

#BLACKDATAMATTERS



In early 2021, TOUCH, The Black Breast Cancer Alliance, Breastcancer.org, Morehouse School of Medicine, Ciitizen, Susan G. Komen, and the Center for Healthcare Innovation partnered in order to design our own research that would investigate the emotional barriers to clinical trial participation for Black Breasties under the umbrella of #BlackDataMatters. Starting with Black Breast Cancer, the mission of Black Data Matters is to put patients in a position of power to directly change a research and medical system that often fails Black patients.

In this Black Breast Cancer and Barriers to Clinical Trial Research study, we aimed to: uncover and seek to understand awareness, perceptions, and beliefs that drive the genuine emotional barriers to clinical trial participation, assess the unmet needs that must be addressed in order to drive participation in clinical trials, and understand the disconnect from current recruiting tactics, information, and messaging.

We started with qualitative research conducted in April 2021 that included focus groups and individual in-depth interviews among Black women diagnosed with, or at risk for, breast cancer, and their family members. In total, we spoke with 48 Black women. We quickly learned the most trusted messengers in the breast cancer ecosystem—more than doctors or any other healthcare professionals—are other Black Breasties. And Black Breasties, the voice of trust, had an incomplete and often incorrect understanding of trials and how the science works and were passing along misinformation. We also learned that there is an overwhelming fear of the unknown.

In their own words, here's what Black women said about why they don't participate:

1. Earned Medical Mistrust & Acknowledgment of Past

"We need messaging to acknowledge the mistakes of the past and let them know what has been introduced to make sure nothing like that happens in the future." — Participant, Stage 3C

"I think of the Tuskegee experiment, honestly, when I think of clinical trials." — Participant, Stage 3B

"From what we've experienced in the past, like the Tuskegee experiments and things such as that, there's just a rooted fear in the community." — Participant, high-risk group

2. Clinical Trials Are a Last Resort

"I always looked at it as the last resort like... nothing else is working, that at that point you really wouldn't have anything to lose so you might as well do a clinical trial." — Participant, Stage 4

"And so I think that kind of last resort, my doctor says, we've tried every medication that's out there. There's nothing else that's going to work for you. Do you want to be a part of this trial? That's the only time when you literally feel, okay, I'm already dying and there's nothing else that's going to help me. This is me doing my best to still stay alive."

— Participant, high-risk group

3. I Will be an Experiment, a Guinea Pig

"Whenever I would hear clinical trial, I would always think experiment because it was never really broken down to me, I never considered it, and I've never been approached personally to participate." —

Participant, Stage 2-3

"And as far as being a guinea pig and trying something new before they've tested it. It's an experiment to me and I don't want to be a part of an experiment. — Participant, high-risk group

"I mean, obviously, most people want to find a cure for this, but a lot of people—I'm sure—would be hesitant to put themselves out as the sort of Guinea pig" — Participant, in remission

4. You'll Get the Sugar Pill and Die

"We know in a trial some people get the A, B, and C drug and some people get the A, B, and sugar drug. So I think that's our biggest fear—I'm doing all of this and then I'm not getting the real deal... Getting the placebo or whatever it is... I mean, the only thing is, and I understand how black people don't want to do trials, is because I know that to prepare for a trial, it's a lot of work and it's very regimented that you have to do all these things. And then just to find out at the end that you didn't get the actual drug. You know, that's pretty discouraging."

— Participant, Stage 4

"But you always get scared. Are you getting the real thing or the sugar pill? And then you don't know until it's over that you didn't get [a real drug]." — Participant, Stage 4

"If you do a trial, you'll get the sugar pill and die!" — Participant, Stage 4

5. We aren't being asked

"Give me the opportunity to say yes or no. Ask me and let me say yes or no. I want to be part of the solution." — Participant, Stage 2B

"Empowerment. Choice. Options. Opportunity. I want to be the one to make that decision without having someone make the decision for me." — Participant, Stage 3C

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"I never thought to ask... one wasn't offered, and I never asked." — Participant, Stage 2A

6. Clinical Science Feels Predatory

"They really don't trust the science and they see a lot of pharmaceutical companies making a lot of money and not coming down to the communities unless they are doing some kind of trial.. they're just experimenting on us for our information. And then they're just going to make money from it, sell it to other people to make more money.' — Participant, Stage 2 BRCA+

"I think we should get recognition, and they shouldn't try to just take our information. I don't like the fact that they take our information, and we don't know if it helps somebody. We don't get recognition for what we've done or compensated for what we've done. I just feel like it's wrong." — Participant, Stage 4

The Case For Clinical Trials

In addition to identifying the key emotional barriers to clinical trial participation, we also sought to understand potential motivators for clinical trial participation. The most impactful was messaging that spoke to participating for fellow Breasties, for future generations, and for the community as a whole.

When presented with this lens, Black breast cancer survivors/ thrivers responded:

"Being a part of history in the making helps reduce the ideas around fear and threat. I'm doing it for myself but also generations of women who have breast cancer. Introduce it in a way that inspires curiosity." — Participant, Stage 3C

"It makes you think beyond just yourself, but the value that you're participating in a clinical trial could give to generations in the future. It speaks to legacy... Your participation could be far-reaching." — Participant, Stage 2-3

"And if you participate in the clinical trial, you can possibly help us to gain knowledge about what is triple-negative and the survival rate for African American women. It could help to go towards finding the positive outcome instead of when you Google and read and you only come up with the negatives." — Participant, Stage 3A

Everything we learned from our research culminated in When We Tri(al), a movement by Black Breasties for Black Breasties dedicated to empowering and educating Black women on the importance of clinical trial participation. Check out the movement at [www.whenwetri\(al\).org](http://www.whenwetri(al).org)!

Thank you to the generous partners who sponsored the #BlackDataMatters initiative and When We Tri(al) movement: Genentech, Bristol Myers Squibb, AstraZeneca, Novartis, Daiichi Sankyo, Pfizer, Seagen, and Eisai.