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Establishing a community advisory board to align harm reduction research with the unique needs of Black and Latine communities

Simon Kapler[1*], Hira Hassan[1], Alexander Jeremiah[1], Katurah Bryant[1,2], Presto Crespo[1,3,4], Nesta Felix[1,5], Sónyi Elena Lopez[1,6], Antonio Morales[1,7], Sean Reeves[1,8] and Ayana Jordan[1]

Abstract

Death from opioid use is a growing public health concern, with stark racial and ethnic disparities. The randomized controlled trial described here aims to improve initiation and engagement in harm reduction services for Black and Latine people who use drugs to minimize mortality in these populations. The trial is informed by a Community Advisory Board (CAB) of stakeholders from racial and ethnic minoritized backgrounds committed to promoting health equity in populations disproportionately impacted by the drug overdose crisis. CABs are an underutilized mechanism for engaging communities in research to improve health outcomes. Hence, in this manuscript we outline the process and methods employed in creating a CAB, describe its impact on our research study, and recognize the challenges and adaptations made to the CAB during the study.

CAB recruitment targeted active community members from Black and Latine communities in the Bronx, NY and New Haven, CT. After attending community organizational meetings in each place, follow-up email efforts were unsuccessful, prompting a revised approach. Emphasizing the study's focus on historically excluded voices, "research-naïve" individuals were sought through online searches and local grassroots organizations, excluding those affiliated with harm reduction groups to minimize bias. Once CAB members were identified, a remote orientation was held, and the CAB began providing regular feedback on research activities, from participant recruitment to educational script details. CAB members' diverse identities and life experiences generated nuanced discussions, which were distilled into feedback improving research materials and recruitment strategies. In the future, the CAB will also guide data analysis and research publications. Other areas of emphasis have included straightforward language in study materials, balanced messaging about harm reduction recommendations, and specific community outreach opportunities. Practical barriers that needed to be addressed for optimal CAB functioning included timely compensation with minimal institutional burden and assistance with meeting coordination and communication.

*Correspondence:
Simon Kapler
simon.kapler@nyulangone.org

Full list of author information is available at the end of the article

The CAB has ensured that Black and Latine community voices are included in guiding our study, promoting equitable and ethical research. As harm reduction research advances, it is essential to center this work around the intersectional identities of people who use drugs to prevent the disproportionate burden and deaths among Black and Latine people.

Keywords Harm reduction, Opioids, Community Advisory Board, Community-Based Participatory Research, Equity, Black, Latino/x/e

Background

Death rates from opioid-involved drug use among Black, Latine, and Indigenous Americans are increasing more quickly than death rates for White people despite comparable rates of opioid use across these groups [1–3]. Drivers of these escalating mortality rates are steeped in structural racism, including inequitable distribution of medication for addiction treatment and limited access to quality culturally informed treatment programs and harm reduction services [3–5]. Inequities in social determinants of health–including mental healthcare access, income disparity, and incarceration for substance use–likely also contribute to increased overdose mortality rates among racial and ethnic minoritized (REM) individuals [6, 7].

Despite the opioid overdose mortality rate decreasing for people racialized as White and Native Hawaiian/Pacific Islander in between 2021 and 2022, it continued to climb for Black, Latine, and Asian, and American Indian/Alaska Native people [1], suggesting that current mainstream approaches to reduce overdose rates among REM people are inadequate. While this research primarily emphasizes Black and Latine populations, it recognizes that Indigenous communities are also experiencing severe impacts from opioid use and overdose, and highlights the need for broader, culturally informed harm reduction strategies. One intervention that holds promise in this regard is access to harm reduction services, particularly with culturally informed interventions guided by Community Advisory Boards (CAB). By discussing the creation of a CAB in the context of the harm reduction movement within a novel randomized control trial, we aim to foster cross-sector collaboration to understand barriers to harm reduction services and collect data aligned with the cultural nuances of Black and Latine people who use drugs.

Harm reduction for substance use was developed to address the holistic needs of Black and Latine people who use drugs (PWUD), sex workers, and transgender and gender non-conforming people. This framing responded to the perceived and real shortcomings of mainstream medical institutions in delivering inadequate substance use treatment to a critical mass of REM communities [8–10]. Harm reduction is a practical approach to health equity rooted in respect for autonomy and optimization of safety: for example, wearing condoms to minimize the risk of sexually transmitted infections. Also, harm reduction is a social justice movement striving to eliminate the inequities that perpetuate disparate health outcomes among PWUD [11]. When applied to PWUD and people with substance use disorders, harm reduction acknowledges that many human beings use drugs for a host of reasons which should not be judged or vilified, centering an approach that non-coercively offers tools to minimize the negative outcomes of certain risky behaviors without necessitating abstinence [12].

The harm reduction movement is rooted in pioneering efforts of Black- and Latine-led groups like the Black Panther Party and the Young Lords [9, 10]. In 1970, they overtook part of Lincoln Hospital in the Bronx, NY to demand better care for low-income REM patients. The Young Lords, the Black Panther Party, and other revolutionaries collectively established a community-led substance use treatment program in Lincoln Hospital ("Lincoln Detox"), where they utilized integrative treatments like the standardized National Acupuncture Detoxification Association (NADA) ear acupuncture protocol alongside political education to complement detoxification [9, 10]. Although harm reduction initially emerged from Black and Latine/community-led grassroots movements, in recent years, its principles regarding substance use have gained greater acceptance among mainstream White America and have become institutionalized within broader public health and legal systems (for example, syringe exchange programs funded by public health departments).

This institutionalization coupled with the lack of full partnership with PWUD from REM communities evokes skepticism among some tied to the harm reduction movement's revolutionary origins [13]. In part, there lies concern whether such institutions can adequately help people from historically excluded backgrounds, and whether they may inadvertently perpetuate systemic racism inherent in institutions [14–16]. To this end, the randomized controlled trial (RCT) entitled "Project UNITE (UNdoing harm and InTEgrating Services)" represents a pivotal shift towards centering the voices and experiences of Black and Latine communities in harm reduction. By partnering with two existing grassroots harm reduction groups founded and led by Black and Latine people serving PWUD from REM backgrounds, Project UNITE aims

to develop and study a culturally responsive integrated harm reduction intervention.

St. Ann's Corner for Harm Reduction (SACHR) of the South Bronx, NY and Sex Workers and Allies Network (SWAN) of New Haven, CT have REM individuals in key leadership roles and were selected as community partners in the study, given the need to partner with more REM people in the harm reduction environment who are familiar with the cultural nuances of Black and Latine people. Since both organizations have extensive knowledge of their communities and strategies for serving PWUDs, they provide essential insight during Project UNITE team meetings that help drive the creation of study materials, recruitment strategy, and intervention delivery. They also will be active partners in recruitment, most notably through conversations with community members and flyer distribution via their mobile outreach vans. Of note, they embody harm reduction principles and provide the basic harm reduction services, which are the cornerstone of each treatment arm in the study.

These sites were chosen because the majority-Black and Latine neighborhoods in the Bronx had among the highest rates of opioid overdose mortality in the US from 2018 to 2021 [5]. Similarly, New Haven mirrors the Bronx's challenges with escalating overdose deaths disproportionately affecting Black and Latine people [17]. New Haven, CT and the South Bronx, NY reflect both the urgent need for better substance use treatment approaches and the benefits of partnering with community members to navigate complex local dynamics in research, as historical inequities in social determinants of health influence substance use in these communities. For example, gentrification in the South Bronx, home to the US' poorest congressional district, continues to reshape the social fabric as it impacts the Black and Latine communities (particularly the historically rooted Puerto Rican population), driving evictions, displacement, unemployment, and over-policing [18, 19]. These changes affect local drug markets, usage patterns, and overdose incidents, and often constrain vital harm reduction efforts [20, 21]. Similarly, New Haven's history is marked by one of the highest degrees of income inequality in the U.S., disproportionately impacting Black and Latine communities and contributing to health disparities, including those tied to drug-related infectious diseases [22–24]. The escalating overdose rates in both areas underscore the importance of addressing drug related deaths in these historically excluded populations.

Project UNITE seeks to assess harm reduction initiation and engagement among Black and Latine PWUD by testing a novel, culturally responsive integrated harm reduction intervention (IHRI) in comparison to services as usual (SAU) at Black- and Latine-led harm reduction organizations. The SAU arm encompasses free syringe exchange and distribution of clean paraphernalia, naloxone, and fentanyl test strips. The IHRI arm is comprised of four weekly educational videos (safer substance use strategies, legal rights of PWUD, coping with stigma against PWUD, and coping with racism) and linkage to mental, legal and housing services, in addition to all SAU services. The RCT compares harm reduction service initiation and engagement over 8 weeks, with follow-ups at 3, 6 and 12 months, to assess changes in substance use and overdose rates as well as mental health and quality of life outcomes.

To honor Harm Reduction's origins as a philosophy developed by and for marginalized populations, Project UNITE utilizes a Community-Based Participatory Research (CBPR) approach, which involves partnering with community members and leveraging their experiential expertise as advisors positioned outside academia to shape all phases of a research endeavor [25]. CBPR attempts to minimize harm caused by study design that does not account for community perspectives; this is crucial to ensuring equitable and effective research on stigmatized topics like substance use since people of diverse races, genders, classes, and other identities interact with harm reduction services differently [26, 27].

The several participatory conversations held at the project's inception were vital to ensuring that the research questions, study design, and health outcomes measured in the trial aligned with the unique needs of Black and Latine PWUD. These conversations were conducted with key stakeholders, including our partnered community harm reduction organizations. After receiving grant funding, we established a Community Advisory Board (CAB) that is central to many CBPR projects. In CBPR, CABs have shown benefit in improving the quality of research studies involving marginalized individuals, such as increased willingness to participate in trials, subject protection measures, and linkage of members to community resources. However, multiple barriers to CAB establishment may contribute to their apparent underutilization in research [28–31]. By establishing a CAB within a CBPR model of Black and Latine community leaders, stakeholders, and researchers, we seek to promote equity in our own research and create a framework for others. Given the noted benefit of having community partners involved in research, more scientists are encouraging community engagement as a tool towards health equity [32].

Our study's 8-member CAB was thoughtfully composed to include two balanced groups of key stakeholders with varied perspectives representing both study locations: the Bronx, NY and New Haven, CT. The CAB included two PWUD who are not currently engaged with our partnered harm reduction organizations, two directors of community harm reduction organizations, two

community members, and two mental healthcare providers. In reality, the CAB members transcended these neatly defined roles. For example, at a CAB meeting one individual filling the "community member" role shared their experience selling drugs, surviving attempted homicide and multiple incarcerations, and becoming an activist. Another "person with lived experience using drugs" who identifies as Black, trans, and disabled described their past selling drugs, current leadership in harm reduction organizations, and ambitions of becoming a psychologist. Further, one "director of a community harm reduction organization" had over 25 years in recovery. These intersectional identities reflect the multifaceted perspectives a diverse CAB can contribute to enrich CBPR. Moreover, through the establishment of our CAB, we laid the groundwork for an approach to harm reduction research that prioritizes equity. This approach places community voices and experiences at its core and recognizes them as essential elements in shaping culturally sensitive interventions that respond effectively to the diverse needs of Black and Latine communities.

Establishing a community advisory board (CAB)

The process of establishing a CAB was initiated by our study coordinator, who led recruitment efforts, seeking individuals deeply committed to and actively involved in their community. The initial selection of CAB members utilized our research team members' direct involvement in the Bronx and New Haven. For example, our principal investigator sought permission from community members to join a community management team meeting in a predominantly Black New Haven neighborhood to discuss drug use and overdose risk. They highlighted the importance of community involvement and invited community members to join the CAB. This prompted some CAB members to join, and others were identified secondhand through these active community members.

Initial attempts at recruitment via email received few responses. After consulting with team members, we updated the script to highlight our study's departure from conventional research approaches and emphasized our commitment to centering the voices of marginalized communities, addressing valid skepticism within these communities toward researchers. Subsequently, several CAB members joined our team through this refined approach. Because we sought "research-naïve" community members, we extended our efforts beyond personal connections and continued recruitment through online searches (Google and LinkedIn) with keywords like "Black," "Latino," "social work," "therapist," "Brown," "South Bronx," and "New York City" guiding our search. We also expanded the criteria for mental healthcare providers to include those without a focus in substance use disorder treatment. Furthermore, we contacted grassroots organizations and social work coalitions for recommendations.

To minimize bias, individuals affiliated to the partnered community harm reduction organizations were excluded from CAB membership. Since certain community partners were directly involved in strategic planning, intervention delivery, and participant engagement, we believed that their presence on the CAB could compromise its mission. As part of the CBPR model, the CAB serves as a space for community leaders and stakeholders to provide informed and authentic guidance for the study, which then is relayed back to the larger research team. Therefore, even though some community partners (e.g., local legal organizations) were initially consulted for study design, they were excluded from serving on the CAB to reduce the likelihood of bias given their role in the study. While we value the insight and wisdom of these organizations in shaping the study to ensure it would be carried out in a way that benefits Black and Latine PWUD, the CAB serves as a separate entity to engender non-biased input on the research study.

We began our search for CAB members in March 2023, and it took about four months to form our CAB. It took an additional two months to find a mental health provider in NY. Our first meeting was conducted on July 18th, 2024, and the CAB has met regularly ever since. For the initial meeting, we held a live, remote orientation. Following an icebreaker introductory activity, the presentation highlighted CBPR's value, how the CAB would function, an overview of the current overdose epidemic, basic clinical research concepts, study design, and future expectations. CAB members participated in lively discussion throughout, asking clarifying questions and expressing enthusiasm. The orientation emphasized clarity of communication around research methodology and terminology, as prior CABs have requested greater background education to feel confident in their roles [33]. We lacked sufficient time prior to trial launch to offer CAB members comprehensive research ethics training–a challenge other CABs have grappled with in recognizing the limited utility of CITI Program trainings for lay people [34]. To address this, we explicitly discussed the minimal risk of harm in the control group (harm reduction Services As Usual) and fostered dialogue around the experiences of participants randomized to either condition in the study.

To respect the expertise of CAB members' engagement, we already compensate CAB members for their time through the fastest, least bureaucratically burdensome mechanism available to us. We will reimburse for travel expenses upon eventual transition to in-person meetings at our partnered community harm reduction organizations and provide food at future in-person meetings; we currently offer support with internet access for virtual

meetings. Initially, we excluded research staff from CAB meetings in the aim of promoting the CAB's autonomy, candid discussion, and critical feedback. To help facilitate discussion and time management during meetings, the study coordinator was included in CAB meetings as a liaison between the CAB and the larger research team. Unlike other CABs, this CAB deliberately lacks specific roles for individual members to avoid replicating power structures, since some CAB members already carried multiple marginalized identities. Instead, the CAB collectively established its own rules and expectations.

The community advisory board (CAB)'s impact on research

The CAB was tasked with reviewing the educational materials created for the study–encompassing providing feedback on the overall concepts (safer substance use strategies, legal rights of PWUD, coping with stigma against PWUD, and coping with racism), the proposed scripts for the educational materials, and the modules themselves. Additionally, the CAB provided valuable insights into our recruitment strategies, suggesting partnerships with specific local community organizations and emphasizing the importance of developing recognition within the community. They also stressed engaging in honest dialogue with community members, leveraging social media for outreach, and including disabled and transgender/gender non-conforming individuals in our recruitment efforts. One CAB member proposed assigning action items and forgoing the upcoming CAB meeting, which would encompass each CAB member discussing the project with 2–3 other people to directly connect them with our research staff. The CAB members themselves also highlighted that what stood out to them about Project UNITE is its origin and focus as a project that came *from* Black and Latine People, is run *by* mostly Black and Latine People, and is *for* Black and Latine People. They indicated that this could be an important aspect to leverage in our recruitment efforts. Also, the CAB is well suited to advise on the grounding of data analysis and writing in community and cultural context. Through these efforts, CABs can promote ethical and equitable research by allowing community members to gatekeep potentially harmful yet inadvertent interactions from reaching study participants or damaging relationships between institutions [27].

Establishing autonomy within the CAB allowed for liberated discussion. For example, one individual praised the inclusion of community voices in developing study materials: "I've seen the harm reduction movement grow from the HIV movement… so to now advocate for this work being done by people of color, and people of color having a voice in service implementation, or at the very least being considered subject matter experts, is huge." CAB members critiqued language in the educational scripts that "sounded written by a doctor," advocating for straightforward, conversational rephrasing. Additionally, several CAB members recommended changing the educational modules' delivery format, emphasizing that illustrations should be added to the pre-recorded videos to maintain participants' engagement. We further responded by hiring a video editor and incorporating CAB recommendations through multiple rounds of edits. Specific feedback also ranged from eliminating unnecessary jargon and imprecise phrasing around drug categories to debating the language used to describe various harm reduction strategies.

CAB members' diverse life experiences and dialogue facilitated the research team's ultimate approach to sharing specific harm reduction recommendations. For instance, one CAB member with experience working in mental healthcare cautioned against recommending that study participants ask a friend to check on them and confirm they have not overdosed, expressing concerns about potential traumatization and unanticipated harms associated with exposure to the medical/addiction treatment system via a friend unfamiliar with the study participant's wishes. Two CAB members with lived experience using drugs disagreed, emphasizing that while prioritizing trusted individuals would be key, this recommendation should not be overly tempered since the alternative may be death. Subsequently, our research team amended the educational module to account for both perspectives and included a hotline for a volunteer organization that PWUD can contact prior to use, asking for a return call in a designated amount of time. If the PWUD does not respond, the volunteer agency contacts local emergency personnel stating the location of person found "unresponsive," an accurate and nonjudgmental descriptor intended to bring a rapid medical rather than a police response.

Challenges and adaptations of the community advisory board (CAB)

Based on the CAB's experience so far, we now recognize three major areas for improvement: optimizing recruitment channels, minimizing institutional burden on CAB members, and enhancing communication strategies with CAB members. As several CAB members contributed directly to the authorship of this article, these lessons reflect perspectives shared by the research team and community members alike and may generalize to other CBPR projects working with marginalized groups.

Challenges to recruitment: Several issues slowed CAB recruitment, most prominently nonresponse from potential members. A higher success rate (3/3) emerged for CAB members who were introduced to the research team in-person at community meetings or through personal contacts compared to those who were cold

contacted (5/15). We speculated that skepticism toward researchers may have played a role despite our efforts to assuage these concerns. Further, many individuals failed to continue responding after initially expressing interest, suggesting that email may be a suboptimal platform for CAB recruitment. Several members expressed their appreciation for meeting reminders and flexibility in the communication style to fit their needs such as sending text messages and voicemails instead of emails. Lastly, several prospective mental health providers of color cited insufficient free time limiting their participation; others who expressed interest did not share our values toward harm reduction, which we felt would have unnecessarily hindered the CAB's functioning.

Minimizing institutional burden: Anticipating slow payments and a burdensome hiring process through our research institution, we acted preemptively to minimize burden on CAB members. CAB members in general [35] and PWUD who are involved in research often express frustration with slow payments from research institutions. Unfortunately, the process of paying CAB members through our academic institution was not intended for involving community members: CAB members would be required to apply as consultants and carry independent insurance, which raised unnecessary practical and financial barriers. To remedy this, we identified an alternative payment mechanism through a state-funded, affiliated institution, which has a history of recognizing community members as experts and thus uses a comparatively streamlined hiring process. Additionally, research staff helped navigate CAB members through the hiring process, including by drafting resumes for CAB members to use independently. Furthermore, we struggled at times to maintain contact with and momentum within the CAB. Identifying an ideal meeting time for all CAB members often proved difficult. We decided on an alternative process for those who may miss meetings by asking members directly for their thoughts. Most CAB members preferred arranging another meeting to share their thoughts, and one suggested providing feedback over email. Since CAB members varied in their responsiveness to emails, iteratively adapting to individuals' preferred modes of communication–as well as message content–proved essential to engagement.

Also, we anticipated the possibility of imbalanced discourse among CAB members of different social statuses due to prior reports from study collaborators. To mitigate this, during the orientation we established that while the CAB would set its own "rules of engagement," it may consider adopting practices that other CABs have found beneficial in the past, including using respectful and non-stigmatizing language, assuming good intentions from others, remaining conscientious of others' intersectional identities, and following democratic meeting rules.

Conclusions

Black and Latine populations face disproportionately escalating rates of death due to opioid-involved overdoses, particularly in the Bronx, NY and New Haven, CT. In addressing these disparities, our RCT has forged critical partnerships with Black and Latine-led harm reduction organizations in both areas. Utilizing a CBPR approach alongside the establishment of a CAB, we have actively sought to minimize any harm caused by a study design that does not sufficiently account for community perspectives. This collaborative effort has required flexibility and creativity, including refining our CAB member recruitment methods, addressing valid skepticism toward researchers, and streamlining cumbersome onboarding and payment processes. Through such means, we prioritized the inclusion of voices historically excluded in the research process and laid the groundwork for more equitable and inclusive research.

By establishing a diverse, representative, largely autonomous CAB, our RCT flourished. Together we refined research strategies and minimized barriers to connection with the communities we sought to serve, facilitating a more methodologically sound and socially responsible research process. Establishing meaningful partnership with community stakeholders in all stages of research on marginalized populations–especially Black, Latine, and Indigenous people who use drugs–is an ethical imperative in harm reduction and beyond. Researchers studying substance use treatment and harm reduction should prioritize community-based participatory frameworks in developing and executing studies to ensure equitable and ethical research practices.

Abbreviations

REM	Racial and Ethnic Minoritized
PWUD	People who Use Drugs
RCT	Randomized Controlled Trial
SAU	Services As Usual
IHRI	Integrated Harm Reduction Intervention
CBPR	Community-Based Participatory Research
CAB	Community Advisory Board

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Author contributions

SK wrote most of the text and contributed significantly to the literature review. HH led the recruitment of the Community Advisory Board (CAB) central to the manuscript and was a major contributor to writing and literature review. AIJe assisted with manuscript writing and revision and organized reference materials. KB, PC, NF, SEL, AM, and SR guided the manuscript through feedback and revisions to the text. AyJo significantly contributed to the text and leads the study in which the Community Advisory Board functions. All authors read and approved the final manuscript.

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Author details
[1]NYU Grossman School of Medicine, New York City, USA
[2]The ZOLA Experience, New Haven, USA
[3]NEXT Distro, New York City, USA
[4]NIH HEAL Initiative Community Partner Committee, Bethesda, USA
[5]NewFlex Youth Programs, Mount Vernon, USA
[6]Democracy Now!, New York City, USA
[7]The Liberated Self Therapeutic Services, LLC, New York City, USA
[8]Connecticut Against Gun Violence, New Fairfield, USA

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