

Bridging the Gap: A Community Advisory Board Promoting Community Engagement in Cancer Research for Ethnically Diverse Populations

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Abstract

Prostate cancer disproportionately affects Black men in the United States, leading to higher mortality rates and health disparities. In addition, based on historical mistreatment and discrimination and the resulting distrust of the medical system, Black populations are consistently underrepresented in health care-related research. Addressing these challenges requires community-driven approaches integrating diverse perspectives and fostering equitable health outcomes. This article describes the formation and impact of The Multidisciplinary Health Outcomes Research and Economics (MORE) Lab Community Advisory Board (CAB) at The University of Oklahoma Health Sciences. We purposefully recruited Black men with CaP and Black health care professionals to serve on a CAB and advise on ongoing research to address quality of life (QoL) issues in ethnically diverse Black CaP survivors. The CAB seeks to mitigate CaP disparities and improve health equity by empowering Black voices and promoting collaborative research practices. The MORE Lab CAB has successfully provided a venue for community members to contribute to designing a culturally relevant research program to improve the QoL in ethnically diverse Black men with CaP. The CAB has been instrumental in developing research goals and tools, implementing a series of town hall meetings to educate and support Black CaP survivors, and disseminating research findings. In conclusion, CABs are potentially critical in guiding research, enhancing community engagement, and advocating for culturally responsive health interventions.

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Introduction

Prostate cancer (CaP) is the second most commonly diagnosed cancer among men in the United States (American Cancer Society, 2024), with Black men facing a considerably higher risk than men of other racial and ethnic backgrounds (Lillard et al., 2022). Black men are more likely to be diagnosed at later stages of the disease, leading to poorer prognosis and higher mortality rates (American Cancer Society, 2022). These disparities are multifaceted and influenced by a complex interplay of biological, socioeconomic, and health care-related factors (Chowdhury-Paulino et al., 2022; Lillard et al., 2022). In addition, Black populations are consistently underrepresented in health-related research, a factor that constitutes a persistent barrier to achieving equitable health outcomes for Black individuals (Lillard et al., 2022). This lack of representation not only exacerbates existing health disparities but limits the generalizability and applicability of research findings to Black populations (Swaby et al., 2021). Addressing these disparities requires a comprehensive approach beyond traditional research paradigms to actively involve the most affected communities. Bridging this gap requires innovative approaches, such as the establishment of Community Advisory Boards (CABs) that actively engage communities in the research process (Patten et al., 2019). Community engagement initiatives play a pivotal role in ensuring that research efforts are culturally relevant and ultimately responsive to community needs (Odedina et al., 2024). CABs can contribute to this goal by fostering inclusive partnerships between researchers and community members and, in the process, helping to identify research priorities, refine study designs, and disseminate findings meaningfully and accessibly (Cunningham-Erves et al., 2017). CABs are composed of community members who are not necessarily scientists but are chosen for their firsthand knowledge, unique perspectives, or extensive involvement in a specific community (Ortega et al., 2018). The role of CABs is crucial in facilitating community engagement in research and ensuring that the research is conducted in a way that is ethical, respectful, and beneficial to the community. This article outlines the development and impact of a CAB focused on guiding

research on CaP disparities within the Black community. The process of forming, recruiting, and sustaining the CAB through The Multidisciplinary Health Outcomes Research and Economics (MORE) Lab (The MORE Lab, 2024) at The University of Oklahoma Health Sciences, as well as the benefits and challenges encountered, productivity outputs, and feedback provided by CAB members are highlighted.

The MORE Lab CAB: Mission and Goals

Founded in 2021, the mission of The MORE Lab CAB is to improve health outcomes and quality of life (QoL) for underserved communities, particularly Black men with CaP, through innovative, community-engaged, and transdisciplinary research. By advocating for the inclusion of diverse Black voices, fostering researcher–community collaboration and trust, and enhancing community empowerment, education, and engagement, the CAB aims to address CaP disparities. The CAB focuses on identifying priority research areas, increasing community engagement, developing tailored interventions, promoting inclusive research practices, raising awareness and advocacy for CaP disparities, and recommending community-based interventions. In summary, the CAB strives to create a culturally responsive research ecosystem that empowers Black CaP survivors and improves health outcomes through community-informed initiatives.

Forming the CAB: Recruitment and Roles

Recruiting members for the CAB was a deliberate process to ensure diverse representation and meaningful community engagement in CaP research. We employed various strategies, including community outreach events and leveraging existing networks with community leaders, partners, and health care providers to identify potential candidates. Selection criteria encompassed personal experiences with CaP, community advocacy, health care involvement, and a commitment to health equity. Recognizing the increasing diversity within the Black population in the United States, including increasing numbers of immigrants from African and Caribbean countries (Odedina et al., 2023; Pew Research Center, 2022), we ensured the

Table 1. Demographic Characteristics of The MORE Lab Community Advisory Board Members (N = 8)

Characteristics	
Age, years (range, mean \pm SD)	60–71, 67 \pm 4
Ethnicity, n (%)	
Native-born Black men	4 (50.0)
African-born Black men	2 (25.0)
Caribbean-born Black men	2 (25.0)
Geographic location within the United States, n (%)	
Southeast	4 (50.0)
Northeast	2 (25.0)
Southwest	1 (12.5)
West	1 (12.5)
Education, n (%)	
High school graduate or less/GED	3 (37.5)
Some college or technical school	3 (37.5)
College graduate	1 (12.5)
Postgraduate	1 (12.5)

Note. MORE = Multidisciplinary Health Outcomes Research and Economics; SD = standard deviation; GED = General Educational Development.

inclusion of ethnically diverse Black men who often face a disproportionate burden of CaP (Ogunsanya, Kaninjing, Ellis, Bamidele, et al., 2024) and bring unique cultural perspectives to the research process (Abraham et al., 2024; Dickey & Ogunsanya, 2018). Our CAB features eight members, including a Black primary care physician and a Black public health professional, to ensure medical and public health perspectives are integrated into the research. CaP is a significant issue for Black men. Membership was voluntary, with expectations for attendance at monthly meetings and active participation. Members were encouraged to engage with their communities to facilitate collaboration between researchers and stakeholders (Newman et al., 2011). Our goal was to recruit a diverse and dedicated group that reflected the demographics, interests, and priorities of the communities served, enhancing the relevance and impact of CaP research interventions. Table 1 reports the demographic characteristics of CAB members.

CAB Meetings

Effectively engaging with a CAB necessitates regular communication and a consistent meeting schedule to maximize participation and productivity (Cramer et al., 2018). Our CAB meets monthly via Zoom, typically on the last Tuesday of each month, following a co-created agenda prepared by the research team and CAB members. The first meeting was held in November 2021. Meetings are audio-recorded, and detailed minutes are

circulated afterward, capturing discussions, feedback, and action items. Sessions begin with check-ins to review previous feedback implementation. Members are expected to attend at least 9 out of 12 meetings annually, with membership renewable each year. Topics for discussion include updates on CaP research in Black men, community engagement efforts, recruitment strategies, Institutional Review Board approvals, and dissemination efforts through podcasts, town halls, and media features. Meetings last about 60 min, and members receive annual compensation of \$1,000. Regular check-ins between meetings ensure ongoing collaboration and support from the research team. Annual surveys are conducted to gauge participant perception of the CAB and its overall impact.

Benefits and Impact of the CAB

CABs offer numerous benefits in research initiatives and community engagement, significantly strengthening the partnership between academia and the community (Cargo & Mercer, 2008). By incorporating the lived experiences and insights of Black men affected by CaP, our CAB enhances the relevance and impact of research studies, ensuring they address this community's specific needs and concerns. This collaboration fosters greater trust and rapport between researchers and the community, promoting more effective and ethical research practices. The impact of our CAB initiatives is highlighted below.

Research Strategy

Peer-Reviewed Articles. Our CAB has critically informed research strategies underpinning our ongoing studies to explore factors influencing the QoL of ethnically diverse Black CaP survivors and the design of culturally relevant interventions to address these issues. Furthermore, CAB-influenced research and discussions have led to contributions in both academic and accessible mediums. Through collaboration, feedback from CAB meetings has been instrumental in refining research questions, methodologies, analyses, and effective dissemination, resulting in the publication of peer-reviewed articles that enhance the scientific understanding of CaP, particularly within Black communities (Ogunsanya et al., 2023, Ogunsanya, Kaninjing, Ellis, Bamidele, et al., 2024, Ogunsanya, Kaninjing, Ellis, Morton, et al., 2024).

Grant Funding. The CAB's activities have directly impacted the acquisition of grants, including three notable grants aimed at enhancing CaP research and support programs. These grants have funded crucial

Table 2. Summary of Feedback From CAB Members: Motivations, Personal Benefits, and Future Goals

Topic	Participant Feedback/Quotes
Motivations for joining CAB	<p>"To share my experience and help others avoid struggles or late diagnosis." . . . Participant 1</p> <p>"Opportunity to talk about counseling and make a positive impact." . . . Participant 2</p> <p>"To provide information to my business community." . . . Participant 3</p> <p>"To share a different perspective in coping with the prostate cancer diagnosis." . . . Participant 4</p> <p>"There is a need for men of color to become aware, active, and intentional with their overall health and care." . . . Participant 5</p> <p>"Wanted to assist with getting the importance of checking your prostate out to men of color." . . . Participant 6</p>
Personal benefits from CAB	<p>"Knowing there are persons with similar issues and learning how they cope, applying some to my survival." . . . Participant 1</p> <p>"There is an emotional aspect to dealing with (prostate) cancer diagnosis. While the CAB has provided me with a forum to share my experience with the diagnosis and my current treatment approach, it has also given me comfort in learning from others who have gone down a path that may be a future for me." . . . Participant 2</p> <p>"It gave me the confidence to tell others that I had been through prostate cancer." . . . Participant 3</p> <p>"It has allowed me to overcome some of my fears and insecurities brought about by the cancer diagnosis and treatment processes." . . . Participant 4</p> <p>"I have learned about the different prostate issues and solutions." . . . Participant 5</p> <p>"Knowledge that other survivors share similar experiences." . . . Participant 6</p> <p>"Personally, I'm now more open talking about myself concerning my experience with prostate cancer." . . . Participant 7</p> <p>"Increased openness in discussing personal experiences." . . . Participant 8</p>
Future goals and recommendation	<p>"Dieting and sexual/affection methods." . . . Participant 2</p> <p>"Side effects of treatment options (short-term and long-term), and subsequent quality of life considerations should be added as areas of discussion." . . . Participant 3</p> <p>"Training current members in public speaking and formation of smaller advocacy teams for community engagements." . . . Participant 4</p> <p>"While CAB members have done a remarkable job sharing and discussing the need for early detection and intervention, we need to be more transparent about how many changes are happening in the knowledge and treatment of the disease." . . . Participant 5</p> <p>"Engaging leading practitioners in the field to educate us on these trends would help us be better resources for other men who may be afflicted with the disease." . . . Participant 6</p> <p>"Focus on improving ways to get men more involved." . . . Participant 7</p> <p>"Regaining sexual health and confidence." . . . Participant 8</p>

Note. CAB = Community Advisory Board.

studies exploring QoL issues in ethnically diverse Black CaP survivors, genetic susceptibility to CaP, and the development and assessment of preliminary efficacy of support tools like mobile health applications, significantly contributing to advancing CaP care and survivor support.

Community Engagement

By bridging the gap between academic institutions and the communities they serve, CABs facilitate the dissemination of research findings back into the community. Thus, they promote health literacy and empowerment and make community members powerful advocates for health. Specific community initiatives from our CAB are listed below.

Town Halls. Together with the CAB, The MORE Lab hosts two virtual town halls annually, with the first

held in April 2022, following a storytelling approach (Ogunsanya et al., 2023). These town halls cover a range of topics relevant to Black men with CaP, such as community health concerns, survivor stories, treatment options, sexuality, mental health, and supportive care. The CAB decides the topics for each town hall. Before dissemination, all promotional materials undergo CAB review to ensure cultural sensitivity and community relevance. CAB members are integral to these events, promoting the town halls, serving as panelists, moderating sessions, and hosting watch parties within their communities.

Media Engagement. CAB members actively participate in various media platforms, including blog articles (Sibyl, 2023a), press interviews (OU News, 2024), and podcast episodes (Sibyl, 2023b, 2023c), to share their experiences and raise awareness about CaP within their

communities. These podcast episodes emphasized early detection, proactive health management, and the importance of mental well-being. They addressed the familial impact of a cancer diagnosis, the role of family support, and effective coping mechanisms for CaP challenges, including the effects of treatment on sexual functioning. By sharing these personal narratives, the episodes raised awareness, provided support, and encouraged others to prioritize their well-being and approach life's challenges with hope.

Book Club. In an innovative approach to engaging members and the broader community, the CAB established a book club focusing on reading materials related to advocacy, wellness, and cancer survivorship. This initiative fosters community, encourages lifelong learning, and provides a supportive space to discuss CaP and general health topics.

CAB Members' Feedback

Feedback from our CAB members corroborates the general benefits, highlighting their motivations for joining and the personal advantages they derive from participation. According to findings from our most recent end-of-the-year survey conducted in early spring 2024, many members joined the CAB to make a meaningful impact and share their experiences to help others. The CAB resonates with members seeking to elevate awareness and engagement among men of color regarding their health. Beyond their initial motivations, members have found significant personal benefits from their involvement. Many reported that the CAB has helped them connect with others facing similar health challenges, offering emotional support, and practical coping strategies. These benefits underscore the valuable role that CABs play in advancing research, enhancing the personal well-being of members, and fostering active community advocacy. Table 2 summarizes CAB members' feedback on the benefits and impact of the CAB.

Key feedback from CAB meetings was the need to enhance members' public speaking skills for effective communication and advocacy. In response, the principal investigator (Ogunsanya) partnered with The Mayo Clinic's advocacy training program, successfully training CAB members in advocacy and engagement, emphasizing peer learning and survivor interaction, and empowering community advocates to convey crucial health information effectively. CAB members emphasized the necessity of continually raising awareness about mental health, elevating comfortability around health conversations, and addressing

the sexual health impacts of CaP within the community. This feedback led to targeted advocacy campaigns and carefully curated town hall topics featuring survivor stories, urologic oncologists, mental health providers, and sex psychologists as speakers. The CAB's openness to incorporating new ideas has enriched these efforts, making town hall meetings highly successful in addressing critical topics such as diagnosis, mental health, and QoL for Black men with CaP. These initiatives directly respond to community needs, fostering stronger bonds and engagement. Feedback on recruitment and engagement highlighted the need for innovative strategies to involve the community in research. As a result, new approaches for recruitment and engagement were developed, particularly for funded grant projects, leading to increased community participation. The CAB stressed the importance of exploring broader engagement opportunities to address a more comprehensive range of health issues beyond CaP. In summary, the CAB has significantly enhanced CaP advocacy, research participation, and community support through targeted efforts and continuous feedback incorporation.

Challenges for the CAB

While CABs provide numerous benefits, they face several challenges. One major issue is sustaining member engagement over time, mainly when competing personal and professional commitments interfere (Minkler & Wallerstein, 2011). Ensuring diverse and representative participation can be difficult, as described in the end-of-the-year feedback from members struggling to get men to attend town hall meetings and be open with their experiences. In addition, a lack of in-person interaction may affect the depth of connection and engagement among members. Strategies to mitigate these challenges include offering alternative ways to participate and fostering community through regular check-ins, community engagement initiatives, and informal virtual gatherings. Securing continuous sustainable funding and resources to support CAB activities, including compensation for members' time and contributions, is a persistent obstacle (Israel et al., 2019). Despite these challenges, CAB members report positive and informative experiences, with most members encountering no significant obstacles, thus highlighting the rewarding nature of their involvement. By addressing these challenges in member engagement and financial sustainability, CABs can strengthen their impact, ensuring that the voices and experiences of the communities they serve are heard and valued.

Future Directions for the CAB

The future direction of our CAB, as informed by the most recent end-of-year survey, will focus on expanding its impact and sustainability through several strategic initiatives. Key areas for future development are enhancing member training and capacity building to empower CAB members as community advocates and leaders. Providing training in public speaking, advocacy, and health literacy can amplify CAB member's influence within their communities and improve engagement efforts (Israel et al., 2019). Another focus is increasing outreach and engagement efforts, particularly among underserved and hard-to-reach populations. This can be achieved through targeted community engagement strategies, including partnerships with local organizations, churches, and other community hubs to raise awareness and participation (Minkler & Wallerstein, 2011). Incorporating innovative approaches, such as virtual town halls and online support groups, can broaden the CAB's reach and inclusivity (Ezeani et al., 2020; Ogunsanya et al., 2023). Ensuring sustainable funding and resources remains a critical priority; seeking grants, partnerships, and community-based funding sources can support CAB activities, including compensating members for their time and contributions (Cargo & Mercer, 2008). Establishing a robust infrastructure for resource allocation will help maintain the CAB's operations and impact over the long term. In addition, there is a need to expand the CAB's focus beyond CaP to create awareness around other disease conditions, especially those affecting the Black community (Allen et al., 2021). Such goals can be achieved through conducting more community engagement events, such as town halls, podcast interviews, and health fairs, to educate and involve the community on a broader range of health issues (Braithwaite et al., 2020). Finally, ongoing evaluation and feedback mechanisms are essential for continuous improvement (Abraham et al., 2023). Regularly assessing the CAB's activities, member satisfaction, and community impact will inform future strategies and ensure that the CAB remains responsive to the needs of its members and the broader community. By implementing these strategies, CABs can continue to thrive and make a meaningful difference, enhancing both research relevance and community health outcomes.

Conclusion

The establishment of The MORE Lab CAB has demonstrated the significant impact of community engagement on health outcomes research for Black

men with CaP. By providing a platform for survivors to share experiences, influence research, and raise awareness, the CAB has fostered trust between researchers and the community, enhanced health literacy, and empowered members as proactive health advocates. The CAB's success in organizing educational town halls, developing advocacy campaigns, and refining digital engagement tools highlights the transformative power of community-driven initiatives. Addressing critical issues like mental and sexual health, community participation in research, and QoL for Black men with CaP, the CAB's efforts offer valuable insights into effective community engagement strategies. These include continuous education, open communication, and innovative recruitment methods, culminating in a model that improves research outcomes and fosters a supportive, informed community network. In summary, The MORE Lab CAB's approach to community engagement has set a precedent for successfully involving community members in health research and advocacy, resulting in increased health literacy, trust, and proactive advocacy within the community.

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