

Review

Engaging African American women in research: an approach to eliminate health disparities in the African American community

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Abstract

Objective: To explore the success of community-based participatory research [CBPR] in engaging African American women to achieve health equity by elucidating community, trust, communication and impact. Recommendations helpful for researchers interested in engaging communities to achieve health equity in the USA are included.

Introduction: African American women experience health disparities of multifactorial etiology and are underrepresented in research. CBPR is a collaborative approach that incorporates perspectives, which address the intricate determinants of health and has been reported as an effective means to address health disparities. Yet, the science of CBPR seems elusive to researchers in the medical field. The opportunity exists to better understand and expand the use of the principles of engagement, replication, and sustainability in engaging African American women in health research.

Methods: A variety of literature regarding engaging African American women in community-based participatory research was reviewed.

Results: CBPR focused on robust engagement of marginalized groups continues to be validated as a vital approach to the elimination of disparities and improved health for all, especially ethnic and racial minority populations. However, limited evidence of focused engagement of African American women was found. Making specific outreach to African American women must be a community and patient engagement priority to achieve health equity.

Conclusions: Continued research is needed which specifically focuses on building and sustaining engagement with African American women and their communities. This research can transform healthcare access, experiences and outcomes by yielding actionable information about what African American women need and want to promote wellness for themselves and their communities.

Key words: African American women, community-based participatory research, community engagement, racism, social determinants of health.

Introduction

Blacks or African Americans (hereafter African Americans or AAs) make up 13.3% (1) of the population yet bear a disproportionate burden of poor health outcomes in the USA in health status, care quality and treatment results (2). Differences in population health between African Americans and non-African Americans have been linked to both ‘downstream’ factors, such as unequal clinical care, and ‘upstream’ factors, such as unequal education, income inequality and historical injustices that manifest through structured systems of inequity (3). Health disparities impacting African Americans span across the course of life beginning before birth (4). African American women are more likely to die from pregnancy-related causes, experience higher infant mortality rates and have low birth weight babies (5). AA women face health and sociocultural challenges and the cumulative impact of coping with chronic stress over time, described as *weathering*. Additionally, AA women experience interwoven complexities of racism, genderism, ageism and classism (6). Despite these challenges, recent advancements include longer life expectancy, decreasing teen pregnancy rates and decreasing HIV infection rates (7). AA women use adaptive behaviors and coping mechanisms to survive and thrive in the face of challenges (8). Engaging AA women in research is a mechanism to illuminate paths to mitigate disparities, thus improving the health of the AA community.

Community-based participatory research [CBPR] is a collaborative approach utilizing community engagement and partnership to identify and reduce disparities for underserved communities (9). CBPR embodies the concept of team science and capitalizes on the strengths and expertise of diverse backgrounds, with those impacted by the problem serving as core partners. Teamwork synthesizes lessons learned from lived experiences of individual and structural discrimination. These narratives can also illuminate intersectional disparities AA women face in promoting and maintaining health.

In this article, we review previous efforts to engage AA women in CBPR on health and offer evidence-based recommendations for health research affirming the value and contributions of AA women. We begin with an overview of community engagement strategies for health equity promotion, with an emphasis on social determinants without including an exhaustive review of CBPR. We proceed to a narrative review and theory-enriched analysis of previous CBPR studies engaging African American women. We conclude with recommendations for inclusive applications of core CBPR principles to inform community engagement science.

Background

Achieving health equity requires integrative strategies to address all sectors of healthcare delivery—including patient–provider communication, culturally responsive care (10), health policies (11) and strategies to address the social determinants of health. These determinants create a context that impacts the health of individuals, influences their behaviors and attitudes and impacts their genetics through epigenetic mechanisms (12,13). Structured systems of power, for example racism, that provide some populations an unfair advantage over others also influence health equity. Some investigators hypothesize racism is the fundamental cause of racial disparities (14). Racism is ‘a system of structuring opportunity and assigning value based on the social interpretation of phenotype’. (15) Racism operates on three levels—personally mediated, internalized and institutionalized impacting health through past and present injustices (14). Racism results in unequal access to quality health care,

mistrust, discrimination, perpetuation of poverty and differing exposures, stresses and opportunities (14,16–18).

Racial disparities are not inevitable for AA women (19). Rust et al. described national trends in disparities showing that specific analysis of ‘Black–White’ mortality rate ratios for women from 1960 to 2000 significantly improved, likely due to programs and policies (20). Innovation and discovery through research at the community level remain crucial today.

In 2014, George et al. observed both common and distinct barriers and facilitators to minority participation in health research. The facilitating factors for AA participation in health research included cultural congruence, benefits to participation, altruism (helping family or community), convenience, low risk of participation and design logistics such as safety assurances, trust in researchers, having choice of treatment in randomized clinical trials, and inclusion of diverse racial/ethnic groups in research. Barriers include mistrust related to research integrity, racism and discrimination. Additionally, inconvenience of participation, concerns about side effects, misconceptions about research, stigma related to mental illness or genetic research and limited health insurance coverage were barriers (21).

Models for engaging AAs in research have been proposed to overcome these challenges. CBPR is one such approach that embraces nine key principles to provide a comprehensive and participatory mechanism to address the complex and multifactorial determinants of health associated with racial/ethnic disparities. Partnership with the community impacted is the core element of CBPR (22). The nine principles are (1) recognition of the community as a unit of identity; (2) building on strengths and resources within the community; (3) facilitation of a collaborative, equitable partnership in all phases of the research, including an empowering and power-sharing process to attend to social inequalities; (4) fostering co-learning and capacity building among all partners; (5) achieving and integrating a mutually beneficial balance between new knowledge and intervention; (6) focussing on the local relevance of public health problems and ecologic perspectives that recognize and attend to the multiple determinants of health; (7) involving systems development using a cyclical and iterative process; (8) disseminating results to all partners and involving them in the dissemination process and (9) including a long-term process and commitment to sustainability (23).

Several studies have focussed on CBPR, which includes engagement as a key component for recruitment, retention, and translation of research findings. Samuel et al. created a community-oriented registry with an advisory board of community members and researchers to decrease sociodemographic barriers to participation and proved successful to engage AAs in research (24). Brown Speights et al. engaged in a community collaboration to assess African American women’s perception of the black infant mortality disparity. The researchers followed the principles of CBPR outlined by Israel (2005) for guidance on true engagement over tokenism and a community placed project versus a project based in the community (23,25). This project included a partnership of a diverse multidisciplinary advisory board including women impacted by infant mortality and demonstrated that principles of immersion and patient-centred care such as empathy, mutual respect, confidentiality, trust, quality and equity of power must be included in efforts to improve health. Similarly, Geitrich et al. conducted research on engaging diverse populations in practice-based networks, which help translate research to clinical practice. The authors demonstrated that CBPR principles engage racial/ethnic minority populations in research throughout each stage, including before and after study completion. Values like building trust and maintaining respect emerged as crucial cornerstones of successfully engaging diverse communities (26).

Health disparities research should be focussed on community engagement, partnership, sustainability, infrastructure and the multiple social determinants of health and their complex interaction within the individual, family and community (27). The CBPR approach is well situated to bring researchers and community together to address these multiple contexts impacting health (23). We propose a CBPR approach affords the opportunity to eliminate disparities, address barriers, capitalize on facilitators of health research and illuminate paths towards equity at the local community level.

Methods

Our primary investigator collaborated with an expert librarian to develop the literature search strategy. In March and April 2016, our team conducted a PubMed literature search with the key phrase 'community based participatory research' in all fields. We then expanded to include the MeSh Major Topic for 'African Americans' and searched all fields for 'community engagement' or the MeSh Major Topic for 'community based participatory research'. We then focussed on studies including women. This process and its outcomes are described in Figure 1.

We collected abstracts and full texts for our final sample of 46 studies. We divided these among three team members for review. For each manuscript, team members completed one row in a table capturing author names, study population, engagement strategy, major contributions, key limitations, central findings, concluding recommendations and miscellaneous details.

Our central inclusion criteria were that a given study must (1) use CBPR techniques, (2) focus on African Americans, (3) have female participants and (4) emphasize engagement of women. Researchers categorized articles by inclusion criteria status: included, undecided and excluded and flagged informational items justifying the inclusion or exclusion decisions. Researchers then reviewed tables generated by the other researchers. The inter-rater reliability was high, with a discrepancy of less than 1%. Final criteria were decided by the first author.

Via group discussion, we shared and built consensus on key patterns we identified during the literature review and coding process. We looked for strengths and gaps in existing research as well as connections between previous efforts and our own project. From these observations, we used theoretical frameworks from clinical and social sciences to analyze our findings and generated recommendations for future community engagement activity using core CBPR principles.

Results

Thirty-nine full-text articles were reviewed, and 28 were included in the narrative review. Nine were excluded because specific engagement of AA women was not a primary focus (Blumenthal 2005, Carson 2012, Close 2013, DeHaven 2011, Gwede 2011, Lichtenberg 2011, Skolarus 2013, Thomas 2013, Zoellner 2010), one was excluded because the engagement of women was unclear (Holden 2011), and one was excluded because community engagement was described as involvement in faith- or community-based organizations (Fothergill 2011). The literature reviewed included studies that specifically focused on AA women and included components of CBPR. Study participants included women at risk of poor health outcomes, including rural residents and low-income individuals.

A variety of health conditions were explored in the reviewed articles (Table 1): diabetes (Pierre-Louis et al 2011); links between obesity, waist circumference, BMI and hypertension (Warren et al 2012); cervical cancer (Haynes et al 2014; Bellinger et al 2014; Clark et al 2014); prenatal care; pregnancy; child bearing and birth outcomes (Baffour et al 2009, Jackson et al 2014, Jones et al 2010, Savage et al 2007, Secor-Turner et al 2010, Tucker Edmonds et al 2015); depression (Nicolaidis et al 2010; Nicolaidis et al and 2013), HIV (Demarco 2014); breast health awareness and knowledge (Wilson et al 2008; Karcher et al 2014) and aging among homeless women (Feen-Calligan et al 2009) (28–44).

Health behaviours targeted included increasing breast cancer screening and prevention (Wilson et al 2008; Powell et al

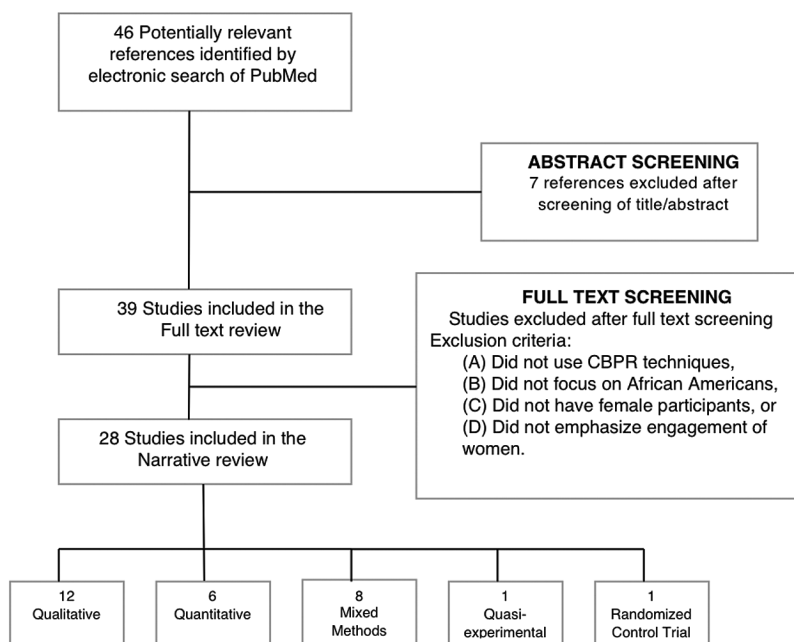


Figure 1. Literature review selection process.

2005; Cardarelli et al 2011), utilization of prenatal care (Tucker Edmonds et al 2015), HIV prevention (Sapiano et al 2013; Hawk 2013), breast health (mammograms, breast self- and clinical exams; Powell et al 2005; Wilson et al 2008; Highfield et al 2014; Karcher et al 2014; Adams 2007), improving diet/healthy eating/healthy food choices (Rowe 2010; Scarinci et al 2014), increasing physical activity (Scarinci et al 2014; Hines-Martin et al 2009) and weight management (Mitchell and Polsky 2013). One article explored the effect of religious involvement on health (van Olphen et al 2003) (38,42,43,45–55). The patient–physician interaction was also discussed. Clark and Bellinger demonstrated the key importance of trust in information from physicians, including culturally competent patient-centred communication and the use of community health workers to convey evidence-based guidelines (e.g. change in cervical cancer screening) (31,32).

A significant focus of the articles reviewed was the exploration of the contexts of health, including the social, cultural, physical, historical, psychological and environmental milieu of the populations explored. Exploring the contexts of health provided a holistic view

of participants' health experiences, understanding and explanatory models of health conditions, perspectives of health and disease and barriers to participating in healthy behaviours. Many articles focussed on low-income AA women or women living in under-resourced areas. Several studies focused on specific age-groups or regional populations in the southern USA.

All included studies used CBPR methods (Table 2). Across reviewed studies, authors reported on collaborating with community members on various phases of research, including (1) designing programs and interventions, (2) designing research tools and instruments, (3) developing methodological approaches, (4) assisting with data analysis and (5) providing feedback to refine and improve the validity of findings and conclusions.

The findings in this narrative review provided insights about the principles of CBPR. Studies focussed on culturally relevant approaches that emphasized the benefit of social connectivity in engaging AA women in research. A common theme was a focus on addressing social determinants of health. Studies highlighted theories related to self-efficacy, resilience, social capital and social

Table 1. Articles included by study method and conditions.

Study design	Total number (%)	Cancer related	Chronic disease except HIV	HIV	Maternal and child health	Lifestyle/social/systems related
Quantitative	6 (21.42)	2	1	2	0	1
Qualitative	12 (42.85)	1	2	1	5	3
Mixed methods	8 (28.57)	5	2	0	0	1
Quasi-experimental	1 (3.57)	1	0	0	0	0
Randomized control Trial	1 (3.57)	0	0	0	0	1
Total	28	9	5	3	5	6

Table 2. Legend areas of study engagement in various phases of research.

Types of engagement in research studies observed	Studies that demonstrated this engagement
(1) Designing programs and interventions (naming programs and projects, selection of health issues, conditions and health priorities to be addressed)	Adams 2007, Baffour 2009, Bellinger 2015, Blumenthal 2005, Cardarelli 2011, Carson 2012, Clark 2014, DeMarco 2012, Feen-Calligan 2009, Gwede 2011, Hawk 2013, Haynes 2014, Highfield 2014, Hines-Martin 2009, Jackson 2015, Jones 2010, Karcher 2014, Lichtenberg 2011, Mitchell 2013, Nicolaidis 2013, Nicolaidis 2010, Pierre-Louis 2011, Powell 2005, Rowe 2010, Sapiano 2013, Savage 2007, Scarinci 2014, Secor-Turner 2010, Skolarus 2013, Thomas 2013, Tucker Edmonds 2015, van Olphen 2003, Warren 2012, Wilson 2008
(2) Designing research tools and instruments (e.g. development of research questions, interview/focus group topics and content, survey content and format)	Adams 2007, Baffour 2009, Cardarelli 2011, Carson 2012, Clark 2014, DeMarco 2012, Feen-Calligan 2009, Gwede 2011, Hawk 2013, Haynes 2014, Highfield 2014, Jones 2010, Lichtenberg 2011, Mitchell 2013, Nicolaidis 2013, Nicolaidis 2010, Pierre-Louis 2011, Rowe 2010, Savage 2007, Scarinci 2014, Secor-Turner 2010, Skolarus 2013, Thomas 2013, Tucker Edmonds 2015, van Olphen 2003, Wilson 2008
(3) Developing methodological approaches (e.g. development of measures/variables to be explored, selection of recruitment and intervention organizations, sites and locations using community members as active program participants as health educators, focus group facilitators and field surveyors, appropriateness of incentives)	Adams 2007, Baffour 2009, Cardarelli 2011, Carson 2012, Clark 2014, DeMarco 2012, Feen-Calligan 2009, Gwede 2011, Hawk 2013, Haynes 2014, Highfield 2014, Hines-Martin 2009, Jones 2010, Karcher 2014, Lichtenberg 2011, Mitchell 2013, Nicolaidis 2013, Nicolaidis 2010, Pierre-Louis 2011, Powell 2005, Rowe 2010, Sapiano 2013, Savage 2007, Scarinci 2014, Secor-Turner 2010, Skolarus 2013, Thomas 2013, Tucker Edmonds 2015, van Olphen 2003, Wilson 2008
(4) Designing programs and interventions (naming programs and projects, selection of health issues, conditions and health priorities to be addressed)	Adams 2007, Baffour 2009, Blumenthal 2005, Cardarelli 2011, Carson 2012, Clark 2014, DeMarco 2012, Feen-Calligan 2009, Gwede 2011, Hawk 2013, Haynes 2014, Highfield 2014, Hines-Martin 2009, Jackson 2015, Jones 2010, Lichtenberg 2011, Mitchell 2013, Nicolaidis 2013, Nicolaidis 2010, Pierre-Louis 2011, Rowe 2010, Sapiano 2013, Savage 2007, Scarinci 2014, Secor-Turner 2010, Skolarus 2013, Thomas 2013, Tucker Edmonds 2015, van Olphen 2003, Wilson 2008

identity (DeMarco) including use of an ecologic systems theory as an approach to recruitment and retention (Hines-Martin) (43,55). Others used creative engagement through the arts to give voice to AA women to facilitate understanding and communication about the complexities of chronic conditions (43,44).

Discussion

Our review of the literature confirmed that successful engagement of AA women through CBPR is feasible and relies on building trusting relationships of longevity, inclusion and affirmation. Our research revealed the importance of a comprehensive scientific approach, proven in several studies to benefit the individual, community and entire population. CBPR is well situated to address the unique complexities and intricacies of improving health disparities. Engagement of impacted communities must be culturally relevant and sincere. Qualitative and mixed-methods approaches can facilitate this process. Several validated mechanisms exist, including creating advisory boards in which community members actively shape each step of research processes.

We anticipated discovering specific engagement strategies particularly suited for women. However, more than half of the time we found that women were included and were the focus of studies in which the disease conditions were specific to and/or more severe in women. In our previous CBPR project, the intersectionality of our participants' perspectives as women, researchers, mothers, minorities, clinicians and/or advocates afforded uniquely impactful insight into strategies and resources for health equity promotion in AA communities. We saw firsthand how interplay between participants' social locations impacted research relationships, communication styles, study trajectories, knowledge outcomes, action strategies and overall framing (25).

Our review revealed many important benefits of the CBPR approach, including the development of programs and interventions focussed on what is meaningful for community members. CBPR is an opportunity to gain an understanding of the social and cultural contexts that influence health behaviours and practices, the application of the unique community perspectives, lived experiences, knowledge, views, needs, health contexts and determinants of health and the structures that shape individual, family and community health (28,33,36,44). CBPR promotes trust and inclusion through the reduction in exploitation or perceived exploitation of vulnerable communities and implementation of research that is more amenable to participants (24). This promotes enhanced recruitment and retention (24,48,53).

This review is consistent with previously described benefits of CBPR including building on existent social ties and established trusted relationships, partnerships, and networks of community organizations (members and leaders), incorporation of shared and culturally appropriate language facilitates communication and understanding and applicability of research instruments (24,45,52,55). CBPR is informative and impactful at the systems, community and individual level. Value comes from factors such as inclusion, collaboration, combined expertise of diverse partners, developing self-management strategies and addressing practical considerations (40,53).

CBPR is not without challenges. Recruitment and project implementation can be time-consuming and labour intensive (45). Additionally, the generalizability of results may be limited as process is grounded in the structure and environment of specific communities (36,38,43,51,55).

Qualitative research, specifically narrative methods, can do much to reveal and diminish a variety of biases that impede research. Focus groups and storytelling create opportunities for social support, mutual bonding, empathy development, and creative thinking. Not unlike results found in 2014 by George et al, themes arose related to knowledge, trust, information processing, location of outreach and preferred type of information received (21). Effective CBPR transforms the boundaries of engaged communities because researchers become community members and vice versa and, in the process, recognize and value the individual contributions of each 'side'. Each participant must see themselves as equally invested in the research and the underlying problem.

Acknowledging and valuing that one person may bring more experiential expertise to the table about research methodology, community engagement, clinical knowledge, personal experiences and/or population data affirms each stakeholder's unique contributions. Optimal CBPR strategies build in opportunities for discussing and appreciating both concordance and discordance in participant perspectives. Our own experiences recommend facilitating this communication through general principles of unselfishness, mutual interest and benefit, finding common ground and acknowledging uncommon grounds, honesty and transparency, trust and accountability, commitment to the end goals, understanding of needs for changing direction and uncovering motives, avoiding ulterior motives and remaining unoffended when the actions of one may seem contrary to the desires of another.

In support of building future CBPR projects engaging AA women and other intersectionally marginalized groups, we encourage health researchers and clinical educators to build community engagement into every stage of training. Previous research and our own experiences suggest that this is best accomplished by emphasizing listening and learning first, rather than intervening and "fixing" phenomena that may be much more complex than they appear. By training our clinical professions students to conduct inclusive and culturally affirming CBPR that meaningfully engages AA women, we give them unique opportunities to conceptualize the diverse and intersecting needs of people whose lives they may one day transform or by whom they will be transformed.

Strengths and limitations

While our search strategy was limited in scope to a non-systematic, narrative review focussed on engaging AA women, this type of review lends itself well to this content material and provides a valuable contribution to medical literature. This review illustrated that an opportunity exists to increase the number of studies that focus on engaging AA women in research. An environmental scan of databases (Web of Science, JSTOR and Google Scholar) found additional relevant content.

Another strength was the observation of a positive impact on the health of AA women at both the individual and the community level. This type of work affords critical insight, gleaning strategies from communities in which disparities are decreasing to help create paths towards health equity (20).

A limitation to our search strategy was that we only included AA and not 'black', which limited the number of studies discovered. Our intent was not to include all people of African descent, for example those from Caribbean or Latin America, as their history, experiences in USA and culture differs from African Americans. We also excluded studies not focussed on engaging African American women; these studies may be a significant contribution to the literature on the CBPR approach, especially the studies in which AA women were a majority of the participants.

Table 3. Recommendations for engaging African American women in community-based participatory research.

1. Collaborate to engage African American women in all aspects of the research study and interventions
2. Create connections through community agencies to build trust with African American women leaders and members from the community
3. Incorporate knowledge and perspectives of African American women within the community into research projects, including understanding the importance of historical contexts (13)
4. Facilitate culturally adapted discussions to increase knowledge and awareness and glean the perceptions of African American women on the disparity at hand and potential solutions (56)
5. Foster partnerships and trust with African American women through continuous collaboration to produce research and action that promotes health equity, leveraging local resources and the intergenerational impact of long-term commitment and enduring relationships
6. Maintain a committee inclusive of African American women from the community that will evaluate projects and serve as liaisons for community voices to enhance the validity and meaningfulness of scientific research
7. Develop a reciprocal process with African American women for training on the framework of health equity, ethics, relationship building, conflict resolution, and guiding rules of relationships (7)
8. Work with African American women to use the research to impact policy regarding social and health inequalities
9. Involve African American women in sharing the research findings with their community, developing further recommendations, and resource development
10. Strive to maintain a long-term relationship and continuously work with African American women in the community to address issues of social and health inequalities

Another limitation was the variability in types of projects, methods, interventions and outcomes observed. While this strengthens the core concept of studies tailored to the particular community that is engaged, it limits the generalizability and comparison. However, the principles of CBPR remain intact, and this study illuminates the strength of using this approach in a variety of settings and types of research protocols (23,47)

Additionally, our conclusions include an opinion-oriented argument based on myriad references and thematic analysis. We caution against overinterpretation of our observational findings. However, results are consistent with prior findings on the importance and impact of engaging African American women as core team members in research.

Many of the studies reviewed referred to CBPR principles without outlining the specifics of community engagement which may limit the interpretation of methodological quality. This review serves as a starting point for a systematic review to further develop the science of community engagement and the expansion of the concept of team science to include the community.

Conclusions

Our narrative review of extant literature suggests that health equity for marginalized populations is best served by a deliberate and evidence-based approach to overcoming barriers to robust and sustained community engagement. This process of achieving and maintaining strong community engagement of AA women begins with awareness of racial injustice and an understanding of the principles of culturally responsive care. Cultivating crucial accountability for community and academic CBPR participants requires careful documentation of research processes, open communication including active reflection on implicit and explicit biases and collaborative strategizing to incorporate knowledge of existing biases constructively into community dialogue.

Based on this narrative review, the authors' results from the African American Women's Perception of Black Infant Mortality in Leon and Gadsden Counties in North Florida, and Israel et al's principles of CBPR (9), we present recommendations for engaging African American women in CBPR in Table 3.

These principles contribute to the science of engagement. This review suggests that engaging African American women in research is a reasonable means to address the health of the community. The recommendations should be further explored in other contexts of

translational research to provide opportunities to engage African American women as leaders in their communities to achieve equity in USA.

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Declaration

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