

# 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.

27. Use of Intubated Assisted Ventilation

a) Duration of 1st episode of intubated assisted ventilation

b) If 1st episode of intubated assisted ventilation > 4 hours, enter duration of first episode  days  Unk

c) If more than 1 intubated assisted ventilation episode, enter total duration of all episodes [optional, SB only]  days  NA  Unk

**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: **S501, S502, S504, S507, S508, S509, S510, S511, S512, S513, S514.**

- 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: <https://www.federalregister.gov/d/2024-06469>.

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		
<b>*Infant's Race/Ethnicity</b> (Check all that apply)	<input type="checkbox"/> American Indian or Alaskan Native	<input type="checkbox"/> Asian
	<input type="checkbox"/> Black or African American	<input type="checkbox"/> Hispanic / Latino
	<input type="checkbox"/> Middle Eastern or North African	<input type="checkbox"/> Native Hawaiian or Pacific Islander
	<input type="checkbox"/> White	<input type="checkbox"/> Other
	<input type="checkbox"/> Unknown	<input type="checkbox"/> Declined

NEW ITEM - COMPLETE FOR INFANTS BORN IN 2025		
<b>*Birth Mother's Race/Ethnicity</b> (Check all that apply)	<input type="checkbox"/> American Indian or Alaskan Native	<input type="checkbox"/> Asian
	<input type="checkbox"/> Black or African American	<input type="checkbox"/> Hispanic / Latino
	<input type="checkbox"/> Middle Eastern or North African	<input type="checkbox"/> Native Hawaiian or Pacific Islander
	<input type="checkbox"/> White	<input type="checkbox"/> Other
	<input type="checkbox"/> Unknown	<input type="checkbox"/> Declined

## STANDARD VISIT (SV) FORM

### Autism Spectrum Screen – 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

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