tchmb
Texas Collaborative for Healthy Mothers & Babies

2023 TCHMB Summit
February 16-17

NEONATAL: Improving CCHD outcomes by addressing SDoH and Health Disparities

Friday, February 17

1:30 - 3:30 PM

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William and Rita Head Distinguished Chair in Developmental and Environmental Neonatology, Professor of Pediatrics, Joe R. and Teresa Lozano Long School of Medicine, UT Health San Antonio

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Improving CCHD Outcomes by addressing social determinants of health and health disparities

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Professor of Pediatrics, Baylor College of Medicine

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Professor of Pediatrics, UT Health San Antonio

UT Health San Antonio Pediatrics

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Disclosure slide

- Drs. Charleta Guillory and Alice Gong have nothing to disclose

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Objectives

- Review the status of Critical Congenital Heart Disease (CCHD) newborn screening in Texas
- Assess current CCHD data in the Birth Defects Registry with emphasis on social determinants of health and disparities
- Describe a case of a Texas newborn affected by CCHD
- Identify and recognize problems within the CCHD Screening Program and Develop Interventions to improve the program

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Texas Pulse Oximetry Project: A Multicenter Educational and Quality Improvement Project for Implementation of Critical Congenital Heart Disease Screening Using Pulse Oximetry

Charleta Guillory, MD, MPH, FAAP[1] Alice Gong, MD[2] Judith Livingston, MEd, MCHES[2]
Liza Creel, MPH, PhD[3] Elena Ocampo, MD[4] Tiffany McKee-Garrett, MD[1]

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Am J Perinatol 2017;34:856–860.

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JOGNN

PRINCIPLES & PRACTICE

The Nurse Champion Model for Advancing Newborn Screening of Critical Congenital Heart Disease

Rachael Farner, Judith Livingston, Suwanna A. Rubio, Maria V. Gutierrez, and Alice Gong for the Texas Pulse Oximetry Project Team

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A Multicenter Initiative for Critical Congenital Heart Disease Newborn Screening in Texas Neonatal Intensive Care Units

Alice Gong, MD[1] Charleta Guillory, MD, MPH[2] Liza Creel, MPH, PhD[3]
Judith Ellen Livingtson, MEd, MCHES[1] Tiffany M. McKee-Garrett, MD[2] Regine Fortunov, MD[2]

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Am J Perinatol 2017;34:839–844.

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TXPOP ToolKit:

https://www.dshs.state.tx.us/newborn/cchdtoolkit

- **Critical Congenital Heart Disease (CCHD) Toolkit**
- Algorithm Card (PDF)
- CCHD NBS PowerPoint Presentation for Physicians (PDF)
- CCHD NBS PowerPoint Presentation for Nurses (PDF)
- Brochure, English/Spanish, positive screen (PDF)
- Brochure, English/Spanish, for families (PDF)
- Sample Physician Order (PDF)
- Sample Nursery Policy (PDF)
- Sample Screening Log (PDF)
- "Taryn's Story" – 4 minute video script (PDF)
- "Lifesaving Newborn Screen" - 30 sec. PSA script (PDF)
- Wall Poster for Newborn Nursery – Algorithm (PDF)

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September 1, 2014, HB 740, 83rd legislature:

§37.78 Exemptions

(1) the parent declines the screening;

(2) the newborn is transferred to another facility before the screening test is performed;

(3) the screening test has previously been completed after birth;

(4) the newborn is discharged from the birthing facility not more than 10 hours after birth and a referral for the newborn was made to another birthing facility, physician, or health care provider;

(5) the newborn has previously been diagnosed with CCHD; or

(6) the newborn has had a post-natal echocardiogram

Texas law mandated CCHD screening for ALL newborns

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§37.79. Reporting

(a) A physician, health care practitioner, health authority, birthing facility, or other individual who has the information of a confirmed case of a disorder for which a screening test is required, shall report a confirmed case to the Department of State Health Services.

(b) Confirmed case information must be submitted to the department's Newborn Screening Unit using the most current reporting method(s) located on the department's Newborn Screening website at http://www.dshs.state.tx.us/newborn/.

TEXAS Health and Human Services | Texas Department of State Health Services

Critical Congenital Heart Disease Reporting Form

Chapter 37, Subchapter E. Newborn Screening for Critical Congenital Heart Disease of the Texas Administrative Code requires a physician, health care practitioner, health authority, birthing facility, or other individual who has information of a confirmed case of a disorder for which a screening test is required, to report the confirmed cases to the department.

Instructions:
1. Complete form for all confirmed CCHD cases
2. Print form
3. Manually sign form
4. Fax signed form to **512-776-7593** Attention: CCHD Program

Facility Name:_____ Facility Location (City):_____

Medical Record #:_____ Mother Texas Resident: ☐ Yes ☐ No

Facility Type: ☐ Hospital ☐ Children's Hospital ☐ Birthing Center ☐ Home Birth

Baby's Name:
First_____ Last_____ Date of Birth:_____

Baby's Ethnicity:

☐ White ☐ African American ☐ Hispanic ☐ Asian ☐ Native American ☐ Other

Baby's Age (in hours at time of screening):_____ Sex: ☐ M ☐ F ☐ Unknown

Mother's Name:
First_____ Last _____

Mother's Maiden Name:_____ Mother

Diagnosis

	Primary Target Condition		Secc
☐ 1	hypoplastic left heart syndrome	☐ 9	co
☐ 2	pulmonary atresia with intact septum	☐ 10	double outlet right ventricle
☐ 3	tetralogy of fallot	☐ 11	Ebstein anomaly
☐ 4	total anomalous pulmonary venous return	☐ 12	interrupted aortic arch
☐ 5	transposition of the great arteries	☐ 13	single ventricle
☐ 6	tricuspid atresia	☐ 14	unspecified secondary
☐ 7	truncus arteriosus		
☐ 8	unspecified primary		

Comments:_____

Diagnosis Timeframe (choose only one):

☐ Prenatal diagnosis

If prenatally diagnosed, did prenatal and post-natal diagnosis match? ☐Yes ☐No

If no what was the prenatal diagnosis?_____

☐ Post-natal diagnosis prior to pulse oximeter screening

☐ Post-natal diagnosis with pulse oximeter screening

Was post-natal echocardiogram performed? ☐ Yes ☐ No

Delivery Outcome: ☐ Live Birth ☐ Non-live birth

Treatment Provided: ☐ Cardiac surgery ☐ Medical management ☐ Supportive care

Baby Status: ☐ Baby Living ☐ Baby Expired

Infant was transported: ☐ Yes ☐ No
If yes indicate for what purpose(s)

New Form coming to website that allows online completion and adds a "Submit" button – still not available

☐ Syndrome/chromosomal anomaly diagnosed

_____ Printed name of person sending report

_____ Title

_____ Signature of person sending report

_____ Date sent

Fax signed form to 512-776-7593 Attention: CCHD Screening

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CCHD Diagnosed Cases by Year of Birth

Reported Screening Results

Reported cases by Year	
2014	54
2015	188
2016	136
2017	93
2018	109
2019	236
2020	167
2021	101
2022	25
blank	14
Total	**1123**

- In the United States, about 8,000 babies born every year have Critical Congenital Heart Defects (CDC).
- Texas should expect about 800 cases annually.

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Data from Texas Birth Defects Registry and Texas Department State Health Services

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CCHD
Reported Screening Results

September 2014 - March 2022

Timeframe	#	%
Post-natal after norm pulse ox	57	5%
Post-natal prior to pulse ox	285	25%
Post-natal with pulse ox	125	11%
Prenatal	22	2%
Prenatal matched to post	468	42%
Prenatal not matched to post	61	5%
blank	105	9%
Total	**1123**	**100%**

Data from Texas Birth Defects Registry and
Texas Department State Health Services

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Critical Congenital Heart Disease (CCHD) Diagnoses

September 2014 - March 2022

Primary Target Conditions	#	Secondary Target Conditions	#
Hypoplastic Left Heart	145	Coarctation of Aorta	196
Pulmomary Atresia	56	Double Outlet Ventricle	108
Tetralogy of Fallot	160	Ebstein Anomaly	26
Total Anomalous Pulmonary	97	Interrupted Aortic Arch	42
Transposition of Arteries	179	Single Ventricle	20
Tricuspid Atresia	51	Unspecified Secondary	102
Truncus Arteriosus	38	**Total***	**1295**
Unspecified Primary	75		

*Some babies have more than one condition listed

Run Date: 4/20/2022

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Disparities in Critical Congenital Heart Defect Occurrence and Outcomes Among Infants in Texas

Birth Defects Epidemiology and Surveillance Branch

Texas Department of State Health Services

Mark Canfield PhD

Charles Shumate DrPH

Dayana Betancourt MPH, MBA

Presentation Outline

I. Epidemiology of Critical Congenital Heart Defects (CCHDs) in Texas
II. Neonate and Infant Survival of CCHDs by Social Determinants of Health
III. Addressing Health Disparities: Connecting Children with CCHDs to Health and Social Services

Epidemiology of Critical Congenital Heart Defects (CCHDs) in Texas

Mark A. Canfield PhD, Director

Birth Defects Epidemiology and Surveillance Branch (BDES)

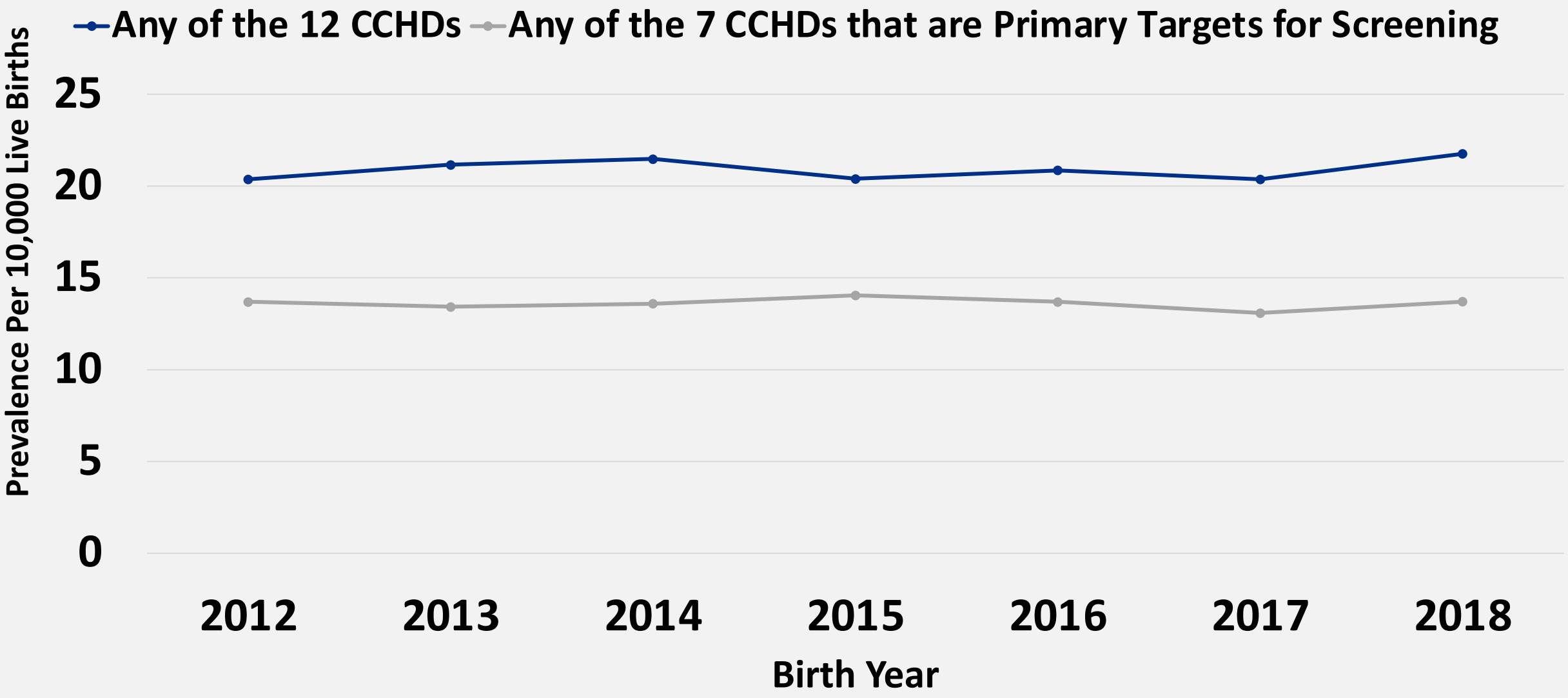
About the Texas Birth Defects Registry

- Active surveillance system (program identifies cases/collects information)
- Computerized database of infants and pregnancies affected by birth defects
- > 400,000 cases
- Case Definition
  - Structural/chromosomal malformations
  - Diagnosed prenatally or in first year after birth
  - Mother is resident in Texas
  - Includes all pregnancy outcomes

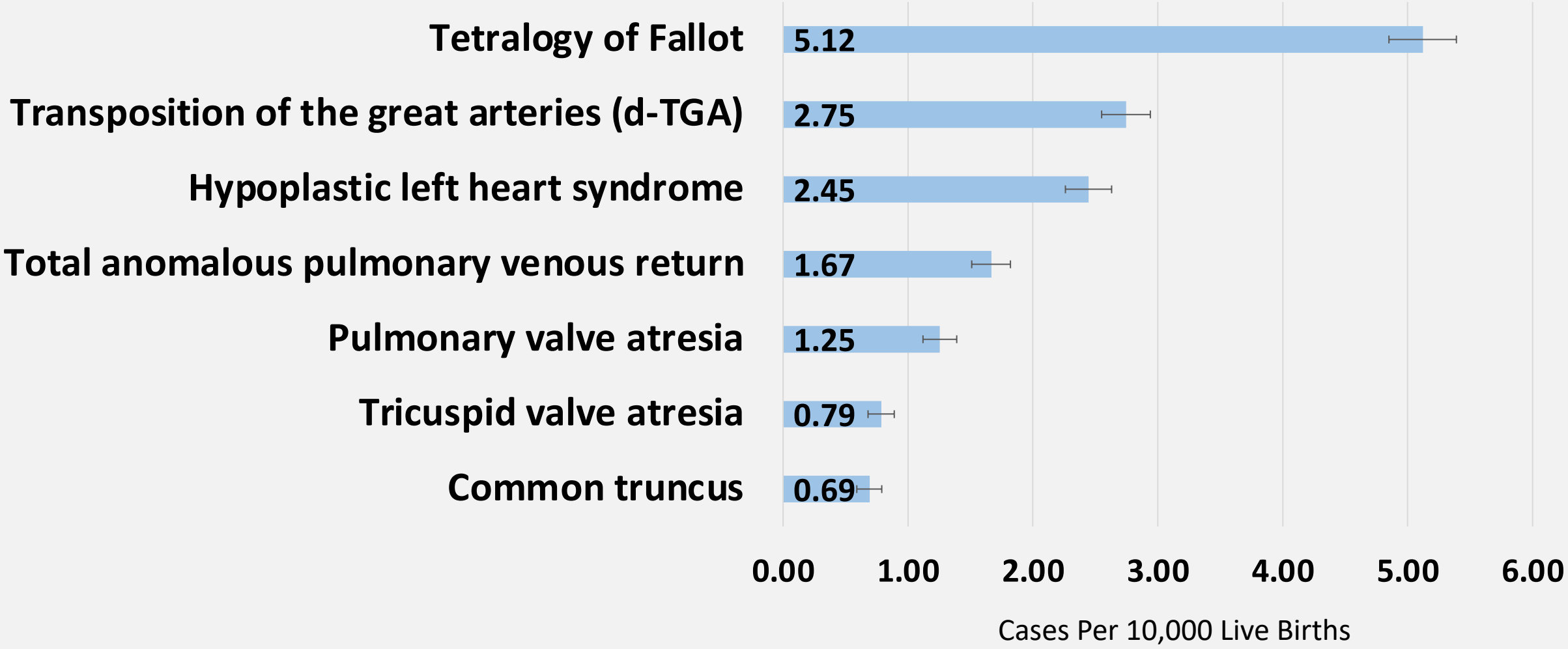
Texas Birth Defects Registry: What We Do With the Data

- Monitor and describe birth defect occurrence and outcomes among children born with birth defects in TX
- Collaborate in related research, prevention activities
- Carry out family outreach activities tied to Registry, connect children to regional social workers
- Conduct cluster investigations

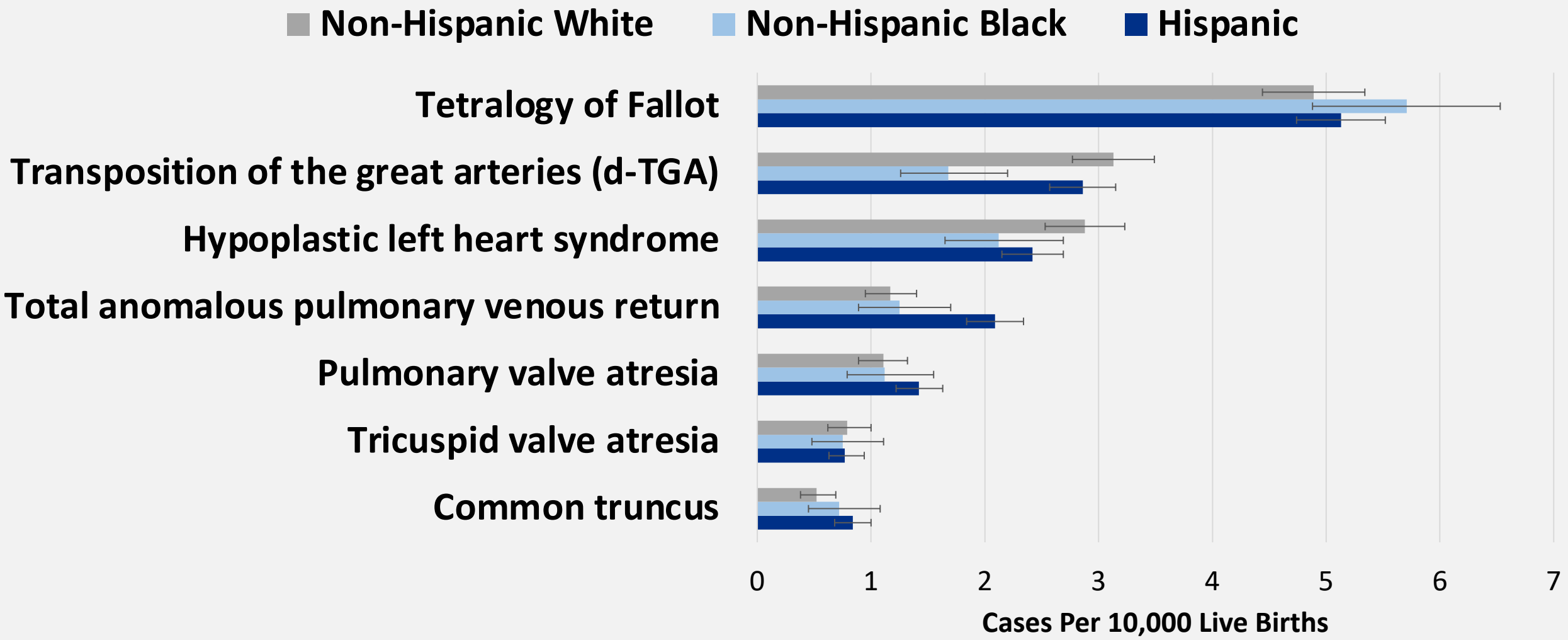
Prevalence of Infants Born with CCHDs in Texas 2012-2018



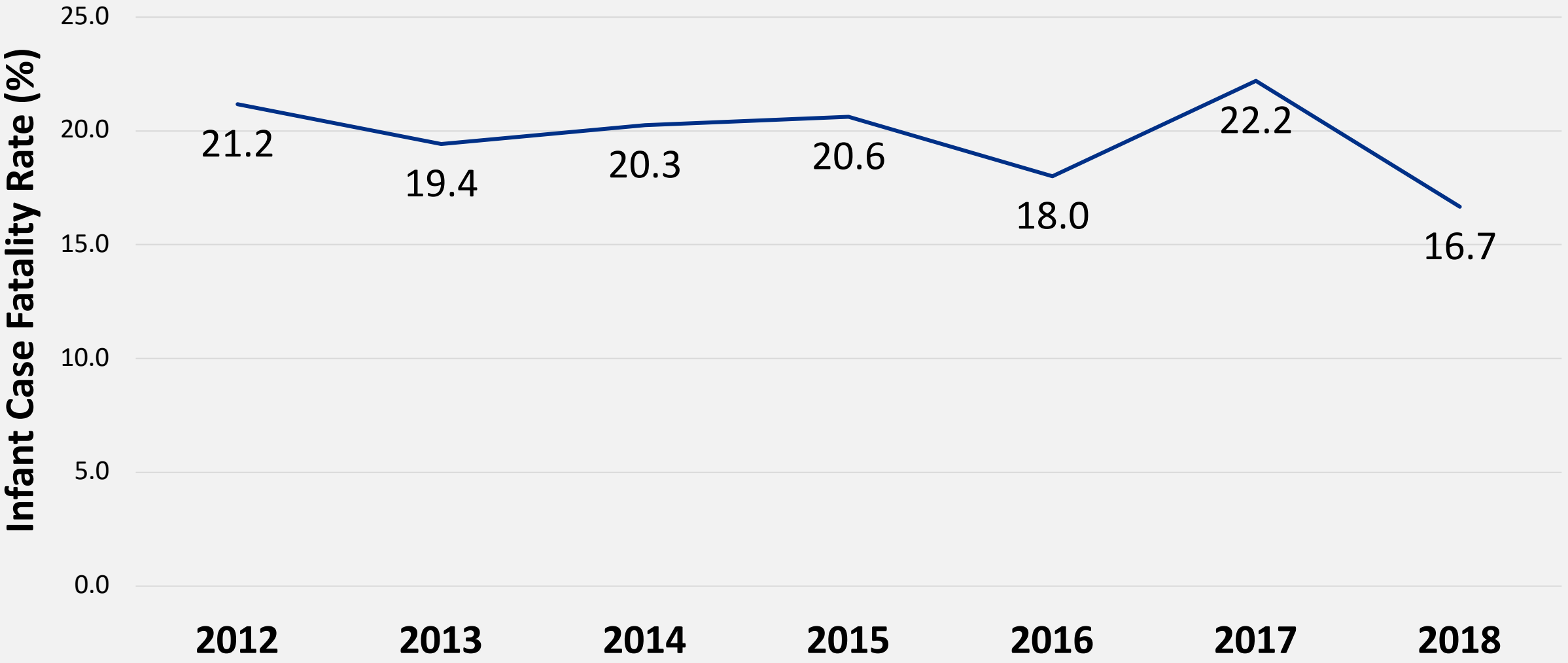
Prevalence of the Seven CCHDs that are Primary Targets for Pulse Oximetry Screening Texas, 2012-2018



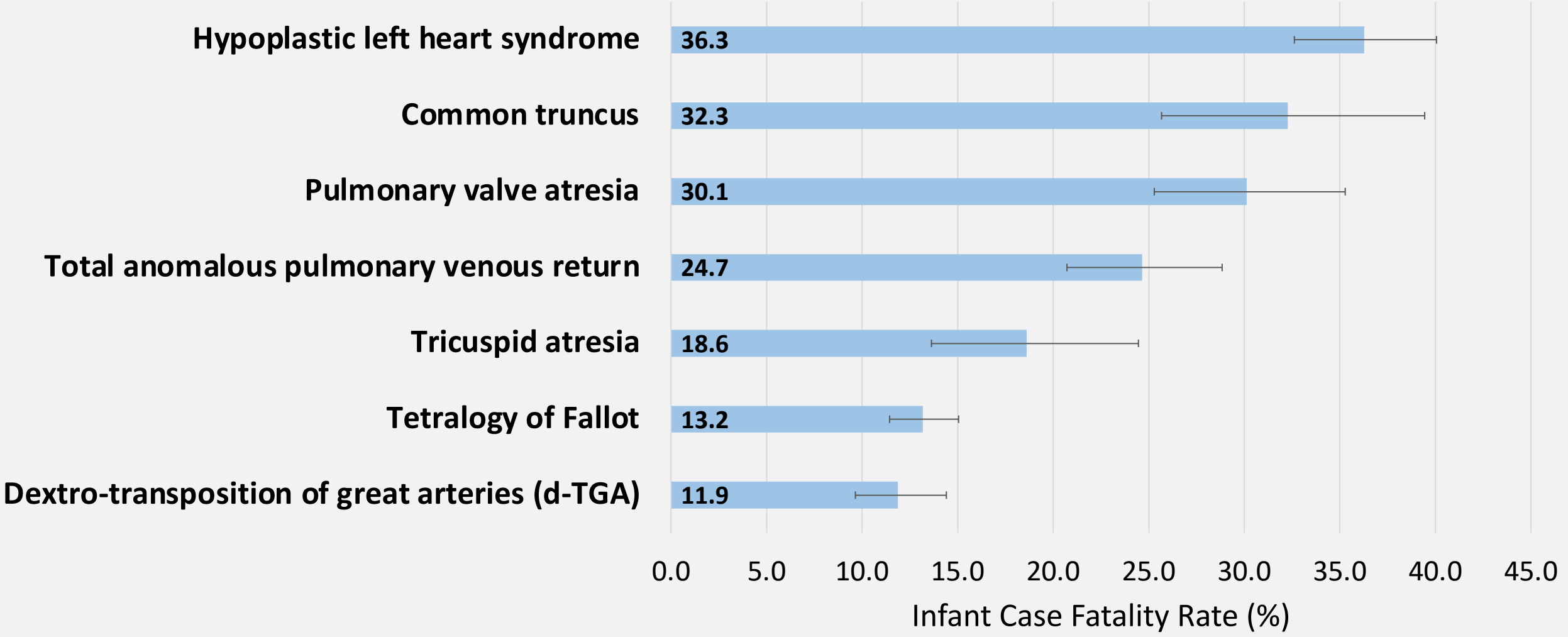
Prevalence of the Primary Screening Target CCHDs by Maternal Race/Ethnicity Texas, 2012-2018



Infant Case Fatality Rate (Deaths/Cases x 100) for the Seven CCHDs that are Primary Targets for Pulse Oximetry Screening Texas, 2012-2018



Infant Case Fatality Rate (Deaths/Cases x 100) for the Seven CCHDs that are Primary Targets for Pulse Oximetry Screening Texas, 2012-2018



Conclusion – Epidemiology of CCHDs in Texas

- CCHD prevalence is consistent with the national figure of ~2 cases per 1,000 live births*
- Two racial/ethnic differences in prevalence were identified:
  - TAPVR is higher among Hispanics and d-TGA is lower among Blacks
  - These findings are consistent with findings from national data*
- Racial/ethnic differences in these phenotypes may result from variations in the prevalence of maternal medical conditions (e.g. diabetes) and maternal risk factors (e.g., maternal education). The Texas and national data were unadjusted for covariates
- No obvious time trends in case fatality for the 7 primary targets overall from 2012-2018
- Highest case fatality was observed for hypoplastic left heart syndrome and common truncus

*Mai, C. T., Isenburg, J. L., Canfield, M. A., Meyer, R. E., Correa, A., Alverson, C. J., Lupo, P. J., Riehle-Colarusso, T., Cho, S. J., Aggarwal, D., Kirby, R. S., & National Birth Defects Prevention Network (2019). National population-based estimates for major birth defects, 2010-2014. Birth defects research, 111(18), 1420–1435. https://doi.org/10.1002/bdr2.1589

Neonate and Infant Survival of CCHDs by Social Determinants of Health

Charles Shumate, DrPH, Senior Scientist

Birth Defects Epidemiology and Surveillance Branch (BDES)

Social Determinants of Health (SDOH) Defined:

The conditions in which people are born, grow, work, live, and age and the wider set of forces and systems shaping the conditions of daily life.

Understanding the role of SDOH on survival among infants with birth defects is challenging.

Why?

- Rarity of birth defects
- The lack of individual-level income data in studies, and
- The overrepresentation of birth defects in lower SES groups

https://www.who.int/health-topics/social-determinants-of-health#tab=tab_1

Botto, L. D., & Mastroiacovo, P. (2018). From cause to care: Triple surveillance for better outcomes in birth defects and rare diseases. European Journal of Medical Genetics, 61(9), 551-555.

Knowles, R. L., Ridout, D., Crowe, S., Bull, C., Wray, J., Tregay, J., ... & Brown, K. L. (2017). Ethnic and socioeconomic variation in incidence of congenital heart defects. Archives of disease in childhood, 102(6), 496-502.

Social Determinants of Health (SDOH) and CHDs/CCHDs

- Prevalent birth defect(s)
- Affecting one of the most complex organs of the human body: the heart
- Range of severity

Results from two recent systematic reviews:

➢ Children of lower SES are at increased risk of CHD-related mortality, but the association between area-based income and CHD-related mortality is conflicting

➢ Common Measures: poverty, low parental educational attainment, uninsurance, transportation barriers, immigration status

Defect severity is the strongest factor affecting survival after surgery.

➢ Univentricle/single ventricle lesions having the poorest outcomes.

Davey, B., Sinha, R., Lee, J. H., Gauthier, M., & Flores, G. (2021). Social determinants of health and outcomes for children and adults with congenital heart disease: a systematic review. Pediatric research, 89(2), 275-294.

Best, K. E., Vieira, R., Glinianaia, S. V., & Rankin, J. (2019). Socio-economic inequalities in mortality in children with congenital heart disease: a systematic review and meta-analysis. Paediatric and Perinatal Epidemiology, 33(4), 291-309.

Spector, L. G., Menk, J. S., Knight, J. H., McCracken, C., Thomas, A. S., Vinocur, J. M., ... & Kochilas, L. (2018). Trends in long-term mortality after congenital heart surgery. Journal of the American College of Cardiology, 71(21), 2434-2446.

Objective #1 and Methods

Calculate neonate (0-27 days) and infant survival for the 7 primary CCHD targets in Texas by SDOH, using the Kaplan-Meier method

Time Period: 2011-2020

N=5,685 TX Birth Defects Registry (TBDR) infants

Univentricular: Pulmonary valve atresia, Tricuspid valve atresia, and Hypoplastic left heart syndrome

Meaningful differences flagged if 95% confidence intervals did not overlap

*Census tract

**Area-based measure

Measures and Sources
Maternal race/ethnicity: Non-Hispanic Black, Hispanic, Non-Hispanic White, Other (*TBDR* and *Birth Certificate*)
Indication of prenatally diagnosed: Yes vs. No (*TBDR*)
Rural areas, maternal census tract* at delivery: Rural (<2,500) vs. Urban areas (>50,000) (*American Community Survey 5 year* and *Birth Certificate*)
Texas-Mexico border residence at delivery: Border vs. Non-border (*Birth Certificate*)
Designated Neonatal Facilities in resident city at delivery: None, Level I-III, and Level IV (*DSHS*)
Area-Based Measures** (*American Community Survey 5 year*) 1. Concentrated poverty, >20%: Tracts with poverty rates of 20% or more are considered concentrated poverty areas 2. Concentrated uninsured, >20%: Tracts with uninsured rates of 20% or more are considered concentrated uninsured areas 3. High unemployment, >5%: Tracts with civilian unemployment rates of 5% or more are considered high unemployed areas

Objective #2 and Methods

- Describe the number of total Z code claims among any primary CCHD lesion
- Report the top five most utilized Z codes in 2018, 2019, and 2020
- Data Source: Linked TBDR-Texas Medicaid Fee for Service and Medicaid Managed Care, 2018-2020

  N=5,685 TBDR infants.

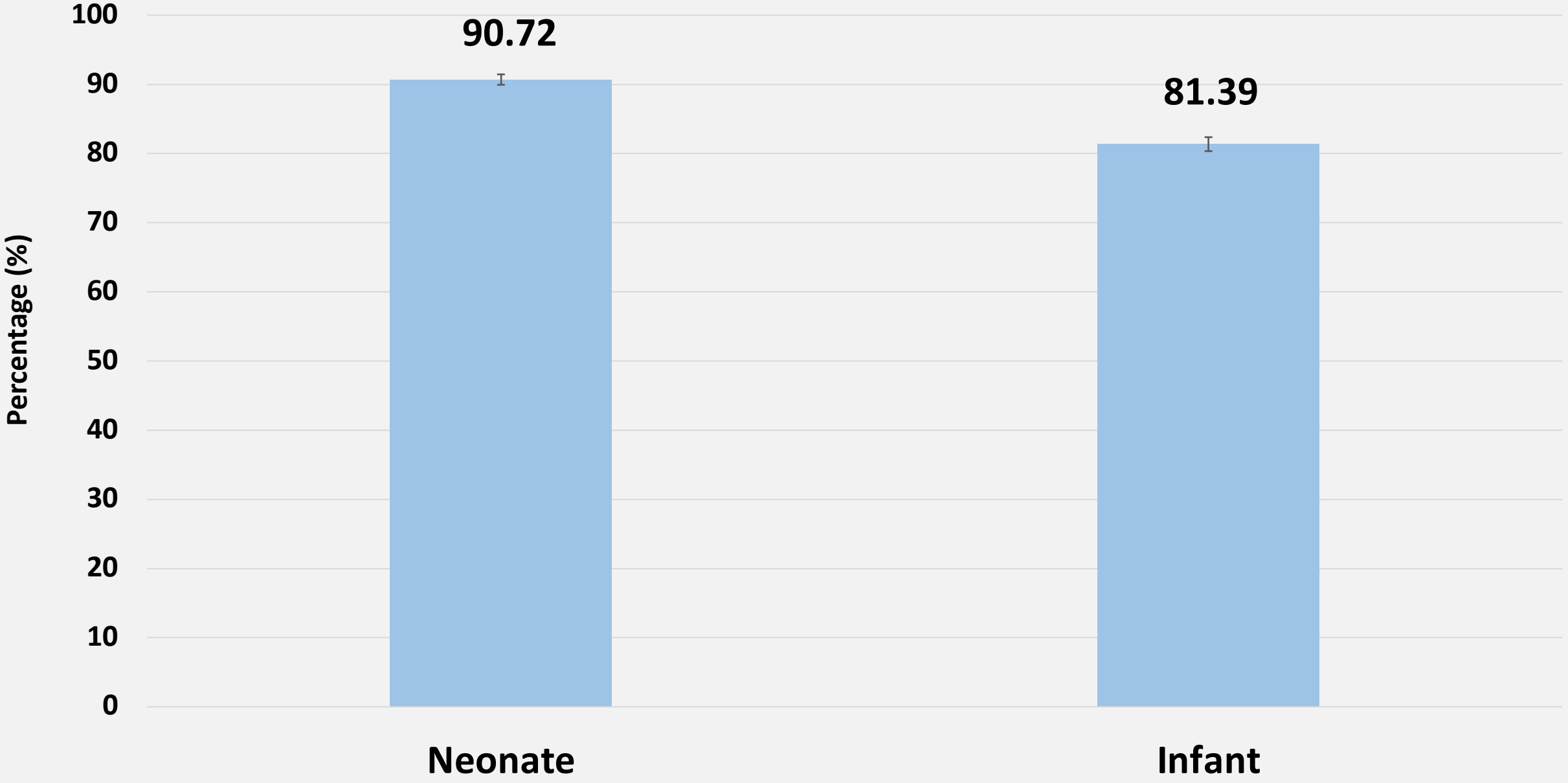
  n= 3,246 linked to Medicaid data

  n= 1,476 linked to Medicaid and birth year between 2018-2020

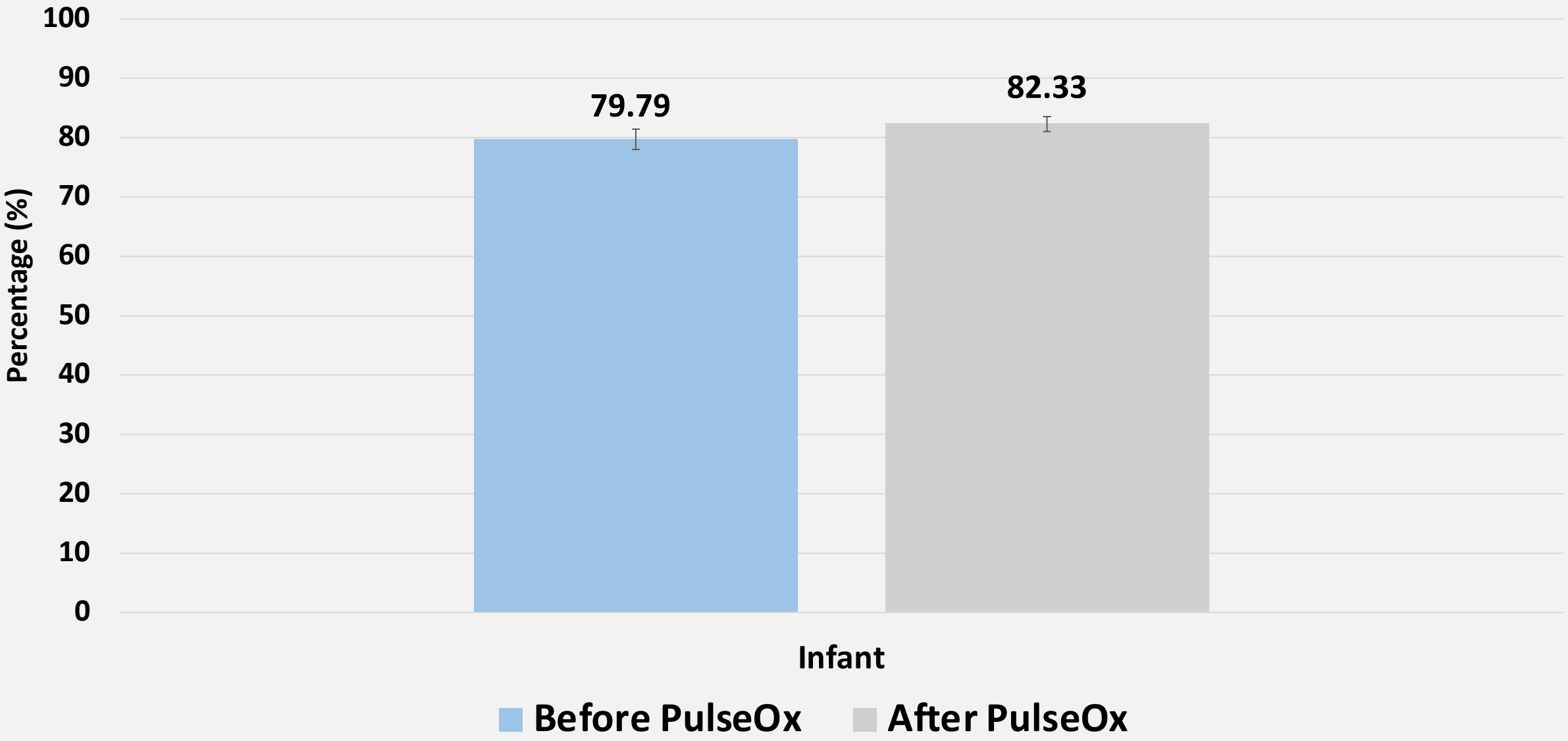
  n= 114 infants and children with a Z code (7%)

Z code	Description
Z55	Problems related to education and literacy
Z56	Problems related to employment and unemployment
Z57	Occupational exposure to risk factors
Z59	Problems related to housing and economic circumstances
Z60	Problems related to social environment
Z62	Problems related to upbringing
Z63	Other problems related to primary support group, including family circumstances
Z64	Problems related to certain psychosocial circumstances
Z65	Problems related to other psychosocial circumstances

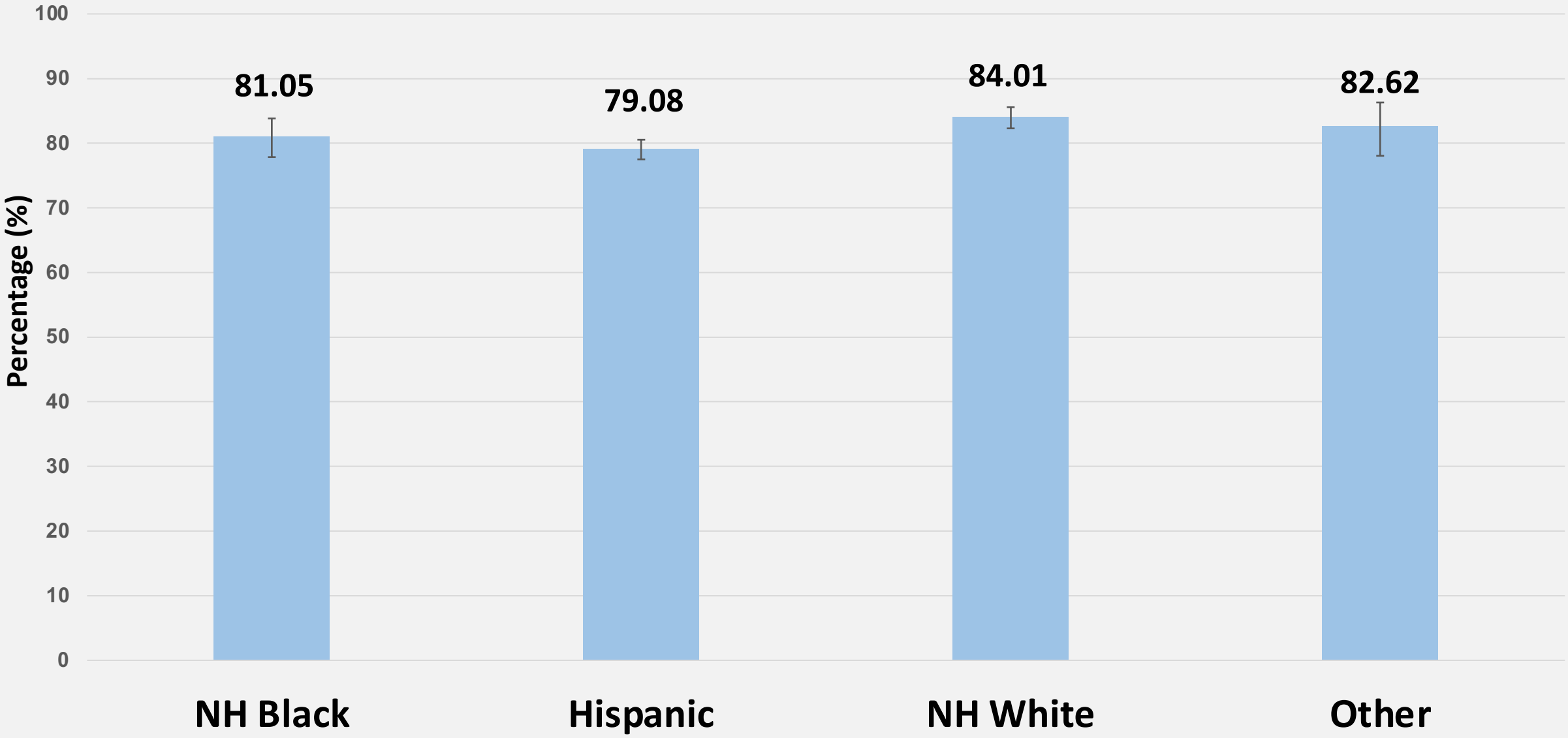
Neonate and Infant Survival, Any Primary CCHD, 2011-2020



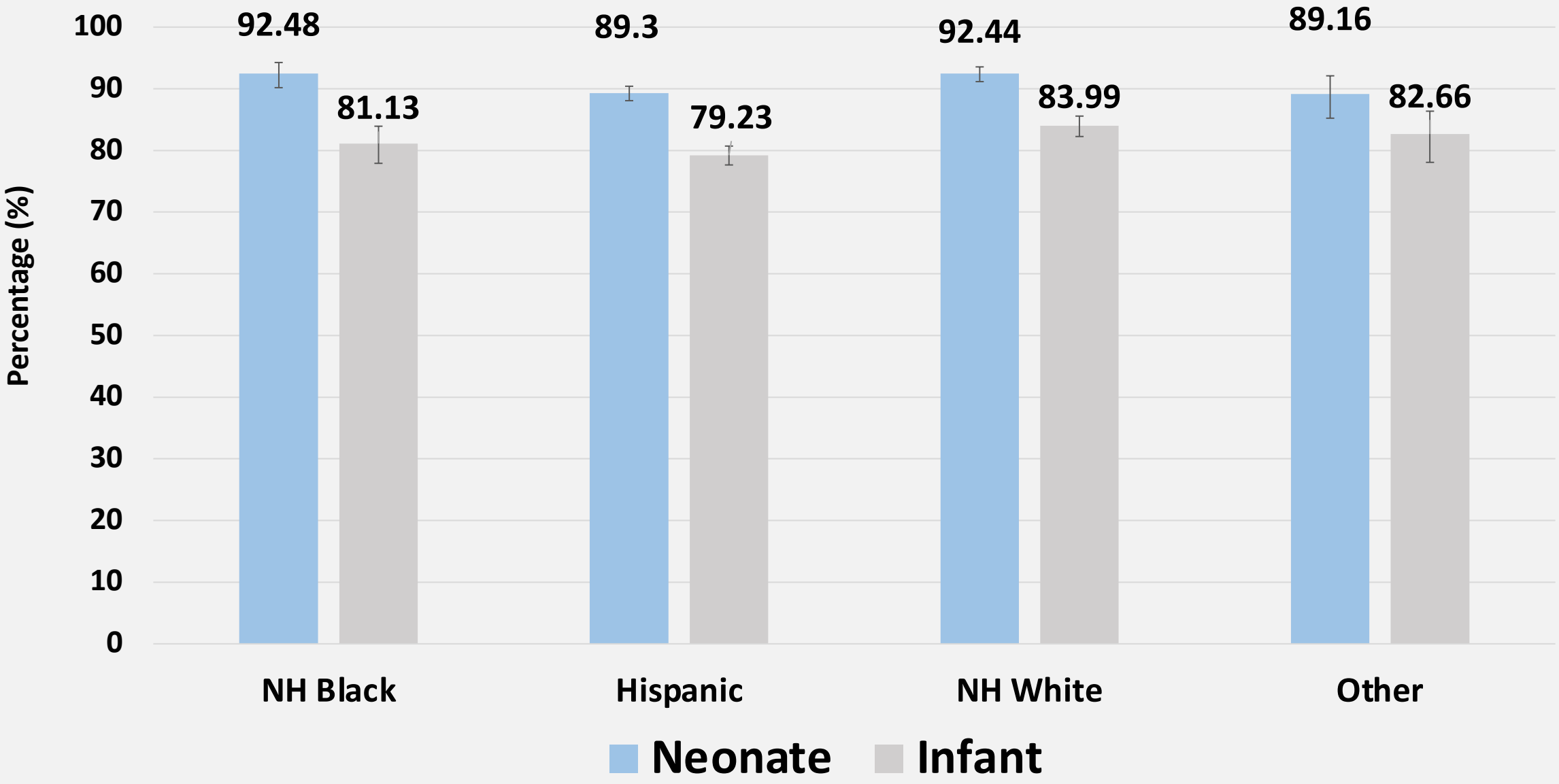
Neonate and Infant Survival by Pulse Oximetry Period, Any Primary CCHD, 2011-2020



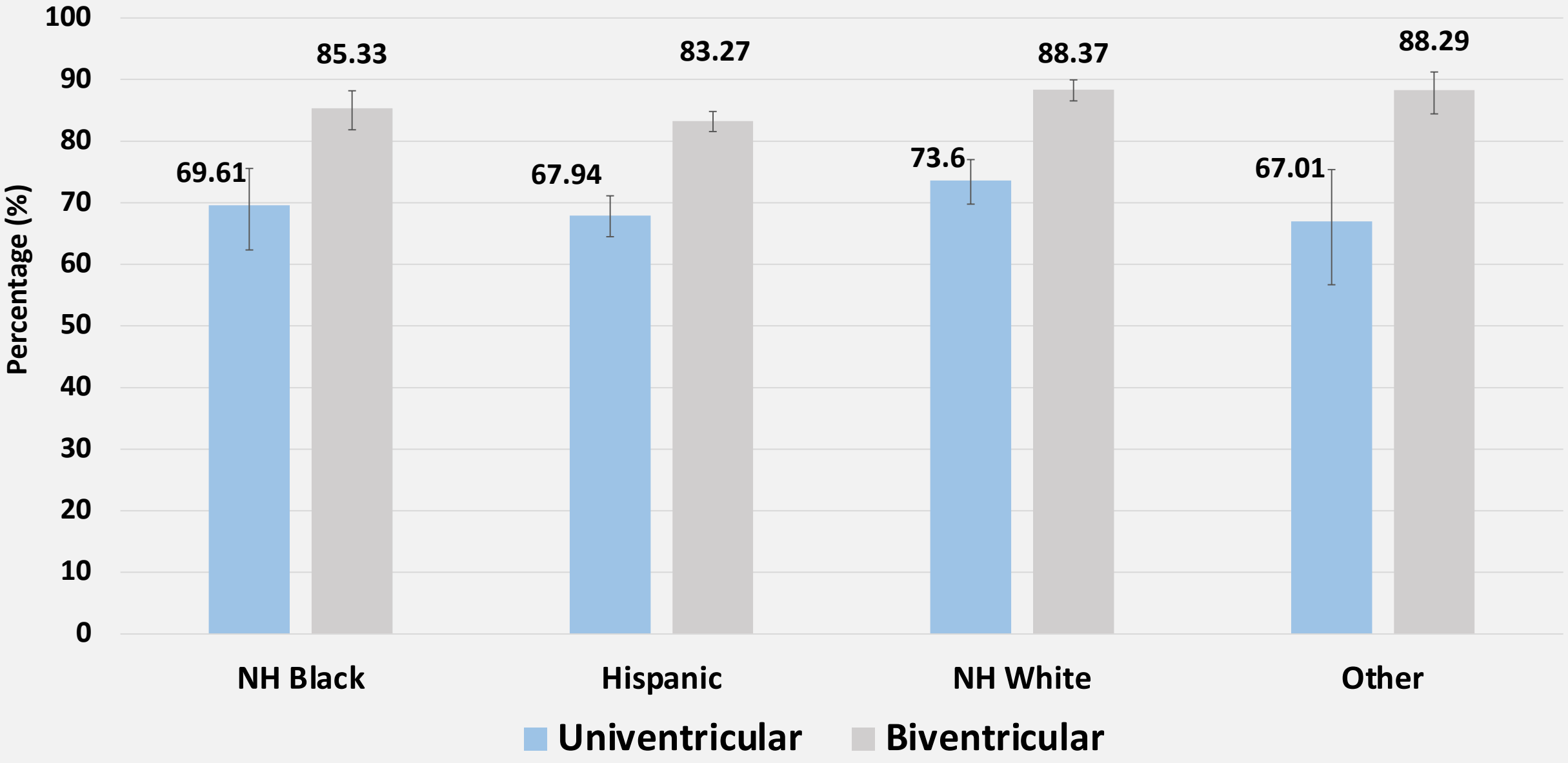
Infant Survival by Maternal Race/Ethnicity, Any Primary CCHD, 2011-2020



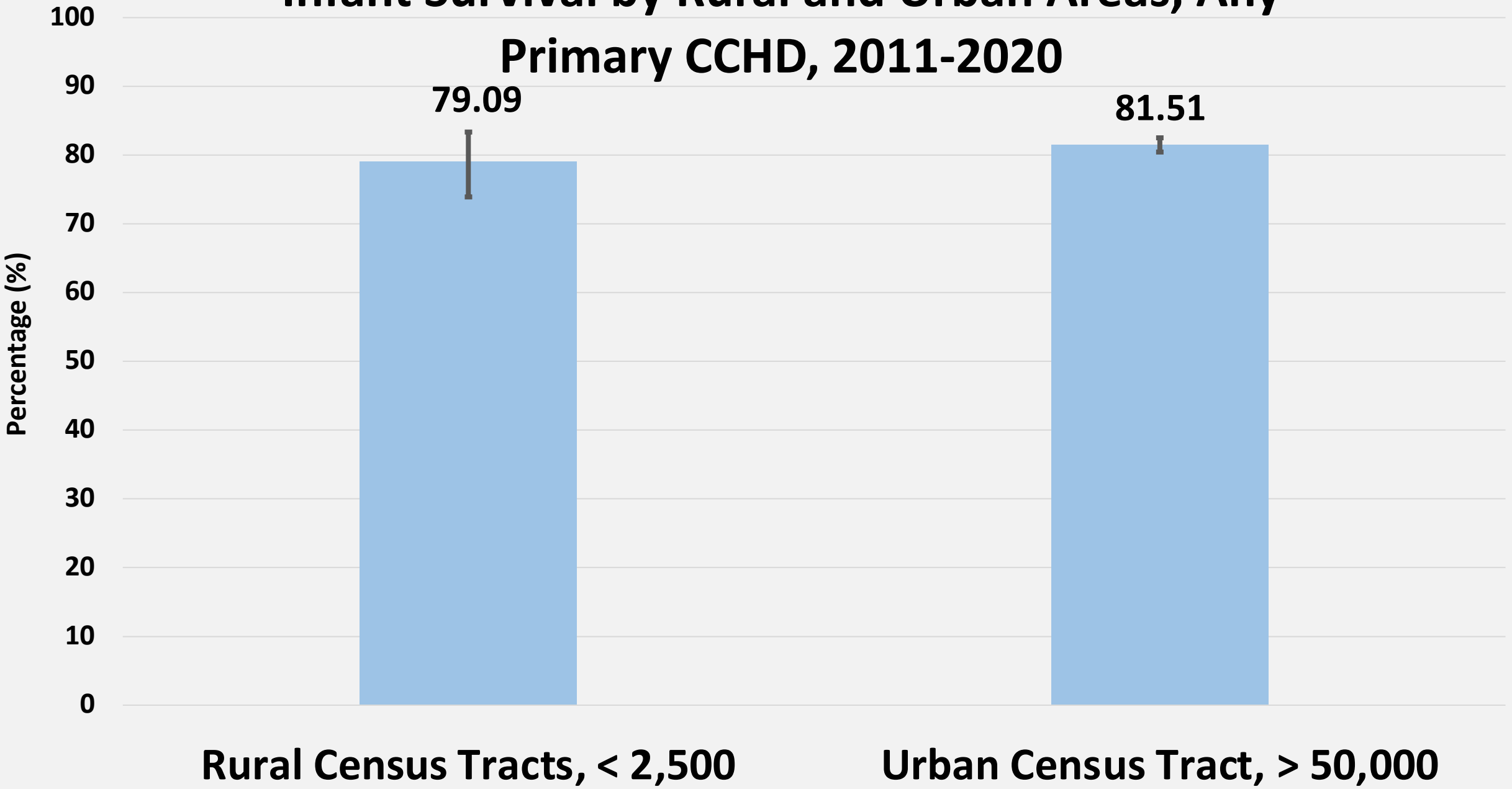
Neonate and Infant Survival by Maternal Race/Ethnicity, Any Primary CCHD, 2011-2020



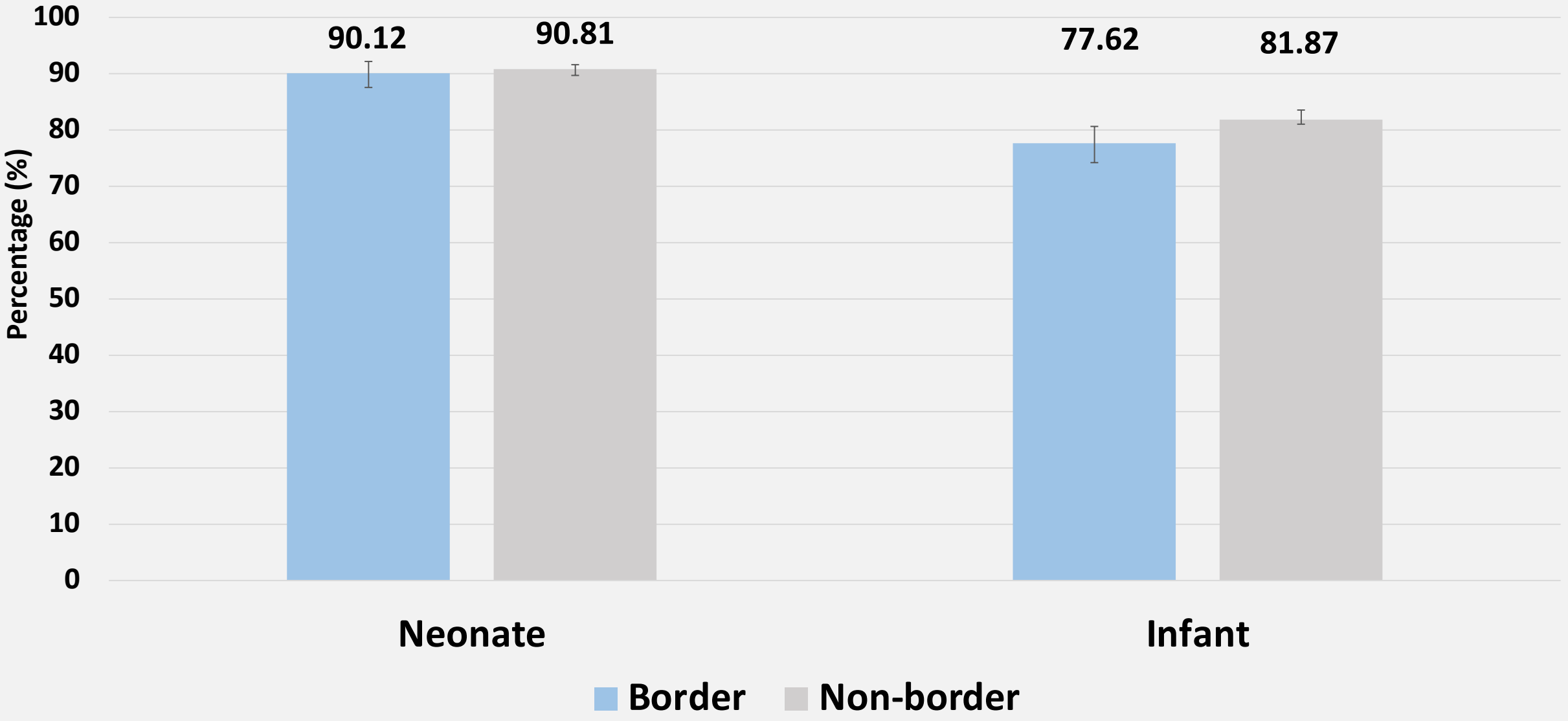
Infant Survival By Univentricular-Biventricular and Maternal Race/Ethnicity, Any Primary CCHD, 2011-2020



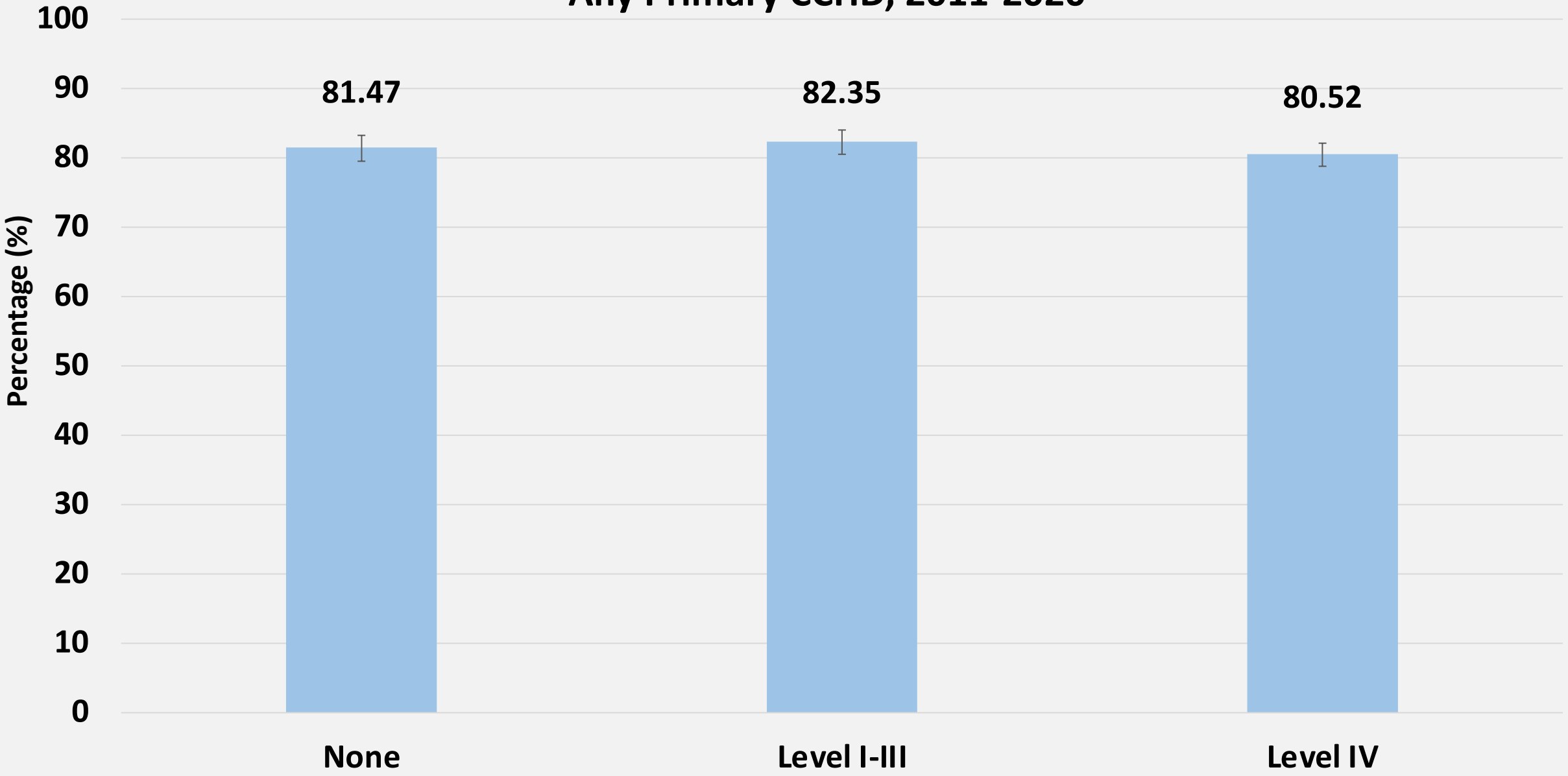
Infant Survival by Rural and Urban Areas, Any Primary CCHD, 2011-2020

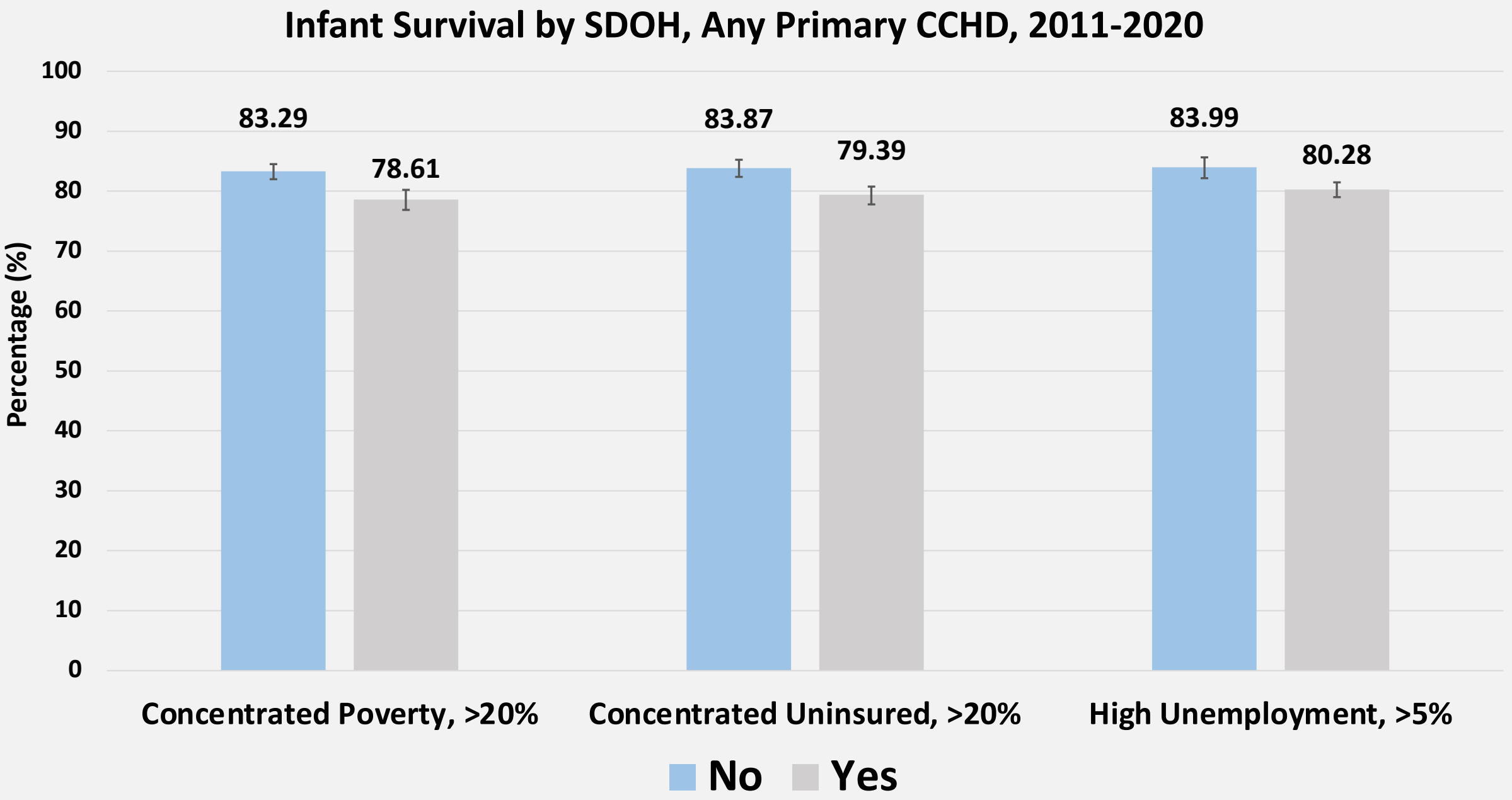


Neonate and Infant Survival by Texas-Mexico Border Residence at Delivery, Any Primary CCHD, 2011-2020

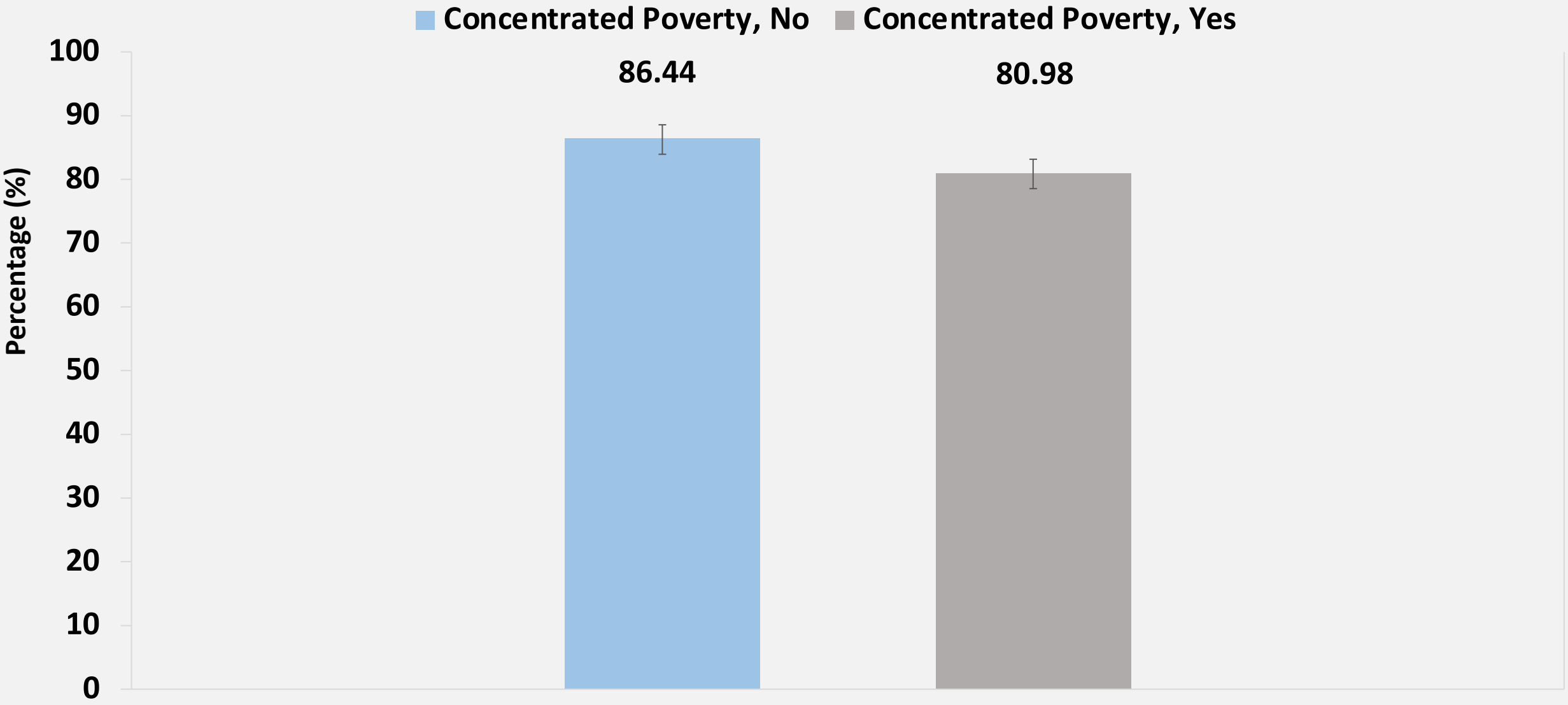


Infant Survival, Designated Neonatal Facilities in Resident City, Any Primary CCHD, 2011-2020

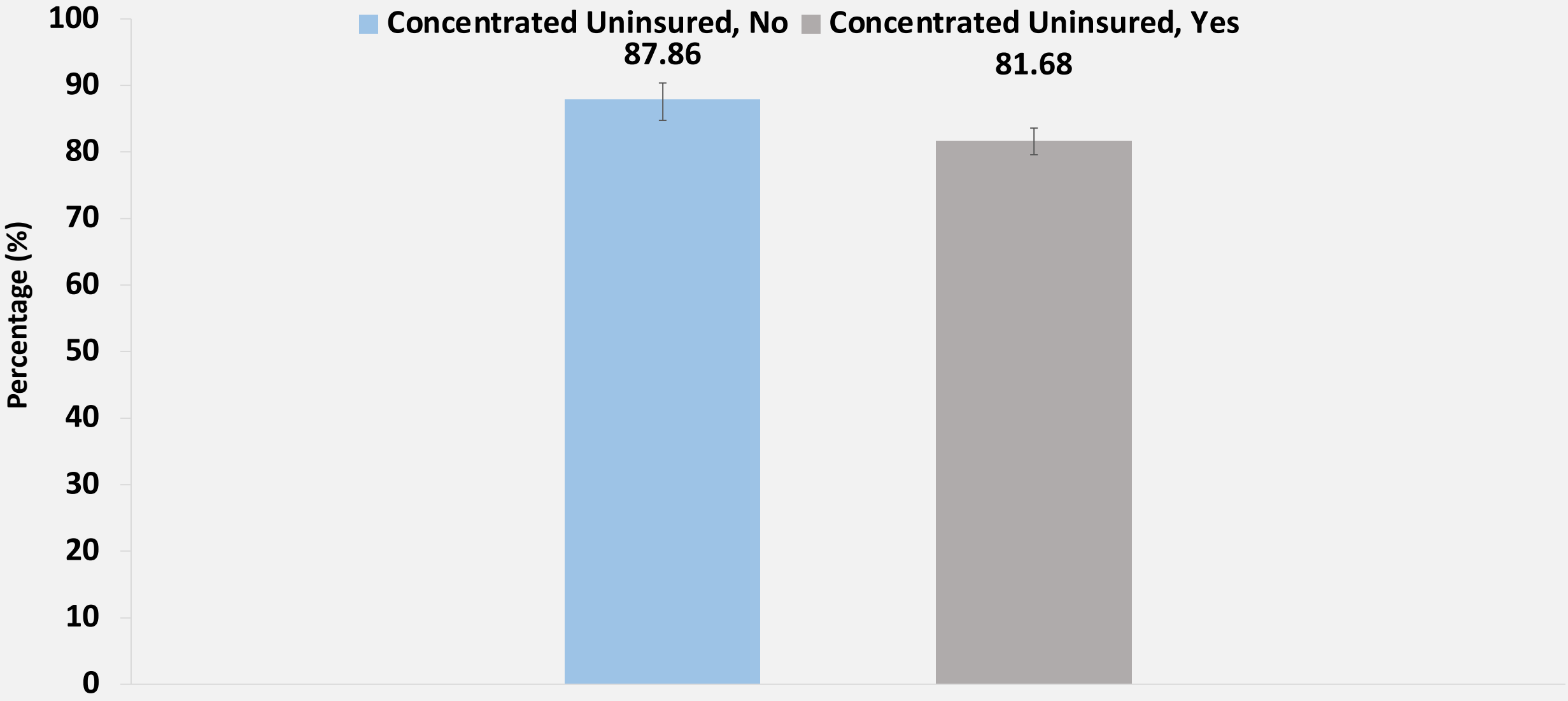



Infant Survival by SDOH, Any Primary CCHD, 2011-2020
100
90
80
70
60
50
40
30
20
10
0
Percentage (%)
83.29
78.61
83.87
79.39
83.99
80.28
Concentrated Poverty, >20%
Concentrated Uninsured, >20%
High Unemployment, >5%
No
Yes

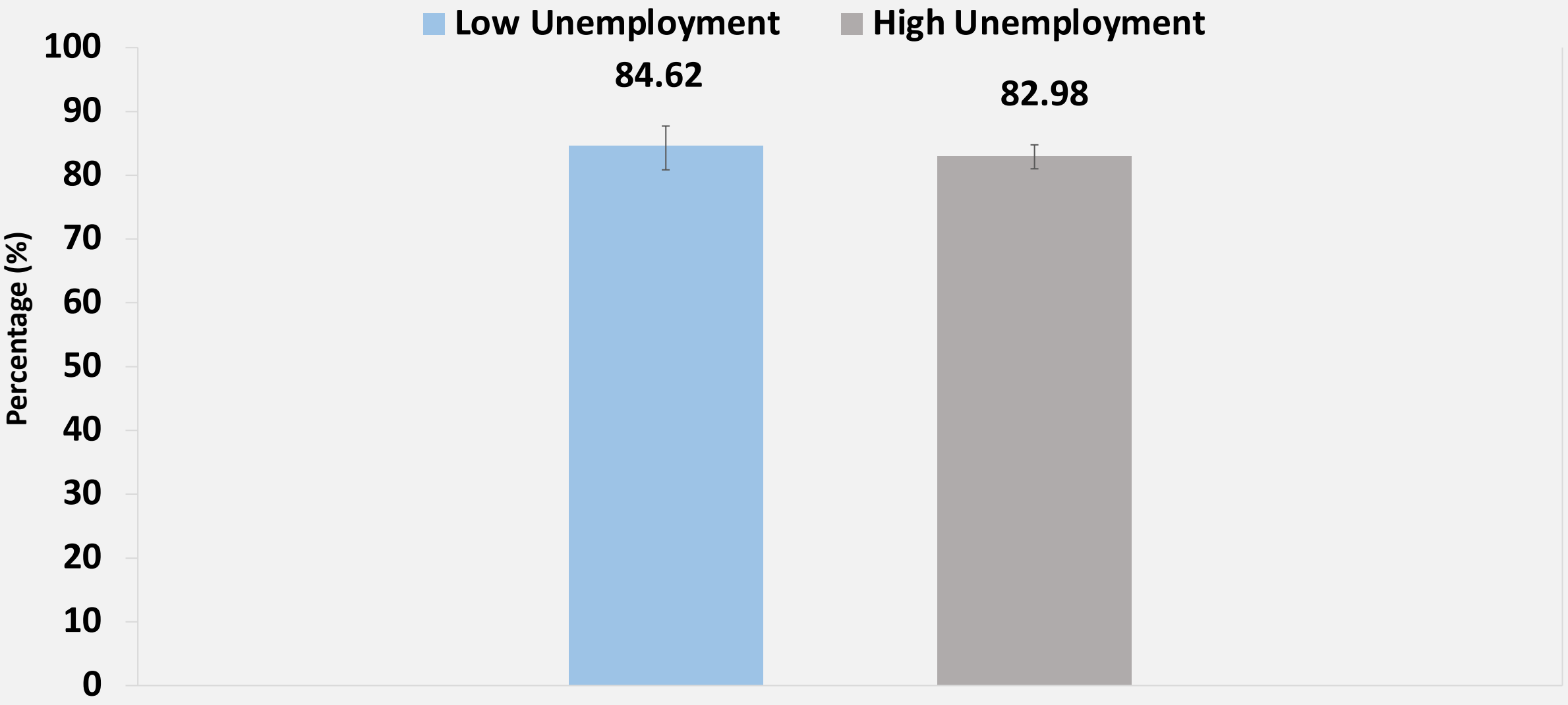
Infant Survival Among Hispanic Infants with Biventricular Defect, Area Poverty, 2011-2020



Infant Survival Among Hispanic Infants with Biventricular Defect, Area Uninsured, 2011-2020



Infant Survival Among Hispanic Infants with Biventricular Defects, Area Unemployment, 2011-2020



Objective #2: Top Five Utilized Z Codes in Fee for Service and Medicaid Managed Care Linked to the Texas Birth Defects Registry, 2018-2020, Any Primary CCHD

Z Code	Description	Percentage (Records, N=120)	Distinct Count Patients (Infant Deaths)
Z62	Child in welfare custody	40%	47
Z63	Problems related to primary support group	31%	35 (3)
Z60	Problem related to social environment	12%	14 (1)
Z65	Problem related to unspecified psychosocial circumstances	8%	9
Z59	Homelessness	3%	6
Z75	Problems related to medical facilities and other health care	6%	1
		100%	N=114/n=4

Conclusion - Neonate and Infant Survival of CCHDs by SDOH

Meaningful differences in survival among infants identified for:

1. Maternal race/ethnicity: lower among Hispanic mothers compared to NH White mothers

2. Infancy vs. neonate period: lower overall survival across maternal race/ethnicity in the infancy period

3. Defect severity: lower survival among infants with univentricular defects

4. Texas-Mexico border: lower survival among infants delivered to mothers who were residents of the Texas-Mexico border

5. SDOH: lower survival observed across three area-based SDOH

- Differences likely driven factors affecting infants and families residing in areas characterized by concentrated poverty and concentrated uninsured and varies by maternal race/ethnicity i.e., unique constellation of social factors Hispanic mothers and families residing in Texas experience

6. Z Codes: Infants and children with CCHDs experience many psychosocial factors/circumstances i.e., an opportunity to use Z codes to inform health care, social services, discharge planning, identify unmet needs, and inform referrals

Addressing Health Disparities: Connecting Children with CCHDs to Health and Social Services

Dayana Betancourt, MPH, MBA, Research Specialist

Birth Defects Epidemiology and Surveillance Branch (BDES)

2020

Birth Defects Epidemiology and Surveillance Branch (BDES) surveys mothers of young children with CCHDs

2021

BDES begins connecting 9-18-month-olds with CCHDs to DSHS social workers

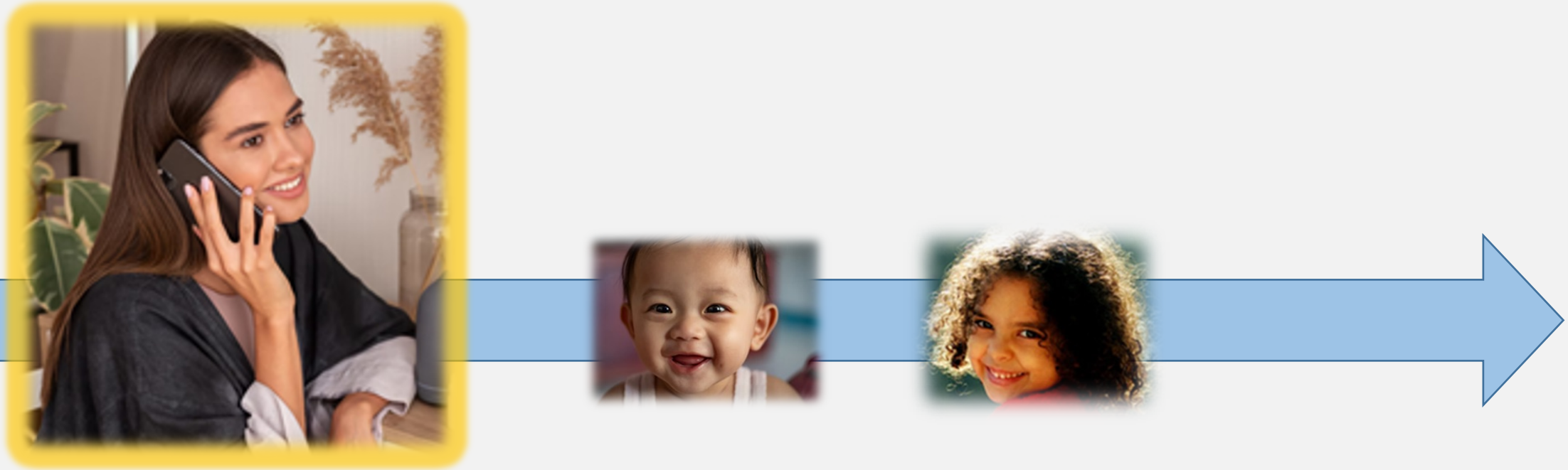
2021

BDES begins connecting 3-year-old children with CCHDs to DSHS social workers

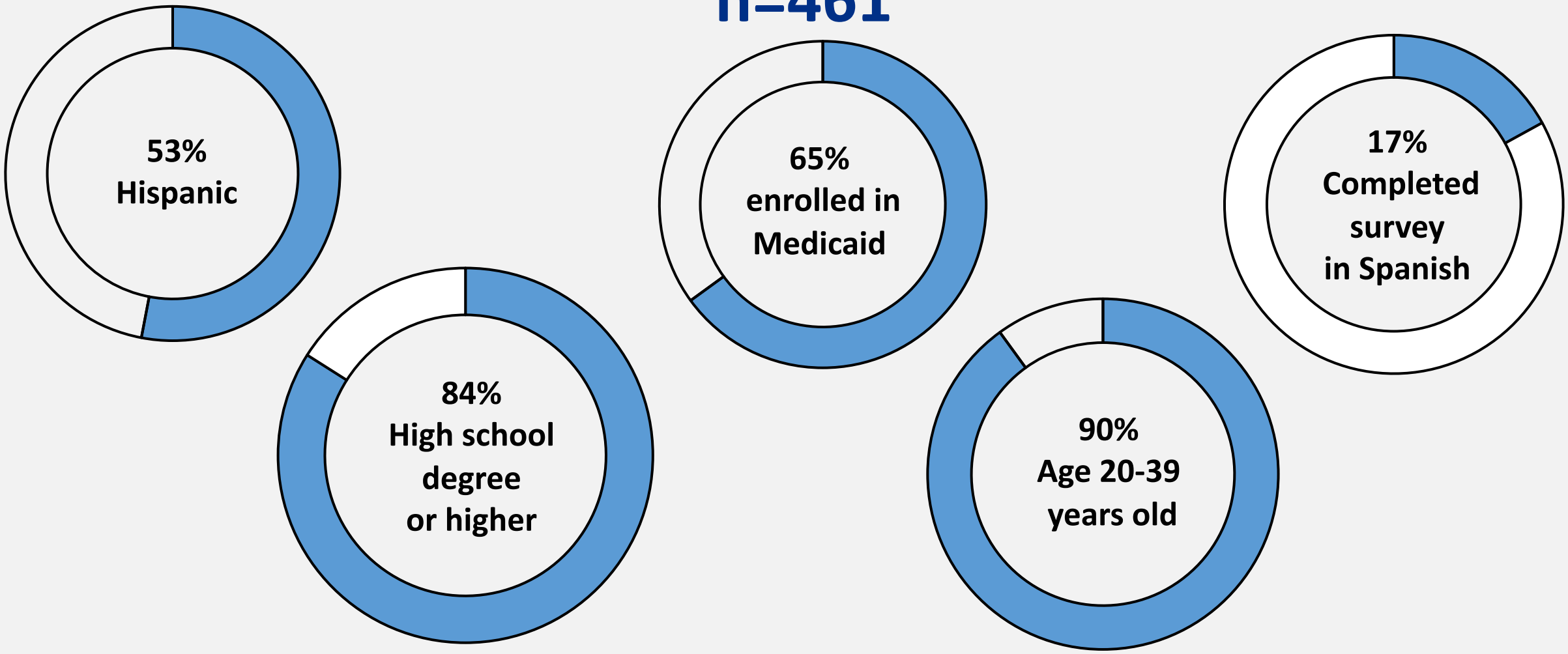
Surveying Mothers of Children with CCHDs in Texas

Survey: BDES surveyed mothers of young children with CCHDs

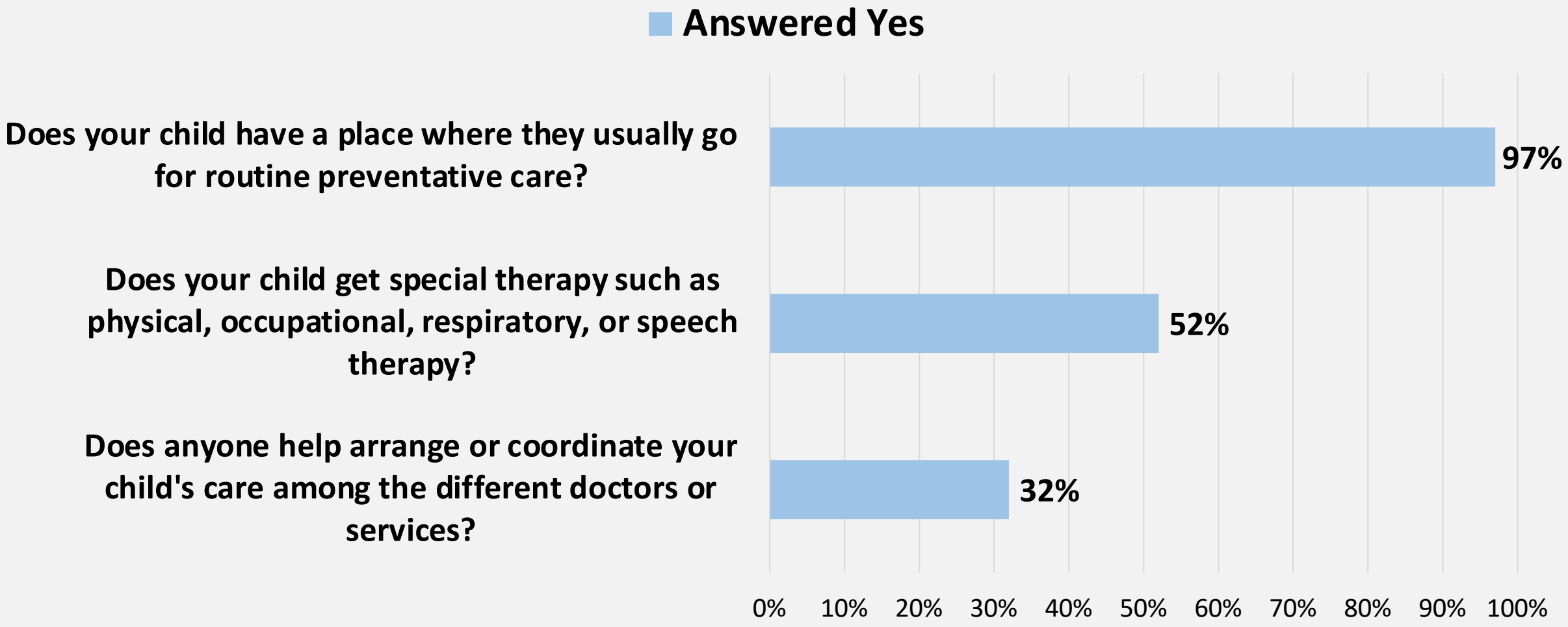
Goal: Identify unmet healthcare needs and barriers to accessing healthcare for their child



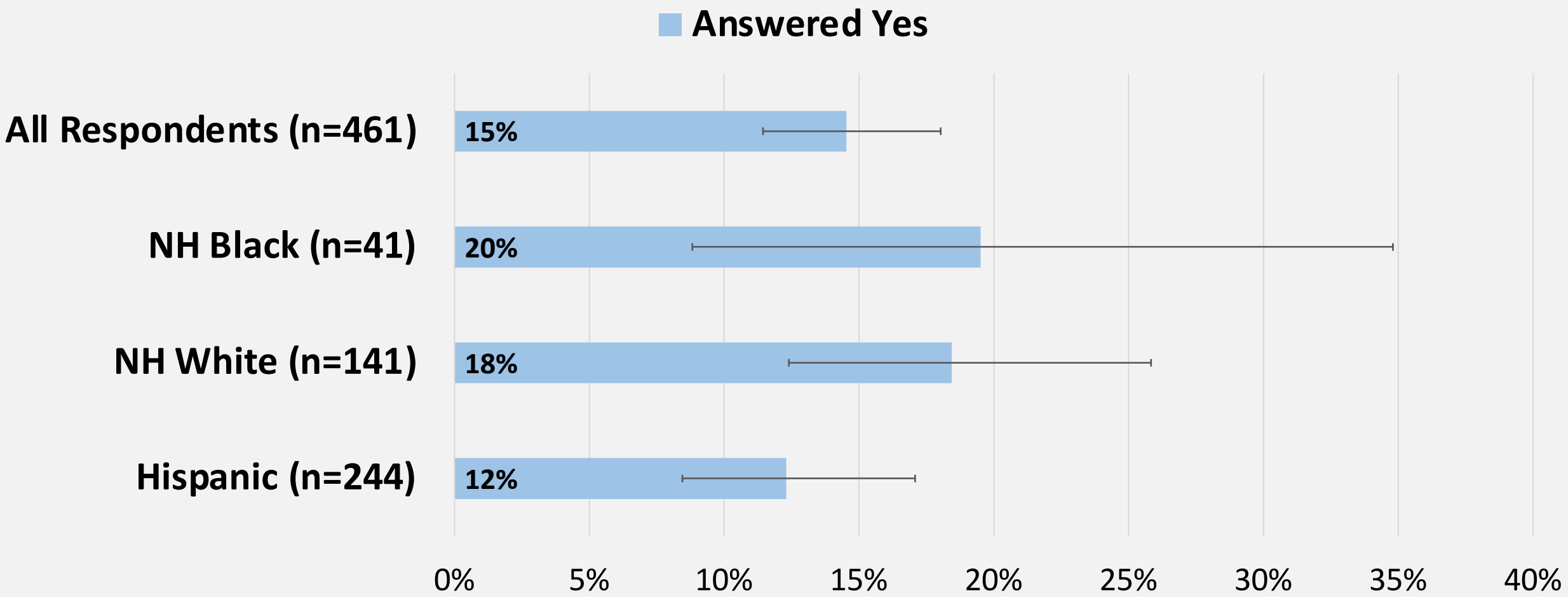
Socioeconomic Characteristics of Mothers of Children with CCHD who Participated in Survey n=461



Access to Services Reported by Mothers of Children with CCHDs (n=461)



During the past 12 months was there any time when your baby needed healthcare but did not receive it, or you had difficulty getting the care he/she needed?



Note: American Indian, Asian, and Other Race/Ethnicity categories are not shown.

Reasons why child with CCHDs did not receive healthcare needed or had difficulty accessing healthcare?

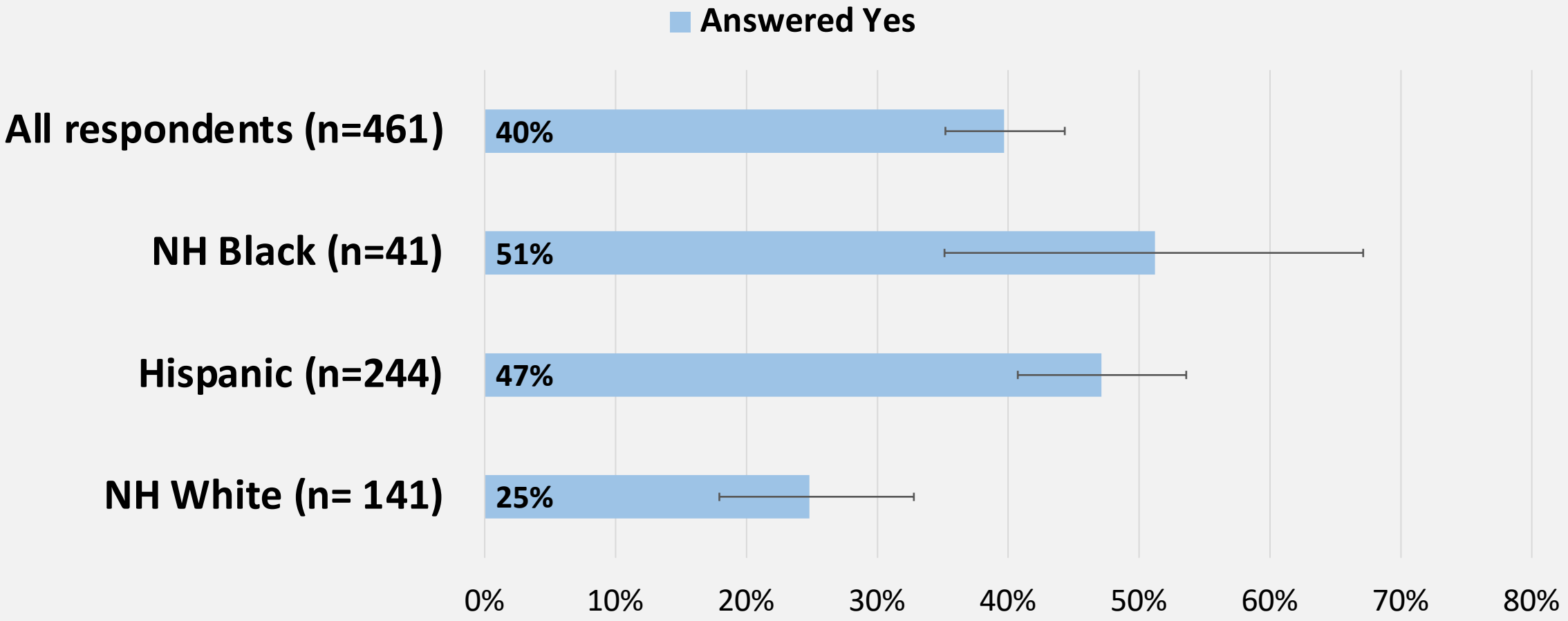
- Insurance issues
- Child not eligible for services
- Issues related to cost

"Insurance didn't want to cover certain things"

"Reached number of allotted therapy sessions dictated by insurance company"

"miscommunication with insurance"

Are you interested in being contacted by a social worker who can talk to you about services your child may be eligible for?



Note: American Indian, Asian, and Other Race/Ethnicity categories are not shown.

Summary – Surveying Mothers of Children with CCHDs in Texas

- 15% of mothers had difficulty accessing healthcare for their child
- 40% of mothers requested to be contacted by a DSHS social worker for assistance accessing health and social services

Connecting Young Children with CCHDs to Social Workers

Referrals: BDES routinely connects young children with select birth defects to DSHS social workers

Goal: Based on the survey with mothers, BDES began including children with CCHDs in this initiative

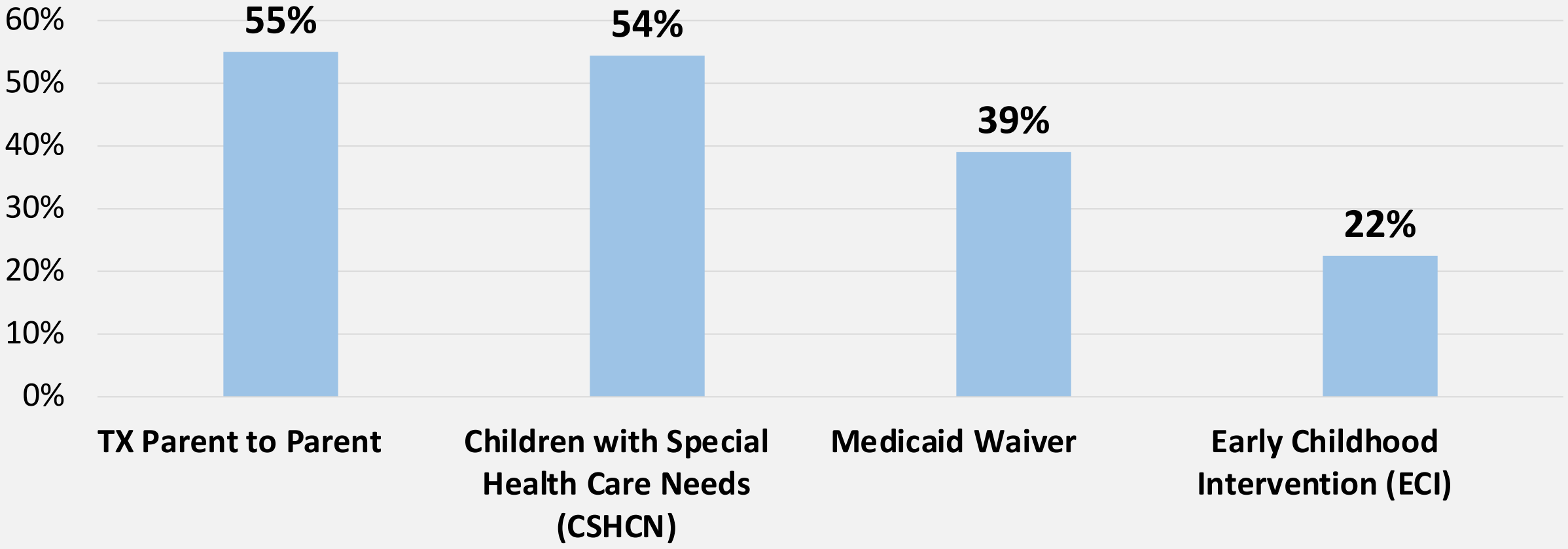
Results of Social Workers Contacting Families of Young Children with CCHDs

- Since May 2021, social workers reached **169 families** of young children with CCHDs and made a total of **596 referrals** to the following types of programs:
  - Medical
  - Financial
  - Developmental
  - Family Support
- **47%** of children were not meeting CDC developmental milestones
- **23%** requested case management
- **Finances** was the most common barrier reported

63%

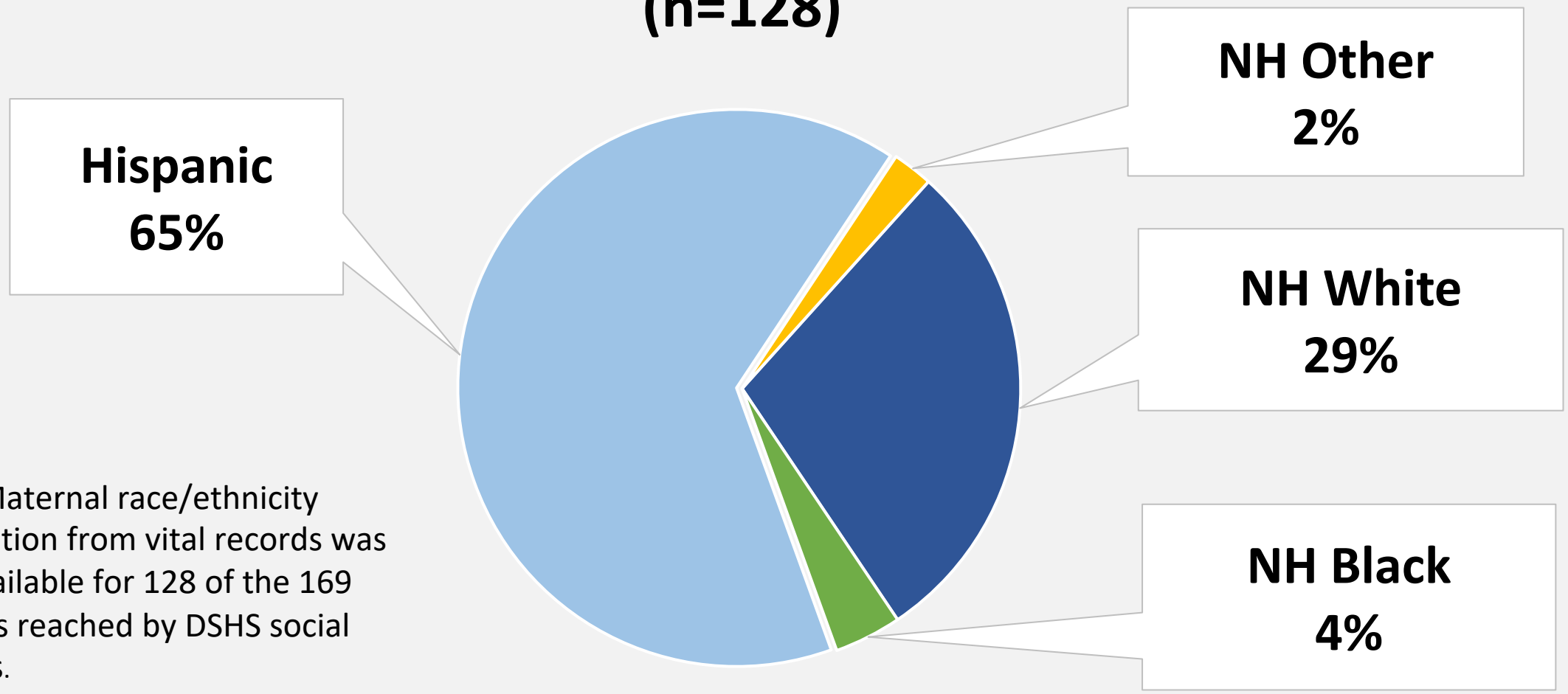
of families reached by DSHS social workers received 2 or more referrals to programs

Top Programs Families of Young Children with CCHDs were Referred to by Social Worker (n=168)



Note: Some families received multiple referrals to programs. All programs are not shown.

Race/Ethnicity of Mothers Reached by DSHS Social Workers for the Referral Initiative (n=128)



Note: Maternal race/ethnicity information from vital records was only available for 128 of the 169 mothers reached by DSHS social workers.

Summary – Connecting Young Children with CCHDs to Social workers

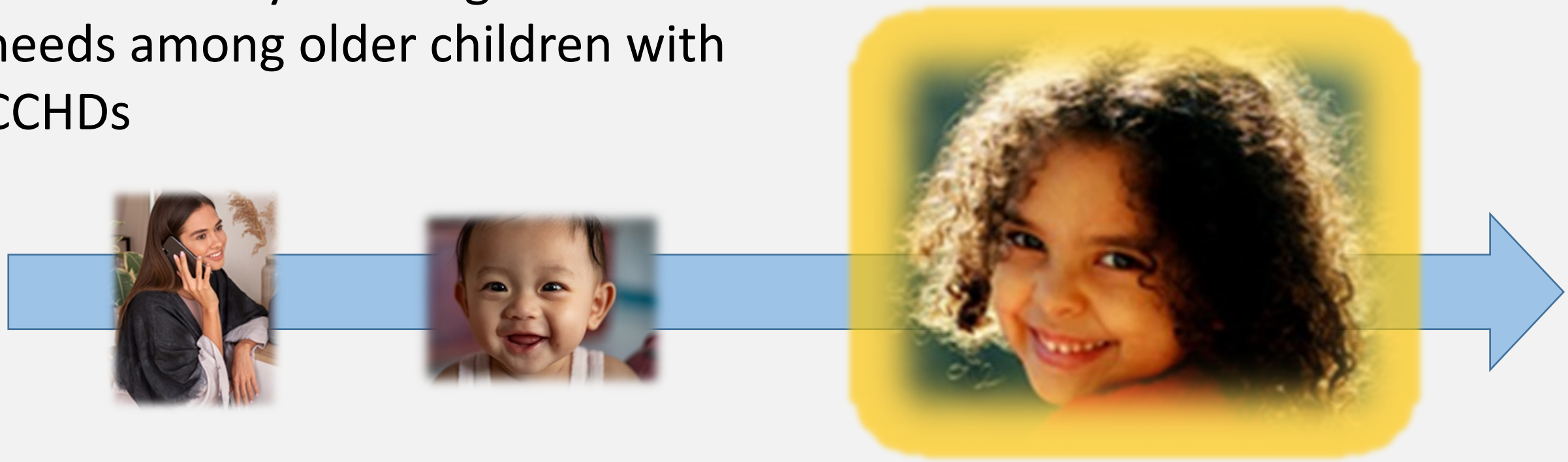
- Results of this initiative suggest that families of young children with CCHDs benefit from being connected with a social worker.
  - Most families (63%) received 2 or more referrals

- Based on maternal race/ethnicity data available from vital records, most children reached by social workers were Hispanic (65%).

Connecting Older Children with CCHDs to Social Workers

Pilot: Initiative to connect older children (3 years old) with CCHDs to social workers in the Houston area

Goal: Identify challenges and unmet needs among older children with CCHDs



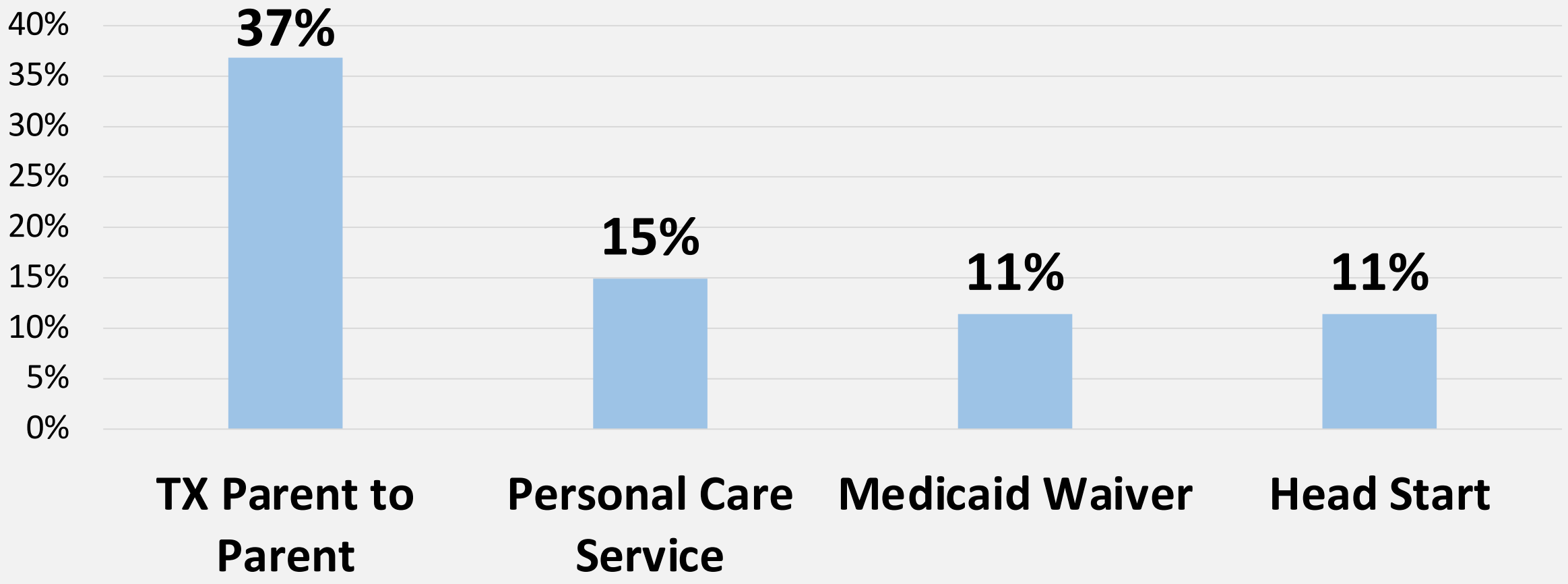
Results of Social Workers Contacting Families of Older Children with CCHDs

- Social workers reached a total of **114 families** and made a total of **170 referrals** to health and social service programs
- **35%** of children were not meeting the CDC developmental milestones
- **24%** of families requested case management
- **Finances** was the most common barrier reported

31%

of families of older children received 2 or more referrals to programs from DSHS social workers

Top Programs Families of Older Children with CCHDs were Referred to by DSHS Social Workers (n=114 families)



Note: Some families received multiple referrals to programs. All programs are not shown.

Summary – Connecting Older Children with CCHDs to Social Workers

- Compared to younger children with CCHDs, older children:
  - Received less referrals to programs
  - Were more likely to be meeting CDC milestones
  - Were equally likely to request case management
  - Also reported finances as the top barrier

- Older children with CCHDs may also benefit from social work contact

Summary

Survey:

- 15% of mothers of children with CCHDs reported difficulty accessing healthcare for their child
- 40% of mothers of children with CCHDs requested to be contacted by a DSHS social worker for information about services

Referrals:

- BDES began connecting young children with CCHDs to DSHS social workers
- 47% were not meeting CDC developmental milestones
- Most families received multiple referrals to programs
- Black families may be underreached

Pilot with Older Children:

- BDES began connecting older children with CCHDs to social workers
- 35% were not meeting CDC developmental milestones
- Families of older children were interested in case management

Conclusion and Looking Ahead

- Mothers of children with CCHDs reported difficulty accessing care and expressed interest in being connected to a social worker
- Issues with insurance and finances are the top barriers to healthcare
- Families of children with CCHDs may benefit from being connected to a social worker for assistance accessing services, regardless of insurance status or child's age

Thank you!

Disparities in Critical Congenital Heart Defect Occurrence and Outcomes Among Infants in Texas

BirthDefects@dshs.texas.gov

TEXAS
Health and Human Services

Texas Department of State Health Services

East Texas family fights for newborn heart screenings

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Indy’s Case Presentation

CARTHAGE, TX (KSLA) - An East Texas family nearly lost their newborn daughter after a routine health screening failed to identify a life-threatening heart condition. Now, they're pushing for mandatory cardiac echocardiograms for newborns in hopes of saving lives. Indy Deason was just one week old when she suddenly turned blue while she was being fed. She went into heart failure and nearly died. The newborn was in the hospital for a month. First, she was taken to a hospital in Nacogdoches.

"She even had the pediatrician stumped. We were in the Nacogdoches hospital for almost a whole day before she went into respiratory distress and they had to intubate her. I mean it happened like in an instant," said Amanda Deason, Indy's mom. After that, Indy was flown to Shreveport before she was ultimately taken to Children's Medical Center in Dallas.

Doctors discovered Indy had a congenital heart defect that caused one of her aortas to be narrowed, forcing her little heart to pump harder. That caused her to have no blood flow to the lower half of her body, and sent her into multi-organ failure. A day before, she was at her week-old check up and was given a clean bill of health. It was not until after her parents rushed their newborn to the hospital that they learned the severity of the situation. "If we wouldn't have taken her in, she wouldn't be with us," said Deason.

Despite tests showing Indy was healthy, her family feels doctors would have found the problem earlier if they had been required to perform an echocardiogram on her heart. It's a defect that affects 1 in every 100 babies every year, according to the Children's Heart Foundation.

"I don't want that to ever happen to anyone else," said Carriston Hendricks, a family friend working to make Indy's Law a reality. "Our biggest concern is there are babies that are sent home every day that are "healthy." And then all of a sudden just like Indy, the unfortunate happens and they're having to rush to an ER.“ 9 months later, Little Indy is happy and healthy. Now, her parents and Hendricks are hoping to use their experience to help save lives.

Last week, they met with Representative Chris Paddie's office to try to get the ball rolling on 'Indy's Law.' It's a bill that would require all doctors to do an echocardiogram before a baby ever goes home."I don't know if we'll ever get our wish - but at this point in time we have our miracle baby and I just want others to have theirs too," said Hendricks. Her parents believe Indy is already influencing the doctors who treated her.

"She has already saved babies lives, they just use extra precaution," said Amanda. "Happy Jesus and the doctors made Indy's heart feel better," said Presley Deason, Indy's big sister. Indy's family and friends are asking everyone to send a letter to Chris Paddie's office, asking him to support this initiative. If you're interested in writing a letter to Paddie's office, you're asked to send them to Ray Wilson.

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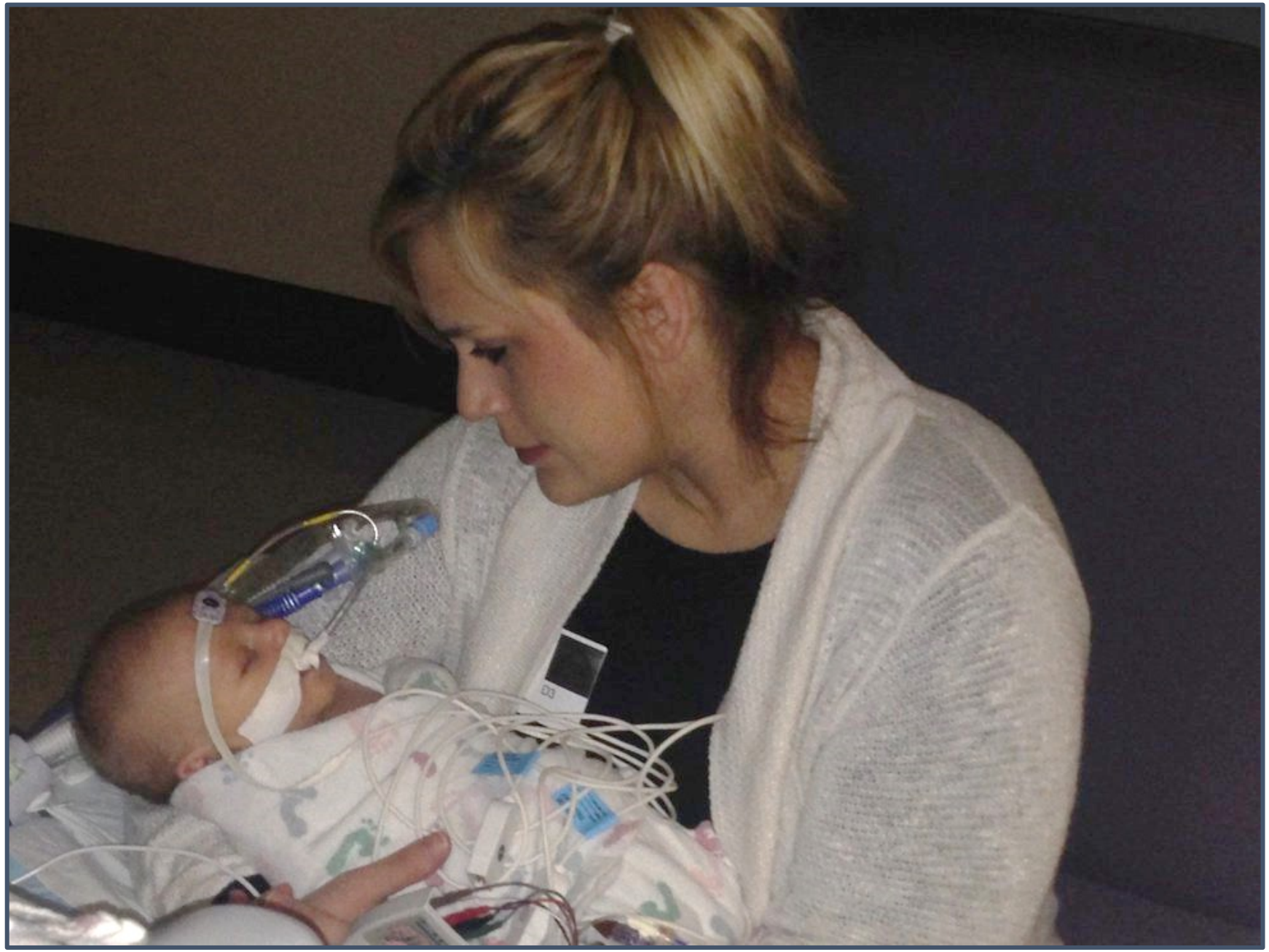

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Recommendations from TX NBSAC

1. The Texas Administrative Code be changed to allow for newborn screening data to be sent to the Newborn Screening Program.
   - substantially change the logistics and costs of the point-of-care CCHD screening (example: to have hospitals use Pulse ox that report data)
2. The Texas Administrative Code be amended to clarify responsibility for CCHD reporting.
   - Add cardiologist to do reporting
3. The Texas Department of State Health Services develop and support a network of community champions to educate and motivate those responsible for CCHD screening and reporting to follow best practices.
   - Utilize Regional Advisory council and TCHMB to promote CCHD screening as Quality Improvement
   - Allow State to know if all delivering hospitals Levels I-IV are following screening guidelines

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CCHD Project Status + Next Steps

1. CCHD project approved by Neonatal Committee members and TCHMB Executive Committee as the next Neonatal Committee project
2. Next step: Develop a needs assessment survey to better understand the landscape of CCHD screening in Texas perinatal hospitals
3. Findings from survey will be used to inform and develop QI project with project workgroup
4. Survey to be distributed via TCHMB in partnership with RAC/PCR Alliance

Problem: Critical Congenital Heart Disease (CCHD)

- Based on projected CCHD data and the Texas Birth Defects Registry Data confirmed CCHD cases are being under reported to the Texas DSHS
- Current Texas state policy requires universal CCHD screening,
  - however, there is no mechanism to verify that all infants are being screened for CCHD in Texas
  - No process to measure compliance or standardization

Needs Assessment

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TCHMB Neonatal Committee:

Critical Congenital Heart Disease (CCHD) Screening Needs Assessment Survey

Overall goal: To improve CCHD screening and reporting processes and reduce missed CCHD cases; what can we do as a state to improve CCHD screening?

Specific Aims: (1) Understand current stage of CCHD screening and reporting, and (2) identify barriers to screening and follow-up among Texas perinatal hospitals

Data collection plan: REDCap survey disseminated via RAC/PCR Alliance to Texas perinatal hospitals

A. Hospital Characteristics

1. Hospital Name
   i. Select from dropdown list of 222 Texas birthing facilities

2. Setting
   i. Mother-baby unit
   ii. NICU
   iii. Other (Specify): _____

3. Your role
   i. Maternal program Manager
   ii. Maternal Medical Director
   iii. NICU Program Manager
   iv. Neonatal Medical Director
   v. Unit Manager/Clinical Manager
   vi. Other (Specify):_____

4. Hospital type
   i. University-based
   ii. Community hospital with university affiliation
   iii. Community-based
   iv. Don't know

5. Annual delivery volume
   i. <1,000 annual births
   ii. 1,000-5,000 annual births
   iii. >5,000 annual births
   iv. We do not have deliveries at our hospital
   v. Don't know

6. Maternal level of care designation

   i. I
   ii. II
   iii. III
   iv. IV
   v. Don't know

7. NICU level of care designation
   i. I
   ii. II
   iii. III
   iv. IV
   v. Don't know

B. Screening and Management

Screening for CCHD of all newborns at a birthing facility has been mandatory in Texas since 2014. Every newborn in Texas should receive CCHD screening.

1. Are you aware of the Texas requirements for screening for CCHD?
   i. Yes
   ii. No

2. Are all babies in all your units screened for CCHD, either by pulse oximetry or by postnatal echocardiogram?
   i. Yes
   ii. No
   iii. Don't know
      1. If no, approximately what proportion of newborns are screened?
         a. Less than half
         b. About half
         c. More than half
         d. Don't know

3. Does your unit have a written or electronic policy on screening for CCHD?
   i. Yes
   ii. No
   iii. Don't know

4. When are infants typically <u>first</u> screened for CCHD in your unit?
   i. < 24 hours after birth
   ii. ≥ 24 hours after birth
   iii. Other (Specify):_____
   iv. Don't know

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5. Do infants in your units routinely receive a 2nd or 3rd CCHD screen?
   i. Yes
   ii. No
   iii. Don't know

6. Does your hospital have capacity to perform a neonatal echocardiogram within the hospital?
   i. Yes
   ii. No
   iii. Don't know

   If yes, what is the availability of echocardiogram at your hospital?
   iv. Available at all times (24/7)
   v. Partial coverage

   If no, what alternative strategies do you use?
   i. Keep baby until evaluation can be performed
   ii. Inpatient transfer to advanced nursery (without cardiac inpatient service)
   iii. Outpatient transfer to center with an echocardiogram machine

7. Is the provider reading the echocardiogram a pediatric cardiologist?
   i. Yes
   ii. No
   iii. Don't know

8. What steps do you follow for a positive CCHD screen? (select all that apply)
   i. Clinical assessment/Pulmonary evaluation
   ii. Order complete echocardiogram (inpatient or outpatient)
   iii. Refer to pediatric cardiology or transfer to facility with pediatric cardiology
   iv. Other (specify): _____

9. How do you manage patients with confirmed CCHD? (select all that apply)
   i. Referral to a pediatric cardiologist
   ii. Connect with support group and/or other resources
   iii. Other (specify): _____
   iv. Don't know

10. What challenges do you currently face with doing newborn heart screening? (select all that apply)
    i. Were not aware of screening requirements
    ii. Costs and/or reimbursement for screening
    iii. Additional workload for screening
    iv. Staff education about how to screen
    v. Lack of screening equipment
    vi. Screening is not built into our current workflow
    vii. Don't know where to refer for follow up
    viii. Other (specify): _____
    ix. We do not experience any challenges

C. Reporting

Texas law (House Bill 740) requires that confirmed CCHD cases are reported to the DSHS Texas Newborn Screening program. Confirmed case information must be entered into the form located on the DSHS website (http://www.dshs.state.tx.us/newborn/) and faxed to DSHS.

1. Are you aware of the requirements for reporting confirmed CCHD cases to the DSHS registry?
   i. Yes
   ii. No
   iii. Don't know

2. Do you have a system in place for reporting confirmed CCHD cases to the DSHS registry?
   i. Yes
   ii. No
   iii. Don't know

3. In your unit, do you have a dedicated person responsible for reporting confirmed CCHD cases to the DSHS Texas Newborn Screening program?
   i. Yes
   ii. No
   iii. Don't know

4. What challenges do you currently face with reporting confirmed CCHD cases to the DSHS Texas Newborn Screening program? (Select all that apply)
   i. Didn't know reporting was mandated
   ii. Don't know what data elements are required for reporting
   iii. Don't know where to report confirmed cases
   iv. Inadequate resources to collect the needed data
   v. Lack of personnel dedicated to reporting
   vi. Reporting system is too time-consuming or cumbersome
   vii. Reporting is not built into our current workflow
   viii. Lack of technical assistance to support reporting
   ix. Other (specify): _____
   x. We do not experience any challenges

D. Improvement Opportunities

1. Are there aspects of CCHD screening that you feel need improvement in your unit?

2. Would you be interested in participating in a quality improvement initiative to improve CCHD screening and referral?
   i. Yes
   ii. No
   iii. Don't know

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What's next?

1. What are some suggestions for a statewide CCDH Screening QI project to improve screening that would be specific to Texas patients?
2. What outcomes could be measured to show CCHD screening improves the lives of patients and their families?

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Picture of TXPOP group

Introduce Drs. Freedenberg, O'Campo, and McKee-Garrett, part of original TXPOP team

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Breakout Sessions with Instructions – 15 min

- Questions we want them to address
  - What needs to be done to improve CCHD screening program
- Timeline-
  - Screening after birth – informing family
  - Interpretation of results and charting onto medical record
  - Report to provider
  - Education of parents of results
  - Next steps

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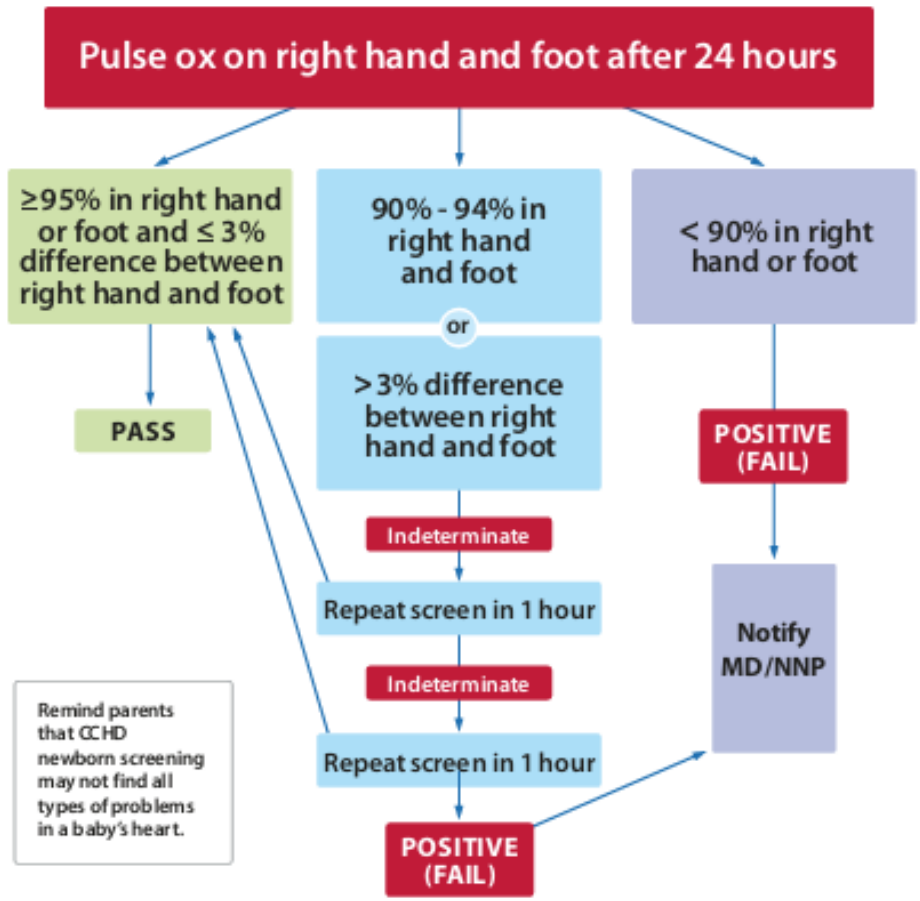
Critical Congenital Heart Disease
Newborn Screening Algorithm



A Joint Educational Initiative of
The University of Texas Health Science Center at San Antonio/Department of Pediatrics, Baylor College of Medicine/Department of Pediatrics and Texas Department of State Health Services

texas pulse oximetry project txpop

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Come back together

- Summarize group suggestions for QI

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Thank You

Any Questions?

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