


SHORT REPORT

Accelerating diversity in Alzheimer's disease research by partnering with a community advisory board

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Abstract

Introduction: Community advisory boards (CABs) and researcher partnerships present a promising opportunity to accelerate enrollment of underrepresented groups (URGs). We outline the framework for how the CAB and researchers at the Indiana Alzheimer's Disease Research Center (IADRC) partnered to accelerate URG participation in AD neuroimaging research.

Methods: CAB and the IADRC researchers partnered to increase the CAB's impact on URG study enrollment through community and research interactions. Community interactions included the CAB collaboratively building a network of URG focused community organizations and collaborating with those URG-focused organizations to host IADRC outreach and recruitment events. Research interactions included direct impact (CAB members referring themselves or close contacts as participants) and strategic impact, mainly by the CAB working with researchers to develop and refine URG focused outreach and recruitment strategies for IADRC and affiliated studies to

Alex Pena-Garcia and Ralph Richards contributed equally to this study.

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increase URG representation. We created a database infrastructure to measure how these interactions impacted URG study enrollment.

Results: Out of the 354 URG research referrals made to the IADRC between October 2019 and December 2022, 267 referrals were directly referred by the CAB ($N = 36$) or from community events in which CAB members organized and/or volunteered at ($N = 231$). Out of these 267 referrals, 34 were enrolled in IADRC and 2 were enrolled in Indiana University Longitudinal Early Onset AD Study (IU LEADS). Of note, both studies require the prospective participants to be willing to do MRI and PET scans. As of December 2022, 30 out of the 34 enrolled participants have received a consensus diagnosis; the majority were cognitively normal (64.7%), with the remainder having mild cognitive impairment (17.6%) or early-stage AD (2.9%).

Discussion: The IADRC CAB-researcher partnership had a measurable impact on the enrollment of African American/Black adults in AD neuroimaging studies. Future studies will need to test whether this conceptual model works for other sites and for other URGs.

KEYWORDS

Alzheimer's disease, community advisory boards, community-engaged research, outreach, recruitment

1 | INTRODUCTION

There is an urgent need to rapidly increase diverse participation for large scale Alzheimer's disease (AD) neuroimaging research studies.¹⁻³ As a result, incorporation of community-engaged research (CER) in outreach and recruitment strategies to increase diverse participation in these more intensive studies is essential. CER is a process to incorporate the voices of the communities as equal partners in the development and outcomes of research. Community Advisory Boards (CABs) serve as the voice of the community and can provide invaluable insight about the development of culturally sensitive outreach and recruitment strategies.^{4,5} Partnerships with CABs present a promising opportunity to accelerate enrollment of under-represented groups (URGs), particularly for racial and ethnic minority groups.⁶⁻⁸ The most populous URGs in Indiana are those who self-identify as African American or Black and will be the focus of this URG framework. We outline the framework for how the CAB and the researchers at the Indiana Alzheimer's Disease Research Center (IADRC) formed a partnership to accelerate URG participation in AD neuroimaging research and describe how we measured the return on investment of this partnership with our database infrastructure.¹

2 | METHODS

The IADRC CAB consists of 2 co-chairs and 10-15 individuals from healthcare, law, education, and faith-based organizations who meet

monthly. The IADRC Outreach, Recruitment, and Engagement Core (OREC) is led by a Core Leader and includes three faculty members with expertise in healthcare disparities, CER, and recruitment science. The CAB co-chairs and selected CAB members who are actively working on affiliated studies and OREC leadership also meet separately each month. When the CAB was founded, we incorporated the nine principles of community-based participatory research to develop novel outreach and recruitment strategies to increase URG participation in AD neuroimaging research (Table S1).⁹ In the process of this incorporation, the CAB and OREC leadership identified two major interactions: community interactions and research interactions (Figure 1). Community interactions include building a network of URG focused community organizations and collaborating with those URG-focused organizations to host IADRC outreach and recruitment events with those organizations (Figure 1, green circles). Research interactions included direct impact (i.e., referrals coming from the community, such as CAB member themselves enrolling as participants or referring close contacts) (Figure 1, blue solid circles) and strategic impact, mainly by developing and refining URG focused outreach and recruitment strategies for IADRC and affiliated studies (Figure 1, blue dashed circles). For example, CAB and OREC leadership would meet regularly during grant planning and proposal development activities for the IADRC P30 and its affiliated studies to discuss the study's proposed aims and strategy. Based on these discussions, the CAB was able to recommend how to tailor the recruitment strategies to meet the specific URG enrollment needs of affiliated studies. For AD-REACH, the Principal investigator (PI) team included CAB members in the qualitative interviews and survey development to ensure the final version of the survey accurately

designed questions to capture challenges and barriers of research participation of African American and Black older adults.¹⁰ For the LEADS diversity supplement, the PI team, OREC team, and the CAB collaborator strategically decided that the outreach and recruitment efforts about early onset AD should be incorporated into our broader URG outreach and recruitment efforts and incorporated a message raising awareness about a stigmatizing, rare disorder into a more acceptable message about health promotion and early detection of AD beginning in mid-life.

Figure 2 outlines the database infrastructure used to capture the CAB's direct impact on the community and research. To measure this impact, we developed three CER databases: (1) the CAB database, which consists of the CAB members' name and contact information; (2) the URG-Focused Community Organizations-Events database, which includes the information about the community organizations; and the (3) self-referral database, which captures information of individuals who contacted the organization expressing interest in research. Pathway 1 measures the CAB's impact in the community through their interactions with URG focused community organizations and events (1A), leading to the identification of prospective URG research participants who are then contacted by the OREC staff to determine their interest and eligibility for IADRC (1B). Pathway 2 measures the CAB's direct impact on increasing URG research participation in which they identified personal and professional contacts at the community level (2A), who are then contacted by the OREC staff to determine their interest and eligibility for IADRC (2B). Based on their interest and eligibility, these prospective URG participants are then enrolled in the IADRC (Pathway 3A) or referred to an affiliated study (3B). If the prospective participants express interest in research participation but are not eligible for a study, they are then placed in a research registry for future contact (3C).

3 | RESULTS

3.1 | Overall impact

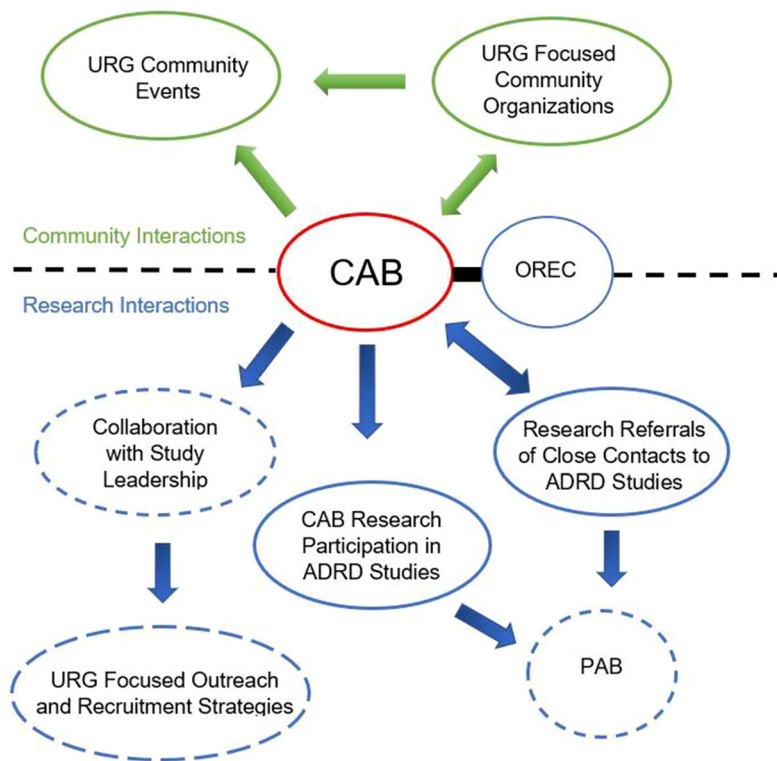
We measured the CAB's overall impact using the above framework from October 2019 to December 2022. They connected the IADRC to 28 URG faith-based and 3 civic organizations and participated in 95 URG-focused community events. Out of the 354 URG research referrals made to the IADRC OREC between October 2019 and December 2022, 267 referrals were directly referred by the CAB ($N = 36$) or were referred from community events in which CAB members organized or volunteered at ($N = 231$). Out of these 267 referrals, 34 were enrolled in IADRC and 2 were enrolled in the IU LEADS. Of note, both studies require the prospective participants to be willing to consider doing MRI and PET scans. As of December 2022, 30 out of the 34 enrolled participants have received a consensus diagnosis; more than half were cognitively normal (64.7%), with remainder having mild cognitive impairment (MCI) (17.6%) or early-stage AD (2.9%), and the majority were female (82.4%).

RESEARCH IN CONTEXT

- 1. Systemic Review:** We conducted a comprehensive literature review in PubMed by searching for relevant keywords about community engaged recruitment strategies focused on increasing underrepresented groups (URGs) Alzheimer's disease (AD) neuroimaging research participation. We cited relevant literature.
- 2. Interpretation:** With the growing number of AD neuroimaging research studies needing large, diverse cohorts, there is an urgent need for URG-focused recruitment strategies and methodology to measure the return on investment of these strategies. We highlight how a community advisory board-researcher partnership can accelerate URG study enrollment in AD neuroimaging research, and outline a conceptual model which describes the pathways by which this partnership can impact URG study enrollment. We also describe a database infrastructure designed to track this return on investment of this partnership.
- 3. Future Directions:** This model will be expanded to include AD neuroimaging recruitment strategies incorporating URG study participants as referral sources and increasing enrollment of URG participants with cognitive impairment.

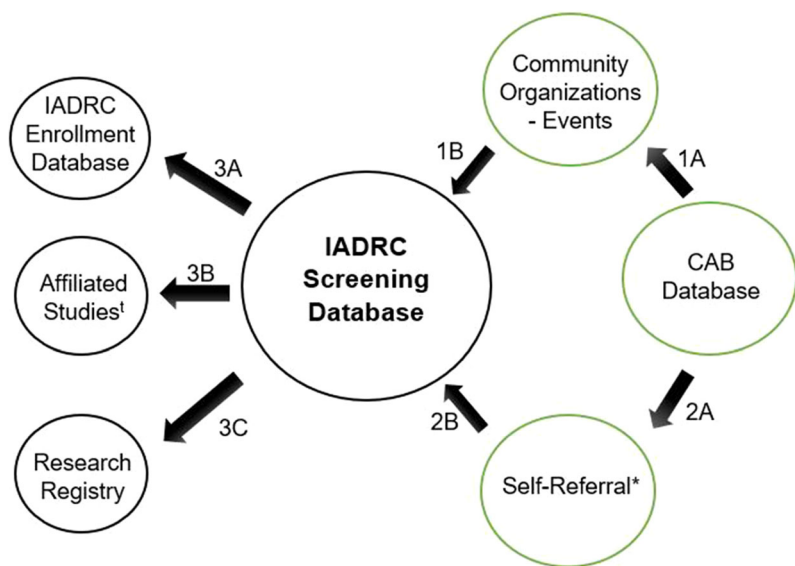
3.2 | Strategic impact

The CAB provided strategic input for two affiliated studies, the NIA IADRC P30 administrative supplement AD-REACH (Promoting Cultural Awareness and Diversity in Research about Alzheimer's Disease and Cognitive Health)¹⁰ and the IU LEADS¹¹ diversity supplement. AD-REACH is a mixed-methods study designed to explore Black older adults' perceptions about ADRD biomarker research with the aim of developing recruitment strategies to increase ADRD biomarker research participation. CAB members participated in focus groups to discuss the facilitators and barriers to participation of Black older adults in AD biomarker research. These data were integral to designing the AD-REACH survey which was administered to 399 community dwelling Black, and non-Hispanic White older adults living in the Indianapolis metropolitan area. The main findings from the AD-REACH survey were that Black older adults were: (1) more hesitant than White older adults to participate in a neuroimaging study (37% vs. 19%); (2) if hesitant, were willing to reconsider their decision with more study information; and (3) were more likely than White older adults to be concerned about study risks (31%) and trustworthiness of researchers (35%). These findings are now being incorporated into the IADRC recruitment strategies and new recruitment materials are being developed to address these concerns.



ADRD: Alzheimer's Disease and Related Dementias
 CAB: Community Advisory Board
 OREC: Outreach, Recruitment, and Engagement Core
 PAB: Participant Advisory Board
 URG: Underrepresented Group

FIGURE 1 Conceptual model of how CABs can accelerate diversity in AD research studies. AD, Alzheimer's disease; CAB, Community Advisory Board.



*Self-referrals include CAB members and community at large.
 ¹Affiliated Studies: IU-LEADS
 Green: Community Engaged Research

FIGURE 2 Database infrastructure to measure impact of the CAB-researcher partnership. CAB, Community Advisory Board.

The LEADS is a National Institute on Aging (NIA)-funded multi-site study examining the clinical phenotypes, neuroimaging markers, and fluid biomarkers in a cohort of participants with early-onset AD (EOAD).¹¹ Since the IU LEADS site did not have a study-specific

CAB, the IADRC CAB identified a specific CAB member who would work directly with the IU LEADS leadership and staff. This CAB collaborator met with the IU LEADS diversity supplement (funded by the Alzheimer's Association) leadership to identify opportunities to

integrate LEADS recruitment with the CAB and OREC URG-focused recruitment strategies. Thirty-two URG referrals were made to LEADS, with more than half ($N = 18$, 56.3%) being direct CAB referrals or from community-based events involving the CAB. Out of these 18 referrals, two were enrolled in LEADS and had a consensus diagnosis of normal cognition.

4 | DISCUSSION

We showed that the IADRC CAB-researcher partnership resulted in measurable impact on URG study enrollment. Earlier studies have described how CABs can facilitate partnerships with URG focused organizations and advise researchers on how to address barriers to participation.^{12,13} We are now building on this earlier work by developing a conceptual framework to characterize the various pathways of this partnership and demonstrating how each of these pathways can lead to measurable increases in URG research enrollment.

One other key aspect of our model (Figure 1) is the duality of the CAB-researcher partnership. In community interactions, the CAB serves as the facilitator between the community and researchers (represented by OREC), whereas in the research interactions, the OREC serves as the facilitator between the researchers in the rest of the center and community (represented by the CAB). This dynamic of “partnership” requires trust between both parties and willingness of each partner to advocate for each other to increase trust levels between the diverse communities and researchers.^{14–16} As the number of AD studies affiliated with the NIA-funded ADRC network expands, strategic synergy of these studies is essential to ensure a unified messaging about the value of AD research participation is being communicated to these diverse communities.

A major limitation is that the predominant racial/ethnic minority group in Indiana identifies as African American/Black and our strategies still resulted in predominantly female enrollment. The applicability of our findings to other URGs and how to expand African American/Black enrollment, especially among males, needs to be examined. Also, we were not able to compare the return on investment for the CAB-focused recruitment strategies to other types of recruitment strategies, such as identification of eligible individuals through electronic health records, clinical referrals, or social media outreach. Furthermore, factors which may have affected our return on investment on enrollment include: (1) this survey being implemented during the height of the coronavirus disease 2019 (COVID-19) pandemic during which enrollment activities were paused; (2) requirement for willingness to do neuroimaging; and (3) 39% of our outreach events were virtual, which is a much more challenging venue to sign up research participants. We will need to expand our database infrastructure to compare these methodologies. Finally, we developed our model utilizing the IADRC infrastructure; the relevance of our work to other ADRCs or sites without an ADRC needs to be further examined.

In summary, we have outlined a framework for how a CAB-researcher partnership can accelerate diversity in AD neuroimaging research. This framework and how we measured its impact on enrollment can be modified and tested at other sites. Future directions include expansion of our conceptual model to include a proposed URG focused Participant Advisory Board (PAB).¹⁷ A PAB will provide invaluable input about the participant experience in the IADRC and affiliated studies and could also be a potential source of successfully engaging prospective URG participants. Also, our CAB-based recruitment strategies enrolled mostly cognitively normal participants. Incorporating approaches designed to identify cognitively impaired individuals, such as strategically placed satellite memory clinics in the diverse communities,^{17,18} into our current model will be important to test whether this strategy can increase representation of cognitively impaired URG research participants.

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CONFLICT OF INTEREST STATEMENT

No conflicts of interest are present for any of the authors. Author disclosures are available in the [supporting information](#).

CONSENT STATEMENT

All human subjects provided informed consent for this report.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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APPENDIX A

Collaborators: Indiana Alzheimer's Disease Research Center Community Advisory Board (IADRC CAB): Ralph Richards, Pastor Christopher Campbell, Mollie Richards, Shokrina Beering, Michelle Bellamy, Denise Harrington-Jones, Patricia Haskett, Lynda Montgomery, Minister Hank Mosley, Pastor Douglas Tate, Harolyn Torain, Dr. Pamella Shaw, Anita Harden, Vanessa Riding, Pastor James Carroll, Pastor David Bacon, Harold Bell.