

MEMORANDUM

TO: Illinois Birthing Centers, Illinois Hospitals, Obstetrics and Gynecology Centers, Women Health Centers, Illinois Newborn Screening Advisory Committee, Pediatric Genetic and Metabolic Specialists, Pediatricians, Family Practitioners, Midwives

FROM: Joshua J. Geltz, PhD
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Division of Laboratories 

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SUBJECT: Common Errors for Newborn Screening Electronic Medical Record Submissions

Recently the Newborn Screening section has witnessed increased discrepancies between demographic information transmitted through electronic submissions (HL7) and information contained on received newborn screening cards. **Complete and accurate demographic information is essential when submitting newborn screening blood card specimens and electronic orders.** The details below are provided to help your system ensure that the correct information is provided to the Illinois Department of Public Health Newborn Screening Program.

1. **BABY'S INFORMATION**

If the legal name of the baby is known, enter the baby's name on both the NBS card and in the EMR for transmission by HL7.

If the legal name of the baby has not been decided, use the baby's sex at birth and the last name of the mother as the name on the NBS card and in the EMR transmission by HL7. For example: (Last Name, First name) Smith, Baby Girl OR Smith, Baby Boy

2. **MEDICAL RECORD NUMBER (MRN)**

Verify that the MRN on the NBS card accurately reflects the MRN on the patient record. The MRN is critical to identify the baby if the legal name is unknown or if the baby's last name is different than that of the mother.

3. **MOTHER'S INFORMATION**

Enter the mother's phone number or the emergency contact information provided at admission. The phone number is critical when contact with a parent is needed to inform them of abnormal test results and long-term follow-up. If the baby is in the care of a surrogate, adoption, or DCFS custody/foster care, put the name of the guardian along with the address and phone number. IDPH requires the information of the person responsible for the baby's care and well-being after discharge. IDPH will be adding a field on the newborn card that requests parents' email address soon.

4. **FEEDING**

The feeding type for the newborn can have a direct result on the interpretation of some of IDPH's newborn screening metabolic test results. Please mark all feeding types that apply.

5. **BIRTH DATE/TIME AND COLLECTION DATE/TIME**

The age at the collection is extremely important and can result in Unsatisfactory test interpretations if the information provided is incorrect. Screening algorithms must have the correct age and weight to determine an accurate result. Collection date and/or time cannot be blank and must be entered accurately.

6. **TRANSFUSED DATE**

A transfusion date should ONLY be entered if the baby has received a blood transfusion. Otherwise, this field should be left blank.

Initial NBS samples must always be collected prior to a blood transfusion and should be collected immediately upon admission to the NICU if you suspect the baby could receive a blood transfusion.

If you enter a transfusion date, we expect the baby to have more adult hemoglobin than fetal hemoglobin. Results will be invalid for hemoglobinopathies, galactosemia, and other disorders. The baby will need to be retested 120 days after transfusion, therefore delaying treatment for a baby with sickle cell disease or other disorders.

7. **COLLECTOR**

The collector's initials function as a point of contact if a field has been left blank or incorrect information was provided. This information is extremely important for IDPH to be able identify an individual to speak with regarding a particular baby.

8. **INITIAL SPECIMEN/REPEAT SPECIMEN**

NICU protocols notwithstanding, an initial specimen that is collected prior to 24 hours of age, must obtain a repeat specimen at 36-48 hours of age for a complete screening of all disorders. If the baby has been received from another facility, mark the specimen as "repeat" as this is the 2nd specimen collected on the same baby.

9. **NICU/SPECIALTY CARE, ANTIBIOTICS, MECONIUM ILEUS, CFTR MODULATOR AND TRANSFER TO ANOTHER FACILITY**

Completing this section accurately is extremely important for analyzing results, especially if results are abnormal. For example, the presence of meconium ileus or the mother being treated by CFTR modulators changes the testing workflow for cystic fibrosis screening at the IDPH newborn screening laboratory.

10. **BIRTH NUMBER AND ORDER**

Completing this field accurately is important for identification of the specimen and to ensure that results are assigned to the correct baby.

11. BIRTHWEIGHT

Accurate birthweight is essential for testing. Screening algorithms and cut-offs are both age and weight related when determining if a baby has an abnormal result. Pre-term and Term babies have different normal values. The format for birthweight must be provided in Grams as a whole number. You must not enter a different type of unit and cannot include any units or identifying text. This field is numeric only.

12. GENDER

Completing gender is important for identification of specimens and to ensure results are assigned to the correct baby.

13. RACE AND ETHNICITY

While this is not a mandatory field, some disorders have a higher incidence in certain populations. Race and ethnicity are helpful when looking at data to adjust result cut-offs.

14. GESTATIONAL AGE

Gestational ages are used for screening algorithms. Cut-off values that are used during testing to determine if a baby has an abnormal result are age and weight related. Pre-term and Term babies have different normal values. Gestational age must be provided in the following format (Number of weeks/Number of days). By way of example, a baby with a gestational age of 37 Weeks and 2 Days is represented as 37.2.

15. BABY'S PHYSICIAN NAME AND PHONE NUMBER AFTER DISCHARGE

Enter the name of the medical provider that will be following the baby AFTER DISCHARGE. This is the provider that will be contacted with any abnormal test results. Delays in reporting results to the baby's medical provider causes delays in treatment which may result in negative outcomes or possibly death of the newborn. Do NOT enter the name of the hospitalist or the name of the provider that ordered the newborn screen.

****If you are a NICU that is a Contact Hospital for IDPH, neonatology or NICU/Peds Department Chair, you may be listed as the discharge provider if the baby is very preterm. However, the name of the baby's medical provider that will follow the baby after discharge should be indicated for any baby that is over 34 weeks gestation.**

16. HOSPITAL SUBMITTER

Provide both the name of the facility and submitter ID when submitting NBS specimen numbers. Providing this information informs IDPH which facility that specimen was collected and allows us to follow up regarding incomplete or incorrect information. This information also ensures billing processes occur correctly with your facility.

CONTACTS and RESOURCES

IDPH Newborn Screening Follow Up Main Phone: 217-785-8101

DPH.NewbornScreening@Illinois.gov

[IDPH Newborn Screening Site](#)