

This preprint article (before peer review) has been accepted for publication in *The Journals of Gerontology: Series A*, published by Oxford University Press. The final authenticated version is available online at:

<https://doi.org/10.1093/gerona/glad259>

Title:

Multi-sectoral collaborations to increase recruitment and retention of diverse older adults in biomedical research

Authors and Affiliations:

Roger Wong, PhD, MPH, MSW

Department of Public Health and Preventive Medicine, Norton College of Medicine, SUNY Upstate Medical University, Syracuse, NY, USA

Jason Rafael Grullon

Norton College of Medicine, SUNY Upstate Medical University, Syracuse, NY, USA

Sarah Elizabeth McNamara, MS

Department of Geriatrics, SUNY Upstate Medical University, Syracuse, New York, USA

Nancy Hovey Smith, MA

NHSmith Consulting, Manlius, New York, USA

Colleen Anne Dillenbeck, MA

Department of Geriatrics, SUNY Upstate Medical University, Syracuse, New York, USA

Kathy Royal

Department of Geriatrics, SUNY Upstate Medical University, Syracuse, New York, USA

Sharon Anne Brangman, MD

Department of Geriatrics, SUNY Upstate Medical University, Syracuse, New York, USA

Corresponding Author:

Roger Wong

2263A Weiskotten Hall

766 Irving Avenue

Syracuse, NY 13210

Phone: 631-533-0163

Email: WongRo@upstate.edu

Main Text Word Count:

3493/5200

Number of Data Elements:

4/5

ABSTRACT

Background:

Older adults, especially racial and ethnic minorities, are historically underrepresented in biomedical research. This study summarizes the development and assesses the impact of a review board involving a multi-sectoral group of stakeholders with the goal of increasing the diversity of older adults in biomedical research.

Methods:

A 25-member board of community members, caregivers, researchers, and clinicians from Upstate New York reviewed three projects presented by researchers, clinician-scientists, and a pharmaceutical company between January and December 2022. For each biomedical research project, the reviews provided guidance to increase the recruitment and retention of diverse older adults engaged in the study. Review board members and presenters completed surveys to provide feedback on their experience in this collaboration.

Results:

There was consistent positive feedback from all members and presenters. From member surveys, feedback trended positive in meetings throughout the year. Several community members and caregivers initially indicated discomfort in expressing their views, however, these concerns subsided over time. Presenters had a very positive experience in the review board's impact on their recruitment strategy and study design, and therefore very likely to use this service again. Recommendations were made to adjust membership criteria, presentation format, and funding needed to sustain this effort.

Conclusions:

Lack of diversity for older adults represented in biomedical research contributes to ethical and generalizability ramifications. The positive feedback from all stakeholders in our multi-sectoral board offers a promising structure for developing similar strategies to increase research diversity within and beyond biomedical aging research.

Keywords: Community Based Participatory Research, Diversity, Health Disparities, Recruitment, Research Engagement, Retention

INTRODUCTION

Older adults, especially from racial-ethnic minority groups, have traditionally been underrepresented and excluded from various aspects of research. Multiple studies have highlighted that racial-ethnic minorities lack representation in biomedical aging research funded by the National Institutes of Health (NIH) (1-3). These inclusion gaps are conspicuous, particularly in the study of Alzheimer's disease and related dementias, other neurodegenerative diseases, cancer, and diabetes. White adults represent an average of 70-80% of the study cohorts compared to single-digit percentages among Black and Hispanic adults (1). In 2020, national headlines elucidated this disparity by drawing attention to the controversy around the United States (U.S.) Food and Drug Administration (FDA) approval of Aducanumab and the study's inappropriately small number of racial-ethnic minority groups enrolled to treat Alzheimer's (4). More broadly, White study participants account for the over-representative majority of those enrolled in biomedical randomized clinical trials (5,6). As a result, research questions related to disease etiology, prevention, and treatment are generalizable for predominantly White and non-Hispanic individuals. This is of concern because older racial-ethnic minority groups have a disproportionately higher risk for many comorbidities including diabetes, heart disease, and hypertension (7).

Inclusive recruitment strategies and representation are a public health imperative that merits attention. In the pursuit of this public health goal, one would find biomedical-related inclusivity and partnerships, at all stages, as a vital centerpiece. By dispelling diversity equity and inclusion misconceptions within the biomedical industry, a shared understanding and united mission can be achieved (8). Beyond the respective ethical and moral dimensions, financial pragmatism is a mutual concern for all stakeholders. If left unaddressed, the projected U.S. healthcare cost is likely to rise from \$320 billion in 2022 to \$1 trillion in 2040 (9). Early implementation of diverse recruitment strategies can mitigate long-term costs by ensuring accurate decision-making at varying levels, reducing the need for expensive pivotal studies on ineffective treatments (8,10). Greater scientific inclusivity would lead to more representative clinical trials, improved study validity, and even a widened market opportunity. These inclusive interventions have the potential to save human lives and taxpayer dollars incurred by healthcare disparities.

On a deeper level, a multitude of motivations and tensions perpetuate among the stakeholders in biomedical research for older adults. For instance, consumers and advocates in the lay community are motivated by altruism, such as finding a cure to a disease (11,12), but many racial-ethnic minority community members distrust the medical, research, and pharmaceutical communities from historical injustices (e.g., Tuskegee Study) and persistent discrimination in health care settings (13,14). Research and clinical institutions are motivated to produce high-impact research but at minimal financial cost and time investment. Pharmaceutical companies are motivated to develop profitable drugs for shareholders, but also pressured to do public good by enacting fair drug prices and developing pharmaceutical solutions to devastating rare diseases — that may not be profitable (15).

Despite these differences across each sector, stakeholders share the common goal of wanting to achieve optimal health for all populations. Because of varying motivations and tensions across the lay community, researchers, clinicians, and pharmaceutical companies, there are limited opportunities to interact and accomplish this shared goal. Thus, we have three objectives in this paper. First, we summarize our development of a review board involving a multi-sectoral group of stakeholders to increase the diversity of older adults in biomedical

research. Second, we share the results of this review board from the perspectives of each sector. Third, we discuss the strengths, weaknesses, and opportunities for this novel approach toward increasing research diversity within and beyond biomedical aging research.

METHODS

Community Research Recruitment Accelerator

Our Community Research Recruitment Accelerator (CRRA), which we describe in this current study, mimics aspects of community-based participatory research (CBPR). Here community members have a voice and become deeply engaged in the scientific research process, such as in conceptualizing the study and providing recommendations for the study design. CBPR is often a valuable approach as it frequently engages a diverse group of community members who may have been historically disenfranchised in research that may not have outcomes relevant or meaningful to a community (16). Similarly, our CRRA is composed of caregivers, community leaders, clinical service providers, and researchers. This collective was developed so that researchers can receive guidance from the CRRA relative to increasing the diversity of racial-ethnic minorities in all stages of research development, from study conceptualization to dissemination.

Although the CRRA reviews research studies broadly in the field of aging, most of the focus thus far has concentrated on studies related to cognitive impairment due to the elevated risk for older populations. At least one week in advance before each meeting with a researcher seeking guidance, materials are distributed to the CRRA, such as recruitment flyers and the presenters' lecture slides. These research materials summarize the study's protocol and diversity goals. During the one-to-two hour meetings, a researcher presents a study that has generally not started active participant recruitment or is in the early phases of recruitment. The researcher's presentation is followed by a question-and-answer session between the researchers and the CRRA membership, in which clarifying questions are answered. Once all questions are answered, the researchers leave the meeting and the CRRA members provide in-depth feedback on the recruitment and retention approaches presented for the study. This offers more authentic feedback given that the researchers are not present, and responses are aggregated to maintain anonymity. After the meeting, feedback is consolidated and sent to the CRRA membership to confirm and provide additional responses, an approach similar to the member-checking technique commonly used in qualitative research. Thus, the overall goal of the CRRA is to provide recommendations to researchers to ensure that their research approaches reflect and address the interests, concerns, and challenges of the intended study participants from all communities. All community members and caregivers were also offered a modest stipend for their time and service.

Data Collection

To date, the CRRA has reviewed three projects between January and December 2022 using an online meeting platform. After each meeting, CRRA participants completed an optional feedback survey, which primarily consisted of Likert scale questions and several short open-ended questions on ways to improve the CRRA. To protect respondent identity in the survey, caregivers and community members were combined. Feedback from researchers and clinicians were also aggregated. Several months after presentations occurred, all presenters were asked to complete a survey that primarily consisted of Likert scale questions as well as short open-ended

questions on strengths, limitations, and opportunities for the CRRA. Finally, a demographic survey was administered to all CRRA members in January 2023.

Analysis Plan

All data were analyzed in Stata 17 (StataCorp LLC, College Station, TX, USA). This study was approved by the SUNY Upstate Institutional Review Board for the Protection of Human Subjects (#1988108-1).

RESULTS

Community Research Recruitment Accelerator Member Characteristics

Among the 25 CRRA members, 36% (N=9) are community members, 36% (N=9) researchers, 16% (N=4) caregivers, and 12% (N=3) clinicians. The community members hold multiple distinct roles, such as ministers/pastors, social workers, and outreach liaisons. The researchers also hold a variety of roles, such as college faculty (three different private and public universities represented) and research support staff, such as study recruiters and clinical trial coordinators. Whereas the caregivers served as directors, organizational co-founders, and support group facilitators. The clinicians involved were all clinician-scientists engaged in multifaceted studies involving older adults.

The mean age was 59.8 years (standard deviation: 12.7, range: 30-79). Most respondents self-identified as either non-Hispanic White (44%, N=11) or non-Hispanic Black (44%, N=11). The rest self-identified as Hispanic/Latino (8%, N=2) or Asian (4%, N=1). Majority of the members also self-identified as female (72%, N=18) with the remainder self-identifying as male (28%, N=20). In addition, most members reported having attained a graduate degree (80%, N=20). A few others marked their highest education as an undergraduate degree (8%, N=2) or high school graduate (8%, N=2). While just one person stated their highest education as “some college” (4%, N=1).

CRRA Member Feedback

Project One

The first project was presented by a team of researchers seeking to recruit participants primarily from the Upstate New York region for an Alzheimer’s study. There were five completed surveys, in which three were from caregivers/community members and two were from researchers/clinicians (Table 1). Both researchers/clinicians reported they felt “very” prepared to participate in the CRRA meeting, whereas all caregivers/community members reported “somewhat” prepared based on the materials sent in advance. All respondents agreed they understood the information presented by the researchers, with a community member elaborating they were surprised at their understanding despite being non-clinical. Regarding their ability to share their views or comments during the meeting, most respondents reported “very able” (60%), however, two caregivers/community members reported “somewhat able” (40%). They elaborated these discussions were a learning curve, or that they felt intimidated because the discussion leaned toward the research or clinical members. All members also agreed they felt “prepared” (60%) or “somewhat prepared” (40%) to review and provide feedback on future studies. One of the caregivers/community members also expressed that getting more CRRA experience will allow them to ease their fears from intimidation.

Project Two

The second project was presented by a clinician-scientist seeking to recruit older adults from the Upstate New York region into a diabetes study. There were 10 completed surveys, with half from caregivers/community members and half from researchers/clinicians (Table 1). All researchers/clinicians reported they felt “very” prepared to participate in the CRRA meeting, whereas several caregivers/community members reported “somewhat” prepared, in which multiple members commented they appreciated the materials that were sent in advance. All respondents agreed they understood the information that was presented. In response to their ability to share their views or comments during the meeting, most respondents reported “very able” (80%), however, two caregivers/community members reported “somewhat able” (40%). One caregiver/community member commented that they were not able to express their opinions unless prompted by the moderator. However, multiple researchers/clinicians commented they actively scaled back their comments to allow the caregivers/community members to share their views more. All respondents also agreed they felt “prepared” (80%) or “somewhat prepared” (20%) to review and provide feedback on future studies.

[Table 1]

Project Three

The third project was presented by a pharmaceutical company seeking guidance to recruit and retain diverse older adults nationally into an Alzheimer’s treatment clinical trial. This project was split into four meetings that centered on a specific theme: study overview, protocol and patient experience, community outreach, and caregiver experience. Only the last three meeting themes solicited feedback, therefore surveys were not administered for the first meeting. Over time, from the first meeting until the last meeting, each evaluation item trended towards increasingly positive feedback (Table 2).

The first meeting was a presentation that provided context on Alzheimer's and the mechanism for the proposed pharmaceutical drug to treat the disease. The second meeting solicited feedback after a presentation that described the protocol for the pre-screen, main screen, and treatment period. Both the caregivers/community members and researchers/clinicians wrote they valued the graphics included in the presentation that visualized and detailed each step throughout the study. One caregiver/community member commented they appreciated how the pharmaceutical company genuinely appeared to respect and incorporate the feedback they received. The third meeting solicited feedback after a presentation on their proposed recruitment activities in community outreach events. Nearly all the open-ended comments in the feedback were added by researchers/clinicians, who expressed they appreciated the clear presentation slides and a list of specific questions sent in advance of the meeting, which allowed them enough time to prepare and provide more constructive feedback. The final meeting solicited feedback on the experience of the caregiver, which is generally necessary for studies in which the study participant has cognitive impairment. There were few responses for the feedback survey, however, one caregiver/community member wrote they also appreciated the presentation and questions were sent in advance to allow them to prepare for the meeting.

[Table 2]

Presenter Feedback

Overall, each presenter had a very positive experience based on all evaluation criteria that covered topics on general satisfaction, recruitment strategy impact, study design impact, and future adoption (Table 3). When asked to describe changes in their recruitment strategy based on CRRA feedback, presenters noted they had revised their recruitment flyers and were developing a video to demonstrate study procedures, such as magnetic resonance imaging. Due to a multi-centered trial, the pharmaceutical company also noted that differences in each community would necessitate a tailored recruitment approach for community engagement.

Regarding study design changes, one presenter marked “not applicable” because their procedures could not be modified due to existing grant funding and collaboration with another university. Another presenter mentioned they would collect additional race-based measures and provide information to local resources when participants are debriefed. The pharmaceutical company discussed they would now provide additional resources to the participant and caregiver to maximize study retention, develop a chat box to answer quick questions, create a calendar to track visits, and create a separate simplified informed consent form to be more comprehensible for a lay audience.

In response to questions on future adoption, all presenters marked they would very likely recommend the CRRA to colleagues, utilize the CRRA for another project, and incorporate CRRA services into a grant budget. One of the presenters clarified they were highly interested in allocating funds for the CRRA but added a caveat — CRRA may not be appropriate for multi-centered studies due to differences in community partnerships at each site.

[Table 3]

All presenters were also asked to comment on strengths, weaknesses, and opportunities for the CRRA (Table 4). The presenters highly valued the ability to directly engage and address the needs of the community instead of making assumptions about how the research would serve the community. Diverse backgrounds and experiences in the CRRA membership were also repeatedly discussed as a major strength, which enabled the presenters to better understand issues they were unfamiliar with. For example, one of the studies offered respite care to alleviate caregiver burden. However, the presenter did not realize that many community members distrust respite care services or did not find this benefit useful.

Several weaknesses were also noted by the presenters. Particularly from the initial meetings, presenters felt minimal research knowledge among the caregivers and community members was problematic, and the membership should include only those that have participated in research before. Two of the projects included recruitment at multiple sites, which the presenters suggested may be a weakness because each site has unique needs. Scheduling was also noted to be a weakness for a large group of 25 CRRA members and multiple presenters during several meetings.

Finally, opportunities to improve the CRRA were shared. All presenters commented that the services provided by the CRRA need to be continued, particularly through financial support. Several presenters also commented that the presentation format could be potentially adjusted in the future, such as allowing more breaks to answer questions and receive real-time feedback.

[Table 4]

DISCUSSION

This study discusses our development of a multi-sectoral board of community members, caregivers, clinicians, and researchers to increase the diversity of older adults in biomedical research. Our results indicate positive feedback from all stakeholders, with an increasingly positive trend as the meetings progressed throughout the year. Not surprisingly, researchers and clinician-scientists felt very prepared and more comfortable in offering comments during meetings. As evidenced from the first meeting, community members initially had discomfort in expressing their views and comments, but these fears from intimidation eased over time by the final meeting. From the start to lessen potential intimidation, CRRA members purposely used first names and not their academic or professional titles. In short, openness was cultivated to enhance cooperative and effective discourse from a broad array of stakeholders.

The efficacy of CBPR approaches should not be overlooked. A 10-year recent systematic review reported that more than 85% of examined studies employing CBPR methods claimed statistically positive outcomes in the rate of accrual of racial-ethnic minority communities for clinical trials (17). As research-community partnerships gradually spread in popularity, more is elucidated regarding research engagement and optimization of a CBPR approach for specific vulnerable populations, such as older adults — particularly in trust-building (18-20). Another recent systematic review also found that involvement of older adults in the research process provided several notable advantages, such as developing a deeper appreciation of older adult issues, making more inclusive decisions, and giving a platform to hear directly from those marginalized (21).

Previous studies involving a community advisory board with partnerships between community members and researchers were found to be a beneficial strategy to increase the diversity of older adults for Alzheimer's biomedical studies (3,22-24). In contrast to prior approaches, our CRRA is distinct in that our membership encompasses more representation from diverse stakeholders and a formal structure that offers services to multiple biomedical studies upon request. Multiple presenters noted the inclusion of diverse community members and caregivers was a tremendous asset, as they could directly seek their guidance to enable their research to be more patient-centered. Inclusivity of community members in all phases of research is repeatedly emphasized as an imperative to increase engagement, foster community trust, and improve community health (25,26). To some researchers, the engagement of community partners at all stages is a vital driver of success in the CBPR model and, when excused, can lead to lackluster results (27,28).

There are opportunities to improve and expand on the CRRA. There were 25 active CRRA members. However, comments from caregivers and community members mentioned there were instances they felt it was difficult to contribute because there were at times multiple people talking at once. A presenter had also commented that a large group made scheduling difficult. Although the size of a community advisory board may vary depending on the research-related objectives and specific goals, some have reported 10-16 members as the ideal range (29). They also stated that any greater number of members has been reported as a greater challenge to facilitate, while any less may lead to low attendance of participants at some meetings. Second, a large duration of the initial meetings was focused on explaining basic research methods instead of providing feedback for the presented project. Caregivers and community members noted this was because they were unfamiliar with research procedures. Likewise, one of the presenters also suggested the lack of research experience among several members was a weakness. They also suggested that members should only be included if they have participated in research studies

before or at least have a basic understanding of research methodology. Third, there was consistent feedback from all members that materials and proposed questions sent one week in advance were very beneficial. This allowed everyone to review the presentation, write down questions, and brainstorm initial feedback in preparation for each meeting. Therefore, this strategy was strongly recommended to continue in future iterations.

For future studies, our CRRA should be considered for replication in other communities, beyond biomedical aging research. In addition, research is needed to increase diversity not only for race and ethnicity, but in other aspects, such as sex, urbanicity, and disability status. To ensure long-term sustainability of similar community advisory boards, an exploration of a fee-for-service model may be warranted. All presenters supported the continuation of our CRRA while one presenter even mentioned fees for this service should be budgeted in grant proposals.

Our study has several limitations. First, most members were from a mid-sized urban community in Upstate New York. The approach we discuss in this paper may not be generalizable to other settings, such as rural areas that often lack representation in biomedical research. Second, our approach aims to increase diversity in biomedical aging research, though our current focus is primarily limited to increasing the representation of Black older adults given the racial-ethnic composition of our membership. Third, our findings reflect comments and changes that were made within one year due to grant restrictions that funded this endeavor, but future research will be needed to examine more long-term changes in participant diversity. Despite these limitations, this study is a noteworthy contribution to the field because to our knowledge, this is the first circumstance in which community members, caregivers, researchers, clinicians, and even a pharmaceutical company have gathered to discuss approaches to increase diversity in biomedical research.

CONCLUSION

At the federal level in the United States, multiple provisions have sought to significantly increase representation of underrepresented populations in biomedical research. For instance, the NIH Revitalization Act of 1993 mandated all federally funded research to include women and underrepresented groups as participants in clinical trials. And yet, after many years, gender and racial-ethnic disparities remain pervasive in clinical trials and publications (30,31). In 2022, the FDA also bolstered the federal commitment by drafting guidance for the pharmaceutical industry to increase underrepresented racial-ethnic enrollment in clinical trials (32).

The ethical and generalizability ramifications of this lapse in representation among clinical research participants are insidious, especially among vulnerable populations. Biomedical research in aging thus has a need for evidence-based inclusive-centered approaches. This study underscores one solution, as evidenced by our CRRA, a review board, where stakeholders unite to address research recruitment challenges. More multi-sectoral collaborations are still in urgent need to meaningfully further recruitment science, quality research, and patient-centered outcomes for all.

FUNDING

This work was supported by the National Institute on Aging (grant R24 AG065163, PI: Mary Sano), and this project was made possible through collaborations with Icahn School of Medicine at Mount Sinai and Recruitment Partners.

AUTHOR CONTRIBUTIONS

R.W., S.E.M., N.H.S., C.A.D., K.R., and S.A.B. conceptualized and designed the study. R.W. and J.R.G. analyzed the data. All authors contributed to all sections of the manuscript and approved the final version of the article.

CONFLICT OF INTEREST

None declared.

REFERENCES

1. Brangman SA. Achieving diversity in study populations: The importance of community engagement. *J Am Geriatr Soc.* 2022;70(11):3080-3086. doi:10.1111/jgs.18043
2. Denny A, Streit M, Stock K, et al. Perspective on the “African American Participation in Alzheimer Disease Research: Effective Strategies” Workshop, 2018. *Alzheimers Dement J Alzheimers Assoc.* 2020;16(12):1734-1744. doi:10.1002/alz.12160
3. Wong R, Amano T, Lin SY, Zhou Y, Morrow-Howell N. Strategies for the Recruitment and Retention of Racial/Ethnic Minorities in Alzheimer Disease and Dementia Clinical Research. *Curr Alzheimer Res.* 2019;16(5):458-471. doi:10.2174/1567205016666190321161901
4. Manly JJ, Glymour MM. What the Aducanumab Approval Reveals About Alzheimer Disease Research. *JAMA Neurol.* 2021;78(11):1305-1306. doi:10.1001/jamaneurol.2021.3404
5. Alegria M, Sud S, Steinberg BE, Gai N, Siddiqui A. Reporting of Participant Race, Sex, and Socioeconomic Status in Randomized Clinical Trials in General Medical Journals, 2015 vs 2019. *JAMA Netw Open.* 2021;4(5):e2111516. doi:10.1001/jamanetworkopen.2021.11516
6. Turner BE, Steinberg JR, Weeks BT, Rodriguez F, Cullen MR. Race/ethnicity reporting and representation in US clinical trials: a cohort study. *Lancet Reg Health Am.* 2022;11:100252. doi:10.1016/j.lana.2022.100252
7. Ahmed N, Conway CA. Medical and Mental Health Comorbidities Among Minority Racial/Ethnic Groups in the United States. *J Soc Behav Health Sci.* 2020;14(1). doi:10.5590/JSBHS.2020.14.1.11
8. Chaudhry MS, Spahn J, Patel S, et al. Myths about diversity in clinical trials reduce return on investment for industry. *Nat Med.* 2022;28(8):1520-1522. doi:10.1038/s41591-022-01858-4
9. Bhatt J, Davis A, Batra N, Rush B. US health care can't afford health inequities.
10. Oh SS, Galanter J, Thakur N, et al. Diversity in Clinical and Biomedical Research: A Promise Yet to Be Fulfilled. *PLoS Med.* 2015;12(12):e1001918. doi:10.1371/journal.pmed.1001918
11. Olsen L, DePalma L, Evans JH. Self-Interested and Altruistic Motivations in Volunteering for Clinical Trials: A More Complex Relationship. *J Empir Res Hum Res Ethics JERHRE.* 2020;15(5):443-451. doi:10.1177/1556264620914463
12. Brenman N, Milne R. Lived time and the affordances of clinical research participation. *Sociol Health Illn.* 2021;43(9):2031-2048. doi:10.1111/1467-9566.13374
13. Lambe S, Cantwell N, Islam F, Horvath K, Jefferson AL. Perceptions, knowledge, incentives, and barriers of brain donation among African American elders enrolled in an Alzheimer's research program. *The Gerontologist.* 2011;51(1):28-38. doi:10.1093/geront/gnq063
14. Hughes TB, Varma VR, Pettigrew C, Albert MS. African Americans and Clinical Research: Evidence Concerning Barriers and Facilitators to Participation and Recruitment Recommendations. *The Gerontologist.* 2017;57(2):348-358. doi:10.1093/geront/gnv118
15. Morgan SG, Bathula HS, Moon S. Pricing of pharmaceuticals is becoming a major challenge for health systems. *BMJ.* 2020;368:l4627. doi:10.1136/bmj.l4627
16. Idris MY, Korin M, Araya F, et al. Including the Public in Public eHealth: The Need for Community Participation in the Development of State-Sponsored COVID-19-Related Mobile Apps. *JMIR MHealth UHealth.* 2022;10(3):e30872. doi:10.2196/30872
17. Julian McFarlane S, Occa A, Peng W, Awonuga O, Morgan SE. Community-Based Participatory Research (CBPR) to Enhance Participation of Racial/Ethnic Minorities in

- Clinical Trials: A 10-Year Systematic Review. *Health Commun.* 2022;37(9):1075-1092. doi:10.1080/10410236.2021.1943978
18. Wright LA, King DK, Retrum JH, et al. Lessons learned from community-based participatory research: establishing a partnership to support lesbian, gay, bisexual and transgender ageing in place. *Fam Pract.* 2017;34(3):330-335. doi:10.1093/fampra/cmz005
 19. Teufel-Shone NI, Schwartz AL, Hardy LJ, et al. Supporting New Community-Based Participatory Research Partnerships. *Int J Environ Res Public Health.* 2019;16(1):44. doi:10.3390/ijerph16010044
 20. Nkimbeng M, Han HR, Szanton SL, et al. Exploring Challenges and Strategies in Partnering With Community-Based Organizations to Advance Intervention Development and Implementation With Older Adults. *The Gerontologist.* 2021;62(8):1104-1111. doi:10.1093/geront/gnab190
 21. James H, Buffel T. Co-research with older people: a systematic literature review. *Ageing Soc.* Published online February 10, 2022:1-27. doi:10.1017/S0144686X21002014
 22. Masoud SS, Glassner AA, Patel N, et al. Engagement with a diverse Stakeholder Advisory Council for research in dementia care. *Res Involv Engagem.* 2021;7(1):54. doi:10.1186/s40900-021-00297-8
 23. Sharma RK, Teng A, Asirof MG, Taylor JO, Borson S, Turner AM. Challenges and opportunities in conducting research with older adults with dementia during COVID-19 and beyond. *J Am Geriatr Soc.* 2022;70(5):1306-1313. doi:10.1111/jgs.17750
 24. Weiner MW, Veitch DP, Miller MJ, et al. Increasing participant diversity in AD research: Plans for digital screening, blood testing, and a community-engaged approach in the Alzheimer's Disease Neuroimaging Initiative 4. *Alzheimers Dement.* 2023;19(1):307-317. doi:10.1002/alz.12797
 25. Key KD, Furr-Holden D, Lewis EY, et al. The Continuum of Community Engagement in Research: A Roadmap for Understanding and Assessing Progress. *Prog Community Health Partnersh Res Educ Action.* 2019;13(4):427-434. doi:10.1353/cpr.2019.0064
 26. Han HR, Xu A, Mendez KJW, et al. Exploring community engaged research experiences and preferences: a multi-level qualitative investigation. *Res Involv Engagem.* 2021;7:19. doi:10.1186/s40900-021-00261-6
 27. Cyril S, Smith BJ, Possamai-Inesedy A, Renzaho AMN. Exploring the role of community engagement in improving the health of disadvantaged populations: a systematic review. *Glob Health Action.* 2015;8:10.3402/gha.v8.29842. doi:10.3402/gha.v8.29842
 28. Sheikhattari P, Shaffer E, Barsha RAA, et al. Building Capacity for Community-Academia Research Partnerships by Establishing a Physical Infrastructure for Community Engagement: Morgan CARES. *Int J Environ Res Public Health.* 2022;19(19):12467. doi:10.3390/ijerph191912467
 29. Kubicek K. Resource for Integrating Community Voices into a Research Study: Community Advisory Board Toolkit. *South Calif Clin Transl Sci Inst Grant UL1TR001855.*
 30. Geller SE, Koch AR, Roesch P, Filut A, Hallgren E, Carnes M. The More Things Change, the More They Stay the Same: A Study to Evaluate Compliance With Inclusion and Assessment of Women and Minorities in Randomized Controlled Trials. *Acad Med J Assoc Am Med Coll.* 2018;93(4):630-635. doi:10.1097/ACM.0000000000002027
 31. Henry BV, Chen H, Edwards MA, Faber L, Freischlag JA. A New Look at an Old Problem: Improving Diversity, Equity, and Inclusion in Scientific Research. *Am Surg.* 2021;87(11):1722-1726. doi:10.1177/00031348211029853

32. U.S. Food and Drug Administration. Diversity Plans to Improve Enrollment of Participants From Underrepresented Racial and Ethnic Populations in Clinical Trials; Draft Guidance for Industry; Availability. U.S. Food and Drug Administration. Published April 13, 2022. Accessed January 28, 2023. <https://www.fda.gov/regulatory-information/search-fda-guidance-documents/diversity-plans-improve-enrollment-participants-underrepresented-racial-and-ethnic-populations>

Table 1. Project One and Two Member Feedback

Evaluation Item	Project 1 (N=5)	Project 2 (N=10)
Member Type		
Caregiver or Community	60% (3)	50% (5)
Researcher or Clinician	40% (2)	50% (5)
Prepared to Participate		
Very prepared	40% (2)	70% (7)
Somewhat prepared	60% (3)	30% (3)
Not prepared	0% (0)	0% (0)
Understood Information About the Study		
Understood	100% (5)	100% (10)
Neutral	0% (0)	0% (0)
Did not understand	0% (0)	0% (0)
Able to Share Views and Comments		
Very able	60% (3)	80% (8)
Somewhat able	40% (2)	20% (2)
Not able	0% (0)	0% (0)
Prepared to Review and Provide Feedback on Future Studies		
Prepared	60% (3)	80% (8)
Somewhat prepared	40% (2)	20% (2)
Not prepared	0% (0)	0% (0)

Table 2. Project Three Member Feedback

Evaluation Item	Meeting 1: Protocol and Patient Experience (N=15)	Meeting 2: Community Outreach (N=8)	Meeting 3: Care Partner Experience (N=3)
Member Type			
Caregiver or Community	60% (9)	37.5% (3)	33.3% (1)
Researcher or Clinician	40% (6)	62.5% (5)	66.7% (2)
Prepared to Participate			
Very prepared	86.7% (13)	87.5% (7)	100% (3)
Somewhat prepared	13.3% (2)	12.5% (1)	0% (0)
Not prepared	0% (0)	0% (0)	0% (0)
Understood Information About the Study			
Understood	93.3% (14)	100% (8)	100% (3)
Neutral	6.7% (1)	0% (0)	0% (0)
Did not understand	0% (0)	0% (0)	0% (0)
Able to Share Views and Comments			
Very able	86.7% (13)	100% (8)	100% (3)
Somewhat able	13.3% (2)	0% (0)	0% (0)
Not able	0% (0)	0% (0)	0% (0)
Prepared to Review and Provide Feedback on Future Studies			
Prepared	66.7% (10)	87.5% (7)	100% (3)
Somewhat prepared	33.3% (5)	12.5% (1)	0% (0)
Not prepared	0% (0)	0% (0)	0% (0)

Table 3. Presenter Feedback

Evaluation Item	Project 1	Project 2	Project 3
General Satisfaction			
Overall Satisfaction in Supporting the Project			
Very satisfied	X	X	X
Somewhat satisfied			
Not satisfied			
CRRA Purpose is Clear			
Very clear	X	X	X
Somewhat clear			
Not clear			
Prepared to Present and Discuss Study Diversity Goals			
Yes		X	X
Somewhat	X		
No			
Experience was Efficient and Well-Organized			
Yes	X	X	X
Somewhat			
No			
Recruitment Strategy Impact			
Feedback was Helpful for Recruitment Strategy			
Very helpful	X	X	X
Somewhat helpful			
Not helpful			
Did / Will Implement Suggestions into Recruitment Strategy			
Yes	X	X	X

Not yet, but may			
No			
Study Design Impact			
Feedback was Helpful for Overall Study Design		N/A	
Very helpful	X		X
Somewhat helpful			
Not helpful			
Did / Will Implement Suggestions into Overall Study Design		N/A	
Yes	X		X
Not yet, but may			
No			
Future Adoption			
Likely to Recommend CRRA to Colleagues			
Very likely	X	X	X
Somewhat likely			
Not likely			
Likely to Utilize CRRA Again			
Very likely	X	X	X
Somewhat likely			
Not likely			
Would Allocate into Grant as a Fee-based Service			
Very likely	X	X	X
Somewhat likely			
Not likely			

Note. CRRA = Community Research Recruitment Accelerator, N/A = Not applicable.

Table 4. Strengths, Weaknesses, and Opportunities Feedback

Strengths	Weaknesses	Opportunities
Able to directly engage community stakeholders.	Community stakeholders have little experience with research.	Members can eventually advise on the strengths and weaknesses of future research projects.
Diversity of member backgrounds and experiences.	Feedback is not always generalizable for studies with multiple sites.	The CRRA will need to be financially supported because the work is critical.
Members identified issues that presenters lack understanding or awareness.	Scheduling a meeting is a challenge for a large group.	Administrative and/or contractual agreements can be better streamlined.
		More flexible presentation format, such as open Q&A, to hear real-time thoughts