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The Community Engaged Digital Alzheimer's Research (CEDAR) Study: A Digital Intervention to Increase Research Participation of Black American Participants in the Brain Health Registry

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Abstract

Background: Although Black/African American older adults bear significant inequities in prevalence, incidence, and outcomes of Alzheimer's disease and related dementias, they are

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profoundly under-included in Alzheimer's Disease research. Community-Engaged Research (e.g., equitable community/science partnerships) is an evidence-based approach for improving engagement of underrepresented populations into Alzheimer's Disease research, but has lacked scalability to the national level. As internet use among older adults from underrepresented populations continues to grow, internet-based research shows promise as a feasible, valid approach to engagement and longitudinal assessment. The Community Engaged Digital Alzheimer's Research (CEDAR) study utilizes a community-engaged research approach to increase the engagement and research participation of Black/African American adults in the Brain Health Registry (BHR) and Alzheimer Disease clinical research.

Objectives: To describe the methods and evaluate the feasibility of the CEDAR culturally-informed digital platform within BHR.

Methods:

Design: All Black/African American participants in BHR were invited to enroll in CEDAR and to consider serving on a newly convened Community-Scientific Partnership Board to guide the study. The community board guided the development a culturally-informed cadre of engagement materials and strategies to increase research participation. Engagement strategies included incentives for study task completion, culturally-informed communications (e.g., landing page, emails and social media), resources about brain health, and video and written testimonials by CEDAR participants.

Setting: BHR, an Internet-based registry and cohort.

Participants: BHR participants self-identifying as Black/African American were invited to enroll. All participants who signed an online informed consent document were enrolled.

Measurements: We report the number of participants invited, enrolled, completed tasks, and volunteered to join the community board. We compared the demographics, cognitive profile, and baseline BHR task completion rates between CEDAR participants and all those invited to join the study.

Results: Of 3738 invited, 349 (9.34%) enrolled in CEDAR. 134 (37% of CEDAR participants) volunteered to join the community board, of which 19 were selected for the community board. Compared to those invited, the CEDAR cohort had a higher percentage of female participants (84.5%) and a lower percentage of participants who identify as belonging to more than one ethnocultural group (21.8%). Compared to those did not enroll in CEDAR, those enrolled in CEDAR had a higher percentage of participants completing all BHR tasks (22%) and a higher percentage of participants completing at least one cognitive test (76%). Those enrolled in CEDAR also had a higher percentage of participants having an enrolled study partner (18%).

Conclusions: A culturally-informed Community-Engaged Research approach, including a remotely-convened community board, to engagement of Black/African American participants in an online research registry is feasible. This approach can be adapted for use in various clinical studies and other settings. Future studies will evaluate the effectiveness of the engagement strategies.

Keywords

Brain Health Registry; Engagement; Community-Engaged Research; Alzheimer's Disease; Black/African American

1. INTRODUCTION

1.1 Health Inequities in Alzheimer's disease and related dementias

Underrepresented populations (i.e., Black/African American and Latinx/a/o adults) experience significant inequities in the prevalence, incidence, and outcomes of Alzheimer's disease and related dementias [1-11]. Underrepresented older adults are 1.5 - 2x as likely to develop dementia as non-Latinx white adults.[2, 12]. Although ethnocultural status (e.g., race, ethnicity) is a sociocultural construct rather than a biological variable, it serves as a proxy for numerous exposures that may result from a complex combination of sociocultural (e.g., racial discrimination,[13-15] socioeconomic status, low years/quality of education), environmental, and structural factors that influence important biological (e.g., diabetes, vascular) [16-18] vulnerabilities. Yet, underrepresented populations are profoundly under-included in Alzheimer's disease and related dementias research.[19-22]. This has the potential to affect the generalizability and external validity of research studies and clinical trials, and amplify health disparities [23].

Inclusion and engagement (e.g., retention, task completion) strategies in the vast majority of observational and interventional studies have generally failed to engage underrepresented populations.[24-36] With the exception of a few studies focused on underrepresented population samples,[1, 11, 32, 37-45] most "samples of convenience" largely enroll non-Latinx white adults with high education and socioeconomic status.[25, 46] Further, participants from underrepresented populations are less likely to complete study tasks, return for longitudinal follow-up, and participate in genetic and biomarker research.[47-52] Although some investigators, often from underrepresented populations themselves, have effectively engaged and included participants from these communities, their methods and results have not successfully been taken up by most clinical investigators. This is a particular problem in large multisite observational and interventional trials, wherein funders, corporate partners, principal investigators, co-investigators, and local study staff may lack the expertise, dedicated resources, and/or motivation to make the substantial investments needed to genuinely increase enrollment of underrepresented populations and engagement in research of Alzheimer's disease and related dementias.

1.2 A Community-Engaged Research Approach

A recent systematic review by Gilmore-Bykovsky[21] demonstrates that a *community-engaged research* approach, founded on Community-Based Participatory Research principles, has repeatedly yielded promising results for improving the representation of Black and Latinx American adults in Alzheimer's disease and related dementias research. Community-engaged research is founded upon active, sustained community collaboration and engagement at *all* stages of the research process, from study inception to dissemination.[21, 53-55] Inclusion and engagement strategies shaped by community-engaged research methods include: authentic, equitable community-science partnerships rather than often marginalized community advisory boards; listening/responding to unique community concerns; and sustained and active engagement with communities. This work takes long-term investment and is more intensive than traditional, colonized approaches to research. Despite the promising preliminary results of community-engaged research approaches to Alzheimer's disease research, the work to date has mostly been hyper local and on a smaller scale as these approaches have historically lacked scalability for broad implementation in largescale, multi-site studies.

1.3 Digital Engagement Approaches to Increasing Research Participation of Underrepresented Populations

Growing evidence supports the feasibility and validity of digital engagement (e.g., digital communications, outreach) for large multi-site studies, and establishment of Internet-based platforms (e.g., registries) to enroll participants and refer them to research studies.[56-64] . Major advantages of Internet-based data collection include scalability, efficiency, reduced cost, frequent data collection, and ability to engage those who cannot participate in in-clinic studies due to geography and travel or financial burden. The recent COVID pandemic, which greatly limited in-person research, further highlights the need for remote, Internet-based approaches. Increasing numbers of older adults,[65] including older adults from underrepresented populations[66, 67] use the internet for a wide variety of activities,[68] and internet-based telemedicine is increasing. However, like in-clinic studies, Internet-based registries under-include underrepresented group participants.[61, 63, 69] [66-68]

Research is needed to adapt well-established community-engaged research methods to an Internet-based approach to scale up previously small-scale, localized, community-engaged inclusion and engagement efforts. The Brain Health Registry (BHR)[63] offers a unique opportunity to do just that. The BHR (N>90,000) is one of the world's largest Internet-based registries dedicated to Alzheimer's disease and aging research. However, similar to most cohort studies and registries, the BHR also has had a poor record of underrepresented population inclusion. BHR includes N=3738 Black participants, comprising only 4% of all BHR participants. This is a major limitation of the current BHR approach.

The overall aim of this project was to evaluate the effectiveness of a culturally-informed, community-engaged, digital research approach to increase research participation (e.g., retention, task completion) of Black/African American (hereafter referred to as Black) participants within the BHR. The purpose of this manuscript is 1) to describe the Community-engaged Digital Alzheimer's Research (CEDAR) study, including how we developed and implemented the culturally-informed digital engagement efforts; and 2) to evaluate feasibility by reporting results from an interim analysis of enrolled participants.

2. METHODS

2.1 The Brain Health Registry (BHR)

The BHR is a public online registry to recruit, screen, and longitudinally monitor participants for aging and cognitive-related research, as well as to refer enrolled participants to other studies.[63, 70] Anyone over the age of 18 is eligible to participate. BHR includes online consent, self-administered cognitive tests, self-report questionnaires, and study partner enrollment and questionnaires[71]. The questionnaires collect demographic, health, cognitive, and lifestyle data. Participants are asked to complete questionnaires and cognitive tests every six months. Participants do not receive feedback about their questionnaire replies or cognitive test results.

2.2 CEDAR Study enrollment

Eligible participants were current BHR participants who self-identify as Black and agreed to be contacted about future research opportunities. BHR participants who did not identify as Black were not included in this study. Study participants were recruited by a series of four culturally-tailored, automated email invitations describing the study. Interested participants could click a link in the email invitation, prompting them to log in to their BHR account and view a page describing the study in detail. Then, after signing an electronic consent form, they could proceed to their study tasks. All CEDAR activities were completed using the BHR online infrastructure.

2.3 CEDAR study activities

2.3.1 Barriers and Facilitators Survey.—All enrolled participants were directed to a brief (5-15 minutes to complete), voluntary, uncompensated, cross-sectional online survey about motivators (e.g., reasons for joining and continuing to participate) and barriers (e.g., reasons that make it difficult to participate) to BHR participation, as well as preferences for engagement strategies and communication channels. Survey respondents could provide their answers using rating scales and free text responses. The final question in the survey allowed participants to volunteer to serve on the Community-Science Partnership Board. Interested participants are asked to enter their name, email address, brief details about their background (where they live, education, occupation, experience with or interest in research and/or interest in helping the Black community), and whether compensation with electronic gift cards is satisfactory.

2.3.2. Community-Science Partnership Board (community board).—Based on our prior community-engaged research experience and expertise, we aimed to have the composition of the community board include no more than 15 – 20 community members and 4 – 6 study scientists. For the selection of our community members, we examined the demographic characteristics (e.g., age, gender, education, geographic location, occupation), self-reported reasons for offering to participate, and relevant experiences of the 134 community members who expressed interest in serving on the community board. We prioritized diversity in all demographic characteristics and interest in or experience with Alzheimer's disease and related dementias. For the selection of study scientists, all 7 study scientists were invited to join the community board. In addition, study staff members participated in an *ex officio* capacity to facilitate certain aspects of the meetings (e.g., logistics, presentation of engagement materials). Two-hour board meetings were convened on a quarterly basis via videoconference as the community board was convened during the pandemic and members resided all over the country and in-person meetings. Thus, remote meetings facilitated the feasibility of community board implementation.

The initial community board meeting oriented the entire board to the study aims, community-engaged research principles, and then the group development of jointly decided processes and goals for the community board. Over the course of the following meetings, the board guided the development of a culturally-informed cadre of engagement materials and strategies to increase research participation of Black adults in the study. Through a process iterative feedback and discussion, the community board informed engagement strategies, including included incentives for study task completion, culturally-informed communications (e.g., landing page, emails and social media), resources about brain health, and video and written testimonials by CEDAR participants. Also of note, all meetings included dedicated “listening sessions” for unstructured time for board members to share their views and sentiments with each other to further promote a sense of teamwork and trust. Towards the end of the project, all members also voted to continue community board meetings, regardless of whether dedicated grant funding would be available.

2.3.3. Financial compensation for completing tasks.—Participants received electronic gift cards for completing each study visit. Partway through the study, the researchers received IRB approval to increase the gift card amount from $25 to $50. The community board members were compensated with $100 gift cards for each board meeting attended.

2.4. Engagement materials/strategies.

The research team employs several strategies for engaging CEDAR participants and improving study retention (see Table 1), including: compensation for task completion, a private Facebook group to share knowledge and facilitate dialogue among prospective and existing CEDAR participants, blog posts and an email campaign to provide resources and educational materials about Alzheimer’s disease and the Black community, participant videos and written testimonials, and a culturally-tailored landing page.

2.5 Participant metrics

After enrollment in BHR, participants complete a questionnaire, which asks them to self-report sociodemographic information. This analysis focused on the following variables: age (continuous), gender (Male, Female, Other, Prefer not to say), race (Asian, Black or African American, Native American or Alaska Native, Pacific Islander, White, Other, Prefer not to say), ethnicity (Latino, non-Latino, Prefer not to say), education attainment (categorical), endorsement of subjective memory concern (*“Are you concerned that you have a memory problem?*”), family history of Alzheimer disease/dementia, and the participants’ self-report Everyday Cognition Scale score. It (continuous, numeric scores range from 1-4) is a 39-item instrument which assesses functional change by asking about the participant’s self- or study partner-reported capabilities to perform everyday tasks in the present versus 10 years prior. These tasks include activities that map to cognitive abilities across six domains[72]. In BHR, participants are asked to complete an Everyday Cognition Scale that has been adapted for an online setting[73]. Analyses also included self-report diagnosis of Alzheimer’s disease, mild cognitive impairment (MCI), and/or dementia. The categorical variable education attainment was converted into a continuous variable called “years of education,” ranging from 6-20 years. Based on the original race variable, we created a dichotomous variable of Black only (self identifies as Black/African American and no other race categories) or More than One Race (self identifies as Black/African American and at least one additional race category).

2.6 Task completion metrics

We measured task completion of invited and enrolled CEDAR participants during participants' last BHR visit prior to the CEDAR invitation. Metrics of task completion included whether they completed at least the BHR core questionnaire (this is the first questionnaire participants complete which asks about demographic information, family history of Alzheimer's disease/dementia, mood, health, medications, and memory) (yes, no), completed all BHR tasks (yes, no), completed at least one cognitive test (yes, no), began at least one cognitive test but had technical difficulties (yes, no), and whether they have an enrolled study partner through the BHR Caregiver and Study Partner Portal.[73] Participants were considered to have an enrolled study partner if their potential study partner completed online informed consent (yes/no).

2.7 Statistical Methods

We compared characteristics of participants who enrolled in CEDAR to characteristics of Black BHR participants who did not enroll. For continuous variables, independent sample t tests were conducted to compare the group means. Cohen's d was reported as effect size. For categorical variables, Chi-square tests were used if ≤20% of expected cell counts were less than 5 and Cramer's V was reported as effect size. Otherwise, Fisher's exact tests were used if > 20% of expected cell counts were less than 5.

3. RESULTS

3.1 Recruitment and enrollment

A total of 3738 Black BHR participants were invited to join CEDAR. 364 (9.74%) participants indicated interest in CEDAR by clicking on the email study link, and **349 (9.34%) enrolled** in CEDAR (Figure 1).

3.2 Participant characteristics

Compared to those who did not enroll in CEDAR, those enrolled (Table 2) were older ($t_{3387} = 6.43$, $p < .001$, Cohen's $d = .33$), had higher education levels ($t_{3375} = 6.30$, $p < .001$, Cohen's $d = .34$), and lower self-report everyday cognition scale score, indicating less self-report cognitive and functional decline ($t_{1246} = -3.61$, $p < .001$, Cohen's $d = .21$). Those who enrolled had a higher percentage of family history of Alzheimer's disease/dementia ($\chi^2 = 24.27$, $p < .001$, Cramer's $V = .09$). Among those who completed or partially completed the survey questions, those who volunteered to join the community board (Table 3) were older ($t_{156} = 2.00$, $p = .047$, Cohen's $d = .29$) and had higher education levels ($t_{191} = 2.63$, $p = .009$, Cohen's $d = .36$) than those who did not volunteer. The cohort of community board volunteers had a higher percentage of those who self-identify as African American/Black only ($\chi^2 = 9.12$, $p = .003$, Cramer's $V = .21$).

3.3. Prior BHR task completion

Among all Black BHR participants invited to join CEDAR, 100% completed at least the BHR questionnaire, 4.1% completed all tasks, 53.2% completed at least one cognitive test, 11.1% attempted a cognitive test but had technical difficulties, and 5.0% have an enrolled study partner (see Table 4). Compared to those who did not enroll in CEDAR, CEDAR participants had a higher percentage of completing all BHR tasks ($\chi^2 = 439.57$, $p < .001$, Cramer's $V = .36$) and a higher percentage of participants completing at least one cognitive test ($\chi^2 = 179.41$, $p < .001$, Cramer's $V = .23$). CEDAR also had a higher percentage of those with cognitive test technical difficulties ($\chi^2 = 32.55$, $p < .001$, Cramer's $V = .10$) and a higher percentage of participants having an enrolled study partner ($\chi^2 = 190.34$, $p < .001$, Cramer's $V = .23$).

3.4. Community-Scientific Partnership Board

A total of 134 (3.58% of all those invited to CEDAR; 37% of those enrolled in CEDAR) community members volunteered to join the community board, of which 19 were selected for the community board. Currently the CEDAR community board has a total of 27 members consisting of 19 Black BHR participants, seven study scientists, and a Latinx marketing/inclusion expert. Community board meetings to date have introduced community members to community-engaged research methods, the study team, and the project goals; included multiple community listening sessions; and offered community board members the opportunity to provide feedback on proposed digital outreach strategies and materials (e.g., website, social media strategy, digital advertising themes and messaging, images and text used in participant communications, dissemination plans).

4. DISCUSSION

The major finding of this study was that a culturally-informed, community-engaged research approach, is a feasible and scalable strategy to enroll Black participants into a research study to increase engagement and research participation. The approach included a novel, remotely-convened community board comprised of individuals residing across the US. Demographic selection biases reflect some of the overall biases of the BHR cohort, including overrepresentation of older adults and those with high educational attainment. Compared to those who did not enroll, those enrolled in CEDAR had higher rates of self-reported family history of Alzheimer's disease/dementia, suggesting that this may be a motivator for enrolling. Remaining challenges are improving overall enrollment rates and increasing sample diversity (e.g., gender, education, cognitive). Future analyses will evaluate the effectiveness of engagement strategies to increase BHR participation by comparing participation levels before and after CEDAR enrollment. This approach can be adapted for use in multiple studies and settings to facilitate inclusion and engagement of Black older adults, and potentially other historically under-included populations in Alzheimer's disease and related dementias research.

We enrolled 349 Black BHR participants into the CEDAR study, representing 9.74% of those invited to join. This enrollment rate is comparable to the average enrollment rate when BHR participants are asked to enroll in additional studies (10%). However, in terms of

BHR task completion, participants enrolled in CEDAR showed a higher level of engagement compared to participants not enrolled in CEDAR, suggesting that the participants enrolled CEDAR were already more engaged. Comparing task completion rates (e.g., having completed at least one cognitive test) with other BHR communities, participants invited to CEDAR (53.2%) had a slightly lower rate compared the overall BHR community (56%), but higher than a large Latinx cohort recently enrolled in BHR (47.8%)[74]. The CEDAR results build on our previous work, in which a combination of community-engaged research methods and digital methods were used to recruit underrepresented populations into Alzheimer's disease research studies. For example, the California Latino BHR (CAL-BHR)[74] demonstrated the feasibility and effectiveness of a similar approach for inclusion and engagement of Latino individuals. Recently, the Alzheimer's Disease Neuroimaging Initiative (ADNI) Diversity Taskforce used culturally informed digital advertising to improve underrepresented population representation in ADNI[54, 75]. To our knowledge, CEDAR is the first study to demonstrate the feasibility of a digital, culturally-informed engagement approach, informed by a community board, focused on improving engagement, retention, and participation of Black adults in Alzheimer's disease and related dementias research. Our findings support the use of digital communications as a tool for engagement in studies[76-79] and emphasize the importance of integrating culturally-informed engagement materials with guidance from community members into the study design[28, 30-32, 51, 80-84]. Since the digital material can be tailored to other ethnocultural populations, this strategy has high potential for scalability and improving the reach of engagement and recruitment.

Researchers interested in this digital community-engaged research approach should consider strategies for fostering dialogue and long-term, bidirectional relationships with community members. This includes strategies for sustaining community boards and financially compensating community board members. Additionally, previous research[82] has demonstrated the effectiveness of direct partnerships with community-based leaders and organizations such as (1) churches and other faith-based institutions, (2) Black fraternities/sororities, and (3) community health clinics for ameliorating distrust and increasing retention of Black participants in clinical Alzheimer's research.

Limitations of the study include multiple selection biases that limit generalizability. First, enrollment in BHR requires participants to have regular access to a device and the Internet, and the cognitive capacity to navigate an unsupervised, remote assessment platform. Our analyses highlight further selection biases for those who chose to join CEDAR from BHR, including a bias for those with high baseline engagement levels in BHR. This may obscure the results of subsequent analyses that evaluate effectiveness of CEDAR engagement strategies by comparing engagement levels before and after the culturally-informed materials were deployed. Additional retention efforts and strategies must be developed to engage participants with lower baseline levels of BHR engagement. Additional analyses to explore the role of social media in engagement, and related issues around privacy concerns, are crucial. The CEDAR study under-samples Black male individuals and Black individuals with lower levels of educational attainment. To improve generalizability, future efforts will include engagement strategies targeted to men and individuals with lower education levels. To better optimize future efforts, we will evaluate the effectiveness of individual engagement strategies in a later study.

This manuscript focused on feasibility and baseline engagement levels of study participants. Future analyses will evaluate the effectiveness of methods by comparing specific BHR registry behaviors (task completion, longitudinal retention) before and after deployment of the engagement strategies. BHR also refers participants to additional research studies[63]. The CEDAR study will also evaluate whether a culturally informed approach improves further research participation of CEDAR participants.

Conclusion

Combining community-engaged research and digital participant communication methods has the potential to efficiently engage Black adults in online Alzheimer's disease research. Future analyses evaluating the effectiveness of specific engagement strategies for improving research participation can inform the development of evidence-based best practices for including and retaining Black individuals in Alzheimer's disease and related dementias research.

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AUTHOR DISCLOSURES

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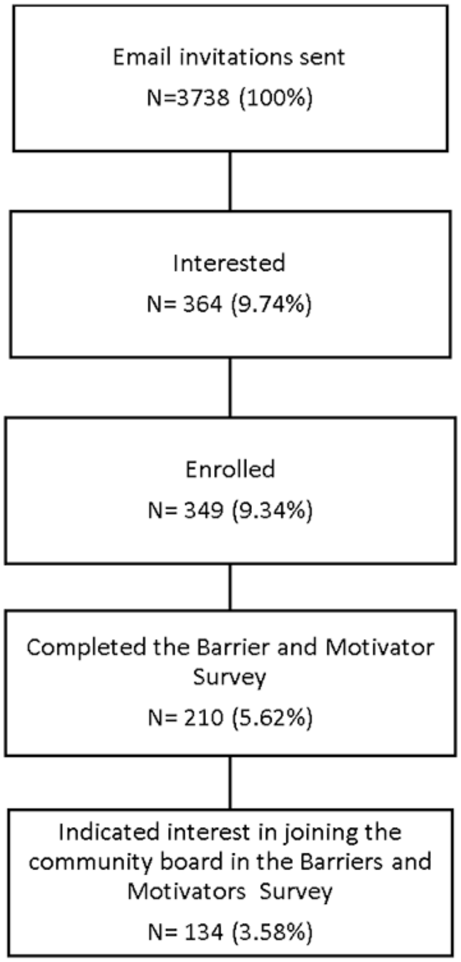

Figure 1.

Participant flow from invitation to enrollment

Table 1:

List of Engagement strategies

Engagement Strategy	Details
CEDAR Facebook group	A private Facebook group was developed to disseminate knowledge and facilitate dialogue among prospective and existing CEDAR participants Posts include resources and educational materials pertaining to Black brain health
Participant testimonials	3 Community-Science Partnership Board members shared their motivations for joining CEDAR and personal experiences with Alzheimer's disease Include both written statements posted to the Brain Health Registry website and brief videos shared with CEDAR participants via email and social media
Investigator videos	Two CEDAR investigators recorded videos explaining the study and the importance of including Black adults in research Videos distributed via social media and email
13-week email engagement campaign	Series of 13 emails sent to CEDAR participants to provide educational resources pertaining to Black brain health Emails also share recent news in the Alzheimer's field
Blog posts	Educational blog posts about brain health are distributed to prospective and existing CEDAR participants via social media channels
Compensation	Compensation for completing study tasks was increased from $25 to $50 partway through the study community board members are compensated $100 per quarterly meeting attended
Landing page	Participants see a culturally tailored landing page when they enroll in CEDAR Landing page contains links to learn more about the study and links to the CEDAR Facebook page
Referrals to other studies	All Black Brain Health Registry participants received an email featuring BHR and collaborator studies Objective was to increase Black representation in studies

Table 2.

Participant characteristics of invited, enrolled, and not enrolled participants

	Participants invited to join CEDAR N= 3738	Black BHR participants enrolled in CEDAR N=349	Black BHR participants who did not enroll in CEDAR N=3389	*p* value from significant test between enrolled vs. not enrolled (Effect size)
Age in years, M(SD)	54.48(12.94)	58.29(11.49)	54.08(13.02)	<.001 (.33) [1]
Min, Max	18, 90	23, 84	18, 90	
Years education, M(SD)	15.48(2.52)	16.25(2.4)	15.40(2.52)	<.001 (.34) [1]
Min, Max	6, 20	12, 20	6, 20	
Gender, n(%)				
Male	620(16.6%)	54(15.5%)	566(16.7%)	.609(.01) [2]
Female	3118(83.4%)	295(84.5%)	2823(83.3%)	
Ethnicity, n(%)				
Latino	303(3.0%)	25(7.2%)	278(8.2%)	.495(.01) [2]
Non-Latino	3322(88.9%)	320(91.7%)	3002(88.6%)	
Declined to state	113(3.0%)	4(1.2%)	109(3.2%)	
Race, n(%)				
African American/Black only	2953(79.0%)	273(78.2%)	2680(79.1%)	.761(.01) [2]
African American/Black mixed	785(21.0%)	76(21.8%)	709(20.9%)	
Self-report memory concern, n (%)	2509(67.1%)	250(71.6%)	2259(66.7%)	.284(.02) [2]
Report family history of Alzheimer's disease , n (%)	1098(29.4%)	146(41.8%)	952(28.1%)	<.001 (.09) [2]
Self-report diagnosis of MCI, n (%)	135(3.6%)	28(8.0%)	107(3.2%)	.307 (.03) [2]
Self-report diagnosis of dementia, n (%)	38(1.0%)	7(2.0%)	31(0.9%)	1.000 (.00) [2]
Self-report diagnosis of Alzheimer's disease, n (%)	20(0.6%)	4(1.2%)	16(0.5%)	.764 [3]
Everyday Cognition Scale score, M(SD)	1.47(0.51)	1.39(0.44)	1.49(0.52)	< .001 (.21) [1]
Min, Max	1, 4	1, 4	1, 3.97	

Note.

[1] = based on independent t test with Cohen's d as effect size.

[2] = based on Chi-Square test with Cramer's V as effect size.

[3] = based on Fisher's Exact test.

Table 3.

Participant characteristics of participants who volunteered to join and not

		Participants who completed/completed partially the survey	**Participants who volunteered**	**Participants who did not volunteer**	***p* value from significant test between volunteered vs. not**
Age in years, M(SD)		57.38(11.36)	58.74(9.76)	55.47(13.10)	.047 (.29) [1]
	Min, Max	24, 81	31, 81	24, 79	
Years education, M(SD)		16.25(2.33)	16.60(2.29)	15.77(2.31)	.009 (.36) [1]
	Min, Max	12, 20	12, 20	12, 20	
Gender, n(%)					
	Male	36(16.7%)	20(15.9%)	16(17.8%)	.853(.01) [2]
	Female	180(83.3%)	106(84.1%)	74(82.2%)	
Ethnicity, n(%)					
	Latino	15(6.9%)	5(4.0%)	10(11.1%)	.074(.12) [2]
	Non-Latino	200(92.6%)	121(96.0%)	79(87.8%)	
	Declined to state	1(0.5%)	0(0.0%)	1(1.1%)	
Race, n(%)					
	African American/Black only	163(75.5%)	105(83.3%)	58(64.6%)	.003(.21) [2]
	African American/Black mixed	53(24.5%)	21(16.7%)	32(35.6%)	
Self-report memory concern, n (%)		157(73.0%)	90(71.4%)	6775.3%)	.637(.03) [2]
Report family history of Alzheimer's disease, n (%)		94(43.7%)	55(43.7%)	39(43.8%)	1.000 (.00) [2]
Self-report diagnosis of MCI, n (%)		17(8.3%)	13(10.8%)	4(4.7%)	.190 (.09) [2]
Self-report diagnosis of dementia, n (%)		6(2.9%)	5(4.2%)	1(1.2%)	.404 [3]
Self-report diagnosis of Alzheimer's disease, n (%)		3(1.5%)	2(1.7%)	1(1.2%)	1.000 [3]
Everyday Cognition Scale score, M(SD)		1.37(0.44)	1.36(0.46)	1.37(0.42)	.899 (.02) [1]
	Min, Max	1, 4	1, 4	1, 3.03	

Note.

[1] = based on independent t test with Cohen's d as effect size.

[2] = based on Chi-Square test with Cramer's V as effect size.

[3] = based on Fisher's Exact test.

Table 4.

Prior task completion of all invited, enrolled and not enrolled in CEDAR

	Total Black participants enrolled in BHR (invited to join (CEDAR) N= 3738	Black BHR participants who did enroll in CEDAR N=349	Black BHR participants who did not enroll in CEDAR N= 3389	*p* values from Chi-Square tests between enrolled vs. not enrolled (Effect size)
Completed at least BHR core questionnaire, n (%)	3738(100.0%)	349(100.0%)	3389(100.0%)	NA
Completed all BHR tasks, n (%)	154(4.1%)	89(22.4%)	65(1.9%)	<.001(.36)
Completed at least one Cognitive Test, n (%)	1988(53.2%)	305(76.8%)	1683(49.7%)	<.001(.23)
Had difficult completing Cognitive Test, n (%)	414(11.1%)	71(17.9%)	343(10.1%)	<.001(.10)
Have an enrolled study partner, n (%)	185(5.0%)	71(17.9%)	114(3.4%)	<.001(.24)