

RESEARCH ARTICLE

Recruiting a prospective community cohort to study Alzheimer's disease and structural and social determinants of health among adults racialized as Black: The ARCHES cohort

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Abstract

INTRODUCTION: This ongoing, prospective study examines the effectiveness of methods used to successfully recruit and retain 238 Black older adults in a longitudinal, observational Alzheimer's disease (AD) study.

METHODS: Recruitment strategies included traditional media, established research registries, speaking engagements, community events, and snowball sampling. Participants were asked to complete an annual office testing session, blood-based biomarker collection, optional one-time magnetic resonance imaging (MRI) scan, and community workshop.

RESULTS: Within the first 22 months of active recruitment, 629 individuals expressed interest in participating, and 238 enrolled in the ongoing study. Of the recruitment methods used, snowball sampling, community events, and speaking engagements were the most effective.

DISCUSSION: The systemic underrepresentation of Black participants in AD research impacts the ability to generalize research findings and determine the effectiveness and

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safety of disease-modifying treatments. Research to slow, stop, or prevent AD remains a top priority but requires diversity in sample representation.

KEYWORDS

Alzheimer's disease, dementia, race, inclusion, social determinants of health

Highlights

- Provide flexible appointments in the evening or weekends, offering transportation assistance, and allowing participants to complete study visits at alternative locations, such as senior centers or community centers.
- Continuously monitor and analyze recruitment data to identify trends, challenges, and opportunities for improvement.
- Implement targeted strategies to recruit participants who are underrepresented based on sex, gender, or education to increase representation.
- Diversify the research team to include members who reflect the racial and cultural backgrounds of the target population, to enhance trust and rapport with prospective participants.

1 | INTRODUCTION

The population of adults 65 years of age and older is projected to increase from 58 million to 88 million by 2050 in the United States.¹ Age is the primary risk factor for Alzheimer's disease (AD), and because the older adult U.S. population will continue to grow, the number of people affected by AD is projected to double from 6.7 million in 2023 to nearly 13 million by 2050.² Adults racialized as Black experience a two-fold risk of AD and related dementias (ADRD) compared to adults racialized as non-Hispanic White (nHW).^{3,4} Recent investigations of why this elevated risk persists pivots from group comparisons using biomarkers⁵⁻⁷ to upstream structural and social determinants of health (S/SDOH).⁸⁻¹⁰ Systemic barriers and chronic deprivation of quality education, healthy and affordable food, safe natural and built environments, and limited health care access impact brain health, aging, and ADRD risk, especially for minoritized populations.¹⁰⁻¹⁴ S/SDOH measurement has lagged significantly across federally-funded cohorts.¹⁵ Similarly, strategies for engaging minoritized communities—particularly with participants racialized as Black—have focused primarily on passive recruitment strategies uninformed by best practices.¹⁶ Historically, enrolling minoritized groups into ADRD research served to fill quotas for comparison to a gold-standard, “control” group, almost exclusively nHW—yet many cohort studies do not reflect the ethnoracial demographic of the United States.^{4,16}

The limited science of effective recruitment, engagement, and retention (RER) of all minoritized populations is a crucial gap.^{16,17} Consequently, studies examining biomarker risk among ethnoracial groups are magnified where comparison is marred by small sample sizes, particularly among those racialized as Black.¹⁸ RER strategies are not a monolith that can be uniformly implemented across demographics (age, race, ethnicity, sex, gender) or location and time. The latter two

components represent a continuum. Most research studies are future oriented, given the prospective nature of observational and clinical trial cohorts. History is often acknowledged as a footnote in an initial understanding of RER strategies, but it is frequently relegated to the background when discussing methodological barriers to participation in ADRD research and ameliorating mistrust for a minoritized group. However, the results, outcomes, and effects observed in ADRD research are informed by RER strategies and driven by history (e.g., perception, belief, policies, stigma, and social problems). Nationally, there are only a handful of community-based cohort studies (MARS,¹⁹ WHICAP,²⁰ Offspring,²¹ HABLE/HABS-HD²²) designed to examine aging, ADRD, and S/SDOH among Black adults. These studies are tailored to their geographic location and have a unique socio-historical understanding of place embedded in the examination of ADRD in their architecture. We adopted an intentional socio-historical approach that accounts for the delicate social fabric underlying the treatment of minoritized groups, fraught with mistrust of medical institutions—both in clinical medicine and research.

The following paragraphs, although detailed, are critical to understanding the context of a specific city and group when beginning a new study. There is a long and publicly documented history of unethical biomedical experimentation conducted on Black people in the US. Landmark events like the Tuskegee Syphilis Study, nonconsensual harvest and use of Henrietta Lack's “HeLa” cells, J. and Marion Sims's inception of modern gynecology are the most infamous medical and scientific atrocities. These are embedded in the bedrock of modern scientific advancement and require no citation. The culmination of these national events created an overarching umbrella of mistrust of research efforts but also impacted health-seeking behaviors, which is indirectly tied to research participation of Black people. Place-specific historical epochs also compound the impact of mistrust within a

particular region. St. Louis, Missouri, is a historically Black, mid-sized Midwestern city with a documented history replete with inequity, disparities, and violence against its Black residents, from housing to health care. As a result, when designing RER strategies, it is beyond crucial to understand the historical and geographic context in which minoritized groups reside.

In 1820, the Missouri Compromise was passed by the U.S. Congress, which admitted Missouri to the Union as a state where the internal and domestic chattel slave trade was legalized. St. Louis, the capital city, was situated on the banks of the Mississippi River, one of the world's most critical commercial waterways, and became a nexus for slavery in the 1830s. As the cotton industry grew, enslaved Blacks were placed on steamboats and sent along the Mississippi to plantations in states of the Deep South. The infamous *Dred Scott v. Sandford* case (1857) decision was catalyzed in the Old St. Louis Courthouse and was known for being one of the worst Supreme Court decisions in the history of the United States. It ruled that the U.S. Constitution was not written with the intention of extending American citizenship to Black slaves after a Black man freed from slavery returned to Missouri, a slave state under federal law. Although these events in Missouri were part of the building blocks leading up to the Civil War, they also cemented a culture of racism toward and negative stereotypes and inequitable treatment of Black residents.

Brutality against St. Louis's Black residents continued into the twentieth century, with historical indices chronicling continued cumulative trauma such as the East St. Louis "Race Riots" (1917); United States Army Chemical Corps' *Operation LAC* that sprayed zinc cadmium sulfide into predominantly Black North St. Louis County (mid-1950s); the construction of the St. Louis Arch (1963–1965) that displaced 19,000 Black families; and the failure of Pruitt-Igoe housing complex (1972–1976) that further disenfranchised the Black community. As time progressed, there was a calculated and targeted divestment from predominantly Black North St. Louis that has played a significant role in the overall distrust of institutions, including medical facilities. This is notably indexed by the rise and fall of the nationally recognized Homer G. Phillips Hospital (HGPH) located in The Ville neighborhood.^{23,24}

HGPH was built in 1937, as a response to the overwhelming need for a public hospital catering to the surrounding neighborhood's Black residents. Following the *Brown v. Board of Education* decision (1954), the hospital was ordered to desegregate, but because of its location and history, the hospital continued to serve a predominantly Black patient population. It was not until 1963 that Barnes Hospital integrated wards to see Black patients, who were often relegated to the wards located in the basement of the facility. At this time, HGPH was one of the largest hospitals in the country, with an unprecedented number of skilled Black nurses, residents, and physicians, many of whom were not permitted to further their professional development at institutions like Washington University in St. Louis or Saint Louis University. HGPH was a site of great pride and medical advancement within St. Louis. However, through the 1960s and following desegregation, insured Black patients began receiving their care from private hospitals, and medical residents transferred to programs with better pay and more modern facilities. This, coupled with the exodus of nHW residents (also known

RESEARCH IN CONTEXT

1. **Systematic review:** Literature on the recruitment and retention of minoritized groups and relevant publications were cited. However, there is a lack of insight into how consideration of geographic and historical context impacts enrollment within a specific region, thus limiting the generalizability of recruitment practices.
2. **Interpretation:** A multi-level recruitment method must be employed to recruit and retain Black participants, with established research registries, snowball sampling, and community events being the most successful.
3. **Future directions:** It is important to tailor research recruitment and retention methods based on the socio-historical and geographical context that surrounds the demographic of interest and how that impacts health-seeking behavior and research participation.

as "white flight") from the city to the county and the advent of Medicare and Medicaid (1965), led to the steady disinvestment in HGPH. In 1979, its demise was cemented when Mayor James Conway ordered the abrupt closure of HGPH and its subsequent merger with City Hospital No. 1, located 5 miles southeast and in the predominantly White neighborhood of Lafayette Square. Like other St. Louis hospitals prior to desegregation, City Hospital No. 1 had previously only served Black patients in the basement of the facility and was the teaching hospital for Saint Louis University School of Medicine. The decision to consolidate services exclusively impacted the access to quality and culturally responsive care for Black North St. Louis residents, especially those who were uninsured.^{25,26}

Shifting into the turn of the century, the modern plight of Black St. Louis residents was compounded by the 2014 murder of Michael Brown in Ferguson, Missouri—a city considered a "sundown" town in the 1960s that now has a 71% Black population.²⁷ This event gained international attention and further galvanized the Black Lives Matter movement. The normalization process of police brutality, incarceration, and discriminatory policing against Black residents reached a boiling point in Ferguson, which rippled nationally and worldwide. The national and local responses to the coronavirus disease 2019 (COVID-19) pandemic beginning in March 2020, exemplified the continued thread of chronic deprivation. The pandemic exacerbated and highlighted health disparities among minoritized groups. Nationally, Black Americans were disproportionately affected by the disease during the first year, with a higher infection rate, hospitalization, and mortality than nHW.^{28,29} In St. Louis, from March 23, 2020 to March 23, 2021, there were 20,649 confirmed cases and 470 deaths.³⁰ Within the first month of COVID-19 being declared a pandemic by the World Health Organization, all 12 confirmed COVID-19 deaths in St. Louis were of Black residents. With 20% of essential workers at this time being Black and hospitals becoming overcrowded, minoritized communities were hit

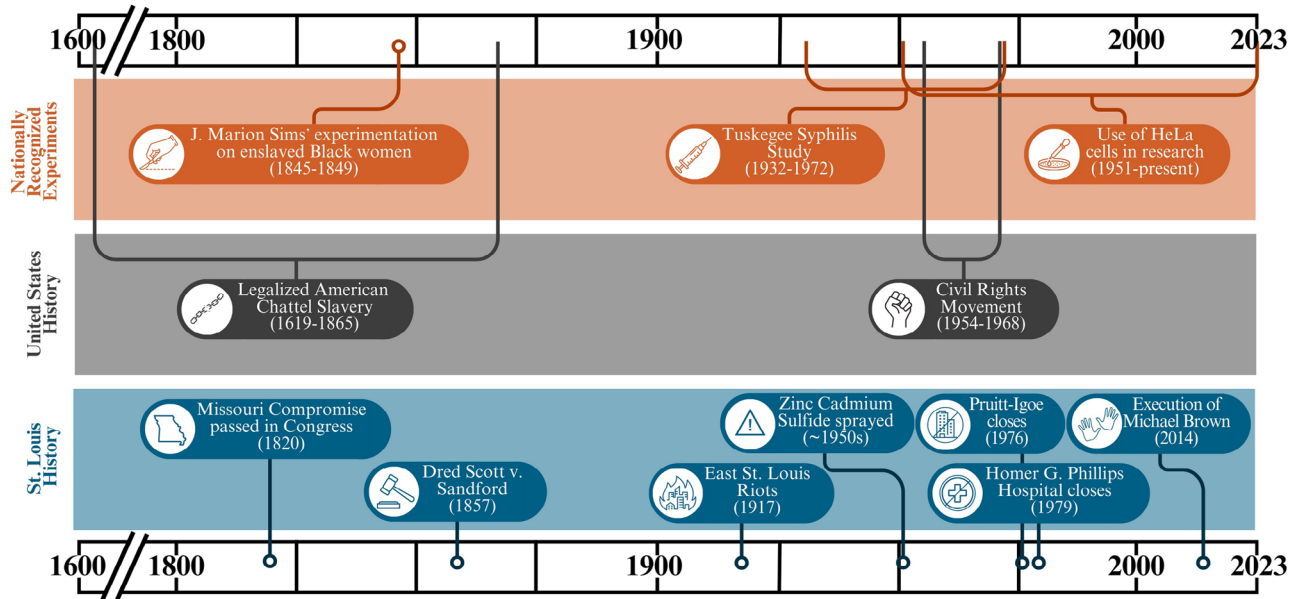


FIGURE 1 Timeline (1600 to 2023) of nationally recognized scientific experiments, United States history, and epochs in St. Louis City impacting individuals racialized as Black and African American.

the hardest by the pandemic.³¹ The long-term effects of history on health-seeking behavior are still being critically examined by policy and public health researchers, but the indelible mark remains a testament to health disparities.

These spatiotemporal events in St. Louis impact perceptions of health, health care access and utilization, and the ADRD research continuum (Figure 1). It is prudent for researchers to understand how the country's history, national research misconduct, and city/place-specific history influence the willingness to engage in research while not treating all Black residents as a homogenous entity. Currently, Black people make up 44.8% of the Greater St. Louis Metropolitan area, including persons across socioeconomic status, age, social network, sex, religion, and education level. However, distrust of medical institutions, structural racism, negative historical indiscretions, lack of access to care, and apathy to community engagement by researchers and larger medical institutions contribute to the lack of representation.⁹ The aging research characterizing health equity via social determinants (ARCHES) study endeavors to determine how stress, poor mental health, and S/SDOH influence aging and ADRD risk among community-dwelling Black people in the Greater St. Louis area. To guide measurement, the National Institute on Aging (NIA) Health Disparities Research Framework³² was used as a template to obtain measures across its 12 dimensions.

2 | METHODS

Participants were required to be 45 years of age or older, self-identify as Black or African American, reside in the greater St. Louis, Missouri metropolitan area or neighboring Illinois, and be cognitively normal as assessed by the Montreal Cognitive Assessment (MoCA-Blind version).

Participants were asked to attend an annual visit to assess S/SDOH and cognition and blood-based biomarkers (during Years 1 and 3). Participants had the option to complete an optional one-time magnetic resonance imaging (MRI) scan as well as an optional community-based system dynamics (CBSD) workshop.

2.1 | Recruitment methods

Staff recruited participants using various methods across the passive-to-active recruitment spectrum beginning March 31, 2022, to the present. This included social media, traditional media (newspaper), locally established research registries, speaking engagements, community events, and a snowball or chain sampling (e.g., a non-probability method where participants and collaborators refer those in their network for participation). A series of promotional literature was created on Canva software to allow adaptability to different media types (e.g., double-sided flyers, postcards, Facebook ads, newspaper ads, etc.). Each of the promotional materials included the study, inclusion/exclusion criteria, study components, time commitment, remuneration, contact information, and a quick-response code on a participant interest survey hosted by Research Electronic Data Capture (REDCap) and connected to the study's website. The flyers were posted on community boards across the Washington University Medical School campus. In addition, study staff provided stacks of 25–50 flyers to local health clinics (e.g., Affinia HealthCare, ArchWell Health, and GreaterHealth Pharmacy & Wellness), community centers (e.g., YMCA, Senior Services, Areas on Aging), and other locations where eligible participants may frequent (e.g., local NAACP branches). Promotional materials and high-quality gifts (bags, fans, water bottles, notebooks, pens, sticky notes, and reusable facemasks) were developed and

featured the study logo and website and were distributed at community events.

A website using a free, institution-specific Uniform Resource Locator was designed by a study coordinator as a repository for study information. The website included pages dedicated to the study's purpose, mission and vision, personnel, news, upcoming events, community resources, and those "interested in participating." The home page and "interested in participating" pages included direct links to a survey that requested the prospective participant's name and a method of contact. Videos about the brain imaging scan process and the importance of Black participation in the research were also featured. A phone number and email address for the lead coordinator were displayed in the margins of each page. All promotional materials were finalized in January 2022.

Staff met with stakeholders in the community to gauge where recruitment would be most effective. This included meeting with trusted political and social leaders in the community. A community advisory board (CAB) and data & safety monitoring board (DSMB) were created in February 2022 and April 2023, respectively, and included community partners/representatives from faith organizations, health care centers, AARP, and Alzheimer's Association, among others. Staff met with the CAB bimonthly to discuss study updates, enrollment status, and methods to improve recruitment. Staff met with the DSMB biannually to discuss enrollment numbers, participant safety, and data integrity and validity.

2.1.1 | Traditional media

A 1/8-page advertisement (\$300 for one-time placement) was placed in the St. Louis American, a local newspaper catering to the Black community, which distributes 60,000 copies each week. This advertisement featured a middle-aged Black man and was printed in black and white. Details included were the study purpose, remuneration, and contact information. This same advertisement, in color, was also placed on the newspaper's associated website home page (\$245 per week) and alternated with other advertisements for 1 week. In addition, advertisements were placed along Metrolink transit lines and bus routes in high-traffic areas with a significant Black population (\$3500 for 8 weeks) between late July and late October 2023. This advertisement featured a middle-aged Black man and was printed in color. Details were identical to those used for the St. Louis American advertisement. In total, 25 Metrolink rail interior cards, 25 bus interior cards, 5 bus shelters, and 5 Metrolink platform windscreens were posted.

2.1.2 | Established research registries

Staff at Washington University's Volunteer for Health Registry office created a consolidated, one-sided flyer with the same details as the flyer created by our lab. This flyer was distributed digitally via weekly email blasts, an ad on the MyChart patient portal, and social media posts (Facebook and Twitter, respectively). The registry had 15,000

participants; 1500 fit the targeted inclusion and demographic (Black adults). An email blast with contact information and details about our study was sent out to 500 eligible participants per week for 3 weeks at no charge. Emails were sent to new, eligible registry participants on a rolling basis.

2.1.3 | Speaking engagements

Speaking engagements were led by our team (PI: G.M.B. [Other race/ethnicity], A.I.B.W. [Black]). Events occurred virtually and in person at local NAACP branch meetings (Madison County NAACP), community centers (Ferguson Community Center, Urban League of Metropolitan St. Louis), public libraries (Cabanne Branch Library), senior service centers (Northside Youth & Senior Services, Lincoln University Cooperative Extension), churches (Berean Missionary Baptist District Association), and community events (Venture Café at the Cortex). The topics discussed provided information about ADRD, warning signs, and current research. The presentations varied from 30 to 60 min, with additional time for questions and answers. All presentations in the community had no specific eligibility for attendees but targeted older adults (65 years and older).

2.1.4 | Community events

Study staff (G.M.B. [Other race/ethnicity], D.L.H. [Black], A.I.B.W. [Black], and C.F.B. [Black]) attended and staffed a table at local community events, none of which had specific eligibility for attendees but were targeted to Black community members and addressed a specific issue both related and unrelated to ADRD and research (e.g., neighborhood social cohesion, law enforcement–community relationship building, gun violence, men's health). The double-sided flyers, postcards, and a variety of branded promotional materials were arranged on the table and given to individuals who stopped by regardless of their interest in participation. A sign-up sheet was placed at the table, so interested individuals could provide their names and method of contact to conduct follow-up communications. Staff also tracked the number of interactions using a handheld tally counter. Of the events attended, 50% took place during the evenings, weekends, or on a holiday. Within the first 22 months, \$3408.23 was spent on purchasing promotional materials (flyers, postcards, bags, pens, etc.).

In addition, the study team organized the first annual participant brunch on Washington University's Danforth campus in April 2023. This event served two purposes: showing appreciation to those who had already enrolled and providing a forum to answer questions and distribute resources. There was no cost for attending, and each participant was invited to bring a guest. Community partners, including the Alzheimer's Association, Oak Street Health, Places for People, STL Village, and Greater Health Pharmacy, were invited to set up tables with information about their organizations and the services that they provide. The program included a series of speakers representing different sectors of ADRD health care and research, and discussions on the

state of health care and the importance of diversity in medicine. Speakers included the study's principal investigators; the Chief Diversity, Equity, and Inclusion Officer for the national Alzheimer's Association [Black]; a geriatrician and associate professor at Washington University School of Medicine [Black]; and the medical director of a local medical center for seniors [Black]. At the close of the event, 30 minutes were allotted for questions to the research team, speakers, and community partners. Attendees were encouraged to visit the information tables before and after the program—guests who were interested in participating provided contact information to a study coordinator directly.

2.1.5 | Snowball sampling

Both enrolled and referred participants recruited others within their social network to participate. Those referred included parents, adult children, coworkers, and friends of participants. Upon request, promotional materials were provided to currently enrolled participants to disseminate within larger social groups like neighborhood listservs, churches, or shared interest groups (e.g., line dance classes, gardening clubs, bible study groups). In addition, participants were provided a \$10 gift card for recruiting two individuals who successfully enrolled in the study (i.e., complete baseline evaluation and blood draw). Additional referrals came via “physician–participant referrals” from local health care providers (e.g., Affinia Healthcare & ArchWell Health) informing their patients, as well as “collaborator–participant referrals” from study staff, CAB, or DSMB members informing relatives, peers, or clients about the study.

2.1.6 | Screening

Those individuals who were interested would express interest in one of three ways: complete a brief survey with their name and contact information, fill out a sign-up sheet, or contact the study coordinator directly via email or phone. Staff would contact those who expressed interest in conducting the screening call. This call covered components of the study, time commitment, and remuneration. In addition, contact information, address, demographics, and point of contact/informational awareness about the study were collected. Data were collected and stored in a password-locked spreadsheet and online database to which only study team members had access. Individuals were informed that if they decided to participate, they would be asked to complete an annual cognitive assessment, a series of surveys targeting details about their environment (i.e., access to health care, neighborhood cohesion, etc.), and a baseline blood collection. At the conclusion of the call, the staff member would administer the Blind Montreal Cognitive Assessment (MoCA-Blind) over the phone. If the participant met the inclusion criteria and received a score of 17 or more, they were invited to schedule their baseline office testing session and blood draw appointment. The cutoff for the MoCA was adjusted (17) to account for an overall lower average grade school

completion within the Black community due to systemic inequalities in education.³³

2.2 | Procedure and testing

Because of the participant age range (minimum: 45 years of age), many interested participants were still employed, whether part-time or full-time. To maximize flexibility, alternative testing times, including evenings and weekends, were offered during scheduling. Upon scheduling office visits, staff asked participants whether they had access to reliable transportation. If they did not, they were offered roundtrip transportation via taxi. This option was also offered for optional components such as the imaging visit, community workshop, and participant brunch. Due to policy changes, local public transport services like Metro Bus and Call-a-Ride experienced funding cuts in early 2023—many participants who previously relied on these services to get to our appointments and other medical and research appointments no longer had that transportation option available. For office testing visits, a packet with an appointment confirmation letter, a copy of the informed consent, directions, parking instructions, and four surveys were then sent to the participant's mailing address.

In addition, our laboratory, like our institution, historically paid participants via paper check that would be mailed to their homes within 4-to-6 weeks after each completed portion. Many participants indicated that research participation was a source of additional income, so having access to those funds as soon as possible was critical to their life circumstances. As a result, our lab instituted the use of a reloadable debit card in which the funds would be released to participants within 72 business hours of a visit. During testing, participants could then choose to receive payment via a debit card or check.

2.2.1 | Initial visit

The data collection was designed to be conducted beyond our site/institution, unlike what most studies traditionally require. If necessary, the entire battery and blood draw could be completed in the community (i.e., at local activity centers, in the home). Testing was conducted by one of two coordinators, both of whom identified as Black. During the testing session, participants completed a series of standardized cognitive assessments, physical measurements, family health reports, and surveys about social determinants (Tables S1 and S2). The 19 surveys were reformatted in REDCap and uploaded to an iPad that can store data without a connection to Wi-Fi. Once connected to a network, the data were uploaded to the study server. A study coordinator with a phlebotomy certification from the National Healthcareer Association would perform the blood draw for baseline appointments. If the blood draw was unsuccessful due to the participant's health or physicality (e.g., previously received chemotherapy, rolling veins), the participant was asked to return later in exchange for a \$10 to \$25 gift card of their choice. A contracted phlebotomist who self-identified as Black and had 20+ years of experience completed these draws for

\$30 per draw. Participants were reimbursed \$75 for each office testing session and \$25 for the blood draw.

2.2.2 | Magnetic resonance imaging

Pre-imaging screening, scheduling, and post-imaging follow-ups were conducted over the phone. Coordinators trained with radiology-specific coordinators to better understand the scanning process and to ensure that all participants were scheduled for scans in a timely manner. Before scheduling, coordinators conducted a 30-minute pre-screening call covering the participant's medical and surgical history including allergies, medications, surgeries, diagnosed conditions, implants, and removable devices. If the participant was considered safe to proceed, they were scheduled for a 90-minute appointment. A packet with an appointment confirmation letter, directions, parking instructions, and an MRI fact sheet was then sent to the participant's mailing address.

On the day of the scan, a coordinator met with the participant 30 minutes before the scan time in the hospital lobby. The coordinator escorted the participant to the research radiology unit, at which point the coordinator reviewed all documents and measured the participant's vitals (e.g., height, weight, blood pressure, temperature, heart rate, and blood oxygen level). Participants would change into disposable scrub pants and linen scrub tops. The coordinator would conduct a final check for removable metals, including earrings, necklaces, hearing aids, false teeth, and hair pins, before escorting the participant to the scanner. The final scanning protocol for the 45-minute MRI session included volume (T1 & T2), white matter hyperintensities (fluid-attenuated inversion recovery), blood flow and perfusion (arterial spin labeling), network and brain connectivity (resting-state functional connectivity), white matter tracts and activity (diffusion tensor imaging). Participants were reimbursed \$75 for completing the scan.

2.2.3 | Community-based system dynamics workshop (CBSD)

CBSD is a form of group model building that provides a structured process and forum for diverse stakeholders to identify issues and prioritize intervention strategies through the language of systems. During the workshop, attendees worked with the support of facilitators to establish a visual map called a causal loop diagram that represents the factors—particularly S/SDOH—and determine how these factors interact together to create a system in which aging results in AD. To examine the participants' beliefs and perceptions about ADRD in the Black St. Louis community, CBSD was used to create their own view of the system.³⁴ Staff carried out five, in-person CBSD workshops over the course of two weekends in March 2023. To schedule the workshops, staff contacted any participants who completed a baseline assessment and signed a consent form that expressed interest in participating in the workshop. Participants selected one of the five available dates and

were asked about their dietary restrictions. Once a date was selected, a packet with an appointment confirmation letter, directions and parking instructions, an agenda, and a brief CBSD overview was sent to the participant's mailing address. Some participants were unable to attend due to personal scheduling conflicts but were told they could attend a second round of workshops in 2024.

The team consisted of two investigators (G.M.B. and J.F.T.) and nine research assistants who facilitated and documented the discussion. The first session started with a community discussion to identify participants' connection to ADRD and why they believe the gap in ADRD risk exists between populations racialized as Black and nHW. A reference mode was used to help visualize this gap. The second session consisted of variable elicitation and wall building to identify the main factors influencing dementia risk. The third session involved building a causal loop diagram to explore the interactions between factors affecting dementia risk among Black older adults in St. Louis and to develop possibilities for intervention. Each workshop lasted 7 hours and was audio recorded on two devices—an iPad and a laptop. Groups of 10 or more participants were split into two groups after the variable elicitation session to better support a productive discussion. All participants were encouraged to answer questions, and those who did not were directly asked for their responses to ensure inclusion of all voices. Participants were reimbursed \$100 for completing the workshop. In addition, breakfast, lunch, and snacks were provided for participants from local Black-owned businesses. Validation tickets were also provided to alleviate the cost of parking on campus.

2.3 | Retention

Beginning in January 2023, a coordinator designed and disseminated a four-page newsletter every quarter to update enrolled participants concerning enrollment, recent events, and breakthroughs in ADRD research. Logic puzzles and general knowledge about ADRD and the brain were also included. The newsletter was sent to participants via email and uploaded to the "News" section of the study's website. Participants without an email address were mailed a physical copy of the newsletter. The participant brunch worked dually as a recruitment and retention event.

3 | RESULTS

A total of 629 individuals expressed interest in participating in the study. Of those, 83 (13%) did not meet a specific aspect of the inclusion criteria (e.g., MoCA-Blind score <17, age <45, did not live in the Greater St. Louis Metropolitan area, did not identify as Black). Of the remaining referrals, 33% either declined participation or were designated "unable to contact" after three consecutive unsuccessful contact attempts (i.e., left a voicemail with no returned call). A staff member inquired about the reason for the decline, which varied. Of those who declined, 34 (45%) were concerned about the study time commitment competing with their personal commitments (e.g., caretaking, work,

TABLE 1 ARCHES recruitment by referral sources.

Participant referrals (n = 629)				
	Enrolled	Screen fail	Decline/no response	Total
Traditional media	29 (12%)	11 (13%)	15 (7%)	75 (12%)
Speaking engagements	12 (5%)	3 (4%)	12 (6%)	29 (5%)
Community events	26 (9%)	8 (10%)	60 (29%)	111 (18%)
Established research registry	74 (31%)	36 (43%)	48 (23%)	192 (31%)
Snowball sampling (SS) total	97 (41%)	25 (30%)	51 (25%)	194 (31%)
• Participant-participant	68 (29%)	13 (16%)	35 (17%)	136 (22%)
• Study-participant	1 (<1%)	4 (5%)	3 (1%)	10 (2%)
• Collaborator-participant	28 (12%)	8 (10%)	16 (8%)	58 (9%)
Unknown source	0	0	18 (9%)	18 (3%)
Total	238	83	207	629

Note: Data are n (%).

routine clinical appointments), 13 (17%) were opposed to completing the blood collection due to fear of phlebotomist inexperience or specimen misuse, and 28 (37%) stated being “generally uninterested” with no reason provided. The remaining referrals have been scheduled for future visits.

Across all inquiries, 75 (12%) were garnered from traditional media (i.e., newspaper ads, physical flyers, Metrolink advertisements [Figures S1–S3]), 192 (31%) from established research registries, 29 (5%) from speaking engagements, 111 (18%) from community events, and 194 (31%) from snowball sampling. The St. Louis American advertisement did not yield any inquiries. A further breakdown of recruitment by source can be found in Table 1.

Snowball sampling was a successful referral and enrollment source, followed by established research registries. Within snowball sampling referrals, 29% were participant-participant, 12% were composed of collaborator-participant, and <1% were study-participant. Participant-participant referrals include current participants or referrals informing an individual. Collaborator-participant referrals include any study staff, CAB, or DSMB member informing an individual about the study. Study-participant referrals include staff of a separate research study informing an individual. Community events ranked third among referral sources. Events that targeted the Black community and/or addressed health literacy, such as health fairs, were the most successful at gaining interest. Staff were able to get 96% of inquiries in this category from six events following the implementation of a sign-up sheet as opposed to distributing literature with study contact information.

Overall, 238 enrolled in the study across all referral sources between April 5, 2022, and February 9, 2024. Of those enrolled, the majority (79%) were female, the sample had above-high school education (15.3 years), and the participants were slightly older (mean age of 64 years) (Table 2). There was a higher prevalence of conditions like hypertension (68% vs 45%³⁵), hyperlipidemia (51% vs 12%³⁶), and obesity (54% vs 49%³⁷) among the sample compared to prevalence in national cohorts. The sample had a mean National Area Deprivation

Index (ADI) of 75.6/100, indicating participants, on average, reside in more disadvantaged block groups (Figure 2). Although the critical mass of participants resided in Missouri, 14 resided in greater Illinois (mean ADI: 75%), 122 in St. Louis County (mean ADI: 74%), 97 in St. Louis City (mean ADI: 79%), and five in greater Missouri (mean ADI: 35%) (Figures S4–S7).

On average, >50% completed a bachelor's degree or higher, and 45% found it “not very hard at all to pay for necessities.” In addition, participants were less likely to report being diagnosed with diabetes, heart attack, and stroke. Compared to the individuals who expressed an interest in participating (n = 238) and enrolled participants (n = 238), there were statistically significant differences across age, sex, and education. Enrolled participants were more likely to be older (mean [SD]; 64.5 [10.0] vs 62.2 [10.4]), female (79.0% vs 77.8%), and were, on average, slightly more educated (mean [SD]; 15.3 [2.6] vs 14.3 [2.7]) (Table 3). Compared to data from the national census,³⁸ our participants had a lower number of male participants (21% vs 49.6%), were slightly more educated based on bachelor's degree or higher (52.9% vs 34.3%), and included more participants who were 65 years of age or older (51.7% vs 17.3%).

Among participants who met the criteria and opted into the study, all completed baseline blood collection, and of those, 24 needed to return for a draw completed by the contracted phlebotomist due to the participant's health or frailty (e.g., previously received chemotherapy, rolling veins). Seven participants needed an evening or weekend appointment, and 25 requested transportation to and from study appointments. Six participants completed their baseline visit at an off-site senior center in Illinois to align with a routine meeting for an organization they all belong to.

In addition, 203 were interested in completing the MRI portion of the study. Since the first participant completed their scan in April 2023, a total of 62 participants have completed it to date, with an additional 14 screened and scheduled to complete an MRI scan through April 5, 2024. ARCHES is a longitudinal study that will continue screening and completing MRI scans. Participants not interested in the imaging

TABLE 2 Baseline participant characteristics.

Demographics	Enrolled (n = 238)
Age, mean (SD)	64.5 (9.7)
45–55, n (%)	48 (20.2)
56–65, n (%)	67 (28.2)
65+, n (%)	123 (51.7)
Sex (female), n (%)	188 (79.0)
Education (years), mean (SD)	15.3 (2.6)
Less than high school (<12 years), n (%)	5 (2.1)
High school/some college(12–15 years), n (%)	107 (45.0)
Bachelor's degree (16 years), n (%)	56 (23.5)
Postgraduate degree (>16), n (%)	70 (29.4)
Alternative income question, n (%)	
Very hard to pay for basics	12 (5.0)
Hard to pay for basics	14 (5.9)
Somewhat hard to pay for basics	43 (18.1)
Not very hard to pay for basics	63 (26.5)
Not hard at all to pay for basics	106 (44.5)
Diagnosed conditions, n (%)	
Hypertension	162 (68.1)
High cholesterol	122 (51.3)
Diabetes	56 (23.5)
Heart attack	7 (2.9)
Stroke	14 (5.9)
BMI, mean (SD)	32.1 (7.43)
ADI National, mean (SD)	75.6 (22.7)
St. Louis City, mean (SD)	78.9 (21.4)
St. Louis County, mean (SD)	73.9 (22.4)
Greater Missouri, mean (SD)	34.5 (8.6)
Greater Illinois, mean (SD)	74.7 (21.4)
Baseline MoCA score, mean (SD)	25.0 (5.1)

Note: Area Deprivation Index National (ADI): No. of participants resided in greater Illinois: 14, St. Louis County: 122, St. Louis City: 97, greater Missouri: 5.

Abbreviations: BMI, body mass index; MoCA, montreal cognitive assessment.

portion cited self-reported claustrophobia or health contraindications (i.e., implanted metal or device).

At the time of our first round of five workshop dates in March 2023, a total of 85 participants were interested in participating in the CBSD workshop, of which 92 enrolled and 59 successfully completed the workshop. We have enrolled 146 additional participants since then, with a total of 203 expressing interest in the workshop. Our next round of workshops is scheduled for May 2024, and it will include all of those participants interested. Participants uninterested in the workshop cited a general lack of interest or concern with engaging with others in that capacity due to anxiety. Participants who were interested

TABLE 3 Comparing demographics between participants enrolled and those who were not enrolled.

	Enrolled (n = 238)	Unenrolled (n = 216)	P-value
Age			
Mean (SD)	64.5 (9.7)	62.2 (10.4)	.0162
Median [min, max]	66.0 [44.0, 92.0]	61.0 [45.0, 90.0]	
Sex			
Male	50 (21.0%)	48 (22.2%)	.842
Female	188 (79.0%)	168 (77.8%)	
Years of education			
Mean (SD)	15.3 (2.6)	14.3 (2.8)	<.001
Median [min, max]	16.0 [9.0, 29.0]	14.0 [8.0, 25.0]	

in the workshop but unable to complete the first round cited scheduling conflicts (e.g., work, surgery recovery, family vacation).

4 | DISCUSSION

Within clinical research, the onus to participate is often implicitly levied on minoritized populations to take the initiative of closing the health disparity chasm.³⁹ This is no different in ADRD research and often captured in generic comments like, “that group is always hard to recruit” or “they just do not seem to be interested in research.” However, the findings from this work and others reify that RER efforts must be intentional and sustained. If RER efforts are limited to passive recruitment strategies (e.g., posting flyers, paying for ads), researchers will continue to struggle with engaging minoritized groups. During the CBSD workshops, participants shared the sentiment that medical institutions and researchers displace accountability and individual responsibility by making minoritized groups solely responsible for repairing centuries of systemic barriers, exclusion/othering, misconduct, and malpractice. Furthermore, researchers must not use traumatic historical events to excuse their own lack of effort to improve trust and successfully recruit participants. With limited, accessible disease-modifying treatments that include representative samples of Black people,^{40,41} the need for additional research to slow down and eventually cure AD remains a top priority for research institutions. Prior work⁴² has supported a multi-pronged approach for RER with persons racialized as Black. This study examined the effectiveness of various recruitment methods for the Black community.

Our primary objective focused on within-group heterogeneity and led us to intentionally adopt an ethnographic approach in which we directly engaged the St. Louis community and metropolitan area to recruit a representative sample that reflect national statistics. In a comparison of cohorts from the National Alzheimer's Coordinating Center (NACC) and Health and Retirement Study, NACC participants were not representative of the U.S. population in key sociodemographic and health factors.⁴³ Our sample had a greater proportion of women, were more educated, and had more older participants compared to the U.S.

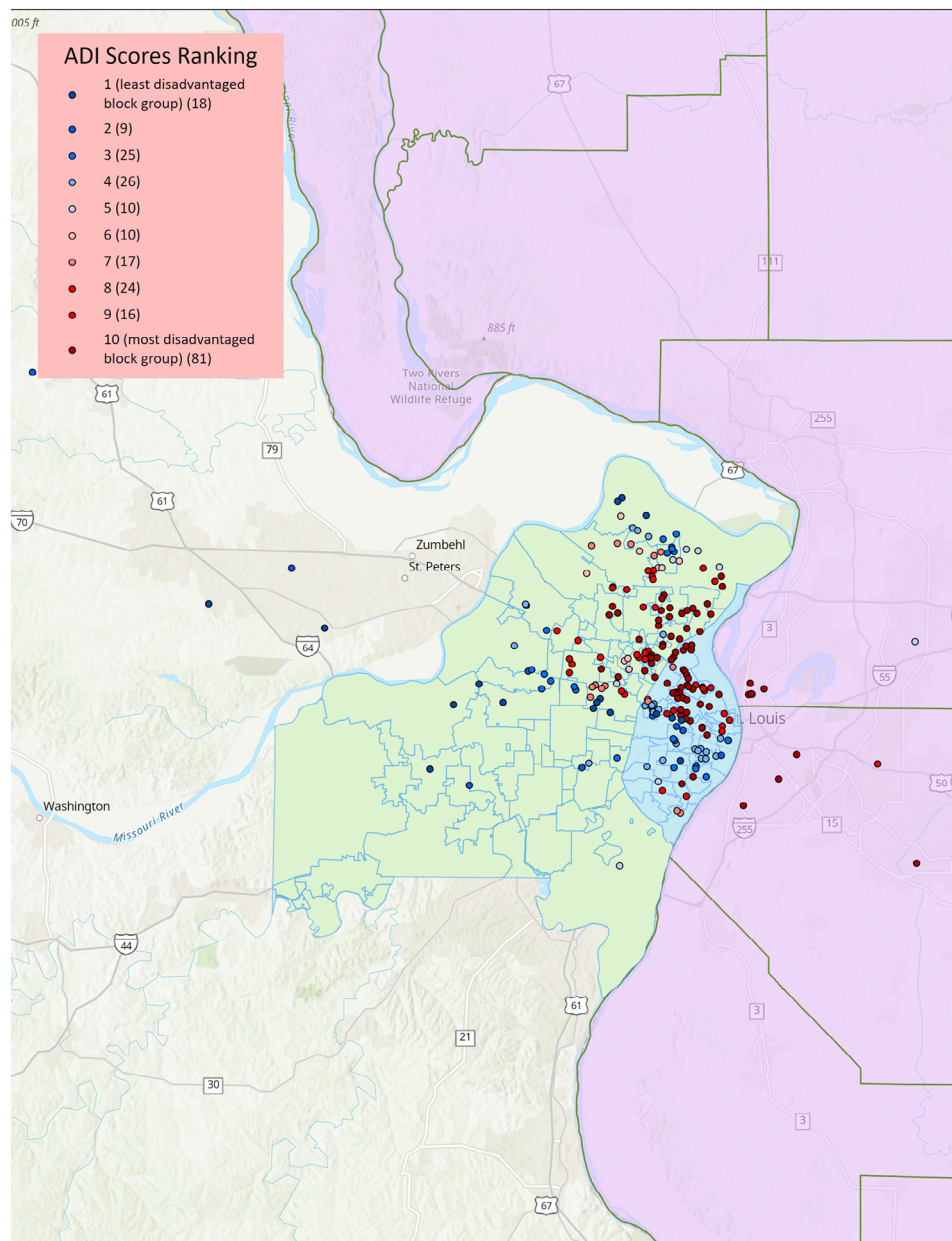


FIGURE 2 Geospatial mapping of participants' home addresses by area deprivation index across St. Louis City (light blue), St. Louis County (light green), Greater Missouri (tan), and Greater Illinois (light purple).

Census³⁸; however, the Census includes all ages, whereas our sample focused on middle to older age adults. Tailoring materials and implementing a secondary inclusion criterion to target men and participants with fewer than 12 years of education can help address potential imbalances in screening and enrollment. Across all methods, we employed two strategies: a general wave of recruitment to capture any and all interested participants and then a more targeted approach to pull representation closer to the national average after additional consultation with the CAB and DSMB. Depending on the neighborhood location and event type, we reviewed the location-specific history with our CAB/DSMB members and integrated noteworthy events in our recruitment talk or discussed their relevance to S/SDOH and brain health. We also drew parallel comparisons across neighborhoods, acknowledging

past injustices, structural racism, or barriers that may have impacted the community's access to education, resources, and research opportunities. Our intentional approach centered on building trust and fostering meaningful relationships with the community to forge a long-term commitment with outreach activities and partnerships with local programs. The findings from this approach emphasize the importance of understanding the historical medical misconduct and its associated place-specific nuances and challenges in overcoming those barriers and the time needed to build trust, invest in the community, and increase participation interest.

It was essential to consider the anticipated risk and burden, agency of biological samples, and perceived invasiveness from the perspective of each prospective participant through the study design. The

mixed-methods battery was structured to have the capability of being administered beyond the geographical confines of our institution. The AD biomarkers were strategically chosen to minimize participant burden. Participants are often more willing to participate in studies that require blood draws or short MRI sequences and reluctant to invasive procedures like a lumbar puncture or imaging with a tracer.⁴⁴ As a part of our study, participants are only asked to complete a blood draw twice over 5 years and an optional brain imaging scan during their first year. Similarly, a diagnostic lumbar puncture was excluded because of the substantial impact of perceived risk (i.e., perception of paralysis risk or permanent injury) and necessity (i.e., medically necessary vs voluntary) on interest in participation. Overall, the study was designed to be low burden with four major components—two of which were optional.

Snowball sampling provided the highest yield for participants, with participant–participant and collaborator–participant interactions supporting the enrolled. Although speaking engagements and attending community events were the third and fifth, respectively, most successful methods of recruitment and enrollment, it is essential to understand that presenting to a group about the current state of ADRD research may help to provide context on why participation is essential even before asking for their participation. Community outreach and raising awareness during presentations engage attendees by initiating a dialogue and providing a voluntary opportunity to participate. The participant brunch encapsulated both methods. It is important to note that not all community events led to successful recruitment. We were requested to speak at three events that did not have participants who fit our criteria (e.g., all attendees were White) or where few people attended.

This study's first aim and first year were dedicated to breaking ground on a new foundation for intentional RER principles to create a longitudinal cohort. Sustained relationships with organizations and the larger community help build trust and establish a presence; however, this process requires substantial time, dedication, and resources. The conventional “Helicopter research” approach and funding sources that support that paradigm will fail 100% of the time because they are not designed to succeed in health disparity research.⁴⁵ This is no different in ADRD research because it fails to acknowledge the core issues that are important to the community and the decades of life experiences that create a higher risk for that population.

Barriers to participation in ADRD are age specific, where younger participants may require more flexibility for study protocols and requirements.⁴⁶ Recruitment methods should be combined to achieve the highest yield, which includes prioritizing community events and speaking engagements targeted to Black residents, utilizing established registries, and collaborating with community partners. This process requires a large amount of time and effort as well as a detailed budget that accounts for a multi-level approach across the passive and active recruitment spectrum.

These results confirm preliminary work,⁴⁷ which suggests traditional media and snowball sampling can be effective means of widely disseminating study details, including procedural components, remuneration, and contact information. Traditional media are implicitly

user-specific in their reach (e.g., regular readers of a newspaper, shoppers frequenting a grocery store). As a result, this passive method needs to be employed in conjunction with other strategies to benefit a more heterogeneous group of participants. Utilizing snowball sampling was the most effective method of recruitment, followed by established registries. Snowball sampling was the most effective method where referrals are more likely to fall within a similar demographic, like socioeconomic status, level of education, or zip code. This is especially true given that participants tend to refer to those within their social groups. For example, participants referred from a historically Black sorority would all have at least a bachelor's degree due to the sorority's admission requirements being the pursuit or completion of a 4-year degree. This may run the risk of biasing the sample if multiple recruitment methods are not employed. However, with snowball sampling being the most effective recruitment strategy overall, it highlighted that with the appropriate level of care, current participants had a positive experience, understood the importance of the research, and found it beneficial to encourage others to join. Researchers must acknowledge that recruitment does not stop once the individual agrees to participate. This was an especially important consideration for the recruitment of Black men. Although it is well established that Black men are one of the most challenging groups to recruit, this is reasonable given the level of mistrust stemming from the historical atrocities and structural racism that disproportionately impact Black men. One example of the latter is with law enforcement, where Black, Hispanic, and Indigenous drivers are stopped in disproportionately higher numbers for benign or suspected traffic infractions in attempts to investigate other crimes when minimal or no evidence exists.⁴⁸ A recent study found that over a 38-year period, the Black race was associated with a 3.5 higher risk of fatal police violence, most deaths involving males.⁴⁹ Of the 49 men enrolled, 20% were referred by a woman in their life (i.e., parent, partner, or adult child). This could reflect the role of Black women as “gatekeepers” of the Black community and that with their trust, men are more likely to invest in it as well.

There are some limitations to the present study. The overwhelming majority of female participants did not reflect the sex demographic in the greater St. Louis Metropolitan area. The average education level of enrolled participants reflected the completion of a college degree, with few participants completing less than a high school diploma. This may be due to the high participant–participant referral rate, which can lead to participants with similar demographics. This is an ongoing study, so more strategies will be employed to increase participation from these groups. This includes connecting with organizations tailored to Black men (e.g., barbershops, prostate awareness groups, local historically Black fraternity chapters, and so on) and those with a high school diploma or less. Finally, as with any phone screening (MoCA-Blind in this study), more effort and cognitive resources are redirected to deciphering the auditory information versus completing the actual task. Phones (landline vs mobile) vary in auditory acuity (300–3500 Hz, whereas humans use information for speech perception spanning 80–14,000 Hz), background noise may occlude hearing, hearing impairments are amplified (e.g., no visual cues present during

face-to-face screening), and other tasks may distract attention from the screening.

5 | CONCLUSION

Prospective studies should consider the personnel, time, resources, and skills needed to execute a multi-level recruitment plan, which includes graphic design, marketing and advertising, branding and printing costs, and community engagement. Participants are more likely to participate in studies with racially congruent study personnel, so having team members with a similar racial background could impact recruitment rates. It is essential to use sustained community engagement, mixed promotional methods, and culturally responsive interactions between research members and participants with the goal of increasing enrollment in clinical research. With the success of the often-overlooked snowball sampling, having a participant ambassador speak on behalf of the study may encourage others to participate as well. During the screening process, it is paramount that demographics for all interested participants are collected to identify and track trends in declines, unsuccessful contacts, and screening failures. With the appropriate consideration, this can help refine the recruitment process and identify points of modification.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

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SUPPORTING INFORMATION

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

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