CPQCC CCS High Risk Infant Follow Up

Data in Action Webinar February 21, 2018



Webinar Overview

- What is CPQCC CCS HRIF?
- Security upgrades, improvements for users
- HRIF usage overview, HRIF reports review
- HRIF referral and follow up barriers, challenges, successes
- Service utilization and <u>unmet needs</u> identified at HRIF visits: "small babies", "big babies"
 - CHD requiring neonatal intervention update, opportunities
- Coming to HRIF
 - Primary data files for sites, expanded special report data release in 1-2 weeks
 - HRIF Clinic Capacity Survey *release today*
 - HRIF Dashboard General concept, call for feedback



California population-based perinatal epidemiology and quality improvement collaboratives













CPQCC

- 130+ hospitals capturing >95% of all VLBW infants.
- Perinatal and neonatal data and short-term outcomes → performance improvement and benchmarking
- Statewide QI collaboratives, QI research

CPQCC CCS HRIF

- A web-based infrastructure for consistent HRIF care, real-time case management.
- Support site-specific performance improvement, state-based assessment, and PI and QI efforts.
- Better understand the NICU-to-early childhood trajectory for high risk infants and families.



Continuum of care structure – unique to California!





Who do we serve? — HRIF Eligibility and Visits





State of California—Health and Human Service
Department of Health Care Se

DATE: October 12, 2016

TO: ALL COUNTY CALIFORNIA CHILDREN'S SER ADMINISTRATORS, CCS MEDICAL CONSULT

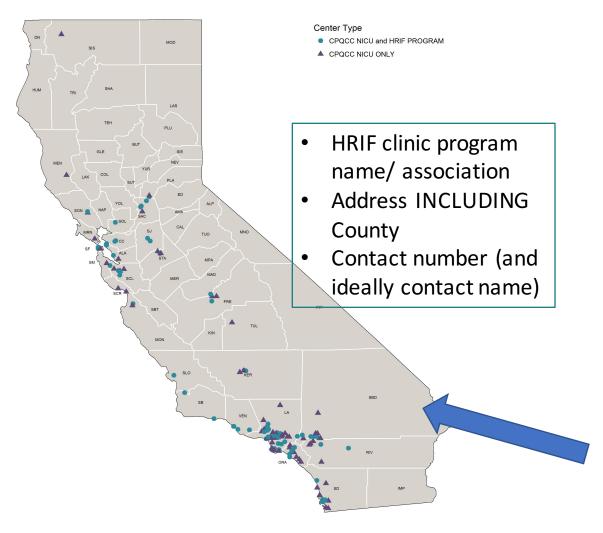
SYSTEMS OF CARE DIVISION (SCD) PROGRAM

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

- ALL infants <1500 grams BW or
 <32 weeks EGA.
- Infants >1500 grams BW with range of neurologic, cardiovascular risk factors.
- Provides for series of visits through 3 years
 - Information about functional and neurodevelopmental, but also use and need for services, hospitalizations, household/family challenges.



Who do we serve? – HRIF providers, data users



- 69 HRIF clinics with registration entry privileges.
- 636 total Duo HRIF users.
 - Some data users, some referralenabled users, some NICU users
 or combinations.

For the future - - will survey to determine additional (satellite) HRIF clinics, site details on "hover and discover" or "click and learn" interactive map components.



Security upgrades and improvements



- Security upgrades and critical maintenance over holiday break – completion required work through mid January.
 - Steps to protect patient information, healthcare systems, and the HRIF Reporting System database.
- Security of the HRIF database further enhanced by using a strategy known as "whitelisting".
 - Registry of approved IP addresses; all entities are denied access, except those included in the whitelist.



Security upgrades and improvements

NO CONNECTION

Access to the HRIF-QCI Reporting System is Restricted to Authorized Users.

If you are having trouble gaining access, it is because your healthcare entity network is not currently recognized.

Please contact your IT department to request the "Public IP Address Ranges" used by the hospital's network. Submit a help ticket at www.cpqcchelp.org (http://www.cpqcchelp.org/) and provide the ranges in the description.

Whitelisting IP address ranges is the new security procedure we have implemented to enhance the security of the system. We apologize if this causes a temporary delay in your access. Thank you for your understanding and assistance in protecting the important data in the HRIF-QCI Reporting System. **NOTE:** Access is only authorized while connected to your organization's network. Access from home or while traveling is <u>not</u> permitted.

If you have any questions or require additional information, please submit a help ticket at www.cpqcchelp.org (http://www.cpqcchelp.org/).

- IP address ranges known for those logged into the system within past 3 months
- Each user to contact their IT
 Department to request the
 IP address ranges used on
 the hospital's network.
- www.cpqcchelp.org help ticket to provide IP address ranges.



 Due to delays arising from required system enhancements and server complexities, we have extended all of the 2018 HRIF Data Finalization Process deliverables deadlines by a month.



DATA FINALIZATION PROCESS (DFP)

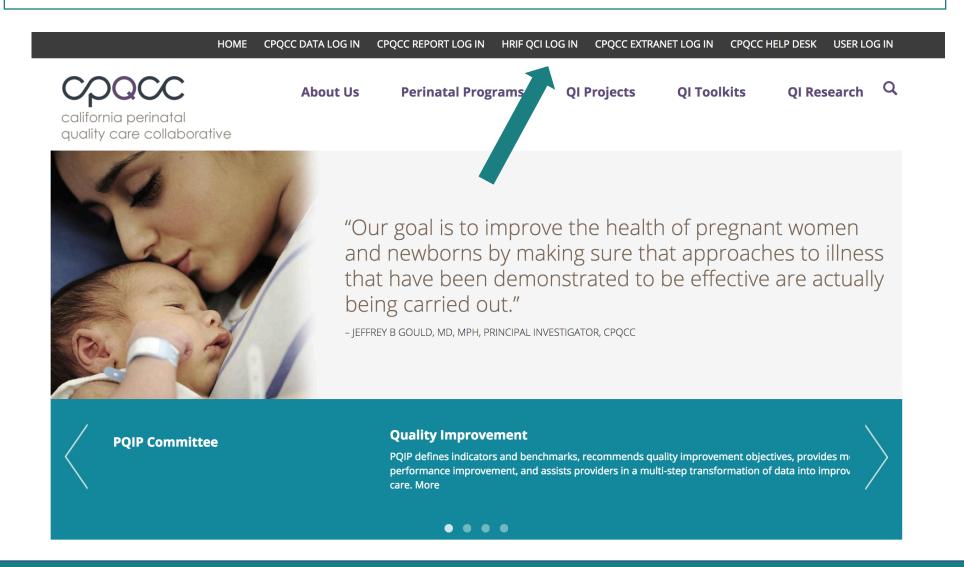
HIGH RISK INFANT FOLLOW-UP QUALITY OF CARE INITIATIVE

Schedule for 2018

JAN - MAR	APR 1 st	MAY 1 st	MAY 2 nd	MAY 17 th	JUL 1 st	JUL 11 st	AUG - DEC
Data Review	Super Star HRIF Program Award	DEADLINE	HRIF Follow- up Rate Award	DEADLINE HRIF CCS Report	DEADLINE	HRIF Crown Award	Data Review
Utilize Reporting System Tools: HRIF Tracker; CPQCC Ref Num; Error & Warning and Closeout Checklist	Submission of No Priority/ Error & Warning Cases for 2014 Born Infants, Closed RR Forms for All 2016 Born Infants AND SV #1 of All expected 2016 Born Infants	Data Final for 2014 Born Infants AND SV #1 of All expected 2016 Born Infants	Core Visit F/U Rates for 2014 Born Infants: 1st => 80% 2nd => 70% 3rd => 60%	2014 Born Infants Confirm report by May 17th	Register ALL 2017 Born Infants AND Confirm HRIF Directory Contacts	Granted to HRIF Programs who meet All Closeout Deliverable Deadlines: Apr 1st, May 17th and Jul 1st	Utilize Reporting System Tools: HRIF Tracker; CPQCC Ref Num; Error & Warning and Closeout Checklist



HRIF Usage Statistics & Reports Review





All CPQCC CCS HRIF - Usage Statistics

- Since 2009 ~ 69,000 high risk infants registered in the CPQCC-CCS HRIF QCI.
 - ~95,000 Standard Visits performed
 - ~7,400 Additional Visits performed
- About 50% are VLBW (<1500 g) ~34,800 of registered/ referred

Other:

- <26 weeks: ~5,500
- <28 weeks: ~13,000
- >37 weeks: ~ 17,000



2014 Birth Year

- For birth year 2014 8403 have been registered in CPQCC CCS HRIF
 - <=1500 grams BW → ~4300
 - <1000 grams BW →~1550
 - <28 weeks GA \rightarrow ~1590
 - >37 weeks → ~2220
 - Other
 - Medi-Cal (any part of insurance of mother) → ~55%
 - Full time employment for primary caregiver → ~34%
 - Primary language in home English → ~72%



2014 Birth Year

	MEDICAL	ELIGIBILIT	Y PROFILE			
edical Eligibility Profile						
Gestational Age at Birth < 32 weeks	4956	59%		51.6%		+
<= 1500 grams		51.6%	52.6%	46.9%	61.7%	←
Oxygen > 28 Days and CLD	853	10.2%	10.7%	4.5%	14.5%	+
Documented Seizure Activity	344	4.1%	4.5%		6.2%	+
iNO > 4 Hours for PPHN	307	3.7%	3.1%	1.8%	4.9%	•
Persistent Apnea	289	3.4%	2.9%	1.5%	4.9%	†
ECMO	71	0.8%	1.5%	1%	1.9%	+
Neonatal Encephalopathy	34	0.4%	1%	0.7%	2%	4



High Risk Infant Follow-up CAQCC california perinatal Quality of Care Initiative quality care collaborative Susan Hintz, MD, Welcome Super User **Find Patient** Registration Referral **Tools Admin** Help **Pending Cases Patient Record** Report Sign Out **HRIF Summary Reports HRIF CCS Reports Usage Statistic Report NICU Report HRIF SUMMARY REPORT** HRIF Summary Report is updated in real time **HRIF Program** ΑII **Discharge NICU** All **Infant's Birth Year** ΑII **Infant's Birth Weight** or Gestational Age **Infant's Qualifying** ΑII **Medical Condition Report Name** -- Select a Report --**View Report**



High Risk Infant Follow-up CAQCC Quality of Care Initiative california perinatal quality care collaborative Susan Hintz, MD, Welcome Super User **Find Patient Pending Cases** Registration **Patient Record** Referral Tools **Admin** Help Sign Out Report **HRIF Summary Reports HRIF CCS Reports Usage Statistic Report NICU Report HRIF SUMMARY REPORT** HRIF Summary Report is updated in real time **HRIF Program** ΑII **Discharge NICU** All **Infant's Birth Year** ✓ All 2009 **Infant's Birth Weight** 2010 or Gestational Age 2011 **Infant's Qualifying** 2012 **Medical Condition** 2013 **Report Name** 2014 2015 2016 2017 2018 **Custom Birth Year**



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High Risk Infant Follow-up Quality of Care Initiative

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High Risk Infant Follow-up Quality of Care Initiative

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High Risk Infant Follow-up COQCC Quality of Care Initiative california perinata quality care collaborative Susan Hintz, MD, Welcome Super User **Find Patient Pending Cases** Registration **Patient Record** Referral Report **Tools Admin** Help Sign Out **HRIF Summary Reports HRIF CCS Reports Usage Statistic Report NICU Report NICU SUMMARY REPORT** NICU Summary Report is updated in real time **NICU Hospital** ΑII **Infant's Birth Year** ΑII ✓ All **Infant's Birth Weight or** ΑII **Gestational Age** Inborn, discharged from my NICU **Infant's Qualifying** ΑII Inborn, transferred out **Medical Condition** Outborn Inborn/OutBorn ΑII **Report Name** -- Select a Report --**Report Section Name** -- Select a Report Section Name --**View Report**

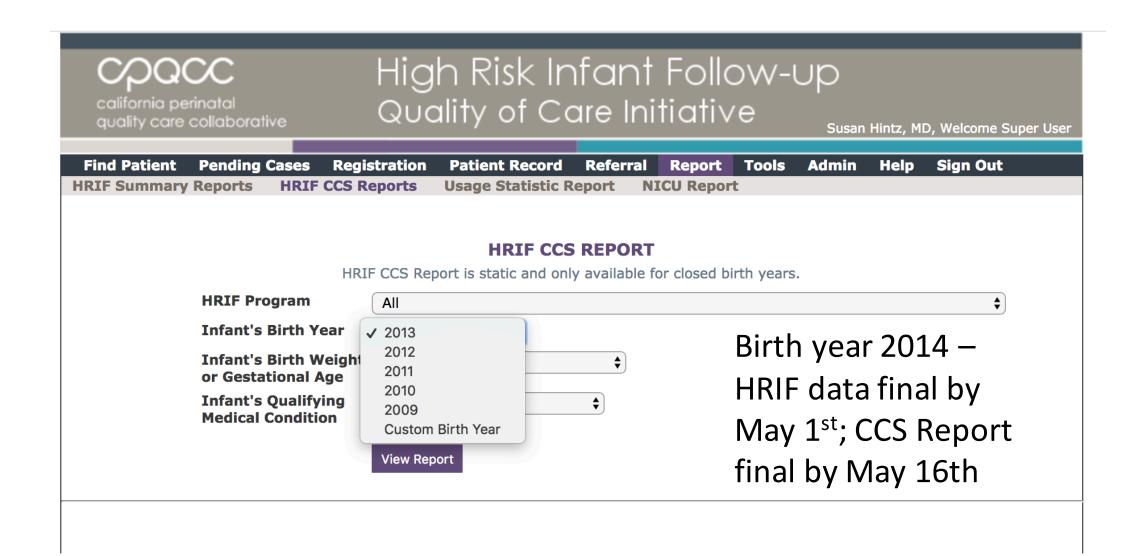


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High Risk Infant Follow-up Quality of Care Initiative

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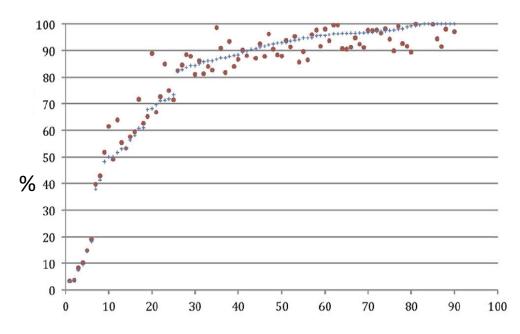
2014 Birth Year (data not final)

Patient description	% seen of expected					
	1 st core visit	2 nd core visit				
< 1000 g	78.6% (median 85.7%)	66.6% (median 73.6%)				
<28 weeks	78.6% (median 83.9%)	65.1% (median 71.2%)				
<26 weeks	81.2% (median 90%)	68.6% (median 75%)				
HIE/Neo Enceph	70.5% (median 78.6%)	57.7% (median 66.7%)				



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.

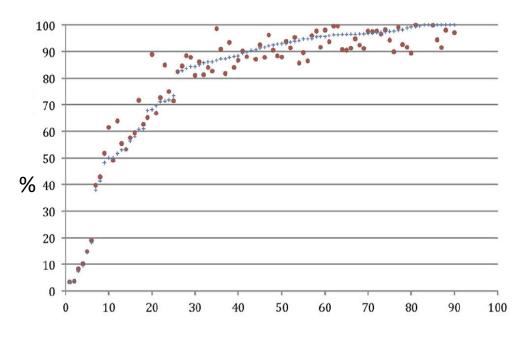


Hintz SR, et al. J Pediatr 2015;166:289-95



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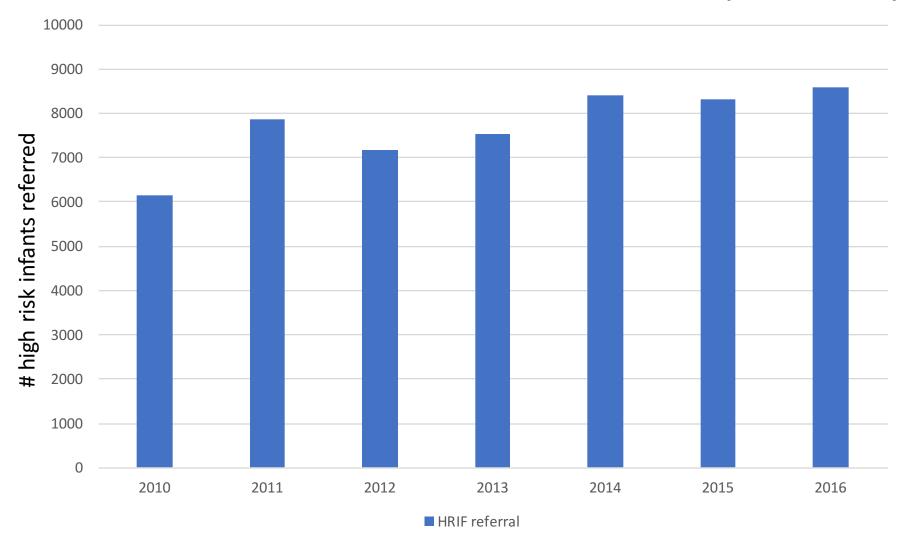
HRIF/CPQCC Match Summary Report for Infants Discharged Home, 1/1/2017 to 12/31/2017

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			



Referral to CPQCC CCS HRIF by birth year

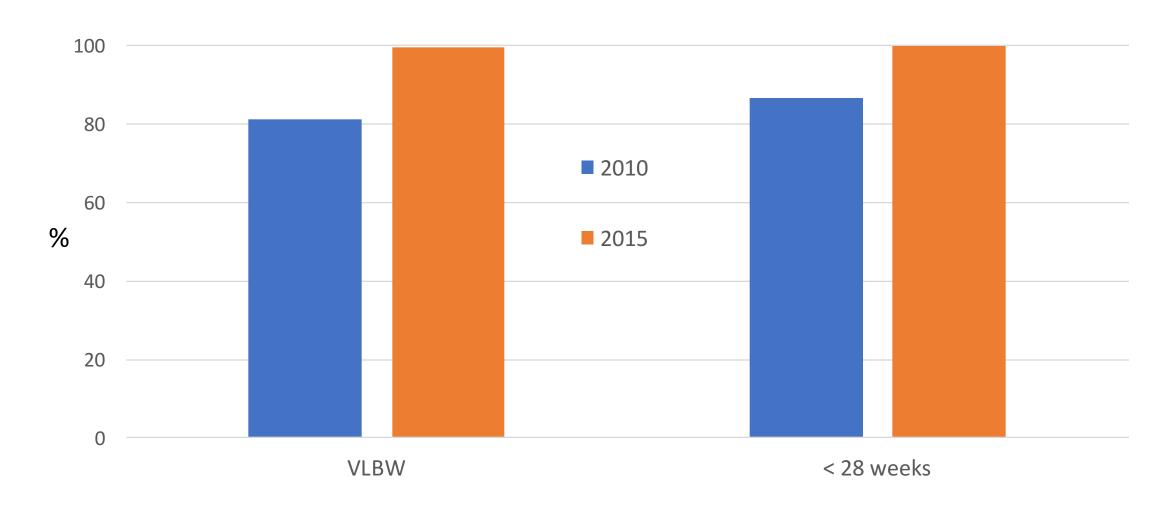


The # of high risk infants referred to CPQCC CCS HRIF has increased since 2010.

From just over 6000/year to more than 8500/year



Improved referral to CPQCC CCS HRIF at NICU discharge





Programmatic and Administrative Barriers to High-Risk Infant Follow-Up Care

Survey details

- 53 questions divided into the following categories: (1) NICU to HRIF referrals, (2) HRIF program structure and personnel, (3) HRIF program visits and follow-up strategies, (4) HRIF program resources, and (5) HRIF challenges.
- 82% of HRIF programs in CPQCC CCS HRIF responded → 90% from Program Coordinators



Tang BJ, et al. Am J Perinatol. 2018 Feb 13. [Epub ahead of print]



Barriers and challenges to successful follow up

Table 2 Strategies to improve no-show rates at HRIF

Strategies used to follow up with families after missed HRIF visit	N (%)
Multiple calls until personal response and reschedule	43 (77)
Postcard or letter by mail	41 (73)
Call to pediatrician	21 (38)
One call only—leave message if no answer	10 (18)
Email	5 (9)
Robo-call	0
Strategies used to remind families of upcoming	HRIF visits
Personal call	52 (93)
Postcard or letter by mail	40 (71)
"Robo-call"	16 (29)
Email	10 (18)
Other	7 (13)

Table 4 Resource needs and barriers in HRIF

Areas considered significant barriers and challenges to successful follow-up	N	(%)
Parent/family work schedule	39	(70)
Parent/family perception that the child is doing well and no need for HRIF	38	(68)
Transportation issues	37	(66)
Patient/family distance from clinic	30	(54)
Insurance	30	(54)
Limited availability for HRIF clinic times	26	(46)
Limited personnel for tracking/follow-up calls in HRIF program	23	(41)
Parent/family refusal for other reasons	18	(32)
Other	10	(18)

Tang BJ, et al. Am J Perinatol. 2018 Feb 13. [Epub ahead of print]



Multivariable model – Factors associated with successful 1st HRIF

Factor	Adjusted OR (95% CI)	p-value
Associated with higher odds	<u> </u>	
Maternal age (vs. <20 years)		
30-39	1.8 (1.3 – 2.3)	<0.0001
40+	1.7 (1.2 – 2.5)	0.007
Maternal prenatal care	2.0 (1.4 – 2.9)	0.0005
Birth weight (vs. 1251-1499 g)		
501-750 g	2.1 (1.6 – 2.8)	<0.0001
751-1000 g	1.8 (1.5 – 2.3)	<0.0001
1001-1250g	1.4 (1.2 – 1.7)	0.0006
Insurance (vs CCS or MediCal only)		
HMO/PPO + CCS	2.0 (1.4 - 2.9)	<0.0001
HRIF program VLBW volume (vs. lowest quartile)		
2 nd quartile	4.5 (2.4 – 8.4)	<0.0001
3 rd quartile	2.2 (1.2 – 4.0)	0.009
Associated with lower odds		
Maternal race African American	0.6 (0.5 – 0.8)	<0.0001
SGA at 33+ weeks	0.7 (0.4 – 0.9)	0.02
One parent 1° caregiver (vs. both)	0.7 (0.6 – 0.8)	0.0001
Miles from HRIF program (vs. lowest quartile)		
Highest quartile	0.6 (0.5 – 0.8)	0.0001
3 rd quartile	0.7 (0.6 – 0.9)	0.008



But why is the HRIF visit even important?



Why is the HRIF visit important?

- The interdisciplinary HRIF team has special expertise to recognize evolving difficulties, identify resources.
- Without the HRIF visit, these needs may not be identified.
 - Earlier identification allows for early intervention, which ultimately may improve outcomes.

Our question: Are substantial incremental medical, functional, and family needs identified at the 1st and 2nd HRIF visit?



Service Utilization at Ist HRIF Visit

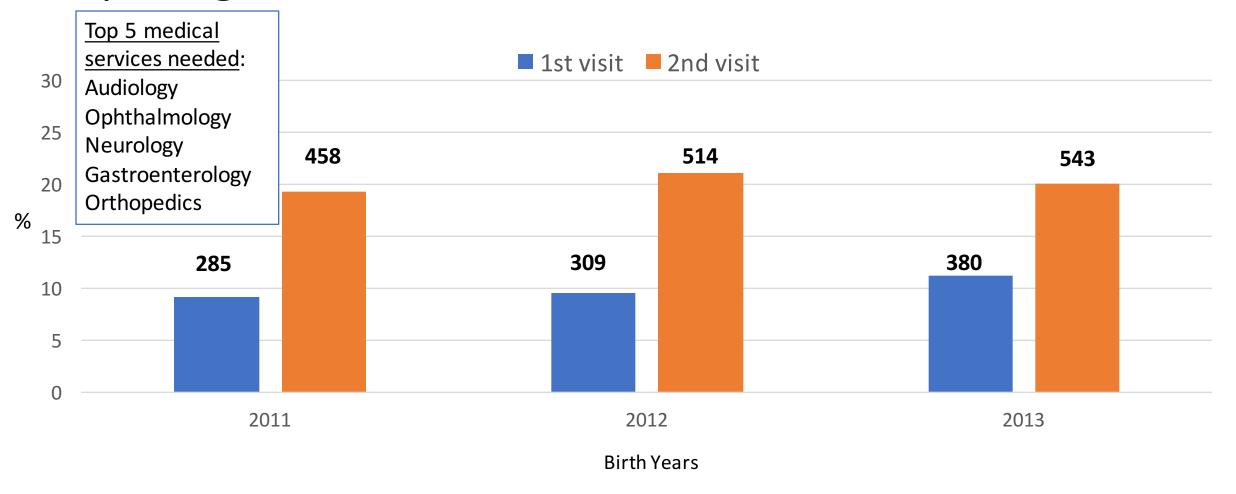
VLBW = very low birth weight; **HIE** = hypoxic ischemic encephalopathy

	VLBW N=4900	HIE N=193
Medical specialties - currently receiving	n (%)	n (%)
0	1845 (38%)	68 (35%)
1 to 2	2502 (51%)	90 (47%)
3 to 4	477 (10%)	30 (16%)
5 or more	76 (2%)	5 (3%)
Special services - currently receiving		
0	3369 (59%)	105 (54%)
1 to 2	1344 (27%)	65 (34%)
3 to 4	168 (3%)	21 (11%)
5 or more	19 (0.4%)	2 (1%)

Median age at follow up = 6 months

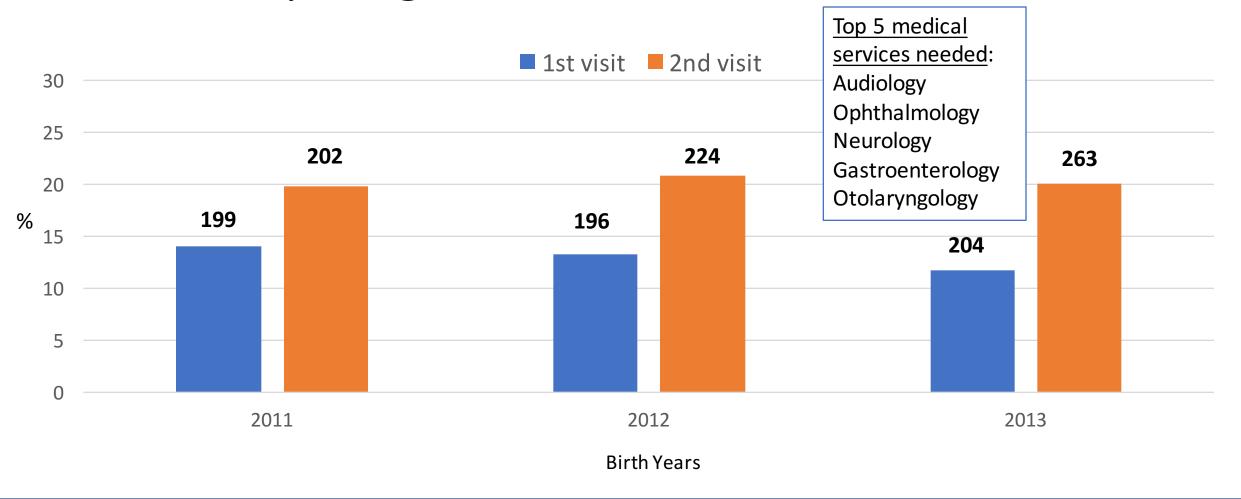


VLBW - Unmet needs for medical subspecialty services requiring referral at 1st and 2nd HRIF visits





"Big babies" - Unmet needs for medical subspecialty services requiring referral at 1st and 2nd HRIF visits







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



Program Letter: 01-0917

September 27, 2017

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

Dear HRIF Medical Director and HRIF Coordinator:

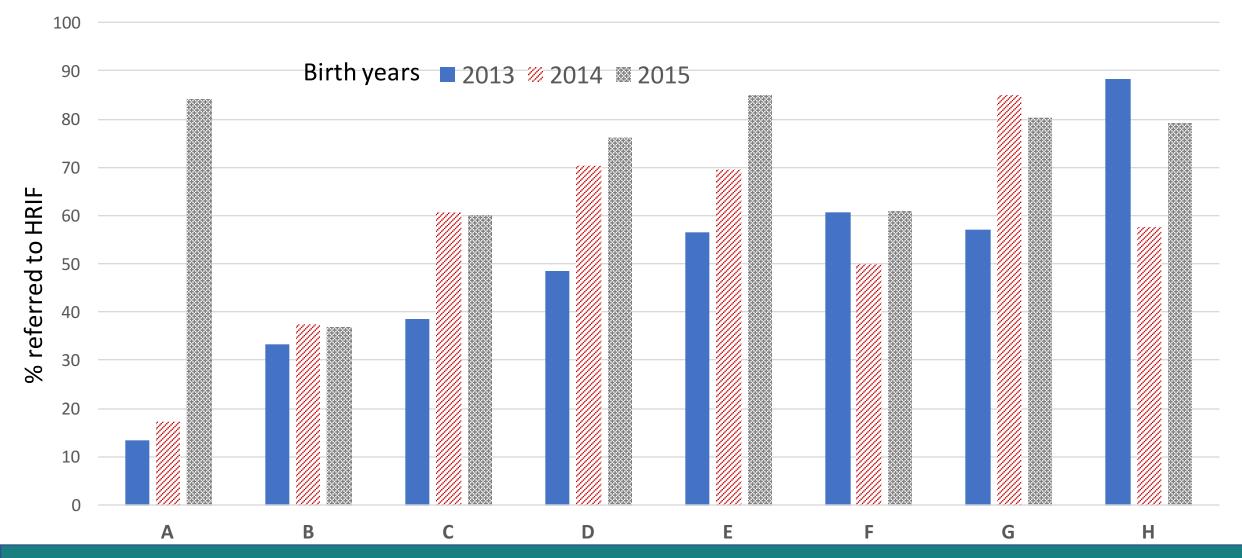
The HRIF Numbered Letter 05-1016 and HRIF Program Letter 01-1016, both dated October 12, 2016, updated the Medical Eligibility criteria for HRIF to include Congenital Heart Disease (CHD) requiring surgery or minimally invasive intervention. This letter is written to address several requests from HRIF local programs to further clarify the CHD Medical Eligibility criteria and provide some case examples.

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.
 - 60.1% referred to HRIF

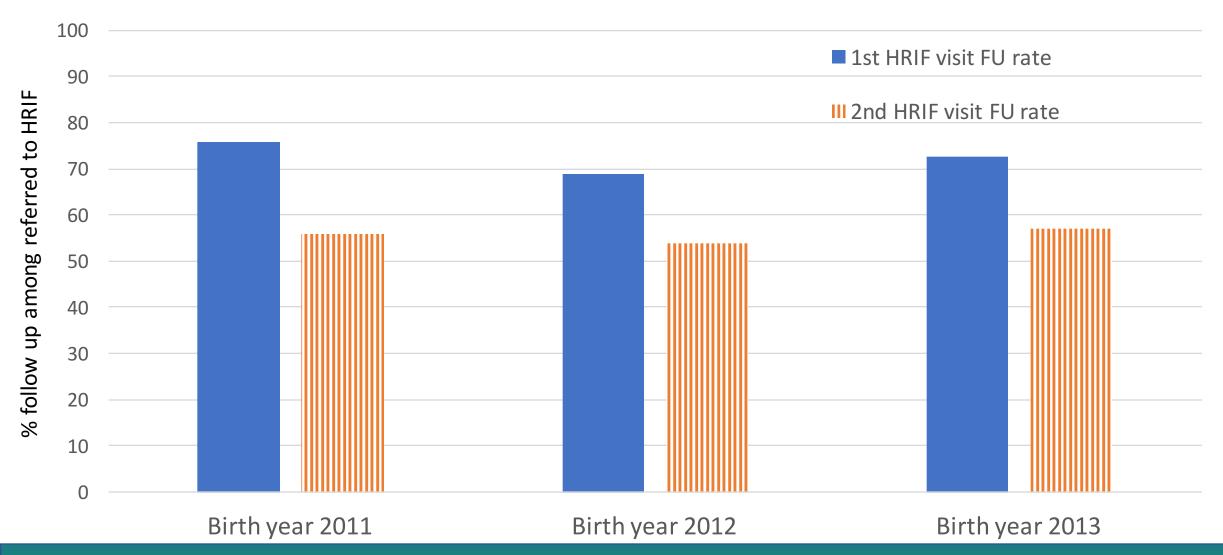


<u>CHD neonates requiring intervention</u> - rates of <u>referral to HRIF at discharge</u>: Highest volume CHD intervention CPQCC NICUs, birth years 2013-2015





Follow up rates to 1st and 2nd HRIF visits among CHD neonates in CPQCC requiring intervention, birth years 2011-2013





Unmet needs for medical subspecialty services requiring referral at 1st and 2nd HRIF visits

Birth year	2011	2012	2013
1 st HRIF visit (n)	153	128	153
Medical services – referred at visit, n (%)			
0 services	120 (78%)	104 (81%)	133 (87%)
1 service	26 (17%)	17 (13%)	16 (11%)
2 or more services	7 (5%)	7 (6%)	4 (2%)
2 nd HRIF visit (n)	113	100	120
Medical services – referred at visit, n (%)			
0 services	78 (69%)	77 (77%)	86 (72%)
1 service	25 (22%)	19 (19%)	27 (23%)
2 or more services	10 (9%)	4 (4%)	7 (6%)



CHD requiring neonatal surgery in California

- Significant opportunities to improve HRIF referral and follow up exist for CHD infants requiring neonatal surgery in California.
- Substantial additional needs are identified at HRIF visits, with ~ 1 in 4 of these children requiring at least 1 service referral at the 2^{nd} visit.
- Process improvements have already been undertaken across
 California through the CPQCC CCS HRIF → clarification of CHD-related HRIF eligibility, highlighting expectations for referral at NICU discharge.



CHD requiring neonatal intervention – Next steps

- Data thus far represent <u>CPQCC CHD patients</u> >
 does not represent comprehensive neonatal CHD population.
- Goal to identify data additions required to cardiac data in California CVICUs — synergize elements to with short forms/ limited data collection instruments.
 - Currently in pilot project with CHLA (VPS database)
- **Will reach out to HRIF groups at major CV sites, assemble key stakeholders at sites, integrate data from CVICUs, facilitate HRIF referrals and FU.





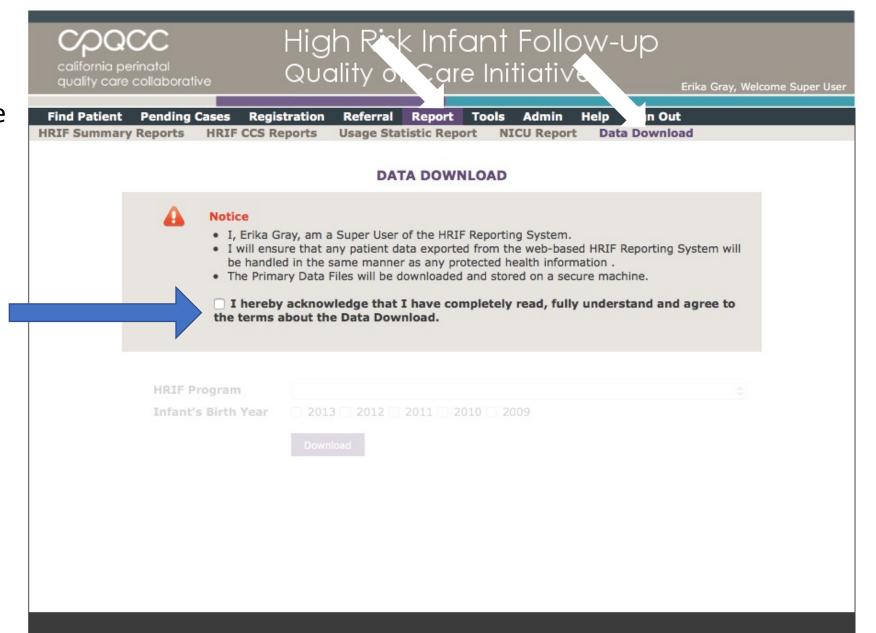
Site-specific Primary Data Files

Available for download in 1-2 weeks!





- Because of the highly sensitive nature of the data, only one individual will be assigned to download these data – The Medical Director of the HRIF clinic.
- The Medical
 Director may
 share the files
 as he/she feels
 appropriate.





cpacc

High Risk Infant Follow-up

california perinatal quality care collaborative	Quality of Care Initiative	Erika Gray, Welcome Super Us
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	DATA DOWNLOAD	
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auality care collaborative

High Risk Infant Follow-up Quality of Care Initiative

RIF Summa	ary Reports HRIF CCS	Reports Usage Stat	tistic Report	NICU Report	Data Download	
		DAT	A DOWNLOA	D		
	I will en be hand The Prin	Gray, am a Super User of sure that any patient da led in the same manner nary Data Files will be d viedged by Erika Gray	ata exported from as any protected ownloaded and si	the web-based d health informat tored on a secur	e machine.	II
	HRIF Program Infant's Birth Year	Lucile Packard Childre ✓ 2013 ✓ 2012 Download				0
ı						



8 Files with each birth year download

- HRIF Primary Data "Read Me" pdf
- HRIF Data Dictionary
 - abc_2012_Registration.csv
 - abc_2012_NoShowVisit.csv
 - abc_2012_AdditionalVisit.csv
 - abc_2012_StandardVisit.csv
 - abc_2012_SvHospReason.csv
 - abc_2012_SvOtherMed.csv

abc_2012_XXXX:

site #_ Birth Year_ data description



HRIF Data Dictionary - screenshot

Α	В	С	D	E	F	G
Section	Variable Name	Item on Form / Description	Revision Information	Data Type	Possible Value	Coding Rules
	VISIT_ID	Not on the form. But this is the unique number corresponding to each standard visit which is used for linking standard visit dataset with hospital reason dataset. Number of hospital visits corresponding to the ith standard visit.		NUMERIC		
	HRIF_ID	HRIF I.D. #		NUMERIC		
	CHANGEABLE_HRIF_ID			NUMERIC		
	CCS_NOT_HRIF_REFID	Infant enrolled in a CCS clinic other than the HRIF program	Added in 2018	NUMERIC	{434, 435, 436}	434 = No; 435 = Yes; 436 = Unknown
	CCS_NUM	CCS#		NUMERIC		
	NOT_CPQCC_ELIGIBLE	Infant NOT CPQCC Eligible	Added in 2012	CHARACTER	True/False	
	CPQCC_NUM_OSHPD	CPQCC Reference (OSHPD Facility Code)	Required since 2010	NUMERIC		
	CPQCC_NUM_PATIENT_SEQ	CPQCC Reference (CPQCC Patient ID Number)	Required since 2010	NUMERIC		
	DATE_OF_BIRTH	Date of Birth	Required since 2010	NUMERIC		
	BIRTH_HOSP_ID	Birth Hospital	Required since 2010	NUMERIC		
	BIRTH_WEIGHT	Birth Weight	Required since 2010	NUMERIC		
	GESTATIONAL_AGE_WEEKS	Gestational Age (Weeks)	Required since 2010	NUMERIC		
	GESTATIONAL_AGE_DAYS	Gestational Age (Days)	Required since 2010	NUMERIC		
	SINGLETON_MULTIPLE_REFID	Singleton/Multiple	Required since 2010	NUMERIC	68, 69, 70, 71, 72, 73,	77 = 5E; 76 = 5D; 75 = 5C; 74 = 5B; 73 = 5A; 72 = 4D; 73 = 4C; 70 = 4B; 69 = 4A; 68 = 3C; 67 = 3B; 66 = 3A; 65 = 2B; 64 = 2A; 63 = Unknown; 169 = Single
	INFANT_GENDER_REFID	Infant's Gender	Required since 2010	NUMERIC	{78, 79, 80}	78 = Unknown; 79 = Female; 80 = Male
Program Registration	INFANT_ETHNICITY_REFID	Infant's Ethnicity		NUMERIC	{81, 82, 83, 170}	81 = Unknown; 82 = Hispanic/Latino; 83 = Non-Hispanic; 170 = Declined
Information	INFANT_RACE_CAT_REFID	Infant's race SINGLE vs. Multi		NUMERIC	{428, 429}	428 = Single; 429 = Multiracial
	INFANT_RACE_REFID	Infant's race	In 2017 race category 86 was seperated into two catergories 88 and 90	NUMERIC	{84, 85, 86, 87, 88, 89, 90, 91, 613}	84 = Unknown; 85 = American (North, South or Central) Indian or Alaskan Native; 86 = Asian, Native Hawaiian or Other Pacific Islander; 87 = Black or African American; 88 = Asian; 89 = White; 90 = Native Hawaiian or Other Pacific Islander; 91 = Declined; 613 = Other
	DISHCARGE_NICU_ID	Hospital Discharging to Home		NUMERIC		
	DATE OF DISCHARGE	Date of Discharge to Home		NUMERIC		



HRIF Primary Data Read Me



HRIF PRIMARY DATA FOLDER

There will be a total of eight (8) files in the CSV (Comma Separated Value) format and were born in the selected birth cohort year names will be listed as "CenterNumber_Bi captures all changes since 2010 as well as

File abc_xxxx_AdditionalVisit.csv contain infants/children who were followed by ce that additional visits were not entered or dataset is HRIF_ID which is unique per pat

File abc_xxxx_StandardVisit.csv contains data from the STANDORD VISIT (SV) FORM except the Hospitalization Since Last Visit and Other Medical Condition sections. It contains all SVs for infants/children who were followed by center abc and born in year xxxx. Each patient is identified by the HRIF_ID. Each distinct visit is identified by the VISIT_ID. An example is shown as follows:

VISIT_ID	HRIF_ID	DATE_OF_VISIT	STANDARD_VISIT_ID
1111	123	13-Sep-13	1
1112	123	5-Dec-14	2
1113	123	6-Nov-15	3
1114	124	1-Jun-12	1
1115	124	13-Sep-13	2
1116	125	6-Jul-12	1

HRIF patient 123 has completed all three standard visits. Each visit is identified through a unique VISIT_ID. Users can sort by HRIF_ID and DATE_OF_VISIT to obtain a chronological standard visit dataset. Another example would be patient 124 who has completed two standard visits, hence there will be only two rows of data designated for that infant/child in the standard visit dataset.



"Special Reports" → goal for site-specific report availability in *Summer 2018*

- Identification and % referral of HRIF eligible infants by major eligibility criteria
- CCS eligible conditions at time of discharge from CCS NICUs and % referral to HRIF
- Identification of additional CCS medical eligibility at HRIF standard visits 1 and 2
 - **Goal to add special services**
- HRIF follow up to 1st and 2nd visits among major HRIF risk categories (VLBW, "big baby", CHD requiring intervention in NICU admission)



HRIF Clinic Capacity issues

- Given the committed work of CPQCC NICUs and HRIF teams to assure referral/ registration to HRIF and follow up,
 - This has uncovered capacity challenges in clinics due to the lack of space and/or availability, resources/ staff, etc.
- In partnership with CCS, we developed a short survey to help identify perceived barriers and challenges related to HRIF clinic capacity.
- The survey also includes a few questions about how HRIFeligible CHD patients are identified, referred and followed in HRIF clinics.
- Will just sent to HRIF programs TODAY --> Due MARCH 7th



Contact Information

Name:		
Email Address:		
Hospital/Center Name:		
	ram / clinic currently experience., difficulties in accommodat	
○ Yes		
○ No		



This is your chance to share your insights (and frustrations) about capacity challenges and barriers with our CCS partners!

Capacity issues

Contributing factors

- i.e., inability to hire staff or providers due to financial or availability issues; limited clinic hours or space; etc.
- Current approach to addressing or avoiding challenges
 - i.e., limit registration to only specific patient groups; attempt to transfer referrals to other HRIF Programs; etc.

Plans to ameliorate

- i.e., new hires; new satellite sites or additional clinic days; etc.
- CHD patients requiring intervention
 - Barriers to following
 - Existence of cardiac follow up clinic in your institution
 - Effectiveness of communication with cardiac teams



Capacity issues

Table 3 Composition of staff in HRIF

Number of providers staffed in clinic	N (%)
1	10 (17)
2	6 (12)
3	9 (17)
4 or more	29 (54)
Dedicated administrative assistant and/or clinic scheduler	N (%)
Do not have a dedicated person	18 (33)
Part-time person	24 (44)
One full-time person	9 (16)
More than one full-time person	4 (7)

Table 4 Resource needs and barriers in HRIF

Areas of significant resource needs for HRIF	N	(%)
Additional funding	30	(54)
More space in clinic facilities and/or expanded number of half-day clinics	28	(50)
Additional personnel for scheduling/follow-up calls	26	(46)
Better access to subspecialists for referrals	19	(34)
Additional personnel for coordination of services	18	(32)
Expansion to additional outreach locations	16	(29)
Other	14	(25)
More medical and NP providers	13	(23)
More psychologists and/or other staff qualified to conduct developmental and behavioral testing	8	(14)

Tang BJ, et al. Am J Perinatol. 2018 Feb 13. [Epub ahead of print]



 Dashboards – CPQCC and explorations for CPQCC CCS HRIF

• GOAL - HRIF Dashboard ~ End of year 2018 (??)







QI Projects

QI Toolkits

QI Research





"Our goal is to improve the health of pregnant women and newborns by making sure that approaches to illness that have been demonstrated to be effective are actually being carried out."

- JEFFREY B GOULD, MD, MPH, PRINCIPAL INVESTIGATOR, CPQCC

PQIP Committee

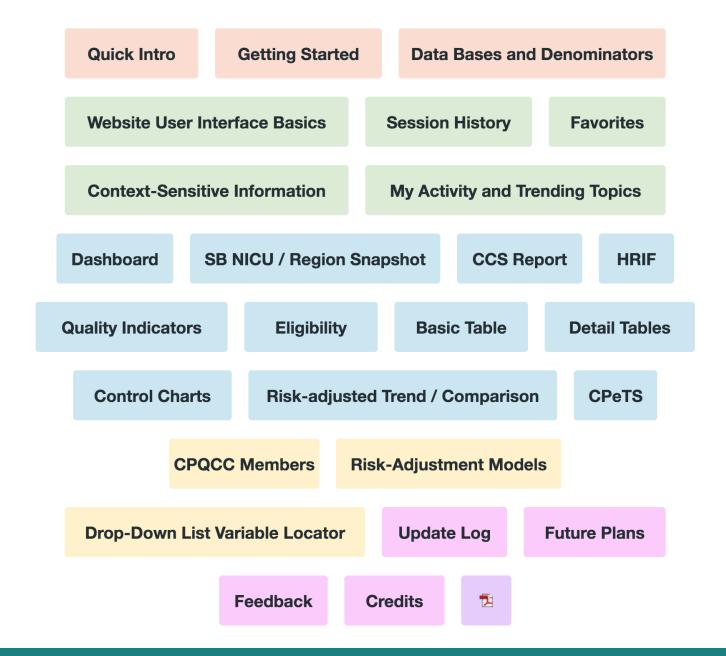
Quality Improvement

PQIP defines indicators and benchmarks, recommends quality improvement objectives, provides maperformance improvement, and assists providers in a multi-step transformation of data into improvement. More

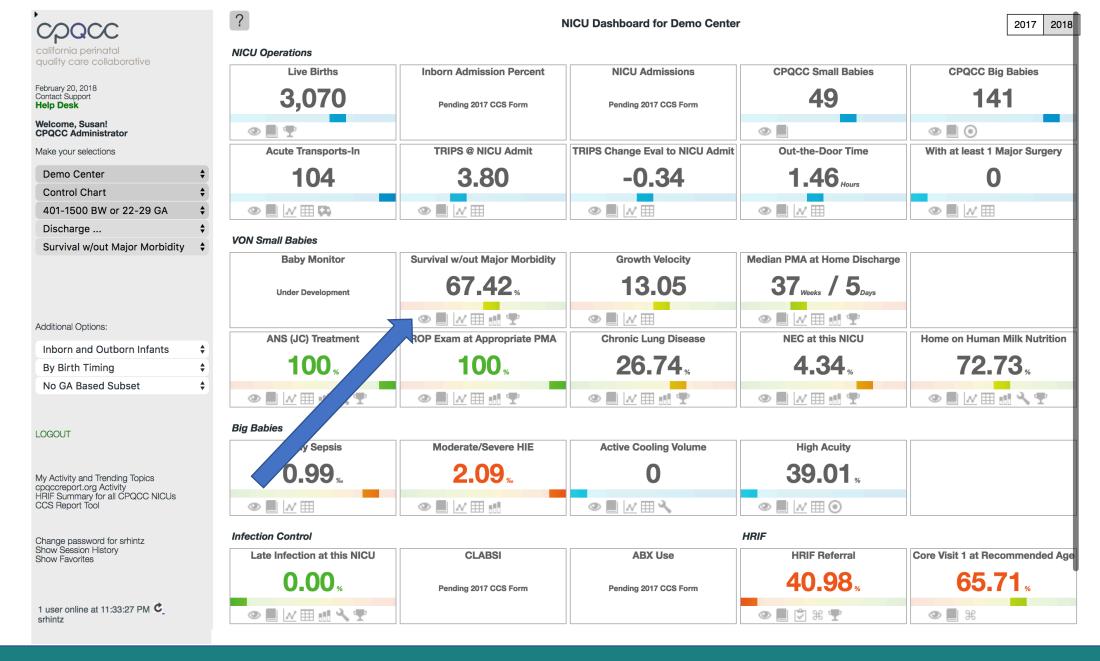




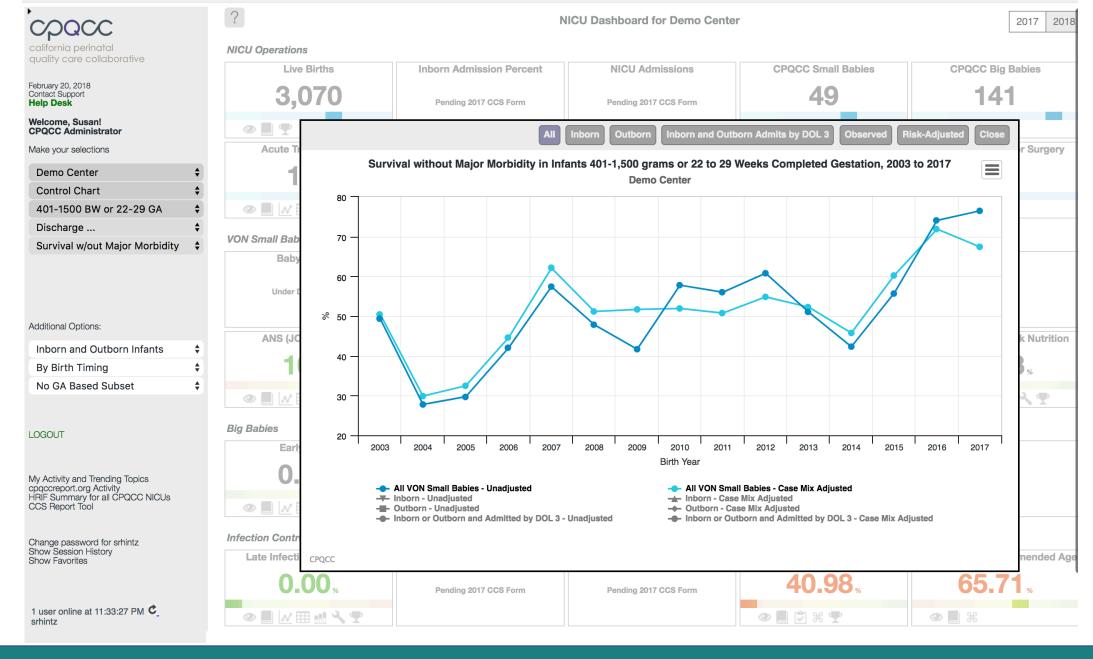










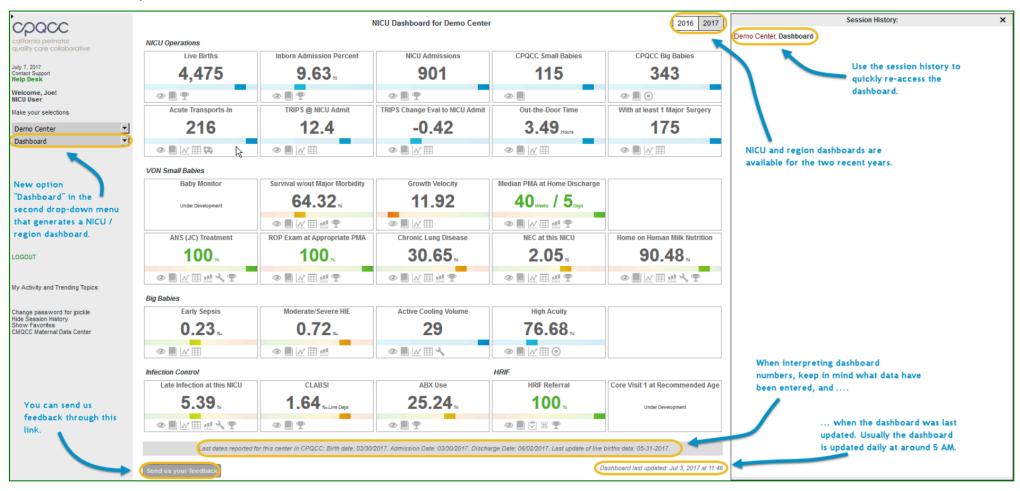




Dashboard

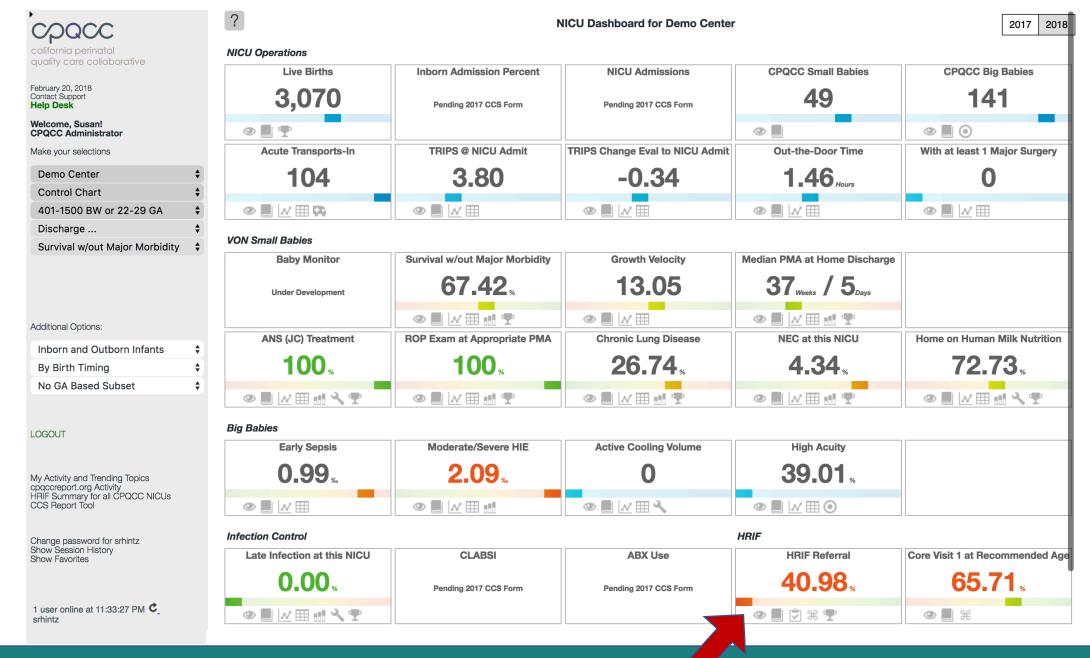
With the July 2017 close-out, the CPQCC data center added NICU and region dashboards to the cpqccreport.org website. The dashboards were the result of a 1-year process guided by the CPQCC PQIP committee with the goal of simplifying access to the many different reports and features of the report website.

An annotated example of a NICU dashboard is shown below.

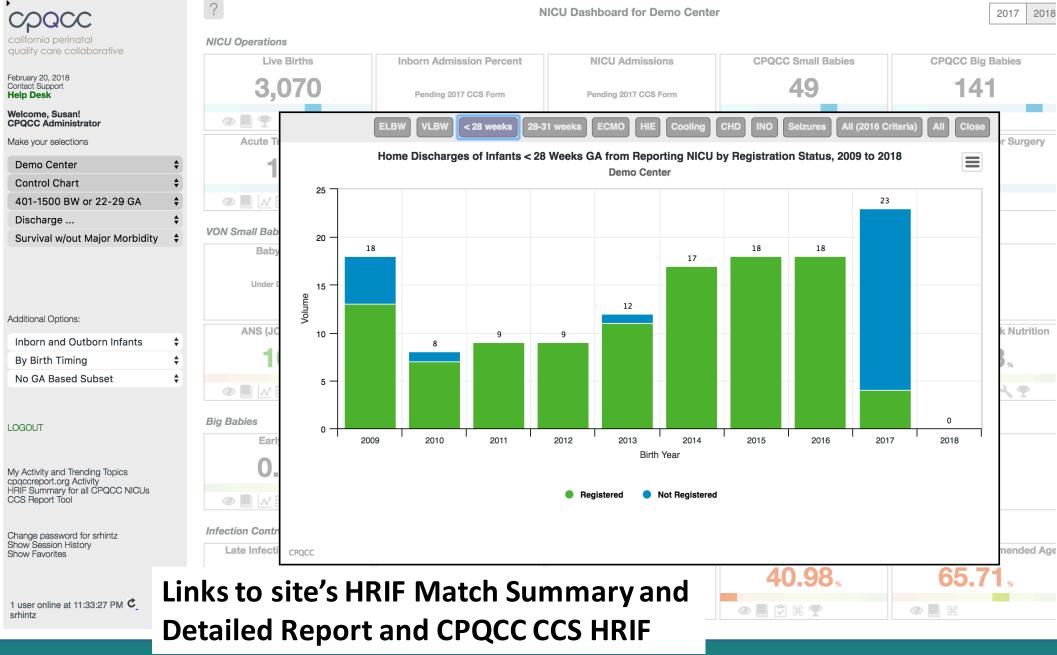


Dashboards are loaded by default upon logon for users with access to a single center. The dashboard shows the current NICU or region status with respect to metrics reflecting NICU operations, VON Small Babies (401 to 1,500 grams or 22 to 29 completed weeks gestation), CPQCC Big Babies, Infection Control, and High Risk Infant Follow-up (HRIF). The different metrics are each shown in separate boxes:

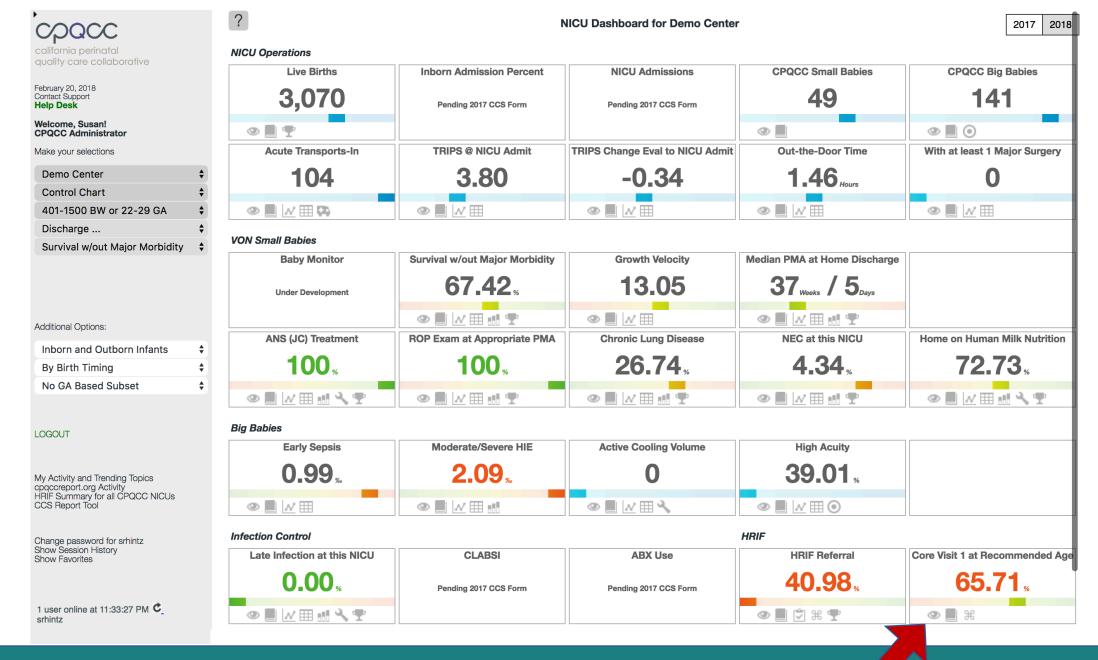
















Potential areas of focus for CPQCC CCS HRIF Dashboard

- → All showing overall HRIF in California, highlighting your site
- → Button filters by eligibility EGA range, ELBW, VLBW, HIE, CHD, etc.
- Follow up rates over standard visits and years –
- Age at follow up visit by standard visit and over years —
- Growth parameters (and %iles), breastmilk at 1st visit
- Hospitalizations, Surgeries, Medications, Equip by visit and over years
- Medical and Special Services -
 - Receiving at visit, required at visit, longitudinal trajectory of referred and received challenges.
- HRIF Program Profile information Medical eligibility, sociodemographic, caregiver information, caregiver concerns



		Core V	isit #1			Core Visit #2			Core Visit #3			
Hospitalizations Since Last Visit	N	%	N	%	N	%	N	%	N	%	N	%
Yes	34	17.2%	469	14.7%	23	14.6%	278	10.7%	17	13.2%	170	8.7%
Hospitalization Reasons												
Respiratory Illness	19	9.6%	231	7.3%	14	8.9%	148	5.7%	10	7.8%	84	4.3%
Having Surgeries During Hospitalization	11	5.6%	151	4.7%	9	5.7%	91	3.5%	4	3.1%	47	2.4%
Other Medical Rehospitalization(s)	4	2%	60	1.9%	1	0.6%	29	1.1%	1	0.8%	14	0.7%
Gastrointestinal Infection(s)	0	0%	21	0.7%	2	1.3%	15	0.6%	1	0.8%	12	0.6%
Other Infection(s)	2	1%	29	0.9%	0	0%	18	0.7%	0	0%	15	0.8%
Seizure Disorder(s)	0	0%	8	0.3%	0	0%	6	0.2%	2	1.6%	9	0.5%
Urinary Tract Infection(s)	0	0%	12	0.4%	1	0.6%	3	0.1%	0	0%	1	0.1%
Surgeries Since Last Visit												
Yes	18	9.1%	263	8.3%	12	7.6%	179	6.9%	13	10.1%	114	5.9%
Surgery Reasons												
Other Surgical Procedures	4	2%	27	0.8%	8	5.1%	42	1.6%	3	2.3%	28	1.4%
Other Gastrointestinal Surgical Procedures	4	2%	19	0.6%	3	1.9%	13	0.5%	0	0%	7	0.4%
Inguinal Hernia Repair	6	3%	111	3.5%	1	0.6%	34	1.3%	0	0%	11	0.6%
Tympanostomy Tubes	0	0%	4	0.1%	3	1.9%	24	0.9%	2	1.6%	24	1.2%
Gastrostomy Tube Placement	1	0.5%	12	0.4%	2	1.3%	10	0.4%	2	1.6%	8	0.4%
Retinopathy of Prematurity	1	0.5%	27	0.8%	2	1.3%	8	0.3%	1	0.8%	2	0.1%
Other Genitourinary Surgical Procedures	0	0%	9	0.3%	0	0%	20	0.8%	2	1.6%	12	0.6%
Other ENT Surgical Procedures	0	0%	10	0.3%	0	0%	16	0.6%	2	1.6%	12	0.6%
Cardiac Surgery	2	1%	18	0.6%	0	0%	4	0.2%	0	0%	4	0.2%
Shunt/Shunt Revision	0	0%	14	0.4%	0	0%	8	0.3%	1	0.8%	7	0.4%

Example site – CCS Report (2013)



california perinatal

High Risk Infant Follow-up Quality of Care Initiative

quality care collaborative	Quality of Care initialive	Susan Hintz, MD, Welcome Sup	er User
		min Help Sign Out	
HRIF Summary Reports HRIF CCS Re	eports Usage Statistic Report NICU Report		
	HRIF SUMMARY REPORT		
	HRIF Summary Report is updated in real time		
HRIF Program	All	\$	
Discharge NICU	All	<u>*</u>	
Infant's Birth Year	All 💠		
Infant's Birth Weight or Gestational Age	All \$		A WEALTH
Infant's Qualifying Medical Condition	All \$		information
Report Name	Standard Visit Summary Report (Core Visit #1)		_
Report Section Nam	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		about your site and California!
	SPECIAL SERVICES REVIEW STATE PROGRAMS AND SOCIAL CONCERNS/RESOURCES		

	Num	%	Num	%	% Median	% Lower Quartile					
		PRIN	MARY CAR	E PROVID	ER						
Child has a Primary Care Provider (Added Jan 2012)											
Yes	195	100%	2883	99.8%	100%	100%	100%	+			
Primary Care Provider Acts as t	he Child	's Medical	Home (Ad	lded Jan 2	012)						
No	180	92.3%	1281	44.3%	43.4%	8.2%	100%	+			
Yes	15	7.7%	1515	52.4%	86.4%	48.8%	95.8%	• —			
		Н	OSPITALI	ZATIONS							
Hospitalizations Since Discharg	e or Last	t Visit									
No	169	86.7%	2593	89.7%	91.5%	85.7%	95.2%	•+			
Yes	26	13.3%	296	10.2%	10.4%	5.9%	15.3%	+			
Hospitalization Reasons											
Respiratory Illness	19	73.1%	181	61.1%	71.4%	33.3%	100%				
Other Infection(s)	3	11.5%	29	9.8%	33.3%	16.7%	57.1%	•—			
Other Medical Rehospitalization(s)	2	7.7%	30	10.1%	21.4%	14.3%	33.3%	•+			
Having Surgeries During Hospitalization	2	7.7%	104	35.1%	50%	25%	100%	• ——			
Unknown	1	3.8%	6	2%	41.7%	13.3%	87.5%	• ——			
Gastrointestinal Infection(s)	1	3.8%	17	5.7%	16.7%	11.3%	25%	• +			

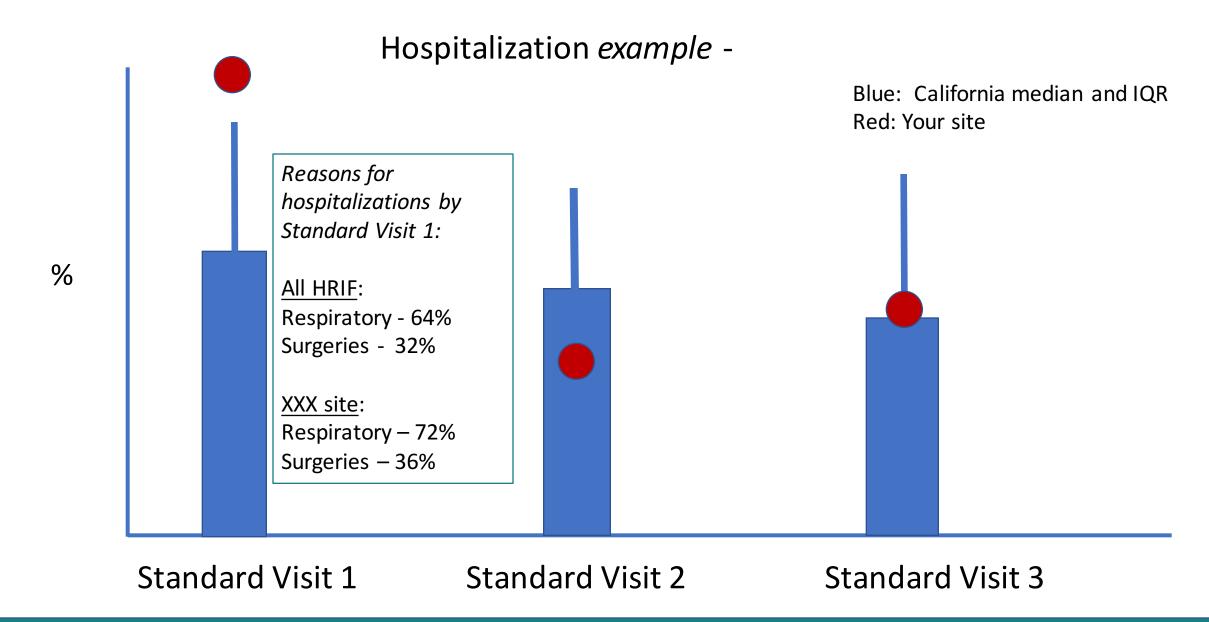


	Num	%	Num	%	% Median	% Lower Quartile	% Upper Quartile				
			MEDICAT	IONS							
Medications Since Discharge or La	Medications Since Discharge or Last Visit										
No	110	56.4%	1777	61.5%	67.2%	50%	84%	++			
Yes	85	43.6%	1111	38.4%	37.9%	18.4%	50%				
Medication Details											
Nutrition Supplements	35	41.2%	408	36.7%	40.8%	29.6%	57.1%	+			
Nutrition Supplements - Dietary (Added Jan 2010)	35	41.2%	385	34.7%	40.1%	27.4%	55.9%	+			
Inhaled Bronchodilators (inter.)	31	36.5%	476	42.8%	46.8%	33.3%	53.6%	•+			
Other	23	27.1%	235	21.2%	25%	15.5%	39%	+			
Inhaled Steroids (daily)	17	20%	145	13.1%	14.5%	8.8%	23.6%	+•			
Inhaled Bronchodilators (daily)	10	11.8%	71	6.4%	10.1%	5.3%	16.7%	+			
Antibiotics/Antifungal	9	10.6%	172	15.5%	17.4%	12.2%	30.5%	•—			
Anti Reflux Medication	8	9.4%	144	13%	14.3%	10.5%	21.7%	•+			
Inhaled Steroids (inter.)	4	4.7%	106	9.5%	14.3%	7.2%	23.3%	•+			
Nutrition Supplements - Enteral (Added Jan 2010)	1	1.2%	40	3.6%	5.3%	3.1%	14.3%	•			
Oral Steroids (Added Jan 2013)	1	1.2%	36	3.2%	8.2%	5.3%	12.2%	•+			
Antihypertensive	1	1.2%	6	0.5%	4.5%	1.3%	8.3%	+			
Anti Seizure Medication	1	1.2%	18	1.6%	4.8%	3.8%	6.7%	••			



		Num	%	Num	%	% Median	% Lower Quartile		_	
				EQUIPN	MENT					
Ī	Equipment Since Discharge or La	st Visit								
	No	170	87.2%	2489	86.1%	93.8%	77.7%	100%		-++
	Yes	25	12.8%	401	13.9%	12.8%	5.6%	24.7%	+	
	Equipment Details									
	Nebulizer	18	72%	321	80%	90%	75%	100%		•—
	Other	3	12%	32	8%	10%	7.7%	25.4%	+	
	Apnea/CR monitor	3	12%	28	7%	20%	15%	22.9%	•+	
	Braces/Castings/Orthotics	2	8%	22	5.5%	12.5%	8%	50%	•	
	Enteral Feeding Equipment (Added Jan 2010)	2	8%	49	12.2%	25%	10%	50%	•—	







HRIF site All California
N % N % Med IQR

BREASTMILK										
Is Child Currently Receiving Breastmilk? (Added Jan 2015)										
None	55	64%	2102		57.1%	45.8%	71.4%	++		
Some	14	16.3%	423	11.8%	12.2%	7.4%	20%	+		
Exclusively	5	5.8%	122	3.4%	4.4%	2.7%	6.7%	+		

	Median	Q1	Q3	Median	Q1	Q3				
PATIENT AGE AND GROWTH METRICS										
Adjusted Age	7 mon	6.2 mon	8.3 mon	6.3 mon	5.4 mon	7.6 mon				
Chronological Age	9.6 mon	8.7 mon	10.8 mon	9 mon	8 mon	10.3 mon				
Weight	17.9 lb 8.1 kg	16.1 lb 7.3 kg	19.4 lb 8.8 kg	16.5 lb 7.5 kg	14.6 lb 6.6 kg	18.5 lb 8.4 kg				
Length	26.4 in 67 cm	26 in 66 cm	27.6 in 70 cm	26 in 66 cm	25 in 63.4 cm	27.2 in 69.2 cm				
Head Circumference	17.3 in 44 cm	16.9 in 43 cm	17.9 in 45.5 cm	17.1 in 43.5 cm	16.5 in 42 cm	17.7 in 45 cm				



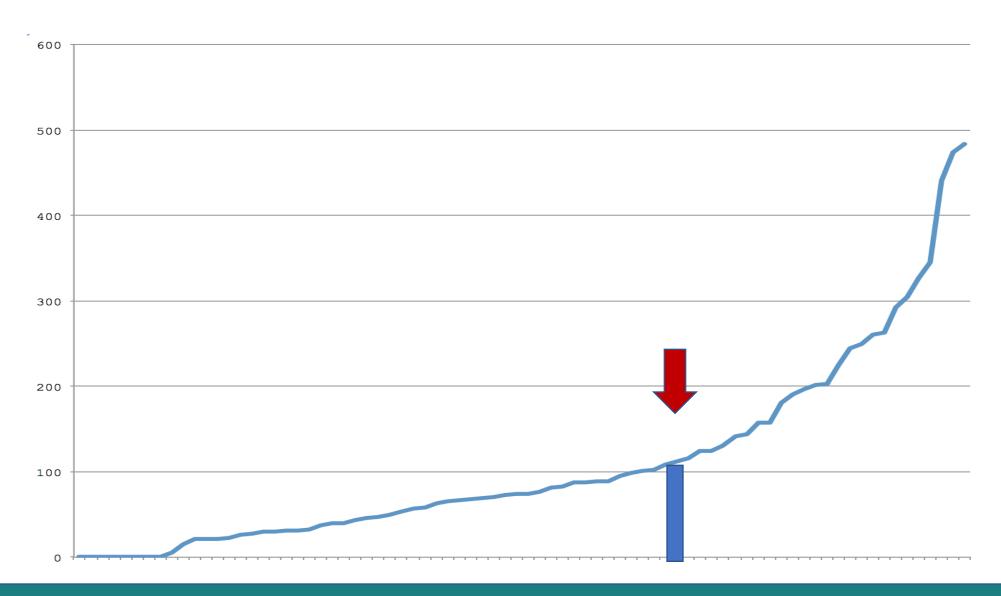
	N	%	N	%	Med	10	QR	
Caregiver Concerns								
Yes	44	51.2%	1200	33.4%	34.7%	19.6%	47%	-+-•
None	42	48.8%	2387	66.4%	66.7%	56.3%	85.7%	• +-
Details of Caregiver Concerns								
Motor Skills, Movement	17	38.6%	497	41.4%	42.9%	28.6%	58.8%	-+
Feeding and Growth	13	29.5%	385	32.1%	33.9%	26%	44.3%	+
Other	9	20.5%	287	23.9%	26.7%	14.3%	50%	*
Behavioral	6	13.6%	49	4.1%	7.1%	5.2%	10.7%	+•
Calming/Crying	2	4.5%	42	3.5%	7%	4.9%	11.1%	+
Speech and Language	2	4.5%	97	8.1%	11.4%	5.9%	17.8%	•+
Sleeping/Napping	2	4.5%	72	6%	9.1%	6.3%	20%	•+-
Vision	2	4.5%	61	5.1%	6.3%	4.4%	12.3%	+
Frequent Illness	1	2.3%	40	3.3%	7%	3.5%	13.1%	•+
Gastrointestinal/Stooling/Spitting- up	1	2.3%	135	11.3%	14.3%	9.7%	28.4%	• +-

All California



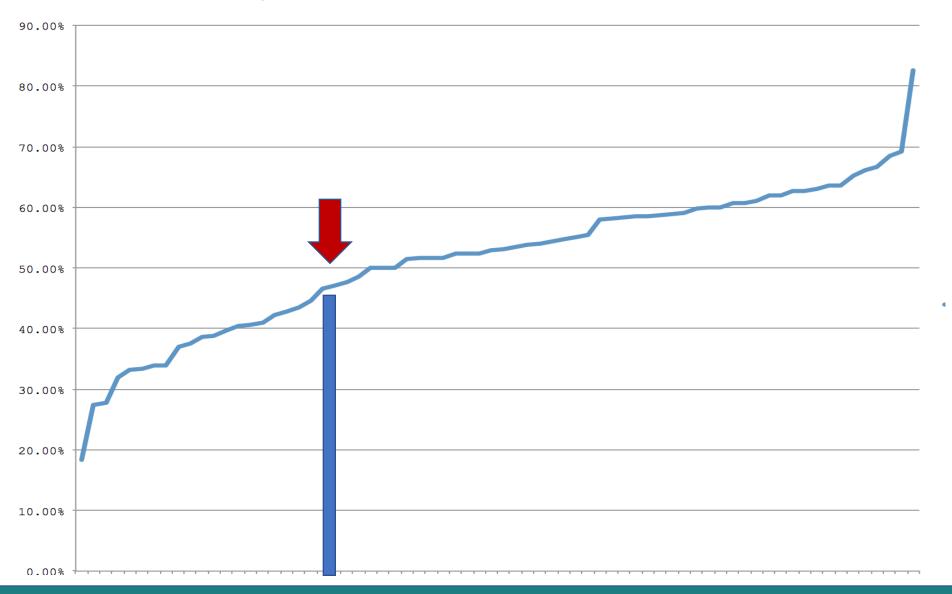
HRIF site

Annual HRIF clinic volume across sites

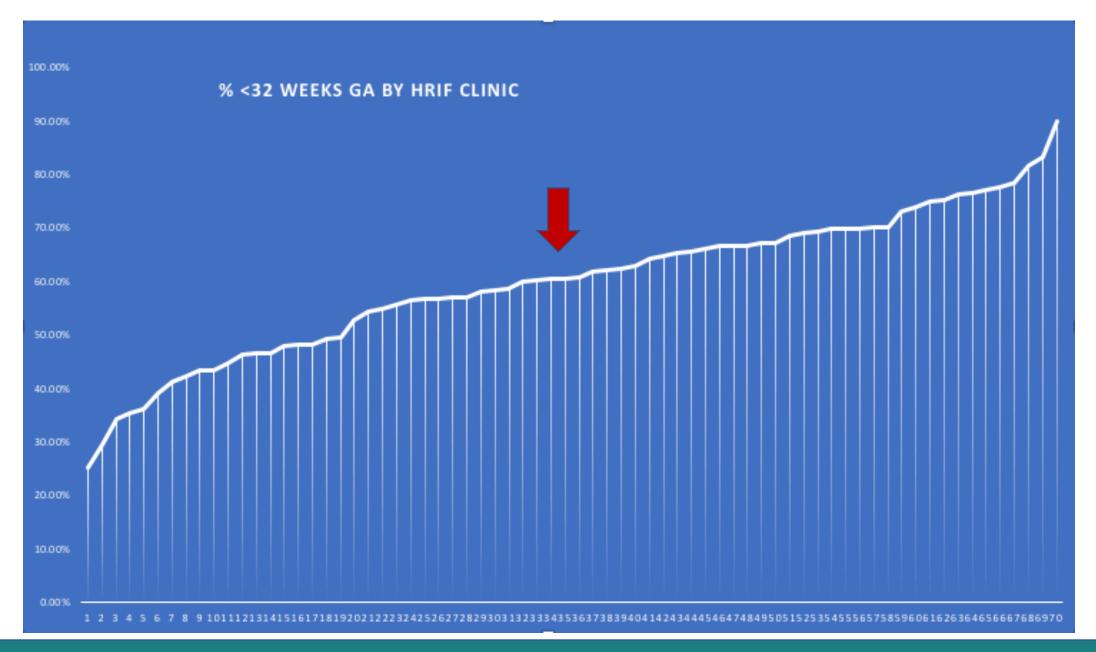




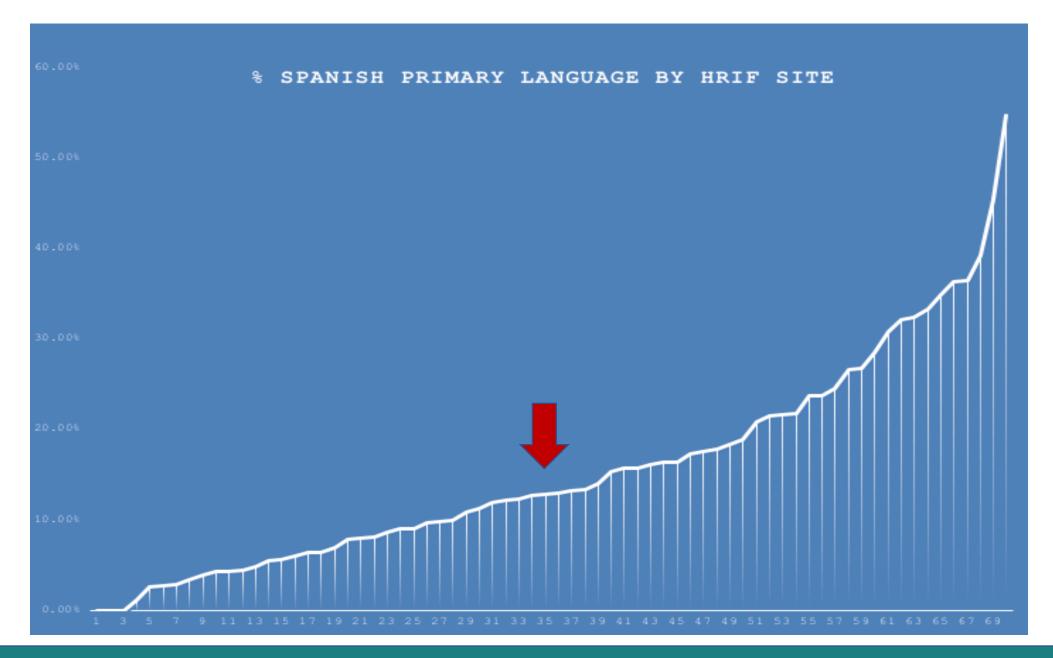
% VLBW across HRIF clinics





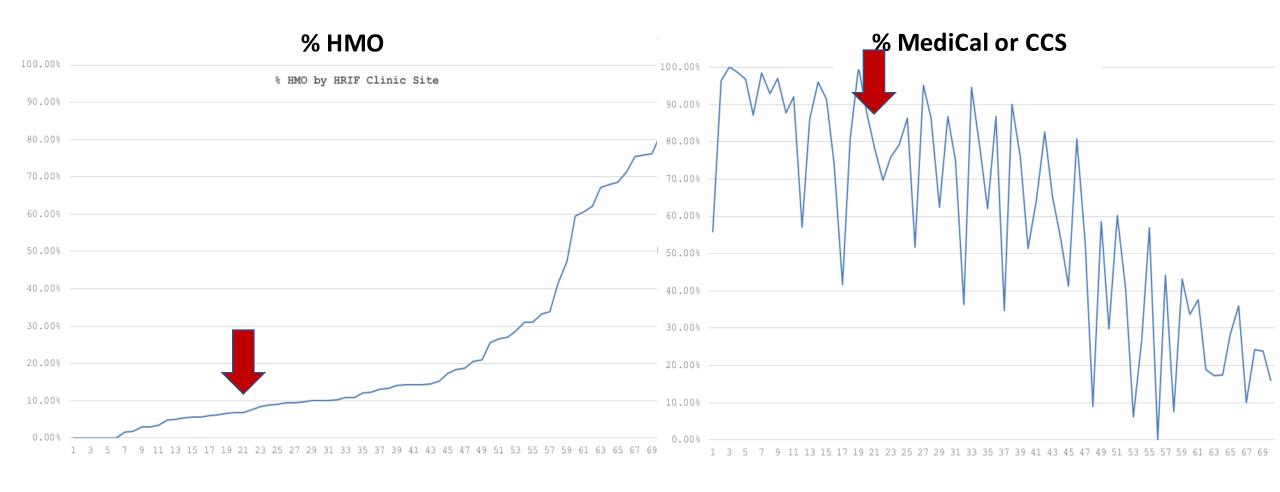








Differences in payor mix across HRIF clinics





HRIF Dashboard Concept: We want your input!

- Most important information to you and what you think is NOT important
- Your favorite choices/ ideas for graphics





DATA FINALIZATION PROCESS (DFP)

HIGH RISK INFANT FOLLOW-UP QUALITY OF CARE INITIATIVE

Schedule for 2018

JAN - MAR	APR 1 st	MAY 1 st	MAY 2 nd	MAY 17 th	JUL 1 st	JUL 11 st	AUG - DEC
Data Review	Super Star HRIF Program Award	DEADLINE	HRIF Follow- up Rate Award	DEADLINE HRIF CCS Report	DEADLINE	HRIF Crown Award	Data Review
Utilize Reporting System Tools: HRIF Tracker; CPQCC Ref Num; Error & Warning and Closeout Checklist	Submission of No Priority/ Error & Warning Cases for 2014 Born Infants, Closed RR Forms for All 2016 Born Infants AND SV #1 of All expected 2016 Born Infants	Data Final for 2014 Born Infants AND SV #1 of All expected 2016 Born Infants	Core Visit F/U Rates for 2014 Born Infants: 1st => 80% 2nd => 70% 3rd => 60%	2014 Born Infants Confirm report by May 17th	Register ALL 2017 Born Infants AND Confirm HRIF Directory Contacts	Granted to HRIF Programs who meet All Closeout Deliverable Deadlines: Apr 1st, May 17th and Jul 1st	Utilize Reporting System Tools: HRIF Tracker; CPQCC Ref Num; Error & Warning and Closeout Checklist





- Need help? Need access?
- Input on other needed reports, dashboard content?
- → <u>www.cpqcchelp.org</u>
- Questions or comments? Feel free to email! srhintz@stanford.edu eegray22@stanford.edu

Solution home / High Risk Infant Follow-up Quality of Care Initiative (HRIF-QCI) / Reporting System



Access to HRIF-QCI Reporting System



Modified on: Tue, 16 Jan, 2018 at 2:34 PM

To be granted access to the HRIF-QCI Reporting System, please submit a help ticket with the following required information:

- 1. Center Name
- 2. Does your center provide HRIF services?
- 3. Full Name:
- 4. Title:
- 5. Email Address:
- 6. Phone Number:
- 7. Computer Public IP Address*
- 8. User Account Access (contacts can have multiple accounts):
 - Data User: CCS-approved HRIF Program staff submits all data forms: Referral/Registration (RR), Standard Visit (SV), Additional Visit (AV) and Client Not Seen Discharge (CNSD) for infants/children receiving follow-up services from their own HRIF Program. Data Users can generate and view the HRIF Summary and HRIF CCS Annual Reports.
 - Referral User: CCS-approved NICU and/or HRIF Program staff who refers HRIF eligible infants to a CCS HRIF Program and only has access to submit the "Referral/Registration (RR) Form". Currently no access to generate or view reports.
 - · NICU User: CCS-approved NICU staff (read-only access) generate and view NICU Summary Report.
- * Please contact your IT department to request the "Public IP Address Ranges" used by the hospital's network. Submit a help ticket at www.cpqcchelp.org and provide the ranges in the description. **NOTE:** Access is only authorized while connected to your organization's network. Access from home or while traveling is not permitted. This is a new security procedure to enhance the security of the system.

