days of age.

All forms have a comments box that is for your use only. It is not required, and information entered in this box will not be entered on the web.

Please enter and enroll all infants that are VLBW, 1500 grams or less.

This Dictionary defines the basic elements of entries for all Information forms.



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Admission

1. Admission Date/Time: Self-explanatory
2. Birth Weight (grams): Birth weight being used by the NICU team to conduct care. If infant outborn please use birth weight recorded at hospital of birth.
3. HC (cm): Head circumference reported at birth and used by NICU team. If no HC recorded at a referring hospital use HC at admission to your NICU.
4. Length (cm): Length reported at birth and used by NICU team. If no length recorded at a referring hospital use length at admission to your NICU.
5. Delivery: Self-explanatory
6. Gestational Age: In completed weeks
7. Before admission to the hospital, what was mom's plan for feeding this baby? This is mother's intention for feeding noted by staff in discussion with the mother on admission of the infant to the NICU.
8. Has a Doctor/Nurse Practitioner spoken to mom about the importance of providing milk for her baby? This question is to be answered once. It may not occur on the day of the infant's admission. If unknown whether such a conversation occurred, record not done.
9. After hospital discharge is mom using a pump? This question refers to arrangements made for mom to pump after DC from the hospital. Presumably discharge may be within a few days of the infant's admission. Answer yes "Yes" to the question is mom pumping when it is known if mom is pumping. Note the date and whether the pump being used by the mother is being rented or supplied by WIC. Note the type of pump in the free space provided. It is possible, though not desirable, that a mom may not get a pump at home for days or weeks. This is critical information in determining how successful we will be in maintain mother's milk supply.

Discharge

10. Discharge Date/Time: Self explanatory
11. Did this baby survive until discharge? Self-explanatory. If "No", skip to question 22 and 23. Discharge includes transfer to another facility.
12. Discharge age in days: Self-explanatory.
13. Discharge weight (grams): Self-explanatory.
14. HC (cm): Head circumference in cm measured on discharge.
15. Length (cm): Length in cm measured on day of discharge.
16. Did this baby go home on supplemental oxygen? Self-Explanatory. This includes oxygen just with feedings.



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17. Did this baby have NEC? We are using the Vermont Oxford Network (VON) definition for NEC. NEC includes Necrotizing Enterocolitis (NEC) diagnosed at surgery, at postmortem examination or clinically and radiographically using the following criteria:

At least one of the following clinical signs present:

- a) Bilious gastric aspirate or emesis
- b) Abdominal distension
- c) Occult or gross blood in stool (no fissure)

And, at least one of the following radiographic findings present:

- a) Pneumatosis intestinalis
- b) Hepato-biliary gas
- c) Pneumoperitoneum

Answer "No" if the infant did not satisfy the above definition of NEC. Infants who satisfy the above criteria but are found at surgery or post-mortem to have a focal perforation should not be coded as NEC.

18. If Yes where did NEC occur? If infant diagnosed at outlying hospital denote "other". If an infant is transferred to your facility and is diagnosed with NEC within four hours of arrival at your hospital denote "other."

19. Did this baby have NEC requiring surgery? Answer "Yes" if infant diagnosed at surgery with NEC. If at surgery an isolated intestinal perforation is discovered do not classify as NEC.

20. Did baby have sepsis? We are using the VON late infection criteria for sepsis. Each of the late infection items is based on whether the infant had the infection after Day 3 of life. In determining the date of Day 3, the date of birth counts as Day 1 regardless of the time of birth. For an infant born at 11:59 PM on September 1,

Day 3 is September 3rd. Use the criteria below when answering each of the late infection questions.

The three late infection items are NOT applicable if:

- a) The infant is discharged home or dies on or before Day 3, or
- b) The infant is transferred from your center to another hospital on or before Day 3 and either is not readmitted to your center before discharge home, death or first birthday, or
- c) Is transferred a second time on or before Day 3.

Otherwise the late infection items are applicable.



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Answer "Yes" if the item is applicable based on the Late Infection Applicability

Criteria above and a bacterial or fungal pathogen is recovered from a blood and/or cerebral spinal fluid culture obtained after day 3 of life. Answer "No" if the item is applicable based on the Late Infection Applicability Criteria and a bacterial or fungal pathogen is not recovered from a blood and/or cerebral spinal fluid culture obtained after day 3 of life.

There are separate considerations for Coagulase Negative Staphylococcus (CONS) infections. Sepsis will be answered "Yes" for CONS sepsis based on the previously described Late Infection Criteria and the infant having all three (3) of the following after day 3 of life:

- a) Coagulase negative staphylococcus is recovered from a blood culture obtained from either a central line, or peripheral blood sample, and/or is recovered from cerebrospinal fluid obtained by lumbar puncture, ventricular tap or ventricular drain.
- b) One or more signs of generalized infection (such as apnea, temperature instability, feeding intolerance, worsening respiratory distress or hemodynamic instability).
- c) Treatment with 5 or more days of intravenous antibiotics after the above cultures were obtained. If the infant died, was discharged, or transferred prior to the completion of 5 days of intravenous antibiotics, this condition would still be met if the intention were to treat for 5 or more days.

Answer "No" if the item is applicable based on the Late Infection Applicability Criteria and any or all of the above are not true.

21. Discharge Destination: Self-explanatory

22. For 24 hour period in previous 48 hrs (not on day of discharge) which best reflects the infant's feeding status: Regarding combination of mothers milk and formula, please note the reason for the combination. If mother has diminished milk supply or has decided to stop pumping/breastfeeding, report "diminished mother's milk." If formula being added to supplement for concerns related to growth (mineral repletion, poor growth etc) indicate "growth."

22. Mom's Ethnicity: Choices are African-American, Asian, Caucasian and Spanish/Hispanic/Latina. More than one choice may be selected. We have limited choices for this initiative to these choices in the interest of simplifying data collection. Ideally this answer should be the same as that reported on the Birth Certificate. If not available please use ethnicity as self-reported by the mother on the birth certificate

23. Payor: Self-explanatory.



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Daily Data Reporting

We are requesting data be reported by shift for each infant for the first 28 days of life. Shifts are designated with times but correspond to day and night shifts. If a shift schedule does not conform to a &AM/7PM pattern please report data for the most representative day and night shift.

24. Did mother hold baby skin to skin on your shift? Skin to skin time is defined as the infant prone on the mother, father or other family member's chest/abdomen for a period of 1 hour. The readiness of infant, parents and staff for skin to skin care needs to be considered by the care team per unit protocol. The family member's chest/abdomen should be bare and the infant undressed except for a diaper. The infant will be placed skin to skin per unit protocol. The infant should be monitored for stability during this period and mother supported as she kangaroos. If this occurs on the shift check "Yes". If a skin to skin or kangaroo care session is interrupted for instability of the infant during transfer or before approximately one hour is reached, check "No" for skin to skin time.
25. Has infant received, on your shift human milk for oral care, maternal milk, donor milk, formula (mark all that apply): Self explanatory
26. Fortifier added to breast/donor milk feedings?: Includes all liquid or powder fortification mixtures. Self-explanatory.
27. Today's weight (grams): Self-explanatory.
28. Have you reviewed the status of mother's milk supply? This refers to LC, nursing or medical staff discussing mother's success and challenges with pumping in a discussion that shift. If no contact with mother answer "No". Then answer both 29 and 30 as "0"
29. How many times has mom pumped in the last 24 hrs? If contact with mother this shift report number of times mother has pumped over prior 24 hours.
30. How much milk has mom expressed in the last 24 hrs? (ml) If contact with mother report the estimate of volume in mls which mother has pumped.