

Using an Equity in Research Framework to Develop a Community-Engaged Intervention to Improve Preexposure Uptake Among Black Women Living in the United States South

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Abstract

In the U.S. South, over half of new HIV diagnoses occur among Black Americans with research lagging for women who face increased HIV rates and low PrEP uptake, among other health inequities. Community engaged research is a promising method for reversing these trends with established best practices for building infrastructure, implementing research, and translating evidence-based interventions into clinical and community settings. Using the 5Ws of Racial Equity in Research Framework (5Ws) as a racial equity lens, the following paper models a review of a salon-based intervention to improve PrEP awareness and uptake among Black women that was co-developed with beauty salons, stylists, and Black women through an established community advisory council. In this paper we demonstrate how the 5Ws framework was applied to review processes, practices, and outcomes from a community-engaged research approach. The benefits of and challenges to successful collaboration are discussed with insights for future research and community impact.

Key words: 5Ws of Racial Equity in Research framework, Black women, community advisory council, implementation science method, sexual health and HIV

The National HIV/AIDS Strategy to end the HIV epidemic (EHE) by 2030 designates Black women as one of the five priority populations disproportionately affected by HIV and calls for HIV prevention efforts to focus on populations and parts of the country carrying the most burden of disease (The White House, 2021), but Black women have not been prioritized in HIV prevention research. Given the inequities in access to care, delivery, HIV outcomes, and biomedical prevention tools, such as pre-exposure prophylaxis (PrEP), there is an exigent need to thoughtfully partner with Black women in the research process if eliminating HIV among this population is to be achieved (Boyd et al., 2023). One strategic way to accomplish this is through community engagement and partnership where women are meaningfully included in the research process, from development to dissemination.

Background

Community Engaged Research

Efforts to encourage and engage Black women in research has been met with significant barriers, including

historical abuses of US Black women by researchers and clinicians that have prevented trust in the research process and health care system (Washington, 2006). Barriers to research participation include limited knowledge about research opportunities, transportation, or childcare for potential participants (Bowleg et al., 2022; Luebbert & Perez, 2016; Randolph et al., 2020). Furthermore, myths and stigma about HIV can further decrease Black women's comfort in participating in HIV-related research efforts (Greenwood et al., 2022; Overstreet & Cheeseborough, 2020). These barriers are compounded by Black women not being prioritized in HIV prevention research and overlooked as high-priority participants in clinical trials of PrEP.

Community engagement is an effective strategy to improve trust and trustworthiness of research to increase participation and begin to reverse the large gap in scientific knowledge about Black populations (Abadie et al., 2018; Cook et al., 2018; Kwizera et al., 2020). Community engagement research can achieve this goal through the core principles of building trusting relationships, creating beneficial partnerships, improving communication, and helping to mobilize the community to advocate for and participate in solving their health concerns (DeShields et al., 2020). In this way, the community is centered, and research revolves around the desires of the community, potentially having a greater effect on improving health inequities and participating in material and system change (Agurs-Collins et al., 2019; Alvidrez

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et al., 2019; Berry et al., 2023), which moves research from recording Black women's voices to informing intervention development, delivery, and content preferences through participation (Bond et al., 2021).

Community Advisory Councils

Community advisory councils (CAC) are critical infrastructure and mechanisms for community engagement research (DeShields et al., 2020; Halladay et al., 2017; Quinn, 2004). CACs typically consist of representative community members and stakeholders who communicate the community's needs, advise researchers on the intervention's potential success, and participate in intervention design and development (Weinstein et al., 2023). Hallmark signs of an effective CAC are shared power and decision making, reciprocity, and shared ownership of the research process and product (Dickson et al., 2020; Halladay et al., 2017), which can produce a greater effect through community growth, social justice gains, and policy change (Israel et al., 2010; Silvestre et al., 2010), especially for communities facing stigma or discrimination (e.g., racial and ethnic minorities, patients living with HIV; Isler et al., 2015; Pinto et al., 2011; Robillard et al., 2020). To date, research on long-running, effective research-CAC partnerships have focused on HIV prevention with male populations (Rhodes et al., 2018; Silvestre et al., 2010). Although there is emerging research with women (DeShields et al., 2020; Robillard et al., 2020), overcoming the deficit of research and barriers for Black women will take more resources. Engaging in participatory research models and methods can help narrow the gap in research by building partnerships and maximizing existing community resources, what Ferré et al. (2010) call community-partnered research. Although resource and time intensive, this community-partnered research approach yields an understanding of lived experience, cultural and social relevance, shared values and preferences, which are significantly important factors when developing real-world interventions for Black women to overcome persistent health inequities and EHE (Bowleg et al., 2022; Centers for Disease Control and Prevention, 2023).

The purpose of this article is to present and model an effective community-partnered research process with Black women using the 5Ws of Racial Equity in Research framework (Who, What, When, Where, and Why; 5Ws; Bentley-Edwards et al., 2022) to evaluate organizing and engagement between research and community partners. We demonstrate how the 5Ws framework can function as a reflexivity-based method for researchers to continuously question equitable participation with CAC

members to produce an effective, culturally relevant HIV prevention intervention with Black women. This type of equitable CAC engagement is employed with the goal of improving power and privilege dynamics, trust, and sustainability of HIV prevention interventions and programs with and for Black women.

Methods

Research Collaboration

The Health disparities through Engagement, Equity, Advocacy and Trust (HEEAT) Research Lab is an interdisciplinary team of researchers and clinicians partnering with business owners and community members on a CAC toward effective community-engaged research. The HEEAT Research Lab and community partners are driven by a core commitment to social justice, community partnerships, meaningful and impactful work, and culturally and socially relevant programs. Engaging with the community throughout the research process from recruitment planning to data collection and analysis to dissemination of research findings back to the community, the HEEAT Research Lab aims to advance equity through innovative, nurse-led models of health care delivery. To address the consistent inequity of PrEP uptake among Black women, the HEEAT Research Lab codeveloped an e-Health intervention, called Using PrEP Doing it for Ourselves Protective Styles (UPDOs), with an established CAC. The community partners assisted the HEEAT lab in considering the unique needs and lived experiences of Black women within the context of social determinants of health and broader culture to improve knowledge and uptake of PrEP among Black cisgender women (Randolph et al., 2022).

Project and Setting

Using PrEP Doing it for Ourselves Protective Styles consist of three components, including beauty salons and stylists as opinion leaders, evidence-based and theory-driven edutainment videos, and the use of a PrEP Navigator to share PrEP information and resources with women (Johnson et al., 2023; Randolph et al., 2022). UPDOs was developed to improve knowledge, awareness, and uptake of PrEP and mitigate PrEP stigma and mistrust among Black women living in the US South (Randolph et al., 2022). A study of the stylists' ($n = 19$) participation in health opinion leader training and the UPDOs intervention provided a baseline understanding of the stylist sample and feedback on intervention implementation. Posttraining, stylists scored high on HIV and PrEP knowledge and commitment to health

advocacy in their community, and they provided qualitative feedback that the training included quality content and instructional methods that facilitated learning and information retention (Johnson et al., 2023). A pilot mixed method study was conducted with Black women ($n = 44$) recruited through beauty salons that were within three urban North Carolina counties. UPDOs was found to be effective in improving knowledge for women who were aware and unaware of PrEP and reducing stigma and medical mistrust (Randolph et al., 2023).

Partnership Equity Analysis

The 5Ws of Racial Equity in Research framework (5Ws) was used as a lens for retrospectively evaluating the research team leaders' (S.R. and R.J.) experiences with CAC collaboration on and project outcomes from UPDOs. This analysis used the 5Ws to question racial equity across the research process, from design to implementation to dissemination. This analysis method is based in deliberate reflection toward "understanding processes, circumstance, and intent" through questioning of 5Ws (Bentley-Edwards et al., 2022, p. 918). It is designed to improve reasoning, learning, and problem solving from the practice of deep reflection on and questioning of the lived experience, similar to techniques gained in health professions' diagnostic and clinical training (Mamede & Schmidt, 2023). This method is a reflexivity strategy for constructing knowledge in qualitative research (Peddle, 2022) that focuses on critical self-reflection of oneself and the research process (Narayanasamy, 2015) and increases the rigor of qualitative research (Bradbury-Jones, 2007).

The 5Ws are categories representing lists of questions that structure and organize reflection, open discussion, and proactive planning (Bentley-Edwards et al., 2022). "Who" thoroughly examines inclusion and exclusion of "all parties involved in research from conception to dissemination" (p. 918). "What" interrogates "the circumstances and extent of research activities" (p. 919). "When" speaks to time and waiting or "whose time is prioritized" because time equity and autonomy are intimately connected to cost or money, acknowledgement, determination of scientific contribution, workload, and expectations (p. 918). "Where" questions the nature of and decision making around locations as sources of equitable access and participation. As a result, "Where" probes beyond the surface to questions of the practical and symbolic. Finally, "Why" investigates intentionality through questions of methodological design, implementation, and data analysis. The intersection of

questions and responses across categories are expected (Figure 1).

The 5Ws and Using Preexposure Prophylaxis Doing it for Ourselves Protective Styles Results

Who Benefits and Decides

"Who" in the 5Ws framework asks researchers to reflect on who benefits from the research process and outcomes, who makes decisions, who are experts, and who is harmed or excluded. To answer the question of who benefits from this research process, the research team knew that Black women, other women in their social networks, men in women's lives, providers, the health care system, and the community would potentially benefit from this research. Benefits would include, but were not limited to, the increased knowledge and awareness that women would gain and the improved uptake that could have a widespread community impact in sexual health outcomes. To this end, an established CAC was included from formative data collection to inform UPDOs content, layout, and design through dissemination of pilot study findings (Bongiorno, 2015; Brizay et al., 2015). The CAC is composed of 11 community members from various backgrounds, including gender, age, education, work/career, income, and lived experiences. Six of the 11 members work in the beauty industry (2 barbers and four stylists) and combined have more than 120 years of experience. The other members include a health care provider, a social worker, a non-profit CEO, and two entrepreneurs/business owners. Given who would benefit from this research in the end, it was important to have representation and acknowledgement of these voices as experts at the table in shared decision making. CAC members met quarterly and more frequently during development and data collection, providing perspectives on intervention content, layout, and design and helping researchers understand what would translate into real-world settings and increase acceptability and sustainability. The research team also recognized the value and expertise of beauty salon stylists in trusted spaces where conversations around relationships and sex occur naturally. Two beauty salon owners and stylists were compensated as consultants on formative and pilot funded research. Consultants met with the research team a total of 8 hours annually for the 2-year funded pilot grant. The scope of work for consultants included a review of data collection tools and methods, strategies for engagement, liaison between research mission and the community, codevelopment of dissemination plan of research back to the community,

5Ws of Racial Equity in Research Framework.



Figure 1 5Ws of racial equity in research framework. Reprinted from Bentley-Edwards, K. L., Jordan Fleming, P., Doherty, I. A., Whicker, D. R., Mervin-Blake, S., & Barrett, N. J. (2022). The 5Ws of racial equity in research: A framework for applying a racial equity lens throughout the research process. *Health Equity*, 6(1), 917-921. <https://doi.org/10.1089/eq.2022.0042>. 5Ws = Who, What, When, Where, and Why.

and strategies for engaging women in trustworthy research. These examples speak to the benefit of partnered research and having a shared vision. This is critical when addressing inequities in communities of color. Trustworthiness, sustainability, and economic development were all key elements of this partnership that are critical to eliminating health disparities in the Black community.

Relevant Research

The “Why” of the 5Ws framework inquires about the relevance of the research, why this group is of interest, why someone would be involved in the work, and why the approach is used. Addressing women’s health issues in beauty salons has a long history of effectiveness, especially in the Black community, for prevention of cancer, HIV, and obesity (Palmer et al., 2021; Sadler et al., 2011; Wilson et al., 2008). The role of beauty salons in reaching Black women can have a community widespread influence due to the strong social networks that exist in the beauty salon setting (Randolph et al., 2021). Thus, our UPDOs project partnered with beauty salons throughout the state of North Carolina to improve awareness and uptake of PrEP. The role of our beauty salon partners was substantial. For example, during formative data collection from stylists in six focus groups (Randolph et al., 2021), one of the beauty salon consultants recommended that the team offer continuing education units (CEUs) to the stylists for

their participation in the focus group. CEUs are required every 3 years for stylists by the State Board of Cosmetology. Stylists viewed focus group discussions as a training, workshop, and informational session that they all found valuable in their roles as stylists and to the community. As a certified educator with the Board of Cosmetology, our beauty salon stylists and consultant partnered with the research team to implement a new directive that all stylist participants residing in North Carolina would receive CEUs and a certificate of completion. For stylists and salons engaged in this project, this was of value to them and allowed them to see the relevance of their participation. Furthermore, this approach contributed to the sustainability of the training beyond grant funding for this project. The research team and salon partner have developed online modules and continue to offer the training twice per year. In addition, the research team has developed a toolkit for others who are interested in replicating or expanding this work and partnering with beauty salons for health promotion. It is important for researchers to consider alternative and complementary incentives to traditional ones.

Overlooked Costs

The conversation of “when” in the 5Ws framework asks researchers to value equity in considering the commodity of time for research activities. Participants, including

CAC members, from marginalized or disadvantaged communities may be hourly workers or entrepreneurs who will not get paid while participating in research that occurs during normal business hours. Researchers must consider schedules, such as when research activities are held, how long they are held, and how to prevent and/or maximize waiting times. In addition to financial compensation for research participants, *when* we give credit to community partners and CAC members is also important to ensuring equity.

The HEAT Lab built time equity into every aspect of the research plan. The CAC meets quarterly with more frequent meetings during intervention development (every 2 weeks to monthly). Because most CAC members are entrepreneurs in the beauty industry with operating hours Tuesday through Saturday, meeting dates were primarily on Mondays to not interrupt usual business activities. The research team had its specific goals of data collection to inform interventions and examine research questions. However, the research process has its own time constraints, limitations that do not always align with community priorities and timelines, and this was discussed. CAC members provided information on best times for research activities to occur. For instance, women consenting to pilot UPDOs were engaged while in the salon and could view the edutainment videos while already waiting on a salon service. This allowed little to no competition with time.

While there were times that our CAC partners were frustrated with administrative delays, we were intentional about furthering the overarching mission to address inequities in the Black community and to sustain relationships. As a result, the HEAT Research Lab supported and partnered with members of the CAC in multiple ways. For example, they contributed to back-to-school events providing school supplies, supporting the writing of grants for CAC members' nonprofits, collecting diapers and other supplies for single parents in underserved communities, and performing educational outreach during the COVID-19 pandemic.

Finally, each CAC member is financially compensated for each meeting, and a meal is usually served. For funded projects, beauty industry partners are paid consultants and receive an honorarium for their time and expertise in meeting project aims. Participants also receive financial compensation. In addition, we were intentional about ensuring that shared credit was given to our CAC and community partners by adding them to presentations and other disseminations of findings either as coauthor or in the acknowledgements section. More about this recognition process is discussed in the “*where*” section.

Prioritizing Values, Resources, and Access

The “*what*” in research asks the questions of what values, resources, and access are prioritized and how do researchers' budgets reflect these questions in equitable ways. The *What* refers to “the circumstances and extent of research activities.” The HEAT Research Lab follows its core values of social justice, building and maintaining community partnerships, generating meaningful and impactful work, and engaging in research that is culturally and socially relevant. During UPDOs planning, the CAC reiterated the lack of representation of Black women in PrEP marketing. The CAC and research team strategy was to be intentional about representation. This included contracting a Black woman owned media firm to develop modules and visuals for the intervention. Equity in community research includes a focus on how resources are allocated and to whom.

Federal research budgets are often not aligned with relevant community engagement needs. For example, the need to gather community members to inform them of research priorities and participation often requires social activities, such as serving brunch or having a luncheon. Although it may seem simple, engaging people in this way is impactful to trustworthiness of the research process; however, federal funding does not support the purchase of food items or other event planning activities. Support for community engagement is often lacking. The HEAT Research Lab has recognized the value of community and prioritized such gatherings as strategies to inform the community of health problems, research being conducted to address those problems, how they can participate in the research, and dissemination of the research findings. Through other funding mechanisms, such as Principal Investigator discretionary funds, the HEAT Research Lab has been able to support these activities. However, many public institutions and historically minoritized institutions do not have the resources available for researchers to spend at their discretion to support community engagement. Additional support of community engagement includes transportation, childcare, and non-academic settings for meetings and community activities.

Power of Local Connection

Historical abuses in the Black community have thwarted trust and trustworthiness of research, which often prevents or decreases engagement of participants from the community of interest. Engaging Black owned and operated businesses that serve a predominantly Black customer population can offer locations and leaders to build, connect with, and maintain community through shared values and missions. Thus, Black owned and

operated businesses, such as beauty salons, are important economic and community anchors for accessing and working with community during research (Koh et al., 2020) and may be preferable to clinical settings (Bentley-Edwards et al., 2022).

Other important questions to consider are where does the power sit, where are the resources shared, and where are findings shared? The core values of mutual respect, trust, colearning, transparency, and true partnership were consistently prioritized. For example, early in the COVID-19 pandemic, beauty industry partners needed support and guidance for returning to work. The research team and beauty industry partners delivered a series of virtual presentations, called Community Conversations, to more than 50 barbers and stylists in North Carolina, Georgia, and Tennessee. Other examples include educational outreach, such as health fairs, information sharing in trusted spaces, and collaborating with council members on activities that aligned with the HEAT mission.

In addition to shared power, sharing resources is also valuable to a long-lasting partnership. For instance, the HEAT Research Lab reciprocates with their community partners in providing grant writing assistance, offering educational community outreach, and no cost registration to a workshop on understanding structural racism. The workshop is mutually beneficial because it increases understanding of one of the core tenets to the work we are trying to accomplish in the community.

In addition, the CAC requested the research team share results in a timely and engaging manner with the community. Therefore, it is necessary to be intentional about where you share research findings and with whom. For the UPDOs project, the research team developed a short 1- to 2-minute results video within 3 months of the intervention ending to be shared with the community. One CAC member/stylist also recommended a regional beauty industry magazine to assist with disseminating research and community partnership information and results. This magazine highlights Black beauty industry professionals and business owners in the community. To date, we have completed two articles with the Huami magazine that highlight the research, the findings, and the community partners' businesses and community efforts. Having clear and concise expectations about engagement in research is critical to successful, mutually beneficial partnerships.

Discussion

This article discussed experiences and strategies for engaging partners when advancing a health equity lens on

the community engaged research process. The key to transitioning from community-engaged research to community-partnered research is to identify and acknowledge existing assets within the community and value that the members of these communities are experts of their own experiences who can work with academic researchers and inform our science by helping us ask the right kinds of questions, use the most appropriate methods, and thus improve research translation (Wallerstein & Duran, 2010). The 5Ws framework offers a simple structure and flexibility for deep inquiry into the intersectionality between community, partnerships, research, and resources through a racial equity lens. The methodological potential for this 5Ws framework is powerful for accessing the perspectives of all stakeholders; interrogating the design and impact of systems; negotiating collective plans and actions; designing impactful research and interventions; speeding up translation of effective research to practice; and improving health inequities. This article presents a retrospective review of UPDOs using the 5Ws, but it is equally effective, if not more important, to use this type of structured thorough examination of race equity throughout the research process and across projects to promote equity across a broader research agenda. The 5Ws is also adaptable to all types of mixed method data collection and analysis to operationalize the 5Ws framework and provide the insights necessary to plan, implement, and share impactful community-based health research. As a result, the 5Ws framework can be an effective tool in community-engaged HIV research with Black cisgender women and youth in the US South and contributing to emerging community-engaged research in the study of dissemination and implementation science (Khazanie et al., 2022; Ramanadhan et al., 2022; Schlechter et al., 2021).

When choosing a CAC, it is important to select individuals and organizations trusted by the community, those with stakes in their community and who have demonstrated a commitment to building and developing their community. This article shared the HEAT Research Lab's experiences engaging a CAC that offered a diverse level of thinking that improved the lab's ability to connect with the community and the design and implementation of our health interventions. Trust and transparency were highlighted as a clear method for engaging communities of color. Fostering community-partner relationships requires listening to and following through with recommendations community members offer because they know their communities well and understand the priorities of their communities. This proved valuable to the development and

implementation of the projects. This was accomplished through successful community-partnered research that used strong nursing–business partnerships that provide a model for future HIV and PrEP research with Black women and youth.

Implications

Community-engaged research is effective in designing and implementing HIV prevention interventions. Employing CAC best practices can improve research processes, practices, and outcomes while encouraging participation with community stakeholders and members not commonly represented, such as beauty industry businesses and professionals. Knowing and practicing best practices require different skills and actions to build strong and effective community partnerships. Using the 5Ws framework or similar methods for deep reflection on engagement actions throughout the research process can help to review and maintain a racial equity lens throughout the research process to improve trust, transparency, and sustainable partnership with Black women and other communities of color when researching and implementing health interventions.

Conclusion

There is an urgent need to rapidly translate evidence-based interventions into real-world clinical and community settings to improve sexual health outcomes and end the HIV epidemic with special attention and efforts given to addressing health disparities among Black women. Aligning with the communities' values, lived experiences, and priorities will require engaging community partners throughout the research process through partnerships with CACs and other efforts. Deep inquiry and reflection using a racial equity lens within the research process, partnership, and outcomes contribution to testing effective culturally and socially relevant interventions improves research and its translation to practice and community uptake. The HEAT Research Lab is committed to taking additional steps to review and gather resources needed to practice equitable practices within community-engaged research that holds promise for reducing health inequities among Black Americans living in the US South.

Disclosures

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Author Contributions

All authors on this article meet the four criteria for authorship as identified by the International Committee of Medical Journal Editors (ICMJE); all authors have contributed to the conception and design of the study, drafted or have been involved in revising this manuscript, reviewed the final version of this manuscript before submission, and agree to be accountable for all aspects of the work. Specifically, using the CRediT taxonomy, the specific contributions of each author is as follows: Conceptualization: S. Randolph, E. Jeter, R. Johnson; Data Curation: S. Randolph, R. Johnson; Formal Analysis: S. Randolph, E. Jeter, R. Johnson; Funding Acquisition: S. Randolph; Investigation: S. Randolph, R. Johnson; Methodology: S. Randolph, E. Jeter, R. Johnson; Project Administration: S. Randolph, R. Johnson; Supervision: S. Randolph; Validation: S. Randolph; Writing—original draft and editing: S. Randolph, E. Jeter, R. Johnson.

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Key Considerations

- Engaging communities of interest throughout the research process is needed to develop and test effective culturally and socially relevant interventions to improve Black women's sexual health outcomes and end the HIV epidemic.
- Practicing deep inquiry and reflection using a racial equity lens to the research process, partnership, and outcomes contribution can improve the translation of effective interventions into practice and community uptake.
- Using an equity framework throughout the research process facilitates improved trust, transparency, and sustainable partnerships with communities of color who have had reason to distrust research.

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