High Risk Infant Follow Up
Data Finalization Process Guildlines

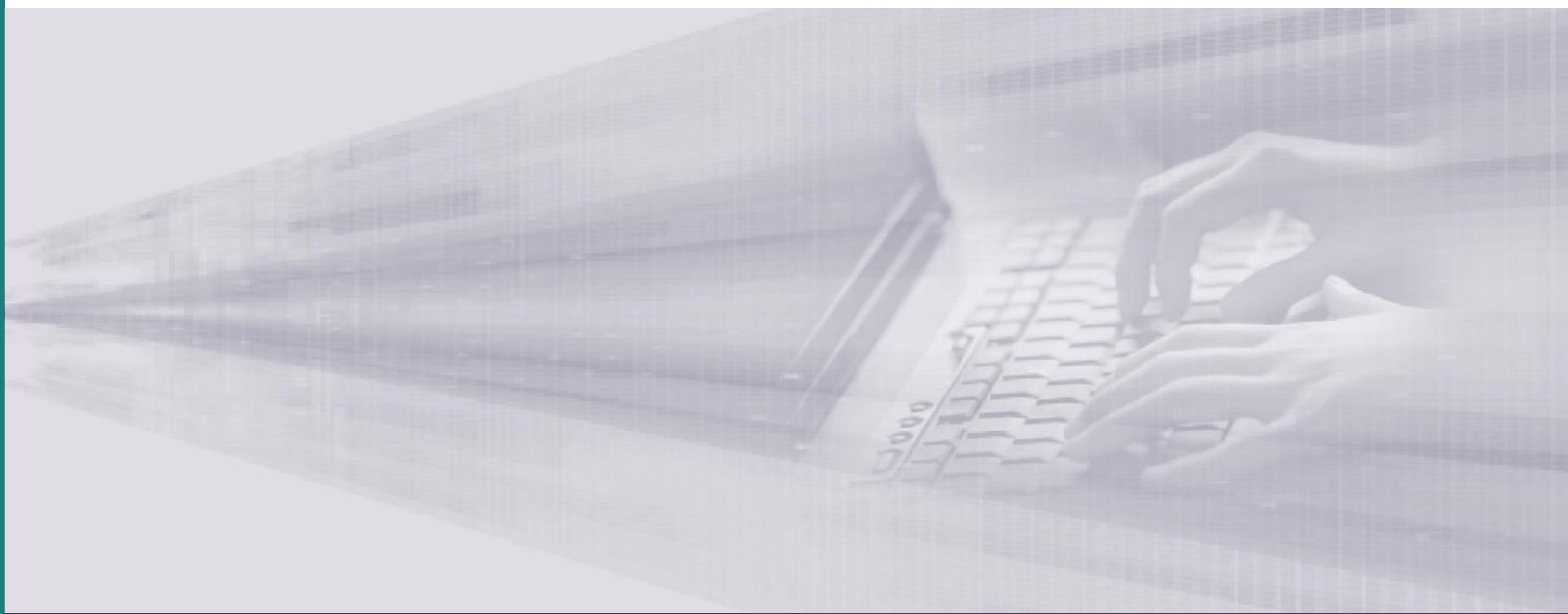HRLL
HIGH RISK
INFANT FOLLOW-UP
CPQCC

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Introduction

The California Perinatal Quality Care Collaborative (CPQCC) and California Children's Services (CCS) launched the web-based High Risk Infant Follow-Up (HRIF) Reporting System to collect and track data on HRIF Program clinics across California. For more details on the HRIF Program, please visit the CPQCC website.

Data Finalization is the process of ensuring that all data that is submitted into CPQCC/CCS HRIF Reporting System database is complete and correct for all infants born in a particular year, and is the joint responsibility of the HRIF Reporting System Support and member hospital NICU and HRIF Program clinic staff. In order to have complete, accurate, and timely data to support quality improvement to improve infant care and outcomes, we undertake this process during the first seven months of each year.

The purpose of these guidelines is to assist our members in meeting our goals and those of the CCS HRIF Program for complete, accurate and timely submission of records, and to allow us to produce a birth year cohort CCS HRIF annual report on behalf of each CCS HRIF Program.

Deliverables and Deadlines

There are a number of milestones spanning a four year period that must be recorded for each infant registered in the HRIF Reporting System. Because these deliverables are based on the age of the infant, you will have deliverables for infants born over multiple years at one time.
For calendar year 2026, the deliverables include:

January - May	Submit a Help Desk ticket (www.cpqcchelp.org) to schedule an optional data review.
April 1st	**Preview the CCS Annual Report** for infants born in 2022
May 1st	Earn the **Super Star Award** by completing the June 1st deliverables by this date.
June 1st	The following deliverables are due: • Submission of no priority cases for infants born in 2022 • Submission of no error or warning cases for infants born in 2022 • Close RR forms for all infants born in 2024 • Submission of SV #1 and/or AV form for all expected infants born in 2024
June 2nd	Earn the **Follow Up Rate Award** for meeting the target core visit follow up rate for infants born in 2022.
June 17th	**Confirm the CCS Annual Report** for infants born in 2022 (available June 2nd).
July1st	• Register/accept all eligible HRIF infants born in 2025 from referring CCS NICUs. • Review and sign off on the HRIF Directory
July 11th	Earn the **Crown Award** by completing all deliverables on time: June 1st, June 17th and July 1st.

For more details, see Timeline for Finalizing Data.

Communication

Email

HRIF Reporting System communications (i.e. system improvement updates and program announcements) will be sent by (mailchimp) email. Make sure to update email addresses and contacts in the Member Directory. To subscribe to the HRIF mailing list complete the online form at: https://www.cpqcc.org/engage/connect-us. Any questions/issues submit a Help Desk ticket.

Help Desk

For questions or assistance, submit a ticket to the Help Desk. You can expect a response to your ticket within 3 days. Tickets are closed if left idle for 5+ days after response by HRIF Support staff. When creating a ticket, include:
- Type (required): **HRIF Database**
- HRIF Inquiry (required): e.g. **Login Issue**, **Training Session** or **Data Finalization**
- Description: **Briefly describe the reason(s) for opening the ticket**

NOTE: CPQCC office hours are Monday through Thursday, 8:00 am – 5:00 pm. All requests sent after hours, on weekends or on holidays will be responded to during office hours.

Resources

- **HRIF Data Resources:** The HRIF Reporting System Manual, reporting forms, and DFP documentation are available on the HRIF Data Resources webpage.
- **CPQCC Member Directory:** provides a list of NICU and HRIF Clinic data contacts for each CPQCC member hospital. The directory is available in the navigation panel in the Reporting System. Keep your centers directory updated with current contact information. This directory is used to contact NICU and HRIF colleagues at other hospitals. To update the list of contacts in the Reporting System click the user icon in the top right corner and select **Update Directory**.

Data Finalization Guidelines

Closeout Checklist Overview

The Closeout Checklist is designed to assist HRIF Clinics throughout the Data Finalization Process. Find the Closeout Checklist under the Tools tab in the Reporting System:

- **#**: the task item number
- **Item:** the description of the deliverable
- **Resource**: links to tools and resources to aid in completing the deliverable
- **Deadline**: the due date
- **Complete:** checkbox/date stamp to indicate the deliverable is complete:
  - Items 1 - 4 and 7 are grayed out. The checkbox will automatically be checked by the system once the deliverable is completed.
  - Item 5 **must** be confirmed by the HRIF Clinic's medical director or coordinator
  - Item 6 **must be checked manually** by HRIF Clinic to complete the deliverable
- **Comment Box:** If needed, add notes in the **User** space about any outstanding or unusual issues that may impact completion of the checklist. HRIF Support staff may make notes in the **Admin** space.

NOTICE

- Closeout Checklist is updated nightly.
- Items #1-4 & 7 are automatically checked by the system or HRIF Support.
- Item #5 **must be confirmed** by the HRIF Medical Director or Coordinator by **June 17th**.
- Item #6 **must be checked manually** by the HRIF Clinic.
- For any questions or requests, submit a help ticket at www.cpqcchelp.org.

#	Item	Resource	Deadline	Complete
1	Submission of no priority cases for infants born in 2022	HRIF Record Tracker	06-01-2026	☐
2	Submission of no error and warning cases for infants born in 2022	Error and Warning Report	06-01-2026	☐
3	Close RR Forms for all infants born in 2024	Error and Warning Report	06-01-2026	☐
4	Submission of SV #1 and/or AV form for all expected infants born in 2024	Error and Warning Report	06-01-2026	☐
5	Confirm the CCS Annual Report for infants born in 2022 *(available June 2nd)*	CCS Report	06-17-2026	☐
6	Register/accept all eligible HRIF infants born in 2025 from referring CCS	CPQCC/HRIF Linkage Report (cpqccreport.org)	07-01-2026	☐
7	Review and sign off on the HRIF Directory	Update Directory Page	07-01-2026	☐

User Comments:

Admin Comments:

Save

Awards

All of your awards will be displayed above your Closeout Checklist. To see the awards that your center has earned, go to **About → Membership → Current Members** on the [CPQCC website](#) and select your center.

To see the entire list of possible awards and download award certificates, go to **About → Membership → Member Awards** on the [CPQCC website](#). For each award your center has received, click on **View Award Certificates** to download your award notice. **NOTE:** Awards will be announced via the CPQCC MailChimp e-mails.

🏅	**Super Star**	Earned by HRIF Clinics that completed items #1 through #4 on the Closeout Checklist by May 1st
✅	**Follow-up Rate**	Earned by HRIF Clinics that meet the follow-up rates for the closing birth year: 1St Visit ≥ 80%; 2nd Visit ≥ 70% and 3rd Visit ≥ 60%
👑	**Crown**	Earned by HRIF Clinics that meet ALL closeout deliverables: June 1st, June 17th and July 1st
🎁	**Surprise**	Granted as a surprise for positive performance in a particular area. This award is not given out every year.

Timeline for Finalizing Data

1. **January thru May – Submit data and edit for completeness and accuracy.** For more on how to use the system tools, see [Reporting System Tools Overview](#).
2. **April 1st – Preview 2022 CCS Annual Report**
   NOTE: The report will update nightly to reflect any 2022 data changes.
3. **May 1st – SUPER STAR Award granted**
4. **June 1st - Deadline** (11:59 pm):
   a. **Born in 2022: infant records are completed and finalized**
      i. Make corrections and close online entry to the RR, SV, AV and CNSD forms for all submitted case records.
      ii. Review the [NICU Reference IDs/Timely Referral](#) tool to verify that all NICU eligible infants have a valid NICU Record ID entered.
      iii. Review the [Record Tracker](#) tool to verify that all case records for the are closed.
      iv. Review the [Error and Warning](#) tool to verify that all case records are complete.
   b. **Born in 2024: close RR forms**
      i. Review the [Error and Warning](#) tool to verify that the all RR forms are closed.
         NOTE: This Form is Closed checkbox must be checked.
   c. **Born in 2024: submission of SV #1 (and/or AV) form for all expected infants**

i.   Review the [Record Tracker](#) tool to verify that all expected infants born in 2023 have a SV #1 or AV form submitted and closed.

5. **June 2nd – FOLLOW UP Award granted**

6. **June 17th - Deadline** (11:59 pm)
   a. **Review and confirm the 2022 CCS Annual Report:**
      i.   The HRIF Clinic Medical Director/Coordinator **must** confirm the report.
      ii. If the HRIF Clinic Medical Director or Coordinator is unable to confirm, then a proxy can confirm the report on their behalf.

7. **July 1st – Deadline** (11:59 pm):
   a. **Born in 2025: Register and accept all eligible HRIF infants**
      NOTE: The HRIF Reporting system will not accept registrations for infants born before 2025.
      NOTE: This item **must be checked manually** by the HRIF Clinic.
      i.   Collaborate with the NICU Data Contacts **or** NICU Discharge Planner to verify that **all** HRIF eligible infants have been referred/registered.
      ii. Review the [HRIF/NICU Match Status Report](#) available on the NICU Reports site at www.cpqccreport.org to identify eligible infants. Submit a Help Desk ticket if you need access to NICU Reports.
      iii. Review the [NICU Reference IDs/Timely Referral](#) tool to verify that all eligible NICU infants (born in 2025) have a valid NICU Record ID.
   b. **Review your center's contact information and sign off on the HRIF Directory**
      NOTE: The Last Modified Date **must** be during the calendar year 2026
      i.   Check to make sure all information is current and complete. In the Reporting System click the user icon 🔵 in the top right corner and select Update Directory.
      ii. It is **required** to enter the first and last name of the person who Last Updated the directory. The text field is located at the bottom of the online form.

8. **July 11th – CROWN Award granted**

9. **August thru December – Submit data and edit for completeness and accuracy.**
   For more on how to use the system tools, see [Reporting System Tools Overview.](#)

Reporting System Tools Overview

Record Tracker

The Record Tracker helps HRIF Clinics track and finalize/close patient records. The system displays the **Date Expected** for when the patient should have been seen for SV #1, #2 and #3, based on the recommended time frames. The **Date Expected** is calculated by using the patient's gestational age. Once the SV form is submitted, the **Visit Date** and the visit **Disposition** will override the **Date Expected.**

Case Status Definitions:

- **All**
- **Priority Cases All** are displayed in red and identify records with current adjusted age ≥37 months with a **non-discharged** disposition and missing standard visit(s).
- **Warning Cases All** are displayed in yellow and identify records with current adjusted age <37 months with a **non-discharged** disposition and the **Date Expected** for when the patient should have been seen for a standard visit(s) has passed.
- **Warning SV #1** identify records without an SV #1 submitted and the **Date Expected** for when the patient should have been seen for this visit has passed.
- **Warning SV #2** identify records without an SV #2 submitted and the **Date Expected** for when the patient should have been seen for this visit has passed.
- **Warning SV #3** identify records without an SV #3 submitted and the **Date Expected** for when the patient should have been seen for this visit has passed.
- **Upcoming SV #1** identify records approaching the **Date Expected** for SV #1
- **Upcoming SV #2** identify records approaching the **Date Expected** for SV #2
- **Upcoming SV #3** identify records approaching the **Date Expected** for SV #3
- **Closed Cases** are patient records with a **Discharged** disposition selected to close the case.

Guidelines (Priority Cases):

1. If the record is missing any Standard Visit (SV), Client Not Seen/Discharge (CNSD) or Additional Visit (AV) forms, **the HRIF Clinic must enter the form(s) and then close the case.**
2. If the patient was never seen, OR the latest SV or CNSD form entered has a **non-discharged** disposition (ex: Scheduled to Return) and the client never returned for further visits, **the HRIF Clinic must submit a CNSD form and select a "discharged" disposition to close the case.**
3. If the patient received all three standard core visits, and the 3rd visit disposition = **Will be followed by another CCS HRIF Clinic**, this indicates that the case is **"open"** due to the **"non-discharged"** disposition entered. **The HRIF Clinic can change the 3rd visit disposition to "Discharged - Completed HRIF Core Visits, Referred for Additional Resources" OR if the client returned for a further visit, submit an AV form and select a "discharged" disposition to close the case.**
4. If the latest SV or CNSD form entered has a disposition = **Will be followed by another CCS HRIF Clinic**, BUT the record was never properly transferred, then there may be a

duplicate record in the system. **Submit a Help Desk ticket** at www.cpqcchelp.org to **resolve this issue. NOTE:** If no duplicates are found, then the HRIF Clinic must submit a CNSD form and select a **discharged** disposition to close the case.

5. If the patient has completed all three standard core visits <u>and</u> has a **discharged** disposition, then the record <u>must</u> have open forms. **The HRIF Clinic must check the "Case History" to make sure all form status are "Closed".**

NICU Reference IDs / Timely Referral

This tool provides a list of all infants registered in your clinic, and allows the HRIF Clinic staff to update NICU Record IDs and view if HRIF eligible infants were referred timely (within 60 days after being discharged to home). Records can be filtered by the infant's birth month and year, by birth weight category: all, Small Baby (≤ 1500 grams), or Big Baby (≥ 1500 grams), or by timely referral category: all, Within 2 months, Between 2-6 months, After 6 months, or Still in Hospital (SIH). **NOTE:** All Small Babies born or discharged from a CPQCC/CCS NICU should have been assigned a NICU Record ID.

NICU Reference ID (definition)

The NICU Reference ID is a combination of:
1. The last six digits of the Health Care Access and Informaiton, HCAI (formerly Office of Statewide Health Planning and Development, OSHPD) facility ID from the <u>discharging/referring or birth</u> CCS-approved NICU
2. The infant/child's NICU Record ID from the <u>discharging/referring or birth</u> CCS-approved NICU hospital, where the infant/child was born or admitted on or before day 28 of life. **The CCS-approved NICU discharging the infant/child home could also be the same facility referring the infant/child to the HRIF Clinic.**

E.g. for a NICU with HCAI (*formerly OSHPD*) ID "12345" and an infant in that NICU whose NICU Record ID is "67899", the NICU Reference ID would be "12345-67899".

> The HCAI (*formerly OSHPD*) ID and NICU Record ID <u>**must**</u> match. If you use the birth hospital's HCAI (*formerly OSHPD*) ID then you <u>**must**</u> use the birth hospital's NICU Record ID.

Every CPQCC/CCS-approved NICU hospital has a NICU Data Contact that keeps a record of all patients who meet the CPQCC NICU eligibility criteria. Use the **CPQCC Member Directory** to identify the NICU Data Contact(s) from the discharging/referring or birth hospital. The directory is available in the side navigation panel in the Reporting System.

NOTE:
- Enter **99999** or check the "Infant NOT NICU Eligible" checkbox, for infants who did not qualify for CPQCC NICU eligibility criteria.

- Enter **00000** for infants when a NICU Record ID has not been assigned at the time of referral/registration to to the HRIF Clinic. If a NICU Record ID is assigned to the infant later, use the "Manage NICU Reference ID" tool to correct the NICU Record ID.
- Enter **77777** for infants who met the CPQCC NICU eligibility criteria, but <u>was never assigned</u> a NICU Record ID.

Error and Warning Report

Use this tool to find missing or incorrect data entries to complete and finalizing data entries. The report will identify records that have issues (**All**; **Duplicate Record**; **Expected SV #1 Missing**; **Met Age Limit for Program**; **Missing Birth Date of Mother**; **Missing Discharge Date**; **Missing NICU Record ID**; **No Forms**; **Open RR Forms**; **Transfer Record Incomplete**) and give you an action plan to resolve the issue. This section explains the issues that will be identified and gives guidelines on how to resolve them.

Issue Definitions

1. **Duplicate Record** - displays matched records across the entire HRIF Database.
2. **Expected SV #1 Missing** - displays records for patients who are ≥ 8 months adjusted age and do not have an SV#1 or AV form.
3. **Met Age Limit for Program** - displays records for patients who are currently ≥ 3 years old and the record has not been closed with a **Discharged** disposition.
4. **Missing Birth Date of Mother** – If **Mother**" or **Both Parents** selected as Primary Caregiver, **Birth Mother's DOB** cannot be left as **Unknown**.
5. **Missing Cardiac Center** – displays records of HRIF infants eligible due to CHD Requiring Surgery or Intervention with **Unknown** coded as the CCS Cardiac Center.
6. **Missing Discharge Date** - displays records with **Still in Hospital** selected on the RR form.
7. **Missing NICU Record ID** - displays patient records with birth weight ≤ 1500 grams with NICU Record IDs coded as **00000**, **99999**.
8. **No Forms** - displays records for patients who are currently ≥ 12 months adjusted age and DO NOT have a SV, AV or CNSD form submitted in the database.
9. **Open RR Forms** - displays open RR forms that need to be closed.
10. **Transfer Record Incomplete** - displays records that have a **Will be Followed by Another CCS HRIF Program** disposition entered on the SV, AV or CNSD forms.

Guidelines to Resolve Issues

1. **Duplicate Records:**
   - Contact the HRIF Clinic with the duplicate case to review the records.
   - Make sure **all** data variables are captured on the RR form (NICU Reference ID, Birth Mother's Date of Birth, Discharge Date to Home, etc).
   - Combine **all** data forms (SV, AV and CNSD) into the current or record of choice.

- The HRIF Clinic **not** currently providing follow up services for the patient should remove the record from the system. At the bottom of the RR form entry screen check **Delete Patient Record**, cite the reason (i.e. Duplicate Record), then click the **Delete** button to remove the record from the system.
  NOTE: Use the **Patient Data Quality Self-Audit Instrument Report** located in the patient's "Case History" to review any details of the record.

2. **Expected SV #1 Missing:**
   - Submit the missing SV #1 or AV form
   - If the child was **never** followed (i.e. not seen in clinic), submit a CNSD form, selext the reason and disposition to document why the patient was not seen in the HRIF Program.

3. **Met Age Limit for HRIF:**
   - Submit a CNSD form to close the patient's record:
         Category: Discharged
         Reason: Select a reason or code as **Other = Aged out of Program**
         Disposition: Discharged – Closed Out of Program

4. **Missing Birth Date of Mother**
   - If the Mother's Birth Date is truly **Unknown** submit a Help Desk ticket to indicate the reason why the information cannot be obtain. In the ticket include the record's HRIF ID number. HRIF Support will document this information in the Closeout Checklist Admin comment box and remove the error/warning notice.

5. **Missing Cardiac Center**
   - Select the **CCS Cardiac Center** where the patient received CHD surgery.
   - Select **Non-CCS Cardiac Center**, if surgery was not performed at one of the listed centers.

6. **Missing Discharge Date:**
   - Uncheck the **Infant Still in Hospital** checkbox
   - Enter the date when the child was discharged to home
   NOTE: **Date of Discharge to Home** is a required field and must be completed.

7. **Missing NICU Record ID:**
   - Contact the NICU Data Contact from the birth **or** discharging CCS-approved NICU to obtain the NICU Record ID. Use the CPQCC Member Directory to obtain Data Contact information. The directory is available in the side navigation panel in the Reporting System.
   - Review the **HRIF/NICU Match Detail Report** available at the NICU Reports site (www.cpqccreport.org). Submit a Help Desk ticket at www.cpqcchelp.org if you have any questions or need access to the NICU Reports site.
   NOTE: The HCAI (*formerly OSHPD*) ID and NICU Record ID <u>must</u> match. If you use the birth hospital's HCAI (*formerly OSHPD*) ID then you <u>must</u> use the birth hospital's NICU Record ID.

8. **No Forms:**
   - Submit the missing SV or AV form(s).
   - If the child was never followed, submit a CNSD form, select the reason and disposition to document why the patient was not seen in the HRIF Program.

9. **Open RR Forms:**
   - Click **This Form is Closed** or **Unable to Complete** checkbox to close the form.
   - If **Unable to Complete**, submit a CNSD form to document the reason for not seeing the patient in clinic.

10. **Transfer Request Requirements and Process:**
    - Contact the CCS HRIF Clinic Coordinator where the patient will be transferred to inform them of the patient.
    - **Provide the HRIF ID#** and apprioriate documentation to the clinic <u>before processing the transfer request in the Reportign System</u>.
    - The case must meet the following requirements to process the transfer request:
      - **All forms are closed** (RR, SV, AV and CNSD).
      - **Will be followed by another CCS HRIF Program** is selected in the most recent form's disposition.
      - The **Seen Date** on the most recent form must be within 60 days when requesting a transfer. If greater than 60 days. Submit a new CNSD form.
    - Watch the <u>How-to Create a Transfer Request</u> video or see <u>How to Transfer a Record to Another CCS HRIF Clinic?</u>. **NOTE**: Help tickets are no longer required to process transfer requests.
    - Transfer request **not approved within 2-weeks** of the transfer request date **will be returned** to the clinic processing the transfer.

HRIF/NICU Match Summary and Match Detail Reports

The NICU Reports site offers two reports that are designed to assist NICUs in identifying HRIF eligible infants and determining their HRIF registration status. These reports are based on a **daily** update of a linkage of NICU infants and HRIF registered infants. To request access to the NICU Report site, please submit a Help Desk ticket. The following automated tasks facilitate these reports:

- Multiple encounters within NICU Database of the same infant are reconciled, and the encounter that resulted in a discharge home is made available for linkage to HRIF.
- The set of NICU infants discharged home is linked to a list of new and updated HRIF registrations daily. This linkage is based on the following information: NICU Record ID number (if provided during the HRIF registration), infant date of birth, infant gender, mother's date of birth, hospital of birth, hospital infant was discharged home from, gestational age at birth, birth weight and multiple status (including birth order).

The daily linkage is based on a probabilistic match technique that generates a match score for each HRIF registration and NICU infant. Matches with a high score are presumed to be matches, however, this technique hinges on accurate reporting of the match variables. Therefore, if an HRIF registration and a NICU record persistently do not match, both, the HRIF registration information and NICU record should be reviewed closely for any discrepancies. If a record continues to not match, please submit a Help Desk ticket.

The **HRIF/NICU Match Summary Report** provides match results for several key groups of HRIF eligible infants. For each group, the number of infants discharged home from the reporting NICU that meets the group criterion is shown, along with the percent of these infants registered with HRIF. A summary report including all years since 2009 and yearly summary reports are available.

The **HRIF/NICU Match Detail Report** provides detailed HRIF registration status information for all NICU infants. This list can be filtered to efficiently find infants who meet HRIF criteria but are not registered.

The CPQCC/HRIF linkage focuses on the following groups of infants who were admitted to the reporting NICU by day 28 of life or earlier, and who are eligible for both NICU and HRIF databases:

- Extremely Low Birth Weight Infants (ELBW) or infants with a birth weight of ≤ 1,000 grams.
- Very Low Birth Weight Infants (VLBW) or infants with a birth weight of ≤ 1,500 grams.
- Infants born at less than 28 weeks completed gestation.
- Infants born at 29 to less than 32 weeks completed gestation.
- Infants born at 36 weeks completed gestation or later and who received a diagnosis of moderate or severe HIE during their NICU stay.
- Infants who experienced active cooling during their NICU stay.
- Infants with ECMO during their NICU stay.

- Infants with Congenital Heart Disease (CHD).
- Infants with Nitric Oxide.
- Infants with Seizures.

The **HRIF/CPQCC Match Detail Report** is helpful for:

- **Identifying unlinked NICU records who should be registered/referred to HRIF**
Set the filter to **Unlinked NICU record, HRIF Eligible due to VLBW, GA, HIE, ECMO, Active Therap Hypoth, CHD, INO, Seizures**.

- **Identifying unlinked HRIF records**
Set the filter to **Unlinked HRIF registration**. Displays HRIF records not matched to a NICU record. **NOTE:** not all of these records will be matched to a NICU record. In fact, some of these infants might not be part of the NICU database (admitted after 28 days; HRIF eligible, but not NICU eligible).

- **Understanding why an HRIF record does not match**
Matching HRIF registrations and NICU records hinges upon finding a minimum level of agreement between the data in the two records. Most important for matching are the birth date, location of birth, infant sex, and multiple status (singleton, twins, triplets, e.g.). For multiples, birth order, number of multiples in set and birth weight are extremely important for identifying matches. Maternal birth date, discharge date and gestational age provide important additional information especially if there is disagreement on the primary match variables. Finally, knowing the NICU Record ID number increases the likelihood of matching a NICU and HRIF records substantially.