EMBRACING ANTI-RACISM IN ADDICTION TREATMENT, RESEARCH AND POLICY:

ENGAGING BLACK PEOPLE WITH LIVED EXPERIENCE OF SUBSTANCE USE DISORDER

Grayken Center for Addiction at Boston Medical Center, Patient-Centered Outcomes Research Institute (PCORI) Engagement Award

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INTRODUCTION

Background

Black people in the US use substances at roughly the same rates as white people. They are slightly more likely to use alcohol and cocaine, and slightly less likely than white people to use methamphetamines, cannabis, and opioids (NSDUH). However, many of the health and social consequences of drug use are more severe for Black people. Not only are they more likely to be charged with a crime for using substances, they are also much more likely than white people to be incarcerated and to have their children removed from their custody.

Black people are also less likely than their white counterparts to receive treatment for substance use disorder (SUD). They are less likely to be offered FDA-approved medication treatment, and less likely to receive residential treatment or outpatient counseling. When they do receive treatment, they are less likely to complete a defined course of treatment, such as a residential treatment program.

When we examined rates of SUD treatment at Boston Medical Center (BMC), which is a large safety-net hospital in the North Eastern region of the United States that serves a significant portion of the hospital's Black patients, we also found large disparities by race. For instance, among patients seen in our emergency department for a substance-related reason (such as an overdose or an injection-related abscess) in 2019, White patients were substantially more likely to receive treatment for SUD in the subsequent six months when compared to Black patients (40% vs 30%).

Faced with evidence of widespread and persistent inequities in the impact of SUD, an interdisciplinary group of clinicians and researchers at Boston University met to try to understand how to change our addiction treatment programs that could address these findings. We discovered a lack of qualitative data to draw from and a lack of information from Black people with a SUD diagnosis to inform this research project. Therefore, we launched a study focused on learning how to make addiction treatment more appealing, effective, and equitable for Black patients.

Project Team

The project team is a large and interdisciplinary group of national experts in addiction medicine, local treatment providers, addiction researchers, graduate-level trainees, health system leaders, and the Council of Experts on Patient Experience (CEPE). The CEPE is a group of people with lived experience of SUD, who were recruited early in this project to collaborate on all aspects of the project design and implementation.

Objective

The qualitative component of the project aims to understand how to improve treatment for substance use disorders (SUDs) for patients who identify as Black. To effectively achieve this aim, we engaged Black patients who have lived experience with SUD and leveraged an anti-racist framework for our inquiry. Our study was prompted by our attempt to understand, (1) why Black patients are less likely to return to Boston Medical



Center (BMC) to follow-up for addiction treatment services after an emergency room visit related to substance use, and (2) what we need to do in order to encourage Black patients to engage with recovery treatment. Therefore, the key question for this project is to learn how to make addiction treatment more appealing, equitable, and effective for Black patients. Key strategies for obtaining information to help us reach this objective were to conduct focus groups with Black people who have SUDs, and to perform literature reviews to understand the findings from prior research on this topic. These focus groups and literature reviews were completed prior to the start of the current project, and the information obtained during these activities formed the basis for this PCORI Patient Engagement project. A key strategy for the Engagement project was to bring together multidisciplinary experts to collaborate with the Project Team to discuss and further develop the initial findings from the focus groups and literature reviews. The larger group then prioritized factors that contribute to the inequities faced by Black patients with SUD, and translated them into action items and a list of key unanswered questions.

METHODS

Developed Major Topic Areas

Prior to focus groups and convenings, we developed a list of topics that we agreed would be important to explore. We called these Major Topic Areas (MTAs), which included clinician and patient race concordance, culturally tailored care, experienced/witnessed trauma, access to pharmacological and non-pharmacological therapies, spiritual/religious influence, involvement with the criminal legal system, and barriers and facilitators to SUD care for pregnant people; all intersecting with treatment processes and outcomes for Black people with substance use disorders. We decided that we wanted to pursue two different types of information about these topics: scoping literature reviews and focus groups with Black patients who have lived experience.

Review Existing Literature

The purpose of these reviews was to identify and map the available evidence on each of the MTAs, and to give a clear indication of the volume of literature and studies available as well as an overview of what is known about how these topics related to treatment access and treatment outcomes. With the support from a Boston University research librarian, we were able to conduct a thorough search that would capture relevant information.

Focus Groups

The project team conducted a series of focus groups in the local BMC neighborhood. The focus groups were held at the Bruce Bolling Building in Nubian Square, Woods-Mullen Shelter and the 112 South Hampton Street Shelter in neighborhoods adjacent to BMC. The lead facilitator for the groups was one of the authors (PR), who himself is Black and has lived experience of SUD; co-facilitators were two other authors, who are also Black (NJ and DHP). A total of seven focus groups were conducted; six of which were with Black people with lived experience of SUD, and one with addiction treatment experts/providers via zoom. Each focus group was up to 90 minutes in duration, and was audio-recorded and transcribed.

The first six groups included eight to ten Black people who had experience using drugs or family members who had experience using drugs. They shared the ways in which barriers to care, including structural, institutional, interpersonal, and internalized racism, influence treatment-seeking, initiation, engagement, retention, and return to substance use. Facilitators also led discussions around what ideal treatment would look like for Black people. Participants in the seventh focus group included addiction treatment experts and providers who provide SUD treatment for Black patients. They were asked about their perception of barriers to SUD treatment for Black patients.

After the conclusion of the focus groups, participants were invited to join our community advisory board. Out of those invited, nine individuals expressed interest and subsequently became members of the "Council of Experts on Patient Experience" (CEPE). These esteemed experts played a crucial role in guiding the project towards the correct path.

Council of Experts on Patient Experience

Over the course of a year, the project team established an ongoing and co-equal partnership between Black people with lived SUD experience and the larger community of clinicians, researchers, and administrators, represented on the project team. This occurred through consistent communication and regular meetings. The first step was bringing together members to outline the purpose of the council and discuss the expectations for its members. One month into the project, the CEPE Group engaged in a 90-minute training session led by Phillip Reason and Daneiris Heredia-Perez. The training utilized the "Connecting Community to Research: A Toolkit" (CCR), developed by Tracy Battaglia, an awardee of the Patient-Centered Outcomes Research Institute (PCORI). The CCR toolkit was a to foster comprehension and confidence regarding research methodologies, while also aiming to enhance active participation in the project work.



Members of our team prepared the CEPE group by leading a meeting prior to each convening. The goal of this meeting was to help prepare each member and give them the tools they need to fully engage in each phase of the project work. Their biggest contribution came during the four convenings. During the convenings, CEPE members were invited to share their expertise. All experts participated in various exercises to build trust and comfort. Icebreakers and small breakout sessions led to participants familiarizing themselves with those in the room, which resulted in increased comfort with sharing personal experiences.

Convenings

The main project activity during the PCORI Engagement Award period was to conduct 4 day-long convenings to review the information gathered from the focus groups and literature reviews and to draw conclusions about the findings from this work. Our goal was to gather input on how to interpret our findings, and to translate them into two different products:

- a) a list of action items that can be used currently to make addiction treatment more appealing, effective, and equitable for Black patients; and
- b) a list of key, unanswered questions that can help to drive a future research agenda.

The convenings were held at Roxbury Community College and Boston Medical Center. Participants were a multidisciplinary group drawn primarily from the Boston area, but also individuals from across the state and several from other parts of the country. The group



included experts in addiction medicine, addiction researchers, mental health providers, policy experts, administrators, graduate-level trainees, epidemiologists, sociologists and health system leaders seeking anti-racist approaches to treatment of SUDs (see appendix). Invitees were chosen based on our knowledge of their expertise in topics related to this project, such as health disparities, the role of racism in healthcare, addiction treatment, and lived experience of SUD. More than half of the attendees identified as People of Color and more than one third of the group acknowledged personal and/or family experiences of SUD.

Each of the four convenings focused on a different theme. These were:

- 1. What **patient-level** factors are most important in determining what makes treatment most appealing and effective for a Black person who has a SUD
- 2. What **provider-level** factors are most important in determining what makes treatment most appealing and effective for a Black person who has a substance use disorder (SUD)
- 3. What **system-level** factors are most important in determining what makes treatment most appealing and effective for a Black person who has a SUD
- 4. What is the impact of **trauma** on determining what makes treatment most appealing and effective for Black people who have SUDs. This was selected as a topic because trauma was such a prominent theme in our focus groups that we thought it merited its own prominent focus.

Change Addiction Treatment and Addiction Treatment Organizations

The text boxes below are the condensed version of recommendations treatment organizations can make in efforts to create treatment that is more appealing, effective, and equitable for Black patients. Examples of organizations include but are not limited to clinics, short-term and long-term residential programs, and outpatient programs. In addition, the recommendations, we have included quotes from focus groups and convening participants to illustrate the bullet points.

1. Require leadership commitment and hold leaders accountable

2. Change organizational operations to promote equity:

- Hold staff accountable for experience of Black patients
- Demonstrate that treatment is designed to meet the needs of Black patients
- Alter the physical environment to convey warmth and hope and to reflect the presence/culture of Black people
- Create a treatment environment that feels welcoming, kind and empathetic for Black patients

"I think from what she is saying regarding staff, holding them accountable to how they are to actual patients, making sure that they have actual training on how to speak to people, and engage. You want to make sure that there is some screening there to make sure that they are actually holding some compassion so they are not coming in and just ignoring people."

3. Change the way that staff are hired, trained, and supported:

- Hire more Black people and POC
- Hire more staff who are trained and can provide high-quality counseling interventions
- Prioritize front-line staff who have lived experience of SUD
- Educate staff and treatment providers about how to work effectively with Black patients
- Engage staff in professional development activities to help them become anti-racist

4. Empower and support patients:

- Create a system of self-governance to allow the patient group to collectively respond to individual patients who violate behavioral norms
- Offer options to help Black people feel a sense of community and belonging in a treatment setting

5. Reshape addiction treatment with a less punitive, more strength-based approach:

- Deconstruct approaches in which patients are judged/not trusted and replace with an approach based on positive reinforcement
- Make care truly patient-centered
- Invite Black patients to evaluate their care, and use their feedback to improve care
- Make peer-based care a cornerstone of treatment
- Implement a proactive system to ensure that all patients are informed of all available treatment options (including medication and non-medication options)
- Incorporate elements of religion/spirituality as an optional treatment component, while recognizing that this will not work for all patients
- Incorporate art, music, drama, martial arts, spoken word into treatment
- Provide non-medication treatment options, such as acupuncture, massage, Reiki
- Honor the importance of family and provide family support
- Help people address shame and internalized stigma
- Foster an environment that creates trust

"I am 45-years old and I know when people respect people—the tone of their voice, how they position their body, how amicable they are, how attentive they are, and the service they are providing. Like he said... in [the] setting you are working [in], you need to be a little more empathetic and compassionate."

- 6. Address trauma:
- Expand the capacity to treat trauma, including racial trauma
- Implement trauma-informed approaches throughout treatment
- Select a method to increase organization's focus and capacity related to trauma
- 7. Remove barriers to receipt of mental healthcare:
- Screen for co-occurring mental health problems
- Combine treatment of co-occurring disorders with all SUD treatment

8. Address social/practical barriers to care:

- Addiction treatment programs should screen patients to assess basic needs
- Residential programs should ensure that patients have practical items that they need in order to participate comfortably

Changes in the Broader Systems that Intersect with Addiction Treatment

Recommendations that broader systems that intersect with addiction can make to improve the experiences of Black people struggling with substance use disorders.



1. Child Welfare: The child welfare system (also referred to as the family policing system) is deeply feared and perceived as biased against Black families. Recognize that fear of separation from children is a major driver for Black parent not seeking treatment for SUD. Inequitable separation practices are central to many problems in Black Communities, destroying families and traumatizing children and parents. The child welfare system needs to be reformed to focus on how to keep families intact, or to reunify, rather than focusing on separation.

"The way Black mothers are treated in that system, specifically Black mothers who have an addiction. Yes it is complicated. I mean, I think for Black mothers who have addictions are so frequently involved with the department of children and families. And we know that Black children are more frequently removed and removed for longer periods of time. And what me as the addiction provider is doing...by law I'm making that referral or that connection to the system that has that triple serving."

2. State-Federal Oversight + Funding of Addiction Treatment Program: Implement system-level policies to increase racial justice for Black patients in addiction treatment services. State-level accreditation of addiction treatment programs should include a requirement and metrics for racial justice within the program.

3. Public Education: Some substance use is motivated by feelings of hopelessness among young people experiencing poverty, low educational quality, and racism. It is important to help students and other young people make plans for how to complete degree programs and help them to conceptualize a professional track after graduation.

4. Hospitals: Black patients who are in crisis and in an emergency department or inpatient setting due to their substance use often do not receive SUD treatment. Create support, such as recovery coaching, to increase rates of treatment engagement.

5. Carceral System: The judicial and carceral systems are deeply rooted in systemic racism; remedies should include drastic decrease in the use of these systems to address substance-related problems.

6. Policing: Many police departments across the country are demonstrably racist, resulting in violence and death for many Black people. Police response should not be used to address substance use.

"In the court systems, it is the law. You see it everywhere. That White kids get [a] lesser sentence than Black [kids do]. That is a fact. When it is drugs or whatever it is, Whites are always getting a less sentence, especially coming from the hood. [They say], "Oh, he's a gangbanger." This guy could just be a guy in college, but they figured he's a gangbanger."

7. Employment: Provide recovery pathways that lead to employment. Historic and systemic racism have limited access to employment opportunities for Black people. If activities entwined with the drug culture are viewed as the only way for someone to earn a living, this is likely to prevent recovery.

8. Mental Health Systems: Expand the definition of traumatic mental health disorders to include racial trauma: traumatic experiences that cause chronic distress are common and damaging among Black people with SUD, in part due to racial trauma. Because the healthcare system (as codified in the Diagnostic and Statistical Manual of Mental Disorders, DSM 5) does not recognize this as a formal diagnosis, it is not possible to diagnose and bill for sub-threshold mental trauma. Partly because of this, our healthcare system largely fails to address it.

9. Community Organization: Partner with non-clinical community organizations, including faith-based organizations, to provide education about SUDs and mental health problems, and inform people about the availability of treatment.

10. Military/VA: Because Black people serve in the military in disproportionate numbers, they will benefit the most from changes aimed at prevention of the development of SUDs and improved SUD treatment for active-duty military and veterans.

Key Unanswered Questions

Following text boxes list out key unanswered questions that were extracted from each conference. These questions and themes were very important however, attendees suggested that more research was needed in order to further understand the impact.

1. ADDICTION TREATMENT

- If addiction treatment were developed specifically for Black people, what would it look like?
- What are best practices to guide collaboration with Black people who have substance use disorders in designing clinical care?
- What treatment models balance a patients need for flexibility (e.g., incorporating spirituality, acknowledging that change may be slowed by social barriers) with the structure that is required to run a program/organization?
- What practical measures can help Black patients feel more empowered in treatment relationships, and able to shape their treatment?
- What will support Black people to feel that they have a right to understand everything that is said and done to them (and decide if that is what they want)?
- What will support Black people to feel empowered to ask medical providers questions about important/difficult issues?
- What would be an effective model for having Black patients advise treatment staff on how to manage problems that arise with Black patients during SUD treatment?
- What is the best approach for including family members in addiction treatment; what approach will feel most supportive/comfortable for Black patients?
- What are the most effective ways to incorporate spirituality and/or religion into addiction treatment in a way that feels supportive to Black people who identify with a faith tradition, but does not feel alienating to those who do not?
- What is the best way to incorporate art, music, drama, spoken word into addiction treatment?
- What are best practices for addressing social barriers to recovery, such as lack of identity document, access to employment/income, lack of housing?
- What strategies can a residential treatment program use to increase new patients' engagement and likelihood of staying in treatment?
- What is the relationship between chronic traumatic stress (subthreshold for PTSD), such as that caused by racial trauma, and development of SUDs?
- What are the best approaches for treating/addressing racial trauma?
- Does treatment of racial trauma help to improve health and functioning?
- Does trauma-informed care increase patients' trust of medical treatment provider and treatment system?
- Does trauma-informed care need to look different from SAMHSA's definition when treating Black people in general, and in addiction treatment specifically?
- What alternative therapies for SUD could be appealing and effective for Black patients?
- How can contingency management be implemented effectively in residential treatment settings? In primary care settings?



2. IMPACT OF RACIAL CONCORDANCE

- How does individual racial concordance between Black patients and addiction treatment providers change outcomes?
- Do Black patients benefit from being treated in organizations that are staffed (primarily or exclusively) by Black people?

3. PROVIDER EDUCATION

- Are there educational interventions that can make addiction treatment providers more able to:
 - Gain and maintain Black patients' trust
 - Treat Black patients in a way that honors their expertise about their experience and treatment needs

4. DESIGNING RESEARCH

 What are best practices for researchers who want to engage the Black community in research on addiction treatment? What is the best participatory design?

Key Unanswered Questions Continued

5. POLICY

 What are optimal operating policies for residential addiction treatment programs in order to decrease the carceral, punitive feel/approach that typically characterizes these settings, and instead create a strength-based empowering approach?

6. EXTERNAL SYSTEMS

- How could schools provide SUD education, screening, and (if necessary) treatment in a way that is culturally tailored and acceptable to Black youth?
- What are the best ways to set up health centers in schools or other spaces that already have community relationships, in order to make them more accessible and welcoming for Black patients?
- What are viable models for child protection that are truly supportive of families staying intact rather than child removal/punitive approach?
- How can states effectively allocate agency funding to promote family unity, and what are suitable metrics for evaluating the safety and well-being of children?
- How can communities address social barriers that prevent parents from regaining custody of children who have been removed from their care due to substance use?
- What approaches are more effective for re-integrating people into society after exit from incarceration, particularly if they have a SUD?