Your Successes:
QI Research & Implementation

October 7, 2020

Webinar Logistics

- Attendees are automatically muted upon entry
- The "chat" function has been disabled. **Please utilize the Q&A box if you are having technical difficulties and to submit any questions you have for the presenters. We will answer as many questions as possible during the Q&A portion of the webinar.**
- The slides and webinar recording will be sent out after the webinar and will also be posted on the CPQCC website at https://www.cpqcc.org/engage/annual-data-training-webinars-2020

Presenters

- **Henry Lee, MD, MS**, Chief Medical Officer, CPQCC
- **Ronald Cohen, MD**, Medical Director, Northern CPeTS
- **Jochen Profit, MD, MPH**, Chief Quality Officer, CPQCC
- **Susan R. Hintz, MD, MS**, HRIF Medical Director, CPQCC

California Perinatal Transport System (CPeTS)

Ronald Cohen, MD

CPeTS BASED PUBLICATIONS 2020

Neonatal transport in California: findings from a qualitative investigation

Vishnu Priya Akula[1] · Laura C. Hedli[1] · Krisa Van Meurs[1] · Jeffrey B. Gould[1,2,3] · Kan Peiyi[3] · Henry C. Lee[1,3]

Received: 2 January 2019 / Revised: 28 April 2019 / Accepted: 17 May 2019 / Published online: 3 July 2019

Abstract

Objective To identify characteristics of neonatal transport in California and which factors influence team performance.

Study design We led focus group discussions with 19 transport teams operating in California, interviewing 158 neonatal transport team members. Transcripts were analyzed using a thematic analysis approach.

Result The composition of transport teams varied widely. There was strong thematic resonance to suggest that the nature of emergent neonatal transports is unpredictable and poses several significant challenges including staffing, ambulance availability, and administrative support. Teams reported dealing with this unpredictability by engaging in teamwork, gathering experience with staff at referral hospitals, planning for a wide variety of circumstances, specialized training, debriefing after events, and implementing quality improvement strategies.

Conclusion Our findings suggest potential opportunities for improvement in neonatal transport. Future research can explore the cost and benefits of strategies such as dedicated transport services, transfer centers, and telemedicine.

Journal of Perinatology (2020) 40:394–403
https://doi.org/10.1038/s41372-019-0409-7

Clinical deterioration during neonatal transport in California

Vidya V. Pai[1] · Peiyi Kan[1,2] · Jeffrey B. Gould[1,2] · Alvin Hackel[3] · Henry C. Lee[1,2]

Received: 7 February 2019 / Revised: 9 July 2019 / Accepted: 23 July 2019 / Published online: 5 September 2019

Abstract

Objective Identify clinical factors, transport characteristics and transport time intervals associated with clinical deterioration during neonatal transport in California.

Study design Population-based database was used to evaluate 47,794 infants transported before 7 days after birth from 2007 to 2016. Log binomial regression was used to estimate relative risks.

Results 30.8% of infants had clinical deterioration. Clinical deterioration was associated with prematurity, delivery room resuscitation, severe birth defects, emergent transports, transports by helicopter and requests for delivery room attendance. When evaluating transport time intervals, time required for evaluation by the transport team was associated with increased risk of clinical deterioration. Modifiable transport intervals were not associated with increased risk.

Conclusion Our results suggest that high-risk infants are more likely to be unstable during transport. Coordination and timing of neonatal transport in California appears to be effective and does not seem to contribute to clinical deterioration despite variation in the duration of these processes.

Journal of Perinatology (2020) 40:377–384
https://doi.org/10.1038/s41372-019-0488-5

QI Research & Implementation in the NICU

Henry Lee, MD, MS

Addressing Disparities in NICU Care

Jochen Profit, MD, MPH

She Was Pregnant With Twins During Covid. Why Did Only One Survive?

Why being Black and giving birth in New York during the pandemic is so dangerous.

MEDICAL DISPATCH

THE ESSENTIAL WORKERS FILLING NEW YORK'S CORONAVIRUS WARDS

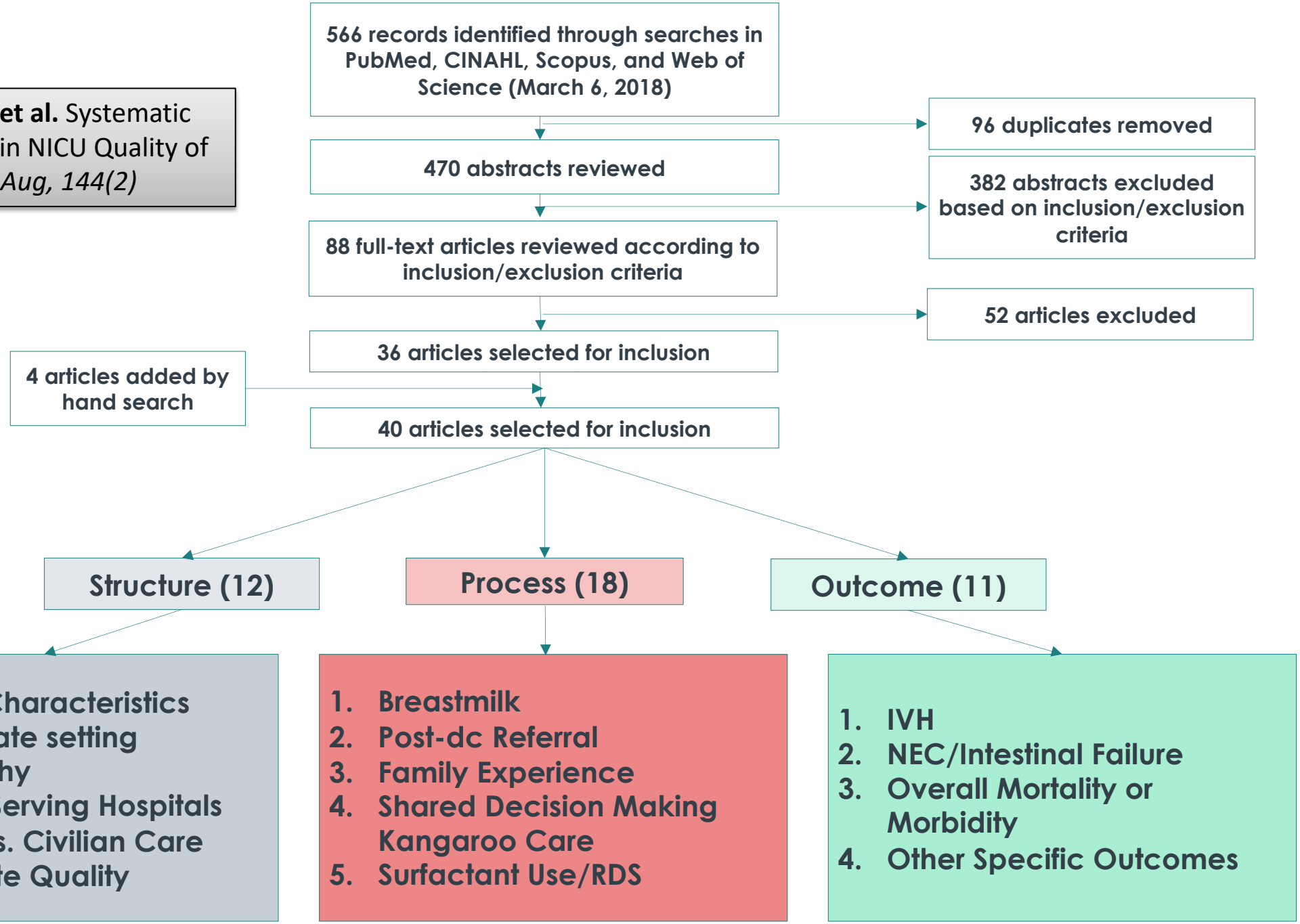
By Dhruv Khullar
May 1, 2020

Delivery people are among the essential workers who must expose themselves and their families to the virus every day. Photograph by Matt Rourke / AP / Shutterstock

For Latinos and Covid-19, Doctors Are Seeing an 'Alarming' Disparity

The outsized infection rate among Hispanics in some states could hobble efforts to quash the spread of Covid-19, prompting states like Oregon to step up testing and take emergency measures.

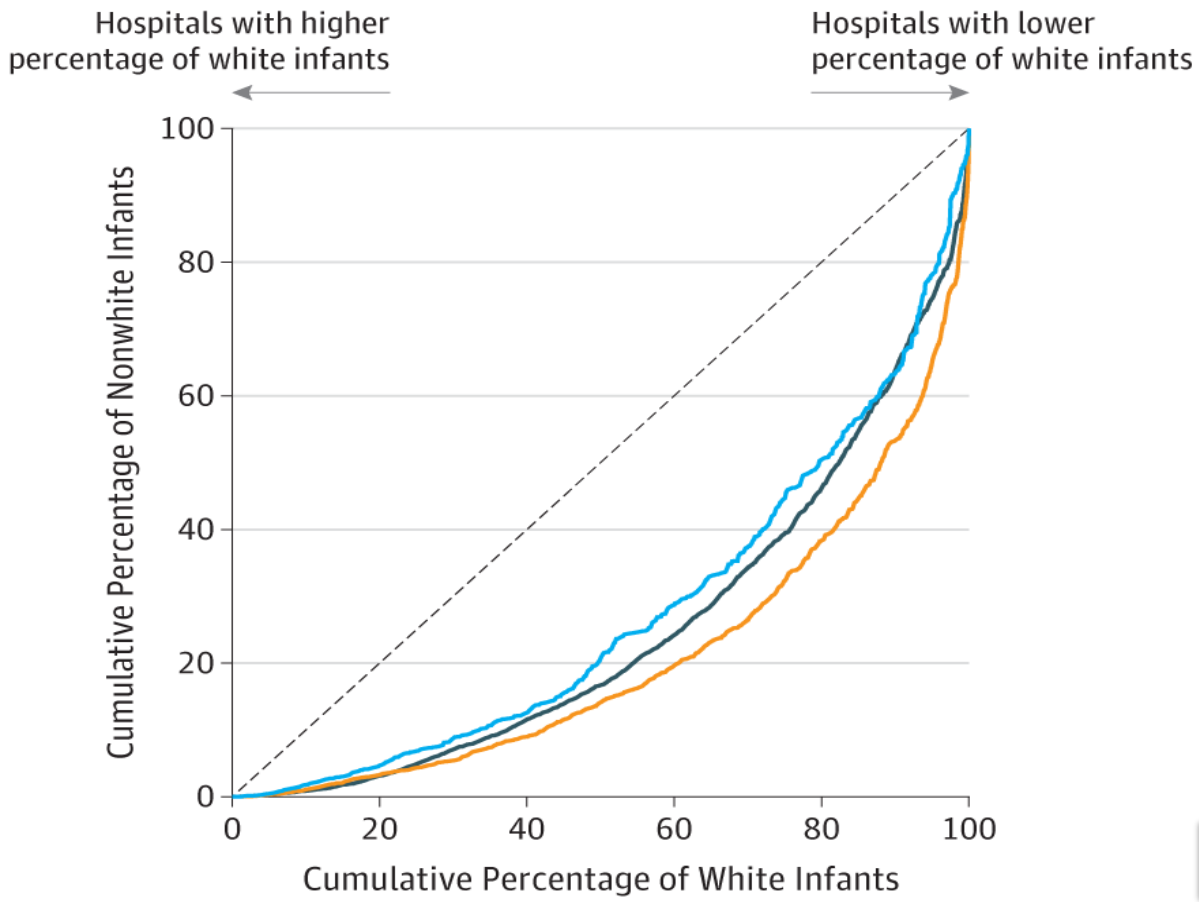
Sigurdson K, Profit J, et al. Systematic Review of Disparities in NICU Quality of Care. *Pediatrics 2019 Aug, 144(2)*



JAMA Network™

Racial Segregation in the NICU

	NICU Segregation Index (95% CI)
Black	0.50 (0.46-0.53)
Hispanic	0.58 (0.54-0.61)
Asian	0.45 (0.40-0.50)




Research

JAMA Pediatrics | Original Investigation

Racial Segregation and Inequality in the Neonatal Intensive Care Unit for Very Low-Birth-Weight and Very Preterm Infants

Jeffrey D. Horbar, MD; Erika M. Edwards, PhD; Lucy T. Greenberg, MS; Jochen Profit, MD; David Draper, PhD; Daniel Helkey, MS; Scott A. Lorch, MD; Henry C. Lee, MD; Ciaran S. Phibbs, PhD; Jeannette Rogowski, PhD; Jeffrey B. Gould, MD; Glenn Firebaugh, PhD

IMPORTANCE Racial and ethnic minorities receive lower-quality health care than white non-Hispanic individuals in the United States. Where minority infants receive care and the role that may play in the quality of care received is unclear.

OBJECTIVE To determine the extent of segregation and inequality of care of very low-birth-weight and very preterm infants across neonatal intensive care units (NICUs) in the United States.

DESIGN, SETTING, AND PARTICIPANTS This cohort study of 743 NICUs in the Vermont Oxford Network included 117 982 black, Hispanic, Asian, and white infants born at 401 g to 1500 g or 22 to 29 weeks' gestation from January 2014 to December 2016. Analysis began January 2018.

MAIN OUTCOMES AND MEASURES The NICU segregation index and NICU inequality index were calculated at the hospital level as the Gini coefficients associated with the Lorenz curves for black, Hispanic, and Asian infants compared with white infants, with NICUs ranked by proportion of white infants for the NICU segregation index and by composite Baby-MONITOR (Measure of Neonatal Intensive Care Outcomes Research) score for the NICU inequality index.

RESULTS Infants (36 359 black [31%], 21 808 Hispanic [18%], 5920 Asian [5%], and 53 895 white [46%]) were segregated among the 743 NICUs by race and ethnicity (NICU segregation index: black: 0.50 [95% CI, 0.46-0.53], Hispanic: 0.58 [95% CI, 0.54-0.61], and Asian: 0.45 [95% CI, 0.40-0.50]). Compared with white infants, black infants were concentrated at NICUs with lower-quality scores, and Hispanic and Asian infants were concentrated at NICUs with higher-quality scores (NICU inequality index: black: 0.07 [95% CI, 0.02-0.13], Hispanic: −0.10 [95% CI, −0.17 to −0.04], and Asian: −0.26 [95% CI, −0.32 to −0.19]). There was marked variation among the census regions in weighted mean NICU quality scores (range: −0.69 to 0.85). Region of residence explained the observed inequality for Hispanic infants but not for black or Asian infants.

CONCLUSIONS AND RELEVANCE Black, Hispanic, and Asian infants were segregated across NICUs, reflecting the racial segregation of minority populations in the United States. There were large differences between geographic regions in NICU quality. After accounting for these differences, compared with white infants, Asian infant

Editorial

Supplemental content

Lorenz Curves for Segregation by Race/Ethnicity in US NICUs ranked by the proportion of white infants from highest to lowest, and the cumulative population percentages of white and minority infants were plotted on the x- and y-axes. If all NICUs had the same racial distribution as the overall population, the curves would fall on the diagonal.

Edwards, Horbar, Profit et al. *JAMA Pediatr 2019*

Original Article

Disparities in Health Care–Associated Infections in the NICU

Jessica Liu, PhD, MPH[1,2] Charlotte Sakarovitch, P
Henry C. Lee, MD, MS[1,2] Jochen Profit, MD, MI

[1]Perinatal Epidemiology and Health Outcomes Research Unit, Divi
Neonatology, Department of Pediatrics, Lucile Packard Children's
Hospital, Stanford University School of Medicine, Palo Alto, Califor
[2]California Perinatal Quality Care Collaborative, Palo Alto, Cali
[3]Division of Biomedical Informatics Research, Department of
Medicine, Stanford University, Stanford, California
[4]Medical Data Lab, Université Côte d'Azur, Nice, France

Am J Perinatol

Abstract

Objectives This stu
associated infection (H
race/ethnicity and its
Study Design This
between 2011 and
Results Risk-adjus
units (NICUs), ran
higher odds of HA
Non-Hispanic bla
tertile of infect
ethnicities suff
Conclusion
variation in infection across
with infection.

Keywords
- infant
- health care–associated infection
- disparity
- risk factors

Health care–associated infection (HAI) is a serious complication among very low birth weight (VLBW; <1,500 g) preterm infants hospitalized in the neonatal intensive care unit (NICU), and infection rates in these infants have ranged from 21 to 30%.[1–4] VLBW infants are especially susceptible to HAI. They are immune-incompetent hosts, require prolonged hospitalization, undergo frequent invasive procedures, and receive prolonged broad-spectrum antibiotics and intravenous nutrition.[1,5–7] In addition, infection risk is conveyed by a combination of maternal health and clinical practice-related factors.[1–3,5,6,8–11]

HAIs are associated with increases in neurodevelopmental impairment, mortality, length of stay, and as a result, increased financial costs of care.[3,6,12–17] Payne et al reported that the occurrence of just one single type of HAI would increase costs of treating VLBW infants by $100 million.[12] Reducing HAI has been a priority in recent years, and successful efforts have been reported from individual NICUs and through collaborative networks, such as the Vermont Oxford Network and the California Perinatal Quality Care Collaborative (CPQCC).[7,18–20]

Vulnerable populations may be differentially affected by HAI because they may receive care in challenged hospitals, which provide lower quality of care,[21–23] or differential treatment within hospitals.[24] HAI is more dependent on

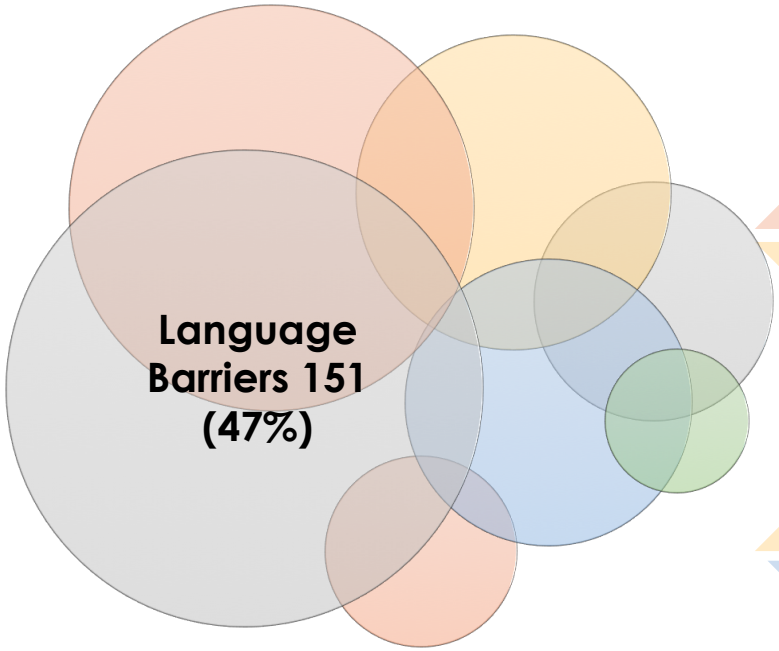
* At the time of this research, Dr. Sakarovitch was a senior statistician at the quantitative sciences unit.

Blacks more likely cared for in hospitals with higher HAI rates

Hispanics more likely to have a HAI

Liu et al. Am J Perinat 2019; Apr 30

Overlapping Dimensions



Types of Disparate Care

Neglectful Care: 83 (26%). NICU staff ignore, avoid or neglect family needs (e.g. breastfeeding support) when considered difficult or unpleasant or when obstacles considered too great to overcome.

Judgmental Care: 82 (26%): Staff evaluate a family's moral status based on race, class or immigration. Circumstances or behaviors judged more harshly. Discrimination occurs through staff attitudes or resource allocation.

Systemic Barriers: 139 (44%): Staff unable or unwilling to address barriers families face such as transportation, child care, housing, employment, translation needs, or religious or cultural needs.

Suboptimal Care: 312 (96%)

Social, Economic or Racial Privilege: 12 (3%)

Priority Treatment and/or Assertive Families: 12 (3%). Families connected to NICU receive priority treatment. Assertive families receive more attention.

Privileged Care: 12(3%)

Sigurdson K, Profit J, et al. Disparities in NICU Quality of Care: A Qualitative Study of Family and Clinician Accounts. *J Perinatol* 2018 Apr 5.

Measures of Family Centered Care

- **NICU family advisory council**
- **Days to first skin-to-skin care**
- **Time to priming with oral colostrum**
- **Delayed social worker encounter**

Research Article

Former NICU Families Describe Gaps in Family-Centered Care

Qualitative Health Research
1–15
© The Author(s) 2020
Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/1049732320932897
journals.sagepub.com/home/qhr
SAGE

Krista Sigurdson[1], Jochen Profit[1], Ravi Dhurjati[1], Christine Morton[1], Melissa Scala[1], Lelis Vernon[2], Ashley Randolph[3], Jessica T. Phan[4], and Linda S. Franck[5]

Abstract

Care and outcomes of infants admitted to neonatal intensive care vary and differences in family-centered care may contribute. The objective of this study was to understand families' experiences of neonatal care within a framework of family-centered care. We conducted focus groups and interviews with 18 family members whose infants were cared for in California neonatal intensive care units (NICUs) using a grounded theory approach and centering the accounts of families of color and/or of low socioeconomic status. Families identified the following challenges that indicated a gap in mutual trust and power sharing: conflict with or lack of knowledge about social work; staff judgment of, or unwillingness to address barriers to family presence at bedside; need for nurse continuity and meaningful relationship with nurses and inconsistent access to translation services. These unmet needs for partnership in care or support were particularly experienced by parents of color or of low socioeconomic status.

Keywords

family-centered care; neonatal care; quality-of-care; grounded theory; patient-and-family engaged research; California; qualitative

A growing body of literature documents parents' critical role in promoting the health outcomes of low birthweight and preterm infants and a variety of models have been promoted toward that end (Franck & O'Brien, 2019). Historically, families were not permitted in the neonatal intensive care unit (NICU) or were only permitted on a limited schedule as "visitors" (White et al., 2013). Family-centered care, as an approach to NICU care, recognizes the strengths and needs of a patient's family and their important role in promoting recovery from illness and long-term health outcomes (Franck & O'Brien, 2019).

The origins of family-centered care can be traced back to British children's hospitals in the 1950s when nurses began to involve parents in the care of their hospitalized children (Jolley & Shields, 2009). The approach came to influence care in the United States over the 1980s, as families gradually came to be seen as active care partners of their children (Brewer et al., 1989). Family-centered care, consisting of interrelated principles and practices that recognize the central importance of family members in an individual's health and well-being, has since been widely applied across the lifespan and in various health care settings (Davidson et al., 2017; Johnson, 2000). It is now understood under the larger umbrella concept of "patient- and family-centered care" in that the principles of working *with* patients and families (rather than doing "to" or "for" them) can be applied to any care setting (Institute for Patient- and Family-Centered Care, 2020). For the purposes of this project involving parents of former NICU patients, we use the term "family-centered care" throughout.

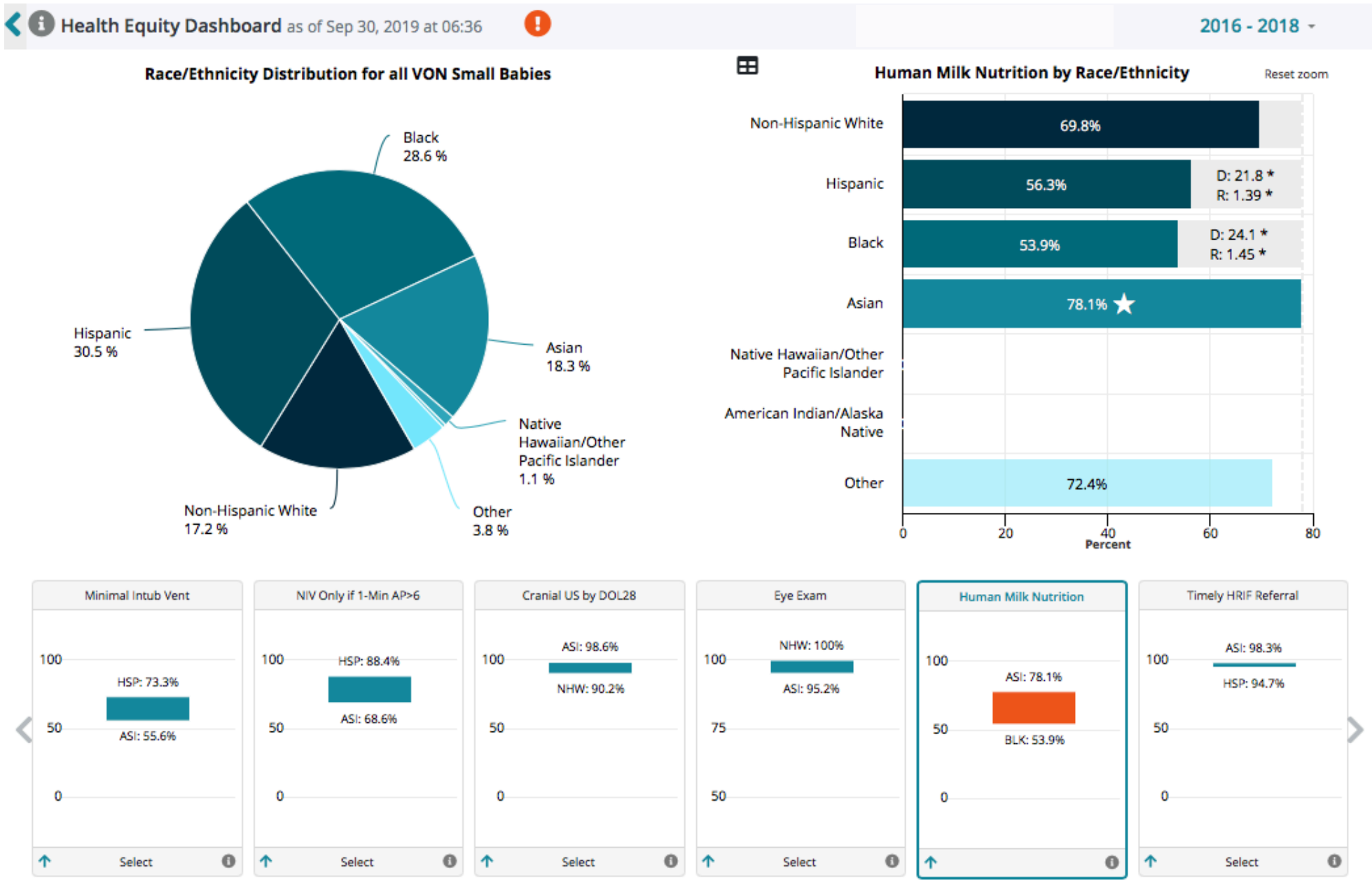
Models of care that explicitly involve families are now considered best practice in the NICU and the implementation of family-centered care promotes mutual respect and shared decision-making between clinicians and families, ensuring timely and quality psychosocial supports and hospital resources that facilitate family well-being and involvement (Committee on Hospital Care and Institute for Patient- and Family-Centered Care, 2012; Franck & O'Brien, 2019). Family-centered care also includes direct care delivered by families to their infants,

[1]Stanford University School of Medicine, Palo Alto, California, USA
[2]Vermont Oxford Network, Burlington, Vermont, USA
[3]GLO Preemies, Sacramento, California, USA
[4]University of South Florida, Tampa, Florida, USA
[5]School of Nursing, University of California, San Francisco, California, USA

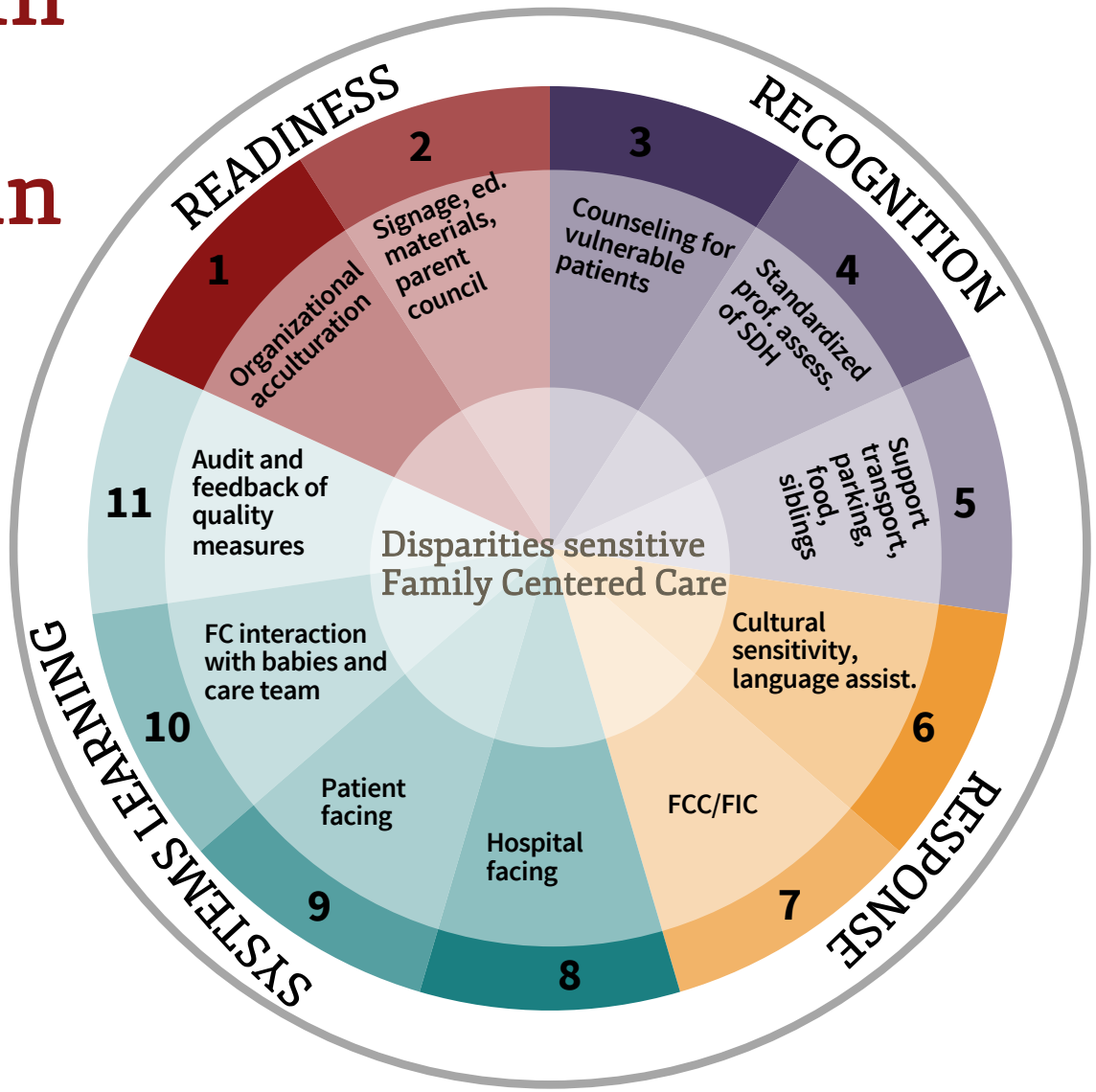
Corresponding Author:
Krista Sigurdson, Department of Pediatrics, Stanford University School of Medicine, MSOB Room x1C19, 1265 Welch Road, Stanford, CA 94305, USA.
Email: ksigurd@stanford.edu

Point-of-care derived measures developed in collaboration with disadvantaged families. Measures selected through a modified Delphi panel that included family representatives.

CPQCC EQUITY DASHBOARD



Changing what we do in the NICU



FCC or Family Integrated Care

Signage, education

Audit and feedback of quality measures by race/ethnicity/language

or over the phone/video

to-skin education

in your child's care at all times."

- Language concordance

CPQCC CCS HRIF:
Data in Action & Quality Improvement

Susan Hintz, MD MS
Medical Director, CPQCC CCS HRIF

What is HRIF?

HIGH RISK
INFANT FOLLOW-UP

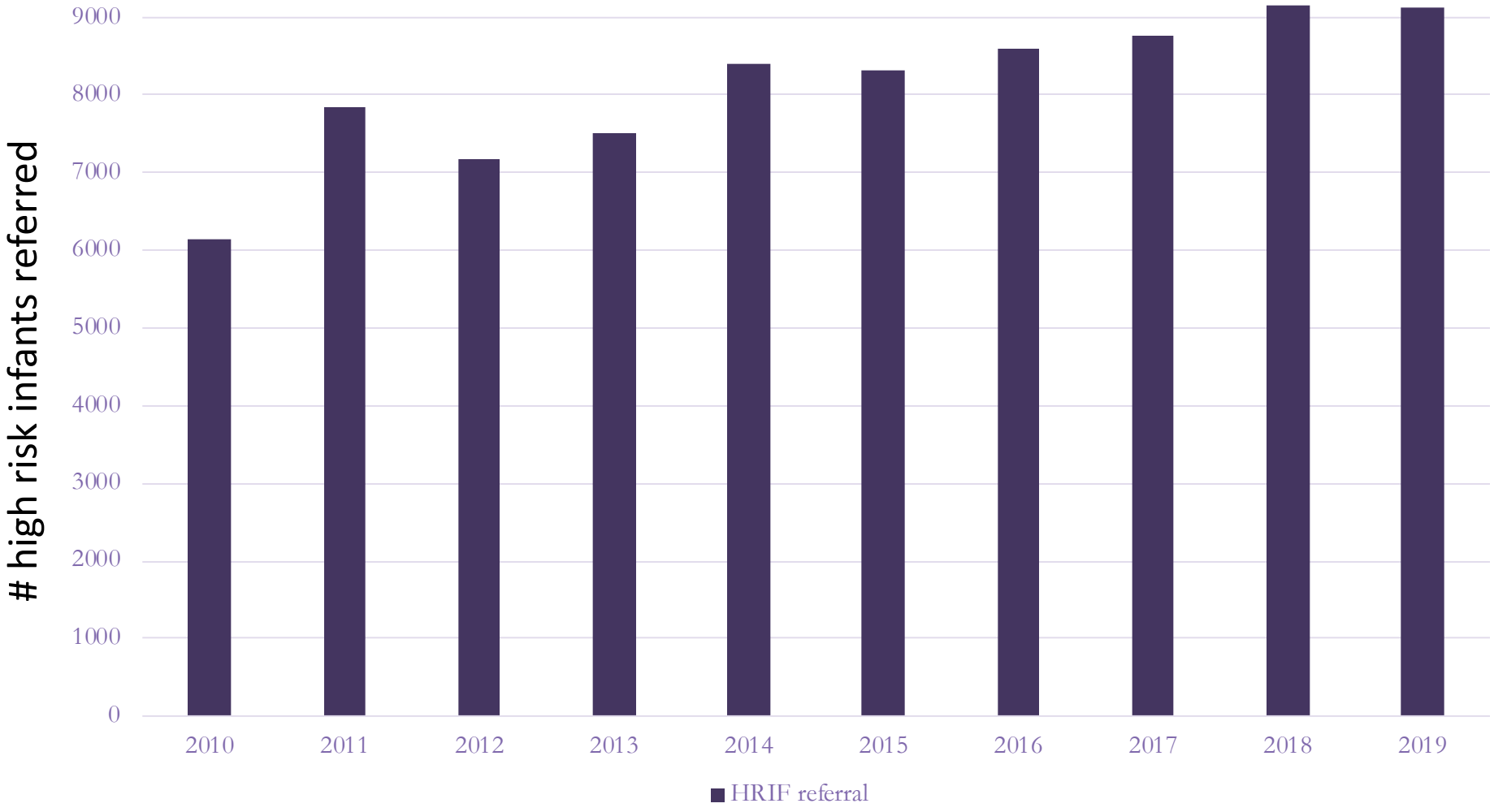
Who do we serve?

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

- California Children's Services originally established a **"NICU Follow Up Program" in 1979**.
- Multiple evolving changes and challenges - -
  - Growing recognition that *we could do better for high risk infants in California.*
- CPQCC partnered with CCS and multiple stakeholders across the state to completely remodel program - **CPQCC CCS HRIF Quality Care Initiative - fully launched in 2010**

Continuum of care structure – unique to California!

Referral to CPQCC CCS HRIF by birth year



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

For birth year 2019: ~1420 infants <28 weeks EGA referred on NICU discharge.

Who do we serve? – *HRIF Medical Eligibility*

DHCS

JENNIFER KENT
Director

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

EDMOND G. BROWN JR
Governor

DATE: October 12, 2016

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

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

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

Medical Eligibility: Small Babies

- Birth weight less than or equal to 1500 g, OR
- GA at birth less than 32 weeks.

Medical Eligibility: Big Babies

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

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

HRIF Visits: Number and timing

- *Provides for **3 "Standard" or core visits***
  - *#1 – 4 - 8 months*
  - *#2 – 12 - 16 months*
  - *#3 – 18 - 36 months*
    - ***NOTE**: CCS has extended support for HRIF visits through 42 months due to the challenges around COVID-19.*

- *Additional visits covered by CCS as determined to be needed by HRIF team-*

HRIF Visits: Content and Structure

HIGH RISK INFANT FOLLOW-UP

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

HIGH RISK INFANT FOLLOW-UP

REPORTING SYSTEM

Susan Hintz, MD, Welcome Super User

Find Patient | Pending Cases | Registration | Referral | Cardiac | Reports | Tools | Admin | Help | Sign Out

HRIF Summary | CCS Annual | NICU Summary | Cardiac Summary | Prog Profile | Service Refs | Data Download | Usage Stats

HRIF SUMMARY REPORT

HRIF Summary Report is updated nightly

HRIF Clinic	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	Standard Visit Summary Report (Core Visit #1)
Report Section Name	-- Select a Report Section Name --

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

cpqcc

cpqcc

To Gain Access to HRIF Reporting System

Contact **Erika** Gray

Program Manager

Erika@cpqcc.org

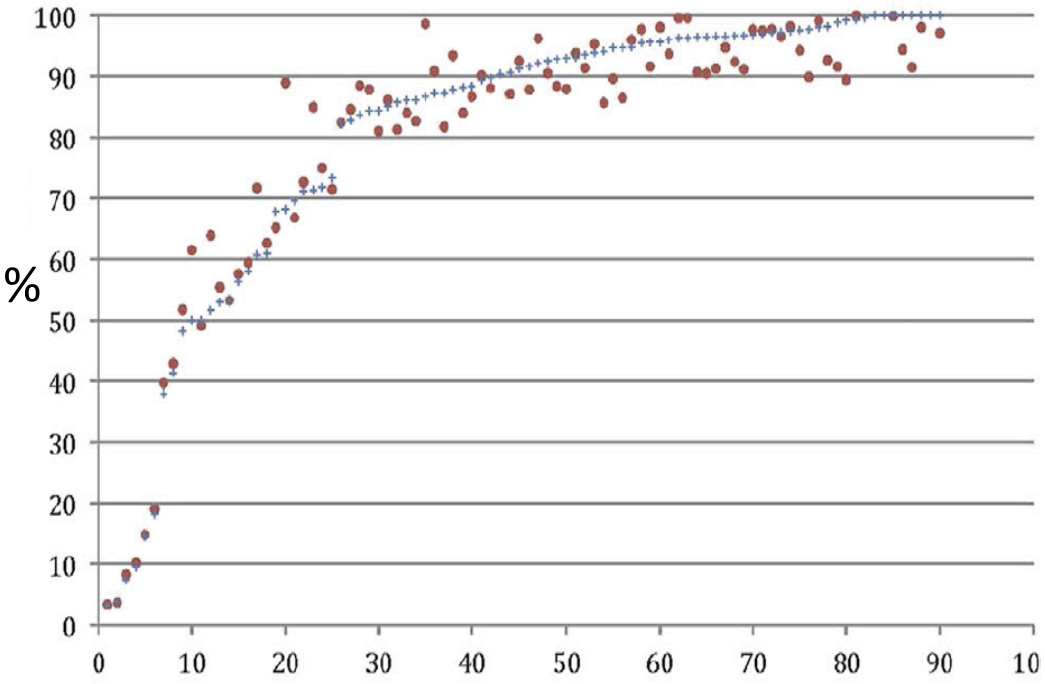
Learning from our patients and families

HIGH RISK INFANT FOLLOW-UP

HRIF QI and Data in Action

Recognition of HRIF referral failure & statewide PI intervention

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



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

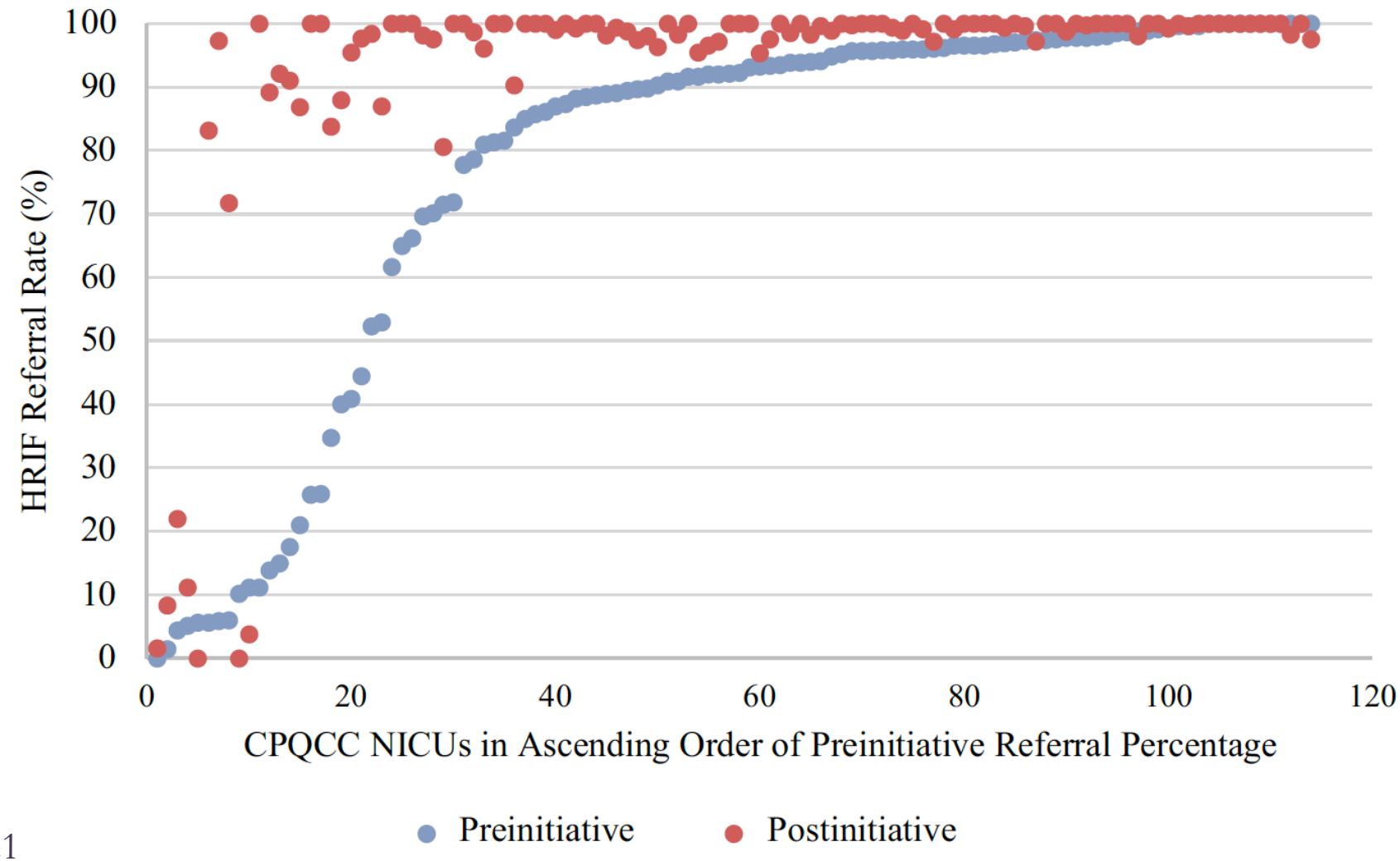
HRIF/CPQCC Match Summary Report for Infants Discharged Home, 1/1/2017 to 12/31/2017

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

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

Improved Referral of VLBW to HRIF in California after PI Initiative

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



Pai V, et al *J Pediatrics* 2020;216:101-108.e1

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

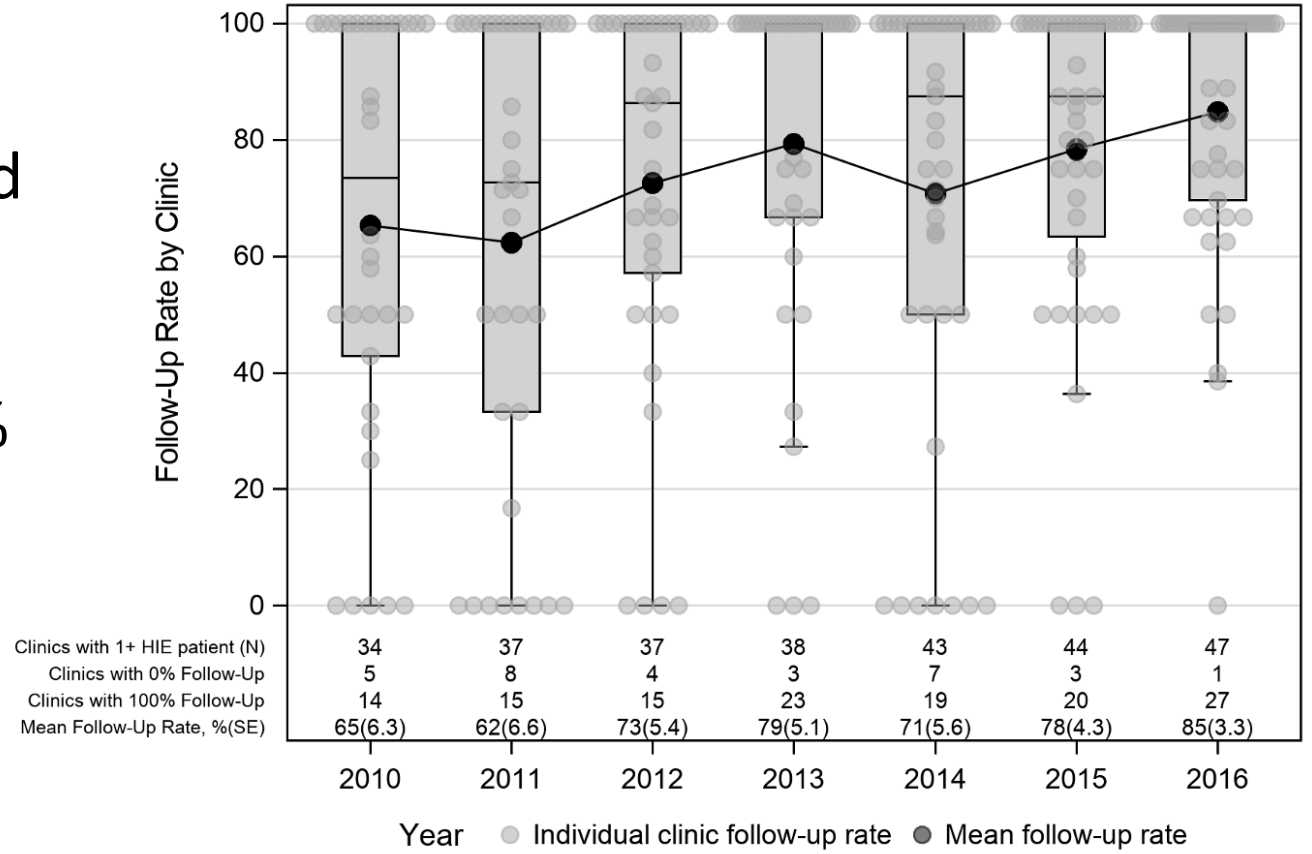
	Pre-intervention	Post-intervention	% change
Maternal race/ethnicity*,†			
African American	1575 (81.7)	1621 (94.6)	12.8 (10.8-14.9)
Hispanic	5088 (81.9)	6123 (95.6)	13.7 (12.5-14.7)
White	3249 (84.6)	3441 (94.2)	9.6 (8.2-11.0)
Asian/Pacific Islander	1469 (84.3)	1780 (94.5)	10.2 (8.2-12.2)
Native American/other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

Pai V, et al *J Pediatrics* 2020;216:101-108.e1

Referral to HRIF and successful 1st visit: Children with Moderate-Severe HIE

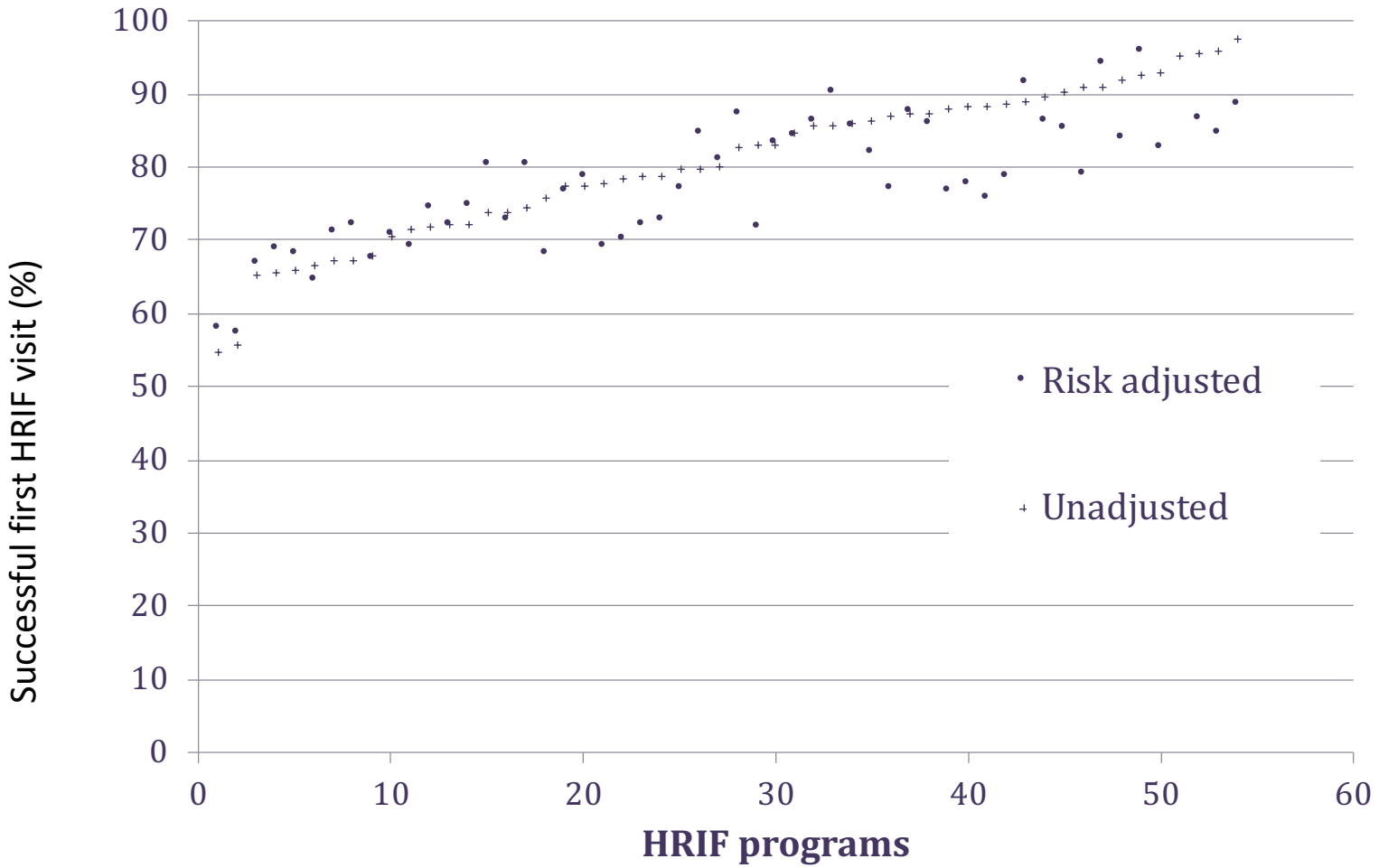
Among infants with moderate-severe HIE in California born 2010-2016 and survived to discharge, **both referral to HRIF and follow up to the 1st visit increased**:

- Referral to HRIF increased from 84.6% in 2010 to 99.4% in 2016.
- Successful HRIF 1st visit increased from 63.8% in 2010 to 79.4% in 2016.



Pai V et al – manuscript submitted

Factors associated with successful **1st high risk infant follow-up visit** for VLBW infants in California



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

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

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

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

Rural residence and failure to attend 2nd HRIF visit among VLBW

- Among VLBW infants who attended a 1st HRIF visit, maternal and sociodemographic disparities, and rural residence were associated with failure to attend a 2nd visit.
- Substantial HRIF clinic variation, risk-adjusted 2nd visit success 43.7% to 99.7%.

Fuller MG, et al – presented at PAS; manuscript in process

Factor	Adjusted OR (95% CI)	p value
Maternal race Black/ African American	0.61 (0.5-0.75)	<0.0001
Public insurance	0.79 (0.69-0.91)	0.0011
Rural residence	0.74 (0.61-0.89)	0.002
Birth weight (vs. 1251-1499g)		
<=750 g	1.82 (1.48-2.25)	<0.0001
751-1000 g	1.39 (1.19-1.63)	<0.0001
1001-1250 g	1.12 (0.97-0.13)	0.124
Surgery in NICU	1.28 (1.05-1.56)	0.014
HRIF Visit 1 at 4-8 months corrected age	2.34 (1.99-2.75)	<0.0001
Early start at HRIF Visit 1	1.39 (1.20-1.61)	<0.0001

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

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 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 BG, et al. Am J Perinatol. 2018;35(10):940-945

HIGH RISK
INFANT FOLLOW-UP

HRIF in time of COVID and beyond

How are HRIF clinics in California responding to the COVID-19 pandemic?

- COVID-19 pandemic has substantively changed the way the most HRIF sites approach follow up care for children and families.
- With onset of the pandemic, the vast majority of HRIF clinics were initially closed – great variation in timing and approach to "reopening", and in non-in person visit structures.
- Current CPQCC HRIF visit structure is **geared toward in-person visits**
  - HRIF teams across the state desire guidance around appropriate instruments for non-in person visits.
  - CCS partners support a non-proscriptive stance in specific instruments.

HIGH RISK INFANT FOLLOW-UP

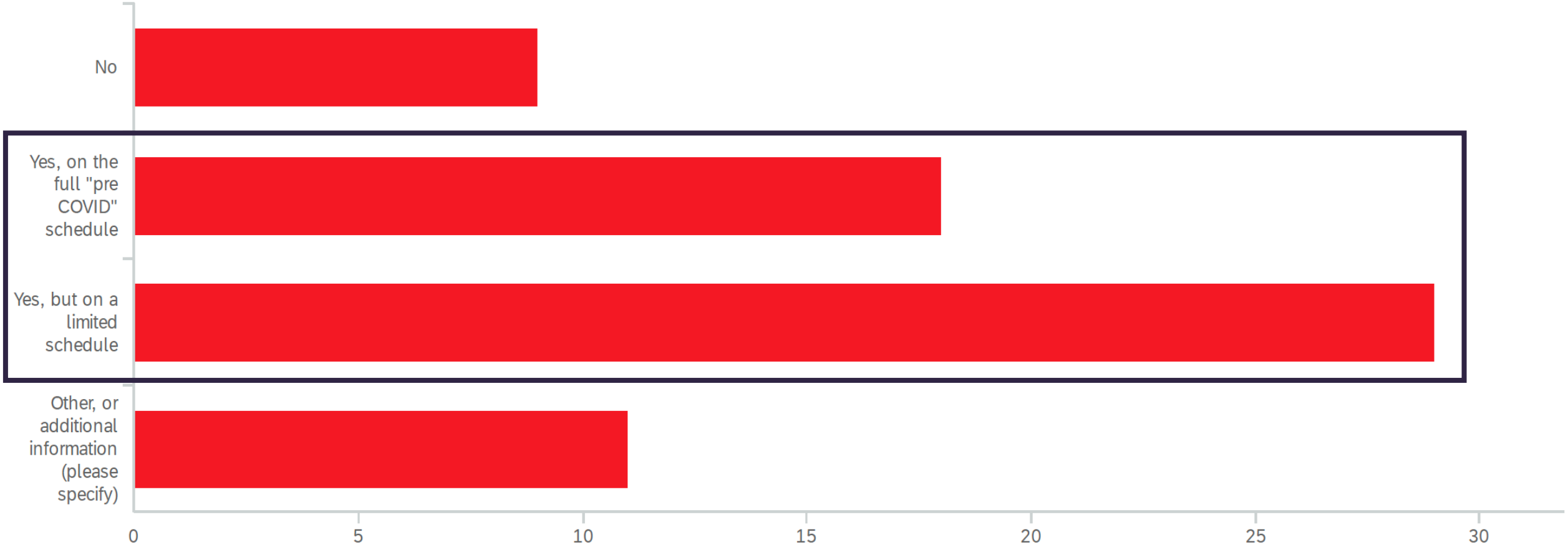
qualtrics.com

Select your HRIF Clinic center:

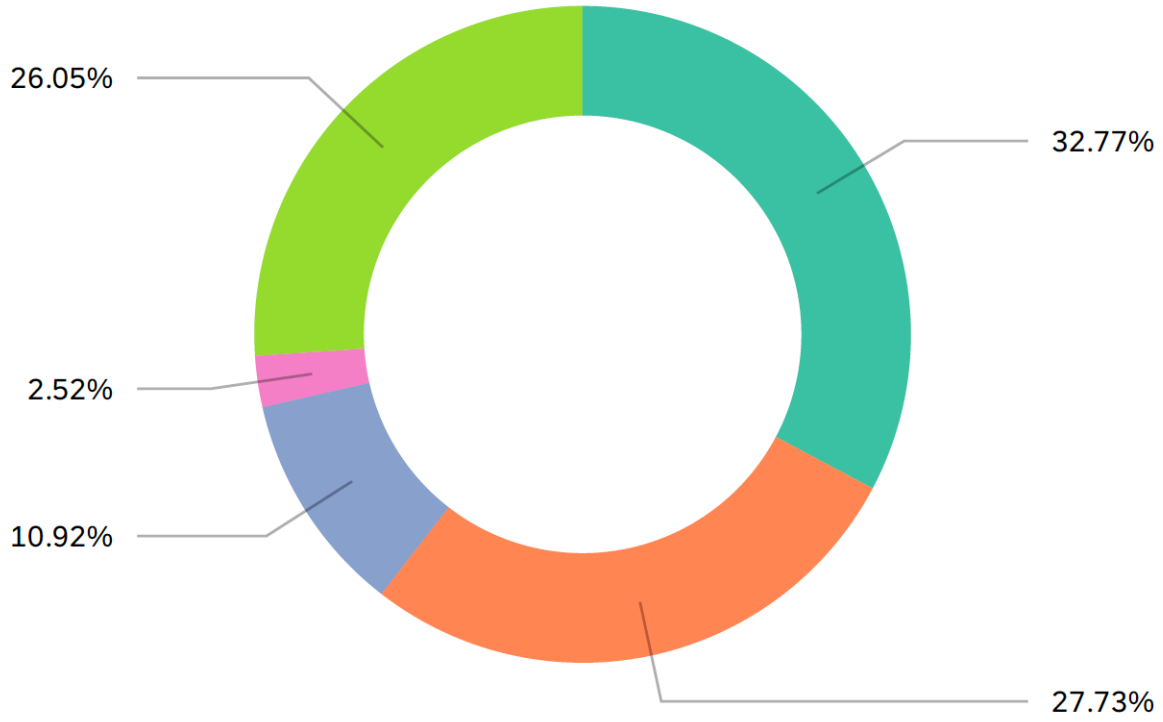
What date (mm/dd/yyyy) did your clinic officially close **in person** (face to face) HRIF visits?

- Most between 3/11- 3/20
- A few outliers – 4/1 – 4/11

Q3 - Has your institution given approval or already started to resume in person (face to face) HRIF visits?



Q6 - How are HRIF children being followed in your clinic during COVID? (check all that apply)

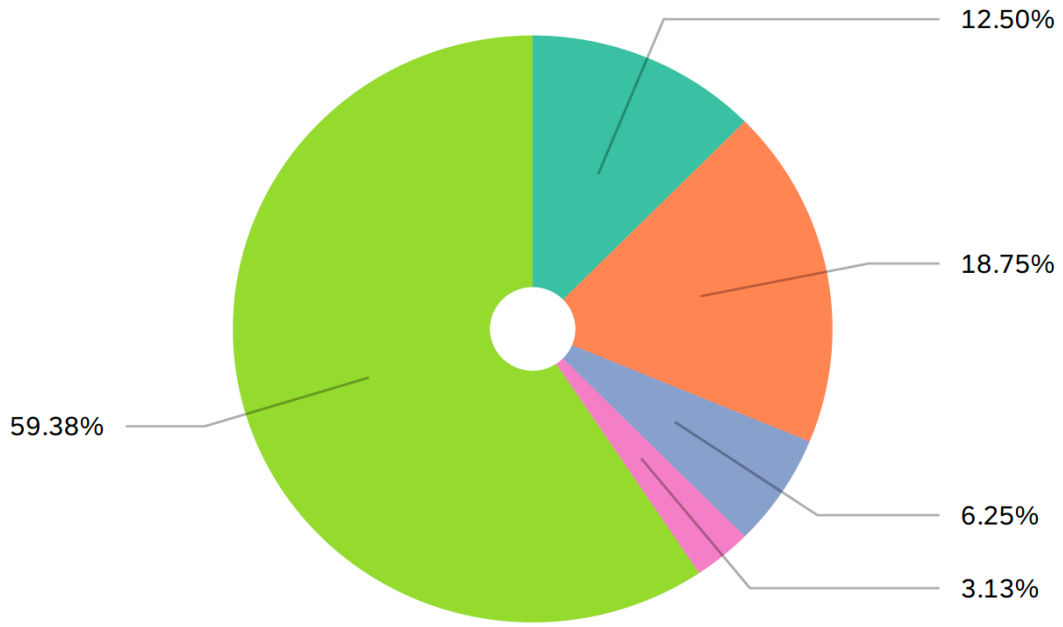


Numerous platforms!!

Telehealth	32.77%	39
Phone calls	27.73%	33
Postcards	10.92%	13
Nothing	2.52%	3
Other	26.05%	31
		119

We are doing telehealth (audio + video) visits
We are making phone calls
We are sending letters/postcards
We are not doing anything
Other (please specify)

Q8 - You indicated that your clinic is NOT doing telehealth visits, what are the barriers to implementing them? (check all that apply)



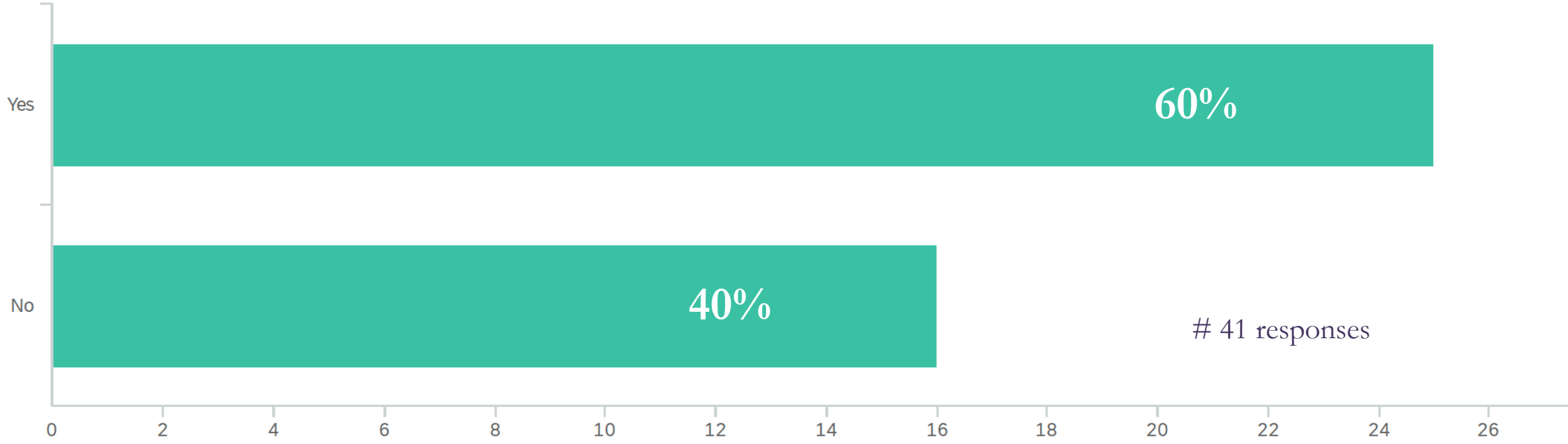
responses - 32

Majority of "other responses" :

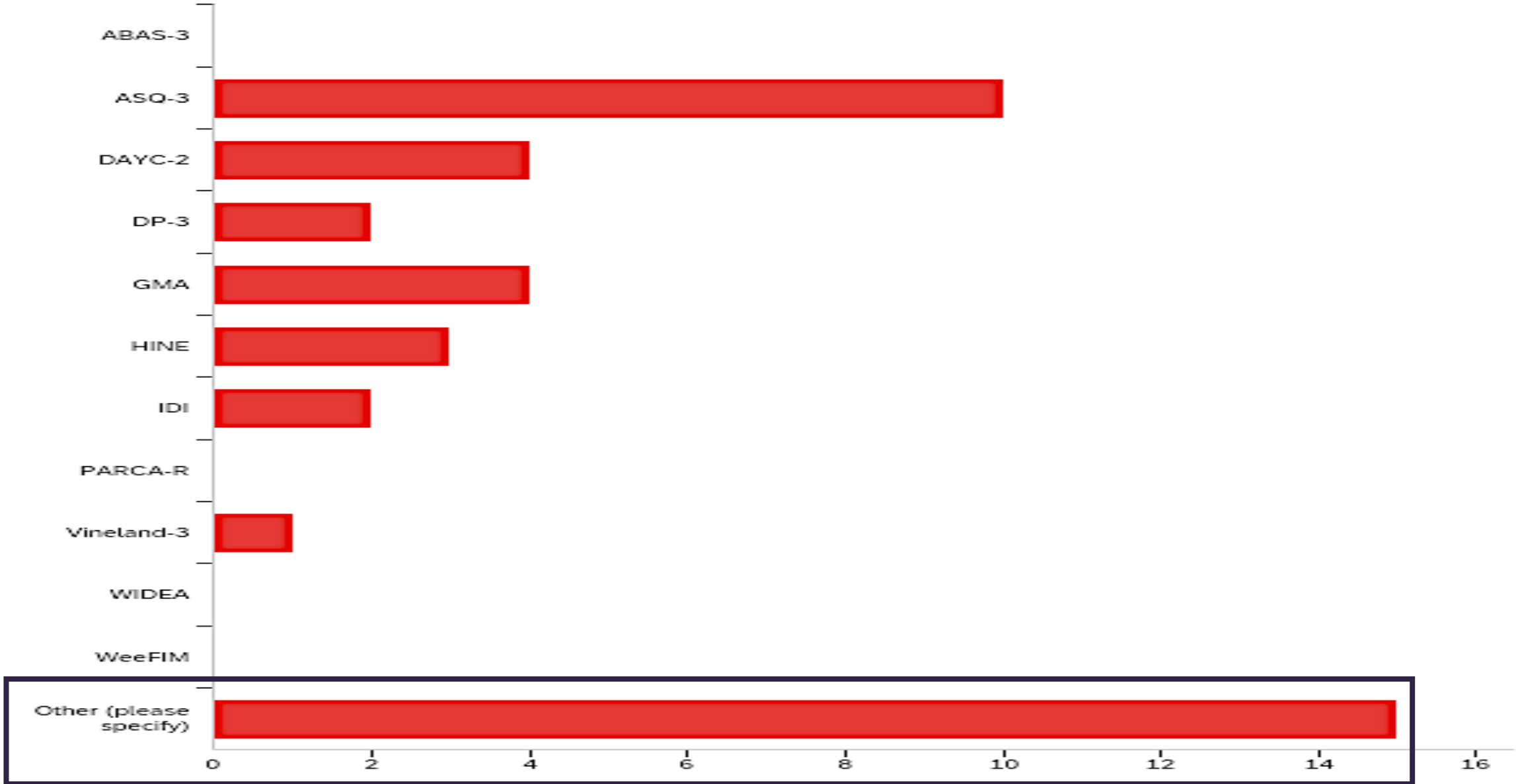
- **Families with limited resources and inability to access telehealth**
- In person visits were resumed → teams felt assessments should be done and in person
- Unknown that other options were supported for HRIF visits besides in person

HIGH RISK INFANT FOLLOW-UP

Q9 - You indicated that your clinic is conducting telehealth visits, are you administering any standardized assessments by telehealth?



Q10 - What assessments are you doing by telehealth? (check all that apply)



Overview – Recent state HRIF visits

- Added "telehealth" option on web-based Standard Visit data entry form in late March 2020
- "In flight" data:

 # HRIF Visits 6/1/20 - 8/31/20

	Missing	Televisit	In Person	Total
SV (% derived Among ALL SV 2882	0 (0%)	1048 (36.36%)	1834 (63.64%)	2882
AV (% derived Among ALL AV 112	0 (0%)	43 (38.39%)	69 (61.61%)	112
Total (% derived Among ALL Visits 2994)	0 (0%)	1091 (36.44%)	1903 (63.56%)	2994

CPQCC HRIF Telehealth Guidance Work Group

- Multiple stakeholders from across the state – psychologists and other providers (physicians and APPs), coordinators, CPQCC and CCS representatives.
- Goals:
  - Better understand current state for HRIF visits
  - Develop high level guidance on options for telehealth to inform HRIF Standard Visit changes
  - Develop guidance on prioritization
  - Highlight pros and cons of telehealth vs. in person visits

CPQCC HRIF Telehealth Guidance Work Group

- **Broad concepts from implementation planning:**
  - **Prioritization strategies** and enhance recognition of barriers for in-person and telehealth visits → which visits, patients, families
  - Underscore value of team visits during telehealth.
  - Advocacy for HRIF clinics currently without telehealth support at their sites.
  - Target **a limited number of *appropriate assessments for telehealth*** – input not only from California but experts across the U.S. and beyond.
  - **Opportunity for quality improvement and prospective investigation of process change implementation**

HIGH RISK INFANT FOLLOW-UP

Beyond the First Wave: Consequences of COVID-19 on High-Risk Infants and Families

Monica E. Lemmon, MD[1,2] Ira Chapman, MD[3] William Malcolm, MD[2] Kelli Kelley[4]
Richard J. Shaw, MD[5] Angelo Milazzo, MD[2] C. Michael Cotten, MD[2] Susan R. Hintz, MD[6]

Am Journal Perinatology in press August 2020

Key Points

- The COVID-19 pandemic is influencing care delivery for high-risk newborns and their families.
- Rapid changes to care delivery are likely to be sustained beyond the initial pandemic response.
- We have an urgent imperative to understand how COVID-19 impacts infant, parent, and family outcomes.

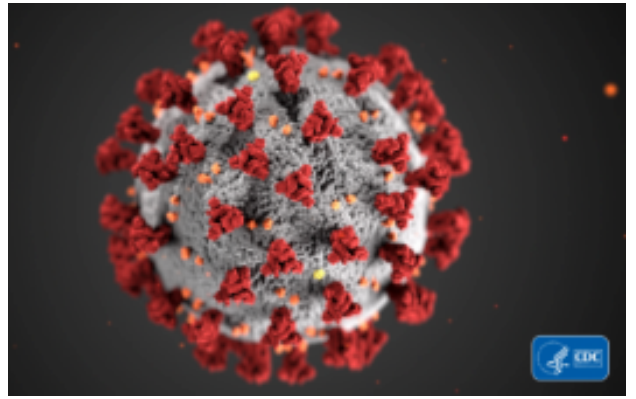
Forbes, June 2020

Photo Credit: Alexander Dummer

Stanfordchildrens.org 2020

COVID-19 in Perinatal- Neonatal Medicine:
Potential gaps in our knowledge?

- Published data suggest that the impact of COVID-19 - the *disease itself* - may be expected not to be substantial in the preterm NICU population.
- However, the *effects* of the COVID-19 crisis – hospital policy changes; resource and services access; financial, employment, and other stressors - *have been felt profoundly by our maternal and neonatal units and the families of our NICU patients.*
- **California – through the CPQCC and HRIF - is uniquely positioned to explore questions related to the broader impact of the COVID-19 crisis.**



What's Next: Impact of COVID-19 on Parents, Families and Children born preterm in California

- Among children born <30 weeks GA from participating CPQCC sites and followed in CPQCC CCS HRIF, how are parents, families and children impacted by the COVID-19 pandemic crisis?

- Project developed in coordination with:
  - CPQCC CCS HRIF Executive Committee
  - HRIF/ Transition Health Equity Work Group

Broad overview: COVID-19 Family Impact Study

- Serial, multilevel parent surveys, linked to information from NICU and HRIF, child NICU and HRIF course.
  - Determine how parents/families of children born < 30 wks are impacted by the COVID-19 pandemic - including parent stressors due to COVID, financial/resource stability, access to medical/special health care services - through 3 years.
  - Evaluate factors associated with impact including sociodemographic disparities, child and family factors, NICU and HRIF site differences.
- Two 6-month birth cohorts of parents/ families:
  - 1) those who were *in the NICU during COVID-19*
  - 2) those who were *already discharged home and in the community during COVID-19*

Broad goalposts: COVID-19 Family Impact Study

- Project start-up **funding** secured –
- Reach-outs, 1:1 zoom meetings, calls with sites done over past 8-10 weeks
  - ~ 10+ sites interested/ committed thus far
- **Upcoming "pre-kick off" Zoom meeting (October 15th)**
- Patient/ Family Health Literacy and Family-Center Care review, translation to Spanish in process.
- **RedCap survey framework** for direct-to-parent survey near complete.
- CPQCC HRIF study grid construct (for participating sites after IRB).
- Research agreement framework in process.
- **Stanford IRB and consent approved**

HIGH RISK INFANT FOLLOW-UP

What will we learn? Why would this be important?

- There will be **a substantial gap** in our understanding of the impact of the COVID-19 pandemic on our patients and their families if we do not investigate the long-term challenges.
- **Inform neonatologists and pediatricians** of potentially substantive impacts of the COVID-19 crisis on parent stressors in the NICU environment and after discharge, and resource/ access challenges in the community.
- **Provide parent-driven data to direct quality and process improvement interventions at institutional and community levels -** to better support patients and families, and to alert state partners to broader challenges for children.

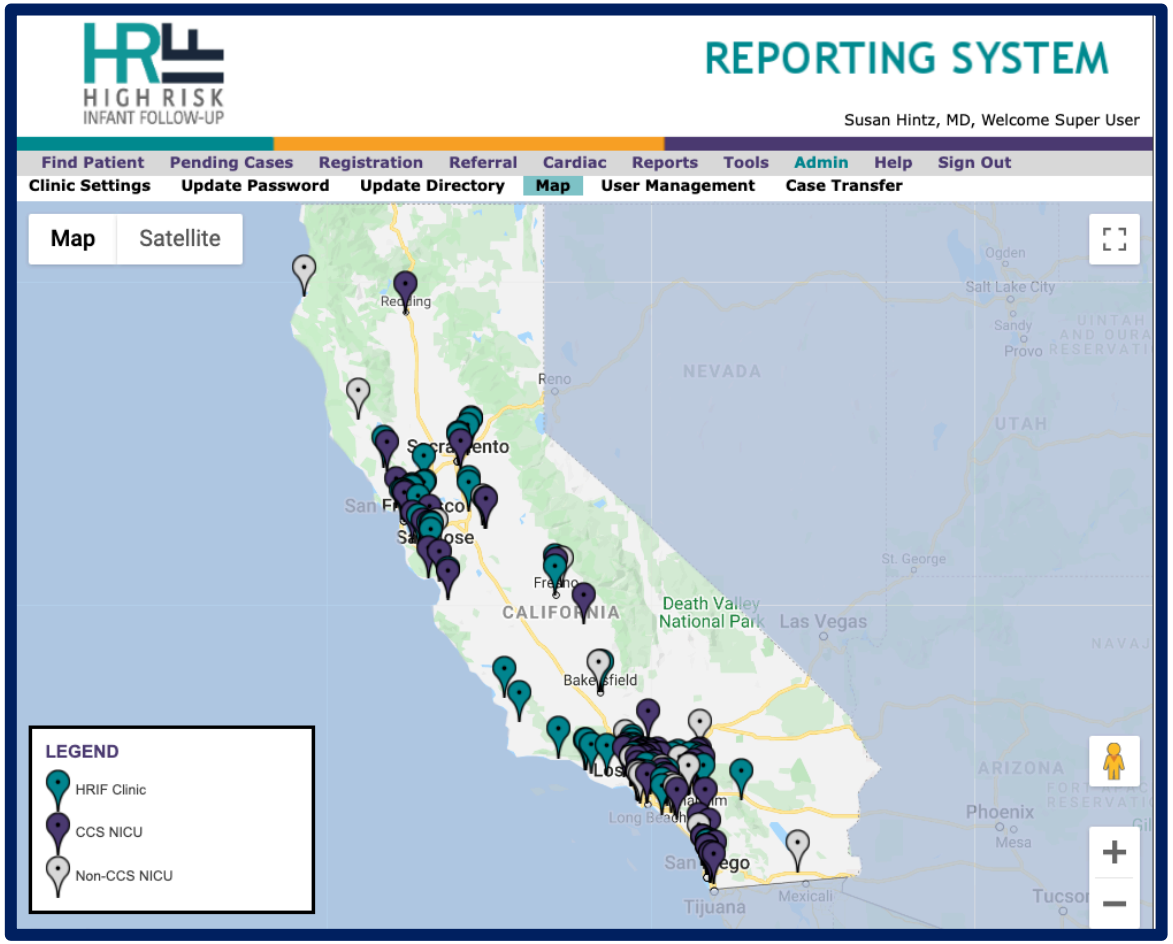
COVID-19 Family Impact Study

Interested in participating?

- We would love to welcome you!
  - Please email me at **srhintz@stanford.edu**

HIGH RISK
INFANT FOLLOW-UP

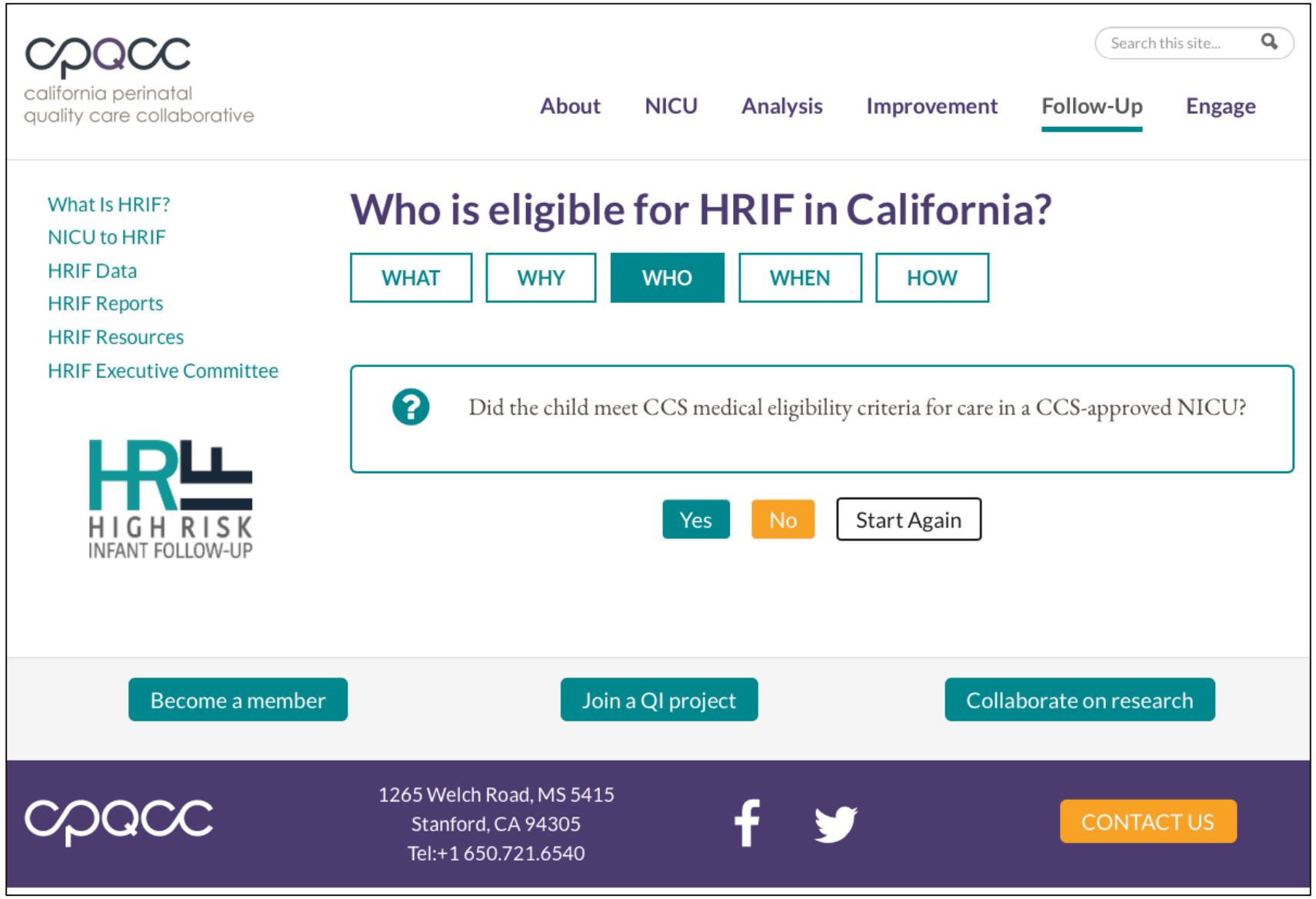
THANK YOU!




HIGH RISK
INFANT FOLLOW-UP

HIGH RISK INFANT FOLLOW-UP

https://cpqcc/follow/what-hrif/who



Q&A Session

Panelists

- **Henry Lee, MD, MS**, Chief Medical Officer, CPQCC
- **Ronald Cohen, MD**, Medical Director, Northern CPeTS
- **Jochen Profit, MD, MPH**, Chief Quality Officer, CPQCC
- **Susan R. Hintz, MD, MS**, HRIF Medical Director, CPQCC

Closing

Recording and Webinar Evaluation

- An email will be sent out after the webinar with a link to:
  - The slides and webinar recording
  - An evaluation survey
- The webinar recording and slides will also be posted at: https://www.cpqcc.org/engage/annual-data-training-webinars-2020

Upcoming Data Training Webinars

https://www.cpqcc.org/engage/annual-data-training-webinars-2020