2026 CPQCC Annual Impact Series

Advancing Quality Improvement Through Data, Partnership, and Innovation

CPQCC
California Perinatal
Quality Care Collaborative

Our members are the strength of this network.

Families are at the heart of why it exists.

Data help us learn, improve, and move forward together.

BABIES AND FAMILIES REMAIN AT THE CENTER



Gianna
Birth Age: 40 weeks & 3 days
Current Age: 5 years old



> “If you’ve never been through it, it’s hard to explain the unique kind of weight you carry walking into an HRIF clinic. It’s a room where every movement, every look, and every developmental milestone is measured, scored, and tracked. The "milestone anxiety" is incredibly real. Every appointment feels like holding your breath, waiting to see how the diagnosis is showing up in her body and her brain.”

Ana Aragon
NICU Mom
CPQCC California NICU Family Advisory Council Member



Welcome & Opening Remarks

Fulani Davis



HRIF: Data and Reports Beyond the NICU

Welcome

October 28, 2026 | 12:00 -1:30 PM

Today: Learn about current HRIF program priorities and how data, reporting, research, and improvement activities support care beyond NICU discharge.

Continuum of care structure – unique to California!









CMQCC

All NICU Admissions
Higher Acuity Admissions
Maternal Exposures
Neonatal Transport Data



RPPC



HRIF

Today's Conversation

Database updates, system resources, and statewide collaborative projects

1. **Family Story, Welcome & Opening Remarks**
   12:00 | [Panelist Name]/Fulani Davis
2. **HRIF Program Updates & Data Finalization**
   12:05 | Erika Gray
3. **EDS, Dashboards and Resources**
   12:25 | Erika Gray
4. **Current Initiatives and Project Updates**
   12:40 | Susan Hintz
5. **Upcoming: Medical Home and Virtual Learning Sessions**
   12:55 | Susan Hintz
6. **Panel Discussion & Audience Q&A**
   1:15 | All Panelists

We will close with 15-minutes for panel discussion and audience questions.

Today's Presenters & Panelists

HRIF: Data and Reports Beyond the NICU



Susan Hintz

CPQCC
HIGH RISK INFANT FOLLOW UP



Erika Gray

CPQCC
HIGH RISK INFANT FOLLOW UP



Fulani Davis

CPQCC
NICU Data Center



Ana Aragon

CPQCC
California NICU Family
Advisory Council Member

Panel Discussion & Audience Q&A with all panelists

HIGH RISK INFANT FOLLOW-UP

Before we Begin

A few quick logistics

Questions

Please use the Q&A feature. We'll hold time for discussion at the end.

Recording & Materials

Presentation materials and resources will be available through the **Annual Impact Series** webpage.

Contact Hours

Attend the full live session **and** complete the evaluation to receive continuing education (CE) credit.

Thank you for being here - and for the work you do every day to support mothers, babies, families, and communities.

Continuing Education Information

MCCPOP
Mid-Coastal California
Perinatal Outreach Program

- If you attend as a team, please contact contactmccpop@stanford.edu for the form to utilize. The form necessitates approval by either a supervisor or nurse educator.
- Attendees will be eligible for contact hours through the the Mid-Coastal California Perinatal Outreach Program (MCCPOP). MCCPOP is approved as a provider of continuing education by the California Board of Registered Nurses, Provider #3104. This course has been approved for **up to** 1.5 contact hours for the 90-minute events and 1.0 contact hours for the 60-minute events.
- Attendees must remain on the webinar for the entire time and are required to complete the evaluation post session, in order to receive contact hours. The evaluation will be available within 2-4 days following the session.
- To receive contact hours (RN) for this webinar, **please remain on the webinar for at least 50 minutes.**



CPQCC California Perinatal Quality Care Collaborative
CMQCC California Maternal Quality Care Collaborative
Stanford MEDICINE School of Medicine
Stanford MEDICINE Children's Health

HIGH RISK
INFANT FOLLOW-UP

CCS HRIF Program & Database Access



CCS HRIF Program

1979 CCS launches statewide "NICU Follow Up Program" to provide follow-up care to high-risk infants discharged from the NICU.

2006 CCS partners with CPQCC to completely restructure and remodel high risk infant follow up

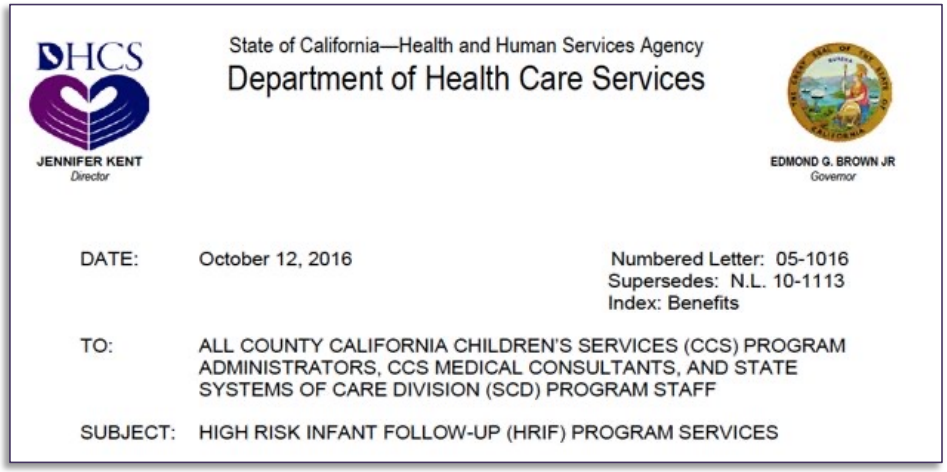
2010 CPQCC CCS HRIF Quality Care Initiative is launched.

Diagnostic Services:

- Comprehensive History & Physical Exam with Neurologic Assessment
- Developmental Assessment
- Family Psychosocial and Needs Assessment
- Hearing Assessment
- Ophthalmologic Assessment
- Coordinator Services

DHCS High Risk Infant Follow-up Program Letter: 01-1016 **(supersedes 01-1113)**

Who Do We Serve? - CCS HRIF Eligibility



DHCS

State of California—Health and Human Services Agency
Department of Health Care Services

JENNIFER KENT
Director

EDMOND G. BROWN JR
Governor

DATE: October 12, 2016

Numbered Letter: 05-1016
Supersedes: N.L. 10-1113
Index: Benefits

TO: ALL COUNTY CALIFORNIA CHILDREN'S SERVICES (CCS) PROGRAM ADMINISTRATORS, CCS MEDICAL CONSULTANTS, AND STATE SYSTEMS OF CARE DIVISION (SCD) PROGRAM STAFF

SUBJECT: HIGH RISK INFANT FOLLOW-UP (HRIF) PROGRAM SERVICES

Medical Eligibility: Small Babies

- Birth weight less than or equal to 1500g

OR

- GA at birth less than 32 weeks

Medical Eligibility: Big Babies

A range of neurologic, cardiovascular risk factors including, but not limited to:

- Placed on ECMO, nitric oxide more than 4 hours, other;
- Congenital heart disease requiring surgery or intervention,
- History of observed clinical or EEG seizure activity,
- History and/or findings consistent with neonatal encephalopathy,
- Other problems that could result in a neurologic abnormality

NICU Referral Requirements

- Each CCS approved NICU must have an organized HRIF Program or a written agreement with another CCS-approved HRIF Program.
- It is the ***responsibility of the discharging to home CCS NICU/hospital or the last CCS NICU/hospital providing care*** to make the referral to the HRIF clinic.

The NICU Referral Process:

1. **Complete Referral/Registration (RR) Form and submit** via HRIF Reporting System at time of discharge to home
2. **Submit a Service Authorization Request (SAR) to the local CCS Office** to gain approval for HRIF services (Service Code Group [SCG] 06 should be requested)
3. **Send a copy of the child's discharge summary** to the HRIF clinic

High Risk Infant Follow-up Program Letter: 01-1016 (supersedes 01-1113)

HRIF Reporting Requirements

The HRIF Coordinator is responsible for **ensuring that data is collected and reported to the Systems of Care Division, CCS HRIF Program and CPQCC.**

The HRIF Coordinator will:

- Coordinate the collection, collation, and reporting of required data
- Provide data to HRIF Reporting System: https://www.ccshrif.org
- Ensure required data is submitted accurately and meets all required deadlines
- Review and share results of HRIF reports with HRIF & NICU teams
- Fully participate in the CCS HRIF Program evaluation
- Provide data and information that is required for the CCS HRIF Program evaluation

HIGH RISK INFANT FOLLOW-UP

Requirements for Access

https://www.cpqcc.org/follow/hrif-data/how

1. **Your hospital must currently have a CCS-approved NICU or HRIF Program**
2. **You must be listed on the Member Directory**

If you do not meet the above qualifications, then an authorized user must request access on your behalf. Make sure to include the authorized person in the help ticket request.

How to Access the Reporting System from Home

- Contact your hospital's IT team
- Install a VPN (Virtual Private Network) access portal on your computer

VPN enables users to send and receive data across a shared or public network as if your computing devices was directly connected to your hospital's private network.

HIGH RISK INFANT FOLLOW-UP

Requirements for Access

https://www.cpqcc.org/follow/hrif-data/how

1. Center Name
★ 2. Computer Public IP Address: Contact your IT department to request the "Public IP Address Ranges" used by the hospital's network and provide the ranges in the description of the help ticket. **Note**: Access to the HRIF Reporting System is only authorized while connected to your organization's network.
3. Does your center provide HRIF services? (Y/N)
4. Full name (First and Last)
5. Title
★ 6. E-mail Address
★ 7. Phone Number
★ 8. User Account Access (contacts can have multiple accounts):

Data User: HRIF clinic staff responsible for submitting all data forms for patients receiving follow-up services in their clinic. Can generate the HRIF Summary and CCS Annual Reports.

Referral User: CCS-approved NICU and/or HRIF clinic staff who refer eligible infants to an HRIF clinic.

NICU User: CCS-approved NICU staff who can generate the NICU Summary Report.

Submit a help ticket at **www.cpqcchelp.org** with the required information listed.

HIGH RISK INFANT FOLLOW-UP

NICU Teams Gain HRIF Access!



NICU leaders and teams should request HRIF database access to:

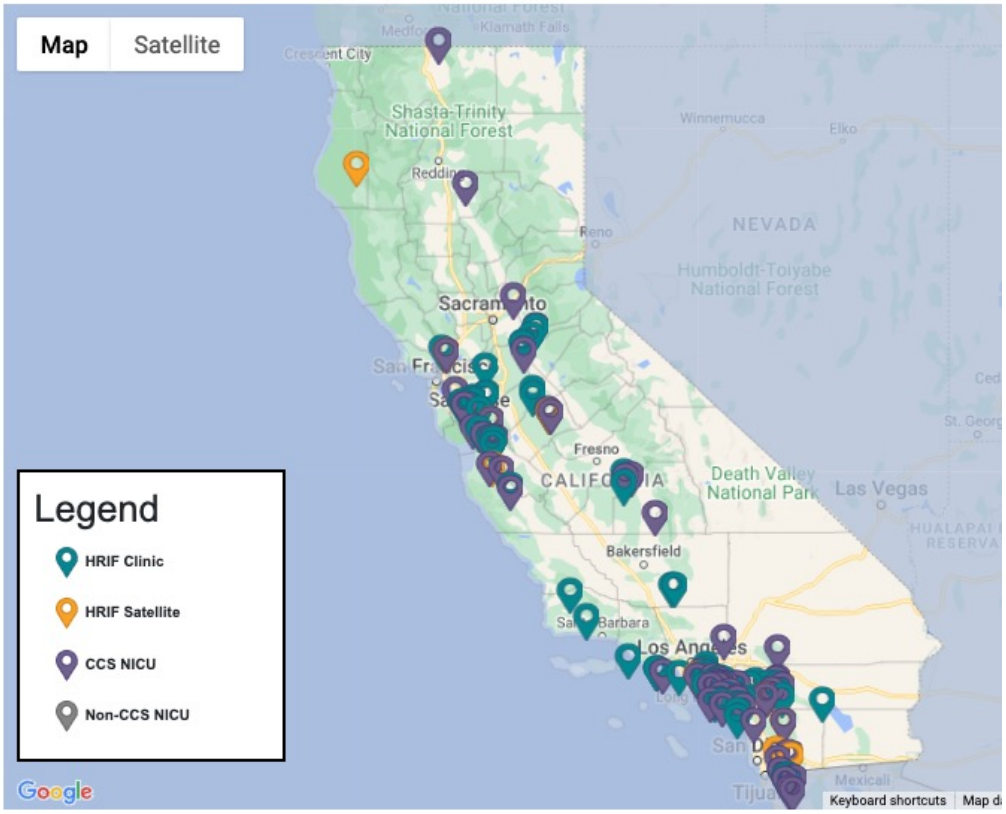
- Refer/Enroll Eligible Patients
- Track and Manage Patient Referrals
- View NICU Summary Reports

Program Updates and Data Finalization



HIGH RISK INFANT FOLLOW-UP

CCS NICUs and HRIF Clinics



125 CCS NICUs

- 23 Regional
- 87 Community
- 15 Intermediate

66 HRIF Program Clinics

- 24 Regional
- 42 Community

12 HRIF Satellite Clinics

HIGH RISK INFANT FOLLOW-UP

By the Numbers: Referrals and Visits

Through October 2026

144,832	high risk infants registered statewide
24,200	< 28 weeks
10,600	< 26 weeks
66,700	VLBWs (≤ 1500 g) registered/referred
217,100	standard visits performed
13,700	additional visits performed

HIGH RISK INFANT FOLLOW-UP

CPQCC ANNUAL IMPACT SERIES 2026

Data Finalization Evaluation

The survey included responses from contacts across 56 NICU/HRIF hospitals.

STRENGTHS

96%
Pop-Up Workshops and 1:1 training sessions helpful

95%
Closeout Checklist and materials helpful

84%
members satisfied with Help Desk & communications

CHALLENGES

53%
interested in Referral Registration Electronic Data Submission (EDS)

52%
identified barriers to submit data

20%
requested reporting form improvements

HIGH RISK
INFANT FOLLOW-UP

2027 Data Item Changes + System Improvements



HIGH RISK INFANT FOLLOW-UP

Referral Registration

Data Item Change



New REQUIRED data items:

- Primary Caregiver
- Education of Primary Caregiver
- Caregiver Employment

NICU Reference ID	Date of Birth	Birth Hospital
Birth Weight	Gestational Age	Singleton/Multiple
Infant's Sex	Infant's Race / Ethnicity	Hospital Discharging to Home
Birth Mother's Date of Birth	Birth Mother's Race / Ethnicity	Insurance
Primary Caregiver	**Education of Primary Caregiver**	**Caregiver Employment**
Primary Language Spoken at Home	Medical Eligibility Profile	

HIGH RISK INFANT FOLLOW-UP

Referral Registration

System Improvement

- The **Still in Hospital** checkbox will be removed from the Referral online entry form.

- Add **Accept and Close** button to pending referrals.
  - If all values are entered the form will be coded "closed" on acceptance.



HIGH RISK INFANT FOLLOW-UP

Standard Visit

Data Item Change



OTHER MEDICAL CONDITIONS			
What is the Child's Current Vaccination Status?			
☐ On Schedule	☐ Not on Schedule	☐ Parent/Caregiver Decline Vaccination	☐ Unknown

What is the Child's Current Vaccination Status?

- **On Schedule**: if the infant/child's is receiving vaccinations according to the recommended age-based immunization schedule.
- **Not on Schedule**: if the infant/child's vaccinations are delayed or being administered according to an alternate immunization schedule.
- **Parent/Caregiver Decline Vaccination**: if the infant/child's parent or primary caregiver declined recommended vaccinations.
- **Unknown**: if the infant/child's vaccination status could not be determined or this information cannot be obtained.

HIGH RISK INFANT FOLLOW-UP

Standard Visit

Data Item Change



- Remove Developmental Assessment Screeners:
  - **Warner Initial Developmental Evaluation of Adaptive and Functional Skills (WIDEA-FS)**
  - **Battelle Developmental Inventory Screening Test, 2nd Edition (BDIST)**

- Add **Parent's Observation of Social Interactions (POSI)** as a screening tool used for **Autism Spectrum Screen**.

- Add **Behavior Intervention Specialist** as a service provider for **Special Services**-Behavior Intervention.

HIGH RISK INFANT FOLLOW-UP

Standard Visit & Additional Visit

Data Item Change



Add **Hammersmith Infant Neurological Exam** assessment scores and observations.

CEREBRAL PALSY (CP) - (Optional)

Was an Exam for Early Detection of High-Risk for Cerebral Palsy Made at this Visit? *(Complete if the Child is < 18 Months Adjusted Age)*

☐ **No** (skip to **Developmental Assessment**)

☐ **Yes**

Select the Assessments Used to Arrive at Early Detection of High-Risk for Cerebral Palsy: (check all that apply)

☐ Alberta Infant Motor Scale (AIMS)	☐ Developmental Assessment of Young Children (DAYC)
☐ General Movement Assessment (GMA)	☐ Hammersmith Infant Neurological Exam (HINE)
☐ Motor Assessment of Infants (MAI)	☐ Magnetic Resonance Imaging (MRI)
☐ Neurological exam with GMFCS assessment	☐ Neuro Sensory Motor Developmental Assessment (NSMDA)
☐ Test of Infant Motor Performance (TIMP)	☐ Other: _____

Complete if the HINE assessment was performed

HINE Global Score: _____ (0 - 78)

HINE Total Asymmetry Score: _____ (0 - 18)

Were the Following Observed on the Exam:

Hypotonia:	☐ No	☐ Yes	Abnormal Posturing:	☐ No	☐ Yes
Hypertonia:	☐ No	☐ Yes	Increased Deep Tendon Reflexes:	☐ No	☐ Yes

HIGH RISK INFANT FOLLOW-UP

Client Not Seen Discharge

Data Item Changes



Remove **COVID-19 Related** from **Appt Cancelled** reason

[Revised definition] If the infant/child is scheduled for standard visit and the parent/caregiver cancelled or rescheduled within 24 hours of the scheduled appointment time.

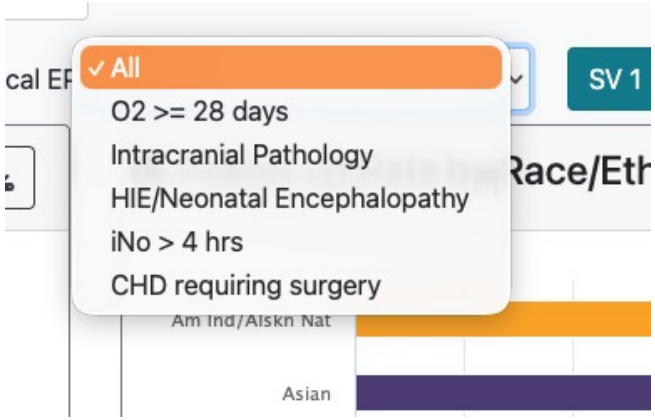
*REASON FOR CLIENT NOT SEEN / DISCHARGE *(Required Field)*	
☐ Appt Cancelled	☐ Parent Declines Due to Cost
☐ Infant Illness	☐ Insurance Authorization Problems
☐ Infant Hospitalized	☐ CCS Denied

Dashboard and Tools

System Improvements

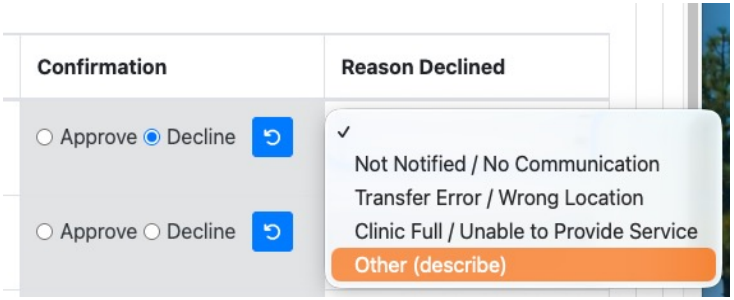
Health Care Access Dashboard

- Includes **Medical Eligibility Profile (EP)** filter options: **O2 >= 28days, Intracranial Pathology, HIE/Neonatal Encephalopathy, iNO>4 hours** and **CHD requiring surgery**.



Case Transfer - Declined Other (text field)

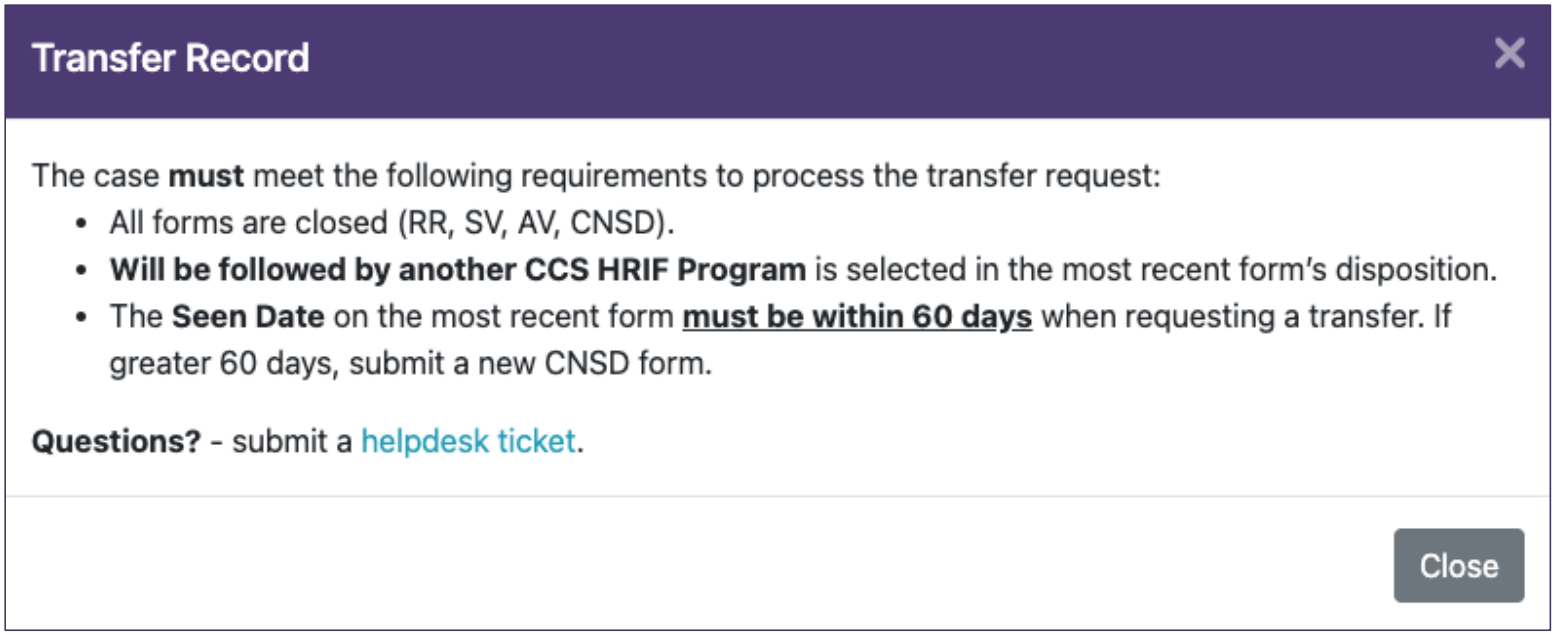
- To improve communication between HRIF Programs [member request]



Case Transfer

How-to-video: https://www.youtube.com/watch?v=YyxRuseXGT4

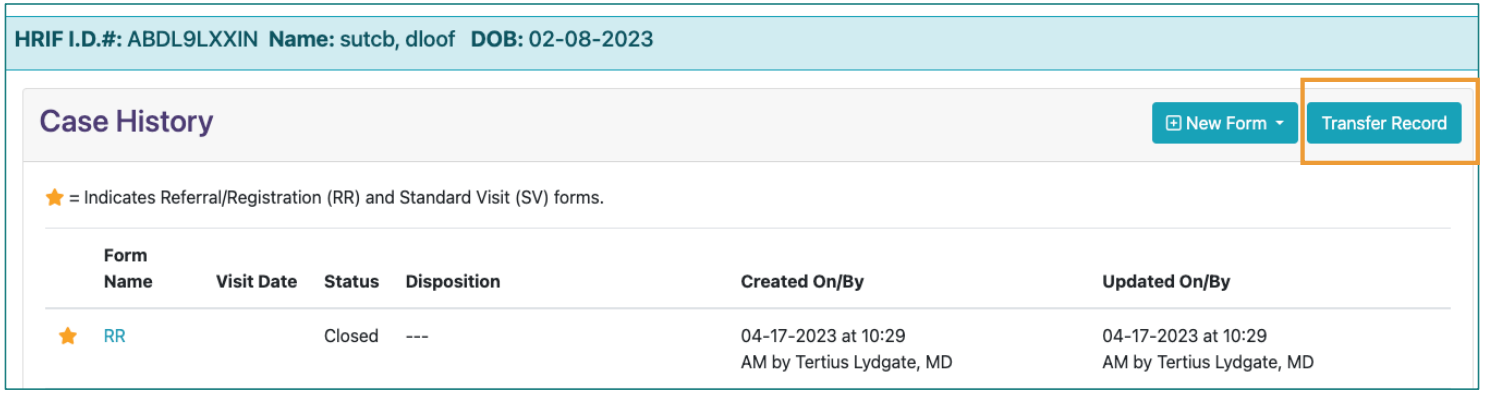
IMPORTANT: Contact the CCS HRIF Clinic Coordinator to inform them of the patient.



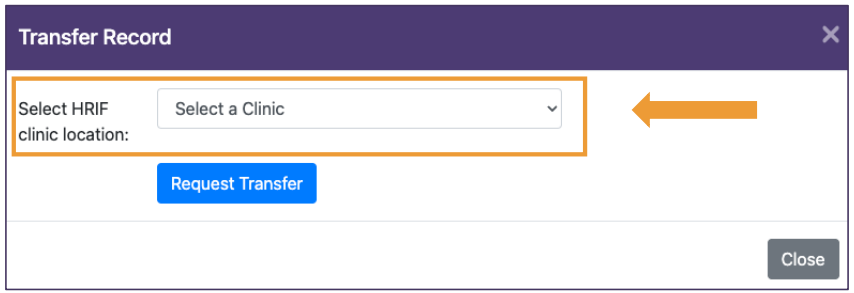
How to Process a Transfer?

How-to-video: https://www.youtube.com/watch?v=YyxRuseXGT4

#1

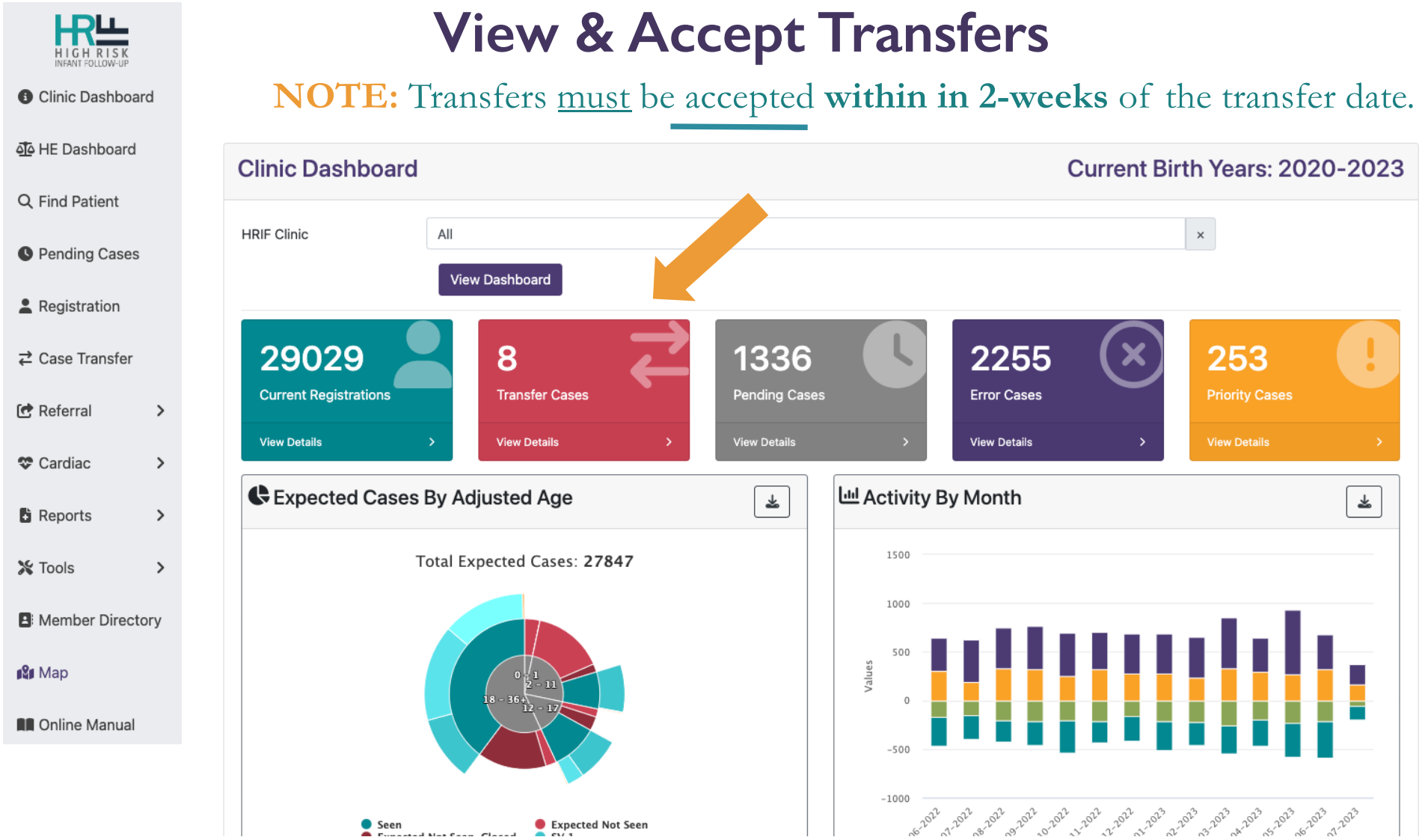


#2

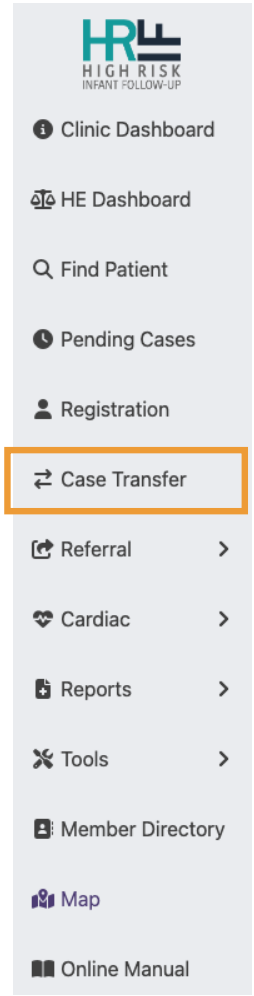


View & Accept Transfers

NOTE: Transfers must be accepted **within in 2-weeks** of the transfer date.



Manage Transfers



Active Transfers

Pending Approval

#	HRIF ID#	DOB	Sex	BW	GA	Requested By/On	Requested HRIF Clinic	Transfer To	Confirmation
1	ABDXO9IOIN	12-17-2024	F	865	27	Erika Gray on 10-21-2026	Hilarious Mitten Hospital	Adaptable Jelly Bean Hospital	○ Approve ○ Decline
2	ABF9YPXOIN	10-12-2024	M	3520	38	Erika Gray on 10-21-2026	Colorful Spaghetti Squash Hospital	Boring Mixer Hospital	○ Approve ○ Decline

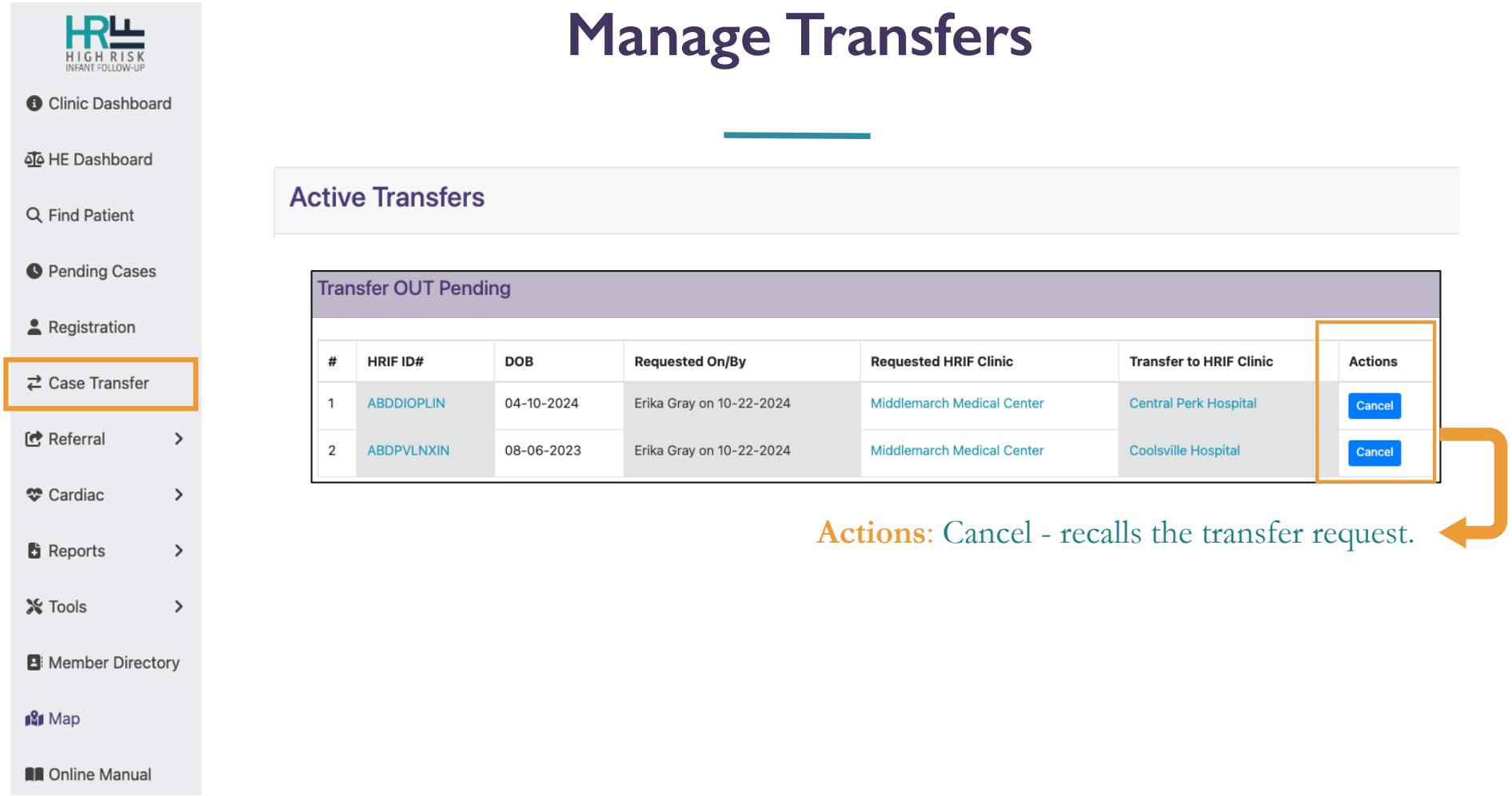
Update Pending Status

NOTE: Transfers not accepted in 2-weeks will be returned.

Requested HRIF Clinic	Transfer To	Confirmation	Reason Declined
Hilarious Mitten Hospital	Adaptable Jelly Bean Hospital	○ Approve ◉ Decline	✓
Colorful Spaghetti Squash Hospital	Boring Mixer Hospital	○ Approve ○ Decline	Not Notified / No Communication Transfer Error / Wrong Location Clinic Full / Unable to Provide Service Other (describe)

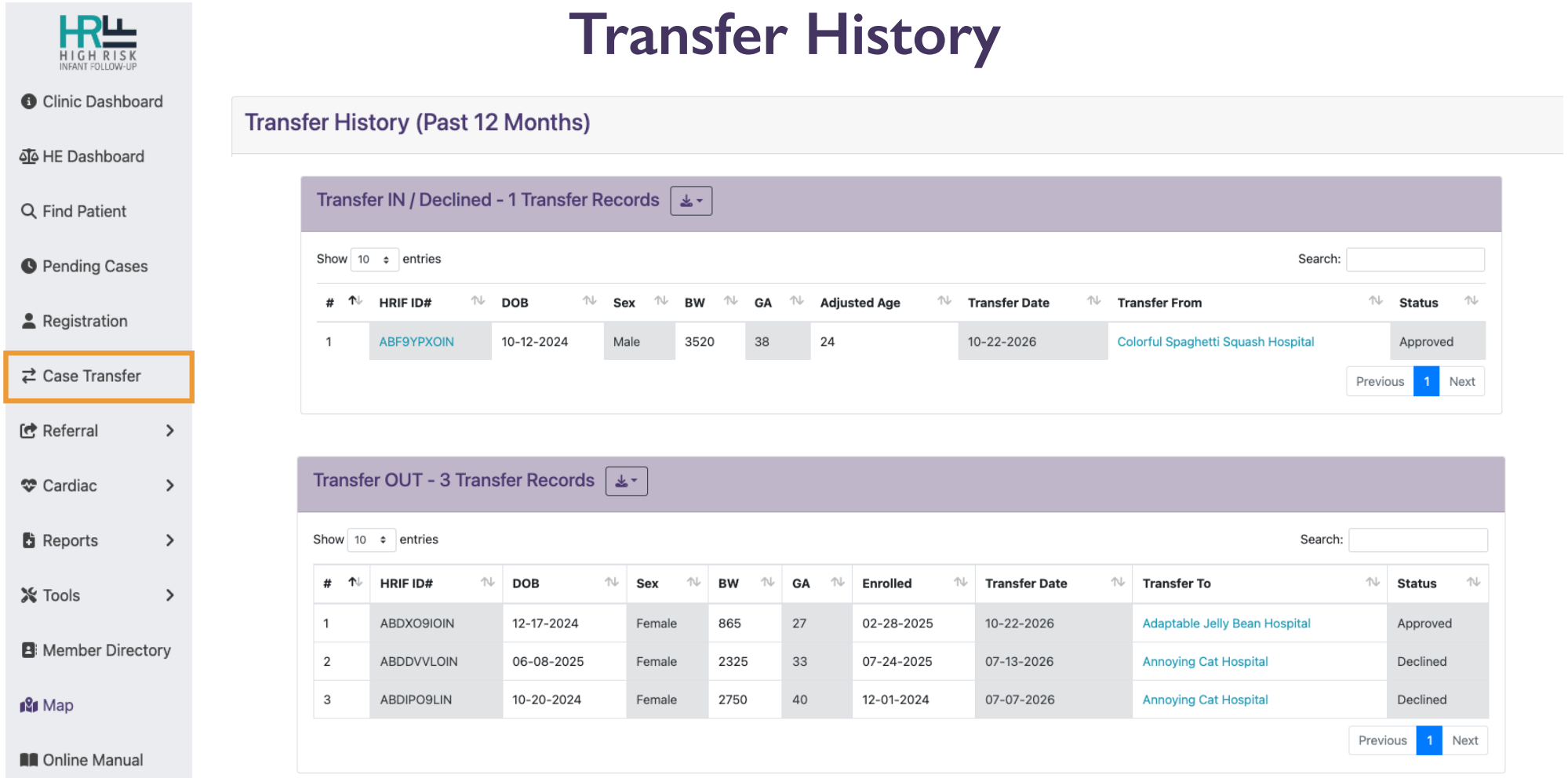
Update Pending Status

Manage Transfers



Actions: Cancel - recalls the transfer request.

Transfer History



HIGH RISK
INFANT FOLLOW-UP



2026
Data Finalization Summary

2026 Data Finalization Review

66 HRIF Clinics

1 **Item 1: Record Closed 2022**
93% complete (62 clinics)

2 **Item 2: No Issues / Errors 2022**
95% complete (63 clinics)

3 **Items 3: Closed 2024 RR Forms**
98% complete (65 clinics)



SURPRISE award granted to sites who achieved 100% timely NICU referral for infants born in 2025

4 **Item 4: SV#1 Submission 2024**
95% complete (63 clinics)

5 **Item 5: Confirmed 2022 CCS Report**
83% complete (55 clinics)

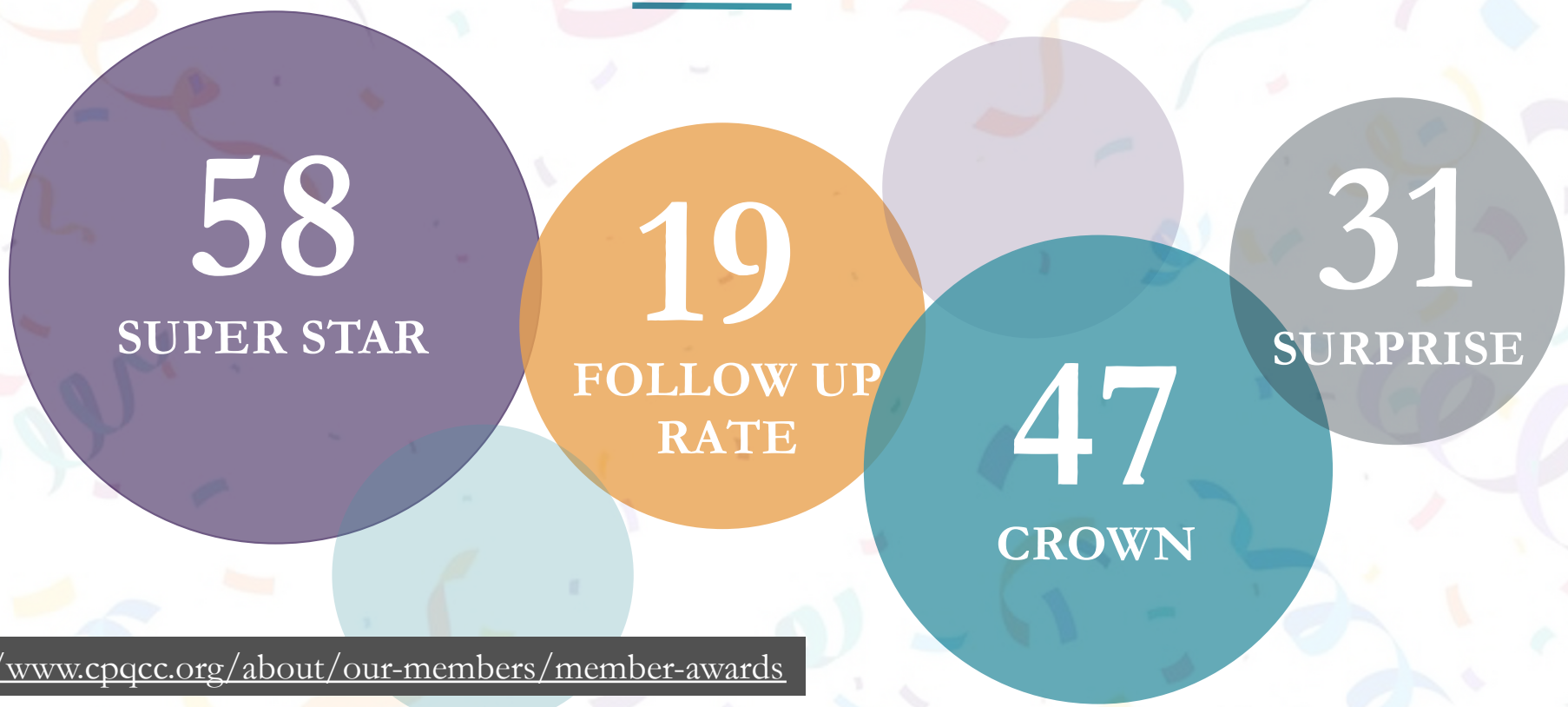
6 **Item 6: 2025 Referral/Registrations**
83% complete (55 clinics)

7 **Item 7: Update Directory**
100% complete (66 clinics)

HIGH RISK INFANT FOLLOW-UP

2026 AWARDS

61 Clinics Received Awards (20 sites received 3+ awards)



https://www.cpqcc.org/about/our-members/member-awards

HIGH RISK INFANT FOLLOW-UP



2027 Data Finalization

2026 Closeout Checklist



Super Star

Complete items 1 – 4 by **May 1st**

#	Item	Resource	Deadline	Complete
1	Submission of no priority cases for infants born in 2023	HRIF Record Tracker	06-01-2027	☐
2	Submission of no error and warning cases for infants born in 2023	Error and Warning Report	06-01-2027	☐
3	Close RR Forms for all infants born in 2025	Error and Warning Report	06-01-2027	☐
4	Submission of SV #1 and/or AV form for all expected infants born in 2025	Error and Warning Report	06-01-2027	☐
5	Confirm the CCS Annual Report for infants born in 2023 *(available June 2nd)*	CCS Report	06-17-2027	☐
6	Register/accept all eligible HRIF infants born in 2026 from referring CCS	HRIF/NICU Match Detail Report	07-01-2027	☐
7	Review and sign off on the HRIF Directory	Update Directory Page	07-01-2027	☐

User Comments:

Admin Comments:

Save

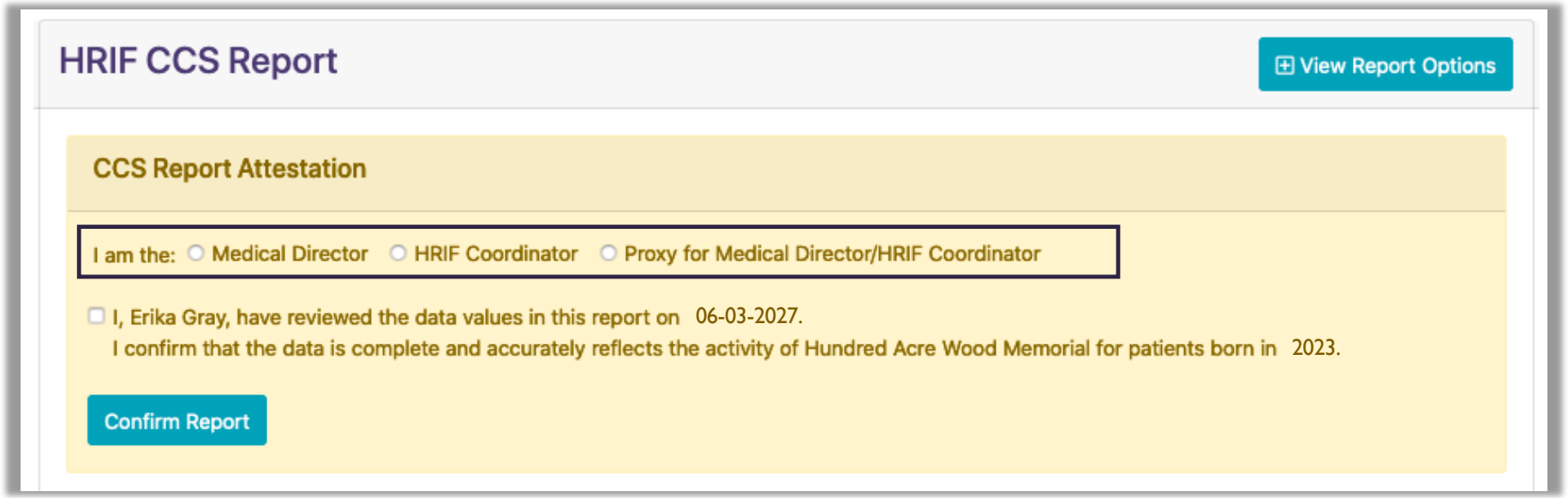


Crown

Complete items 1 – 7 by the **Deadline**

Item #5. Confirm HRIF CCS Annual Report

Report available June 2, 2027



HRIF CCS Annual Report

Go to Report: Follow Up Status / Patient Assessment / Hospitalization & Surgeries / Medical & Special Services / General & Resource Assessment / Neurologic & Neurosensory Exam / Developmental Assessment / Other Medical Conditions

Table 1. Follow Up Status

Back to Top

	Core Visit #1				Core Visit #2				Core Visit #3			
	HCAI Expected* 134		All Expected* 3761		HCAI Expected* 130		All Expected* 3721		HCAI Expected* 129		All Expected* 3665	
	N	%	N	%	N	%	N	%	N	%	N	%
Among Registered Cases												
Seen Cases	129	96.3%	2895	77%	105	80.8%	2197	59%	83	64.3%	1525	41.6%
Closed Cases Infant Expired	1	0.7%	31	0.8%	1	0.8%	39	1%	1	0.8%	41	1.1%
Closed Cases Moved Out of State/Country	5	3.7%	102	2.7%	9	6.9%	134	3.6%	10	7.8%	188	5.1%
Closed Cases Other	2	1.5%	468	12.4%	7	5.4%	964	25.9%	36	27.9%	1671	45.6%
Cases NOT Seen But Expected	3	2.2%	398	10.6%	18	13.8%	561	15.1%	10	7.8%	469	12.8%
Seen Cases Visit Conducted (Added Mar 2020/rev Jan 2021)												
Telehealth (audio + video observation)	16	11.9%	112	3%	36	27.7%	309	8.3%	35	27.1%	237	6.5%
In-person	3	2.2%	329	8.7%	25	19.2%	1045	28.1%	47	36.4%	1253	34.2%
Closed Cases Other												
Discharged - Closed Out of Program	2	100%	410	87.6%	7	100%	847	87.9%	29	80.6%	1363	81.6%
Discharged - Graduated	0	0%	0	0%	0	0%	15	1.6%	4	11.1%	119	7.1%
Discharged - Completed HRIF Core Visits, Referred For Additional Resources	0	0%	0	0%	0	0%	2	0.2%	2	5.6%	26	1.6%
Discharged - Will be Followed Elsewhere	0	0%	58	12.4%	0	0%	95	9.9%	1	2.8%	154	9.2%

Item #6. Registered All Infants Born in 2026

MUST be checked manually by the HRIF Clinic by **07-01-2027**

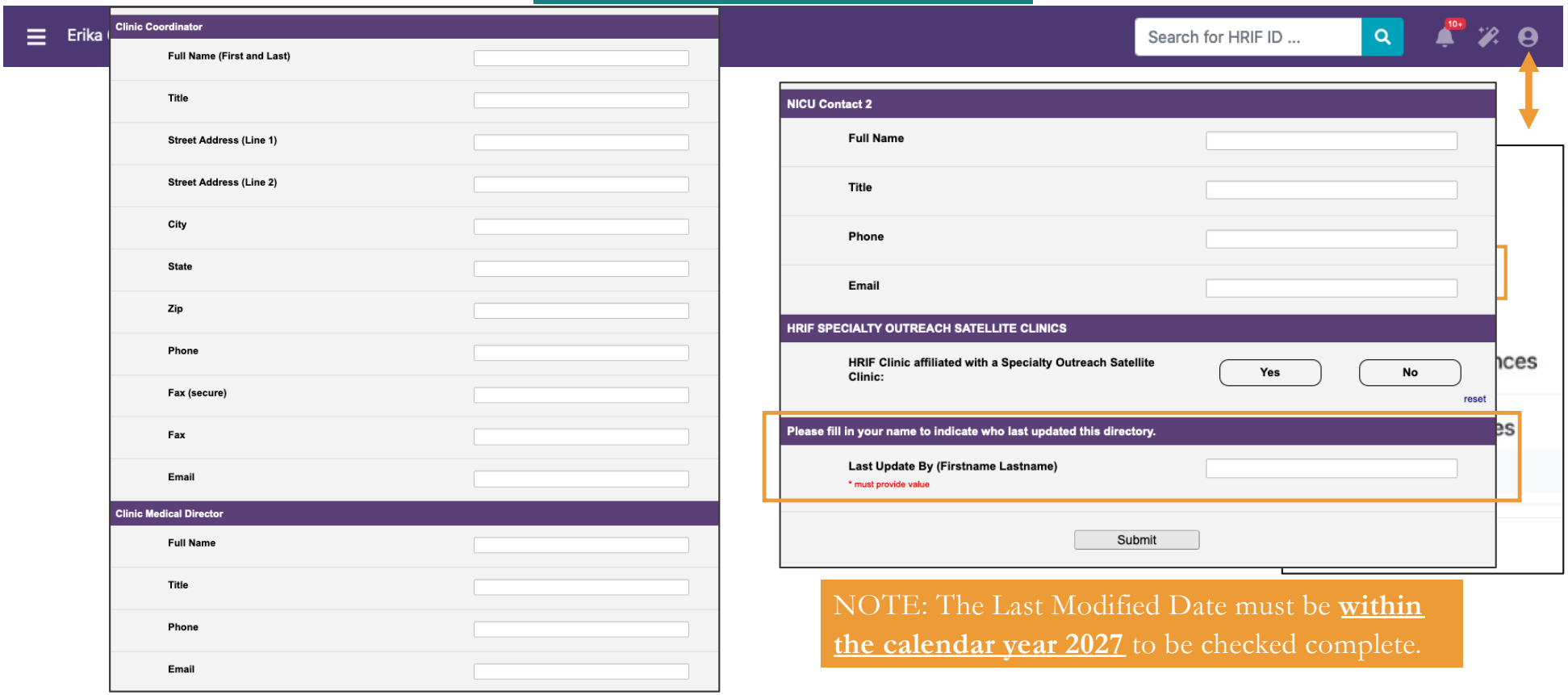
6	Register/accept all eligible HRIF infants born in 2026 from referring CCS	HRIF/NICU Match Detail Report	07-01-2027	☒

Save

Submit a Help Desk ticket to request access to view the HRIF/NICU Match Reports available in the NICU Database at www.cpqccreport.org

Update HRIF Directory

Item #7 – Closeout Checklist



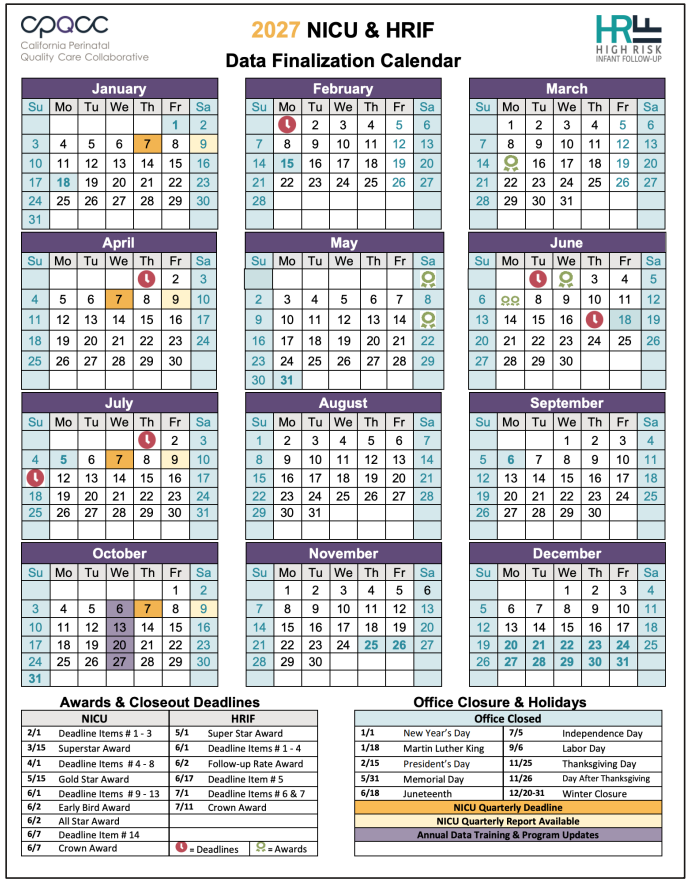
NOTE: The Last Modified Date must be **within the calendar year 2027** to be checked complete.

2027 Data Finalization Materials

HRIF Data Resource:

https://www.cpqcc.org/follow/hrif-data-resources

- NICU & HRIF Calendar
- Process Guidelines
- Quick Reference Sheet
- Schedule



CPQCC California Perinatal Quality Care Collaborative

2027 NICU & HRIF

Data Finalization Calendar

HIGH RISK INFANT FOLLOW-UP

January

Su	Mo	Tu	We	Th	Fr	Sa
					1	2
3	4	5	6	7	8	9
10	11	12	13	14	15	16
17	18	19	20	21	22	23
24	25	26	27	28	29	30
31						

February

Su	Mo	Tu	We	Th	Fr	Sa
		2	3	4	5	6
7	8	9	10	11	12	13
14	15	16	17	18	19	20
21	22	23	24	25	26	27
28						

March

Su	Mo	Tu	We	Th	Fr	Sa
	1	2	3	4	5	6
7	8	9	10	11	12	13
14		16	17	18	19	20
21	22	23	24	25	26	27
28	29	30	31			

April

Su	Mo	Tu	We	Th	Fr	Sa
					2	3
4	5	6	7	8	9	10
11	12	13	14	15	16	17
18	19	20	21	22	23	24
25	26	27	28	29	30	

May

Su	Mo	Tu	We	Th	Fr	Sa
2	3	4	5	6	7	8
9	10	11	12	13	14	
16	17	18	19	20	21	22
23	24	25	26	27	28	29
30	31					

June

Su	Mo	Tu	We	Th	Fr	Sa
				3	4	5
6		8	9	10	11	12
13	14	15	16		18	19
20	21	22	23	24	25	26
27	28	29	30			

July

Su	Mo	Tu	We	Th	Fr	Sa
					2	3
4	5	6	7	8	9	10
	12	13	14	15	16	17
18	19	20	21	22	23	24
25	26	27	28	29	30	31

August

Su	Mo	Tu	We	Th	Fr	Sa
1	2	3	4	5	6	7
8	9	10	11	12	13	14
15	16	17	18	19	20	21
22	23	24	25	26	27	28
29	30	31				

September

Su	Mo	Tu	We	Th	Fr	Sa
			1	2	3	4
5	6	7	8	9	10	11
12	13	14	15	16	17	18
19	20	21	22	23	24	25
26	27	28	29	30		

October

Su	Mo	Tu	We	Th	Fr	Sa
					1	2
3	4	5	6	7	8	9
10	11	12	13	14	15	16
17	18	19	20	21	22	23
24	25	26	27	28	29	30
31						

November

Su	Mo	Tu	We	Th	Fr	Sa
	1	2	3	4	5	6
7	8	9	10	11	12	13
14	15	16	17	18	19	20
21	22	23	24	25	26	27
28	29	30				

December

Su	Mo	Tu	We	Th	Fr	Sa
			1	2	3	4
5	6	7	8	9	10	11
12	13	14	15	16	17	18
19	20	21	22	23	24	25
26	27	28	29	30	31	

Awards & Closeout Deadlines

NICU		HRIF	
2/1	Deadline Items # 1 - 3	5/1	Super Star Award
3/15	Superstar Award	6/1	Deadline Items # 1 - 4
4/1	Deadline Items # 4 - 8	6/2	Follow-up Rate Award
5/15	Gold Star Award	6/17	Deadline Item # 5
6/1	Deadline Items # 9 - 13	7/1	Deadline Items # 6 & 7
6/2	Early Bird Award	7/11	Crown Award
6/2	All Star Award		
6/7	Deadline Item # 14		
6/7	Crown Award	= Deadlines	= Awards

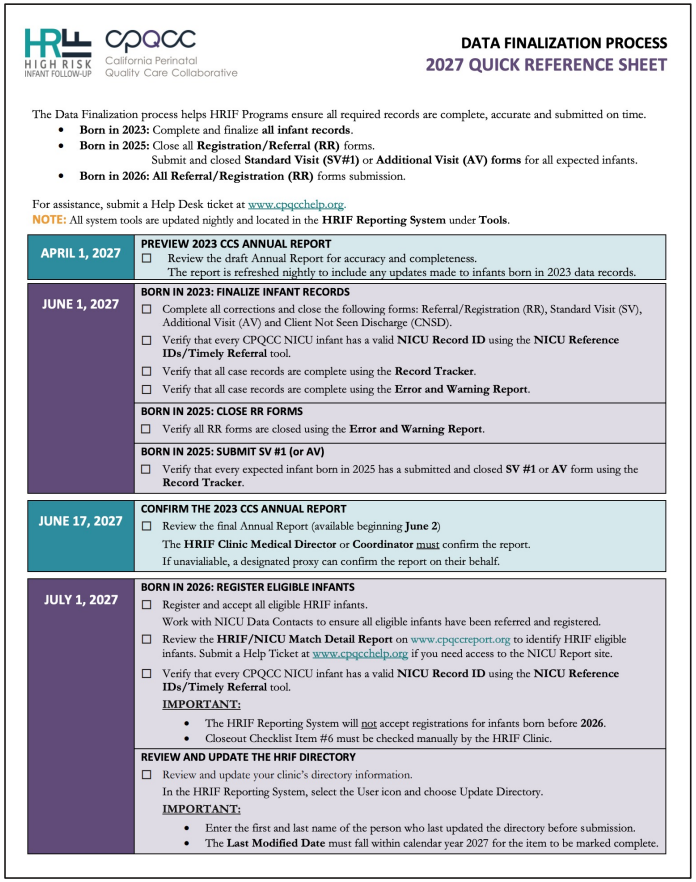
Office Closure & Holidays

Office Closed			
1/1	New Year's Day	7/5	Independence Day
1/18	Martin Luther King	9/6	Labor Day
2/15	President's Day	11/25	Thanksgiving Day
5/31	Memorial Day	11/26	Day After Thanksgiving
6/18	Juneteenth	12/20-31	Winter Closure

NICU Quarterly Deadline

NICU Quarterly Report Available

Annual Data Training & Program Updates



HIGH RISK INFANT FOLLOW-UP

CPQCC California Perinatal Quality Care Collaborative

DATA FINALIZATION PROCESS

2027 QUICK REFERENCE SHEET

The Data Finalization process helps HRIF Programs ensure all required records are complete, accurate and submitted on time.

- **Born in 2023:** Complete and finalize **all infant records**.
- **Born in 2025:** Close all **Registration/Referral (RR)** forms.
  Submit and closed **Standard Visit (SV#1)** or **Additional Visit (AV) forms** for all expected infants.
- **Born in 2026: All Referral/Registration (RR)** forms submission.

For assistance, submit a Help Desk ticket at www.cpqcchelp.org.

NOTE: All system tools are updated nightly and located in the **HRIF Reporting System** under **Tools**.

APRIL 1, 2027

PREVIEW 2023 CCS ANNUAL REPORT

- ☐ Review the draft Annual Report for accuracy and completeness.
  The report is refreshed nightly to include any updates made to infants born in 2023 data records.

JUNE 1, 2027

BORN IN 2023: FINALIZE INFANT RECORDS

- ☐ Complete all corrections and close the following forms: Referral/Registration (RR), Standard Visit (SV), Additional Visit (AV) and Client Not Seen Discharge (CNSD).
- ☐ Verify that every CPQCC NICU infant has a valid **NICU Record ID** using the **NICU Reference IDs/Timely Referral** tool.
- ☐ Verify that all case records are complete using the **Record Tracker**.
- ☐ Verify that all case records are complete using the **Error and Warning Report**.

BORN IN 2025: CLOSE RR FORMS

- ☐ Verify all RR forms are closed using the **Error and Warning Report**.

BORN IN 2025: SUBMIT SV #1 (or AV)

- ☐ Verify that every expected infant born in 2025 has a submitted and closed **SV #1** or **AV** form using the **Record Tracker**.

JUNE 17, 2027

CONFIRM THE 2023 CCS ANNUAL REPORT

- ☐ Review the final Annual Report (available beginning **June 2**)
  The **HRIF Clinic Medical Director** or **Coordinator** must confirm the report.
  If unavialiable, a designated proxy can confirm the report on their behalf.

JULY 1, 2027

BORN IN 2026: REGISTER ELIGIBLE INFANTS

- ☐ Register and accept all eligible HRIF infants.
  Work with NICU Data Contacts to ensure all eligible infants have been referred and registered.
- ☐ Review the **HRIF/NICU Match Detail Report** on www.cpqccreport.org to identify HRIF eligible infants. Submit a Help Ticket at www.cpqcchelp.org if you need access to the NICU Report site.
- ☐ Verify that every CPQCC NICU infant has a valid **NICU Record ID** using the **NICU Reference IDs/Timely Referral** tool.

IMPORTANT:

- The HRIF Reporting System will not accept registrations for infants born before **2026**.
- Closeout Checklist Item #6 must be checked manually by the HRIF Clinic.

REVIEW AND UPDATE THE HRIF DIRECTORY

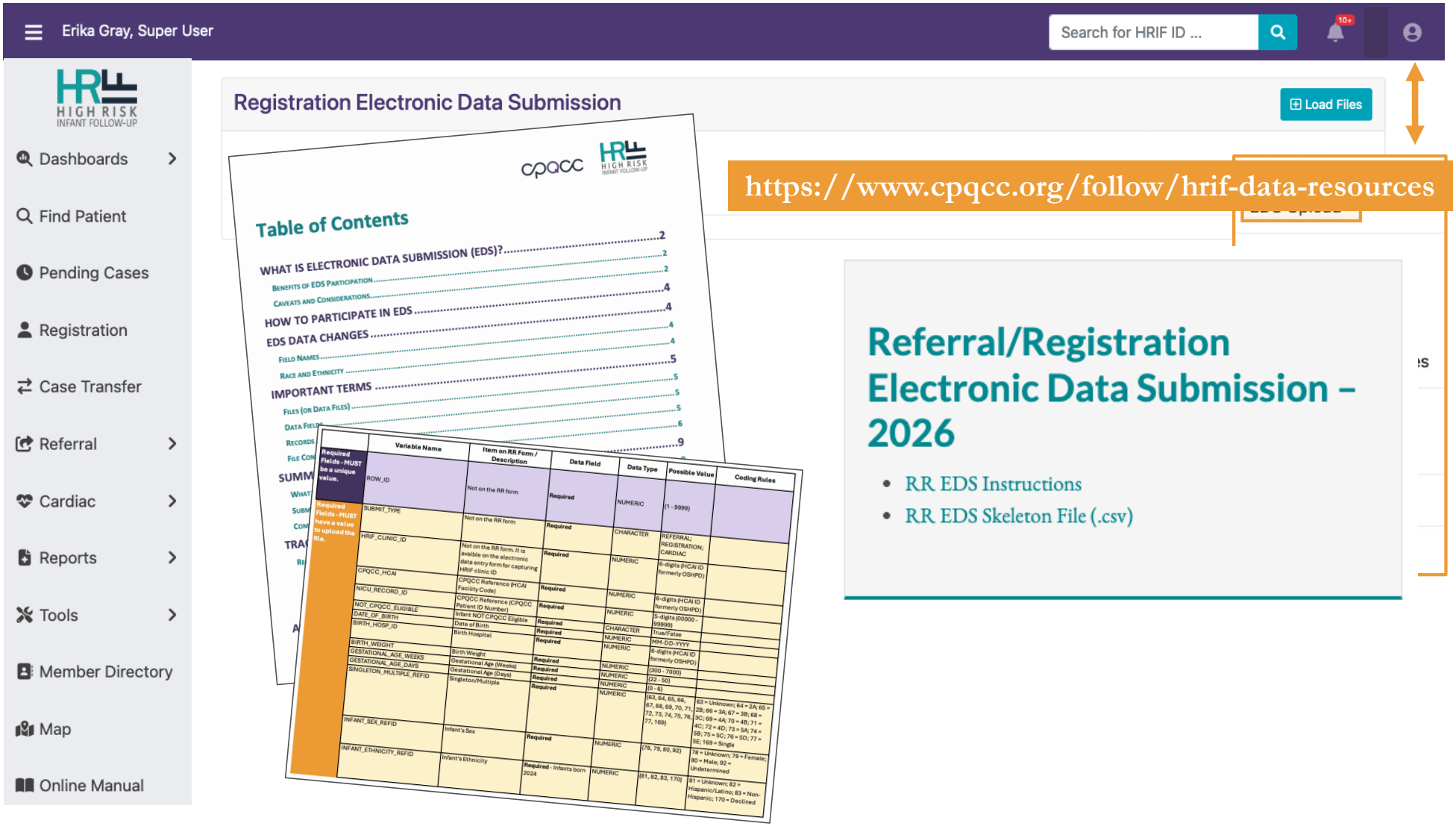
- ☐ Review and update your clinic's directory information.
  In the HRIF Reporting System, select the User icon and choose Update Directory.

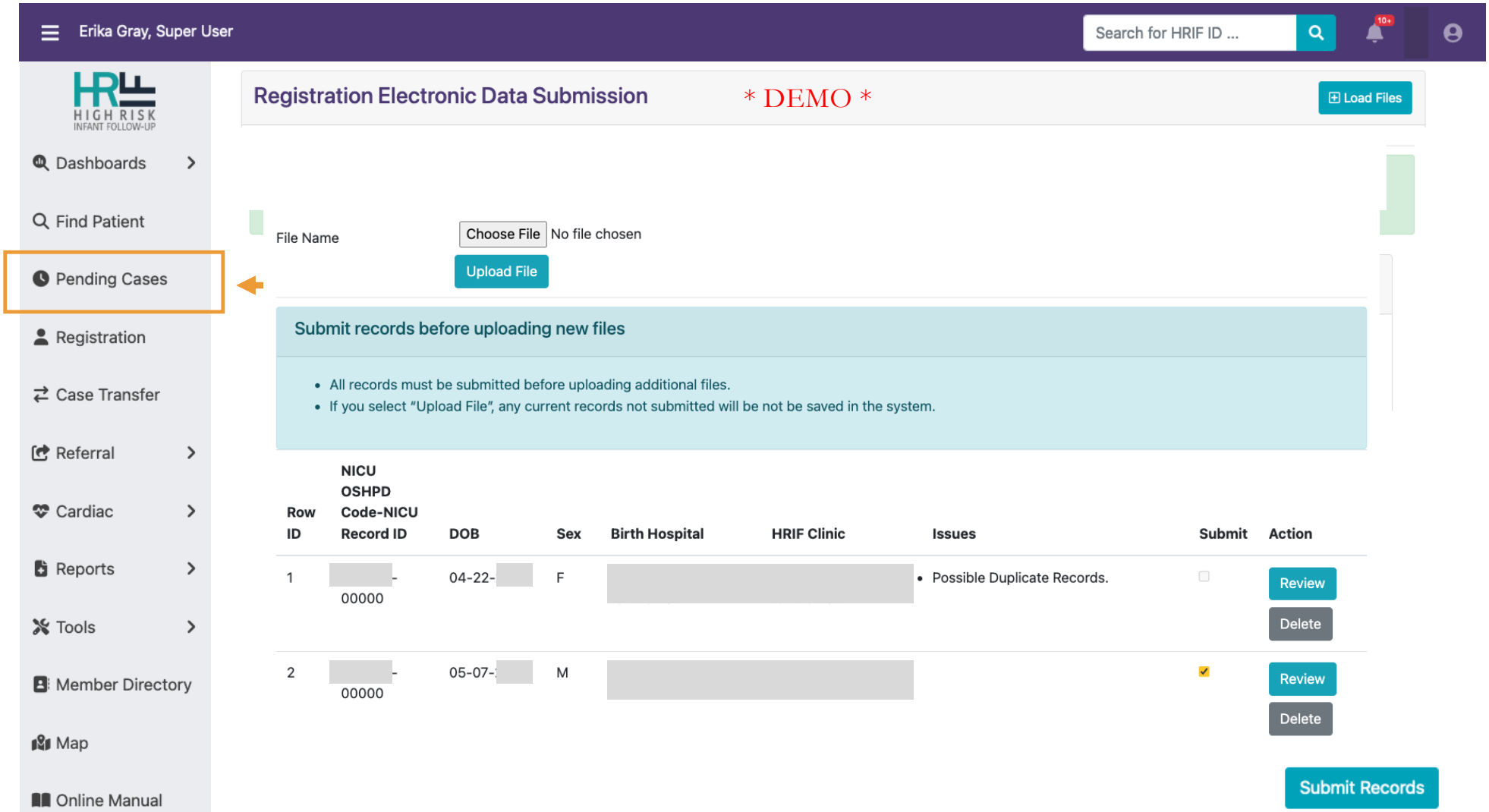
IMPORTANT:

- Enter the first and last name of the person who last updated the directory before submission.
- The **Last Modified Date** must fall within calendar year 2027 for the item to be marked complete.

EDS, Dashboards and Resources




Erika Gray, Super User
Search for HRIF ID ...
HIGH RISK INFANT FOLLOW-UP
Dashboards
Find Patient
Pending Cases
Registration
Case Transfer
Referral
Cardiac
Reports
Tools
Member Directory
Map
Online Manual
Registration Electronic Data Submission
Load Files
cpqcc
Table of Contents
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BENEFITS OF EDS PARTICIPATION 2
CAVEATS AND CONSIDERATIONS 2
HOW TO PARTICIPATE IN EDS 4
EDS DATA CHANGES 4
FIELD NAMES 4
RACE AND ETHNICITY 4
IMPORTANT TERMS 5
FILES (OR DATA FILES) 5
DATA FIELDS 5
RECORDS 6
FILE CONTENTS 9
SUMMARY
WHAT
SUBMISSION
CONTENTS
TRANSMISSION
RESOURCES
APPENDIX
Required Fields - MUST be a unique value.
Required Fields - MUST have a value to upload the file.
Variable Name
Item on RR Form / Description
Data Field
Data Type
Possible Value
Coding Rules
ROW_ID
Not on the RR form
Required
NUMERIC
(1 - 9999)
SUBMIT_TYPE
Not on the RR form
Required
CHARACTER
REFERRAL; REGISTRATION; CARDIAC
HRIF_CLINIC_ID
Not on the RR form. It is avaible on the electronic data entry form for capturing HRIF clinic ID
Required
NUMERIC
6-digits (HCAI ID formerly OSHPD)
CPQCC_HCAI
CPQCC Reference (HCAI Facility Code)
Required
NUMERIC
6-digits (HCAI ID formerly OSHPD)
NICU_RECORD_ID
CPQCC Reference (CPQCC Patient ID Number)
Required
NUMERIC
5-digits (00000 - 99999)
NOT_CPQCC_ELIGIBLE
Infant NOT CPQCC Eligible
Required
CHARACTER
True/False
DATE_OF_BIRTH
Date of Birth
Required
NUMERIC
MM-DD-YYYY
BIRTH_HOSP_ID
Birth Hospital
Required
NUMERIC
6-digits (HCAI ID formerly OSHPD)
BIRTH_WEIGHT
Birth Weight
Required
NUMERIC
(300 - 7000)
GESTATIONAL_AGE_WEEKS
Gestational Age (Weeks)
Required
NUMERIC
(22 - 50)
GESTATIONAL_AGE_DAYS
Gestational Age (Days)
Required
NUMERIC
(0 - 6)
SINGLETON_MULTIPLE_REFID
Singleton/Multiple
Required
NUMERIC
(63, 64, 65, 66, 67, 68, 69, 70, 71, 72, 73, 74, 75, 76, 77, 169)
63 = Unknown; 64 = 2A; 65 = 2B; 66 = 3A; 67 = 3B; 68 = 3C; 69 = 4A; 70 = 4B; 71 = 4C; 72 = 4D; 73 = 5A; 74 = 5B; 75 = 5C; 76 = 5D; 77 = 5E; 169 = Single
INFANT_SEX_REFID
Infant's Sex
Required
NUMERIC
(78, 79, 80, 92)
78 = Unknown; 79 = Female; 80 = Male; 92 = Undetermined
INFANT_ETHNICITY_REFID
Infant's Ethnicity
Required - Infants born 2024
NUMERIC
(81, 82, 83, 170)
81 = Unknown; 82 = Hispanic/Latino; 83 = Non-Hispanic; 170 = Declined
https://www.cpqcc.org/follow/hrif-data-resources
Referral/Registration Electronic Data Submission – 2026
RR EDS Instructions
RR EDS Skeleton File (.csv)


Erika Gray, Super User
Search for HRIF ID ...
HIGH RISK INFANT FOLLOW-UP
Dashboards
Find Patient
Pending Cases
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Cardiac
Reports
Tools
Member Directory
Map
Online Manual
Registration Electronic Data Submission
* DEMO *
Load Files
File Name
Choose File
No file chosen
Upload File
Submit records before uploading new files
All records must be submitted before uploading additional files.
If you select "Upload File", any current records not submitted will be not be saved in the system.
Row ID
NICU OSHPD Code-NICU Record ID
DOB
Sex
Birth Hospital
HRIF Clinic
Issues
Submit
Action
1
-00000
04-22-
F
Possible Duplicate Records.
Review
Delete
2
-00000
05-07-
M
Review
Delete
Submit Records

HIGH RISK INFANT FOLLOW-UP

NICU Teams Gain HRIF Access!



NICU leaders and teams should request HRIF database access to:

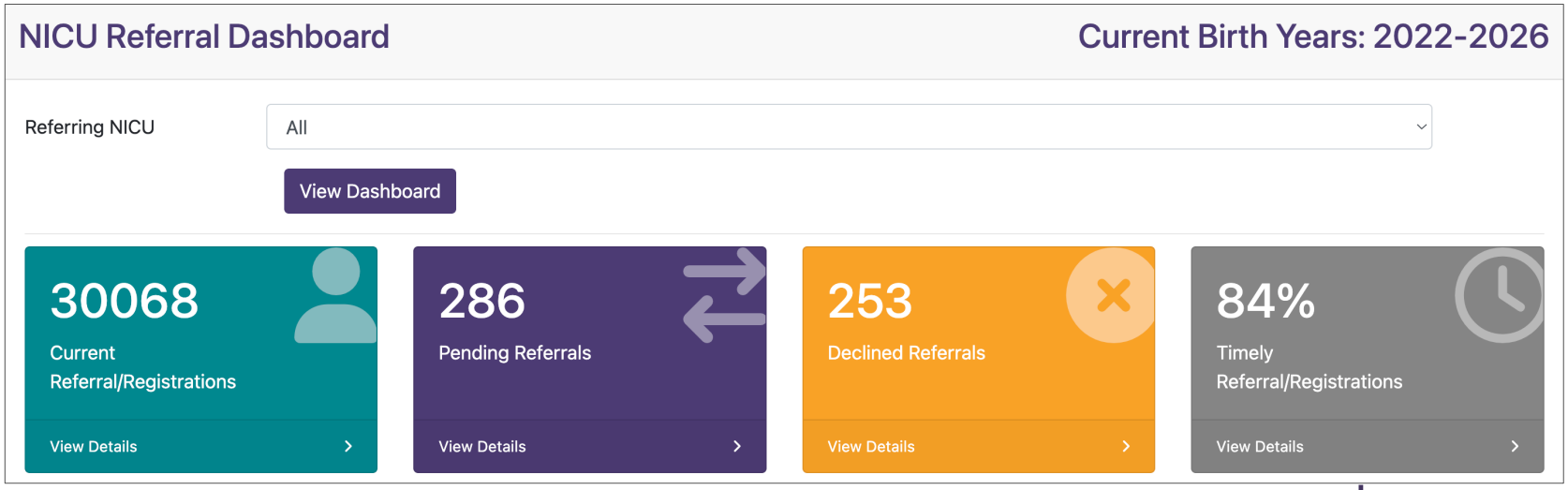
- Refer/Enroll Eligible Patients
- Track and Manage Patient Referrals
- View NICU Summary Reports

NICU Referral Dashboard

HIGH RISK
INFANT FOLLOW-UP



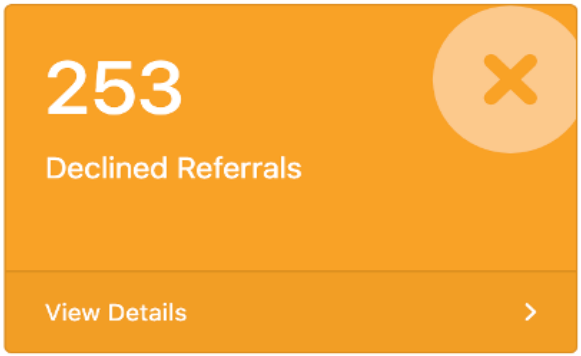
NICU Referral Dashboard



View Details:
Opens a referral distribution pie chart.

View Details:
Opens Referral Pending Cases – displays the pending and/or declined referral cases (actionable items)

View Details:
List patient cases referred to a HRIF Program after 60 days.



Referral Pending Cases

CCS NICU: All

View Pending Cases

Rejected Referral Forms | Patients Referred to HRIF Clinic Pending Acceptance | EDS Records Uploaded within Last 6 Months

Patients Referred to Another HRIF Clinic Pending Acceptance - 286

Search:

	HRIF ID#	DOB	Sex	BW	GA wks	NICU Ref ID	Referred On/By	Referred To HRIF	Referral Status
1	QBD99YVOIV	11-22-2025	F	1180	31	MWZMGC-11485	12-23-2025 at 07:11 PM by First11241 Last11241	Slow Nail File Hospital	Pending
2	DBPL9YVOIY	10-20-2025	M	2960	38	EJJZMZ-00000	12-18-2025 at 04:43 PM by First11601 Last11601	Scared Doughnut Hospital	Pending
3	HDBN9DVOI9	11-22-2025	M	2300	36	CZGEKM-99999	12-14-2025 at 12:05 AM by First11220 Last11220	Grumpy Dragonfly Hospital	Pending
4	RYBPVYVOIO	10-05-2025	M	1345	28	ZKKZJZ-04870	12-08-2025 at 07:56 AM by First10178 Last10178	Playful Garbage Bag Hospital	Pending

Showing 1 to 286 of 286 entries

HIGH RISK INFANT FOLLOW-UP

84%

Timely Referral/Registrations

View Details >

Referrals Over 60 Days

Copy
Excel
CSV
Print

Show 10 entries

Search:

HRIF ID	DOB		BW	GA wks	NICU HCAI	NICU Record ID	Days to Referral
ABDIYOOOIN	01/28/2024	F	1240	31	SGZMKC	24010	465
ABF9LODXIN	03/14/2022	F	1285	33	JSSMKM	3406	148
ABF9NOLLIN	01/10/2024	M	3900	40	JSSMKM	3562	115
ABF9PODXIN	07/31/2022	M	1290	32	JSSMKM	3435	71
ABF9VDLLIN	12/02/2023	M	1910	34	JSSMKM	3552	106
ABF9XIPXIN	02/04/2023	M	1530	31	JSSMKM	99999	64
ABF9XVVLIN	07/27/2024	M	2965	35	JSSMKM	3632	72
ABF9YPXOIN	10/12/2024	M	3520	38	JSSMKM	99999	168
ABFDILIXIN	07/24/2022	M	2580	34	JSSMKM	3443	77
ABFDLIPXIN	02/08/2023	F	1530	31	JSSMKM	99999	87

Showing 1 to 10 of 4,756 entries

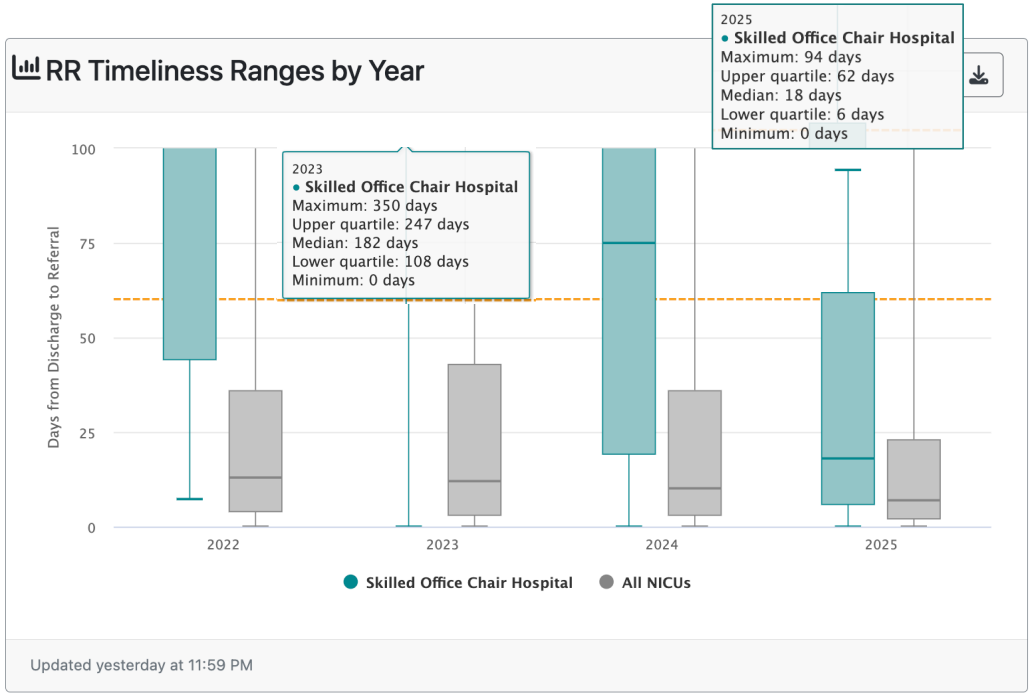
Previous 1 2 3 4 5 ... 476 Next

Close

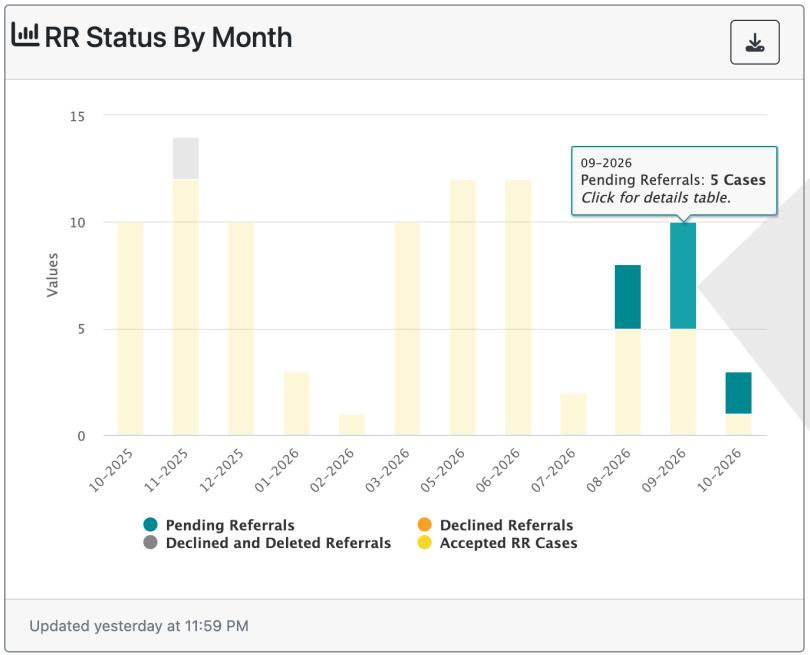
Click icon to download patient lists

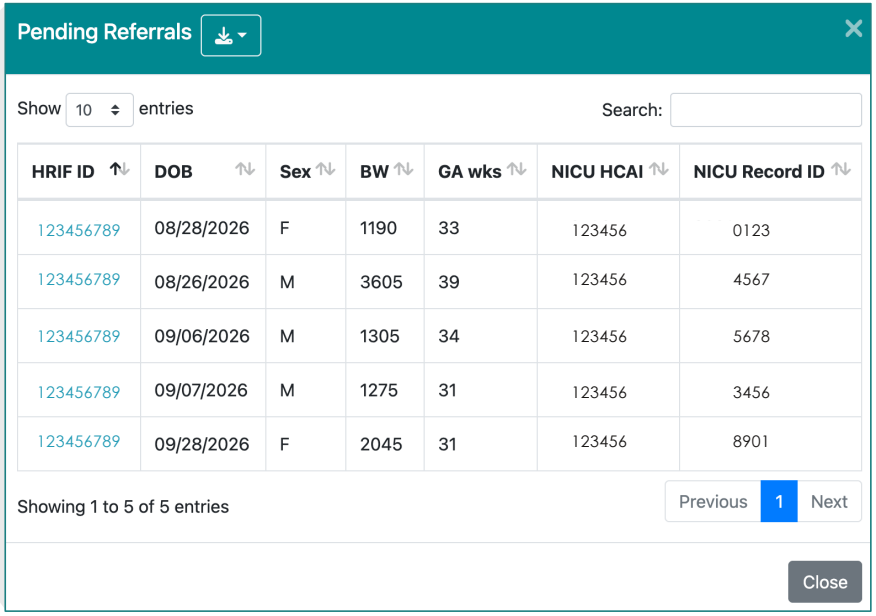
HIGH RISK INFANT FOLLOW-UP

NICU Referral Dashboard



NICU Referral Dashboard





Click on chart to display patient cases by category.

Referral Users can only view RR form.

NICU Referral Dashboard



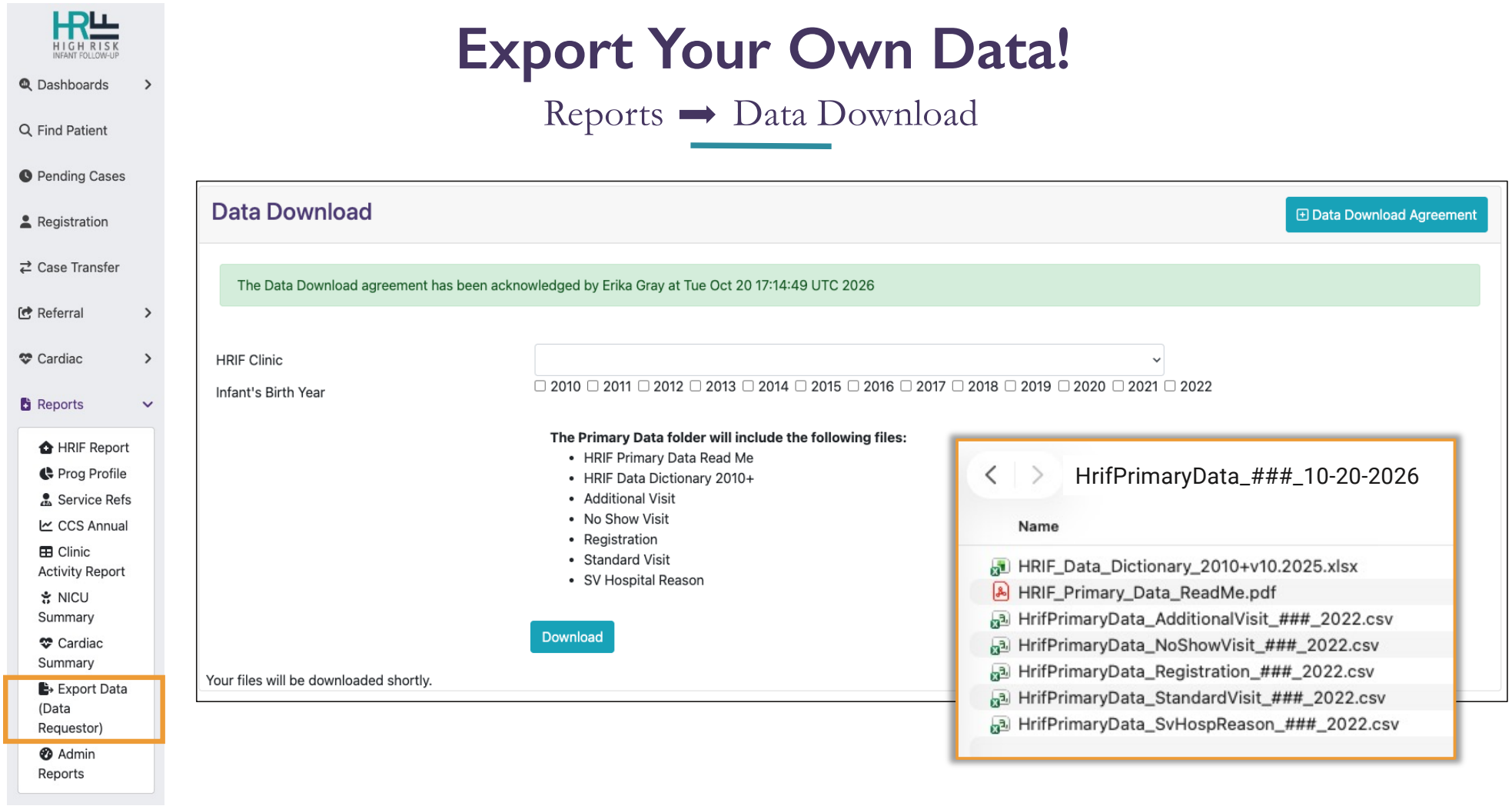
Not Expected

Show 10 entries Search:

HRIF ID	DOB	Sex	BW	GA wks	NICU HCAI	NICU Record ID	Reason
123456789	01/08/2026	F	3890	36	274043	5220	Infant/Family Moved Out of State
123456789	04/27/2026	M	1540	31	274043	5289	Not Expected Due to Age
123456789	05/19/2026	F	1650	33	274043	5303	Not Expected Due to Age
123456789	05/16/2026	F	1950	31	274043	5301	Not Expected Due to Age

Export Your Own Data!

Reports ➡ Data Download



HRIF Reports Webpage

https://www.cpqcc.org/follow/hrif-reports

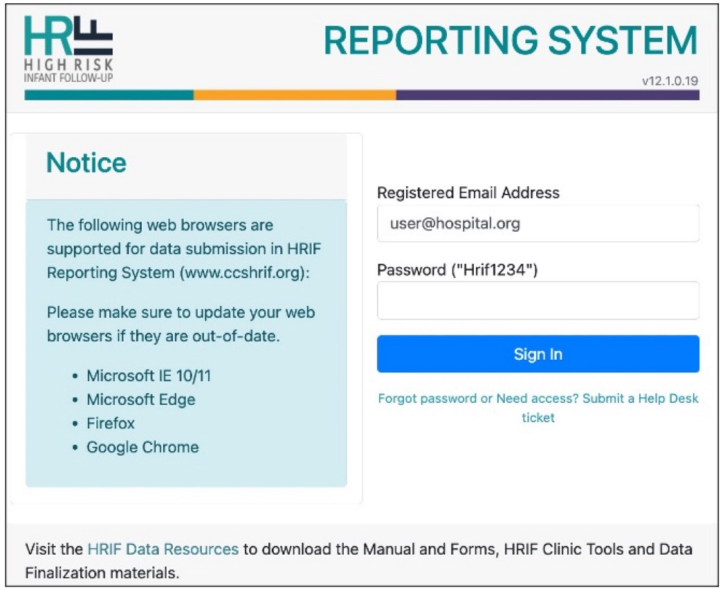
Follow-Up

- What Is HRIF?
- NICU to HRIF
- HRIF Data
- HRIF Reports
- HRIF Data Resources
- HRIF Executive Committee

Explore HRIF Outcomes

Visit our HRIF Sample App to generate system reports for yourself.

Learn how to use the Sample App in this 1 minute video.



Sample App – NICU Summaries 1-minute video:
https://www.youtube.com/watch?v=siLYdNpCOiA

Resources & Support



Announcements!

POP UP WORKSHOP

Training sessions to learn about database features.

- **Data Finalization Process / Closeout Checklist** (Jan 15 @ 12:30 - 1:30pm) - Register

RESOURCES

Early Detection of High Risk Cerebral Palsy

- View Overview and Resource documents

CPQCC & PARTNERSHIP EVENTS

- 2025 Early Detection of CP Workshop (Oct 27 @ 9am - 4pm) - Register
Hosted by Early Identification and Intervention for Infants (EI3) network.

- Improvement Palooza 2026 (Mar 18 @ 9am - 5pm)

- View the Schedule and Register
- Watch Highlights from IP2025

- Early Start Family Resources Center (FRCs)
Webinar showcases parents and staff from four Early Start FRCs serving the Bay Area
the recording, slides and resources.

- **Database & System Improvements**
- **Program Updates** (New clinics, name changes)
- **Data Finalization -** Deliverables and Deadlines
- **QI Surveys** (i.e.. Annual evaluations, ROCs)
- **Reporting System Reminders**

UPDATED: CCS PROGRAM MANUAL - SPECIAL CARE CENTERS STANDARDS

The California Department of Health Care Services has released an updated **CCS Program Manual of Procedures, Chapter 3.37.1: Special Care Center General Information and Core Standards**.
***QUESTIONS:** Contact DHCS CCS HRIF at hrif@dhcs.ca.gov.

YOUR IDEAS MATTER!

Help us improve the HRIF Reporting System.
Tell us:

- What would make reporting easier?
- What new features would you love to see?
- How has HRIF data helped drive your QI work?

***Share your feedback and help shape what's next!**

HIGH RISK INFANT FOLLOW-UP

Reporting System Tools

Record Tracker

Assist clinics with **tracking, submission and closing** patient records.

NICU Reference IDs/ Timely Referral

Clinic staff can **update missing CPQCC NICU Record IDs** and patient timely HRIF referral.

Error & Warning Report

Alerts data users of **missing or incorrect data entries** and an provides an action plan to resolve the issue:

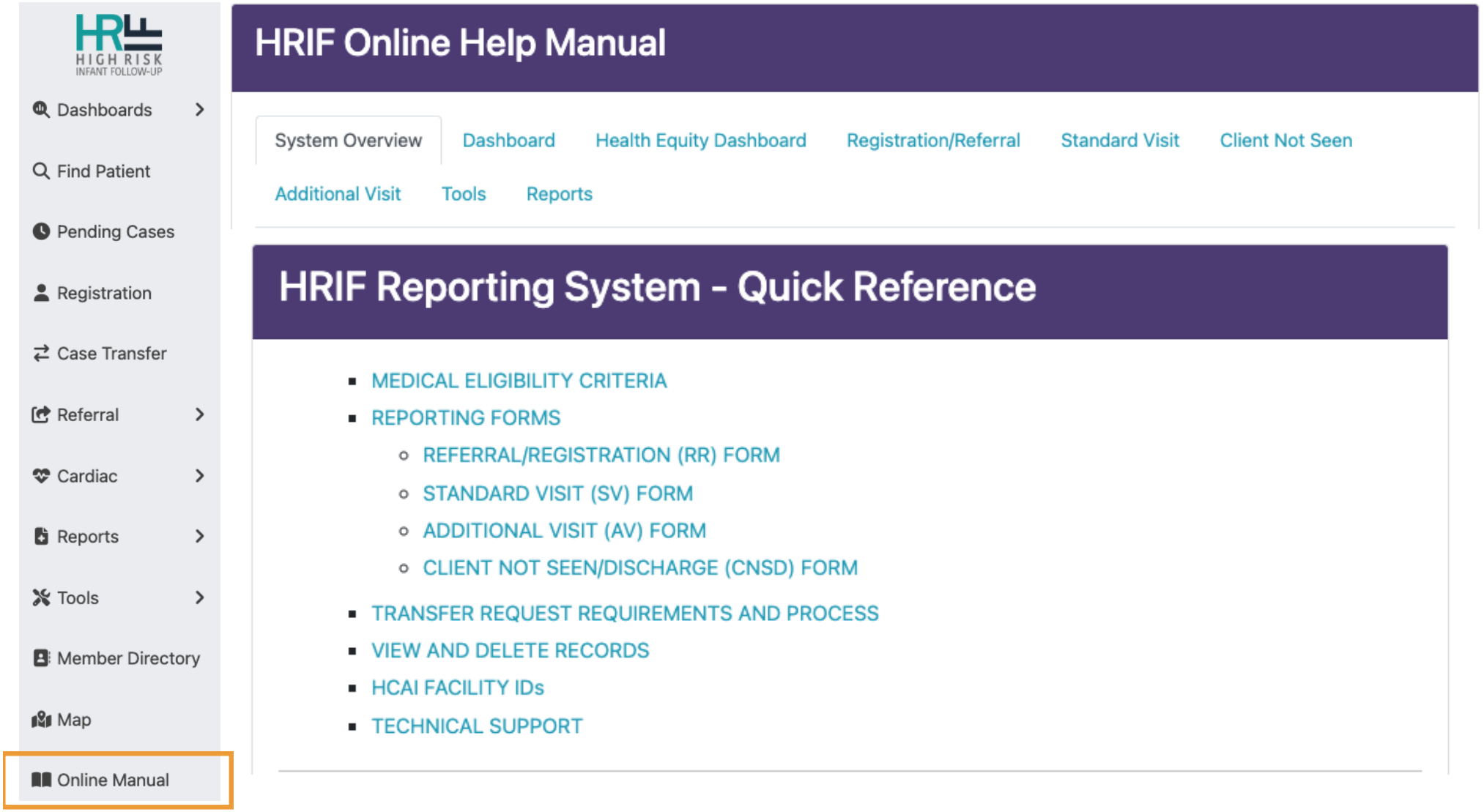
- Expected SV #1 missing
- Missing NICU Record ID
- Duplicate Record

Case History

Clinics can **create, manage and track patient records** that have been **transferred to/from another clinic.**

Closeout Checklist

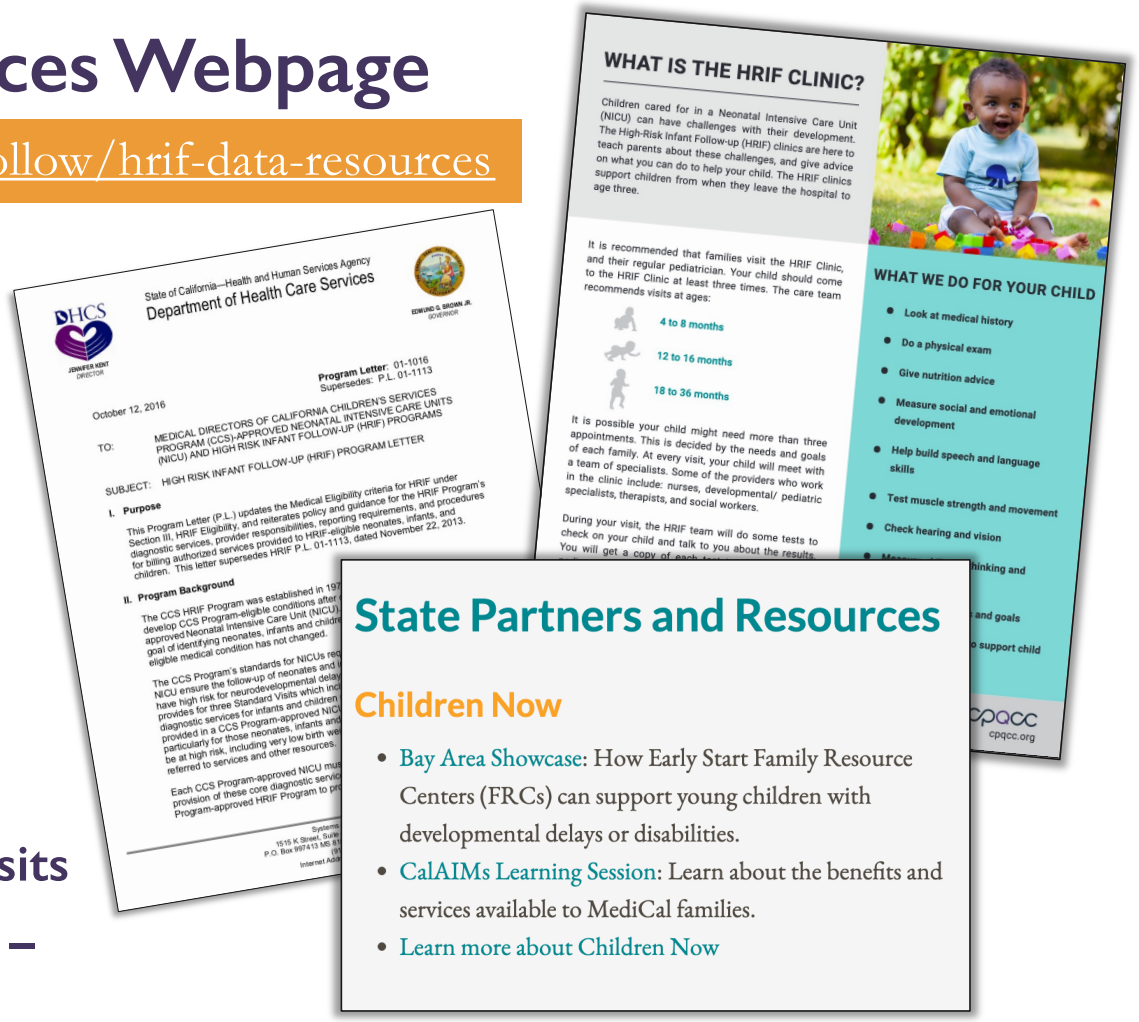
This tool provides a **list of items to assist clinics in finalizing (closing) submitted data.**


HIGH RISK
INFANT FOLLOW-UP
Dashboards
Find Patient
Pending Cases
Registration
Case Transfer
Referral
Cardiac
Reports
Tools
Member Directory
Map
Online Manual
HRIF Online Help Manual
System Overview
Dashboard
Health Equity Dashboard
Registration/Referral
Standard Visit
Client Not Seen
Additional Visit
Tools
Reports
HRIF Reporting System - Quick Reference
MEDICAL ELIGIBILITY CRITERIA
REPORTING FORMS
REFERRAL/REGISTRATION (RR) FORM
STANDARD VISIT (SV) FORM
ADDITIONAL VISIT (AV) FORM
CLIENT NOT SEEN/DISCHARGE (CNSD) FORM
TRANSFER REQUEST REQUIREMENTS AND PROCESS
VIEW AND DELETE RECORDS
HCAI FACILITY IDs
TECHNICAL SUPPORT

Data Resources Webpage

https://www.cpqcc.org/follow/hrif-data-resources

1. **CPQCC Website**: www.cpqcc.org
   - What Is HRIF?
   - HRIF Data Resources
   - CCS – Program Number Letters
2. **Data Finalization**
3. **HRIF Family Handout**
4. **CCS NICU HRIF Eligible Infants Referral Guidelines**
5. **HRIF Guidance for Telehealth Visits**
6. **HINE & Early Detection of High – Risk Cerebral Pasly**



DHCS CCS State Contact

CCS HRIF Program Policy and Procedures

QUESTIONS

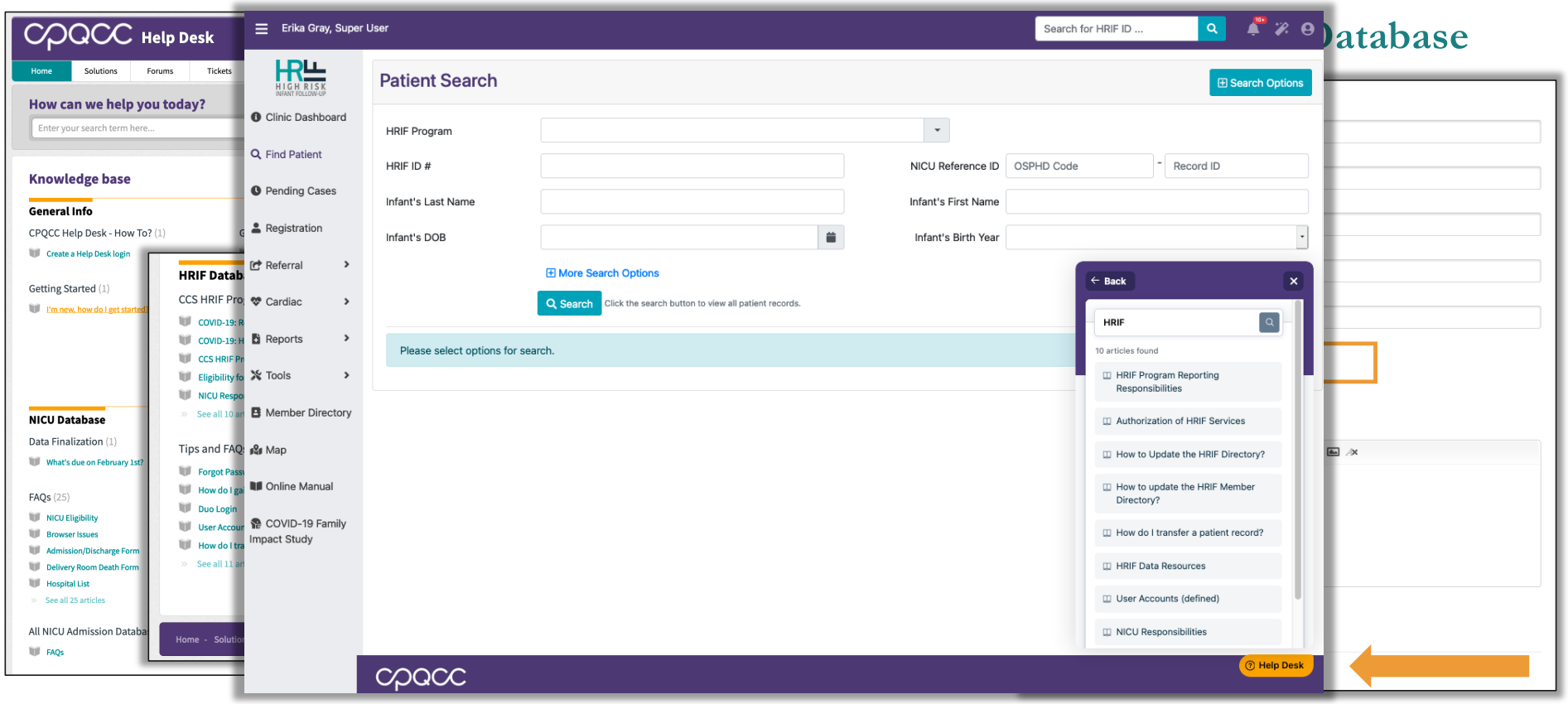
- CCS Special Care Centers Standards
  - https://www.dhcs.ca.gov/wp-content/uploads/2026/07/ccs-chapter-3-37-core-scc.pdf
- Becoming a California Children's Service Provider
  - https://www.dhcs.ca.gov/services/ccs/Pages/ProviderEnroll.aspx
- Service Authorization Service (SAR) & Billing/Insurance
- CCS County Issues
- Whole Child Model
  - URL https://www.dhcs.ca.gov/services/ccs/Pages/CCSWholeChildModel.aspx

California Department of Health Care Services (DHCS)
HRIF@dhcs.ca.gov

HIGH RISK INFANT FOLLOW-UP

Need More Assistance!

Submit a Help Desk ticket at www.cpqcchelp.org



HIGH RISK INFANT FOLLOW-UP

** Pop-Up Workshop **

Data Finalization Process & Closeout Checklist

February 4, 2027



Short informal trainings that will provide users a deep dive into to specific reporting system features or engage in new system improvements. (Max 30 participants)

Agenda

- 20 - 30 mins – Review Topic
- 15 mins – Q/A and open discussion

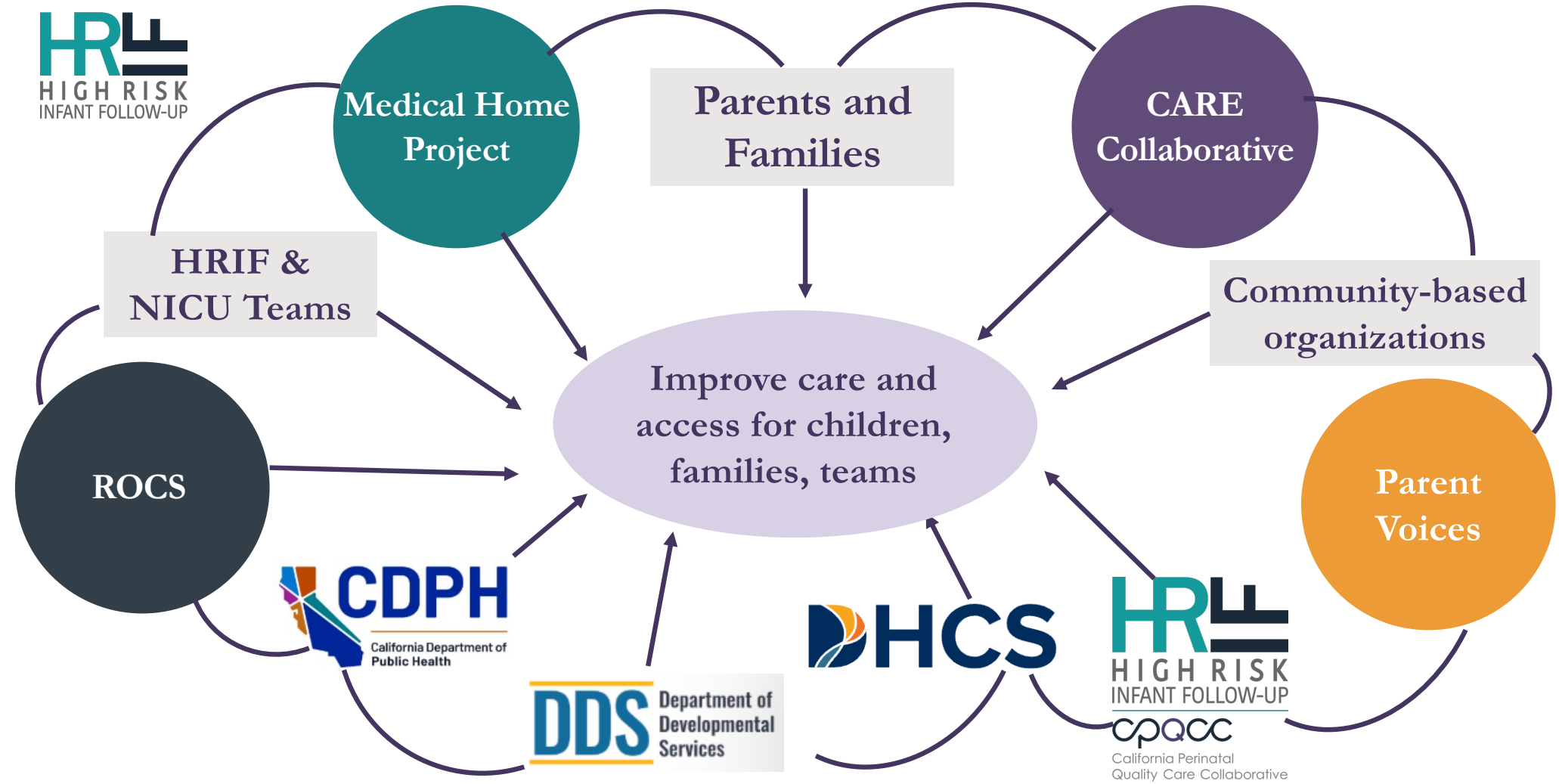
WORKSHOP TOPICS:

- ❖ **Data Finalization/Closeout Checklist**
- ❖ **Reports (HRIF/NICU Summary, Clinic Activity)**
- ❖ **NICU Referral Dashboard**
- ❖ **Health Care Access Dashboard**
- ❖ **System Tools (Tracker, Error & Warning)**
- ❖ **EDS Option – Referrals/Registrations**

Current Project Updates



HIGH RISK
INFANT FOLLOW-UP


HRIF
HIGH RISK
INFANT FOLLOW-UP
Medical Home Project
Parents and Families
CARE Collaborative
HRIF & NICU Teams
Community-based organizations
Improve care and access for children, families, teams
ROCS
Parent Voices
CDPH
California Department of Public Health
DHCS
DDS
Department of Developmental Services
HRIF
HIGH RISK
INFANT FOLLOW-UP
CPQCC
California Perinatal Quality Care Collaborative



PARENT VOICES

Your Experience Matters. Help Improve NICU and Follow-Up Care

HIGH RISK INFANT FOLLOW-UP

About | NICU | Analysis | Improvement | Follow-Up | Engage | For Families & Communities

Search...

Quality Improvement Projects

Improvement

- Health Equity
- Current Projects
  - Motivating & Optimizing Maternal Milk in Safety Net NICUs (MOMMS)
  - Collaborating for Access and Resources in Early Life (CARE) Collaborative
  - Parent-Family Voices Collaborative Project for Centers
- Previous Projects
- Tools
- Workgroups
- Perinatal Quality Improvement Panel (PQIP)
- QI Fundamentals Course
- Quality Improvement Awards

Our quality improvement (QI) projects are designed to help NICUs improve specific areas of care using evidence-based practices. We offer large, multi-site "collaborative" projects as well as smaller, more targeted approaches. Quality improvement projects are open to all CPQCC member hospitals.

- View the Hospital Engagement Requirements
- View the QI Collaborative Engagement Strategy & Predictors

ABP Maintenance of Certification Part 4 Credit

CPQCC has been authorized by the American Board of Pediatrics (ABP) to evaluate QI projects against the ABP's standards and approve them for Maintenance Of Certification (MOC) credit. As a Pediatric Portfolio Sponsor, we are thrilled to offer physicians participating in our quality improvement activities MOC Part 4 credit. For more information, please contact CPQCC Associate Director of Quality, Courtney Nisbet.

Read more about MOC credits for COVID-19 related learning and improvement.



Motivating & Optimizing Maternal Milk in Safety Net NICUs (MOMMS)



Collaborating for Access and Resources in Early Life (CARE) Collaborative



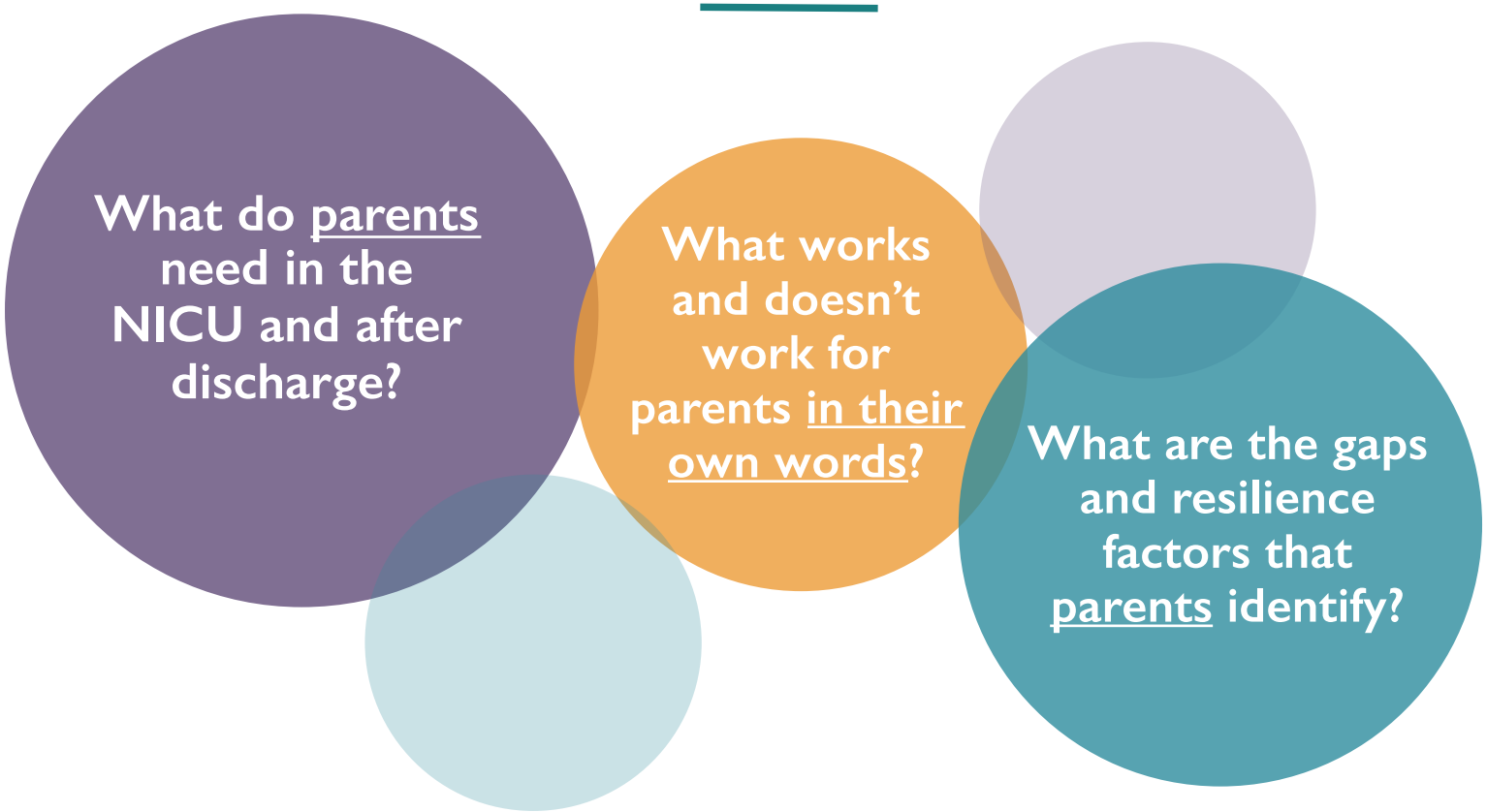
Parent Voices Project

Want to learn more about quality improvement?

The Institute for Healthcare Improvement has a variety of resources designed to help you learn the principles behind quality improvement and put them into practice in your unit.

Listening to Parent Voices

What works and what doesn't work for parents and families during their journey?



PARENT VOICES

What helped parents and what were barriers in the NICU and <u>after</u> discharge?

Mixed methods project *learning from parents* of children <32 weeks in NICU & HRIF

- **Surveys** → easy access, short, open-ended questions
  - <u>4 languages</u>, values parents' time ($10 gift card).
- **Interviews** → option to share contact information for in depth virtual interview
  - Goal – 30 parent interviews ($50 gift card).



PARENT VOICES

Qualitative Interviews

Site Type
hospital and clinic settings

Gestational Age
across age groups

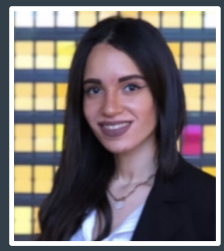
Region
across California

Parent/Caregiver
mother, father, caregiver

Language
diverse language preference

Community
rural and urban communities

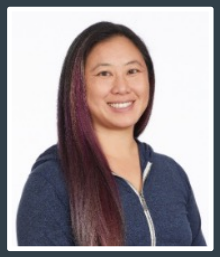
Goal: Ensure diverse and inclusive family representation.



Elix Colon



Jessica Liu



Susan Perez

PARENT VOICES

Where are we now?

21 of 31

interested NICU/HRIF sites have contributed parent survey responses.

184

surveys received:

20 NICU

164 Follow up

GOAL: 200-250

15

confidential parent interviews have been conducted so far – and more to come!

Survey Collection Period: September 2025 – (? Likely end December 2026)

PARENT VOICES

Future goals for NICU, HRIF & beyond

In this project, **we will center and learn from parent voices, and leverage results to**:

1) Disseminate findings, **educate NICUs and HRIF clinics** about challenges and resilience factors for parents in their journey.

2) Partner with parents, providers to **create parent-involved NICU to home and community tools**.

3) ***Ultimate goal****: Convene parents, teams, state and community stakeholders, to prioritize and incorporate findings from other projects and initiatives to* ***translate to state-engaged QI initiative****.*

PARENT VOICES

THANK YOU!

- Anderson Lucchetti Women's & Children's Center
- Doctors Medical Center
- John Muir
- KFH Roseville
- KFH San Francisco
- KFH San Leandro (Hayward)
- KFH Santa Clara
- KFH Walnut Creek
- LAC/Harbor-UCLA Medical Center
- Lucile Packard Children's Hospital Stanford
- Miller Children's & Women's Hospital
- Natividad Medical Center - NICU
- San Antonio Regional Hospital
- Santa Rosa Memorial Hospital - NICU
- Sharp Mary Birch Hospital for Women & Newborns
- UC Davis Medical Center
- UCSD Health
- UCSF Benioff Children's Hospital Oakland
- UCSF Benioff Children's Hospital San Francisco
- Valley Children's Hospital
- Zuckerberg SF General Hospital – NICU

HIGH RISK INFANT FOLLOW-UP

ROC

Resources and Opportunities in Clinics

Identify "boots on the ground" clinic challenges and successes in operations and supports– and develop solutions to address clinical operations and access issues.

SERIES OF SURVEYS

Survey Completion

Survey 1: Clinic Operations

(Coordinator FTE% and clinic structure/scheduling)

100% (66) HRIF Program participation

Survey 2: HRIF Program Support

(Referral process and case management)

93% (62) HRIF Program participation

91%

HRIF Clinic Teams completed both surveys (n=61)

Highlights: Survey Responses

*CCS HRIF clinic annualized referral volume, median (IQR)	97.3 (48.5–156.3) Max: 521
- Quartile 1	<49
- Quartile 2	49-98
- Quartile 3	99-157
- Quartile 4	>157

- **Teams use MULTIPLE strategies** to identify infants eligible for referral, track patients for follow-up visits, and contact/ schedule/ reschedule.
- **53 (87%) make 3-4** attempts to schedule/ reschedule before closing out of program.

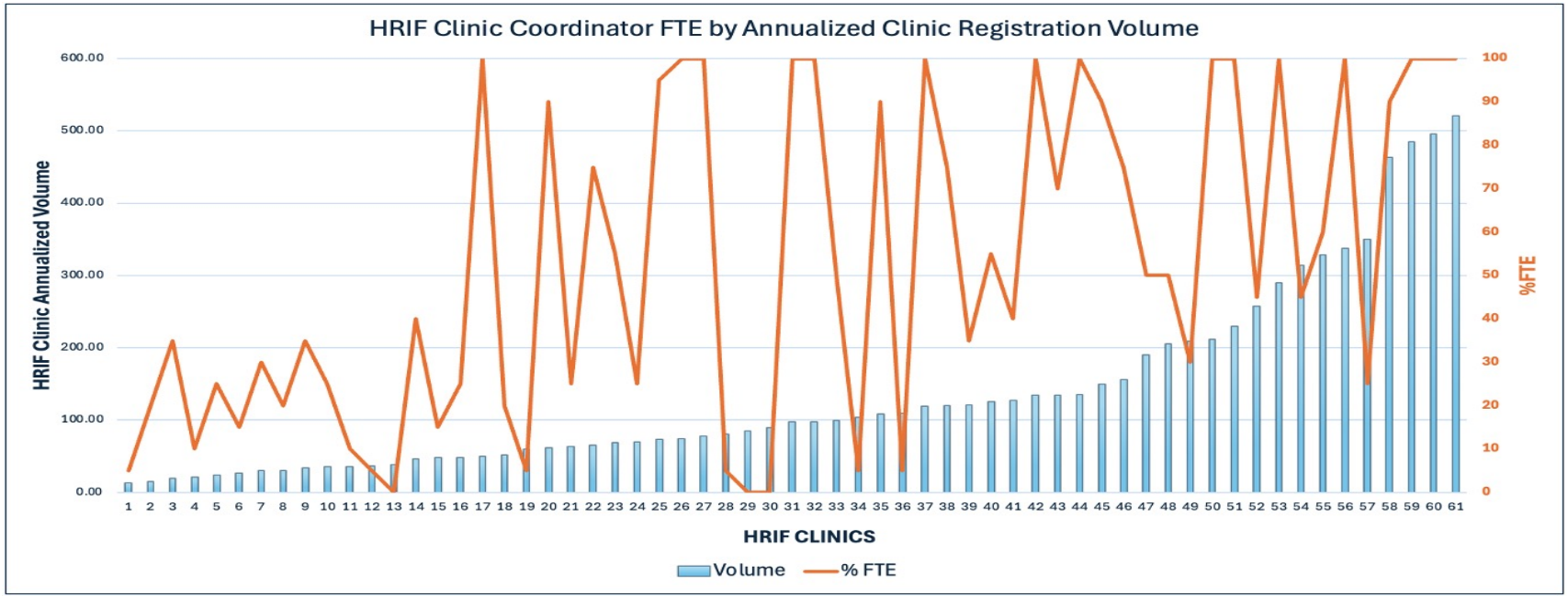
Highlights: Survey Responses

Serves as HRIF clinic coordinator, n (%)	
RN/ nurse specialist	40 (65.5%)
OT or PT	3 (4.9%)
Social Worker	6 (9.8%)
Pediatric NP	4 (6.6%)
Psychologist	0 (0.0%)
Pediatrician/ Neonatologist	4 (6.6%)
Other	4 (6.6%)

- **Clinic coordinator FTE median (IQR) = 45% (20-95%)**
- **37 (60%) reported that no other team roles assist in clinic coordinator duties**; did not differ by clinic volume (quartile) or coordinator FTE quartile

Highlights: Survey Responses

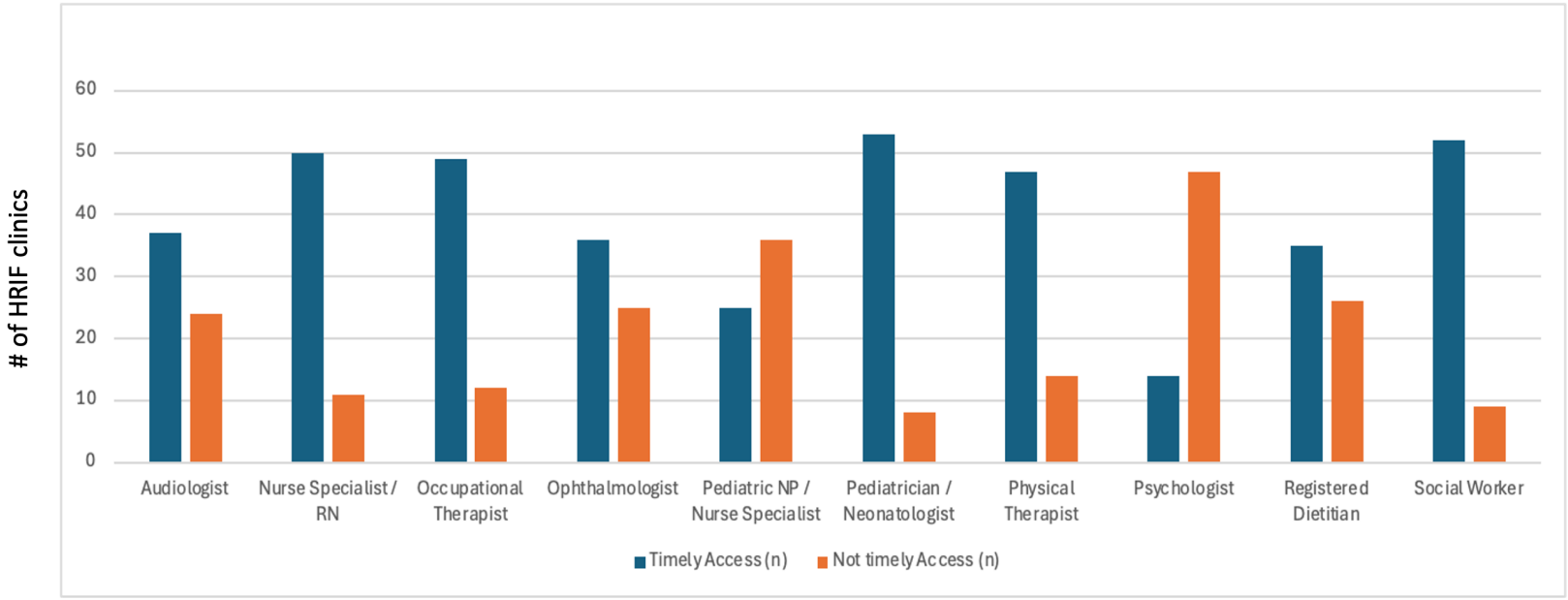
- Coordinator FTE quartile was associated with clinic volume quartile (p=0.0008), **but individual coordinator FTE varied widely across HRIF clinics**



Highlights: Survey Responses

- **Support scores** were constructed (scores 0–5+) based on responses about team roles and staff support for 1) parent outreach after missed visits, and 2) family assistance in follow-through with referrals
- Most clinics reported at least 1 staff assisting with these important family-facing clinic tasks, HOWEVER -
  - **Clinic volume (quartile) was NOT significantly associated with support scores** for outreach after missed visits (p=0.52) or helping families follow through with referrals were not associated with volume quartile (p=0.99).

Highlights: Survey Responses



- Reported timely access varied by provider type. Timely access was also not significantly associated with clinic volume (p=0.52).

HIGH RISK INFANT FOLLOW-UP

Additional Questions

ROC Resources and Opportunities in Clinics

- **Center:**
- **Email Address:**
- **My HRIF Clinic is primary part of / staffed by:**
  - Developmental and Behavioral Pediatrics
  - General Pediatrics
  - Neonatology
  - Other

A brief, two-question survey will be sent the first week of November.

100% HRIF Program participation expected – THANK YOU!



Additional Questions

- **How would you describe the core services provided by your HRIF clinic?**
    1. **Primarily related to CCS HRIF visit components** including neurodevelopmental screening and testing.
    2. **Inclusive of some medical treatment or support** (i.e., advancing NG feeds, changing medication dose or starting new medication, etc.)
    3. **A comprehensive care clinic** (i.e., would include all primary care, on point for urgent care, and as advice provider, etc.)
    4. **Other** (please describe)

- **Please indicate how your HRIF Clinic core services are provided:**

  [question displays if 2 or 3 is selected above]
    - Services are **provided throughout the entire three-year follow-up period**.
    - Services are **offered for a limited duration**.

THANK YOU to the ROCS Work Group - - and to ALL HRIF clinic teams!

HRIF clinic team members from across California

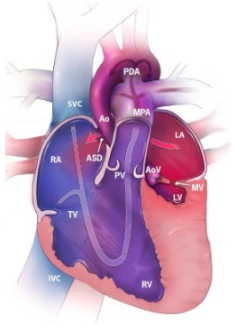
- Rupalee "Palee" Patel, RN, BSN, C-PNP, MS, DNP
- Sandra Lombardi-Lytle RN, CCM, PHN, IBCLC
- Madhu Bhogal, MD
- Raquel Brekken, MD
- Natalie Chan, MD
- Lilia DeJesus, MD
- Dina Gonzalez, RN
- Stephanie Lewis, MN, CPNP
- Nicole Pinney, Sr LVN

CPQCC HRIF team

- Erika Gray, BS
- Elix Colon, PhD
- Tianyao Lu, MS

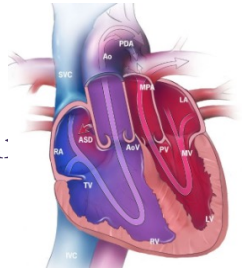
HIGH RISK INFANT FOLLOW-UP

Early post-discharge resource use and needs for CCHD: TGA and SV



Background

- Children born with complex congenital heart disease (CCHD) requiring neonatal surgery or other intervention in the neonatal period have substantial medical complexity and ongoing care needs.
- Existing literature has focused on surgical or longer-term outcomes, but early post-discharge health, resource and service utilization, and gaps in care remain less well characterized.
- This information could assist in more comprehensive parent and family support and counseling, help inform medical team discharge planning, and guide future efforts to improve care coordination and address gaps i post-discharge services and supports



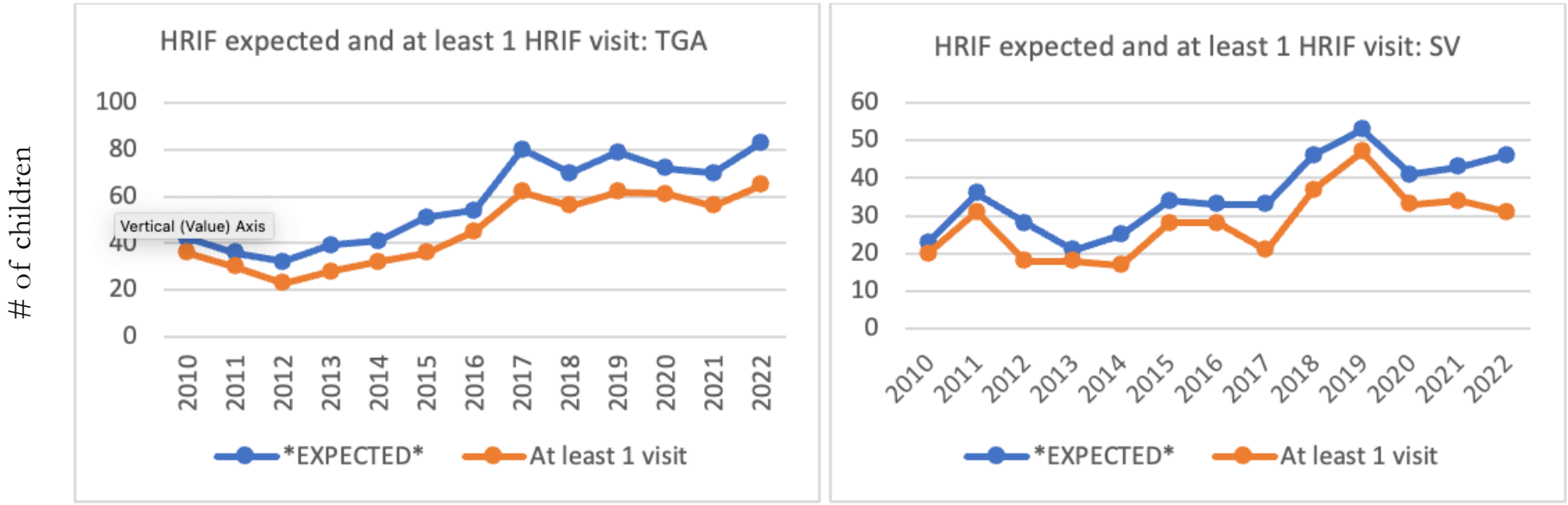
TGA and SV – early post-discharge

Objective

- Among infants with high risk cyanotic CHD categories (TGA and SV), born 2010-2022 and referred to HRIF, our objectives were to characterize early post-discharge medical resource and service utilization, caregiver concerns, and unmet additional service and support needs at the 1st HRIF visit.

This work aligns with California Title V Priority Needs Statement for CYSHCN to improve access to supports and services for children and youth with special health care needs

TGA and SV: Referral and follow up



- Increasing # referred to HRIF with TGA and SV from 2010 -2022, consistent with escalated statewide education around this eligibility criteria and release of CCS letter 01-0917.
- Follow up to at least 1 HRIF visit by 12 months of age (TGA, 73.6%; SV, 70%).

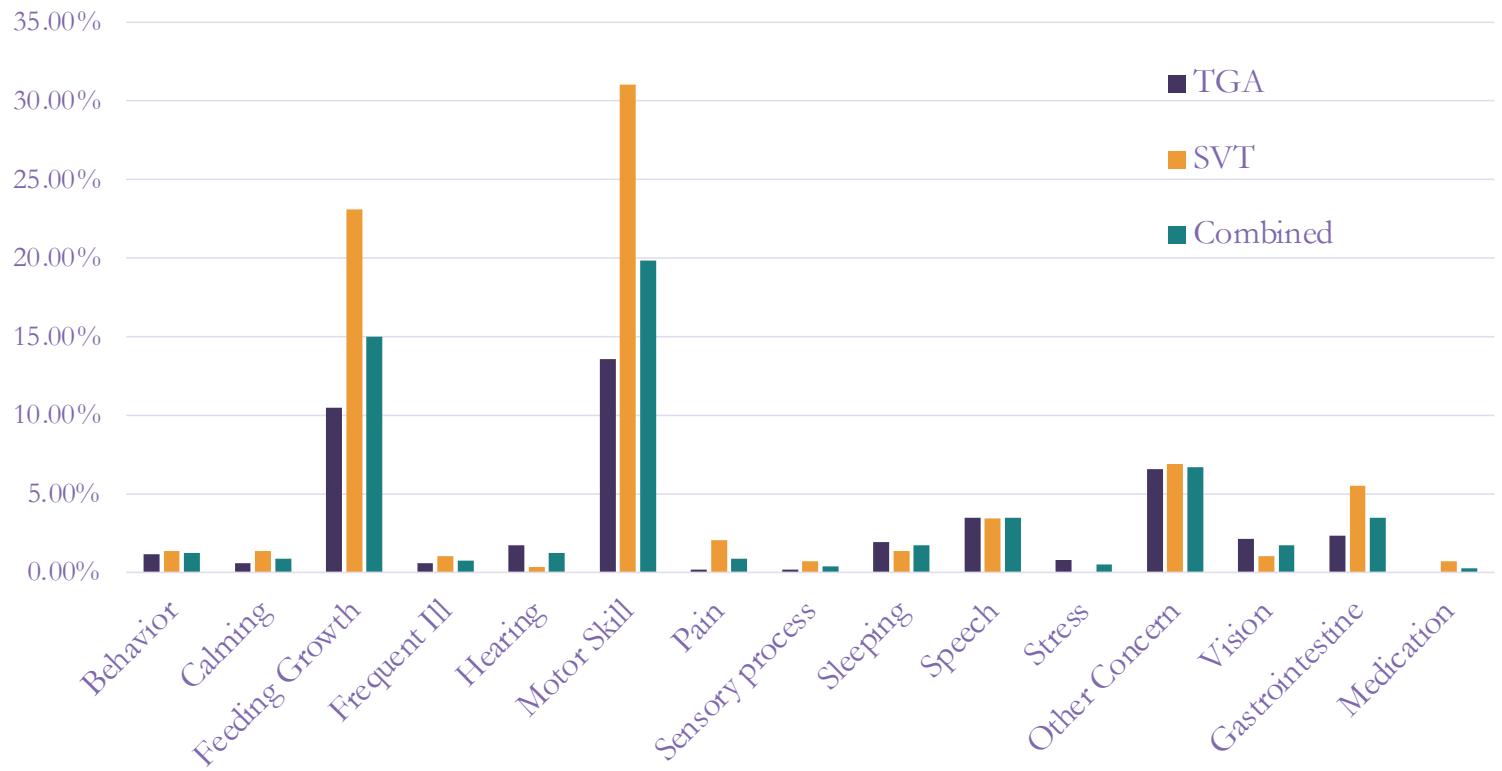
Resource and Service Utilization at 1st HRIF visit

Resources and Services IN PLACE at 1st HRIF visit	TGA (516)	SV (290)
Any medications	61.2% (316/516)	83.5% (242/290)
- 4 or more medications	21.7% (112/516)	56.9% (165/290)
Any equipment	15.3% (79/516)	41.4% (120/290)
Receiving any medical services	94.0% (485/516)	95.5% (277/290)
- Receiving 2 or more	40.1% (207/516)	65.5% (190/290)
- Receiving 4 or more	8.7% (45/516)	19.7% (57/290)
Receiving any special services	28.7% (148/516)	41.4% (120/290)
- Receiving 2 or more	13.4% (69/516)	18.3% (53/290)
Receiving Early Start	16.1% (83/516)	27.6% (80/290)

Resource and Service UNMET NEEDS at HRIF visit

Gaps / need for referrals and caregiver concerns at 1st visit	TGA	SV
Need at least 1 medical service referral	13.8% (68/516)	14.8% (43/290)
Need at least 1 special service referral	35.8% (185/516)	56.9% (165/290)
- Need 2 or more special service referrals	15.8% (82/516)	25.5% (74/290)
Need Early Start referral	20.7% (107/516)	31.0% (90/290)
At least one caregiver concern	32.4% (167/516)	47.2% (137/290)
Feeding abnormal or suspect on oral-motor assessment	6.7% (33/490)	26.5% (71/267)

TGA and SV: Caregiver concerns



- **Overall, 38% of parents shared at least one area of concern, significantly higher among SV vs TGA.**
- Multiple concerns also more common among SV (23%) vs. TGA (9%)

Factors Associated with Unmet Special-Service Needs

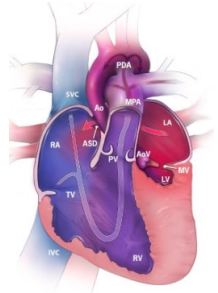
Multivariable analysis: Outcome = Need for ≥2 additional special-service referrals at first HRIF visit

- **Independently associated:**
  - **SV** (vs TGA) → aOR 1.7, 95%CI 1.2–2.4.
  - **Caregiver concerns** → aOR 1.8, 95%CI 1.3–2.6
  - Analyses also showed higher odds of needing ≥ 2 SS referrals for those with Spanish primary language vs. English and lower odds for HMO/PPO vs. Medi-Cal

Key takeaway: Highlights gaps despite ongoing healthcare engagement; underscores the importance of eliciting caregiver concerns, systematically reassessing needs, and addressing potential barriers to service access.

HIGH RISK INFANT FOLLOW-UP

Next steps



Continue analyses to identify variable associated with variation, unmet needs, and opportunities to improve post-discharge care and service access.

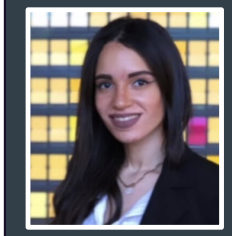
Share and integrate findings with cardiac programs, NICUs, HRIF teams, families, community partners, and state agencies as part of broader statewide improvement efforts.

Translate data into action through integration into future collaborative, equity-informed QI, shared learning, and stronger connections between healthcare and community-based services.

***Our shared goal:* To turn statewide data and diverse perspectives into coordinated action that improves care, service access, and outcomes for infants and families.**

Trajectory and Perceptions of Telehealth

Experience of a statewide HRIF program from COVID-19 to current



Elix Colon



Erika Gray



Tianyao Lu

Manuscript in process

1) Describe the statewide HRIF program response to the COVID-19 pandemic, including the development of tools and approaches to support telehealth implementation.
2) Characterize longitudinal patterns in telehealth use as well as clinic, regional, and sociodemographic factors associated with variation in use.
3) Examine HRIF clinic team experiences with and perspectives on the benefits and challenges of telehealth through a mixed-methods approach.

Interagency / Other Partnerships

Upcoming Medical Home Project & Virtual Leaning Sessions



HIGH RISK INFANT FOLLOW-UP

HIGH RISK INFANT FOLLOW-UP

CDPH California Department of Public Health



What can we do to better understand and improve family-centered medical home access for children in California?

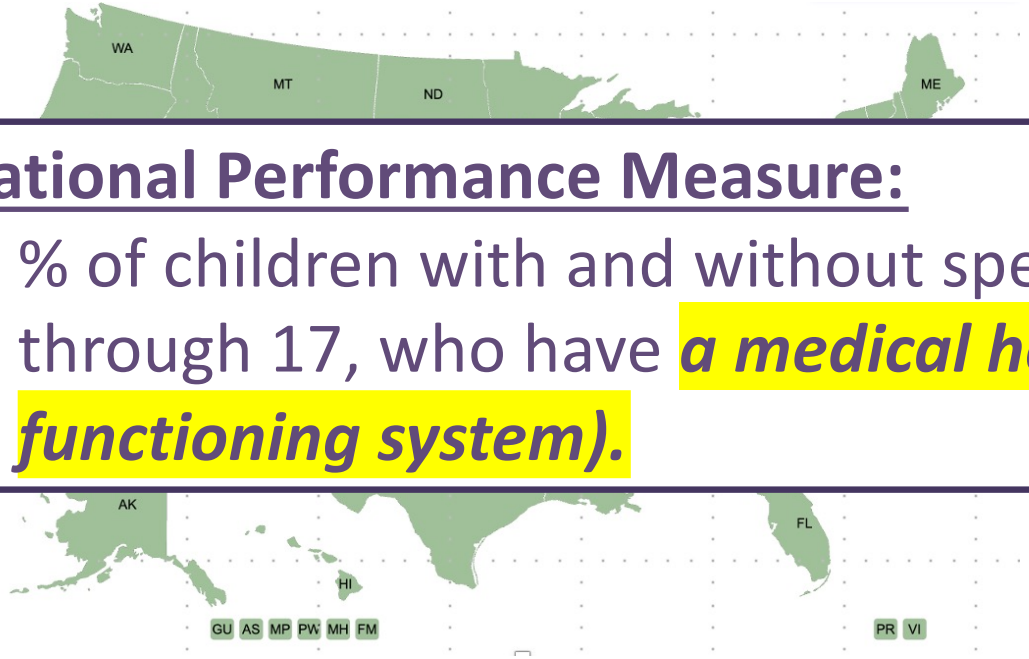
Focusing on children and families at the beginning of their journey

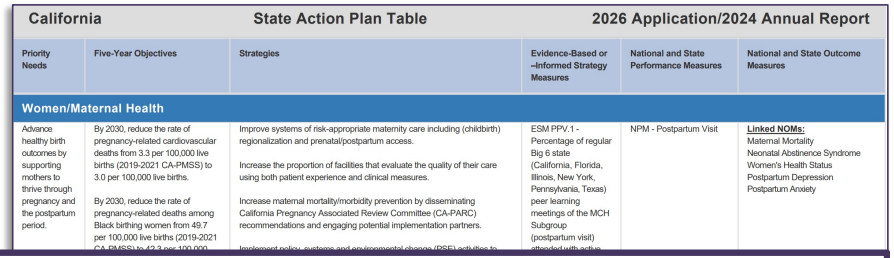
CDPH California Department of Public Health

https://mchb.tvisdata.hrsa.gov/Home/StateActionPlan

HRSA Maternal & Child Health

Title V Maternal and Child Health (MCH) Services Block Grant



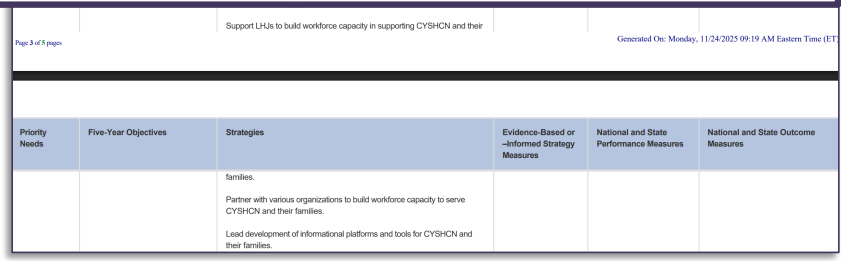


California State Action Plan Table 2026 Application/2024 Annual Report

Priority Needs	Five-Year Objectives	Strategies	Evidence-Based or –Informed Strategy Measures	National and State Performance Measures	National and State Outcome Measures
Women/Maternal Health					
Advance healthy birth outcomes by supporting mothers to thrive through pregnancy and the postpartum period.	By 2030, reduce the rate of pregnancy-related cardiovascular deaths from 3.3 per 100,000 live births (2019-2021 CA-PMSS) to 3.0 per 100,000 live births. By 2030, reduce the rate of pregnancy-related deaths among Black birthing women from 49.7 per 100,000 live births (2019-2021 CA-PMSS) to 42.2 per 100,000	Improve systems of risk-appropriate maternity care including (childbirth) regionalization and prenatal/postpartum access. Increase the proportion of facilities that evaluate the quality of their care using both patient experience and clinical measures. Increase maternal mortality/morbidity prevention by disseminating California Pregnancy Associated Review Committee (CA-PARC) recommendations and engaging potential implementation partners.	ESM PPV.1 - Percentage of regular Big 6 state (California, Florida, Illinois, New York, Pennsylvania, Texas) peer learning meetings of the MCH Subgroup (postpartum visit)	NPM - Postpartum Visit	**Linked NOMs:** Maternal Mortality Neonatal Abstinence Syndrome Women's Health Status Postpartum Depression Postpartum Anxiety

National Performance Measure:

- % of children with and without special health care needs, ages 0 through 17, who have ***a medical home (receive care in a well-functioning system).***



Support LHJs to build workforce capacity in supporting CYSHCN and their

Page 3 of 5 pages

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Priority Needs	Five-Year Objectives	Strategies	Evidence-Based or –Informed Strategy Measures	National and State Performance Measures	National and State Outcome Measures
		families. Partner with various organizations to build workforce capacity to serve CYSHCN and their families. Lead development of informational platforms and tools for CYSHCN and their families.			

HIGH RISK INFANT FOLLOW-UP

Medical Home Definition

American Academy of Pediatrics

A medical home is an approach to providing comprehensive and high quality primary care. A medical home should be the following:

- **Accessible**: Care is easy for the child and family to obtain, including geographic access and insurance accommodation.
- **Family-centered**: The family is recognized and acknowledged as the primary caregiver and support for the child, ensuring that all medical decisions are made in true partnership with the family.
- **Continuous**: The same primary care clinician cares for the child from infancy through young adulthood, providing assistance and support to transition to adult care.
- **Comprehensive**: Preventive, primary and specialty care are provided to the child and family.
- **Coordinated**: A care plan is created in partnership with the family and communicated with all health care clinicians and necessary community agencies and organizations.
- **Compassionate**: Genuine concern for the well-being of a child and family are emphasized and addressed.
- **Culturally Effective**: The family and child's culture, language, beliefs and traditions are recognized, valued and respected

HRSA Maternal & Child Health

https://mchb.hrsa.gov/programs-impact/focus-areas/children-youth-special-health-care-needs-cyshcn

Home | Funding | Programs & Impact | Data & Research | About Us

Home » Programs & Impact » Focus Areas » Children and Youth with Special Health Care Needs (CYSHCN)

Children and Youth with Special Health Care Needs (CYSHCN)

We are dedicated to improving the health and well-being of children and youth with special health care needs (CYSHCN). We do this through partnerships at the federal, state, and local levels. Families with lived experience are central partners in all that we do.

Who are CYSCHN?

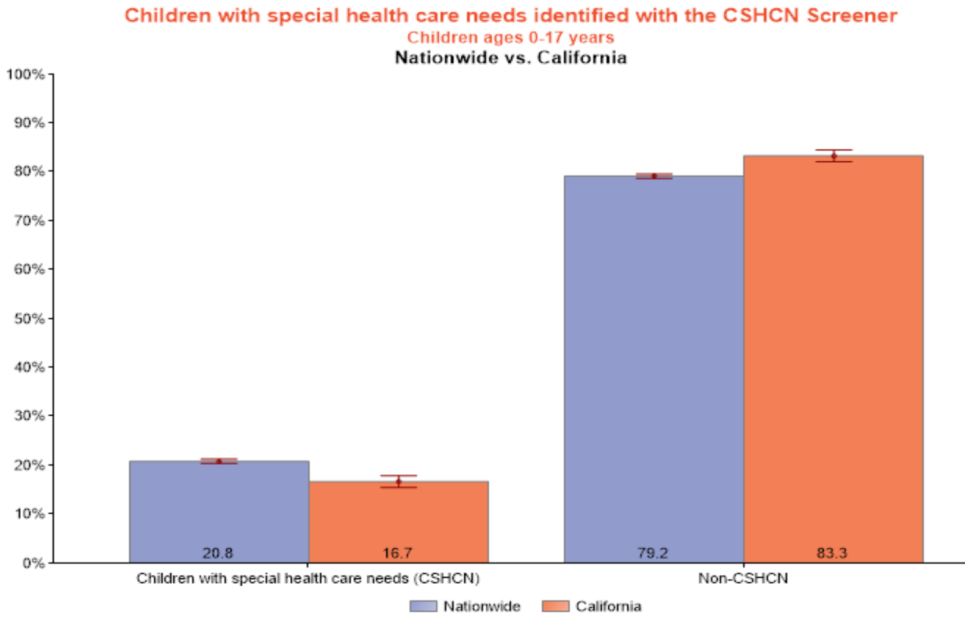
CYSHCN have or are at increased risk for having chronic physical, developmental, behavioral, or emotional conditions. They have conditions such as asthma, sickle cell disease, epilepsy, anxiety, autism, and learning disorders. They may require more specialized health and educational services[i] to thrive, even though each child's needs may vary.

Data Resource Center for Child & Adolescent Health
A project of the Child and Adolescent Health Measurement Initiative

Data from the National Survey of Children's Health (NSCH)

NSCH examines the physical & emotional health of children – ***including questions as to whether children receive coordinated care in a "medical home".***

~ 1 in 5 children (20.8%) (0-17 yrs) in the U.S. had a special health care need → 15.1 million children.



- In 2022-23: nationwide, ~ 60% of CYSHCN 0-17 years did NOT have a medical home → **~65% of CYSHCN 0-5 yrs did NOT have a medical home.**

High level project overview

- To assess gaps and successes in access to and perceptions of availability of a medical home
  - Parents of children in HRIF; providers and care teams; community stakeholders.

Exploring access to Medical Home

A mixed-method quantitative survey and qualitative interviews



Part 1 Statewide QUANTITATIVE component

Parent survey (23 questions):

- NSCH questions
  - Medical home questions (14)
  - Early Intervention questions (3)
- Child/family questions (6)

Will provide evidence-based data about medical home engagement from an enriched population of high-risk children and families.

Parent Recruitment and Participation

- Recruitment uses IRB-approved materials with QR codes, ensuring voluntary participation and minimal burden on staff.
- Flyer and linked survey will be available in English, Spanish, Mandarin and Vietnamese.

What will HRIF teams be asked to do for the SURVEY component?

To distribute the flyer to parents and families of all children enrolled in HRIF, ages 0–3 years.



Exploring access to Medical Home

A mixed-method quantitative survey and qualitative interviews



Part 2 Pilot QUALITATIVE component

Interviews with Parents & Community Stakeholders in 5 diverse areas (CDPH Local Health Jurisdiction = LHJ)

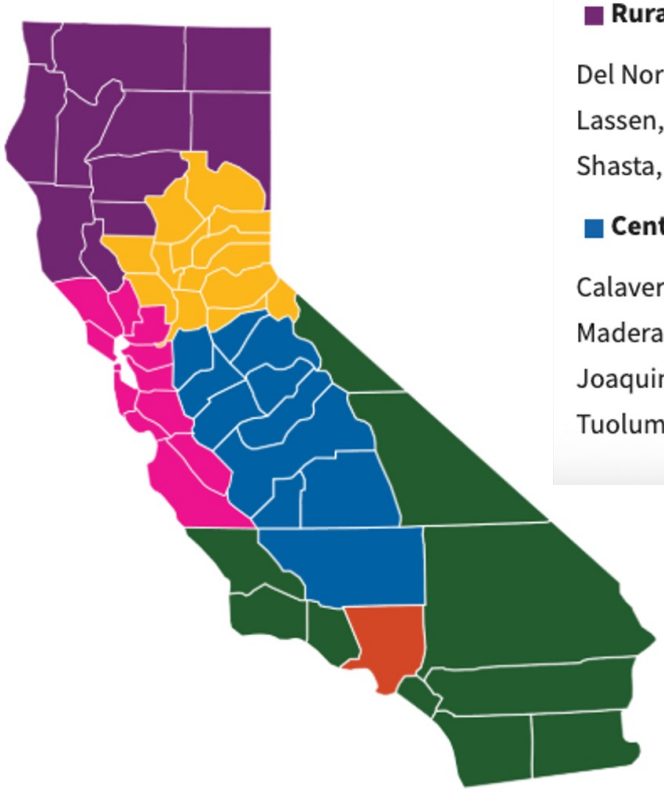
- Parent interviews (5-8 per LHJ)
- Key stakeholders (10-20 per LHJ)
  - HRIF & NICU teams
  - Community pediatric/ family providers
  - Interagency teams: CDPH LHJ; DDS Regional Center/ Early Start
  - First 5/ HMG; Family Resource Centers

Identify challenges or barriers, and bright spots to connections to a Medical Home.

Explore providers perceptions of Medical Home availability.

HIGH RISK INFANT FOLLOW-UP

CDPH California Department of Public Health



Rural North

Del Norte, Glenn, Humboldt, Lake, Lassen, Mendocino, Modoc, Shasta, Siskiyou, Tehama, Trinity

Central California

Calaveras, Fresno, Kern, Kings, Madera, Mariposa, Merced, San Joaquin, Stanislaus, Tulare, Tuolumne

Greater Sierra Sacramento

Alpine, Amador, Butte, Colusa, El Dorado, Nevada, Placer, Plumas, Sacramento, Sierra, Sutter, Yolo, Yuba

Southern California

Imperial, Inyo, Mono, Orange, Riverside, San Bernardino, San Diego, San Luis Obispo, Santa Barbara, Ventura

Bay Area

Alameda, City of Berkeley, Contra Costa, Marin, Monterey, Napa, San Benito, San Francisco, San Mateo, Santa Clara, Santa Cruz, Solano, Sonoma

Los Angeles

City of Long Beach, Los Angeles, City of Pasadena

There are 6 regions as identified by CDPH Regional Public Health Office, covering 61 local health jurisdictions (58 county + 3 city health departments)

Exploring access to Medical Home

A mixed-method quantitative survey and qualitative interviews



Part 2 Pilot QUALITATIVE component

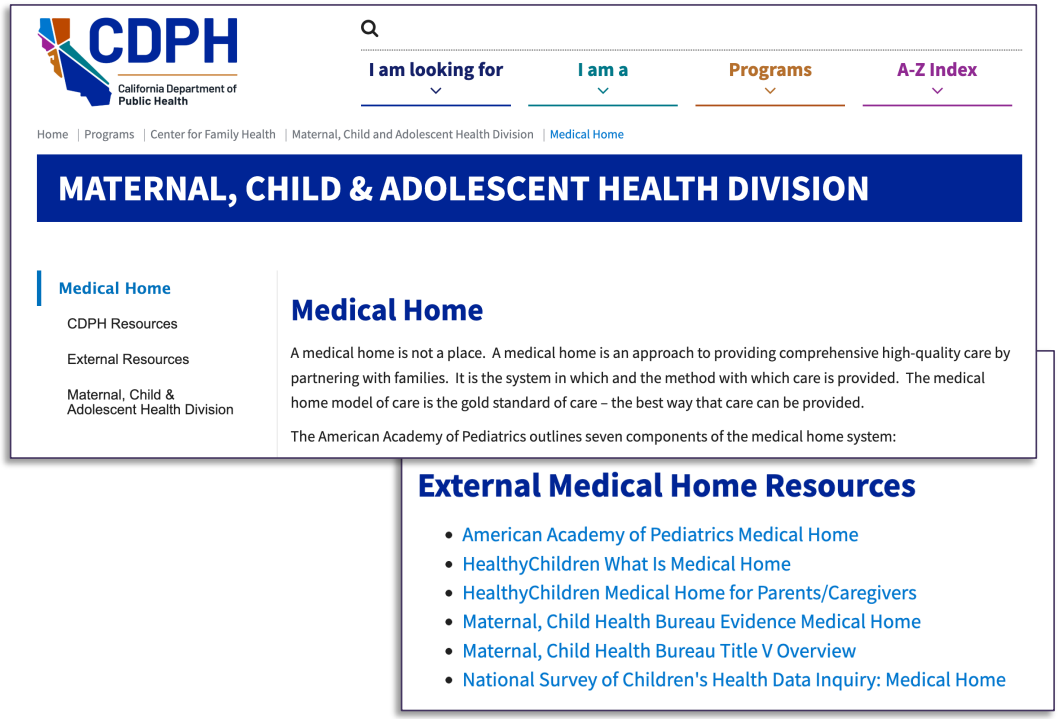
What will we ask of HRIF teams for QUALITATIVE component?

- For most – **NOTHING**!
- IF your HRIF site is within one of the areas chosen by CDPH:
  - Share your on-the-ground experience in a virtual interview with us – recommend community providers for reach out, share challenges, successes, strategies related to medical home in your community
  - Connect us with parents who might be interested / willing to be interviewed.
  - **For interviews: Parents will receive $50 gift card; HRIF site will receive lunch delivered!**

Medical Home Resources

Continuing collaborations with CDPH around website and resources



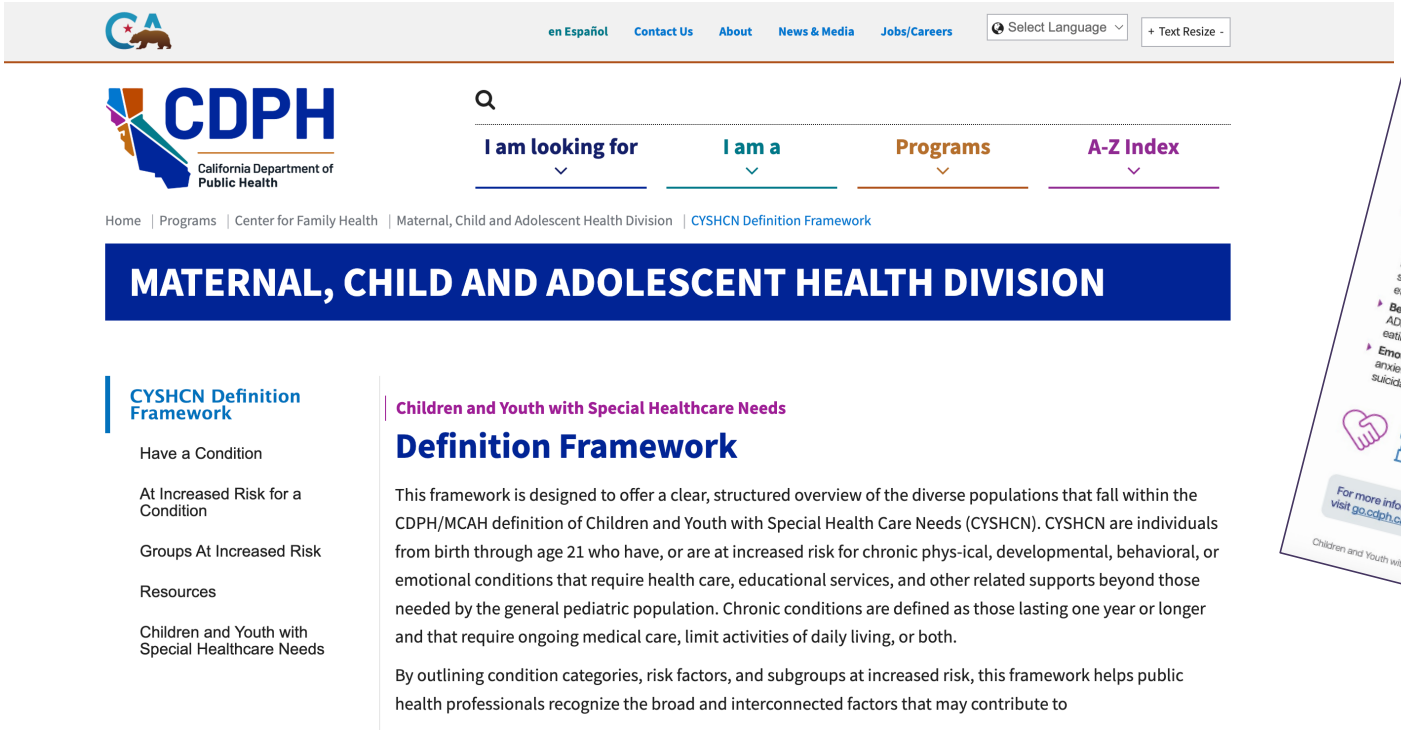


https://www.cdph.ca.gov/Programs/CFH/DMCAH/Pages/Medical-Home/Medical-Home.aspx

HIGH RISK INFANT FOLLOW-UP

CDPH CYSHCN website

Continued Collaborations, Expanding Resources





https://www.cdph.ca.gov/Programs/CFH/DMCAH/Pages/CYSHCN/CYSHCN-Definition-Framework.aspx

HIGH RISK INFANT FOLLOW-UP

Ideas to smooth implementation / launch?

Discussion?



Children Now

Mission and Advocacy

Who They Are:

- A nonpartisan children's advocacy organization founded in 1988, dedicated to driving policy change at the state and local level to improve child outcomes across health, education, early childhood, and child welfare.

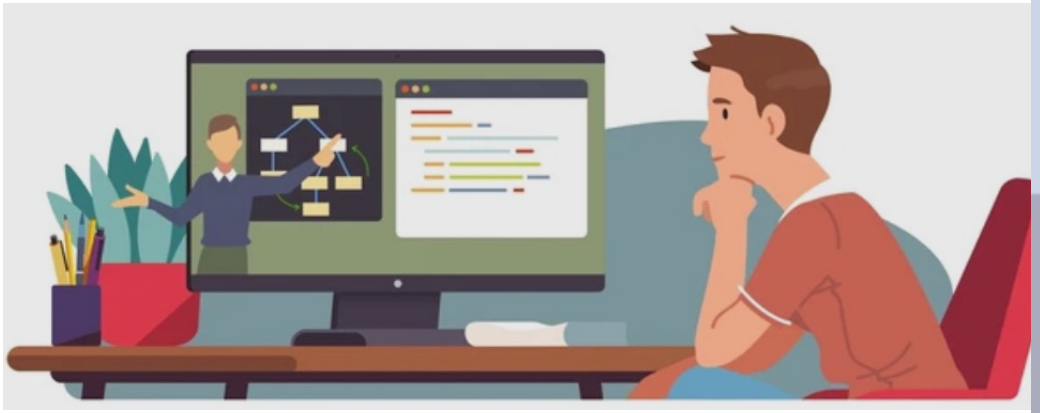
What They Do:

- Children Now deeply engages with state agencies —particularly those impacting child health, welfare, and Medi-Cal such as DHCS —often acting as an **advocacy and policy partner**, supporting broader reforms and facilitating stakeholder collaboration.

Children Now

Collaboration with CPQCC HRIF:

- Children Now and CPQCC have collaborated on virtual learning events and information exchanges on topics/ services/ resources of importance to our patients and families.





How can CalAIM Support Families of Babies with Medi-Cal?

June 4, 2026

What is CalAIM? The historic CalAIM initiative, launched in 2022, is intended to transform Medi-Cal delivery systems into more whole-person care that addresses health-related social needs through more integrated care.

The state has made significant investments to build out the infrastructure needed to deliver CalAIM benefits and services. However, there is a gap in the understanding of on-the-ground providers about what CalAIM can offer Medi-Cal members and how they can connect their patients to that care.

The webinar was a basic overview of CalAIM benefits and services, aimed for NICU, HRIF, and pediatric providers.

How can CalAIM Support Families of Babies with Medi-Cal?

June 4, 2026

Overview of Medi-Cal, CalAIM, and Medi-Cal Managed Care

Transportation benefits (nonmedical and non-emergency medical)

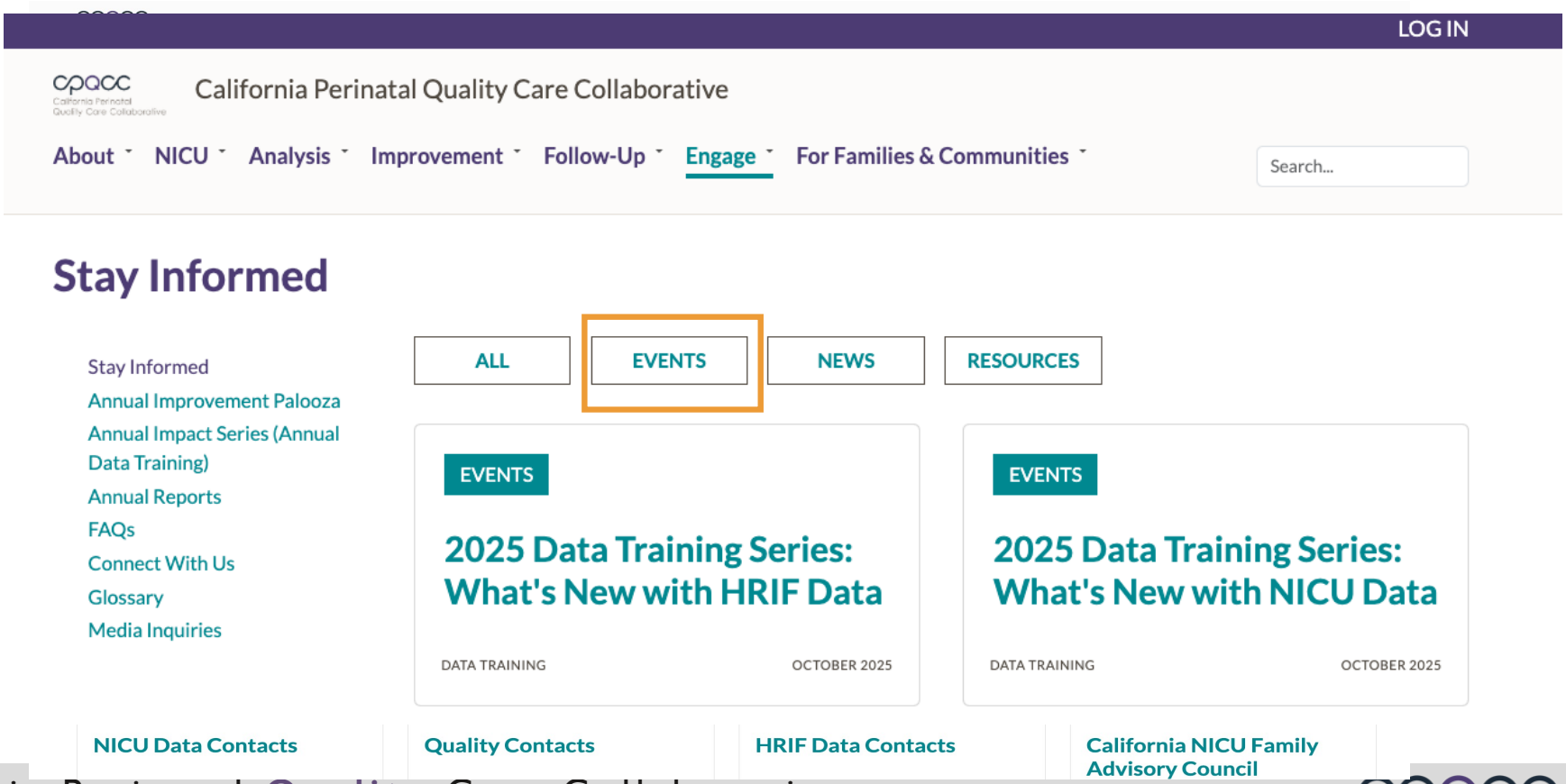
Community Supports (housing supports services, respite care services, etc)

Medically tailored meals

Care coordination / population health benefits

- Community Health Worker (CHW)
- Enhanced Care Management (ECM) services
- Doulas
- Transitional Care Services (TCS)

How can CalAIM Support Families of Babies with Medi-Cal?



HIGH RISK INFANT FOLLOW-UP

Virtual Learning Session: How Can CalAIM Support Families with Babies in Medi-Cal

Stay Informed
Annual Improvement Palooza
Annual Impact Series (Annual Data Training)
Annual Reports
FAQs
Connect With Us
Glossary
Media Inquiries

CPQCC California Perinatal Quality Care Collaborative

Children Now

Date:
Jun 4, 2026, 12:00pm

Location:
Virtual

WATCH RECORDING »

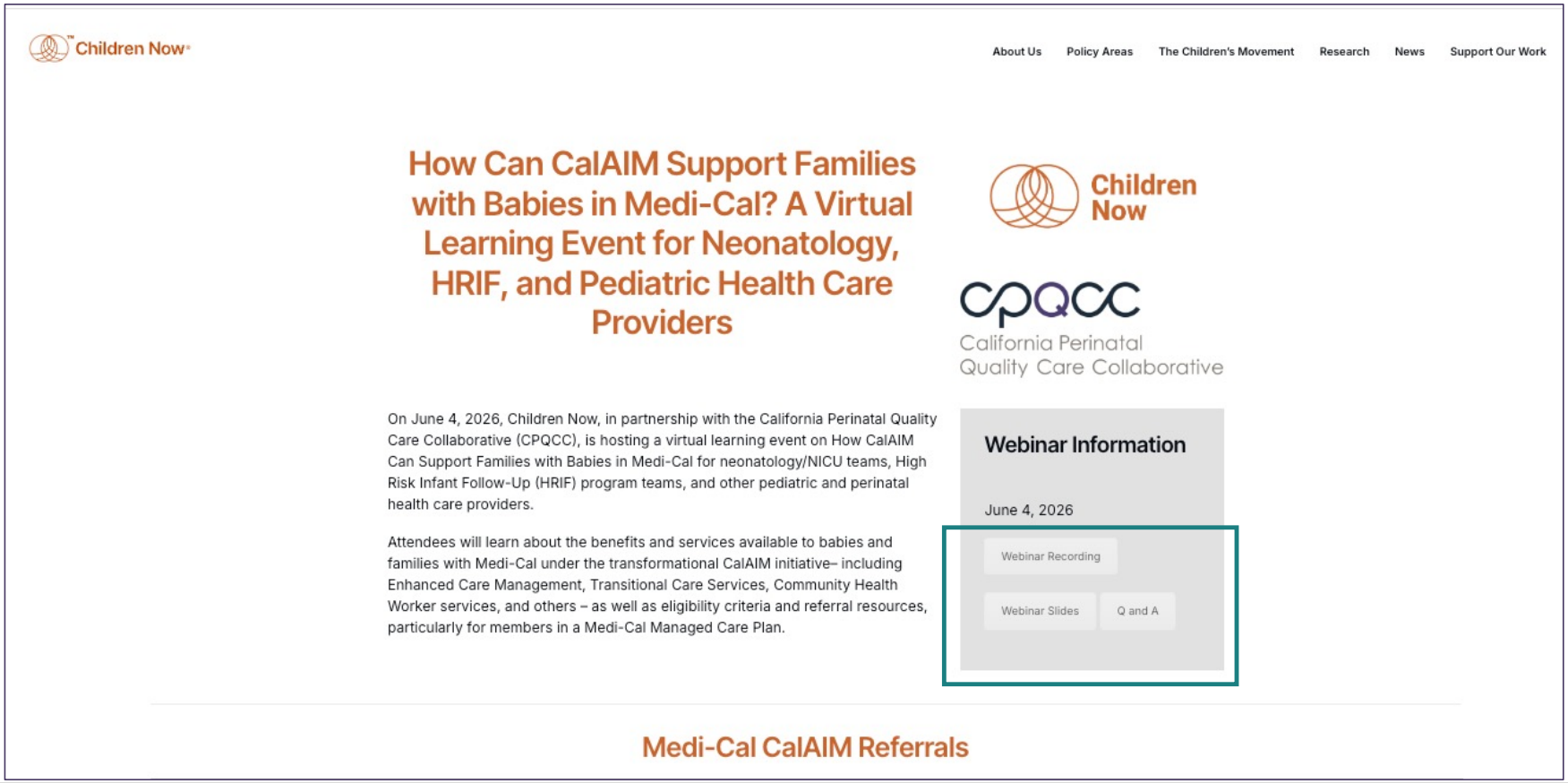
Virtual Learning Session: How Can CalAIM Support Families with Babies in Medi-Cal

Join CPQCC and Children Now on Thursday, June 4 from noon-1 p.m. PT for a virtual session titled, "How Can CalAIM Support Families with Babies in Medi-Cal?" This session will provide an overview of CalAIM benefits and services including Enhanced Care Management, Transitional Care Services, and Community Health Worker, plus eligibility criteria and referral resources particularly for members in a Medi-Cal Managed Care Plan.

Register for the session and share with those in your network who may want to learn more about the benefits and services available to babies and families with Medi-Cal under the CalAIM initiative. Continuing Education credit available!

View Resources

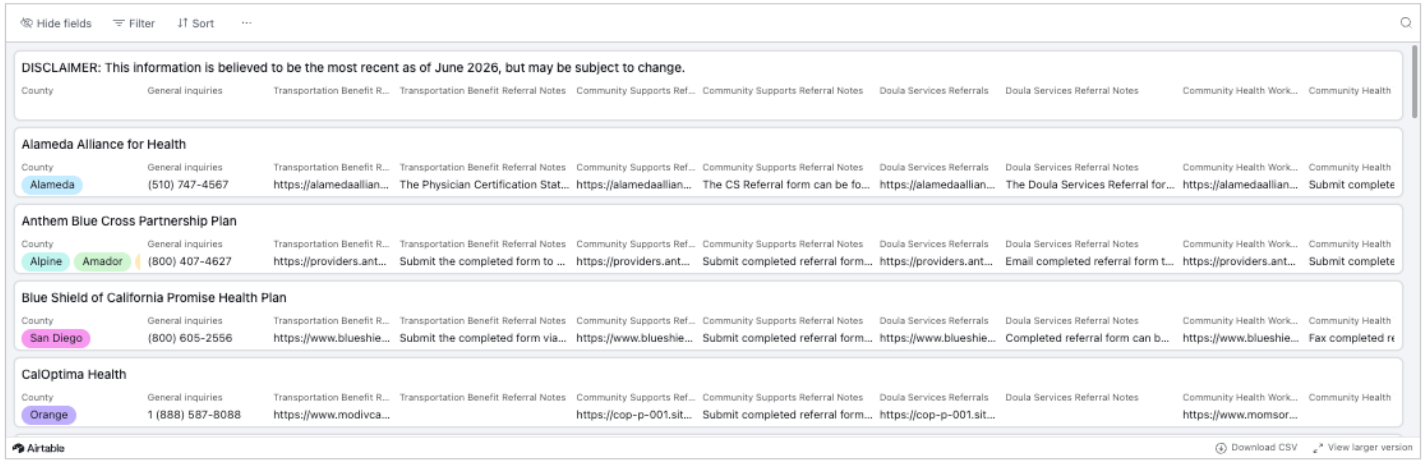
https://www.childrennow.org/how-can-calaim-support-families-with-babies-in-medi-cal/



HIGH RISK INFANT FOLLOW-UP

https://www.childrennow.org/how-can-calaim-support-families-with-babies-in-medi-cal/

Medi-Cal CalAIM Referrals



Hide fields | Filter | Sort

DISCLAIMER: This information is believed to be the most recent as of June 2026, but may be subject to change.

County	General inquiries	Transportation Benefit R...	Transportation Benefit Referral Notes	Community Supports Ref...	Community Supports Referral Notes	Doula Services Referrals	Doula Services Referral Notes	Community Health Work...	Community Health
Alameda Alliance for Health									
Alameda	(510) 747-4567	https://alamedaallian...	The Physician Certification Stat...	https://alamedaallian...	The CS Referral form can be fo...	https://alamedaallian...	The Doula Services Referral for...	https://alamedaallian...	Submit complete
Anthem Blue Cross Partnership Plan									
Alpine, Amador	(800) 407-4627	https://providers.ant...	Submit the completed form to ...	https://providers.ant...	Submit completed referral form...	https://providers.ant...	Email completed referral form t...	https://providers.ant...	Submit complete
Blue Shield of California Promise Health Plan									
San Diego	(800) 605-2556	https://www.blueshie...	Submit the completed form via...	https://www.blueshie...	Submit completed referral form...	https://www.blueshie...	Completed referral form can b...	https://www.blueshie...	Fax completed re
CalOptima Health									
Orange	1 (888) 587-8088	https://www.modivca...		https://cop-p-001.sit...	Submit completed referral form...	https://cop-p-001.sit...		https://www.momsor...	

Airtable | Download CSV | View larger version

Reference Resources

Medi-Cal Transportation benefits
Download this resource.

Medi-Cal Community Supports
Download this resource.

Medi-Cal Care Coordination & Population Health Management
Download this resource.

Future CPQCC/ Children Now webinars

1) Early Start FRCs → Southern CA/ Los Angeles Showcase

2) NICU and HRIF case examples: Leveraging CalAIM Medi-Cal benefits for our patients and families

Please share your experiences and expertise!
Case examples will be anonymous and de-identified!

HIGH RISK INFANT FOLLOW-UP

CPQCC ANNUAL IMPACT SERIES 2026

From data to impact, together



Behind every data point is a baby, a family, and an opportunity to improve care.

HIGH RISK INFANT FOLLOW-UP

DISCUSSION

Panel Discussion & Audience Q&A

What questions are coming up about HRIF Program, data/ system improvements, reports/dashboards, QI projects, or upcoming learning sessions?

Please continue submitting questions through the Q&A.

HIGH RISK INFANT FOLLOW-UP

EVALUATION & CONTACT HOURS

Before You Go

Evaluation

Your feedback helps us improve future sessions.

Scan the QR code below

Contact Hours

Attend the full live session (at least 60 min) **and** complete the evaluation to receive credit.

Please reference the information on slide 9 for more information.

Recording & Slides

Materials will be posted on the CPQCC website **Annual Impact Series:**

https://cpqcc.org/engage/annual-impact-series-webinars-2026

Thank you for taking a few minutes to share your feedback.

Thank you

for joining us today

We appreciate the work you do across the CPQCC community and look forward to continuing this collaboration.




HRL
HIGH RISK
INFANT FOLLOW-UP