



CPQCC CCS HRIF *2020 Data Training*

October 2019

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Overview -

- How did we get to CPQCC CCS HRIF? - HRIF background, evolution, data usage
- What can I learn about my patients? – HRIF System Reports for HRIF **and** NICU teams
- How are we helping to inform the larger clinical and research community? - Highlights of HRIF data in action
- What's new and what's next? – Cardiac expansion project

CPQCC CCS HRIF:



Background,
evolution,
current state



Background and History:

Follow up for infants at high risk in California

- California Children's Services originally established a “**NICU Follow Up Program**” in **1979**.
- Multiple evolving changes and challenges - -
 - Growing recognition that *we could do even better for high risk infants in California.*
- CPQCC partnered with CCS, HRIF clinics, other private and public partners to completely remodel program - **CPQCC CCS HRIF Program** -

Continuum of care structure – unique to California!



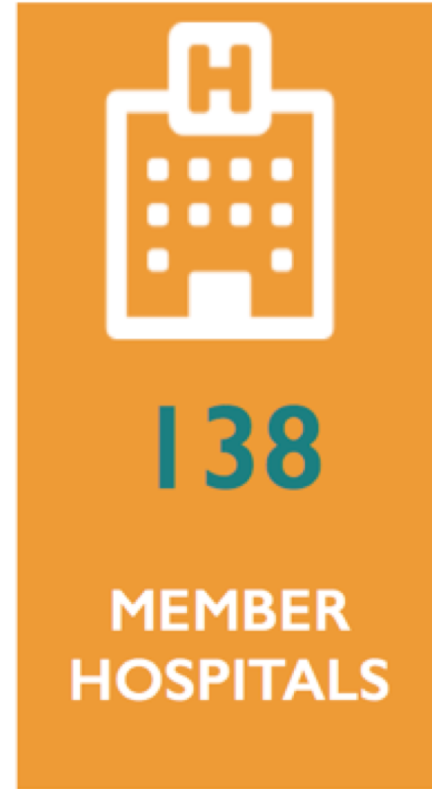
BY THE NUMBERS



CMQCC

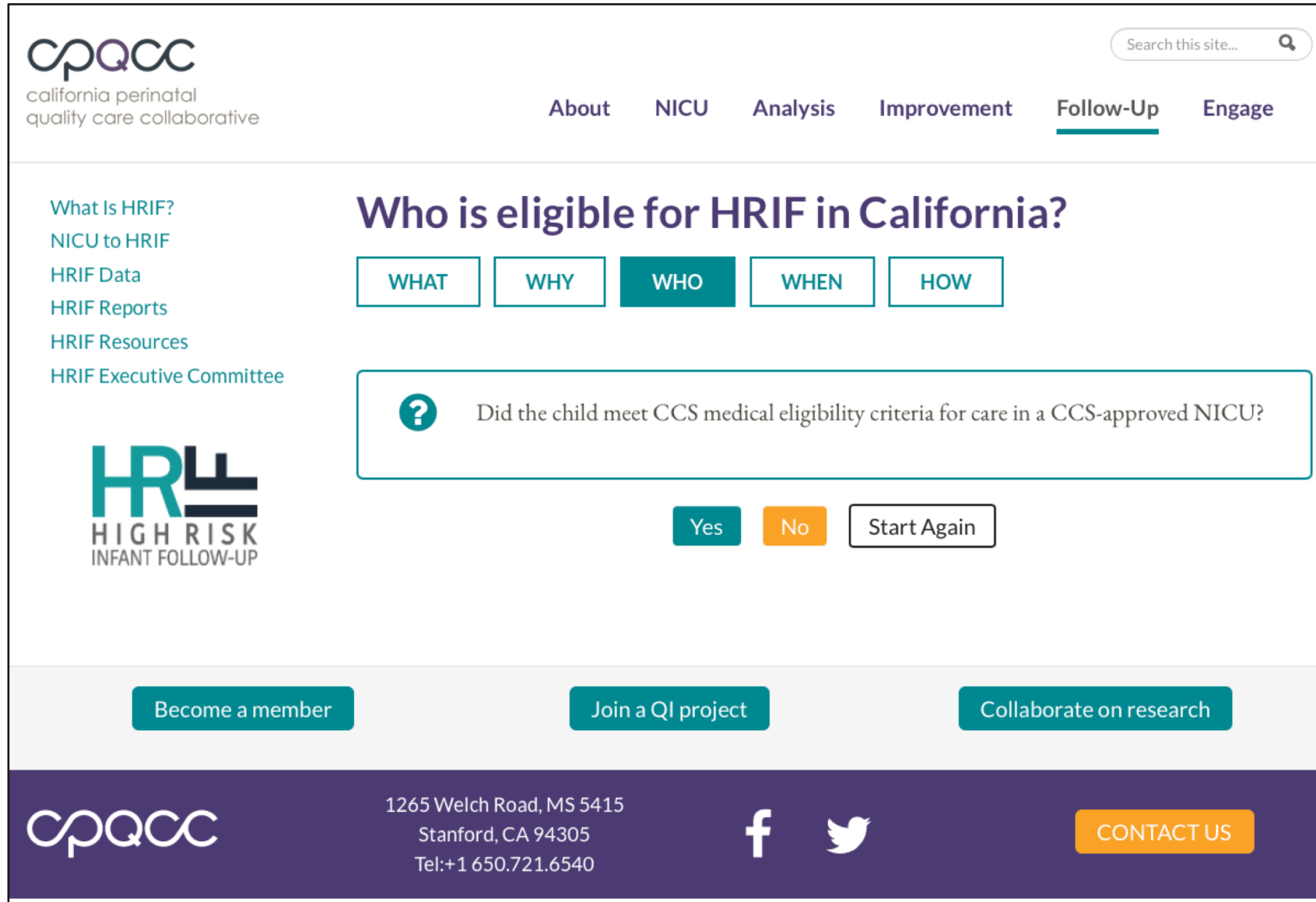


CPeTS



CPQCC





The screenshot shows the CPQCC website with the following elements:

- CPQCC Logo:** California perinatal quality care collaborative
- Navigation:** About, NICU, Analysis, Improvement, Follow-Up, Engage
- Search:** Search this site...
- Left Sidebar:**
 - What Is HRIF?
 - NICU to HRIF
 - HRIF Data
 - HRIF Reports
 - HRIF Resources
 - HRIF Executive Committee
- Main Content:**
 - ## Who is eligible for HRIF in California?
 - Navigation tabs: WHAT, WHY, **WHO**, WHEN, HOW
 - Question: **?** Did the child meet CCS medical eligibility criteria for care in a CCS-approved NICU?
 - Buttons: Yes, No, Start Again
- Footer:**
 - Buttons: Become a member, Join a QI project, Collaborate on research
 - CPQCC Logo, Address: 1265 Welch Road, MS 5415, Stanford, CA 94305, Tel:+1 650.721.6540
 - Social media icons for Facebook and Twitter
 - CONTACT US button

Who do we serve? – *HRIF Medical Eligibility*



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



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 1500 g,
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

HRIF Visits: Number and timing



- *Provides for 3 “Standard” or core visits*
 - *#1 – 4 - 8 months*
 - *#2 – 12 - 16 months*
 - *#3 – 18 - 36 months*
 - *Additional visits covered by CCS as determined to be needed by HRIF team-*

HRIF Visits: Content and Structure



- Neurosensory, neurologic, developmental assessments, autism screening, but much more –
 - Hospitalizations, surgeries, medications, equipment
 - Medical services and Special services
 - Data obtained about “Receiving”, “Referred”, but also “Referred and NOT receiving” and why.
 - Early Start, Medical Therapy Program -
 - “Concerns and Resources” – Living/ care arrangements, caregiver concerns, language in household, family social economic stressors

By the Numbers

January 2009 through October 2019

~83,900

high risk infants registered statewide!

118,045

Standard Visits performed

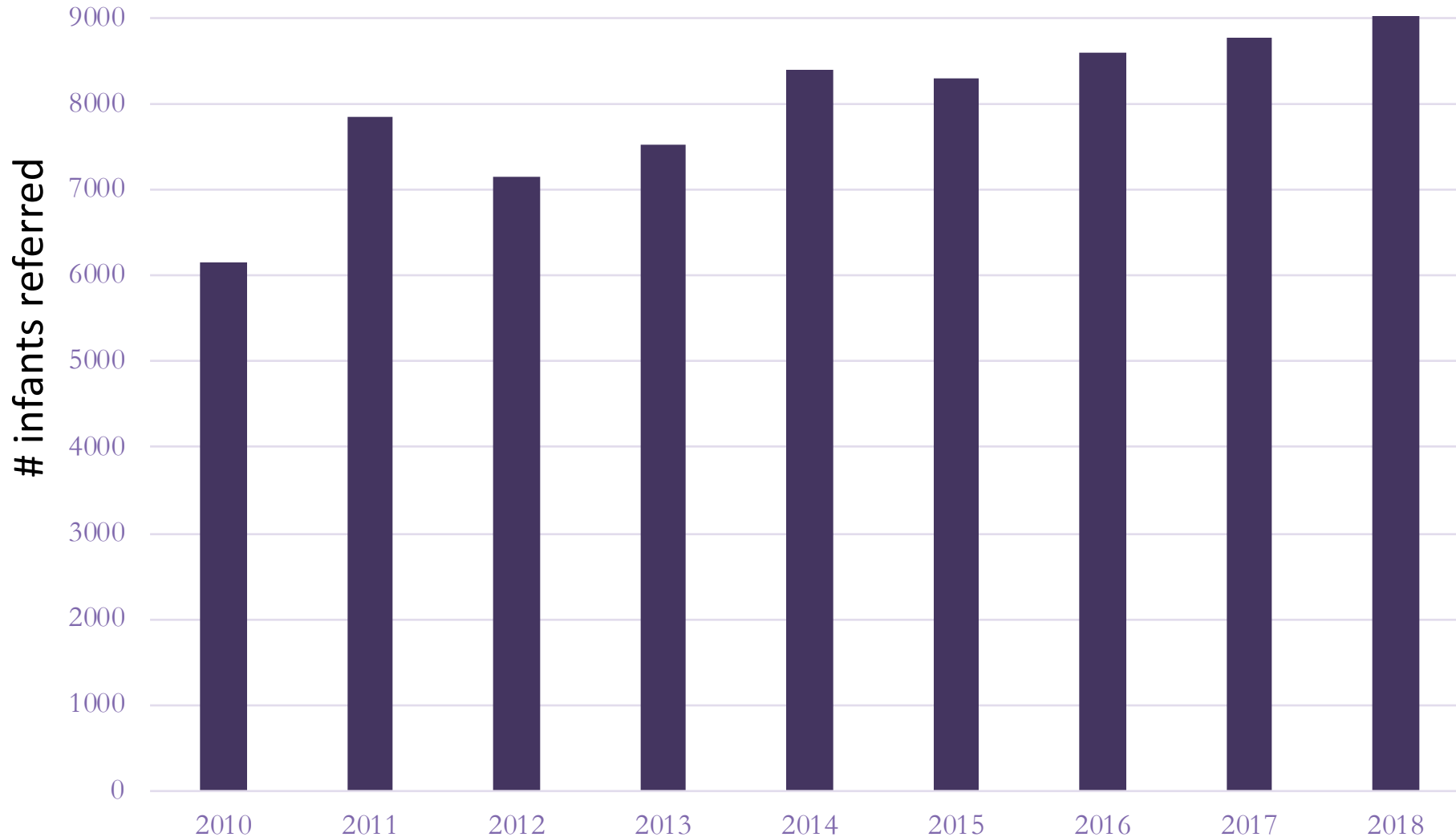
~9,000

Additional visits performed

41,300 (49%)

Infants ≤ 1500 g registered/ referred

Referral to CPQCC CCS HRIF by birth year



The # of high risk infants referred to CPQCC CCS HRIF has **increased since 2010.**

**For birth year 2018:
~1450 infants <28 weeks EGA referred on NICU discharge.*

Learning from
our patients
and families

HRIF
HIGH RISK
INFANT FOLLOW-UP

HRIF System
Reports



To Gain Access to HRIF Reporting System

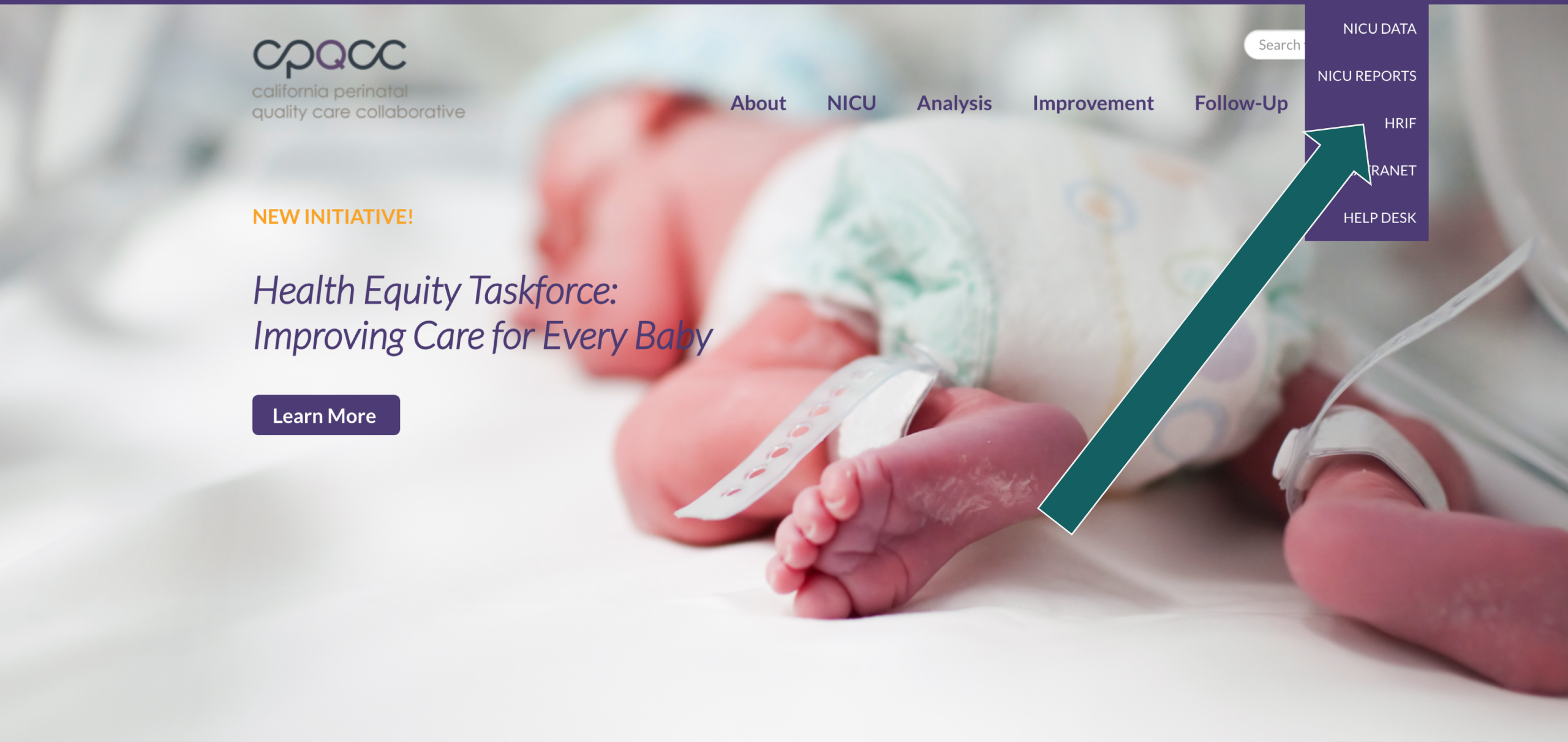
Contact **Erika** at
Erika@cpqcc.org or 650-725-1306



NEW INITIATIVE!

Health Equity Taskforce: Improving Care for Every Baby

Learn More



- Find Patient
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- HRIF Summary**
- CCS Annual
- NICU Summary
- Cardiac Summary
- Prog Profile
- Service Refs
- Data Download
- User Stats

HRIF SUMMARY REPORT

HRIF Summary Report is updated nightly

HRIF Clinic: All

Discharge NICU: All

Infant's Birth Year: All

Infant's Birth Weight or Gestational Age: All

Infant's Qualifying Medical Condition: All

Report Name: -- Select a Report --

View Report

Select *YOUR HRIF* program or *ALL* California programs

HRIF SUMMARY REPORT

HRIF Summary Report is updated nightly

HRIF Clinic

Discharge NICU

Infant's Birth Year

Infant's Birth Weight or Gestational Age

Infant's Qualifying Medical Condition

Report Name

[View Report](#)



Select ALL discharging NICUs referring to you or specific NICU

HRIF SUMMARY REPORT

HRIF Summary Report is updated nightly

HRIF Clinic

Discharge NICU

Infant's Birth Year

- ✓ All
- 2009
- 2010
- 2011
- 2012
- 2013
- 2014
- 2015
- 2016
- 2017
- 2018
- 2019
- Custom Birth Year

Infant's Birth Weight
or Gestational Age

Infant's Qualifying
Medical Condition

Report Name

HRIF SUMMARY REPORT

HRIF Summary Report is updated nightly

HRIF Clinic

Discharge NICU

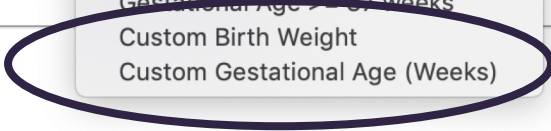
Infant's Birth Year

Infant's Birth Weight or Gestational Age

Infant's Qualifying Medical Condition

Report Name

- ✓ All
- Birth Weight < 1000 grams
- Birth Weight <= 1500 grams
- Birth Weight > 1500 grams
- Gestational Age < 26 weeks
- Gestational Age < 28 weeks
- Gestational Age < 32 weeks
- Gestational Age < 37 weeks
- Gestational Age >= 37 weeks
- Custom Birth Weight
- Custom Gestational Age (Weeks)



HRIF SUMMARY REPORT

HRIF Summary Report is updated nightly

HRIF Clinic

Discharge NICU

Infant's Birth Year

Infant's Birth Weight or Gestational Age

Infant's Qualifying Medical Condition

- ✓ All
- O2 >= 28 days
- Intracranial Pathology
- HIE/Neonatal Encephalopathy
- iNo > 4 hrs
- CHD requiring surgery

Report Name

HRIF SUMMARY REPORT

HRIF Summary Report is updated nightly

HRIF Clinic

Discharge NICU

Infant's Birth Year

Infant's Birth Weight or Gestational Age

Infant's Qualifying Medical Condition

Report Name

- ✓ -- Select a Report --
- Registration Summary Report
- Standard Visit Summary Report (Core Visit #1)
- Standard Visit Summary Report (Core Visit #2)
- Standard Visit Summary Report (Core Visit #3)
- Standard Visit Summary Report (0 - 11 months)
- Standard Visit Summary Report (12 - 17 months)
- Standard Visit Summary Report (18 months and above)

HRIF SUMMARY REPORT

HRIF Summary Report is updated nightly

HRIF Clinic

Discharge NICU

Infant's Birth Year

Infant's Birth Weight or Gestational Age

Infant's Qualifying Medical Condition

Report Name

Report Section Name

- ✓ -- Select a Report Section Name --
- FOLLOW UP STATUS AND DISPOSITION
- MEDICAL ELIGIBILITY PROFILE
- SOCIODEMOGRAPHIC FACTORS (DATA CAPTURED ON RR FORM)
- LANGUAGE ASSISTANCE AND INSURANCE
- PATIENT AGE AND GROWTH METRICS
- CAREGIVER AND LIVING ENVIRONMENT
- INTERVAL HOSPITALIZATIONS AND SURGERIES
- INTERVAL MEDICINES AND EQUIPMENT
- MEDICAL SERVICES REVIEW
- NEUROSENSORY ASSESSMENT
- NEUROLOGICAL ASSESSMENT AND CEREBRAL PALSY
- DEVELOPMENTAL ASSESSMENT AND AUTISM
- SPECIAL SERVICES REVIEW
- STATE PROGRAMS AND SOCIAL CONCERNS/RESOURCES
- OTHER MEDICAL CONDITIONS

HRIF SUMMARY REPORT

HRIF Summary Report is updated nightly

HRIF Clinic

Discharge NICU

Infant's Birth Year

Infant's Birth Weight or Gestational Age

Infant's Qualifying Medical Condition

Report Name

Report Section Name

[View Report](#)

HRIF Clinic	
Total Reg : 178	
Total Expected : 171	
Total Seen : 163	
Num	%

All HRIF Clinics		
Total Registered		
Total Expected		
Total Seen		
Num	%	%

https://www.ccshrif.org/hrif/secure/loadDetailedReportRecordByStatus.action?rptType=h...

ccshrif.org/hrif/secure/loadDetailedReportRecordByStatus.action?rptType=hrifRpt...

STANDARD VISIT SUMMARY REPORT (CORE VISIT #1)
CASES NOT SEEN BUT EXPECTED: 6

HRIF Program: [Redacted]
 Discharge NICU: All
 Infant's Birth Year: 2015
 Infant's Birth Weight/Gestational Age: Birth Weight <= 1500 grams
 Infant's Medical Eligibility Profile: All
 Report Date: 2019-10-15

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HRIF ID#	DOB	Discharge NICU	Reason Not Seen
1 40	01-21	4	No-show/Reason Unknown
2 10		3	West No-show/Reason Unknown
3 40		0	em - Parent Competing Priorities
4 40		2	Lack of Transportation
5 40		4	S Parent Competing Priorities
6 40		4	S Parent Competing Priorities

FOLLOW UP STATUS

Visit Completion

Among Registered Cases

Seen Cases	163	91.6%	3198	75.9%
Closed Cases Moved Out of State/Country	7	3.9%	107	2.5%
Closed Cases Other	2	1.1%	365	8.7%
Cases NOT Seen But Expected	6	3.4%	433	10.3%

Among Expected Cases

Seen Cases	163	95.3%	3198	80%
Closed Cases Other	2	1.2%	365	9.1%
Cases NOT Seen But Expected	6	3.5%	433	10.8%

Seen Cases

Seen within the Window	154	94.5%	2654	83%	84.7%	77.8%	94.5%	+
Seen after the Window	7	4.3%	415	13%	12.4%	5.9%	18.2%	+
Seen before the Window	2	1.2%	129	4%	6.3%	3%	20%	+



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HRIF SUMMARY REPORT

HRIF Summary Report is updated nightly

HRIF Clinic

Discharge NICU

Infant's Birth Year

Infant's Birth Weight or Gestational Age

Infant's Qualifying Medical Condition

Report Name

Report Section Name

	HRIF Clinic		All HRIF Clinics					Comparison with All HRIF Clinic Data
	Num	%	Num	%	% Median	% Lower Quartile	% Upper Quartile	
LANGUAGE ASSISTANCE								
Interpreter Used								
No	102	98.1%	5421	92.8%	97%	90%	100%	↑
Yes	2	1.9%	420	7.2%	6.5%	2.5%	13.4%	↑
Interpreter Language Used								
Spanish	2	100%	387	92.1%	100%	88.9%	100%	↓
INSURANCE								
Insurance Combinations (Top 10)								
Commercial HMO	68	65.4%	1120	19.2%	7.5%	2.4%	21.9%	↑ •
Medi-Cal	24	23.1%	473	8.1%	5.5%	1.3%	10.6%	↑ •
Healthy Families	3	2.9%	27	0.5%	0%	0%	0%	↑
Commercial PPO	3	2.9%	732	12.5%	5.3%	0%	17.1%	↑
Unknown	2	1.9%	42	0.7%	0%	0%	0%	↑
CCS + Medi-Cal	2	1.9%	2401	41.1%	42.1%	10.1%	65.6%	• — ↑
Point of Service/EPO	1	1%	58	1%	0%	0%	0.3%	↑
CCS	1	1%	487	8.3%	0.6%	0%	3.7%	↑
Insurance								
Commercial HMO	68	65.4%	1277	21.9%	15.4%	7%	32.6%	↑ •
Medi-Cal	26	25%	3048	52.2%	55.3%	31.2%	82.7%	• — ↑
Other	3	2.9%	37	0.6%	1.8%	1.2%	3.2%	↑
Commercial PPO	3	2.9%	992	17%	14.7%	5.8%	31.4%	• — ↑
CCS	3	2.9%	3277	56.1%	65.8%	31.8%	85%	• — ↑
Unknown	2	1.9%	46	0.8%	1.9%	1.1%	2.5%	↑
Point of Service/EPO	1	1%	106	1.8%	2.4%	1.7%	3.4%	↑

- Find Patient
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- Data Download

HRIF SUMMARY REPORT

HRIF Summary Report is updated nightly

HRIF Clinic [Redacted]

Discharge NICU All

Infant's Birth Year 2015

Infant's Birth Weight or Gestational Age All

Infant's Qualifying Medical Condition All

Report Name Standard Visit Summary Report (Core Visit #1)

Report Section Name LANGUAGE ASSISTANCE AND INSURANCE

[View Report](#)

A different HRIF program – same birth year and patient filters

STANDARD VISIT SUMMARY REPORT (CORE VISIT #1)

Discharge NICU: All
 Infant's Birth Year: 2015
 Infant's Birth Weight/Gestational Age: All
 Infant's Medical Eligibility Criteria: All
 Report Date: 2019-10-15

	HRIF Clinic		All HRIF Clinics					Comparison with All HRIF Clinic Data
	Num	%	Num	%	% Median	% Lower Quartile	% Upper Quartile	
LANGUAGE ASSISTANCE								
Interpreter Used								
No	64	73.6%	5421	92.8%	97%	90%	100%	• +
Yes	23	26.4%	420	7.2%	6.5%	2.5%	13.4%	+ •
Interpreter Language Used								
Spanish	23	100%	387	92.1%	100%	88.9%	100%	•
INSURANCE								
Insurance Combinations (Top 10)								
CCS + Medi-Cal	70	80.5%	2401	41.1%	42.1%	10.1%	65.6%	+ •
CCS + Commercial PPO	5	5.7%	164	2.8%	0%	0%	2%	•
Commercial HMO	3	3.4%	1120	19.2%	7.5%	2.4%	21.9%	+ •
Commercial PPO	3	3.4%	732	12.5%	5.3%	0%	17.1%	+ •
Medi-Cal	3	3.4%	473	8.1%	5.5%	1.3%	10.6%	+ •
CCS + Point of Service/EPO	2	2.3%	18	0.3%	0%	0%	0%	•
Medi-Cal + Point of Service/EPO	1	1.1%	3	0.1%	0%	0%	0%	•
Insurance								
CCS	77	88.5%	3277	56.1%	65.8%	31.8%	85%	+ •
Medi-Cal	74	85.1%	3048	52.2%	55.3%	31.2%	82.7%	+ •
Commercial PPO	8	9.2%	992	17%	14.7%	5.8%	31.4%	+ •
Point of Service/EPO	3	3.4%	106	1.8%	2.4%	1.7%	3.4%	•
Commercial HMO	3	3.4%	1277	21.9%	15.4%	7%	32.6%	+ •

HRIF SUMMARY REPORT

HRIF Summary Report is updated nightly

HRIF Clinic

Discharge NICU

Infant's Birth Year

 Min: Max:

Infant's Birth Weight or Gestational Age

Infant's Qualifying Medical Condition

Report Name

Report Section Name

[View Report](#)

	HRIF Clinic		All HRIF Clinics					Comparison with All HRIF Clinic Data
	Num	%	Num	%	% Median	% Lower Quartile	% Upper Quartile	
PRIMARY CARE PROVIDER								
Child has a Primary Care Provider (Added Jan 2012)								
Yes	354	100%	15281	99.7%	100%	99.7%	100%	•
Primary Care Provider Acts as the Child's Medical Home (Added Jan 2012)								
Yes	298	84.2%	8122	53%	64.3%	12.9%	90.9%	—+•
No	54	15.3%	6609	43.1%	30.7%	8.3%	90.9%	•—+
Unknown	2	0.6%	590	3.9%	1.5%	0.6%	4%	↑
HOSPITALIZATIONS								
Hospitalizations Since Discharge or Last Visit								
No	290	81.9%	12799	83.5%	86%	80%	90.6%	•+
Yes	63	17.8%	2503	16.3%	14%	10%	19.9%	↑
Unknown	1	0.3%	19	0.1%	0.4%	0.3%	0.8%	↑
Hospitalization Reasons								
Respiratory Illness	29	46%	1582	63.2%	59.5%	45.8%	75%	•+
Having Surgeries During Hospitalization	26	41.3%	923	36.9%	35.9%	27.1%	54.5%	•+
Other Medical Rehospitalization(s)	7	11.1%	438	17.5%	16.7%	9.1%	23.6%	•+
Urinary Tract Infection(s)	3	4.8%	43	1.7%	4.1%	2.3%	6.6%	↑
Other Infection(s)	2	3.2%	179	7.2%	7.1%	4.8%	12.5%	↑
Unknown	1	1.6%	65	2.6%	5%	2.4%	8.8%	↑
Nutrition/Inadequate Growth (Added Jan 2010)	1	1.6%	103	4.1%	5.1%	3%	10.9%	↑
Gastrointestinal Infection(s)	1	1.6%	121	4.8%	6.2%	4.6%	11.4%	↑

SURGERIES

Surgeries Since Discharge or Last Visit

No	317	89.5%	13870	90.5%	91.2%	88.7%	94.7%	+
Yes	36	10.2%	1434	9.4%	9%	6.2%	11.4%	-
Unknown	1	0.3%	17	0.1%	0.4%	0.3%	1%	-

Surgery Reasons

Inguinal Hernia Repair	14	38.9%	581	40.5%	43.5%	33.3%	53.8%	+
Cardiac Surgery	5	13.9%	111	7.7%	9.1%	5.7%	15.4%	-
Other ENT Surgical Procedures	5	13.9%	50	3.5%	7.7%	4%	11.5%	-
Other Surgical Procedures	4	11.1%	157	10.9%	13.9%	8.7%	16.2%	-
Retinopathy of Prematurity	3	8.3%	158	11%	13.2%	7.7%	26.3%	+
Circumcision	2	5.6%	193	13.5%	11.1%	5.3%	37.5%	-
Shunt/Shunt Revision	2	5.6%	73	5.1%	7.9%	5.2%	13.5%	-
Other Gastrointestinal Surgical Procedures	2	5.6%	123	8.6%	10.8%	7.8%	16.4%	-
Tympanostomy Tubes	1	2.8%	22	1.5%	5.5%	4%	7.4%	-
Other Genitourinary Surgical Procedures	1	2.8%	59	4.1%	5.5%	3.2%	9.8%	-

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SERVICE REFERRALS REPORT

This report is only available for closed birth years.

HRIF Clinic

Infant's Birth Years

Custom Birth Year Range Min: Max:

Infant's Birth Weight or Gestational Age

Birth Weight <= 1500 grams

Infant's Qualifying Medical Condition

All

Standard Visit:

Standard Visit Summary Report (Core Visit #1)

[View Report](#)

2012 - 2015 INFANTS WITH BIRTH WEIGHT <= 1500 GRAMS AT SV #1

Service Referrals Report is updated nightly

2012	2013	2014	2015
# Seen: 43	# Seen: 39	# Seen: 38	# Seen: 39

EARLY START AND MEDICAL THERAPY PROGRAM

Early Start Referral or Receiving	16.3%	20.5%	18.4%	38.5%
Medical Therapy Program (MTP) Referral or Receiving (added Jan 2013)	4.7%	10.3%	0.0%	7.7%

MEDICAL SERVICES REFERRAL SUMMARY

Medical Services Received Prior to Visit

Medical Specialties

Any Medical Specialty	88.4%	76.9%	86.8%	89.7%
Audiology	4.7%	10.3%	2.6%	10.3%
Cardiology	14.0%	17.9%	31.6%	15.4%
Craniofacial (added Jan 2014)	0.0%	0.0%	0.0%	0.0%
Endocrinology	0.0%	0.0%	0.0%	2.6%
Gastroenterology	14.0%	10.3%	10.5%	17.9%
Hematology/Oncology (added Jan 2010)	0.0%	0.0%	2.6%	0.0%
Metabolic/Genetics	4.7%	7.7%	13.2%	7.7%
Nephrology	4.7%	2.6%	2.6%	0.0%
Neurology	4.7%	2.6%	5.3%	7.7%
Neurosurgery	0.0%	0.0%	0.0%	0.0%
Ophthalmology	76.7%	66.7%	76.3%	82.1%
Orthopedic	0.0%	0.0%	0.0%	0.0%
Otolaryngology (ENT)	4.7%	10.3%	0.0%	2.6%
Pulmonology	16.3%	46.2%	39.5%	30.8%
Surgery	11.6%	12.8%	15.8%	7.7%
Urology	4.7%	5.1%	10.5%	5.1%

Group Summary

No Medical Services	11.6%	23.1%	13.2%	10.3%
Received 1 or 2 Medical Services	67.4%	41.0%	52.6%	61.5%
Received 3 or More Medical Services	20.9%	35.9%	34.2%	28.2%

Medical Services Referred at Time of Visit

Medical Specialties				
Any Medical Specialty	16.3%	33.3%	13.2%	17.9%
Audiology	11.6%	15.4%	0.0%	2.6%
Cardiology	0.0%	0.0%	0.0%	0.0%
Craniofacial (added Jan 2014)	0.0%	0.0%	0.0%	0.0%
Endocrinology	0.0%	0.0%	0.0%	0.0%
Gastroenterology	2.3%	0.0%	0.0%	2.6%
Hematology/Oncology (added Jan 2010)	0.0%	0.0%	0.0%	0.0%
Metabolic/Genetics	0.0%	0.0%	0.0%	2.6%
Nephrology	0.0%	0.0%	0.0%	2.6%
Neurology	0.0%	5.1%	0.0%	5.1%
Neurosurgery	0.0%	0.0%	0.0%	0.0%
Ophthalmology	16.3%	17.9%	13.2%	5.1%
Orthopedic	0.0%	0.0%	0.0%	0.0%
Otolaryngology (ENT)	0.0%	0.0%	0.0%	0.0%
Pulmonology	2.3%	0.0%	0.0%	0.0%
Surgery	0.0%	0.0%	0.0%	0.0%
Urology	0.0%	0.0%	0.0%	0.0%

Group Summary				
No Medical Service Referrals	83.7%	66.7%	86.8%	82.1%
Referred to 1 or 2 Medical Services	14.0%	33.3%	13.2%	17.9%
Referred to 3 or More Medical Services	2.3%	0.0%	0.0%	0.0%

If not for **HRIF visit**, referrals for these patients would at the very least have been further delayed.



Special Services Referred at Time of Visit

Special Services

Any Special Service	41.9%	53.8%	42.1%	28.2%
Behavior Intervention	2.3%	0.0%	0.0%	0.0%
Feeding Therapy	2.3%	2.6%	0.0%	0.0%
Hearing Services	7.0%	12.8%	0.0%	2.6%
Infant Development Services	4.7%	5.1%	0.0%	2.6%
Nutritional Therapy	2.3%	0.0%	2.6%	0.0%
Occupational Therapy (OT)	2.3%	0.0%	0.0%	2.6%
Physical Therapy (PT)	39.5%	28.2%	39.5%	23.1%
Social Work Intervention	0.0%	2.6%	0.0%	0.0%
Speech/Language Communication	2.3%	0.0%	0.0%	0.0%
Vision Services	7.0%	17.9%	13.2%	2.6%
Visiting, Public Health, and/or Home Nursing	0.0%	0.0%	0.0%	0.0%

Group Summary

No Special Service Referrals	58.1%	46.2%	57.9%	71.8%
Referred to 1 or 2 Special Services	37.2%	48.7%	42.1%	25.6%
Referred to 3 or More Special Services	4.7%	5.1%	0.0%	2.6%

HRIF SUMMARY REPORT

HRIF Summary Report is updated nightly

HRIF Clinic

Discharge NICU

Infant's Birth Year

 Min: Max:

Infant's Birth Weight or Gestational Age

Infant's Qualifying Medical Condition

Report Name

Report Section Name

[View Report](#)

SOCIAL CONCERNS/RESOURCES

Social Concerns and Resources

Caregiver-Child Disruptions or Concerns

No	271	94.4%	21833	96.8%	98.7%	96.3%	99.7%	
Yes, Referred to Other Community Resources	13	4.5%	131	0.6%	0.8%	0.4%	1.1%	
Yes, Referral Not Necessary	3	1%	420	1.9%	1.3%	0.6%	3.6%	

Economic/Environmental Concerns/Stressors

No	205	71.4%	21646	96%	98.8%	95.9%	100%	
Yes, Referred to Other Community Resources	64	22.3%	364	1.6%	1.1%	0.4%	2.4%	
Yes, Referral Not Necessary	18	6.3%	321	1.4%	1.2%	0.5%	3.6%	

Community and Relationship Concerns

No	253	88.2%	21993	97.5%	99.5%	98.2%	100%	
Yes, Referred to Other Community Resources	32	11.1%	313	1.4%	0.7%	0.3%	1.9%	
Yes, Referral Not Necessary	2	0.7%	137	0.6%	0.8%	0.3%	2.1%	

Parent-Child Concerns

No	275	95.8%	21645	96%	98.9%	96.6%	99.7%	
Yes, Referred to Other Community Resources	7	2.4%	285	1.3%	0.8%	0.3%	2.2%	
Yes, Referral Not Necessary	5	1.7%	473	2.1%	1.3%	0.5%	2.7%	

CPS Referral

No	272	94.8%	21886	97%	97.5%	95.7%	99.4%	
Yes	13	4.5%	648	2.9%	3.2%	1.1%	4.4%	
Referred at Time of Visit	2	0.7%	18	0.1%	0.6%	0.2%	0.7%	

[Find Patient](#) [Pending Cases](#) [Registration](#) [Referral](#) [Cardiac](#) [Reports](#) [Tools](#) [Admin](#) [Help](#) [Sign Out](#)

[HRIF Summary](#) [CCS Annual](#) [NICU Summary](#) [Cardiac Summary](#) [Prog Profile](#) [Service Refs](#) [Data Download](#)
[Usage Stats](#)

HRIF SUMMARY REPORT

HRIF Summary Report is updated nightly

HRIF Clinic

Discharge NICU

Infant's Birth Year

 Min: Max:

**Infant's Birth Weight
or Gestational Age**

**Infant's Qualifying
Medical Condition**

Report Name

Report Section Name

[View Report](#)

Developmental Assessment Test Performed Details

Bayley III Test (Hardcopy and Computer) - [Scores Table](#)



Cognitive Composite

>= 85	96	68.1%	1898	7
71 - 84	18	12.8%	289	1
<= 70	25	17.7%	298	1
Did not Assess	2	1.4%	5	

Receptive Language

>= 7	89	63.1%	1665	6
5 - 6	26	18.4%	457	1
<= 4	25	17.7%	292	1
Did not Assess	1	0.7%	41	

Expressive Language

>= 7	91	64.5%	1546	6
5 - 6	23	16.3%	468	1
<= 4	26	18.4%	378	
Did not Assess	1	0.7%	40	

Language Composite

>= 85	67	47.5%	1296	5
71 - 84	41	29.1%	674	20.0%
<= 70	31	22%	369	14.7%
Did not Assess	2	1.4%	85	3.4%

STANDARD VISIT SUMMARY REPORT (CORE VISIT #3)

Discharge NICU: All
 Infant's Birth Year: Custom Birth Year Range: 2012-2015
 Infant's Birth Weight/Gestational Age: Gestational Age < 28 weeks
 Infant's Medical Eligibility Profile: All
 Report Date: 2019-10-15

[Print This Page](#)

	HRIF Program		All HRIF Programs	
	Mean	Std Dev	Mean	Std Dev
Bayley III Test (Hardcopy and Computer)				
Cognitive Composite	85.78	23.4	91.07	21.57
Receptive Language	8.82	9.28	8.24	5.36
Expressive Language	7.91	7.12	7.85	4.38
Language Composite	81	23.35	85.21	17.5
Fine Motor	9.68	8.2	9.76	6.62
Gross Motor	9.42	10.27	8.83	8.23
Motor Composite	86.45	19.24	88.87	19.99
Social-Emotional Composite	0	0	95.29	20.71
Adaptive-Behavior Composite	0	0	79	16.15

20.0%	20.4%	10.5%	30.5%	
14.7%	12.8%	8%	21.6%	
3.4%	4.3%	2.9%	70.3%	

[Find Patient](#) [Pending Cases](#) [Registration](#) [Referral](#) [Cardiac](#) [Reports](#) [Tools](#) [Admin](#) [Help](#) [Sign Out](#)

[HRIF Summary](#) [CCS Annual](#) [NICU Summary](#) [Cardiac Summary](#) [Prog Profile](#) [Service Refs](#) [Data Download](#)
[Usage Stats](#)

HRIF CCS REPORT

HRIF CCS Report is static and only available for closed birth years.

HRIF Clinic

Infant's Birth Year

Infant's Birth Weight
or Gestational Age

Infant's Qualifying
Medical Condition

[View Report](#)

1. Follow Up Status
2. Patient Assessment Quality Indicators at Core Visits
3. Hospitalization and Surgeries
4. Medical and Special Services
5. General and Resource Assessment
6. Neurologic and Neurosensory Exam
7. Developmental Assessment

492 Registered Infants in 2015 for [REDACTED]

[REDACTED] Incomplete Priority Cases for 2015 is 0 / 492 (0.0 %)

Table 2. Patient Assessment Quality Indicators at Core Visits [Back to Top](#)

	Core Visit #1				Core Visit #2				Core Visit #3			
	Seen		All		Seen		All		Seen		All	
	37	3162	37	3162	35	2519	35	2519	33	1799	33	1799
	Median	Q1, Q3	Median	Q1, Q3	Median	Q1, Q3	Median	Q1, Q3	Median	Q1, Q3	Median	Q1, Q3
Adjusted Age	6.1	5.6, 7.1	6.3	5.4, 7.6	14.9	14.5, 15.8	14.5	12.6, 17.5	30.1	29.6, 30.9	27.2	24.4, 30.8
Chronological Age	8.8	7.9, 9.7	9.0	7.9, 10.2	17.4	16.8, 18.5	17.1	15.3, 20.1	30.1	29.6, 30.9	27.2	24.4, 30.8
	N	%	N	%	N	%	N	%	N	%	N	%
N, % of total seen with weight data	32	86.5%	2787	88.1%	31	88.6%	2211	87.8%	32	97%	1528	84.9%
N, % of total seen with head circumference data	36	97.3%	2997	94.8%	35	100%	2385	94.7%	32	97%	1513	84.1%

DATA DOWNLOAD



Notice

- I, Susan Hintz, MD, am a Super User of the HRIF Reporting System.
- I will ensure that any patient data exported from the web-based HRIF Reporting System will be handled in the same manner as any protected health information .
- The Primary Data Files will be downloaded and stored on a secure machine.

Acknowledged by Susan Hintz, MD at Thu Oct 17 22:06:52 PDT 2019

HRIF Clinic

Infant's Birth Year

2010 2011 2012 2013 2014 2015

The Primary Data folder will include the following (8) files:

- HRIF Primary Data Read Me
- HRIF Data Dictionary 2010
- Additional Visit
- No Show Visit
- Registration
- Standard Visit
- SV Hospital Reason
- SV Other Medical Conditions

Download



HRIF Primary Data ReadMe.pdf



HRIF_data_dictionary_2010+.xlsx



HrifPrimaryData_AdditionalVisit_2014.csv



HrifPrimaryData_NoShowVisit_2014.csv



HrifPrimaryData_Registration_2014.csv



HrifPrimaryData_StandardVisit_2014.csv



HrifPrimaryData_SvHospReason_2014.csv



HrifPrimaryData_SvOtherMed_2014.csv

There is a NICU Summary Report too!

What's that report for?



NICU SUMMARY REPORT

NICU Summary Report is updated nightly

NICU Hospital

Infant's Birth Year

Infant's Birth Weight or Gestational Age

Infant's Qualifying Medical Condition

Inborn/OutBorn

Report Name

Report Section Name

[View Report](#)

NICU teams can review post-discharge outcomes of patients *from the NICU perspective*.

Filter by inborn/ outborn

Same report section options as HRIF

To Gain Access to HRIF Reporting System

Contact **Erika** at
Erika@cpqcc.org or 650-725-1306
to access reports!

Data in Action: Highlights from California HRIF analyses

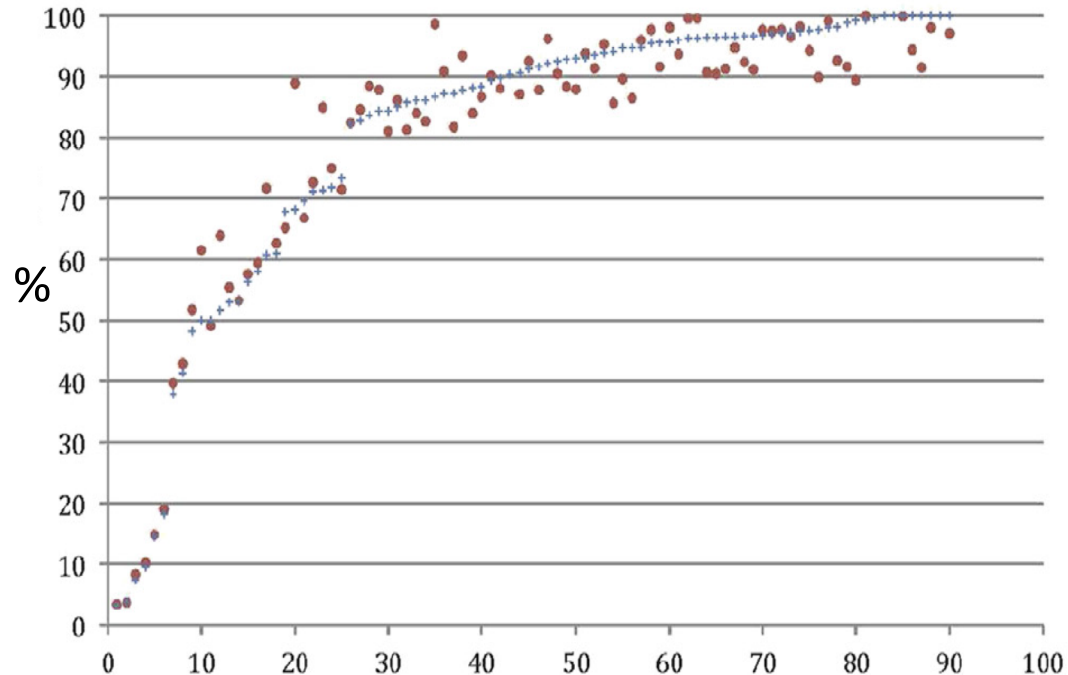


The first step to benefitting from high risk infant follow up ...

...getting referred to HRIF and getting to the 1st visit!

Recognition of HRIF referral failure & statewide PI intervention

Overall VLBW referral rate to HRIF was just 80% at NICU discharge for birth year 2010-2011.



Hintz SR, et al. J Pediatr 2015;166:289-95

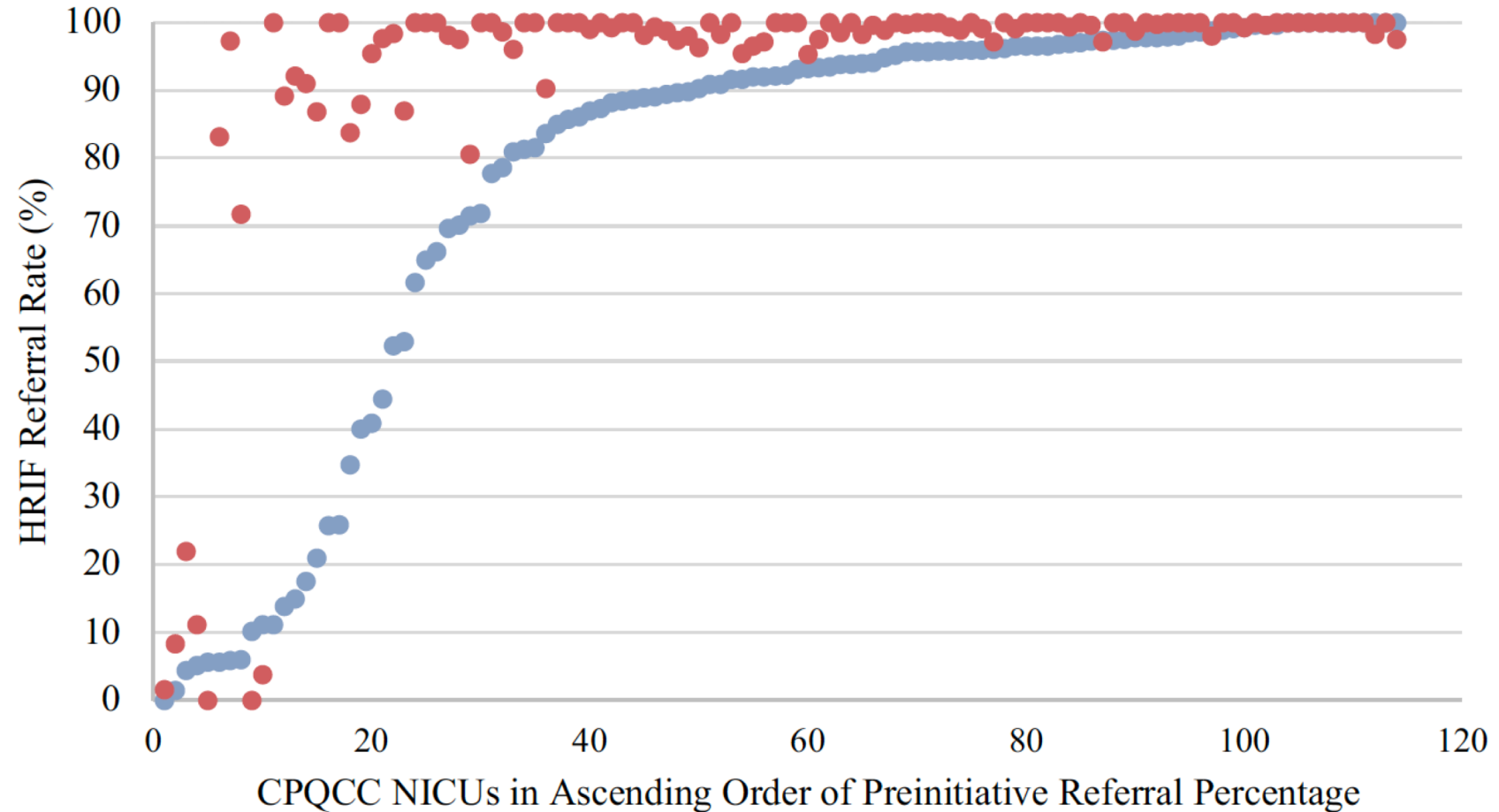
HRIF/CPQCC Match Summary Report for Infants Discharged Home, 1/1/2017 to 12/31/2017

This report is preliminary as the data collection is on-going.

HRIF Category	N Infants	Infants Referred to HRIF	Referral %	Referral % CCS NICUs	Referral % Regional NICUs
Very Low Birth Weight Infants (<=1,500 grams)	35	35	100.0	92.1	92.6
Extremely Low Birth Weight Infants (<1,000 grams)	8	8	100.0	92.2	90.5
Gestational Age < 28 Weeks	8	8	100.0	91.1	91.5
Infants with Moderate/Severe HIE	14	14	100.0	95.0	95.2
Infants with Cooling	23	23	100.0	94.0	94.9
Infants with ECMO	2	2	100.0	86.4	85.4
Infants with Congenital Heart Disease	28	28	100.0	83.2	83.2
Infants with Nitric Oxide	13	13	100.0	85.4	85.5
Infants with Seizures	24	24	100.0	82.1	82.8
Infants Referred for any of the Reasons Above	100	100	100.0	90.1	89.8
Additional Infants with Gestational Ages 28 to 31 Weeks	18	18	100.0	91.4	91.5
Infants Referred for any of the Reasons Above	118	118	100.0	90.3	90.0
CPQCC Infants Referred for Other Reasons		36			
All Referrals		154			

Improved Referral of VLBW to HRIF in California after PI Initiative

- **Pre-intervention** period - birth 1/10-6/13: **83%** referred
- **Post-intervention** period birth 7/13-12/16: **95%** referred



Pai V, et al *J Pediatrics*, October 2019 (epub ahead of print)

● Preinitiative

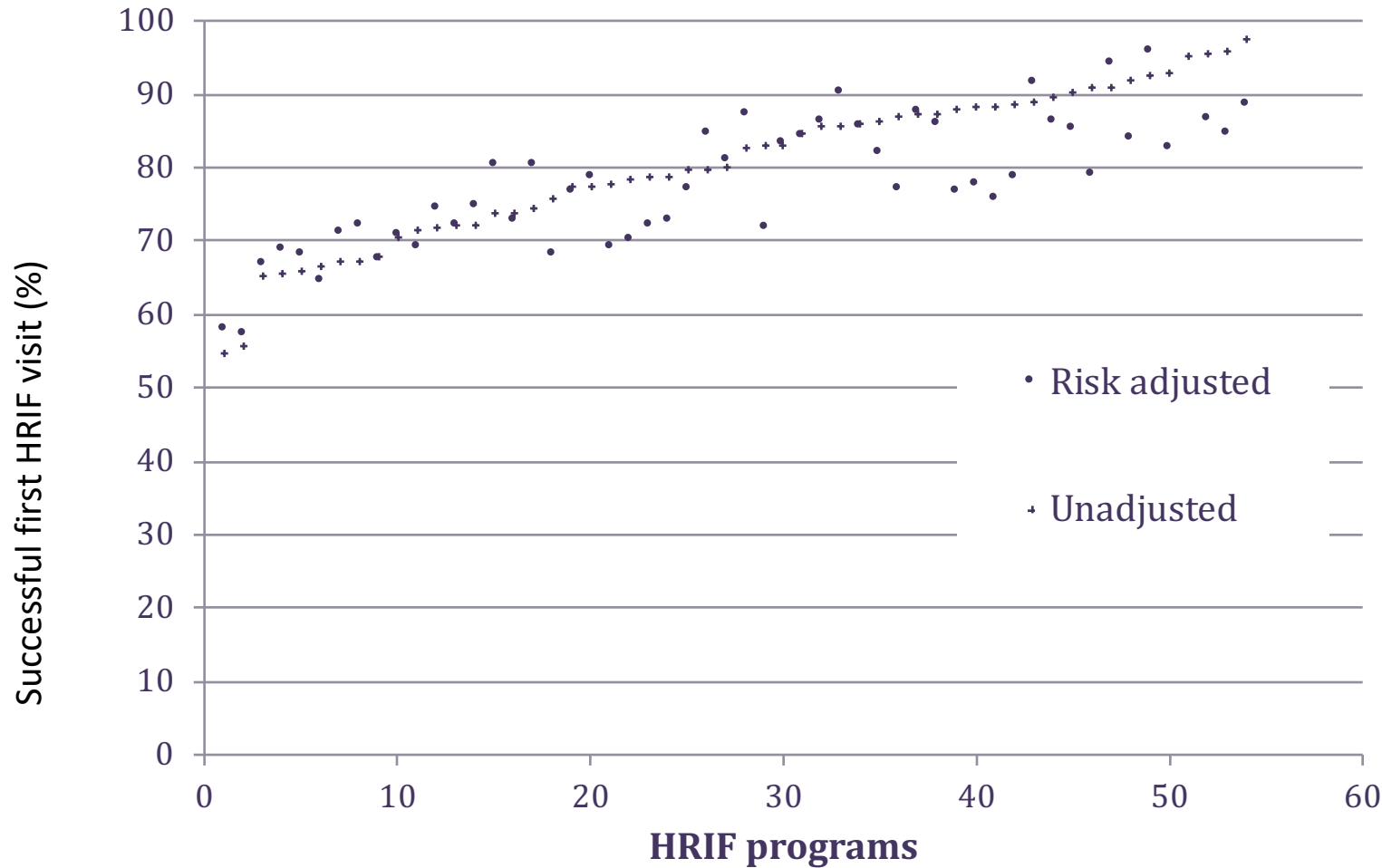
● Postinitiative

Substantial improvements in referral rates across sociodemographic and clinical factors, and reduction of variation by site and region – but disparities remain

	<u>Pre-intervention</u>	<u>Post-intervention</u>	<u>% change</u>
Maternal race/ethnicity^{*,†}			
African American	1575 (81.7)	1621 (94.6)	12.8 (10.8-14.9)
Hispanic	5088 (81.9)	6123 (95.6)	13.7 (12.5-14.7)
White	3249 (84.6)	3441 (94.2)	9.6 (8.2-11.0)
Asian/Pacific Islander	1469 (84.3)	1780 (94.5)	10.2 (8.2-12.2)
Native American/other	298 (84.9)	373 (93.3)	8.3 (3.9-12.8)
Small for gestational age^{*,†}			
≤32 weeks estimated gestational age	2537 (81.4)	3007 (94.3)	12.9 (11.3-14.5)
≥33 weeks estimated gestational age	788 (70.0)	1083 (92.7)	22.7 (19.6-25.7)
Appropriate for gestational age	8377 (85.1)	9302 (95.4)	10.3 (9.5-11.2)
Discharging NICU volume^{*,†}			
Lowest quartile	240 (43.6)	396 (65.6)	22.0 (16.4-27.6)
Second quartile	1477 (74.3)	1741 (87.0)	12.7 (10.3-15.1)
Third quartile	2699 (77.2)	3100 (94.5)	17.2 (15.6-18.8)
Fourth quartile	7296 (90.4)	8162 (99.2)	8.8 (8.1-9.5)

Pai V, et al *J Pediatrics*, October 2019 (epub ahead of print)

Factors associated with successful 1st high risk infant follow-up visit for very low birth weight infants in California



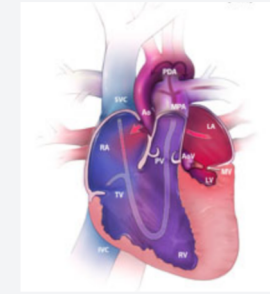
There was variability in observed successful first HRIF visit rates, **ranging from 54.7% to 97.9%**, which remained after risk adjustment.

Hintz SR, et al. J Pediatr. 2019; 210:91-98.e1

Factor	Adjusted OR (95% CI)	p-value
Associated with higher odds - -		
Maternal age (vs 20-29)		
30-39	1.48 (1.27, 1.72)	<0.0001
Maternal prenatal care	1.92 (1.34, 2.77)	0.0004
Birth weight (vs. 1251-1499 g)		
<=750 g	2.11 (1.69, 2.65)	<0.0001
751-1000 g	1.81 (1.51, 2.17)	<0.0001
1001-1250 g	1.34 (1.14, 1.58)	0.0005
Severe ICH	1.61 (1.12, 2.3)	0.0093
Insurance (vs CCS or MediCal only)		
HMO/PPO + CCS	1.65 (1.19, 2.31)	0.003
Two parent 1 caregiver (vs. one only)	1.18 (1.03 - 1.36)	0.019
HRIF program VLBW volume (vs. lowest quartile)		
2 nd quartile	2.62 (1.88, 3.66)	<0.0001
3 rd quartile	1.55 (1.15, 2.10)	0.0045
Associated with lower odds - -		
Maternal race African American	0.65 (0.54, 0.78)	<0.0001
Miles from HRIF program (vs. lowest quartile)		
Highest quartile	0.69 (0.57, 0.83)	0.0002
3 rd quartile	0.79 (0.65, 0.96)	0.018

Hintz SR, et al. J Pediatr. 2019; 210:91-98.e1

Cardiac Expansion Project –



HRLL
HIGH RISK
INFANT FOLLOW-UP



Cardiac HRIF Expansion Project:

What is this and *why are we doing it?*



Clarification of CHD eligibility for HRIF



JENNIFER KENT
DIRECTOR

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



EDMUND G. BROWN J
GOVERNOR

September 27, 2017

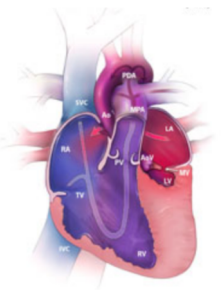
Program Letter: 01-0917

To: Medical Directors and Coordinators of California Children's Services
Program (CCS) - Approved High Risk Infant Follow-up (HRIF) Programs

Subject: Clarification of Congenital Heart Disease Eligibility Criteria

... admission to a **NICU** or **directly to a PICU** or **CVICU** within the neonatal period, and surgery or minimally invasive therapeutic intervention (such as catheter-based balloon angioplasty) for CHD during that hospitalization...

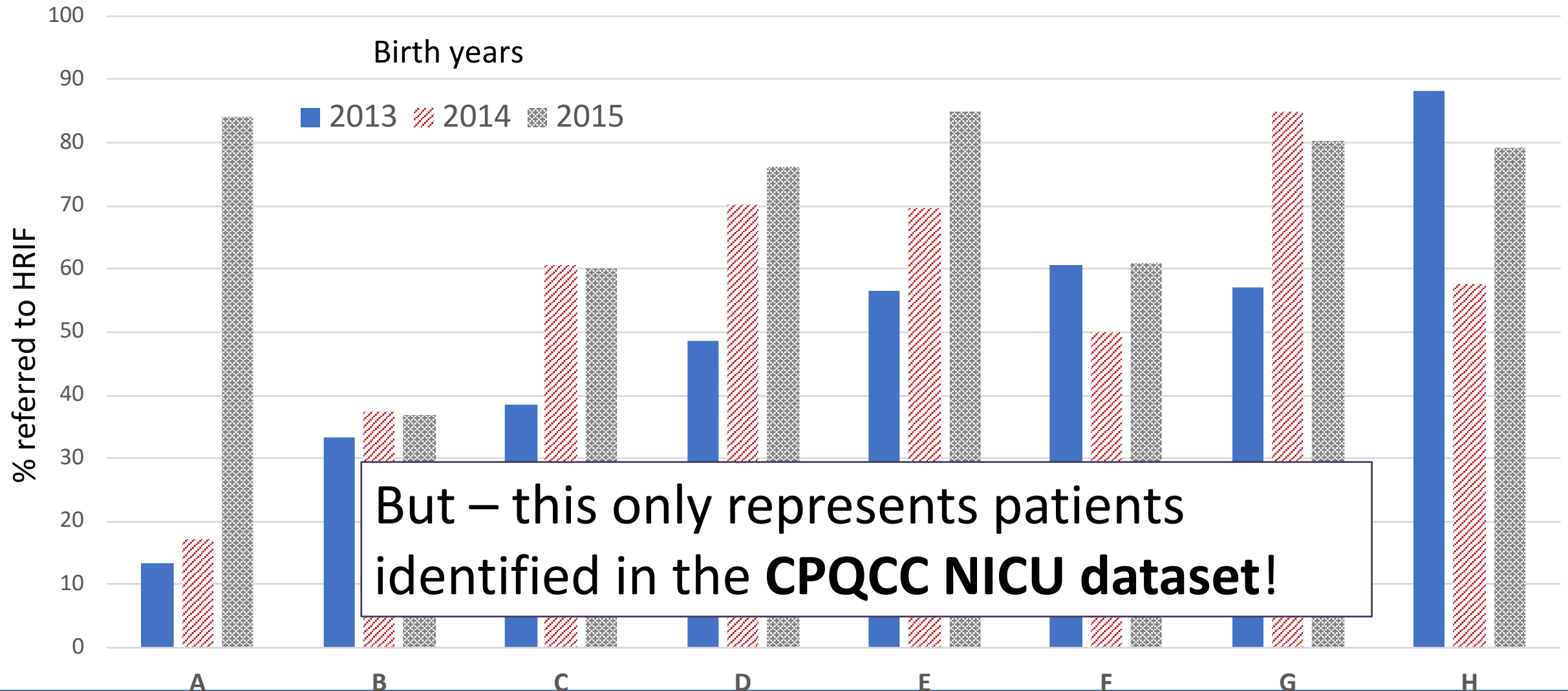
Scope of the problem



For birth years 2013-2015, of 41,689 CPQCC infants survived to discharge home

- 2124 had been identified with major CHD diagnoses.
 - 46.2% referred to HRIF.
- **1319 had CHD requiring intervention per CPQCC database**
 - **Only 60.1% referred to HRIF**

CHD neonates requiring intervention - rates of referral to HRIF at discharge: Highest volume CHD intervention CPQCC NICUs, birth years 2013-2015



The NICU Database for infants born in 2017 is complete. HRIF registration is possible for up to 3 years from discharge home.

CSV



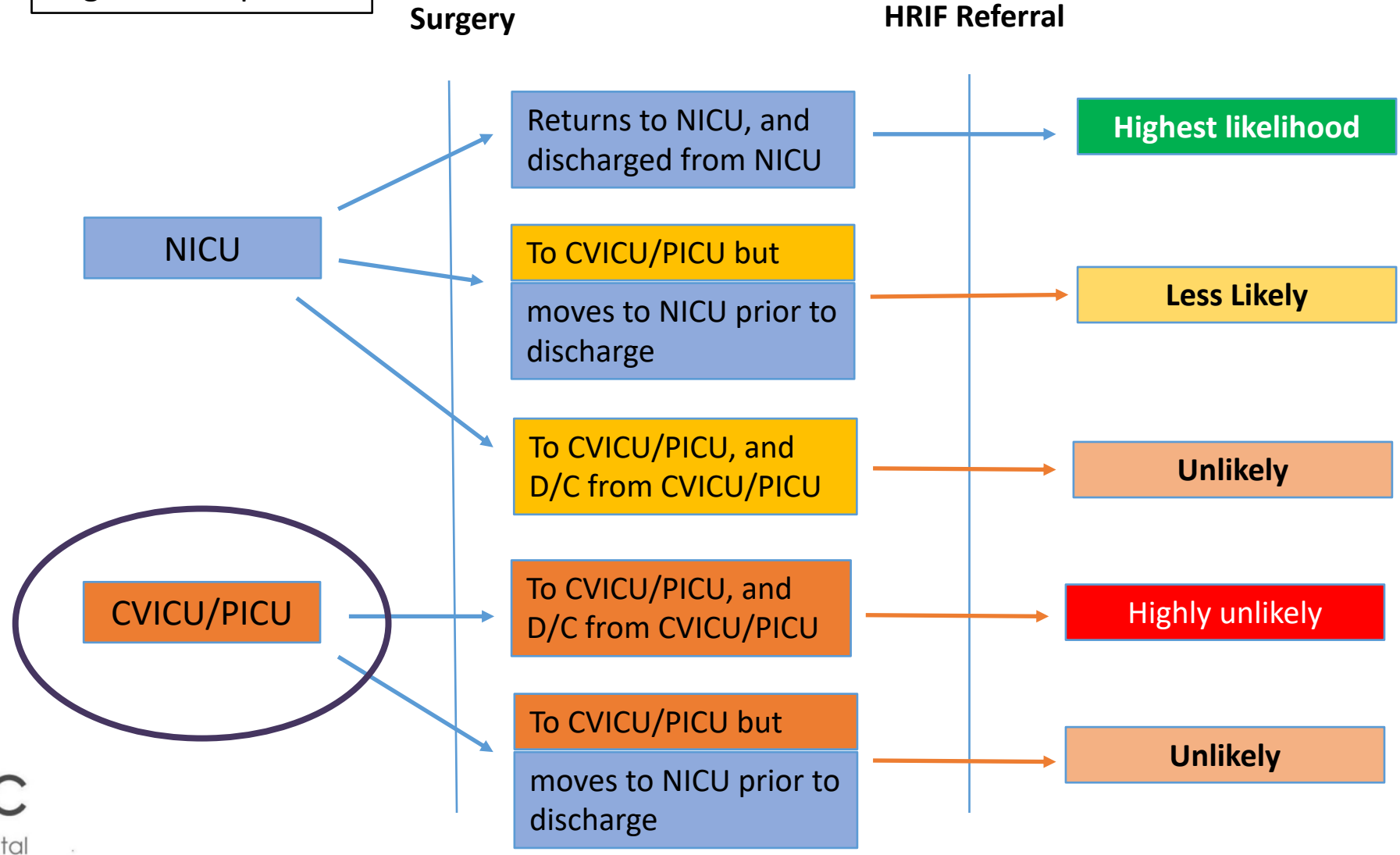
HRIF Group	Reporting Center					Regional NICUs	
	N Eligible	N Referred	% Referred	N Timely	% Timely	% Referred	% Timely
HRIF referrals by reporting NICU excluding referrals on behalf of other CCS NICUs							
All HRIF referrals by reporting NICU		368		341	92.66		81.48
NICU records at reporting NICU for infants discharged home from reporting NICU							
Linked HRIF/NICU infants referred with NICU record at reporting NICU		262		245	93.51		82.72
Linked HRIF/NICU Infants referred with confirmed HRIF eligibility reasons ▶	209	208	99.52	197	94.71	99.75	84.52
Very low birth weight infants (<=1,500 grams)	77	77	100	76	98.7	99.93	90.27
Extremely low birth weight infants (<1,000 grams)	29	29	100	29	100	100	91.62
Gestational age < 28 weeks	31	31	100	31	100	100	91.77
Gestational age 28 to 31 weeks	58	58	100	56	96.55	99.7	90.8
Infants with moderate/severe HIE	19	19	100	18	94.74	100	83.99
Infants treated with active therapeutic hypothermia	32	32	100	31	96.88	100	82.74
Infants treated with ECMO	2	2	100	1	50	97.96	79.17
Infants treated with surgery for Congenital Heart Disease	55	54	98.18	48	88.89	99.28	75.42
Infants treated with inhaled Nitric Oxide > 4 hours	27	27	100	23	85.19	100	76.98
Infants with seizures	25	25	100	24	96	99.72	76.2
Linked HRIF/NICU infants referred for Other Reasons		54		48	88.89		74.56
NICU records at reporting NICU for infants discharged home after transport to non-CCS NICU							
Linked HRIF/NICU infants referred with NICU record at reporting NICU		1		1	100		63.16
Linked HRIF/NICU Infants referred with confirmed HRIF eligibility reasons ▼	3	1	33.33	1	100	85.94	65.45
Linked HRIF/NICU infants referred for Other Reasons		0		na	na		0
Other HRIF referrals by reporting NICU							
All other HRIF referrals		105		95	90.48		77.18
Linked HRIF/NICU infant referred by reporting NICU but no NICU record at reporting NICU		25		24	96		82.33
Linked HRIF/NICU infant referred and still-in-house per NICU record		0		na	na		na
Infant referred to HRIF by reporting NICU, but not linked to any NICU record		80		71	88.75		74.66

For detailed information on the HRIF/NICU match status, select the HRIF/NICU Match Detail report option in the navigation bar. The above table reflects HRIF registrations through 10-15-2019. Any changes in your data after this date are not reflected in the report shown. To view detailed HRIF outcomes reports visit the [HRIF Reporting System](#).

Initial admission location for CPQCC eligible, HRIF eligible CHD patient

Location(s) post- surgery or intervention

? HRIF referral?



CHD + surgery neonates are NOT all entered in CPQCC depending on care path!!

Ultimate goals:

- 1) Obtain information and input leading to solutions to better capture the entire CHD HRIF-eligible population in California
- 2) Provide opportunities for improved continuity of care.



Identified discrepancies underscore importance of consistent method to refer eligible CHD neonates →

EDS System

Electronic Data Submission (EDS)

Cardiac Summary Report



REPORTING SYSTEM

Susan Hintz, MD, Welcome Super User

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[HRIF Summary Usage Stats](#) [CCS Annual](#) [NICU Summary](#) [Cardiac Summary](#) [Prog Profile](#) [Service Refs](#) [Data Download](#)

CARDIAC CENTER SUMMARY REPORT

Cardiac Center Summary Report is updated nightly

Cardiac Center	<input type="text" value="All"/>
Infant's Birth Year	<input type="text" value="All"/>
Infant's Birth Weight or Gestational Age	<input type="text" value="All"/>
Infant's Qualifying Medical Condition	<input type="text" value="All"/>
Report Name	<input type="text" value="-- Select a Report --"/>
Report Section Name	<input type="text" value="-- Select a Report Section Name --"/>

[View Report](#)





Join us for our first annual
IMPROVEMENT PALOOZA

A deep dive into the exciting world of quality improvement

Are you wondering how to start an improvement project in your unit? Curious about how the culture of your NICU influences the quality of care?

Join us for CPQCC's first Improvement Palooza, held in conjunction with the 2020 CAN Cool Topics in Neonatology Meeting!

March 6, 2020 || 8am – 4pm || Coronado Island Marriott Resort & Spa

Designed to help NICU teams supercharge their quality improvement journeys, Improvement Palooza is a can't miss event.

For more information visit www.cpqcc.org/improvement-palooza-2020

HRLL

HIGH RISK
INFANT FOLLOW-UP

Hypoglycemia clarification –





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

April 24, 2019

Program Letter: 01-0419

To: Medical Directors and Coordinators of California Children’s Services
Program-Approved High Risk Infant Follow-up Programs

Subject: Clarification of Hypoglycemia Medical Eligibility Criteria

HRIF Medical Eligibility in these cases requires admission to a Neonatal Intensive Care Unit or directly to a Pediatric Intensive Care Unit within the neonatal period as outlined in N.L. 05-1016 Section III or in P.L 01-1016 Section III.

An unstable infant with hypoglycemia will be considered eligible for HRIF if intervention (intravenous [IV] boluses and/or IV glucose infusion) is required in an intensive care setting specifically for the treatment of hypoglycemia for at least 48 hours, or if there is a diagnosis of congenital hyperinsulinemia or other congenital endocrinopathy associated with hypoglycemia. Evidence of seizures or brain injury by neuroimaging with hypoglycemia meets medical eligibility criteria for HRIF referral regardless of etiology. Similarly, hypoxic-ischemic encephalopathy complicated by hypoglycemia may be associated with increased risk for adverse neurodevelopmental outcomes, but neonatal encephalopathy alone would meet medical eligibility criteria for HRIF referral.

These clarifications are consistent with the California Children’s Services (CCS) Program’s goal of assuring identification and referral of those who are most vulnerable and at highest risk.

Feedback, issues, queries

- Request from one or two of the CPQCC NICU medical directors for a "further clarification" of the clarification, specifically to avoid any misinterpretation that *any baby* on IV fluids with dextrose would need to be referred to HRIF.
- Several concerns raised that clinic staff / sites would be “penalized” for failing to refer *any* patient who was in the NICU and needed IV dextrose.
- Misinterpretation that hypoglycemia is a “new HRIF eligibility” when in fact this was a clarification of a previously unclear eligibility.
- A few problems with authorization for hypoglycemia.

Interpretation of feedback, responses to sites

- Main concern from some sites seems to be around being “penalized” or “required” to refer – i.e., included as a CPQCC deliverable. **However, there is NO hypoglycemia data collected in CPQCC NICU dataset – thus no way to link this item.** The following was sent to several sites in response to queries after discussion with and on behalf Dr. Jocson/ CCS:

Interpretation of feedback, responses to sites

- *This clarification was undertaken at the request of physicians and coordinators who were challenged and concerned by the vague verbiage around hypoglycemia in the High Risk Infant Follow-Up (HRIF) Numbered Letter ... and is in no way meant to penalize NICUs or HRIF clinics. In fact, given that the CPQCC NICU dataset does not include hypoglycemia data, there is no possibility, nor any plan, to include this eligibility criteria as part of the matched summary table or as a deliverable. **The verbiage in the clarification is meant to provide guidance for HRIF eligibility, and to support referrals for those who meet these criteria. The clarification document allows for flexibility.***

Interpretation of feedback, responses to sites

- Other issues to underscore
 - Hypoglycemia is not a new HRIF eligibility criteria – this is a clarification of an *existing eligibility* that provides *guidance and flexibility* to clinicians.
 - If providers or coordinators are having challenges with securing authorization for HRIF referral for a patient meeting hypoglycemia eligibility, **Dr. Jocson has recommended that providers re-submit with the HRIF program letter and clarification letter as further justifying documentation, and reach out to her with concerns.**