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Engaging Black Women With Lived Experience in Research Studies: Recommendations to Researchers

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Abstract

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Purpose

Black people have endured the effects of systemic and systematic racism for centuries. They have suffered the disparities of health systems, criminal legal systems, educational systems, and more. While these systems are informed, changed, and improved by research studies that identify flaws and shortcomings within them, the experience of Black people has often been underrepresented in this work. Through this project, we identify the barriers to research involvement that this community experiences, as expressed by members of this group themselves. We develop recommendations to researchers on how to engage Black women with lived experience in the development and execution of research studies.

Methods

Guided by a team of five recovery leaders — Black women with lived experience of substance use disorder (SUD) and criminal legal system involvement (CLSI) — women from five states (Georgia, Michigan, New York, Pennsylvania, and Texas) with this same lived experience were compensated to participate in discussions and focus groups. Of them, 125 recovery staffers took part in discussions and patient-centered outcomes research training, while 51 focus group participants took part in 90-minute sessions. Focus groups utilized semi-structured interview guides designed to elicit information about individuals' experiences with SUD treatment and recovery support services, as well as capture their perspectives and experiences of clinical research involving Black women.

To ensure a diversity of thought and response, focus groups were made up of Black women from differing backgrounds, bringing a range of understanding and intersectionality. Our call for participation invited self-identified Black women with self-identified experience with substance misuse and the legal system. The resulting cohort included Black women of mixed races, ages, and gender identities.

In analyzing data from the focus groups, the project team members individually reviewed the transcripts, recordings, and written notes from each session. Each member identified common or prevalent themes and ideas lifted in each space. Team members then met to discuss and compare the commonalities and themes from their own reviews, thus gaining consensus on the final themes to be addressed by the group's recommendations. Once the list of issues for recommendation was established, further extensive discussion took place to determine what the recommendation would be about the topic, how it should be addressed, why, and what the expected response should be because of our recommendation. We also discussed the language and tenor of each recommendation.

Results

The findings of our focus group are that there is an inherent lack of trust in the system of research by this community, and a fear of potential harm. The lack of relationship between research institutions and the community — and the dearth of a research workforce that looks like and understands the population — contribute to this lack of trust. The women repeatedly expressed frustration that researchers knew nothing about them or their past trauma, ongoing struggles, and priorities. They often feel used, with researchers having little regard for their expertise as people with lived experience.

Several participants expressed that they are often unaware of potential opportunities to participate in studies, which was attributed to the lack of intentionality in outreach to this population. Additionally, even if there is knowledge of studies, after participation, the lack of follow-up about results is discouraging.

Conclusion

Black women with lived experience in SUD and CLSI face barriers to participation in studies that could potentially change the systems they use. The following recommendations, derived from comments and discussions of focus group participants, are a basic level of tools that researchers should use to engage Black women with lived experience in their studies. They are based on careful consideration of the major themes, as well as the concepts behind patient-centered outcomes research and comparative effectiveness research. Implementing some of the recommendations will require time prior to the development of studies. Others can simply be incorporated into the developed studies.

Based on the focus groups, the Black Women CARE project recommends that researchers:

1. Intentionally engage Black women with lived experience
2. Build relationships and build trust
3. Follow trauma-informed engagement approaches
4. Equate lived experience with expertise
5. Follow up with research participants afterwards
6. Compensate research participants for their time and expertise
7. Study what matters to community members

Introduction

You're asking the wrong questions, in the wrong way, to the wrong people.

What do Black women, who have endured the trauma, stigma, and life consequences related to experience with substance use disorder (SUD) and the criminal legal system involvement (CLSI) need from research, recovery, and treatment systems, the broader health system, and society? The recommendations from the Black Women Consulting to Advance Addiction Research and Engagement (CARE) project lay an essential foundation to answering these questions.

Black people have endured the effects of systemic and systematic racism for centuries. They have suffered the disparities of health systems, criminal legal systems, educational systems, and more. While these systems are informed, changed, and improved by research studies that identify flaws and shortcomings within them, the experience of Black people has often been underrepresented in this work. Therefore, the improvements have done little to serve and elevate this community. Nowhere is this more relevant than in the area of substance use disorder, its treatment, and its services.

In fact, community-based participatory research that might bring in these perspectives is being done, but not in the best way possible, often lacking sensitivity and hindered by unconscious bias (Cunningham, 2024). This results, again, in the underrepresentation of Black voices, which perpetuates the dearth of systemic change and allows ongoing harm to continue. To implement studies that result in findings relevant to Black women with lived experience, researchers need to understand the issues and barriers that keep the voices of this group silent. By following these recommendations, researchers can develop studies that — from their inception — ask the right questions of the right people in the best way.

Background on the Problem

Overdose deaths have reached an all-time high in the United States, topping 100,000 in 2021 (Center for Disease Control and Prevention, 2021), and drug overdose deaths among Black people rose precipitously during the COVID pandemic (Panchal, Garfield, Cox, & Artiga, 2021) as a myriad of barriers to receiving care for substance use disorders (SUD) were exacerbated. The overdose death rate is especially high for people returning to the community from incarceration and even higher for women (Waddell, Baker, Hartung, Hildebran, & al., 2020).

Black women, who represent only 13 percent of the U.S. population (Women of Color in the United States (Quick Take), 2023) but 29 percent of the 231,000 women incarcerated (Kajstura, 2019), are particularly vulnerable. The number of women incarcerated, including Black women, continues to grow, driven in part by drug-related arrests and problematic prioritization of punishment above treatment for addiction. About 70 percent of incarcerated women in state prison or jail have substance use issues (Bronson, Stroop, Zimmer, & Berzofsky, 2020), histories of abuse, trauma, and mental health diagnoses. Systemic and systematic racism, stigma, and the long-term consequences of incarceration complicate their pathways to recovery. One small study of formerly incarcerated women in a treatment program found that stigmatization was a common occurrence, and prior experiences with addiction and crime subsumed any recovery behaviors (Gunn AJ, 2016).

Some research suggests Black people have lower rates of SUD treatment completion (Saloner B, 2013), but formerly incarcerated Black women with histories of substance use disorders are woefully missing from studies, including patient-centered comparative clinical effectiveness research. Without such engagement, there will continue to be a dearth of comprehensive, culturally effective treatment models for this population that address their individual and generational trauma and achieve better outcomes for them. However, Black women with lived experience of SUD and CLSI (henceforth, Black women with lived experience) are often reluctant to participate in research because of the history of harm to Black people from past scientific research (Scharff DP, 2010) (George, Duran, & Norris, 2014).

It is time to confront the issues and barriers that keep the voices of this group excluded from research head on. This resource gives specific recommendations to researchers on how to engage Black women with lived experience in the development and execution of research studies. We address the barriers to research involvement that this community

experiences, as expressed by members of this group themselves. Using their own stories and words, this document is meant to challenge researchers' preconceptions about the needs, impacts of trauma, and views of Black women with lived experience regarding studies and their relationship to them. After reading the text, researchers will understand not only the need to engage this group in studies that inform recovery services and supports, but also the preparation involved in honest and positive connection to advance the development and implementation of research in ways that do not inflict further harm and trauma, and lead to recovery and treatment practices that fully meet the physical and emotional needs of Black women with lived experience.



"The views I had on research, it really ain't going to be about us, it's not going to yield any desired results, but the research and data matters."

IN THEIR OWN WORDS: Pennsylvania

Overall Mistrust of Health System and Research

While medical, clinical, and other research studies are necessary and beneficial, there is a problem with some research. For example, people with privilege make most of the decisions on what research occurs. And regardless of the choice of research, Black, Indigenous people of color (BIPOC) communities are often left out (Scharff DP, 2010). Community members, especially those from communities of color, are not often directly engaged in designing the studies. Researchers don't always actively and intentionally recruit members of BIPOC communities; instead, they blame low participation rates on their refusal to engage. As a result, outcomes research isn't always based on the outcomes that matter to these groups.

Also concerning are the inherent issues of racism, genderism, sexism, and other forms of oppression that BIPOC communities — in our case, Black women with lived experience — have had to endure within the health care system, overall. There are documented disparities between White and Black people in the areas of substance use disorder treatment (Substance Abuse and Mental Health Services Administration, 2020). Likewise,

Black Americans are systemically undertreated for pain due to false beliefs about their pain tolerance (Trawalter, 2020). Black communities suffered significantly more from COVID-19 than white communities. Black patients receive lesser quality of care in hospitals (Gangopadhyaya, 2021).

Due to the history of harm, trauma, and mistrust that exists in some BIPOC communities regarding the research process and health system broadly, BIPOC people are often unwilling, unable, or simply not asked to participate (Newsome, 2021). And while the studies most notable for their harm against Black people (Henrietta Lacks' cancer cell research and the Tuskegee Syphilis Study) are generally used as ethically indefensible examples, barriers to safe, consenting, and beneficial scientific practices within Black communities remain intact and the effect of racism still has the potential to exclude Black people from beneficial scientific work (Ileka, 2020).

Focus Groups

Focus Group Composition and Recruitment

The Black Women CARE Project Team includes recovery leaders — Black women with lived experience of SUD and CLSI — in five states: Georgia, Michigan, New York, Pennsylvania, and Texas. Each recovery leader enlisted and trained 25 peer recovery staff members about patient-centered research and its importance, while listening to their experiences and perceptions of research studies. These peer recovery staffers engaged a broader group of Black women with lived experience to spread the word about patient-centered outcomes research (PCOR) and recruit some for participation in focus groups about how researchers should engage Black women in studies. From each state, 10 to 15 women participated in focus group sessions (51 total)(see methodology in appendix). They were compensated for their time and expertise.

The women were asked about their sentiments toward research studies, willingness or unwillingness to participate, and their reasons for either. Their answers give great insight into the thoughts and attitudes regarding barriers that keep Black women from research studies, how they feel Black women are treated within the studies when they do participate, and what researchers need to do to better engage them.

To ensure a diversity of thought and response, focus groups were made up of Black women from differing backgrounds, bringing a range of understanding and intersectionality. Of course, a natural diversity of experience comes from the geographical spread of participant states: Georgia, Michigan, New York, Pennsylvania, and Texas. The political climate in New York, for example, is vastly different from that of Texas or Georgia. Each state has its own policy and posture toward gender diversity, criminal legal system involvement, and race. (See appendix for focus group questions.)

To further ensure diverse views, our call for participation invited self-identified Black women with self-identified experience with substance misuse and the legal system. The resulting cohort included Black women of mixed races, ages, and gender identities. The women brought their own perspectives based on their own circumstances and experiences within the systems they navigated.



“There needs to be more education [available to potential participants] about research.”

IN THEIR OWN WORDS: New York

Our participants also had diverse experiences with research. Some participants were familiar with research studies and how to apply for inclusion. Others had no knowledge of how to know when studies were looking for subjects, let alone how to be included in them.

Recommendations for Researchers

The following recommendations are only a basic level of tools that researchers should use to engage Black women with lived experience in their studies. They are based on careful consideration of the major themes that arose from focus group discussions, as well as the concepts behind patient-centered outcomes research and comparative effectiveness research. Implementing some of the recommendations will require time prior to the development of studies. Others can simply be incorporated into the developed studies. All of them, regardless of the stages in which they appear, are important steps to the engagement of Black women with lived experience in research studies.

These recommendations are derived from the comments and discussions of the focus group participants.

Based on the focus groups, the Black Women CARE project recommends that researchers:

1. Intentionally engage Black women with lived experience
2. Build relationships and build trust
3. Follow trauma-informed engagement approaches
4. Equate lived experience with expertise
5. Follow up with research participants afterwards
6. Compensate research participants for their time and expertise
7. Study what matters to community members

1. Intentionally Engage Black Women With Lived Experience

Focus group learning: Our focus group participants reiterated the lack of trust, need for compensation, and fear of harm. Additionally, participants expressed that they were often unaware of potential opportunities to participate in studies.

“

“I’ve never been invited to the table. They just get together and come up with their own plan without asking for our input.”

IN THEIR OWN WORDS: Texas

Recommend: To better engage Black women with lived experience, recruitment must be intentional. They will not necessarily seek out research studies. In many instances, their priority is simply living and maintaining their recovery. However, the standard excuse, that Black women with lived experience won’t participate in studies, is not sufficient justification for not including them. Researchers must be purposeful in their recruitment strategies, engaging this community even before the studies begin.

“

“I value my friend’s opinion and I asked ‘L’ some questions when I have to, when I feel uncomfortable. The last research I did, I realized they were using me. So now, if I look around, I need to see who’s going because I know they aren’t going to go any BS.”

IN THEIR OWN WORDS: Michigan

Intentional recruitment entails seeking out messengers and community members trusted by Black women with this experience.

Develop materials and communications that not only reach them where they are but are clear and understandable to them, so they have all the information they need to make a free and informed choice. As we explore later, developing relationships within this community is crucial to the success of outreach efforts. In fact, members of this community should be part of the development stage of research studies. The basic bar for researchers to study Black women with lived experience is that studies must, from germ to conclusion, look at and engage diverse Black women with lived experience.



“They should go into the communities where these individuals are and let them know about the research studies.”

IN THEIR OWN WORDS: Pennsylvania

Consult with women with lived experience as advisors

The engagement of Black women with lived experience from the beginning of the research study development to the end of the dissemination of the study results and analysis is necessary. However, identifying Black women who have lived experience, understand and trust the research process and long-term benefits, and have access to and standing in the community so they can assist in building the relationships needed can prove difficult. **To fill this gap, a consulting corps of advisors — who have lived experience and ties, credibility, and trust in the community — should be used to advise researchers.**

A consulting corps understands the distrust, struggles, and trauma of women with lived experience because they are members of this population, themselves. Likewise, they have the trust of their peers. They speak the language of their peers. They understand the goals and aspirations of their peers and know what is important to them. They also hold their trust and can aid researchers in drafting studies that best engage them. In fact, the corps' purpose is to advise the research and clinical communities on meaningful

engagement of people with lived experience of SUD and CLSI in patient-centered research/clinical effectiveness research studies, and to advise on priority research topics and outcomes. Such advisors can be found in Black-community-based women's, youth, spiritual, LGBTQ+ and other organizations that interact with this community regularly. Community health workers can also make good advisors.

Hold educational or informational sessions to explain the study and its intentions

Finding trusted members of the community requires spending time in the community. Take time in study preparation to introduce the study organization, the researchers, and the intended purpose of the potential study to community leaders and influencers. These trusted members of the community — especially those with lived experience — can help researchers design studies that will best engage this population.

2. Build Relationships and Build Trust

Focus group learning: Women with lived experience view researchers' lack of familiarity with their experience, their needs, and their trauma as a barrier to their participation in studies. Too often, researchers "swoop" into a community, seeking to study its members in isolation, with little to no prior knowledge about them. The women in our focus groups repeatedly held up the lack of trust and the lack of relationship as a theme.

Recommend: Taking the time to build a relationship with the groups you wish to study not only helps you relate to them but also builds trust.

“

“You have to engage in your community to know it. You have so many people that study but don't go into the trenches or talk to the people on the corners: they're too afraid to talk to the people and can't find out what they have going on and why they make the choices that they make.”

IN THEIR OWN WORDS: Michigan

Be in/from the community

Women with lived experience trust the people with whom they have most and positively interacted in their community. Participants expressed that seeing or hearing about opportunities from their peers or leaders in their community who held their trust removed some of the suspicions they felt. Their fears are allayed for two reasons. First, they have built a foundation of transparency with these members of their community. Second, often, these trusted community members look like themselves — Black women, or, at least Black.



“I would be more inclined [to be involved] in research done by more Black people — they would probably care more. Not to say the old white man don’t care, but have you had any conversations with black women? Do you know trauma is the gateway to addiction and maybe having the researcher know all of this about trauma and maybe it would [help to know] anything about my community.”

IN THEIR OWN WORDS: Georgia

The need for an increase in members of the research community who are from communities of color cannot be overstated. The Black community is underrepresented in science and research (Ladyzhets, 2020). Funding for Black scientists lags behind that of their white counterparts (Taffe & Gilpin, 2021).

Considering the trust felt by these women of peers and those who look like them, **the need for an increase in members of the research community who are from communities of color is critical.** Such representatives can more easily build the relationships necessary to fully engage Black women with lived experience in studies.



“They [researchers] can make sure that the facilitator is someone that looks like them or also has similar lived experiences.”

IN THEIR OWN WORDS: Pennsylvania



“Don’t make research so white. We need to see people who look like me.”

IN THEIR OWN WORDS: New York

Learn their priorities

Without knowing the community of Black women with lived experience, researchers cannot know what they consider to be the important outcomes of SUD treatment and recovery. Previous PCORI-funded work *Peers Speak Out: Priority Outcomes for Substance Use Treatment and Services*, suggested that Black people prioritize different treatment outcomes than white people. For example, there is a greater emphasis on addressing basic needs than on stopping all drug use.

Participants in *Peers Speak Out* were asked to give a brief overview of what successful treatment and recovery looks like for them (full report). The participants in that work identified several desired outcomes including:

1. Staying alive
2. Improving quality of life

3. Reducing harmful substance use
4. Improving mental health
5. Meeting their basic needs
6. Increasing self-confidence/self-efficacy
7. Increasing connection to services and supports



“I would consider success if a person feels like they were heard...I’ve been to treatment 20–something times, in many states. A lot of the times, no one asked me what I wanted to know, what did I want to leave here with.”

IN THEIR OWN WORDS: Michigan

Similarly, women in our focus groups identified meeting the basic needs of living as a priority recovery outcome:

1. Being able to manage life
2. Being able to meet basic needs
3. Connecting to supports and gaining skills and connecting to family; networking; continuing (continuity of) care
4. Stability
5. No drugs
6. Being able to maintain a drug-free, stable lifestyle, and knowing how to safeguard your recovery



Success from treatment and recovery services means:
"Learning different tools to use during anxiety or mental anguish rather than running; 1:1 counseling; recognizing her behaviors and being taught about boundaries and the ability to practice [those] boundaries."

IN THEIR OWN WORDS: Texas

Additionally, focus group participants noted that researchers need to understand the role of family and reunification after incarceration. Without this understanding, there is a communication gap between this community and the researchers who study them, leading to feelings of distrust and alienation. Only once researchers develop a relationship with this community of women, can they realize how important basic and stable living situations are to them, and how much this need outstrips the need for abstinence from substances.



"You have to know who people are."

IN THEIR OWN WORDS: New York

Learn their language

Researchers do not always understand or have not received the training necessary to incorporate the perceptions, experiences, and language nuances of minority populations into their work. **The result is studies, communications, and interactions that assume the cultural perspective of the majority in their conduct and verbal interactions and betray their own biases — unconscious or otherwise.** Such assumptions lead to the

distrust by this community of everything from the premise of studies to the communications about them to the motives of the researchers themselves.

The language of researchers — hypotheses, control groups, qualitative vs. quantitative analysis — may be foreign to some community members. Sitting in a session that explains a study in scientific terms could be like sitting in a room where one knows they are the subject of the conversation but does not know what is being said about them. Such interactions do not engender trust, especially from an already distrustful cohort.

Instead, researchers should speak in terms familiar to this group, and understand the terms they use. For example, when a woman uses the term “recovery,” is she speaking of abstinence from substance use or safe usage? What is understood by the term “substance?” In today’s understanding, opioids come immediately to mind. However, in some communities, the term might represent cocaine or its derivative crack, alcohol, over-the-counter medications, or other substances with the potential for misuse. Understanding the language and cadence of life for a black woman reentering the community after incarceration is important. Learning the differences in this cadence and language between a member of the LGBTQ+ community, for example, or another population can also help build relationships.

Even more important, researchers must remember that, at times, their own language can be stigmatizing, stereotyping, and harmful. Lack of cultural competence impedes the positive engagement — and even future engagement — of some populations. The more women with lived experience hear the language of their community, the more they will engage.

Relying on experts from and within this community can enable the researchers to adapt their language and messaging sensitively and genuinely to be more familiar, uplifting, affirming and respectful to potential study participants.

3. Follow Trauma-Informed Engagement Approaches

Focus group learning: Focus group participants stressed that researchers need to appreciate the effects of trauma as they engage women with lived experience. Language, unconscious biases, and disrespect all add to the feelings of harm this population lives with.



[Researchers need to ask]: “What kind of childhood environment did you have? [What about] Housing? What trauma did you go through?”

IN THEIR OWN WORDS: Texas

The traumatic effects of systemic and systematic racism – especially when intersected with other biases such as misogyny, ageism, or homophobia, are documented. Experiences of race-based discrimination can have detrimental psychological impacts on individuals and their wider communities (Mental Health America, n.d.).



“They [researchers] should understand that she [a woman with lived experience] is not an ‘angry Black woman.’ She is a woman of passion with generations of trauma flowing through her blood, and she deserves the compassion and grace that is due to her race.”

IN THEIR OWN WORDS: Pennsylvania

Having suffered the double or triple whammy — racism plus SUD, plus legal issues — the psychological and physical trauma the women with lived experience have endured cannot be overstated. Incarceration alone is inherently harmful to physical health and can have devastating and long-lasting effects on mental health (Quandt, 2021) (Latham-Mintus, Deck, & Nelson, 2022).

Add SUD, and the limited employment opportunities for some upon reentry to the community, and the trauma runs deep and can seem insurmountable. The loss of dignity,

privacy, choice, and often family and livelihood are but samples of the ongoing trauma they experience.

For some, the battle to regain their own respect for themselves is ongoing. Our focus group participants expressed the hardship of carrying this burden and the everyday load of living in a society that devalued them from the day they were born. For others, being sent to inappropriate treatment options that don't address their level or type of substance misuse is another form of trauma.



“We have trust issues from how we have been treated. I was at a rehab where the staff was calling Black folks ‘niggers’ and threatening to send us back to jail.

IN THEIR OWN WORDS: Pennsylvania

Recommend: When approaching the development of studies that will engage them, researchers should have a clear understanding of their participants' life situation. Preliminary engagement with trusted community leaders and consultants can illuminate the trauma potential participants have endured.

Appreciating and considering trauma shifts the focus from: “What’s wrong with you?” to: “What happened to you, and how does what happened to you shape you and your viewpoint?” Only by acknowledging and affirming that the trauma — either system- or person-inflicted — is real and ever-present, can researchers fully and honestly engage participants and begin to gain their trust.



“Trauma can be the gateway to addiction and maybe having the researcher know all of this about trauma...maybe it would help.”

IN THEIR OWN WORDS: Georgia

4. Equate Lived Experience With Expertise

Focus Group Learning: A repeated complaint of participants in our focus groups who have been included in research studies is that they felt used, unheard, and misrepresented. Questions seemed inappropriate for their experience, relaying the sense that researchers knew or cared little about them, their community, their background, and trauma or the implications they held.

Similarly, they felt their answers were twisted to suit a pre-supposed viewpoint. Answers taken out of context delivered unintended messages proving or disproving assumptions in keeping with the goals of the researcher, rather than for the ultimate gathering of useful and beneficial information.

Recommend: Including Black women with lived experience in research study development assures that questions are drafted in a manner that respects the dignity of participants. It also limits the effects of unconscious bias that could creep in from a researcher unfamiliar with the audience.

When participants feel respected for their knowledge and contributions, they will more likely be open and transparent in their engagement.

“

“Why are white people involved in making decisions for Black women? They should ask Black women directly. Advertisement and information lacks when it comes to help for Black women in recovery. Get more Black women involved to spread the word.”

IN THEIR OWN WORDS: Pennsylvania

In fact, women with lived experience are experts in the subject matter of living with SUD, the effects of incarceration or other legal system involvement. They either have lived it or are living it daily. Researchers must treat them as the experts they are. **Studies should be developed with the view of learning something new from these experts, rather than affirming what is already known.**

“

“Allow me to tell my story without researchers pulling out parts of my story that they think will be useful. All of my stories are useful in my community because we often share some of the same stories.”

IN THEIR OWN WORDS: Michigan

5. Follow Up With Research Participants Afterwards

Focus Group Learning: Women with lived experience expressed the frustration that researchers had little interest in helping them. For some, this was a barrier to participation in studies — the feeling of being used briefly to answer random questions in areas that did not relate to them or take part in activities that held little to no benefit for them. **Those who said they did take part relayed the same feeling afterward, with the addition that there was never any follow-up from the researchers.**



“Does change happen from studies? If people can see the improvements, trust happens. But we don’t, so we don’t trust studies.”

IN THEIR OWN WORDS: New York

These subject matter experts understand the value of research to the systems they use — in concept. However, comments from those who were included in studies revealed that there was no information available to them about the outcomes of the studies. Little changed within their own circle of existence to show that the studies made any difference for them or the systems they navigate.



“After asking questions for research and collecting information, is it actually being reported and reviewed or put in a database?”

IN THEIR OWN WORDS: Pennsylvania

Participants in research studies do so because they wish to contribute to the betterment of systems for themselves and those who follow them. It is important for them to see — or at least hear about — the potential ramifications for the time and effort they expended. Hearing nothing once the study is complete lends to the feelings of being exploited, discarded, and retraumatized.



“[We need] more information coming into it: what does the research entail and, afterwards with the information received, what are you going to do with this information?”

IN THEIR OWN WORDS: Georgia

Recommend: Researchers should ensure that the results of studies are made available to their participants. **Follow-up can be direct or through the trusted community members who served to help recruit experts.** Providing a simple link to a final report on a researcher’s website is tempting. However, more thorough and personal follow-up communications are warranted to avoid the impression that participants are no longer useful or cared about.

6. Compensate Research Participants for Their Time and Expertise

Focus Group Learning: As in any contractual circumstance, focus group participants expressed the need for fair compensation for their involvement in studies. **The need for monetary gain was less important, though, than the confirmation that researchers valued their time and expertise.** Society puts little value on persons with SUD and criminal legal history; even so, it is realistic for women with this specific experience to expect to be valued by researchers seeking their input.



“My views on research studies are straightforward. I feel that if [someone] participates in research, she should be compensated! [Also], for the longest time I felt as if research studies were a waste of time. I think those views came from not seeing the results.”

IN THEIR OWN WORDS: Pennsylvania

For their participation in these focus groups, the women were compensated. Likewise, the members of the project team have been compensated for their time and input. Compensation reflected the considerable level of expertise the women have on the subject.

Recommend: Researchers should expect to compensate study participants at every stage of their involvement. Since building the relationship and developing the study parameters and components should include these subject matter experts, compensation for them should be built into the budget proposals from the start.

7. Study What Matters to Community Members

Focus Group Learnings: Our focus groups want to see research studies about what types of services and service providers best help this community find success, as they define it. For example, to address the trust issue for this community, participants suggest studies about the health care and SUD treatment and recovery workforce and how to increase the representation of BIPOC providers, as well as irregularities and trauma caused by some health and recovery systems.

Other suggested study issues include addressing the intersectionality between mental health issues, SUD, and trauma, or finding the best ways to help this community with the basic social determinants of health such as housing, employment, and other needs, the lack of which can become barriers to success.

Importantly, even this population is heterogenous with a broad range of characteristics that must be accounted for when developing studies about them. Consulting experts

about and within the community will help researchers develop relevant studies.

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“The type of questions they should be asking, like: ‘What has worked for you? What has been the consistent thing that has kept you with your recovery, to be involved with early recovery and sustained my recovery?’ And then: ‘Why? What happened?’”

IN THEIR OWN WORDS: Georgia

Recommend: Including members of the community in the conversations that generate research studies lets investigators hear from subject matter experts about what continuing needs exist for women with lived experience. With their help, researchers can begin to address the questions important to building successful support systems. Such help can be found in a consulting corps of subject matter experts.

Appendices

Appendix 1

Focus Group Methodology and Analysis

Pathways to treatment and recovery are highly personalized. Self-efficacy plays a key role in propelling an individual toward recovery. It is important for individuals to define their own life goals and design their unique journey towards those goals. This increases individual engagement and improves their treatment and recovery support outcomes. Community-based participatory research is being done to address these issues, but not in the best way possible. To implement studies that result in findings relevant to Black women with lived experience, researchers need to better understand the problems and barriers that keep the voices of this group silent. This results, again, in the underrepresentation of Black voices, which perpetuates the dearth of systemic change and allows ongoing harm to continue.

Approach

The Black Women CARE Project Team includes five Recovery Leaders — Black women with lived experience of SUD and criminal legal system involvement — one in each of five states: Georgia, Michigan, New York, Pennsylvania, and Texas. Each Recovery Leader guided 25 peer recovery staff members in recruiting and engaging Black women with lived experience for participation in focus groups about their treatment and recovery journey and their thoughts about researchers' engagement of Black women in studies.

As part of this Temple University institutional review board-approved project, 10 to 15 women from each state took part in 90-minute focus group sessions, with a total of seven groups with 51 women across the study. Notes and data were collected by another team member or by recording the sessions, which were held both in person and virtually. Participants were compensated for their time and expertise.

Focus groups were conducted throughout May and June 2023, utilizing semi-structured interview guides designed to elicit information about individuals' experiences with SUD treatment and recovery support services, as well as capture their perspectives and experiences of clinical research involving Black women.

The women were asked about their sentiments toward research studies, willingness or unwillingness to participate, and their reasons for either. Their answers gave great insight into the thoughts and attitudes regarding barriers that keep Black women from research studies, how they felt Black women are treated within the studies when they do participate, and what researchers need to do to better engage them.

To ensure a diversity of thought and response, focus groups were made up of Black women from differing backgrounds, bringing a range of understanding and intersectionality. Our call for participation invited self-identified Black women with self-identified experience with substance misuse and the legal system. The resulting cohort included Black women of mixed races, ages, and gender identities.

Analysis

As a first step, the project team members reviewed the transcripts, recordings, and written notes from each focus group. The goal was for each member to identify the common or prevalent themes and ideas lifted in each space. While each member of the team was reviewing the same material as every other member of the team, the purpose of the duplicative effort was to ensure that all the materials were reviewed by multiple people, thereby ensuring that no common theme would be missed.

The next step was for the team members to meet to discuss and compare the commonalities and themes from their own reviews. As expected, themes varied (though not significantly) depending on the reviewer's lens, so not all reviewers identified the same themes and priorities. The importance of discussion about prevalent themes and priorities was to identify priority themes considering how and how often they appeared in the focus groups. Several meetings were held to identify those themes and revisit the group notes for anything missing. Those discussions included clarification about the fervency and tenor of the issues as they were raised in each focus group session. For example, did the issue arise in passing at each session (e.g., it would be nice if there was food or a meal offered by researchers), or was there passion associated with the issue that was raised in each session (e.g., it is really important that researchers get to know us so we can trust them)? The driving indicator for inclusion in the recommendations was how important the issue was to the focus group participants — how often the issue arose, how much time was spent on the issue, the emotions that arose, the consensus on the issue within the focus group session, etc.

Once the list of included topics for recommendation was established, further extensive discussion took place to determine what the recommendation would be about the topic,

how it should be addressed, why, and what the expected response should be because of our recommendation. Also, we discussed the language and tenor of the recommendation.

Appendix 2

Focus Group Questions

Participants in each focus group answered and discussed eight questions in sessions that lasted one-and-a-half to two hours. Each session was facilitated by state leaders who are Black women with lived experience. The women were asked each question and given time to elaborate on and discuss their answers. Note-takers were assigned, but not part of the participant group.

Question 1: What do you consider success from treatment?

- Building on previously conducted PCORI-funded work engaging people with lived experience with substance use disorders, participants were asked to give a brief overview of what successful treatment and recovery looks like for them.

Question 2: What are your views about research?

- Participants explained what they knew about research and discussed what fueled their views about it.

Question 3: Talk about a time you participated or declined participation in a study or why not.

- Participants related experiences with research studies when they were included. They also discussed instances when they declined to participate and the overarching reasons for each, including both negative and positive experiences.

Question 4: What might increase participation?

- Participants brainstormed barriers to engagement in research studies and ideas about overcoming them.

Question 5: How can researchers better engage Black women with lived experience?

- Participants described ways they, as Black women with specific lived experiences, would like to be approached and engaged in research. They also discussed the specific needs of their community.

Question 6: What should the industry know about you with lived experience?

- Participants discussed their overall needs, life experiences, and the importance of researchers' understanding of their intersectional space.

Question 7: What do you wish researchers would investigate?

- Participants discussed the specific issues faced by their community and the need for research to target those issues in studies.

Question 8: What questions should they be asking?

- Participants discussed the types of questions researchers should be asking — and how they should be asking them — to get a fuller understanding of the community, thereby gaining results that are representative of their experiences.

Appendix 3

Black Women CARE Project Team

The engagement of Black women with lived experience from the beginning of the research study development to the end of the dissemination of the study results and analysis is necessary. However, identifying Black women who have lived experience, understand and trust the research process and long-term benefits, and have access to and standing in the community so they can assist in building the relationships needed can prove difficult. To fill this gap, the Black Women Consulting to Advance Addiction Research and Engagement (CARE) is available to advise researchers.

The Black Women CARE Consulting Corps understand the distrust, struggles, and trauma of women with lived experience because they are members of this population, themselves. Likewise, they have the trust of their peers. They speak the language of their peers. They understand the goals and aspirations of their peers and know what is important to them. They also hold their trust and can aid researchers in drafting studies that best engage them. In fact, the Corps' purpose is to advise the research and clinical communities on meaningful engagement of people with lived experience of SUD and CLSI in PCOR/CER studies, and to advise on priority research topics and outcomes.

Black Women CARE Project Team & Consulting Corps

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