CPeTS, NICU, HRIF Database Changes

2024 Birth Year

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INTRODUCTION

We never stop working to improve care for California's most vulnerable infants and children, and we know you don't either. Every year, CPQCC staff, members, experts and volunteers review and reconsider the data elements being collected to be sure we're staying on the cutting edge of neonatal quality improvement care. Elements are sometimes added, removed, or renamed and renumbered.

In addition, other groups often make changes to data elements or definitions that necessitate changes to CPQCC data collection:

- High Risk Infant Follow-up (HRIF)
- California Perinatal Transport Systems (CPeTS)
- California Children's Services (CCS)
- Vermont Oxford Network (VON)

This document describes the changes that have been made to the 2022 NICU, CPeTS, and HRIF data sets.

CALIFORNIA CHILDREN'S SERVICES (CCS)

No Changes

TRANSPORT DATA SET (TRS)

No Changes

NICU ADMISSION DISCHARGE (A/D) AND DELIVERY ROOM DEATH (DRD) FORM

DEMOGRAPHICS (TAB 2, ITEM 17a.)

Item 17a. Maternal Antenatal Conditions: Chorioamnionitis

Change:

Add note: The diagnosis of chorioamnionitis can be made clinically, from amniotic fluid testing, or histopathologic analysis of the placenta or umbilical cord.

DELIVERY ROOM & FIRST HOUR AFTER BIRTH (TAB 3, ITEM 22h.)

Item 22h. Delivery Room Resuscitation: Supraglottic Airway Device

Change:
Name change of **"Laryngeal Mask Airway"** to **"Supraglottic Airway Device"** and add note.

Updated 2023 Definition:
Select "Yes" if the infant received any intermittent positive pressure breaths via a supraglottic airway device in the delivery room or during the initial resuscitation performed immediately after birth. Intermittent positive pressure breaths may be administered using an anesthesia bag, self-inflating bag, or other device that generates intermittent positive pressure.

Add note:
There are many types of supraglottic airway devices, including laryngeal mask airway (LMA) devices.
A face mask is not considered a supraglottic airway device for the purposes of this definition.

POST-DELIVERY DIAGNOSES AND INTERVENTIONS - RESPIRATORY (TAB 4, ITEMS 29, 31)

Item 29. Respiratory Distress Syndrome (RDS)

Change: Modified the definition for RDS to update the requirement for supplemental oxygen to maintain pulse oximeter saturation from 85% to 88% within the first 24 hours of life.

Updated 2024 Definition:
Central cyanosis in room air, or a requirement for continuous positive airway pressure (CPAP), positive end expiratory pressure (PEEP) and/or supplemental oxygen to maintain a pulse oximeter saturation over ~~85%~~ 88% within the first 24 hours of life.

Item 31. Meconium Aspiration Syndrome

Change: Modified the definition for Meconium Aspiration Syndrome to remove "or pneumonia".

Updated 2024 Definition:
Absence of culture proven early onset bacterial sepsis ~~or pneumonia~~. The diagnosis of culture proven early onset bacterial sepsis ~~or pneumonia~~ requires a positive blood culture obtained within 72 hours of birth.

HRIF REPORTING SYSTEM DATA SET

REFERRAL / REGISTRATION (RR) FORM

Program Registration Information - Infant Race and Birth Mother's Race

Change: Include an **Unknown** option when determining Single or Multiracial
Definition: Select **Unknown** if this information cannot be obtained.

Change: Revise **Unknown** race definition for Infant Race and Birth Mother's Race
Definition:
Infant Race: Select **Unknown** if the parent or primary caregiver cannot identify or refuse to declare a race.
Birth Mother's Race: Select **Unknown** if the birth mother cannot identify or refuse to declare a race.

Medical Eligibility Profile - Other Problems that Could Result in Neurological Abnormality

Change: Remove the **Other** - **text entry field**.

STANDARD VISIT (SV) FORM

Interval Medical Assessment - Medications Since Last Visit

Change: Add new items **Allergy Medication** and **Levothyroxine**.

Change: Add **Beyfortus/Nirsevimab** to Synagis/Palivizumab medication selection.
Revised data item to display as **Synagis/Palivizumab or Beyfortus/Nirsevimab**

Medical Services Review

Change: Add **Dermatology** medical service selection

Cerebral Palsy (CP) – Was Early Cerebral Palsy Diagnosis Made?

Change: Add new section **Early Detection of Cerebral Palsy**
Definition: In response to concerns around potential delay in cerebral palsy (CP) diagnosis and therefore possible delay in data-driven interventions, a large working group of international experts and parent stakeholders published guidelines for early CP detection and based on a systematic review of the evidence

(2, 3). This included a comprehensive review and recommendations regarding standardized assessment tools at different timepoints (see Appendix _ Figure from Novak et al, JAMA Pediatrics 2017 in the Part III – Appendices section of the manual). Since then, publications have described implementation of this approach in single sites and organizational systems (4). In addition, recent publications have further described best practice guidelines for communicating with parents when diagnosis of a disability is made.

We are aware that some California sites have launched integration of standardized assessments to optimize early CP detection. Therefore, we have expanded the Standard Visit queries regarding CP diagnosis to earlier ages aligned with questions about standardized assessments used.

Was Early Cerebral Palsy Diagnosis Made?
Complete if the Child is <18 months adjusted age.

- Select **No** if the infant/child does not have cerebral palsy. Proceed to Developmental Assessment.
- Select **Yes** if the infant/child cerebral palsy assessment indicates High Risk or Definite.

  Select the Assessment Used to Arrive at Early Diagnosis of Cerebral Palsy:
  - Proceed to select all assessments used.
  - Alberta Infant Motor Scale (AIMS)
  - Developmental Assessment of Young Children (DAYC)
  - General Movements Assessment (GMA)
  - Hammersmith Infant Neurological Examination (HINE)
  - Motor Assessment of Infants (MAI)
  - Magnetic Resonance Imaging (MRI)
  - Neurologic exam with GMFCS assessment
  - Neuro Sensory Motor Development Assessment (NSMDA)
  - Test of Infant Motor Performance (TIMP)
  - Other (text field)

Developmental Core Visit Assessment - Developmental Test

Change: Remove Battelle Developmental Inventory, 2 Edition (BDI-2) and replace with **Battelle Developmental Inventory, 3 Edition (BDI-3)**
Definition: This test is scored using both standard scores and scale scores.
Standard Scores are used for 5 domains (Adaptive, Personal-Social, Communication, Motor, and Cognitive).
Scale Scores are used for 4 sub-domains (Receptive Language, Expressive Language, Fine Motor, and Gross Motor).

- Enter the score at the appropriate range for each domain.
- Select Unable to Assess if the infant/child was uncooperative during the test or if this information cannot be obtained.
- Select Did Not Assess if the domain/scale is not used for the infant/child's developmental assessment.

The following are the score ranges:

Standard Scores
Domains: Adaptive, Personal-Social, Communication, Motor, and Cognitive

- Accelerated Development (130-155)
- Advanced Development (120-129)
- High Average (110-119)
- Average (90-109)
- Low Average (80-89)
- Mild Developmental Delay (70-79)
- Significant Developmental Delay (45-69)

Autism Spectrum Screen – Has a Diagnosis of Autism Spectrum Disorder Been Made?

Change: Add a new item **Has a Diagnosis of Autism Spectrum Disorder Been Made? (Optional)**
Definition:

- Select **No** if the infant/child has not been diagnosed with autism spectrum disorder. Proceed to – Was an Autism Spectrum Screen Performed During This Visit?
- Select **Yes** if the infant/child has been diagnosed with autism spectrum disorder. Proceed to – Early Start (ES) Program.

Social Concerns and Resources – Food Insecurity

Change: Modified **Food Insecurity** definition
Definition: Choose one of the options if intervention is necessary; in the instance that the primary caregiver within the past 12-months: Worried whether their food would run out before they got money to buy more OR the food they bought just didn't last and they didn't have money to get more. NOTE: Some families receiving food and nutrition services such as CalFresh Food or Women, Infants & Children (WIC) may experience food insecurities.

CLIENT NOT SEEN / DISCHARGE (CNSD) FORM

Reason for Client Not Seen / Discharge

Change: Add new item **Clinic Visit Considered Unnecessary**
Definition: Select Clinic Visit Considered Unnecessary, if the family was informed that HRIF services are not needed by the infant/child's health care professional (General/Family Practitioner, Pediatrician, Nurse Practitioner).

Change: Modified **Lost to Follow-up** definition
Definition: Select Lost to Follow-up if unable to initiate contact with the family after multiple attempts.

Change: Modified **Unable to Contact** definition
Definition: Select Unable to Contact if the HRIF Coordinator is not able to get in contact (phone, letter, email, etc.) with the family to schedule an appointment after multiple attempts.
NOTE: The HRIF Coordinator should inform the infant/child's pediatrician that the family is not responding, and they are unable to contact the family.