Harm Reduction Journal

METHODOLOGY

Open Access

CENTER-ing Black voices: incorporating lived experience across the research process to advance equity in drug treatment and outcomes

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Abstract

Background Black people in the United States face persistent and increasing inequities in addiction treatment access and drug overdose death. Incorporating people with lived experience through community based participatory research (CBPR) approaches can improve understanding of drivers of and solutions to such inequities. However, practical and systemic challenges limit incorporating Black people with lived experience with substance use across each step of the research process. This paper describes the methods, recommendations, and lessons learned from a research team and Black-led community advisory board (CAB) working together across the research process to promote equity in harm reduction and addiction treatment.

Methods The CENTER Initiative is an academic—community partnership established to address increasing drug overdose deaths affecting the Black community in St. Louis, Missouri. The CAB comprised 10 Black people with lived experience recruited with the help of community-based agency partners. Academic staff dedicated to liaising with the CAB encouraged establishing structure and bylaws toward a self-governing CAB with decision-making power independent of agency partner and research teams.

Results The CAB and research team collaborated across all stages of the research process including design (e.g., deciding inclusion criteria), recruitment (e.g., flier development and participant referrals), data collection (e.g., conducting qualitative interviews), analysis (e.g., qualitative coding), and dissemination. Aligned with CBPR principles, dissemination activities extended the impact of the research to create sustainability and community empowerment (e.g., through advocacy, direct intervention, capacity building, and funding). Key lessons learned for working with a CAB facing intersectional oppression include a balanced approach incorporating structure and flexibility, a need for adequate personnel and funding support, and the importance of relationship building.

Conclusion Integrating people with lived experience into the research process through CBPR can mitigate the harms and inefficiencies of research while enhancing its community impact. The CENTER CAB and research partners creatively collaborated across each step of the research and translated their findings to practical community

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empowerment and sustainability in innovative ways. Research institutions, funders and other stakeholders must support building relationships and capacity among academics and people with lived experience to advance racial health equity and justice in substance use research and outcomes.

Keywords Community based participatory research, Community advisory board, Racial equity, Lived experience, Overdose, Substance use treatment, Racial disparities, Black harm reduction

Background

Black people in the United States are overburdened by substance use consequences yet underserved by treatment for substance use disorder (SUD) [1, 2]. Black people who use drugs (BPWUD) face disparities in criminal-legal contact [3, 4], SUD treatment access [2, 5, 6], and drug-involved death, including overdose [1, 7]. Disparities are driven by social determinants of health that manifest from systemic racism, but the specific determinants driving the burden of substance use consequences among BPWUD are often unclear or speculative [8]. To identify racism-related social determinants and develop appropriate interventions for reducing substance use disparities, community-engaged approaches involving people with lived experience (PWLE) at the intersection of drug use and Black racial identity are critically needed.

Community-engaged research approaches like community based participatory research (CBPR) are well-suited for investigating and redressing disparities among communities systemically excluded from and harmed by research [9–12]. Community-based participatory research (CBPR) has been described as a "gold standard" collaborative approach to conducting research with affected communities that contributes to social change and promotes justice [12–15]. CBPR equitably involves community members from inception to completion of the research process and is based on two pillars [15, 16]. First, the ethical pillar protects marginalized communities from further harm by engaging with those communities to realize the research process [15]. Second, the community empowerment pillar calls for transferring power from the institutions traditionally holding it to the communities traditionally denied it [15, 17]. To provide structure for carrying out these pillars, CBPR often involves a community advisory board (CAB) (or similarly named group) of PWLE in the community or with the condition of interest (e.g., working with a population, having a condition, and/or sharing similar demographic characteristics). As representatives of their communities, CABs can build trust and reduce power imbalances between researchers and communities, amplify the perspectives of marginalized groups in the research enterprise, and facilitate the research process [18].

Despite the benefits of CBPR, most research has described CAB involvement specific to early parts of the research process, such as informing research priorities, developing study materials, and facilitating recruitment and data collection [19–22]. Systematic reviews of CBPR studies find the majority report community member involvement in the former activities (63% or more) but only 34–47% involve the community in dissemination and only 21–37% in data analysis [9, 23]. In CBPR focused on substance use, CABs including PWLE are described predominantly as contributing to research design, instrument and intervention development, and recruitment [15, 16, 24, 25]. From the researcher's perspective, CABs may be primarily involved as participant interfacing and consulting entities due to the practical challenges of engaging individuals without scientific training across the research process. From the community perspective, CAB members may want to optimize their involvement, engaging primarily in research stages aligned with their skills, capacity, and preferences. Indeed, previous research has pointed to diverse learning needs and competing demands as challenges in engaging community members in research [11], including those with lived experience with substance use [25]. Among PWLE with substance use, research has also highlighted the challenges of a lack of self-efficacy in advising research-related content and role dissonance, or tension due to the differential expectations for serving in a distal strategic, advisory role rather than in a proximal community-facing, service or advocacy role [24]. Thus, with adequate training, communication, and onboarding, CBPR may better integrate PWLE with substance use across research stages to reduce research harms and increase its practical impacts, as called for by the pillars of CBPR.

Challenges in community-engaged research are expected when studying a highly stigmatized and impairing condition like SUD. These challenges escalate when working with those also disenfranchised from access to systems as a function of systemic racism–who often harbor healthy distrust of institutions [26]. Accordingly, there is a critical lack of diversity in research engaging PWLE in substance use and mental health

research [27]. Overcoming these challenges is critical to realizing research that contributes to health equity and justice among BPWUD rather than further harm or ineffectiveness. The current manuscript begins to address this gap by describing the activities of a CAB made up of PWLE convened for a project aimed at reducing the burden of opioid overdose in St. Louis' Black community. The current paper was written collaboratively by the CAB and research team, with members from both serving as authors. We describe the triumphs and challenges of working together to promote equity in harm reduction and SUD treatment approaches through research, advocacy, and community empowerment activities. Although CAB members were involved in all aspects of paper development, the impact of these activities are highlighted in the following sections by italicized testimonies from individual CAB member authors, which were written for the current manuscript.

Methods

Setting & background

The CENTER Initiative (centerstl.org) is an academic-community partnership established in 2021 in response to increasing drug overdose deaths in St. Louis, MO's Black community. Since the mid 2010s, overdose deaths among Black individuals have outpaced those among White individuals in the U.S. broadly [1] and in St. Louis. From 2019 to 2020, the region saw a 32% increase in opioid-involved deaths among Black individuals relative to 17% among White individuals [28]. As the COVID-19 pandemic exacerbated this crisis by disrupting access to basic needs and magnifying existing racial health inequities, core partners from University of Missouri–St. Louis (UMSL), Family Care Health Centers (a federally qualified health center), and Power4STL (a non-profit providing holistic care for physical and psychological trauma) convened with four additional secondary nonprofit partners to carry out the following mission: *To reduce overdose, confront the impact of trauma, and invest in the long-term wellbeing of Black people most impacted by addiction, drug use, and overdose in the St. Louis region.*

Funded by the Missouri Foundation for Health (2021–2024), CENTER's overall goals included changing the narrative around drug use and recovery, promoting safe use and harm reduction, and increasing traditional and non-traditional intervention options for Black communities. The initiative prioritized amplifying community voices and lived experience to identify needs and solutions that resonated with those most impacted and provide a foundation to address identified needs through collaboration and coalition building.

Recruitment and composition

Given those priorities, CENTER's UMSL-based team–made up of two faculty with expertise in addiction science and three staff focused on project management and research implementation–worked with leadership from grant partners to recruit eight CAB members. This number was chosen based on a budget of $20,000 per year to compensate them for their time in meetings, capacity building activities (e.g., travel, professional development), and events. Staff's explicit goal was that greater than 50% of the CAB were individuals with *direct* lived experience with drug use and/or SUD (i.e., versus indirect experience as a family member or provider) and greater than 50% were Black and/or African American. Researchers created a flier to recruit for a community event to discuss the new CENTER project and network with potential CAB members, circulating it to current and former community consultants, local providers, and CENTER's contracted partners. The event was held at a partner nonprofit, drawing 20 people who indicated interest in connecting with staff to learn more about the opportunity. Some of these individuals had previously served as community-based consultants on UMSL projects but most were new to the academic team. The academic team planned to interview those who were interested to assess interest and skills, then present notes from those interviews to leadership from community partner organizations to make final selection decisions collaboratively. However, upon follow up, only eight of the 20 event attendees committed to board membership (two were previous consultants of UMSL). The academic team felt relieved to not have to exclude potential members based on an interview and selection process they designed, highlighting the importance of interrupting traditional power dynamics that favor academic partners. Some strategies could include engaging existing community partners to develop eligibility criteria and participate equally in the interview and selection process [18] rather than being leveraged merely for recruitment and consulted for final selection.

Over the three years the CENTER CAB met (June 2021–June 2024), there were expected membership changes. One member felt the mission was not aligned with their personal priority to engage in direct community service per the role dissonance previously mentioned. Another moved away from St. Louis for a career opportunity, and a third faced personal hardship that led to their absence. After establishing their own agencies and bylaws, the CAB elected two new members based on their own connections and improved understanding of their mission, which had developed over time through meeting dialogue, engagement in research, and improved individual capacity. Throughout

the grant term, all ten members were Black and seven identified as people with direct lived experience with drug use and/or SUD. Their professional experience ranged and varied over the course of the grant period. Approximately one-third of CAB members worked in salaried professional roles in the SUD field, one-third worked as peer support or community health workers, and one third were retired or unemployed. Three individuals led or started a nonprofit during their time as CENTER CAB members and two also served as faith leaders in the community.

Structure and governance

CENTER aimed to establish a self-governing CAB with decision-making power independent of staff, agency partner, and research teams. Aligned with previous research [18, 29], staff helped the CAB establish bylaws outlining requirements and procedures for membership, elected roles and responsibilities, and the decision-making process. These activities were distributed across the first six months of meetings to integrate relationship building and mission-driven projects rather than only administration. Besides bylaws and orientation to the goals of the CENTER project, other onboarding topics included introductions to the problem of opioid overdose in the local community, harm reduction principles, research design and the scientific method, CAB purposes and best practices, and principles of CBPR.

Elected roles included a chair and co-chair; these roles did not have a term limit and were served for the full duration of the CAB. Regarding membership, after the initial CAB was recruited, nomination procedures for new members involved self-nomination or nomination by others, followed by voting via open ballot (e.g., show of hands). Potential new members required sponsorship by a current CAB member or CENTER staff or partner, submission of a biography statement, and a meeting with current members. During the decision-making process, the CAB voted for a quorum of 60 + % (five of eight when full) to be present to proceed with any vote. All voting for membership, bylaw changes, or other decisions was majority rule.

CAB members were required to serve a minimum of one year and attend one in-person 2-h meeting a month held at UMSL or a local community partner site, including sites recommended or provided by CAB members. Meetings comprised administration, project-related training and professional development workshops, networking visits from potential partners, planning various CENTER activities, and opportunities for reflection. In years 2–3, CAB members were also invited to participate in CENTER project workgroups with staff, partners, and volunteers to achieve specific goals. Examples of workgroups included training and curriculum development, Black-led harm reduction coalition building, harm reduction and overdose education and naloxone distribution, community engagement and events, and external advocacy and public affairs. Finally, the chair and co-chair met with CENTER staff via Zoom approximately two weeks before each CAB meeting to set the agenda and priorities for the next meeting. The chair and co-chair volunteered this time, viewing it as part of their leadership responsibilities. Otherwise, to support time and expertise, CAB members were compensated $50 per hour for all CAB and workgroup meetings, research activities, and any other CENTER-related dissemination or community-based activities. They were also provided transportation if requested and served dinner at each monthly 2-h meeting. CAB meetings and preparation activities were consistently supported by multiple CENTER staff members, highlighting the robust infrastructure needed to maintain an effective CAB composed of PWLE that can operate across various priorities.

Results

CAB activities across the research process

The CENTER initiative included two research projects that built upon each other. CENTER Black Advocates (CBAdvocates) [30] included focus groups with peers and community health workers working with BPWUD and was developed in collaboration with organizational partners during grant writing and executed in collaboration with them and the CAB. CENTER Black Voices (CBVoices) interviewed BPWUD directly and was designed in collaboration with the CAB based on CBAdvocates findings. In the following sections, we describe how the CAB and research team worked together at various stages of the research process to execute these studies.

Design stage

CBAdvocates was designed before the CAB was established in collaboration with community partner organizations during the grant writing process. However, we used CAB meeting time to collaborate on the design of CBVoices. In general, CAB members were enthusiastic about the prospect of interviewing BPWUD, who they felt had been excluded from popular narratives of those impacted by the opioid overdose crisis. They wanted to focus on those who actively use opioids, which led to inclusion criteria of past 30-day opioid use. They also decided to sample only Black men for two reasons. First, Black men were most impacted by overdose in St. Louis (e.g., with a drug-involved death rate of 337–374 per 100 K from 2020 to 2023 relative to a rate of

168–200 among White men and 106–110 among Black women) [31]. Second, the CAB felt Black men in St. Louis faced significant social marginalization and they hoped interviews would serve as a show of empathy and compassion toward this group:

> *It changed the narrative; it gave so much awareness. The men was more surprised than we were. They never had experienced nobody interviewing them, and caring about how they felt, and caring about their needs, or anything like that. -Harriet Montgomery*

CAB members and partner organizations also provided detailed feedback on researcher-created drafts of the interview guide for CBVoices. This collaboration was critical to bridging cultural and regional linguistic differences between BPWUD and researchers, many of whom were not Black and not native to St. Louis. CAB members revised questions to simpler language and language in which Black people tend to speak to avoid misunderstandings or degradation. See Table 1 for examples of questions drafted by the research team, and revised questions informed by the CAB and community-based partners.

> *Not everyone understands the crucial barrier to code switching, the translations of cultural Ebonics' and the vernacular to the "Black" tongue. Code switching is different based on many factors like culture and regions. -Arial Collins*

Recruitment stage

As in most CBPR [9, 23], CAB members were key to designing recruitment materials. For CBVoices, they provided significant revisions to a draft flier provided by the research team, with edits focused on appropriate tone (e.g., including a more serious photo rather than one of smiling models), person-first and empowering language (e.g., "Black men deserve to be heard"), and simplified descriptions of the commitment and compensation (Fig. 1):

> *It was important to make sure that PWLE and marginalized people had a voice. As I got a better understanding of the CAB, it was to be representative of what could further the conversation around SUD. My goal has been to help people–particularly African Americans and urban people with addiction–and to empower our communities. -Andreas Prince*

Although the research team had planned to recruit primarily from a contracted community partner organization, CAB members facilitated a partnership with another organization providing services to those very early in recovery (< 30 days). They stressed the importance of interviewing both Black men actively using drugs and those recently abstinent to capture varied perspectives on the same topic. The team successfully recruited 40 participants in nine months.

Data collection stage

Originally, research staff planned to collect data, serving as interviewers for CBVoices just as they served as focus group facilitators for CBAdvocates. However, while planning the design of CBVoices, both CAB members and research staff raised concerns about whether Black men would feel discomfort or hesitancy disclosing personal topics to White women research staff during interviews. This initial concern eventually led to discussions about the value PWLE could add to qualitative data collection by creating a sense of familiarity and shared understanding among research participants. Ultimately, these discussions led to a collaborative decision to include CAB members as "community interviewers." During a CAB meeting, the faculty research lead trained all CAB members

Table 1 Examples of interview questions drafted by the research team and final versions revised by the CAB and community partners

Draft question (Research team)	Revised question (CAB and community partners)
Are there ways in which using drugs helps you cope with trauma/hardships in life?	How do drugs help you get through?
Narcan/naloxone is one way to prevent an active opioid overdose. What do you know about Narcan?	Tell me about experiences you've had responding to an overdose or using Narcan?
What role does your neighborhood play in your drug use and/or recovery?	What kinds of support do you have in your neighborhood / where you live? Is there anything in your neighborhood that makes things worse for you?
Can you tell me what you know about fentanyl test strips?	How do you react when you hear about a bad batch of drugs? How do you know if fentanyl is in your drugs?
Are there ways in which gun violence and the drug trade interact in St. Louis?	What have your experiences been with gun violence as someone who uses drugs?

Fig. 1 Recruitment flier collaboratively created by the community advisory board and research team

in qualitative interviewing techniques. For another meeting, CENTER staff rented a computer lab to help CAB members complete CITI Program training modules required by the UMSL Institutional Review Board (IRB) to interface with participants. This session lasted approximately three hours. Some members were unable to complete the training during this time and were later assisted individually by research staff. Others deemed the training burdensome or less of a priority relative to other responsibilities and CAB activities. Five CAB members completed CITI Program and qualitative interview training.

These five individuals were added to the IRB for CBVoices as individual community consultants. The university IRB liaison was unfamiliar with CBPR and the inclusion of community members in the data collection process and questioned this addition. In response, the research leads educated the IRB about the principles of CBPR and the importance of including PWLE in data collection given the cultural marginalization of BPWUD and mistrust this group may have for academic researchers. Ultimately, the IRB approved the inclusion of community interviewers as research staff if research team members remained responsible for ensuring research protocols were followed, including managing informed consent and compensation procedures during interviews. Four CAB members participated in interviews, first observing or assisting interviews conducted by a Black woman research team member. Once they were comfortable, these CAB members conducted interviews, with available research team members (both Black and White) observing, and if necessary, providing assistance.

> *Quite often, we're not involved in the solution side of talking to people who have been through some of the things we've been through. We have been in that lifestyle and so some of the questions and things being asked, they're things the CAB has lived through before or things they're helping people through now. It was good to have someone in the room who knew what was going on on the other side. We were able to add our own input just in case there was something we wanted to ask that wasn't necessarily on the interview guide. We made sure the interviews were on the right track. -Burton Barr*

Analysis stage

According to systematic reviews, a minority of CBPR involves community members in the data analysis process [9, 23]. Because we found little previous guidance for involving CAB members in the qualitative analysis process, the research team piloted two separate analysis activities with the group. For CBAdvocates, after research staff generated their initial set of codes via open coding [32], they introduced the codes to CAB members during a meeting. Each code name, code description, and an illustrative quote were included on a notecard. In breakout groups, CAB members reviewed codes and grouped them into higher-order categories (as in axial coding) [32]. The CAB's qualitative feedback on codes and quotes were recorded as memos. These informed the research team's axial coding process, helping to define and contextualize themes. The CAB helped guide the research team toward identifying themes representing manifestations of systemic racism (*Healthcare and Service Barriers* and *Lack of Trust in Systems and Providers)* and their relationship to the core phenomenon, a lack of safety, security, stability and survival [see [30] for details].

Based on the success of this pilot coding activity and feedback from CAB members that Black men should be involved in interpreting interviews sampling Black men, the research team trained CAB members to serve as analytic support for CBVoices. Three CAB members (all Black men with direct lived experience) elected to serve as "community coders." Following a 2-h training session and opportunities for practice with data from CBAdvocates, community coders and research team coders convened monthly during the analysis process (approximately eight months) to review transcripts. Research team members presented coding discrepancies that were difficult to reconcile and sections of text that were difficult to interpret. The community coders helped decode language specific to the culture of BPWUD in St. Louis and identify data segments aligned with the codebook and guiding research questions.

> *When you grew up in the streets and when you are dealing with opioids or any type of drug, you talk in code. And only people that can understand the code really know what you're talking about. It's been a while since I've been in the streets, but the code is still the same. - Alfred Long*

Dissemination stage

The CENTER CAB facilitated both academic and community-based dissemination of findings for CBAdvocates. First, CAB members helped the research team interpret study findings and provided approval of the paper before publication. Then, they guided translation of findings to the community through advocacy (e.g., provider and policymaker education, media engagement) and community education (e.g., tabling, events, infographic and training material development). For example, CAB members and CENTER staff created infographics reflecting the most important results from CBAdvocates to handout at community events (see Fig. 2), ensuring translation of academic research findings to culturally relevant and accessible material aligned with community needs. As evidenced by the current paper, CAB members were also critically involved in disseminating their own research innovations. They presented to providers and community members at local conferences to connect research findings to their personal and clinical experiences and advocate for the inclusion of marginalized populations in research.

> *Being able to present and let people know that first*

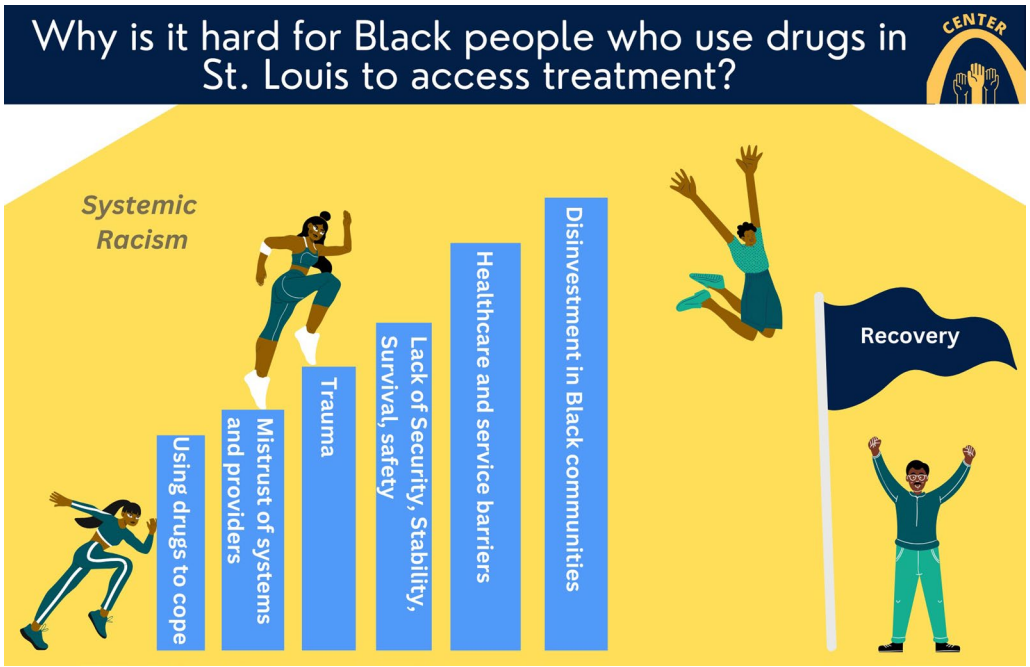

Fig. 2 Infographic created by the community advisory board to disseminate research results in community settings

of all, it's not just researchers. It's PWLE that have lived through this and is actually coexisting in this space to where now, we're starting to help. In other words, we're going to go beyond the numbers and the data. This is actually a human experience. And just being able to connect with people like that, it was beautiful. -Keith Lofton

CAB members also identified target groups and crafted key messages for those groups, including both professional and community audiences. Findings from CBAdvocates, which detailed the connection between systemic racism and the burden of overdose in St. Louis' Black communities [30], resonated among CAB members. Nonetheless, one lamented, "How do we get White people to care about this?" referring to the disconnect between dominant treatment and policy institutions and the needs of BPWUD. This disconnection between CAB members' knowledge–based on their lived experience–and the knowledge of mainstream healthcare professionals and other stakeholders led CENTER staff to present findings to the region's substance use treatment providers, social workers, behavioral health providers, and other professionals working in systems serving BPWUD. Thus, in addition to interpreting findings that illuminated practical manifestations of racism-related social determinants of overdose for a broad academic audience, CAB members practically translated those findings into actionable mitigation strategies for providers in their own community.

From research to praxis: toward community empowerment & sustainability

The ethical pillar of CBPR responds to a longstanding history of researchers exploiting vulnerable communities, including engaging with communities solely for the duration of a research study–leaving them with limited support and few benefits of participating in research [33]. Thus, the core principles of CBPR call for not only mutual engagement, learning, and action-reflection during the research endeavor, but also a commitment to sustainability beyond its scope for social transformation [18]. Accordingly, the CENTER CAB and research team engaged in the following activities that extended their impact beyond traditional research products and into community-based praxis, or the critical social action facilitated through knowledge generation and reflection [34, 35].

Advocacy: As Missouri faces some of the highest rates of Black fatal overdose in the U.S. [1], the problem crossed the desk of local and national stakeholders in media and policy. CENTER leadership (i.e., research faculty and executive leadership at nonprofit/healthcare partners) were traditionally contacted to comment on these problems. As CAB capacity grew, the team identified PWLE as better voices to bridge the gap between the streets of St. Louis and mainstream

institutions. Thus, the CAB often engaged with local news media, emphasizing the significant impact of the overdose crisis and the critical need for investment and intervention in St. Louis's Black neighborhoods [e.g., 36]. They also met with local and federal government officials to advocate for naloxone access in public housing and highlight the negative impacts of war-on-drug-policies on BPWUD. Finally, their local and community-based presentations educated the broader community on the social determinants driving addiction and overdose among BPWUD and how to redress them.

Direct Intervention: In addition to their roles in CENTER as strategic advisors, research collaborators, and advocates, CAB members were ubiquitously passionate about directly serving BPWUD. Direct intervention kept the CAB actively engaged with the community, allowing them to assess the appropriateness and timeliness of CENTER's larger strategies. The CAB helped plan and implement local events, including a series of Healing Circles designed to create safe spaces for BPWUD. They packed essential harm reduction supplies like naloxone and fentanyl test strips for statewide distribution and participated in community festivals to disburse supplies and infographics they created. Events served as a bidirectional opportunity to share CENTER research findings and hear firsthand about emerging community needs.

CAB members also developed and led their own initiatives in the community and their workplaces. One CAB member, Keith Lofton, launched a Christmas coat drive in response to dissatisfaction with how agencies addressed the basic needs of BPWUD. The drive supported individuals in unstable housing, disconnected from their families, or experiencing other barriers to meeting their resource needs during the holiday season by providing winter clothing, hygiene kits, and catered meals. Other CAB members were instrumental in supporting Keith's venture, using their professional positions to secure financial support and volunteering their time. As supporting such grassroots activities became a CAB-identified priority, CENTER also contributed, purchasing over 60 coats, advertising the event in the community, and helping to track its impact with participants. Several members also worked for local substance use treatment providers in roles from peer specialist to clinical supervisor. They used their connections as CAB members to increase access to harm reduction supplies in their organizations and referral connections with other agencies. One CAB member, Gerald Dennis, built new connections with CENTER partner Power4STL, a provider of holistic harm reduction services, and Family Care Health Centers, a federally qualified health center, to develop an informal referral network connecting harm reduction services, primary healthcare, and traditional inpatient and outpatient treatment for BPWUD. CENTER and the CAB helped provide a communal space for troubleshooting, case consultation, and planning to support this new network in filling service gaps.

Capacity and Power Building: CBPR can improve health disparities both by strengthening research findings and through the inherent health value of research engagement [37]. Thus, CENTER's investment in CAB members through relationship-building and professional development built sustainability by shifting power to PWLE. During meetings, CAB members received training to amplify their impact in the community, covering topics such as working with technology, program evaluation, outreach and engagement, program budgeting, and civic engagement. They also attended national harm reduction conferences to learn from and network with people conducting similar work with marginalized communities. Through these activities and their relationship building with CENTER stakeholders, CAB members grew in their own skills, capacity, and power.

> *For me as a recovering person and as a professional, I've had limited exposure or opportunity to gather data and information that would later be used to write a grant. This was a process that, without the CAB, wouldn't have happened for me. Now, I can actually look at data from start to finish and how data is gathered and realize its importance. Also, I learned how important it is to have data that is representative of a certain group of people in order to help change and create a different narrative. So that right there for me was a gift, a great opportunity to impact the SUD community. -Andreas Prince*

For example, author Keith Lofton joined the CAB after six years in recovery. At the time, he was living in recovery housing. He is now a certified peer specialist and community health worker, working at a local treatment agency and leading his own nonprofit. He is well known in the community for his advocacy and passion for using outreach to connect BPWUD with needed harm reduction tools and services. Keith partially credits his time as a CAB member for his personal and professional growth. Although the grant funding has ended, the harm reduction and racial equity efforts initiated by Keith and his fellow CAB members continue as a result of their collective and individual development.

Funding: The CAB contributed to the financial sustainability of CENTER by seeking funding to support aligned community initiatives. In the final year of the grant, the CAB and greater CENTER team aimed

to develop a permanent, Black-led harm reduction coalition in St. Louis. The CAB was a central contributor to an inter-agency workgroup comprising SUD and behavioral health treatment providers, public health officials, harm reduction activists, academics, and PWLE. CAB members helped create a mission, vision, and values for the emerging coalition, informed by networking with national Black harm reduction experts. Through workgroup meetings and coalition building, CENTER research staff, partners, and CAB members collaboratively developed infrastructure necessary for a grant proposal, including goals and objectives, partners and collaborators, budget requirements, and a project rationale based on CENTER's research findings and successes. This led to a successfully funded 3-year planning grant to develop an independent St. Louis Black Harm Reduction Coalition as a 501(c)3 organization. Although UMSL researchers and staff remain involved in this project in a support role, the grant is led by and housed at a Black-led nonprofit organization, aligned with the community empowerment pillar of CBPR.

Lessons learned and recommendations

Consistent with existing literature, CENTER's CAB and research team encountered challenges, including low self-efficacy, role dissonance, competing health and social demands, and conflict. Nevertheless, we saw many triumphs including maintenance of full board membership, consistent governance, and robust participation in meetings and outside events. We also engaged consistently across two qualitative research projects, working together to extend results beyond academic theory to praxis through advocacy, direct intervention, power-building, and funding. The following sections highlight four key lessons learned and offer recommendations for engaging with a CAB in future research efforts.

#1: Financial and personnel support drives infrastructure and sustainability

The CENTER team partially attributes its success to the flexible support provided by foundation funding. This included the sustained effort of 2–4 full-time staff members who attended each CAB meeting and facilitated training opportunities, research tasks, and workgroup meetings. Staff were also available to CAB members by phone, text, and email to answer questions and help mitigate personal or professional barriers to engagement (e.g., issues with technology, family emergencies, job losses and transitions). Staff and research team members were also flexible in their job roles and responsibilities, allowing them to respond to CAB-identified priorities and activities toward sustainability (e.g., grant writing). It was crucial to the success of CENTER that the project budget included financial support to compensate CAB members for their community expertise and labor, and to address any needs that might hinder their engagement (e.g., transportation). The project funder also allowed for the flexibility of the budget to support arising needs, including capacity building and education topics identified by the CAB, so members were equipped with skills needed to effectively advise the project as it evolved. For example, during CAB member onboarding, academic and research staff discussed the budget, including how many CAB hours per month could be supported by the grant. Based on these discussions, CAB members collaboratively decided what kinds of activities fell into scope of their own compensation and created a process to consider proposals to fund and support arising needs from within the CAB (e.g., professional development activities) or the local community.

Compensating CABs has become the rule rather than exception [38] reflecting increased federal funding for CBPR over the past two decades and increased emphasis on engaging underrepresented groups in research [23]. Nevertheless, major federal funding agencies largely prioritize projects addressing individual and proximate determinants of health and disease, rather than social and structural determinants, which may be more relevant to communities impacted by racism and other forms of oppression [39]. Thus, predominant funding structures typically leave those CBPR studies rooted in the priorities of the community underfunded, which exacerbates inequities in research representativeness as well as in local relationships between researchers and community members with lived experience. Regardless of the funder, as a new CBPR project, CENTER would neither have been established nor successful without robust and flexible funding. Such projects cannot be realized without financial support for both dedicated staff and community partners. To effectively support a new CAB, especially one comprising PWLE, funders must allow for flexible spending across budget categories and timelines, a practice that is becoming more common but still practically limits CBPR [16], whereas researchers must budget sufficiently for dedicated staff and financial support. Planning and budgeting are best done in collaboration with community partners and potential CAB members during the application process and may even include the development of initial processes and bylaws regarding spending and compensation practices. Researchers should avoid prescribing such practices, allowing CAB members the agency to negotiate the supports needed to participate and the value of their time, knowledge, and resources.

#2: Structure facilitates progress and consistency

Structure was a central component to communication and collaboration between the CAB and research team. This included establishing decision-making structures, which set the CAB up for success in the subsequent decisions that arose among themselves and in the larger Initiative. We also benefited from allocating structured time in each meeting for educational workshops, administrative decisions, and discussion of research tasks. As many CAB members were new to both research and advisory board membership, using a structured approach led to more robust engagement and ensured priorities were addressed in a timely manner. For example, open-ended discussion questions asking CAB members to make decisions about CENTER research or other priorities often caused confusion and circular conversations. We found it more effective to provide written materials or examples of previous initiatives' strategies for CAB members to react to with targeted areas for brainstorming, feedback, or revision. Per lesson #1, this required significant staff time and effort to conduct research and prepare materials in advance of CAB meetings. As previous recommendations suggest, researchers engaged in CBPR with PWLE, and other marginalized groups should prioritize consistent and clear expectations for community partners and build administration and governance into their project timelines [19]. Structured agendas, consistent processes, and prepared materials adapted to the diverse learning needs of CAB members allows academic–CAB teams to best use their limited time together and facilitates a predictable and gratifying experience for CAB members.

#3: Flexibility centers community priorities

Although we recommend project teams commit to creating structure, it is also important to remain flexible, allowing for iteration based on CAB needs. We learned researchers and academic staff must be responsible for creating a safe space for disagreements and conflict. This includes willingness to diverge from meeting agendas, providing ample time for reflection and discussion, and revisiting ideas regularly as plans shift to practice. Conversely, it is the CAB's responsibility to revise and rethink research and project designs to better align with community needs and preferences. Academic–CAB teams must be open to making significant changes, including changes to the study's methodology, sample, or the research question. For example, the original research plan initially included an additional research project besides CBAdvocates and CBVoices. This aim and its planned methods were neither a priority to community partners nor did they find the methods feasible in context. Thus, we abandoned this aim and used the unallocated time and funds to realize CAB-identified priorities and projects. We recommend CBPR projects commit to longer work plans to moderate urgency around deliverables and incorporate the time for reflection that is needed to align community priorities and research methods.

#4: Relationship provides foundation

We cannot overstate the power of meaningful relationship building as a mechanism of our partnership's success. Although the research team recruited CAB members based on common overarching goals and values, we found that a strong working alliance was a product of quality time, developing over shared time together in-person. It took time and consistency for CAB members to trust the intentions and methods of the research staff and feel comfortable sharing their unfiltered opinions due to historical and current harm and disenfranchisement perpetuated by research and research institutions. Thus, it was important to regularly and explicitly share our values with each other, support each other's personal and professional projects and events, and stay in touch outside of meetings. Addressing conflicts, repairing relationships, and making time to get to know each other personally created a shared identity among both the academic team and CAB members, leading to increased participation and a deeper sense of belonging and purpose. Researchers must invest their time and resources in connecting with the community beyond the scope of the contracted or planned project work. These relationships are the drivers of community-engaged research's impact and sustainability.

Conclusion

Integrating PWLE into the research process through community-engaged approaches like CBPR can mitigate the harms and inefficiencies of research while enhancing its community impact. The CENTER CAB and research partners creatively collaborated across each step of the research and translated their findings to practical community empowerment and sustainability outcomes to advance Black harm reduction and substance use treatment in St. Louis. Formally engaging community members who face stigma and social marginalization at the intersection of substance use and anti-Blackness requires adequate funding and personnel, a balanced approach incorporating structure and flexibility, and a research team committed to the personal, professional, and collective well-being of CAB members. Research institutions, funders and other stakeholders must continue enacting policy changes that support building relationships and capacity among

academics and PWLE to advance racial health equity and justice in substance use research, treatment, and outcomes.

Abbreviations

BPWUD	Black people who use drugs
CAB	Community advisory board
CITI	Collaborative institutional training initiative
CBPR	Community based participatory research
IRB	Institutional review board
PWLE	People with lived experience
UMSL	University of Missouri—St. Louis
SUD	Substance use disorder

Acknowledgements
The authors would like to acknowledge and thank the CENTER Initiative's grant partners, who were critical in recruiting and developing the CENTER Community Advisory Board and in holding them and the academic research team accountable to our shared goals and vision. These partners include staff and leadership at Power4STL, Family Care Health Centers, The St. Louis Community Health Worker Coalition, The Behavioral Health Network of Greater St. Louis, The St. Louis Regional Health Commission, and the St. Louis Integrated Health Network. They would also like to thank and acknowledge former Community Advisory Board members and CENTER staff, including Alex Duello and Sterling Higdon for their critical contributions and roles in this work.

Author contributions
DEB and MEP originally conceptualized and outlined the current manuscript. DEB, MEP, KDC, DDB, RG, BB, AC, GD, KL, AL, HM and AP were critically involved in developing the procedures and materials depicted and described herein. DEB, MEP, KDC, DDB, RG, BB, AC, KL, AL, HM, and AP contributed to initial drafts of the manuscript. DEB provided oversight of all procedures described and manuscript drafting and revision. RPW secured funding for the project, provided feedback and oversight on the procedures, materials, and direction of the project, and critically revised the manuscript. All authors read and approved the manuscript for submission.

Funding
The research described in this article was funded by the Missouri Foundation for Health. The foundation had no role in the conceptualization or design, data collection or analysis, or decision to publish the current manuscript.

Availability of data and materials
Data sharing is not applicable to this article as no datasets were generated or analyzed during the current study.

Declarations

Ethics approval and consent to participate
The current study does not involve the use of human data. However, the research procedures described in this article were approved by the Institutional Review Board at the University of Missouri—St. Louis (Project #2052586).

Consent for publication
Not applicable.

Competing interests
DEB is a Guest Editor for Harm Reduction Journal's 2025 Special Collection, "Community-Engaged Harm-Reduction Research for Social Justice." The authors have no other competing interests to report.

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Received: 20 September 2024 Accepted: 1 April 2025
Published online: 21 April 2025

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