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Stanford MEDICINE

The Value of High Risk Infant Follow Up in California

The CPQCC CCS High Risk Infant Follow Up QCI: Integrating a Statewide Continuum of Care

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Overview

- Background
  - The CPQCC, and the CPQCC-CCS partnership
  - Revitalization, goals of the statewide HRIF program
- Implementation of CPQCC-CCS HRIF Quality Care Initiative
  - "Nuts and bolts", usage statistics
  - Web-based processes, tools and reports
- CPQCC CCS HRIF – research and ongoing projects
  1. Referral of VLBW to HRIF
  2. Making it to the 1st HRIF visit
  3. Value of the HRIF visit
  4. Periviable survivors at early HRIF visit
- Opportunities & future goals – Leveraging the CPQCC-HRIF continuum

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The California Perinatal Quality Care Collaborative
CPQCC

- The CPQCC includes more than 130 member hospitals, representing over 90% of all neonates cared for in California NICUs – and **over 95% of VLBW infants**.
- Perinatal and neonatal information and short-term outcomes, allowing for data-driven **performance improvement and benchmarking** throughout California.
  - Web-based data submission and site-specific report access
- Framework for ***quality improvement*** – regional and statewide QI activities, development of QI toolkits, etc.
- **Since 2004, California Children's Services (CCS) has mandated that all CCS NICUs be part of CPQCC.**

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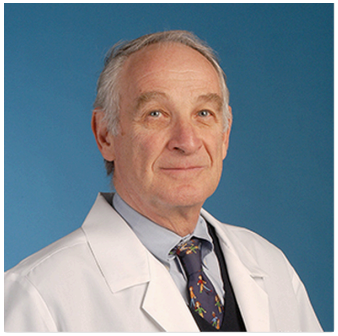
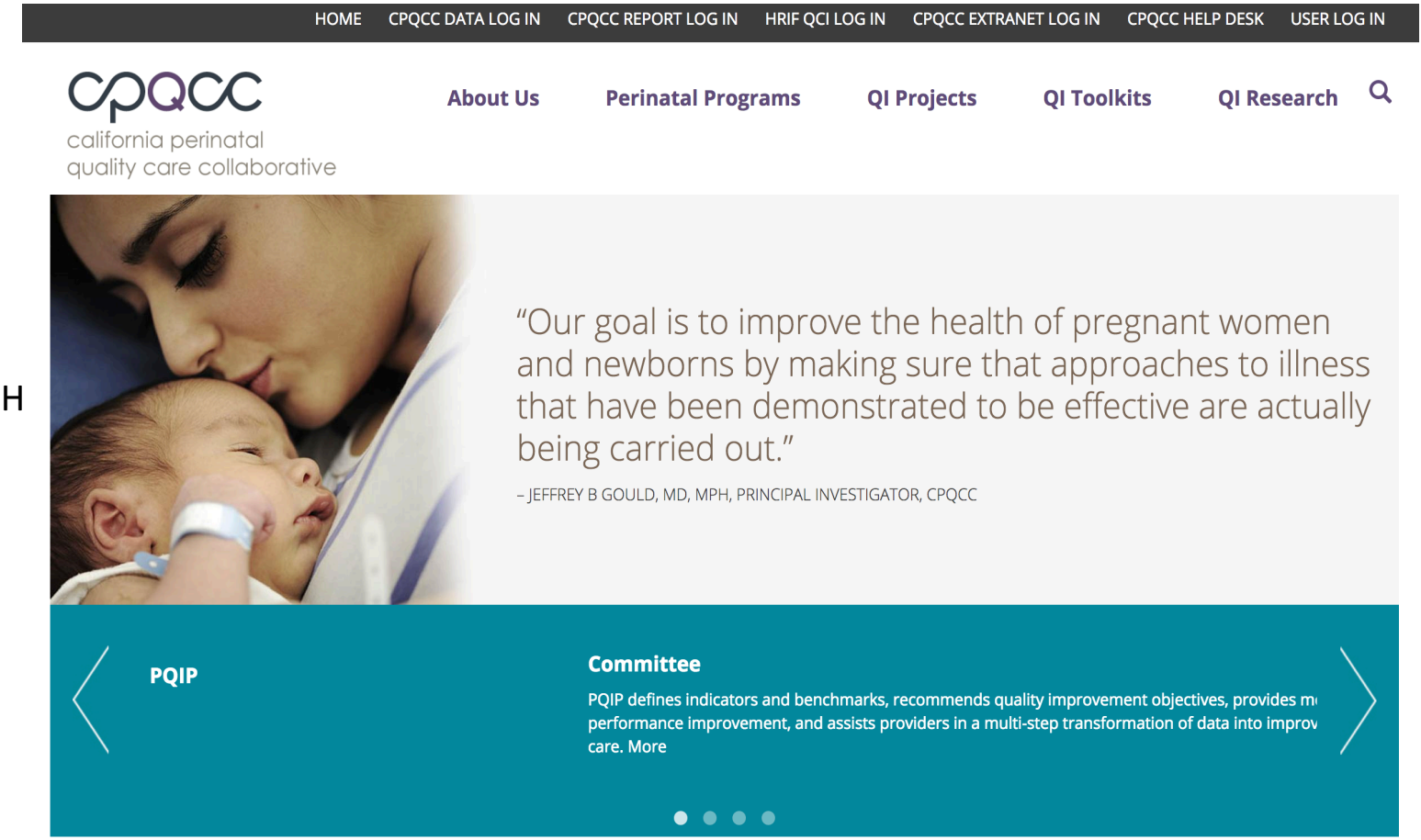
- **Robust network of stakeholders** – public and private, obstetric and neonatology – to advance quality of care.
- Research focused on **quality improvement, disparities in care and outcomes, resource allocation**.



Jeff Gould, MD, MPH

Henry Lee, MD, MS



https://www.cpqcc.org/

facebook

CPQCC

Background and History: *Follow up for infants at high risk in California*

- The California Children's Services (CCS) is administered by the California Department of Health Care Services (DHCS), Systems of Care (SOC) Division
  - Collaborates with California Department of Public Health on Title V activities.
- CCS originally established a **"NICU Follow Up Program" in 1979** to identify infants who had or could develop CCS-eligible medical conditions.
- **But there was a growing recognition that *we could do better in California* - CCS, others - concurrent with growth of CPQCC.**

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CPQCC-CCS High Risk Infant Follow Up

- CCS reached out to CPQCC to partner to ***restructure and revitalize*** NICU Follow up,
- **Multiple public and private stakeholders assembled throughout the state by the CPQCC** – follow up program directors, coordinators, NICU directors and staff, parents, CCS representatives, public policy experts, etc.
  - The new CPQCC-CCS HRIF was *launched* 2009/ 2010
- **The mission and standards of CCS were unchanged –**
  - Require each CCS-approved NICU to ensure the follow-up of high risk infants discharged from the NICU.

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What issues were identified in the previous CCS "NICU follow up program"?

- Medical eligibility criteria unclear to NICUs and programs.
- Number of visits provided by CCS, target age at follow up, and visit structure – all unclear.
- Registration process, visit summary → paper/ fax
  - *No central coordination*, no tracking, no site-specific data or tools; # programs, patients enrolled, FU rates not known.
- No routine communication between programs across CA, or FU-NICU communication strategy; no stakeholder oversight.
- NICU-HRIF linked framework did not exist - collaborations and joint quality improvement not possible.

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What was required for the restructured CPQCC-CCS HRIF QCI program?

- HRIF eligibility clarification
- Overhaul HRIF visit elements, structure, focus
- Create a completely web-based data reporting system; online tools, reports, resources; support real-time case management;
- Allow HRIF programs and NICUs to compare their activities with all other sites, and the CCS to assess site successes/ challenges;
- *Link with CPQCC database*; potentially link with CCS datasets in future
- Initiate analyses to ultimately inform QI and PI initiatives

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In broad strokes –

- **Create a new infrastructure for consistent HRIF care**:
  - Develop and maintain a *clinical* quality care framework.
- **Understand NICU-to-childhood trajectory**:
  - Build a *true continuum of care structure*, linking to CPQCC perinatal-neonatal dataset
- **Data review and analysis**:
  - Sites and state evaluate challenges/ barriers/ gaps/ disparities - targeting areas for improvement.
- Develop a framework for *statewide* **PI and QI initiatives** to enhance access, influence public policy, improve outcomes.

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Erika Gray – Program Manager

One of THE MOST important components of building this program!

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Implementation, "Nuts and Bolts", web-based reports

Medical Eligibility

- ALL infants < or = 1500 grams BW or <32 weeks EGA
- If >1500 grams BW, infant eligible for a broad variety of defined indications, including:
  - unstable by multiple definitions including hypotension and hypoxia, clinical findings c/w encephalopathy
  - ECMO, iNO >4 hours or other PH treatment, oxygen >=28 days, seizures, intracranial pathology a/w adverse outcome, HIE, CNS infection, CHD requiring surgery (updated criteria in 10/2016 Numbered Letter), "other"
- **Expectation by CCS: All who meet criteria will be referred to CPQCC-CCS HRIF by NICU.**

Visits

- *Provides for* at least *3 "Standard" or core visits - additional visits are covered as determined to be needed by HRIF team-*
  - *#1 – goal range 4-8 months*
  - *#2 – goal range 12-16 months*
  - *#3 – goal range 18-36 months*

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HRIF core or "standard" visits

- Neurosensory, neurologic, developmental assessments, autism screening, ***but much more*** –
  - Hospitalizations, surgeries, medications, equipment
  - Medical services and Special services
    - Information obtained not only about "Receiving", "Referred" but also "Referred and NOT receiving" ***and why***.
  - Early Start, Medical Therapy Program -
  - "Concerns and resources" - Living and care arrangements, caregiver concerns, primary language in household, social and economic stressors for the family.

All CPQCC-CCS HRIF – Usage stats

- **Since 2009 - ~ 61,800+ high risk infants** registered in the CPQCC-CCS HRIF QCI.
- Only **about 50% are VLBW (≤1500 g).**
  - **~31,400 of registered/ referred are VLBW**
- **Other:**
  - <32 weeks: ~ 36,000
  - <28 weeks: ~11,600
  - <26 weeks: ~5,100
- **69 HRIF programs in California**

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Reports and Tools

- **REPORTS** for site-specific and statewide review:
  - HRIF Summary report
  - NICU report
  - *Link to CPQCC website:* HRIF referral report
  - CCS Annual report

- **TOOLS** for maintaining clinical quality of care framework:
  - MOP, forms; eligibility reminders; Resource Corner
  - HRIF Tracker; Errors and Warnings
  - Quick patient search
  - CPQCC patient number search

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HOME | CPQCC DATA LOG IN | CPQCC REPORT LOG IN | HRIF QCI LOG IN | CPQCC EXTRANET LOG IN | CPQCC HELP DESK | ADMIN LOG IN

NOTE: 2-step security sign in

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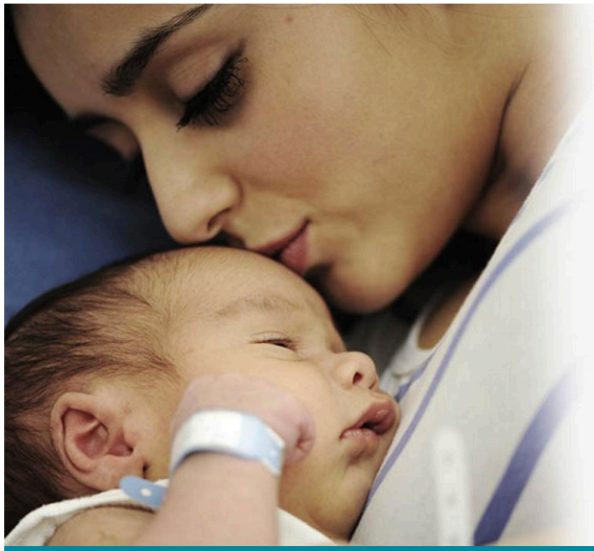
About Us | Perinatal Programs | QI Projects | QI Toolkits | QI Research



"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

PQIP defines indicators and benchmarks, recommends quality improvement ob provides models for performance improvement, and assists providers in a mult transformation of data into improved patient care. More

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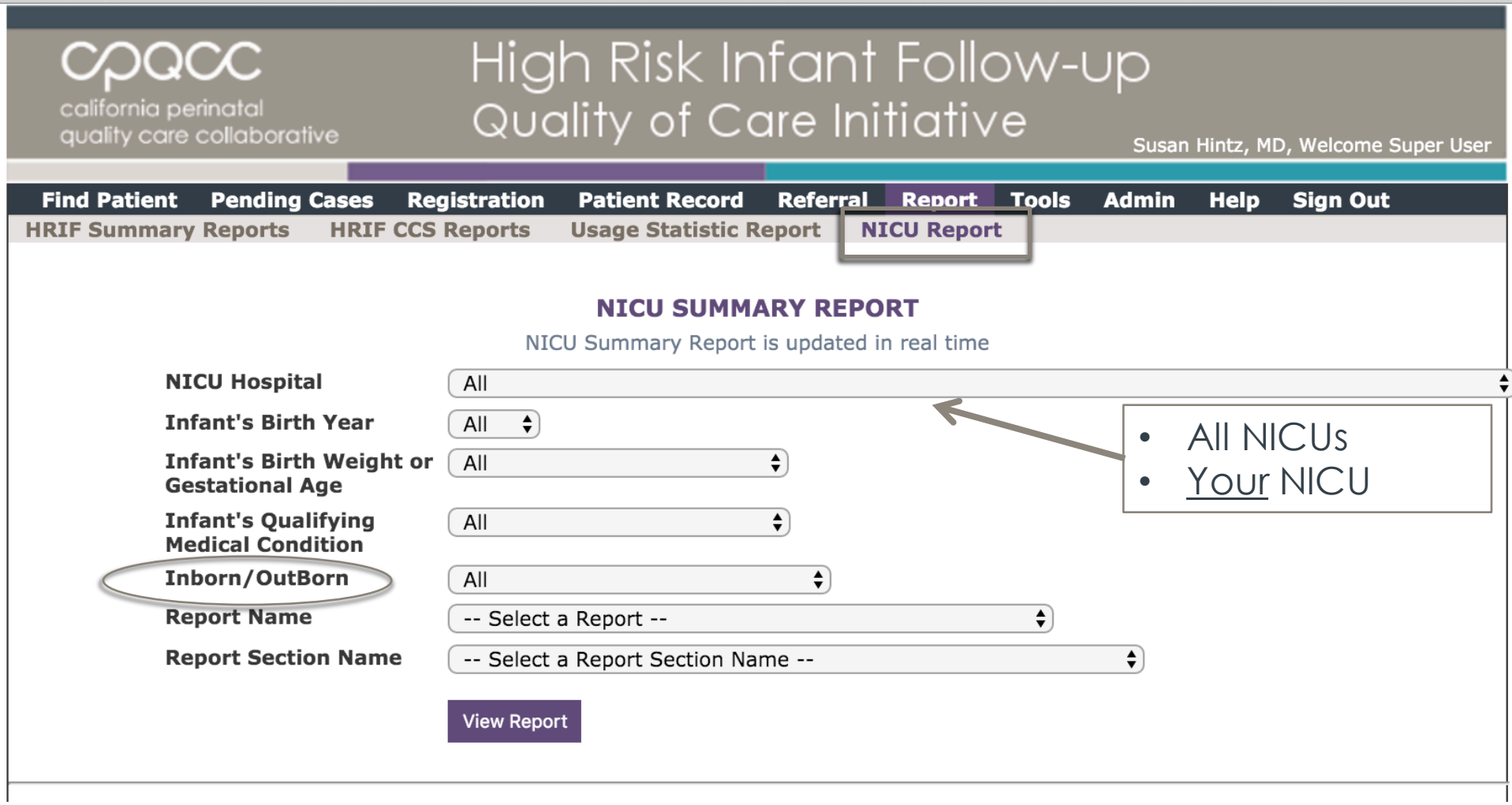

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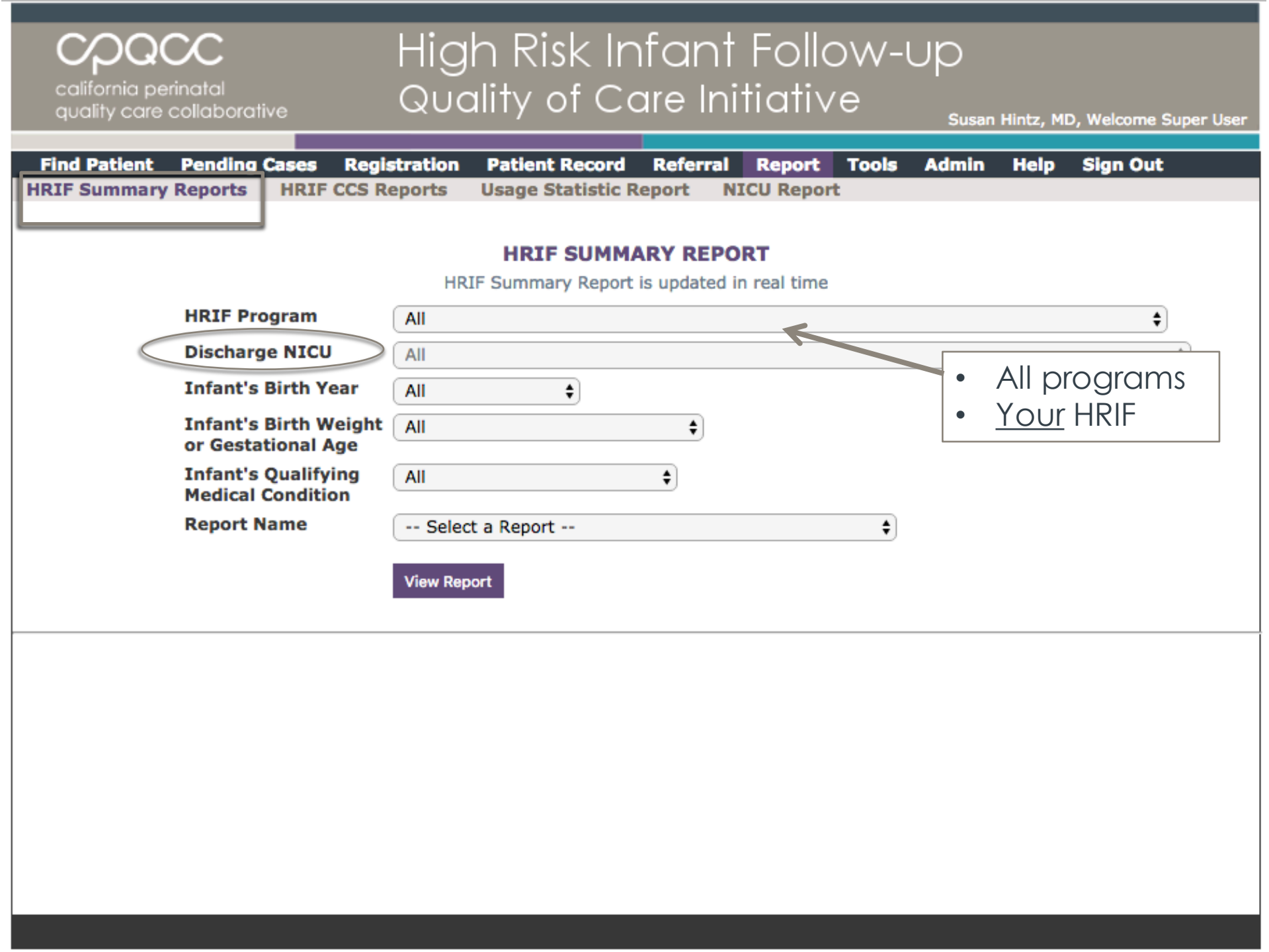
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Registration
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Help
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HRIF CCS Reports
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NICU Report
HRIF SUMMARY REPORT
HRIF Summary Report is updated in real time
HRIF Program
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
All programs
Your HRIF

HRIF SUMMARY REPORT

HRIF Summary Report is updated in real time

HRIF Program All

Discharge NICU All

Infant's Birth Year

- ✓ All
- 2009
- 2010
- 2011
- 2012
- 2013
- 2014
- 2015
- 2016
- 2017
- 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 in real time

HRIF Program All

Discharge NICU All

Infant's Birth Year All

Infant's Birth Weight or Gestational Age

- ✓ 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)

Infant's Qualifying Medical Condition

Report Name


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Referral
Report
Tools
Admin
Help
Sign Out
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NICU SUMMARY REPORT
NICU Summary Report is updated in real time
NICU Hospital
All
Infant's Birth Year
All
Infant's Birth Weight or Gestational Age
All
Infant's Qualifying Medical Condition
All
O2 >= 28 days
Intracranial Pathology
HIE/Neonatal Encephalopathy
iNo > 4 hrs
Inborn/OutBorn
Report Name
Report Section Name
-- Select a Report Section Name --
View Report
To come in the next year:
More filters, especially
cardiac surgical/
intervention patients

NICU SUMMARY REPORT

NICU Summary Report is updated in real time

NICU Hospital All

Infant's Birth Year All

Infant's Birth Weight or Gestational Age All

Infant's Qualifying Medical Condition All

Inborn/OutBorn All

Report Name

- ✓ -- Select a 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)

Report Section Name

NICU SUMMARY REPORT

NICU Summary Report is updated in real time

NICU Hospital All

Infant's Birth Year All

Infant's Birth Weight or Gestational Age All

Infant's Qualifying Medical Condition All

Inborn/OutBorn All

Report Name -- Select a Report --

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

STANDARD VISIT SUMMARY REPORT (CORE VISIT #1)

HRIF Program: [redacted]
HRIF Program Oshpd Code: [redacted]
Discharge NICU: All
Infant's Birth Year: 2012
Infant's Birth Weight/Gestational Age: Gestational Age < 26 weeks
Infant's Medical Eligibility Criteria: All
Report Date: 2017-01-07

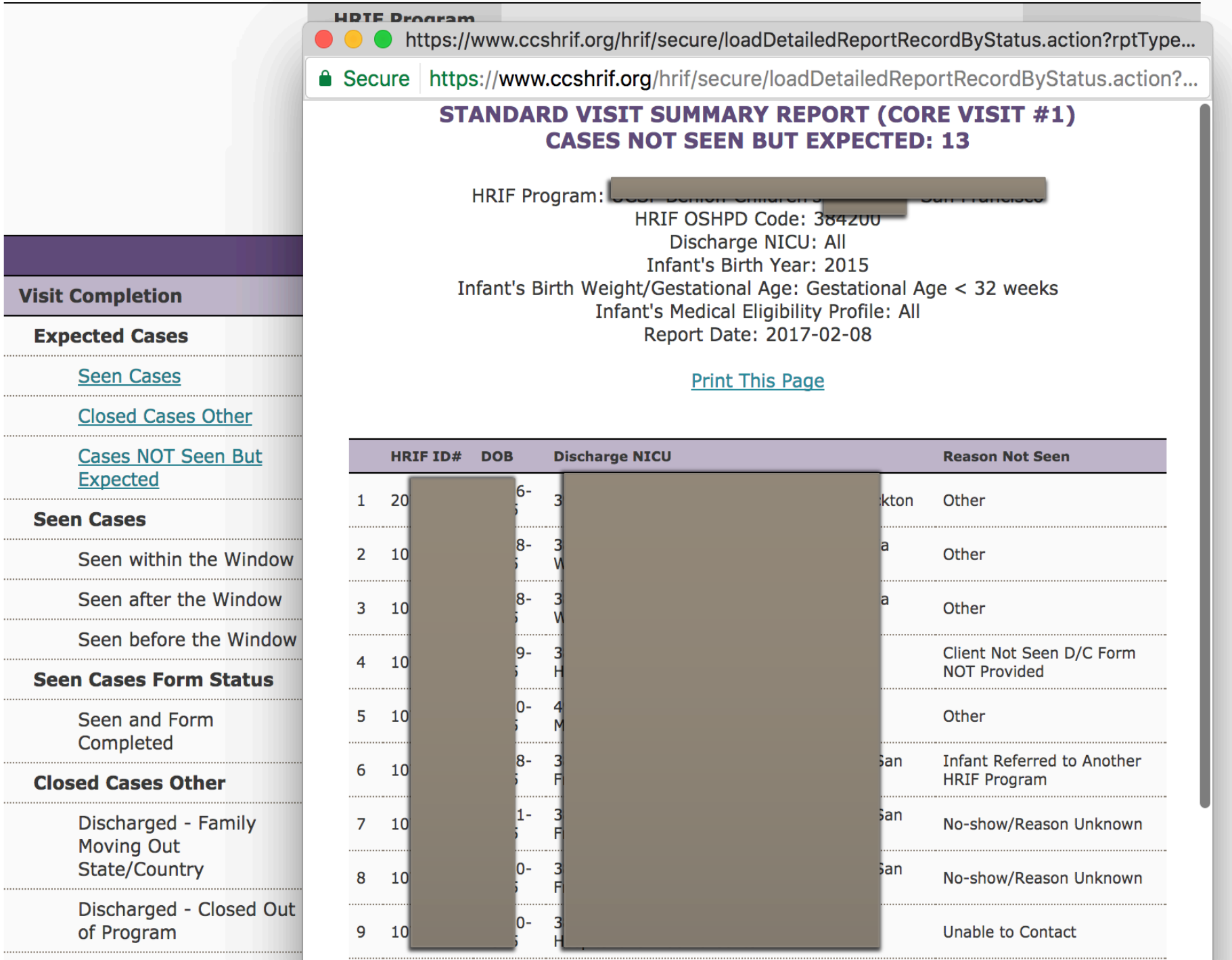
	HRIF Program [redacted] Total Reg : 15 Total Expected : 15 Total Seen : 15		All HRIF Programs Total Registered Cases : 592 Total Expected Cases : 587 Total Seen Cases : 505					Comparison with All HRIF Programs Data
	Num	%	Num	%	% Median	% Lower Quartile	% Upper Quartile	
FOLLOW UP STATUS								
Visit Completion								
Expected Cases								
Seen Cases	15	100.0%	505	85.3%	97.6%	80.0%	100.0%	
Seen Cases								
Seen within the Window	13	86.7%	438	86.7%	95.5%	80.0%	100.0%	
Seen after the Window	1	6.7%	55	10.9%	20.0%	10.6%	33.3%	
Seen before the Window	1	6.7%	12	2.4%	40.0%	10.5%	70.0%	
Seen Cases Form Status								
Seen and Form Completed	15	100.0%	505	100.0%	100.0%	100.0%	100.0%	
VISIT DISPOSITION								
Disposition of Seen Cases								
Scheduled to Return	15	100.0%	500	99.0%	100.0%	100.0%	100.0%	

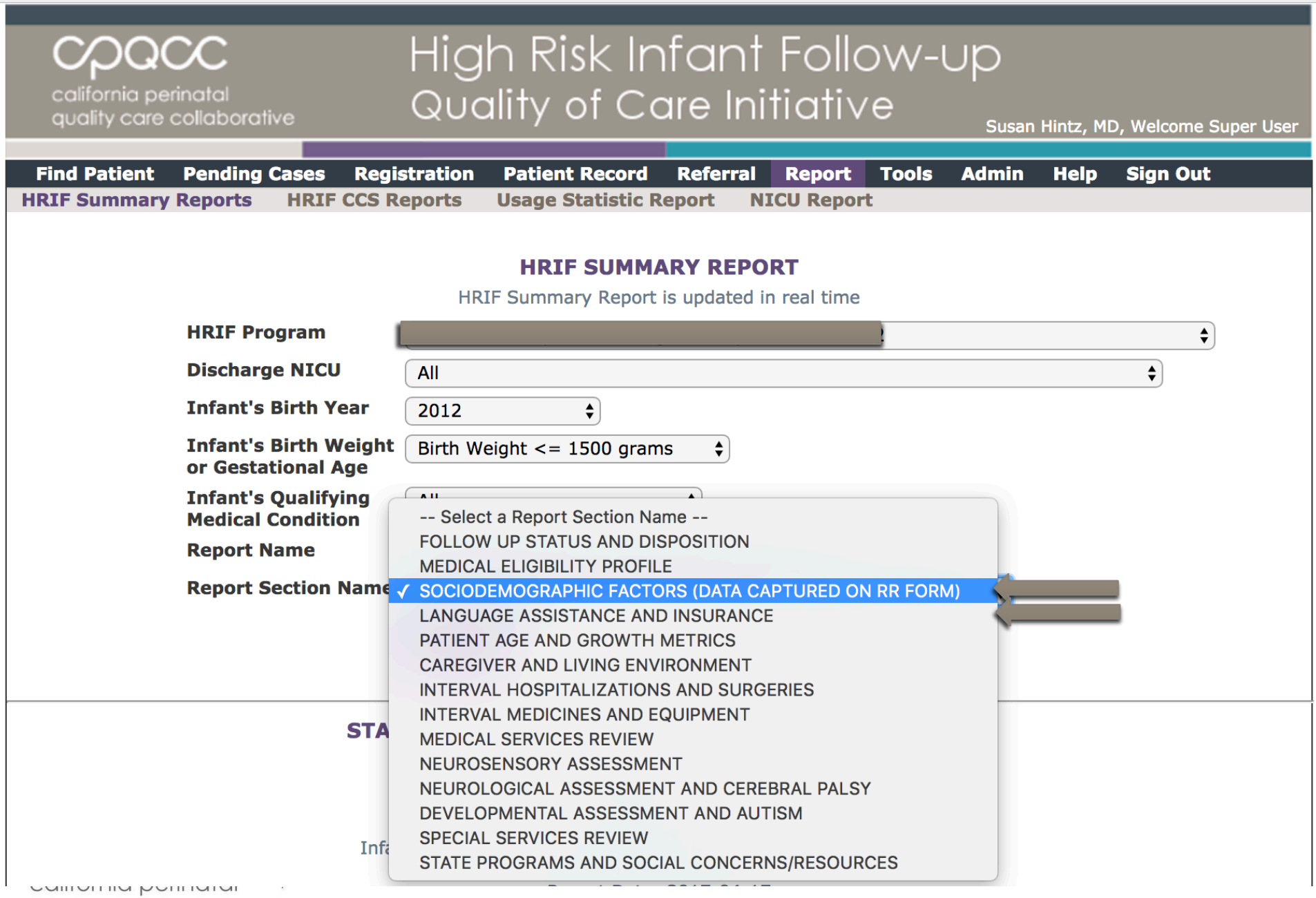
End of Report

STANDARD VISIT SUMMARY REPORT (CORE VISIT #1)

HRIF Program: [redacted]
HRIF Program Oshpd Code: [redacted]
Discharge NICU: All
Infant's Birth Year: 2015
Infant's Birth Weight/Gestational Age: Gestational Age < 32 weeks
Infant's Medical Eligibility Criteria: All
Report Date: 2017-02-08

	HRIF Program ([redacted]) Total Reg : 120 Total Expected : 120 Total Seen : 98		All HRIF Programs Total Registered Cases : 4841 Total Expected Cases : 4823 Total Seen Cases : 3429					Comparison with All HRIF Programs Data
	Num	%	Num	%	% Median	% Lower Quartile	% Upper Quartile	
FOLLOW UP STATUS								
Visit Completion								
Expected Cases								
Seen Cases	98	81.7%	3429	70.8%	77.1%	63.6%	87.0%	
Closed Cases Other	9	7.5%	633	13.1%	11.7%	6.8%	20.6%	
Cases NOT Seen But Expected	13	10.8%	761	15.7%	9.8%	4.4%	22.0%	
Seen Cases								
Seen within the [illegible]dow	86	87.8%	2934	85.6%	89.5%	79.5%	94.9%	
Seen after the Win[illegible]w	10	10.2%	364	10.6%	9.4%	5.8%	15.0%	
Seen before the Window	2	2.0%	131	3.8%	6.3%	2.0%	14.5%	
Seen Cases Form Status								
Seen and Form Completed	98	100.0%	3413	99.5%	100.0%	100.0%	100.0%	


HRIF Program
Visit Completion
Expected Cases
Seen Cases
Closed Cases Other
Cases NOT Seen But Expected
Seen Cases
Seen within the Window
Seen after the Window
Seen before the Window
Seen Cases Form Status
Seen and Form Completed
Closed Cases Other
Discharged - Family Moving Out State/Country
Discharged - Closed Out of Program
https://www.ccshrif.org/hrif/secure/loadDetailedReportRecordByStatus.action?rptType...
Secure
https://www.ccshrif.org/hrif/secure/loadDetailedReportRecordByStatus.action?...
STANDARD VISIT SUMMARY REPORT (CORE VISIT #1)
CASES NOT SEEN BUT EXPECTED: 13
HRIF Program:
HRIF OSHPD Code: 384200
Discharge NICU: All
Infant's Birth Year: 2015
Infant's Birth Weight/Gestational Age: Gestational Age < 32 weeks
Infant's Medical Eligibility Profile: All
Report Date: 2017-02-08
Print This Page
HRIF ID# DOB Discharge NICU Reason Not Seen
1 Other
2 Other
3 Other
4 Client Not Seen D/C Form NOT Provided
5 Other
6 Infant Referred to Another HRIF Program
7 No-show/Reason Unknown
8 No-show/Reason Unknown
9 Unable to Contact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HRIF Program
Discharge NICU
All
Infant's Birth Year
2012
Infant's Birth Weight or Gestational Age
Birth Weight <= 1500 grams
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
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DEVELOPMENTAL ASSESSMENT AND AUTISM
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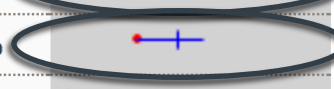
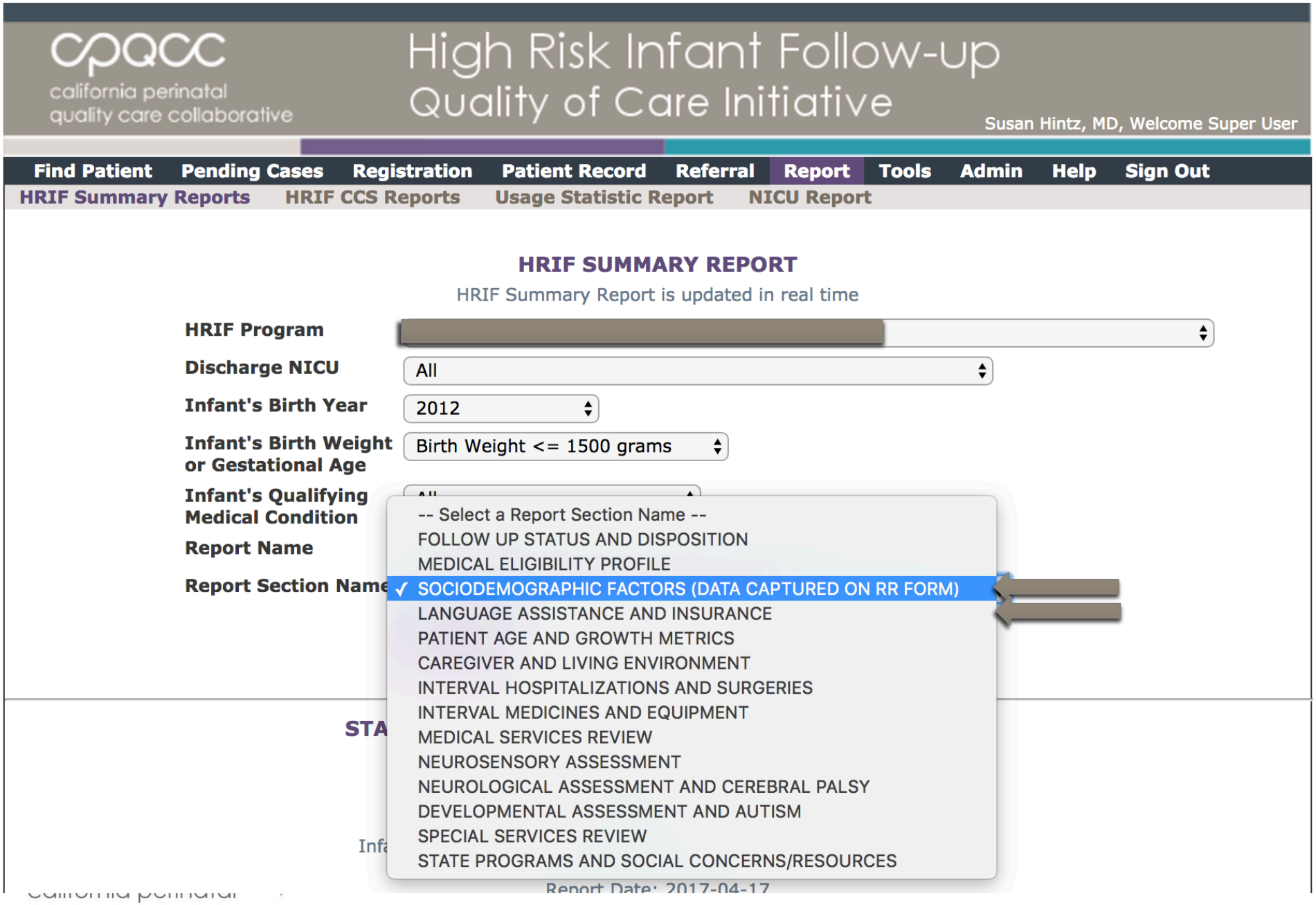
	HRIF Program [redacted] Total Reg : 132 Total Seen : 111		All HRIF Programs Total Registered Cases : 3795 Total Seen Cases : 2903					Comparison with All HRIF Programs Data
	Num	%	Num	%	% Median	% Lower Quartile	% Upper Quartile	
DEMOGRAPHICS OF BIRTH MOTHER								
Ethnicity of Birth Mother								
Hispanic/Latino	68	61.3%	1302	44.9%	44.2%	30.9%	61.6%	
Non-Hispanic	41	36.9%	1479	50.9%	54.7%	35.5%	66.1%	
Unknown	1	0.9%	95	3.3%	4.8%	2.5%	7.4%	
Declined	1	0.9%	27	0.9%	3.8%	3.4%	9.5%	
Race Category of Birth Mother								
Single	108	97.3%	2814	96.9%	100.0%	97.0%	100.0%	
Multiracial	3	2.7%	89	3.1%	3.4%	2.3%	7.1%	
Race of Birth Mother								
White	63	56.8%	1287	44.3%	46.2%	27.4%	65.5%	
Asian, Native Hawaiian or Other Pacific Islander	20	18.0%	394	13.6%	13.6%	9.0%	21.4%	
Other	12	10.8%	539	18.6%	15.6%	8.2%	29.1%	
Unknown	10	9.0%	192	6.6%	9.0%	3.9%	14.8%	
American (North, South or Central) Indian or Alaskan Native	4	3.6%	77	2.7%	4.0%	2.9%	6.5%	
Black or African American	2	1.8%	367	12.6%	12.5%	6.5%	24.2%	

LANGUAGE ASSISTANCE								
Interpreter Used								
No	89	80.2%	2636	90.8%	95.5%	84.5%	100.0%	
Yes	22	19.8%	267	9.2%	12.2%	4.3%	25.9%	
Interpreter Language Used								
Spanish	21	95.5%	245	91.8%	100.0%	100.0%	100.0%	
Vietnamese	1	4.5%	8	3.0%	14.3%	10.0%	16.7%	
INSURANCE								
Insurance Combinations (Top 10)								
CCS + Medi-Cal	72	64.9%	1296	44.6%	49.2%	10.9%	69.6%	
CCS + Medi-Cal + Commercial PPO	8	7.2%	21	0.7%	0.0%	0.0%	0.0%	
CCS + Medi-Cal + Commercial HMO	7	6.3%	16	0.6%	0.0%	0.0%	0.0%	
Commercial HMO	6	5.4%	595	20.5%	7.2%	0.0%	17.9%	
CCS + Medi-Cal + Point of Service/EPO	4	3.6%	4	0.1%	0.0%	0.0%	0.0%	
CCS + Commercial PPO	3	2.7%	61	2.1%	0.0%	0.0%	0.3%	
CCS + Commercial HMO	3	2.7%	62	2.1%	0.0%	0.0%	0.5%	
Commercial PPO	2	1.8%	361	12.4%	4.4%	0.0%	15.2%	
Medi-Cal	2	1.8%	221	7.6%	3.6%	0.0%	13.3%	
Insurance								
CCS	97	87.4%	1616	55.7%	64.3%	27.9%	91.7%	
Medi-Cal	93	83.8%	1592	54.8%	64.5%	28.4%	82.8%	
Commercial HMO	17	15.3%	698	24.0%	15.3%	7.3%	42.4%	
Commercial PPO	14	12.6%	466	16.1%	15.5%	8.4%	28.8%	
Point of Service/EPO	7	6.3%	42	1.4%	4.7%	1.6%	7.0%	
Other	1	0.9%	20	0.7%	3.4%	1.9%	6.3%	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Report Date: 2017-04-17
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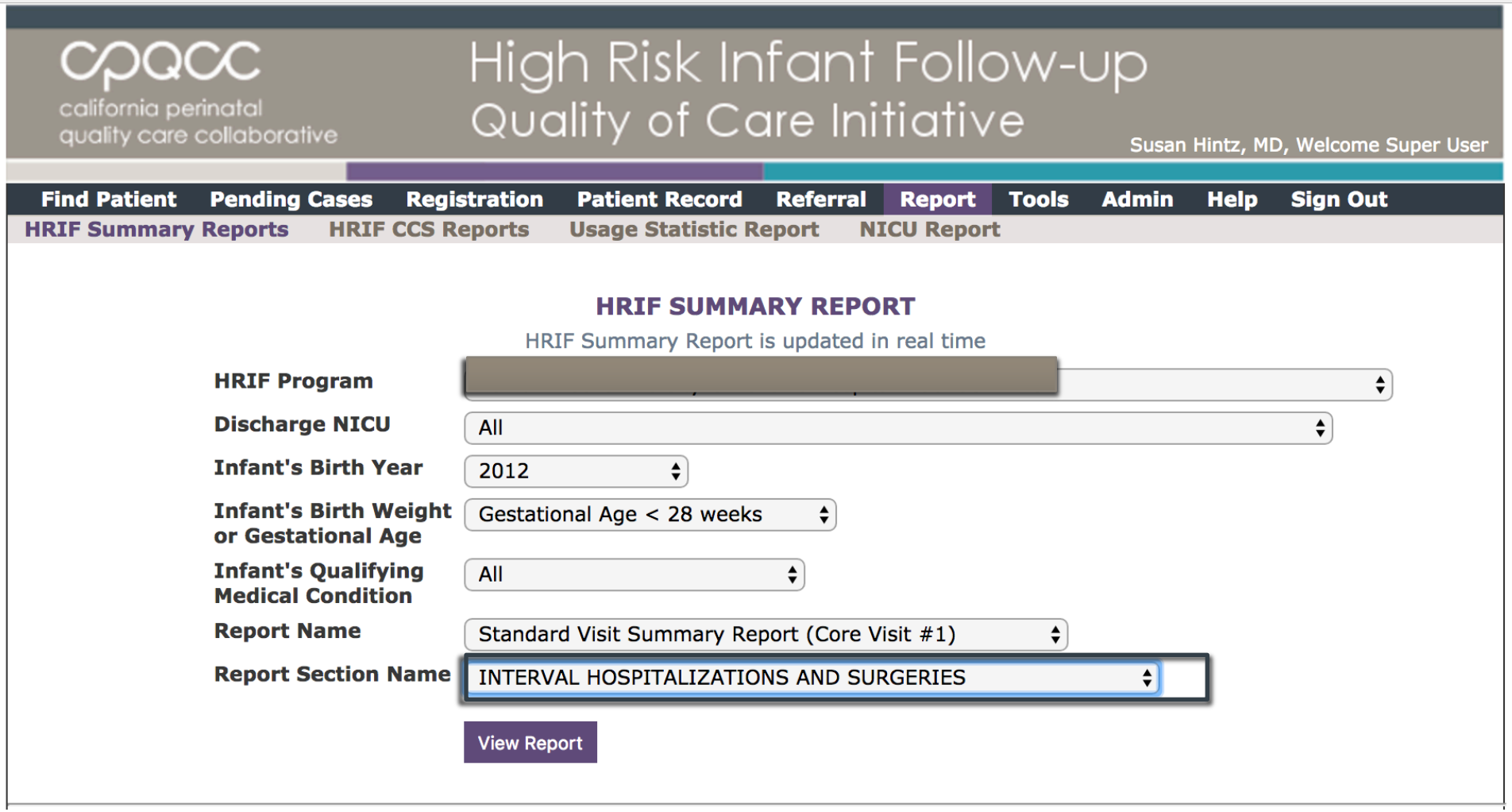
LANGUAGE ASSISTANCE								
Interpreter Used								
No	66	100.0%	2636	90.8%	95.5%	84.5%	100.0%	
INSURANCE								
Insurance Combinations (Top 10)								
Commercial PPO	32	48.5%	361	12.4%	4.4%	0.0%	15.2%	
CCS + Medi-Cal	11	16.7%	1296	44.6%	49.2%	10.9%	69.6%	
Commercial HMO	7	10.6%	595	20.5%	7.2%	0.0%	17.9%	
Medi-Cal	7	10.6%	221	7.6%	3.6%	0.0%	13.3%	
CCS + Commercial PPO	3	4.5%	61	2.1%	0.0%	0.0%	0.3%	
Medi-Cal + Commercial HMO	3	4.5%	17	0.6%	0.0%	0.0%	0.0%	
CCS + Commercial HMO	2	3.0%	62	2.1%	0.0%	0.0%	0.5%	
Medi-Cal + Commercial PPO	1	1.5%	8	0.3%	0.0%	0.0%	0.0%	
Insurance								
Commercial PPO	36	54.5%	466	16.1%	15.5%	8.4%	28.8%	
Medi-Cal	22	33.3%	1592	54.8%	64.5%	28.4%	82.8%	
CCS	16	24.2%	1616	55.7%	64.3%	27.9%	91.7%	
Commercial HMO	12	18.2%	698	24.0%	15.3%	7.3%	42.4%	

DEMOGRAPHICS OF BIRTH MOTHER								
Ethnicity of Birth Mother								
Non-Hispanic	54	81.8%	1479	50.9%	54.7%	35.5%	66.1%	
Hispanic/Latino	12	18.2%	1302	44.9%	44.2%	30.9%	61.6%	
Race Category of Birth Mother								
Single	63	95.5%	2814	96.9%	100.0%	97.0%	100.0%	
Multiracial	3	4.5%	89	3.1%	3.4%	2.3%	7.1%	
Race of Birth Mother								
White	40	60.6%	1287	44.3%	46.2%	27.4%	65.5%	
Black or African American	16	24.2%	367	12.6%	12.5%	6.5%	24.2%	
Asian, Native Hawaiian or Other Pacific Islander	11	16.7%	394	13.6%	13.6%	9.0%	21.4%	
PRIMARY CAREGIVER								
Primary Caregiver								
Both Parents	58	87.9%	1735	59.8%	69.3%	50.0%	83.2%	
Mother	7	10.6%	1036	35.7%	28.0%	15.0%	45.7%	
Other Relatives/Not Parents	1	1.5%	18	0.6%	3.0%	1.7%	3.4%	
Primary Caregiver Education								
College Degree	31	47.0%	470	16.2%	14.3%	7.4%	29.2%	
High School Degree/GED	14	21.2%	469	16.2%	15.5%	10.0%	24.4%	
Some College	10	15.2%	463	15.9%	15.2%	8.6%	23.1%	
Graduate School or Degree	8	12.1%	231	8.0%	9.2%	4.9%	13.9%	
Unknown	2	3.0%	861	29.7%	24.4%	10.9%	57.1%	
Some High School	1	1.5%	244	8.4%	9.1%	5.9%	15.6%	



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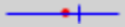
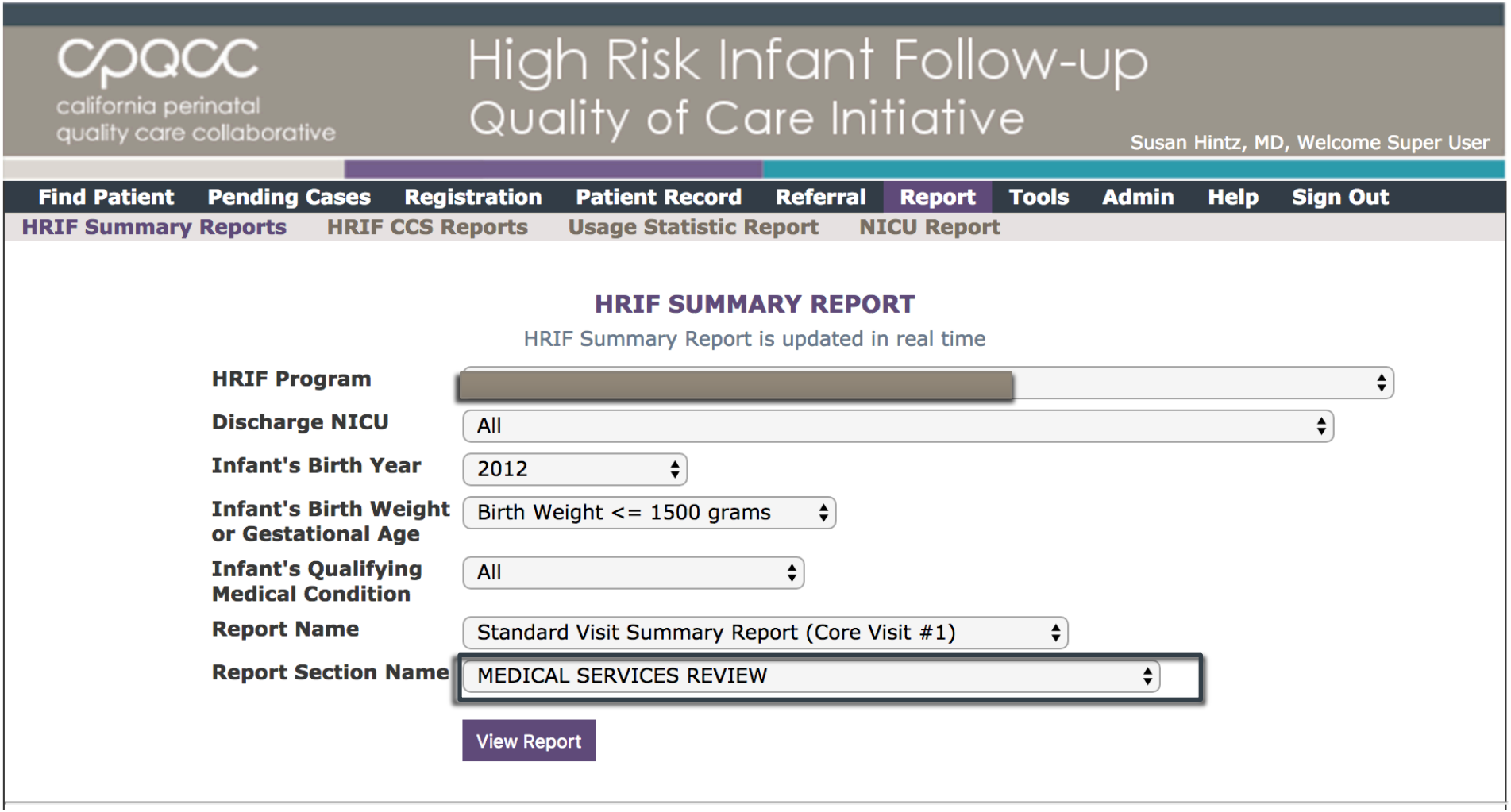
	HRIF Program [redacted] Total Reg : 97 Total Seen : 65		All HRIF Programs Total Registered Cases : 1422 Total Seen Cases : 1182					Comparison with All HRIF Programs Data
	Num	%	Num	%	% Median	% Lower Quartile	% Upper Quartile	
PRIMARY CARE PROVIDER								
Child has a Primary Care Provider (Added Jan 2012)								
Yes	65	100.0%	1179	99.7%	100.0%	100.0%	100.0%	
Primary Care Provider Acts as the Child's Medical Home (Added Jan 2012)								
Yes	62	95.4%	649	54.9%	83.2%	35.7%	95.6%	
Unknown	2	3.1%	64	5.4%	19.7%	6.7%	41.8%	
No	1	1.5%	469	39.7%	50.0%	13.8%	100.0%	
HOSPITALIZATIONS								
Hospitalizations Since Discharge or Last Visit								
No	45	69.2%	912	77.2%	80.9%	69.4%	88.5%	
Yes	20	30.8%	268	22.7%	24.2%	15.7%	32.4%	
Hospitalization Reasons								
Respiratory Illness	15	75.0%	193	72.0%	80.9%	45.8%	100.0%	
Other Medical Rehospitalization(s)	5	25.0%	54	20.1%	25.0%	23.1%	50.0%	
Having Surgeries During Hospitalization	4	20.0%	100	37.3%	45.5%	30.8%	77.8%	
Unknown	1	5.0%	8	3.0%	14.3%	9.4%	18.8%	
Gastrointestinal Infection(s)	1	5.0%	8	3.0%	25.0%	9.1%	33.3%	
Nutrition/Inadequate Growth (Added Jan 2010)	1	5.0%	18	6.7%	20.0%	16.7%	33.3%	



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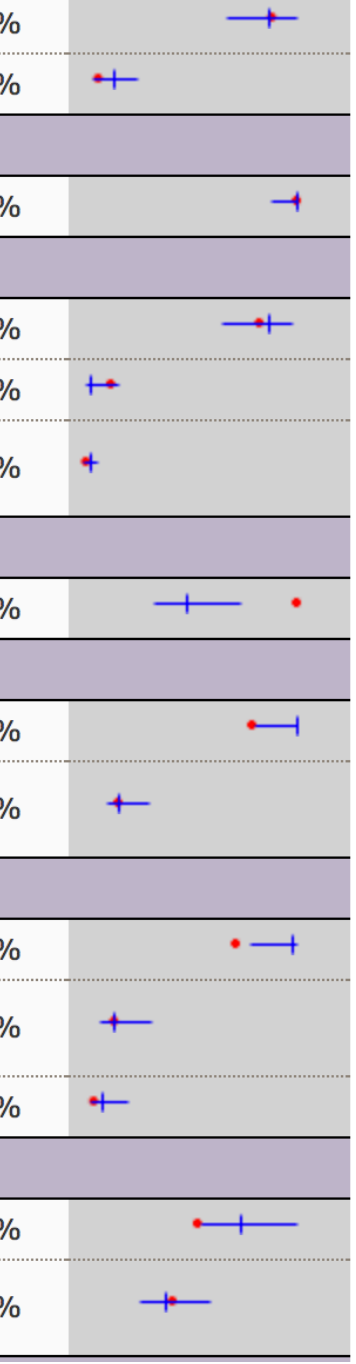
	HRIF Program [redacted] Total Reg : 94 Total Seen : 81		All HRIF Programs Total Registered Cases : 3795 Total Seen Cases : 2903					Comparison with All HRIF Programs Data
	Num	%	Num	%	% Median	% Lower Quartile	% Upper Quartile	
MEDICAL SERVICES REVIEW								
Child Receiving or Being Referred for Medical Services								
Yes	73	90.1%	2212	76.2%	81.2%	52.9%	96.4%	
No	8	9.9%	689	23.7%	25.0%	8.0%	55.4%	
Medical Services Summary								
Ophthalmology	68	93.2%	1753	79.2%	85.7%	70.4%	92.6%	
Pulmonology	19	26.0%	432	19.5%	17.1%	8.3%	28.2%	
Cardiology	18	24.7%	351	15.9%	14.8%	10.4%	21.9%	
Gastroenterology	15	20.5%	349	15.8%	14.6%	8.9%	24.2%	
Neurology	15	20.5%	209	9.4%	8.3%	5.9%	18.0%	
Surgery	15	20.5%	263	11.9%	15.2%	8.3%	19.2%	
Audiology	13	17.8%	385	17.4%	12.9%	8.4%	27.6%	
Urology	7	9.6%	149	6.7%	7.4%	4.5%	10.3%	
Orthopedic	5	6.8%	54	2.4%	4.4%	2.2%	7.1%	
Metabolic/Genetics	4	5.5%	66	3.0%	4.0%	2.4%	6.8%	
Otolaryngology (ENT)	4	5.5%	94	4.2%	5.6%	3.9%	8.2%	
Hematology/Oncology (added Jan 2010)	3	4.1%	18	0.8%	3.8%	2.2%	5.7%	
Neurosurgery	3	4.1%	75	3.4%	5.8%	3.9%	10.0%	
Endocrinology	2	2.7%	45	2.0%	3.8%	2.4%	6.3%	
Nephrology	2	2.7%	42	1.9%	3.7%	2.8%	6.3%	

Audiology							
Referred at Time of Visit	7	53.8%	123	31.9%	45.5%	25.5%	84.6%
Receiving	6	46.2%	235	61.0%	66.7%	46.2%	100.0%
Cardiology							
Receiving	15	83.3%	287	81.8%	100.0%	75.0%	100.0%
Complete (added Jan 2010)	3	16.7%	59	16.8%	25.0%	14.5%	45.9%
Endocrinology							
Receiving	2	100.0%	34	75.6%	100.0%	100.0%	100.0%
Gastroenterology							
Receiving	14	93.3%	297	85.1%	100.0%	80.0%	100.0%
Referred at Time of Visit	1	6.7%	13	3.7%	13.4%	10.3%	22.3%
Hematology/Oncology (added Jan 2010)							
Receiving	1	33.3%	14	77.8%	100.0%	100.0%	100.0%
Referred at Time of Visit	1	33.3%	1	5.6%	33.3%	33.3%	33.3%
Complete (added Jan 2010)	1	33.3%	3	16.7%	50.0%	41.7%	75.0%
Metabolic/Genetics							
Receiving	3	75.0%	49	74.2%	100.0%	100.0%	100.0%
Referred at Time of Visit	1	25.0%	7	10.6%	37.5%	25.0%	50.0%
Nephrology							
Receiving	2	100.0%	40	95.2%	100.0%	100.0%	100.0%
Neurology							
Referred at Time of Visit	11	73.3%	54	25.8%	35.4%	25.0%	50.0%
Receiving	4	26.7%	140	67.0%	88.2%	55.4%	100.0%
Referred, but Not Receiving	1	6.7%	18	8.6%	20.0%	16.0%	33.3%

Another site – All patients

	HRIF Program [redacted] Total Reg : 91 Total Seen : 75		All HRIF Programs Total Registered Cases : 7465 Total Seen Cases : 5305					Comparison with All HRIF Programs Data
	Num	%	Num	%	% Median	% Lower Quartile	% Upper Quartile	
MEDICAL SERVICES REVIEW								
Child Receiving or Being Referred for Medical Services								
Yes	70	93.3%	3742	70.5%	72.7%	47.8%	86.7%	
No	5	6.7%	1561	29.4%	29.6%	13.8%	54.8%	
Medical Services Summary								
Ophthalmology	54	77.1%	2354	62.9%	67.3%	51.4%	81.3%	
Neurology	18	25.7%	711	19.0%	14.5%	10.2%	25.4%	
Gastroenterology	11	15.7%	641	17.1%	14.8%	9.8%	19.2%	
Audiology	11	15.7%	720	19.2%	12.5%	6.8%	25.0%	
Pulmonology	11	15.7%	585	15.6%	13.3%	9.1%	20.7%	
Surgery	9	12.9%	469	12.5%	13.2%	7.4%	16.8%	
Metabolic/Genetics	8	11.4%	270	7.2%	6.6%	4.8%	10.4%	
Cardiology	7	10.0%	723	19.3%	16.7%	11.4%	25.0%	
Otolaryngology (ENT)	5	7.1%	191	5.1%	5.4%	3.7%	6.8%	
Nephrology	4	5.7%	103	2.8%	3.6%	2.2%	5.8%	
Urology	3	4.3%	259	6.9%	6.5%	4.1%	10.6%	
Neurosurgery	2	2.9%	208	5.6%	6.3%	3.2%	9.8%	
Orthopedic	1	1.4%	131	3.5%	4.1%	2.2%	7.1%	
Audiology								
Referred at Time of Visit	7	63.6%	257	35.7%	50.0%	27.2%	88.9%	
Receiving	2	18.2%	409	56.8%	65.2%	41.8%	100.0%	
Complete (added Jan 2010)	2	18.2%	54	7.5%	13.3%	6.9%	52.8%	
Referred, but Not Receiving	1	9.1%	41	5.7%	8.1%	4.2%	19.0%	

Neurology							
Receiving	16	88.9%	560	78.8%	87.2%	68.3%	100.0%
Referred at Time of Visit	2	11.1%	110	15.5%	18.2%	8.0%	27.9%
Neurosurgery							
Receiving	2	100.0%	187	89.9%	100.0%	88.2%	100.0%
Ophthalmology							
Receiving	45	83.3%	1965	83.5%	87.5%	66.7%	98.0%
Referred at Time of Visit	9	16.7%	161	6.8%	7.7%	5.4%	20.0%
Referred, but Not Receiving	3	5.6%	163	6.9%	7.1%	4.5%	10.3%
Orthopedic							
Referred at Time of Visit	1	100.0%	33	25.2%	50.0%	36.1%	75.0%
Otolaryngology (ENT)							
Receiving	4	80.0%	160	83.8%	100.0%	80.8%	100.0%
Complete (added Jan 2010)	1	20.0%	17	8.9%	20.0%	14.3%	33.3%
Pulmonology							
Receiving	8	72.7%	489	83.6%	98.2%	78.9%	100.0%
Complete (added Jan 2010)	2	18.2%	69	11.8%	18.2%	11.3%	35.0%
Referred at Time of Visit	1	9.1%	27	4.6%	13.1%	7.0%	23.8%
Surgery							
Receiving	5	55.6%	310	66.1%	75.0%	57.1%	100.0%
Complete (added Jan 2010)	4	44.4%	152	32.4%	41.4%	29.5%	61.1%



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Project highlights

Project highlights, ongoing work

- Referral of VLBW infants to HRIF in California
- Factors associated with successful 1st HRIF visit
- Value of HRIF visit for children and families in California
- Periviable survivors at 1st HRIF visit

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HRIF Referral of VLBW infants

Advances in care have improved survival rates for VLBW infants, but infants remain at risk for neurodevelopmental sequelae.

AAP has emphasized the critical need to integrate HRIF into a coordinated discharge plan for VLBW infants for early identification and referrals.

- **Our question: How well are we doing in California in referring VLBW infants (CCS eligible) to HRIF at discharge?**

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AAP COFN. Hospital Discharge of the High Risk Neonate. *Pediatrics* 2008; 122:1119-1126

Objectives

- **Objective:** Among VLBW infants in the CPQCC, to determine referral rates and factors associated with referral to the CPQCC CCS HRIF

Methods

- **Design:** CPQCC-CCS HRIF databases linked; infants <1500 g BW, born 2010 and 2011 included.
- Multivariate logistic regression was used to examine independent associations of demographic and clinical variables, NICU volume and level, and region with HRIF referral

Results

- **10433** VLBW infants born 2010/2011 in CPQCC →
  - **Among <u>all</u> NICUs:**
  - **8071 discharged home → 6424 referred to HRIF (80%)**

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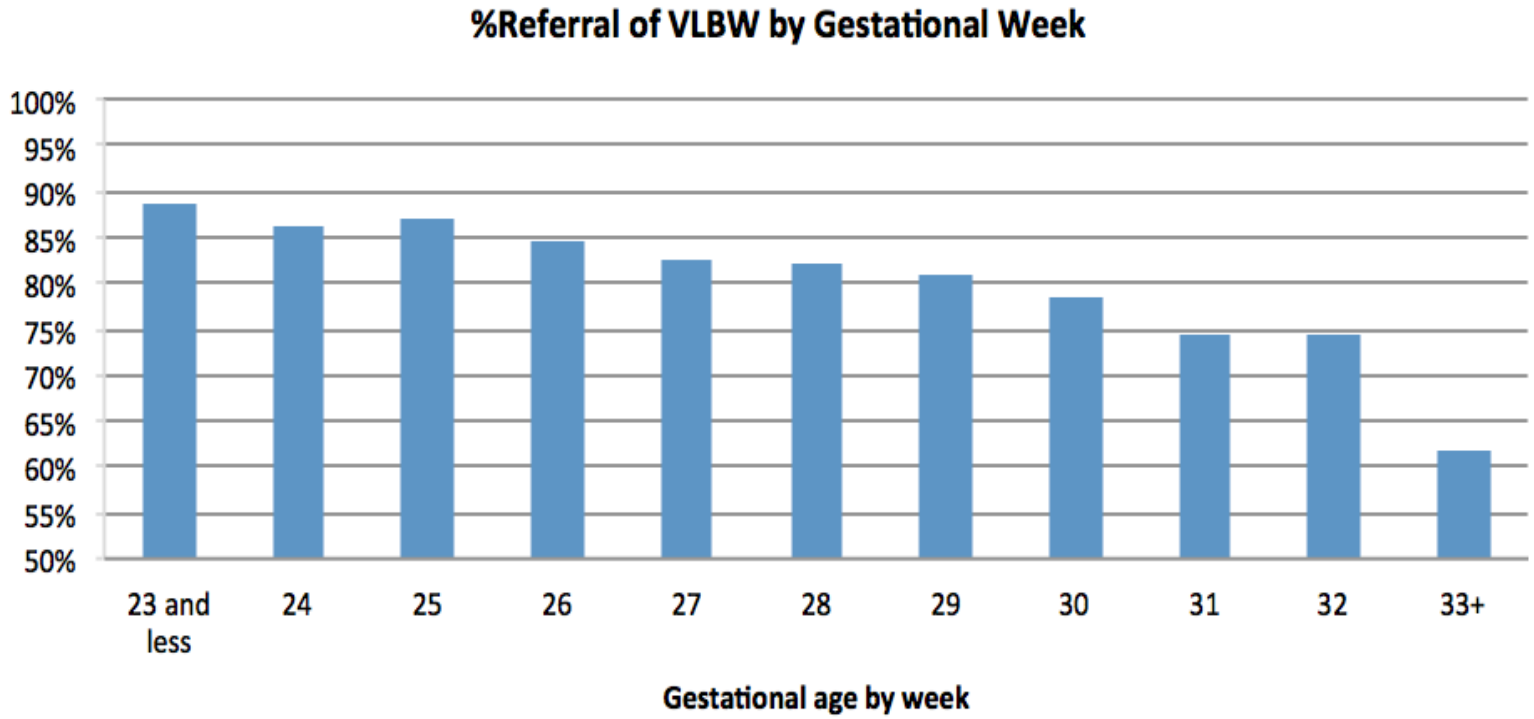
J Pediatr 2015;166:289-95

Results

Referral rates by EGA – *significant decline in referral rate with increasing EGA*



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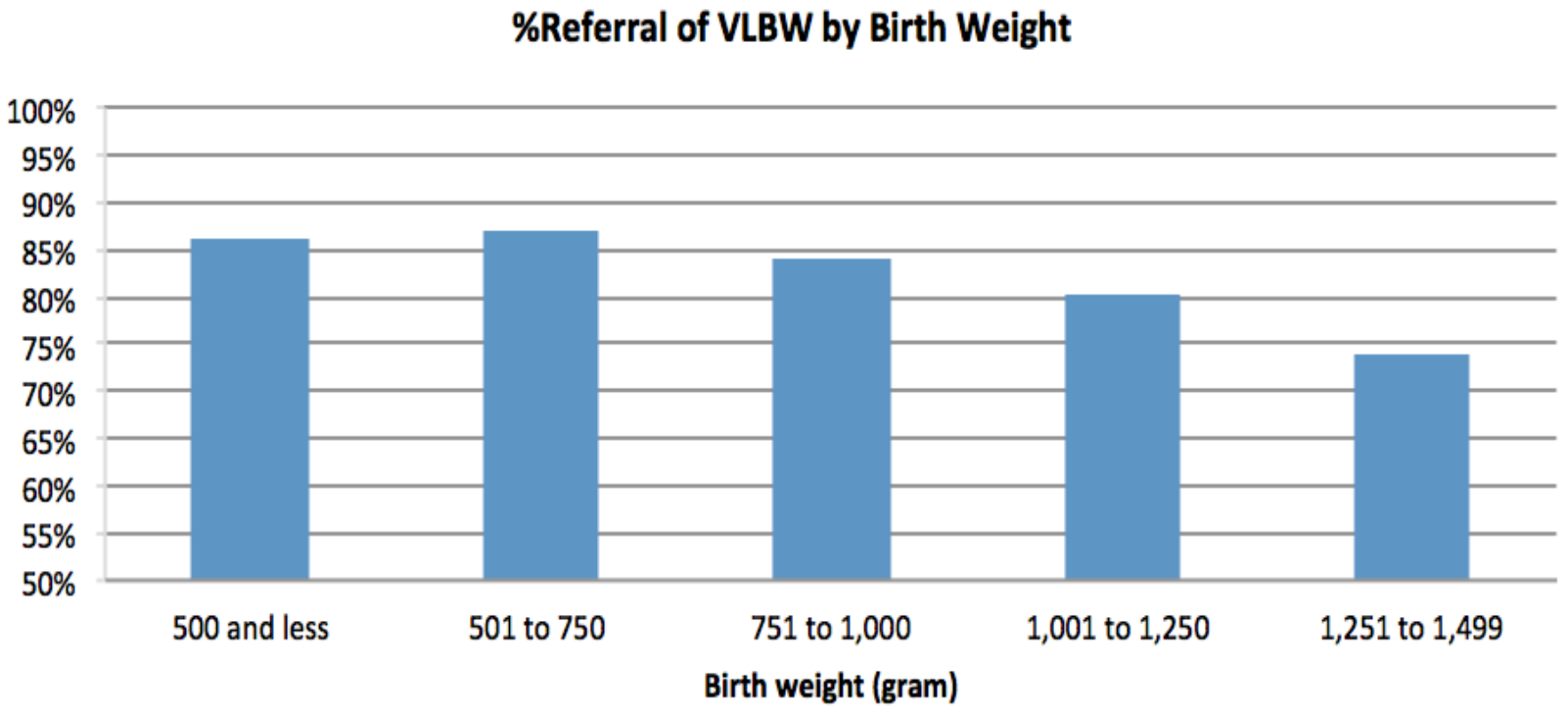
Results

Referral rates by BW – *significant decline in referral rate with increasing BW group*



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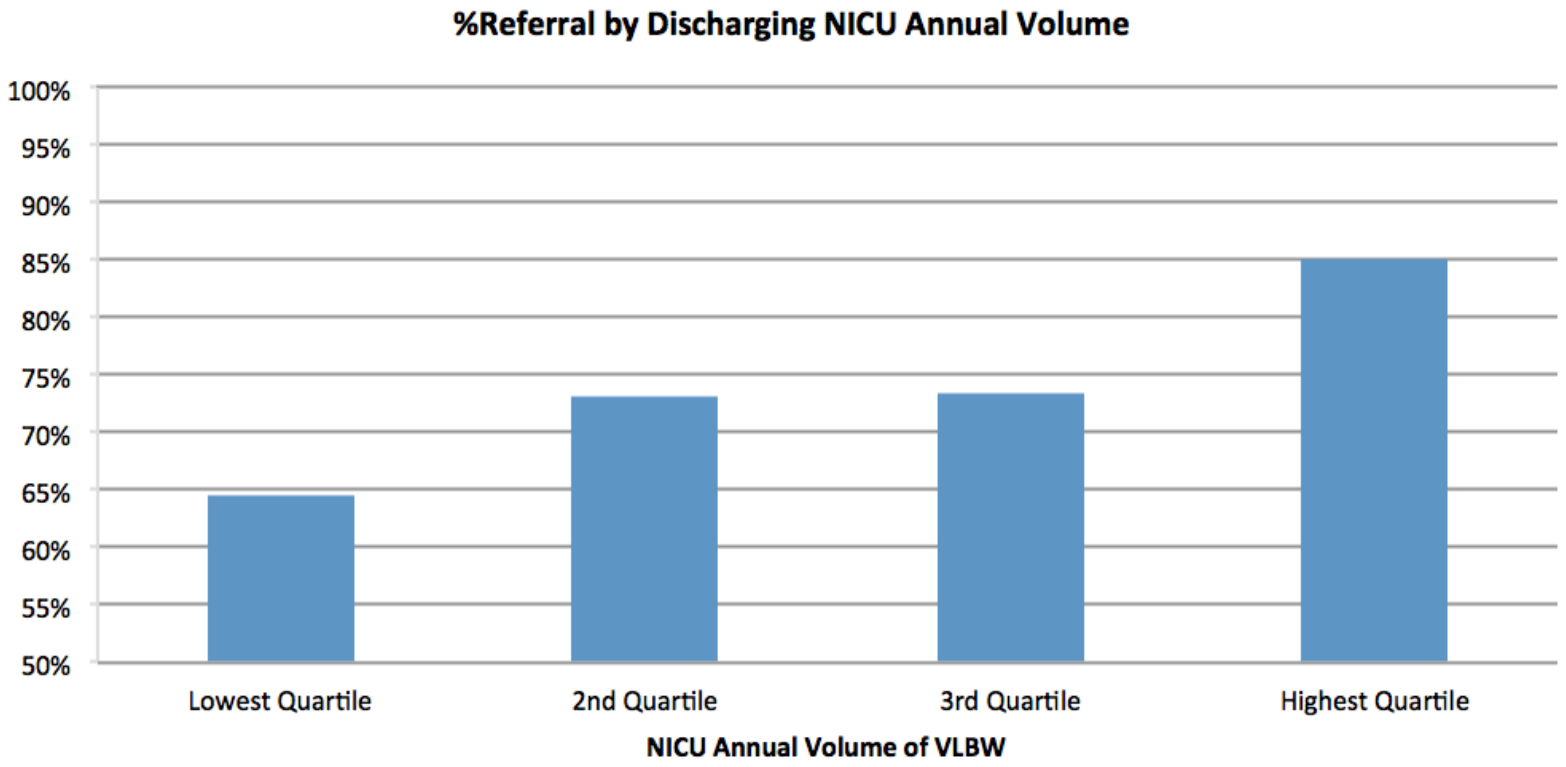
J Pediatr 2015;166:289-95

Results

Referral rates by NICU volume – *significant increase in referral rate for higher volume NICUs*



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J Pediatr 2015;166:289-95

Results

- **Higher odds for HRIF referral was associated with:**
  - Lower BW, higher NICU volume, discharging NICU level, outborn;
- **Lower odds for HRIF referral was associated with:**
  - SGA, Maternal African-American or Hispanic race vs. white, *congenital anomalies, O2 at 36 weeks.*

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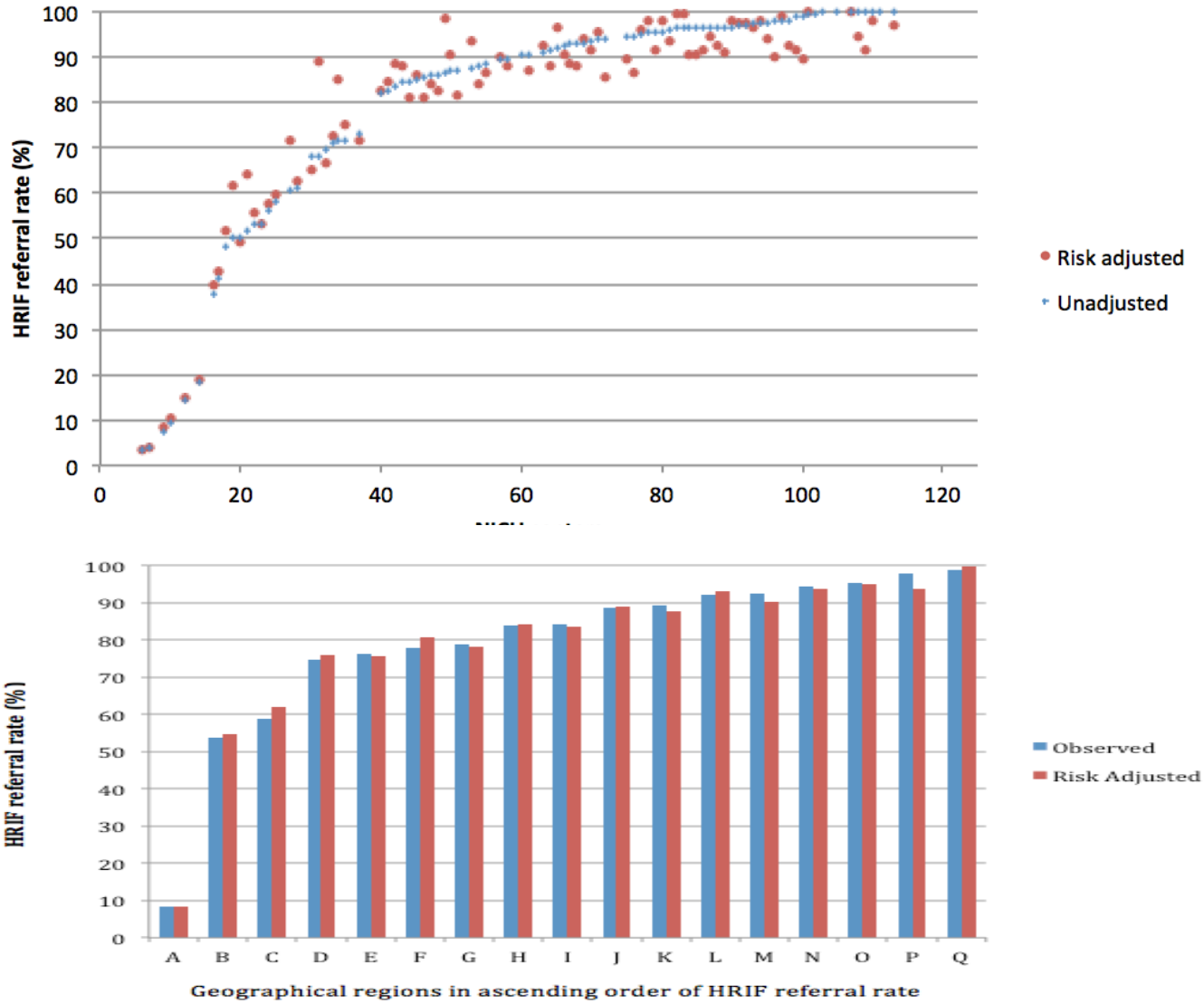
Table II. Results of multivariable logistic regression model for referral to CPQCC-CCS HRIF for VLBW infants in California born in 2010 and 2011 and survived to discharge*

	aOR	95% CI	*P* value
Maternal race			
White	1.0 (REF)		
African American	0.58	(0.47-0.71)	<.0001
Hispanic	0.65	(0.56-0.76)	<.0001
Asian	1.02	(0.80-1.28)	NS
Other	1.08	(0.69-1.70)	NS
BW			
1251-1499 g	1.0 (REF)		
≤750 g	1.92	(1.5-2.45)	<.0001
751-1000 g	1.66	(1.37-2.0)	<.0001
1001-1250 g	1.24	(1.06-1.45)	.006
SGA status			
AGA	1.0 (REF)		
SGA ≤32 wk	0.79	(0.68-0.92)	.0025
SGA ≥33 wk	0.37	(0.30-0.45)	<.0001
Oxygen at 36 wk	0.78	(0.66-0.93)	.0045
Discharging NICU CCS level			
Regional	3.11	(2.25-4.31)	<.0001
Community	2.07	(1.54-2.77)	<.0001
Intermediate	1.0 (REF)		
Non-CCS	0.21	(0.07-0.66)	.0074
NICU volume			
Lowest quartile	1.0 (REF)		
2nd quartile	2.01	(1.50-2.70)	<.0001
3rd quartile	1.58	(1.22-2.06)	.0006
4th quartile	1.61	(1.24-2.08)	.0003
Outborn	1.63	(1.34-1.97)	<.0001
Congenital anomalies	0.81	(0.66-0.99)	.039

NS, not significant; *REF*, reference.
*Infants who were never admitted or transferred to a CCS NICU at any point during their initial hospitalization course were excluded from the model.

There was wide variability in referral among California regions (8%-99%) and NICUs (<5%-100%), which remained after risk adjustment.



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Take-home messages:

- Disparities and barriers to HRIF referral exist in California –
  - Some likely related to perceptions of risk (i.e., EGA, BW), and other resources/referrals (i.e., congenital anomalies).
  - Some may be associated with sociodemographic disparities, and/or indicative of resource challenges and imbalances within NICUs and across the state.
  - ? Unmeasured indicators of risk associated with finding of higher referral in outborn, D/C from higher level.
- **These findings presented immediate opportunities toward targeted QI initiatives to improve HRIF referral**

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Follow-on to our findings: Implementing QI/PI process:

- CPQCC HRIF Referral Reports
  - Developed and launched in **direct response to analyses of HRIF referral at NICU discharge**
    - *A true *process improvement tool* –
  - Through the near real-time CPQCC-HRIF linkage, this report provides NICUs with data on their site HRIF referral rates for targeted high risk groups.
  - ***Enhances communication between referring NICUs and HRIF programs.***

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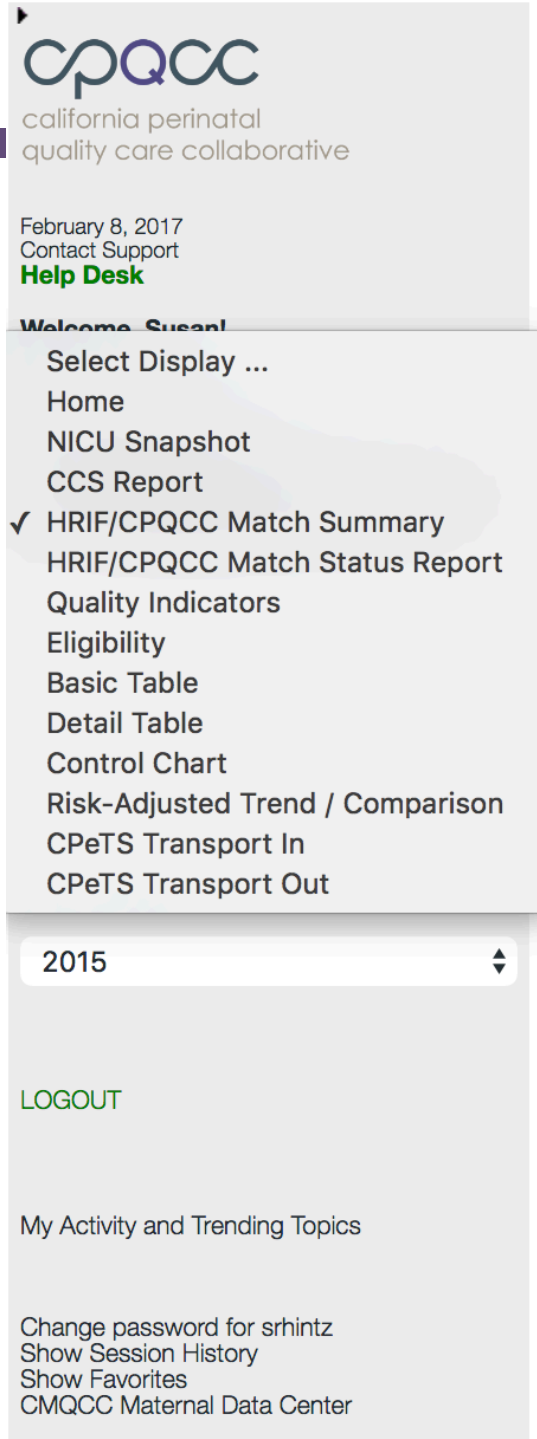

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HRIF/CPQCC Match Summary Report for Infants Discharged Home, 1/1/2015 to 12/31/2015

The CPQCC data collection for infants born in 2015 is complete. HRIF registration is possible for up to 3 years from discharge home.

California Perinatal Quality Care Collaborative (CPQCC)

HRIF Category	N Infants	Infants Referred to HRIF	Referral %	Referral % CCS NICUs	Referral % Regional NICUs
Very Low Birth Weight Infants (<=1,500 grams)	72	72	100.0	99.9	99.9
Extremely Low Birth Weight Infants (<1,000 grams)	36	36	100.0	100.0	100.0
Gestational Age < 28 Weeks	32	32	100.0	100.0	100.0
Infants with Moderate/Severe HIE	5	5	100.0	100.0	100.0
Infants with Cooling	10	10	100.0	100.0	100.0
Infants with ECMO	8	8	100.0	100.0	100.0
Infants Referred for any of the Reasons Above	*91*	*91*	*100.0*	*100.0*	*99.9*
Additional Infants with Gestational Ages 28 to 31 Weeks	22	22	100.0	99.9	100.0
Infants Referred for any of the Reasons Above	*113*	*113*	*100.0*	*99.9*	*100.0*
CPQCC Infants Referred for Other Reasons		119			
All Referrals		*232*			

For detailed information on the HRIF/CPQCC match status of infants discharged home from your NICU, select the HRIF/CPQCC Match Status Report option in the navigation bar.

The above table reflects HRIF registrations through &hrifreportDT.. Any changes in your data after this date/time are not reflected in the report shown.

Deliverable to CPQCC and CCS

- Maintaining 100% referral to HRIF of infants surviving to discharge home for very high risk groups was determined to be a **deliverable** to CPQCC and CCS.
  - Extremely preterm, ELBW, infants with HIE who underwent therapeutic cooling, ECMO
- This is reviewed as a **quality indicator** for all NICUs in considering CCS approval.

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Pre/ post intervention: VLBW and <28 wk EGA referral rates

- VLBW
  - Birth year 2010 referral rate → 81.3%
  - **Birth year 2015 referral rate → 99.9%**
- <28 week EGA
  - Birth year 2010 referral rate → 86.7%
  - **Birth year 2015 referral rate → 99.9%**

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Making it to 1st HRIF visit for VLBW

- Early identification and intervention may improve outcomes for VLBW infants.
- Those lost to follow up (LTFU) or followed with difficulty are at higher risk for adverse outcomes – therefore, it is crucial to identify risk factors for LTFU to enhance HRIF participation.
- **Our question: If referred to HRIF from NICU, how well are we doing in getting our VLBW infants to a 1st HRIF?**

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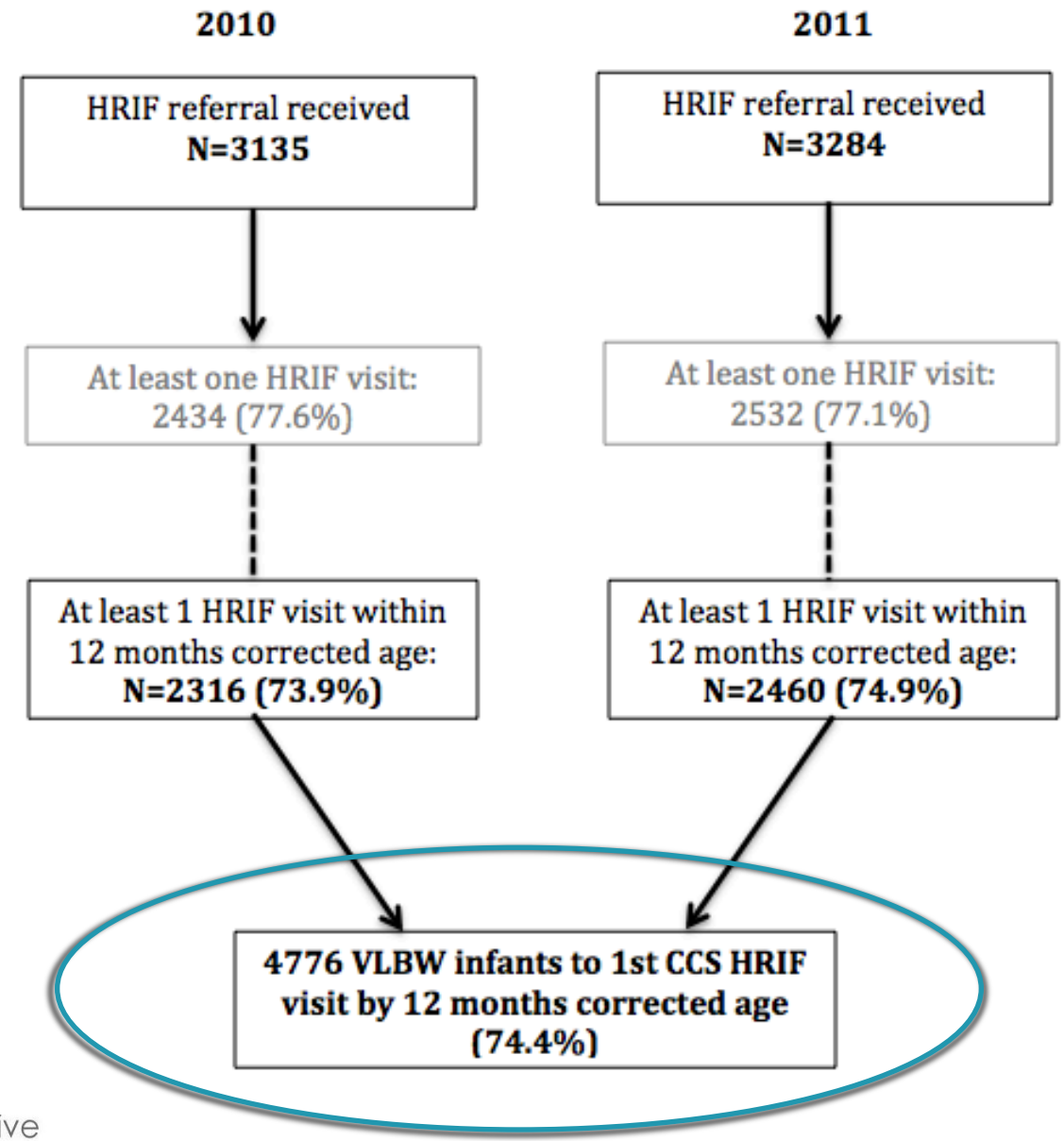
Callanan C, et al. Children followed with difficulty: how do they differ? J Pediatr Child Health. 2001; 37: 152-156

Results: Follow up rates



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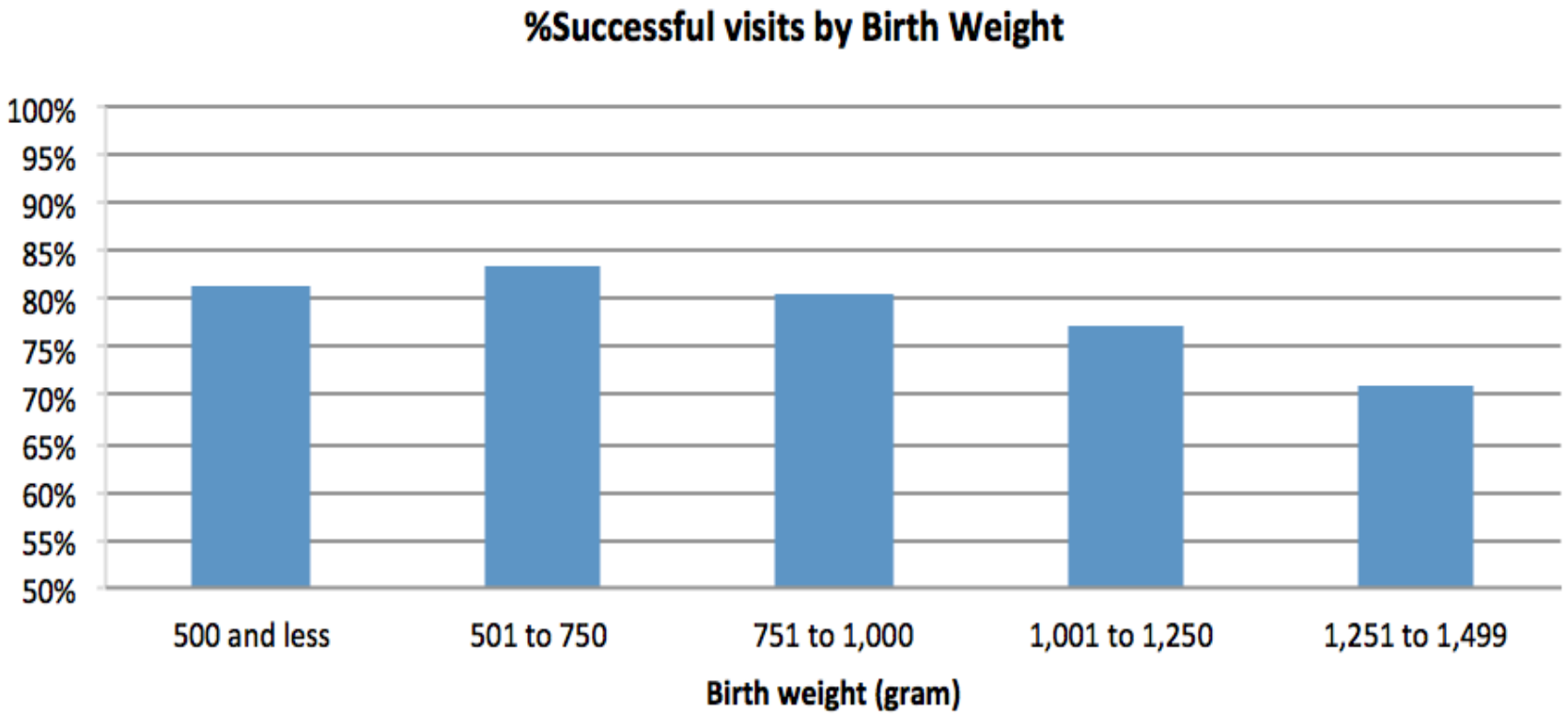
Results:

Successful first HRIF visit less likely with increasing BW.



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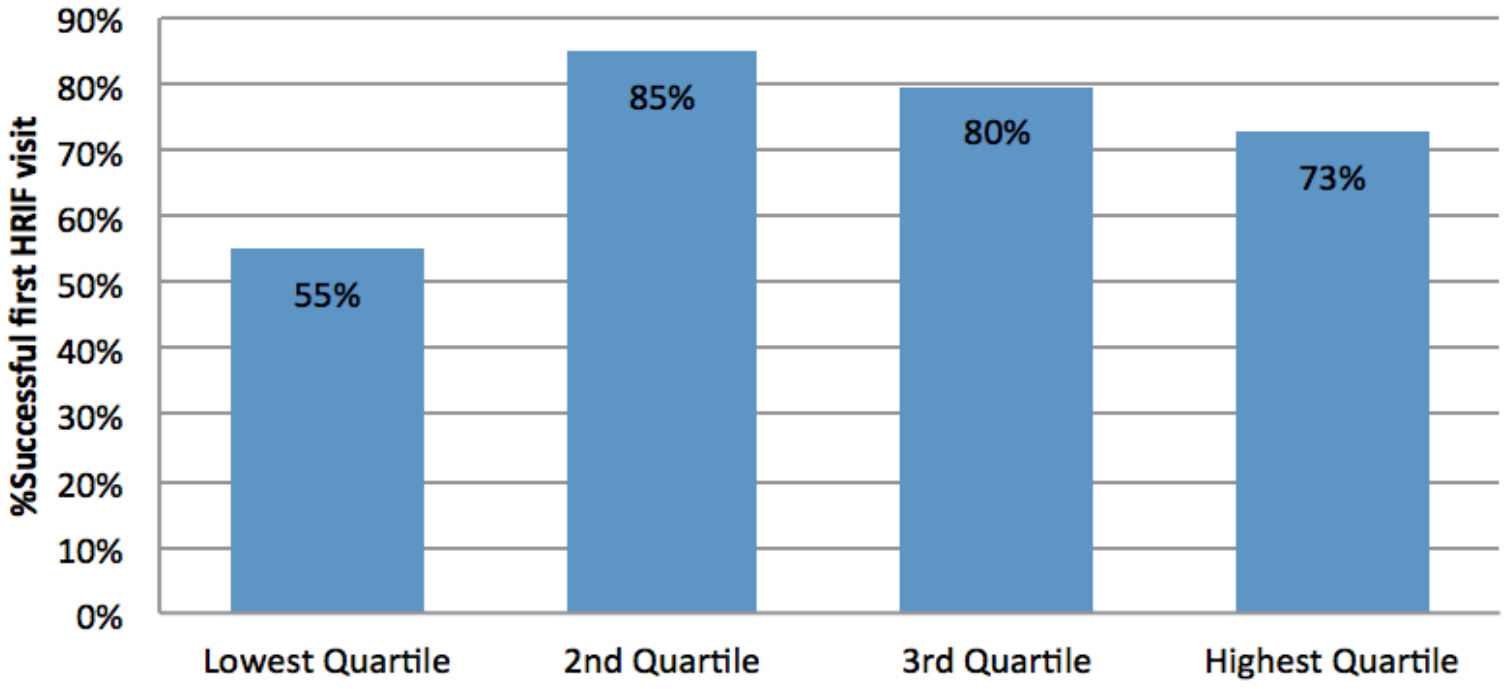
Results:

HRIF program volume quartile – *successful HRIF visit less likely for lowest volume HRIF programs.*



Volume quartile based on average HRIF visit volume 2010 and 2011

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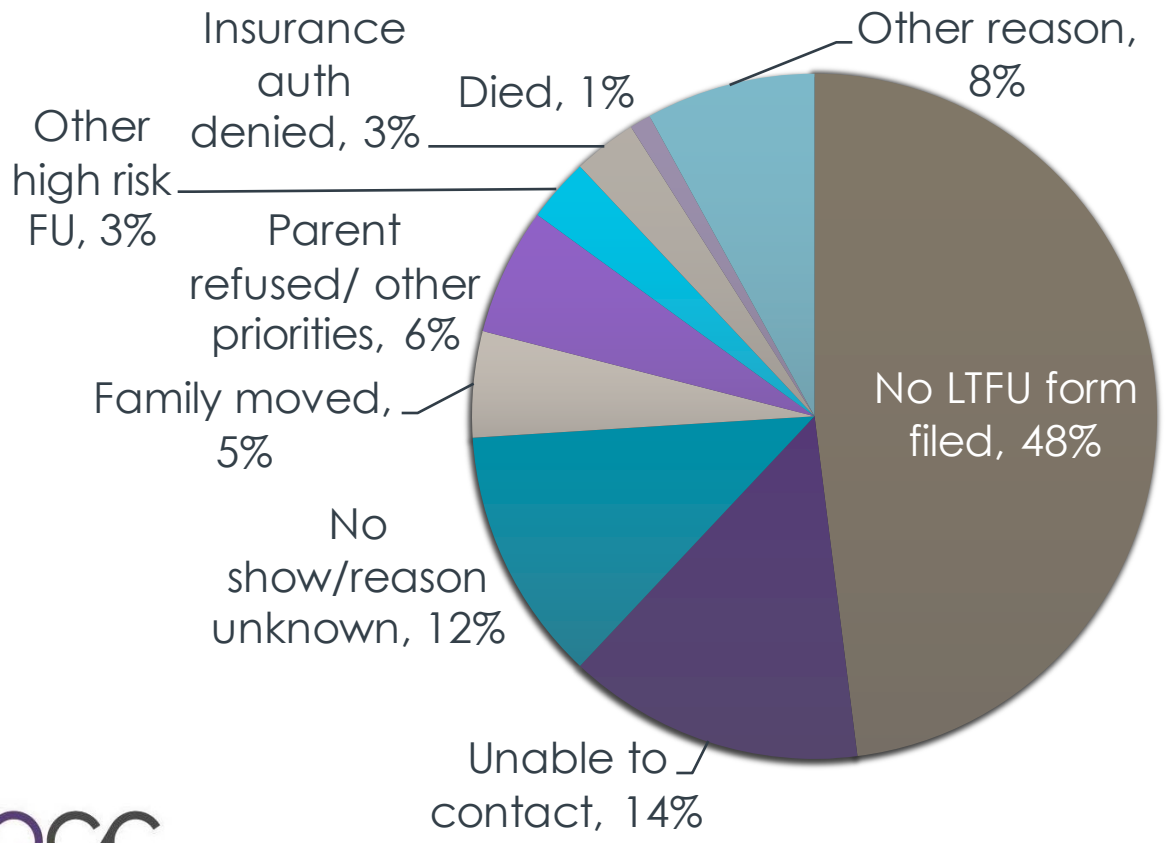
Reasons for loss to follow up



60% = no reason documented (Client Not Seen Form **not** filed, or reason on Client Not Seen Form = reason unknown)

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Multivariable model – Factors associated with successful 1st HRIF

Factor	Adjusted OR (95% CI)	p-value
Associated with higher odds - -		
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
1001-1250 g	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*)		
2nd quartile	4.5 (2.4 – 8.4)	<0.0001
3rd 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
3rd quartile	0.7 (0.6 – 0.9)	0.008

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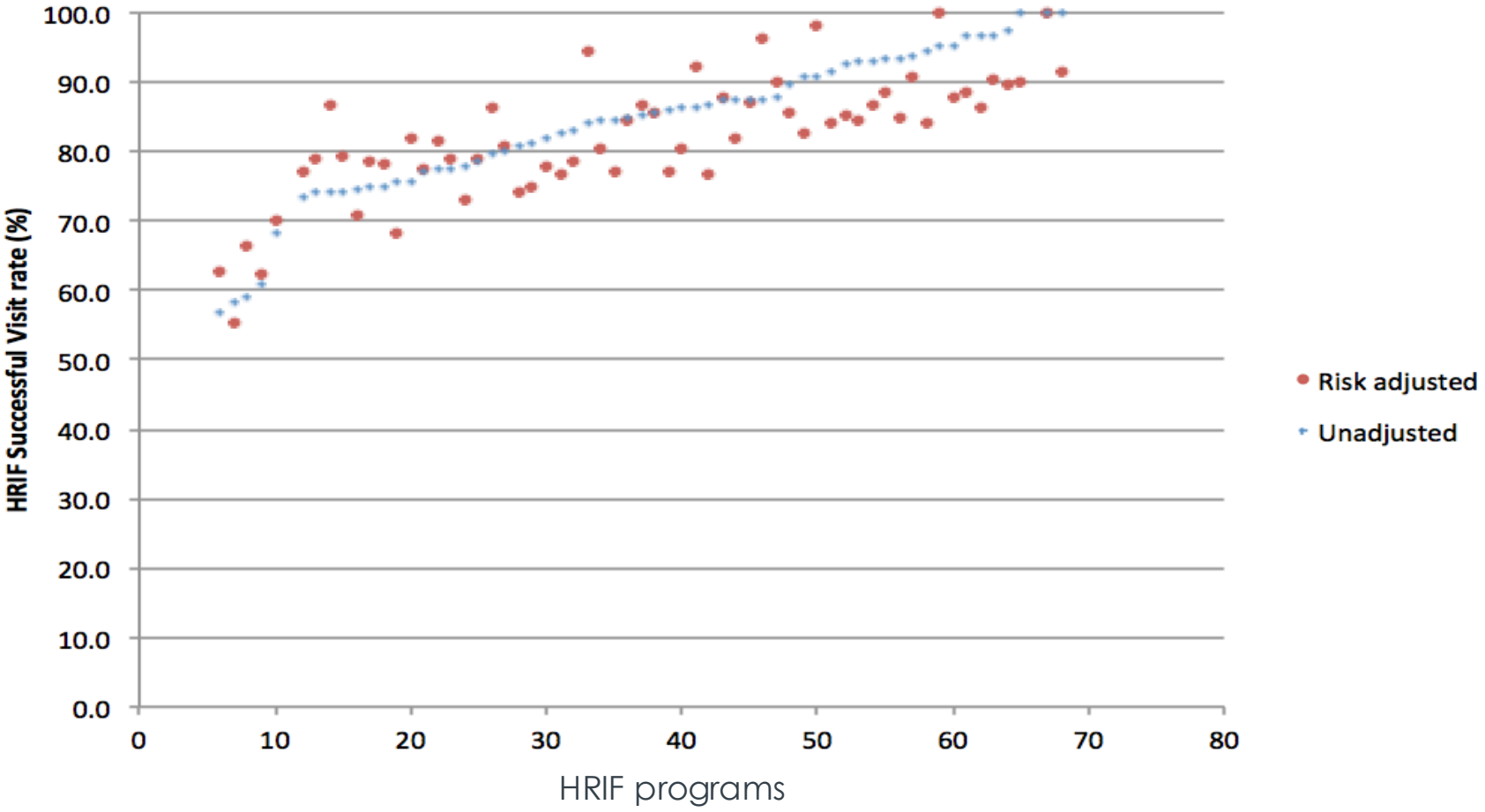
Primary caregiver employment (p<0.001), and college education (p=0.005) were associated with successful HRIF, but not included in final models due to volume of missing data.

There was variability in successful 1st visit among regions (61%-88%) and HRIF programs (57%-100%), which remained after risk adjustment.



Note: The graph showed HRIF programs with more than 20 infants only.

Take home messages

- Overall rate for at least one HRIF visit by 12 mo CA was only 74% for VLBW in this statewide HRIF program.
- Results demonstrate **disparities in successful HRIF engagement in California.**
- **Projects launched** → understand program/ family barriers to HRIF attendance; changes to HRIF data infrastructure to "force" capture of more detailed information about LTFU.
- **Point to opportunities and need for post-discharge QI initiatives, including getting to the 1st HRIF team visit**

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But is the 1st HRIF visit even important?

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The value of the HRIF visit

Background

- The AAP has highlighted HRIF integration in discharge planning as a quality benchmark.
- The interdisciplinary HRIF team has special expertise to recognize evolving difficulties requiring evaluation and intervention, and identify available resources.

Value of HRIF visit : Background

- **We hypothesized that without the HRIF visit, these needs may not be identified consistently**.
  - Earlier identification allows for early intervention, which *ultimately may improve outcomes, and reduce later resource utilization burden*.

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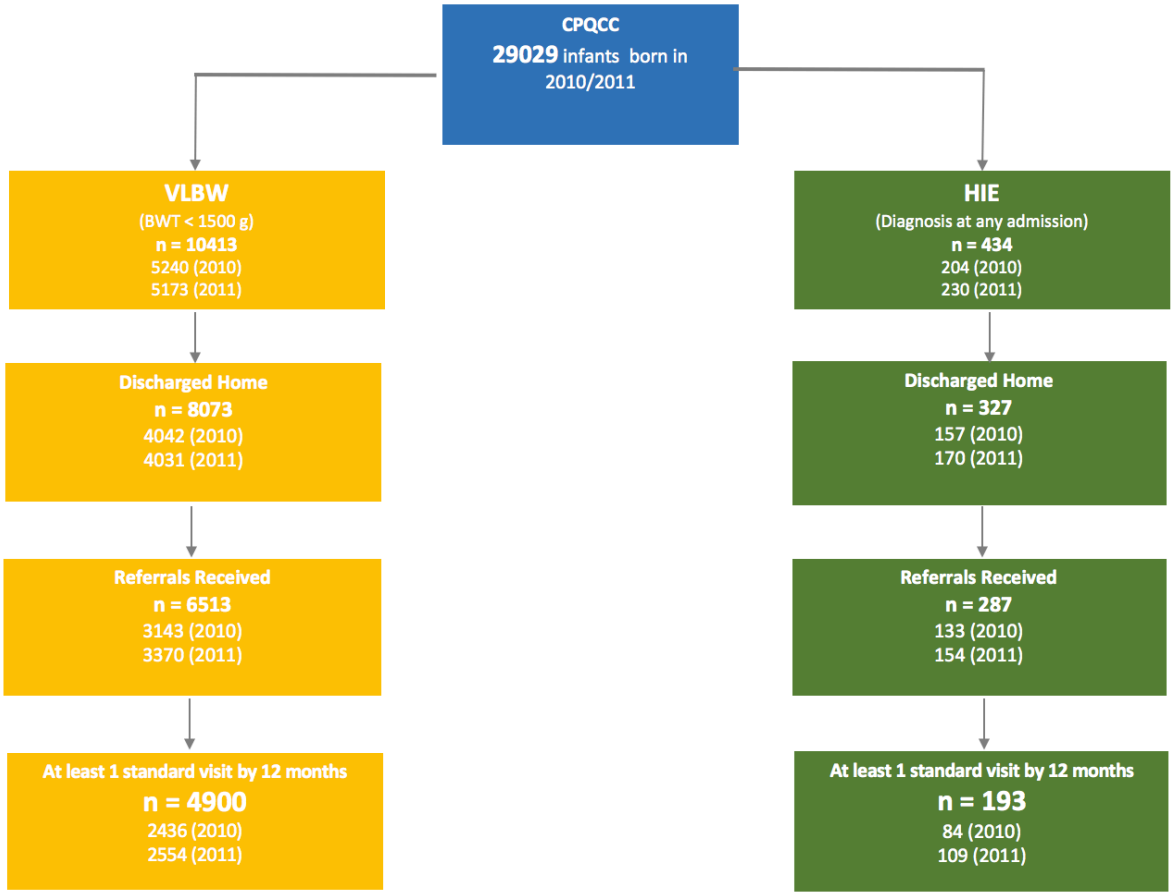
Aims - Value of HRIF visit

- **Our question: How can we delineate the importance of the HRIF visit to patients, families, and the state?**
  - Among VLBW and term HIE infants born 2010 and 2011 in CPQCC and referred to HRIF:
    - Determine rates of service use at the 1st HRIF visit
    - Determine **rates of referrals to needed medical/ special services, EI services *at the HRIF visit***
    - Characterize significant **resource & social concerns revealed and/or addressed *at the HRIF visit*.**

Results: Value of HRIF visit



81% referral rate

75% FU rate

87% referral rate

67% FU rate

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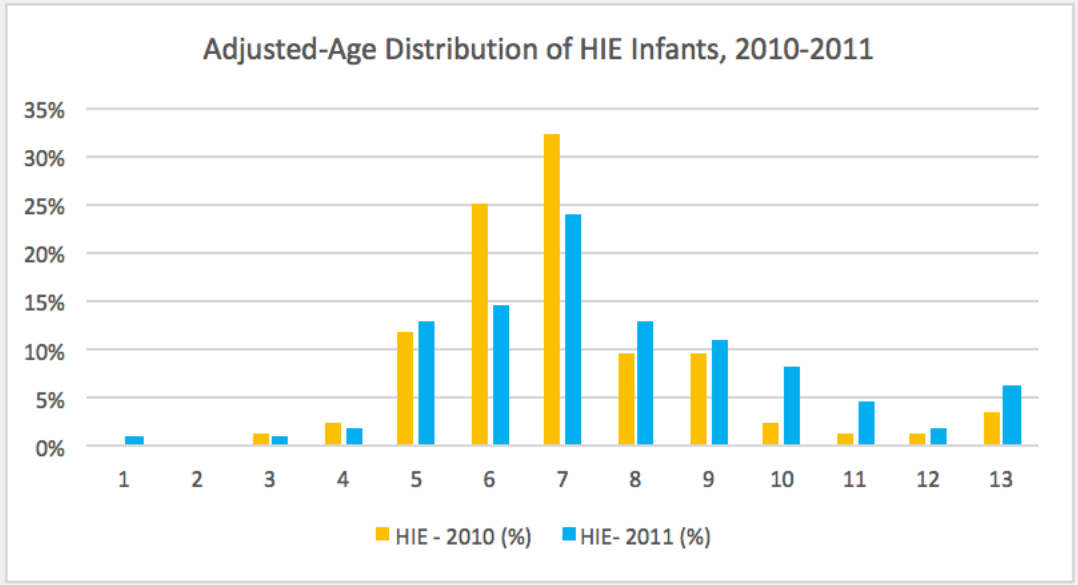
Value of HRIF visit

Results

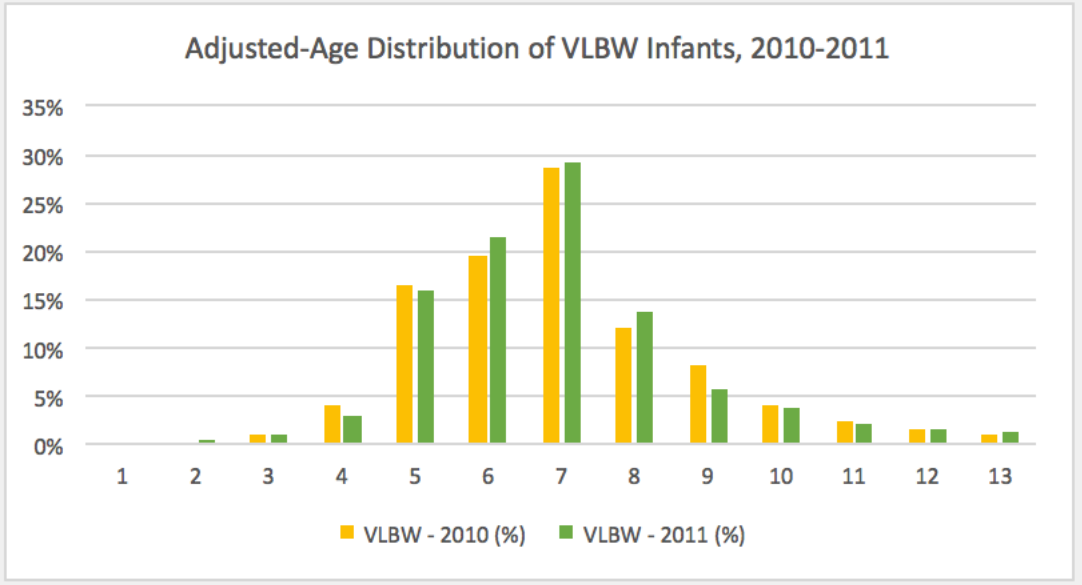
- **99% of VLBW and 100% of HIE indicated they had a primary medical care provider.**

Results – Adjusted age distribution at visit



Median 7 months

Median 6 months



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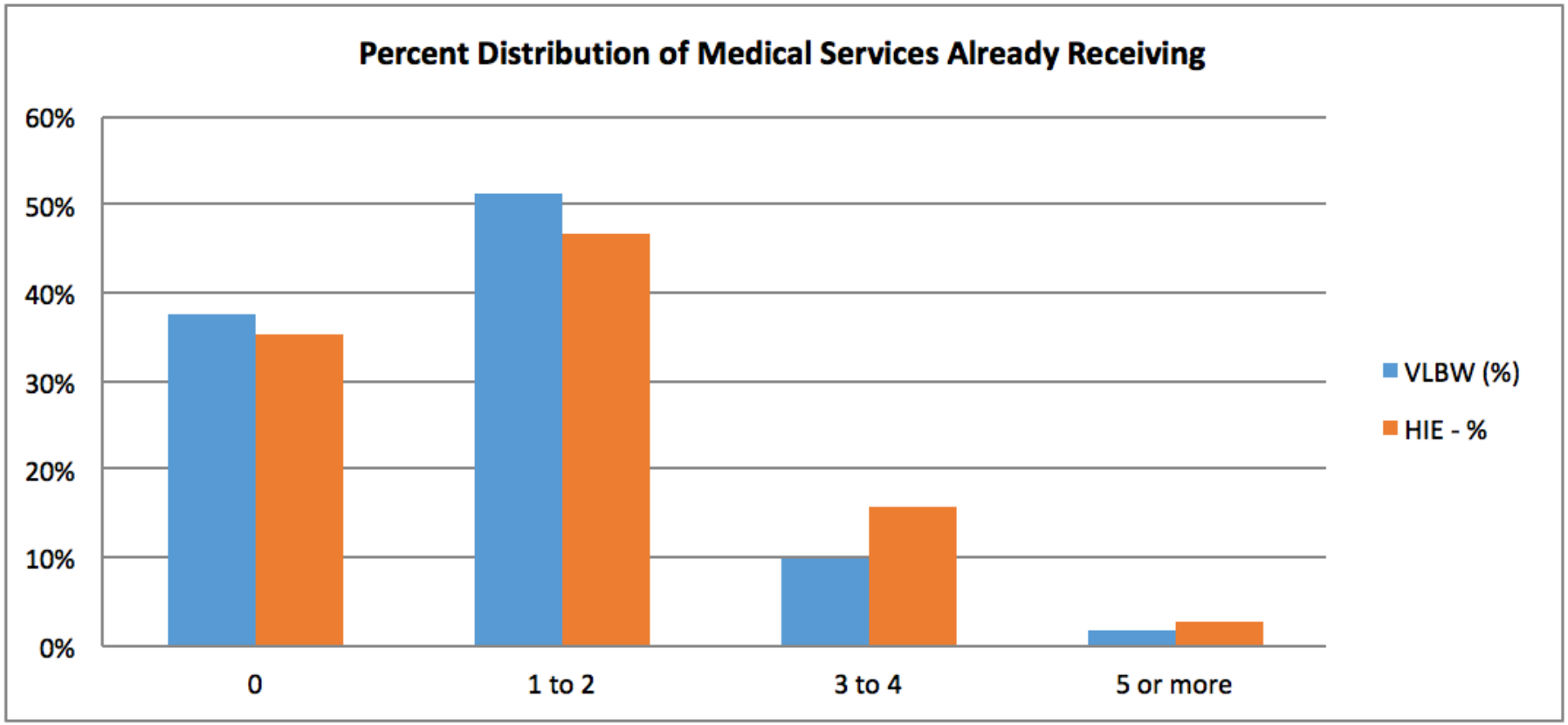
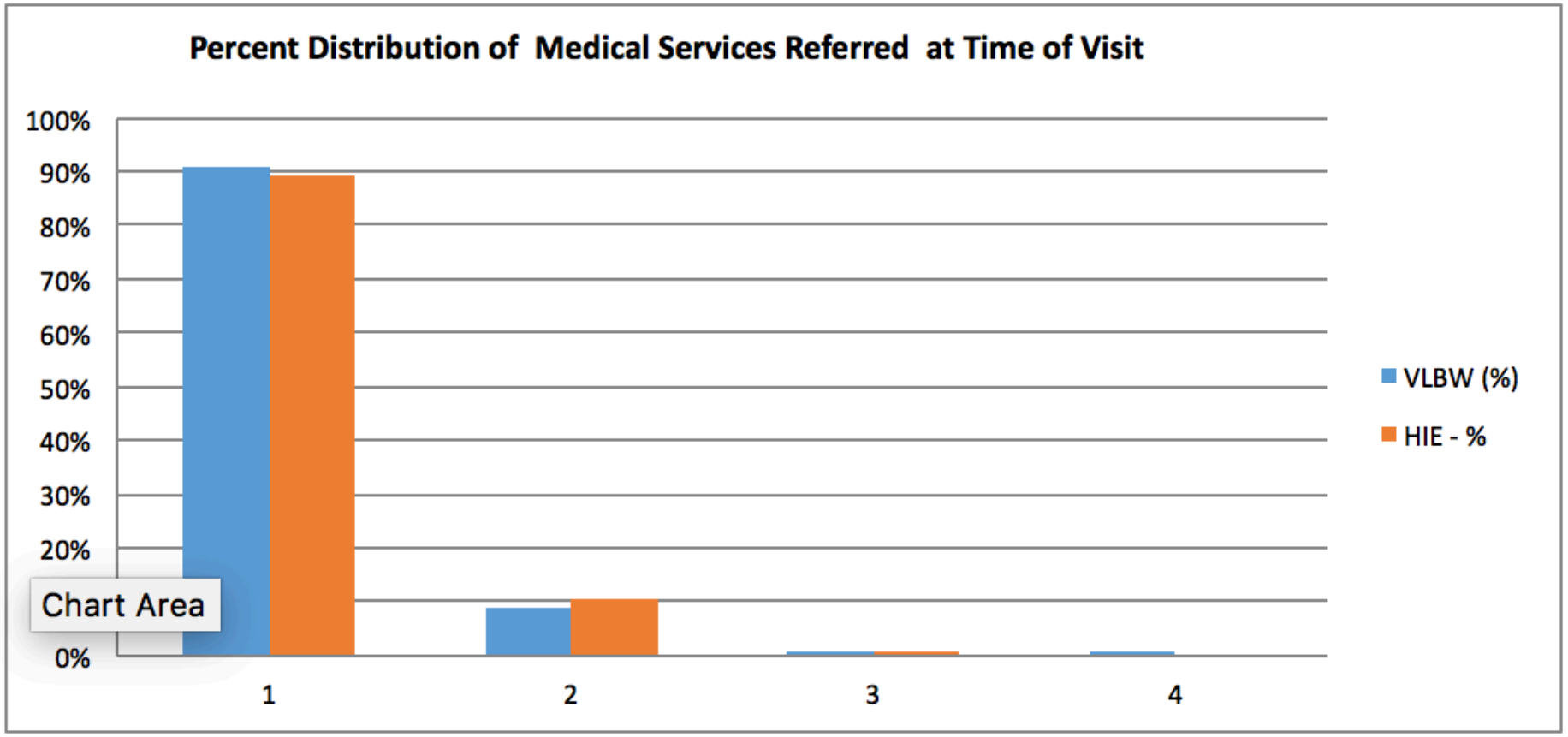
Medical services – Already receiving at visit

Total Medical Services (Already Receiving)	VLBW (N)	VLBW (%)	HIE (N)	HIE - %
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%
	4900		**193**	



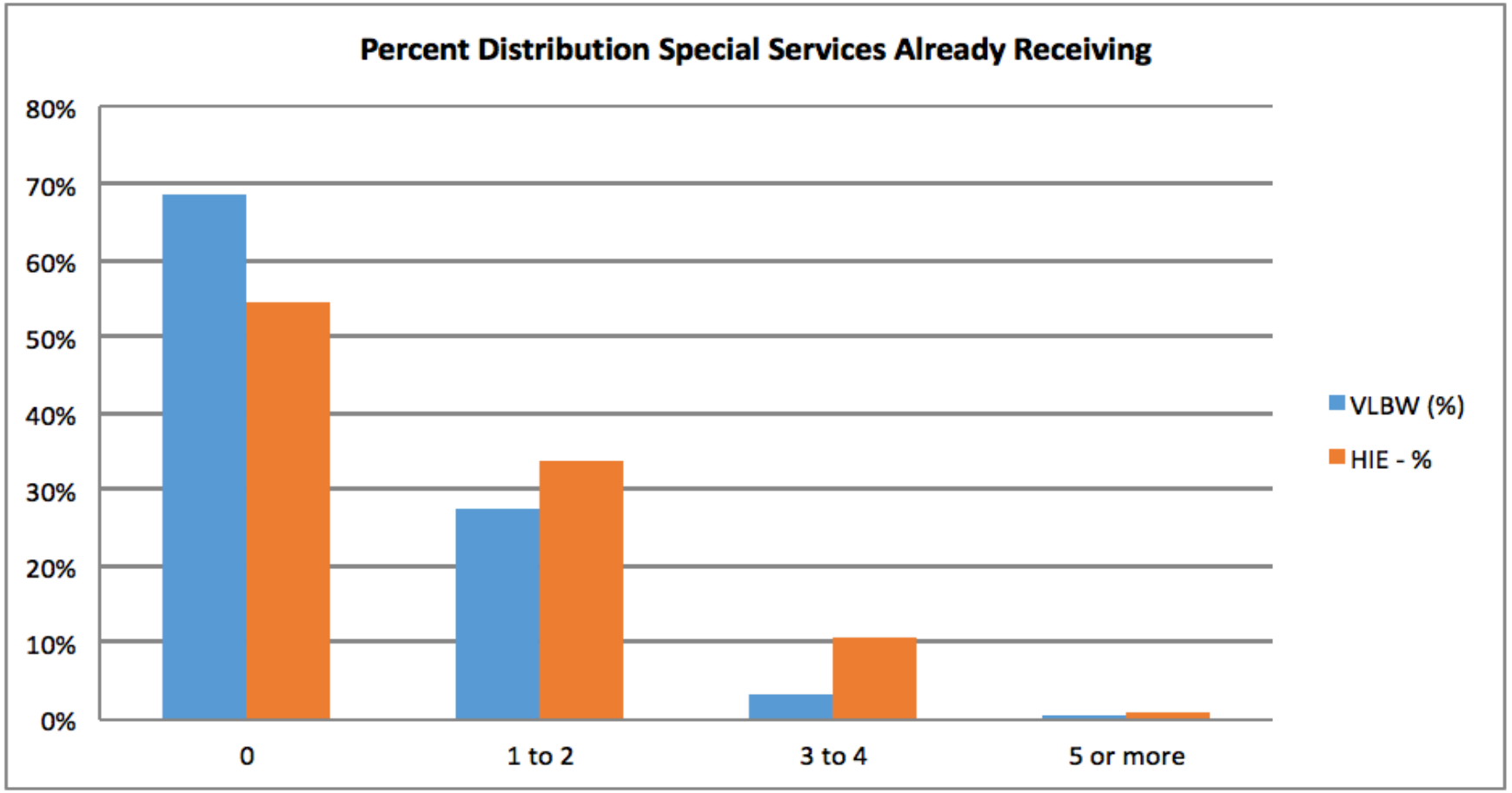
Medical services – REFERRED AT VISIT

Total Medical Services (Referred at time of visit)	VLBW (N)	VLBW (%)	HIE (N)	HIE - %
0	4459	91%	172	89%
1 to 2	423	9%	20	10%
3 to 4	17	0%	1	1%
5 or more	1	0%	0	0%
	4900		**193**	



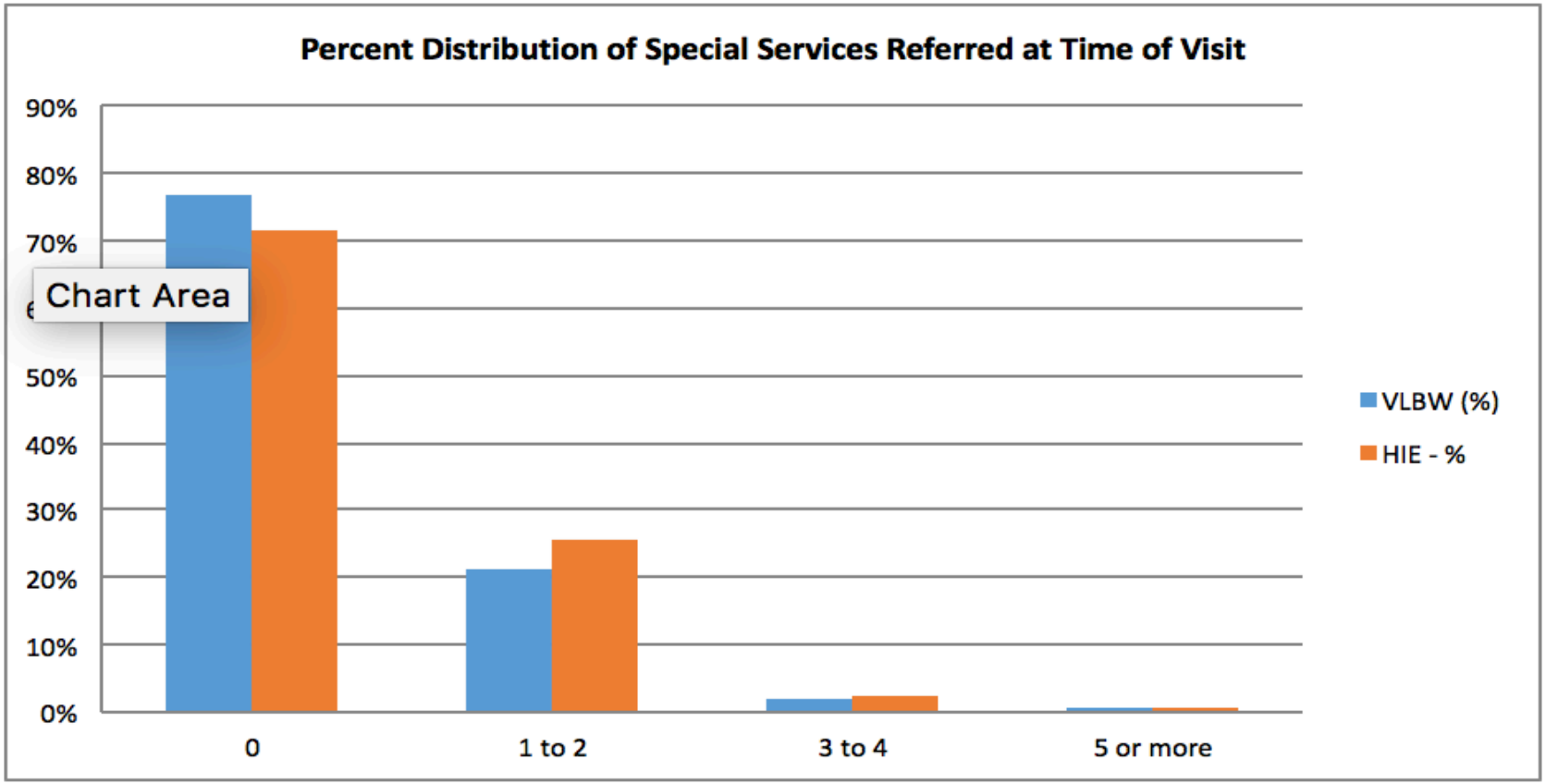
Special services – Already receiving at visit

Total Special Services- Already receiving	VLBW (N)	VLBW (%)	HIE (N)	HIE - %
0	3369	69%	105	54%
1 to 2	1344	27%	65	34%
3 to 4	168	3%	21	11%
5 or more	19	0%	2	1%
	4900		**193**	



Special services – REFERRED AT VISIT

Total Special Services - referred at time of visit	VLBW (N)	VLBW (%)	HIE (N)	HIE - %
0	3757	77%	138	72%
1 to 2	1035	21%	49	25%
3 to 4	101	2%	5	3%
5 or more	7	0%	1	1%
	4900		**193**	



Program and regional factors

- HRIF program variation in referral:
  - % referred for HIE: 0-100% for both medical and special services
  - % referred for VLBW: 0-45% for medical services, 0-60% for special services

Preliminary factors overview

- VLBW – factors associated with special services referral at HRIF visit
  - ***Lower odds***: mother 40+; college degree or higher (compared with HS degree);
  - ***Higher odds***: mother Hispanic; one parent; foster/adoptive (compared with 2 parents); not employed; Spanish or Vietnamese speaker;

Conclusions: Value of HRIF visit

- High service use is common for VLBW and HIE children by the first HRIF visit, but **substantial additional needs are identified by the HRIF team**.
- Despite the fact that ~100% had primary care providers, **~25% of children required at least 1 referral at the 1st HRIF visit**, underscoring its value.
- Further characterization of regional variation and factors associated with increased referral needs may present QI opportunities.

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Periviable survivors at 1st HRIF visit

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Periviable survivors at 1st HRIF visit

Background

- Follow up studies of extraordinarily preterm infants (<26 weeks EGA) have focused on neurodevelopmental impairment at 18-36 months corrected age (CA). These data are often used for prognosis and to guide counseling around treatment decisions.
- However, other endpoints may be more meaningful to families. Further, earlier post-discharge functional and family impact outcomes have rarely been reported in the literature among periviable survivors.

Periviable survivors at 1st HRIF visit

Objectives

- Among infants born at 22+0 to 25+6/7 weeks EGA during 2010-2012 in CPQCC NICUs, and surviving to 1st HRIF visit by 12 months corrected age (CA), we examined **early post-discharge medical and special service use and needs, other resource requirements, and caregiver concerns**.

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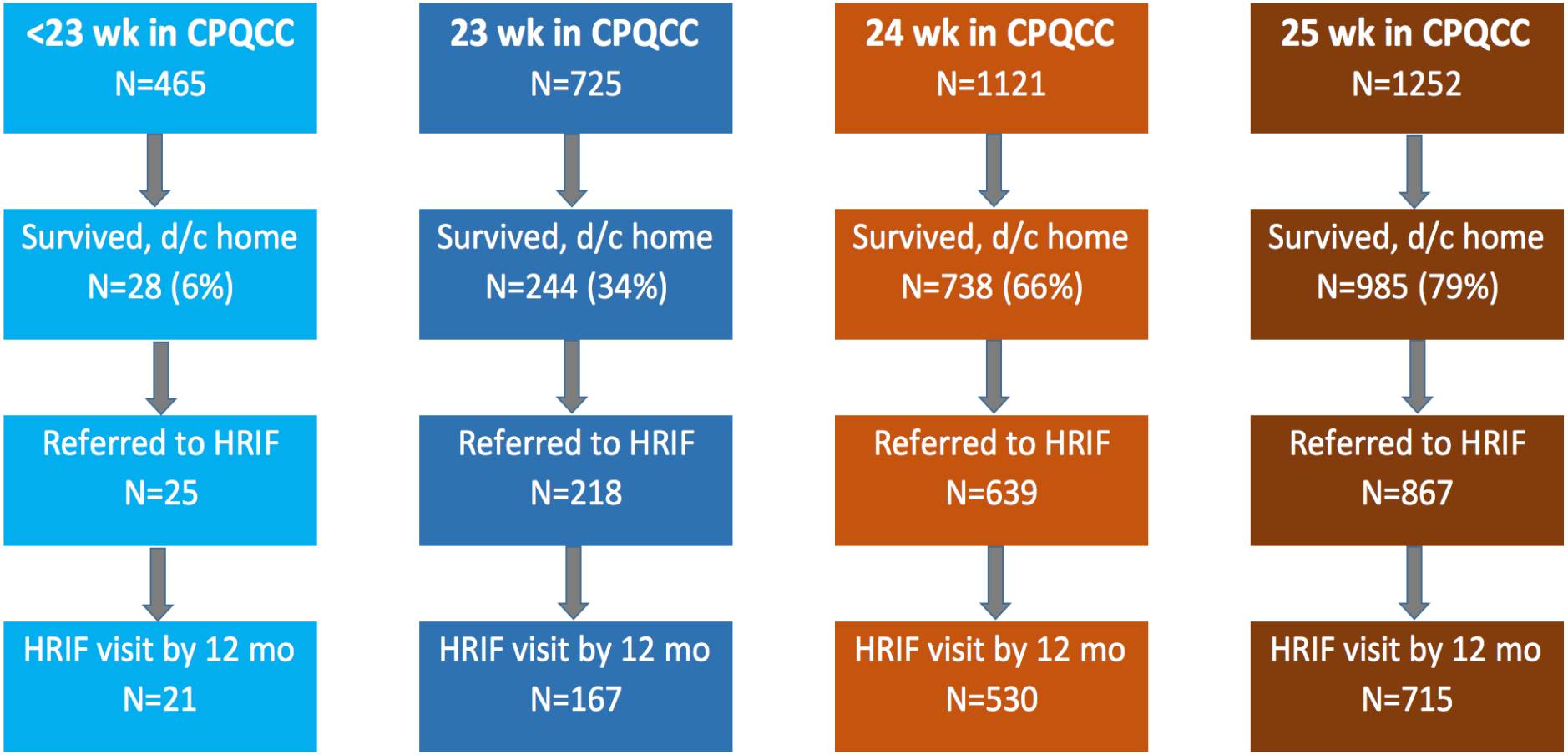
Periviable survivors at 1st HRIF visit

Results

- Of 1995 CPQCC infants <26 weeks EGA discharged home (56% survival), and 1433 (82% of those referred to HRIF) had 1st HRIF visit by 12 mo CA.

Patient flow by EGA from birth in a CPQCC NICU (2010-2012) through 1st HRIF visit (median age: 6 mo CA)



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Periviable survivors at 1st HRIF visit

Results

- Median age at visit was 6 mo (IQR=2 mo) CA.
- Rates of hospitalizations and surgeries by 1st HRIF visit, and medication and equipment, medical and special services used and needed, and caregiver concerns are shown by EGA and overall.

		<23 weeks EGA	23 weeks EGA	24 weeks EGA	25 weeks EGA	ALL
		N=21	N=167	N=530	N=715	N=1433
ANY hospitalization since discharge		5 (24%)	46 (28%)	136 (26%)	189 (26%)	376 (26%)
	Mean # hospitalizations	2	1.5	1.39	1	1.44
ANY surgery since discharge**		3 (14%)	34 (21%)	79 (20%)	109 (15%)	225 (16%)
	Inguinal hernia repair	1 (5%)	7 (4%)	24 (5%)	33 (5%)	65 (5%)
	ROP surgery	2 (10%)	8 (5%)	12 (2%)	27 (4%)	49 (3%)
ANY current medication, supplement		13 (62%)	119 (71%)	366 (69%)	489 (68%)	987 (69%)
	Daily inhaled steroids	1 (5%)	24 (14%)	58 (11%)	76 (11%)	159 (11%)
	Oxygen	4 (19%)	35 (21%)	93 (18%)	96 (13%)	228 (16%)
	Anti-reflux	0	40 (24%)	109 (21%)	142 (20%)	291 (20%)
	Daily or intermittent broncho-dilators	8 (38%)	52 (31%)	151 (28%)	176 (25%)	387 (27%)
	Nutritional supplement	8 (38%)	62 (37%)	163 (31%)	217 (30%)	450 (31%)

TABLE 2. Medical and special service use/ need for referral at 1st HRIF visit, and reported caregiver concerns (median age: 6 months CA)

		<23 weeks EGA	23 weeks EGA	24 weeks EGA	25 weeks EGA	ALL
		N=21	N=167	N=530	N=715	N=1433
Medical specialties*						
Receiving	any	17 (81%)	147 (88%)	421 (79%)	544 (76%)	1129 (79%)
	3 or more	5 (24%)	57 (34%)	150 (28%)	172 (24%)	384 (27%)
Additional referral at visit	any	7 (33%)	26 (16%)	68 (13%)	73 10%)	174 (12%)
Special services*						
Receiving	any	18 (86%)	122 (73%)	391 (74%)	474 (66%)	1005 (70%)
	3 or more	7 (33%)	38 (23%)	128 (24%)	148 (21%)	321 (22%)
Additional referral at visit	any	7 (33%)	68 (41%)	175 (33%)	233 (33%)	473 (33%)
Caregiver concerns about child**						
	Any	8 (38%)	78 (47%)	205 (39%)	289 (40%)	580 (40%)
	Motor skills	5 (24%)	31 (19%)	118 (22%)	139 (19%)	293 (20%)
	Feeding, growth	2 (10%)	30 (18%)	55 (10%)	104 (15%)	191 (13%)
	Vision	1 (5%)	13 (8%)	16 (3%)	27 (4%)	57 (4%)

Periviable survivors at 1st HRIF visit

Conclusions

- This analysis provides a unique view of early post-discharge medical and functional outcomes among extraordinarily preterm survivors.
- Medical and resource use and need was substantial, and observed similarly across EGA.
- Further characterization of the trajectory of functional and family-centered outcomes may provide a more complete picture, and assist in better education and counseling.

PAS 2017 abstracts

- **Value of the HRIF Visit**
- **Medical, functional, and family outcomes at the first HRIF visit among periviable survivors**

  - *Neonatal Epidemiology, Health Services Research Poster Cluster 4*
  - *Tuesday, May 9, 2017 - 7:00 AM to 10:00 AM*

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Opportunities and future goals-
Leveraging the CPQCC continuum

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Complex Congenital Heart Disease in California

Potential to expand a population-based quality of care partnership

CCS HRIF Eligibility

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

JENNIFER KENT
Director

EDMOND G. BROWN JR
Governor

(g) Congenital heart disease requiring surgery or minimally invasive intervention.

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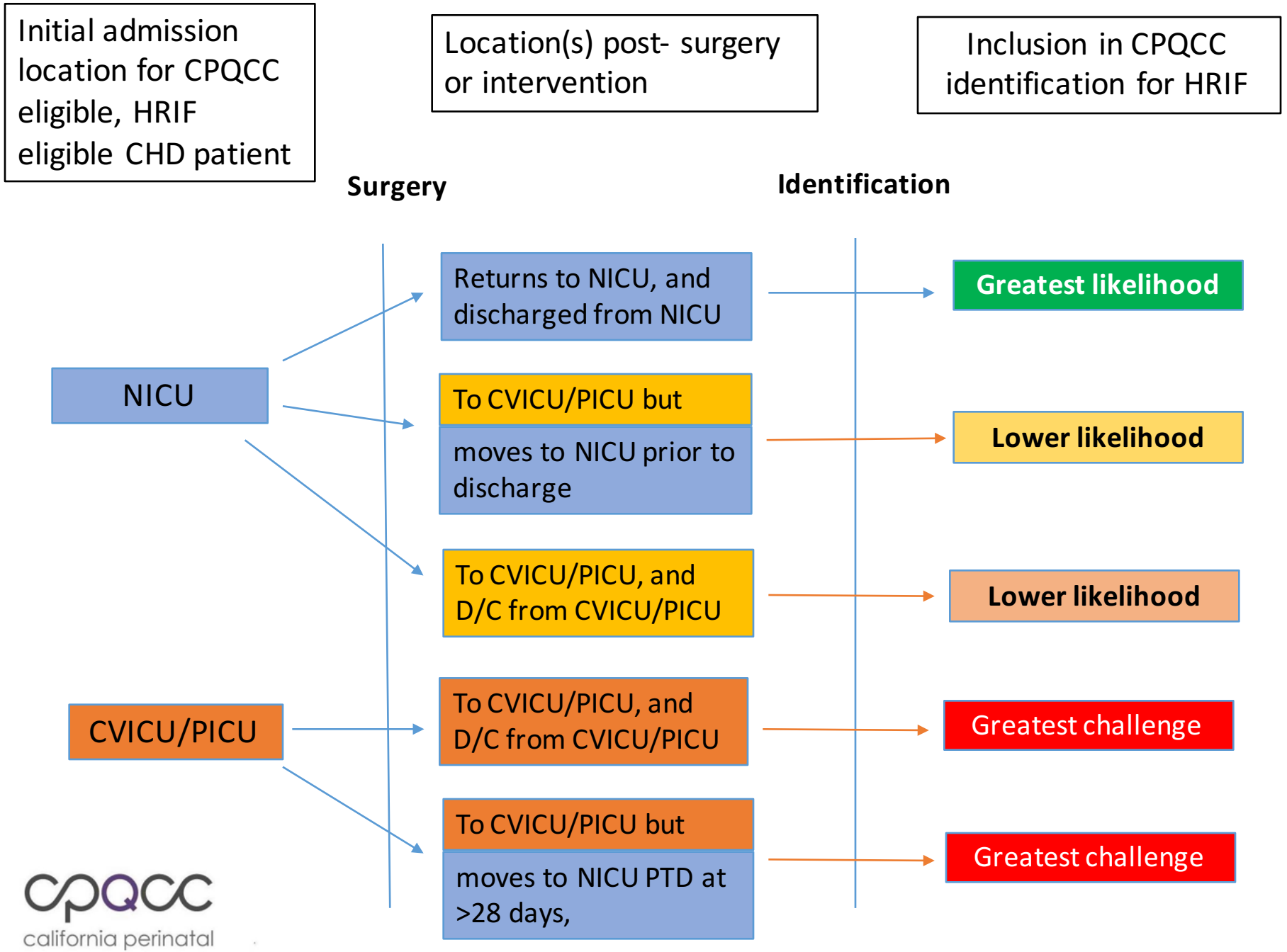
Overview and drivers for change

- What were issues of concern?
  - Survival of complex CHD improved with surgical and medical care advances → **but remain at high risk for morbidities, neurologic injury, impairments**.
  - Literature that exists is single center or small regional results → **population-based data about the continuum of care and outcomes for complex CHD are needed**.
  - Recognition that focus must urgently shift **to follow up outcomes and quality indicators for children with CHD**
  - **Opportunities to expand quality and care improvement efforts in California** to CVICUs and cardiac teams

Challenges to capture?


Initial admission location for CPQCC eligible, HRIF eligible CHD patient
Location(s) post- surgery or intervention
Inclusion in CPQCC identification for HRIF
Surgery
Identification
NICU
CVICU/PICU
Returns to NICU, and discharged from NICU
To CVICU/PICU but moves to NICU prior to discharge
To CVICU/PICU, and D/C from CVICU/PICU
To CVICU/PICU, and D/C from CVICU/PICU
To CVICU/PICU but moves to NICU PTD at >28 days,
Greatest likelihood
Lower likelihood
Lower likelihood
Greatest challenge
Greatest challenge
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Focus on CPQCC patients

- The CPQCC is a framework *already in place* - and in collaboration with the CCS - to collect important information from before delivery, during NICU stay, and through discharge
- ***How could we harness the CPQCC-HRIF continuum in partnership with the state to better understand and serve newborns and children with complex CHD across California?***

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Complex cardiac patients in California

What can we learn from CPQCC-CCS HRIF linked data?

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Preliminary analyses – CPQCC to HRIF for complex CHD

	Birth Year			
	2013	2014	2015	Overall
Babies from CPQCC from 2013 -2015 (N)	14780	15348	15322	45450
Death (including early death)	1217	1184	1192	3593
Survive to Discharged home	13503	14065	14030	41598
Still in hospital at age of 1	9	5	7	21
Unknown	51	94	93	238
Among Survivors to discharge, how many YES = congenital anomalies (49 a)	2824	2822	2818	8464

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Preliminary analyses – CPQCC to HRIF for complex CHD

By cardiac diagnosis	2013	2014	2015	Total
Among Survivors to discharge and congenital anomalies, with the following diagnostic codes (on 49b)				
"Other lethal or life threatening" (200)	258	248	308	814
Truncus (201)	13	19	18	50
TGA (202)	117	105	109	331
TOF (203)	98	106	95	299
Single Ventricle (204)	18	17	18	53
DORV (205)	62	71	75	208
Complete AV canal (206)	39	36	44	119
Pulmonary Atresia (207)	80	72	73	225
Tricuspid Atresia (208)	32	18	14	64
HLHS (209)	68	72	60	200
Interrupted Aortic Arch (210)	21	18	23	62
TAPVR (211)	41	56	52	149
Coarctation (212)	120	96	141	357
Any with above diagnoses	687	691	730	2108
Those referred to HRIF program	268 (39%)	278 (40%)	390 (53%)	**936 (44%)**

Preliminary analyses – CPQCC to HRIF for complex CHD

	Birth Year			
	2013	2014	2015	Overall
Babies from CPQCC from 2013 -2015 (N)	14780	15348	15322	45450
Death (including early death)	1217	1184	1192	3593
Survive to Discharged home	13503	14065	14030	41598
Still in hospital at age of 1	9	5	7	21
Unknown	51	94	93	238
Among Survivors to discharge, how many with "Other" surgery (YES = 43 a)	2228	2222	2189	6639

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Preliminary analyses – CPQCC to HRIF for complex CHD

By cardiac intervention*

	2013	2014	2015	Total
Among Survivors to discharge and other surgery, with the following surgical codes (43 b)				
Repair of coart (S502)	82	50	80	212
Repair of major vascular injury (S503)	24	30	29	83
Repair or palliation of CHD (S504)	262	259	281	802
Heart Transplant (S505)	1	1	3	5
Other open heart surgery (S500)	94	78	67	239
Cath with balloon septostomy (S602)	39	53	36	128
Cath with aortic valvuloplasty (S603)	14	10	13	37
Cath with pulm valvuloplasty (S604)	41	34	26	101
Other interventional cath (S600)	30	30	40	100
Any with above surgical codes	452	411	442	1305
Those referred to HRIF program	**221 (49%)**	**223 (54%)**	320 (72%)	**764 (59%)**

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Challenges: Cardiac CPQCC patients

- ~600-700 *survivors to discharge* with complex CHD per year are in the CPQCC database
- **400-450 per year required surgical or cath-based interventions for CHD in the initial neonatal hospitalization.**
- HRIF-CPQCC linked data shows that **only 40-60% were referred to HRIF overall from 2013-2015 birth years** (although improving over the birth years!).

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Take home message

- **Eligible children with complex CHD in California who qualify for and could benefit from HRIF are not being identified and referred – even if just focusing on those in the CPQCC.**
- **This alone constitutes a significant quality challenge for California.**

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Opportunities identified

- California already has a unique CPQCC infrastructure that combines **data collection, data reports, and process and quality improvement**.
- The CPQCC umbrella has already deployed quality improvement solutions for infants in California – - **both in the NICU and in transition to HRIF referral**.
- Identification of CPQCC patients with cardiac anomalies and need for intervention can be identified – **but will require algorithm building and testing.**

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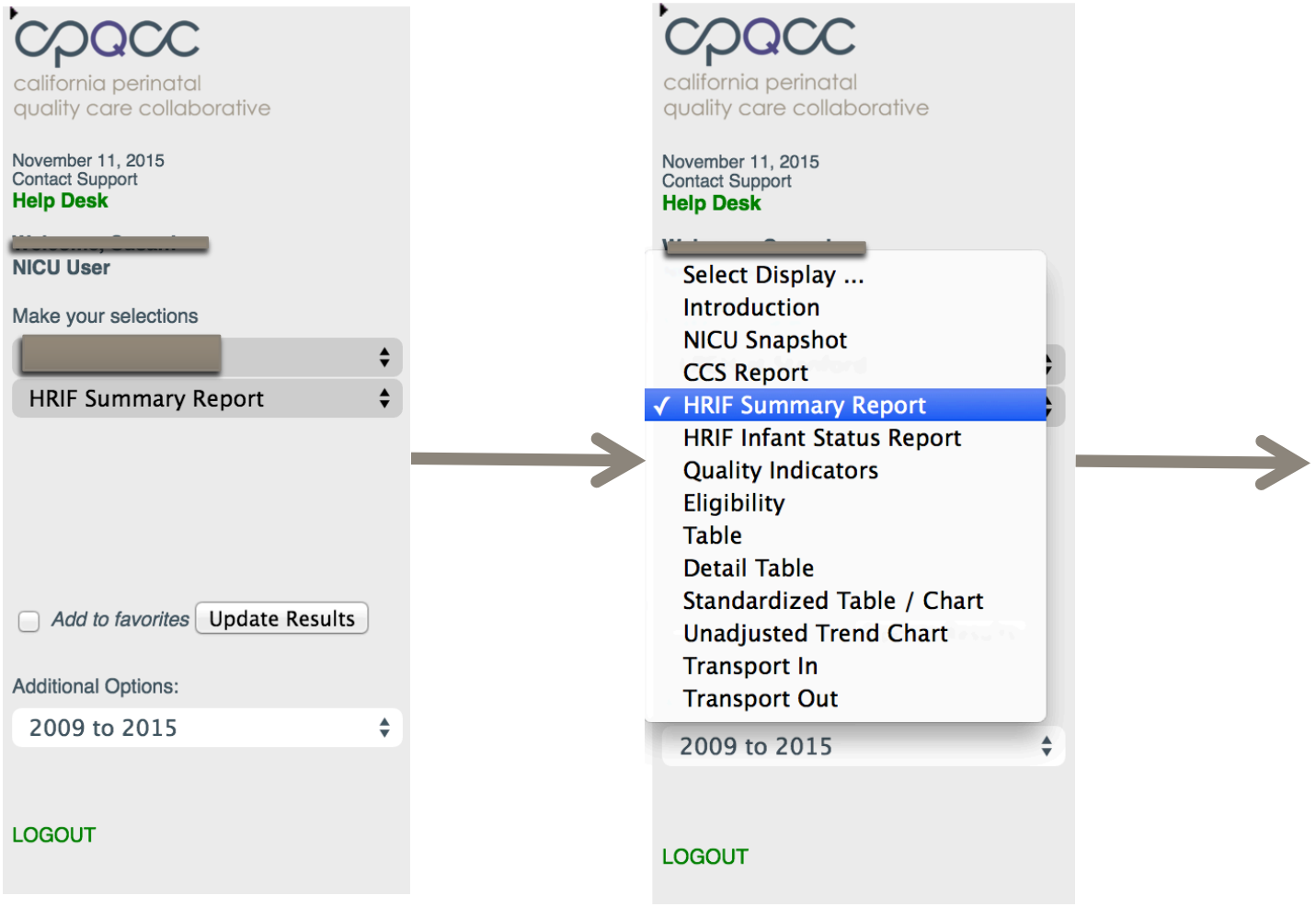
CHD in California: Could be added to CPQCC HRIF Linkage report



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November 11, 2015
Contact Support
Help Desk

[redacted]

Make your selections

[redacted]

HRIF Summary Report

Additional Options:

2014

LOGOUT

My Activity and Trending Topics

Change password [redacted]
Show Session History
Show Favorites
CMQCC Maternal Data Center

CPQCC-CCS Linked HRIF Referral Summary for Infants Discharged Home, 1/1/2014 to 12/31/2014

The CPQCC data collection for infants born in 2014 is complete. HRIF registration is possible for up to 3 years from discharge home.

California Perinatal Quality Care Collaborative (CPQCC)

[redacted]

HRIF Category	N Infants	Infants Referred to HRIF	Referral %	Referral % CCS NICUs	Referral % Regional NICUs
Very Low Birth Weight Infants (<=1,500 grams)	70	70	100.0	99.9	NA
Extremely Low Birth Weight Infants (<1,000 grams)	26	26	100.0	99.9	NA
Gestational Age < 28 Weeks	24	24	100.0	99.9	NA
Infants with Moderate/Severe HIE	6	6	100.0	100.0	NA
Infants with Cooling	21	21	100.0	99.8	NA
Infants with ECMO	5	5	100.0	100.0	NA
Infants Referred for any of the Reasons Above	*96*	*96*	*100.0*	*99.9*	*NA*
Additional Infants with Gestational Ages 28 to 31 Weeks	24	24	100.0	99.6	NA
Infants Referred for any of the Reasons Above	*120*	*120*	*100.0*	*99.8*	*NA*
CPQCC Infants Referred for Other Reasons		87			NA
All Referrals		*207*			*NA*

For detailed information on the HRIF-CPQCC link status of infants discharged home from your NICU, select the HRIF Infant Status Report option in the navigation bar.
The above table reflects HRIF registrations through 11-09-2015. Any changes in your data after this date/time are not reflected in the report shown.

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Take home message

- The CPQCC-HRIF continuum has already demonstrated capability to identify eligible high risk patients, and substantially improve HRIF referral rates for VLBW infants in CPQCC.

- **Strategies similar to those employed previously– i.e., flag in a linked CPQCC-HRIF report - could be undertaken to enhance identification and HRIF referral of complex CHD patients.**

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Goals for future –

- **Obtain addition information from CPQCC and HRIF providers to:**
  - Understand local and regional practice variations,
  - Learn from HRIF-NICU-CVICU teams with successful coordination,
  - Determine perceived challenges to HRIF referral,
  - Assess need for education and heightened awareness of CCS HRIF eligibility and expectations.
    - Enhancing opportunities to identify and refer eligible children with complex CHD *may require differing approaches across the state*.

Examples of CPQCC non-eligible cases

Non-CPQCC eligible CHD patients:

- Admitted to NICU after 28 days
- Admitted to NICU within 28 days, but does not need surgery or meet other CPQCC eligibility at that time
- Never admitted to NICU

Resulting gaps in data and communication

Gaps:

- If not part of CPQCC, cannot flag these patients, identify eligible patients/ track HRIF referrals, measure successes.
- Very limited/ no perinatal/neonatal data available
- Inability to link to CPQCC dataset - precludes goal for longitudinal continuum of care dataset

Possible FUTURE steps to expand capture at later ages

"CPQCC-Heart form":

- Short form with CPQCC ID (if CPQCC eligible), diagnosis, surgery, unit
- Partial data for all CHD patients (complete data for CPQCC eligible)
- Referral/Registration for all CHD patients

In addition:

- Augmented interface between HRIF and CVICU will enhance identification/ referral.
- Educational efforts with CVICU teams will enhance identification/ referral.

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Transition from NICU to Home

Potential for intervention in California?

Outcomes and interventions - ***Beyond the NICU***

- Post-NICU; **most complex** medical conditions, enormous service needs, substantial clinical and support follow up.
- Although improving, **parent integration in NICU is limited** – preparation for the possible challenges of discharge is scant.
  - The change from "complete support" to nearly absent support can lead to problems and missteps in medical care, massive emotional impact on mother/ family.
- **Social-emotional impact** on mother/ parents; anxiety, stress, depression→ exacerbates child, family challenges.
- **Pediatrician/ medical home** → limited time, experience.

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Van Wassenauer AG, et al. *Dev Med Child Neur* 2016; Andrews B, et al. *NeoRev 2011; Treyvaud K, et al. Pediatrics* 2014; Aagaard H, et al. *JBI* 2015

HRIF/ Early intervention

- "Early intervention" may encompass many different components, services, disciplines –
  - Some highly focused (i.e., motor/ physical outcome), some more comprehensive and encompass focus on family…
  - Some begin in the NICU, some only after discharge…
  - Some focus on medical/ developmental outcomes, other functional…
- Diverse in their components, but also in their primary outcomes - -

Spittle A et al. Cochrane Database 2012, CD005495

Many approaches and studies - - **what can we conclude?**

- Programs that recognize **maternal/family anxiety and stress** as part of the challenges that face the child have **most comprehensive effect on outcomes**.
- Interventions with individually **family-centered and home-based components**, enhancing **parent responsiveness**, have **greatest long term impact on *childhood developmental* outcomes**.
- Programs must combine elements assuring **child health/ service support** *with* **parent/family resilience.**
- **Ideally**: include focus on the infant, parent/caregiver, and the environment - beginning in the NICU and continuing beyond.

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Van Wassenauer-Leemhuis AG, et al. *Dev Med Child Neur* 2016, 58 (S4): 67-72; Guralnick M. J Dev Beh Ped 2012, 33:352–364

Do we need NICU-to-home transition interventions in California?

- **Substantial at-risk population**:
  - More than 500,000 births in 2014 - - ~ 7000 very preterm, ~3500 extremely preterm births annually.
  - Diversity in resource availability, service access.
- **Significant disparities** in resources across NICUs and HRIF programs in California, and subsequently, in approach to NICU-to-home transitions.
  - CPQCC-HRIF program survey; referral to HRIF, discussions.
- **Robust infrastructure** in place for NICU to HRIF intervention and quality improvement in place in California.

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Getting to a transition intervention -

- **Step 1: Determine risks for failure to refer to HRIF from NICU discharge, for loss to follow-up, delineate value of HRIF.**
  - **Substantial progress on this aim with projects and analyses thus far -**
- **Step 2: Drill down on facilitators and barriers in transition from NICU to HRIF with key stakeholders.**
  - Focus groups, site visits - *parents, NICU teams, HRIF teams, primary care providers, CCS stakeholders, other insurers and providers* - qualitative research approaches.

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Getting to a transition intervention -

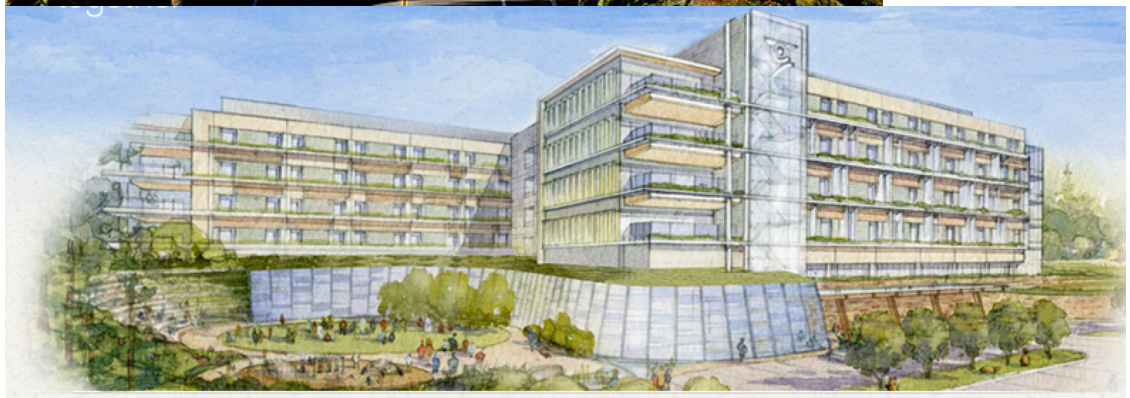
- **Step 3: Develop final components for intervention program.**
  - Elements of the NICU to home transition program will include key components:
    - NICU engagement - team mentoring, education, tools
    - NICU physician and nursing education
    - Family focused transition planning
    - Home visits → at least through 6-9 months
  - Others - Post-discharge parent peer support group; "chat group" or email peer support group; text message system/ mobile app for reminders, encouragement, etc.

Getting to a transition intervention -

- **Step 4: Compare effectiveness of the HRIF Transition Program to usual care.**
  - Conduct an implementation trial using a step-wedge design in 3-5 NICU+HRIF programs.
    - California wide? = **aspirational**, altruistic, not $$ feasible
  - Outcomes (ideally ~18 months) to include - 1) parent anxiety / self-efficacy, 2) HRIF and PMP follow-up rates to 1st and 2nd visit, 3) healthcare utilization, 4) child health outcomes.

Challenges to reshaping the future

- Much is invested in the survival of the highest risk babies.
  - We now must invest to assure the best possible **life course outcomes** for these children and families.
- Understanding factors related to trajectory of early outcomes remain important – but the time has come to take the next, challenging steps to improve the ultimate outcomes for our patients and their families.



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