

2022

ANNUAL REPORT

CPQCC



# **2022 IN REVIEW**

- LETTER FROM LEADERSHIP

  GROWING THE CPQCC FAMILY
- FEATURE
  FAMILIES AS THE FOUNDATION OF HIGH-QUALITY,
  INCLUSIVE CARE
- 10 FEATURE STATEWIDE FAMILY ADVISORY COUNCIL
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## Dear Friends,

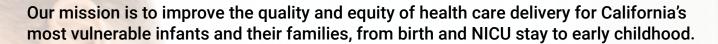
Every year, as the weather begins to warm, we look forward to writing this letter and getting to tell you about the wonderful work that the CPQCC family is engaged in. This year is special because our "family" – faculty, staff, members, volunteers, and partners – is growing.

After a year of careful planning and recruitment, this February we welcomed the parents who make up the inaugural statewide CPQCC Family Advisory Council (funded by a grant from the Lucile Packard Foundation for Children's Health, Palo Alto, California) to the CPQCC family. Family centered care is key to NICU infants' health and wellness, and how families are integrated and cared for in the NICU affects how they can care for their children. CPQCC's Family Advisory Council represents California's diversity and will advise CPQCC, develop new family-centered projects at the state level, and help improve systems of care in NICUs across California so families face fewer disparities in care and barriers and challenges in their ability to care for their infant.

You'll learn more about the Family Advisory Council and other family-focused programs in this report. Other highlights of 2022 include:

- At Improvement Palooza 2022, families took center stage in "Families as the Foundation of High Quality, Inclusive NICU Care," setting new records for number and geographic spread of attendees.
- We continued the conversation around supporting NICU families through three IP2022 Conversation Circles on Health Literacy, How to Create a Family Advisory Council, and Improving Outcomes for Families with a Non-English Language of Preference.
- We launched the NICUs Enabling Optimal Brain Health (NEOBrain) Collaborative, a statewide QI collaborative for CPQCC members that centered neuroprotective and family-centered care for the most vulnerable NICU infants.
- HRIF introduced a new graphical Health Equity Dashboard that makes it easier for clinics to view their patient processes and outcomes by race and ethnicity

As spring creeps closer, we at CPQCC remain committed to our number one priority:



We are so happy to be doing this work in conjunction with our new colleagues on the FAC and with our extensive community of members, partners, and volunteers. May 2023 bring positive change and peace to us all.

### **JEFFREY B. GOULD**

Chief Executive Officer

#### **JOCHEN PROFIT**

Chief Quality Officer

### **HENRY C. LEE**

Director of Data and Research Collaborations

#### **SUSAN HINTZ**

HRIF Medical Director

#### **REBECCA ROBINSON**

Administrative Director

#### **COURTNEY C. BREAULT**

Associate Director of Quality





Family-centered care is care that enables and supports families to act and feel like parents."

Sarah DiGregorio, Author,
 Journalist, NICU Family
 Member



You have to be willing to listen to parents share their experiences as they experienced them. Being able to advocate is a privilege that many people don't have. If you really want the truth of people's experience, you have to create a fertile environment for that to happen."

 Kimberly Novod | Founder of Saul's Light, NICU Family Member



Remember that these infants are more than just their saturation rate, their bilirubin, their milestone markers.
They, like you, have a story and their experiences with you absolutely inform their outcome."

Meridith Merchant, Advocate,
 Psychologist, NICU Family
 Member



[We need to] acknowledge the value of parental wisdom."

– Meridith Merchant, Advocate, Psychologist, NICU Family Member

CPQCC's annual Improvement Palooza is a one-day quality improvement conference designed specifically for NICU teams, held every March in Coronado, California. The conference is hosted in conjunction with the annual Cool Topics in Neonatology Conference, held by the California Association of Neonatologists.

On March 4, 2022, 381 people from across the United States joined together virtually for Improvement Palooza 2022: Families as the Foundation of High Quality, Inclusive NICU Care. After years of including family voices as one component of our annual conference, in 2022, we turned the stage over to our family partners.

Says Courtney Breault, CPQCC's Associate Director of Quality, "We've realized that it's not enough to include families in our day or on our care teams. They should be the team's heart, the very center of it. We must stop and listen to families for what they are...the real experts on their infants. That is what IP2022 is all about."

#### IP2022 included:

- A keynote address titled "Families
   Are Essential" by Sarah DiGregorio, a
   journalist and author of the book Early:
   An Intimate History of Prematurity and
   What it Means to Be Human and mother
   to a NICU graduate.
- A panel discussion with five NICU family members
- Two rounds of family-centered care lightning sessions

Recognizing how a lack of equity and inclusivity affects the NICU's family experience, IP2022 also included sessions on cultural humility and trauma-informed care.

Listening to families is not limited to one day. The dialogue started at IP2022 has continued throughout the past year through a series of "conversation circle" webinars, open to all CPQCC members, on "The Importance of Health Literacy and Parent Education in the NICU" (June 2022), "How to Create a Family Advisory Council" (September 2022), and "How to Improve Outcomes for NICU Families with a Non-English Language of Preference" (NELP) (January 2023). In 2023, CPQCC will begin meeting with our new statewide Family Advisory Council (see page 11 for more details), moving from listening to working alongside our family partners.

Says Breault, "At the end of the day, it all comes down to listening and partnership."



I wish everyone working in a NICU would hear Ithese stories]. I have heard so many times that a parent tried to get the NICU staff to listen to their concerns. and when they wouldn't - the outcome is often devastating - this should be a NEVER EVENT!!!"



[It is] so important to hear the family's perspective. Sometimes it's very difficult to hear but necessary. The first step is to be willing to listen and acknowledge that [there are] issues that really need to be regularly addressed."

- IP2022 Attendee

- IP2022 Attendee

For more information on IP2022, including highlights from the day and recordings of the conversation circles, please visit <a href="https://www.cpqcc.org/">https://www.cpqcc.org/</a> IP2022



The California NICU Family Advisory Council is one of CPQCC's flagship projects for 2022-2023 and represents our commitment to elevating *vital voices*, a key pillar under our strategic plan. The project is funded through a grant from the Lucile Packard Foundation for Children's Health.

Evidence suggests that many important milestones in the NICU, including skinto-skin, breastfeeding, and discharge readiness, depend on active family participation. However, across California, family participation in the NICU varies widely and has been shown to vary by race/ethnicity, language of preference, and insurance status (Obregon, 2019; Sigurdson, 2019). California has a diverse population, with many families having immigrated from countries worldwide. Further, over 46% of California births between 2018-2020 were to Hispanic mothers. A failure to fully address the needs or barriers to being at the bedside of the diverse range of NICU families in California may exacerbate health disparities and worsen infant outcomes across the state.

Families who have had a child in the NICU have a unique ability to improve care at a systemic level by shaping programs and policies to meet the specific needs of families currently in the NICU and post-discharge. For example, family representatives might participate in activities such as optimizing the NICU space and equipment, creating and improving educational resources for NICU parents, designing and pursuing quality improvement projects, or reviewing policies and protocols. All of these can enhance familial experience and satisfaction in the NICU setting.

However, less than a third of California NICUs have a formal Family Advisory Council (FAC), and even fewer involve families in selecting or designing their NICU's quality improvement projects

# **Objectives for the California NICU Family Advisory Council**

**Objective 1:** Develop a diverse statewide Family Advisory Council to advise CPQCC and California NICUs and High Risk Infant Follow-Up Clinics on their activities.

**Objective 2:** Create educational materials and documents to guide and support other organizations in developing their own Councils and make these freely available on the CPQCC website. Materials will be disseminated through webinars and targeted announcements.

**Objective 3:** Work with 10 California NICUs to establish, support and sustain their own Family Advisory Councils.

(VON data, 2020). NICUs may not have active family input because of gaps in administrative organization, knowledge of implementation strategies, or financial/human resources and support.

As a leader in improving care for NICU infants, CPQCC is uniquely positioned to encourage hospitals across the state to systematize the inclusion of NICU family voices. Elevating family voices will bring positive changes to how NICUs and follow-up clinics operate and improve care processes; everyone in the healthcare setting will benefit.

In November 2022, CPQCC was awarded a grant from the Lucile Packard Foundation for Children's Health to establish a statewide Family Advisory Council that represents California's diversity, with the goal of shaping systems of care within NICUs and their associated HRIF clinics to improve infant outcomes, particularly for marginalized populations. This effort will focus on establishing channels for family feedback and engagement with CPQCC and within NICUs across the state.

### Michelle Wrench



Michelle Wrench is a NICU Nurse and mother to twins who spent 6 weeks in the NICU at El Camino Hospital in Mountain View, California after being delivered at 30-weeks' gestation due to maternal preeclampsia.

Michelle will serve as the inaugural chair of the California NICU Family Advisory Council.

With the help of Michelle Wrench and Malathi Balasundaram, CPQCC has selected 13 members for the inaugural California NICU Family Advisory Council. The Council represents the diversity of California in many ways and includes representatives from Northern and Southern California and the Central Valley. Members include NICU mothers and fathers, a Spanish-speaking parent, and individuals from the LGBTQ+ community, different races and ethnicities, socioeconomic statuses, and educational attainments. In addition, the 13 members have had a broad range of NICU experiences, including clinical diagnosis,

length of stay, and infant outcomes. These perspectives will enable us to build a more powerful family presence across California NICUs.

The California NICU Family Advisory
Council will be led by inaugural chair,
Michelle Wrench, with support from
Caroline Toney-Noland, CPQCC Program
Manager and Rebecca Robinson, CPQCC
Administrative Director. The Council met
for the first time in early February 2023.
Members of the Council have also been
invited to CPQCC's Improvement Palooza
2023 to meet and mingle with NICU
clinicians from across the state.

## Malathi Balasundarm



Malathi Balasundaram is a Clinical Associate Professor at Stanford School of Medicine, Attending Neonatologist at El Camino Health, and a Co-Chair of the Family-Centered Care Taskforce. Dr. Balasundaram won the CPQCC/ California Association of Neonatologists David Wirtschafter Award for Ql along with the El Camino Hospital FCC Team in 2021 for their work integrating families as active participants in the NICU experience. She also won the award as an individual in 2022. Dr. Balasundaram is a member of CPQCC's Perinatal Quality Improvement Panel (PQIP).

For more information on the California NICU Family Advisory Council, contact Caroline Toney-Noland at ctn@stanford.edu.



#### **NEOBrain Collaborative at a Glance**

Time Period: June 2022 - June 2024

**Target Population:** VLBW Infants < 32 weeks gestation

Number of Sites: 25

When the faculty panel for the NICUs Enabling Optimal Brain Health (NEOBrain) QI Collaborative began designing the two-year initiative, they knew that the key to their success would be ensuring that families played a central role. Evidence has shown that parent-infant interactions are critical to an infant's stress regulation<sup>1</sup>, and that stress can harm the developing brain<sup>2,3</sup>. In addition, preterm infants who receive positive and sensitive interactions with their families are shown to demonstrate less emotional reactivity, anxiety, and fewer depressive symptoms and are less withdrawn<sup>4</sup>.

The NEOBrain faculty panel knew they would need to include parents in the quality improvement process with intention. While CPQCC has always recommended that NICU QI teams involve family members on the QI team, NEOBrain represents the first time it has been a formal expectation for all participating sites. Family leads have a clear set of responsibilities on the QI team and attend both monthly site meetings and monthly collaborative-wide meetings. In addition, the faculty panel has established monthly "family office hours," an informal monthly touch base run by the panel's two family representatives – Jennifer Canvasser and Necole McRae. Family office hours are an unstructured time for the collaborative's family leads to connect. collaborate, and brainstorm on how to move forward with collaborative change

ideas. To date, the family leads at the site level have created a pamphlet to educate other NICU families on how to initiate skinto-skin care with their infants and advocate for themselves as crucial care team members.

## **Potentially Better Practices**

Promote and reinforce encounters with the infant and family that are developmentally supportive and positive

Ensure family integration in care to improve outcomes, build confidence and promote attachment

Develop a process for Developmental Time Out

The critical role of families in neuroprotection is evident in all aspects of the collaborative. The collaborative's "potentially better practices" (PBPs) emphasize the importance of having parents hold and provide positive touch to their infants during stressful and painful procedures and the necessity of early and frequent skin-to-skin care. In addition, sites are encouraged to view the family unit as their patient, rather than solely the infant, and to practice family-integrated care (FICare), a collaborative care model

that involves parents as equal partners and aims to minimize infant-parent separation and increase infant-parent closeness during the NICU stay. A central goal of FICare is improving parent competence, confidence, and well-being, thus ensuring better outcomes for the family unit. To that end, the collaborative has deployed a family survey to gauge how confident families feel caring for their infants upon the transition to home. The bedside team approaches families to complete the survey shortly before discharge. The survey is available in English and Spanish and can be completed on a phone, tablet, or printout. Teams are then empowered to use the information collected through the surveys to implement change ideas that will increase family confidence and competence. NEOBrain's primary outcome metric measures the

percentage of parents that report care competence at discharge using the tool.

Says, Courtney Breault, Associate Director of Quality at CPQCC and Co-Director of the NEOBrain Collaborative, "We're looking at the overall experience in the NICU [and how that promotes and protects brain health] and trying to make it better. Families are at the very heart of that."

# **NEOBrain Faculty Panel**

# Collaborative Co-Director/Physician Lead

Elizabeth Rogers, MD

Collaborative Co-Director/CPQCC Lead

Courtney Breault, MSN, RN, CPHQ

Research Scientist/Neonatal Occupational Therapist

Bobbi Pineda, PhD, OTR/L, CNT

CNS/NNP

Mindy Morris, DNP, NNP-BC, CNS, C-ELBW

Family Faculty Lead

Jennifer Canvasser, MSW

**Family Faculty Specialist** 

Necole McRae

Epidemiologist/Biostatistician

Xin Cui, PhD, MPH

Epidemiologist/Biostatistician

Jessica Liu, PhD, MPH

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- 1. Waddington, Chandra, et al. "Family integrated care: Supporting parents as primary caregivers in the neonatal intensive care unit." Pediatric investigation 5.02 (2021): 148-154.
- 2. Levene MI, Fawer CL, Lamont RF. Risk factors in the development of intraventricular haemorrhage in the preterm neonate. Arch Dis Child. 1982 Jun;57(6):410-7. doi: 10.1136/adc.57.6.410. PMID: 7092304; PMCID: PMC1627666. 2Nadine Griffiths, Kaye
- 3. Spence, Alison Loughran-Fowlds, Bjorn Westrup, Individualised developmental care for babies and parents in the NICU: Evidence-based best practice guideline recommendations, Early Human Development, Volume 139, 2019
- 4. Vinall, Jillian, et al. "Parent behaviors moderate the relationship between neonatal pain and internalizing behaviors at 18 months corrected age in children born very prematurely." PAIN® 154.9 (2013): 1831-1839

For more information about the NEOBrain Collaborative, contact Courtney Breault at courtney@cpqcc.org.

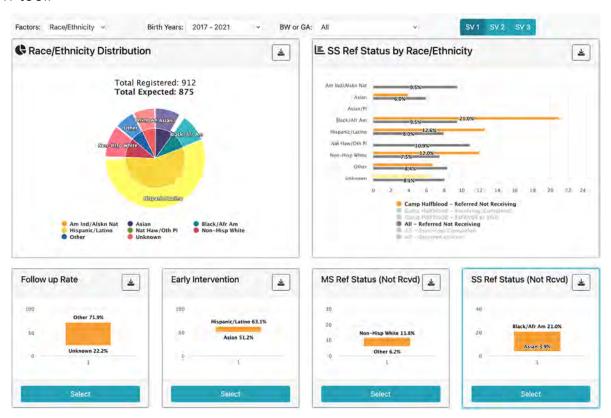


# **High Risk Infant Follow Up (HRIF)**

High Risk Infant Follow-Up is a program established by the state's California Children's Services (CCS) division in partnership with CPQCC which oversees outpatient "follow-up" for infants requiring additional developmental care after discharge from the NICU through local HRIF clinics. HRIF clinics provide follow-up care (through the course of three "standard visits" between NICU discharge and age three, as well as any additional visits deemed needed by the HRIF team) to all infants born before 32 weeks of gestation, or with a birth weight less than 1500 grams, as well infants with a range of neurological and/or cardiovascular risk factors.

## Launch of the HRIF Health Equity Dashboard

In December 2022, the HRIF team rolled out a brand-new tool to ensure that all high-risk NICU graduates in California receive equitable, high-quality follow-up care. Below is an excerpt from an interview with HRIF Program Manager Erika Gray about this innovative new tool.



## Why is this project important, and what benefits does it provide?

Equitable care for all! All eligible HRIF patients should receive the services they need to develop optimally, regardless of their race, ethnicity, location, or socioeconomic background. The HRIF Health Equity dashboard will help clinical teams to view a

breakdown by race/ethnicity of the patients seen at their clinic, allowing them to track if certain groups are being seen less frequently and implement interventions to address those disparities. Additional filters will allow users to drill down by birth cohort, birth weight, primary language, and insurance status.

#### Who will benefit from this new tool?

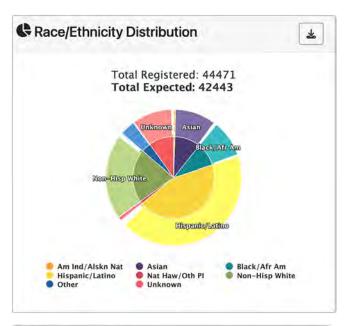
The HRIF Health Equity Dashboard will be available to all 66 CPQCC CCS HRIF Clinics across California and benefit more than 9,000 high-risk infants and their families referred to HRIF at NICU discharge each year.

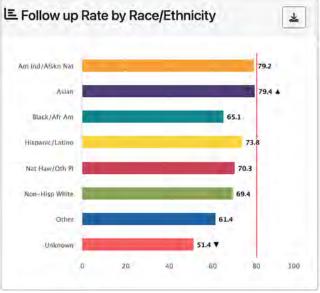
# How does this affect the patient experience?

Many high-risk infants discharged from the NICU deal with complex and chronic conditions requiring specialized medical care and other support. However, these conditions often take time to present.

Attendance at all three standard HRIF visits is critical to timely diagnosis and early intervention. Research has shown that sociodemographic characteristics, social determinants of health, and perinatal and neonatal medical factors are associated with lower visit attendance. The HRIF Health Equity Dashboard has the potential to improve patient experience and family

engagement by making clinics aware of any disparities in visit attendance and ensuring that all high-risk infants are receiving equitable follow-through care.





For more information about the HRIF Health Equity Dashboard contact Erika Gray at erika@cpqcc.org.

#### **NICU Database**

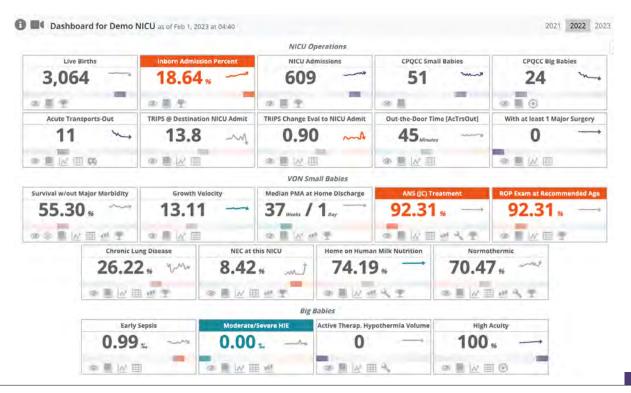
At CPQCC, data is at the heart of what we do. Through our NICU Database, we collect critical information on the care provided in over 90% of California NICUs and on acute transports in and out of these units. This data is used to identify areas of high and low performance, monitor the effects of improvement interventions, and conduct research that advances the quality of neonatal care.

### **Celebrating Clinical Excellence**

In July 2022, CPQC began recognizing member hospitals that have achieved excellence in three clinical measures: antenatal steroid (ANS) use, retinopathy of prematurity (ROP) eye exams conducted at the appropriate chronological age, and rate of hospital-acquired infections (HAI). Top-performing NICUs received an email highlighting their data and congratulating them on their achievements. A total of 112 NICUs achieved "top performer" status on at least one of the identified measures, and 20 NICUs achieved top performance on all three measures. The following is the breakdown of performance by measure:

- 86 NICUs achieved 100% ANS use
- 77 NICUs conducted 100% of ROP eye exams at the appropriate chronological age
- 29 NICUs achieved an HAI rate of 0%

We appreciate our member NICUs' hard work and dedication to providing the highest quality care to patients and families. We hope that by recognizing our top performers, teams will be able to celebrate their achievements and look for additional areas of potential improvement.



## **Quality Improvement**

CPQCC's quality improvement toolkits are the foundation of our QI program and serve as a source of evidence-based "potentially better practices" on a range of clinical topics for sites to test, adapt, and adopt. To date, CPQCC has published 13 QI toolkits and numerous other standalone tools. Toolkits are regularly reviewed by the PQIP QI Infrastructure Subcommittee and revised based on current literature. A complete library of CPQCC's QI Tools can be found at <a href="https://www.cpqcc.org/improvement/qi-tools">https://www.cpqcc.org/improvement/qi-tools</a>

## **Updated Toolkit - Preventing Hospital-Acquired Infection in the NICU**

Over the past 20 years, through efforts of single and multi-center NICU quality improvement (QI) projects and collectively through state collaboratives, the rates of central line-associated bloodstream infections (CLABSIs) and, subsequently, hospital-acquired infections (HAI) in the NICU have been reduced. However, despite these improvements, HAI remains a persistent challenge in the NICU, resulting in increased length of stay, morbidity and mortality, and increased hospital costs. In addition, very low birthweight (VLBW) infants hospitalized in the NICU are at an increased risk for HAI.

This 2022 revision of the original toolkit (published in 2007) builds upon CLABSI prevention efforts, shifting the focus toward a broader approach to HAI prevention by encouraging the use of "hospital-acquired bacteremia" or "non-CLABSI bloodstream infection" incidence as an important and more global measurement of NICU quality. To that end, this toolkit addresses other potential sources of hospital-acquired bacteremia, such as the skin and gut, and delineates potentially better practices to address these areas. Along with CLABSI prevention efforts, this more comprehensive approach to HAI prevention is needed to protect the youngest and tiniest NICU patients.

Several potentially better practices are explored within this toolkit under five categories, including:

- 1. Hand Hygiene
- 2. NICU Quality Improvement and Culture
- 3. General Principles of HAI Prevention
- 4. Skin Considerations and HAI Prevention
- 5. Antibiotic Stewardship/Multi-Drug Resistant Organisms (MDRO)

The toolkit was authored by lead authors Robin Clifton-Koeppel, DNP, CNS, CPNP, RNC-NIC and Rachelle Sey, Ph.D., APRN, CNS, RNC-NIC and contributing authors Talal B. Seddik, MD; Susan M. Bowles, DNP, APRN-CNS; Carolyn Lund, RN, MS, FAAN, and Nick Mickas, MD.

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- Standardize Dressings and Securement Techniques that Minimize Catheter Migration and Extraluminal Introduction of Microorganisms Along the Tract of the Catheter
- Use Products and Techniques to Minimize Risk for Medical Adhesive-Related Skin Injury
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# V. ANTIBIOTIC STEWARDSHIP AND PREVENTING/REDUCING MULTIDRUG RESISTANT ORGANISMS

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#### Antibiotic Stewardship

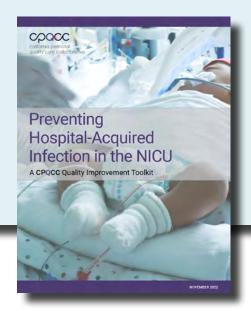
- Establish a Multidisciplinary Collaborative Approach to Diagnostic and Antimicrobial Stewardship
- Measure the Effectiveness of Diagnostic and Antimicrobial Efforts in the NICU
- Develop Antimicrobial and Diagnostic Stewardship Interventions
- Develop Clinical Pathways and Guidelines for Common Neonatal Infections

#### **Multidrug Resistant Organisms**

- Implement Measures to Recognize and Prevent Staphylococcus Aureus Infection in the NICU, Including MRSA
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#### **CONCLUDING REMARKS**

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## **QI Research**

The data that we collect provides a rich opportunity for research and analysis. Our research program is built on the understanding that the insights generated will inform improvements in care in NICUs around the world. Research is conducted internally by our team and through partnerships with investigators from across the country.

#### 2022 Publications

CPQCC published 10 new articles in peer-reviewed journals in 2022 with collaborators from across the state and country. We are incredibly grateful to CPQCC members for contributing data for quality improvement that makes this research possible and advances our understanding of neonatal care.

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