

VOICES, STORIES AND EXPERIENCES OF BLACK WOMEN

PHASE II: COMMUNITY ENGAGEMENT ACTIVITY REPORT

Informing the Establishment of a
Trenton-Based Maternal & Infant
Health Innovation Center

20
23





We would like to thank all the women, men, families and community partners in Trenton who contributed to and participated in this project.





Acknowledgments

The John S. Watson Institute for Urban Policy and Research at Kean

The John S. Watson Institute for Urban Policy and Research at Kean University is dedicated to deepening the analysis around critical public policy challenges and broadening the range of policy ideas and perspectives. The Institute plays a critical role in researching issues affecting the state's urban centers and developing solutions to address them. Named in honor of the late N.J. Assemblyman John S. Watson (the nation's first African American chairperson of an appropriations committee), the Institute serves as a vital resource for New Jersey decision-makers and communities through a practical, nonpartisan, hands-on approach to informing public policy.

Kean University

Kean University is a public cosmopolitan university that serves undergraduate and graduate students by providing world-class academic instruction, and real-world experiences for career success. Kean University is a member of the Hispanic Association of Colleges and Universities and a Hispanic-Serving Institution (HSI) – as they proudly serve Latinx first-generation college students as one third of the student body. With Kean University's continued advancements in academics and scholarship, the university was designated the first public urban research university in New Jersey in November 2021.



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Overview of Goals

As an extension of our 2022 study Voices, Stories and Experiences of Black Women (Phase 1), the John S. Watson Institute for Urban Policy and Research at Kean University's Maternal and Child Health Equity Team was asked to share information about the planned Maternal and Infant Health Innovation Center (MIHIC) with Trenton residents as a part of Nurture NJ's community engagement efforts. The Team implemented the following community engagement activities:

- **Communication:** Community engagement through social media outreach and in-person outreach were used as approaches to inform Trenton residents about the MIHIC.
- **Dissemination of Findings:** Community cafés were designed to share and discuss findings from Phase 1; provide maternal and infant health resources; and inform Trenton women about the MIHIC.
- **Expanding Our Reach:** Focus groups and surveys were conducted to reach diverse populations to assess needs and assets, and to identify recommendations to inform the creation of the MIHIC.

The Maternal and Child Health Equity Team

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Communication

Social Media Outreach

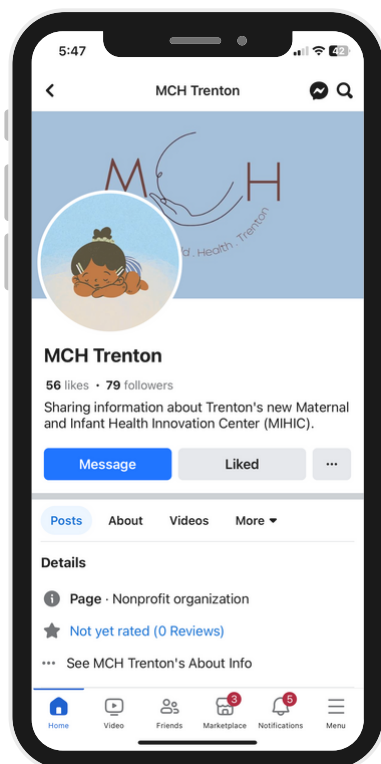
One of the recommendations of the 2021 Nurture NJ Maternal and Infant Health strategic plan was to establish a Trenton-based Maternal and Infant Health Innovation Center (MIHIC). To increase awareness of the planned center the Team created a social media campaign using a Facebook (FB) group.

From July through October 2023, two to four postings a week were made on the [MCH Trenton Facebook page](#). Attention-grabbing captions, pictures and videos provided information about the MIHIC and interactive posts shared community perspectives and feedback. Approximately 80% of respondents to our social media outreach were women. Examples of their comments are shared below.

+ 
People Reached
9,685


Impressions
11,163


Engagements
397



"Black Maternal and Infant Health is important to me because Black women often have greater challenges with: work place accommodations; postpartum depression and access to mental health care; prenatal educational care"

"Who you have working there plays a major part in women actually wanting to have their babies here in Trenton!!!!"

"I would like to see more consideration, respect and support for the birth plan requests of the mother. As well as providers become more informed on natural births"

"I just want to know what's the plan to get these beautiful babies resources when they are brought into this world. This City does not do a good job with taking care of families"

"Yeah cus it was crazy that Trenton lost its only place for moms to have their kids here. We def need this ASAP."

"Proper healthcare from people who also look like us. In my opinion more mothers will be comfortable if they could relate to their caregivers. Mothers seeing the city of trenton, Nj on their child's birth certificate would also give them pride in the place they call home."

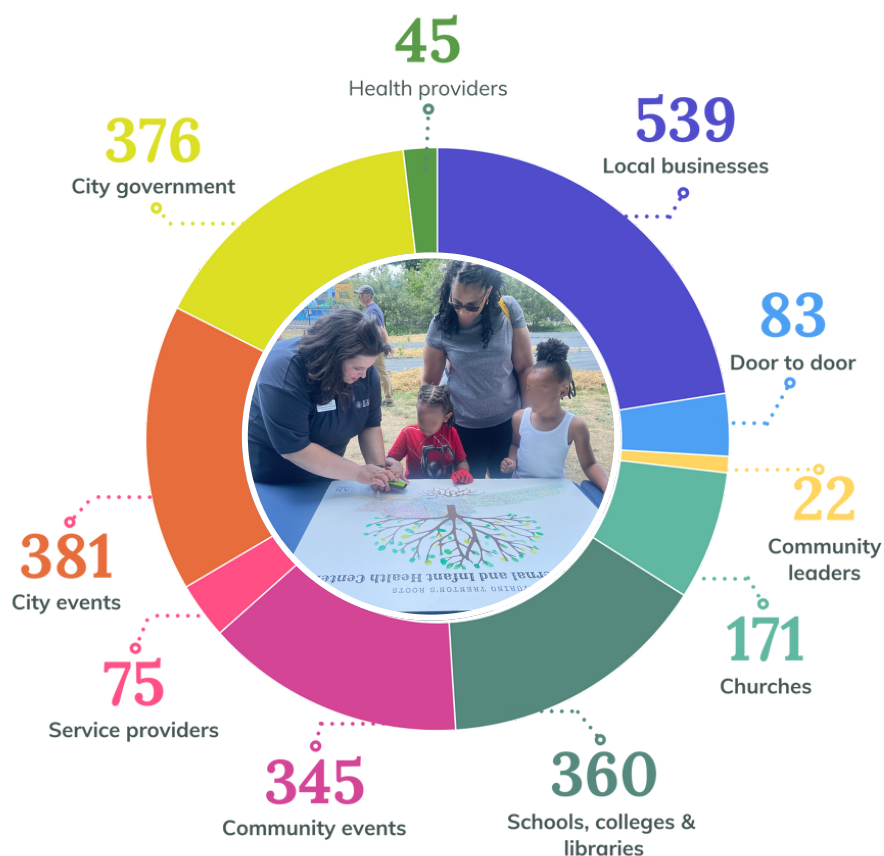
"This is too needed. I wish they were doing this when I was about to have my kids"



Communication

In-Person Outreach

On-the-ground community outreach was achieved through word of mouth and by sharing over 2500 flyers and postcards throughout Trenton. From July through October 2023 working with Trenton leaders and residents, the Team attended a wide range of neighborhood and city-wide community events such as Capital City Farm Juneteenth Festival, National Night Out, and Trenton Family Festival. Team members canvassed Trenton neighborhoods throughout all four wards and commercial districts. We worked with a community partner and its youth leadership summer program to recruit students who distributed flyers in their neighborhoods. This graphic shows the number of flyers distributed to various types of locations in Trenton and surrounding areas.



Front of distributed flyer



Back of distributed flyer



Dissemination of Findings

via Community Cafés

As a way to share the findings, confirm their accuracy, and share next steps following the completion of the environmental scan in 2022, the Team met with local partners and residents. In partnership with a Black-owned local art studio, Art and Soul, the Team designed celebratory community events (Community Cafés) to share and discuss findings from the 2022 MCH study and provide resources to support participants and residents.



Two Community Cafés were created, one with on-the-ground service providers such as doulas and nurses, on August 19, 2023, and the other with Trenton residents, on October 26, 2023, located within walking distance of where they lived. Over a catered dinner for participants and their families, we gave an overview of the Nurture NJ initiative spearheaded by the First Lady's Office and the MCH project, including time for Q&A. We discussed with participants the findings from Phase 1 to make sure the results accurately represented their experiences and to obtain additional recommendations to the MIHIC. Participants took turns reading out loud the findings from posters passed around the room and shared their experiences and feedback.

To thank our participants, we created a painting activity used as a strategy to cope with stress and to celebrate. We chose dandelions as the subject to paint as a symbol of strength, resilience, hope, optimism, and healing. Before painting began, we asked each of them to write a word or phrase on the blank canvas representing a challenge or a hope that could aid towards personal growth. After they completed their paintings, they shared what the experience meant to them, they exchanged information with one another, and we ended the evening by the Team disseminating maternal and infant health resources pertaining to this project (i.e. NJEDA one-pager about the Trenton-based MIHIC and MCH Project [community resource pamphlet](#) and report).





Expanding Our Reach

via Focus Groups

Black women in Trenton, New Jersey are a diverse group by age, ethnicity, and income. There are many ethnic groups with distinct and culturally specific needs and assets. Following our Phase 1 findings, the Team explored the diversity of a few of these groups in a more focused manner that included conversations with men. In Phase 1 women shared that the entire family (including men) needed maternal and infant health information and support:

“My daughter’s father has mental illness so he’s incapable of paying child support. But he still wants to help out. He wants to be there [although] certain things he can’t do. But a lot of things he can do, [but] where’s the services to help him? Just because he have a mental illness, don’t mean he’s a bad person.” (Phase 1 MCH Report, pg 34)

In an effort to reach out to a wide range of communities within Trenton, the MCH Team partnered with community groups, leaders, and churches to conduct six separate focus group sessions with:

- Haitian Women (July 30, 2023)
- Low-income Women (September 14, 2023)
- Liberian Women (two focus groups on September 17, 2023)
- Black Men (October 12, 2023)
- Affluent Black Women (October 24, 2023)

Following IRB approval (#23-062201, 6/27/23), the Team worked with partners to adapt recruitment flyers for each population. We assembled six 45-60 minute in-person focus groups with 53 participants and collected surveys from 41 participants. After one of the focus groups for low-income women, in partnership with a local church, we created a community outreach event for about 50 people in an area of concentrated poverty. The Team used a translator from Kean University and community transcription services to translate all recruitment materials and focus group protocols for Haitian women. For Phase II, we employed the same methods as in Phase 1. The Phase 1 report describes those methods in detail.



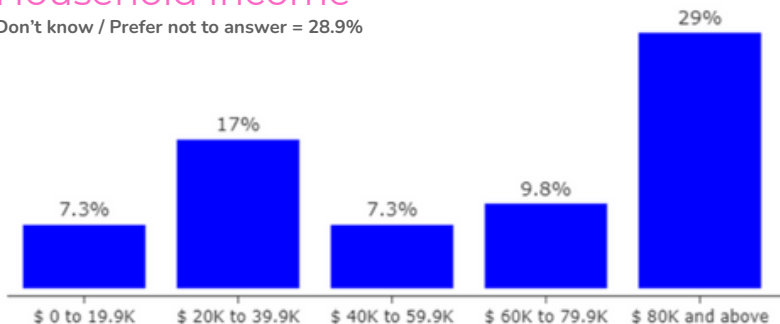
Front of recruitment flyer



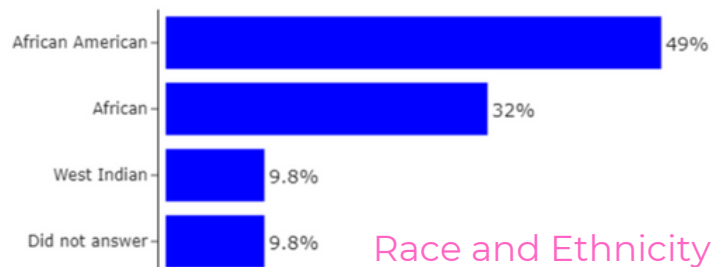
Focus Group Demographics

Household Income

Don't know / Prefer not to answer = 28.9%

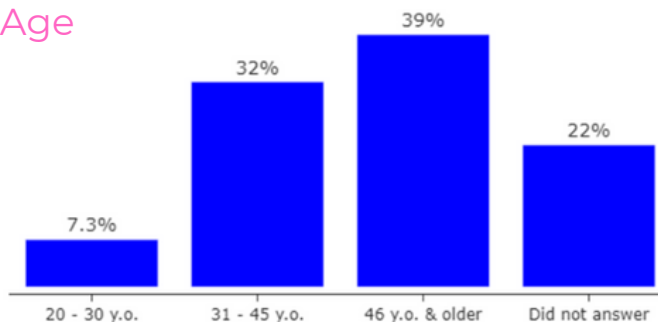


Survey participants reported race and ethnicity, age, education and income. The majority of survey respondents were Black women. The median age was 45 years old. Over half had at least some college education. The average household income was between \$52,000 to \$66,000. Eighty-seven percent of participants described their health as good to excellent. Forty percent have been told by a doctor that they were overweight or obese.



Race and Ethnicity

Age



Education Level





Focus Group

Haitian Women

“

Medication is expensive. I tried to buy 10 pills when they stopped the brand name coverage, it cost me \$110.

”

Immigration status, finances and insurance were all obstacles to accessing health care.

“

Some women can't afford to go get check-ups.

”

Participants cited limited communication, lack of trust and lack of cultural awareness as obstacles to quality care.

“

As long as you continue not to ask questions, they keep prescribing you medication over and over again...the doctor kept changing the medicine without any exam.

”



Women experienced stress due to poverty and multiple health problems, affecting their mental health.

“

Losing a child four times is not easy for your mental health at all.

”



Focus Group

Low-income Women

“ See I need food stamps, my food ran out ... And this little security check, that doesn't last. I gotta pay rent and everything and try to feed myself. And then it's hard for me to get around to get to the [food] pantry because you know I can barely walk. ”

Lack of transportation, food, education, and complexity of healthcare systems intersected to prevent access to care.

“ I don't want no health insurance that's free and you're giving me the crappy insurance, you know what I mean? I can only go to the physical doctor, but I can't go to the dentist. I go to the dentist and the physical doctor, but now I can't go to the OBGYN. ”

Participants described a wide range of trauma including within healthcare systems.

“ That's [name of hospital]. Whooh! I was really really sick. They was trying to keep my baby and make me die. So my mother hurried up and transported [me] out of that hospital. Because it does happen. ”

“ ...they didn't really talk to you and understand what you're saying and help you. ”

Women discussed feeling not seen or heard by healthcare providers.

“ All they want is your insurance. Because I'm trying to tell you what's going on with me, you're trying to tell me that I'm lying, how are you gonna tell me I'm lying about my body? ”



Focus Group

Liberian Women

Participants cited poor communication, cultural differences and lack of trust as obstacles to quality care.

I'm asking the Dr. a question. A Spanish lady, just come and start speaking Spanish [and] the doctor forget that I'm asking you a question. You turn to her and yall start speaking Spanish.



5 out of 11
reported difficulty understanding doctor's instructions and medical paperwork.

...she told me don't play with boys. So if I don't play, if I play with boys, what's happening? 'Don't play with boys, that's what happens!' That's not an education.

Participants discussed having limited knowledge about maternal and infant health before, during and after pregnancy within the home, school and healthcare settings.

We learned about diseases and all that. You wasn't learning at home, you know, how to put on a condom, all that, we learned that in school.



7 out of 11
reported feeling emotionally upset as a result of how they were treated based on their race, ethnicity and culture.

I'm like oh you know when you see it in the family but you never know. You[re] like that's just her she's just standoffish.

Mental health stigma within families led to reluctance to seek information and treatment.



7 out of 11
women had trouble paying for a doctor, dentist, or medicine for themselves and/or their child.

I was going through depression and never knew none of that.



Focus Group

Black Men

Participants discussed being rushed and misdiagnosed during healthcare encounters.

“You're in and out, you're rushed ... Hopefully diagnosing, most likely you're gonna misdiagnose. It wasn't enough time to check out what's going on and you're on your way.”

“I think when a baby does pass away, we kind of look at like, it's more on the mom, like it's more traumatic for the mom and the dad [is] kind of just like okay, you know, people think it is what it is, but I believe we're very much involved in [and] affected by the death of infants.”

Participants discussed how traumatic experiences influence their relationships and role as fathers.

.....



5 out of 9

men reported needing mental health support.

“I broke up a fight ...two nights ago, over a homicide that occurred 20 years ago...so it never goes anywhere. Right. So we have to understand that our communities are damaged...”

Participants discussed the lack of access to culturally specific information preparing them for fatherhood and supportive partnerships with women.

“You got to make it relatable, because they're not gonna hear it.”

“You know, I was having a baby. And I was like, I don't even know why I'm having a baby, like, what the heck is going on?”

Participants described a lack of access to quality health care because institutionalized racism leads to healthcare systems that are hostile to them by design.

“If you don't have insurance, they're gonna push you in the hallway somewhere, baby and all. I saw that too.”



5 out of 9

men experienced discrimination, harassment and being made to feel inferior because of their race, ethnicity and culture.



Focus Group

Affluent Women

Many women in the group expressed a need for more culturally diverse health care providers and environments including birthing options within Trenton.

“

Diversify, diversify the workplace...having people who look like us to [provide] care.

”

“

I'm thinking, if you knew that I had the first miscarriage, where was the extra care questions, treatment and everything for me for this one. But [with] all of this, I didn't know that we weren't as important as other people.

”

Participants cited institutionalized racism and its impact on patients and providers.

.....



6 out of 10

experienced discrimination, harassment or were made to feel inferior because of their race, ethnicity or culture.

“

I lost all these teeth through my pregnancies. I had two miscarriages...And he said, I can't believe between your other doctors and your dentist, no one checked your vitamin D.

”

“

As a child living in Trenton, and the first experience I experienced was the loss of my mother due to medical malpractice...I wouldn't go to the dentist...wouldn't go to the doctor...initially that trauma of being exposed to that, it gave me a resistance to even I was hesitant to go to a doctor, just as people nowadays basically [are] threatened by police officers or authorities.

”

Incidents of malpractice leading to trauma have caused distrust.



Conclusion

The 2022 study Voices, Stories and Experiences of Black Women (Phase 1) explored the nuanced and complex ways in which social determinants of health and lack of access to quality care impact maternal and infant health outcomes, particularly for Black women.

In this Phase 2 report we describe the community engagement activities we undertook to support the success of a planned Trenton-based Maternal and Infant Health Innovation Center (MIHIC). Our approach emphasized the diversity among Black women and families. We used community engagement as a means to share information about the Center; to introduce and discuss Phase 1 findings with residents; and to reach out to additional communities in Trenton, including its African and Caribbean Black communities. We created partnerships with community leaders and organizations to reach members of tight-knit communities where they live, work and pray.

Our Team made more than 750 in-person contacts throughout the four wards of Trenton, more than 9000 social media contacts, and an additional 1250 contacts through postcards and flyers. At our community cafes and focus groups, we used an interactive approach to share information, participate in dialogue, introduce coping techniques, and discuss new strategies to address Black maternal and infant mortality.

In the additional communities that we reached out to using focus groups, we found that the needs, challenges, resources, and solutions were consistent with the findings for Black women reported from Phase 1, with additional culturally specific insights and perspectives. The conversations with both women and men in the focus groups revealed and differentiated the needs of each population. Due to the small number of focus groups completed for each unique population, we combined and selected comments which can be found in the Appendix. Further engagement with diverse communities including African, Caribbean, African American women, Latina, men and youth would help ensure that the Center meets the needs of Trenton's diverse communities to help promote health equity for its mothers, infants and families.



Appendix

Focus Group Participant Themes & Quotations

Food Insecurity

“But we need healthy [options], I need that kale, but I gotta go get that watered down lettuce. Instead, I need spinach, which we know our bodies definitely need, especially when you're pregnant. But I will have to settle for green beans, we have to be able to afford it when we're pregnant.”

“And so oftentimes you might have to make a choice as to get the healthier choice, or do I just get you know, the processed choice. And I dread if I have to go into that grocery store, ... and I hold my nose the entire time I'm shopping.”

Transportation

“All of those facilities that provide resources for prenatal care or anything, are in Hopewell. Transportation is an issue.”

Access to Care

“For younger children, or elderly people, a lot of people don't have transportation. Yes. So people depend on the buses, but then if it does [exist], if it's not near your route, you're gonna miss doctor's appointments, because you don't have the money to get an uber or taxi. So transportation is really, really important.”

“Oh, you have to apply [to services] online before you can get it. Come on, man. It's a little difficult for people who don't even have [a] computer...”

Quality of Care and Services

“In the hospital, I remember a doctor coming in, and it was a holiday weekend. And he told me oh it's a holiday weekend. And I just got there because I was five months pregnant. I had dilated three centimeters. My sac was leaking. And he had the audacity to come into my room and tell me I should go home because there are more germs here in the hospital. And if it's a viable pregnancy after the holiday, you should come back. And I just remember saying how dare you say, if it's a viable pregnancy to me. I know that I was dismissed because of the color of my skin. I know that I wasn't given the care and compassion because of the color of my skin.”

“You can go to the doctor and tell them what's wrong back then. And he listened, but right now they don't listen to me. You have high blood pressure. You need to stop this. And don't do that. But now the doctors don't really care, all they care about [is] that insurance. That's all they care about.”



Mental Health

“Because when I think about how I felt when I first became pregnant, the thoughts that came to my mind, the diagnosis that came along with it, my physical appearance, postpartum depression.”

“I was drinking everyday, I wasn't eating, I wasn't socializing, I wasn't dating, I was depressed. So depression is really hard. It's there, mental health, and you don't get control of it.”

“I sit in the house and I just cry, you know I ask God, thank you, please give me the strength.”

Trauma

“I think it's extremely traumatic...[the] risk of [an infant] dying or living is traumatic for us too because I think we are along that process as well. We are just as involved as the mother during those nine months. You're waiting for this baby to come out, you got dreams or aspirations for what your baby is going to be. And you might be involved with the name, shopping, you know, everything...to having a kid, a baby, you, you've been involved [in] the whole process.”

Systemic Racism

“I think honestly, I would love to learn more about you know, Black maternal health from Black people. I think when you go to hospitals and stuff like that, it's a bunch of people that don't look like you, [and] they're telling you about yourself.”

“It's by design.”

Knowledge and Information Sharing

“But I found that I didn't find literature that had information specific to Brown and Black babies. All the literature and all the resources and information was always geared to Caucasian or White infants.”

“When our women are going in, they get checked. They leave, they have the baby, they send them home with some papers, and they send them on their way.”

“Now talking about home remedies, there is no Haitian that does not consume home remedies. During the Covid period, Haitians bought a huge amount of ginger, lime, and cinnamon. All of us were drinking tea all day long. And it is really helpful to compensate. So, we mixed between home remedies and medication.”



Community Assets

"I love the diversity. There's different cultures here, there's different, you know, different groups you can learn from different people. They say like, you could survive in New York, you can survive anywhere. But I think if you could survive in Trenton, you could definitely survive anywhere. You meet a bunch of different people, different walks of life. That's what I love the most about it."

"The love from the community. Trentonians. Despite what happens in the city, the Trentonians pull together to help uplift and support. And just the programs that are out there just to build each other up and help each other out."

"And also, doulas, doulas help, have helped a great deal. Absolutely. A great deal. Having a doula makes a big difference."

Recommendations

"MRI and then everything...and mammogram all in one spot so you don't have to go to here to here to get one."

"I need support from my peers like that support right here, you know what I mean? So when I'm sick I need that support, because...I might not feel comfortable talking to you about some personal things."

"So if we have a clinic that's talking about all women, and infants, and stuff like that, if it's presented to the different churches to different schools, they will appoint the person that can actually get behind it and make the people come out."