



# Increasing BIWOC Representation in Breast Cancer Clinical Trials

February 2021

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#### **Conventions Used In This Report**

Certain terminology will be used throughout this report to qualify the frequency of responses:

- Most or Many: 75% or more of the audience
- Majority: More than half of the audience
- Some: Less than half of the audience

- Several: 5-7 respondents
- Few: 3-4 respondents
- Couple: 2 respondents

Due to a limited sample and the qualitative nature of this research, all numbers contained in this report are directional only and may not be projectable to the overall population.



# Sample & Methodology

#### **Primary Research Objective:**

To understand the experiences of women in healthcare and uncover solutions to increase representation of BIWOC women in clinical trials.

Due to sample limitations, findings throughout this report are divided into four main segments: Black, Hispanic, Asian, and White.

Please keep in mind that while every effort was made to capture the nuances of each group, generalizations were made as it is impossible to fully capture the uniqueness of every woman's story.

Nov 11 – Dec 29, 2020		Nationwic	de 45-Minute	Telephone Interviews	
		Breast Cancer Patients	General Population	Total	
	BIWOC	36	7	43	
	White	8	8	16	
	Total	44	15	59	

Note: Additional demographic information can be found in the appendix.

#### **Interview Flow:**

Introduction & Healthcare Experiences

**Clinical Trial Understanding** 

**Clinical Trial Barriers** 

How to Increase BIWOC Representation



# **Demographic Details**

PATIENTS	American Indian, Alaska Native	Asian	Black or African American	White	Other**	TOTAL
Not of Hispanic, Latinx, or Spanish origin	1	7	17	8	2	35
Mexican, Mexican American, Chicano				1		1
Puerto Rican					2	2
Other Hispanic, Latinx, or Spanish Origin*			1	1	4	6
TOTAL	1	7	18	10	8	44

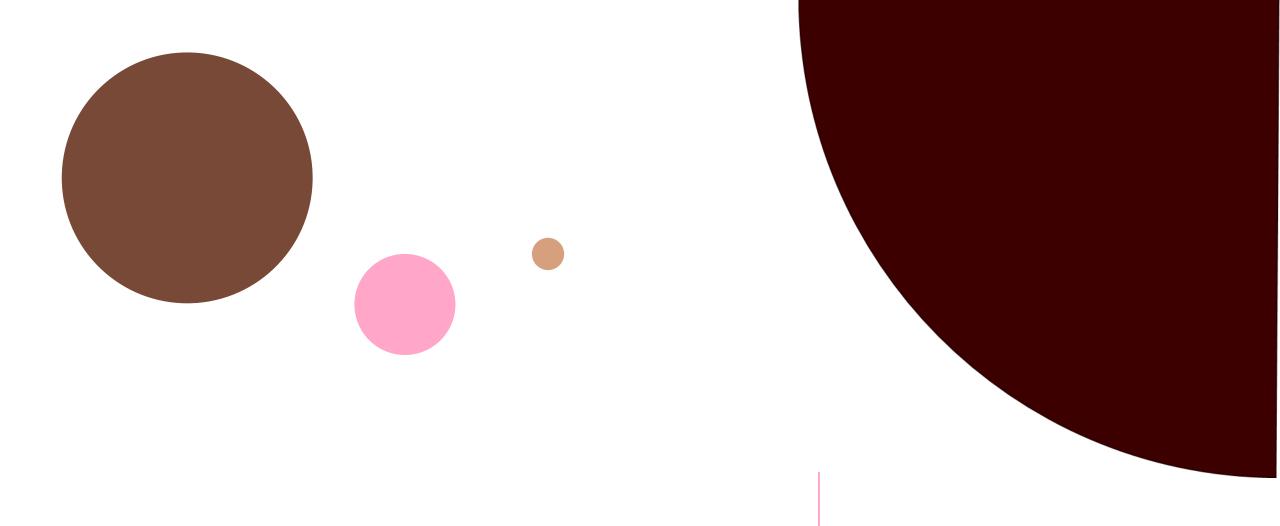
GENERAL POPULATION	American Indian, Alaska Native	Black or African American	White	Other**	TOTAL
Not of Hispanic, Latinx, or Spanish origin		3	8		11
Mexican, Mexican American, Chicano	1			2	3
Other Hispanic, Latinx, or Spanish Origin*			1		1
TOTAL	1	3	9	2	15

Breast Cancer Stage			
Stage 0	1		
Stage I	11		
Stage II	13		
Stage III	12		
Stage IV	7		

Age			
20-29	4		
30-34	9		
35-39	13		
40-44	12		
45-49	8		
50-54	2		
55-59	8		
60+	2		

\*Costa Rican, Latinx, Salvadorian, Spaniard \*\*Ethiopian, Hispanic, Latina, Mestizo, Mixed African/Spanish/Indigenous, Central American





Healthcare Experiences



#### **BLACK WOMEN**

(N = 22\*)

Often described negative experiences with healthcare due to medical racism.

Many shared experiences that included:

- Concerns and pain being dismissed
- Being treated as drug seekers
- Misdiagnoses
- Not being cared for appropriately
- Being treated in a demeaning way

#### **Greatest Hurdles**

In addition to the weight of systemic racism affecting healthcare, Black women experience inconsistencies with healthcare professionals in terms of the level of care and consideration afforded to them. Access to healthcare can also be limited.

#### Feelings towards Healthcare Stakeholders

#### **Doctors & Nurses**

Mixed feelings about doctors but said some are better than others.

Prefer doctors who look like them or at least practices where there is a black nurse/staff member.

Nurses are considered much more caring and compassionate.



#### Pharmaceutical Companies

Believe they are "in it for the money" and wish that in addition to making a profit they were more patient-centric.

#### **Government Agencies**

Mixed reactions; some did not know enough to react, others said FDA/CDC tries to help but should do more.

\*Findings on this page encompass all Black/African American respondents and 2 Ethiopian patients.



### **Black Women**

"I would say I've had kind of negative treatment by a lot of healthcare professionals. I had my appendix rupture many years ago and when I went to the emergency room, they treated me like I was just looking for like drugs...First I had gone to an urgent care, a Patient First. And then they sent me to the ER. I went to the ER, they treated me horribly bad. The doctor came and was just really kind of rude to me and didn't really spend any time and then sent me home basically and told me to take Imodium. I had food poisoning but then it had gotten so bad that I went back to the original urgent care I went to and then they said 'well go to a different emergency room' and then within 5 minutes of being, I'm telling you 5 minutes of being there, the doctor was like 'OK, this is serious.' They did blood work on me, realized something was really wrong, realized my appendix had ruptured, and then I was in emergency surgery. That Doctor actually said, 'Can I pray over you before I perform this procedure?' I've had kind of one bad experience after another with treatment from various doctors, that I feel like a lot of my health issues were dismissed or made to seem like they weren't as bad and then they were actually really pretty bad."

#### I FXICON AI FRTI

Black patients are 3.8x more likely to talk about waiting than are white patients. Waiting in hospitals Waiting to get treatment. Waiting for results. So.

Much. Waiting.



#### LEXICON ALERT

Black patients were **4.7x** more likely to talk about **pain** than were white patients.





"I was in my 20s when [my mom] passed, so...it had probably been about two years of us chasing doctors and trying to find answers [when she was finally diagnosed. I wanted to tell the doctor] you're dismissing what she's telling you and you're just **giving her textbook answers**...[to] just lose some weight, lose some weight...By the time we actually caught the last doctor that figured it out, that listened maybe five more minutes, they were like it's pancreatic cancer and you have three months. And that time frame that we ran and ran and she felt like she's running into the ground...Honestly, at the time it was going on I really did think my mom's doctor was racist and didn't care that this black woman was in there 'cause, I mean, she was in full-on tears every time she went in there and it was just like all it was [was] just a **tummy** ache, [and they would say] I'll give you something different for your stomach ache... and it just was very, very dismissive not even like, there was no empathy there."

"...every time [my mom] would always tell us you need to be really good, nice, you know, to all the medical professionals...whenever we went to the doctor's office, we made sure we dressed up to the nines...I mean speaking very candidly, if you don't look like you're some drug pusher then they're more likely to hopefully believe you, and so, and if you have a relationship with the nurses and they know you as a kind person and a nice person, and all of that, then they're hopefully going to be more likely to believe you, you know, and so for her she was best friends and so close to the doctors and nurses, and they loved her, and because of that when we went in for our pediatrician visits or whatever it was, if we had stomach aches or things like that, they were more likely to believe that."





#### HISPANIC WOMEN (N = 13\*)

Often described negative experiences with healthcare rooted in language and cost/access barriers.

The older generations typically had the more negative experiences.

Some also described being treated as drug seekers or in a demeaning way because physicians do not always understand how they show pain.

#### INDIGENOUS WOMEN (N = 2\*)

Indigenous women were especially distrustful of the government because of the treatment of Indigenous people throughout history.

Of the two Indigenous respondents, one also identified as Mexican/Mexican American/Chicano, so their findings were included on this page for reporting purposes because their feedback was in line with Hispanic respondents.

However, the Indigenous women emphasized that they do not like being generalized as BIWOC because they are proud of their heritage and prefer that it is individually emphasized.

#### **Greatest Hurdles**

Similar to Black women, Hispanic women also face access challenges and the weight of systemic racism in healthcare. Language barriers can make communicating with healthcare professionals even more complicated.

#### Feelings towards Healthcare Stakeholders

#### **Doctors & Nurses**

Trust doctors who look like them, but there are not many out there.

Feel white doctors do not understand them and do not take them seriously.

Nurses were described as caring and welcoming, especially compared to doctors.



# Pharmaceutical Companies

Most focused on the medicines being too expensive. Some confusion around pharmaceuticals and their relationship to insurance companies and the government.

#### Government Agencies

Limited understanding of what this group does. Believe that the FDA approves meds but think they can get bought off.



#### LEXICON ALERT

ispanic + Indigenous patients were 2.3x more likely than other groups to mention **government** issues, such as how the **state** you live in can determine access.

# Hispanic Women

"Growing up we avoided going to the doctor, you know. You know, you didn't go to the doctor for every little thing, you waited until it got so bad that you had to, like you were almost dying because you had no choice at that point. You really didn't go because you either can afford just to go to get your regular checkups, you waited until it was absolutely an emergency and you dreaded going because it was not a, you know, a **positive experience**. You didn't go to get well because it was just not, like I said, it was not a positive experience. And now it's like it's just such difference. As an adult I made it a priority to become employed in a large corporate organization where I had access to healthcare, to **insurance**, so that I can be, you know, keep up with my, you know, with my well woman exams and all of my check-ups so I didn't have to go through that...healthcare is such a critical aspect for me because of what it was like for me growing up."



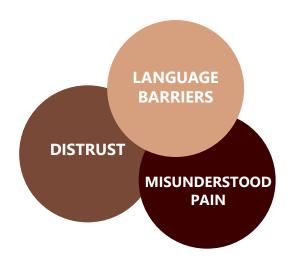
"I personally, I **always saw my mom having difficulty maybe explaining things to the doctors because of the language barrier**...And just witnessing my older siblings trying to help,
be the middle person between a doctor [and] my mom, so they can communicate even though, you
know, my siblings were adolescents themselves...The **sense of frustration**, I could see [on] my
mom's face...it might have been a sort of like an **embarrassment** for her."

"[My mom] gets so frustrated because people always tell her she looks good, and she told me she was gonna change her middle name to 'you look so good' right...And I think that a lot of times...doctors and clinics...[are] just not used to [us]. I mean, there's a whole thing like Black don't crack or you know like they're funny. They're cute, you know, but I just think that doctors from particular racial makeup like Asian or white are not used to seeing what pain looks like or how it ages on other backgrounds. Yeah, like it's the same with anger and if this thing was happiness and the same with vernacular like you just don't, you're just not used to seeing how it ages like I know a ton of 80-something-year-old women who have a lot of health issues that look as good as my mom, you know, like I know I see 'em all the time. Right but **when she** goes to the doctor it's like a phenomenon, like 'Oh my God, she's not frail. She's not wrinkly and she's not **skinny**.' You know. And she's pushing herself to walk even if she shouldn't. Yeah, right they're not used to like the loud **one who's gon' make herself walk.** Even if she's out of breath and can't, you know, like they're not used to. That kind of my mother is aggressive with her own body, she's aggressive. You know, and they're not used to it, but she had to be, didn't really have a choice."



# Indigenous Women

"It was my mom's primary care, and he spoke Spanish, so my mom felt comfortable with him 'cause she also spoke Spanish...So, she was more comfortable with him because he was Brown, and he was Hispanic as well, and that's like a loose term any anytime I use the word Hispanic it's with the indigenous understanding that they are native. Most of our tribe comes from northern Mexico. We have a couple reservations here in southern Arizona, but I have family down also in northern Mexico that is not Mexican; they are Yaqui. So, it gets tricky because the Yaqui tribe is fluent in Spanish, Yaqui, and English, so the majority of people who we would normally see as Hispanic have a lot of indigenous **blood as well.** So, for my mom she felt comfortable with that because that was one of the languages and she wasn't fluent in...It's very hard to find an indigenous MD or **DO**...My mom trusted him, so he was our primary doctor following that."



"I was about three years old, and I had an eye stye that would not go away...And my mom is trying so many home remedies. My mom is not a believer in going to the doctor. I am Indigenous so my mom had herbs in the back yard that she was growing. She would turn that into a paste and put that on top of my eyelid...I think if the nuns [at school] wouldn't have kept telling my mom you need to take her to a specialist, I don't know that I ever would have gone to a doctor [while I was] that young."

"When I had thyroid cancer... I had to fight for 9 months with several different providers. Unfortunately, even with my breast cancer, it was the same thing. I kept saying, 'Hey, I'm having a lot of pain in this area, [and the doctor said] you know, 'oh, you know mammogram looks OK; MRI looks fine.' I'm like, 'you don't understand. I said, 'I cannot wear a bra,' that's how bad it was. Now I'm having nipple pain [and] it's getting worse, so again I had to actually go and find **another doctor.** Like again I had to fight because you know why would I make up breast pain? And that's what I think in my head is, do they not believe me that I'm having pain? I'm coming to them, I'm telling them I can't wear a bra, it's so painful what you know what else do I need to do? So, there's a little bit of disappointment but I know that if there's a disappointment with one provider, I can always find someone who will listen, I just have to unfortunately keep looking. And that gets frustrating, and you just start to panic and after having cancer once, yeah, you have that fear of reoccurrence, right? So in in the back of my mind there's always that 'what is this pain? Is it cancer?' And I wish providers would listen."





#### **ASIAN WOMEN**

(N = 7)

Often more trusting of healthcare than other segments due to family members who work within healthcare.

Many spoke of generational differences, and that their parents/grandparents were usually the influence that was more skeptical of treatments or doctors.

The older generations also face language barriers when receiving their own care.

#### **Greatest Hurdles**

Asian women overall may be more open to and aware of the healthcare system compared to other BIWOC, although some can face language barriers and family skepticism when it comes to deciding treatments.

#### Feelings towards Healthcare Stakeholders

#### **Doctors & Nurses**

Overall positive feelings towards all healthcare professionals because many have doctors and nurses in their families.



#### Pharmaceutical Companies

Deeper understanding of pharmaceutical companies and the research involved because they usually know researchers.

#### Government Agencies

Believe they are supposed to be a trusted source, but the COVID-19 pandemic introduced some skepticism.



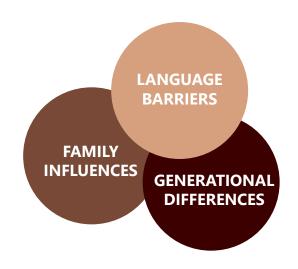
#### I FXICON ALERT

Asian patients were 1.9x more likely to talk about **using technology** tha were white patients—whether exploring online support groups, visiting healthcare websites, or utilizing their patient portal.



### **Asian Women**

"My mom growing up was always a big proponent of going to the doctor when you're not feeling well. But then I think once I got sick, she now almost like avoids it because she doesn't want to go, like I think it's kind of left a bad taste in her mouth, you know the emotional trauma of it. But I think on the other side my dad is a doctor, so you know he's been in the medical field his entire life, so it's normal for him and like you know it's more like on the research side of things too so it's just a whole other perspective. I think overall they were just wanting to make sure that I had kind of that the best like possible care right, and like I think coming from my dad's perspective it was more of a where are they still doing research about breast cancer? Were they still on top of maybe teaching too because that's where you get like the newest information."



"For my parents, language is a huge barrier...I think they only understand probably 3/4 of what they're told, which is, like I can't, you know, it's unfortunate I can't go with them. Last I heard is my dad now has gout but, you know, who knows how much they understood from that appointment. Luckily, my mom is more proficient in English so, and she usually, she's on YouTube all the time, so I think she's probably been looking for videos on gout, but another thing is like there is misinformation out there, and what she was doing for my cancer too, you know, like she was telling me what foods to eat, what foods to avoid, so it's really tough because, you know,

there's just so much information out there you don't know

what is good information or what's not."

"I have no, well **for me I'm an open book and I want the world to know**, like, it doesn't matter your age, I was only 33 when I was diagnosed, so I'm trying to tell my family and friends, don't ever hesitate to get checked. **I wonder** like the older people if maybe they're ashamed or they think they did something that caused their cancer. My mom also, she was like, 'you ate too much sugar, you had too much stress in your life,' like she was trying to come up with an explanation of why I got cancer, even though the medical community keeps telling me, 'you didn't do anything; it was just bad luck."





#### WHITE WOMEN

(N = 16)

Most white women have had positive experiences and believe that their negative interactions with the system are the exception, not the rule, when it comes to healthcare.

Some white women believed their experiences were tied to health insurance, because better insurance gives you better care.

#### **Greatest Hurdles**

As with all the respondents, white women can face challenges with access depending on where they live or their insurance. They also must learn to advocate for themselves, but their hurdles are not driven by their ethnicity.

#### Feelings towards Healthcare Stakeholders

#### **Doctors & Nurses**

Overall positive interactions with all healthcare professionals.

Many have family members or friends who work in medicine.



#### Pharmaceutical Companies

Grateful for the medications that pharmaceutical companies produce, but often feel they are "in it for the money."

#### Government Agencies

Some have positive reactions and said they are needed to regulate things whereas others feel they are corrupt.

"I think the first question would be whether I've done everything prior to joining a clinical trial, you know, whether I've tried **traditional**, what's already out there."

#### LEXICON ALERI

White patients are 18.4x more likely to talk about **traditional** healthcare than are BIWOC patients, sometimes suggesting the clinical trials are outside or different from healthcare in general



### White Women

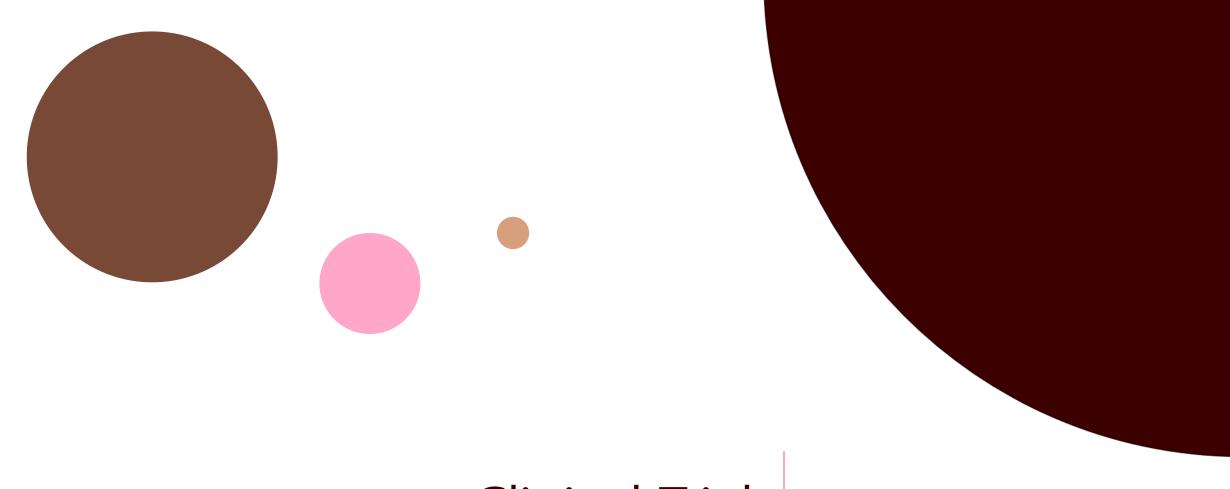
"When I was younger I always, you know, doctors are always right 100% of the time, but I think it's interesting as I get older and I hear different perspectives and a lot of people – you know, some doctors disagree with other doctors, and say, some doctors, you know, value different things than others, so I think that's interesting as I get older to see that there are different doctors to go to. So yeah, **I definitely** have a lot of trust in the medical field, I would say, just since my mom is a nurse then I feel as through my education, as I'm in college, and through high school, and all my classes and just yeah, I do feel like the medical field is the safe place, and a place where you can get the help you need and that they're always striving to innovate and learn more about different things and **medications** and things like that."



"I've had many different experiences in healthcare with friends and with family, and I have a friend who, she was a homeless woman who lives on, you know, the whole Social Security and you know, welfare and Medicaid, and I was assisting her with her healthcare and she, when we went into the hospital, was pretty much ignored. The staff was not very helpful to her, and I found it quite disappointing. **And then in contrast, one** thing I remember was my dad recently had open heart surgery and my dad has great insurance, and not only were they like, over the top supportive and helpful of **him**, they were, you know, they wanted him to stay even longer, and my friend, they want to get her out as soon as they could...So maybe I'm a little biased there because I've had bad experiences, but the one was a man and he was actually quite good at what he did, and then the other was a man, but he was very horrible. You know, to a woman who was going through such a traumatic experience."

"If I'm seeing my family doctor, I know that I can talk to him and I feel like he's not judging me, he's trying to help me. I know that my cardiologist is, his best interest is for my heart, so I'm pretty much ok with going to the doctor now, I still get nervous cuz, I mean, obviously don't know what's gonna happen or, you know, if I'm having a symptom, but I feel, I'm comfortable now that I'm older."



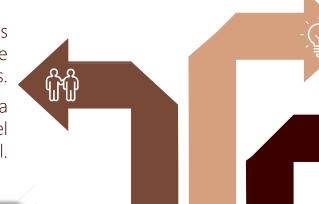


Clinical Trial Understanding

# **Clinical Trial Understanding**

Women who know someone else who has participated in a clinical trial are generally more open to participating in one themselves.

Facebook groups, especially FTBOU, provide a place for women to learn about trials and feel more comfortable with the process overall.



Most respondents would not be proactive in asking their doctor to participate, even though patients tended to have a greater understanding of trials.

> The COVID-19 pandemic has made clinical trials more top of mind. However, it has also introduced some skepticism around healthcare and government agencies in general.







- Black women had mixed levels of understanding of clinical trials.
- They were most aware of the history of clinical trials such as Tuskegee and use of Henrietta Lacks' cells.
- They tend to believe:
  - Only doctors share information about clinical trials
  - People with money participate because they have greater access
  - o Placebo means no treatment
  - Trials are a "last resort" and require travel

- Hispanic women had a limited knowledge and understanding of clinical trials or what would be involved.
- Most expect that their doctor would offer it if it was appropriate.
- They often believe they are not being offered trials due to doctors' prejudices.
- Asian women were more knowledgeable about clinical trials, but they had some misunderstandings.
- They tend to believe:
  - o Trials are a "last resort" option after they have tried all established protocols
  - Participating would be "exhausting" due to scheduling and travel

- · White women have a better understanding of clinical trials and positive impressions overall.
- They tend to believe everyone benefits from clinical trials.
- Several said you must "be educated" or "have connections" to be recommended by your doctor to participate in a clinical trial.
- Like other segments, they also believed trials are a "last resort."
- Only one white respondent mentioned Tuskegee/Henrietta Lacks.



# **Clinical Trial Experiences**

Clinical trial discussions and participation varied across segments.

BIWOC women were more likely than white women to have never even discussed a trial with a doctor.

Furthermore, white, early-stage breast cancer patients were more likely to have discussed and/or participated in clinical trials while BIWOC often did not discuss or participate until at later stages.



- The two Black trial participants decided to participate because others insisted (brother, nurse).
- Others chose not to participate because their questions were not adequately answered.



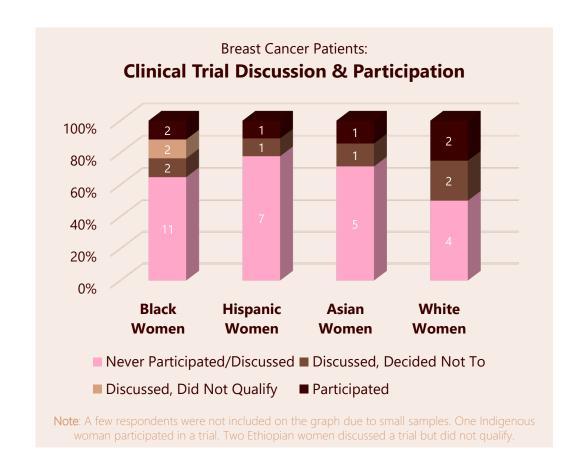
• One Hispanic woman was offered a trial but decided not to participate because she was concerned about side effects and managing childcare.



 One Asian woman chose not to participate in a trial after doing research on the trial itself and feeling it was not different enough from her current treatment to pursue.



• Two white women decided not to participate in a trial because they did not know if they would receive the trial drug or placebo.







Clinical Trial Barriers

# Clinical Trial "Baggage"

In addition to barriers that prevent BIWOC from participating, clinical trials themselves have a lot of baggage that needs to be addressed.

#### Abuse of the BIPOC Community throughout History

BIWOC are profoundly aware of the historic role of Black people in medical research and the unethical treatment they faced. This knowledge, which includes Tuskegee and Henrietta Lacks, fuels their distrust. White women typically did not mention these events.

BIWOC also cited the massacres and mistreatment of their communities throughout history, which gives them little reason to trust "the system" with their lives. The younger generation of BIWOC women were more motivated to work through the distrust to help future generations.

#### **Limited Awareness of Clinical Trials**

Most women have never really considered or thought about clinical trials. They are more likely to wait for the doctor to present it as an option rather than advocating for themselves to participate.

#### Assumptions of How Clinical Trials Work

Most believe that clinical trials are only an option when they have exhausted all other established treatments.

Many also believe that if they were to enroll, they would either receive the experimental treatment or no treatment whatsoever (placebo). BIWOC usually fear they would end up with no treatment.

Clinical trial designs can be complicated, and many do not understand that they would be monitored throughout the trial and at least receive standard of care.



#### **EFFECTS OF COVID-19 CLINICAL TRIALS**

The recent publicity of COVID-19 trials has, in some ways, added to the "baggage's because of how quickly the trials are being done, which leads to additional skepticism and distrust.

On the other hand, COVID-19 trials offer a contrast to more "established" research, like breast cancer, which some patients believe is more trustworthy in the context of COVID-19 trials.



### **Barriers: Access**

Simply getting women in the door can be a challenge.

#### Location:

Access to quality healthcare systems with connections to clinical trial researchers is one of the first limiting factors that prevents BIWOC from enrolling in trials. Proximity and ability to travel, including limited transportation options, often increases location challenges. White women often tried to think of solutions, while BIWOC were usually facing bigger picture location/transportation problems that they could not problem solve.

#### Insurance / Cost:

On top of location limitations, insurance, especially Medicaid/Medicare, limit which doctors they can see. Several women spoke about being on Medicaid and having to go to local clinics for care where they rarely saw the same doctor, if they got to see a doctor at all.

#### Language:

Language differences create yet another hurdle for Hispanic and Asian women. Some struggle to find providers who speak their language and pamphlets/learning materials are rarely translated.

#### Relative Impact on Each Segment:

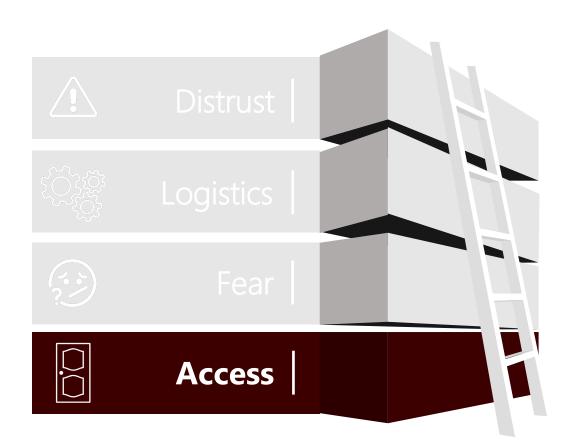












#### LEXICON ALERT



White patients were 3x more likely to talk about **transportation** issues than were BIWOC patients—often trying to think of ways to solve the issues of inconvenient bus schedules, not having a car or even a car seat.

"If [patients] use public transportation that doesn't fit within the hours [researchers] need, like find ways to make it work. like have some kind of Uber payment available so, you know, like, oh ok, well you need to be there at 5 in the morning and the bus doesn't run until 6 you can, we'll take care of your Uber over, or something like that, I mean, there's gotta be a way to break down barriers."

# **Barriers: Fear**

There is a lot of fear and misunderstanding surrounding trials.

#### "Guinea Pig":

One of the biggest fears among Black women is that they will be the "guinea pig." This is typically driven by the medical community's historical wrongdoings, but some women overcame this by learning more about how trials are designed and monitored.

#### Misunderstanding:

Many BIWOC fear the unknown of clinical trials. Clinical trials are not taught in schools, at home, or on social media/television, so they remain somewhat taboo. There is fear that they could not receive any treatment if in the placebo group.

#### Shame:

In general, BIWOC do not discuss healthcare in their families, and some patients did not know breast cancer ran in their family until they were diagnosed. Asian women spoke about a sense of shame in their families when they got sick, which

was usually perpetuated by older generations. Cancer signaled weakness and that they did something wrong.

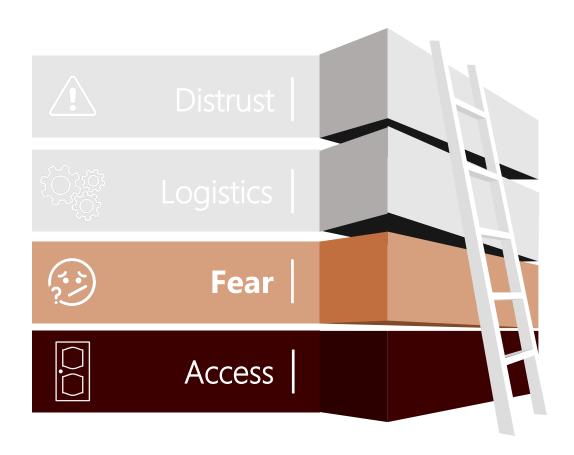
#### Relative Impact on Each Segment:













# **Barriers: Logistics**

As primary caregivers and employees, the logistics of participating in a trial make things even more complicated.

#### Time:

Most women, regardless of ethnicity, are juggling multiple demands in their lives, and sometimes the anticipated time demands of a clinical trial are too daunting for them to take on

#### Childcare:

Women with children are first concerned with who will watch their kids or take them to activities if they are part of a clinical trial. Some do not have a network of family/friends to help with this responsibility.

#### Time off Work:

Some women do not have the luxury of flexible schedules or employers who will work with them so they can get to doctors' appointments. Coordinating their work schedules is typically challenging enough with their standard treatments, and they anticipate clinical trial schedules would be even worse.

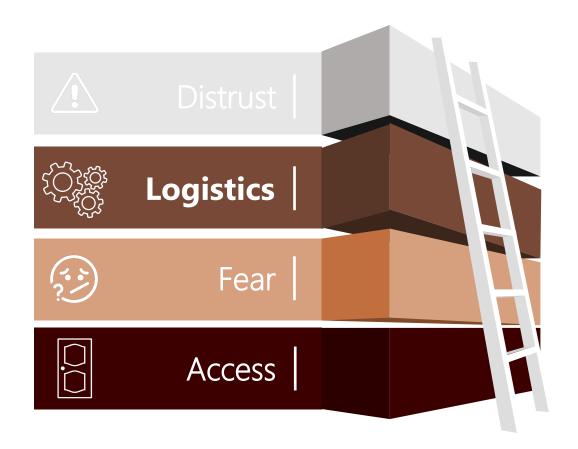
#### Relative Impact on Each Segment:













### **Barriers: Distrust**

The biggest hurdle for BIWOC is an untrustworthy system that has consistently let them down.

#### Unsure of Trustworthy Sources:

Some women said they do not know who to trust for information, and they do not know how to find out about trial opportunities. They are understandably skeptical of any outside source except for family, friends, and trusted doctors.

#### Conditioned to Being Underrepresented:

BIWOC are used to being underrepresented in many areas, and to having their voices being suppressed. Some ask, "why now?" when it comes to clinical trials.

#### Systemic Racism:

Systemic racism has created a healthcare system where there are very few BIPOC doctors or researchers. Women want to have a doctor who looks like them and understands them. A couple Black women said they prefer to see Black doctors whenever possible, but those Black doctors are rarely conducting clinical trials. A lack of representation at every level of the healthcare system fuels distrust among BIWOC patients.

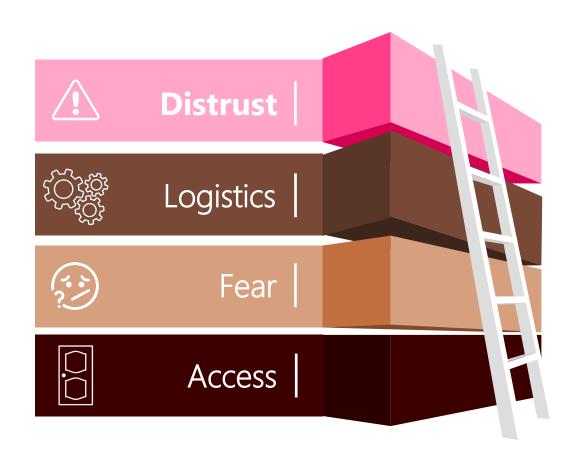
#### Relative Impact on Each Segment:













#### American Indian BC Patient

"Oh, I think 100% is the mistrust of the community, the medical community. I mean I don't fault any minority group for having **reservations** or wondering, right? I mean it's just disgusting knowing that the government could allow something like that...How do you reassure community that's been devastated by providers, by the government, that was supposed to take care of them but then inoculated them with syphilis?

#### Black BC Patient

"You still have to worry about how am I gonna run my household, especially as a woman of color, who typically a lot of times are single-family or single-parent households. Single-income households or whatever you wanna call it. It's really, it's really hard to just put everything aside and say I'm going to participate in this when you're worried about how you're going to make your ends meet, if you do that. So, it's almost like, do I participate in this clinical trial that may save my life, or do I pay my – do I go to work and pay my bills so I can take care of my kids and my family? And that shouldn't be an issue. That shouldn't be a factor that someone has to consider when accepting a clinical trial."

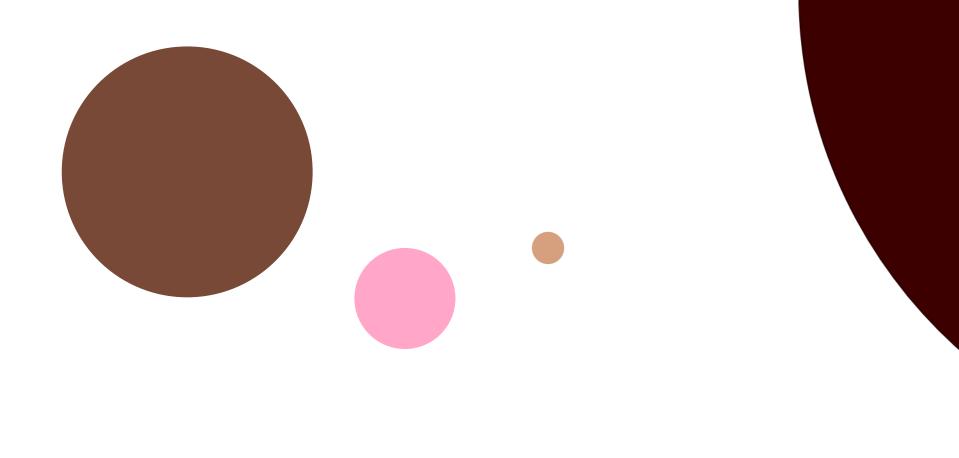
#### Black BC Patient

"I don't want to be a guinea pig where you just become an experiment....no regards of my life, you just wanted to see what the results are. There's been, well, the reason, minorities say that because there's a history of them doing that to us."

#### Black BC Patient

"Imagine someone's telling you to do something, but the people telling you to do something nobody looks like you. It's, you know, I think that what a lot of white Americans don't understand is the representation piece because everything is made to represent white people, everything like, you know, from dolls to TV to everything and it it's like, I, it's like a distrust like it, ok, you're telling me to do something that could potentially harm me, but you don't look like me, you don't have my experiences, we're not the same person, we couldn't be the same person cuz we don't have the same life experiences. And I think it's even worse because people try to acknowledge that, like people try not to acknowledge that representation is a thing. What should it matter, you know, as long as, you know, they give the information? But then we all know the messenger is important."





# Recommendations

Based on respondent suggestions and strategic considerations.

Healthcare Professional Considerations





#### Ensure diversity training for all HCPs

BIWOC often feel dismissed, rushed, and discriminated against.

02

# Educate patients about the benefits of clinical trials and how they have been improved

There are many historically-based misconceptions about clinical trials that can be addressed by a trusted HCP. Many patients are also not aware of the benefits and incentives of clinical trials.

03

#### Actively recruit BIWOC for clinical trials

Many expect clinical trial information to come from their HCP, and they feel as though they are not being given opportunities. White women have been offered more clinical trials than BIWOC.

04

#### Ensure trials are open across all facilities

A few feel as though large healthcare systems target wealthier facilities for clinical trials.

05

#### Engage with BIWOC in their communities

Patients are more likely to be engaged with a trial if the researchers come to them, whether that be going door to door or engaging with churches, community centers, etc.



# When possible, have BIPOC HCPs or researchers talk to BIPOC patients about clinical trials

Patients often said they are more trusting of "someone who looks like me," but if that is not possible, resources like the FTBOU coffee table book can help increase BIWOC representation in offices.







Patients are more likely to trust someone who looks like them, and if they speak their language it would help further communication.

#### Provide transparency

02

Patients want the mistakes of the past addressed. They want to know what the risks/side effects are and how the treatment is supposed to work.

Consider the timing of the conversation

Patients feel overwhelmed immediately after diagnosis and need time to process before discussing a clinical trial.

# Ensure that clinical trial representatives are reachable and able to answer questions Patients need someone to help them navigate the pro-

Patients need someone to help them navigate the process step by step. They are more likely to participate if they feel heard and respected by the trial representative.

Provide easy-to-understand, health-literate materials in "plain English" and multiple languages

Many BIWOC describe language barriers or said they have a difficult time understanding medical terminology.

# Set clear expectations Patients want to understand how much time the trial will take, whether it will be covered by insurance, and what it will involve.







Many are unaware of the incentives for participation and believe it costs money to participate. A few suggested providing \$20 gift cards to patients to participate in the initial conversation.

- Provide Logistics Assistance: transportation, childcare, weekend/evening appointments

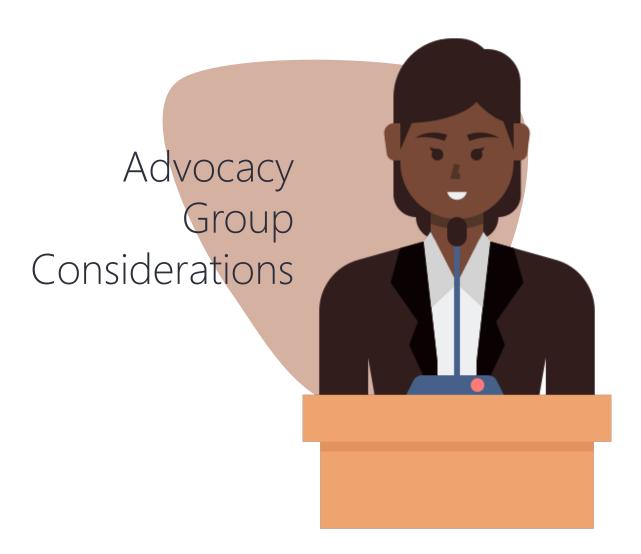
  Patients discussed logistical challenges to participation such as not having a way to get to appointments, not having anyone to watch
- Strive for diverse representation in trials and publish the exact breakdowns

  Several patients believe there should be quotas set for diversity in clinical trials to ensure equal representation.

their children, and not being able to take time off work.

- Provide education on how clinical trials work
  Patients need clinical trials to be explained in a simple manner. Many believe that if they are in the placebo group, they will not receive any treatment.
- Explicitly call out the benefits of BIWOC participation
  BIWOC patients may be more willing to participate if they
  believe they are helping others in their community.
- Engage with BIWOC communities

  Patients are more trusting of people in their own communities. They also want BIWOC HCPs to be included and kept up-to-date on clinical trials.



# Find BIWOC Patient Ambassadors with clinical trial experience

Patients are more likely to trust and identify with someone in their own community, especially if they have had a positive experience with a clinical trial.

Offer education or Q&As about clinical trials

Patients have many questions and misconceptions

about clinical trials and are often unaware of the

about clinical trials and are often unaware of the benefits/incentives.

Highlight the importance of BIWOC participation

Many patients would be willing to participate just to help others in their community and to help change underrepresentation.

Provide support throughout the entire process

Patients have questions prior to, during, and after a trial, and they are looking for a trusted resource to help answer these questions.

Encourage BIWOC BC patients of all stages to ask more questions about clinical trials

04

Most wait for their doctor to mention a clinical trial rather than asking about them or researching them, or they believe clinical trials are only for severe disease.



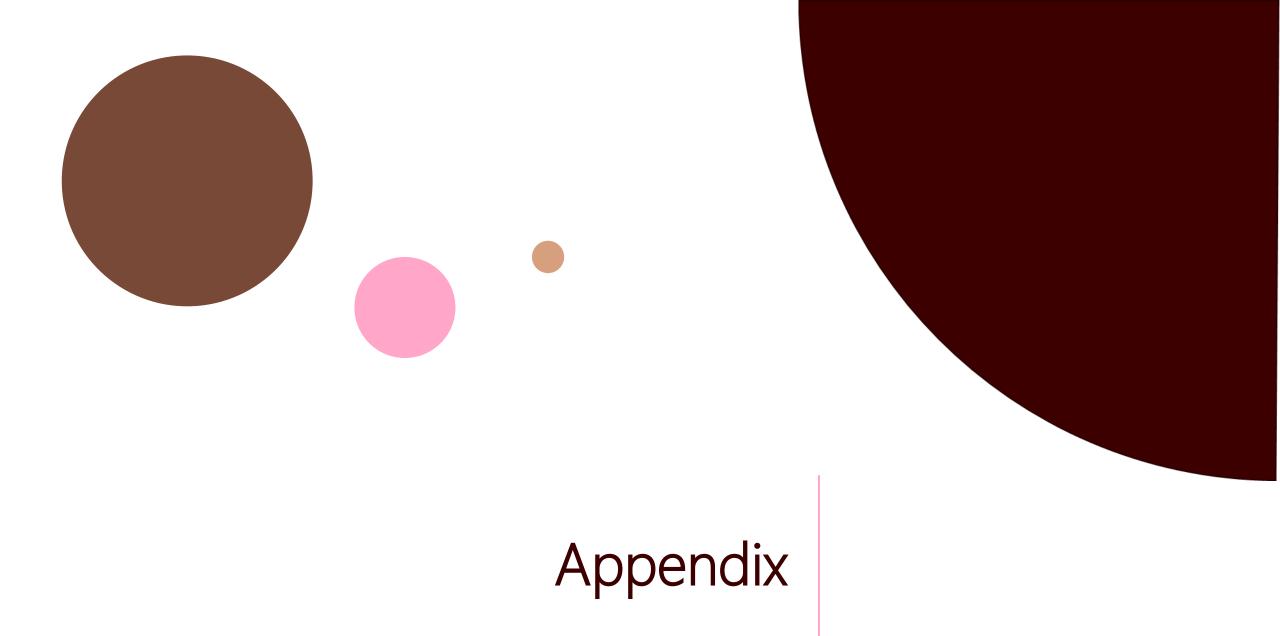
# Overall, respondents feel hopeful for the future, and they are grateful for the conversations FTBOU is facilitating.

"I think this is a good start right here, asking the questions—that I believe is a start...and as I was saying about hearing other people's stories, I think that is a huge thing, actually, 'cause I personally don't know anyone that I know of who have been in a clinical trial."

— Black Patient

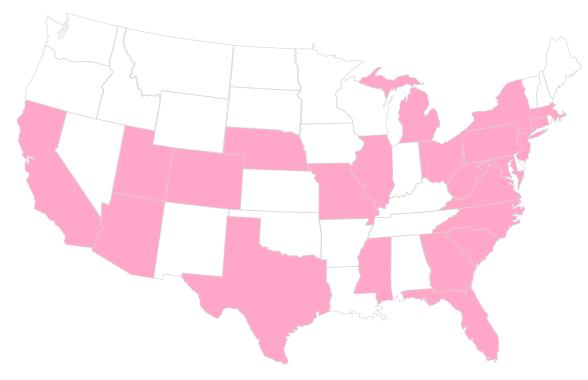
"Change starts when it no longer feels like clinical trials or access to clinical trials is a secret club. I will know that change is happening when I see communication for clinical trials more mainstream...We get [advertisements] all day every day from drug companies for the existing drugs, but we don't have communications for new drugs coming down the pipeline...There just needs to be more communication, more transparency around it." — Black Patient

"It is, it is a **systemic** thing that is validated by individual **experiences** that people are still having, and so if you can invalidate the systemic thing then you'll start to chip away at that mistrust in the community as a whole...and how you really do that is changing the face of medicine." - Asian Patient



# **Demographic Details**

STATE	#
Arizona	1
California	4
Colorado	3
Connecticut	1
Florida	3
Georgia	2
Illinois	2
Maryland	1
Massachusetts	1
Michigan	6
Mississippi	1
Missouri	2
Nebraska	3
New Jersey	1
New York	3
North Carolina	3
Ohio	2
Pennsylvania	4
South Carolina	1
Texas	9
Utah	1
Virginia	4
West Virginia	1



Proximity to a Major City	
1 - 2 hours – It takes some time.	4
2+ hours – It's a hike!	4
About 1 hour – I'm fairly close.	11
About 30 minutes – I live right outside the city.	20
No driving needed – I live there.	19



"And I think as a result there wasn't a lot of attention that was paid to medicine necessarily. Like, for my dad as he was growing up, and so you know, as is the case in those types of situations, they didn't have a lot of money, but you know – the whole 9 yards, and so when he got to be an adult and then had kids himself, it was, you know, I want better for my kids. I want them to have the things that I didn't have, and so all of that stuff was paid very close attention to for us, but at the same time, you know, you do hear those influences, and you have those influences and you kind of hear how they compete with each other, but also get to understand, like I understand how my dad's idea of everything was born. I also understand how my – why grandfather thought, you know, the way that he did. So, I think I've never heard anybody say anything negative about the experience that my mom had when she was sick. They don't really talk about, you know, the doctors or the medical care that she received very much, which now, actually, now that I'm thinking about it is also pretty interesting. You know, I have — I have an uncle who's an emergency room doctor, a cousin who's a urologist. So, I definitely have a lot of family like, in the medical profession as well. You know, as I mentioned, that obviously I have aunts who're nurses." — Asian patient

"Every time you see even commercial just about cancer in itself where are Black women in these pictures? Like even when my mom passed from pancreatic cancer, you saw a bunch of white men and Black women are almost leading in pancreatic cancer as well. And it's crazy that they you know it's just because they're just not seen, that they're also not heard. So, if you don't see them, you thinking all Black women don't deal with that." — Black Patient

"I definitely think it, you know, goes back to with my parents and the, you know, generational just distrust of the medical community and not wanting to, you know, feel like you're a guinea pig. And I also think it has to do with even now, you know, sometimes just having difficult relationships with healthcare providers and feeling dismissed." — Black Woman

"I left a message, I left a long, detailed voice message, and then I left emails and they would get back to me like 3 days later. Here's the thing, it's a contradiction. You can't tell me to hurry up and make a decision, but then I have a question that you can't give me an answer and they weren't complicated questions, I'm not smart enough to ask hard questions. All I was asking was could you just tell me how many appointments is gonna be? But they were not getting back to me and all I kept thinking was if you're this raggedy on this end of it, how am I going to jump in a whole clinical trial with you? 'Cause that already tells you that it's like a relationship if you see signs at the beginning of a relationship, that may be indicated, this how I think anyway, that's already set it up how things are going to be. I thought I don't wanna do a clinical research or anything because y'all are not timely, and now I'm already in it and don't wanna get back to me? I'm good, thank you. That's not working for me, and I feel that way to this day. Why should take that back? No, I won't just do any clinical study if people are kind of weird about getting back to me, and the professional and the functional part, because that's telling you how it's going to be. And when it comes to my health and cancer, I don't have time to be really messing around like that." — Black Patient

"Fear. I think fear, fear of the unknown, fear of, you know, what, you know, vou know, historically what has been happening and what has happened with these clinical trials with us, and I think that having the trust in the researchers in science and doctors and everything, I think so, the fear and the trust, that's kind of shaky." — Black Patient

"Well, to be honest, when I first heard like, when the doctor was like, you know, you qualify for this trial, in my mind I was like, 'so there is nothing else they can do for me,' cuz I thought clinical trials were for people that were out of options and then, you know, I realized that yeah, sometimes that is the case but at the same time there's others that, you know they are, they are just trying to find out if this would work for or have, you know, like in this one it would be like, you know, if it, does it work to not only take the cancer away but keep it away for longer. So yeah, it was, when I first heard it, it was like, 'ok, so I'm done,' because I think for me it was like clinical trials, I thought of that they were just for people that were out of options." — Hispanic Patient

"A lot of people use social media now, even maybe doing like YouTube shorts, you know how like you're looking at, I look at a lot of like hair tutorials and things like that, yeah cutting with advertisement that you have to look at to watch your rest of your tutorial like, even if it's like, little blurbs like that to get it out there, that, ok, this is what's needed, this is how, you know we can, that's how you're gonna, to me, reach people more nowadays because people have short attention spans. So, what happened because, short and to the point, but know that it's a need, you know?" — Black Patient



"Well, I think we all benefit, right? The more information we have about any sort of condition the better standard of care our physicians, nurses, you know, therapists can provide so I think everybody benefits." – White Gen Pop

"Things move too quickly: I think there needs to be more follow-up and more than one conversation. Like I found just when like the, I think it was two different clinical trials that were presented to me, it was just sort of mentioned like off hand, like go do some reading, look it up, here's a stack of paperwork, let me know what you decide and there wasn't really much else beyond that, and I feel like that's putting just way too much of a burden, especially on, you know, women who might have a number of other priorities in addition to whatever health crisis they're dealing with too, you know, go do all that research and reading on their own. I think just like follow-up phone calls, visits, like walking people through the paperwork and the time, financial commitment." – Asian Patient

"Well. Not to get too deep but, considering the the first woman of color were actually the only ones given clinical trials on surgeries and things like that, if you want to go there. So that might be why now a women of color may be a little less reluctant to trust medical professionals, that they did have their best interests at heart in doing something like that and be, I mean, it just goes with the systematic discrimination that, especially that this country has, I mean, why wouldn't we be underrepresented, we're underrepresented in a lot of things, so (xx)." – Black Patient

"I think a lot of people have the same perceived notion that I had about clinical trials. Either that's a good drug, it's a good drug or you're gonna die. It's the last resort gamble that you take if you run out of all other options, and it's the Hail Mary for you, and that's just what I grew up thinking, but I again I've seen a lot of testimonials of people who have had it dissipate it, and they're, you know, right now there's no evidence of disease, or adjusting well, or thriving or doing whatever years later, and you know, that's inspiring." – Black Woman

"Do doctors get diversity training at all? Cuz I feel like, I mean, I just feel like maybe they don't, and they come – you know doctors are human beings too – so they they come in with their own biases that they have in their head. And you know, if they don't have that diversity in their everyday lives, you know, or in their communities yet, but they service different members of the community, I can see where they could make judgments and assumptions, so I think that it would be best if they could learn how to actually, maybe get to know their patient a little bit better than just a cursory." – Black Patient

"A Black woman who if you raise your voice then you're considered combative and you're angry and you're upset. That they wanted to pacify me every time I would get louder because I felt that if I didn't get louder and sometimes, don't get me wrong, during the loudness there was tears. But you have to understand that even though I got loud I was still hurting. So, if I was crying and talking to you at the same time, it wasn't anger. I was also the angry did come because I felt like I wasn't listened to." — Black Patient

"I was just so happy to hear of a medical professional who was not afraid to say, I'm gonna take your race into consideration. You know, I'm not gonna pretend I'm colorblind. I'm gonna take that into consideration 'cause it is something that we should consider when it comes to your healthcare." – Black Patient

"If you want to get a word out, you share with someone who people trust. Share with their peers, with somebody who looks like them. Make sure that you're using language that they can understand. Make sure that it is free of judgment. A lot of people don't want to participate in these things because they feel like they're going to be ostracized because of it. If it's ever found out that they participated, or that it's gonna impact them in a negative light." — Black Patient



"I think for me if it was presented by a doctor, I guess that I felt like I can trust and that, I think, addressed my concerns like I wasn't stupid, or I wasn't like just being like overdramatic, you know, or something. That's just like – I totally understand your concerns. You know, clinical trials are statistically, you know, many people of color don't want to participate, and I get why you know, and, but this is what we're doing differently, and this is what's happening and even the thing of like, you know, we're making sure that it is, it's being as safe as possible. You know, for those that are people of color coming in, so that way we can make it safer, you know, in the future and have more opportunities in the future for people of color, and I think if that was said and that – in that confidence and with sincerity and compassion, I think that would make a huge difference, because then I would feel like, you thought this through." – Black Patient

"I think having doctors of color speak out about it too. Right like it coming from people who you don't trust is not going to make it more trustworthy no matter how up front they are about it, right like we really using it. Doctors that are from the community and in the communities that are gonna speak out about it and represented in back it up also." — Hispanic Patient

"As I said before the way it was presented to me it looked like extra work, and if I'm trying to cure cancer, and I'm already in shock because anytime something traumatic, at anything you're in shock and when they approached me, I was in shock. and I don't know if that's the condition that they considered, like this woman is probably sure if we just told her this year I had aggressive stage three triple negative no less breast cancer, so I was kind of in shock. So, someone in shock doesn't wanna be hit with a whole bunch of other extra stuff, all I heard was chemo, I'm wondering if my or they were removing my breasts, I was thinking about my son, thinking about how I could tell my son, I was thinking about how I was going to get my friend to baseball practice, I was not just the whole idea of clinical trials was like what? Who? How? I just didn't understand and from what I could understand it sounded like extra work because I asked what would be involved. Oh well you're going to have to come in and you'll have to get a physical outside of the physical we did, you'll also have to have blood drawn, we'll I also have to monitor you. And the whole time my brain is really like chill, checked, it looks like a bunch of extra stuff. What I wasn't realizing because the way it was presented is what they were telling me was that all this extra stuff is good stuff. It's like a gift bag." — Black Patient

"I mean, for me personally I just, if I, maybe, people aren't as aware of the lack of representation, you know, so maybe more articles and things that would come out to say 'hey, by the way, this is, you know, we're not represented. This is how it could benefit you' and, you know, that I think that would be better...I think that for for me, education with help, you know if I had maybe been more aware that that was an issue." – Black Patient

"People gotta realize they're not experiments. They're tryna save your life, it's not like a test. You don't wanna be played like a dummy, so, more research, more contact with people. Let me know you honest about this clinical trial. You're not trying to experiment on a person just yeah, something big, where you put all of us together and don't look at color like give us all the same opportunity to live. We wanna live just like anybody else. Wanna live just give us the opportunity to do that and just to understand it is not experimenting with us, we really tryna help you." — Black Patient

"What it felt like to me when they approached me about the clinical trial it was literally no different than when I have purchased cars. I'm in an office. There is someone on the other side of the desk. They have paperwork in front of me, and a pen with literally highlighted parts and little stickers by where I need to sign, and they're reading through a lot of material very, very quickly that you have no idea what they're talking about. I don't know if you've ever made a major purchase, but unless you're like a genius, you don't know what them people are talking about." – Black Patient



"Having people from similar backgrounds, similar demographic. Speaking on things that they have done and help the people that look like them." — Black Patient

"You know the saying: the squeaky wheel gets the oil, so I want to be the squeaky wheel, or the squeaky wheels, to try to stop this, not just in my family, but anyone who's dealing with this situation, young women of color." -- Black Patient

"I think that it takes having a seat at the table, having representation, and effort to outreach, show their face, support community-based organizations for us to do the work. And I for one refuse to do the work for people who do not support me, who do not disclose everything to me. Maybe have local ambassadors, or someone who can champion for those companies that look like me who can be actively involved in outreach in our communities. And then it takes putting on and sending money to ensure as far as marketing material, you know, working with, those clinical staff, or doctors who pretty much their clientele are people like me, and having them, you know, working more closely with them to ensure that those marketing pieces are there, that they're like — I just feel like they need to be more community-focused, and inclusive from design, from design to after. So, for me it's also the after. For example, let's take, this is a study too, there was a study called the sister study and sister study was looking, you know, it was, it was really geared a lot of it about the whole, you know, genetic thing. You know, one of my sisters participated who was not, does not have the BRCA gene and she participated and never got any information about what happened after that! You know. That's the people I'm talking to and who are calling me, understand my community, understands my need, understands my – that I may have those underlying – not trusting issues and that they address them and that they are probably about addressing them." – Black Patient

"I mean, another way we could do that is probably, you know, have more bus drives, you know, bus screenings out into these communities, these churches, these neighborhoods, these community centers, civic centers, soup kitchens, you know, wherever you're gonna find the BIWOC people, you know, who all probably haven't had access or money or availability to go to doctors like this and get these kind of tests because it was out of their reach and now they can get these screenings and these doctors can, you know, put them in connection with where they could get the best help. I mean, if we can as a society, if we can sit here and do that for dogs, we should be able to do it for people." – Hispanic Patient

"I didn't trust any of it. I just didn't — like I looked at the papers, the one was taking an aspirin for every day, for I can't remember how long, and I was just like, this isn't, it just didn't make any sense and I just didn't — I just don't like taking medicines that don't, that doesn't make sense to me. I don't know the long-term effects of taking an aspirin every day for a year or two or whatever it was, and the other one was a stage for drugs that they were trying to see if it would work to — more for prevention from those that are late stage but not stage 4 yet, and when I read through the side effects, I, like I specifically asked my doctor, like I said, can you let me know like, if there are like a lot of these side effects happening, and do you know if it's happening in people of color, like you know, and can you let me know that, and he was like, 'well, I don't know that information. I'm not sure,' and I was like, I mean, I guess for me my experience right before that was huge because I had heard from my doctor's, my oncologist, oh, you're just going to get a little bit of redness from the radiation and it's going to be a little bit red. Well, my skin is brown, so I don't get red. I got black, and I got third degree burns, and I found out that many of the people, you know, that are Black also got those — those same experiences that I did, and the effect that the medications had on those of us that were of color versus some of my white friends that were breast cancer survivors, it was also different and not everything was exactly like, down the line different, but there were different experiences, and for me and for my doctor not to know that, and not to like dismiss it, and to make it seem like it's fine like, this is what, you know, this is what the side effects are. It's less likely to happen to you." — Black Patient

"I've already spoken with them [my parents] about it, and they are opposed. They are heavily opposed to clinical trials. They don't trust them. There was, they don't want me to be the Guinea pig for any drugs." – Black Patient



"I would not do it, I think the only time I would not do a clinical trial unless it's like 100% sure that it's not going to affect my health in any way possible in the future, you know, or make it worse or, you know, contributing possible side effects that can be long term or life changing. I don't want to be the guinea pig." — Black Patient

"Yeah no, I just, I just like, you know, because I think there is systemic racism, I think that, I think that, you know, without necessarily meaning it, you know, I think some people do, that like there's just, there does seem like there are more white people in higher level positions and I think that, that it seems like there's just been more access to internet, access to information, access to so much for white people that so many little things start to happen like, you know, you can be more aware of trials because you have more access to information that, and I don't think just because of the internet that I'm talking about that or just education, but it just seems like, it just seems like there's more, I dunno, and maybe it is just access to information is, you know, just really simplistic way to, maybe that's just what it boils down to for me that I think that. And you hear, you know, you often hear that black women, or people of color, maybe it is just all BIWOc, probably, that they, they're just not treated as nicely and empathetically when in hospitals, when in situations so maybe they're not of, made offers that these white people are offered. I'm a white person, you know, and it's...just like...not as easily offered or shared information, I don't know." — White Woman

"I work at a public health company, but I don't do clinical trials so, I do admin work. So, I know how important clinical trials are, but I also understand the skepticism that people, Black people have of clinical trials, but I absolutely think they're necessary and I, in a perfect world, would hope that, you know, more things like this are happening so that Black people can see why being enrolled in clinical trials is so important. I think it's one of the key blocks, some of the biases in medicine, because then there's actual solid proof that biases exist, you know, when people are looking at it acknowledge that, and then I think once that's acknowledged it'll be easier to try to get Black people into clinical trials, once you see, hey, we acknowledge the problem, this doing about it, we'd still like you to participate." – Black Patient

"How do we build trust? You know, it's like any relationship, it's that intention, being intentional about getting to know the needs of the people that you are serving and putting your pride down about whether it's pharma or whether it's, you know, politics, whatever your political stance is, whatever side you're on like people are people, people are hurting and I think it's getting into the community and having healthy conversations and hearing people out with their concerns and not necessarily trying to fix it right then and there but just giving, having a safe space to have those conversations of, you know, I don't trust this doctor because he's this race or I don't trust, you know, this type of whatever it may be. But there has to be consistency, you know, consistency in a relationship builds trust, so if there's no consistency and it's just a transactional piece every time, people are not going to want, like they're not going to trust the system if there's no consistency." — Asian Patient

"So, this whole, the whole system's broke and I think Black people and other people of color have so much more going on, like, just with their health and needing to be taken care of, that half of them don't even care about clinical trials. So, there has to be so much more education to be done, and make, and make people of color feel like they are actually cared about in the medical field in... general before they would even start to care about clinical trials." – Black Patient

"Just simply being available. Just, oh God. I mean, it could be basic things, you know. I'm sure that all of these companies, pharmaceutical companies, they have where they participate in community outreach, so why not do community outreach in the community where there are disparities? Where people are using your medication. So, for example, if you know that there's an area of town where a lot of people are using this medication, and you can see that the schools are, you know, in need of book bags, provide 'em book bags. Or providing lunches or meals over the weekend, doing that. Or free blood pressure checks in the churches in that area, or you know, things like that. Because we know that companies give a certain percentage for tax reasons and all of that. Making sure that those dollars are being put back into those communities. Building those relationships, talking to those people, seeing what they need. So that way, that's how you build trust. Because you have to be involved, you have to be boots on the ground. It can't just be a conversation of a text message or email; it has to be action. Putting action behind words." — Black Patient



## Our Commitment to For the Breast of Us

Thank you for choosing Sommer Consulting (Linguis-Techs, Inc. dba Sommer Consulting) for your research needs. We greatly appreciate the opportunity to have partnered with FTBOU on this important project.

Sommer Consulting is committed to driving change and we would be happy to partner again in the future as additional questions arise.

We stand ready to answer any questions, provide additional insights, or simply discuss the implications of this project's findings.

Questions regarding this project or methodology may be directed to Juliette Faughnan at <u>juliette@sommerconsulting.com</u> or Mary Fox at <u>mary@sommerconsulting.com</u>, or by phone at (215) 860-8152.

As additional needs arise, we hope you will call upon us to discuss how we may be of assistance.

Thank you.



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