

# NICU Database Getting Started Manual

*Birth Year 2024*

# Table of Contents

<b>ABOUT THE NICU MANUALS .....</b>	<b>1</b>
<b>INTRODUCTION.....</b>	<b>2</b>
<b>WHO WE ARE .....</b>	<b>2</b>
<b>OUR MEMBERS AND PARTNERS.....</b>	<b>2</b>
Members .....	2
Vermont Oxford Network (VON) .....	3
High Risk Infant Follow-up (HRIF) Program .....	3
California Perinatal Transport System (CPeTS).....	3
California Children’s Services (CCS).....	4
California Maternal Quality Care Collaborative (CMQCC) .....	4
Regional Perinatal Programs of California (RPPC) .....	4
<b>WHAT WE DO.....</b>	<b>4</b>
NICU Database, including NICU and Transport data sets .....	5
NICU Reports .....	5
HRIF Reporting System (Data and Reports) .....	5
All NICU Admissions Database (optional) .....	5
CCS Supplemental Form and Reports.....	6
VON Data.....	6
<b>HELP AND SUPPORT .....</b>	<b>6</b>
<b>OTHER RESOURCES.....</b>	<b>7</b>
<b>GETTING STARTED .....</b>	<b>7</b>
<b>CENTER CONTACTS.....</b>	<b>7</b>
<b>LOGGING IN .....</b>	<b>8</b>
Add New User ID.....	8
Reactivate User ID.....	8
Change Password .....	8
Forgot Password .....	9
<b>HCAI ID AND NICU CENTER ID.....</b>	<b>9</b>
<b>IDENTIFYING AND TRACKING ELIGIBLE BABIES.....</b>	<b>10</b>
<b>WHICH BABIES ARE ELIGIBLE? .....</b>	<b>10</b>
<b>TRACKING ELIGIBLE INFANTS.....</b>	<b>10</b>
Record ID.....	11
Patient Log (Optional) .....	12
Transport Log.....	12
Pending Eligibility Log (Optional) .....	12
NICU Activity Log / CCS Activity Log (Optional).....	12

## About the NICU Manuals

Information on the NICU Database and NICU Reports can be found in several manuals. Here is a brief list with descriptions. If you have questions, please file a Help Desk ticket at [cpqcchelp.org](http://cpqcchelp.org).

**Getting Started** – fundamental information for new members and new data contacts about CPQCC and partners, about the NICU Database and NICU Reports, and how to get connected and start submitting data.

**Is That Baby Eligible?** – eligibility criteria for the NICU Database (Small Babies and Big Babies), High Risk Infant Follow-Up, and the Vermont Oxford Network.

**NICU Manual of Definitions**– definitions for every field in the NICU Database (for example, infant’s birth weight, gestational age, head circumference) and guidance on how to enter data for each.

**EDS (Electronic Data Submission) Instructions** – how to upload a file (.csv or .txt format) containing many infants’ records at once into the NICU Database.

**EDS Specifications** – definitions for all fields (some required, some optional) in an EDS file.

## Introduction

### Who We Are

The California Perinatal Quality Care Collaborative (CPQCC) is a statewide network of California’s neonatal intensive care units (NICUs) and High Risk Infant Follow-up (HRIF) Programs, committed to improving the quality of care for California’s most vulnerable infants. A member-driven organization, our work is directed by volunteer committees of neonatologists, nurses, developmental care specialists, data abstractors, and quality improvement (QI) experts from across the state who share our commitment to high quality neonatal care. Together, we are proud to be making substantial improvements in the health and wellbeing of California’s infants.

Via our member hospitals, CPQCC collects high quality information on perinatal outcomes and resource utilization, which then allows for performance improvement and benchmarking processes in perinatal care throughout California.

### Our Members and Partners

#### Members

CPQCC’s members are the NICUs caring for 95% of the Very Low Birth Weight infants (VLBW’s) born in California and the HRIF clinics providing follow-up care after discharge.

Member NICUs enter data on eligible infants (both VLBW’s or “Small Babies”, and “Big Babies” with acute medical or surgical conditions, whose care begins during the first 28 days of life, known as the “perinatal period”) into the NICU Database, and analyze their data on the NICU Reports site. This allows them to review their hospital’s performance and compare it to similar hospitals across California (for example, other community hospitals) or against the entire CPQCC network.

Member HRIF clinics enter data on all infants eligible for follow-up care (all babies eligible for entry into the NICU Database qualify, as do other babies with specific medical criteria) into the HRIF Reporting System, a portal for both data entry and for viewing reports which compare HRIF clinic performance across the state.

### **Vermont Oxford Network (VON)**

The Vermont Oxford Network (VON) is a nonprofit voluntary collaboration of health care professionals working together as an interdisciplinary community to change the landscape of neonatal care. Founded in 1988, VON comprises teams of health professionals representing neonatal intensive care units and level I and II care centers around the world, in support of their mission to improve the quality and safety of medical care for newborn infants and their families through a coordinated program of research, education, and quality improvement projects.

All members of CPQCC are members of the VON with full access to VON services including Annual Quality Management Reports. This manual contains copyrighted material of the Vermont Oxford Network, which is used with their permission.

### **High Risk Infant Follow-up (HRIF) Program**

California Children's Services (CCS) established the High Risk Infant Follow-up (HRIF) Program in 1979, to provide follow up care for neonates and infants discharged from the NICU who are at high risk for neurodevelopmental delay or disability. The CCS HRIF Program oversees HRIF clinics across the state that provide three or more Standard Visits to eligible infants. Visits include a limited number of outpatient diagnostic services for infants and children up to three years of age, whose care was provided in a CCS Program-approved NICU.

All of the 68 HRIF clinics in California are members of CPQCC and enter data on the infants and children they treat into the HRIF Reporting System, which is managed by CPQCC.

For more on the High Risk Infant Follow-up Program, choose Follow-Up from the top menu on the CPQCC website.

### **California Perinatal Transport System (CPeTS)**

The California Perinatal Transport System (CPeTS) was established in 1976, with the intent of developing a dispatch service to facilitate transport of critically ill infants and mothers with high risk conditions to regional Neonatal Intensive Care Units (NICUs) and Perinatal High Risk Units (PHRUs).

Perinatal and neonatal transport data is collected and analyzed in CPQCC's NICU Database, for regional planning, outreach program development, and outcome analysis. This data is referred to as the Transport data set.

In addition, the [CPeTS website](#) tracks bed availability in CCS-approved NICUs to assist with transport planning and patient referral.

### **California Children's Services (CCS)**

The [CCS](#) program provides diagnostic and treatment services, medical case management, and physical and occupational therapy services to children under age 21 with [CCS-eligible medical conditions](#). Examples of CCS-eligible conditions include, but are not limited to, chronic medical conditions such as cystic fibrosis, hemophilia, cerebral palsy, heart disease, cancer, traumatic injuries, and infectious diseases producing major sequelae.

The CCS program is administered as a partnership between county health departments and the California Department of Health Care Services (DHCS).

CCS sets the standards for NICUs in California, and helps provide guidance and leadership to CPQCC.

### **California Maternal Quality Care Collaborative (CMQCC)**

CPQCC's sister organization, [CMQCC](#), was founded in 2006 at Stanford University School of Medicine, together with the State of California, in response to rising maternal mortality and morbidity rates. The two organizations work collaboratively to address maternal and perinatal health issues.

### **Regional Perinatal Programs of California (RPPC)**

The Regional Perinatal Programs of California (RPPC), established in 1979, provides quality improvement resources, consultation, and technical assistance to hospitals and health care providers. The nine California regions were established to create comprehensive, cooperative networks of public and private health care providers within geographic areas to assure the well-being of pregnant women and their babies and to promote access to appropriate levels of high quality care.

CPQCC and CMQCC provide data, reporting, and support to RPPC staff working with our member hospitals.

## **What We Do**

CPQCC collects data on eligible infants during their NICU episode of care from member hospitals. Using this data, we provide the hospitals with reports for quality improvement and to allow comparison between NICUs at the same level (e.g. Regional) and across the entire CPQCC Network. On the hospitals' behalf, we provide required reports to CCS. As membership in CPQCC includes membership in VON, we also send data to VON on a daily basis.

This section explains the data sets and reports that CPQCC provides.

## NICU Database, including NICU and Transport data sets

Member hospitals enter information about eligible infants into the NICU database. This includes information about “episodes of care” that begin during the perinatal period, as well as acute transport into or out of a NICU (acute transport is defined as transport for urgent medical or surgical reasons).

The information in the NICU Database is organized by birth year. Every spring, all CPQCC member hospitals must take part in cleaning up and “finalizing” the data that was entered for the previous birth year (example – data finalization for babies born in 2017 occurs in spring 2018). Once this process is complete, CPQCC produces reports that are required to be submitted annually to CCS for all CCS-approved NICUs. CPQCC sends these reports to CCS automatically once they are generated and approved by the member NICU.

## NICU Reports

The [NICU Reports site](#) provides many ways for a member hospital to examine their data and consider it from a quality improvement perspective, from the Dashboard that displays numerous indicators associated with patient volume and with quality of care, to the Small Baby NICU snapshot, which concentrates on a subset of important issues such as necrotizing enterocolitis (NEC) and intraventricular hemorrhage (IVH), displaying the hospital’s performance against that of the CPQCC network.

## HRIF Reporting System (Data and Reports)

HRIF collects data on infants and children who are eligible for follow-up care in an HRIF clinic. HRIF eligibility is described in [Is That Baby Eligible?](#) and on the CPQCC website under Follow-up.

The High-Risk Infant Follow-up Program Data and Reports site is described in more detail in the [HRIF manual](#).

## All NICU Admissions Database (optional)

CPQCC members had expressed the desire to track not only the NICU Database eligible infants through CPQCC, but all infants cared for in their NICU.

CPQCC responded by creating a simple and minimal tool to track all NICU admissions for members who wish to use it. Users enter a small set of information about each infant admitted, with additional information optional. Information that members have already entered into CPQCC’s main NICU Database can be transferred over to the All NICU Admissions Database directly. In addition, members can upload additional data by uploading a .csv file.

A key feature of the All NICU Admissions Database is the ability for members to automatically populate additional fields of the required annual CCS form, which is used to generate the CCS report.

The All NICU Admissions Database can be found on the NICU Data site. To view the All NICU Admissions Database manual, open the All NICU Admissions Database and select the PDF icon.

### **CCS Supplemental Form and Reports**

As a step in the annual data finalization process, members must complete their annual CCS form so that the annual report can be provided to the state of California on the member's behalf.

The CCS supplemental form records the number of live births at the reporting NICU's hospital (or, for satellite NICUs, the number of live births at the hospital location hosting the satellite NICU), NICU admissions, transport-in and transport-out activity, and mortality information that is based on **all** NICU admissions. In summary the CCS supplemental information is used to provide a synopsis of the overall activity in a NICU based on **all** infants admitted to the NICU within the first year of life.

The annual CCS Report serves a dual purpose: fulfilling the CCS requirement to report on all NICU activity of CCS-accredited hospitals, and efficiently utilizing the mortality and morbidity-specific outcomes from the NICU Database. The report contains data from two sources, the CCS supplemental form and the NICU Database.

Once Data Finalization has been completed, It is the responsibility of the NICU medical director or their designee to confirm the final CCS Report for accuracy and completeness.

### **VON Data**

As part of CPQCC, member NICUs receive membership in the international Vermont Oxford Network. CPQCC automatically uploads NICU data to VON on a regular basis, so that members can see their data as compared against a broader network of NICUs than just those in California.

Members also have access to Nightingale, VONs online reporting tool, which offers members comprehensive historical and up-to-date information on patient demographics, outcomes, and interventions. VON provides secure access to confidential center and network data, with access controlled by each member center.

### **Help and Support**

You can contact the NICU Data Center team by submitting a ticket through our Help Desk system at [www.cpqcchelp.org](http://www.cpqcchelp.org). Please feel free to ask any data related questions or raise any issues you have through this system. The Help Desk also provides a set of Frequently Asked Questions for quick answers to common questions.

Input from our members is very important to us, so please contact us whenever you have comments, questions, or issues.

## Other Resources

Links to:

- [Is That Baby Eligible?](#)
- [Appendices](#)
- [HRIF manual](#)
- [CCS standards](#)
- [All NICU Admissions Database manual](#)
- [CPeTS](#)

## Getting Started

### Center Contacts

All contacts will receive informational emails from CPQCC. Please keep the NICU Data Center team informed of any changes to your center's contact information. To update your contact information, please refer to the [Data Finalization Guidelines](#) under February 1<sup>st</sup> Deliverables.

<b>Title</b>	<b>Responsibility</b>
<b>NICU Report Contact</b>	Receives all reports that are sent out to your center via email or US mail, including all report related correspondence.
<b>Data Contact #1</b>	Enters all data and keeps in constant contact with the NICU Data Center team about all aspects of their center's data.
<b>Data Contact #2</b>	Designated secondary contact.
<b>Neonatologist Contact</b>	Designated Neonatologist contact for your center.
<b>Transport Contact #1</b>	Primary contact at your center responsible for all data on infants acutely transported into or out of your NICU.
<b>Transport Contact #2</b>	Second person responsible for all transport data for your center.
<b>QI Contact #1</b>	Primarily responsible for looking for quality improvement topics suggested by your center's data.
<b>QI Contact #2 CNS/Nursing Educator</b>	Second person responsible for quality improvement based on your center's data.



<b>Invoice (Payment) Contact</b>	Responsible for CPQCC invoices and payments for your center.
----------------------------------	--

CPQCC's Member Contact Report is available as a downloadable Adobe PDF file and includes all member contact information alphabetically by hospital. Log in to [www.cpqccdata.org](http://www.cpqccdata.org) and click on the CPQCC/HRIF-QCI Directory link.

## Logging In

Access to the NICU Data site and NICU Reports site is password-protected; member contacts receive a single user ID and password that work for both sites.

New member centers fill out a Contact Report as part of their onboarding procedure, specifying who the Report Contact and Data Contact #1 are. Their logins for the NICU Data site and the NICU Reports site will be created within 24 hours.

Users must log in to NICU Data or NICU Reports at least once every 90 days, or their accounts will be suspended. This provides extra safeguards for the confidential data we collect. See below for how to reactivate a user ID if it has been suspended.

### Add New User ID

To request access to the NICU Data and Reports sites, submit a Help Desk ticket at [cpqcchelp.org](http://cpqcchelp.org). You must be a current member of the hospital to which you are requesting access, **and** you must be listed on the hospital's contact report.

If you don't meet these criteria, **another authorized user** must request access for you.

In the help desk ticket, please provide the following information for the new user:

- Full name (first and last)
- E-mail address (please make sure this is current and working)
- Need access to NICU Data site ([www.cpqccdata.org](http://www.cpqccdata.org))? (Y/N)
- Need access to NICU Reports site ([www.cpqccreport.org](http://www.cpqccreport.org))? (Y/N)

### Reactivate User ID

To reactivate a suspended user ID, submit a [Help Desk](#) ticket.

### Change Password

Members can change **their own** passwords on the NICU Data site or the NICU Reports site by selecting "Change Password" in the left side menu. (the password change will apply to both sites)

Your password must be changed once a year. If you have not changed your password in more than 365 days, you will receive a reminder to change your password, and the system will route you to the

password change page at your first logon. If your password is set to expire in 10 days, you will receive one email notification regarding your password's expiration.

Your new password must be different from and not too similar to any previously used password. In addition, we have tightened the policies for repeated logins with incorrect user credentials. If a login fails 5 times, the user account is locked for 15 minutes.

To change your password:

1. Log into the NICU Data site
2. Select “Change Password” from the menu
3. Follow the instructions.

New passwords must be at least eight characters long and must contain:

- At least 1 upper case character
- At least 1 lower case character
- At least 1 number
- Also allowed, but not required, are the following characters: ? - \_ ^ ! . :

## Forgot Password

If you forget your password, you have two options.

1. At the login screen for the NICU Data or the NICU Reports site, select “Forgot Password.” Enter the User ID and email address associated with your account. We offer two ways to retrieve your user credentials:
  - Resend my credentials: If your user information can be located, you will receive an email with a new, temporary password. Please log in with the temporary password and then change it as soon as possible.
  - Send me a reset link: You will receive a reset link via email that you can use to reset your password. The link will be active for 15 minutes starting from the time you request it.
2. Submit a [Help Desk](#) ticket. Data center staff will assist you by sending you either:
  - Secure email including your user credentials: user ID, first and last name of user registered, new password, and your access rights.
  - Email including a password-reset link. The reset link allows you to specify a new password. The reset link will be active for 15 minutes starting from the time you request it.

## HCAI ID and NICU Center ID

Every hospital is identified by a code assigned by the Health Care Access and Information, HCAI (formerly Office of Statewide Health Planning and Development, OSHPD). These codes, known as

HCAI IDs, are publicly available, and are used in the Transport data set to identify the hospitals that babies have been transported between. They are also used, with NICU Record IDs, to identify infants and children in the HRIF Reporting System. The HCAI ID is also used in linking data in different databases and in facilitating CPQCC hospital audits.

In addition, CPQCC assigns each member center a confidential, unique center identification number. This **NICU Center ID** is used to identify the center on all forms and reports. It is confidential and will not be shared with other centers.

NICU and HRIF have two member directories:

- The publicly available directory on the CPQCC website, which lists centers by county
- The members-only directory on the NICU Data site, which lists centers alphabetically and includes all member contacts.

Both include the centers' HCAI IDs; neither one contains NICU Center IDs. Please keep your NICU Center ID confidential to help ensure the security of your data.

## Identifying and Tracking Eligible Babies

Some important steps to take and questions to answer in preparing for entering data into the NICU Database:

1. Identify which babies are eligible for the NICU Database.
2. Track all eligible infants using optional CPQCC-provided logs [located on the NICU resource page](#) or similar tools.
3. Decide whether to enter data via the web interface or electronic data submission (EDS). The web interface allows the data contact to enter data on a single infant at a time, while EDS allows the member center to upload a file which can contain many infants' records in .csv or .txt format. For further information, please see the [EDS Instructions and Specifications for each birth year](#).

### Which Babies are Eligible?

For a complete description of eligibility for entry into the NICU Database, eligibility for High Risk Infant Followup, and VON eligibility criteria, please see the manual **Is That Baby Eligible?** You can also review the eligibility page on the NICU data resource page or use the eligibility decision tree if you are unsure whether an infant qualifies for the NICU database.

### Tracking Eligible Infants

In order to keep track of eligible infants and be able to determine which have been entered into the NICU database, and be able to connect back to their medical records at the member hospital, while also maintaining confidentiality and data security, it is important that each member hospital maintain a set of documents or “logs” **at their site**.

**NOTE:** The NICU Database does not contain any medical record numbers or names, so it is important to keep internal logs that allow you to correlate an infant’s medical record number at your center with their NICU Record ID. Please do not share any PHI (i.e medical record numbers, names, etc.) with CPQCC.

All eligible infants should be tracked in a Patient Log (this is an example; sites may have their own format or type). The log must include their medical record number, which identifies their records at the member center, and their NICU Record ID, described in the next section, which identifies them *during a particular episode of care* in the CPQCC NICU Database.

## Record ID

The NICU Database is “event-based”, meaning that each record represents one “episode of care” for an infant (so the same infant might have multiple records in the database). (Reminder: to be eligible for the NICU Database, the episode of care must have **started** during the first 28 days of life.)

An episode of care is defined as all the care that an infant receives until they are discharged to home. If an infant is moved from your NICU to another unit within your Center (Step-Down Unit, Well Baby Nursery, Pediatrics Ward, Intermediate Care Nursery, PICU, etc.), continue collecting data until discharge to home, transport to another hospital, or death. If the infant is readmitted to the hospital **from home**, that is considered a new episode of care.

Included in a single episode of care:

- Admission and readmission to the NICU, PICU, or any other units within the hospital (“Hospital A”)
- Acute transport to and from other hospitals (“Hospital B”)
- After care at Hospital B, readmission directly to Hospital A

Not included (that is, this starts a new episode of care):

- Readmission to the hospital after being discharged to home (from any hospital).

Each episode of care is identified by:

- The NICU Record ID
- The “NICU Record ID,” a five digit unique number which identifies a particular infant **during a single episode of care.**

**NOTE:** Record ID is sometimes referred to as “Infant ID” or “Network ID”. Record IDs are not shared between centers, so if a baby is transferred, each center will have a separate set of records

regarding the care provided. CPQCC's NICU Data Center staff reconcile information on a monthly basis about each infant's care in different hospitals.

### **Patient Log (Optional)**

Once you have identified an infant that is eligible for the NICU Database, enter their name and medical record number into your center's Patient Log. Add the infant's Record ID as follows:

- For the **very first infant** entered from your center into the NICU Database, use the five digit number **00001**.
- For each subsequently entered infant or episode of care, increment the record ID by one (00002, 00003, e.g.).
- If you are not sure what your starting record ID number is, please submit a help desk ticket.
- Do not reuse numbers, even in new birth years.

The Patient Log correlates the member center's medical record number and the CPQCC NICU Record ID; it also records admission status, tracks data entry into the NICU Database, and allows for data quality audits by the NICU Data Center staff as needed.

### **Transport Log**

The Transport Log tracks eligible infants who have been acutely transported between hospitals. These infants may be coming from or going to a non-CPQCC NICU.

In order to be eligible, they must be transported on or before the 28<sup>th</sup> day of life, for acute medical, diagnostic or surgical therapy.

**NOTE:** Babies who are transported solely for insurance or bed availability reasons **are not eligible**.

Enter the infant's NICU Record ID as assigned in the Patient Log to complete the Transport Log.

### **Pending Eligibility Log (Optional)**

This log is used to track potentially eligible infants who do NOT initially meet the eligibility criteria at admission to the NICU but might become eligible. For example, an infant at risk for respiratory problems might be listed here and, if given assisted ventilation for greater than four continuous hours, would then be assigned a NICU Record ID and added to the Patient Log.

### **NICU Activity Log / CCS Activity Log (Optional)**

This worksheet can be found as part of the CCS Supplemental Form on the NICU Data Resources page of the CPQCC website. It is used to track all infants born in your hospital and to track

potentially eligible infants for the CPQCC and/or the California Children's Services High-Risk Infant Follow-up (CCS HRIF) Program. Use this log to enumerate and validate data for completing the Annual CCS Supplemental Form.

We recommend that you keep your logs in a safe and secure place. Make copies of each completed log for your records.