DEFINE Colorado

Centering families in the NICU

Family-Centered Care Task Force

September 12, 2024

Data-driven Engagement of Families to Improve the NICU Experience

Definition: Patient and Family Engagement

"A set of behaviors by patients, family members, and health professionals and a set of organizational policies and procedures that foster both the inclusion of patients and family members as active members of the health care team and collaborative partners with providers and provider organizations."

AHRQ. Guide to Patient and Family Engagement. May 2012

Measurement Dilemmas

- How should parental engagement be measured?
  - ? Time spent in the NICU
  - ? Presence on medical rounds
  - ? Understanding of the infant's medical conditions
  - ? Comfort and proficiency with infant care
  - ? Mom, dad, grandparents, other caregivers

The impact of parental primary language on communication in the neonatal intensive care unit

Mauricio A. Palau[1] · Maxene R. Meier[2] · John T. Brinton[2] · Sunah S. Hwang[1] · Genie E. Roosevelt[3] · Thomas A. Parker[1]

Figure 1: Fewer Spanish-Speaking Parents Correctly Identify the Diagnosis

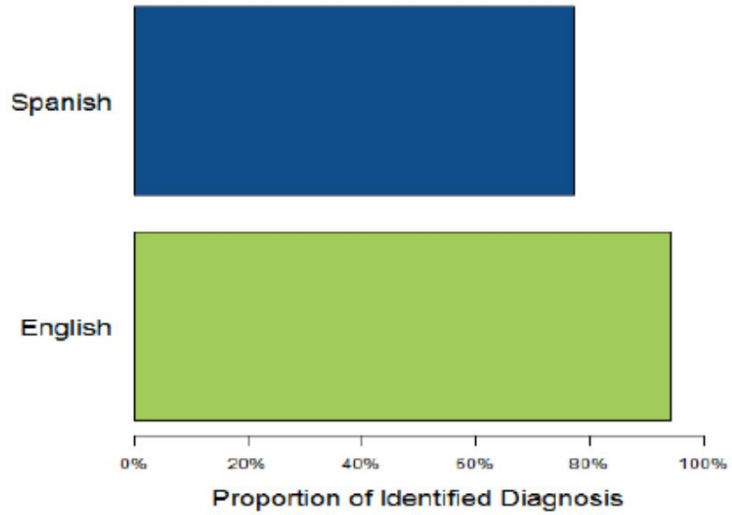


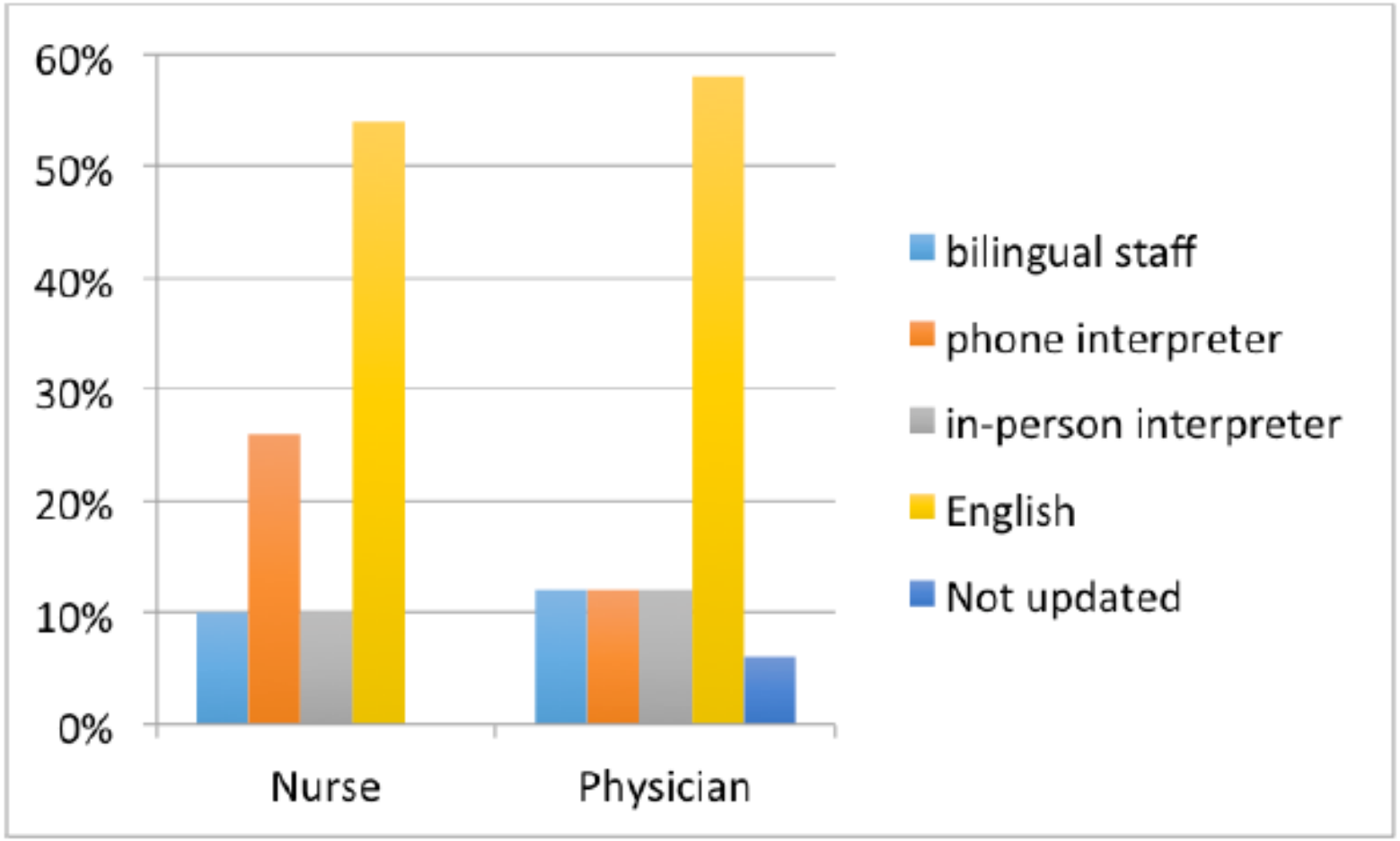
Table 2: Decrease in Odds of Understanding Based on Language Spoken

	Univariate model	Adjusted model
Odds Ratio (95% CI)	0.20 (0.07, 0.64)	0.24 (0.06, 0.93)

Note: English speakers were the referent group.

Palau MA, Meier MR, Brinton JT, Hwang SS, Roosevelt GE, Parker TP. J Perinatol 2018.

Figure 3. Proportion and Method of Updates to Spanish-speakers by Care Provider



Palau MA, Meier MR, Brinton JT, Hwang SS, Roosevelt GE, Parker TP. J Perinatol 2018.

RESEARCH ARTICLE

The Association of Social Factors and Time Spent in the NICU for Mothers of Very Preterm Infants

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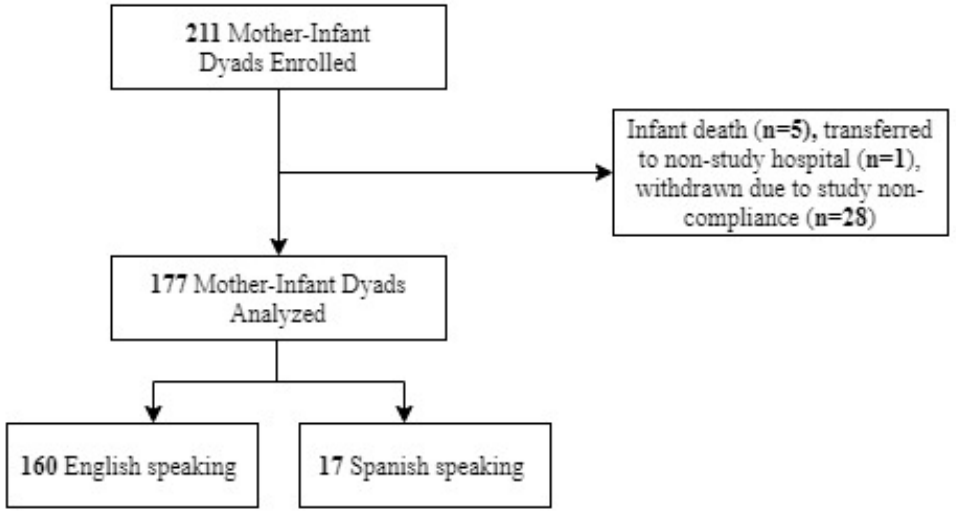

Bourque, et al. Hosp Peds, 2021

Social Factors Associated with Maternal Time in the NICU – Overall Cohort

	Adjusted Odds Ratio (95% Confidence Interval)
Race/Ethnicity	
Non-Hispanic White	REF
Other	0.71 (0.32, 1.56)
Annual Household Income	
<$50,000	REF
$50,000-99,999	1.74 (0.72, 4.24)
≥$100,000	**5.68 (1.77, 18.19)**
Travel Time to NICU	
<30 minutes	**7.85 (2.81, 21.96)**
30-60 minutes	**5.86 (2.02, 17.02)**
>60 minutes	REF
Other Children	
Yes	REF
No	**3.15 (1.39, 7.11)**

Bourque, et al. Hosp Peds, 2021

DEFINE Colorado QIC Key Driver Diagram

Aim Statement	Primary Drivers	Secondary Drivers	Potential Change Concepts
By December 2023, hospitals will improve family engagement in NICUs by: *1. Improving parental report of engagement in infant health and development during NICU hospitalization by 20%* *1. Reduce disparities in parental report of engagement by race/ethnicity, primary language, and distance from hospital by 20%*	Communication between NICU staff and families; among NICU providers *Measure: 1) Parental report of timely and consistent communication from providers; 2) Timing of first family meeting; 3) Frequency of family updates/meetings*	Language barrier between providers and parents	1) Increase use of interpreter services often and early
		Lack of timely and frequent family updates	1) Standardize timing and content of first family meeting after admission
		Inadequate family presence (during rounds, for infant cares)	1) Reduce parking cost; 2) Provide public transportation vouchers; 3) Minimize restriction of sibling visitation; 4) On site childcare for siblings; 5) Overnight accommodations for families; 6) Provide meals as needed
		Inconsistency in understanding of infant care plans among providers	1) Improve communication among medical consultants and primary team; 2) improve communication among primary team and nurses
	Social and financial supports for families *Measure: 1) date of first social worker contact; 2) parental report of social and financial needs being met*	Current social services not comprehensive to address all needs	1) Social determinants screening tool; 2) establish referral service
		Social workers bandwidth; timely availability	1) Utilize parent peer support groups
		Inadequate family support in primary language	1) Increase use of interpreter services often and early
		Inadequate mental health support	1) Introduce universal screening for parental depression/anxiety; 2) Provide mental health support during NICU hospitalization
	Family engagement in Hands-On NICU care *Measure: Skin to skin and breastfeeding continuation (through day 7, 28, and discharge)*	Inadequate family presence	1) Reduce parking cost; 2) Provide public transportation vouchers; 3) Minimize restriction of sibling visitation; 4) On site childcare for siblings; 5) Overnight accommodations for families; 6) Provide meals as needed
		Families and NICU staff have unclear expectations about parental role in the NICU; lack of parental empowerment	1) Educate family on all aspects of care they can participate in; 2) Development of peer-support groups; 3) Standardize family participation in infant's care (FICare)
		Language barriers	1) Increase use of interpreter services often and early
		Mother's own milk (MOM) protocols, policies, and supports	1) Introduce MOM education and support during prenatal period; 2) Early pumping initiation; 3) Early and frequent skin to skin; 4) Address lactation issues by phone/telehealth
	Family participation in discharge planning *Measure: 1) parental report of discharge readiness; safe sleep adherence post-discharge; 2) Timing of initiation and completion of discharge checklist*	Lack of shared decision making in discharge planning	1) Educate family on all aspects of care they can participate in; 2) Development of peer-support groups; 3) Standardize family participation in infant's care (FICare)
		Language barrier	1) Increase use of interpreter services often and early
		Inadequate family presence	1) Reduce parking cost; 2) Provide public transportation vouchers; 3) Minimize restriction of sibling visitation; 4) On site childcare for siblings; 5) Overnight accommodations for families; 6) Provide meals as needed
		Compliance with safe sleep practices in NICU	1) Standardize infant sleep practices and environment for all NICU infants

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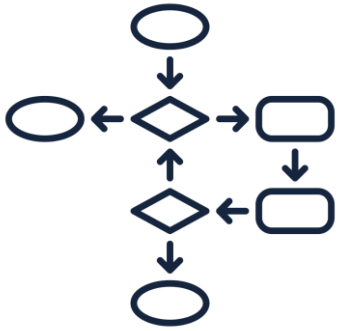
Equity-Focused Quality Improvement (EF-QI)

Stratified sociodemographic data & intentional comparator groups

Families & community partners as compensated stakeholders

Identifies & names **root causes** of inequities



Focuses on **systems** NOT individuals

Incorporates EQUITY into every step of a QI initiative

Reichman, V., Brachio, S. S., Madu, C. R., Montoya-Williams, D., & Peña, M.-M. (2021). Using rising tides to lift all boats: Equity-focused quality improvement as a tool to reduce neonatal health disparities. Seminars in Fetal and Neonatal Medicine.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FIRST
Family Integration to ReStore Trust

FIRST Program Phases

Training

MoMMA's Voices Training

Participants will complete a Patient Family Partner Certification Course that includes:

- advocacy training
- quality improvement education
- opportunities for continuing education in specialty areas of patient engagement

Participants will attend the annual Champions for Change Summit, hosted by MoMMA's Voices. The Summit:

- empowers those with lived expertise to make necessary changes in maternal health
- provides opportunities for connection among provider and patient advocates and for honoring the affected families we work so hard for

Family Integration Services

Serve on a Committee

CPCQC's committees advise and inform the decisions and direction of the organization's programs. Specific committees include:

- Programs and Services
- Finance & Audit Committee
- Development Committee
- SuppOrting vAginal delivery for low Risk mothers (SOAR)
- Colorado Alliance for Innovation on Maternal Health Substance Use Disorder (CO AIM SUD)
- Data-driven Engagement of Families to Improve the NICU Experience in Colorado (DEFINE Colorado)

Participants in FIRST may also form a new Family Engagement Committee to contribute to the development and evolution of the FIRST Program

Participants in FIRST can also apply to join the Board of Directors

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How to Engage Lived Experience Experts (LEX) in Your NICU

STEPS:

1. **Designate one or two clinical team or staff liaison member(s) to take lead on and streamline LEX engagement in the DEFINE CO Quality Improvement (QI) Program**
   - Review your NICU and/or health system policies regarding family engagement and assess the extent to which family engagement strategies are currently implemented, including whether your hospital has dedicated personnel, programs, and resources to support family experience and engagement efforts.
     - Outside of more direct contacts, consider connecting with NICU leadership, Human Resources, Volunteer Services, and Social Work.
   - Consider ongoing attendance to and participation in DEFINE CO's annual forum, quarterly webinars and quarterly all hospitals meetings, and/or monthly advisory committee meetings to build collaboration skills on family integration in QI.
2. **Connect with the DEFINE CO LEX Engagement Team for resources and support**
   - Primary Contact: Brace Gibson, CPCQC's Director of Policy and Engagement; bgibson@cpcqc.org
     - Our team will work with yours to develop an engagement plan and alleviate institutional barriers to LEX partnership. We can help provide your NICU's family partner(s) with compensation for their time and expertise, QI and family partner trainings, flexible and diverse engagement opportunities, as well as mentorship and ongoing support.
3. **Leverage the DEFINE CO program to recruit LEX and strengthen engagement**
   - Utilize the DEFINE CO survey approach for targeted, efficient recruitment:
     - Three months after the program's post-discharge survey is sent (i.e., four months post-discharge for the family), another automated survey is sent to inquire about a family's interest in serving as LEX.
     - The survey directs the family to a secure CPCQC interest form. The DEFINE CO LEX Engagement Team manages the interest forms, initial outreach to families, and assessment of readiness.
     - For hospitals specifying interest in and capacity for direct, site-level engagement of LEX (as noted in your hospital's engagement plan), LEX contact info is provided to the site's LEX engagement leads.
   - Utilize direct referrals or open recruitment: Site leads may also provide families with the Engagement Team's contact info or direct link to CPCQC's interest form, either through personal referral or flyers posted in your NICU.

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Lived Experience Expert (LEX) Engagement - Resources & Additional Information

Benefits of Engaging LEX at Your Hospital

- Integrate family members into the care team and facilitate a more collaborative healthcare environment in which families, clinicians, and hospital staff all work together to improve clinical care models.
- Improve the safety and quality of infant care (in-hospital and at-home).
- Increase access to and utilization of patient resources and support.
- Improve patient and provider experiences.

For more information on family-centered care, the benefits of LEX collaboration, and strategies to educate staff and build your hospital's team of family engagement champions:
Resource: Better Together- Partnering with Families: Strategies for Educating Staff
Source: Institute for Patient- and Family-Centered Care (IPFCC)

Types of Engagement

The degree of LEX engagement may depend on various factors such as:

- Scope of your DEFINE CO team's work
- Bandwidth and competing interests of the LEX
- Extent of reimbursement/compensation of the LEX
- Preferences, comfort, and experience levels of the LEX to engage at various levels given their life circumstances and experiences during NICU hospitalization.

The engagement types listed below are suggestions and should be adapted to best suit the context of the DEFINE hospital site.

A) **Attendance at DEFINE CO Hospital Team meetings (in-person or virtual) - frequency and duration will vary across sites**
B) **A + ad hoc reviews of guidelines, policies, family-facing materials etc.**
C) **A + B + leadership role in the DEFINE Hospital Team (along with a clinical team member and with mentor support from the DEFINE Program LEX Engagement Team)**

Compensation

The DEFINE program promotes equitable engagement of family partners as a core component of its quality improvement framework; this includes LEX compensation for their time, expertise, and collaboration. Compensation can be monetary or nonmonetary, and will be dependent upon the degree(s) of LEX engagement, as well as your hospital's resources and policies. In

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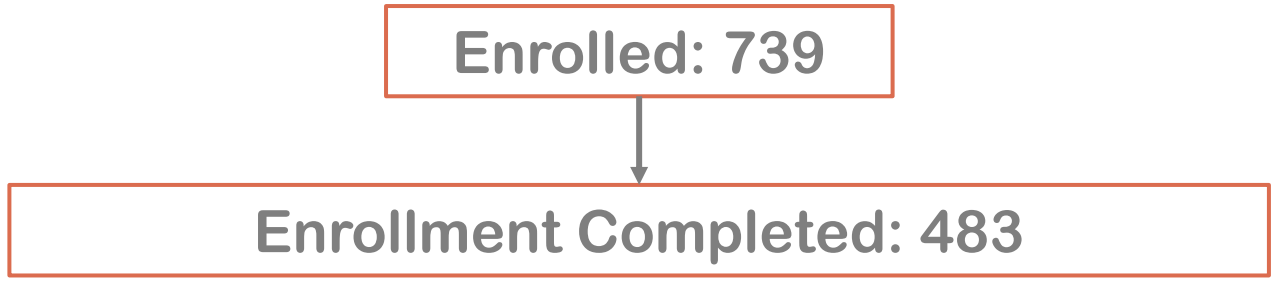
Data Report

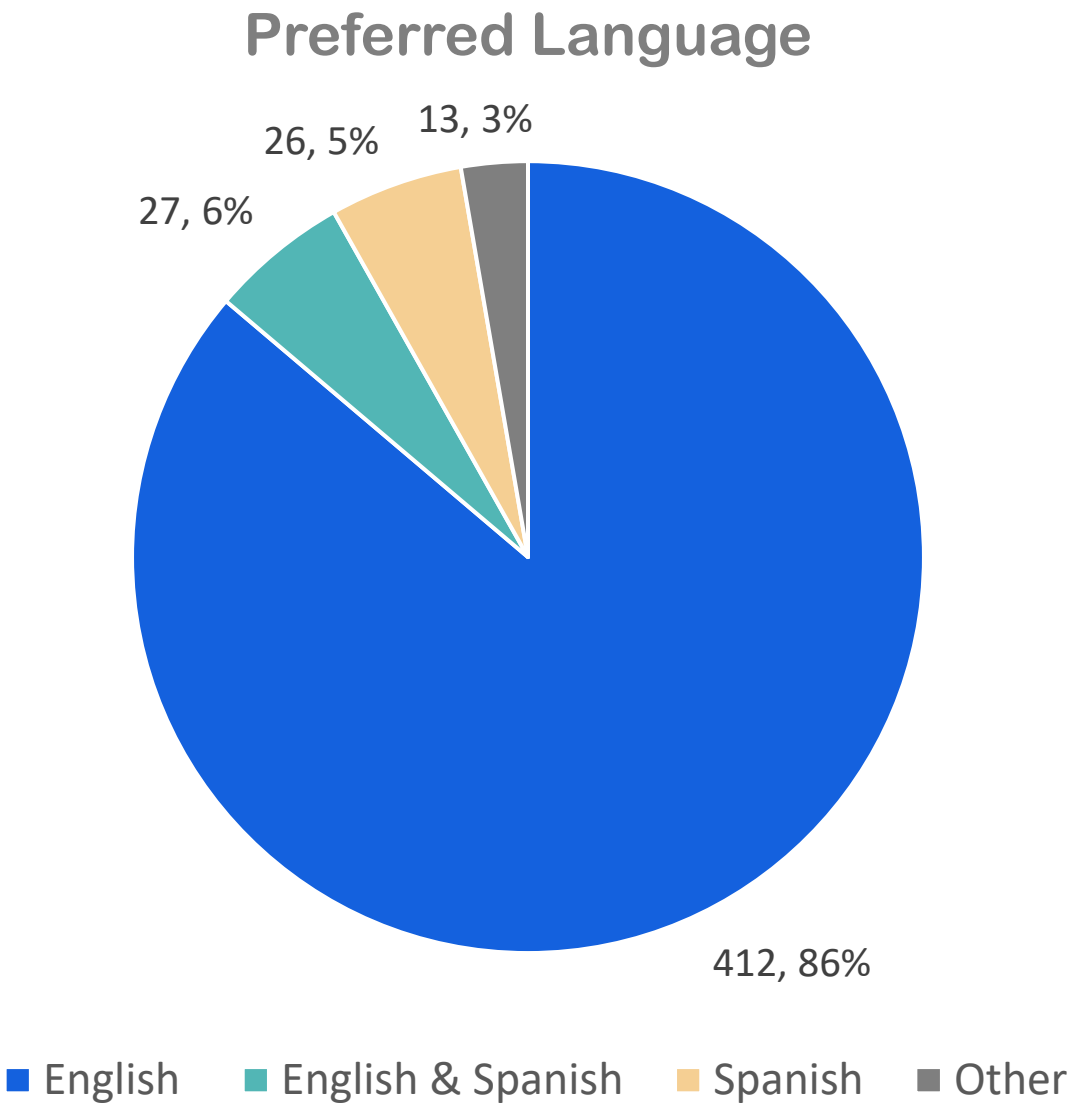
Responses

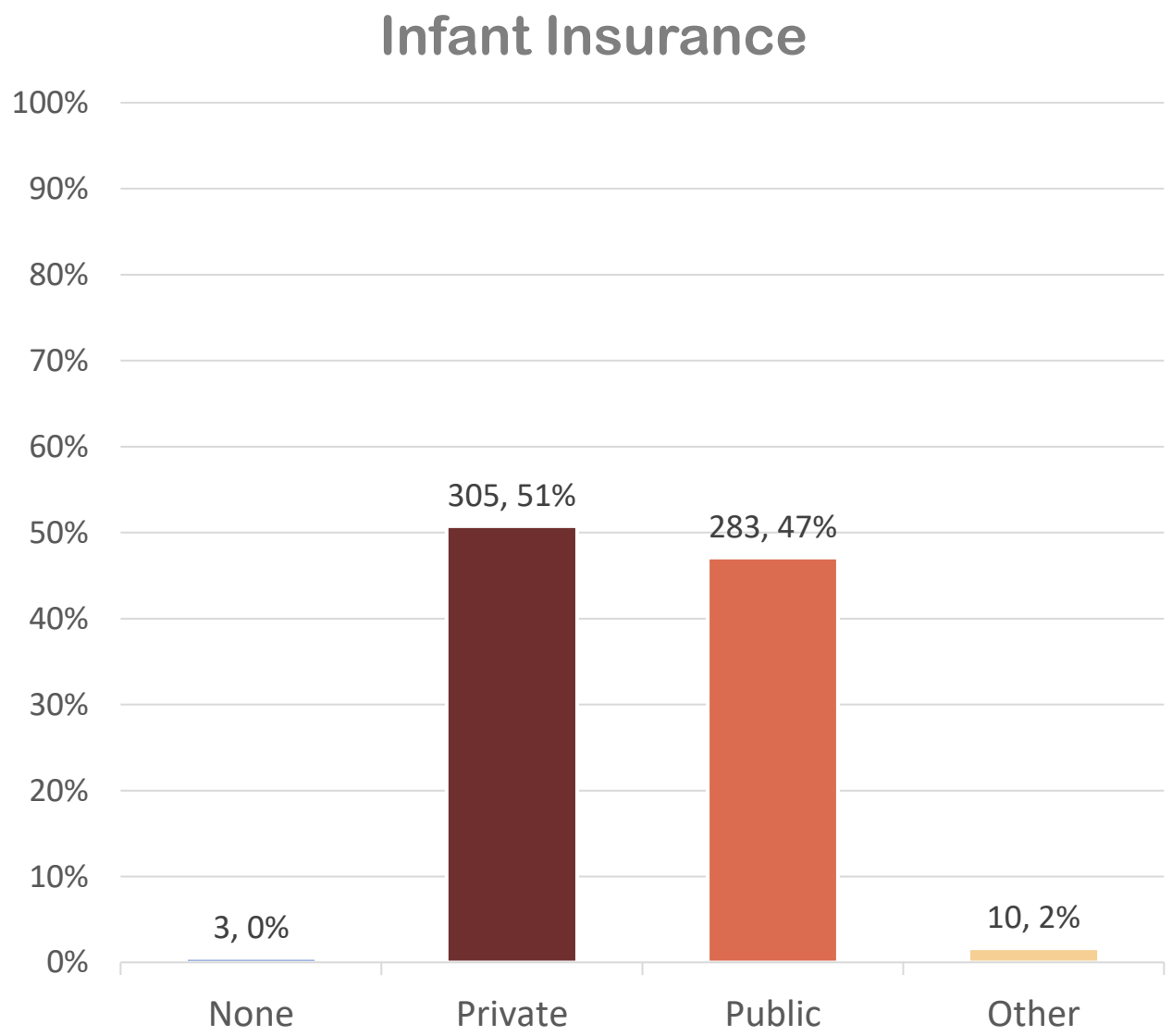


Post-Discharge Survey Completed: 178

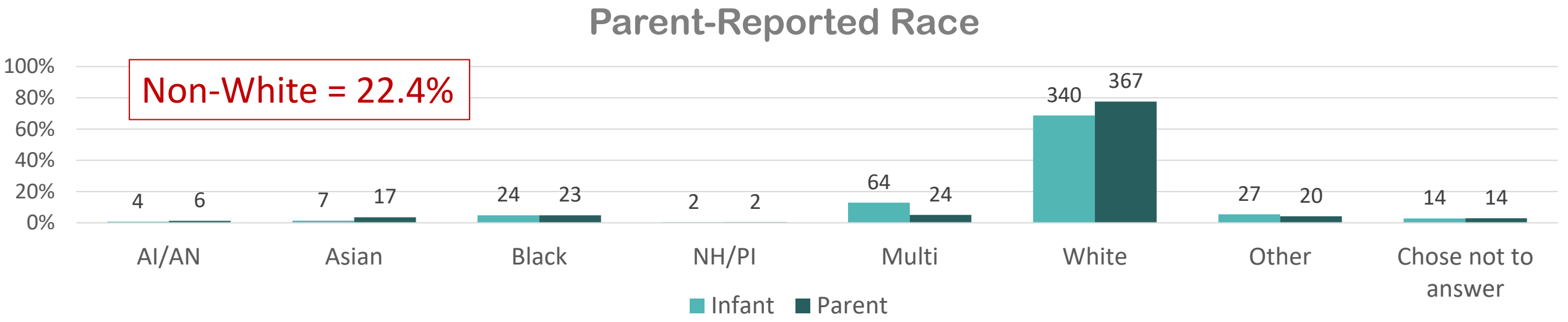
Chart-Abstracted Data: 570

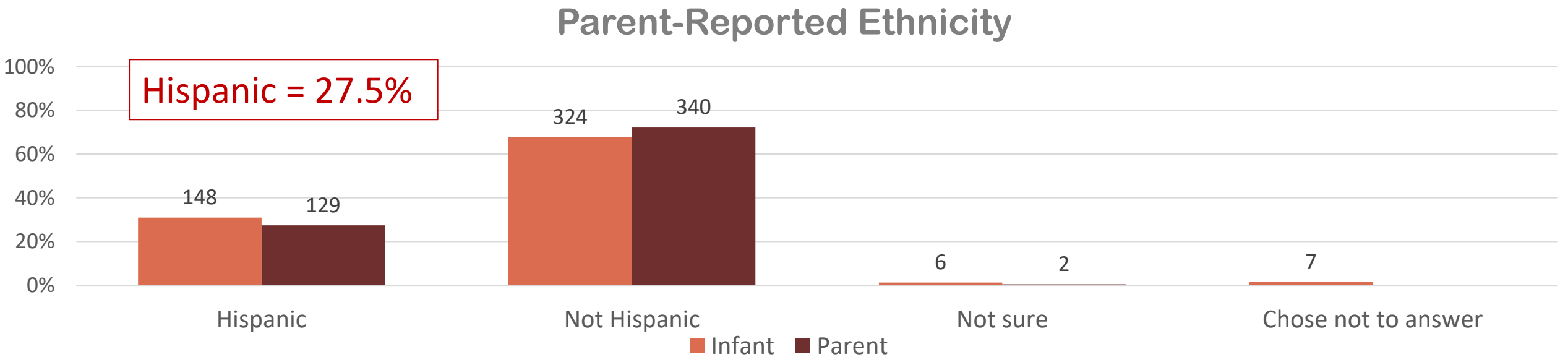
Language & Insurance



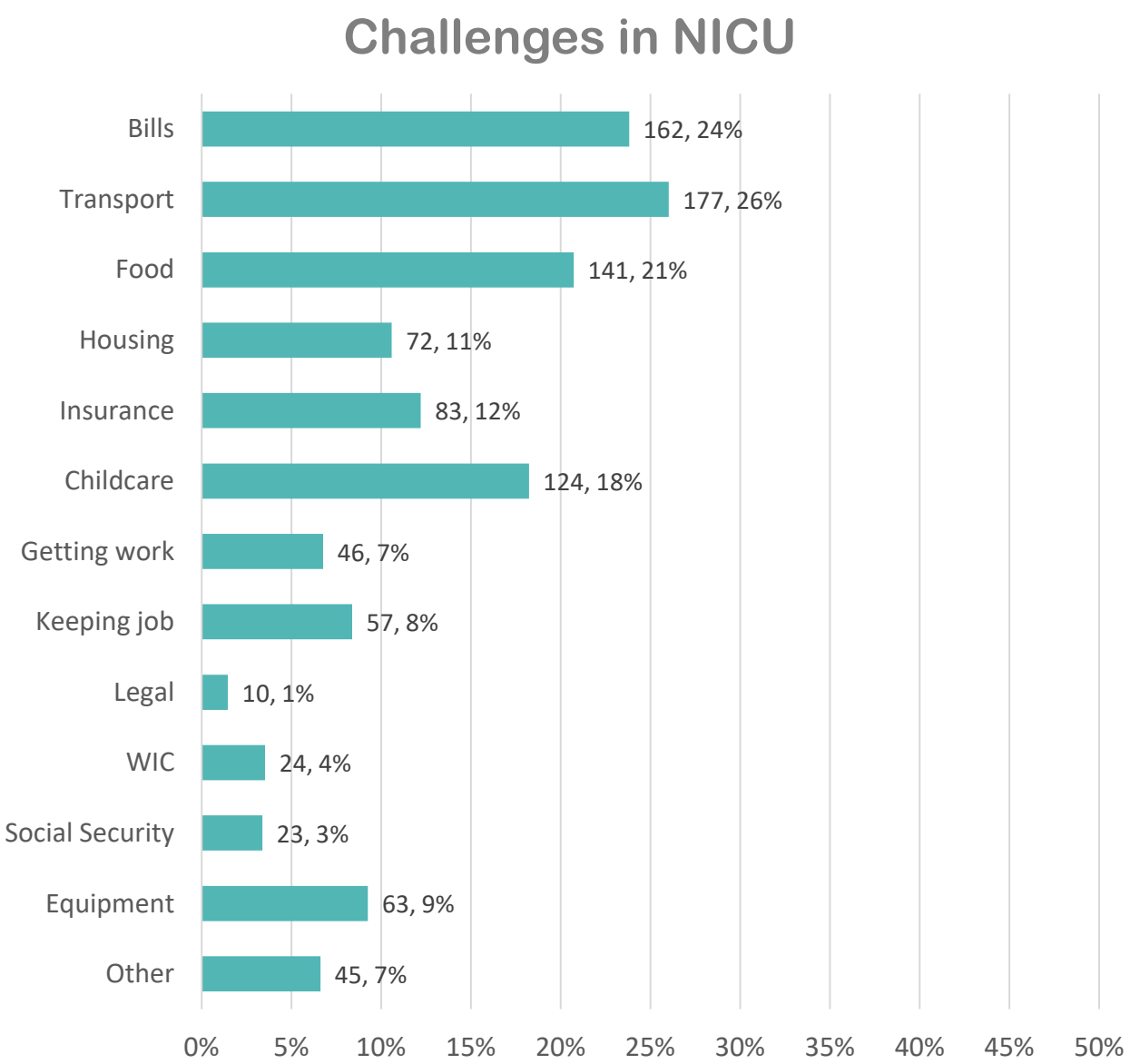


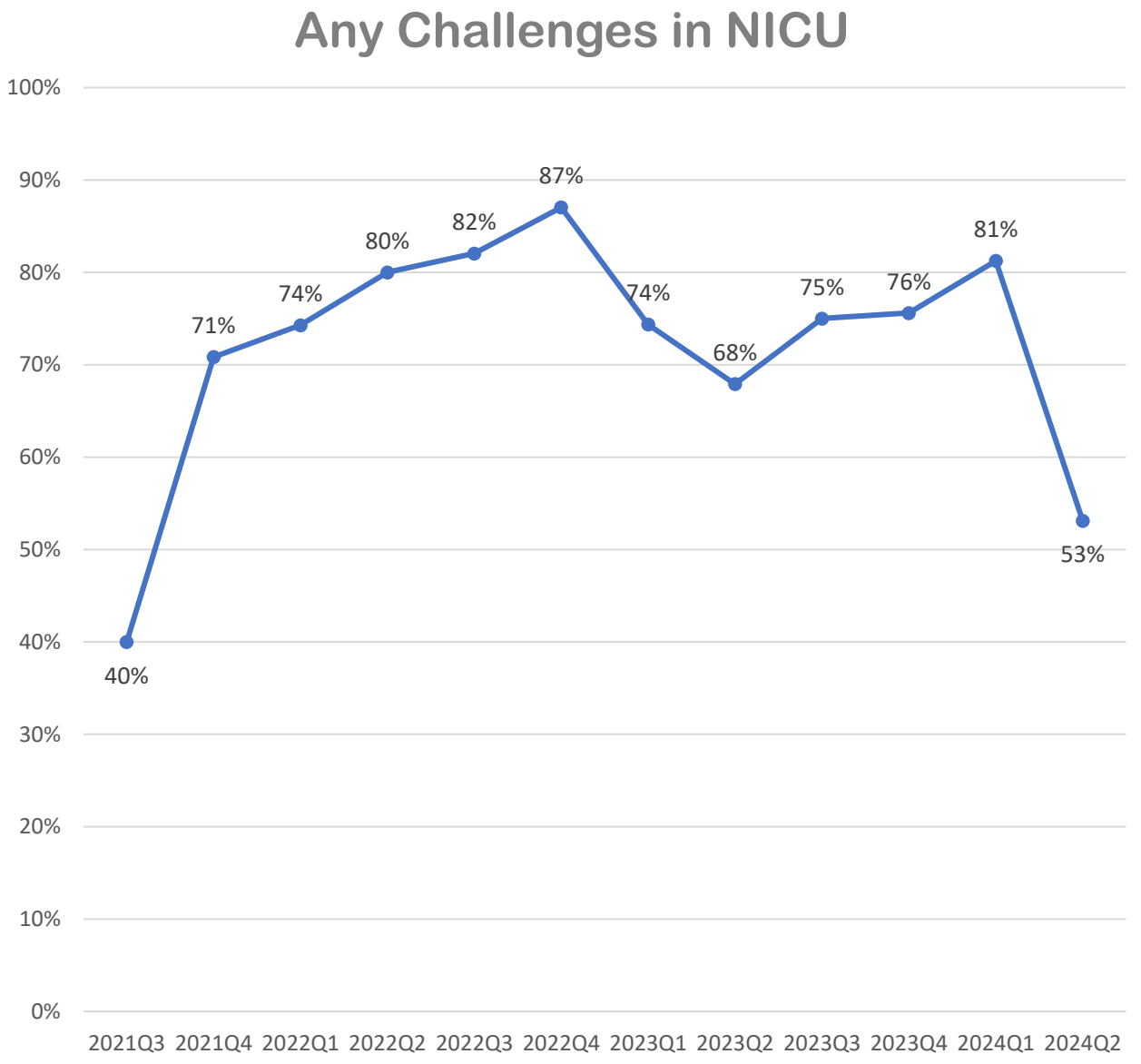
Race & Ethnicity





Parental Burdens: NICU





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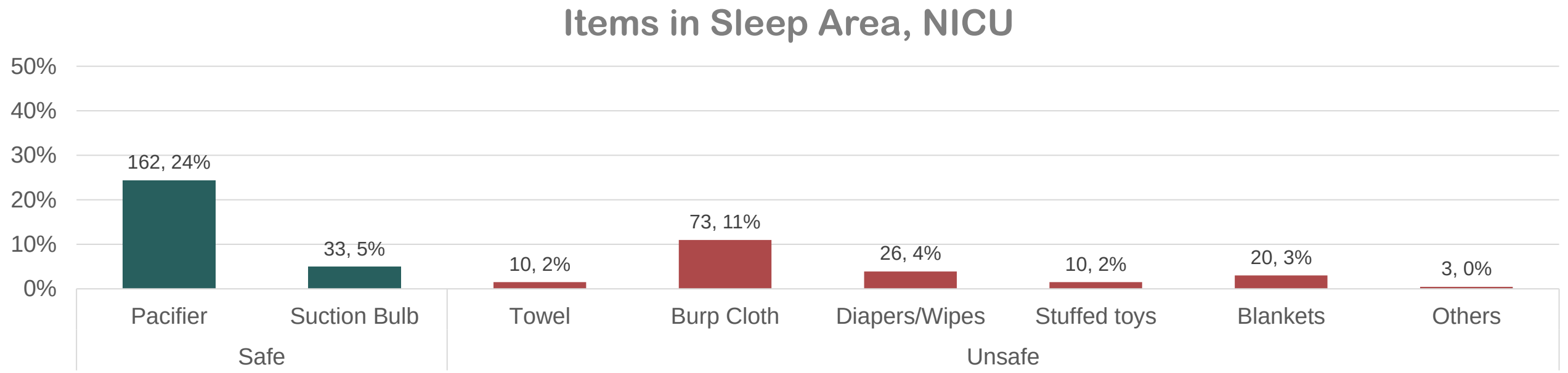
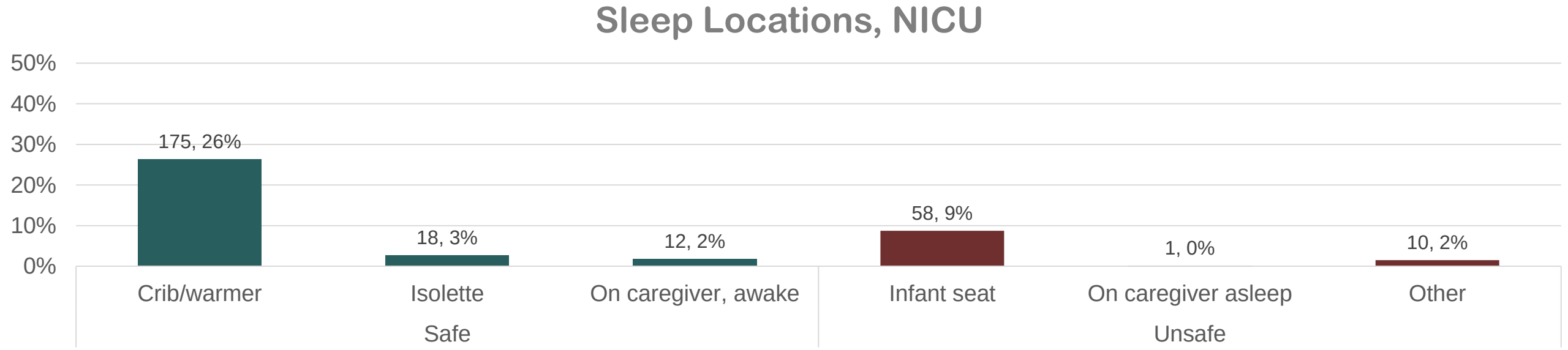
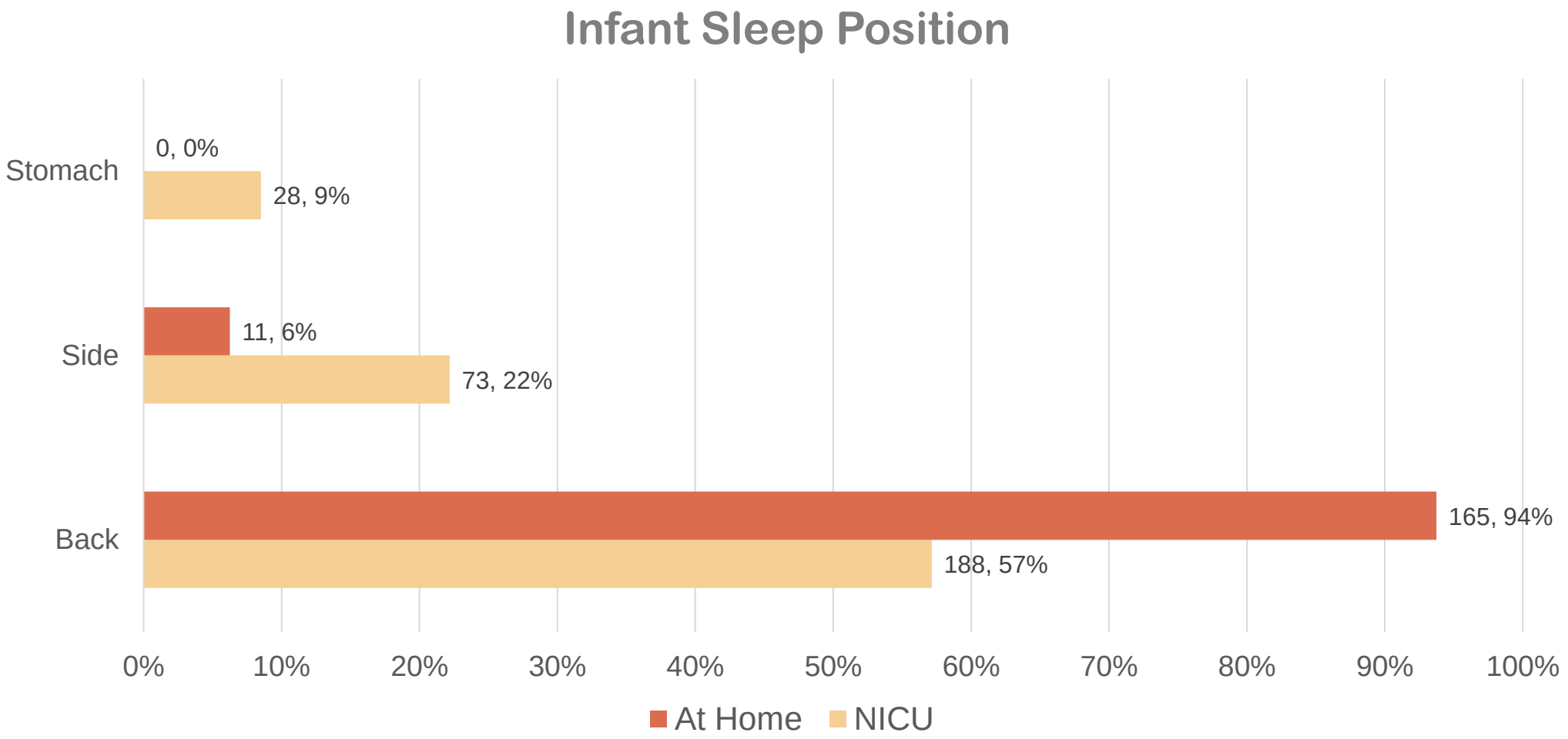
SLEEP WELL UPDATES

Sleep Behaviors: NICU

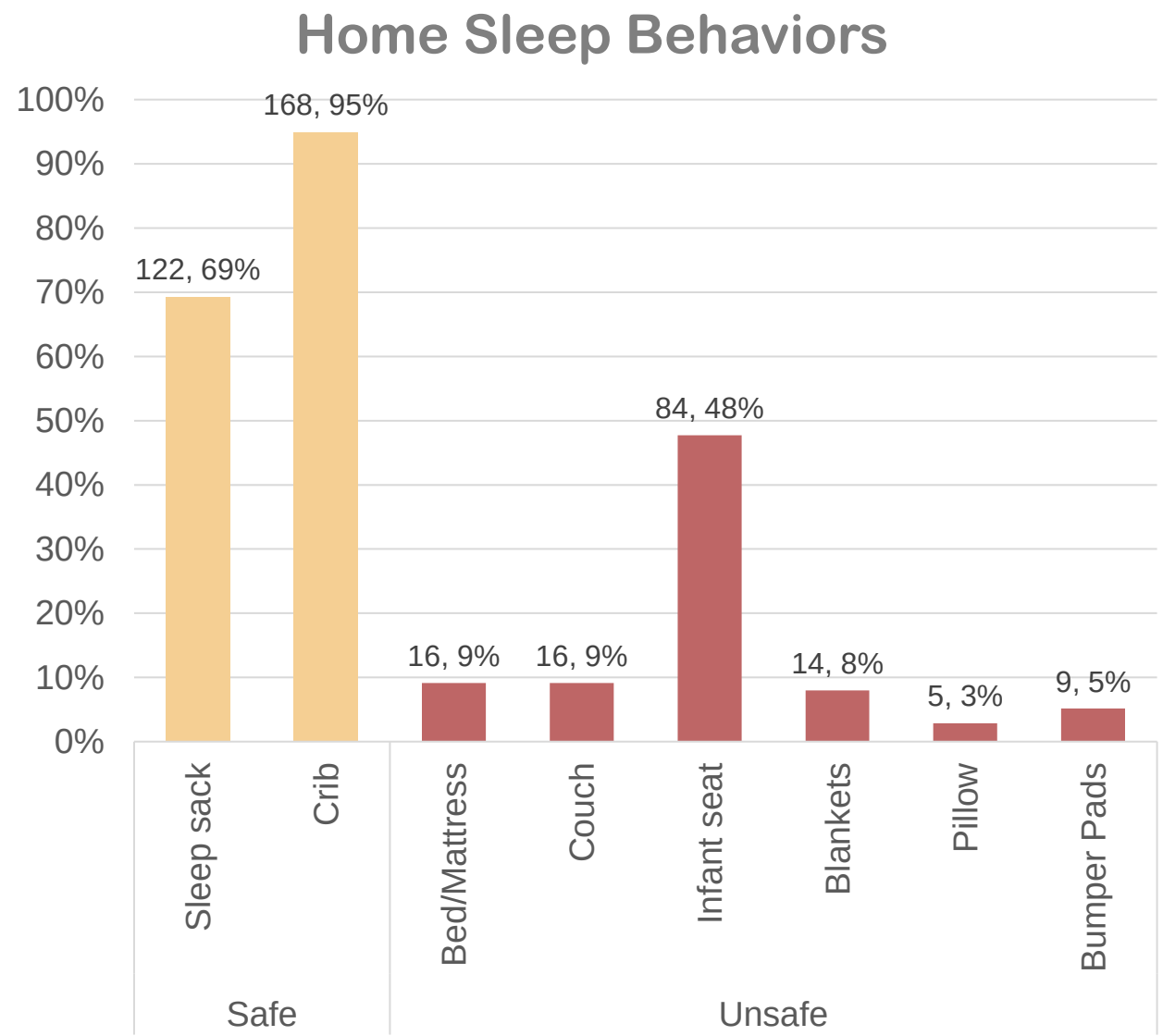


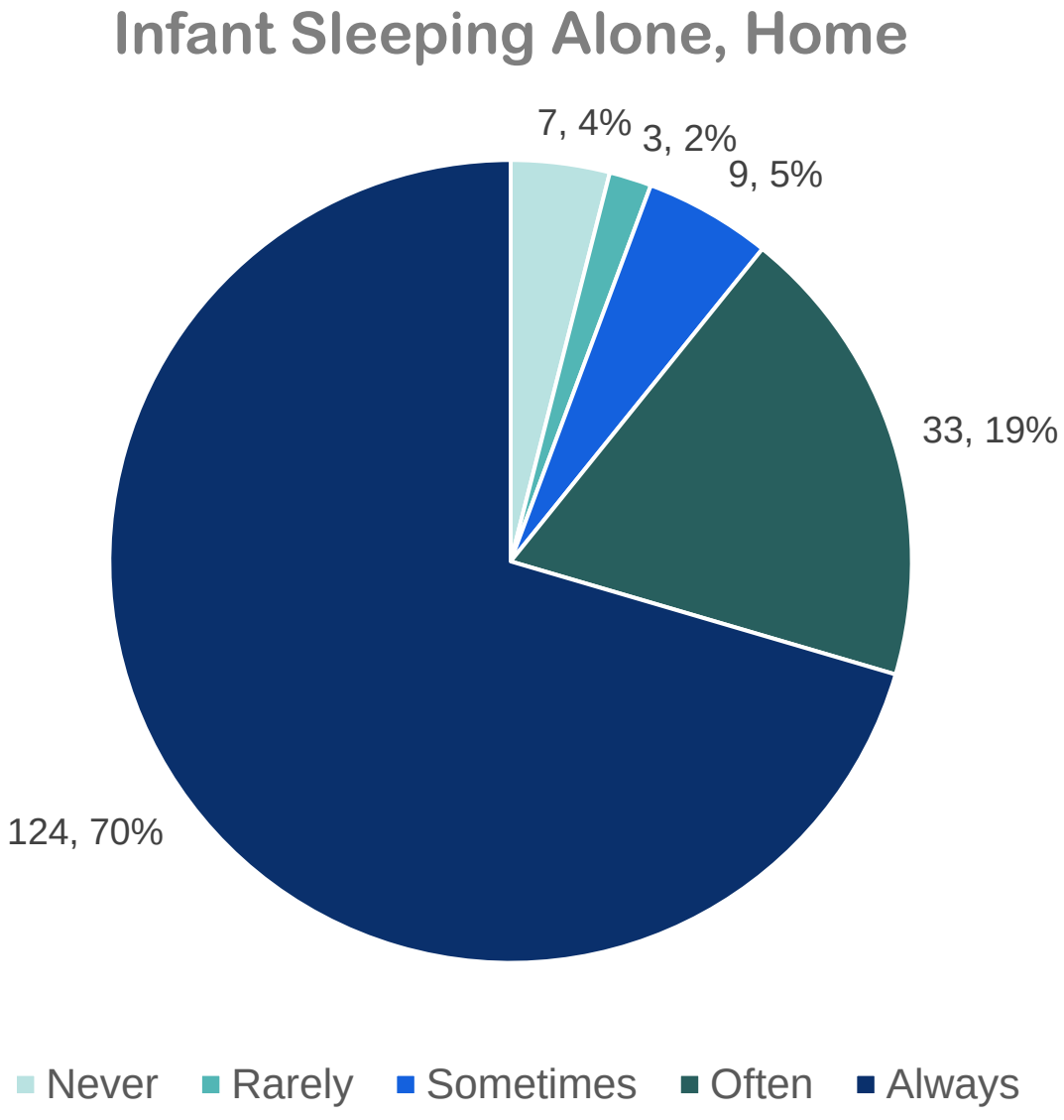


Safe Sleep Position

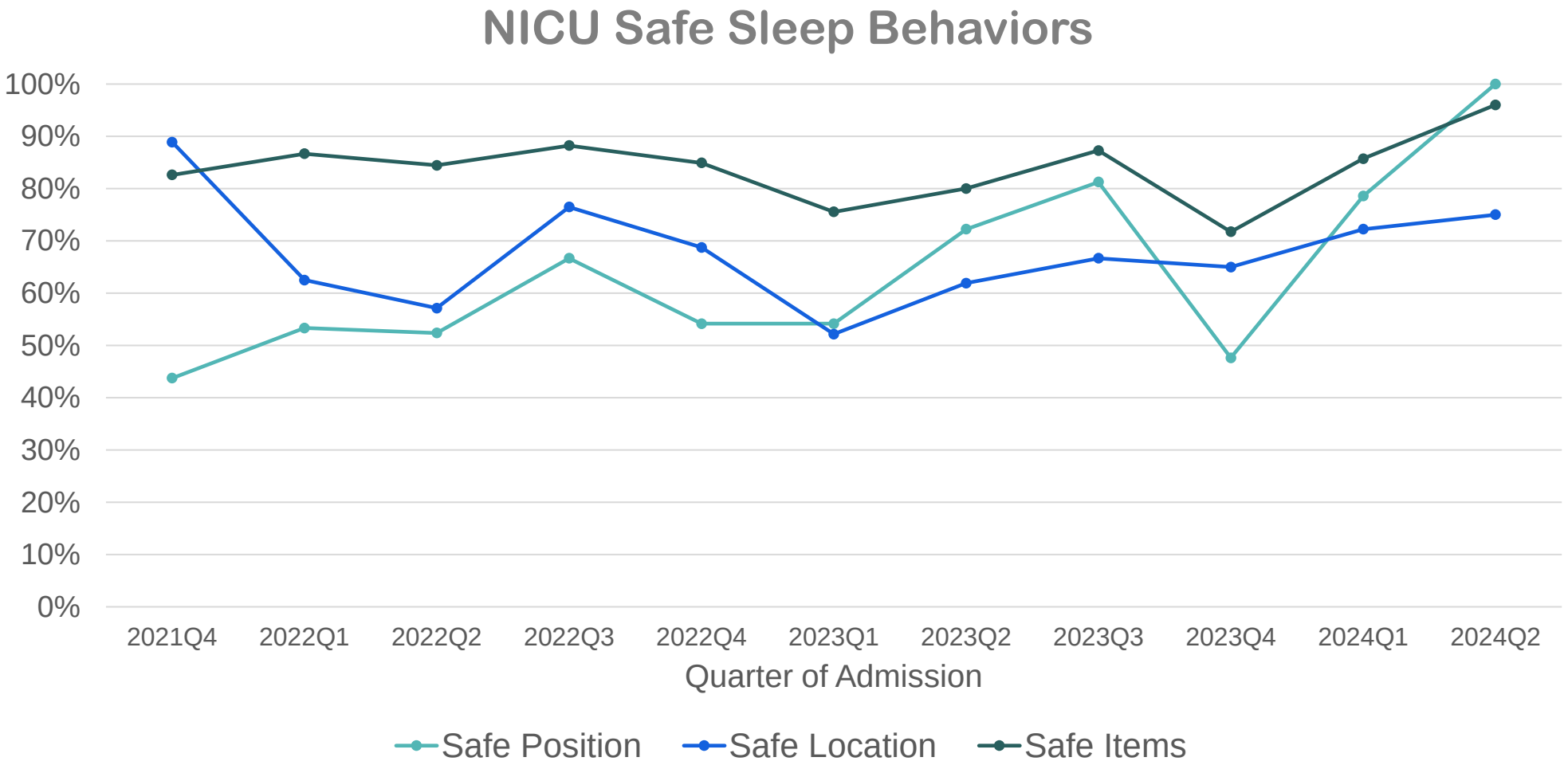


Post-Discharge Sleep





Safe Sleep: NICU

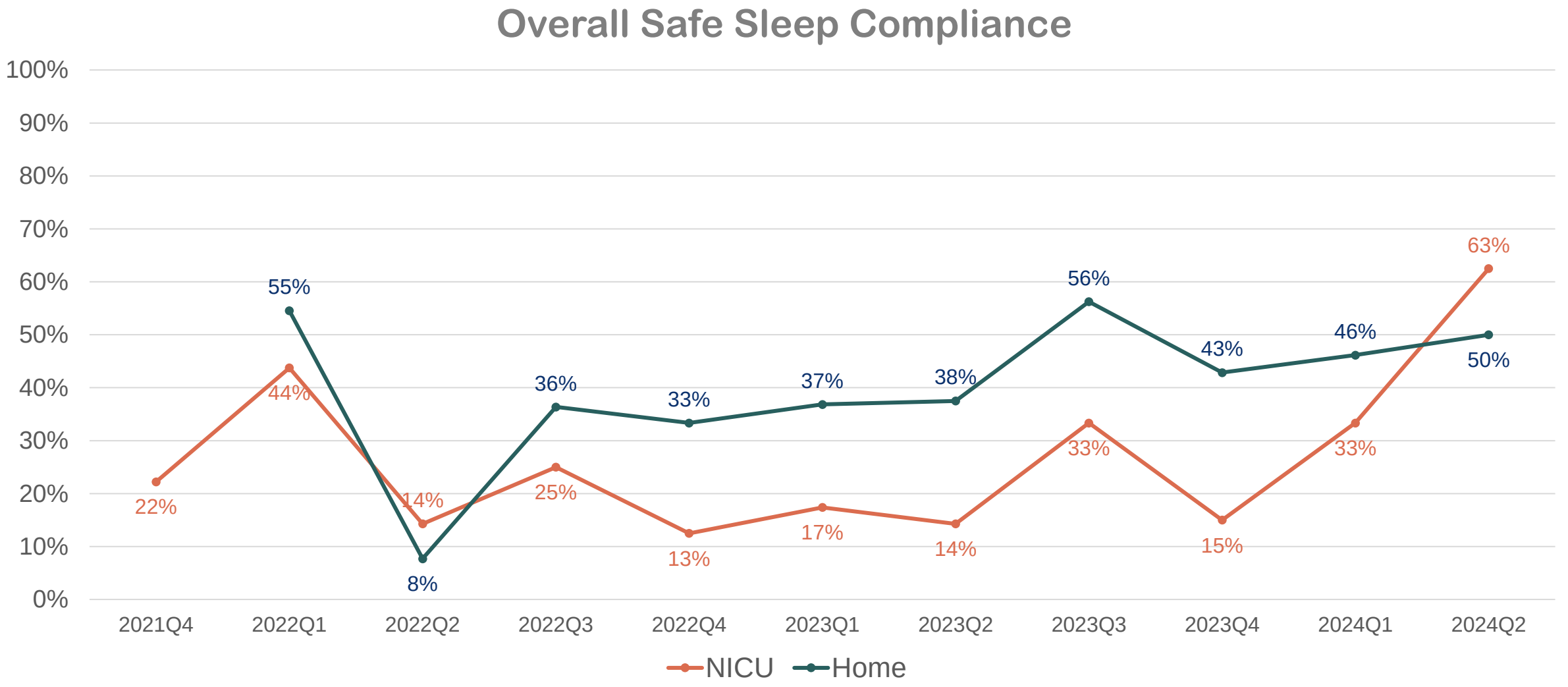


Safe Position:
on back only (no side or stomach)

Safe Location:
crib/warmer, Isolette, on awake caregiver (no infant seat or on sleeping caregiver)

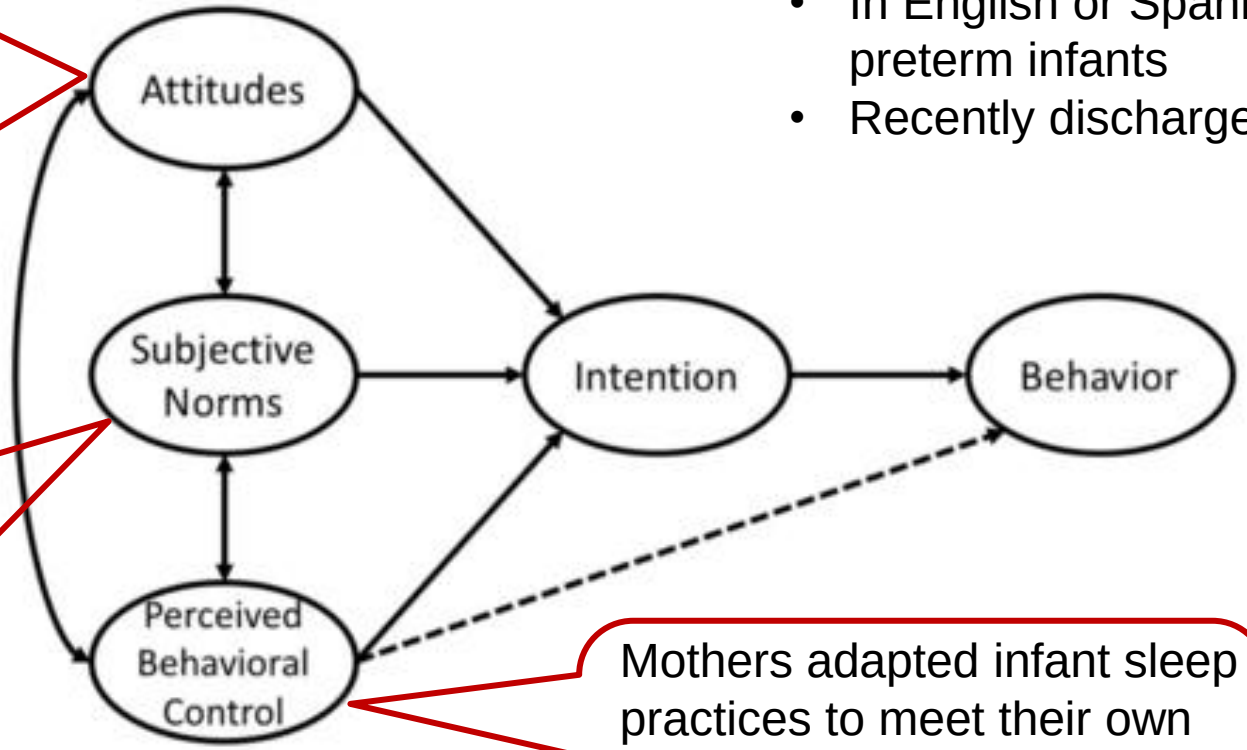
Safe Items:
Suction bulb or pacifier permitted (no other items)

Overall Safe Sleep



Mothers' fear about their infants' vulnerable preterm state related to suffocation, apnea of prematurity, and reflux influenced infant sleep practices.

Education received in the NICU and advice from other health care providers, family, friends, and media impacted their choices.



Mothers adapted infant sleep practices to meet their own needs and address the perceived safety and comfort of infants.

Theory of Planned Behavior

- 23 in-depth interviews
- In English or Spanish with mothers of preterm infants
- Recently discharged from 4 NICUs

Hwang SS, Parker MG, Colvin BN, Forbes ES, Brown K, Colson ER. J Perinatol. 2021

Colorado NICU Safe Sleep Videos

CHCO Safe Sleep Video 3 fine cut on Vimeo

Acknowledgements

- Our Rocky Mountain Babies and Families
- DEFINE Hospital Teams
- Rebecca Allen
- Heather Reichenbach
- Emily Fawaz
- Sahra Cahoon
- Blair Weikel
- Brace Gibson
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