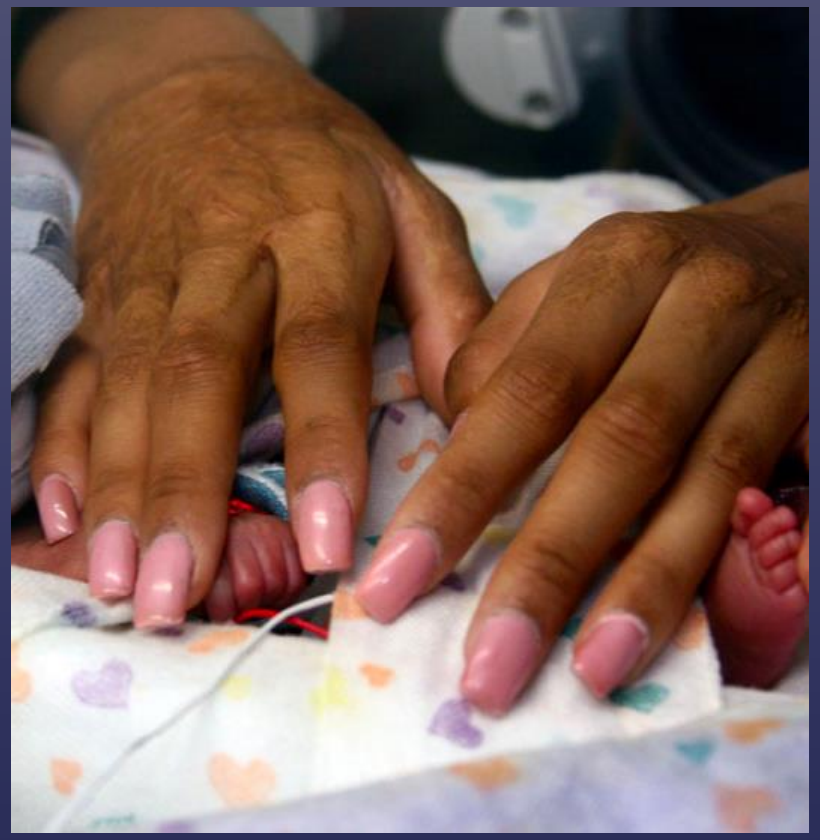




Centering the Family in NICU Care

Sunah Susan Hwang, MD MPH PhD

October 15, 2021

Financial Disclosures

- No relevant financial relationships with any commercial interests.

Objectives

- Review the recent literature on the effect of parental engagement in the NICU on infant and family health outcomes.
- Describe the barriers to parental engagement in the NICU.
- Describe the Colorado quality improvement effort to improve parental engagement in the NICU.

Case: Baby LS

- 25 2/7 week infant, BW 620 grams
- Born to a 28 yo G3P3 mother, C/S for worsening pre-eclampsia
- Maternal Hx: depression/anxiety on Zoloft, hypothyroid on Synthroid
- Infant's hospital course (LOS 118 days):
  - Resp: Surf x 3, HFOV, Conv, CPAP, HFNC, LFNC
  - CV: Hypotension s/p dopa, PDA – Indocin x 2, PDA ligation
  - FEN/GI: TPN to NG feeds BM/DBM, medical nec x 1, at DC BM 26kcal
  - HEME/ID: s/p pRBCs, s/p 10 days Amp/Gent/Flagyl for medical nec
  - NEURO: b/l grade 2 on DOL 7 HUS

Case: Baby LS

- Parental-Infant hospital course:
  - Spanish-speaking family: Consistent translator available for rounds, care conferences, infant care education
  - Hospital space: sleep space for parents, few weeks prior to discharge- transition to a room resembling a studio apartment
  - Parental mental health: NICU-dedicated mental health specialist; weekly sessions with MOC and FOC, separately and in conjunction
  - Parenting education: Medical care of infant; parental-infant interaction to optimize neurodevelopmental outcomes, parenting efficacy
  - Parental leave: For MOC – 12 months: 6 months paid, 6 months partially paid; For FOC – 6 months: 3 months paid, 3 months partially paid

Review of the Literature

Definition: Patient and Family Engagement

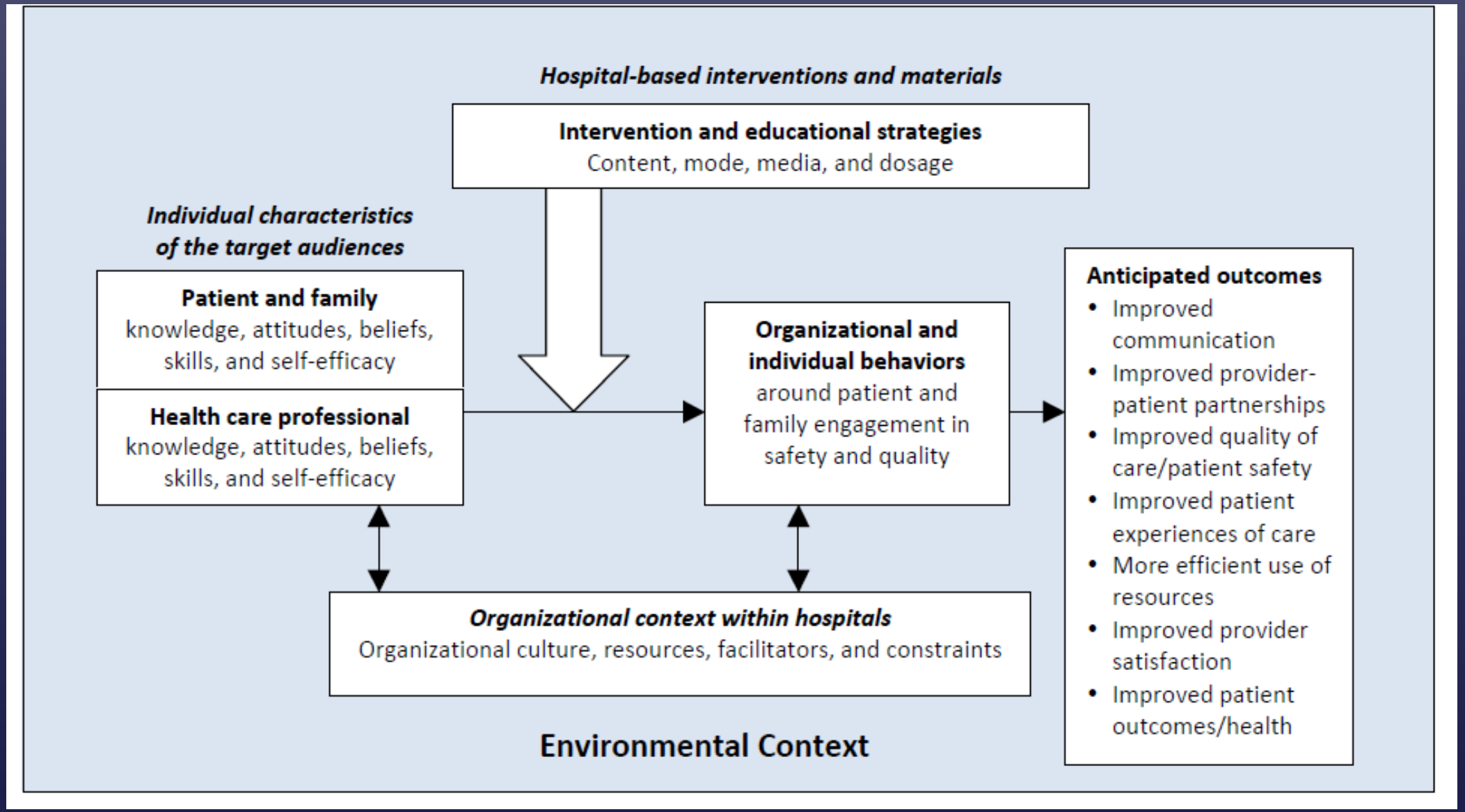
"A set of behaviors by patients, family members, and health professionals and a set of organizational policies and procedures that foster both the inclusion of patients and family members as active members of the health care team and collaborative partners with providers and provider organizations."

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

Conceptual Framework



AHRQ. Guide to Patient and Family Engagement. May 2012

Conceptual Framework

Samra et al. JOGNN. 2015

Quality Improvement: Care of Infants with NAS

An Initiative to Improve the Quality of Care of Infants With Neonatal Abstinence Syndrome

Matthew R. Grossman, MD,[a] Adam K. Berkwitt, MD,[a] Rachel R. Osborn, MD,[a] Yaqing Xu, MS,[b]
Denise A. Esserman, PhD,[b] Eugene D. Shapiro, MD,[a,c] Matthew J. Bizzarro, MD[a]

abstract

BACKGROUND AND OBJECTIVES: The incidence of neonatal abstinence syndrome (NAS), a constellation of neurologic, gastrointestinal, and musculoskeletal disturbances associated with opioid withdrawal, has increased dramatically and is associated with long hospital stays. At our institution, the average length of stay (ALOS) for infants exposed to methadone in utero was 22.4 days before the start of our project. We aimed to reduce ALOS for infants with NAS by 50%.

METHODS: In 2010, a multidisciplinary team began several plan-do-study-act cycles at Yale New Haven Children's Hospital. Key interventions included standardization of nonpharmacologic care coupled with an empowering message to parents, development of a novel approach to assessment, administration of morphine on an as-needed basis, and transfer of infants directly to the inpatient unit, bypassing the NICU. The outcome measures included ALOS, morphine use, and hospital costs using statistical process control charts.

Departments of [a]Pediatrics, [b]Biostatistics, and [c]Epidemiology, Yale University School of Medicine and School of Public Health, New Haven, Connecticut

Dr Grossman conceptualized and designed the project, drafted the initial manuscript, and coordinated data collection; Drs Berkwitt and Osborn helped design the project, collected data, and critically reviewed the manuscript; Ms Xu and Dr Esserman carried out the statistical analysis and critically reviewed the manuscript; Dr Shapiro helped analyze data and critically reviewed the manuscript; Dr Bizzarro helped design the project and critically reviewed the manuscript; and all authors approved the final manuscript as submitted and agree to be accountable for all aspects of the

Grossman et al. Pediatrics 2017

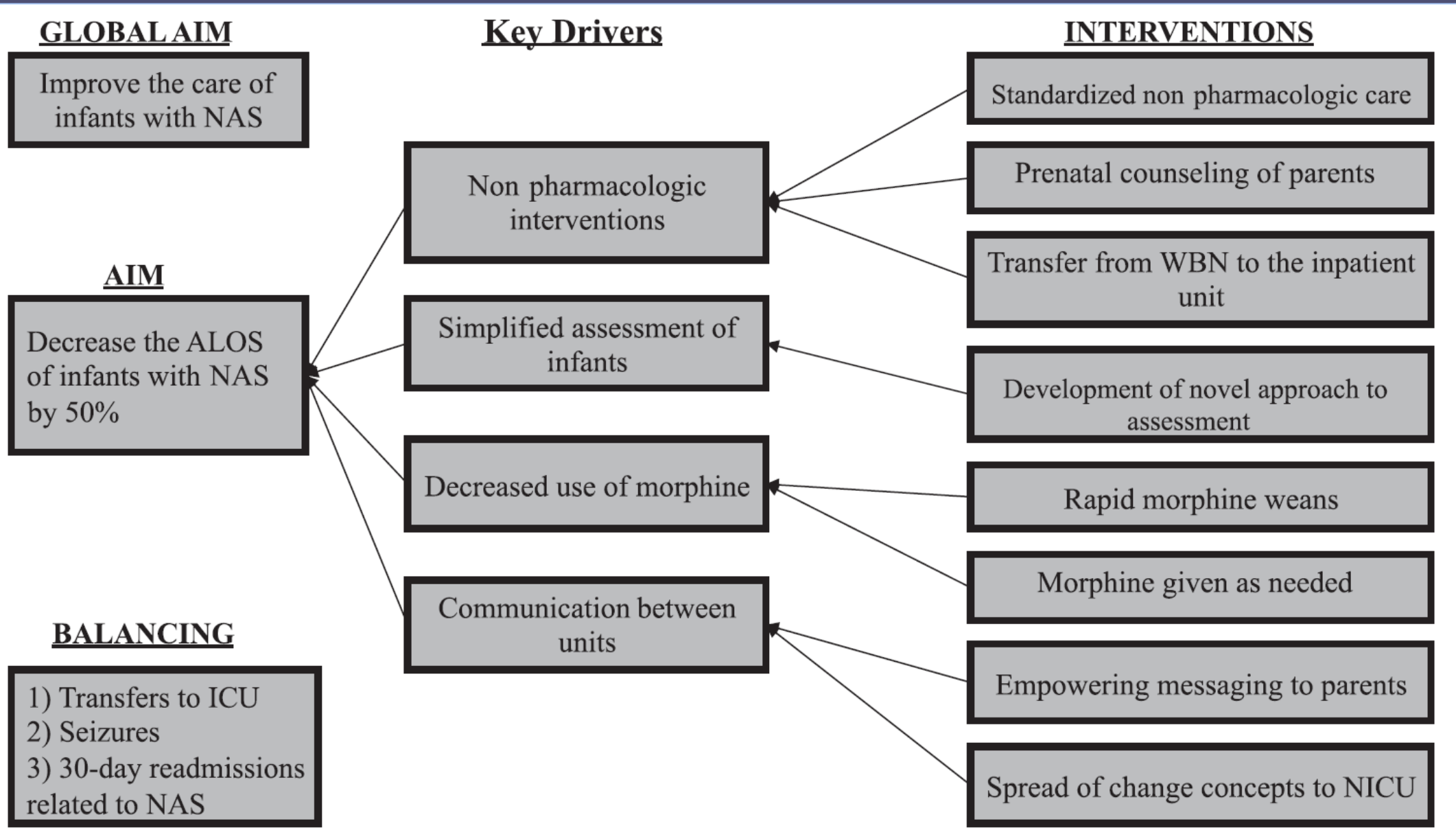
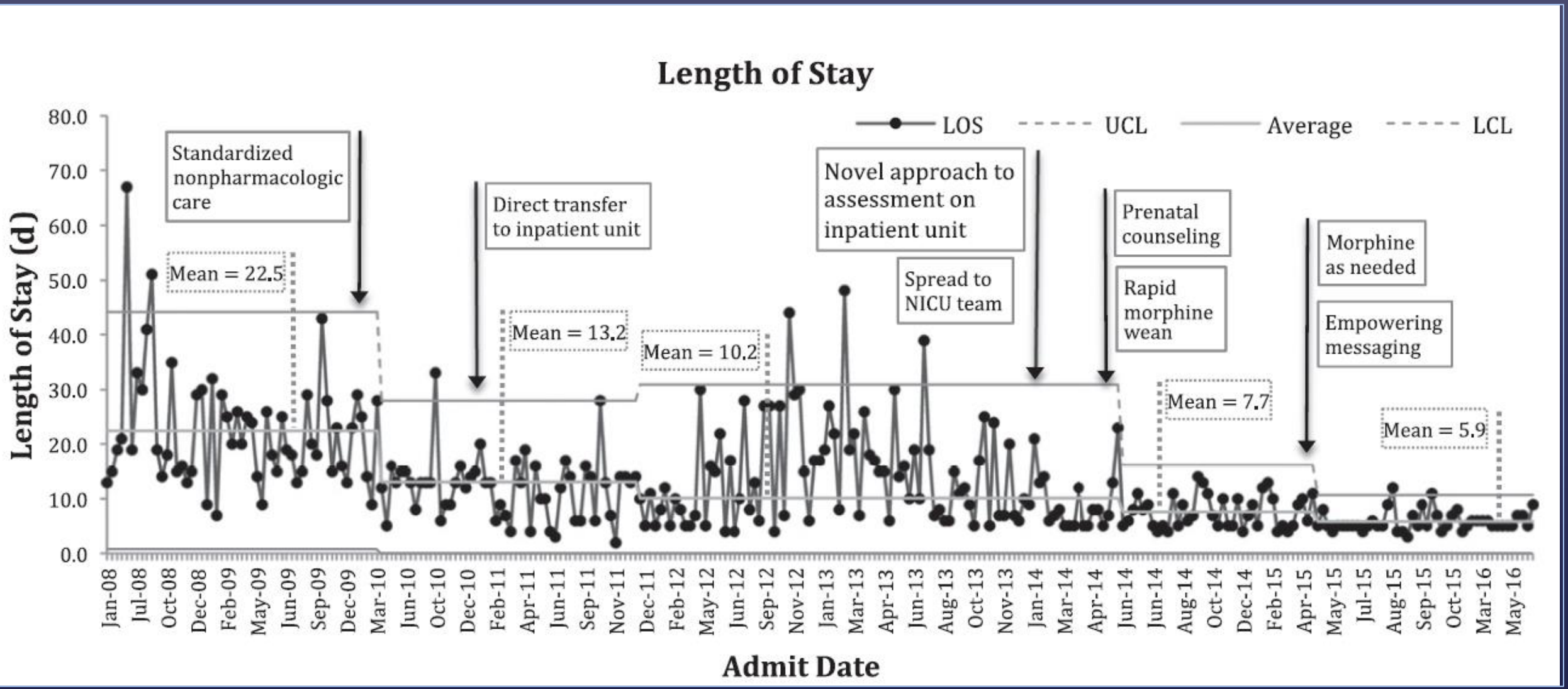


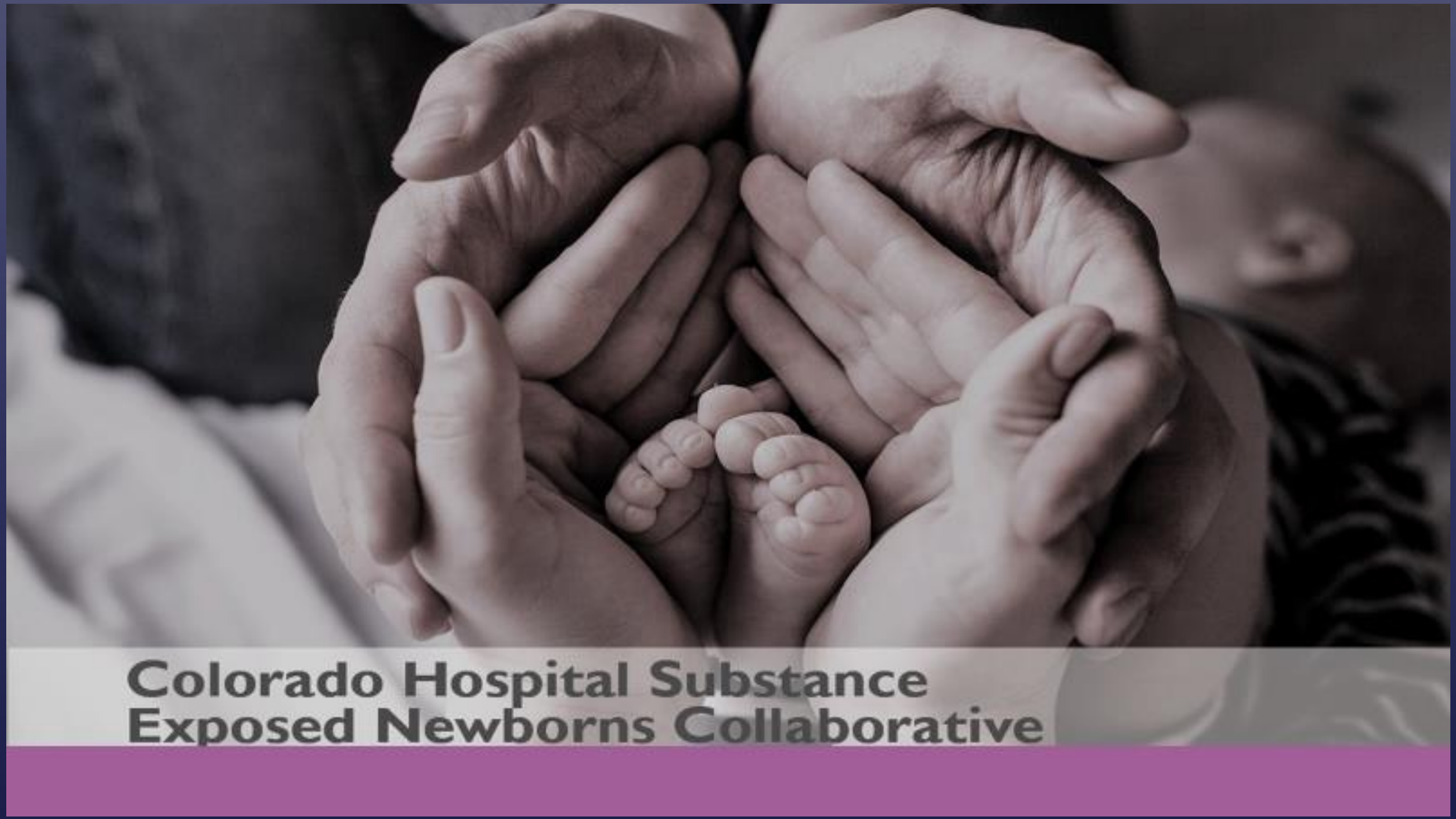
FIGURE 1

Key driver diagram for NAS quality improvement project.

Grossman et al. Pediatrics 2017

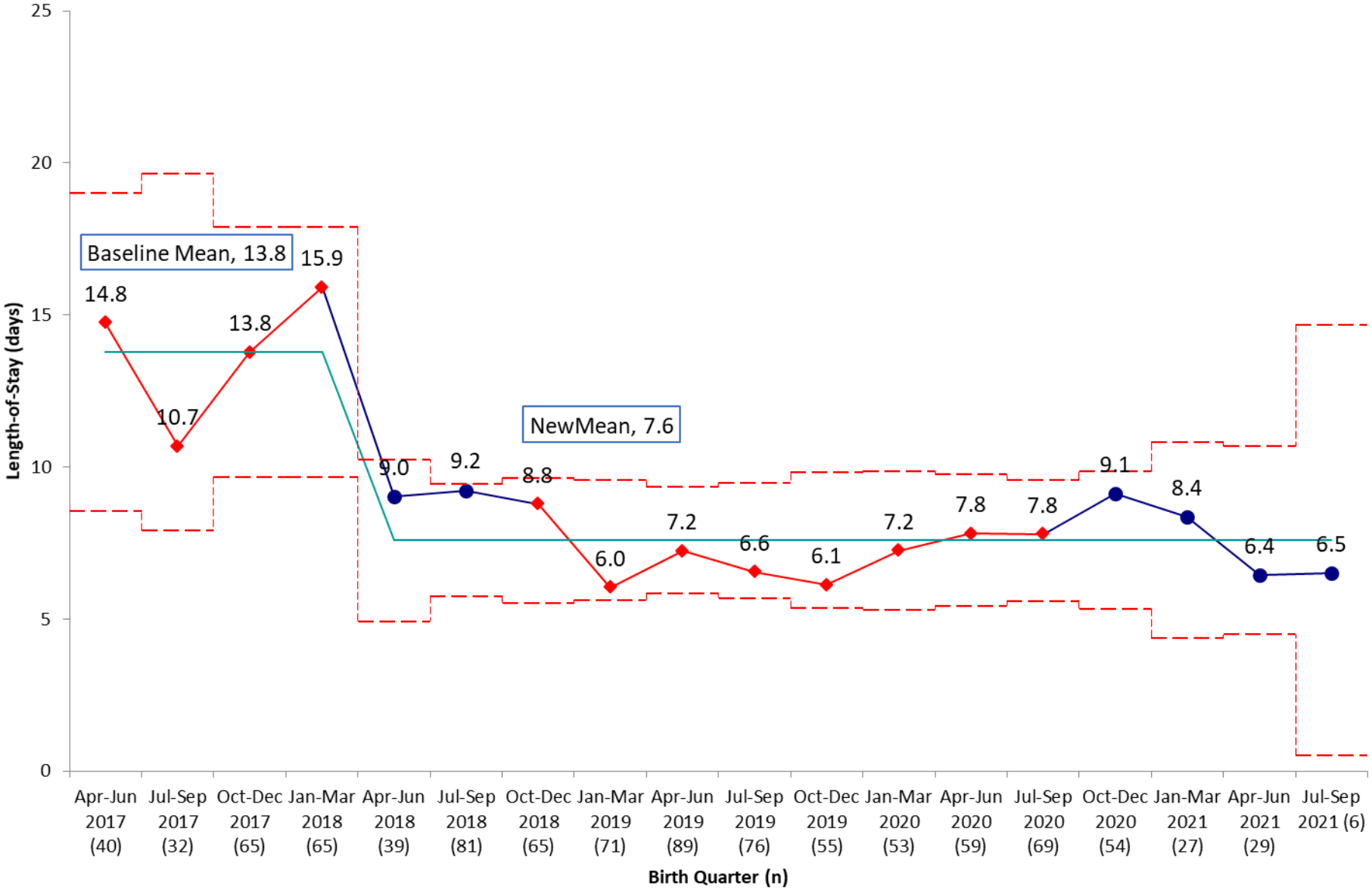


Grossman et al. Pediatrics 2017


Colorado Hospital Substance
Exposed Newborns Collaborative

CHoSEN QIC Cohort: Length-of-Stay of OEN, n= 975

(≥35 weeks gestational age, no dx affecting LOS)

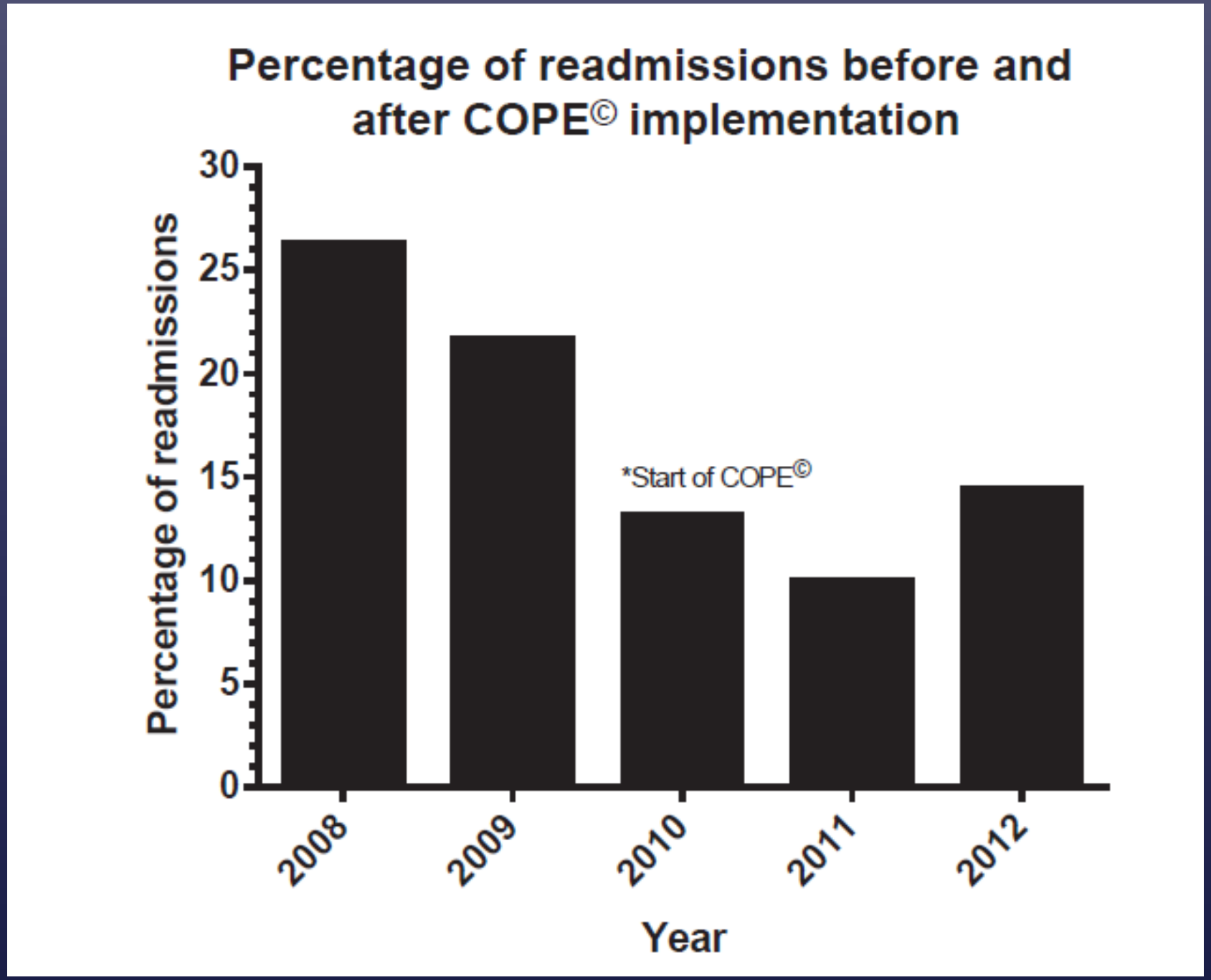


Empowerment programme for parents of extremely premature infants significantly reduced length of stay and readmission rates

J Gonya (Jenn.Gonya@nationwidechildrens.org), E Martin, R McClead, L Nelin, E Shepherd

Center for Perinatal Research, The Research Institute at Nationwide Children's Hospital, Columbus, OH, USA

- **Creating Opportunities for Parent Empowerment (COPE) Program**
- Small baby pod within a Level IV NICU
- 303 total infants: 135 PRE (2008-2009) vs 168 POST COPE (2010-2012)
- Intervention: Tool designed to help parents learn about the NICU environment, understand how their premature baby may look or act and identify ways that they can support their baby's development.
- Phase 1: 2–4 days after admission, Phase 2: 4–8 days after admission, Phase 3: 7-day period before discharge, and Phase 4: 1–2 weeks after discharge.



Gonya et al. Acta Paediatrica 2014

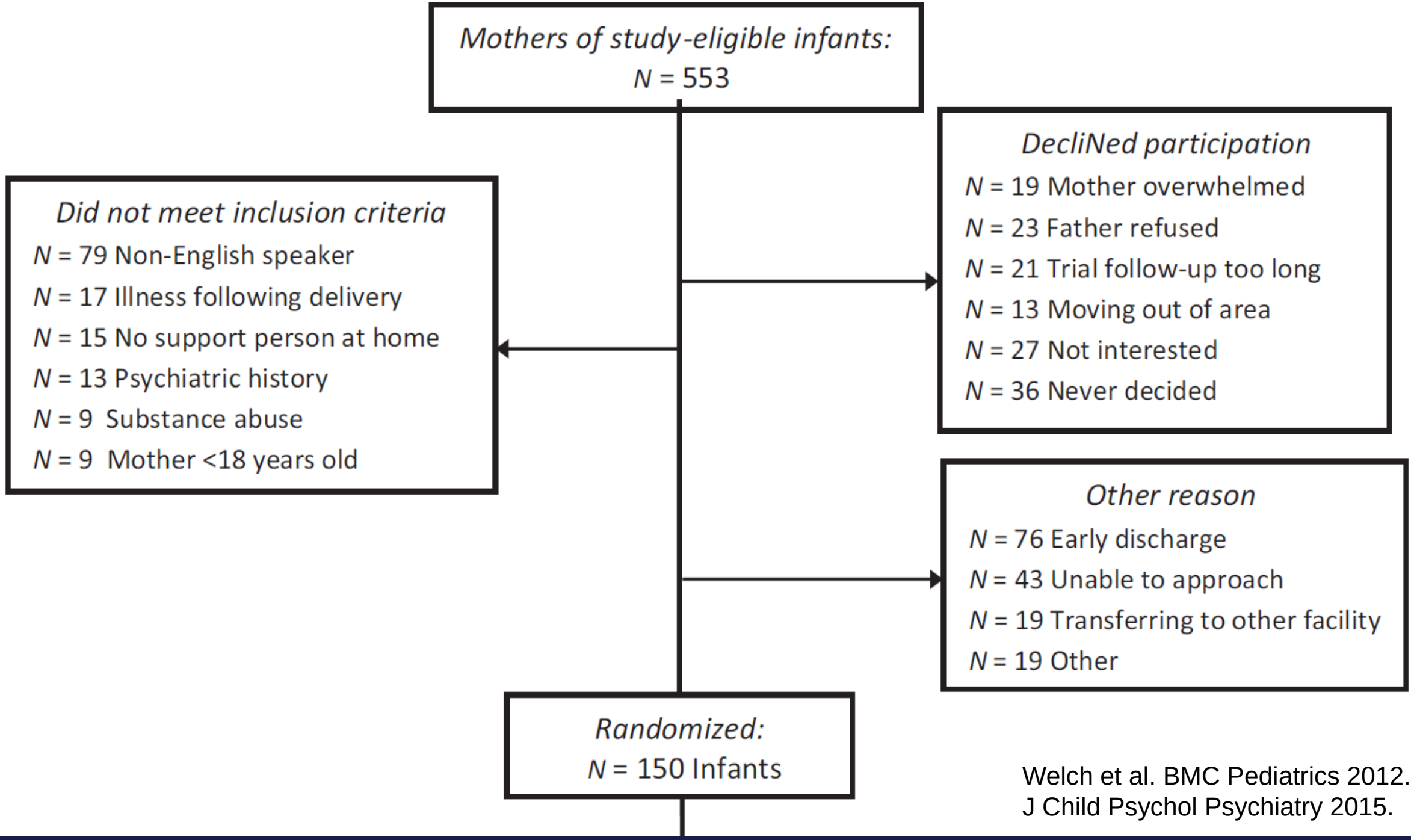
	No-COPE® (n = 135)	COPE® (n = 168)	p-value
Gestational age (weeks)	24.6 ± 1.0	24.7 ± 1.0	0.41
Birthweight (grams)	721 ± 161	731 ± 168	0.62
Admit day of life	15.9 ± 19.6	16.8 ± 16.3	0.72
Mortality (%)	21.8	16.8	0.20
Intermittent positive pressure ventilation (days)	47.3 ± 43.4	43.7 ± 33.9	0.54
Necrotising enterocolitis (%)	15.8	17.9	0.86
Sepsis (% of coagulase negative *Staphylococcus aureus* infection)	18.5	10.7	0.07
Fungal infection (%)	9.2	7.8	0.80
Intraventricular haemorrhage (%)	48.7	51.8	0.68
Medicaid insurance (%)	75	64	0.27
Length of stay (days)	139.6 ± 61.9	127.1 ± 55.8	*<0.05*
Rate of readmission (%)	23.9	13.2	*0.05*

Gonya et al. Acta Paediatrica 2014

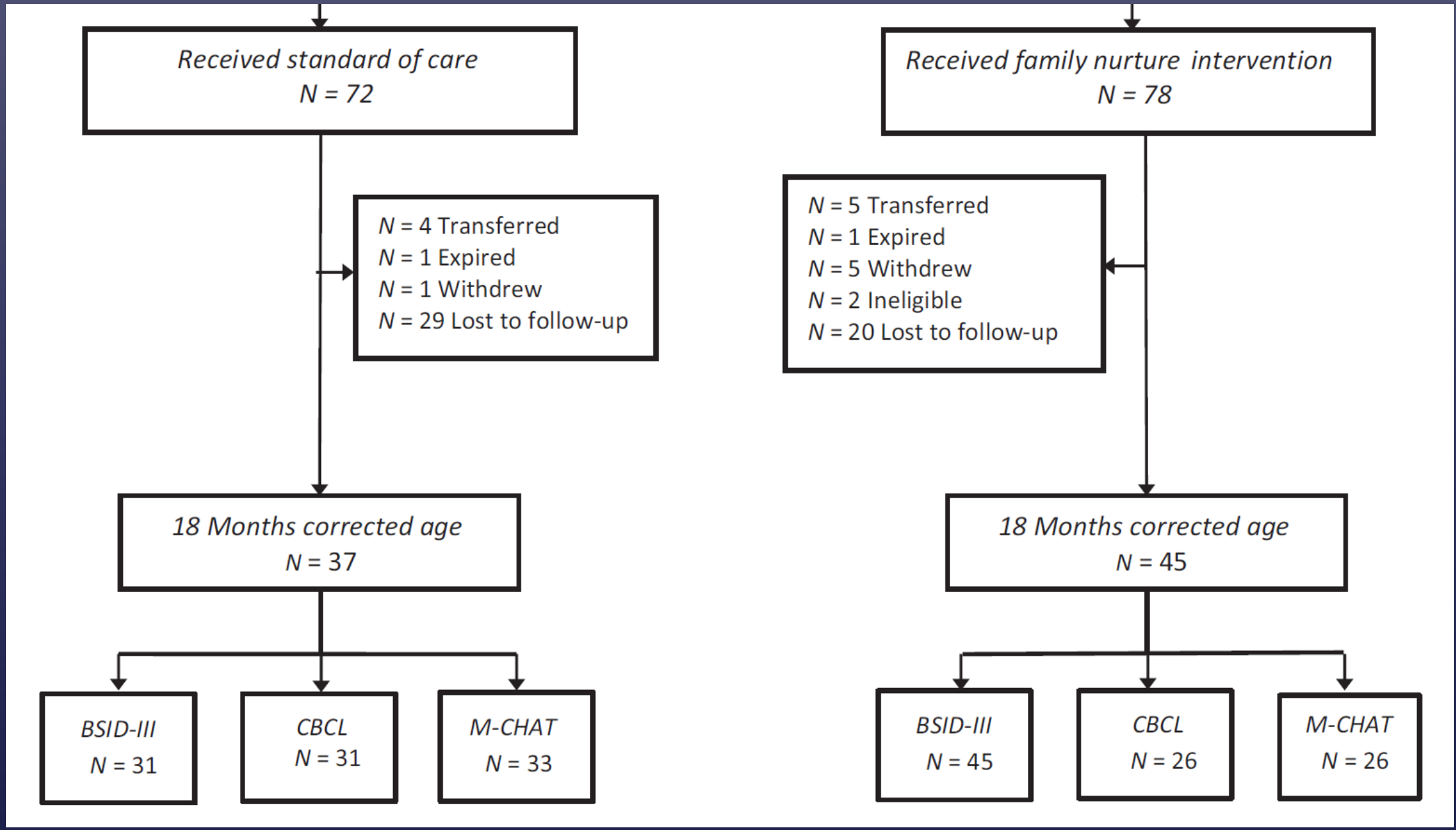
Family Nurture Intervention (FNI)

- Randomized clinical trial: Standard Care (SC) vs FNI
- 26-34 weeks gestational age; Morgan Stanley Children's Hospital in NYC
- Intervention – calming activities by mothers with facilitation by trained Nurture Specialists
  - In the isolette - calming interactions between mother and infant via odor exchange, firm sustained touch and vocal soothing, and eye contact
  - Outside the isolette - during holding and feeding via the Calming Cycle
  - Family sessions designed to engage help and support the mother.

Welch et al. BMC Pediatrics 2012.

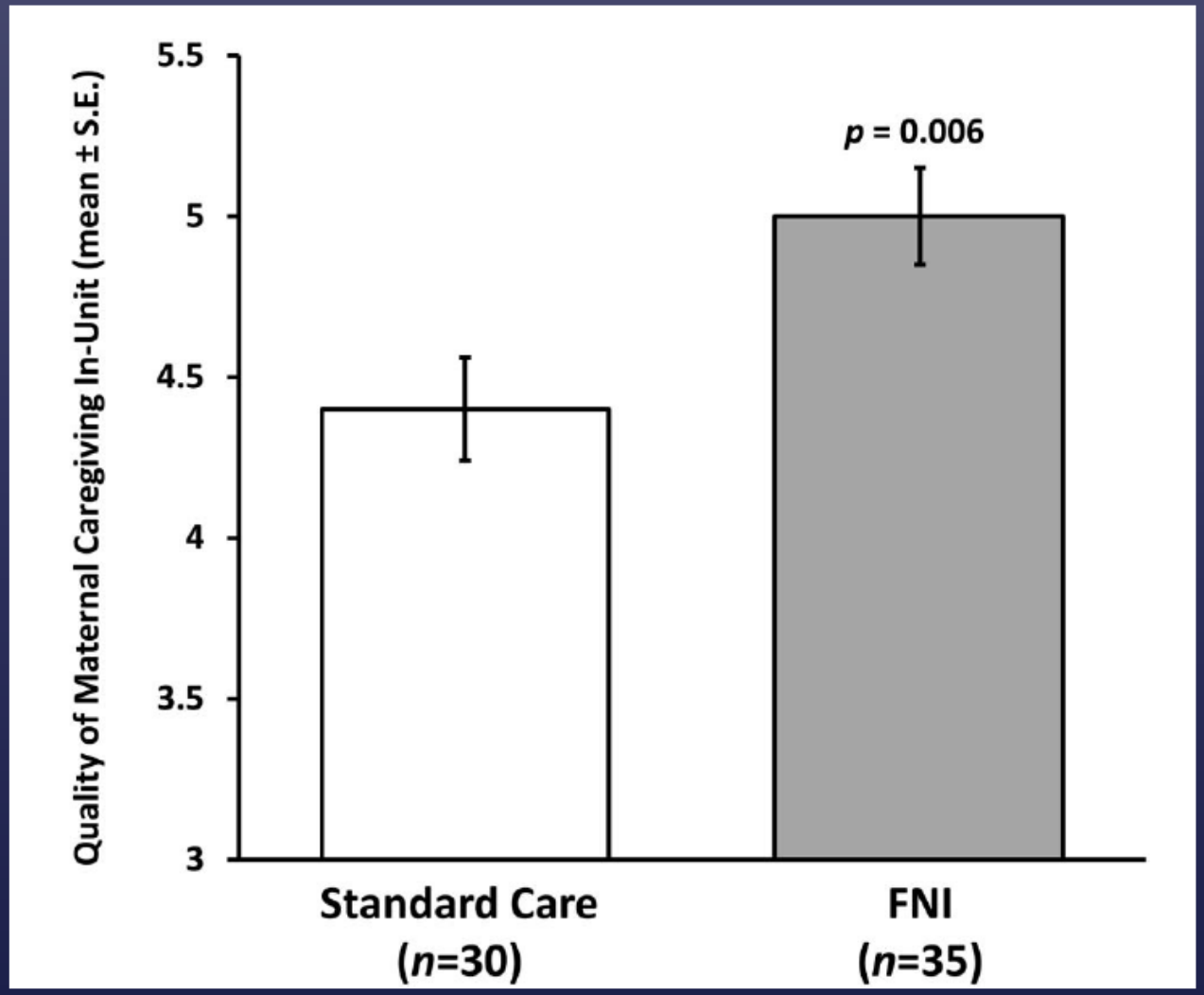


Welch et al. BMC Pediatrics 2012.
J Child Psychol Psychiatry 2015.

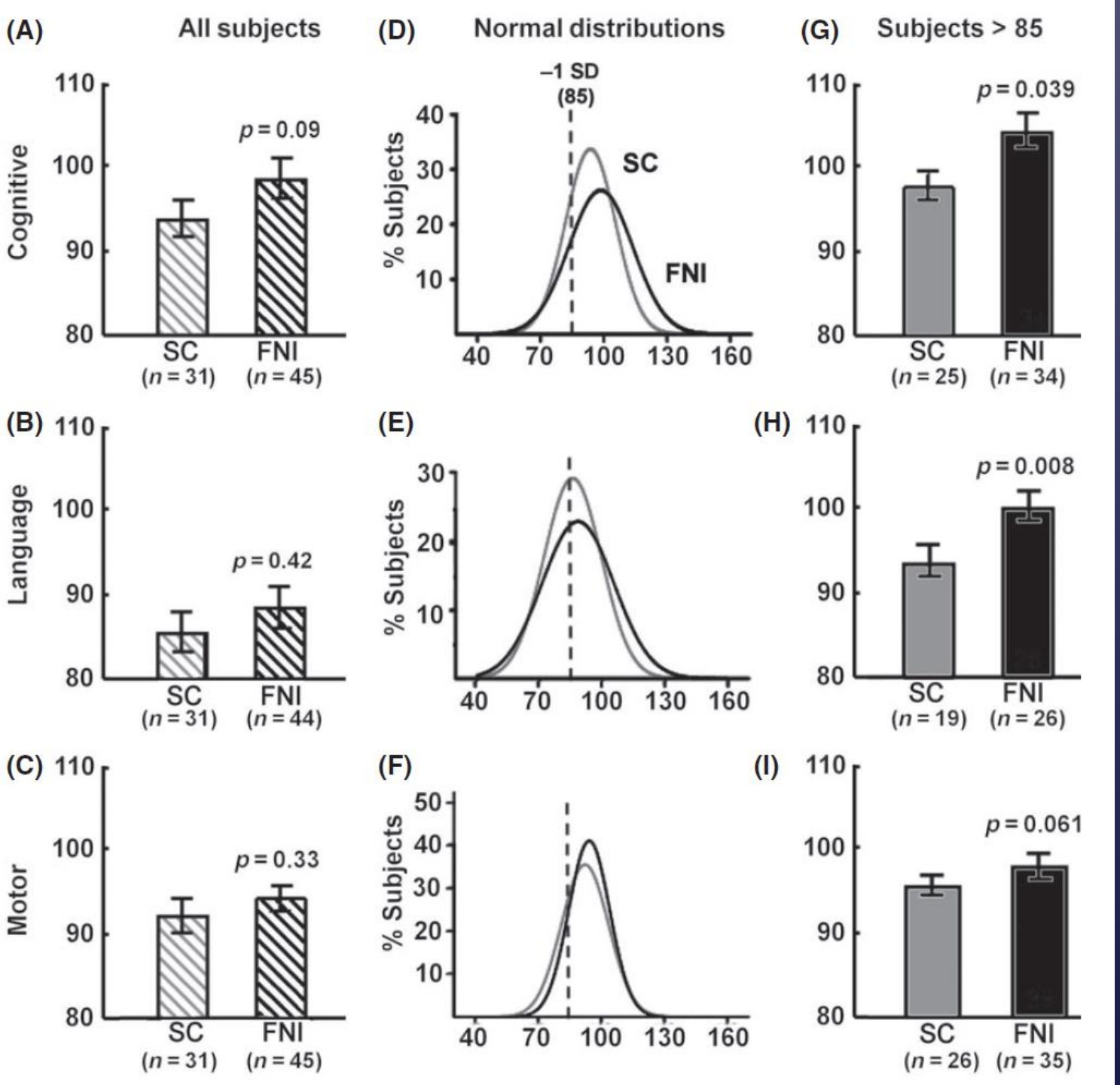


Welch et al. BMC Pediatrics 2012.
J Child Psychol Psychiatry 2015.

Results: Quality of Maternal Caregiving



Hane et al. J Dev Behav Pediatr 2015.



Developmental Outcomes: 18 mo corrected GA

Welch et al.
J Child Psychol Psychiatry 2015.

The Stockholm Neonatal Family Centered Care Study: Effects on Length of Stay and Infant Morbidity

WHAT'S KNOWN ON THIS SUBJECT: Although advances in technology and medical treatment have allowed more infants to survive, morbidity remains high. The NICU environment and early parent-infant interaction have been associated with infant health and length of hospital stay.

WHAT THIS STUDY ADDS: Data from this study indicate that parents staying in the NICU from admission to discharge may reduce the total length of stay for infants born prematurely. An individual-room NICU design could have a direct effect on infant stability and morbidity.

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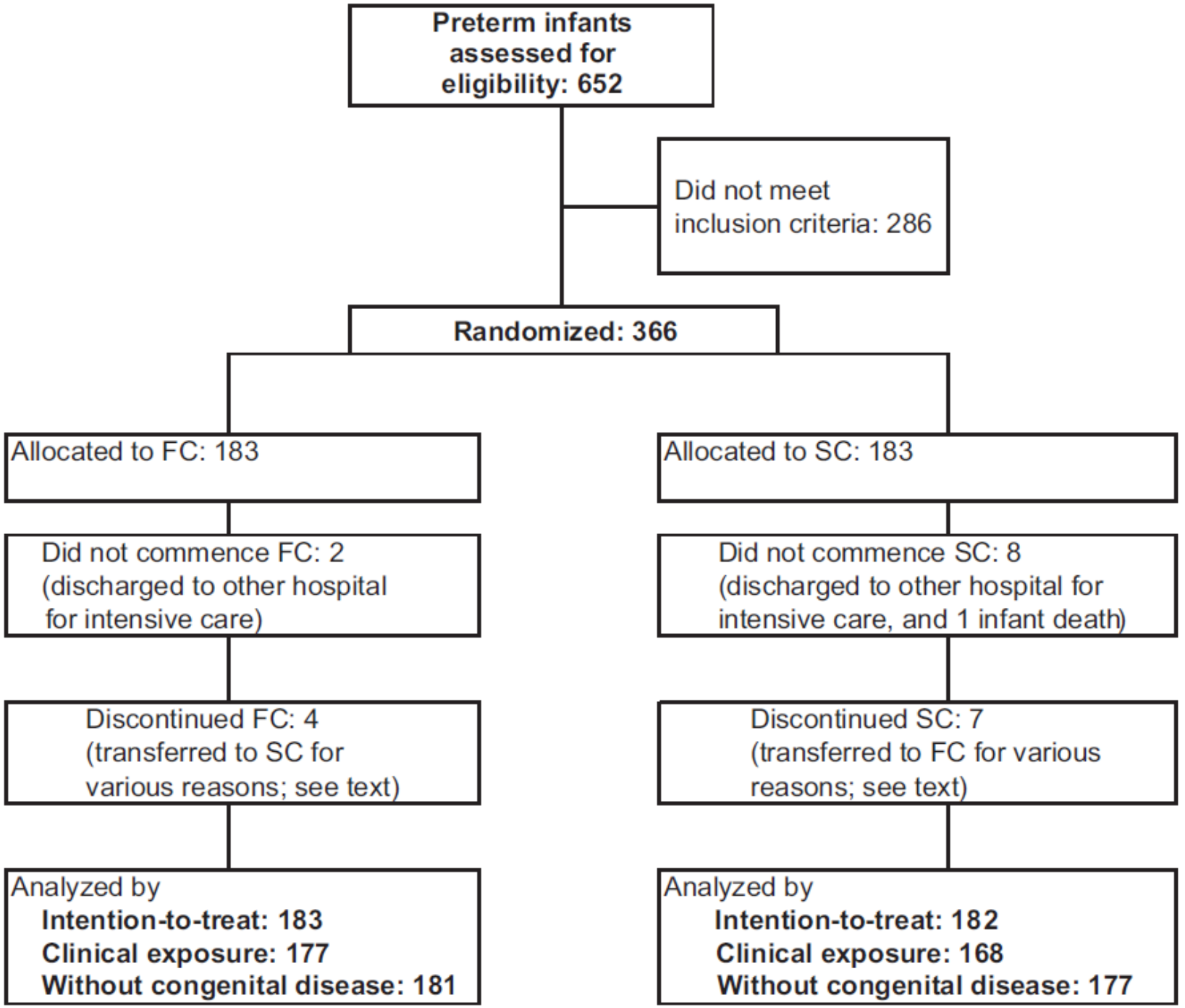
KEY WORDS
parental involvement, preterm, length of stay, morbidity, family centered care

- Randomized controlled trial in 2 Level II Units in Sweden
- Family care (FC) ward vs Standard Care (SC) Ward

Ortenstrand et al. Pediatrics 2010.



Ortenstrand et al. Pediatrics 2010.

Intervention

Family Care Ward	Standard Care Ward
Separate/private rooms	Multiple infants in a space/pod
Beds for both parents, private bathroom	Couple of rooms for parents to say a few days prior to discharge
At least 1 parent at bedside 24 hrs a day	During the daytime, parents advised to be with their infant as much as possible

Ortenstrand et al. Pediatrics 2010.

Results: Family Care vs Standard Care

Outcome	Difference	P-value
Length of stay		
All infants	5.3 days	0.25
< 30 weeks	10.1 days	0.02
30 – 34 weeks	4.4 days	0.16
35 – 36 weeks	1.4 days	0.39

Moderate to Severe BPD

Family Care: 1.6% vs Standard Care: 6.0%

Adjusted Odds Ratio 0.18 (0.04-0.8)

Ortenstrand et al. Pediatrics 2010.

Family-Integrated Care (FIC)

- Cluster randomized controlled trial
- 19 Canadian, 6 Australian, and 1 New Zealand tertiary-level NICU
- Inclusion criteria:
  - Born at ≤ 33 weeks
  - On low/no respiratory support
  - Primary caregiver commits to minimum of 6hrs per day with infant between 7am-8pm
- Primary outcome: Infant weight gain at 21 days after enrollment
- Secondary outcomes: breastfeeding, clinical outcomes, safety, parental stress, anxiety, and resource use.

O'Brien et al. BMC Pediatr 2015.

Family-Integrated Care (FIC)

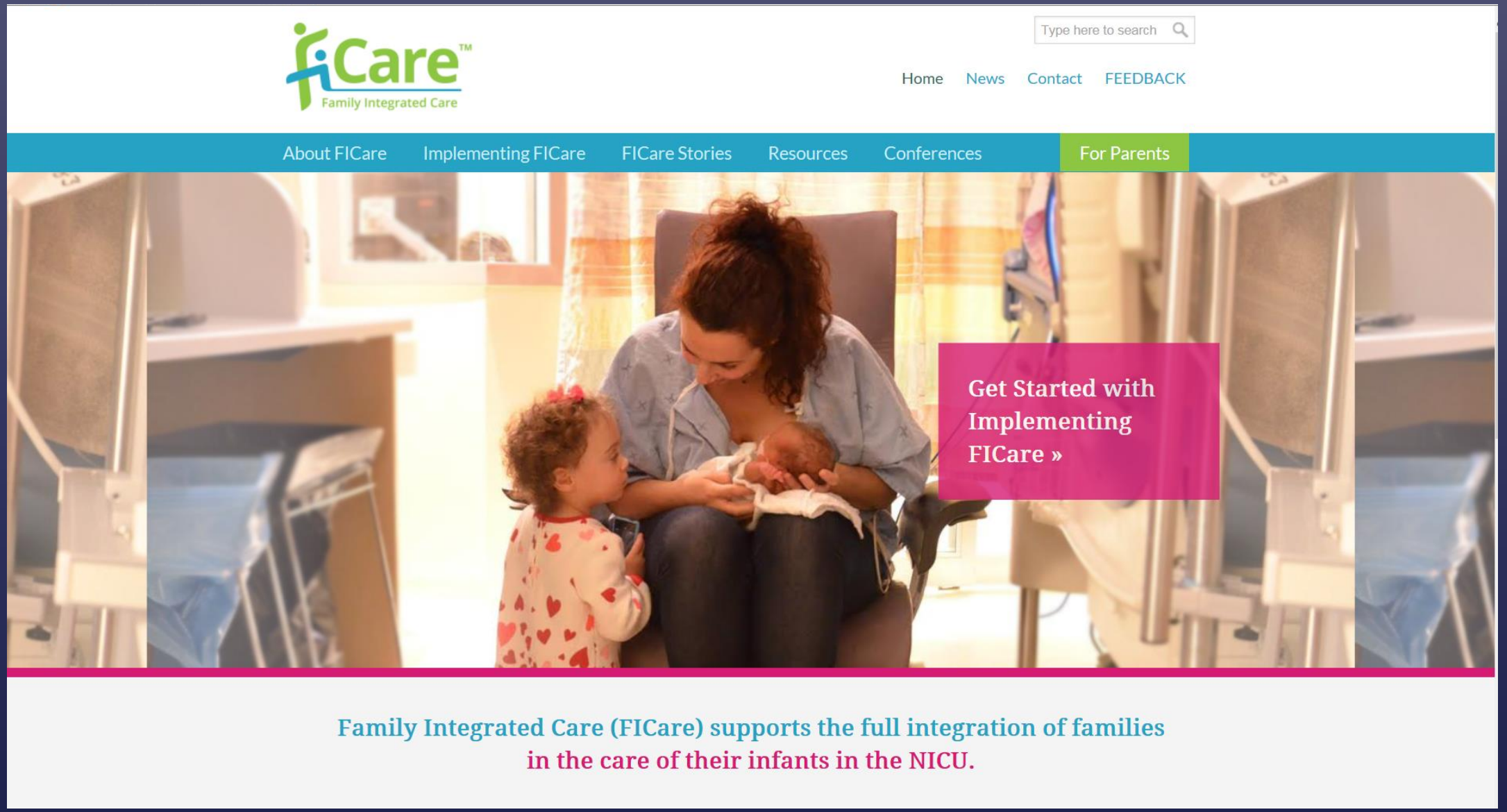
- Parents
  - Trained by FICare program coordinator to provide majority of infant's care – feeding, bathing, skin-to-skin
  - Attend daily medical rounds, basic charting, maintain a diary of their infants' medical status
  - Education program on medical care of preterm infants, preterm infant development, coping in the NICU, discharge preparation, optimizing interaction with their infants.
  - Psychosocial support through volunteer veteran parents, social workers, and mental health specialists
- NICU Providers
  - Attend a 2-day training program in Toronto
  - Each NICU team organized a 4 hour training workshop for their nurses

O'Brien et al. BMC Pediatr 2015.

Results

Outcomes	FICare 895 infants (14 sites)	Standard Care 891 infants (12 sites)	P-value
Weight gain at day 21 (mean change in Z-score)	1.58	1.45	<0.0001
Average daily weight gain (mean, grams)	26.7	24.8	<0.0001
Exclusive breastfeeding at discharge	70%	63%	0.016
Parental Stress Score	2.3	2.5	<0.00043
Parental Anxiety Score	70.8	74.2	<0.0045

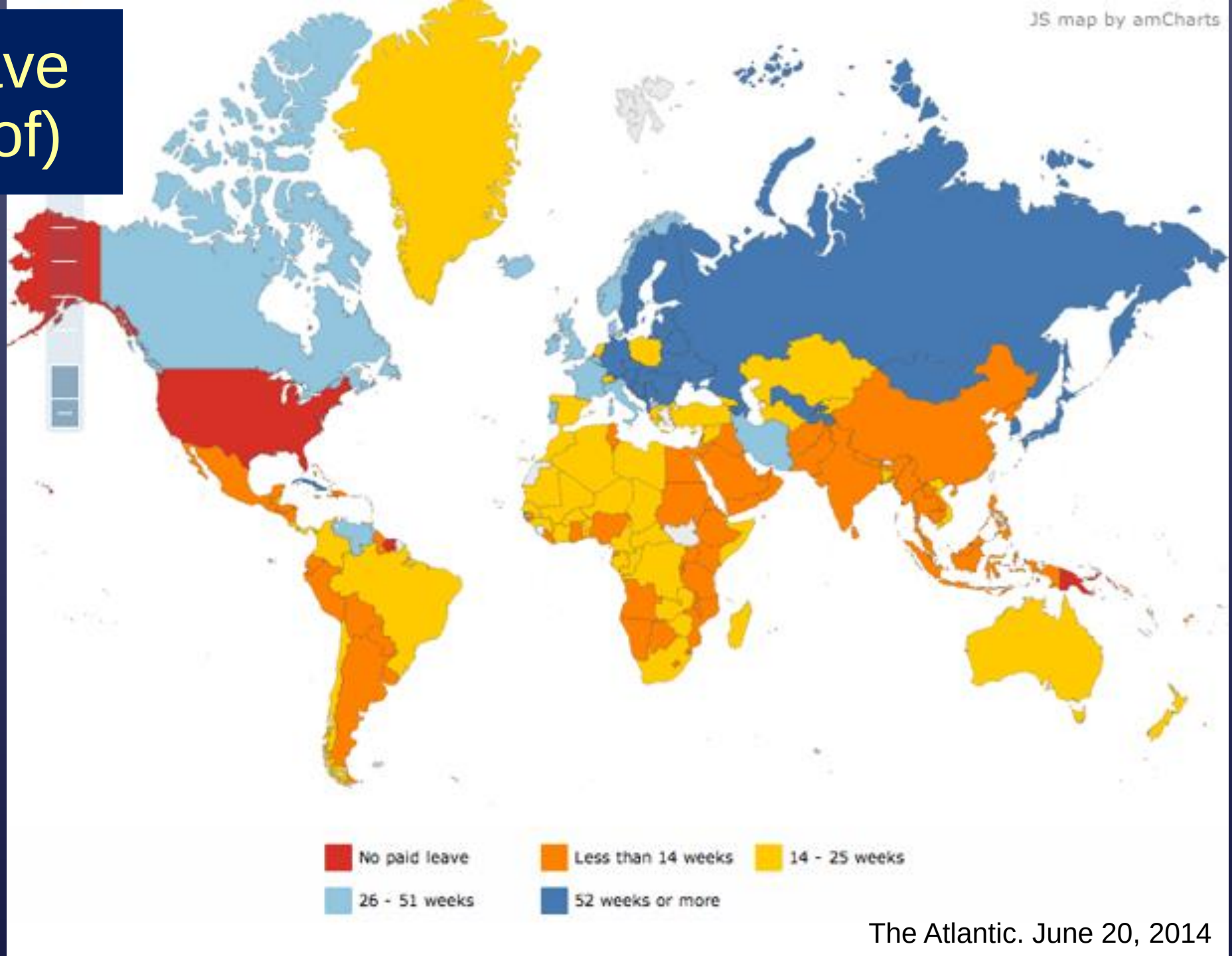
O'Brien et al. The Lancet Child & Adol Health. April 2018.



http://familyintegratedcare.com

Barriers to Parental Engagement

Maternity Leave (or lack thereof)

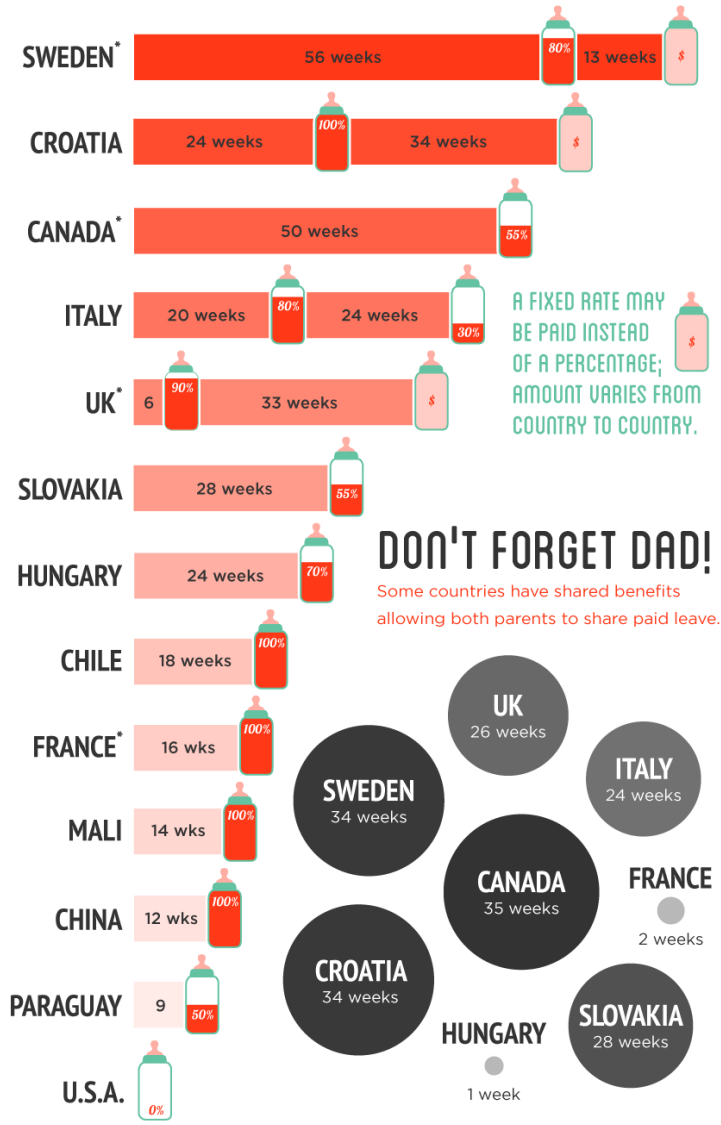


The Atlantic. June 20, 2014

PAID MATERNITY LEAVE

How do nations compare when it comes to government mandated paid leave?

LENGTH OF LEAVE && % OF WAGES PAID



A FIXED RATE MAY BE PAID INSTEAD OF A PERCENTAGE; AMOUNT VARIES FROM COUNTRY TO COUNTRY.

DON'T FORGET DAD!

Some countries have shared benefits allowing both parents to share paid leave.

* PERCENTAGE OF WAGES ARE PAID UP TO A CEILING

SAME-SEX AND ADOPTIVE PARENTS ARE ALSO ELIGIBLE FOR LEAVE BENEFITS IN CANADA, SWEDEN, FRANCE & THE UK.

3 YEARS

Central European countries have the **longest maternity leave** regulations. In some countries, the standard duration is 3 years.

YES, BOSS!

In many countries, paid leave **benefits are provided by employers**. In the U.S.A., women rely on employers to provide paid leave.

$0

Only **4 countries have no mandated paid leave**:
Liberia
Swaziland
Papua New Guinea
U.S.A.

WOMEN&&TECH

Created for Women && Tech • Designed by Ivonne Karamoy **@ivonnekn**

SOURCES: United Nations Statistics Division, June 2012, http://unstats.un.org/unsd/demographic/products/indwm/ • UK Government Benefits, November 2012, https://www.gov.uk/statutory-maternity-pay • The U.S. Social Security Administration, 2010 - 2012 data, http://www.ssa.gov/policy/docs/progdesc/index.html • International Network on Leave Policies & Research, April 2012, http://www.leavenetwork.org/

Women & Tech. http://womenandtech.com/infographic-paid-maternity-leave

ELSEVIER

Journal of Health Economics 19 (2000) 931–960

JOURNAL OF HEALTH ECONOMICS

www.elsevier.nl/locate/econbase

Parental leave and child health

Christopher J. Ruhm*

Department of Economics, Bryan School, University of North Carolina at Greensboro, P.O. Box 26165, Greensboro, NC, USA

National Bureau of Economic Research, USA

- Annual aggregate data for 16 European nations; 1969-1994
- 16 countries offered a minimum of 10 weeks of paid leave
- 6 nations offered more than 6 months of paid leave
- Full-pay weeks ranged from 9 weeks in Greece to 58 weeks in Sweden

Parental Leave and Child Health

- 10 week extension in leave predicted a decrease
  - Infant deaths: 1% - 2.9%
    - 2.5% decrease in infant mortality = decline in infant death rate from 13.2 to 12.9 per 1000 live births
  - Post-neonatal deaths: 3.7- 4.5%
  - Child fatalities: 3.3% - 3.5%
- 91 and 172 years of parental leave are required to save one life
- Cost per life saved is between $2.0 and $3.8 million
- Value of life typically in $3 to $7 million range

Ruhm. J Health Econ. 2000

Maternity Leave and Infant Outcomes

- Policy change in December 2000 from 25 to 50 weeks of paid leave in Canada lead to a 40% increase in exclusive breastfeeding for 6 months (Baker et al. 2008)

- Maternal employment in the first year of life associated with lower scores on Bracken School Readiness at 36 months (Brooks-Gunn et al; 2002)

Maternity Leave in the U.S.

- Family and Medical Leave Act of 1993
  - 12 weeks of UNPAID leave per year for mothers of newborns or newly adopted children
  - Restricted to:
    - Employees in a firm of 50 or more employees
    - Be employed with the same business for 12 months, accumulated at least 1250 works hours over the 12 months

- State-level variation in maternity leave policies
  - California, New Jersey, Rhode Island, and New York
  - Colorado: Family Medical Leave Insurance Program (FAMLI)
    - Social insurance program: 12 weeks of partially-paid leave to care for themselves or a loved one

Distance & NICU Visitation

- Decreased visiting frequency with increased distance from home to hospital
  - Effect evident with both mothers and fathers

Distance from home to hospital	Visiting Frequency Mother (d/week)		Visiting Frequency Father (d/week)	
<30km	6.5	p <0.001	5.3	p <0.001
≥30km	5.6		3.3	

c/o Stephanie Bourque

Latva, *et al*. *Acta Paediatr*. 2007.

Back-Transport After Acute Care in CHCO NICU

- To describe the referral patterns of premature infants from lower levels of care to CHCO NICU
- To identify predictors of back-transport
- For infants who were not back-transported, determine length of stay beyond clinical stability
  - Full NG feeds and low flow nasal cannula

Bourque et al. MCHJ 2018

Data Sources

- Children's Hospital Neonatal Database
  - Prospectively collected data form 29 participating Children's Hospitals with regional NICUs
  - Level IV Designation
  - >50% outborn infants, > 400 annual admissions, > 25 inpatient beds
  - CHCO Participation since 2010

- Independent data abstraction
  - Epic chart review for verification, specific variables

Bourque et al. MCHJ 2018

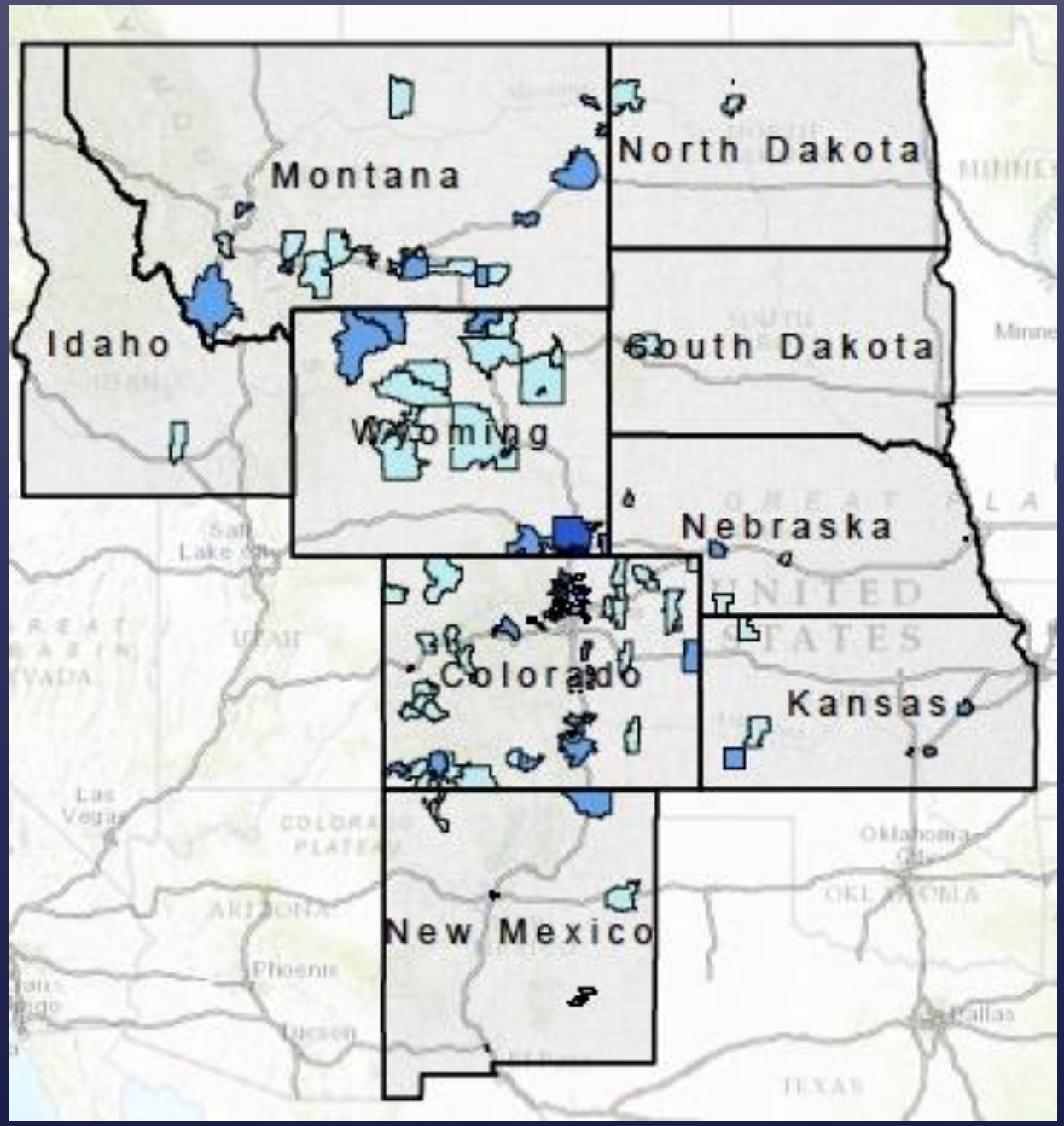
Inclusion & Exclusion Criteria

- Included
  - Infants ≤ 32 weeks GA admitted to CHCO NICU between 2010-2014
  - Maternal residence outside the Denver metro area
    - Defined by 6 immediately surrounding counties
  - Transported to CHCO NICU prior to discharge

- Excluded
  - Infants ≥33 weeks GA
  - Infants whose mothers live within the Denver metro area
  - Infants previously discharged home who were readmitted

Bourque et al. MCHJ 2018

NICU Admissions by Zip Code



c/o Stephanie Bourque

Adjusted Analysis: Predictors of Back-Transport

Variable	AOR	95% CI
Maternal Race		
White	REF	
Non-White	0.8	(0.2, 2.5)
Maternal Ethnicity		
Not Hispanic/Latino	REF	
Hispanic/Latino	0.9	(0.3, 3)
Maternal Age (per 1 year increase in age)	1	(0.9, 1.1)
Insurance Status		
Private	REF	
Public	**0.3**	(0.1, 0.9)
Referring Hospital Distance (per 100 miles)	**1.4**	(1.2, 1.7)
IVH Grade (per 1 grade increase in severity)	**1.4**	(1, 1.9)

Bourque et al. MCHJ 2018

LENGTH OF STAY BEYOND CLINICAL STABILITY

Median LOS in Level IV NICU for infants not back-transported was **28.5 days** beyond being on LFNC and full enteral feedings

Bourque et al. MCHJ 2018

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

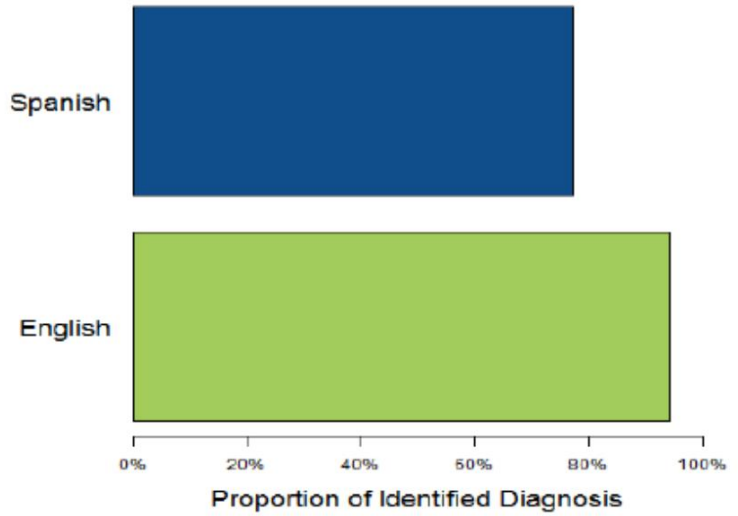


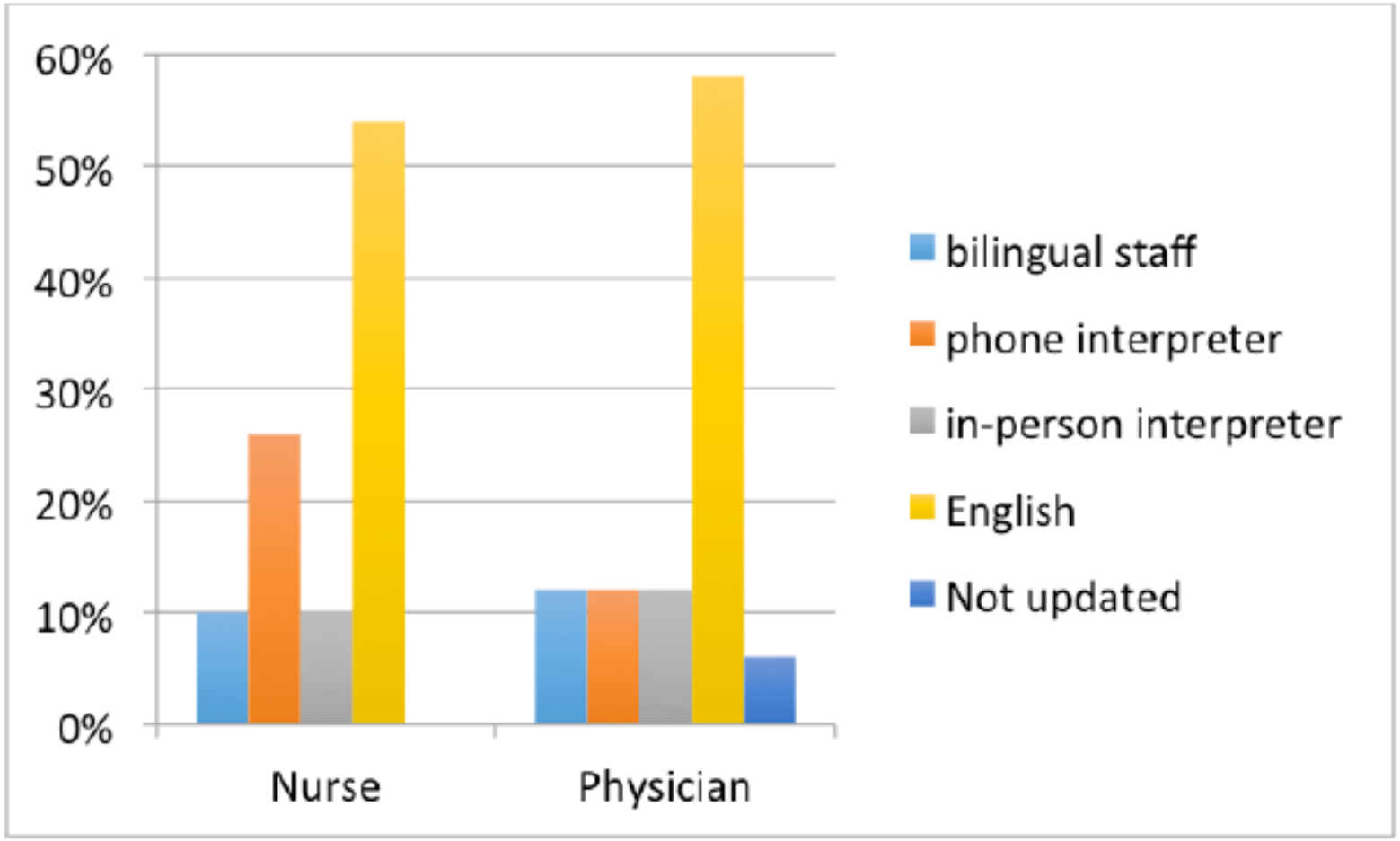
Table 2: Decrease in Odds of Understanding Based on Language Spoken

	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.

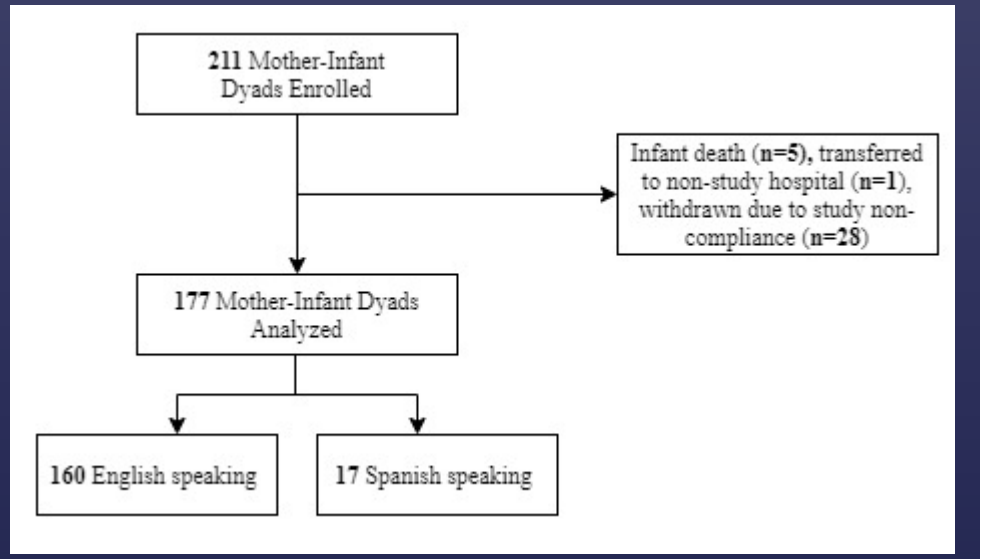
Palau MA, Meier MR, Brinton JT, Hwang SS, Roosevelt GE, Parker TP. J Perinatol 2018.

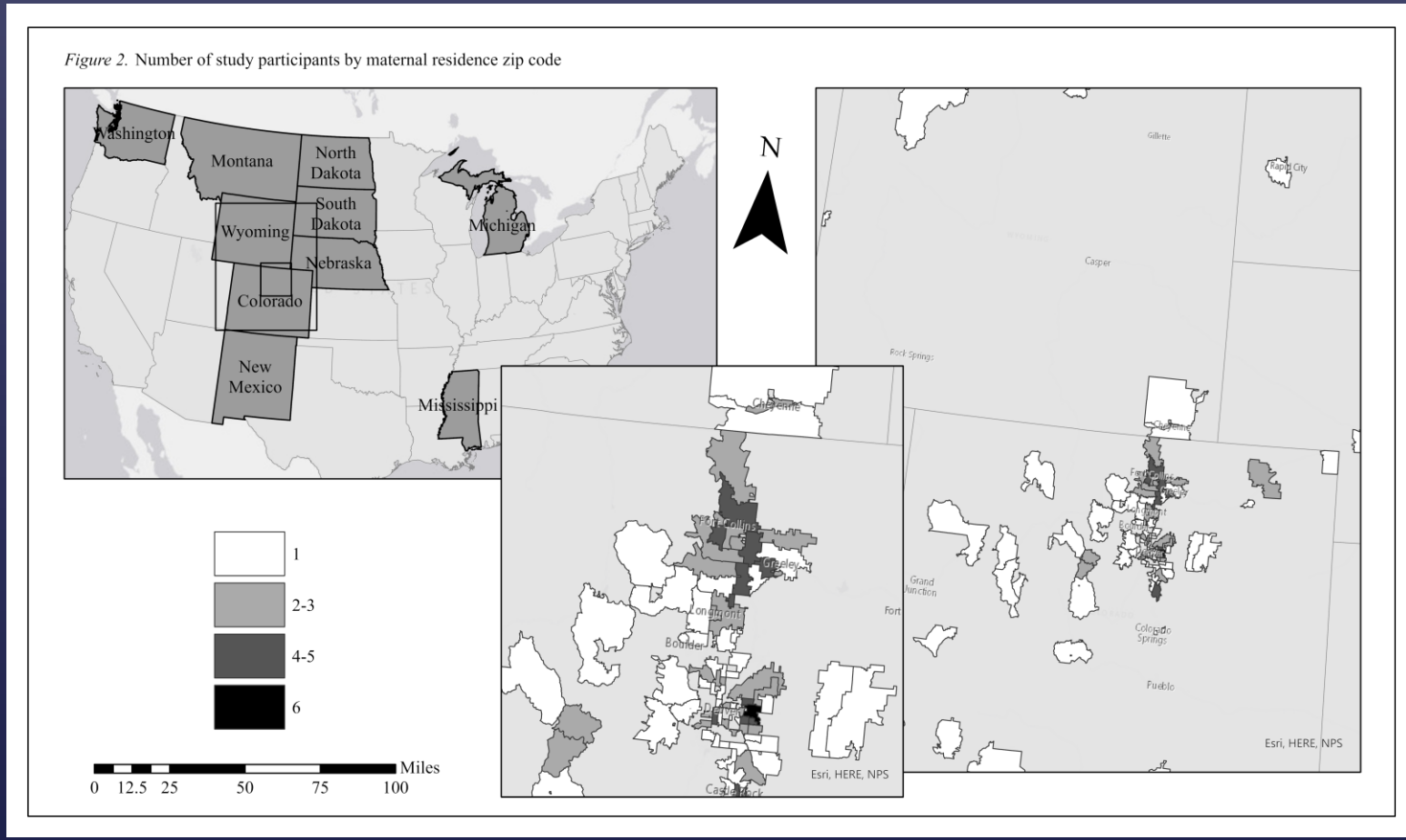
Figure 3. Proportion and Method of Updates to Spanish-speakers by Care Provider



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

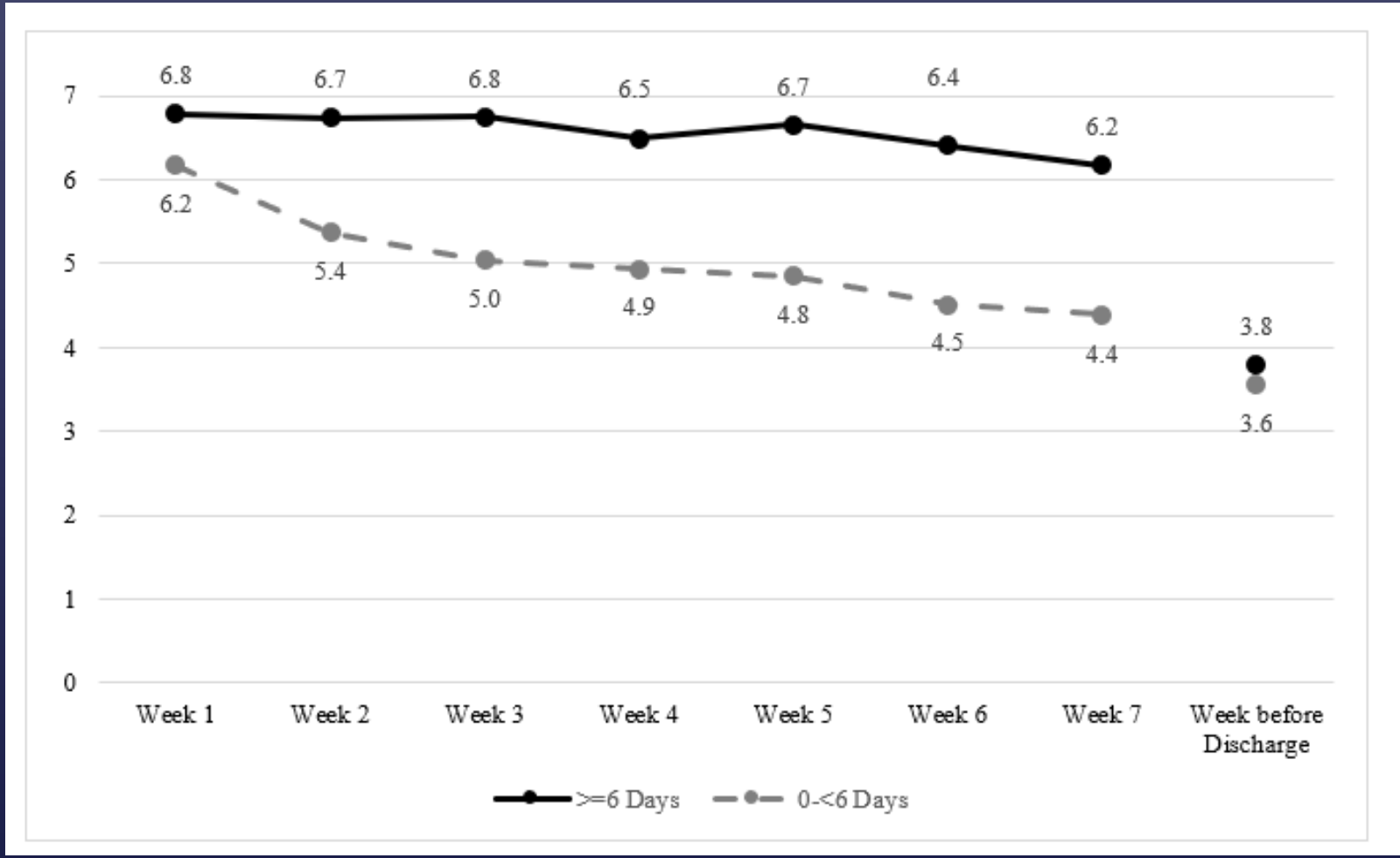
Maternal Engagement in the NICU





Bourque, et al. Hosp Peds, 2021

Average Maternal Time in the NICU during Birth Hospitalization – Overall Cohort



Bourque, et al. Hosp Peds, 2021

Social Factors Associated with Maternal Time in the NICU

Maternal Factors	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

Diversity (or lack thereof)

- Disparities in satisfaction, engagement, outcomes by
  - Race
  - Education
  - Income
  - Gender
  - Disability

Race/Ethnicity

- Parents of Children with Special Health Care Needs
- 38886 CSHCN <18 years of age in the National Survey of CSHCN, conducted from 2000 to 2002

Race/Ethnicity	Dissatisfied with care
Black	13%
Hispanic	16%
White	7%

Ngui et al. Pediatrics 2006

Race/Ethnicity

Parents of Children with Special Health Care Needs

- The Hispanic/white dissatisfaction disparity disappeared after adjustment for interview language.

- Black/white disparities in dissatisfaction with care disappeared only after adjustment for family-centered care factors.
  - Inadequate time spent with the provider
  - Amount of information given by providers to families,
  - Provider listening skills, and partnership with families.

Ngui et al. Pediatrics 2006

ORIGINAL ARTICLE

Racial differences in parental satisfaction with neonatal intensive care unit nursing care

AE Martin[1,2], JA D'Agostino[1,2,3], M Passarella[1,2] and SA Lorch[1,2,3,4,5]

Black parents were dissatisfied with:
(1) Inattentive nurses who communicated poorly and dismissed their concerns and requests (50%)
(2) nurses who were disrespectful and impersonal (35%)
(3) inconsistent care given by multiple caregivers in an understaffed NICU (15%)

White parents were dissatisfied with:
(1) Inconsistent care given by multiple caregivers in an understaffed NICU (56%)
(2) inattentive nurses who communicated poorly and did not inform and involve parents in the care process (24%)
(3) disrespectful and impersonal nurses (20%)

Martin et al. J Perinatol 2016.

Patient Race/Ethnicity and Quality of Patient–Physician Communication During Medical Visits

Rachel L. Johnson, MD, PhD, Debra Roter, DrPH, Neil R. Powe, MD, MBA, and Lisa A. Cooper, MD, MPH

- Audiotape and questionnaire data collected in 1998 and 2002
- Quality of medical-visit communication among African American versus White patients
- 458 African-American and White patients who visited 61 physicians in the Baltimore,Md–Washington, DC–Northern Virginia metropolitan area.
- Outcome measures assessed the communication process, patient-centeredness, and emotional tone of the medical visit were derived from audiotapes coded by independent raters.

Johnson et al. AJPH 2004.

	White Patients (n = 202)[a] Mean (95% CI)	African American Patients (n = 256)[a] Mean (95% CI)	P[b]
Medical-visit communication process measures			
Duration of visit, minutes			
Univariate model	15.91 (14.36, 17.47)	15.27 (13.84, 16.71)	.46
Multivariate model[c]	9.64 (2.01, 17.28)	9.01 (1.97, 16.05)	.59
Speech speed[d]			
Univariate model	23.22 (22.17, 24.28)	22.81 (12.71, 23.90)	.38
Multivariate model[c]	19.91 (14.96, 24.86)	19.90 (15.08, 24.72)	.98
Measures of patient-centered communication			
Physician verbal dominance[e]			
Univariate model	1.24 (1.16, 1.32)	1.43 (1.34, 1.53)	<.001
Multivariate model[c]	1.50 (0.98, 2.01)	1.73 (1.20, 2.26)	<.001
Physician patient-centeredness[f]			
Univariate model	1.31 (1.02, 1.60)	1.02 (0.89, 1.14)	<.05
Multivariate model[c]	1.91 (0.76, 3.07)	1.58 (0.68, 2.48)	.08
Measures of medical-visit affective tone			
Patient positive-affect score			
Univariate model	17.59 (17.23, 17.96)	16.50 (16.09, 16.92)	<.001
Multivariate model[c]	16.65 (14.31, 18.99)	15.77 (13.47, 18.06)	<.001
Physician positive-affect score			
Univariate model	12.68 (11.91, 13.45)	11.90 (11.26, 12.55)	.02
Multivariate model[c]	14.12 (11.48, 16.75)	13.19 (10.56, 15.82)	.02

Johnson et al. AJPH 2004.

Gender Differences: Evidence from Pediatric Visits

- Prospective study of videotaped communication between 212 children, parents, and physicians during office visits
- Compared to male physicians,
  - Female physician visits were 29% longer ($p < .001$)
  - Female physicians engaged in more social exchange ($p < .01$), more encouragement and reassurance ($p < .01$), more communication during physical exam ($p < .05$), more information gathering ($p< .01$)
  - Children were most satisfied with physicians of the same gender ($p< .05$)
  - Parents were more satisfied with female physicians ($p < .05$)

Bernzweig et al. Arch Pediatr Adolesc Med. 1997

Disability

AMA Journal of Ethics®
October 2016, Volume 18, Number 10: 1041-1049

MEDICINE AND SOCIETY

Why Increasing Numbers of Physicians with Disability Could Improve Care for Patients with Disability

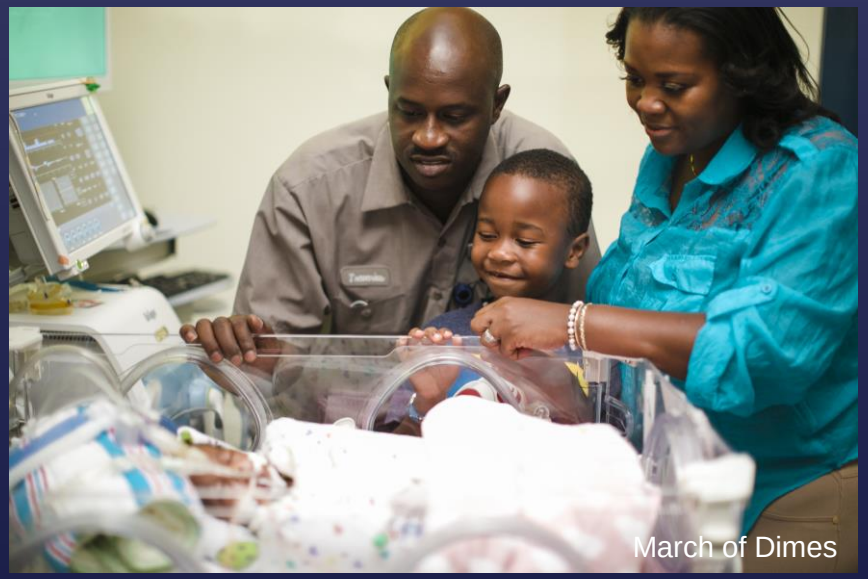
Lisa I. Iezzoni, MD, MSc

"Research suggests that racial and ethnic concordance between patients and physicians can significantly enhance cross-cultural communication and patients' health care experiences, participation in clinical decision making, intentions to adhere to clinicians' recommendations, and satisfaction with care. Perhaps concordance improves these outcomes because many minority patients distrust clinicians from racial or ethnic backgrounds who do not share their daily experiences—that is, who have not "walked in their shoes". Could concordance in disability status between physicians and patients eliminate disparities in health status, access to health care, and quality of health care, and generate better health outcomes?"

However, "increasing the number of physicians with disability requires recognizing the absolute primacy of patient safety".

Data-driven Engagement of Families to Improve the NICU Experience in Colorado

(DEFINE Colorado)



School of Medicine
UNIVERSITY OF COLORADO

cpcqc

DEFINE Colorado QIC Key Driver Diagram

Aim Statement	Primary Drivers	Secondary Drivers	Potential Change Concepts
By December 2022, hospitals will improve family engagement in NICUs by: *1. Improving parental report of engagement in infant health and development during NICU hospitalization by 20%* *2. 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

By December 2022, hospitals will improve family engagement in NICUs by:

1. *Improving parental report of engagement in infant health and development during NICU hospitalization by 20%*

2. *Reduce disparities in parental report of engagement by race/ethnicity, primary language, and distance from hospital by 20%*

Database Inclusion Criteria

- Admitted to level 2, 3, or 4 NICUs
- Admitted at least 14 days
- No restrictions on parents/caregiver presence during the hospital stay due to significant social issues
- For large volume centers, first 15 admissions who meet above criteria

Database

- Centralized REDCap data system
- Business associate agreement for non-CHCO and non-UCH sites
- Patient level EMR data + parental surveys
- Quarterly reports for each site and entire collaborative

Parental Survey Protocol

NICU ADMISSION

- Within first week of infant admission, hospital team member informs parents about DEFINE and asks permission to send a survey by email or text after two weeks of admission.
- Once parental permission is obtained, hospital team member will create a REDCap record and generate a parent ID.

2-4 WEEKS POST-ADMISSION

- Once infant has been hospitalized for at least two weeks, team member will enter clinical and demographic data into REDCap
  - Parent email address and phone number is entered and survey is automatically sent out based upon dates we select.
- Parent survey #1

Parental Survey Protocol

NEAR DISCHARGE

- Hospital team member will send parent survey #2 within 48 hours of discharge.

1 MONTH POST DISCHARGE SURVEY

- Parent survey #3 will be sent by DEFINE.

Business Agreements/DUA/IRB

- UCH-affiliated
- CHCO-affiliated
- Others

Discontinuation of Pulse Oximetry Checks (DPOC)

Improving Parental Confidence for Infants Nearing Discharge: Key Driver Diagram

Primary Drivers | **Secondary Drivers** | **Change Concepts**

Global Aim: Increase parental confidence and ability to monitor infant-based feeding signals (and decrease alarm fatigue among staff) by transitioning appropriate patients approaching discharge to intermittent pulse oximetry monitoring checks (IPOC).

SMART Aim: By May 2019, DHMC NICU will increase the percentage of eligible infants who are receiving IPOC in the 48 hours prior to discharge from 0% to 50%

Outcome measure:
 # patients on IPOC / all eligible discharges

Stakeholders:
NICU MD Team
NICU ACP Team
NICU Nursing Team (CE, EP)
NICU RT Team (CS)
NICU Parents and Caregivers

Unit Practice of Continuous Pulse Oximetry (CPO) until physical discharge

- Lack of nursing guidelines for IPOC initiation
  - **Develop and implement nursing guidelines for IPOC initiation**
  - *Process Measure: # IPOC Nursing Forms Completed*
  - *Balancing measure: # of patients who meet criteria for IPOC but "fail" and go back to CPO*
- Lack of structured caregiver education regarding feeding signals and cardiorespiratory warning signs
  - **Implement caregiver education module in English and Spanish; (individual and in discharge class); add to Discharge Readiness Tool**
  - *Process Measure: # of caregivers who complete module (as verified by QR code)*
- Failure to consistently identify patients who do not require continuous pulse oximetry
  - **Charge RN audit process to identify infants who may be eligible for IPOC based on LFNC/RA status and lack of ABD events.**
  - *Process measures: # of audits completed, # of infants identified*
  - *Balancing measure: Charge RN time burden*

Global Aim Assessment:
- Post-intervention Caregiver Survey(s) of education module and self-reported feeding signal awareness
- Pre- and Post- Intervention Nursing Survey of Alarm Fatigue and perceived caregiver feeding signal awareness

9/10/2020

c/o Meg Kirkley MD MPH

Family Partnership Quality Improvement Collaborative

Discharge Readiness at Children's Hospital Colorado

Children's Hospital Colorado

Objective: To improve family participation and engagement in discharge planning with the goal of standardizing the approach to introducing discharge planning, earlier introduction of key items needed prior to hospital discharge, ensuring adequate teaching and identifying potential barriers to discharge.

Approach:

1) Introduction of Patient and Family Education Checklist to parents/caregivers at 32 weeks corrected gestational age or when infant is off positive pressure ventilation (≤2 LPM HFNC) and on full volume enteral feedings
2) Tracking completion of educational video modules during hospitalization

c/o Stephanie Bourque and Elizabeth Schierholz

St Joe's NICU Aim for Family Integrated Care

"To work in partnership with parents to create a consistent and nurturing environment where parents feel engaged, enabled, educated, and empowered as the primary caregivers for their baby. We believe parents are experts in their baby's care. The overall goal of family integrated care is to support parents in becoming equal members of the neonatal team and participate in providing active care for their infant with the help of a competency-based training"

What is Family Integrated Care

- A model of care in the NICU where parents are the primary caregivers for their infants
  - Feedings (breast, bottle, and tube feeds)
  - Diaper changes
  - Obtaining Vital signs
  - Bathing
  - Giving oral medications
  - Tracking progress
  - Participating in medical rounds
  - Decision-making
  - Keeping record of care (charting)
  - Weighing babies

FEBRUARY 2020

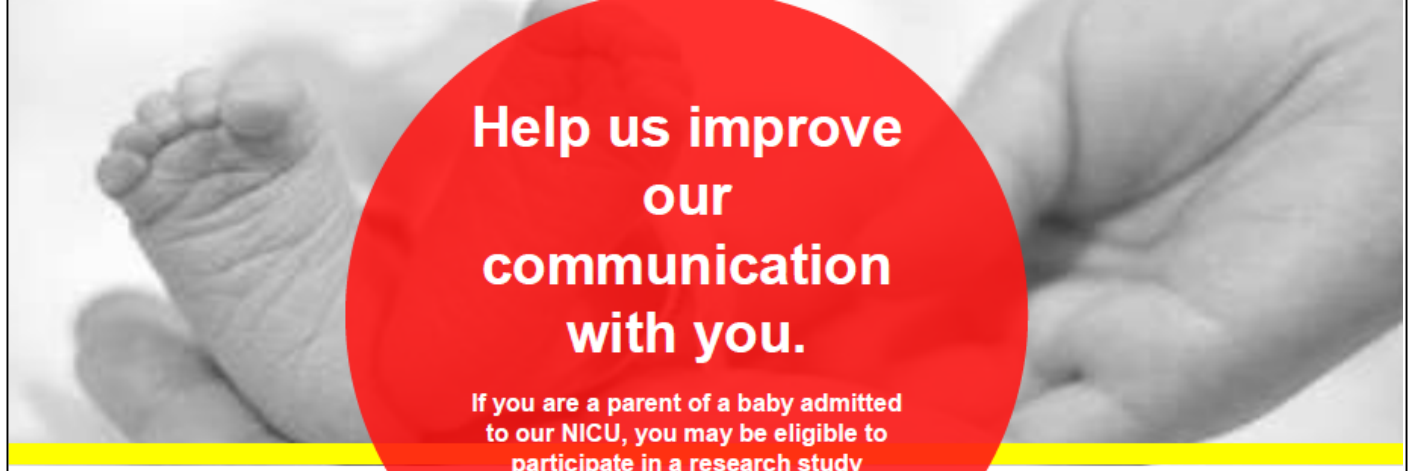
Parent 2 Parent Partnership Program

Ensuring our parents and families have a unique support system that extends beyond the comprehensive care provided by our physicians, nurses, case workers, therapies and other clinicians.

Children's Hospital Colorado
Here, it's different.™

Support by a Parent Partner

- Psychosocial Support
  - Relatability - common experience
- Resource Navigation
  - Sharing of information inside and outside the healthcare system
- Self-Management
  - Coping strategies and Empowerment



Help us improve our communication with you.

If you are a parent of a baby admitted to our NICU, you may be eligible to participate in a research study seeking to improve communication with your medical team.

Improving provider-parent communication in our NICU is important to us.

We are conducting a study to better understand how doctors and medical team providers can better communicate with parents whose infants are admitted to the NICU.

- We hope to understand parent experiences and preferences for the communication they receive from their baby's medical team (doctors & advanced practice providers)
- Includes a recorded in-person or remote interview with one of our research team members that will last 45 minutes to one hour
- All information will remain confidential and will not affect your baby's medical care

Participants will receive:

- A $30 electronic gift card to Target

Location

- A one-time 45-60-minute interview conducted wherever most convenient for you – at your baby's bedside, via telephone or even zoom.

Are you eligible?

- You have a baby admitted to our NICU for >14 days
- Your baby has been admitted to the hospital since birth
- You speak English or Spanish

If you're interested in learning more about the study or have questions, scan QR code below to get connected with study team member

NEONATAL INTENSIVE CARE UNIT

Supporting Preemie Respiratory Outcomes (SPROUT) Transitional Team

Our team is focused on caring for premature babies who need long-term mechanical ventilation (a machine that helps patients breathe when they can't breathe on their own) to treat long-term breathing and lung problems caused by chronic lung disease.

Parents and caregivers are an important part of the care team: we value your input into your child's care.

Whenever possible, SPROUT Transitional Team Attending Neonatologists (board-certified doctors who specialize in the care of preterm babies and are responsible for all patient care) will care for your baby. Our Neonatal Fellows, Neonatal and Pediatric Nurse Practitioners, Neonatal Nurses, and Respiratory Therapists may also care for your baby during your time in the NICU. On nights and weekends, we will follow the care plan created by the primary team and will respond to any emergencies or new clinical developments.


Jim Barry, MD


Stephanie Bourque, MD


Stephanie Chassen, MD


Jason Gien, MD


Kathleen Hannan, MD


Sadie Houin, MD


Sunah Hwang, MD, PhD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Next Steps

ENGAGE ADDITIONAL NICUS IN COLORADO AND THE GREATER ROCKY MOUNTAIN REGION

SEND OUT BUSINESS AGREEMENTS TO PARTICIPATING SITES

TRAIN HOSPITAL TEAMS ON REDCAP USE AND DATA ENTRY (BASELINE DATA COLLECTION)

VIRTUAL SITE VISITS TO SUPPORT INTERVENTION SELECTION AND IMPLEMENTATION

ENGAGE OTHER COLORADO ORGANIZATIONS FOR BROADER EXPANSION AND SCOPE

Conclusions

- Parental engagement in the NICU leads to better infant and family health.
- While there are significant barriers to parental engagement, evidence-based interventions are available and should be strongly considered as part of routine neonatal intensive care.

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