

**Evidence-Based Strategies to Increase Racial and Ethnic Diversity in Clinical Trials of  
Alzheimer's Disease & Related Dementias (ADRD)**

by

**Samantha Rosenberg**

Bachelor of Science, University of Pittsburgh, 2018

Bachelor of Arts, University of Pittsburgh, 2018

Submitted to the Graduate Faculty of the  
Department of Behavioral and Community Health Science  
School of Public Health in partial fulfillment  
of the requirements for the degree of  
Master of Public Health

University of Pittsburgh

2024

UNIVERSITY OF PITTSBURGH

SCHOOL OF PUBLIC HEALTH

This essay is submitted

by

**Samantha Rosenberg**

on

April 22, 2024

and approved by

**Essay Advisor:** Steven M Albert, PhD, MA, MS, Professor, Behavioral and Community Health Science, School of Public Health, University of Pittsburgh

Essay Reader: Helena M VonVille, MLS, MPH, Research and Instruction Librarian, School of Public Health Library Liaison, Health Sciences Library System, University of Pittsburgh

Essay Reader: Kirk Erickson, PhD, Research Professor, Department of Psychology, Dietrich School of Arts and Sciences, University of Pittsburgh

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# **Evidence-Based Strategies to Increase Racial and Ethnic Diversity in Clinical Trials of Alzheimer’s Disease & Related Dementias (ADRD)**

Samantha Rosenberg, MPH

University of Pittsburgh, 2024

## **Abstract**

Public Health Significance: Given the rapidly aging and diversifying U.S. population, prevalence of Alzheimer’s disease and related dementias (ADRD) is projected to increase substantially in the coming decades. This demographic shift, coupled with persistent inequities in resource access and ongoing structural racism, is likely to exacerbate existing health disparities in ADRD burden for communities of color unless substantive systemic changes are implemented.

Background & Objectives: Despite the disproportionate impact on racial and ethnic minorities, these groups remain consistently underrepresented in ADRD research trials. Addressing this gap requires evidence-based recruitment strategies to enhance research participation among these populations. The overall goal of this essay was to identify such strategies; first through a review of the existing literature, and second in a secondary analysis of recruitment data from an ongoing ADRD trial.

Methods: A comprehensive literature review explored research participation prevalence among racial and ethnic minorities, factors influencing participation, and effective recruitment strategies or interventions. The secondary analysis examined recruitment data from an ongoing ADRD trial for older Black adults to evaluate the efficacy of various recruitment approaches.

Results: Results from the critical literature synthesis found several effective recruitment strategies including community-oriented outreach, diverse research team composition, word-of-mouth referrals, and monetary compensation. Results from the secondary data analysis

corroborated community outreach as an effective method for recruiting and retaining Black/African American older adults, while also highlighting the considerable financial investments required for such activities.

Implications: Future ADRD research trials should carefully select recruitment strategies based on study objectives and resource constraints. Prioritizing community outreach for participant recruitment is essential, while also balancing cost-effective alternatives such as traditional advertising. Overall, this essay found that recruitment science, in the context of ADRD research, is still in its early stages. Further research, in addition to meaningful engagement with community stakeholders, remains imperative to determine the most effective recruitment strategies. Institutional-level policies and initiatives play a pivotal role in disseminating valuable resources to researchers and monitoring clinical trial diversity over time.

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## Preface

I would like to express my sincere gratitude to all those who supported me in balancing work commitments and academic pursuits during the completion my Master's degree.

Thank you to my supervisor, Dr. Kirk Erickson, for his support throughout my graduate studies. My involvement in Dr. Erickson's research lab over the past several years has not only been enriching but also served as inspiration for multiple projects during my time as a graduate student. I am thankful for the opportunities he provided me to apply classroom knowledge to real-world projects.

I am also thankful to the members of my essay committee, Dr. Steven Albert and Helena VonVille for their invaluable contributions. Dr. Albert's guidance as an academic advisor has been instrumental, while Helena's continual support across multiple projects during my academic journey has been truly immeasurable. Their constructive criticism and insightful suggestions have significantly enhanced the quality of this essay.

To my family and friends, I extend my deepest gratitude for your endless love, encouragement, and understanding, especially during the most challenging moments. Your belief in me has been a constant source of strength and motivation, and I am forever thankful for your unwavering support.

Thank you to my partner, whose love, support, and belief in my abilities have kept me grounded throughout this entire journey. I can't thank you enough for all your time spent traveling on the PA Turnpike and all our time together talking over Facetime.

Finally, a special thank you to my cat, Luna, whose comforting presence was an absolute lifeline during times of stress.

## 1.0 Introduction

Age-related dementia refers to a decline in cognitive function that typically occurs as people age. It encompasses a range of conditions where individuals experience a gradual and progressive deterioration in memory, thinking, and reasoning abilities as a result of changes in the brain (Alzheimer's Association, 2024). Alzheimer's disease (AD) is the most common form of age-related dementia, but other types, such as vascular dementia, Lewy body dementia, and frontotemporal dementia (FTD), also fall under this category (U.S. Department of Health and Human Services [DHHS], 2024a). This essay will use the term Alzheimer's disease and related dementias (ADRD) to refer to these conditions collectively.

Recent evidence estimated that 6.9 millions Americans age 65 and older are currently living with Alzheimer's dementia (Rajan et al., 2021) and the number is expected to grow substantially over the next few decades. By 2030, it's estimated that the proportion of individuals age 65 and older will make up over 20% of the population, primarily due to the entirety of the baby-boom generation (born between 1946 and 1964) reaching this age bracket (Alzheimer's Association, 2024). Further, the population of older adults 65 and older is expected to reach 82 million in 2050, up from 58 million in 2022 (Alzheimer's Association, 2024). As the elderly population in America continues to grow, the main risk factor for Alzheimer's dementia – age – will drive an increase in both new diagnoses and existing cases. Projected estimates suggested that by 2060, the population of individuals aged 65 and older living with Alzheimer's dementia will reach 13.8 million (Rajan et al., 2021).

It's crucial to acknowledge that the risk of ADRD isn't evenly distributed across all demographic groups in the United States, and there is significant variation in the burden

experienced, particularly by race and ethnicity. Research indicated that the prevalence of Alzheimer's dementia among adults over 65 was approximately 19% for Black older adults and 14% for Hispanic older adults, compared to 10% for White older adults (Rajan et al., 2021). Moreover, studies suggested that Black older adults were roughly twice as likely to have ADRD compared to their White counterparts, with Hispanic older adults being about 1.5 times as likely as White older adults (Manly et al., 2022; Rajan et al., 2019). These disparities were attributed to historic and ongoing structural racism, which have created barriers to accessing equitable resources and opportunities relative to White Americans. Socioeconomic stressors, environmental obstacles, and discriminatory practices have further compounded the social and biological stress experienced by Black Americans, a phenomenon known as allostatic load (Savold et al., 2023). This heightened stress serves as a risk factor for a range of chronic conditions, including cognitive decline and age-related diseases (American Psychological Association [APA], 2012).

Furthermore, disparities in healthcare access led to higher rates of missed or delayed diagnoses of ADRD among Black and Hispanic older adults compared to White older adults. Data from Medicare beneficiaries aged 65 and older indicated that Alzheimer's or another dementia has been diagnosed in 10.3% of White older adults, 12.2% of Hispanic older adults, and 13.8% of Black older adults (Matthews et al., 2019). However, these percentages likely underestimate the true burden for Hispanic and Black populations since prevalence studies, which capture all dementia cases regardless of healthcare utilization, suggested even higher rates (Alzheimer's Association, 2024). As the number of AD cases is projected to increase substantially over the coming decades, so too is racial and ethnic diversity. Projections for older adults between 2018 and 2040 anticipate a 75% increase in the American Indian population, an 88% increase in the Black population, a 113% increase in the Asian population, and a 175% increase in the Hispanic

population, compared to a 32% increase in the White population (Administration for Community Living [ACL], 2021). This demographic shift, coupled with persistent inequities in resource access and ongoing structural racism, is likely to worsen existing health disparities in ADRD burden for communities of color unless substantive systemic changes are implemented.

Recognizing the pressing and escalating burden of ADRD, the National Plan to Address Alzheimer's Disease was established in 2011. A central component of this initiative was the expansion of research aimed at preventing and treating ADRD (U.S. DHHS, 2023). Specifically, the plan underscored the need to address the challenge of enrolling individuals in clinical trials who reflect the diversity of the nation's population, particularly racial and ethnic groups at heightened risk for ADRD (U.S. DHHS, 2023). Research studies have long history of overlooking those experiencing the greatest disease burden. As far back as 1979, the Belmont Report highlighted the vulnerability of minority populations as research participants, noting their frequent exclusion (National Academies of Sciences, Engineering, and Medicine, 2016). Moreover, the National Institute on Minority Health and Health Disparities (NIMHD) acknowledged the historical reliance of clinical trials on predominantly White male participants, resulting in significant gaps in our understanding of diseases and conditions (U.S. DHHS, 2024b). This exclusion of racial and ethnic minorities from research participation has led to clinical and policy decisions that inadequately address the needs of all individuals.

The National Institutes of Health (NIH) Revitalization Act of 1993 established guidelines for the inclusion of women and racial/ethnic minorities in all NIH-funded clinical research, but despite these efforts, enrollment has still been low among these groups (NIH Revitalization Act, 1994). A systematic review of 101 global AD drug trials found that less than half of the included studies reported race/ethnicity data for enrolled participants (46 studies, 45.5%) and the median

reported percentage of White participants in all studies was 94.7% (Franzen et al., 2022). A similar systematic review looked at the documentation of race and ethnicity data from 49 randomized control trials (RCTs) on currently-marketed AD drug treatments and found that 59.2% of RCTs included any information on the race/ethnicity of participants (Canevelli et al., 2019). These reviews suggest that the true representation of racial and ethnic minorities in ADRD studies is masked by a significant underreporting of demographic information. To address this critical issue, it is imperative to develop and implement more robust reporting mechanisms for data pertaining to race and ethnicity.

All of this suggests a growing need for evidence-based recruitment strategies to enhance the recruitment of racial and ethnic minorities into ADRD research trials. The overall goal of this essay was to identify those strategies; first in a review of the existing literature (Chapter 2), and second in a secondary analysis of recruitment data from an ongoing ADRD trial (Chapter 3). Following that, Chapter 4 will discuss the overall conclusions from these findings and provide recommendations for future research.

## **2.0 Critical Literature Synthesis**

### **2.1 Introduction**

As discussed in the previous chapter, there has been a concerted effort to improve representation of racial and ethnic minorities in clinical research since the 1993 NIH Revitalization Act (NIH Revitalization Act, 1994). The overall goal of this literature synthesis was to describe the state of minority representation in ADRD research in the U.S. since then. More specifically, the objectives were to describe: 1) the prevalence of racial/ethnic minority recruitment and participation, 2) the barriers and facilitators to racial/ethnic minority recruitment and participation, and 3) strategies and/or interventions to improve racial/ethnic minority recruitment and participation.

### **2.2 Methods**

To complete this literature synthesis, modified guidelines from the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) were used (Page et al., 2021). A risk of bias assessment for included studies was not included due to time constraints.

#### **2.2.1 Inclusion and Exclusion Criteria**

To be eligible for the present synthesis, included studies needed to focus on ADRD research and address the objectives of this literature synthesis, including studies that described the

prevalence of racial/ethnic clinical trial diversity, barriers/facilitators to research participation, or an intervention/strategy to enhance research recruitment and retention efforts. Additionally, included studies were required to include or stratify by racial/ethnic minority subgroups. Eligible racial and ethnic minority groups were based on the NIH Guidelines for the Inclusion of Minorities in Clinical Research and include: African American or Black, American Indian or Alaska Native, Asian, Hispanic or Latino, and Native Hawaiian or Other Pacific Islander (US Department of Health and Human Services, 2001). Lastly, included studies needed to be conducted in the U.S. and after 1993, which reflects the year the NIH Revitalization Act was enacted. Reviews with an international focus were considered, but only included if the secondary studies were clearly stratified by country such that data could be extracted only from the U.S. studies.

Two types of publications were included in this synthesis: reviews and primary studies. Included reviews aimed to summarize existing literature as related to the three objectives and included systematic or scoping reviews, or reviews with clearly-defined methodological processes that can be reproduced. In contrast, primary studies described original research related to the present objectives, including qualitative methods such as focus groups, key informant interviews, photovoice, and community-based participatory research (CBPR), or quantitative methods such as surveys, secondary data analysis, and pre-test/post-test trials. This synthesis will sometimes refer to the studies that were included within a review. To avoid confusion, the studies discussed in the context of a prior review will be referred to as “secondary studies.”

Studies were excluded from the present synthesis if they failed to meet inclusion criteria, including a focus on caregivers or caregiving, ADRD treatment or prevention, or the reporting of race and ethnicity data in the absence of a recruitment/retention intervention. Additionally, studies were excluded if they were the wrong publication type (e.g. editorial, commentary, conference



proceeding/poster, etc.) or if the publication was already included as a secondary study within an included review.

### **2.2.2 Search Strategy**

The search strategy was developed in collaboration with an experienced health sciences librarian. The searches were conducted on September 22, 2023 and October 5, 2023 within the following three databases: Medline (Ovid), APA PsycInfo (Ovid), and Embase (Elsevier). A combination of Medical Subject Heading (MeSH) terms, title, abstract, and keywords were used to develop the initial Medline search which was checked against a known set of studies. The search was then adapted to search other databases. The full search strategy can be found in the [Supplemental Materials](#). A minor revision was made to the search filter and the Medline search was completed again on November 2, 2023 to ensure that all relevant studies were captured. Duplicates were removed after the initial search using the Amsterdam Efficiency Deduplication (AED) method (Otten, de Vries, & Schoonmade, 2019). EndNote (Clarivate) was used to store all citations found in the search process and to remove any duplicates not found using the AED method.

### **2.2.3 Selection Process and Data Extraction**

After duplicate references were removed, a multi-step approach for study selection was used. First, a single reviewer (the author of this essay) screened all titles and abstracts for the reviews only. Next, the same reviewer completed full text review for the reviews that passed initial screening and made final selections. The reviewer then created an inventory to document all of the

secondary studies that were included within the selected reviews. Finally, the reviewer screened all titles and abstracts for the primary studies and completed subsequent full text review. This time, however, the reviewer compared each primary study to the inventory created previously and excluded any primary study that was already included as a secondary study. The full inventory for all included studies (review, primary, and secondary) can be found in the [Supplemental Materials](#).

To summarize all included studies, data extraction was guided by PRISMA for the reviews and by the Consolidated Standards of Reporting Trials (CONSORT) for the primary studies. For the reviews, the following data were extracted: review type, objectives, inclusion criteria, databases used, critical appraisal methods, number and time frame of included studies, and overall findings. For the primary studies, data were extracted for: objectives, trial design, participant characteristics, sample size, components for analysis (i.e. independent and dependent variables), and overall findings. Additionally, all studies were examined for data relevant to the three objectives of the present synthesis: statistics on the prevalence of racial/ethnic minority research participation, barriers/facilitators to research participation among racial/ethnic minorities, and recruitment strategies to improve racial/ethnic minority participation. All extracted data are summarized, tabulated, and described in the following results section.

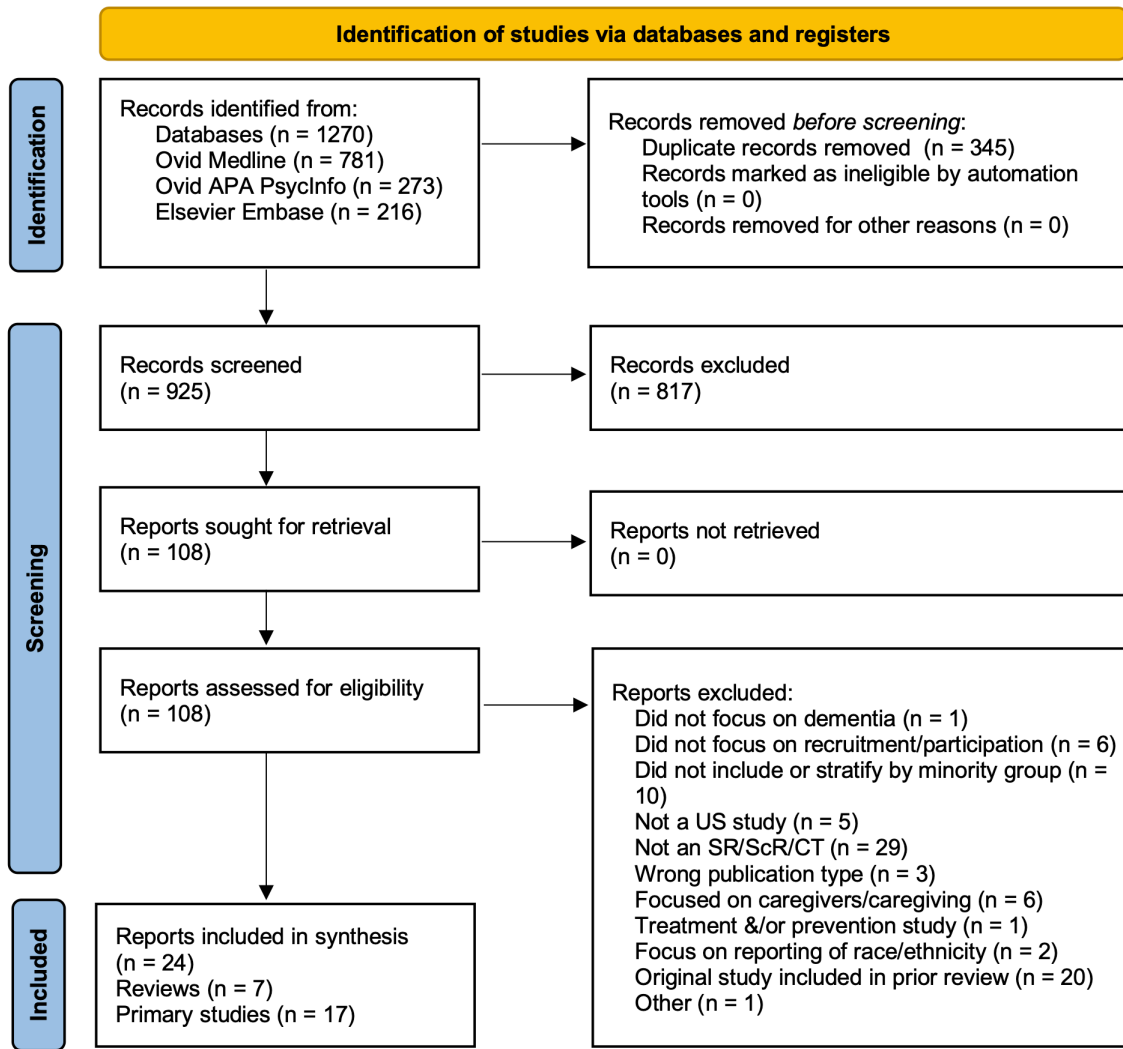
## **2.3 Results**

### **2.3.1 Study Selection**

Of the 925 unique citations identified by the search strategy, 817 were excluded based on the title/abstract, and another 84 studies were excluded after full text review. The final sample

included 24 studies, consisting of 7 reviews and 17 primary studies. Full details for study selection and reasons for exclusion can be found in Figure 1. One review by Lim et al. (2023) initially appeared to meet inclusion criteria, but was ultimately excluded post-hoc because the included secondary studies could not be verified, resulting in insufficient support for their findings. Summaries for all included reviews and primary studies can be found in Appendix Tables 1 and 2, respectively.

Figure 1. PRISMA Flow Diagram of Included Studies



### 2.3.2 Prevalence of Participation (Objective 1)

Objective 1 aimed to quantify the prevalence of racial and ethnic minority participation in ADRD research trials. While nearly all included studies touched on this topic in various ways within their backgrounds and rationale, only one study, a review by Vyas et al. (2018), provided quantitative data by conducting a systematic review and meta-analysis. The researchers looked at randomized clinical trials (RCTs) that included both an intervention and comparison group and

aimed to improve cognitive function among participants with dementia or mild cognitive impairment (MCI). The authors identified 96 studies for inclusion, including 8 studies from the U.S. For each RCT, they extracted data on the number of participants included in the RCT, as well as the proportion from a particular ethnic group. Data from the 8 U.S. studies can be found in Table 1 with additional calculations from the author of this essay to determine weighted-proportion for each racial/ethnic group. For example, in order to find the weighted-proportion of White participants, first the total number of White participants was calculated for each study by multiplying the total number of participants by the proportion extracted by Vyas et al. ( $716 \times 0.873 = 625$  White participants for Farlow et al.). Next, the number of White participants was totaled for all 8 studies and then divided by the total number of all participants across all studies ( $3586/3913 = 0.9164$ ).

Across the 8 studies, there was a total of 3913 participants enrolled and the weighted-proportion of White participants was 91.64%. In contrast, the weighted-proportion for Black participants was 3.38%, 0.44% for Hispanic participants, 0.13% for Asian participants, and 4.44% for all other races/ethnicities. According to Census data from 2000, just before most of these studies were published, about 75.1% of the U.S. population was White, 12.3% was Black or African American, 13.0% was Hispanic or Latino, and 3.6% was Asian (US Census Bureau, n.d.). The differences between weighted-proportion of participants and Census data show that Whites were vastly overrepresented in ADRD research, while all other races and ethnicities were underrepresented. It should also be noted that within the Vyas et al. study, there were no specific representation of American Indian or Alaskan Native, or Native Hawaiian or Other Pacific Islander subgroups.

**Table 1. Prevalence of Racial/Ethnic Minority Participation in ADRD Research**

Secondary study within Vyas et al. (2018) Author (year)	Participants enrolled										
	Total no.	% White	No. White	% Black	No. Black	% Hispanic	No. Hispanic	% Asian	No. Asian	% Other	No. Other
Farlow et al. (2013)	716	87.3	625	6.6	47	0	0	0	0	6.2	44
Henderson et al. (2009)	152	91.5	139	0.7	1	7.9	12	0	0	0	0
Mohs et al. (2001)	431	92.1	397	2.8	12	0	0	0	0	5.1	22
Schneider et al. (2005)	513	87.3	448	6.8	35	0	0	0	0	5.8	30
Silverberg et al. (2008)	215	97.6	210	0	0	0	0	0	0	2.4	5
Tariot et al. (2000)	978	92.8	908	0	0	0	0	0	0	7.2	70
van Dyck et al. (2000)	850	95.5	812	4	34	0.6	5	0	0	0	0
Wolkowitz et al. (2003)	58	82.5	48	5.2	3	0	0	8.9	5	3.4	2
<b>Totals &amp; Weighted %</b>	<b>3913</b>	<b>91.64</b>	<b>3586</b>	<b>3.38</b>	<b>132</b>	<b>0.44</b>	<b>17</b>	<b>0.13</b>	<b>5</b>	<b>4.44</b>	<b>174</b>

*Note.* Data was partially extracted from a table within Vyas et al. (2018) Supplemental Material

### **2.3.3 Barriers and Facilitators to Participation (Objective 2)**

Findings from Objective 1 showed that racial and ethnic minorities were underrepresented in ADRD research trials. To expand upon this, the goal of Objective 2 was to explore the factors that affect recruitment and participation of racial and ethnic minorities into ADRD research trials, including those that make the process more challenging (barriers) and those that help ease the process (facilitators). Of the 24 included studies, 17 (71%) addressed Objective 2. Within the 14 primary studies, a variety of study designs were used to examine barriers and facilitators including focus groups, qualitative interviews, surveys, photovoice, CBPR, secondary data analysis, and pre-test/post-test trial. Additionally, three reviews summarized some of the known barriers and facilitators that have been documented previously in the literature.

In their scoping review, Godbole et al. (2022) summarized barriers and facilitators into the following six categories: attitudes and perceptions, communication and outreach, cognition and understanding, mobility and access, study design, and incentive. These categories were used to summarize and sort all barriers and facilitators across all 17 included studies. During data extraction and classification, an additional seventh category was added for awareness and education. Tables 2 and 3 summarize all the barriers and facilitators found, document either the primary or secondary study from which the factor was found, and tally the total number of citations for each factor. Appendix Table 3 cross-references the study ID for each primary and secondary study, which can be matched to those within Tables 2 and 3.

Barriers to participation varied across the seven categories, with attitudes and perceptions accounting for about 46% (48/105) of all citations. The most documented individual barrier was mistrust of research/medical staff or institutions, with a total of 22 individual citations. Other attitudes and perceptions that were often documented were stigma or negative attitude about

research/ADRD and fear of injury, complication, or invasiveness of procedures. Additionally, challenges with mobility and access were also well-documented, accounting for about 17% (18/105) of all citations; most notably, a lack of transportation to study sites was reported frequently. Challenges with study design accounted for 12% (13/105) of all citations, and barriers associated with communication and outreach accounted for 10% (10/105) of all citations. The most common barrier to participation within the communication and outreach was an insufficient amount of information about study procedures and processes.

Facilitators to participation were more numerous than barriers and were distributed differently across the categories. Communication and outreach accounted for 30% (58/193) of all citations, followed closely by attitudes and perceptions with 28% (54/193) of all citations. Within communication and outreach, the most well-documented facilitators were use of culturally-tailored information and recruitment campaigns, as well as clear transparency of all research processes, protections, and risks/benefits. Additional facilitators to minority participation that addressed attitudes and perceptions included hiring racial and ethnically concordant research staff, as well as continued presence and tangible investment in the community. The availability of incentives were also a common motivator for participation, accounting for 18% (35/193) of all citations, with many participants suggesting that research participation be reframed as a social responsibility or an act of altruism.



**Table 2. Inventory of Reported Barriers to Participation**

Category	Barrier	Primary Study ID	Secondary Study ID	Total No. of Citations
Attitudes & perceptions	Mistrust/distrust in medical/research staff or institutions	5,10,44,51,58	2,4,11,12,14,18,22,25,29,35,37,40,41,43,47,56,66	22
	Stigma or negative belief associated with topic	5,10,44,51,55	32,39	7
	Fear of injury, complication, or invasiveness of procedures	5,52,58	14,25,28,29	7
	Religious views that are inconsistent with research participation	5	11,18	3
	History of unethical research	51,58	-	2
	Disinterest in medication studies	9	-	1
	Disinterest in certain study procedures (blood draw, LP, etc.)	9	-	1
	General lack of interest	9	-	1
	Perceived burden of study trial	42	-	1
	Negative prior experience with health professionals	58	-	1
	Perception that research instruments are not culturally-tailored	58	-	1
	Perception that research is only advantageous to white populations	-	18	1
<b>Total</b>	-	-	<b>48</b>	
Communication & outreach	Insufficient information about study procedures and processes	49	18,25,29,37,48,66	7
	Lack of age-appropriate communication tools	-	22,36	2
	Lack of bilingual researchers or translators	-	39	1
<b>Total</b>	-	-	<b>10</b>	
Cognition & understanding	Complicated consent form & research paperwork	58	22	2
	Problems with cognition, vision, hearing, and use of technology	-	36	1
	<b>Total</b>	-	-	<b>3</b>
Mobility & access	Lack of transportation	27,52	14,22,25,34,66	7
	Time demands	5,52,58	8	4
	Socioeconomic status associated with geographic strata	-	4,25,41	3

	Community or family roles that impact participation	5	66	2
	Competing work schedules	9	22	2
	<b>Total</b>	-	-	<b>18</b>
Study design	Procedures involved may be invasive	55	14,28,37	4
	Age limits of study protocol	9	19,22	3
	Shortcomings with recruitment procedures or targets	-	22,36,60	3
	Absence of a study partner	9	-	1
	Exclusionary health conditions	9	-	1
	Failure to meet study criteria regarding cognition	53	-	1
	<b>Total</b>	-	-	<b>13</b>
Incentive	Seeing no relevance or benefit to participation	5,10	22,24,61	5
	Socioeconomic status and financial barriers	-	22,25,66	3
	<b>Total</b>	-	-	<b>8</b>
Awareness & education	Limited knowledge about ADRD	50	2,3	3
	Limited knowledge about potential research opportunities	5,44	-	2
	<b>Total</b>	-	-	<b>5</b>
<b>Grand Total</b>				<b>105</b>

**Table 3. Inventory of Reported Facilitators to Participation**

Category	Facilitator	Primary Study ID	Secondary Study ID	Total No. of Citations
Attitudes & perceptions	Racial & ethnically concordant research staff	44,49,51,58	11,15,16,23,25,30,43,48,65,63,70	15
	Continued presence & tangible investment in the community	5,10,44,51,52,58	3,16,17,30,57,65,63,70	14
	Developing trust & trustworthiness gradually over time	10,42,44,49,58	18,23,25,48	9

	Endorsement from trusted community leaders/organizations	44	17,38,57,59	5
	Testimonials/narratives from past participants	44,46,58	61	4
	Endorsement from trusted health professionals	49,51	-	2
	Demonstrate integrity, empathy, compassion, dependability	51,58	-	2
	Involving community members in the research process	10	-	1
	Positive prior experience with clinical research	42	-	1
	Treating participants and researchers as equals	58	-	1
	<b>Total</b>	-	-	<b>54</b>
Communication & outreach	Culturally-tailored information & recruitment campaigns	44	1,3,6,15,16,17,30,54,57,65,70	12
	Transparency of research process, protections, risks & benefits	10,44,49,51,52,58	12,22,33,47	10
	Engagement of community leaders	10,44	3,17,20,30,57,65	8
	Develop community-based partnerships to be involved with study planning & recruitment	-	1,22,25,39,45,47	6
	Cultural competency training for research staff	-	3,7,16,17,20,54	6
	Dissemination of research findings	44,49,51,58	71	5
	Outreach in culturally-specific media & community spaces	9,44	61	3
	Translation & interpretation for multiple languages	50	39,61	3
	Promotion from trusted health professionals/organizations	44	26	2
	Phone calls & personal mail rather than email or text reminders	-	22,36	2
Community website to share stories of research participation	46	-	1	
	<b>Total</b>	-	-	<b>58</b>
Cognition & understanding	Engage with role of caregiver	-	13,24,62,64,68,69	6
	Research materials & study consent are easy to understand	44,52	61	3
	Use of plain language in study materials	51,58	-	2
	Utilize the Triadic encounter approach for recruitment	-	21,67	2
	Incorporate visual information when communicating	58	-	1
	<b>Total</b>	-	-	<b>14</b>

Mobility & access	Locations & timings of events that are convenient for participants	-	3,8,15,18,25,34,63	7
	Provide free transportation	44,52	22,25,34	5
	Rotating location of events to reach a more diverse community	-	1	1
	<b>Total</b>	-		<b>13</b>
Study design	Age range modification based on topic of study	-	19,22	2
	Lifestyle modification/nonpharmaceutical studies	5,52	-	2
	Open randomized study instead of blinded randomized study	-	19,22	2
	Noninvasive study procedures	52	-	1
	Opt-out instead of opt-in recruitment approach	-	22	1
	Test recruitment methods in a pilot feasibility study	-	60	1
<b>Total</b>	-	-	<b>9</b>	
Incentive	Availability & appropriateness of incentives/compensation	5,44,46,49,52,58	8,15,16,22,25,31,57,63,70,71	16
	Reframe participation as a social responsibility/altruism	5,10,44,51,58	14,18,35,37	9
	Perceived benefits for the individual/community	42,58	22,25	4
	Desire to help family	-	37,43,56	3
	Engage prior volunteers who may already understand value of research	-	19,22,32	3
<b>Total</b>	-	-	<b>35</b>	
Awareness & education	Educational resources on ADRD & prevention	46,50,51,58	-	4
	Education on the benefits of research & the need for diversity	10,58	-	2
	Start education & promotion at a young age	10,44	-	2
	Normalizing topics of memory problems & brain health	10	-	1
	Promoting examples of good research	10	-	1
<b>Total</b>	-	-	<b>10</b>	
<b>Grand Total</b>				<b>193</b>

### **2.3.4 Strategies to Improve Recruitment and Participation (Objective 3)**

Findings from Objective 2 showed that there are numerous factors that influence the recruitment and participation of racial and ethnic minorities into ADRD research trials. In response to low minority group participation, efforts for enhancing diversity of participants have been the subject of many research studies, and Objective 3 aimed to capture these efforts by summarizing the recruitment strategies that have been documented in the literature. Of the 24 included studies, 22 (92%) addressed the goals of Objective 3, including five reviews and all 17 primary studies. All of the primary studies had a priori intention to recruit racial and ethnic minorities as trial participants, including studies that targeted Black/African American participants, Hispanic/Latino participants, Korean American participants, and Asian American/Pacific Islander (AAPI) participants. Additionally, four of the primary studies included White participants as a comparison group.

The present synthesis summarized recruitment strategies into the following five categories: community outreach, traditional advertisement, collaboration with healthcare or research groups, referral, and other (categories were modified from the Wong et al. (2019) review). For each of the 22 studies, data were extracted on the types of strategies used to recruit trial participants. For documentation of the reviews, the specific secondary study for each recruitment strategy could not be ascertained; instead, only the total number of secondary studies were extracted for each strategy. Table 4 summarizes all of the recruitment strategies listed within the included studies and the number of times each strategy was cited.

**Table 4. Inventory of Reported Recruitment Strategies**

Category	Recruitment source/strategy	No. of primary studies	No. of secondary studies	TOTAL CITATIONS
Community outreach	Give community presentations	2	24	26
	Collaboration with community partners/organizations*	6	19	25
	Educational campaign/programming on brain health & AD*	2	15	17
	Engage with/empower trusted community leaders	0	16	16
	Establish presence & trust in the community through investment*	1	9	10
	Engage senior centers/housing facilities	3	7	10
	Engage churches & pastoral leadership	3	6	9
	Participate in community events/health fairs*	5	3	8
	Create a community advisory board (CAB)*	4	4	8
	Community outreach - non-specified*	2	4	6
	Culturally-tailored community events & recruitment materials*	2	2	4
	Campaign to promote diversity in research	2	0	2
	Testimonials from past research participants	2	0	2
	Create community website for study participants	1	0	1
	Create a youth ambassador program	1	0	1
	Empower participants so they feel valued	1	0	1
Narratives from families with AD	0	1	1	
<b>Total</b>		<b>37</b>	<b>110</b>	<b>147</b>
Traditional advertisement	Flyers/posters, brochures, information sheets	6	12	18
	Newspaper advertisements*	3	12	15
	Radio/television advertisements	2	12	14
	Direct mailings/newsletters	5	5	10
	Social media	5	4	9
	Advertise in culturally-specific media*	2	1	3
	Use registered voting lists	0	1	1
<b>Total</b>		<b>23</b>	<b>47</b>	<b>70</b>

Collaboration with healthcare or research groups	Leverage existing research registries/databases	7	19	26
	Engage with healthcare providers/specialists	0	17	17
	Engage with healthcare/memory clinics	3	11	14
	Partnership with AD research centers/coalitions/campaigns	4	3	7
	Engage primary care practices, medical centers, hospitals	0	5	5
	Engage with social service agencies	0	1	1
	Engage with caregiver registries/centers	0	1	1
	Search medical records	0	1	1
	<b>Total</b>	<b>14</b>	<b>58</b>	<b>72</b>
Referral	Word-of-mouth/chain referrals*	5	7	12
	In-home interviews*	0	9	9
	Referrals from other studies	1	1	2
	Referrals from physicians	1	0	1
	Group surveys*	0	1	1
	<b>Total</b>	<b>7</b>	<b>18</b>	<b>25</b>
Other	Employ diverse research teams*	1	14	15
	Provide monetary compensation*	1	12	13
	Interpretation & translation of research/recruitment materials*	1	13	14
	Employ bilingual workers*	1	9	10
	Formative research before recruitment begins	0	6	6
	Develop cultural competency	0	6	6
	Offer flexible options for research participation	1	4	5
	Phone bank/calls*	1	3	4
	Use simplified language in research materials	0	2	2
	Triangulation of information gathering	0	1	1
Monitor & evaluation of recruitment data	0	1	1	
	<b>Total</b>	<b>6</b>	<b>71</b>	<b>77</b>
<b>Grand Total</b>		<b>87</b>	<b>304</b>	<b>391</b>
<i>Note.</i> *Strategies that have been evaluated as being effective in at least one included study. See Table 5 for more details.				

Of all the documented recruitment strategies, those that fell under the “community outreach” category accounted for about 38% (147/391) of all citations. More specifically, well-documented strategies included giving community presentations, collaborating with community partners/organizations, educational campaigns on brain health and AD, and engaging with/empowering trusted community leaders. Additionally, the “other” category accounted for about 20% (77/391) of all citations, and included strategies such as employing a diverse research team, providing monetary compensation to research participants, and providing interpretation/translation of all study materials. About 18% (72/391) of included citations fell under “collaboration with healthcare or research organization.” Most often, these studies recruited participants by leveraging an existing research registry/database, engaging with individual healthcare providers/specialists, or engaging with healthcare/memory clinics. An additional 18% (70/391) of citations related to the strategies that are categorized as “traditional advertisement” like flyers, posters, brochures, newspaper ads, and radio/television ads. Finally, the “referral” category accounted for 6% (25/391) of all citations, including word-of-mouth or chain referral recruitment strategies.

#### **2.3.4.1 Effectiveness of Recruitment Strategies**

While strategies to recruit racial and ethnic minority participants into ADRD research were well-documented, there was less evidence of support as to which strategies actually worked. That is, only about half of the included studies (12/22, 55%) included any kind of evaluation as to whether the recruitment strategies employed were effective in achieving their recruitment goals. Table 5 summarizes the studies that offered an evaluation and documents what the overall findings were.



**Table 5. Summary of Techniques Used to Evaluate the Effectiveness of Recruitment Strategies**

Author (Year)	Technique for Evaluation	Overall Findings/Conclusions
<i>Reviews</i>		
Brijnath et al. (2022)	Authors assessed studies for quality based on proxy indicators, 4/57 (7.0% met all criteria). Based on the high quality studies, the authors made conclusions about the essential practices to increase representation of ethnic minorities in ADRD research.	<p>The authors conclude that there is no "one size fits all" strategy to recruitment; it's an ongoing process that requires authenticity, and an understanding local context is critical. Strategies that help include:</p> <ul style="list-style-type: none"> <li>• Use of bilingual &amp; bicultural workers</li> <li>• Translation of study materials to participants' preferred language</li> <li>• Working in partnership with communities to build trust and engage communities</li> <li>• Use of culturally-appropriate tools and materials, considering differences in education and literacy</li> </ul>
Esiaka et al. (2022)	Included secondary studies were required to evaluate the effectiveness of recruitment strategies aimed at increasing the participation of African Americans in ADRD research. Included studies used either pre-test/post-test or retrospective analysis to evaluate effectiveness.	<p>Effective approaches included:</p> <ul style="list-style-type: none"> <li>• Creating long-lasting community partnerships between academic researchers &amp; older Black community members</li> <li>• Face-to-face discussions (e.g. in-depth at-home interviews, or group interviews)</li> <li>• A "phonathon" in which staff members worked together at a bank of telephones</li> <li>• Personal referrals from trusted individuals</li> <li>• Partnership with local organizations to serve as recruitment sites</li> </ul>
Gilmore-Bykovskiy et al. (2019)	Within the included secondary studies, the predominant method of evaluating the effectiveness of recruitment activities was to closely track the number of new enrollments. Of the 7 studies that described recruitment approaches, only 1 described a prospective intervention.	<p>The authors conclude that:</p> <ul style="list-style-type: none"> <li>• The overall strength of evidence regarding effective strategies for bolstering minority recruitment is both low and limited to specific populations</li> <li>• Metrics for quantifying effectiveness are inconsistent, and may lack empiric support</li> <li>• It's unclear how well included studies characterized heterogeneous populations due to inconsistent reporting surrounding ethnicity</li> </ul>

Wong et al. (2019)	Out of 19 included studies, 17 (89.5%) evaluated the effectiveness of recruitment strategies, but through varying methods, including pre-post designs or post-test only designs; no study used an RCT design.	<p>The authors recommend that:</p> <ul style="list-style-type: none"> <li>• Investigators should consider implementing evidence-based recruitment strategies</li> <li>• Future research should use more rigorous study designs to increase study quality</li> <li>• Studies implementing multiple strategies should evaluate each one separately</li> <li>• Future studies should focus on Latino and American Indian populations, given a lack of existing evidence and elevated risk for ADRD</li> </ul>
<i>Primary Studies</i>		
Bardach et al. (2021)	The purpose was to explore whether attendance at AA community events was an effective strategy for recruitment of AA participants, as compared to attendance at general-audience community events. Researchers used descriptive statistics to examine the relationship between event attendance and research participation.	<ul style="list-style-type: none"> <li>• Community outreach events were effective for encouraging research engagement</li> <li>• AA-focused events reached a large number of AA individuals, but attendance at AA-focused events was not statistically related to research engagement</li> <li>• Attendance at general-audience events reached a smaller absolute number, but the relationship to research engagement was clear</li> </ul>
Lee et al. (2023)	The purpose was to demonstrate how community-based geographical information system (GIS) methods can be used effectively to recruit Korean American participants for the Asian Cohort for Alzheimer's Disease (ACAD) study.	<p>Researchers successfully met their recruitment goal and concluded that recruitment benefited from a combination of strategies including:</p> <ul style="list-style-type: none"> <li>• Population-tailored GIS data</li> <li>• Detailed understanding of the target population &amp; existing community capacity</li> <li>• A respected relationship between community and researchers</li> <li>• Use of a community advisory board</li> </ul>
Mindt et al. (2023)	The purpose was to evaluate the effectiveness of a culturally-informed, community-engaged digital research approach to increase research participation of Black/African American participants in a Brain Health Registry (BHR).	<p>Researchers successfully met their recruitment goal and concluded that their approach was feasible and scalable by using:</p> <ul style="list-style-type: none"> <li>• A community advisory board with financial compensation for board members</li> <li>• Digital communications as a tool for engagement</li> <li>• Culturally-informed research materials with guidance from community members</li> </ul>
Passmore et al. (2023)	The study used StoryDeck methodology to determine the most salient factors affecting the decision to participate in LP research studies among AA adults with prior experience in AD research.	<p>Participants preferred ADRD LP studies that:</p> <ul style="list-style-type: none"> <li>• Were led by AA researchers</li> <li>• Offered the highest incentive available</li> <li>• Offered full disclosure of research results to participants</li> <li>• Recruited participants through physicians' offices, as opposed to community events</li> </ul>

Perales-Puchalth et al. (2020)	Researchers conducted a pre-test/post-test trial to examine whether exposure to a culturally-informed ADRD educational presentation increased desire to participate in ADRD research among Hispanic older adults.	<ul style="list-style-type: none"> <li>• High interest in participating increased from 61.7% at pre-survey to 80.9% at post-survey</li> <li>• 64.0% of trial participants left their contact info to participate in future research</li> <li>• 41.1% of those exposed to the presentation enrolled into an ADRD cohort study</li> </ul>
Raman et al. (2021)	Researchers conducted a retrospective analysis of recruitment data from a preclinical AD medication trial to examine the sources of recruitment for underrepresented racial and ethnic groups.	<ul style="list-style-type: none"> <li>• Local site efforts (such as referrals &amp; community outreach) were the primary sources of recruitment for Black, Hispanic, and Asian participants, followed by local earned media</li> <li>• Centralized recruitment methods (such as national media) were less effective at reaching Black, Hispanic, and Asian participants, indicating the importance of trust &amp; trustworthiness in recruitment, which may be lacking in paid advertising</li> </ul>
Stout et al. (2020)	Researchers conducted a retrospective analysis to examine the effectiveness of traditional media vs. social media in the recruitment of AA and NHW participants into an existing longitudinal cohort study on preclinical AD & driving.	<ul style="list-style-type: none"> <li>• Traditional print media (newspapers) were effective at recruiting both NHW and AA participants</li> <li>• Targeted advertisement in a culturally-specific AA newspaper was particularly effective at recruiting AA participants</li> <li>• Social media was effective at recruiting NHW participants, but not AA participants</li> </ul>
Ta Park et al. (2023)	The purpose was to demonstrate how a CBPR-based approach to the development of an ADRD research registry was effective at enrolling AAPI participants. The registry outpaced their target and successfully enrolled over 7000 participants.	<p>Researchers credit CBPR methods with their success, including:</p> <ul style="list-style-type: none"> <li>• Strong community partnerships &amp; community participation in all phases of research process</li> <li>• Established presence &amp; trust in the community</li> <li>• Offering the registry website in multiple languages &amp; having bilingual staff to help assist</li> </ul>

Three of the included primary studies evaluated the effectiveness of their recruitment strategies by comparing initial results of a pilot strategy to their overall recruitment goal (Lee et al., 2023; Mindt et al., 2023; Ta Park et al., 2023). In each case, researchers leveraged community-based approaches to successfully meet their target recruitment goals within a given time period. Another three primary studies evaluated effectiveness by conducting a retrospective analysis of recruitment data (Bardach et al., 2021; Raman et al., 2021; Stout et al., 2020). Results from these studies showed that effective strategies for recruitment included community outreach events, word-of-mouth referrals, and advertisements in culturally-specific media. Another two primary studies evaluated effectiveness by employing a pre-test/post-test trial design (Passmore et al., 2023; Perales-Puchalth et al., 2020). In Passmore et al. (2023), participants were exposed to different narratives that described potential research scenarios for an ADRD study. Post-test survey results showed that participants preferred scenarios where the studies were conducted by racially concordant staff, offered the highest incentive, and disclosed full study results. In Perales-Puchalth et al. (2020), participants completed surveys both before and after attendance at an educational ADRD presentation. Results showed that interest and actual enrollment in ADRD research increased following exposure to the educational presentation.

Additionally, four of the included reviews evaluated the effectiveness of recruitment strategies. In Esiaka et al. (2022), there was a priori intention to only include studies that evaluated effectiveness, primarily using retrospective analysis and pre-test/post-test trial methods. Gilmore-Bykovskiy (2019) described studies that primarily used retrospective analysis to evaluate effectiveness. The authors concluded that the overall strength of evidence regarding effective strategies for bolstering minority recruitment was both low and limited to specific populations. In Wong et al. (2019), most of the included studies used pre-test/post-test trial design to evaluate

effectiveness; the authors concluded that future research aimed at improving racial/ethnic minority participation should employ more rigorous study designs in order to increase study quality. Finally, Brijnath et al. (2022) assessed included studies for quality based on proxy indicators. Based on the studies identified as high quality, the authors concluded that there is no "one size fits all" strategy to recruitment; it's an ongoing process that requires authenticity and an understanding of local context.

## **2.4 Conclusions**

Since the NIH Revitalization Act was enacted in 1993, evidence regarding the importance of racial/ethnic minority representation in ADRD research has been widespread, but also limited in scope. Results from the current literature synthesis showed that racial and ethnic minorities were underrepresented in ADRD research trials, a myriad of barriers and facilitators to racial/ethnic minority participation have been documented, and numerous strategies to improve the recruitment and participation of racial/ethnic minorities have been reported – although, there was less evidence to support which strategies were the most effective. To quote Gilmore-Bykovskyi et al. (2019), “recruitment science, as applied to ADRD research engagement, reflects a field in early stages of development, with many creative approaches being adopted to broaden inclusivity” (p. 764).

Facilitators to recruitment and participation were primarily suggestions and prospective ideas directly from racial/ethnic minority participants as to what might work to boost participation, in theory. In contrast, recruitment strategies were actual methods employed by researchers to try to recruit real participants. The recruitment strategies with the highest strength of evidence perfectly matched to the facilitators with the highest number of citations, suggesting that

researchers have taken the recommendations from participants seriously and that the ideas suggested from participants are legitimate and feasible. In sum, ADRD studies seeking to include a diversity of participants should adopt a variety of community outreach activities (collaboration with community partners, establish trust and presence in the community, use of culturally-tailored materials, etc.), employ a diverse/bilingual team of research staff, leverage word-of-mouth referrals, and provide monetary compensation.

The present synthesis found that there is still limited evidence on whether recruitment strategies to bolster the participation of underrepresented minorities can be generalized between racial and ethnic subgroups. Additionally, there is limited evidence as to whether recruitment strategies can be generalized to research on other health conditions, or if they can be scaled to larger, more wide-reaching study designs. Future research should explore how recruitment and participation strategies differ by racial/ethnic subgroups (including, heterogeneity within a subgroup) and if there are any universal strategies that can apply to all subgroups. Additionally, future research should explore how the findings of this synthesis are consistent with or differ from research involving other health problems (i.e. cancer, heart disease, respiratory conditions, etc.). Lastly, future studies should explore better methodologies for evaluating the effectiveness of recruitment strategies.

The present literature synthesis had some limitations. Primarily, the synthesis was conducted by only one person, which increased the potential risk of bias from being introduced. Additionally, critical appraisal of the included reviews was missing due to time constraints and overall scope of this essay.

In the following chapter, the author describes a secondary analysis of recruitment data from a local ADRD research trial. Results from this literature synthesis can be compared to the results

from the secondary analysis in order to show how the local study succeeded and where there might be areas for improvement.

## **3.0 The REACT! Study**

### **3.1 Study Overview**

The Rhythm Experience and Africana Culture Trial (REACT!) was a randomized controlled trial designed to examine the efficacy and effectiveness of African Dance as a method to improve cognitive function among older Black or African-American adults. Previous research has shown that physical activity (PA) interventions may be effective at improving neurocognitive function and reducing the risk of dementia (Erickson et al., 2011; Buchman et al., 2012). However, as discussed in the previous chapter, African Americans are often excluded or underrepresented in this kind of research, making it difficult to generalize the results to a wider population. To address this research gap, REACT! examined whether a culturally-relevant form of PA, such as African dance, may entice more community members to participate than a typical PA intervention which may not be culturally-tailored. The primary aim of REACT! was to examine whether a 6-month African dance intervention, as compared to an educational control group, improves cognitive performance among African Americans aged 60-80.

#### **3.1.1 Study Flow and Activities**

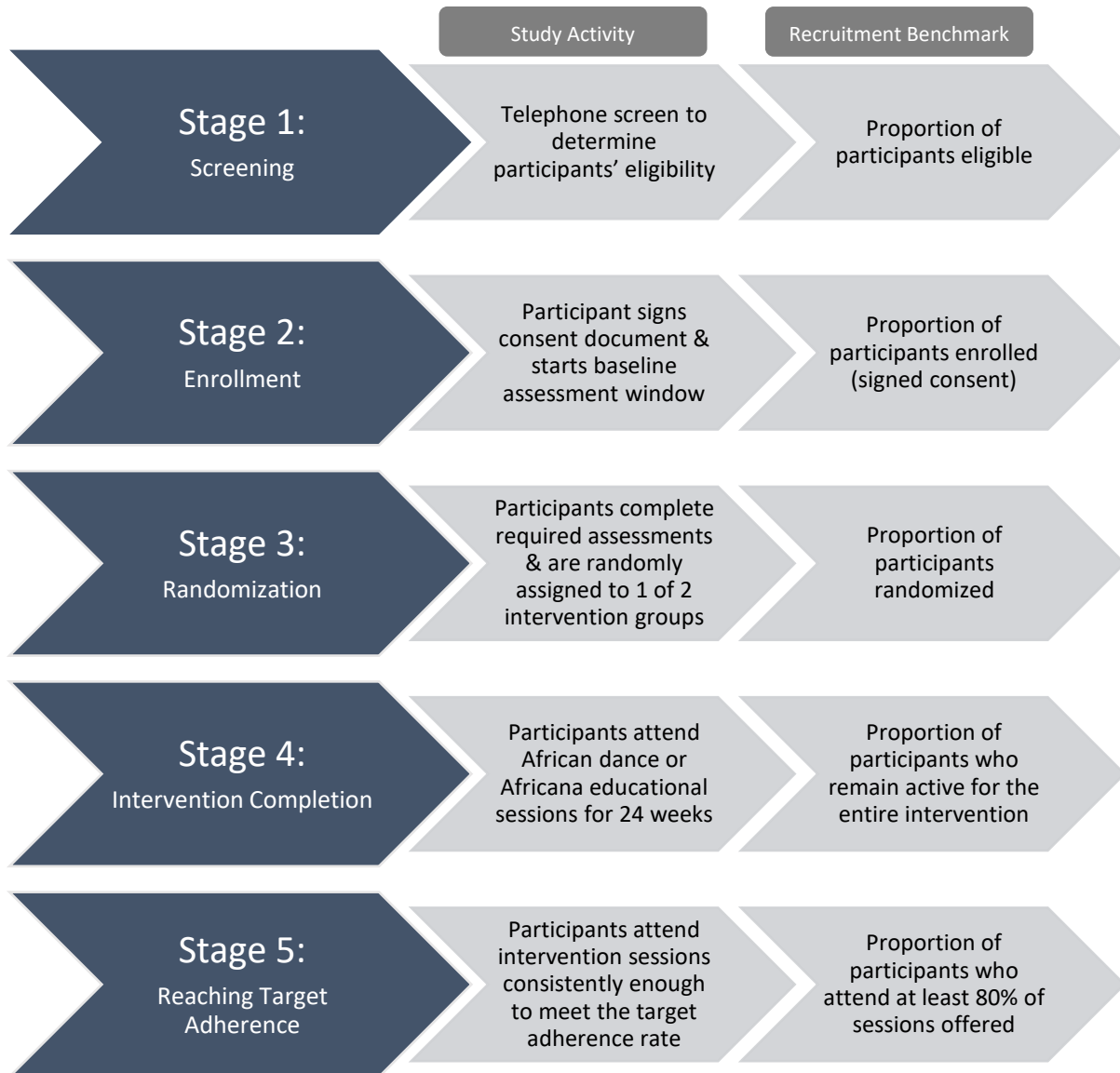
Study activities for those enrolled in REACT can be divided into three phases of study flow: baseline assessments, intervention, and post-intervention assessments. The intervention was 24 weeks, while each of the assessment periods (baseline and post) were about 4-6 weeks, on average, for a total participation length of about 8-9 months. The present analysis examines



participation within the first two phases, details of which are described below. The third phase (post-intervention assessments) repeated the same assessment activities as baseline and was not included in the present analysis.

The study flow during baseline and intervention phases of REACT! can further be divided into five stages: screening, enrollment, randomization, intervention completion, and reaching target adherence. A summary of research activities during these stages can be found in Figure 2. By examining the transitions between stages, researchers can pinpoint the reasons for why a participant may have been “filtered” out of the study flow. In other words, between each stage, a participant either continued or discontinued their participation. Participation could be discontinued either because the participant did not meet eligibility criteria, highlighting research-level barriers, or because they chose to drop out, calling attention to individual-level barriers. In either case, as discussed in the previous chapter, it is imperative for researchers to minimize these barriers as much as possible in order to maximize participation and retention.

**Figure 2. Summary of REACT! Study Flow**



Stage 1 started participation in REACT!, when a staff member called a potential participant to complete a telephone screening interview. During the screening, the staff member described the study and answered any questions the participant might have had. If the participant expressed an interest in moving forward, the screener then asked questions to determine their eligibility. Eligibility depended on the participants' availability to attend the intervention, their past medical history, and their current cognitive status, which was evaluated by using the Telephone Interview

for Cognitive Status (TICS). This was the first point in which participants may have faced barriers to participation.

Eligible participants continued to Stage 2 (enrollment), which occurred at the start of the first study visit. A staff member reviewed the informed consent document in great detail with the participant, usually taking about 20-30 minutes, and then answered any questions. Once the participant signed the consent document, they were considered enrolled in the study, marking the start of a six-week window to complete all baseline assessments. Frequently, eligible participants chose not to complete this stage. Prior to signing consent, many participants decided they were no longer interested in participating, or other commitments arose that prevented them from continuing. Thus, this was the second point in which participants could face barriers to participation/retention.

Stage 3 (randomization) relied on the successful completion of all required baseline assessments, thus, for the purposes of this analysis, all activities associated with the assessments are described in Stage 3. The first baseline assessment included a series of cognitive tests, including the Montreal Cognitive Assessment (MoCA) which was used to evaluate whether the participant had any signs of mild cognitive impairment (MCI). Second, participants were asked to complete a fitness assessment, which included a VO<sub>2</sub> submaximal exercise test and a Senior Fitness Test. The cognitive and fitness assessments were used to further assess participant eligibility, beyond what was asked during screening. The third assessment was an MRI scan of brain structure and function, results of which did not impact eligibility. However, for most of the recruitment period from 2019 to late 2023, the MRI scan was a required assessment, meaning that if a participant was unable to complete the scan due to safety reasons or claustrophobia, they were no longer eligible. Lastly, participants were asked to complete an optional blood draw. Some

participants discontinued participation while completing the baseline assessments, often because they failed to meet eligibility criteria, or because they were no longer interested. After successfully completing all required assessments and meeting all of the final eligibility criteria, participants received a “pre-randomization” call to review study requirements and expectations regarding the intervention. After confirming commitment to study, participants were randomly assigned to one of two intervention groups. Randomization determined whether the participant would be in the experimental group, taking African dance classes, or in the control group, receiving an educational program on Africana culture and history. If someone was unable to meet the final eligibility criteria or no longer expressed interest/commitment to the study, they were not randomized and were filtered out of the study flow again, marking the third barrier point to participation/retention. After a participant was successfully randomized, they started the intervention program and continued to Stage 4.

Stage 4 encompassed the 24-week period in which the participant completed all intervention activities. In the African dance class, participants learned about traditional African music and learned African dance choreography from an experienced dance instructor. The class was designed as a moderate intensity exercise class; each participant wore a heart rate monitor and was encouraged to dance within their target heart rate zone, as determined by the baseline fitness assessment. The cultural education group focused on learning about and experiencing Africana culture through interactive class discussions, lectures, and hand-on demonstrations. Topics in both intervention groups covered several regions of Africa and spanned hundreds of years of history from pre-colonialization to post-colonialization. Intervention classes were offered at two community centers in Pittsburgh: the Wilkins School Community Center and the Homewood Community Engagement Center. Regardless of group assignment, participants were asked to

attend a 1-hour long class in-person, three days per week on Mondays, Wednesdays, and Fridays. Each intervention class was offered twice per day – once in the morning and once in the afternoon, corresponding to one of the two community centers. Participants could choose which time of day/location they prefer, but had to stick with that decision for the duration of the intervention. From April to August 2020, the intervention classes were modified and held virtually over video conference due to the COVID-19 shutdown. The 24-week intervention was a significant commitment, which could sometimes be difficult for participants to complete fully. Participants who consistently attended classes each week were considered “active,” however, they were allowed to withdraw from the study at any point without consequence, thus presenting the fourth and final point in which participants could face barriers to participation/retention. If a participant completed the full intervention, they naturally moved to Stage 5.

The researchers acknowledged that there was a target number of classes needed for the experimental treatment to be effective, which was the focus of Stage 5. For REACT!, that point was established as a target adherence rate of 80%. In other words, participants were encouraged to attend at least 80% of intervention classes during the 24-week period in order to maximize the potential benefits of the intervention. To incentivize reaching this goal, REACT! participants received monetary compensation every three weeks during the intervention, as long as they attended at least 80% of classes offered. There were a significant number of participants who completed the full intervention, but did not reach the target adherence goal. The researchers did not document the reasons for why a participant did not reach the 80% goal.

## **3.2 Recruitment and Retention Methods**

### **3.2.1 Objectives**

REACT! experienced several challenges with recruitment and retention of participants, although recruitment goals were ultimately met. The objective of the present analysis was to take a detailed approach to examining these challenges in order to learn how future studies might bolster participation among older Black/African Americans. Specifically, the present analysis aimed to examine 1) which recruitment strategies were the most effective at enrolling and retaining participants in the REACT! trial, 2) whether recruitment strategy had any association with participant characteristics, 3) whether reasons for exclusion differed by recruitment strategy, 4) whether changes to recruitment in January 2023 had any effect on recruitment and retention numbers, and 5) the cost of enrolling/randomizing participants across each recruitment strategy.

### **3.2.2 Participant Eligibility**

REACT! aimed to recruit 150 older adults from neighborhoods across Pittsburgh. To be eligible, participants had to self-identify as African American or Black and had to be between the ages of 60 to 80 at the time of enrollment. Additionally, participants could not have serious cognitive impairment, as indicated by scores on the TICS and MoCA, have no history of brain injury, and no current diagnosis of neurological or psychiatric condition. Additionally, participants had to be able to ambulate without the assistance of a walking device, be able to complete a submaximal fitness test, and have no history of balance problems or falls. Lastly, participants had

to be able to attend the intervention during the times classes are offered, have a reliable means of transportation, and have a willingness to be randomized to either intervention group.

### **3.2.3 Recruitment Methods**

Recruitment for REACT! began in May 2019 and finished in January 2024. The recruitment period was extended beyond its original projection due to the COVID-19 pandemic, which shut down recruitment operations for about nine months. At the time of this analysis, recruitment was still ongoing. Several recruitment strategies were being used, all of which received Institutional Review Board (IRB) approval. Participants self-reported their recruitment source at the time of screening and were able to select all sources that applied. For the purposes of this analysis, all recruitment strategies have been sorted into three categories: postcards, research registries, and “other.”

#### **3.2.3.1 Postcards**

Postcards, and other similar mass mailing campaigns, are one of the most frequently-used and traditional sources of advertising for research trials. Throughout the 4.5 year recruitment period from May 2019 to January 2024, a total of 126,413 postcards were mailed out for the study. The postcard was designed by the University of Pittsburgh Marketing Department, with direction from the REACT! leadership team. Postcards were mailed out in batches of about 3,500, roughly every three weeks. REACT! outsourced the printing and mailing of materials by use of two University-approved vendors: CDI Printing Services, Inc. and Pittsburgh Mailing. Pittsburgh Mailing used criteria supplied by the REACT! team to generate a list of mailing addresses to send the postcards to. Criteria included age and racial demographics (African American, ages 60 to 80),

as well as specific zip codes across the city. Certain neighborhoods were targeted more frequently, including those with a higher population of African American/Black residents, as well as the neighborhoods that surrounded the community centers where intervention classes were held. A total of 28 zip codes were targeted across Pittsburgh and Allegheny County.

### **3.2.3.2 Research Registries**

Research registry databases are another resource frequently used to recruit participants into research trials. The Pitt+Me Research Recruitment Program was established by the University of Pittsburgh Clinical and Translational Science Institute (CTSI) to help research teams in the area meet their recruitment goals. Participants voluntarily signed-up for the registry and supplied some basic information on their demographics, health history, and preferences for research participation. Registry participants received regular emails and mailings alerting them to when a study was available. They were also able to manually browse on the Pitt+Me website for any studies that may be of interest. If they expressed an interest, participants were then pre-screened online or through the Pitt+Me call center. Participants who were potentially eligible were referred to study teams for additional screening through an online portal. REACT! used the Pitt+Me research registry since recruitment began in May 2019.

### **3.2.3.3 Other Strategies**

Additional recruitment strategies included: referrals, word-of-mouth, community presentations, social media, and other print advertising like flyers, newspaper ads, and bus ads. Due to the relative frequency of use, these strategies can all be combined into one “other” category. Referrals and word-of-mouth advertising usually occurred when a current or former REACT! participant told a friend or family member about the study. Educational community presentations



were given at various health fairs and community events throughout the city. Social media advertising included using Facebook and Twitter to promote the study. Traditional print flyers and newspaper ads were used sparingly, given the low success rate as compared to other recruitment strategies. Lastly, REACT! engaged in two bus advertising campaigns through Pittsburgh Regional Transit (PRT). A total of 60 bulkhead advertisements were posted on Pittsburgh city buses for the duration of two months.

#### **3.2.3.4 Adjustments to Recruitment**

Recruitment numbers were monitored on a weekly and monthly basis throughout the entire recruitment period in order to track what was working and what was not. In January 2023, the research team implemented two changes in an attempt to increase the rates of enrollment and randomization. First, the total monetary compensation for participants was increased from \$465 to \$595. The primary reason for this increase was to reflect the rising cost of living following the COVID-19 pandemic. Second, REACT! began supplying a “Participant Handbook” to every participant enrolled in the study. The handbook was designed by the author of this essay to fulfill their community practicum requirement. The goal of the handbook was to improve transparency and communication during the baseline assessment period in order to decrease participant drop-outs during this stage of study flow. The results of a feedback survey revealed that REACT! participants were interested in learning more about the research process, including how groups were assigned and how their privacy was protected. The Participant Handbook attempted to acknowledge the unequal power dynamic between researchers and participants by breaking down the research process in a way that was digestible and easy for participants to understand. For example, the handbook included a glossary section that defined research terms that are often unique to the research space, like “randomization” and “principal investigator.” Additionally, the

Participant Handbook also included contact information for the research team, a timeline of study participation, an overview of study assessments, maps and addresses for all study locations, and a frequently-asked-questions section. The Participant Handbook was written in plain language at an eighth-grade reading level to maximize accessibility; it now serves as the primary resource guide for participants in the study. A copy of the handbook can be found in the [Supplemental Materials](#).

### **3.2.4 Statistical Analysis**

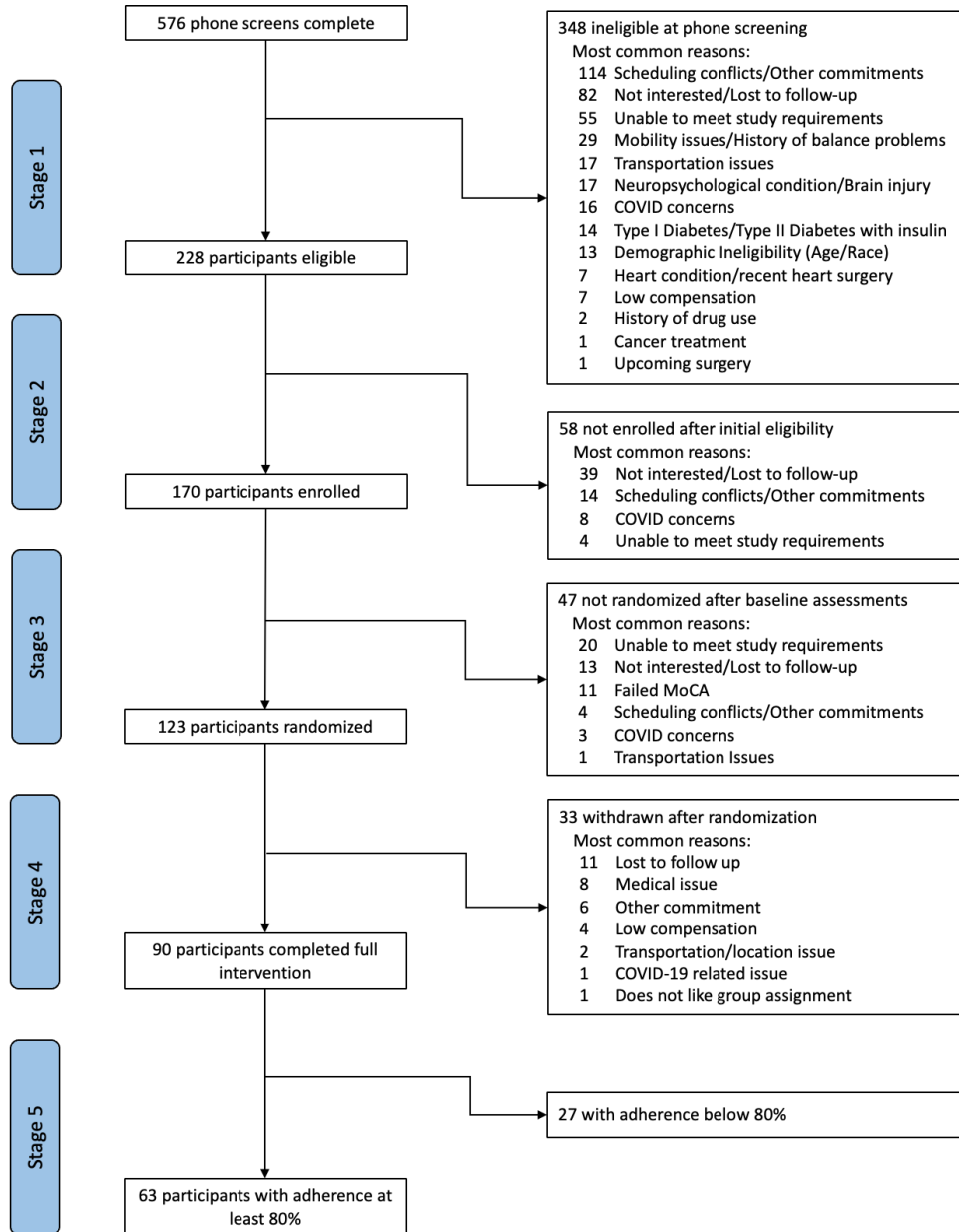
Because study activities and enrollment were still ongoing, the present analysis did not include a full dataset of all participants. Analyses were conducted in December 2023 and included an examination of adherence rates. Therefore, only participants who had the potential to complete the intervention by December 2023 were included in the present analysis. Due to the length of intervention and baseline study activities, this corresponds to participants who were recruited no later than May 2023. In sum, participants were included in the present analysis if their date of screening fell on or before May 31, 2023. Two participants were manually removed from analyses because their participation extended past December 2023, despite being screened before the cutoff date. All statistical analyses were conducted using Microsoft Excel (Version 16.75) and Stata SE (Version 18.0).

### 3.3 Recruitment and Retention Results

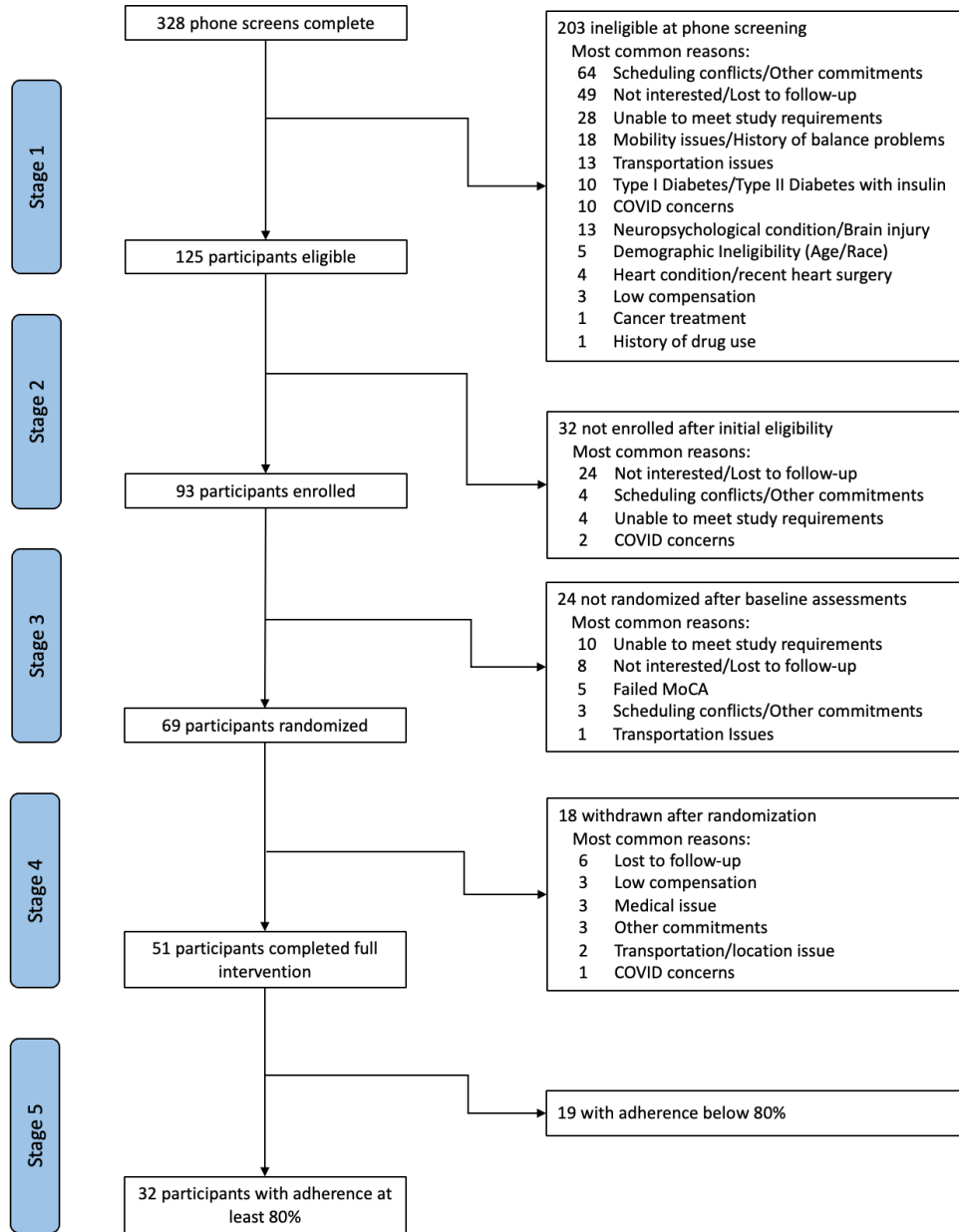
#### 3.3.1 Study Flow Diagrams

In total, 576 telephone screens were completed between May 1, 2019 and May 31, 2023. Figure 3 summarizes the number of participants who completed each stage of the study flow. After completing screening in Stage 1, 228 participants were eligible to continue forward. After signing the consent document in Stage 2, 170 participants were enrolled in REACT!. After Stage 3, 123 participants were randomized. In total, 90 participants completed the full intervention. And lastly, a total of 63 participants completed the intervention with an adherence rate of at least 80%. The goal of the present analysis is to examine the differences in enrollment and retention numbers across the different recruitment strategies used. In total, 328 participants screened for REACT! identified their source of recruitment as a postcard, 98 identified their recruitment source as a research registry, and 104 identified their recruitment source as “other.” A total of 59 participants could not identify their recruitment source, and thus were excluded from all strategy-specific analyses. Figure 4 presents the total number of participants in each stage of the study flow among those who identified postcard as their recruitment source. Figures 5 and 6 do the same for each of the other two recruitment strategies. Further discussion of the study flow diagrams are presented in the subsequent sections.

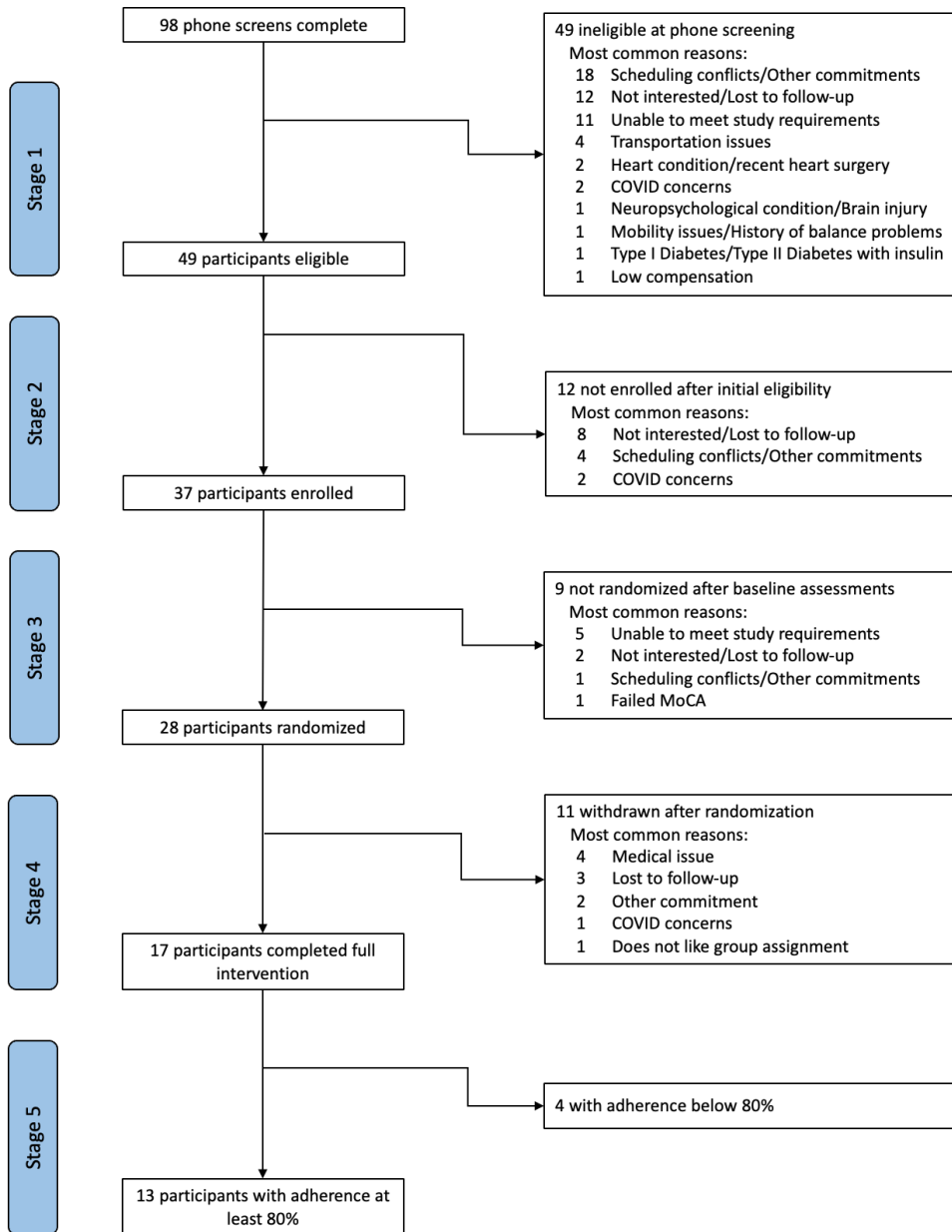
**Figure 3. Recruitment Flow Diagram for All Strategies**



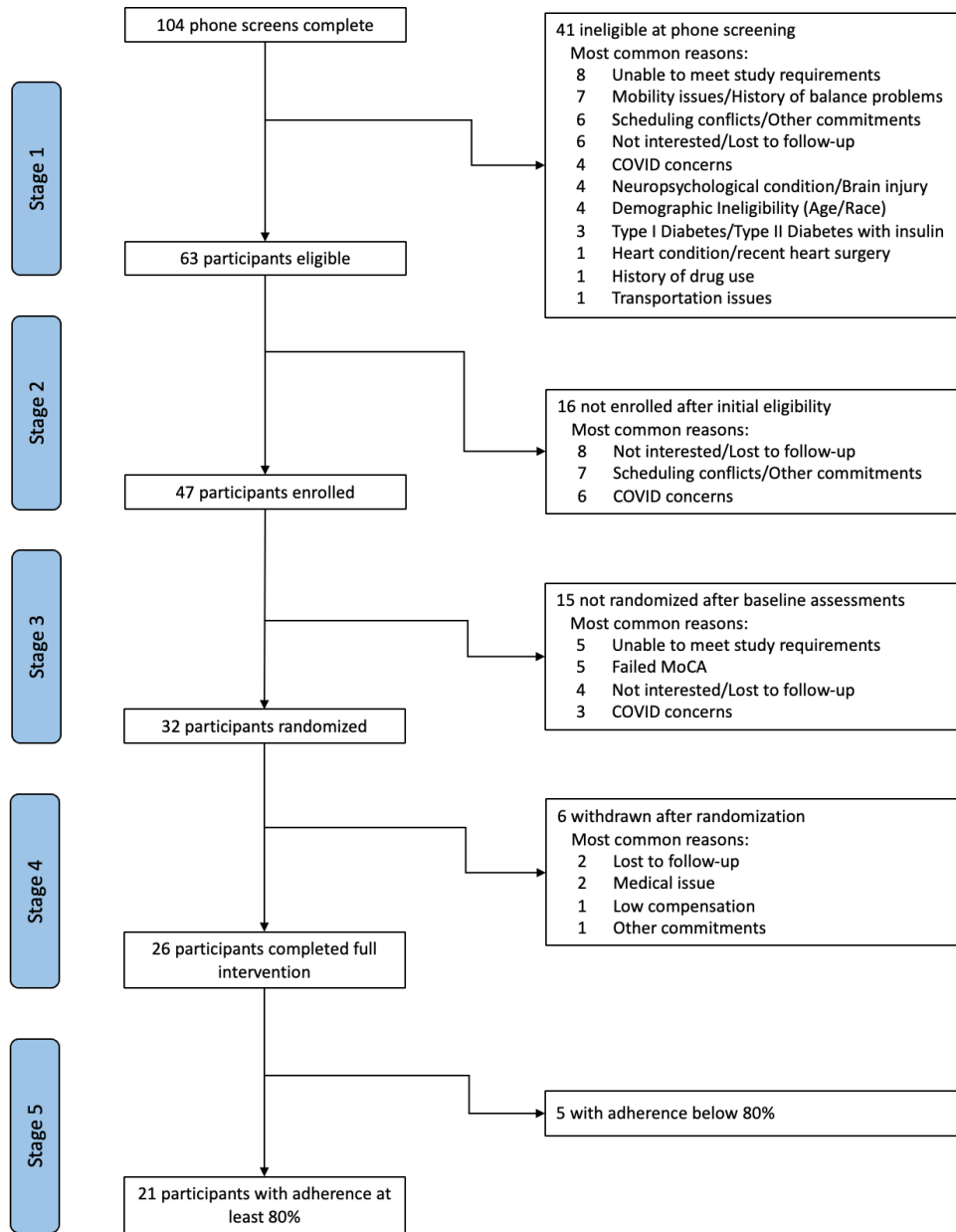
**Figure 4. Recruitment Flow Diagram for Postcards**



**Figure 5. Recruitment Flow Diagram for Research Registries**



**Figure 6. Recruitment Flow Diagram for "Other"**



### 3.3.2 Key Proportions

To further examine the differences in enrollment and retention numbers across all recruitment strategies, five key proportions were calculated from the study flow diagrams.

Proportion 1 was the number of participants eligible, out of the total number of screens complete. Proportion 2 was the number of participants enrolled, out of the total number of eligible participants. Proportion 3 was the number of randomized participants, out of the total enrolled participants. And the pattern continues for the remaining proportions such that each proportion calculated the number of participants who completed a stage of study flow, out of the total number of participants available to potentially complete that stage. A summary of these proportions and the resulting calculations are presented in Table 6. Among all recruitment strategies, just under 40% of all potential participants screened for REACT! were eligible to continue forward to the next stage of study flow. For the subsequent stages, about 70-75% of participants successfully passed through to the next stages of study flow.

A chi-square test of independence showed that there was a significant difference in key proportion 1 between all recruitment strategies ( $X^2 (2, N = 530) = 17.5, p < .001$ ). More specifically, the “other” recruitment strategy had a greater proportion of eligible participants than the postcard strategy ( $X^2 (1, N = 432) = 16.2, p < .001$ ), and the research registry strategy had a greater proportion of eligible participants than the postcard strategy ( $X^2 (1, N = 426) = 4.4, p = .036$ ). This implies that both the “other” and research registry recruitment strategies were more successful in finding eligible participants than the postcard strategy. Additionally, analysis showed that there was a significant difference in key proportion 4 between the research registry and “other” strategies ( $X^2 (1, N = 60) = 3.10, p = .078$ ), implying that the “other” strategy was more successful in finding participants that complete the full intervention as compared to the research registry strategy.



**Table 6. Summary of Key Proportions**

Key Proportion	All strategies		Postcards (A)		Registries (B)		Other (C)		p-value			
	No. of participants	Percent	No. of participants	Percent	No. of participants	Percent	No. of participants	Percent	A B C	A B	A C	B C
1 Eligible / Total screened	228 576	39.6%	125 328	38.1%	49 98	50.0%	63 104	60.6%	0.000*	0.036*	0.000*	0.131
2 Enrolled / Total eligible	170 228	74.6%	93 125	74.4%	37 49	75.5%	47 63	74.6%	0.988	0.880	0.976	0.912
3 Randomized / Total enrolled	123 170	72.4%	69 93	74.2%	28 37	75.7%	32 47	68.1%	0.679	0.861	0.446	0.445
4 Completed intervention / Total randomized	90 123	73.2%	51 69	73.9%	17 28	60.7%	26 32	81.3%	0.195	0.198	0.420	0.078†
5 Adherence at least 80% / Total completed intervention	63 90	70.0%	32 51	62.7%	13 17	76.5%	21 26	80.8%	0.216	0.300	0.106	0.735

*Note.* \*Significant at  $\alpha < 0.05$ , †Significant at  $\alpha < 0.1$

### 3.3.3 Demographics

In the present analysis, demographic information revealed if there were any differences in participant characteristics across the recruitment strategies. Demographic information was collected for each participant at various stages of the study flow. During screening in Stage 1, participants were asked for their age, gender, and preferred transportation method. After enrollment in Stage 2, participants were asked to complete a series of questionnaires as part of the baseline assessments. Within these questionnaires, participants were asked about their education, number of people living in their household, income, and employment status. A summary of all demographic characteristics is presented in Table 7.

Among all recruitment strategies, the average age of participants was 66.5 years (SD = 7.2). This remained consistent when examining each recruitment strategy individually. Among all recruitment strategies, about 80% of participants screened were female. This was fairly consistent for the postcard and research registry strategies. However, for the “other” strategy, about 74% of participants screened were female. This implies that the “other” strategy may have been slightly more effective at attracting male participants as compared to postcards and research registries. Among all recruitment strategies, about 60% of participants used a car as their preferred transportation method and about 33% relied on the bus for transportation. For both postcards and research registries, the preference for cars became more pronounced. However, for the “other” strategy, about 51% of participants used a car as their preferred transportation and about 43% took the bus. This implies that the “other” strategy was more effective in attracting participants who took the bus to the study, which makes sense considering that the “other” strategy included the use of bus advertisements.

**Table 7. Summary of Demographic Characteristics**

Variable	All strategies		Postcards		Registries		Other	
	N	Value	N	Value	N	Value	N	Value
<b>Age in years</b>								
Average (SD)	414	66.5 (7.2)	233	66.8 (6.8)	80	65.9 (9.0)	91	66.5 (6.0)
Missing	162	-	95	-	18	-	13	-
<b>Gender</b>								
Female	262	79.4%	152	80.4%	54	83.1%	63	74.1%
Male	68	20.6%	37	19.6%	11	16.9%	22	25.9%
Missing	246	-	139	-	33	-	71	-
<b>Transportation method</b>								
Car	226	60.3%	135	64.0%	54	67.5%	48	51.1%
Bus	125	33.3%	63	29.9%	21	26.3%	40	42.6%
Other (Walk, bicycle, rideshare, etc.)	24	6.4%	13	6.2%	5	6.3%	6	6.4%
Missing	201	-	117	-	18	-	10	-
<b>Education, No. of years completed</b>								
Average (SD)	169	14.7 (2.4)	92	14.8 (2.4)	37	15.1 (2.2)	47	14.5 (2.6)
Missing	1	-	1	-	0	-	0	-
<b>Education, Highest degree earned</b>								
High school grad, or less	48	31.0%	27	31.4%	12	31.6%	11	28.2%
Associate degree	33	21.3%	20	23.3%	8	21.1%	6	15.4%
Bachelor's degree	30	19.4%	15	17.4%	6	15.8%	12	30.8%
Master's degree	31	20.0%	18	20.9%	8	21.1%	7	17.9%
Doctorate, or other professional degree	2	1.3%	1	1.2%	1	2.6%	0	0.0%
Other specify	11	7.1%	5	5.8%	3	7.9%	3	7.7%
Missing	15	-	7	-	0	-	8	-
<b>No. of people living in household</b>								
Average (SD)	138	1.7 (1.0)	74	1.7 (1.0)	33	1.6 (0.8)	37	1.8 (1.1)
Missing	32	-	19	-	4	-	10	-
<b>Earnings in last 12 months</b>								
Less than \$25,000	52	37.1%	22	29.7%	14	41.2%	18	47.4%
\$25,000 through \$49,999	30	21.4%	20	27.0%	6	17.6%	5	13.2%
\$50,000 through \$74,999	22	15.7%	15	20.3%	4	11.8%	3	7.9%
\$75,000 through \$99,999	7	5.0%	5	6.8%	2	5.9%	1	2.6%
\$100,000 and greater	2	1.4%	1	1.4%	1	2.9%	0	0.0%
Don't Know	5	3.6%	3	4.1%	1	2.9%	1	2.6%
Decline to answer	22	15.7%	8	10.8%	6	17.6%	10	26.3%
Missing	30	-	19	-	3	-	9	-
<b>Family income in last 12 months</b>								
Less than \$25,000	43	30.7%	19	25.7%	11	32.4%	13	34.2%
\$25,000 through \$49,999	33	23.6%	18	24.3%	9	26.5%	8	21.1%
\$50,000 through \$74,999	12	8.6%	8	10.8%	3	8.8%	1	2.6%
\$75,000 through \$99,999	11	7.9%	7	9.5%	3	8.8%	1	2.6%

\$100,000 and greater	6	4.3%	5	6.8%	1	2.9%	1	2.6%
Don't Know	8	5.7%	4	5.4%	1	2.9%	3	7.9%
Decline to answer	27	19.3%	13	17.6%	6	17.6%	11	28.9%
<i>Missing</i>	30	-	19	-	3	-	9	-
<b>Employment status</b>								
Working full-time	9	6.0%	6	7.5%	3	8.6%	0	0.0%
Working part time	23	15.2%	12	15.0%	5	14.3%	7	16.7%
Unemployed or laid off	2	1.3%	1	1.3%	1	2.9%	0	0.0%
Looking for work	7	4.6%	2	2.5%	1	2.9%	4	9.5%
Keeping house or raising children full-time	2	1.3%	1	1.3%	0	0.0%	1	2.4%
Retired	108	71.5%	58	72.5%	25	71.4%	30	71.4%
<i>Missing</i>	19	-	13	-	2	-	5	-

Among all recruitment strategies, the average number of years of education completed was 14.7 (SD = 2.4), which remained fairly consistent when looking at each strategy individually. The distribution of highest degree earned was consistent between the postcard and research registry strategies, but differed when it comes to the “other” strategy. Most notably, around 30% of participants from the “other” strategy had earned a Bachelor’s degree, as compared to about 16% of participants for postcards and research registries. The average number of people living in a participants’ household was consistent across all recruitment strategies and no discernable pattern could be identified regarding participants’ earnings and family income. Lastly, the distribution for employment status remained consistent across all recruitment strategies; the vast majority of study participants (71.5%) were retired, which makes sense considering the time commitment requirements for the study and the target age range.

### 3.3.4 Reasons for Exclusion

Figures 3-6 include information related to barriers to participation/retention and reasons for a participant not continuing forward in the study flow. Across all recruitment strategies, the most common reason for participants' ineligibility at Stage 1 was scheduling conflicts/other commitments. This means that a participant did not have enough time to commit to the study due to other obligations, or that they were unable to attend the intervention at the scheduled times. This remained the most common reason for ineligibility for the postcard and research registry strategies as well. However, for the "other" strategy, the most common reason for ineligibility was being unable to meet study requirements. This refers to a participant who was ineligible for/refused to complete a required study assessment, or perhaps they were unwilling to be randomized.

At Stage 2, the most common reason for a participant not enrolling in the study was that they were no longer interested or were lost to follow-up. This remained true across all recruitment strategies. Participants may have canceled their first study appointment after deciding that they were no longer interested in the program, or sometimes a participant was unable to be contacted to reschedule after not arriving to the first appointment.

Across all recruitment strategies, the most common reason for not being randomized into an intervention group was that a participant was unable to meet the study requirements. Again, this means that they were either ineligible to complete a required baseline assessment, or that they refused to complete a required baseline assessment. Most often, this occurred in relation to the VO<sub>2</sub> submaximal fitness test, or to the MRI scan.

Once in the intervention, the most common reason for a participant withdrawal was being lost to follow-up. This means that a participant stopped attending intervention classes without warning, and they were unable to be contacted afterwards by the research staff to learn more about

the reason. This remained true for the postcard and “other” recruitment strategies. However, for research registries, the most common reason for participant withdrawal was a medical issue. Oftentimes a participant had a medical condition that presented itself and prevented them from completing the full intervention program. The reasons for why a participant may not have reached the target adherence rate of 80% were not formally documented.

### **3.3.5 Timepoint Comparison**

To evaluate whether the changes to recruitment in January 2023 were effective at improving enrollment and retention numbers, the data was split into two timepoints. Timepoint 1 (T1) included screening dates from May 1, 2019 to December 31, 2022, while timepoint 2 (T2) included screening dates from January 1, 2023 to May 31, 2023. In total, 464 phone screens were completed during T1, and 112 screens were completed during T2. Table 8 summarizes the key proportions for both timepoints. A two sample Z test of proportions showed that within the “other” recruitment strategy there was a significant difference in key proportion 1 between T1 and T2 (55.1% vs 93.3%,  $z = -2.81$ ,  $p = .005$ ). This means that for the “other” recruitment strategy, the proportion of eligible participants increased significantly after the changes in recruitment. Because the new Participant Handbook is given out at the time of enrollment, after participant eligibility is determined, it is safe to assume that the Participant Handbook did not contribute to this result. Instead, it is more likely that the change in compensation amount had some positive effect on finding eligible participants from the “other” recruitment strategy. The change in compensation amount was meant to account for the increased cost of living following the COVID-19 pandemic. It is possible that participants recruited by the “other” strategy were more likely to have been

affected financially by COVID-19, and thus the increase in compensation was successful in attracting this subset of participants.

**Table 8. Summary of Timepoint Comparison**

Key Proportion	Timepoint 1 (May 2019 to Dec 2022)				Timepoint 2 (Jan 2023 to May 2023)				p-value			
	All strategies	Postcards	Registries	Other	All strategies	Postcards	Registries	Other	All strategies	Postcards	Registries	Other
	Value	Value	Value	Value	Value	Value	Value	Value	Value	Value	Value	Value
1	39.4%	40.2%	49.4%	55.1%	40.2%	31.1%	52.4%	93.3%	0.8859	0.1571	0.8055	0.005*
2	77.0%	76.5%	78.9%	75.5%	64.4%	65.2%	63.6%	71.4%	0.082**	0.264	0.2984	0.757
3	71.6%	87.2%	73.3%	64.9%	75.9%	73.3%	85.7%	80.0%	0.6427	0.1696	0.4918	0.3623
4	73.3%	75.9%	54.5%	83.3%	72.7%	63.6%	83.3%	75.0%	0.9587	0.3972	0.2006	0.601
5	68.9%	63.6%	66.7%	80.0%	75.0%	57.1%	100.0%	83.3%	0.6303	0.7414	0.1399	0.8558

*Note.* \*Significant at  $\alpha < .05$ , \*\*Significant at  $\alpha < .1$



Additionally, results showed that across all recruitment strategies there was a significant difference in key proportion 2 between T1 and T2 (77.0% vs. 64.4%,  $z = 1.74$ ,  $p = .082$ ). This means that the proportion of participants who enrolled in the study actually decreased after making the recruitment changes in January 2023. Again, the Participant Handbook was given out after enrollment, so it can be assumed that the handbook did not influence this change in proportions. It is possible that the change in compensation amount could have had some unintended negative effect that caused this decrease, however, it is more likely that some other unknown variable was responsible for this change.

### **3.3.6 Cost of Enrolling/Randomizing Participants**

To further compare the three recruitment strategies, the costs of enrolling and randomizing participants were calculated, employing a two-step approach. First, the total expenses associated with each strategy were computed, encompassing both material costs and labor costs, including staff hours. Across all three strategies, staff labor was imperative for fundamental tasks such as screening, scheduling, and administrative activities. This was quantified by multiplying the staff's annual salary (\$35,000), their effort devoted to these tasks (50%), and the duration of the project (4 years), amounting to a total of \$70,000. In addition to this foundational cost, the postcard strategy incurred additional expenses for materials, specifically for printing and mailing each postcard. With approximately 96,700 postcards mailed during the analysis period from May 2019 to May 2023, at an average cost of \$0.31 per postcard, the expenditure for postcard materials amounted to \$29,977. Consequently, the overall cost of implementing the postcard strategy totaled \$99,977, covering both materials and staff labor. Conversely, the registry recruitment strategy leveraged the Pitt+Me platform at no additional cost, thus solely incurring the \$70,000 base

expense for screening staff labor. Finally, the "other" strategy's total cost included various components, such as educational materials for community presentations (approximately \$2,000), traditional advertisements (around \$500), and expenses for two bus ad campaigns (\$3,280). Moreover, this strategy entailed additional staff hours for community outreach activities, computed in a similar manner to screening staff hours, resulting in an additional \$16,000. Collectively, the total cost of implementing the "other" strategy amounted to \$91,780.

**Table 9. Cost of Each Recruitment Strategy**

Variable	Postcards		Registries		Other	
	No. of pts	Cost	No. of pts	Cost	No. of pts	Cost
TOTAL COST						
Materials	-	\$29,977.00	-	\$0.00	-	\$5,780.00
Staff hours A	-	\$70,000.00	-	\$70,000.00	-	\$70,000.00
Staff hours B	-	N/A	-	N/A	-	\$16,000.00
<i>Total</i>	-	<i>\$99,977.00</i>	-	<i>\$70,000.00</i>	-	<i>\$91,780.00</i>
COST PER PARTICIPANT						
Enrolled	93	\$1,075.02	37	\$1,891.89	47	\$1,952.77
Randomized	69	\$1,448.94	28	\$2,500.00	32	\$2,868.13

Next, the costs were calculated per participant, a crucial metric in assessing the efficiency of each strategy. This involved dividing the total cost by the number of participants enrolled and randomized within each strategy. For the postcard strategy, 93 participants were enrolled, with 69 ultimately randomized, resulting in per participant costs of \$1,075 and \$1,449, respectively. In the case of registries, the per participant cost stood at \$1,892 for 37 enrolled participants and \$2,500 for the 28 participants randomized. Finally, the "other" strategy incurred per participant costs of

\$1,953 for 47 enrolled participants and \$2,868 for the 32 randomized participants. A summary for all recruitment costs can be found in Table 9.

### **3.4 Conclusions**

The analysis of key proportions revealed distinct trends in the effectiveness of recruitment strategies for REACT!. Notably, the postcard strategy emerged as the least efficient method for attracting eligible participants, whereas the "other" strategy proved most successful in securing participants who completed the full study intervention. However, a closer examination of absolute numbers unveiled a contrasting picture, with the postcard strategy consistently attracting the highest participant count at each stage of the study flow. For instance, it yielded 125 eligible participants, surpassing the registry and "other" strategies, which brought in 49 and 63 eligible participants, respectively. This stark variance can be attributed to the comparatively lower cost associated with the postcard strategy in comparison to the other approaches. Indeed, the cost analysis underscored this point, revealing that the postcard strategy incurred the lowest costs per participant (\$1,449 for randomized participants), whereas the "other" strategy incurred the highest costs (\$2,868 for randomized participants), nearly double that of the postcards.

The demographic analysis also yielded intriguing insights, showcasing distinctive traits among participants recruited via the "other" strategy compared to those from the postcard and research registry methods. Notably, individuals engaged through the "other" strategy exhibited a higher likelihood of being male, utilizing bus transportation, and holding a Bachelor's degree. These variations in participant characteristics may have influenced intervention completion rates. The diverse array of participant characteristics observed in the "other" strategy could have

contributed positively to meeting the retention goals set for REACT!. Furthermore, it's worth highlighting that the "other" strategy stood out as the most community-oriented approach, leveraging community presentations and word-of-mouth referrals. As discussed in the previous chapter, community-oriented outreach has been recognized as one of the most effective methods for recruiting and retaining racial and ethnic minority participants in research trials – a finding corroborated by the outcomes of this analysis. However, the debate between quality and cost inevitably arises. While the "other" strategy demonstrated the highest proportion of participants completing the full intervention, signifying a quality recruitment approach, it also incurred the highest costs. For future iterations of REACT! and similar studies, striking a balance between traditional recruitment methods like postcards and community outreach activities will be crucial for optimizing recruitment outcomes. This balanced approach aims to maximize the likelihood of reaching recruitment targets effectively.

Many of the reasons for exclusion represented individual-level characteristics that prevented a participant from continuing in the study. However, many of the reasons for exclusion represented research-level characteristics, which had a broader capacity to prevent many participants from participating. A closer examination of these research-level barriers to participation is warranted. Among the most prevalent reasons for exclusion from the REACT! study were conflicts arising from time commitments and scheduling, along with difficulties in meeting study requirements. Scheduling conflicts occurred most often when participants expressed inability to attend the intervention at the prescribed times. Future iterations of the REACT! program could overcome this barrier by offering additional options such as evening classes, alongside current morning and afternoon options. Evening classes would also likely attract more participants who are still working, adding further diversity to the study sample. Of course, this

solution also likely requires an influx of resources. Regarding time commitment conflicts, instances where participants couldn't adhere to the required intervention frequency or duration were common. To overcome this barrier, future iterations of the study could consider reducing the length of intervention or the required number of days. However, changing the structure of the intervention could impact the efficacy of the experimental group, and therefore requires a much closer examination, which is outside the scope of this essay. Lastly, failure to meet study requirements often stemmed from ineligibility or reluctance to undergo baseline assessments such as fitness testing and MRI scans. REACT! leadership acknowledged that the MRI scan was a significant barrier to participation and took the necessary steps to make the MRI scan an optional assessment rather than a required one. This change occurred after May 2023 and therefore could not be examined in the present analysis. Future works could examine whether making the MRI scan optional had any impact on the enrollment and retention of study participants.

In conclusion, this analysis found the “other” recruitment strategy to be the most effective at retaining participants in the REACT! trial, albeit at a higher expense. Despite this, REACT! researchers ultimately succeeded in reaching their recruitment goals by successfully balancing high-quality recruitment strategies with budgetary needs. Moving forward, similar studies should take heed of this delicate balance, leveraging a diverse array of recruitment strategies to optimize outcomes. Moreover, researchers should explore avenues to alleviate participant burden, potentially by streamlining study requirements and broadening the accessibility of intervention programs, thereby ensuring inclusivity and maximizing participation.

## 4.0 Discussion

The overall goal of this essay was to identify evidence-based recruitment strategies to enhance participation in ADRD research among underrepresented racial and ethnic minorities. Results from the critical literature synthesis found that the strategies with the highest strength of evidence included implementing of a variety of community-oriented outreach activities, employing a diverse team of research staff, leveraging word-of-mouth referrals, and providing monetary compensation for research participation. Results from the REACT! study data analysis corroborated community outreach as an effective method for recruiting and retaining Black/African American older adults, but it also shed light on the considerable financial investments required for such activities.

It's crucial to acknowledge that the outcomes of the literature synthesis were based on studies employing different methodologies than REACT!. A substantial portion of these studies utilized qualitative, mixed methods, or CBPR approaches, typically characterized by smaller sample sizes, and none were RCTs. Thus, the findings from the literature synthesis may not be directly transferable to REACT! or similar RCTs. Instead, researchers should tailor their recruitment methods based on overarching objectives, appropriate study design, target sample size, and budgetary constraints. Studies with smaller sample sizes or less stringent design requirements should prioritize community outreach in their recruitment strategies, while those necessitating larger samples or more rigorous methodologies should strike a balance between community outreach and cost-effective alternatives such as traditional advertising.

In summary, this essay found that recruitment science in the context of ADRD research remains in its infancy, highlighting the pressing need for more robust tools to tackle the challenges

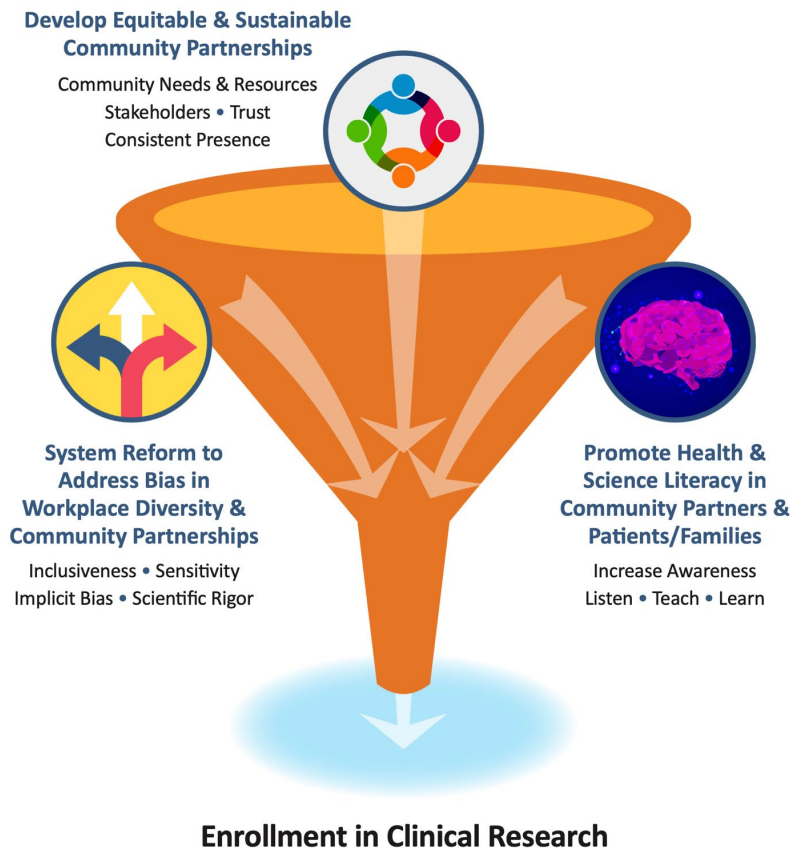
of recruiting racial and ethnic minorities effectively. Encouragingly, there exists institutional-level guidance to confront these obstacles. The NIA, as part of the National Plan to Address Alzheimer's Disease, has developed the Alzheimer's Disease and Related Dementias Clinical Studies Recruitment Planning Guide, alongside a web-based repository known as Alzheimer's and Dementia Outreach, Recruitment, and Engagement (ADORE) Resources (National Institute on Aging [NIA], 2019). These resources serve to compile and disseminate best practices, tools, and materials to support recruitment activities. Within this repository, numerous research materials are available, including sample recruitment plans, promotional materials, consent forms, and training guides. Emphasizing the iterative nature of ADRD recruitment science, the planning guide stresses the importance of sustained and meaningful engagement with community stakeholders to determine the most effective recruitment strategies. Furthermore, it advocates for the adoption of process-oriented evaluation measures, focusing not solely on accrual rates but also on the progress made in cultivating deeper community partnerships, thereby propelling these initiatives forward (NIA, 2019).

While additional research is warranted to pinpoint best practices, the NIA's planning guide has identified that the "most promising efforts for enhancing recruitment and retention of diverse participants revolve around cultivating community relationships and addressing specific localized barriers" (NIA, 2019, p. 1). Specifically, the guide outlines three key strategies: 1) developing equitable and sustainable community partnerships, 2) promoting health and scientific literacy among all community members, and 3) instituting systemic reforms to mitigate biases in workplace diversity and community collaborations (NIA, 2019). Figure 7, extracted directly from the planning guide, encapsulates the overarching objective of these strategies. Structured hierarchically, the guide presents two to three specific tasks beneath each key strategy to guide

implementation. Moreover, numerous suggested steps and performance indicators are provided under each task to gauge success. For example, within the first key strategy, the second specific task involves cultivating trust between community stakeholders and research teams to forge robust, sustainable partnerships and shared ownership of the research mission. Recommended actions include establishing a community advisory board (CAB) and collaborating with its members to form a mission ensuring continued responsiveness to community needs. The NIA also proposes success indicators for this task, such as CAB members introducing research staff to community members, ensuring CAB membership reflects the diversity of local or targeted populations, high attendance rates of CAB members at meetings and community events, and growth and retention of CAB membership, among others (NIA, 2019). These tasks and steps, aligned with the facilitators and recruitment strategies outlined earlier in Chapter 2, suggest that the NIA has integrated established evidence into their planning guide.



**Figure 7. Key Strategies for Effective Recruitment**

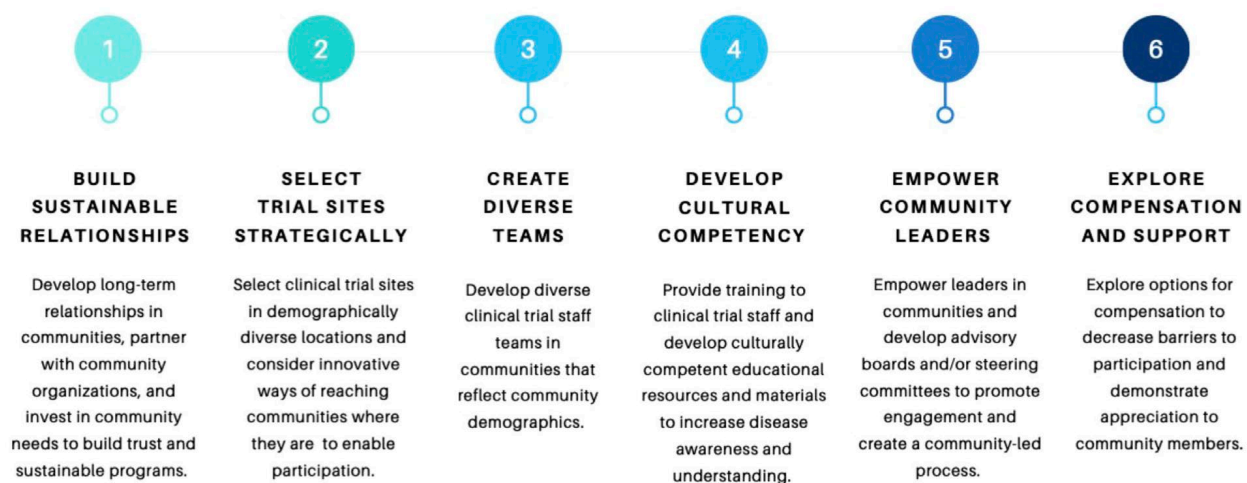


**Note: Effective Recruitment = Intentional & Equitable Community Engagement. Reprinted from “Alzheimer’s Disease and Related Dementias Clinical Studies Recruitment Planning Guide,” by National Institute on Aging [NIA], 2019, Reprinted with permission.**

To further elucidate the complexities of successful community outreach and partnership, Savold et al. (2023) developed a comprehensive six-step process, summarized in Figure 8. In their work, the authors identified additional steps for community engagement extending beyond those outlined in the NIA Recruitment Planning Guide, notably including the strategic selection of trial sites and the exploration of compensation and support mechanisms. These additional steps align closely with findings from the literature synthesis. Specifically, challenges with mobility and access to trials sites was cited as a common barrier to participation, while offering monetary

compensation for participation was frequently cited as one of the best facilitators to participation. While the recommendations developed by Savold et al. were based on studies involving only Black participants, their applicability easily extends to other underrepresented groups.

**Figure 8. Best Practices for Effective Community Engagement**



**Note: Best practices to improve clinical trial participation for Black Americans. Reprinted from “Barriers and solutions to Alzheimer’s disease clinical trial participation for Black Americans,” by J. Savold, M. Cole, & R. J. Thorpe, 2023, *Alzheimer’s & dementia*, Reprinted with permission.**

The NIA Recruitment Planning Guide and the recommendations from Savold et al. converge on a shared emphasis of time necessary for cultivating and sustaining trusted community partnerships. Savold et al. (2023) underscored the need for long-term commitment, advocating for the establishment of a consistent presence within the community, facilitation of resource connections, and support for community initiatives. Echoing this sentiment, the NIA Recruitment Planning Guide advises a minimum of two years for the establishment of robust community partnerships before initiating study recruitment (NIA, 2019). Moreover, the NIA underscores that

maintaining long-term relationships with communities necessitates ongoing commitment before, during, and after the trial phase. This commitment aligns with earlier findings from the literature synthesis, emphasizing the significance of disseminating study results after trial completion to participants and communities as a catalyst for research participation. It is evident that continual demonstration of trust and reciprocity is essential for establishing and maintaining mutually-beneficial partnerships between researchers and the community.

It's crucial to keep in mind that the ultimate goal of implementing these recruitment strategies is to enhance diversity in ADRD research, thereby reducing health disparities between racial/ethnic minorities and their White counterparts. However, as highlighted in Chapter 1, there remains a significant gap in robust mechanisms for measuring and evaluating diversity, posing challenges in monitoring and tracking progress towards this goal. Agboola and Wright (2024) acknowledged this challenge and developed a Clinical trial Diversity Rating (CDR) framework to assess the demographic diversity of clinical trials. This framework was developed through a four-step process involving a scoping review, a cross-sectional study, creation of the framework itself, and integration of feedback from an advisory group (Agboola & Wright, 2024). Notably, the applicability of this framework extends beyond the confines of this essay, as it was created to be adaptable to research across all health conditions, not solely ADRD. Furthermore, it incorporates an evaluation of demographic characteristics beyond race/ethnicity, including age and sex, broadening its applicability and relevance .

The framework relies on the calculation of the “participation-to-disease representation ratio” or PDRR. For example, consider the prevalence of AD among older Black adults, which is approximately 19%. If study "X" enrolls a study sample consisting of 8% older Black adults, the PDRR would be  $0.08/0.19$ , resulting in 0.42. Agboola and Wright (2024) drew upon established

literature by Poon et al. (2013) to designate a PDRR score of 0.8 or higher as indicative of "adequate representation." Subsequently, they devised a scoring system for representation based on the PDRR: a PDRR of 0.8 or above earns a score of 3, 0.5 to <0.8 earns a score of 2, >0 to <0.5 earns a score of 1, and a PDRR of 0 receives a representation score of 0 (Agboola & Wright, 2024). This process of PDRR calculation and subsequent conversion to a representation score is repeated for each demographic characteristic encompassed in the study. For example, if study X reports demographic data for four race/ethnicity groups – Black, Hispanic, Asian, and White – the maximum representation score would be 12. Based on the cumulative representation score, the study is then assigned a diversity rating – either good, fair, or poor – for each of evaluated demographic categories (e.g., race/ethnicity, sex, and age). Agboola and Wright (2024) tested the validity of their framework on 172 studies across a variety of health conditions and found that 36% were rated as poor for racial and ethnic diversity, 53% were rated as fair, and 10% were rated as good. Thus, this framework establishes a tangible, quantifiable method for gauging diversity in clinical trials, which can be used to track changes over time. Five years from now, a future study could follow the same parameters as Agboola and Wright and evaluate diversity ratings for another 172 studies, compare the outcomes to the earlier findings, and evaluate whether any changes occurred. In sum, the CDR framework provides a feasible solution for measuring and monitoring progress of diversity in clinical trials.

As the prevalence of ADRD and racial/ethnic diversity are expected to grow substantially over the next several decades, it becomes increasingly imperative to confront the challenges of equitable representation in clinical trials in order to reduce, and ideally eliminate, health disparities associated with ADRD. It is essential to encourage researchers to pursue this objective earnestly, leveraging evidence-based recruitment strategies and drawing upon the support offered by

resources like the NIA ADRD Clinical Trials Recruitment Guide, as well as assessing trial diversity through the utilization of the CDR framework. Moreover, additional backing from institutions such as the NIH can play a pivotal role in disseminating vital resources and monitoring progress over time. By embracing community-partnered research and rallying around a shared goal of health equity, ADRD researchers can collectively strive towards eliminating health disparities.

## **Appendix A Supplemental Content to the Critical Literature Synthesis**

**Appendix Table 1. Summary of Included Reviews**

Title (Year)	Objectives	Inclusion Criteria	Databases Used	Critical appraisal	No. of eligible studies (total no. of studies)  Publication dates of eligible studies	Overall findings
<b>Systematic reviews</b>						
Gilmore-Bykovskiy et al. (2022)	To synthesize available evidence for the recruitment & retention of study participants from minority backgrounds, and to report participants' views on ADRD research participation	Studies that: 1) examined recruitment and/or retention of participants from minority backgrounds in ADRD research or reported on participants' views regarding ADRD research participation, 2) included evaluation data related to recruitment/retention efforts, 3) were available in English, and 4) were published in a peer-reviewed journal after 1/1/2010	CINAHL (EbscoHOST) Medline (PubMed) PsycINFO (Ovid)	Quality Assessment Tool (QAT) for Quantitative Studies (*EPHPP) All 17 quantitative studies rated as "weak."  Checklist for qualitative studies ( <sup>b</sup> JBI) 3 of 5 met all 10 criteria 1 of 5 met 4 criteria 1 met 3 criteria	N = 22 (22)  2010 - 2017	The overall strength of evidence regarding effective strategies for bolstering recruitment & retention of minorities in ADRD research was both low & limited to specific populations. Metrics for quantifying effectiveness of recruitment efforts were inconsistent.
Vyas et al. (2018)	To conduct a systematic review and meta-analysis to examine the inclusion of ethnic groups in dementia treatment trials	Studies that: 1) were a phase 3 or 4 RCT, 2) included community-dwelling participants with a diagnosis of dementia MCI, 3) included both an intervention and a comparison group, and 4) focused on improving cognitive function, measured by change in cognition as either a primary or secondary outcome	clinicaltrials.gov Embase Medline	Not reported	N = 96 (8)  2000 - 2013	Ethnicity of participants in the included RCTs was not well reported, and non-Caucasian ethnic groups were not well-represented. Among the included U.S.-based studies, Caucasians represented 90.8% of all participants.
Wong et al. (2019)	To identify strategies for the recruitment and retention of racial/ethnic minorities in AD & dementia clinical research, as well as the quality of evidence and related gaps in the literature	Studies that: 1) targeted at least one racial/ethnic minority group, 2) implemented a recruitment or retention strategy in AD or dementia clinical research, 3) were conducted in the U.S., 4) were published in English through a peer-reviewed journal	CINAHL (EBSCO) Embase Medline (EBSCO) PsycINFO Scopus	Study team used the Quality Assessment Tool (QAT) for Quantitative Studies. All included studies were rated for quality a "weak."	N = 19 (19)  1993 - 2016	Community outreach & collaboration with health care providers were typically the most effective strategies. Most of the available literature on recruitment & retention in ADRD research was specific to AAs. Less than half of all included studies included formal evaluation of the effectiveness of a strategy.
<b>Scoping reviews</b>						

Brijnath et al. (2022)	To: 1) investigate approaches to enhance the recruitment of ethnic minorities in the U.S. and other HIC in dementia research, 2) identify high-quality studies in this area, and 3) make recommendations for consistent practice	Studies that: 1) had a priori intention to recruit ethnic minorities into the study, 2) had a trial or cohort study design, 3) were conducted in HIC, as defined by the World Bank, and 4) were published January 1, 2020 to January 7, 2020	CENTRAL CINAHL Embase Medline PsycINFO	Study team developed proxy indicators for good practice in conducting research with ethnic minorities. Of the U.S.-based studies, 4 (7.0%) met all criteria for quality assessment, indicating high quality studies.	N = 66 (57) 2010 - 2020	The most common techniques to facilitate recruitment & participation were the interpretation and translation of study materials and the employment of bilingual/bicultural researchers. The studies identified as high-quality primarily used community-based recruitment strategies. Recommendations to improve representation reflected these findings and also included ways to enhance data collection, reporting, and analysis.
Godbole et al. (2022)	To summarize what is currently known about inclusion and representation of underrepresented groups, identify gaps that remain in NIH-sponsored research, and to inform strategies to achieve equitable inclusion in AD/ADRD and aging research	Studies that: 1) focused on AD/ADRD or other aging-related topics, 2) included diverse racial and ethnic populations and groups that are underrepresented in research, 3) described recruitment/retention efforts, 4) included participants 55+, and 5) were sponsored by NIH	Medline (Ovid) PubMed	Opted not to include	N = 436 (305) 2000 - 2019	Included studies lacked consistency on the reporting of participant racial and ethnic characteristics. Researchers highlighted the need to improve collection and standardization of reporting as a necessary first step to advancing equitable inclusion in ADRD research.
<b>Narrative reviews</b>						
Esiaka et al. (2022)	To identify evidence-based recruitment strategies that help increase participation among older African Americans in AD research	Studies that: 1) evaluated the effectiveness of recruitment strategies aimed at increasing AA participation in AD or aging studies, 2) included either a control and intervention group, pretest-posttest design, or retrospective cohort analyses, 3) were conducted in the U.S., 4) were published in English, and 5) were published in a peer-reviewed journal	PubMed	N/A	N = 8 (8) 1993-2018	Long-standing community outreach & education were consistently found to be the most effective strategies to increase AD research participation among older AAs. Researchers can better attract & retain participants by providing full transparency on research purposes, protocols, and protections.



Savold et al. (2023)	To explore the barriers impacting participation in clinical trials among Black Americans and how the pharmaceutical industry can play a role in improving equity & inclusion.	Articles that: 1) identified barriers to participation in AD CTs for Black Americans and/or explored solutions for improving equity & inclusion in AD CTs, 2) were written in English, and 3) published in the U.S.	Google Scholar PubMed Scopus	N/A	N = 26 (26)  2002-2022	Pharmaceutical companies have not yet developed the resources needed sustainably engage with racially diverse communities and overcome the barriers to participation. Recommendations to improve inclusion of Black Americans in CTs included fostering sustainable relationships in communities, prioritizing community-led processes, building diverse teams & cultural competency, and innovating access to CT sites.
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Note. <sup>a</sup>EPHPP: Effective Public Healthcare Panacea Project (<https://www.ehphp.ca/quality-assessment-tool-for-quantitative-studies/>); <sup>b</sup>JBI: Joanna Briggs Institute (<https://jbi.global/critical-appraisal-tools>)

**Appendix Table 2. Summary of Included Primary Studies**

<b>Author (Year)</b>	<b>Objectives</b>	<b>Study Design</b>	<b>Participants</b>	<b>Sample Size</b>	<b>Components for Analysis</b>	<b>Overall Findings</b>
Amofa et al. (2023)	To assess potential barriers to participation in aging & clinical research among Black Americans	Mixed methods - focus groups + survey	Black American adults residing in North Florida (ages 26-86)	N = 50 (4 FGs)	Emergent themes from FGs Barriers to Research Participation Questionnaire (BRPQ) Perceptions Regarding Investigational Screening for Memory in Primary Care (PRISM-PC)	Results from focus groups & surveys show mistrust in researchers & time demands as potential barriers, while the availability of/perceived incentives are potential facilitators.
Bardach et al. (2020)	To explore whether attendance at AA-focused community events encourages research participation, as compared to general audience community events	Observational	African Americans who attended at least one event at a specific community center (ages not reported)	N = 773	Count of: total events attended, AA-focused events attended, general audience events attended Records of prior research participation	Community outreach events are an effective strategy for encouraging research engagement. Attendance at AA-focused events is not statistically related to research engagement.
Bardach et al. (2021)	Use photovoice to explore barriers & facilitators to AD research participation among AAs and identify strategies to enhance engagement	Photovoice	African American community members (ages 35-86)	N = 21	Photographs from participants Emergent themes from group discussions	Emergent themes include: 1) mistrust, 2) avoidance/fear of AD, and 3) seeing the risks of research but not the benefits. Suggestions to overcome barriers include gradually building up trust, normalizing topics of brain health, and reframing research as a social responsibility or form of service
Graham et al. (2023)	To examine factors that influence enrollment of AAs in biomedical studies and whether the availability of transportation increases participation	Secondary analysis of recruitment data	Potential participants for an exercise intervention trial in the DELMARVA area (ages 55+)	N = 493	Participant enrollment status Participant access to transportation (Yes or No)	AA participants were less likely to have transportation than White participants. Transportation may be a mediator to clinical trial participation among AAs.
Lee et al. (2023)	To demonstrate how community-based GIS methods can be used effectively to recruit elderly KAs as research participants	Community-based participatory research (CBPR) + GIS	Older Korean Americans residing in New Jersey (ages 60+)	N = 60	Census data Key informant interviews GIS mapping tools	Successful recruitment of KA older adults benefited from using population-tailored GIS methods

<b>Lingler et al. (2023)</b>	To explore attitudes and behaviors regarding interest in research following exposure to culturally-informed narratives of research participation	Prospective survey	Black or African American adults residing near Pittsburgh (ages 18-79)	N = 500	Video narrative Survey questions on attitudes & behaviors regarding research participation	The relationship between trust and likelihood of study enrollment was partially mediated by perceptions of benefit
<b>Marquez et al. (2022)</b>	To explore: 1) barriers and facilitators to clinical trial participation, and 2) strategies to increase research representation among Latinos in California	Focus groups Key informant interviews	Latino/Hispanic adults Latino/Hispanic older adults Caregivers to a Latino individual CBO administrators	N = 54 (8 FGs) N = 75 (9 FGs) N = 52 (8 FGs) N = 12 (12 interviews)	Emergent themes from FGs & interviews	Participants wanted to better understand ADRD and participate in ADRD research, but had limited awareness of opportunities. Strategies to increase representation include raising awareness and promoting altruism.
<b>Mindt et al. (2023)</b>	To describe the development and interim results of a culturally-informed, community-engaged approach to recruitment of Black participants into an AD study	Community-based participatory research (CBPR)	Community partners including Black research registry participants, study scientists, and a Latinx marketing expert (ages not reported)	N = 19	Emergent themes from group discussions Feedback from CAB Enrollment status	By leveraging a culturally-informed community-engaged approach, researchers successfully recruited 349 Black participants into an AD study.
<b>Passmore et al. (2023)</b>	To explore the acceptability of participation in AD research involving LPs among AA adults	StoryDeck Qualitative interviews	African American adults with prior experience as an AD research participant (ages 40-81)	N = 61	StoryDeck hypothetical scenarios Post-survey Post-interview	Almost all participants were able to identify at least one study scenario involving LP in which they would be willing to participate. The most important driver of decision making was the disclosure of research results.
<b>Perales-Puchalth et al. (2020)</b>	To examine whether participating in an ADRD education presentation would increase desire to participate in research	One arm pre-post trial	Hispanic older adults recruited from senior centers near Kansas City (ages 60+)	N = 50	Culturally-tailored educational event on ADRD Pre-survey Post-survey	Participants showed an increase in desire to participate in ADRD research following an educational presentation.
<b>Portacolone et al. (2020)</b>	To: 1) examine factors related to trust that influence participation in dementia research among older AA adults, and 2) provide actionable strategies to improve representation	Focus groups Key informant interviews	Older African Americans residing near Detroit or the San Francisco Bay (ages 51-93) Caregivers to an older AA individual CBO administrators	N = 91 (10 FGs) N = 44 (5 FGs) N = 11 (11 interviews)	Emergent themes from FGs & interviews Feedback from CAB	Distrust is a major barrier affecting participation in dementia research among AA adults. Recommended strategies to build trust include strong commitment to the community and collaborations with trusted CBOs.

<b>Pugh et al. (2022)</b>	To collect qualitative data on the beliefs towards dementia and the willingness to participate in prevention interventions among AAs in the southern U.S.	Focus groups	Older African Americans residing near Baton Rouge (ages 61-85)	N = 51 (4 FGs)	Emergent themes from FGs	Barriers & facilitators to research participation were consistent with prior research. Participants expressed willingness to participate in lifestyle interventions to reduce risk of developing dementia.
<b>Raman et al. (2021)</b>	To examine the recruitment sources and reasons for screen failure among racial/ethnic minority participants in a preclinical AD trial	Secondary analysis of recruitment data	Cognitively-normal older adults who showed elevated brain amyloid during a screening visit (ages 65-85)	N = 5945	Self-reported race/ethnicity Recruitment sources Reasons for screen failure	Minority participants (as compared to White participants) were more likely to be recruited from local site efforts & local media, and were more likely to be excluded based on failure to meet cognitive criteria. Actionable recommendations to improve minority representation in preclinical AD trials were described.
<b>Salazar et al. (2020)</b>	To 1) examine the relationship between race/ethnicity & willingness to participate in AD clinical trials, and 2) explore whether research attitudes acts as a mediator	Cross-sectional survey	Adults residing in Orange County and enrolled in an AD research registry (ages 18+)	N = 2749	Self-reported race/ethnicity Assessment of research willingness Research Attitudes Questionnaire (RAQ)	Ethno-racial minority participants were less willing than NH White participants to be contacted for studies that involved procedures typically required for AD prevention trials. Research attitudes were not found to mediate this relationship.
<b>Shaw et al. (2023)</b>	To explore how neurovascular clinical trials are perceived among older Midwestern AAs	Photovoice	Cognitively-normal older Black or African American adults with at least 1 CV risk factor and no prior participation in an ADRD intervention trial	N = 10	Photographs from participants Emergent themes from group discussions	Barriers & facilitators to research participation were consistent with prior research. Components of trust were discussed in relation to enhancing diversity in neurovascular trials.
<b>Stout et al. (2020)</b>	To examine the effectiveness of traditional vs. social media in recruiting AA and NHW participants into an existing longitudinal cohort study on preclinical AD & driving	Secondary analysis of recruitment data	Cognitively-normal older adults residing in St. Louis who drive regularly (ages 65+)	N = 546	Self-reported race/ethnicity Recruitment sources	Traditional print media was successful at recruiting both AA and NHW participants, however, social media was only successful at recruiting NHWs. Other recruitment methods, such as word-of-mouth were moderately successful for both groups.

Ta Park et al. (2023)	To describe the development, implementation, and early results of a research registry targeted at recruiting AAPIs as research participants	Community-based participatory research (CBPR) Focus groups	Community partners from seven AAPI cultural groups (ages not reported)	N = 123	Emergent themes from FGs Feedback from CAB Enrollment survey	By leveraging community-based partnerships, the research registry successfully recruited over 7000 potential AAPI research participants.
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**Appendix Table 3. Inventory of Studies Pertaining to Barriers & Facilitators**

Study ID	Author (Year)	Cited as a primary study	Cited as a secondary study within a review by:		
			Gilmore-Bykovskiy et al. (2022)	Godbole et al. (2022)	Savold et al. (2023)
1	Ajrouch et al., 2020			X	
2	Alzheimer's Association (2002)				X
3	Alzheimer's Association (2008)				X
4	Alzheimer's Association (2021)				X
5	Amofa et al. (2023)	X			
6	Babulal et al. (2019)				X
7	Ballard et al. (2010)				X
8	Baquet et al. (2008)				X
9	Bardach et al. (2020)	X			
10	Bardach et al. (2021)	X			
11	Boise, Hinton, Rosen, and Ruhl (2017)		X		
12	Boise, Hinton, Rosen, et al. (2017)		X		
13	Brodsky & Green, 2002			X	
14	Chao et al., 2011		X		
15	Clark et al. (2019)				X
16	Coakley et al. (2012)				X
17	Cocroft et al. (2020)				X
18	Darnell et al., 2011		X		
19	Deane et al., 2020			X	
20	Denny et al. (2020)				X
21	Dudley et al., 2015			X	
22	Forsat et al., 2020			X	
23	Gelman, 2010		X		
24	Gilmore et al., 2019			X	
25	Gilmore-Bykovskiy et al., 2021			X	
26	Graham et al. (2018)				X
27	Graham et al. (2023)	X			
28	Hooper et al., 2013		X		
29	Howell et al., 2016		X		
30	Hughson et al. (2016)				X
31	Indorewalla et al. (2021)				X
32	Jang et al., 2018			X	
33	Jefferson et al., 2013		X		
34	Jefferson, Lambe, Chaisson, et al., 2011		X		
35	Jefferson, Lambe, Cook, et al., 2011		X		
36	Lacey et al., 2017			X	
37	Lambe et al., 2011		X		

38	Langbaum et al. (2023)			X
39	Lim, Mohaimin et al., 2020		X	
40	Lincoln et al. (2021)			X
41	Lines et al. (2014)			X
42	Lingler et al. (2023)	X		
43	Littlechild et al., 2015		X	
44	Marquez et al. (2022)	X		
45	Marshall et al., 2020		X	
46	Mindt et al. (2023)	X		
47	Mitchell et al., 2020		X	
48	Neugroschl et al., 2016		X	
49	Passmore et al. (2023)	X		
50	Perales-Puchalth et al. (2020)	X		
51	Portacolone et al. (2020)	X		
52	Pugh et al. (2022)	X		
53	Raman et al. (2021)	X		
54	Robinson et al. (2020)			X
55	Salazar et al. (2020)	X		
56	Schnieders et al., 2013		X	
57	Shaw et al. (2022)			X
58	Shaw et al. (2023)	X		
59	Shin & Doraiswamy (2016)			X
60	Stewart et al., 2020		X	
61	Ta Park et al., 2021		X	
62	Tuijt et al., 2021		X	
63	U.S. Food and Drug Administration (2022)			X
64	Vick et al., 2018		X	
65	Weiner et al. (2007)			X
66	Williams et al., 2010		X	
67	Wolff & Roter, 2012		X	
68	Wolff et al., 2015		X	
69	Wolff et al., 2017		X	
70	Woods-Burnham et al. (2021)			X
71	Zhou et al. (2017)		X	X

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