# CPeTS, NICU, HRIF Database Changes

2025 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 2025 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 (ITEM 2)**

Item 2. Head Circumference at Birth (entries allowed should be between 10.0 cm and 70.0 cm.)

UPDATE: The lower limit for this item was removed to allow the entry of values lower than 10.0 cm.

#### MATERNAL HX (ITEM 10a/b.)

Item 10a. Mother's Hispanic Origin [HISP] Item 10b. Mother's Race [MATRACE]

**UPDATE:** This item has been merged and updated into one item and added a new classification and format based on the Office of Management and Budget (OMB) update for maternal race and ethnicity. The following items will also be added: **Other, Declined and Unknown**, and the ability to select multiple options. **Reporting:** We plan to use the same basic ranking format that is currently being used for maternal race/ethnicity.

#### Item 10. Mother's Race and Ethnicity

- American Indian or Alaska Native
- Asian
- Black or African American
- Hispanic or Latino
- Middle Eastern or North African
- Native Hawaiian or Pacific Islander
- White
- Other
- Declined
- Unknown

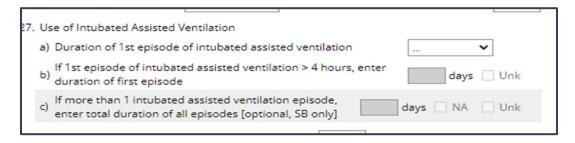
NOTE: While you can select multiple choices, note that if you select Declined or Unknown, all other options will be grayed out. See below.

10.	Maternal Race and Ethnicity
	American Indian or Alaska Native
	Asian
	Black
	Hispanic or Latino
	Middle Eastern or North African
	Native Hawaiian or Pacific Islander
	☐ White
	Other
	Declined
	Unknown

# **RESPIRATORY (ITEM 27c.)**

Item 27c. If > 1 Episode of Intubated Assisted Ventilation, Total Duration of Intubated Assisted Ventilation (Optional as of 2023: Small Babies only)

If an infant experienced more than 1 episode of intubated assisted ventilation, enter the total duration of intubated assisted ventilation days summed across all episodes.



**UPDATE**: Extended to Big Babies as optional.

#### OTHER DIAGNOSES - PDA SURGERY (ITEM 43g.)

Item 43g. PDA Surgery in conjunction with Repair or Palliation of Congenital Heart Disease

**UPDATE**: We have added 10 new surgery codes that can be used to identify the cardiac surgery that was done with the PDA surgery.

If an infant has PDA surgery, and if the PDA surgery is done in conjunction with a surgery related to CHD (i.e., the check box for item 43g is checked), the user must specify at least one of the following surgery codes: \$501, \$502, \$504, \$507, \$508, \$509, \$510, \$511, \$512, \$513, \$514.

- S501 Vascular Ring division
- S502 Repair of coarctation of the aorta
- S504 Repair or palliation of congenital heart disease
- S507 Norwood procedure with Sano modification
- S508 Norwood procedure with aortopulmonary shunt
- S509 Hybrid surgery (ductal stenting and bilateral branch pulmonary artery banding)
- S510 Truncus arteriosus repair
- S511 Arterial switch
- S512 Repair of total anomalous pulmonary venous return
- S513 Aorta pulmonary shunt
- S514 Pulmonary artery banding

#### **DISPOSITION (ITEM 59)**

Item 59. Head Circumference at Initial Disposition (entries allowed should be between 10.0 cm and 70.0 cm.)

**UPDATE:** The lower limit for this item was removed to allow the entry of values lower than 10.0 cm.

#### HRIF REPORTING SYSTEM DATA SET

#### REFERRAL / REGISTRATION (RR) FORM

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

**UPDATE:** New data items: **Infant's Race/Ethnicity** and **Birth Mother's Race/Ethnicity** will be added to align with the Office of Management and Budget (OMB) revised Statistical Policy Directive No.15 (SPD 15): Standards for maintaining, collection and presenting federal data on race and ethnicity. Reference: <a href="https://www.federalregister.gov/d/2024-06469">https://www.federalregister.gov/d/2024-06469</a>.

This change will combine race and ethnicity into one data item; include two additional categories: **Middle Eastern or North African** and **Declined**; and allow multiple selections.

#### **NOTE:**

- This data item will be used for all infants born in 2025.
- Selecting **Declined** or **Unknown** categories will cancel (grey out) the other race/ethnicity options.

**Reporting:** We plan to use the same basic single race ranking format that is currently being used for ethnicity and race. Starting 2027, the reporting tables and displays will be extended to include the multiple race categories.

NEW ITEM - COMPLETE FOR INFANTS BORN IN 2025								
*Infant's Race/Ethnicity (Check all that apply)	□ American Indian or Alaskan Native     □ Black or African American     □ Middle Eastern or North African     □ White     □ Unknown	☐ Asian ☐ Hispanic / Latino ☐ Native Hawaiian or Pacific Islander ☐ Other ☐ Declined						
NEW ITEM - COMPLETE FOR INFANTS BORN IN 2025								
*Birth Mother's Race/Ethnicity (Check all that apply)	American Indian or Alaskan Native Black or African American Middle Eastern or North African White Unknown	☐ Asian ☐ Hispanic / Latino ☐ Native Hawaiian or Pacific Islander ☐ Other ☐ Declined						

#### STANDARD VISIT (SV) FORM

<u>Autism Spectrum Screen</u> – Was an ASD diagnosis made at this visit (i.e. concurrent DBP evaluation)?

UPDATE: New item Was an ASD diagnosis made at this visit (i.e. concurrent DBP evaluation)? (Optional)

#### **Definition:**

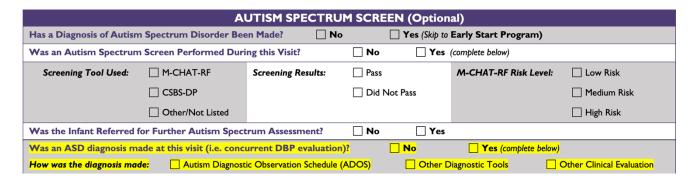
**NOTE:** This data item was added for those HRIF Program sites that conduct comprehensive CCS-paneled Developmental Pediatrics and/or psychology evaluations at the time of the infant/child's HRIF core clinic visit. This is **not an expectation** for HRIF Program clinic visits.

- Select No if the infant/child was not diagnosed with autism spectrum disorder (ASD) at this visit
  concurrent with a Developmental Behavioral Pediatrics (DBP) or psychology evaluation. Proceed to
  Early Start (ES) Program.
- Select **Yes** if the infant/child was diagnosed with autism spectrum disorder (ASD) at this visit concurrent with a Developmental Behavioral Pediatrics (DBP) or psychology evaluation. Complete the **How was the diagnosis made** question.

#### How was the diagnosis made:

Select the appropriate evaluation instrument used to make the ASD diagnosis:

- Autism Diagnostic Observation Schedule (ADOS)
- Other Diagnostic Tools
- Other Clinical Evaluation



#### **Social Concerns and Resources**

#### **UPDATE:** New option Already Receiving Services

**Definition:** If the child/family is currently receiving intervention services prior to the clinic visit. **NOTE:** if additional intervention services are needed at the time of the clinic visit, select the appropriate "**Yes**" option below.

- Select Yes, Referral Not Necessary
- Select Yes, Referred to Social Worker
- Select Yes, Referred to Other Community Resources

#### **Other Medical Conditions**

UPDATE: Remove Has the Child Been Tested for COVID-19? and Was the Delay Due to COVID-19 Pandemic? data items.

# ADDITIONAL VISIT (AV) FORM

# Autism Spectrum Screen (Optional)

**UPDATE:** Add **Autism Spectrum Screen (Optional)** section from the Standard Visit form.

AUTISM SPECTRUM SCREEN (Optional)								
Has a Diagnosis of Autism Spectrum Disorder Been Made? No Yes								
Was an Autism Spectrum Screen Performed During this Visit? No Yes (complete below)								
Screening Tool Used:	☐ M-CHAT-RF	Screening Results:	Pass	M-CHAT-RF Risk Level:	Low Risk			
	CSBS-DP		Did Not Pass		Medium Risk			
	Other/Not Listed				High Risk			
Was the Infant Referred for Further Autism Spectrum Assessment? No Yes								
Was an ASD diagnosis made at this visit (i.e. concurrent DBP evaluation)? No Yes (complete below)								
How was the diagnosis made:  Autism Diagnostic Observation Schedule (ADOS)  Other Diagnostic Tools  Other Clinical Evaluation								