RESEARCH ARTICLE

Effects of sex, race, ethnicity, and education on online aging research participation

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Abstract

Introduction: This study aimed to identify the relationship of sociodemographic variables with older adults participation in an online registry for recruitment and longitudinal assessment in cognitive aging.

Methods: Using Brain Health Registry (BHR) data, associations between sociodemographic variables (sex, race, ethnicity, education) and registry participation outcomes (task completion, willingness to participate in future studies, referral/enrollment in other studies) were examined in adults aged 55+ (N = 35,919) using logistic regression. All models included sex, race, ethnicity, education, age, and subjective memory concern.

Results: Non-white race, being Latino, and lower educational attainment were associated with decreased task completion and enrollment in additional studies. Results for sex were mixed.

Discussion: The findings provide novel information about engagement in online aging-related registries, and highlight a need to develop improved engagement strategies targeting underrepresented sociodemographic groups. Increasing registry diversity will allow researchers to refer more representative populations to Alzheimer’s and related dementias prevention and treatment trials.

KEYWORDS

aging research, brain health registry, education, engagement, ethnicity, internet, race, research registry, retention, sex
1 | BACKGROUND

With 5.8 million Americans affected by Alzheimer’s disease (AD),
cognitive decline and dementia caused by Alzheimer’s disease and
related dementias (ADRD) are a major medical challenge. Sociodemographic
disparities clearly exist in ADRD prevalence and incidence, clinical
and neuropathological features, and biological and medical risk factors.2–7
For example, there is a greater prevalence in women,1
Black/African Americans, and Latinos.8,9 Age-adjusted dementia risk
differs across Latino ethnic groups,10 with evidence of elevated risk
among Caribbean Latinos in New York City,11 but not among Mexi-
Can American in California.12 African Americans are approximately
twice as likely to develop dementia as non-Latino whites,13 whereas
for all Asian American subgroups, lower dementia incidences com-
pared to whites have been reported.14 It is believed that differences
in genetics, lifestyle, health, and socioeconomic risk factors, especially
educational attainment,15,16 are likely responsible for most of these
disparities.17

A major barrier to the development of new dementia research is
that many clinical studies recruit slowly, but never reach their tar-
get enrollment, and experience greater than expected loss to follow-
up.18,19 This problem is further exacerbated by lack of representa-
tiveness in terms of race, ethnicity, sex, education, and socioeconomic
status.2–20 In addition, emerging evidence supports sociodemographic
differences in research participation (brain donations, lumbar puncture
(LP), and genetic studies21–23) and that interactions between sociode-
mospheric factors and enrollment factors (eg, recruitment source) may
influence ADRD outcomes.24 These selection issues, which include dif-
erential enrollment, attrition, and retention, limit the impact and gen-
eralizability of ADRD research findings.25

One way of accelerating clinical study recruitment are registries26
developed to increase efficiency of prescreening, and referral to
studies,27 especially ADR prevention trials.26 Registry participants
tend to have higher research study enrollment rates compared to indi-
viduals who are contacted through other means.29 A variety of local
and national ADRD-related registries exist in the United States,30–35
which differ in purpose and format. The National Strategy for Recruit-
ment and Participation in Alzheimer’s Disease Clinical Research lists
assessment of registry performance and identification of key audi-
ces as strategic priorities that will improve participation in ADRD research.36

As technology adoption increases among older adults and minority
groups,27 online AD registries represent a promising approach to effi-
ciently recruit and assess a diverse sample of older adults. Although
the different registries together have enrolled many hundreds of thou-
sands of participants, they underrepresent males, non-whites, and non-
Latinos.32–35 Increasing the sociodemographic diversity of registry
participants is crucial for producing more generalizable research find-
ings, elucidating ADRD health disparities, and developing effective
therapeutics. There is emerging evidence about motivators affecting
registry enrollment,32–35 but little is known about effective strate-
gies for bolstering recruitment and retention of underrepresented
populations.30,38 Online registries, although they require computer
and internet access and literacy, might be able to support the recruit-
ment and retention of underrepresented populations, for example,
through targeted digital advertising and the ability to adapt the reg-
istry website and assessments (eg, content translations and cultur-
ally appropriate presentation). The Brain Health Registry (BHR)35 is
an internet-based registry with more than 70,000 participants that
recruits participants from the general public and from other sources,
and supports online long-term assessment and monitoring of cognition
and function.

The goal of this study was to determine associations between sociodemographic factors (race, sex, ethnicity, and education) and
online registry participation once a person has enrolled (study task
completion, withdrawal, interest in future studies, referral to clini-
cal studies) in older adults in the BHR. We tested the hypotheses
that those from underrepresented sociodemographic groups in AD
research (Latino, non-white race, male, lower educational attainment)
have lower BHR task completion and higher withdrawal rates; are less
willing to participate in different forms of future research studies; and
have less response, interest, and enrollment in referral studies con-
ducted independent of the BHR.

RESEARCH IN CONTEXT

1. Systematic review: The authors reviewed the liter-
are using electronic databases (eg, PubMed) and
search engines (Google Scholar). Sociodemographic fac-
tors affecting Alzheimer’s and dementia in-clinic research
participation (eg, enrollment, retention) have been iden-
tified; however, it is not yet well understood how sociodemographic factors affect participation in online
Alzheimer’s and dementia related research registries.

2. Interpretation: Our findings suggest that race, ethnicity,
and education are associated with online registry par-
ticipation. This is overall consistent with past findings
using in-clinic data and provides novel information about
online aging-related registries. Further, the findings high-
lit sociodemographic groups that could be targeted in
efforts to increase online research registry participation.

3. Future directions: Future studies will extend these find-
ings by identifying other factors that independently and in
combination influence online registry participation. Fur-
ther, based on these findings, future studies could develop
and evaluate targeted strategies to improve registry par-
ticipation in Alzheimer’s and dementia research.
2 METHODS

2.1 Sample used in this study

Developed by researchers at the University of California, San Francisco, BHR is a public website and online research registry for recruitment, assessment, and longitudinal monitoring focusing on cognitive aging. Since the start of the registry in 2014, more than 70,000 participants have enrolled. Participants provide electronic informed consent before completing a series of online and unsupervised self-report questionnaires (eg, demographics, medical history, overall health, memory complaints, family history of AD, depression, sleep, exercise, and diet) and cognitive assessments. Participation is voluntary and not compensated. Participants are invited to complete questionnaires and cognitive assessments every 6 months. More information about BHR can be found in supporting information and Weiner et al. This analysis included 35,919 BHR participants living in the United States, aged 55 years or older at the time of registration.

2.2 Measures

2.2.1 Sociodemographic characteristics

Upon registration, participants complete a profile questionnaire, which asks them to self-report sociodemographic information. This analysis focused on the following four self-identified sociodemographic variables: sex (male, female), race (white, African American, Asian, Native American, Pacific Islander, multiple, other), Latino ethnicity (Latino, non-Latino), and education attainment. Multiple categories of race were collapsed into two categories (white, Non-white) allowing the comparison of underrepresented races in the United States to the majority race. The categorical variable education attainment was converted into a continuous variable called years of education, ranging from 6 to 20 years. As covariates, the analysis also included age at baseline, which has previously been shown to affect study participation, and endorsement of subjective memory concern (“Are you concerned that you have a memory problem?”) as the concern might motivate higher participation.

2.2.2 Registry participation

BHR withdrawal and completion of BHR tasks (self-report questionnaires and cognitive assessments) were considered metrics of registry participation. Participants who communicated a desire to no longer participate in BHR were regarded as withdrawn (eg, participants can change consent status in their BHR account or e-mail BHR staff). For self-report questionnaires, a "core" battery was defined that included the three BHR questionnaires most commonly used to assess a participant’s eligibility for other research studies (demographics, medical history, and a short health and cognitive screening questionnaire). For cognitive assessments, the completion of the four subtests of the Cogstate Brief Battery (CBB) was used. The CBB is a computerized cognitive assessment battery and has been validated under supervised and unsupervised conditions in various populations, including aging and AD/ADRD studies. Only participants whose CBB scores met preset integrity criteria were included. All task completion metrics were assessed both at baseline (tasks were completed at least once) and longitudinally (tasks were completed at least two times). Longitudinal task completion was used as a measure of retention.

2.2.3 Willingness to participate in future studies

BHR participants are invited to complete a questionnaire about their willingness to participate in different types of research. Willingness was defined as an affirmative response to the following questions: "Would you be willing to (1) give a saliva sample for research, (2) give a blood sample for research, (3) undergo a brain scan (MRI scan) for research."

2.2.4 Referral

BHR refers participants to other studies including observational studies and clinical trials. Participants are only referred if they indicated willingness to be contacted about future studies. Referral studies can specify referral criteria (eg, location, age, self-reported diagnosis, etc) and only BHR participants meeting those criteria will be invited. Eligible participants are sent an e-mail (referral e-mail), describing the referral study and providing instructions for next steps (see supporting information for more info). For the analysis, only those participants who have been sent a referral e-mail at least once were included. The three referral metrics were whether invited participants (1) responded to the referral e-mail (clicked on the embedded link in a referral invitation e-mail); (2) indicated interest in the referral study on a BHR landing page after having clicked the e-mail link; and (3) were actually enrolled in the referral study, as reported by the referral study staff.

2.3 Statistical analyses

Descriptive information including the sample size and percentages of this sample were tabulated for sex, race, Latinos, education, and subjective memory concern. The overall objective of these statistical analyses was to assess associations between sociodemographic variables and registry participation (withdrawal, task completion, interest in future studies, referrals). To assess these associations, we used a series of multivariable binomial logistic regressions. Each registry participation outcome metric was modeled separately. The outcome metrics included: (i) baseline task completion (CBB completed at least once, no = 0, yes = 1; all core questionnaires completed at least once, no = 0, yes = 1); (ii) longitudinal task completion (CBB completed at least twice,
no = 0, yes = 1; all core questionnaires completed at least twice, no = 0, yes = 1; withdrawal status (withdrawn = 0, active = 1); (iii) willingness to participate in future studies ([1] provide a saliva sample for research (no = 0, yes = 1), [2] provide a blood sample for research (no = 0, yes = 1), [3] undergo a brain scan (magnetic resonance imaging (MRI)) for research (no = 0, yes = 1)); (iv) referral (responded to referral e-mail (no = 0, yes = 1), indicated interest in referral (no = 0, yes = 1), enrolled in referral study (no = 0, yes = 1)). The following independent variables were included in each model: sex (male = 0, female = 1), Latino (non-Latino = 0, Latino = 1), race (white only = 0, any other race/combination of races = 1), education in years (6–20), age at baseline, and subjective memory concern (no = 0, yes = 1). The following independent variables were included in each model: sex (male = 0, female = 1), Latino (non-Latino = 0, Latino = 1), race (white only = 0, any other race/combination of races = 1), education in years (6–20), age at baseline, and subjective memory concern (no = 0, yes = 1). The following independent variables were included in each model: sex (male = 0, female = 1), Latino (non-Latino = 0, Latino = 1), race (white only = 0, any other race/combination of races = 1), education in years (6–20), age at baseline, and subjective memory concern (no = 0, yes = 1). Adjusted odds ratios (aOR) and 95% confidence intervals (CI) are reported for the models. False discovery rate analysis was used to correct for multiple comparisons (multiple participation outcomes). Participants were included if they had data to complete the different logistic regression analysis models. All analyses were done in R [46] (see supporting information for more info).

3 | RESULTS

3.1 | Sample characteristics

Of the 69,505 who have enrolled in BHR, 35,919 were aged 55+ and living in the United States. These participants were included in all subsequent analysis (Table 1). The mean age was 65.7 years (standard deviation = 7.29) and 59% endorsed a subjective memory concern.

3.2 | Task completion

3.2.1 | Baseline task completion

Sex, race, Latino, and education were all significantly associated with having completed the CBB at least once (Table 2 and Table S3 in supporting information). Specifically, higher education was associated with higher odds of having completed CBB once. Identifying as Latino, non-white, or female was associated with lower odds of having completed CBB once. Regarding the completion of the core questionnaires, sex, race, Latino, and education were also all significantly associated (Table 2). Similar to the CBB completion, higher education was associated with higher odds of having completed all core questionnaires at least once and identifying as Latino or non-white was associated with lower odds. Contrary to the CBB completion results, female sex was associated with higher odds of completing the core questionnaire.

3.2.2 | Longitudinal task completion

Race, Latino, and education were significantly associated with having completed CBB at least twice and sex, race, Latino, and education were all associated with having completed the core questionnaires at least twice (Table 2 and Table S3). Lower odds of longitudinal task completion were found for Latinos and non-whites and higher odds were found for participants with more years of education. Female sex was associated with higher odds of having filled out the core questionnaires at least twice.

3.3 | Withdrawal status

For withdrawal status, there was a significant association with race, but not Latino ethnicity, sex, or education (Table 2 and Table S3). Identifying as non-white and endorsing memory concerns were associated with higher odds of withdrawal from BHR.

3.4 | Willingness to participate in future studies

Only education showed significant associations with willingness to participate in future studies (Table 3 and Table S3). More years of education was associated with lower odds of being willing to participate in a future MRI brain scan. In addition, memory concern was associated with higher odds of being willing to participate in future blood draw, saliva sample, and MRI scan study procedures. Younger age was associated with lower willingness to undergo a future MRI scan.

| TABLE 1 | Participant characteristics for demographics and memory concern (n = 35,919) |
|---------|-------------------|---------------------|------------------|
|         | %                 | N                   |
| Sex     |                   |                     |
| Male    | 28.6%             | 10,254              |
| Female  | 71.4%             | 25,630              |
| Ethnicity |                 |                     |
| Hispanic or Latino of any race | 3.2%     | 1145               |
| Non-Hispanic or Latino | 90.1%     | 32,378             |
| Declined to state | 3.0%     | 1073               |
| Race    |                   |                     |
| White   | 84.0%             | 30,180              |
| Black/African American | 3.9%     | 1399               |
| American Indian and Alaska Native | 0.3%     | 122               |
| Asian   | 1.9%              | 689                 |
| Native Hawaiian/Other Pacific Islander | 0.1%     | 46                 |
| Some other race | 2.0%     | 701               |
| Two or more races | 2.7%     | 970               |
| Educational attainment |         |                     |
| Less than high school graduate | 0.3%     | 105               |
| High school graduate, GED, or alternative | 5.8%     | 2070              |
| Some college or associate’s degree | 26.6%     | 9563             |
| Bachelor’s degree or higher | 65.7%     | 23,612            |
| Memory concern |         |                     |
| Yes     | 59.3%             | 21,292              |
| No      | 34.7%             | 12,473              |
### TABLE 2  Associations between sociodemographic characteristics and registry engagement

|                      | Adjusted odds ratio | 95% Confidence interval |
|----------------------|---------------------|-------------------------|
| **Completion**       |                     |                         |
| CBB completed at least once (N = 32,647) |                 |                         |
| Latino               | 0.75                | 0.66, 0.86              |
| Female               | 0.92                | 0.88, 0.97              |
| Years education      | 1.13                | 1.12, 1.14              |
| Non-white            | 0.55                | 0.51, 0.59              |
| Age                  | 1.00                | 1.00, 1.01              |
| Reported subjective memory concern | 1.16               | 1.11, 1.21              |
| **Core self-report completed at least once (N = 32,647)** |                 |                         |
| Latino               | 0.75                | 0.65, 0.86              |
| Female               | 1.16                | 1.10, 1.23              |
| Years education      | 1.13                | 1.12, 1.15              |
| Non-white            | 0.46                | 0.43, 0.50              |
| Age                  | 1.00                | 1.00, 1.01              |
| Reported subjective memory concern | 1.17               | 1.12, 1.24              |
| **Retention**        |                     |                         |
| CBB completed at least twice (N = 32,647) |                |                         |
| Latino               | 0.60                | 0.51, 0.70              |
| Female               | 0.97                | 0.92, 1.03              |
| Years education      | 1.13                | 1.12, 1.11              |
| Non-white            | 0.52                | 0.48, 0.57              |
| Age                  | 1.00                | 1.00, 1.01              |
| Reported subjective memory concern | 1.24               | 1.18, 1.30              |
| **Core self-report completed at least twice (N = 32,647)** |                |                         |
| Latino               | 0.63                | 0.55, 0.73              |
| Female               | 1.13                | 1.08, 1.19              |
| Years education      | 1.13                | 1.12, 1.14              |
| Non-white            | 0.47                | 0.44, 0.51              |
| Age                  | 1.00                | 1.00, 1.01              |
| Reported subjective memory concern | 1.30               | 1.24, 1.36              |
| **Not withdrawn (N = 32,638)** |                 |                         |
| Latino               | 0.95                | 0.70, 1.28              |
| Female               | 1.04                | 0.93, 1.15              |
| Years education      | 0.99                | 0.97, 1.01              |
| Non-white            | 0.85                | 0.72, 1.00              |
| Age                  | 1.05                | 1.04, 1.06              |
| Reported subjective memory concern | 0.79               | 0.72, 0.87              |

Note: CBB, Cogstate Brief Battery; Core self-report questionnaire consists of the following: Brain Health Registry questionnaires: profile, location, initial, and medical history.

### TABLE 3  Associations between sociodemographic characteristics and willingness to participate in future studies

|                      | Adjusted odds ratio | 95% Confidence interval |
|----------------------|---------------------|-------------------------|
| **Willing to provide saliva samples for research (N = 5988)** |                 |                         |
| Latino               | 0.81                | 0.32, 2.04              |
| Female               | 1.05                | 0.77, 1.42              |
| Years education      | 0.97                | 0.91, 1.02              |
| Non-white            | 1.20                | 0.70, 2.06              |
| Age                  | 0.99                | 0.98, 1.02              |
| Reported subjective memory concern | 1.71               | 1.30, 2.23              |
| **Willing to provide blood samples for research (N = 5757)** |                 |                         |
| Latino               | 0.70                | 0.34, 1.40              |
| Female               | 0.97                | 0.75, 1.25              |
| Years education      | 1.00                | 0.96, 1.06              |
| Non-white            | 1.08                | 0.71, 1.66              |
| Age                  | 0.99                | 0.98, 1.01              |
| Reported subjective memory concern | 1.66               | 1.33, 2.07              |
| **Willing to undergo MRI scans for research (N = 5448)** |                 |                         |
| Latino               | 1.29                | 0.62, 2.69              |
| Female               | 0.83                | 0.67, 1.02              |
| Years education      | 0.96                | 0.92, 0.99              |
| Non-white            | 0.88                | 0.63, 1.23              |
| Age                  | 0.97                | 0.96, 0.98              |
| Reported subjective memory concern | 1.83               | 1.52, 2.19              |

Note: CBB, Cogstate Brief Battery; Core self-report questionnaire: Brain Health Registry questionnaires (profile, location, initial, medical history). Abbreviation: MRI, magnetic resonance imaging

### 3.5  Participation in additional research

#### 3.5.1  Response to study invitations

For this analysis the sample was the total number of referrals of BHR participants aged 55+ to additional research studies outside BHR (N = 54,652). Participants could be referred to multiple outside studies. Sex, race, Latino, and education were all significantly associated with having responded to referral e-mails (Table 4 and Table S3). Latinos and non-whites were associated with lower odds of responding to invitation e-mails to referral studies and females and those with higher education were associated with higher odds of responding.

#### 3.5.2  Interest in studies

Education and race were associated with indicating interest in referrals. Participants with more years of education were associated with higher odds of indicating interest in referral studies and non-whites were associated with lower odds.
3.5.3 | Enrollment in studies

All sociodemographic variables were significantly associated with being enrolled in referral research studies. More years of education were associated with higher odds of enrolling in referral studies and identifying as Latino, non-white, or female was associated with lower odds.

4 | DISCUSSION

The major findings were that Latino ethnicity, non-white race, and lower educational attainment were significantly associated with lower online registry participation. These findings support our hypotheses that sociodemographic factors influence online registry participation and highlight sociodemographic groups that could be targeted in efforts to increase research online registry participation.

The first major finding was that Non-white race and Latino ethnicity was associated with decreased BHR participation. Identifying as Latino was associated with lower BHR participation at baseline and longitudinally, as well as lower response and enrollment rates to referral studies. Non-white race was associated with having withdrawn from BHR, lower completion and retention rates, as well as lower referral responses, interest, and enrollment. While little is known about similar associations in other registries, these results are consistent with previous in-clinic findings of higher retention rates in whites in NIH-funded Alzheimer’s Disease Research Centers (ADRC) and other ADRD studies. Data from the National Alzheimer’s Disease Center (NACC) database also showed that non-Latino, white ADRC participants were more likely than non-whites and Latinos to have genetic samples available and that the ratio of completed brain donations to number of patients enrolled was significantly less in Latino patients compared to non-Latino whites. Another study found that race influenced agreement to undergo LP in ADRCs. This suggests that racial and ethnic groups are not just underrepresented in ADRD research, but also participate less in research after enrollment both in an in-clinic and online setting. The NACC data did not show any association between race/ethnicity factors and willingness to participate in future study tasks. However, previous research found negative associations between African American race and willingness to participate, for example, in a hypothetical preclinical ADRD trial and willingness to assent to brain donations. Future analyses should investigate potential differential participation of different racial groups in BHR, especially those who are minimally represented or entirely absent from this literature, including American Indians/Alaskan Natives and Pacific Islanders.

The second major finding was that the associations between sex and participation were mixed. Female sex was associated with higher completion of the core questionnaires at baseline and longitudinally. Previous ADRD in-clinic research results support this finding. On the other hand, females had lower completion of the CBB at baseline, lower response rates to referral invitations, and lower rates of actual enrollment in studies. The difference between core questionnaire and CBB completion is interesting and requires further analysis, such as determination of whether sex effects are due to participants not attempting to start the CBB, failing to complete once the test is started, or completing the test, but the scores fail integrity checks. The difference between willingness to participate in future research and lower referral response and enrollment rates might be related to women being more agreeable when asked about interest.

The third major finding was that higher educational attainment was associated with higher task completion and retention rates, as well as with higher referral response, interest, and enrollment. Previous evidence regarding the association between education and study participation is mixed. Some in-clinic studies found no association, whereas in a recent analysis of data from ADRCs, higher education was associated with higher retention. However, consistent with our findings, a meta-analysis found that lower education background was identified as a risk for dropping out of internet-based interventions. It has been suggested that low educational attainment is related to drop-out due to more difficulties understanding study procedures and limited abilities using technology, which may result in less motivation to complete and continue to complete online study tasks. In addition, individuals from a lower educational background might also have less access to technology and be more burdened by spending time on...
unpaid registry tasks. However, higher education was also associated with less interest in participating in future research requiring MRI. This is contrary to previous research which found that interest in participating in MRI research was higher for higher education. Potentially more educated people know more about the burdens of undergoing an MRI and are therefore less willing to undergo it. Also, participants who sign up for an online registry might be less willing to undergo time-consuming in-clinic procedures that are perceived as invasive or more cumbersome.

Finally, subjective memory concern was associated with higher registry participation for almost all outcomes studied. This supports the hypothesis that a major motivation for participating in online research is concern about one’s memory due to a fear or worry of developing ADRD, and this idea is supported by the fact that memory concern is associated with certain personality traits, for example, high neuroticism. The one exception was that, in our study, memory concern was associated with higher rate of withdrawal from BHR. The interpretation of this is unclear. Because a small percentage of participants actively withdraw from BHR by contacting study staff or changing consent status in their BHR account (n = 3255, 4.4% of total), a larger sample size of those who withdraw is needed to replicate and better understand this finding.

The information gained in this study can inform novel efforts to improve registry participation for underrepresented groups, including increased participant communication (reminder e-mails, invitations to complete follow-up tasks), and tailored content and communication to address known research participation barriers and facilitators. For example, racial/ethnic minority groups commonly experience mistrust, fear, stigma, and competing demands/durden as barriers and culturally tailored study material and benefits to participation as facilitators to research participation. To address these, various incentives could be offered to address participation burden and the registry website, assessments, and public relations could be translated into different languages (eg, Spanish, Chinese), be culturally tailored, and be adapted to a grade reading level appropriate for participants from lower educational backgrounds. Further, registries could also offer educational material to decrease stigma (eg, about memory impairment or research participation) and highlight protection of data and privacy, as well as the low risk associated with registry participation to address common fears. However, further research is needed to investigate registry participation barriers and facilitators experienced by actual online registry members or potential members of these less participating groups.

There are also several factors which could affect the associations found in this study, for example, other sociodemographic factors (eg, marital status, household income, socio-economic status, and job type/status), psychiatric and overall health, family history of AD, digital literacy, source of enrollment, time between completed testing sessions, and compensation of referral studies. Future analyses investigating associations and interactions between these variables and research participation are crucial for elucidating the interplay between multiple sociodemographic, cognitive, health, and other factors. Such analyses are now under way. Related, future analyses creating meaningful categories for continuous variables such as age and education are likely to aid the interpretation and applicability of the results.

This study had some limitations. Due to the online nature of the study, as well as the BHR overall design (eg, the website is in English and assumes high literacy), BHR is subject to multiple selection biases, for example, for those with internet and computer access, high literacy, and the ability to understand English. All of these, as well as other biases, are likely to result in data not missing at random. Like many clinical samples, our registry sample underrepresents Latinos, non-whites, males, and individuals with an education less than a bachelor’s degree, which impacts interpretation of the findings and their generalizability. For example, the underrepresented groups who participate in the registry may not represent the characteristics of the overall racial, ethnic, or educational group being studied. In addition, this analysis combined different racial underrepresented groups into one “non-white” group due to sample size concerns. However, this approach did not allow us to explore different registry behaviors between non-White racial groups. Finally, while we limited our analyses to older adults due to our ADRD focus, future studies are needed to determine whether the results hold for younger participants.

In conclusion, this study shows that Latino ethnicity, race, sex, and educational attainment are associated with online registry participation of older adults. The results increase our understanding of factors affecting minority engagement and retention in online ADRD research and highlight the need for the development of targeted online engagement strategies tailored to certain sociodemographic groups.

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SUPPORTING INFORMATION
Additional supporting information may be found online in the Supporting Information section at the end of the article.

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