



BLACK WOMEN'S
LEARNING INSTITUTE

ENGAGE. EMPOWER. EDUCATE.

A NATIONAL SURVEY
ABOUT BLACK WOMEN'S
HEALTH & WELLNESS



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For questions about the survey and other inquiries,
you can reach us here: info@bwli.org

Engage. Empower. Educate. is a national survey seeking information about Black women's health and wellness conducted by the Black Women's Learning Institute in August and September 2021.

The Black Women's Learning Institute (BWLI) is a national center targeting the health and wellness needs of Black women across the lifespan. We especially focus on systematically disadvantaged communities in Louisville and Baton Rouge. We provide safe platforms and facilitate critical conversations that provide a deeper understanding of the history and current issues that impact the health and lives of Black women. We also create pathways for Black women to inform their clinical providers about what they need to achieve optimal health.

**BWLI's mission is to improve
health outcomes for Black women across the
lifespan through programming responsive
to their needs and concerns.**

Through translational research, BWLI serves as a vehicle to inform the development of health programs that respect the experience and intersecting identities of Black women. Our vision is to achieve health equity for Black women free of implicit and explicit bias.

1. Characterizing the Sample – *Who were the women in the study?*

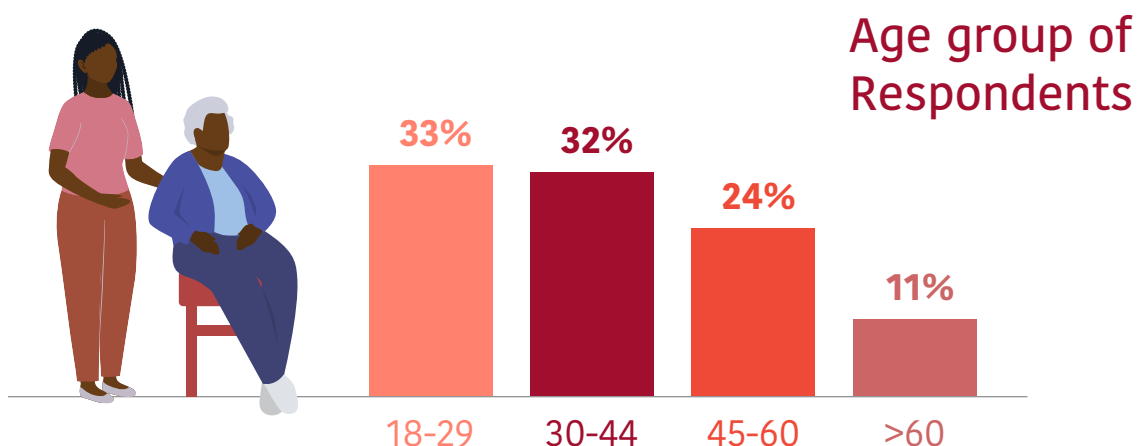
1,600

total sample size

1,039

self-identified as Black women

The *Engage. Empower. Educate.* survey included responses from 1600 women throughout the US. Approximately two thirds of the sample (n=1039) were Black women, and 83% were from southern states. The survey collected critical information about Black women's health and wellness for six weeks between August - September 2021. Recruitment occurred through BWLI's professional network, social media, family, friends, and through snowball sampling.



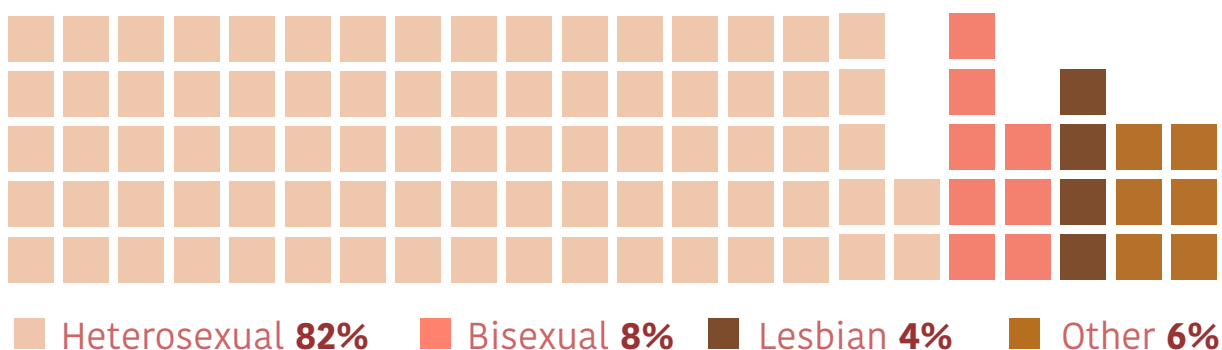
The survey highlights intersectionality among Black women. It is important for health care providers to communicate with Black women through a lens of intersectionality, understanding and recognizing that Black women are not a monolith. Intersectionality is the inextricable way in which social categorizations like race, gender, sexual orientation, and

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socioeconomic status intersect. The majority of women in the survey felt like being Black was the most important part of their identity. For many Black women, intersecting identities create overlapping systems of discrimination when seeking health care.

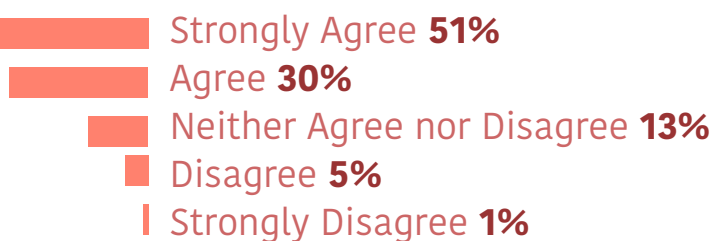
Sexual orientation



The majority identified as straight or heterosexual and a minority identified as gay, lesbian, homosexual, bisexual or questioning.



Being Black is the most important part of my identity

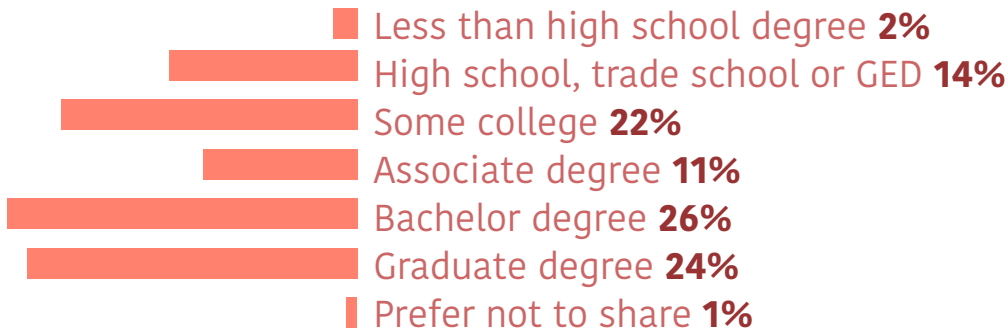


Most women in the sample strongly agreed or agreed that being Black is the most important part of their identity and about half the sample had a bachelor or graduate degree.

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Highest level of education completed



Relationship status



Single **40%**



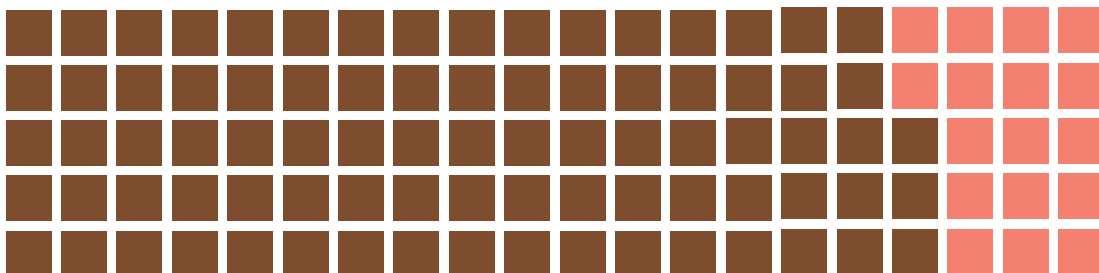
Married **34%**



In a committed relationship
but not married **12%**

About 4 out of 10 women in the sample were single, a third of the sample were married, and the rest were in a committed relationship.

State of residency



Southern states
83%

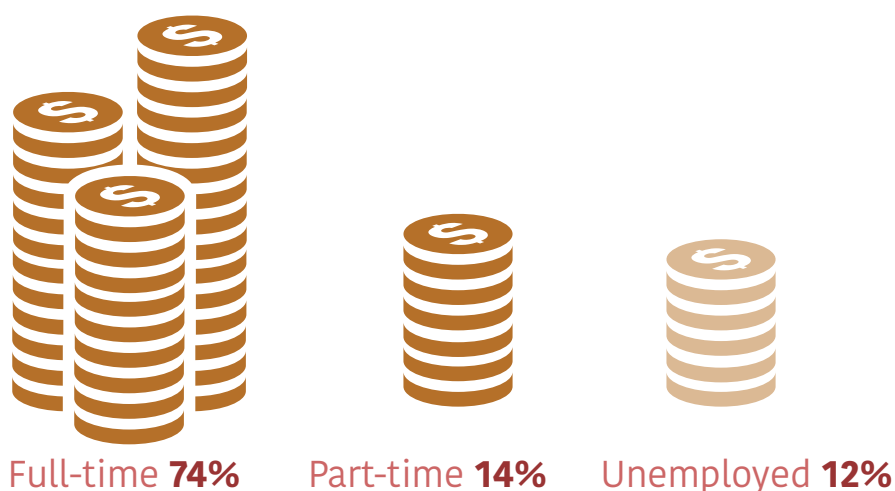
Northern states
17%

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Eighty three percent (83%) of the women were from southern states including Texas, Georgia, North Carolina, Tennessee, Louisiana, Kentucky, Arkansas, Alabama, South Carolina, and Mississippi. More than half of the women in the sample were working full-time.

Employment status



2. Health Concerns + Accessing Healthcare



What are the biggest barriers to accessing healthcare for you?



Those that responded “other” noted:

- “out of pocket cost, high copays, deductibles, financial, under insured” **
- “Finding a Black doctor, doctors who care” **
- “time, work, busy lifestyle” **
- “Doctors that accept medicaid”
- “Location”
- “Specialty doctors”
- “Doctors often discriminate against fat women, discrimination based on weight, weight judgements” **
- “Ensuring the doctor that cares, respects, respects, and is well informed professionally and culturally in your network”

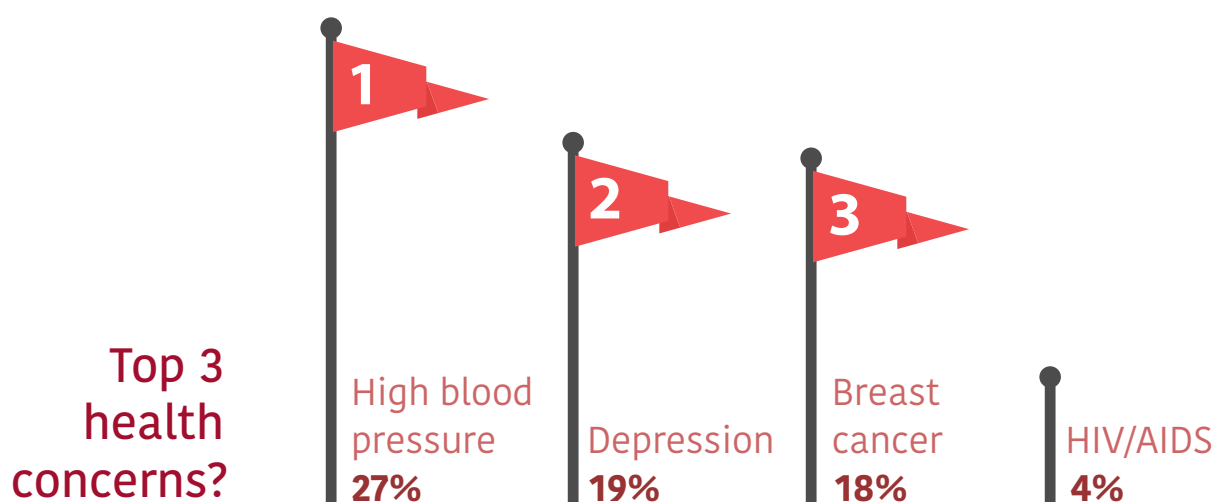
** multiple responses



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The findings from this survey support the literature which documents the challenges Black women experience when navigating the US healthcare system. Black women are disproportionately affected by HIV/AIDS, accounting for 14 times the rate of new HIV diagnoses among their White counterparts and approximately 5 times the rate of new HIV diagnoses among Latinas.¹



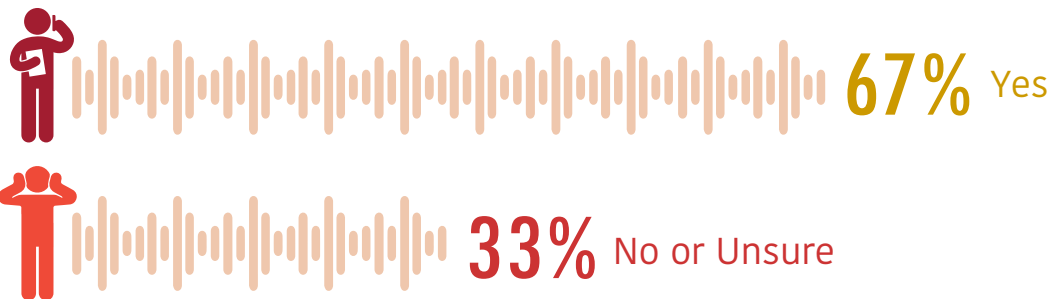
Despite this disproportionate burden of HIV disease among Black women, so few in the survey identified HIV/AIDS as a top health concern.

BWLI consulted with regional clinical and non-clinical partners in Baton Rouge and Louisville to better understand why low HIV risk perception persists among Black women locally. They reported a lack of HIV prevention education, and a lack of provider and community conversations as drivers for low risk perception. Black women are not having conversations about HIV prevention in medical settings even though the survey shows the majority of Black women have a primary care provider and are accessing healthcare on a regular basis. These conversations are also not happening in social settings where Black women traditionally bond and discuss issues that impact their lives largely due to pervasive HIV/AIDS-related stigma and discrimination.

¹ <https://www.kff.org/hiv/aids/fact-sheet/black-americans-and-hiv-aids-the-basics/>

3. Quality of Healthcare

Do you believe your health care providers listen to your health concerns?



It is hugely problematic that one in three respondents reported that their health care providers are not listening to their health concerns. One young woman noted:



“I had a bad experience with a doctor which is why I won’t go unless it’s a Black woman. They never really have your best health interests at heart.”

When asked about their experiences with discrimination from health care providers, Black women responded:

- “Access to care needs to be easier, remove stereotypes”
- “Listen to us when we voice concerns”
- “..Doctors need to listen to Black women”
- “I’ve seen providers build more rapport with white patients”

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How often do you experience discrimination from health care providers?

48% Always, Usually or Sometimes

52% Rarely or Never

It is well documented in the literature that Black women experience wear and tear on their bodies due to chronic stress over time. This stress activates stress responses and inflammation which damage the body and brain. These issues are further exacerbated by the negative experiences Black women have with the US healthcare system, not feeling heard or understood by their medical providers. Blacks are consistently undertreated for pain compared to Whites. A 2016 study of over 200 White medical students found that half the sample believed Black people have thicker skin or less sensitive nerve endings than White people.² Additionally, a recent article showed medical providers who scored high on a modern racism scale were less likely to discuss or prescribe PrEP with their Black patients. These decisions were explained by providers believing that Black patients would likely not take PrEP as prescribed.³

² <https://www.pnas.org/content/113/16/4296>

³ <https://pubmed.ncbi.nlm.nih.gov/34506359/>

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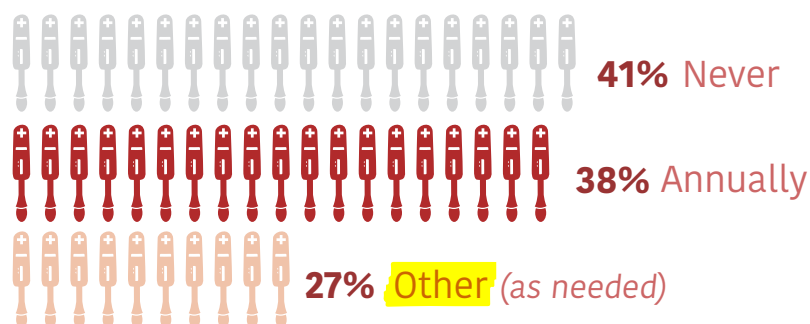
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Medical mistrust, implicit bias and the intersecting identities of Black women can create overlapping and interdependent systems of discrimination and disadvantage in all aspects of their life including healthcare. This type of implicit bias drives greater inequities in PrEP use among Black women. In the Engage. Empower. Educate. survey, women reported the following ways their healthcare experiences could be improved:

- “If healthcare providers took Black women’s health concerns more seriously and weren’t dismissive about it”
- “That we are treated more fairly and not like a junkie when we are in pain”
- “Doctors that actually listen to Black people”
- “Terminate racial discrimination in hospitals”

4. HIV/AIDS Prevention

How often
do you get
tested for
HIV?



About 4 out of 10 women in the sample never get tested for HIV, another 4 out of 10 get tested for HIV annually, and the rest reported getting tested for HIV as needed.

Multiple respondents noted the following under “other”:

- “Never...I am HIV positive, living with HIV”
- “When sexually active, when necessary, or have a new partner”
- “Only when concerned, needed or necessary”
- “Not sexually active in a way I can catch it”
- “When pregnant”
- “During STD screenings, pap smears”
- “More than 5 years ago”

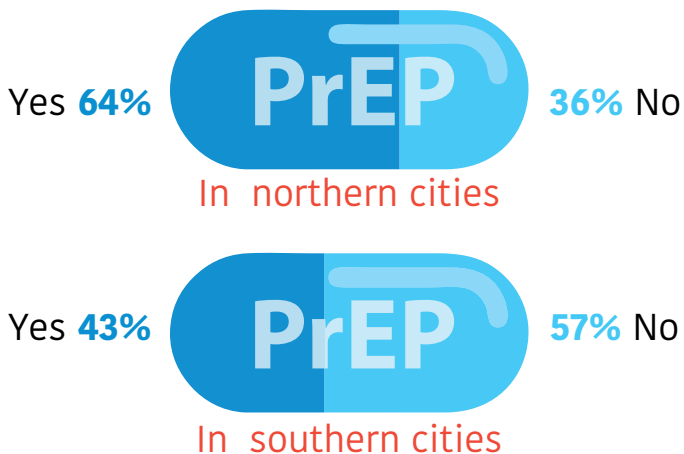


Survey results show that even among a diverse sample of Black women, HIV testing remains low. Many participants stated they only test for HIV during pregnancy, or on a need basis, “When my body has a change, or I believe him to have been with someone else.”

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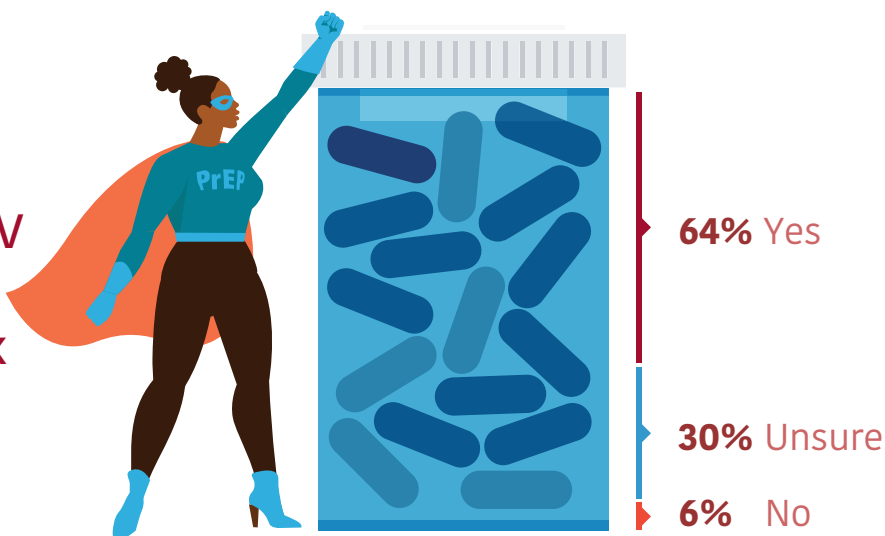
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Are you familiar with a once daily pill called PrEP which prevents HIV?



Overall, Black women have low levels of HIV knowledge and awareness about PrEP. The survey highlighted significant differences between northern and southern cities in the US around PrEP knowledge and trust.

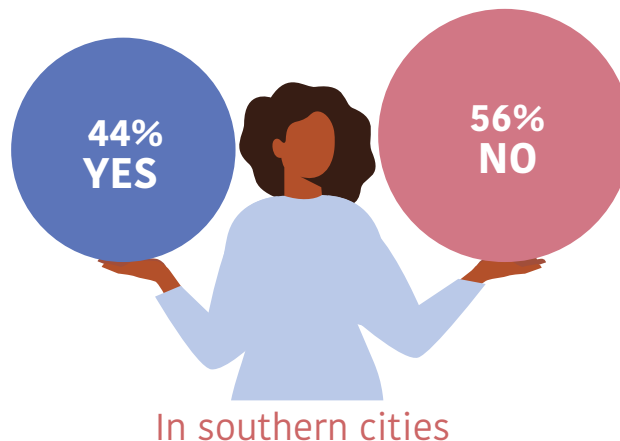
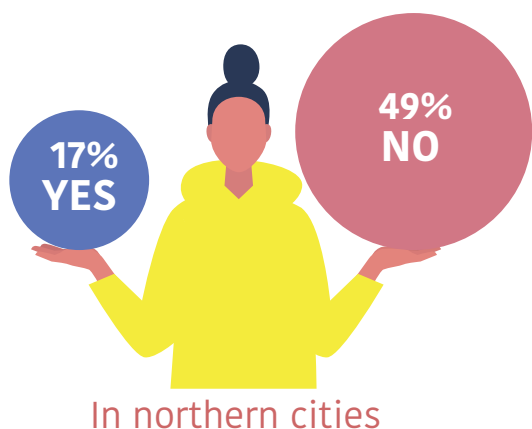
Do you believe PrEP is an important HIV prevention tool for Black women?



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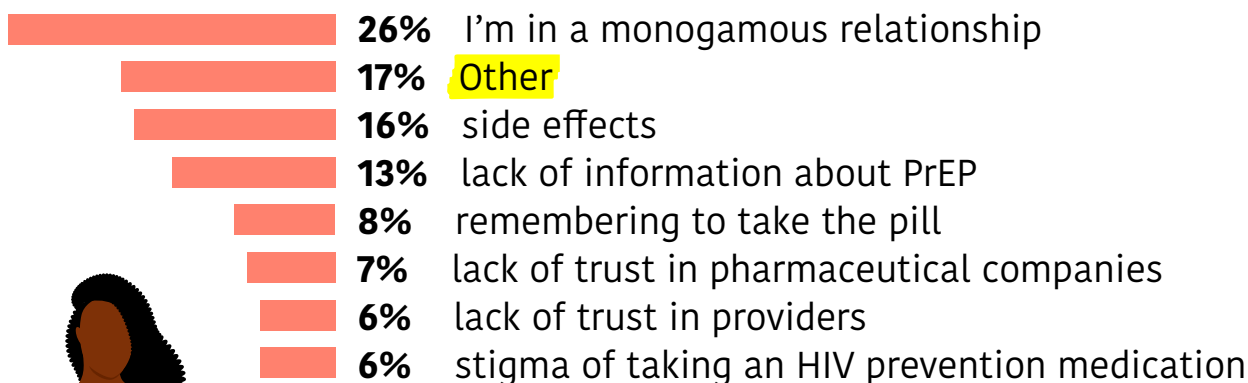
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Would you consider or are you already taking PrEP?



The majority of women in the sample believe PrEP is an important HIV prevention tool for Black women, but at least half are not or would not take PrEP themselves. This points back to risk perception and is worth further exploration.

What are your concerns about taking PrEP? (for those who said “maybe” or “no”)



Those in the category **other** reported the following:

“I don’t have HIV/AIDS nor does my partner”

“I do not have HIV”

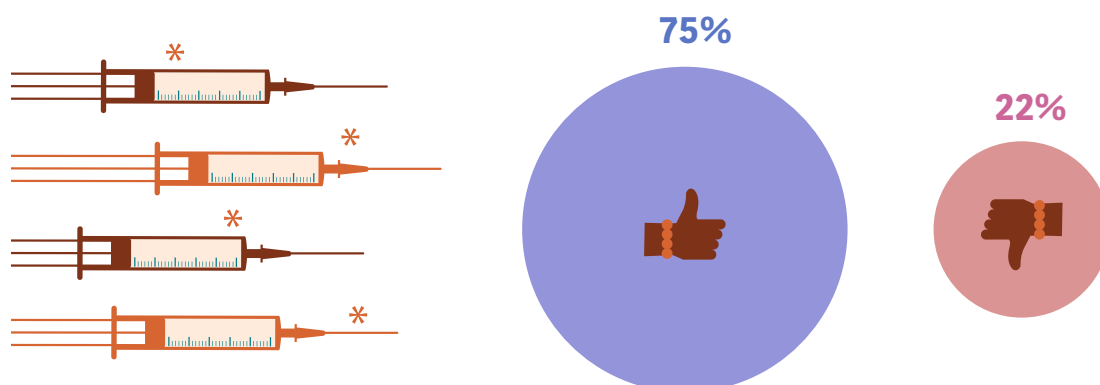
“Do not have a need to take the pill”

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Women who responded “maybe” or “no” to whether they would consider taking PrEP reported being in a monogamous relationship, concern about side effects, lack of information about PrEP, and several said they wouldn't consider it because they are HIV negative, further highlighting a lack of knowledge.

Do you generally feel comfortable taking injections to prevent disease?

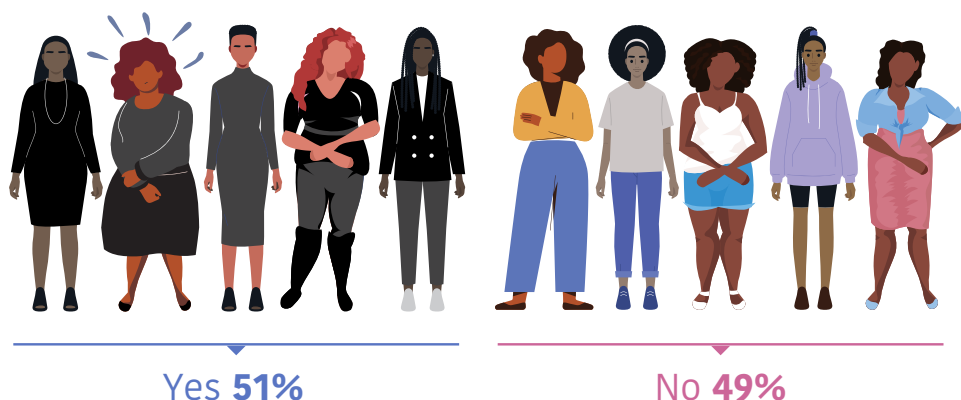


As injectable HIV prevention medications continue to be developed as well as important innovations like the COVID-19 vaccine, it is important to note that 75% of the sample said they generally feel comfortable taking injectable medications.

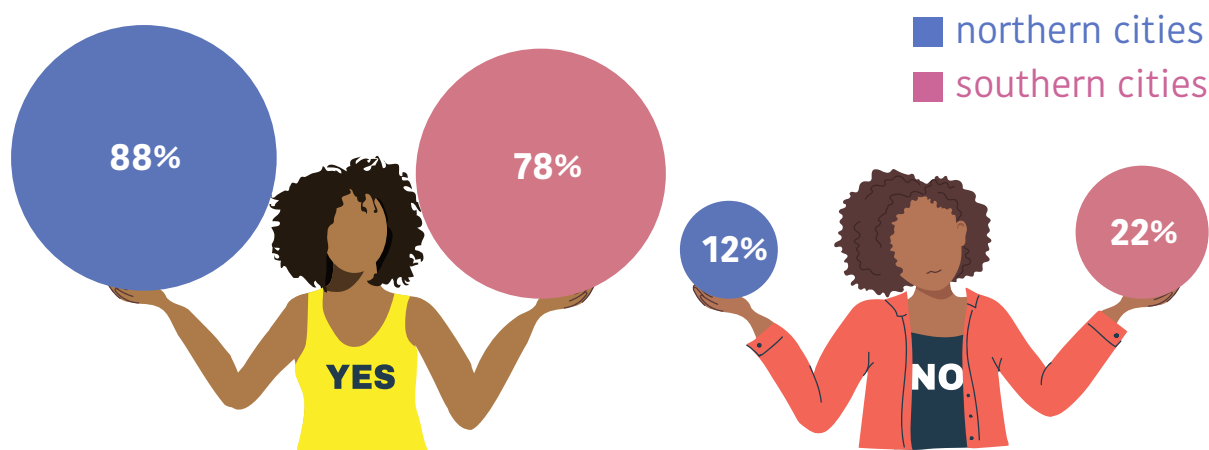
5. COVID-19

Early on in the COVID-19 pandemic, celebrities like Madonna and the governor of New York at the time, Andrew Cuomo, remarked that COVID-19 was “the great equalizer”. This was not the case at all as COVID-19 has disproportionately affected Black communities. A market research company called YouGov conducted a poll for the Economist and two thirds of respondents did not know anyone who had died due to COVID-19. ⁴ This is a stark contrast to the women in the Engage. Empower. Educate. survey - half the sample knew another Black woman who died due to COVID-19.

Do you know
Black women who
have died due
to complications
from COVID-19?



Have you taken the COVID-19 vaccine?

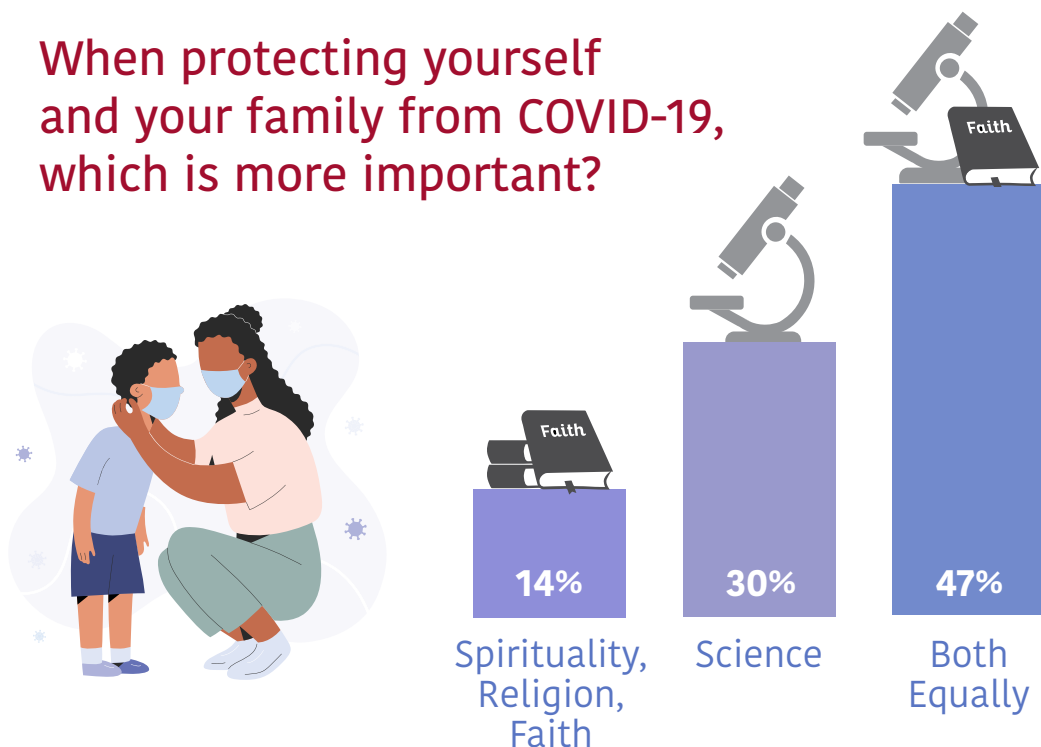


⁴ <https://docs.cdn.yougov.com/h2rgoa7a3x/econTabReport.pdf#page=36&zoom=100,48,140>

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When protecting yourself and your family from COVID-19, which is more important?



Do you think COVID-19 vaccination status influences your relationship choices?

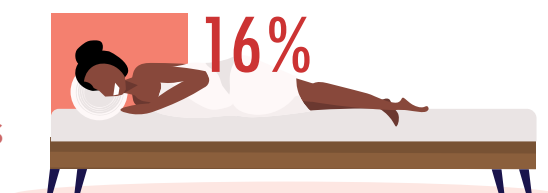
Yes, the COVID-19 vaccination status of my sexual partner influences my choice



No, the COVID-19 vaccination status of my sexual partner doesn't matter



I'm unsure if my sexual partner's COVID-19 vaccination status influences my choice



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The COVID-19 pandemic highlighted the importance of health messaging and lack of trust in the government and medical system by Black people overall. Many COVID-19 related messages did not resonate with Black women because of the race related health disparities and inequities that are exacerbated by a racist healthcare system. COVID-19 serves as a window into how people view the government, public health, and pharmaceutical companies. COVID-19 is both a reflection and a driver of suspicion among Black women and disengagement in care including HIV prevention, treatment and care. We can not just message from the lens of science. As seen by the survey question, “when protecting yourself and your family from COVID-19, which is more important?”, 50% of Black women responded that spirituality/religion/faith was equally as important as science.

6. Summary & Next Steps

Most of the Black women in this sample are engaged in their healthcare. The majority have primary care providers they see on a regular basis and are not relying on emergency care to address health issues. Despite this, Black women are not receiving the information they need to make informed decisions around HIV prevention, treatment or care. Medical providers are either not engaging their Black women patients in conversations about HIV prevention (including PrEP) and screening as appropriate, or Black women are not trusting their medical providers enough to discuss these issues. Many Black women noted that they would prefer to have a Black clinical provider but did not know how to access one. In the survey, many women expressed medical mistrust, and reported receiving substandard care because of their race. This highlights the need for more comprehensive tools for health care providers and change champions to provide clear strategies and approaches to providing high quality anti-racist clinical care to Black women.

We haven't even scratched the surface in engaging Black women in PrEP use. Correct and up-to-date information and messaging needs to either come from our health systems or a reliable source that Black women can understand, trust and act upon. When asked about the reasons for not taking PrEP, many participants said "I don't take it because I don't have HIV". The purpose of PrEP is not well understood within this population, especially in the south. Many Black women also noted that they didn't think PrEP was for women due to the way it has been marketed. This suggests there is a need for more targeted health literate PrEP campaigns focused on Black women.

It is important to consider that when asked about protecting themselves from COVID-19, nearly half the sample said they rely on spirituality, religion, faith and science equally. This means collaborating with faith based groups is a key entry point for developing and delivering important and accurate public health messages from trusted sources.

7. In their Words

Participants were asked if there was anything else they would like us to know about. Here are some of their words:

- "I know about PrEP that people use to prevent the spread of HIV, but I'm not so sure if you take it if you already have it or if you're trying to prevent it."
- "The way that we discuss sex, health, reproductive...and women's bodies in general... it's taboo. Nobody talks about sex to young Black girls and we can't really solve any problems without having these discussions. Making spaces where young Black girls are comfortable asking questions about their bodies... we need to have more comfortable dialogue about these issues."
- "Re-evaluating standards to check for racial bias in healthcare"
- "More representation of Black women Providers who actually care about Black women, yes we are strong but we still need support"
- "I would love for our doctors to know that we are fully human, just like the other women that they treat"
- "Having secure access to mental health resources geared toward Black women"
- "Open minds"
- " Having access or a database of Black Primary Care Doctors in Louisville"
- "More health care organizations focusing on Black women's health. Education is a big factor around improved outcomes. Addressing all the social determinants and mental health would help improve Black women's health"

8. Acknowledgments

We would like to thank **Gilead Sciences** for their generous support to fund this project. We also want to acknowledge our **Community Advisory Board** for their thoughtful contributions and guidance throughout the development and dissemination of the survey.

Dana Smith; Louisville, KY
Hope Wellness Center; Louisville VA Medical Center

Shawn Moore; Louisville, KY
Black Community Development Corporation; Jefferson County Public Schools

Anne Wiseman; Largo, MD
Heart to Hand, Inc.

Dorcas Baker; Baltimore, MD
Johns Hopkins Univ. School of Nursing

Marvin Anderson; Baton Rouge, LA
All Life Ministries; Live Higher, Inc.

Mauda Monger; Jackson, MS
COO My Brother's Keeper

Meta Smith Davis; Baton Rouge, LA
HIV/AIDS Alliance Region

Orisha Bowers; Memphis, TN

Sashika Baunchand; Baton Rouge, LA
AIDS Healthcare Foundation; Outstanding Mature Girlz (OMG)

Adrienne Barksdale; Washington, D.C.
DC Health

