

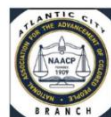
Community Led Patient Experience

NAACP Maternal Experience Survey

Helen Hannigan, MGA

Maternity Action Plan Work Session:
Collecting and Using Data to Improve Equity and Quality

1/27/2023



FAMILY HEALTH INITIATIVES

Total Responses

216

Most Recent
Survey End Date:
1/4/2023

Prematurity Prevention Initiative

- Clinical Expertise
- Clinical Intervention
- Assessment
- Community Engagement
- Community Voice

A Partnership from the Start

- **NJ Department of Health**
 - Melita Jordan
 - Nashon Hornsby, Esq.
- **Clinical Leadership**
 - Dr. Ron Librizzi, DO
 - Dr. Wendy Warren, MD
 - Dr. Judy Ruffin, MD
 - Dr. Dianne Timms, MD
 - Dr. Lisa Gittens-Williams
- **Community Partners**
 - Partnership for Maternal and Child Health of Northern NJ
 - Southern NJ Perinatal Cooperative
 - Acenda
 - Advocates for Children of New Jersey
 - Central NJ Family Health Consortia

NAACP-AC Black Infant and Maternal Mortality Task Force

- Committed to mitigating disparities that impact black birthing people and their families.
- Legislators, health professionals, educators, faith-based leaders, community members and many others who seek change in their communities and the state at large.
- Committed to building a community-level action response to the social and birthing injustice in New Jersey.

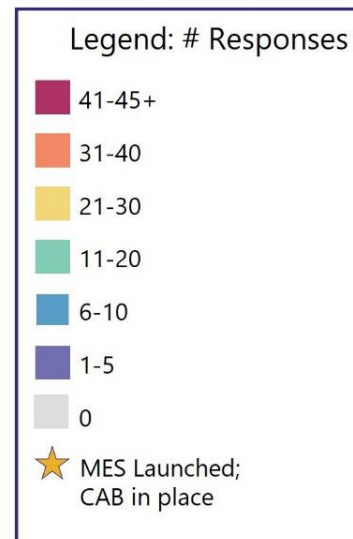
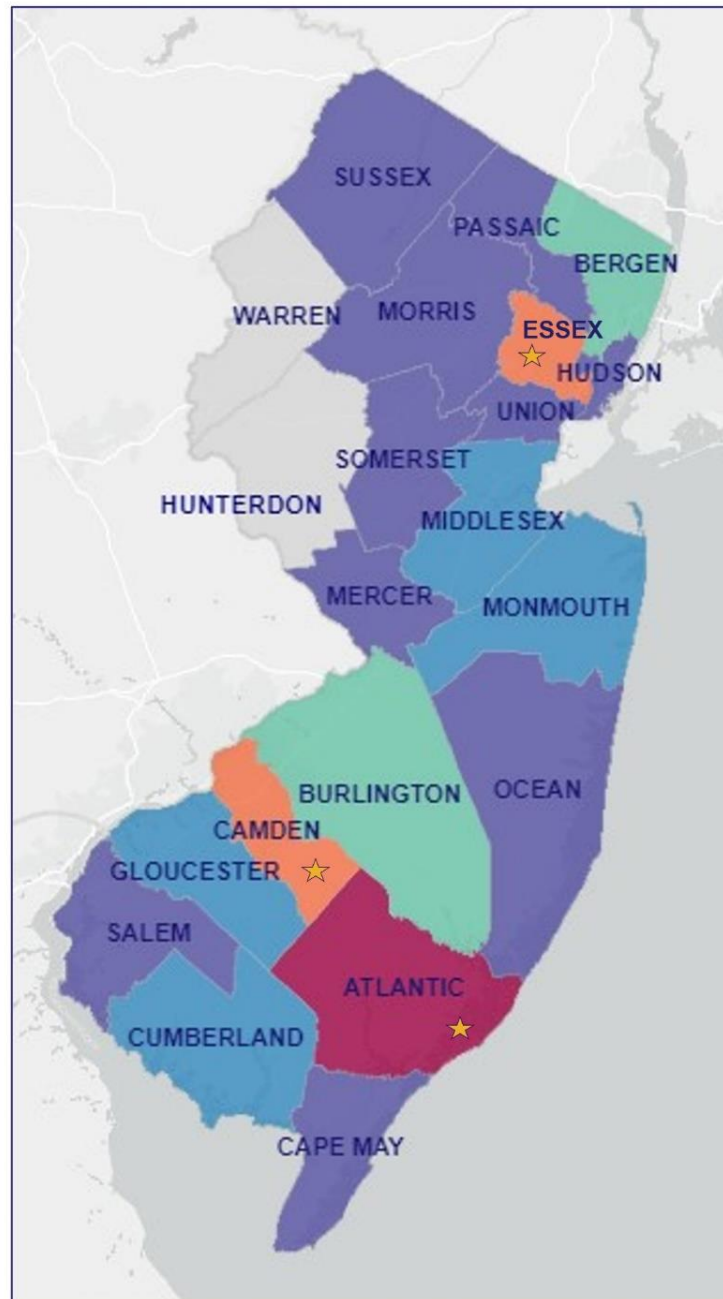
MES Responses through 1/20/2023

Total Responses

216

Most Recent
Survey End Date:
1/4/2023

MES Data: # Responses by County



County	Total Complete
Atlantic	20%
Bergen	5%
Burlington	6%
Camden	18%
Cape May	3%
Cumberland	4%
Essex	17%
Gloucester	3%
Hudson	2%
Mercer	2%
Middlesex	5%
Monmouth	3%
Morris	2%
Ocean	1%
Passaic	2%
Salem	2%
Somerset	1%
Sussex	1%
Union	1%
Total	100%

As of **January 20, 2023**,
55% of responses ($n=119$) came from **counties with a Community Advisory Board (CAB) in place:**
Atlantic, Camden, and Essex counties, with a total of **216 responses** across NJ.

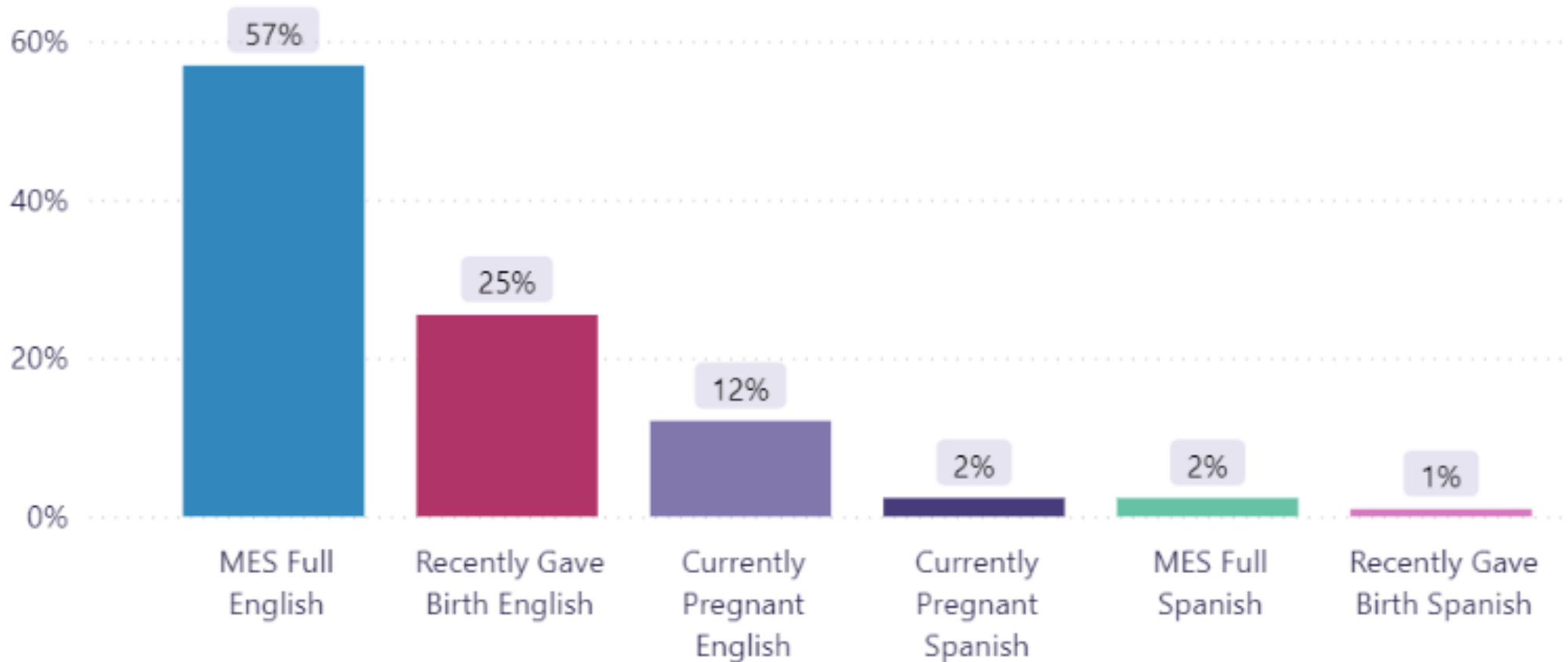
MES Responses through 1/20/2023

Total Responses

216

Most Recent
Survey End Date:
1/4/2023

% Responses by Survey Breakout



Categories include 2022 & 2021 survey links

As of **January 20, 2023** there were **216 responses** across all MES Breakouts.
59% ($n=128$) of responses came through the MES Full Survey- English or Spanish.
41% ($n=88$) of responses came through one of the MES Breakouts, English or Spanish.

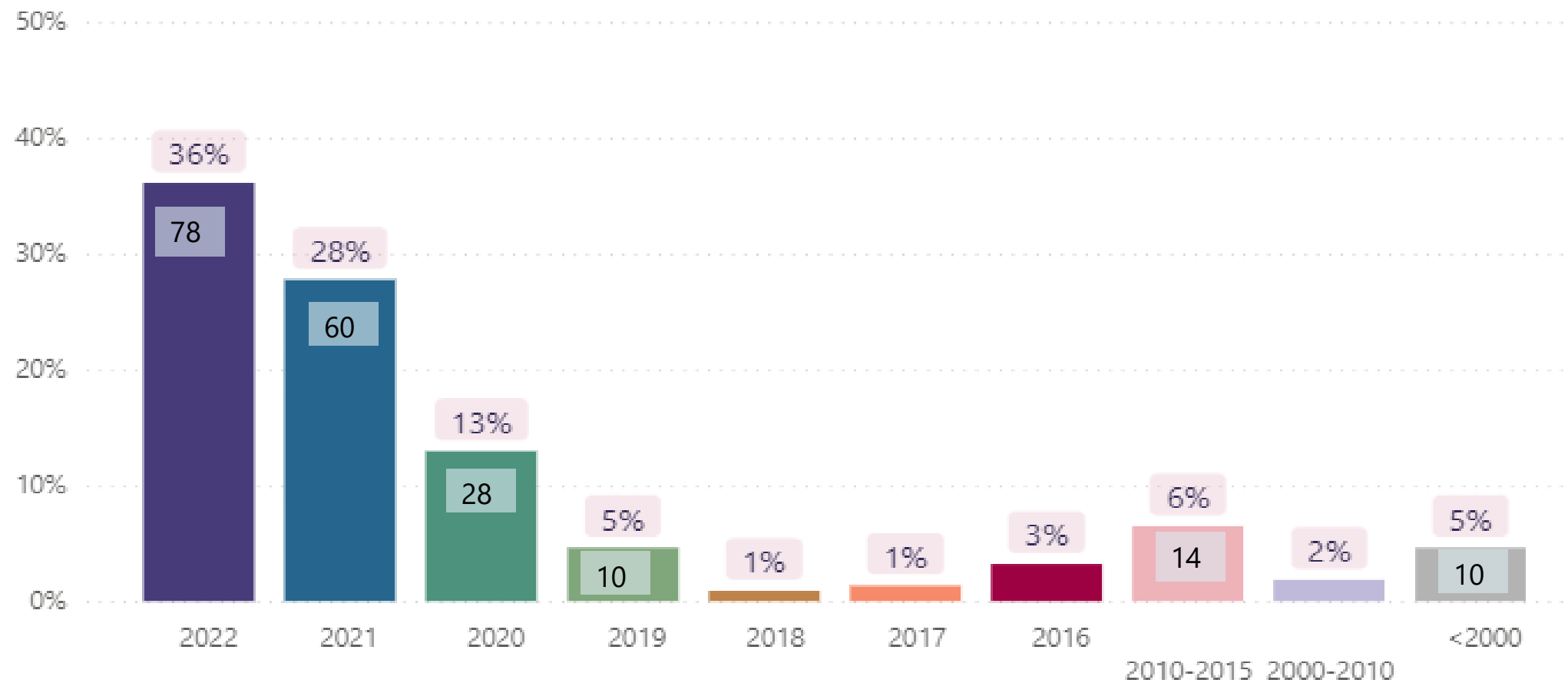
MES Responses through 1/20/2023 by Year of Pregnancy

Total Responses

216

Most Recent
Survey End Date:
1/4/2023

of Responses by Year of Pregnancy



As of **January 20, 2023**, out of **216** responses,

36% ($n=78$) of respondents were pregnant in **2022**.

28% ($n=60$) were pregnant in **2021**.

13% ($n=28$) were pregnant in **2020**.

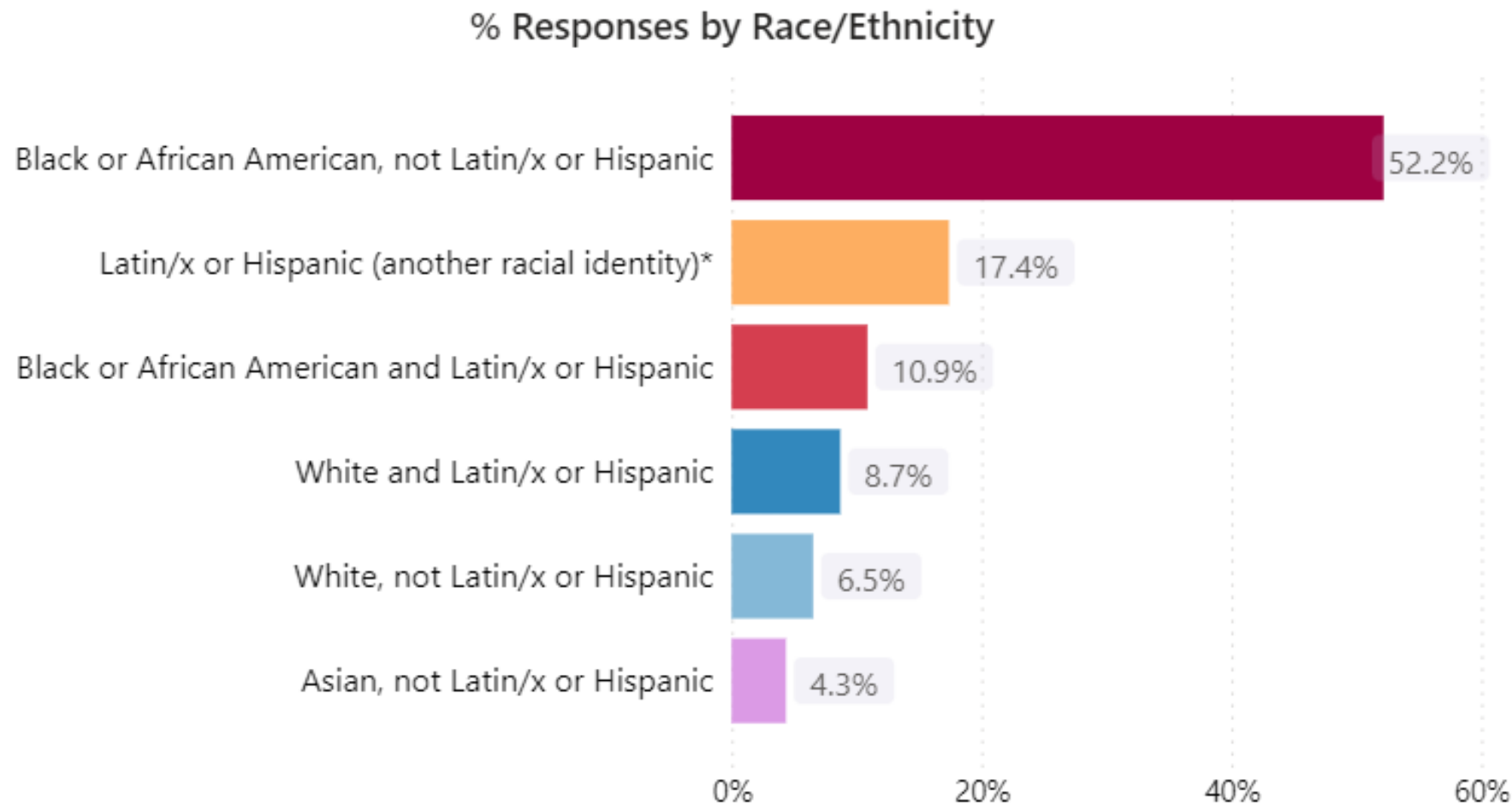
5% ($n=10$) were pregnant in **2019**.

Of the 216 respondents, 14% ($n=31$) were pregnant at the time of response and may deliver and/or have delivered in 2023.

86% ($n=185$) of respondents **discussed a pregnancy outcome** including live birth, termination, or stillbirth after 21 weeks.

MES Responses by Race/Ethnicity, 1/1/2021-12/31/2021

Total Responses
46

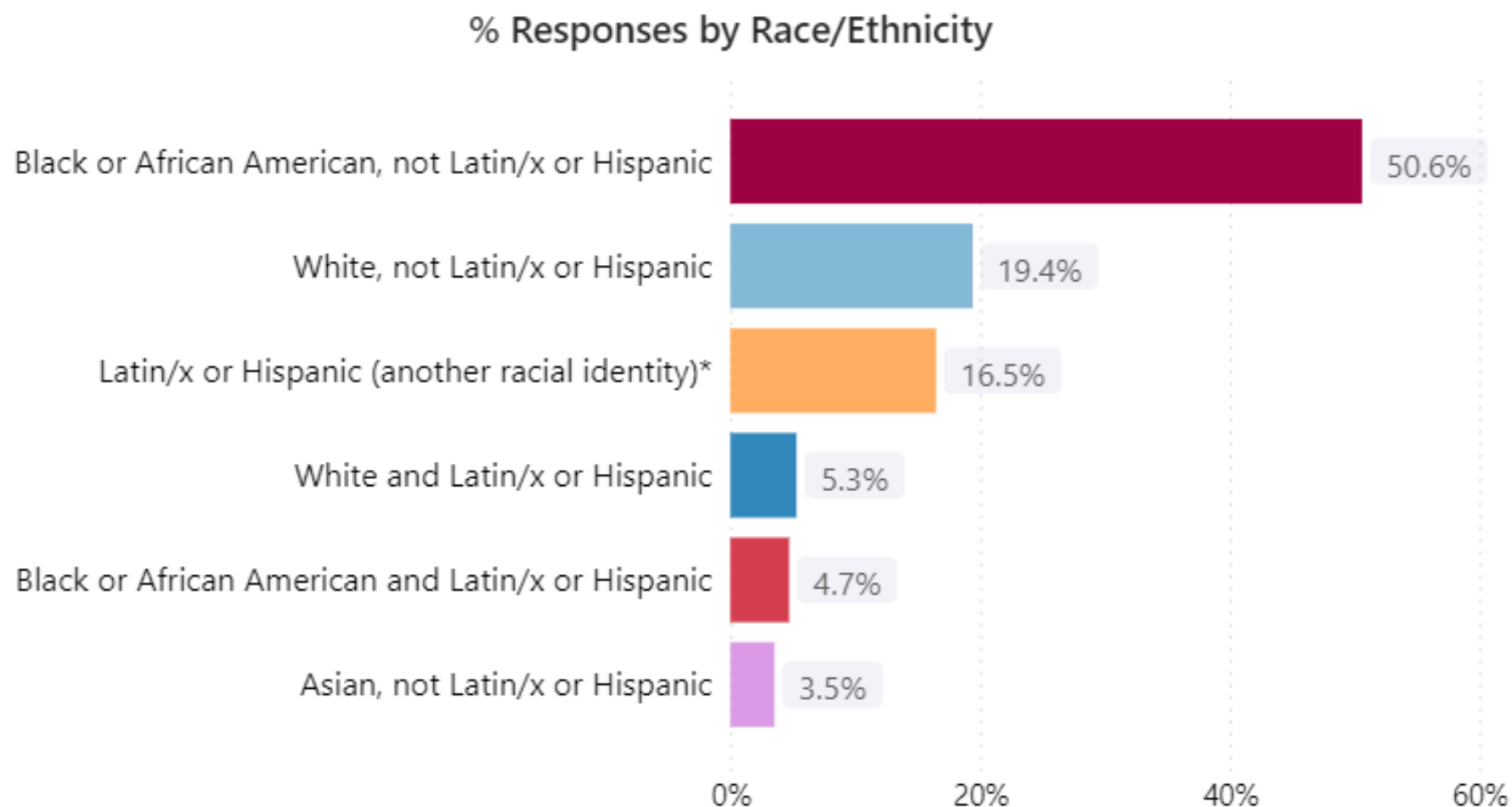


Of the 46 responses collected in 2021,

63% of respondents ($n=29$) identified as **Black or African American**,
36% of respondents ($n=17$) identified as Latina, Latin/x, or Hispanic (of any race)

MES Responses by Race/Ethnicity, 1/1/2022-1/4/2023

Total Responses
170



Of the 170 responses collected in 2022-2023,

55% of respondents ($n=94$) identified as Black or African American,
26% of respondents ($n=45$) identified as Latina, Latin/x, or Hispanic (of any race).

MES Responses by Predefined Age Groups, through 1/20/2023

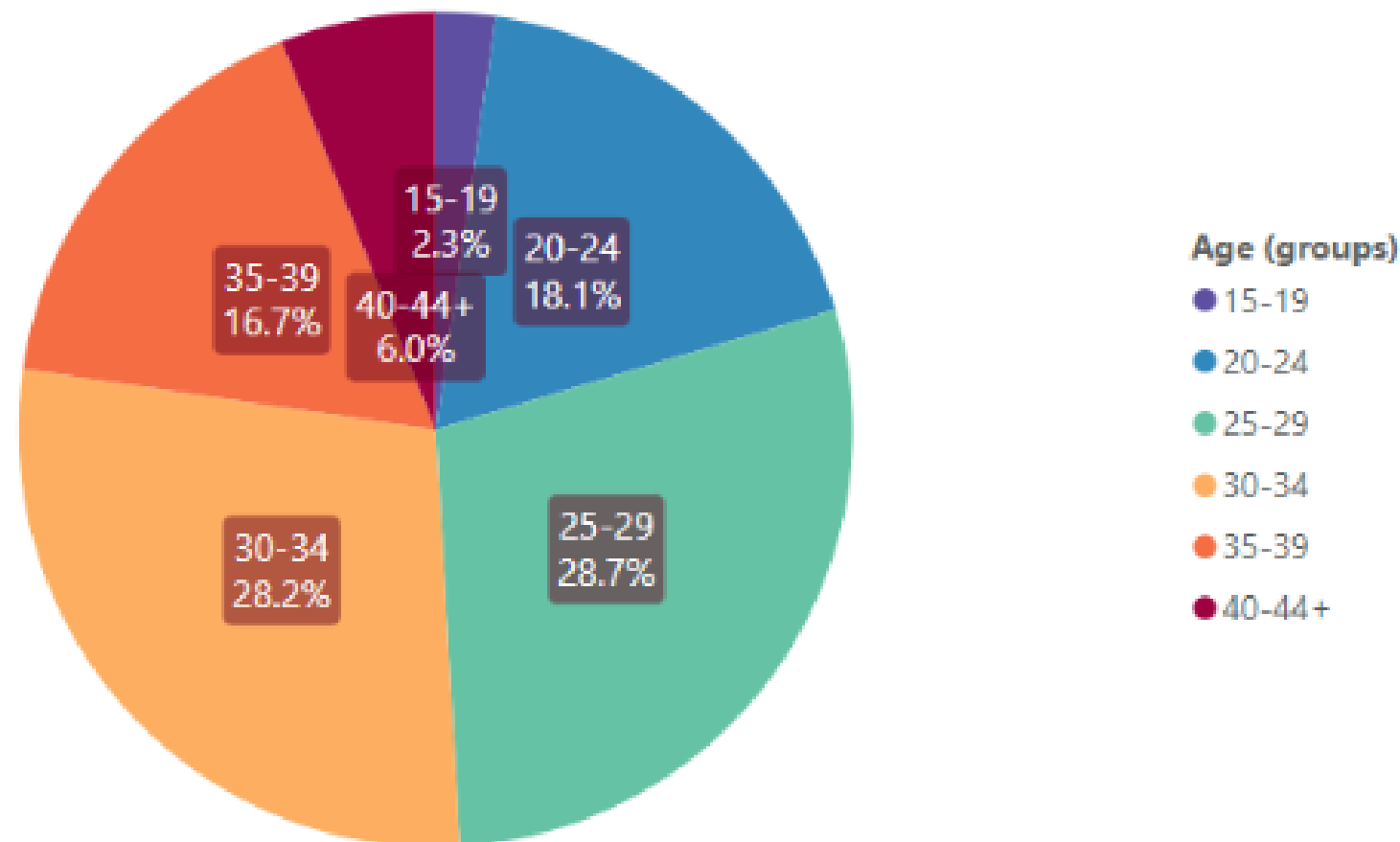
% Responses by Predefined Age Groups

Total Responses

216

Most Recent
Survey End Date:

1/4/2023

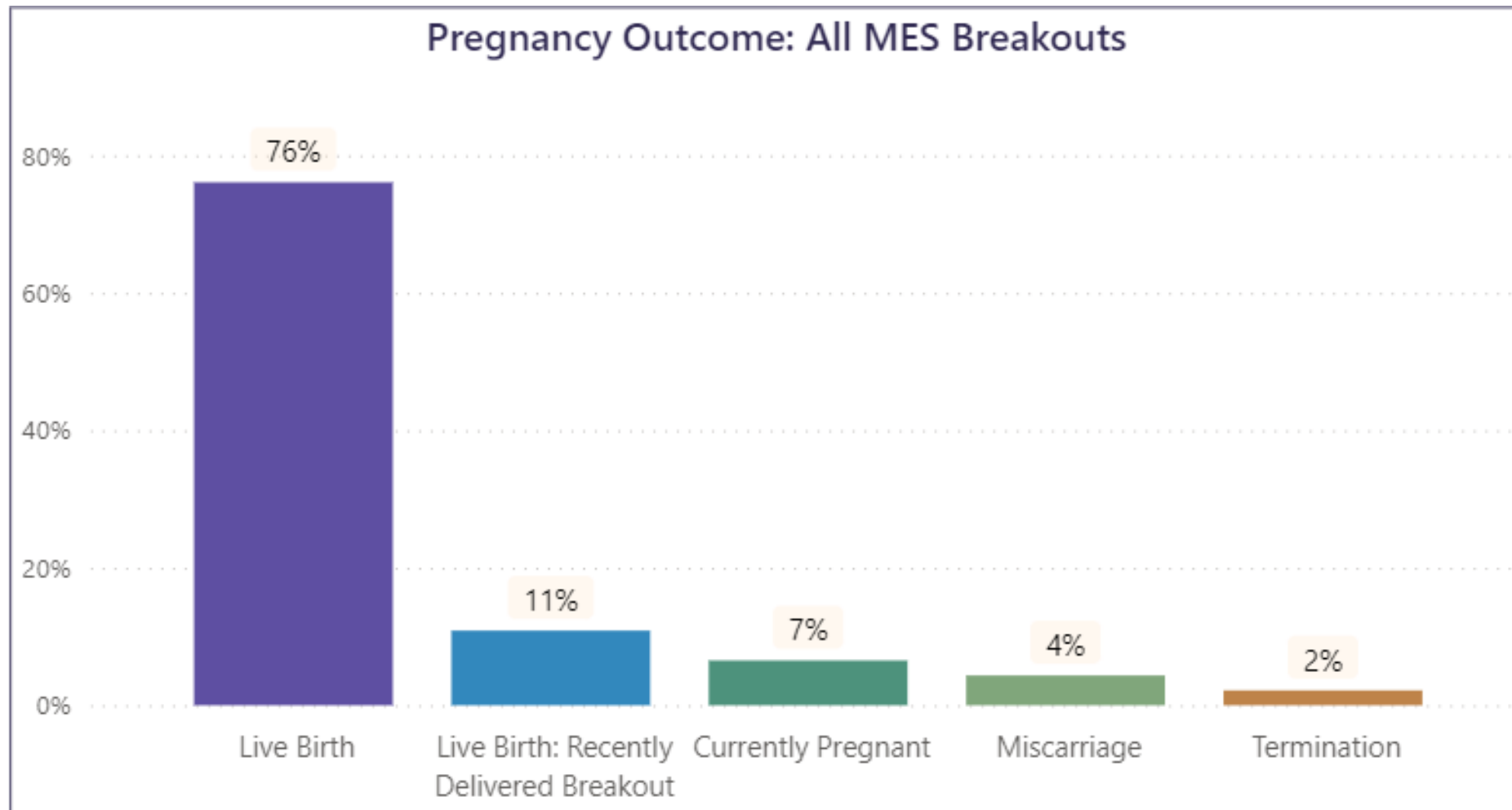


As of **January 20, 2023**, out of **216 total responses** across all age groups,
20% of respondents ($n=44$) were **ages 15-24**.
57% of respondents ($n=123$) were **ages 25-34**.
23% of respondents ($n=49$) were **ages 35-44+**

MES Responses by Pregnancy Outcome, 1/1/2021-12/31/2021

Total Responses

46



Of the 46 responses collected in 2021,

76% of respondents ($n=35$) experienced a live birth and responded to the Full MES,
11% of respondents ($n=5$) experienced a live birth and responded to the Recently Delivered Breakout,
7% of respondents ($n=3$) were currently pregnant and responded to the Currently Pregnant Breakout or Full MES,
6% of respondents ($n=3$) experienced a miscarriage, termination, or stillbirth after 21 weeks*

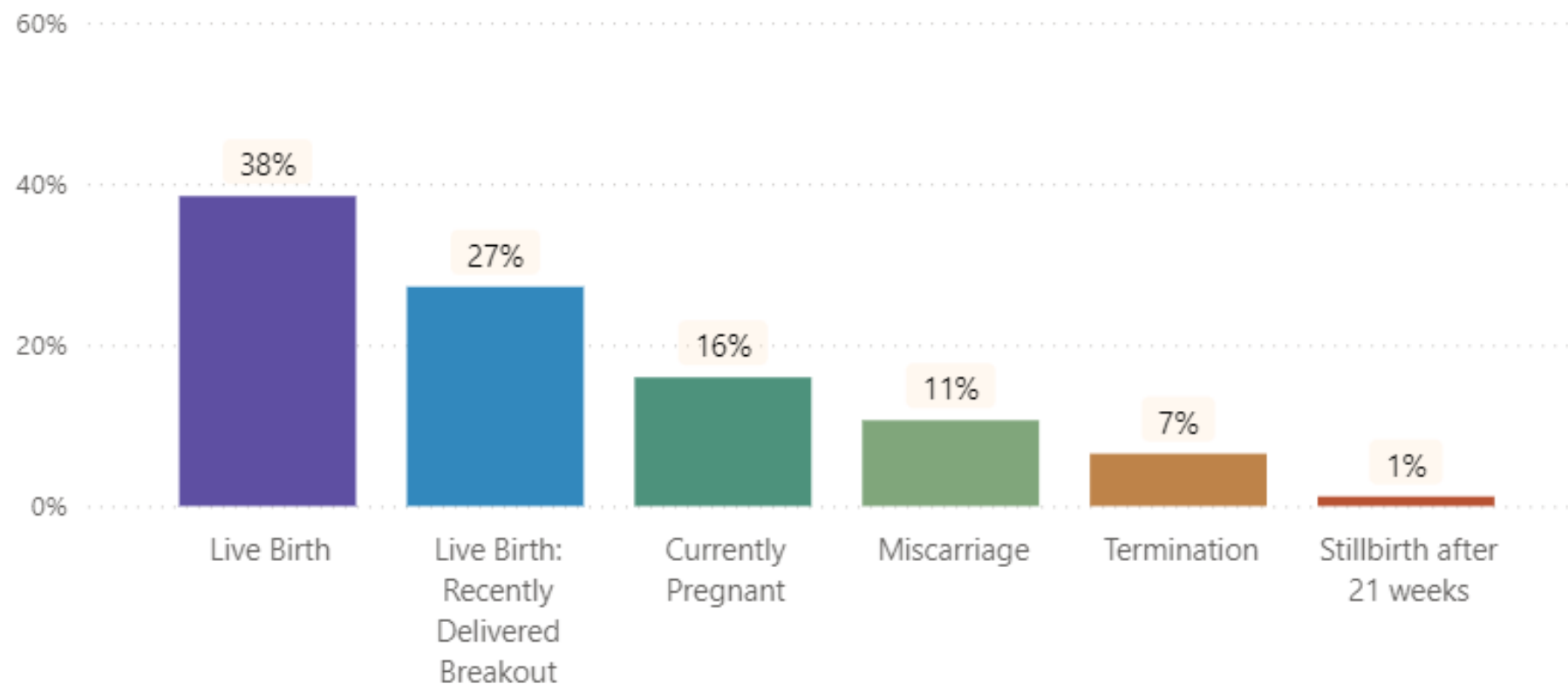
*Due to small numbers of respondents, this category is currently combined for narrative purposes and will be further broken out when more responses are received

MES Responses by Pregnancy Outcome, 1/1/2022-1/4/2023

Total Responses

170

Pregnancy Outcome: All MES Breakouts



Of the 170 responses collected in 2022-2023,

38% of respondents ($n=65$) experienced a live birth and responded to the Full MES,
27% of respondents ($n=46$) experienced a live birth and responded to the Recently Delivered Breakout,
16% of respondents ($n=27$) were currently pregnant and responded to the Currently Pregnant Breakout or Full MES,
18% of respondents ($n=31$) experienced a miscarriage, termination, or stillbirth after 21 weeks*

*Due to small numbers of respondents, this category is currently combined for narrative purposes and will be further broken out when more responses are received

NAACP Maternal Experiences Survey



* Thank you for completing this survey and sharing your story.

Your personal story is important to us, and we want you to control how it is shared. We want you to be confident that any responses you share will remain confidential and will not be associated with your personal information.

☐ Please check this box to indicate that you have read the paragraph above and agree to share your story.

Consent Information

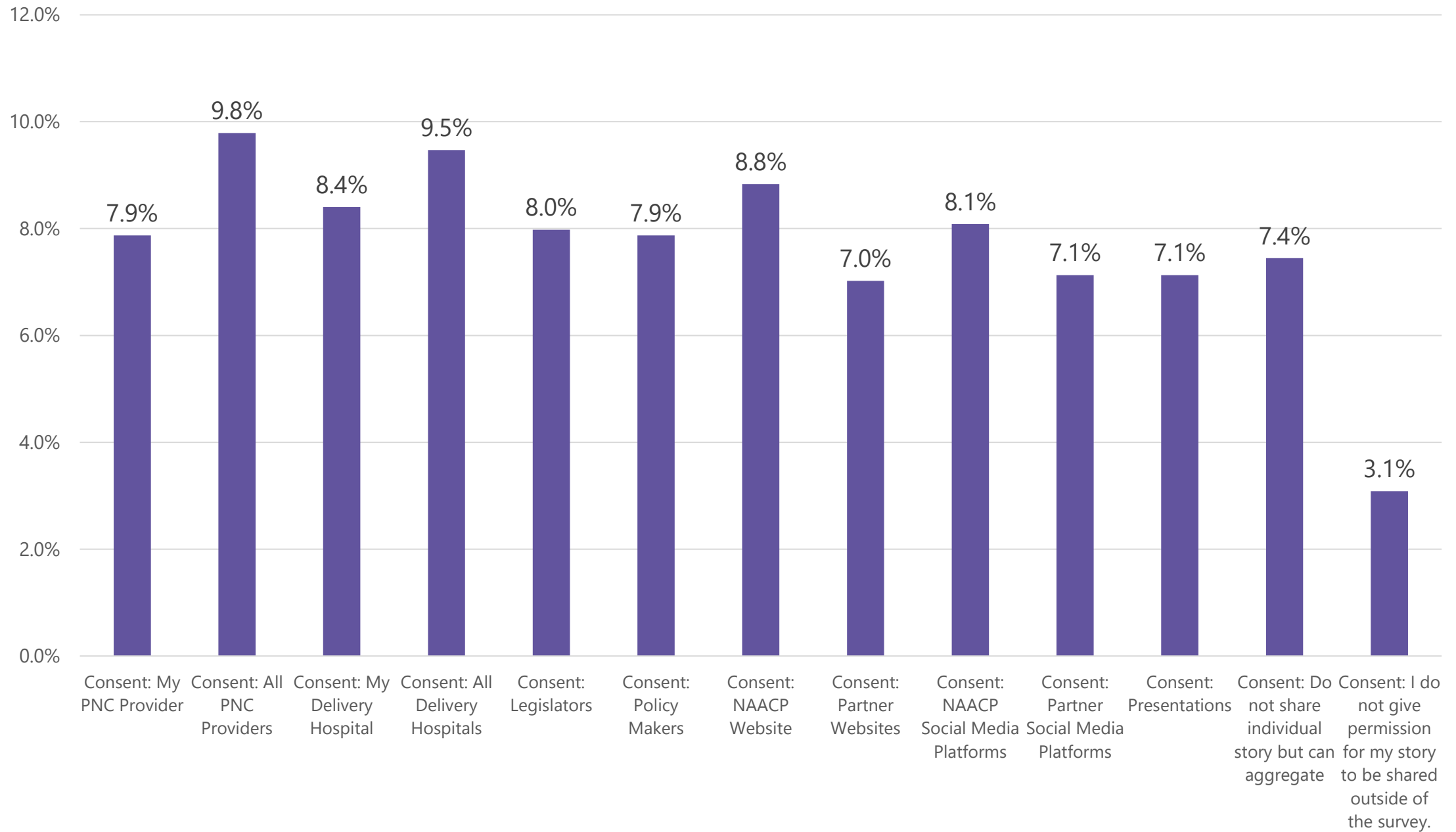
Please check as many boxes below that indicate with whom we may share your story.

- ☐ My Prenatal Provider
- ☐ All Prenatal Providers
- ☐ My Delivery Hospital
- ☐ All Delivery Hospitals
- ☐ Legislators
- ☐ Policy Makers
- ☐ NAACP Website
- ☐ Partner Websites
- ☐ NAACP Social Media Platforms
- ☐ Partner Social Media Platforms
- ☐ Presentations
- ☐ I do not want my individual story shared, but it is okay to combine it with others' stories when analyzing and reporting about the survey.
- ☐ I do not give permission for my story to be shared outside of the survey.

Comments:

MES Responses: Consent Responses through 1/20/2023

Consent Options: All Respondents



MES Responses: Prenatal Care Negative Treatment through 1/20/2023

Data is Statewide; Stories from Respondents who Consented to Share their Story

Total Responses

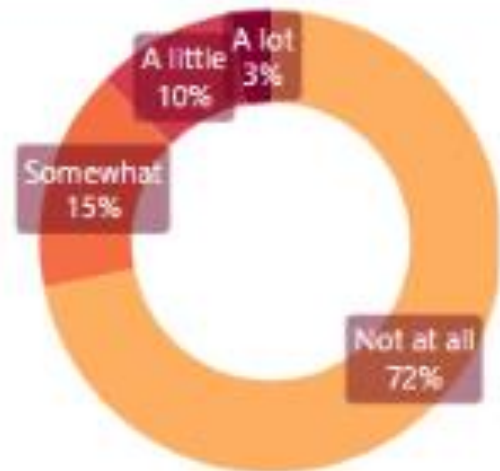
135

Most Recent
Survey End Date:

1/4/2023

Race or Ethnic Background Caused Negative Treatment by Prenatal Care Provider

Black or African American, of any Ethnicity



Total Responses,
Black or African
American

73

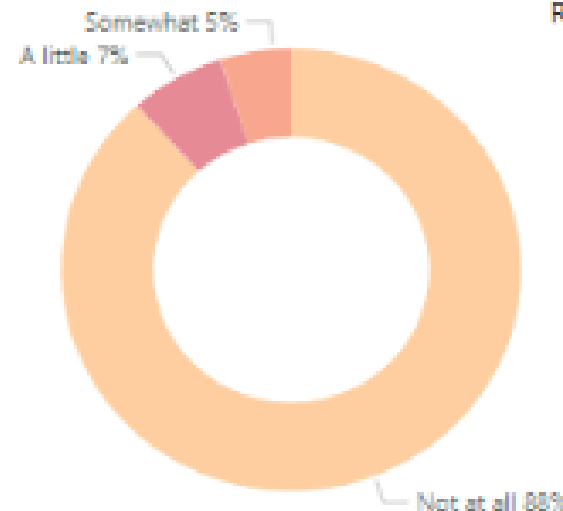
Question Text:

"Do you think your race and/or ethnic background caused negative treatment by your doctor, nurse, and/or midwife?"

¿Considera que su raza y/u origen étnico afectó negativamente en el modo en que la trató su equipo de atención en el parto?"

Race or Ethnic Background Caused Negative Treatment by Prenatal Care Provider

Total Responses,
Racial ID other
than Black



62

Hispanic or Latina, white, Asian, Another or Multiple Racial Identities or Ethnicities

My 1st pregnancy, I had **pre eclampsia**. My OB **didn't thoroughly explain all the risks** with it. I learned quickly once at the hospital. **My education should have started during my prenatal visits**, explaining what can happen to me and the baby.

I had to have a **C section** and **my pain afterwards was not address well**. I believe maybe no one believe my pain level.

I had **private insurance, my own OBGYN**, but **after attending nursing school**, I know why my concerns were ignored, **Implicit Bias**."

From one respondent's Prenatal Care: Story for which they gave consent to share

"Provider X has a very **diverse staff** for prenatal and OB care. There are **black and Latina doctors** so it was much more **competent culturally and I felt supported**. My Dr **advocated for me and insisted I be treated respectfully**.

My Dr was also able to **explain risks to me** and **provide statistics on how these things impact me** based on my race and ethnicity."

From one respondent's Prenatal Care: Story for which they gave consent to share

MES Responses: Prenatal Care Negative Treatment through 1/20/2023

Data is Statewide; Stories are from Respondents who Consented to Share their Story

Stories from Prenatal Care Negative Treatment Comments

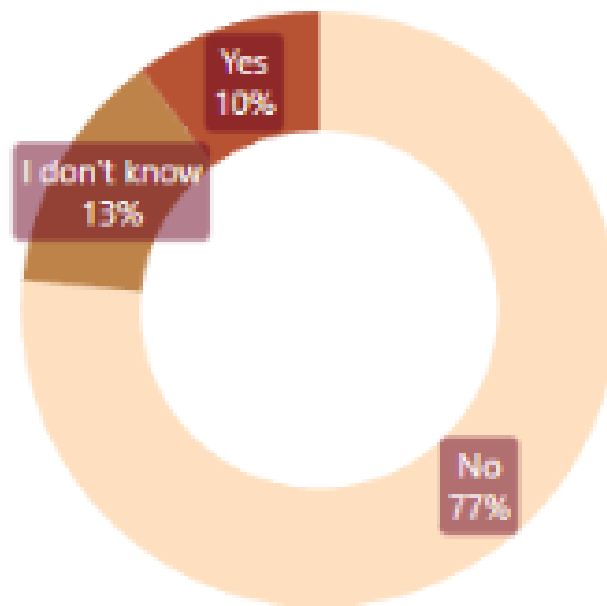
Total Responses

135

Most Recent
Survey End Date:

1/4/2023

How Paid for Care Caused Negative Treatment by Prenatal Care Provider



Question Text:

"Do you think something from the list below caused negative treatment by your doctor, nurse, and/or midwife?
Medicaid status or how I paid for my care"

"¿Cree que algo de la lista a continuación provocó un tratamiento negativo por parte de su médico, enfermera y / o partera?
Estado de Medicaid o cómo pagué mi atención"

Did how you paid for your care negatively influence how you were treated?

"My office is for **Medicaid or out of pocket copay based off income**. Its a **longer wait time** and **limited services** but it has **everything I require**. "

Excerpt from one respondent's Prenatal Care Comments for which they gave consent to share;

When I was on Medicaid going for prenatal care in the hospital clinic. I felt that the nps and obgyn were **rushing in and out of there after doing the pelvic exams and sonograms and concerns** and I had about **swelling in my legs and feet were brushed off**. I was told to put my feet up **no connection was ever made about pre-eclampsia** and my key tones kept coming back hi but there was no directions what to do about that except they were asking me if I was eating enough and I was eating enough. **No aftercare was set up** except for the postpartum exam during which **they asked me if while they were down there if I wanted my tubes tied! Seriously?**

Excerpt from one respondent's Labor & Delivery Story for which they gave consent to share;

"I **could only get certain care or treatments** because of the **state insurance until there was a problem**."

Excerpt from one respondent's Prenatal Care Comments for which they gave consent to share;

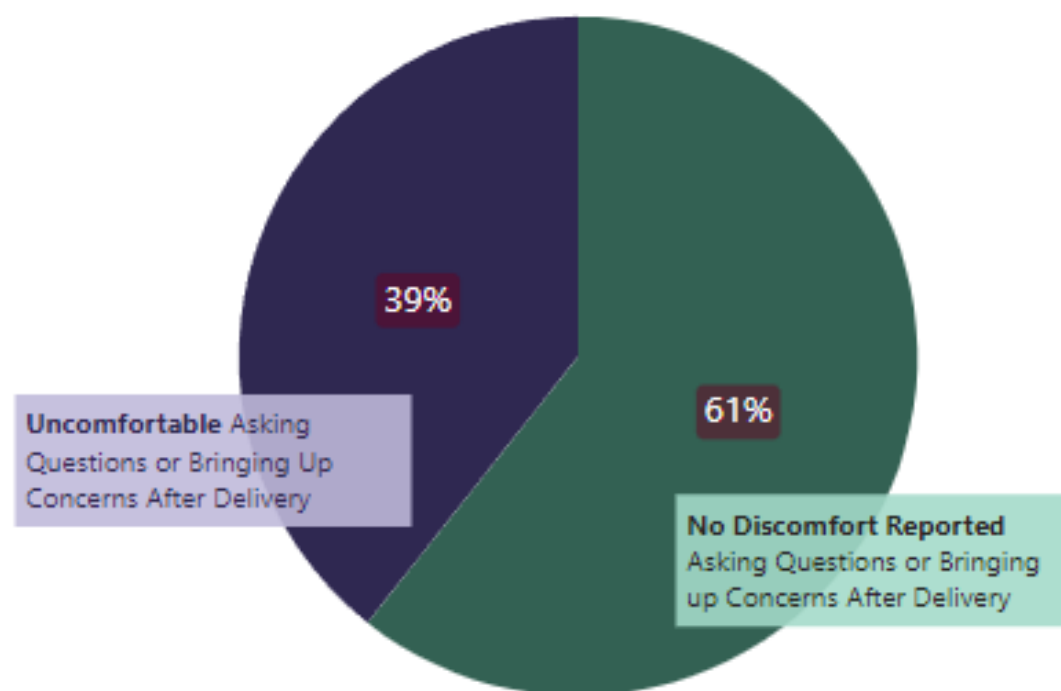
This question will be further broken out by racial identity and ethnic group when more responses have been collected in future reports and presentations.

MES Responses: Discomfort Asking Questions or Bringing up Concerns After Delivery through 1/20/2023

Data is Statewide; Stories are from Respondents who Consented to Share their Story

Discomfort Asking Questions or Bringing up Concerns After Delivery

Total Responses
151
Most Recent
Survey End Date:
1/4/2023



1. As of **November 18, 2022**, out of **150 total responses** who received questions regarding after their delivery, before being discharged from a hospital,
2. **39%** of respondents ($n=59$) **reported discomfort asking questions or bringing up concerns** after delivery before being discharged from a hospital.
3. **61%** of respondents ($n=91$) **did not report discomfort asking questions or bringing up concerns** after delivery before being discharged from a hospital

One of the ladies had pulled my baby off my nipple very hard while my baby was feeding. **She said that it was more important to get done what she had to do first, as far as giving my baby shots and footprints.** I was just bonding my baby after a few minutes into birthing her and the lady showed no care in me breastfeeding my child. **She didn't look like she wanted to be there** or didn't look like she liked or loved her job.

Excerpt from one Atlantic County respondent's Labor and Delivery Story for which they gave consent to share

"I delivered during a pandemic...I felt like they just wanted me in and out. I felt like a number not a patient."

Excerpt from one Atlantic County respondent's Post-Delivery Story for which they gave consent to share

I received quality care from the health practitioners and I was able to **recuperate** fully. They **helped me cope with depression.**

Excerpt from one Atlantic County respondent's Post-Delivery Story for which they gave consent to share

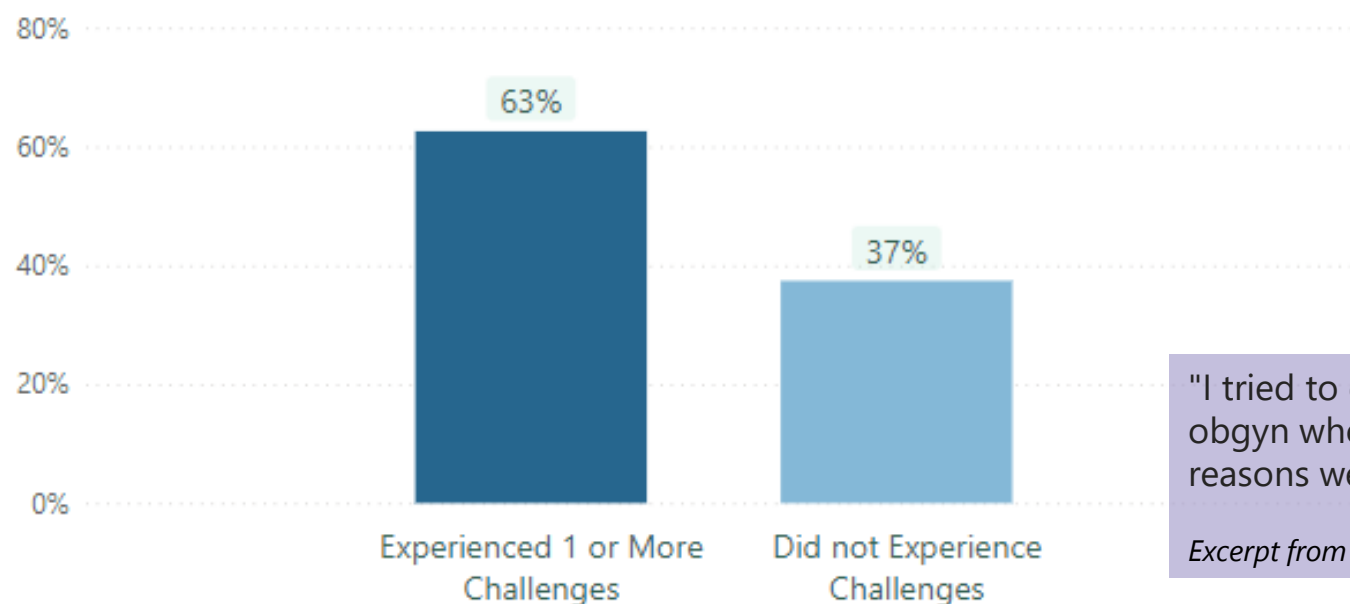
MES Responses: Post-Discharge Challenges or Complications through 1/20/2023

Data is Statewide; Stories are from Respondents who Consented to Share their Story

Total Responses

150

Experienced Complications and/or Challenges After Arrived Home



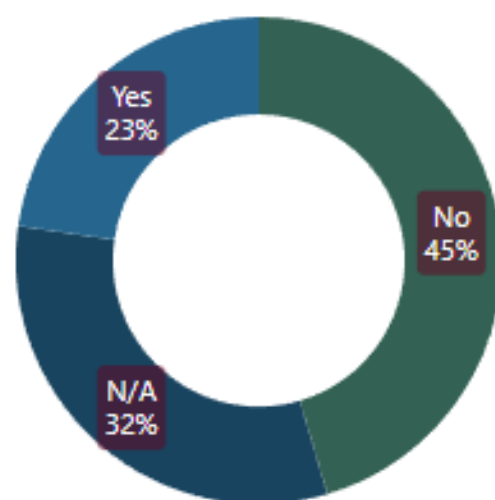
"I did experience pain and headache. I contacted the hospital and they **responded quickly** with the help I needed. Everything was sorted and I had an easy time with the child."

Excerpt from one respondent's Post-Discharge Story for which they gave consent to share

"I tried to get [the] name of [the] np who did my prenatal care and [the] obgyn who also did my prenatal care **and I could not get appointments** the reasons were **not taking patients or moved out of area.**"

Excerpt from one respondent's Post-Discharge Story for which they gave consent to share

Ask for Help from a Medical Team If Experienced Post-Discharge Complications



During my postpartum appointment I was asked by the medical assistant, "Are you breast feeding?" I also had appointments because my breast were so sore from milk production. Also, **almost 2 years later** I still have **pelvic pain that no doctor seems to care about.** Also, **I did not qualify for maternity leave because my babies died.** That is an insult. **Miscarriages should be covered under maternity and not disability.** I had to return to work within a certain timeframe or I would be terminated.

Excerpt from one respondent's Post-Discharge Story after experiencing a miscarriage for which they gave consent to share

During the **newborn assessment** when the **newborn provider** asked about the postpartum anxiety and depression screening **I expressed heightened anxiety** which **wasn't met with much receptivity** . **I then searched resources outside of my child's pediatrician.**

Excerpt from one respondent's Post-Discharge Story after experiencing a miscarriage for which they gave consent to share

In Mothers' Words



To read Danica's full story visit
<https://www.njpreterm.org/mes>



To read Takimah's full story, visit
<https://www.njpreterm.org/mes>

TOMAR LA ENCUESTA EXPERIENCIA MATERNAL

COMPARTIR.

SER ESCUCHADO.

ESPERAR CAMBIO.



Presentado por: NJ NAACP Black Infant and Maternal Mortality Taskforce

Complete la Encuesta de Experiencia Materna para ayudar a mejorar la atención y reducir las injusticias para las personas Negras que dan a luz. Tu experiencia ayudará a producir cambios y mejores resultados en Nueva Jersey.

SI HA TENIDO UNO DE LOS SIGUIENTES:

- Nacimiento Vivo
- Nacimiento Muerto
- Aborto Espontáneo
- Aborto



Escanee el código QR
para participar o visite:
njpreterm.org/mes

Comparte tu
experiencia y recibe
un regalo especial.

Si tiene preguntas sobre la encuesta,
comuníquese con Christine Ivery al
civery@fhiworks.org o al
609-206-8206.

La Iniciativa de Prevención de la Prematuridad es un programa de Iniciativas de Salud Familiar (FHI) respaldado por fondos del Departamento de Salud de Nueva Jersey. FHI es una agencia subsidiaria de Southern NJ Perinatal Cooperative. 2021.



TAKE THE MATERNAL EXPERIENCE SURVEY

SHARE.

BE HEARD.

EXPECT CHANGE.



Presented by: NJ NAACP Black Infant and Maternal Mortality Taskforce

Complete the Maternal Experiences Survey to help improve care and reduce injustices for Black birthing people. Your experience will help to produce change and better outcomes in New Jersey.

IF YOU'VE HAD ONE OF THE FOLLOWING:

- Live birth
- Still birth
- Miscarriage
- Abortion



Scan the QR code to
participate or visit:
njpreterm.org/mes

Share your experience
and receive a special gift.

If you have questions about the
survey, contact Christine Ivery
at civery@fhiworks.org or
609-206-8206.

The Prematurity Prevention Initiative is a program of Family Health Initiatives (FHI) supported by funding from the NJ Department of Health. FHI is a subsidiary agency of the Southern NJ Perinatal Cooperative. 2021.



How to Access the MES Implementation Report

Updated December 2022

1. Visit <https://www.njpreterm.org/mesreport>
2. Complete a short registration
3. Download the Report and MES Flyer



MES Implementation Report



*Please complete this
short form to access
the report results.*

(we promise we won't sell it or spam your email)

First Name *

Last Name

Email *



Data Notes

1. Introduction (Pg. 3)

In the most recent report from the New Jersey Maternal Mortality Review Committee (NJMMRC), Nantwi et al. (2022) reported in New Jersey from 2016-2018, the Pregnancy Related Mortality Ratio (PRMR) for Black, non-Hispanic women (39.2 deaths per 100,000 live births) was 6.6 times higher than the PRMR for white, non-Hispanic women (5.9 deaths per 100,000 live births). The PRMR for Hispanic and/or Latino women (20.6; n=37) was 3.5 times higher than the PRMR for white, non-Hispanic women. The PRMR is defined in the same report (2022) as the number of pregnancy-related deaths per 100,000 live births (p. 6). Though 13.4% of all live births (n=40,822) were to non-Hispanic Black women from 2016-2018, 36.4% (n=16) of all pregnancy-related deaths in NJ were also to non-Hispanic Black women in the same time frames (Nantwi et al., 2022).

2. Introduction (Pg. 3)

According to 2019 data from the NJ Birth and Death Certificate Database from NJ DOH, the Infant Mortality Rate (IMR) per 1,000 Live Births for infants who were Black, non-Hispanic was 8.5. The IMR for infants who were white, non-Hispanic was 2.9.

3. Maternal Mortality & Morbidity Trends (Pg. 5)

Pregnancy-related deaths are defined by the CDC (2019) as deaths that occur during pregnancy or within 1 year of the end of pregnancy that are related to the pregnancy. The NJ MMRC (2022) defines pregnancy-related death as "a death during or within one year of pregnancy, from a pregnancy complication, a chain of events initiated by pregnancy, or the aggravation of an unrelated condition by the physiologic effects of pregnancy" (p. 16).

4. Statewide Data: Preterm Births (Pg. 6)

According to finalized 2020 birth data from the NJ Birth Certificate Database from NJ DOH, the statewide percentage of all births that were preterm (less than 37 weeks gestational age) was 9.3%. When data were queried on July 5, 2022, there were 9,018 preterm births out of 97,146 live births in New Jersey in 2020.

5. Infant Mortality (Pg. 7)

This chart groups statewide data in 3-year timeframes by race and ethnicity to illustrate the IMR from 2010-2019 (most recent available data year.) The IMR is the number of infant deaths before their 1st birthday per 1,000 Live Births in the same year or group of years.

The MES highlights experiences of Black birthing people in a safe manner embedded with identity acceptance and respect.

The NAACP MES is open to respondents of all races and ethnicities.

Respondents may be of any age.

Respondents will not be turned away from any county in NJ.

All responses are deidentified, reviewed for validity, and processed for reporting.

References

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<https://www.cdc.gov/reproductivehealth/maternal-mortality/docs/pdf/Pregnancy-Related-Deaths-Data-MMRCs-2017-2019-H.pdf>