



LAYERED:

A Report on Black Women's
Perceptions of Clinical Trials

May 2024

gci health



The Gaps in Clinical Trial Participation

The healthcare industry is beginning to recognize the need for equity in clinical trial participation, noting that without the participation of everyone, medicine does not work for all. Kathryn G. Schubert, president and chief executive officer of the Society for Women’s Health Research, shared in a recent op-ed that, “The vast majority of biomedical research was conducted exclusively on white men until Congress passed a law in 1993 requiring the inclusion of women and minorities in clinical studies funded by the National Institutes of Health (NIH).” That means that up until 30 years ago, approved medications, vaccines and devices were primarily tested on heterosexual, able-bodied, seemingly healthy, white men.

Gender representation in clinical trials is progressing, but not at equity. While women represent 51% of the U.S. population, they generally account for just 40% of clinical trial participants.¹ Recognizing that the need to ensure diversity is the cornerstone of drug development, leading healthcare institutions have

launched initiatives like the [All of Us research program](#). Additionally, the Biden Administration issued an executive order prioritizing women’s health research. In response, agencies like the NIH have committed hundreds of millions of dollars in federal funding to invest in researchers and early-stage companies that are developing interventions that aim make women healthier.

“We simply don’t know enough about how to prevent, detect and treat the conditions that affect women uniquely, disproportionately or differently. And that’s the result of a choice: Because, for decades, ‘business as usual’ has meant understudying and underfunding research on women’s health.” – First Lady, Dr. Jill Biden.

Despite having worse health outcomes, exacerbated by factors like healthcare bias and weathering — where poverty or racism wear the body down and accelerate disease — Black women are largely absent from current clinical trial research.

Breast Cancer

Black women are still dying at a nearly **40%** higher rate from the disease than white women.²

Black women may be genetically predisposed to higher incidences of triple-negative breast cancer compared to white women.³

Nearly half of Black women with metastatic breast cancer never receive information about clinical trials.⁴

Heart Disease

Black women are more likely than white women to have a heart attack.⁵

~49%

of African American women over age 20 have some type of heart disease, like:⁶

- Clogged arteries in the heart, arms or legs
- High blood pressure
- Angina (chest pain)
- Stroke

Black adults are underrepresented in NIH-funded cardiovascular clinical trials. Most of these trials do not specify a Black enrollment target and, largely, do not report specific plans to enroll Black adults in their studies.⁷

Alzheimer’s Disease

Experiences of racism, a highly prevalent psychosocial stressor among African Americans, are associated with lower subjective cognitive function.⁸

Women, regardless of race or ethnicity, are twice as likely to develop dementia as men. Black individuals are 2-3 times more likely to develop dementia than white individuals, putting Black women acutely at risk.⁹

Lack of inclusion for Black patients in ongoing clinical trials is also a significant issue, with some studies finding **less than**

3% of enrollees identified as Black or African American.¹⁰

The U.S. Food and Drug Administration (FDA) issued [draft guidance](#) in 2022 for “developing plans to enroll more participants from underrepresented racial and ethnic populations in the U.S. into clinical trials.” Commissioner, Robert Califf, M.D., shared that, **“Achieving greater diversity will be a key focus**

throughout the FDA to facilitate the development of better treatments and better ways to fight diseases that often disproportionately impact diverse communities.” However, the FDA’s efforts are just a recommendation, and the diversity action plan is not a mandate or requirement for healthcare companies to deliver on.

Why we want to understand Black women’s perceptions of clinical trials

As an agency committed to creating communications strategies that advance clinical trial access, GCI Health wanted to better understand the attitudes of Black women around clinical trial participation. We conducted a comprehensive device-agnostic online survey of a representative sample of 500 Black women ages 18 and older across the U.S. in August 2023.

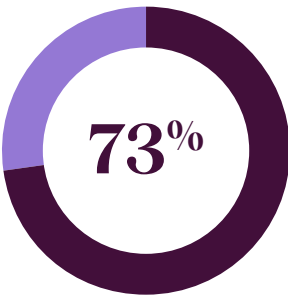
Spearheading this research, Kianta Key, Group Senior Vice President, GCI Health, and creator of the Identity Experience (IX) framework, began by leaning into her own lived experience. Current literature and experts suggest that mistrust of the healthcare system is preventing Black women from enrolling in clinical trials. Yet, in conversations with members of her family and community, Key noticed something different — something more layered, multifaceted and nuanced.

In response, GCI Health set out to hear directly from Black women about their beliefs, attitudes and barriers to clinical trial participation. The outcomes from this data were also nuanced, multidimensional and layered. We hope our initial findings are one of the many catalysts for driving new ways of thinking that bring us closer to exceeding the FDA’s guidelines and fulfilling our shared responsibility to transform clinical trial design and communications.

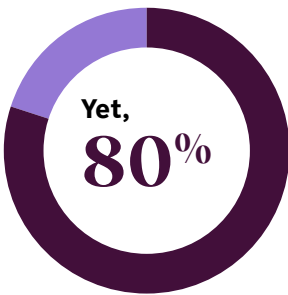
Key Insights From Layered

For clinical trials, Black women are not hard-to-reach — they are left out.

Although Black women over-index for chronic diseases and have higher mortality rates across cancers, they under-index as clinical trial participants. From 2015 to 2019, “Only 6% of trial participants in cardiovascular trials were Black or African American women. In oncology trials, only 2% of participants were Black women versus 84% White women.”¹¹ While it has been assumed that Black women may be hesitant or fearful of joining a clinical trial, the survey revealed the opposite. Even though nearly one-third of the women surveyed live with a chronic health condition or disability, 64% of these women shared that they have never been asked to participate in a clinical trial.



73% of Black women surveyed have never been asked to participate in a clinical trial



80% are open to participating in one

Perceptions and firsthand experiences around clinical trials are positive.

Most survey respondents were positive to neutral about clinical trials. In a Pew Research Center focus group highlighting the perceptions of clinical trial participation among Black and Hispanic Americans, a Black woman aged 40-65 shared, “I’d do it because I think they [clinical trials] help people, in the long run. It can help somebody, so I have no qualms with it.”¹²

Of the survey respondents who indicated that they said yes to participating in a clinical trial, **68% shared that they had a good or exceptional experience.**



49% of Black women have positive to somewhat positive perceptions of clinical trials

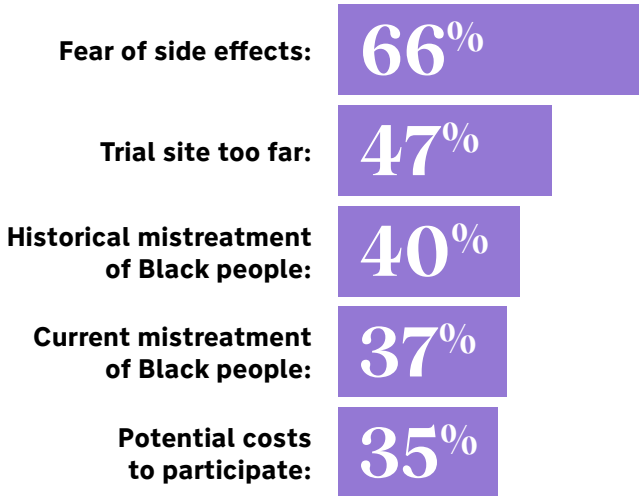
41% have neither positive nor negative perceptions of clinical trials

10% have negative perceptions of clinical trials

Safety is a top priority for clinical trial participation among Black women.

There are historical and contemporary healthcare injustices that continue to be an unhealed scar for Black people, particularly Black women. The appropriation of Henrietta Lacks’ cancer cells.¹³ The medical bias¹⁴ that disregards pain. The fact that Black women have the highest maternal mortality rate in the U.S., almost three times the rate of white women.¹⁵ Even [Serena Williams’](#) symptoms of a blood clot were nearly ignored by her healthcare team following the birth of her daughter.¹⁶ Given past and current realities, Black women want to ensure that participating in a clinical trial will be safe. This is consistent when we asked about factors that would encourage participation, too.

The top five reasons cited for not participating in clinical trials:



The top five things to know about a clinical trial to consider participating:

1. It is a safe trial
2. I would be compensated for my time
3. Side effects are minimal
4. I will be closely monitored by medical staff
5. My doctor supports my participation



Clinical trial influence extends beyond the doctor’s office.

When Black women were asked to rank influencers who could impact their decision to participate in a clinical trial, the top influencers varied across age groups:

Under 39

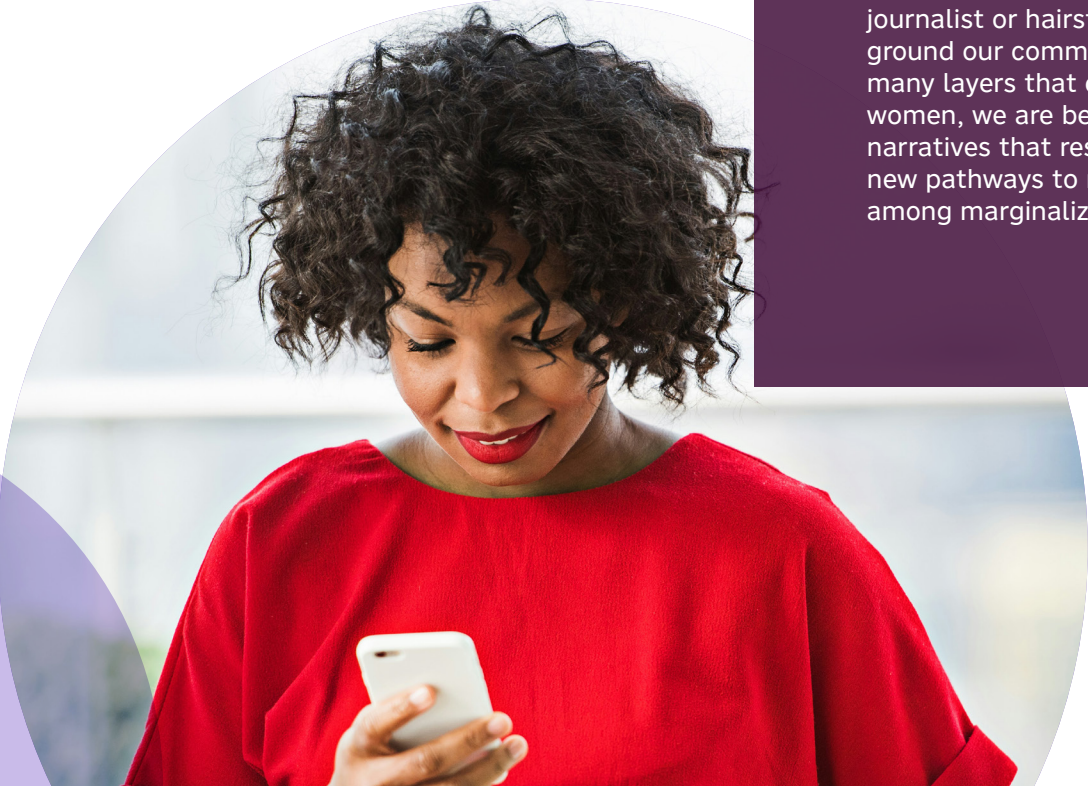
cited someone they follow on social media, a celebrity or a journalist/media outlet

Age 40-59

ranked their self-care team (e.g., hair stylist, nail tech) followed by a media outlet

Age 60+

noted a member of their healthcare team, family member, friend or patient advocate



Layered Lessons That Can Help Shape Clinical Trial Recruitment Efforts

In building this report, we were drawn to the collage work of South African visual artist [Lunga Ntila](#). In an [interview](#), she describes her design process as being about, “Inspecting identity, reimagining a limitless future, through intention and exploring different narratives. This formula allows us to explore and challenge the ideologies that govern the different facets that exist within us.”¹⁷

Taking a cue from Ntila’s process, we are reimagining the clinical trial journey — from recruitment to advocacy. As Black women are layered and multidimensional, our communications strategies must mirror this reality if we are intent on positively shifting the perceptions of trials and increasing participation. Here are four lessons from the survey that might get us there:

1
Lead with intersectionality.
Black women are not a monolith, and as their multidimensional identities influence their healthcare decision making, they will also guide their decisions to join a clinical trial. Healthcare providers will always play a critical role, but they are often not the only influential voice for Black women, especially across generations. It is important to look through the lens of intersectionality to align with voices that can deliver messaging that will resonate, whether that is through a celebrity, journalist or hairstylist. If we ground our communications in the many layers that comprise Black women, we are better able to create narratives that resonate and form new pathways to nurture trust among marginalized communities.

2
Champion clinical trial education.
While many survey respondents have a positive perception of clinical trials, 41% have neutral perceptions. With the FDA’s guidelines to diversify clinical trials, we should see a positive shift if there is a collective effort to educate the public about the value of trial participation and establish authentic connections. This will take courage. As Maya Angelou wrote, “Courage is the most important of all the virtues, because without courage you can’t practice any other virtue consistently.”¹⁸ Together, industry partners, advocacy groups, healthcare professionals, agencies and government entities can instill trust and increase participation through consistent clinical trial education that is representative of the many people we want to reach.

3
Double down on safety messaging.
While we hope to continue to expand this research to other cohorts, the survey respondents offered a cornerstone to understand what matters most: safety. The survey revealed that 80% of Black women are willing to participate in a clinical trial, but they need to know that it will be safe. If messaging about safety is most important for a community of women most burdened by chronic diseases, then it will likely be important to other groups and encourage their participation, too. There is also an opportunity to elevate the positive experiences of Black women who have participated in clinical trials to serve as a counternarrative and send the message that, “Today’s trials are made for you.”

4
Traditional forms of communication remain important.
As communicators find new ways to integrate artificial intelligence (AI) and digital platforms into outreach plans, traditional channels should not be forgotten. Television was the third highest ranked channel for clinical trial communications among survey respondents. Like improv, taking a “yes, and” approach to distributing content across various channels to reach Black women about clinical trial will be essential. For example, Black-owned media companies like [Urban One](#) (founded by a Black woman, Cathy Hughes) offer a convergence of media options that can help with the execution of a multichannel clinical trial outreach strategy where they can amplify a local voice across radio, social media and television.

The scope of our work as communicators can be limited, but it ladders up to the same intended outcome: we want everyone to be healthy. We have the capacity to amend the standard of care where clinical trials are offered and accessible: it will just take a multilayered approach.

For a deeper view into the intersectional data or to learn more about how we are applying Identity Experience (IX) to bring communities to the center of clinical trial participation, please reach out to clinicaltrials@gcihealth.com.

Special Thank You

Compiling this report was a collaborative effort from supporters in and outside of GCI Health. Health communications, particularly health equity, is hard work, and it takes big minds and greater hearts to remain steadfast and ensure everyone has the care that they deserve.

A special thank you to the GCI Health team, including:

Kristin Cahill, Amy Inzanti, Matthew Graffeo, Danielle Dunne,
Eleanor Petigrow, Mary Cronin, Tiffany Bullock, Khyllah Jean,
Dr. Breanna Symmes, Carly Hochman and Amide Jean

To LaTroya Hester of Comms Noire for connecting us with brilliant women in healthcare including:

Kimberly Richardson
Black Cancer Collaborative

Kanika Harris
Black Women's
Health Imperative

Claudia Hardy
O'Neal Comprehensive
Cancer Center at UAB

Kayla Nixon
Foundation for Women's
Cancer

Nicole Deggins
Sista Midwife
Productions

Tara Bowman
O'Neal Comprehensive
Cancer Center at UAB

References

1. AAMC. Published, March 26, 2024. Accessed May 22, 2024. <https://www.aamc.org/news/why-we-know-so-little-about-women-s-health>
2. Breast Cancer Research Foundation. Black women and breast cancer: why disparities persist and how to end them. 2023. Accessed August 10, 2023. <https://www.bcrf.org/blog/black-women-and-breast-cancer-why-disparities-persist-and-how-end-them/>
3. Siddharth S, Sharma D. Racial Disparity and Triple-Negative Breast Cancer in African-American Women: A Multifaceted Affair between Obesity, Biology, and Socioeconomic Determinants. *Cancers*. 2018;10(12):514. doi:10.3390/cancers10120514
4. American Society of Clinical Oncology. Study Finds Nearly Half of Black Women With Metastatic Breast Cancer Never Receive Information About Clinical Trial Participation. May 26, 2022. Accessed August 10, 2023. <https://old-prod.asco.org/about-asco/press-center/news-releases/nearly-half-black-patients-metastatic-breast-cancer-are-not#:~:text=%E2%80%94survey%20of%20metastatic%20breast,to%20enroll%20in%20a%20trial>
5. Benjamin EJ, Muntner P, Alonso A, et al. Heart disease and stroke statistics-2019 update: A report from the American Heart Association. *Circulation*. 2019;139:e56–e528. doi:10.1161/CIR.0000000000000659
6. Black Women's Health Imperative. Heart Disease In Black Women: The Big Issue You Might Not Know About. 2021. Accessed August 10, 2023. <https://bwhi.org/2021/02/02/heart-disease-black-women-big-issue-might-not-know/>
7. Prasanna A, Miller HN, Wu Y, et al. Recruitment of Black Adults into Cardiovascular Disease Trials. *J Am Heart Assoc*. 2021;10(17):e021108. doi:10.1161/JAHA.121.021108
8. Coogan PF, Schön K, Li S, et al. Experiences of racism and subjective cognitive function in African American women. *Alzheimer's & Dementia: Diagnosis, Assessment & Disease Monitoring*. 2020;12(1):e12067. doi:10.1002/dad2.12067
9. Southern Illinois University School of Medicine. Black women at increased risk for Alzheimer's. February 10, 2023. Accessed August 10, 2023. <https://www.siumed.edu/news/black-women-increased-risk-alzheimers>
10. Shaw A, Perales-Puchalt J, Moore TM, et al. Recruitment of older African Americans in Alzheimer's disease clinical trials using a community education approach. *J Prev Alzheimers Dis*. 2022;9(4):672-678. doi:10.14283/jpad.2022.82
11. Whyte J. Racial and Ethnic Representation of Participants in US Clinical Trials of New Drugs and Biologics. *JAMA*. 2022;327(10):985. doi:10.1001/jama.2022.0875
12. Pew Research Center. How Black and Hispanic Americans views clinical trials. November 29, 2022. Accessed November 3, 2023. <https://www.pewresearch.org/short-reads/2022/11/29/how-black-and-hispanic-americans-view-clinical-trials/>
13. The New York Times. Henrietta Lacks, Whose Cells Were Taken Without Her Consent, Is Honored by W.H.O. October 15, 2021. Accessed August 10, 2023. <https://www.nytimes.com/2021/10/13/science/henrietta-lacks-cells-who.html>
14. Advil. Advil_Plain_Equity_Project_Infographic_FINAL.pdf. Believe My Pain. Accessed November 1, 2023. https://www.believemypain.com/content/dam/cf-consumer-healthcare/bp-believemypain/en_US/pdfs/Advil_Plain_Equity_Project_Infographic_FINAL.pdf
15. Centers for Disease Control and Prevention. Working Together to Reduce Black Maternal Mortality. April 3, 2023. Accessed August 10, 2023. <https://www.cdc.gov/healthequity/features/maternal-mortality/index.html>
16. CNN. After Serena Williams gave birth, 'Everything went bad.' January 11, 2018. Accessed August 10, 2023. <https://www.cnn.com/2018/01/10/health/serena-williams-birth-c-section-olympia-bn/index.html>
17. Bubblegum Club. A Blueprint to Lunga Ntila. March 26, 2019. Accessed November 3, 2023. <https://bubblegumclub.co.za/features/a-blueprint-to-lunga-ntila/>
18. Big Think. Words of Wisdom: Maya Angelou: Courage is the Most Important Virtue. September 19, 2016. Accessed November 3, 2023. <https://bigthink.com/words-of-wisdom/maya-angelou-courage-is-the-most-important-virtue/>