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Understanding online registry facilitators and barriers experienced by Black Brain Health Registry participants: The Community Engaged Digital Alzheimer’s Research (CEDAR) study

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Abstract

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BACKGROUND: Failure of Alzheimer’s disease and related diseases (ADRD) research studies to include and engage Black participants is a major issue, which limits the impact and generalizability of research findings. Little is known about participation of Black adults in online ADRD-related research registries.

OBJECTIVES: As part of the Community Engaged Digital Alzheimer’s Research (CEDAR) Study, this study aims to increase our understanding of facilitators and barriers of Black adults to participating in ADRD-related online registries, as well as to understand their preferences for communication channels.

DESIGN, SETTING, PARTICIPANTS, MEASUREMENTS: We invited all Black participants enrolled in the Brain Health Registry (BHR) to complete a cross-sectional online survey. The survey consisted of rating scales and open-text questions asking about their attitudes towards brain health research, reasons for joining and continuing to participate in BHR, difficulties with participating, and preferences for modes of contact and website usage.

RESULTS: Of all invited Black BHR participants (N=3,636), 198 (5.5%) completed the survey. The mean age was 58.4 (SD=11.3), mean years of education were 16.3 (SD=2.4), and 85.5% identified as female. Reported facilitators for joining and continuing to participate in BHR were personal interest (e.g., learning more about own brain health) and altruism (e.g., helping research). Among additional registry features which could encourage return, receiving feedback or scores about BHR tasks was rated the highest. Of those who found BHR participation difficult (21%), the most frequent reason was time burden. The most preferred way of receiving study information was via email. Participants reported that the websites that they used the most were YouTube and Facebook.

DISCUSSION: The results of our study can inform the development of culturally-responsive registry features and engagement efforts to improve inclusion and participation of Black adults in online ADRD research. Providing participants with feedback about their registry performance and reducing the number of registry tasks are among the recommended strategies.

Keywords

Brain Health Registry; Facilitators; Barriers; African Americans; Black Americans; Alzheimer’s Disease; Dementia; Brain Health; Health Equity; Health Disparities; Survey

1 INTRODUCTION

Alzheimer’s disease and related dementias (AD/ADRD) are a large and growing public health threat[1]. The incidence of AD is disproportionately high in Black/African American (hereafter referred to as Black) communities and they may have more risk factors (e.g., heart health issues) compared to the non-Latinx White population[2, 3]. The incidence of AD and risk factors are often attributed to a combination of sociocultural (e.g., discrimination, racism, access to quality healthcare and education) and structural determinants of health (e.g., government process, policies)[4] and vascular, body mass index, and genetic factors[3, 5–10]. Furthermore, research studies suggest that AD course, symptom severity, and medication response are different in Black adults versus non-Latinx White adults[3, 6]. Black individuals also experience earlier age of onset, less APOE ε4 allele association

with AD, and more severe cognitive impairment[3]. Yet, our understanding of AD health disparities in Black individuals remains obscured by lack of data and inconsistencies in findings[11]. One contributing factor is the chronic under-inclusion of Black individuals in AD/ADRD related research studies[12–16]. Under-inclusion limits the reach of dementia science, reduces the generalizability and validity of findings, and limits our ability to understand health disparities.

Previous literature has documented structural and systemic barriers, as well as historical events (e.g., Tuskegee study) which contribute to the failure of research studies to include participants from Black communities. For example, common barriers include a failure of research studies to provide education about AD and research, transportation to studies, and appropriate compensation for participation, as well as the failure of researchers to gain the trust of Black communities[17–21]. A thorough understanding of the structural, systemic, and individual barriers that lead to failure to include Black community members is needed to move the field forward.

The Brain Health Registry (BHR)[22] is an AD/ADRD-related public online registry (N>95,000) which longitudinally assesses cognition, health, and function and refers participants to other in-clinic and online studies. However, like in-clinic studies and trials, many online registries, including BHR, under-include and underrepresent Black participants [22–24] when compared with the US Census data[22] [25]. Further, BHR has so far failed to substantively engage Black participants, evidenced by lower completion rates of study tasks, lower rates of return for follow-up study visits, and lower levels of participation in additional genetic and biomarker research compared to non-Latinx White BHR participants [26]. To begin to address BHR's failure to engage Black participants, the CEDAR: Community Engaged Digital Alzheimer's Research project was founded as a sub-study of the BHR. CEDAR aim is to increase the engagement and retention of currently enrolled BHR participants who self-identify as Black. As part of the CEDAR study, we conducted a cross-sectional mixed methods online survey among currently enrolled Black BHR participants to broaden our understanding of their facilitators and barriers to BHR participation, as well as preferences for engagement and communication channels. Herein we provide a quantitative and qualitative summary of the survey responses, which can be utilized to develop culturally-informed BHR engagement strategies for Black participants in our study and more broadly in the AD/ADRD research field.

2 METHODS

The survey data presented in this paper was collected as part of the *CEDAR: Community Engaged Digital Alzheimer's Research* project, a sub-study of the BHR. The CEDAR project aims to increase the inclusion, engagement, and retention of currently enrolled BHR participants who self-identify as Black. As a first step of this study, Black BHR participants were invited to complete a cross-sectional online barriers and facilitators survey, which will be used to inform development of engagement and retention strategies. A description of the larger CEDAR project and results will be reported in a separate manuscript.

2.1 Brain Health Registry

The BHR is a publicly available voluntary online ADRD-related research registry to recruit, screen, and longitudinally assess adults (aged 18 and older), as well as to refer participants for cognitive- and aging-related research [22, 27, 28]. BHR participants are recruited from the general public using many methods, for example, digital advertising, cross-promotion with other studies and registries, and earned media. The registry includes an online consent, self-report questionnaires (e.g., sociodemographic, health, cognitive, and lifestyle), self-administered neuropsychological tests, and study partner enrollment and questionnaires. Participants are invited to complete the online neuropsychological tests and questionnaires every 6 months.

2.2 Overall approach

All BHR participants self-identifying as Black who agreed to be contacted about future research opportunities were invited to join the CEDAR study, including the survey, via a series of culturally-informed emails. Only participants enrolled in the CEDAR study were presented with the opportunity to complete the survey. This voluntary cross-sectional survey was hosted by Qualtrics and was available from August 2021 to April 2022 and available in English only. The UCSF Institutional Review Board approved the survey. The survey took approximately 10–15 minutes to complete and was suitable for completion via mobile devices and laptops/computers. Before the launch, the study team tested the survey's technical functionality. There was a financial incentive for completing this survey and/or BHR remote assessments. Reminder emails with culturally-informed messaging were sent to all invited participants who did not sign the study consent (day 8, 15, and 30 after original invitation email), as well as to those who signed the consent, but who did not start the survey within 3 days of signing. Reminders to complete the survey were implemented in March 2022. Of 3,641 invited participants, eleven (0.3%) started the survey two or more times. Only the survey entry with the higher number of answered survey questions was used.

2.3 Measures

Questions were developed by reviewing the literature regarding research engagement and were discussed among the research team to establish content validity. This online survey consisted of 11 questions, including one multiple choice question allowing multiple responses, seven matrix tables in which respondents rated statements/answer options on scales, and six questions with free-text responses. All questions were optional. Please see Table 1 for all survey questions in the order in which they were administered, as well as the available answer options and format.

2.4 Respondent sociodemographic data

Participants self-report the following within the BHR online portal: race (Asian, Black/African American, White, Native American, Pacific Islander, Other, decline to state); ethnicity (Latino, non-Latino, declined to state); age (continuous); gender (male, female, other, unknown); educational attainment (grammar school, high school, some college, two-year degree, four-year degree, Master's degree, doctoral degree, professional degree); endorsement of subjective memory concern (*"Are you concerned that you have a memory*

problem?"); and family history of AD/dementia (“*Do you have any biological parents, full siblings, or biological children who have been diagnosed with Alzheimer’s Disease?*”). The variable educational attainment was converted into a continuous variable ranging from 6–20 years. A new race variable was created with the categories “Black only”, “Black and other races”, and “declined to state”. If information was missing for the variables gender, ethnicity, and race, we also added a category “unknown”.

2.5 Statistical Analysis

Descriptive statistics for demographic variables including percentages, n , means, and standard deviations (SD) were calculated for all invited participants. For continuous variables such as age and years of education, independent sample t-tests were conducted to compare means between those who did not respond to the survey and those who responded. Cohen’s d was reported as effect size. For categorical variables such as gender and race, chi-square tests for association were used if 20% of expected cell counts were less than five and Cramer’s V was reported as effect size. Fisher’s exact tests were used if > 20% of expected cell counts were less than five. Both completed and partial responses were analyzed. Frequencies for each option were provided. If a question had a scale of more than four categories, we regarded it as continuous variable, calculated the mean and standard deviations. We also conducted pairwise comparison using Bonferroni correction to test if the mean score difference was statistically significantly different between the different question statements. All statistical analyses were done in R (4.2.0) [29] and using the package “psych”.

2.6 Qualitative Analysis

The data of the free-text responses was analyzed using an open-coding approach and thematic analysis[30]. As the associated questions were optional, blank responses were skipped. First, to become familiar with the data, two members of the research team who were not involved in the design and administration of the survey read the free-text responses at least two times and drafted initial categories. Second, they met to openly code, assess the categories, and confirm themes. The research team determined that the six survey questions with free-text responses could be divided between two overarching research interests: “Research participation” and “Barriers to research participation”. See Table 1 for information about which questions were included in each of the two interests. Classifying the questions allowed the research team to develop themes and categories separately for each interest.

3 Results

3.1 Survey response

A total of 3,641 Black BHR participants were invited to enroll in CEDAR and of those 280 (7.7%) enrolled and 278 (7.6%) started the survey. Of those enrolled in CEDAR and presented with the survey, 256 (91.4%) answered the survey. Figure 1 presents the attrition from invitation to completed survey, including information about partial responses. There were 22 BHR participants who started the survey, but did not answer any questions, 58

partial responses, and 198 complete responses. Of all who started the survey, 256 (92.1%) had at least partial data.

3.2 Sample characteristics

Detailed information about the characteristics of the survey respondents is given in Table 2. Compared to those who did not start the survey, those who started reported that they were significantly older ($t_{342}=6.28, p<.001$, Cohen's $d=.34$) with more years of education ($t_{330}=6.26, p<.001$, Cohen's $d=.37$), were more likely to report a family history of AD, ($\chi^2_1=8.06, p=.005$, Cramer's $V=.05$), and less likely to report a memory concern, ($\chi^2_1=14.28, p<.001$, Cramer's $V=.06$). All results following this participant characteristic section use data of respondents with at least partial responses ($N=256$). Respondents with at least partial data (this includes respondents with partial and complete data) were on average 58.44 years old ($SD=11.27$), 16.31 years of education ($SD=2.35$), and most identified as female (85.5%, $n=219$) and as Black/ only (79.7%, $n=201$). Fourteen (0.5%) self-identified as Latinx/o/a. A total of 93 (36.3%) participants self-reported a family history of AD and 133 (52.0%) self-reported memory concerns. Table 2 also compares the demographic characteristics of those who partially completed the survey and those who fully completed it.

3.3 Research Participation

Table 3 provides summary statistics and information about pairwise comparison for all survey questions.

3.3.1 Attitudes towards brain health research—Most respondents (80.5%, $n=206$) described their attitude towards brain health research as positive.

3.3.2 Reasons for joining BHR—Participants were asked to rate the importance of different reasons for joining the BHR. The two highest rated statements were: “*I want to learn about my own brain health*” ($M=4.66, SD=.74$) and “*I want to help research to benefit the brain health of future generations*” ($M=4.61, SD=.73$). There was no significant difference between means of the two highest rated statements ($p = .10$, Cohen's $d = .21$). The statement with the lowest importance rating was “*I was referred by someone I know*” ($M=1.25, SD=1.39$) and compared to the two highest rated statements, the statement received a significantly lower rating of importance.

3.3.3 Reasons for continuing to participate in BHR—When asked about the importance of different reasons for continuing to participate in BHR, the following two statements received the highest ratings: “*I want to learn about my own brain health*” ($M=4.67, SD=.75$), “*I want to help with current research/treatments for brain health*” ($M=4.65, SD=.74$). No significant mean difference was found between the two highest rated statements. The statement which received the lowest rating of importance was “*I was referred by someone I know*” ($M=1.87, SD=1.48$) and pairwise comparisons showed that this mean was significantly lower than the means of the two highest rated statements.

3.3.4 Research participation qualitative results—Participants expressed their interest in research participation across five themes: relationships, identity, personal

knowledge, altruism, and diversity. See Table 4 for themes, subcategories of themes, as well as counts and quotes for each subcategory.

Relationships.: Most participants stated an interest in participating in brain health research because they had a family history of AD or dementia. Those with personal experience interacting with afflicted loved ones wanted to participate to improve their outlook and the outlook of their friends and family.

Identity.: For the identity theme, three sub-categories emerged: *Worry about memory loss*, *personal health*, and *age*. With regard to “*worry about memory loss*,” many participants were mindful of their own brain health and some admitted participating in BHR because they are worried about memory loss in their future. Participants were aware of their age and the effects of getting older on their personal health. Therefore, they were interested in maintenance of their current brain health and prevention of future issues.

Altruism.: For altruism, four sub-categories were identified: 1) *researchers – want to help researchers*; 2) *importance – believes research is important*; 3) *cure – interest in finding a cure*; 4) *help – wants to help*. The largest subcategory of responses was from participants who highlighted the importance of research. These responses included statements about positive attitudes or beliefs that brain health research is important. Common responses also discussed prevention of brain health diseases and several responses specifically mentioned treatment because of hope that researchers discover a cure.

Personal knowledge.: For this theme, two sub-categories were identified: 1) *brain – interest in brain itself* and 2) *educational – interest in science and learning*. Several participants were eager to participate due their interest in the brain and related science. Several participants also saw participating in BHR as an opportunity to learn.

Diversity.: Respondents cited interest in increasing the diversity within the present study and AD research in general and also worries about the brain health research gap for diverse populations.

3.5 Reasons which make participation in BHR difficult

The majority 202 (78.9%) answered “*I do not have any difficulties with participation.*” Among those who reported difficulties ($n=54$), the most common reasons were “*I don’t have enough time*” ($n=19$, 35.2%) and “*The tasks take too much time*” ($n=19$, 35.2%).

3.5.1 Barriers to research participation qualitative results—When asked to describe why participation in the survey was difficult, participants’ explanations followed four themes: time, attitude, technology, and health. See Table 3 for themes, subcategories of themes, as well as counts and quotes for each subcategory.

Time.: The majority of barriers indicated by participants fell into the category of time. Among the participants who indicated time as a barrier, lack of personal time was the most frequent, followed by participants reporting that the amount of registry tasks is burdensome.

Few, but some participants reported procrastination, or putting tasks off until later, as a barrier to participating in the registry.

Attitude.: Several barriers to participation were associated with participant's perceptions of the registry itself. Perceiving little to no value of the registry was reported most frequently. Additionally, some participants seemed to not understand the purpose of the registry.

Technology.: Participants reported both personal technical issues (e.g., inconvenience of having to use a computer), as well as technical issues with the registry website.

Health.: Some participants reported that personal health was a barrier to participation. However, health was the least frequently cited barrier of participation.

3.6 Additional BHR features which encourage return or completion of study tasks

In terms of additional BHR features suggested in the survey, participants were most interested in "*Summary of your performance on brain tests*" ($M=4.67$, $SD=.68$), followed by "*Personalized report based on how you answered questionnaires*" ($M=4.59$, $SD=.85$). Post-hoc comparisons found no difference between the means of the two highest rated statements. The statement with the lowest mean was "*More frequent newsletters*" ($M=2.85$, $SD=1.32$), which was significantly lower than the means of the two highest rated statements.

Respondents were also asked to indicate the importance of the factors that encouraged them to return to the BHR or to complete all the study tasks. Participants were most encouraged by "*Scores or feedback on brain tests*" ($M=4.63$, $SD=.71$), followed by "*More details on how my participation helps research or impacts my community*" ($M=4.20$, $SD=1.04$). Pairwise comparison revealed that the mean rating of "*Scores or feedback on brain tests*" was significantly higher than the mean rating of "*More details on how my participation helps research or impacts my community.*" The statement with the lowest mean rating was "*Better technical support*" ($M=2.85$, $SD=1.37$), which was also significantly lower rated than the two highest rated statements.

3.7 Preference for ways of receiving information

In terms of preferred ways of receiving information, respondents preferred email most ($M=4.64$, $SD=.81$), followed by text ($M=3.75$, $SD=1.46$). The least preferred ways were phone calls ($M=2.35$, $SD=1.54$) and blog posts ($M=1.39$, $SD=.96$).

3.8 Frequency of using different websites

Participants were asked how often that have used different websites over the past two months. YouTube was the most visited website ($M=2.68$, $SD=.93$), followed by Facebook ($M=2.59$, $SD=1.25$). The least frequently used websites were TikTok ($M=1.34$, $SD=.78$) and Snapchat ($M=1.13$, $SD=.54$).

4. Discussion

This study aimed to better understand online registry facilitators, barriers, and preferred communication channels of Black BHR participants. The major findings were (1) that

reported facilitators centered around personal knowledge and altruism; (2) that most reported no difficulties participating, but among those who did, the main barrier was time; and (3) email, YouTube, and Facebook are popular channels to reach and engage with older Black adults.

Key factors that facilitated joining and continuing to participate BHR were related to personal benefits and altruism. The most endorsed reason for both joining and continuing was a desire to learn more about their own brain health. Similarly, when asked about additional features for BHR, participants were interested in gaining feedback about their participation (e.g., score on neuropsychological tests). This is consistent with previous research which identified that providing benefits (including test results) to the participant helps improve research participation [17, 31–33]. Providing timely and continued feedback or information about participants' brain health addresses the identified facilitators for joining and continuing to engage in research and may offset the cost and/or burden of participation and potentially make participants feel respected and understood. This finding highlights an important shortcoming of the BHR – not providing the participants with any results or feedback about their completed questionnaires and tests, which could provide them with information about their own brain health. While disclosure of neuropsychological test results, genetic results, and amyloid PET scans is currently a topic of great interest and debate in AD in-clinic studies [31, 34, 35], less research has focused on providing results or feedback in a remote setting without the presence of a clinician. When deciding to provide results in a remote setting, researchers must consider technical, logistical (e.g., features of the disclosure protocol), ethical, and safety issues (e.g., misinterpretation of results, psychological distress) and concerns about legal liability [31, 36, 37]. In addition, many commonly used instruments are developed and tested in a non-Latinx White population, so they may not be valid in participants from diverse backgrounds. This threat to validity needs to be taken into account even when providing results person with a clinician and is heightened in an online setting without an involved clinician [38]. Some studies are already providing results to participants, for example, the Alzheimer's Prevention Trial Webstudy (APT Webstudy) is providing their registry participants with cognitive test scores and graphical representations of longitudinal performance [39]. Another way of offering participants information about their brain health is through providing educational material which could be general or personalized. Another key facilitator identified in this survey was altruism. In terms of altruism, the desire to help future generations and advancing science were often cited as reasons for participation. Altruism is also a commonly reported motivator for participating in research in general and the Black community in particular [17, 18, 33, 40–43]. Follow-up studies need to determine whether inclusion and engagement materials focusing on providing feedback and altruism are successful in enrolling and engaging participants from the Black community in digital and in-clinic research over a period of time.

Regarding barriers to BHR participation, most survey respondents stated to have no difficulties participating. This result is not surprising considering that only a small and previously engaged number of Black BHR participants completed this survey. Yet it greatly limits our findings since we did not acquire the perceptions of Black adults who we failed to include (both in BHR in general and this survey). This is an important gap which future

BHR research and research in general needs to continue to explore and address, through broader reach such as focus groups and nationally-representative surveys[44]. Of those who experienced difficulties, the main perceived barriers were related to time. Participants reported both a lack of time and that BHR tasks were too time intensive, which is consistent with previous research findings [17, 45]. Possible ways to address this issue in the BHR and other studies is by shortening assessments, being upfront about the time burden (e.g., provide information about percent completed), and giving participants the opportunity to break up the assessments into multiple sessions. The BHR website has recently undergone changes to address this issue by streamlining tasks to reduce. We have not yet determined if these changes will have a significant impact on the experience of BHR participants.

The most preferred way of receiving information from BHR was email, followed by text. Currently BHR only communicates via email with participants. To be able to include text communication and support in research studies, significant development work is needed. Considerations for text expansion include, for example, the management of participants whose phone numbers change and the appropriateness of text content for variable cell phone displays. In terms of website use, participants reported to most frequently use YouTube followed by Facebook. These results are consistent with a report from the Pew Research Center[46] in which both online platforms (Facebook and YouTube) rank highest among older adults and individuals from Black communities. However, evidence about the use of YouTube as a recruitment and inclusion tool is still in its infancy [47, 48]. Previous BHR efforts to engage with potential participants, including commonly under-included ethnocultural groups, have primarily focused on Facebook, Google, and Bing [22, 49]. As part of another research study, BHR is currently testing and comparing Facebook, Google, and YouTube ads tailored to Asian, Black, and Latinx adults, but the results about the effectiveness of this approach are still outstanding. Based on the current results, YouTube is an additional channel for future digital inclusion efforts among the Black community. This could include YouTube channels with videos about studies or laboratories, as well as digital advertisement placed within existing videos.

4.1 Limitations

This study is not without limitations. This study suffers from multiple selection biases including for those with internet access, ability to read and write in English, high literacy, those already enrolled in the BHR, and those responding to the survey invitation. Like many research samples, this survey also underrepresents male participants and individuals with an education attainment less than a high school degree. Further, aside from education, BHR does not collect any other socioeconomic (e.g., income, quality of education) and sociocultural factors (e.g., discrimination) which could impact responses. This greatly impacts the interpretation and generalizability of our findings, and it remains unclear whether our results are applicable to a broader segment of Black community, especially those most underrepresented and underserved who are at greatest risk for AD/ADRD. Future efforts should focus on reaching adults from the Black community not currently enrolled in BHR or other research registries to understand the facilitators and barriers and help put into context the results from the present study. Furthermore, this analysis did not include information about the original recruitment (e.g., social media) source to BHR. Future

research would benefit from including this information to help provide more context to the results regarding the participant's frequency of using certain websites. Another limitation is the relatively low survey completion rate (5.4%). In BHR, enrollment rates for BHR referral studies are on average 10%, which is higher than the current study. However, the average referral study enrollment rate of 10% is across all participants and not specifically for Black BHR participants. In a previous analysis we found that BHR is less successful in enrolling non-White BHR participants in BHR referral studies compared to White BHR participants [26]. In addition, only participants enrolled in the CEDAR study were presented with CEDAR survey. Of those who enrolled in CEDAR, 91.4% answered the survey. Future BHR survey studies could be sent to participants directly instead of requiring enrollment in an engagement study. The BHR is actively developing efforts to respond to these limitations.

4.2 Conclusion

In conclusion, our study provides insight into facilitators and barriers to online registry participation experienced by Black BHR participants, as well as their preferred modes of communications. These results will inform the development of culturally-informed efforts to increase the participation (enrollment and registry task completion) of Black BHR participants and can assist other researchers and developers in refining and improving their online registries or research studies. Overall, providing participants with feedback about their registry performance and information about their brain health, as well as reducing the time burden are among the recommended strategies to facilitate research engagement of Black participants. More work is needed to understand facilitators and barriers from a more diverse community of Black adults (e.g., gender, socioeconomic status) and Black adults who are not already enrolled in a study.

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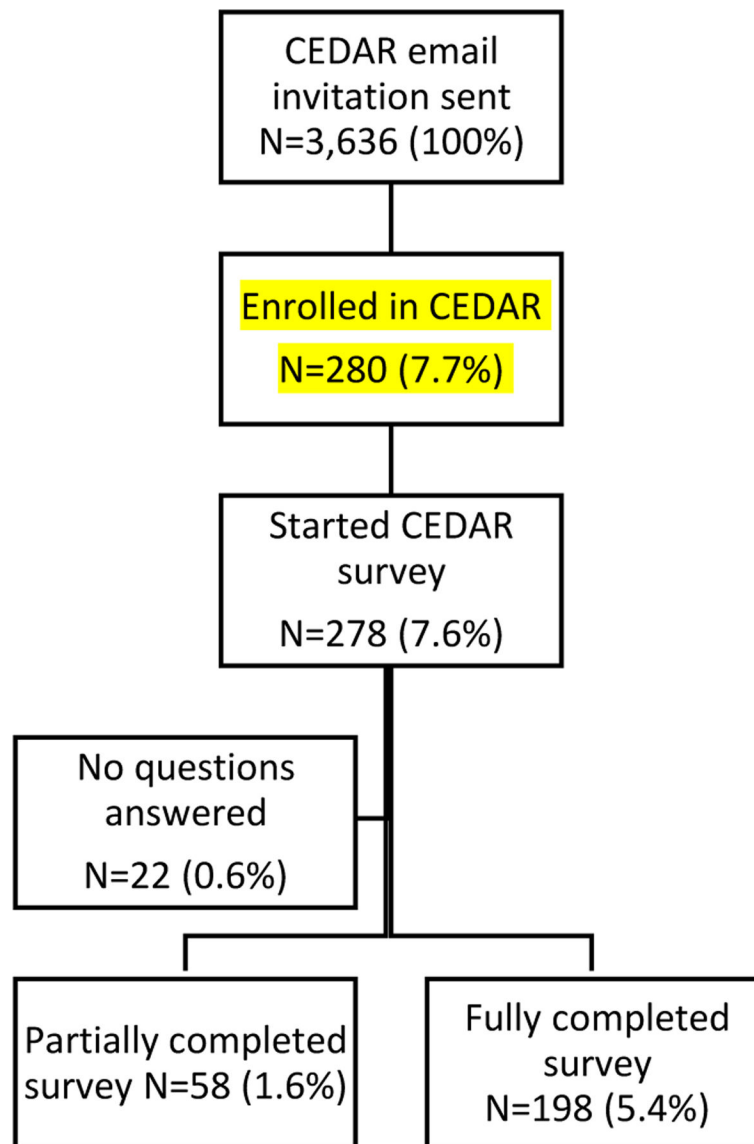


Figure 1.
Gradual attrition of respondents from survey invitation and completion.

Table 1.

Survey questions in order with response options and response formats

Question	Response options	Response format
Which of these answer(s) best describe reasons that make participation difficult for you? (Please select all that apply.)	<ul style="list-style-type: none"> • I am no longer interested • I do not have enough time • The tasks take too much time • I do not understand the tasks/the tasks are too difficult • I do not want to answer some questions in the task • I do not like it • I forgot • I had technical difficulties • I do not see a benefit for me • I had a difficult incident/experience with the tasks. Explain ^{*^} • I do not have any difficulties with participation • I had a difficult incident/experience with the tasks. Explain: [*] • Other: ^{*^} 	Check if applicable *Includes free text reply option
What (if anything) can help you overcome these difficulties?	N/A	Free text reply [^]
On a scale from 1–5, rate how important each reason was to you for joining the Brain Health Registry.	<ul style="list-style-type: none"> • I want to learn about Brain diseases such as Alzheimer’s • I want to learn about my own brain health • I want to help with current research/treatments for brain health • I want to help research to benefit the brain health of future generations • Someone I know has/had a brain disease such as Alzheimer’s • I was referred by someone I know • Other ^{*#} 	
On a scale from 1–5, rate how important this reason is to you for continuing participation in the Brain Health Registry	<ul style="list-style-type: none"> • I want to learn about Brain diseases such as Alzheimer’s • I want to learn about my own brain health • I want to help with current research/treatments for brain health • I want to help research to benefit the brain health of future generations • Someone I know has/had a brain disease such as Alzheimer’s • I was referred by someone I know • I enjoy completing the study tasks • Other ^{*#} 	Least important (1), (2), (3), (4), Most important (5), N/A (6)
What best describes your attitude towards brain health research?	N/A	Positive (1), Neutral (2), Negative (3), No opinion (4)
Can you explain why you gave that answer?	N/A	Free text reply [#]
On a scale of 1–5 how interested would you be in these additional features?	<ul style="list-style-type: none"> • Additional cognitive tests 	Least important (1), (2), (3), (4), Most important (5), N/A (5)

Question	Response options	Response format
	<ul style="list-style-type: none"> • More of the current study tasks available on smartphones and tablets • Specific information and resources regarding brain disease • More frequent newsletters • Summary of your performance on brain tests • Other* 	
On a scale of 1–5 how much would this encourage you to return to the Brain Health Registry or complete all the study tasks?	<ul style="list-style-type: none"> • Monetary compensation • Fewer questionnaires or brain tests • A chance to win a prize • Better technical support • More educational resources • Additional opportunities to participate in clinical research • More details on how my participation helps research or impacts my community • Other* 	Not interested (1), (2), (3), (4), Very interested (5), N/A (6)
Over the past 2 months, how often have you used the following websites?	<ul style="list-style-type: none"> • Facebook • Twitter • Instagram • TikTok • Snapchat • YouTube • LinkedIn • Pinterest • Other* 	Not at all (1), Several days (2), More than half the days (3), Nearly every day (4)
Please rate your preference for these ways to receive information on a scale from 1–5.	<ul style="list-style-type: none"> • Phone call • Text • Email • Postcard • Radio. What station do you listen to?* • Blog. What blogs or bloggers do you follow?* • Webinar • Social media Which social media channel(s)?* • Other* 	Do not prefer (1), (2), (3), (4), Prefer the most (5), I do not use this (6)

* Note. =Includes free text reply option;

=questions analyzed in qualitative analysis of “Research Participation”;

^ =questions analyzed in qualitative analysis of “Barriers to Research Participation”

Table 2.Comparison of participant characteristics (total sample size $N= 3,636$)

Variables	Survey not started (n=3,358)	Survey started (n=278)	Test Statistic (<i>p</i>)	Effect size	Survey partially completed (n=58)	Survey fully completed (n=198)	Test Statistic (<i>p</i>)	Effect size
Age in years, M(SD)	54.0 (13.0)	58.5(11.2)	$t_{342} = -6.27$ $p < .001$.34 ¹	62.6 (10.9)	57.2 (11.1)	$t_{94} = -3.28$ $p = .001$.49 ¹
Range	72	59			48	57		
Years education, M(SD)	15.4(2.5)	16.3(2.3)	$t_{330} = -6.26$ $p < .001$.37 ¹	16.2 (2.4)	16.4 (2.3)	$t_{87} = .47$ $p = .640$.07 ¹
Range	14	8			8	8		
Gender, n (%)			$\chi^2_1 = .17$ $p = .682$.02 ²			$\chi^2_1 = 4.30$ $p = .038$.14 ²
Male	558 (15.4%)	43 (15.5%)			3 (5.2%)	34 (17.2%)		
Female	2,800 (77.0%)	235 (84.5%)			55 (94.8%)	164 (82.8%)		
Ethnicity, n (%)			$\chi^2_1 = 2.10$ $p = .152$.03 ²			Fisher's exact test $p = .201$	N/A
Latino	278 (7.7%)	16 (5.8%)			1 (1.7%)	13 (6.6%)		
Non-Latino	2,970 (81.6%)	258 (92.8%)			57 (98.3%)	183 (92.4%)		
Declined to state	4 (3.0%)	4 (1.4%)			0 (0.0%)	2 (1.0%)		
Race, n (%)			$\chi^2_1 = .02$ $p = .886$	<.01 ²			$\chi^2_1 = 4.70$ $p = .030$.15 ²
Black only	2,652 (72.9%)	218 (78.4%)			52 (91.2%)	149 (75.3%)		
Black and other races	706 (19.4%)	60 (21.6%)			6 (10.5%)	49 (24.8%)		
Self-report memory concern, n (%)	2,057 (56.6%)	142 (51.1%)	$\chi^2_1 = 14.28$ $p < .001$.07 ²	38 (65.52%)	95 (47.9%)	$\chi^2_1 = 4.85$ $p = .028$.15 ²
Report family history of AD, n (%)	931 (25.6%)	100 (35.9%)	$\chi^2_1 = 8.06$ $p = .005$.06 ²	24 (41.4%)	69 (34.9%)	$\chi^2_1 = .28$ $p = .469$.04 ²

¹Note. = Cohen's *d*.²= Cramer's *V*.

Table 3.

Survey questions summary statistics and pairwise comparisons

Question	Significant pairwise comparison*	N	M	SD	IQR
Q1: Which answer(s) best describe your reason for joining the Brain Health Registry					
Q1a: I want to learn about Brain diseases such as Alzheimer's	Q1b, Q1f, Q1g	222	4.41	0.98	1
Q1b: I want to learn about my own brain health	Q1f, Q1g	222	4.66	0.74	0
Q1c: I want to help with current research/treatments for brain health	Q1f, Q1g	222	4.60	0.76	1
Q1d: I want to help research to benefit the brain health of future generations	Q1f, Q1g	222	4.61	0.73	1
Q1e: Someone I know has/had a brain disease such as Alzheimer's	Q1f, Q1g	222	4.42	1.28	1
Q1f: I was referred by someone I know	Q1g	83	1.25	1.39	0
Q1g: Other		55	2.47	1.77	4
Q2: Which answer(s) best describe your reason for continuing participation in the Brain Health Registry?					
Q2a: I want to learn about Brain diseases such as Alzheimer's	Q2b, Q2f, Q2g, Q2h	222	4.46	0.92	1
Q2b: I want to learn about my own brain health	Q2e, Q2f, Q2g, Q2h	222	4.67	0.75	0
Q2c: I want to help with current research/treatments for brain health	Q2e, Q2f, Q2g, Q2h	222	4.65	0.74	0
Q2d: I want to help research to benefit the brain health of future generations	Q2f, Q2g, Q2h	222	4.59	0.77	1
Q2e: Someone I know has/had a brain disease such as Alzheimer's	Q2f, Q2g, Q2h	222	4.32	1.38	1
Q2f: I was referred by someone I know	Q2g	82	1.87	1.48	1
Q2g: I enjoy completing the study tasks	Q2h	222	3.73	1.47	2
Q2h: Other		48	2.17	1.64	3
Q3: If the Brain Health Registry released additional features, which of the following would you be interested in?					
Q3a: Personalized report based on how you answered questionnaires	Q3b, Q3c, Q3d, Q3e, Q3g	212	4.59	0.85	1
Q3b: Additional cognitive tests	Q3c, Q3e, Q3f, Q3g	212	4.24	0.96	1
Q3c: More of the current study tasks available on smartphones and tablets	Q3d, Q3e, Q3f, Q3g	212	3.73	1.44	2
Q3d: Specific information and resources regarding brain disease	Q3e, Q3f, Q3g	212	4.21	0.97	1
Q3e: More frequent newsletters	Q3f, Q3g	212	2.85	1.32	2
Q3f: Summary of your performance on brain tests	Q3g	212	4.67	0.68	0
Q3g: Other		212	2.19	1.72	3
Q4: What would encourage you to return to the Brain Health Registry or complete all the study tasks?					
Q4a: Monetary compensation	Q4b, Q4c, Q4d, Q4f, Q4h, Q4i	212	3.86	1.27	2
Q4b: Fewer questionnaires or brain tests	Q4e, Q4f, Q4g, Q4h, Q4i	212	3.16	1.25	2
Q4c: A chance to win a prize	Q4e, Q4f, Q4g, Q4h, Q4i	212	3.02	1.48	2
Q4d: Better technical support	Q4e, Q4f, Q4g, Q4h, Q4i	212	2.85	1.37	2
Q4e: More educational resources	Q4f, Q4g, Q4h, Q4i	212	3.67	1.17	2
Q4f: Scores or feedback on brain tests	Q4g, Q4h, Q4i	212	4.63	0.71	1
Q4g: Additional opportunities to participate in clinical research	Q4h, Q4i	212	4.01	1.10	2
Q4h: More details on how my participation helps research or impacts my community	Q4i	212	4.20	1.04	1
Q4i: Other		212	2.04	1.60	2
Q5: Over the past 2 months, how often have you used the following websites?					

Question	Significant pairwise comparison*	N	M	SD	IQR
Q5a: Facebook	Q5b, Q5c, Q5d, Q5e, Q5g, Q5h, Q5i	212	2.59	1.25	3
Q5b: Twitter	Q5c, Q5d, Q5e, Q5f, Q5i	212	1.67	1.03	1
Q5c: Instagram	Q5d, Q5e, Q5f, Q5h, Q5i	212	1.89	1.14	1.25
Q5d: TikTok	Q5e, Q5f, Q5g	212	1.34	0.78	0
Q5e: Snapchat	Q5f, Q5g, Q5h	212	1.13	0.54	0
Q5f: YouTube	Q5g, Q5h, Q5i	212	2.68	0.93	2
Q5g: LinkedIn		212	1.61	0.87	1
Q5h: Pinterest		212	1.54	0.76	1
Q5i: Other		212	1.35	0.91	0

* Note. Significant pairwise comparisons with Bonferroni correction. For example, for Q1a, this demonstrates that the mean of the response option Q1a (I want to learn about Brain diseases such as Alzheimer's) is significantly different from the mean of the response options Q1b (I want to learn about my own brain health), Q1f (I was referred by someone I know), and Q1g (Other).

The scale for Questions 1 through 4 ranges from "1"–"5." The scale for Question 5 ranges from "1"–"4."

Table 4.

Themes, sub-themes, counts and quotes for research participation and barriers to registry participation

Themes	Sub-themes	Counts	Quote
Research participation			
Relationships	Family and/or Friends history of dementia	41	<i>“My Mother’s quality of life was shortened by Alzheimer’s. I’s such a devastating affliction for victims and care givers, that I want to support research that may come up with ways to prevent, cure, and manage it.”</i>
Identity	Worry about memory loss	9	<i>“[With family history] I’m now have the target on my back (in God’s name it won’t be hit!!!) and I need to do all I can to make sure any and all research is done to find a cure for those following me.”</i>
	Personal health	21	<i>“I have a more positive attitude toward brain health research since I have some health issues that may ultimately/eventually benefit from such research.”</i>
	Age	9	<i>“As I age, I want to better understand, My aging process, and what I can do to keep or sharpen my cognitive skills.”</i>
Altruism	Researchers – want to help researchers	13	<i>“I am affected by this disease and want to know and grow and help researchers.”</i>
	Importance – believes research is important	44	<i>“What is this, the dark ages? Are people really coming out with negative attitudes towards brain research?”</i>
	Cure – interest in finding a cure	16	<i>“I would like to participate in increasing the knowledge about brain health and hope that my participation will help with diagnoses and treatments in the near and distant future.”</i>
	Help – wants to help	13	<i>“I know we need to find an answer and I want to help and feel it’s my responsibility to help [...] But truly support the research.”</i>
Personal knowledge	Brain – interest in brain itself	23	<i>“The brain is everything. I want to know more.”</i>
	Educational – interest in science and learning	12	<i>“I feel we all can contribute to the knowledge base by sharing our experiences. It costs nothing, so why not? I trust the science!!”</i>
Diversity	Progress – wants more research on diverse populations	8	<i>“I am glad that you are including Black people in your study. We have a higher possibility of developing brain problems, so of course we should be included!”</i>
	Concern – worried about the brain health gap	11	<i>“Very little research, specifically for persons of color. My hope has been that attention would eventually be turned in that direction if I stay the course long enough.”</i>
Barriers to registry participation			
Time	Personal lack of time	20	<i>“I’m busy working and sometimes don’t have enough time to stop and take a survey.”</i>
	Procrastination	4	<i>“I get the emails reminding me to participate and I procrastinate in the moment and then completely forget.”</i>
	Amount of registry tasks	7	<i>“Some time with a busy schedule the task can be time consuming.”</i>
Attitude	Value of the registry	6	<i>“The study impact is difficult to see, how is this study positively impact the African American community?”</i>
	Misinterpretations of the registry	2	<i>“When I complete the test/evaluation measures, I want to receive feedback on my results. I have had several neuro psych tests and my examiner always give feedback.”</i>
Technology	Technical issues - personal	8	<i>“It’s more convenient to use my phone then I forget to do it in my computer later.”</i>
	Technical issues - registry	6	<i>“ Your screen froze. By the time I received a reply to my informing the team about the problem other responsibilities took over my time.”</i>
Health	Personal health	3	<i>“I have mental health issues that interfere with my ability to participate at times.”</i>