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RESEARCH ARTICLE

How intention to join an Alzheimer's participant recruitment registry differs by race, ethnicity, sex, and family history: Results from a national survey of US adults

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Abstract

INTRODUCTION: Alzheimer's-focused participant recruitment registries are tools for accelerating enrollment into studies, however, registry members are primarily White women.

METHODS: We conducted a national online survey of 1501 adults ages 50–80, oversampling for Black and Hispanic/Latino respondents, assessing intention to join a generic "brain health" registry and to join a registry that required specific tasks.

RESULTS: Intention to join a registry was low (M 3.48, SD 1.77), and lower than intention to join a registry requiring specific tasks. Intention was greatest for registries requiring completing surveys (M 4.70, SD 1.77). Differences in intention were primarily between White women and Black women; differences between other groups were limited to specific tasks required.

DISCUSSION: The results indicate uncertainty about what a registry is, its purpose, and/or the concept of "brain health." Using the Reasoned Action Approach (RAA) to develop evidence-based outreach messages describing a registry and required tasks may increase diversity.

KEYWORDS

Alzheimer's, diversity, participant, prevention, Reason Action Approach, recruitment, registry

1 | BACKGROUND

Approximately 6.2 million people are living with Alzheimer's disease (AD) in the United States (US) and this number is projected to reach 13.8 million by 2060.[1] Black and Hispanic adults are more likely than White non-Hispanic adults to have AD or AD-related dementias (ADRD).[2–4] Despite Black and Hispanic adults having a higher prevalence and incidence of AD/ADRD[2–4] and more potentially modifiable risk factors for AD/ADRD,[5,6] AD/ADRD studies often fail to enroll diverse participants, thereby limiting the generalizability of the findings.[7–9]

Participant recruitment registries are used to connect volunteers to studies. In the United States, there are several online registries for AD studies, each of which emphasizes the need for healthy older adults to join, given the number of studies focused on identifying or intervening at the earliest biological and cognitive stages of the disease. With one notable exception,[10] these registries consist primarily of White non-Hispanic women.[11–15] If these programs are to play an impactful role recruiting participants for AD/ADRD studies, it is imperative that they become more diverse.

Several studies have examined the facilitators for participating in AD/ADRD research, including facilitators for ethnocultural groups,[16–21] though few have focused specifically on enrolling in a research registry (as opposed to clinical research participation), nor whether facilitators differ between racial, ethnic, or sex groups, or having a family history of the disease. Jefferson et al. reported that the most common reasons for joining a registry were: advancing research about AD (56%), benefiting others (21%), and personal concerns for memory (13%).[20] Glover et al. asked about decision-making for enrolling in a registry soon,[22] reporting that altruism and convenience of home visits were facilitators of enrolling. They did not identify differences among racial/ethnic groups in trust of research, although they reported that older woman trusted research and related findings more than men, and that older Black adults were more motivated and inspired to participate in research compared to older White adults.[22] Previous semi-structured interviews conducted using the Reasoned Action Approach (RAA) found that joining a registry would be a positive experience, would help advance science, and would be supported by their networks (family, friends). Differences among racial, ethnic, and sex groups only emerged on select elicited beliefs about joining a registry, including[1] Black and Hispanic participants were more likely than non-Hispanic White participants to report that a "bad thing" would be being asked to participate in an experimental or invasive treatment[2]; more Black and Hispanic participants cited "helping others" by participating in studies as a "good thing" compared to non-Hispanic White participants; and[3] men were more likely than women to mention confronting personal cognitive decline as "bad thing".[23]

1.1 | Theoretical framework

The RAA is a psychosocial framework for predicting and changing human behavior.[24] The focus of the model is one's intention to perform a specific behavior (the "target behavior," i.e., joining a registry) as both a dependent variable of specific beliefs associated with the behavior and as a predictor of behavior. The RAA assumes that behavior is determined primarily by intentions and has been used for developing messages that evoke target behaviors.[25] Essentially, RAA-based communication strategies are designed to reinforce the beliefs that are positively associated with intention and counter-argue the beliefs that are negatively associated with intention, and have been used across a range of behaviors.[26–28] No previous studies have used the RAA to improve diversity of AD/ADRD research or registries.

The present study, which builds upon our prior work,[23] is a nationally representative online survey of older adults in the United States to assess intention to join a registry in the next 30 days along with intention to join if it required specific tasks.[11–15] Understanding differences in intention among racial, ethnic, or sex groups, and those with/without family history of AD, could aid in the development of outreach messages to increase diversity of registry members.

RESEARCH IN CONTEXT

1. **Systematic Review**: The authors reviewed the literature using PubMed and reviewed online Alzheimer's-focused participant recruitment registries in the United States. For nearly all registries, their members are primarily White women. Of the studies that have examined facilitators and barriers to joining a registry, nearly all have surveyed their existing members to identify differences between racial, ethnic, or sex groups, or other risk factors for the disease (e.g., family history).
2. **Interpretation**: Our findings suggest there is a lack of understanding about what a registry is or its purpose. We hypothesize that the current lack of diversity in registries may be resolvable if evidence-based outreach messages are developed that clearly describe the registry and the tasks required of members.
3. **Future Directions**: Future studies should focus on developing and testing culturally-sensitive and evidence-based messages that aim to increase enrollment of historically underrepresented groups into registries.

2 | METHODS

Data were collected as part of a larger project, **S**tudy **T**o **E**xpand registry **P**articipation of **U**nderrepresented **P**opulations (STEP-UP), to use the RAA as the theoretical model to design persuasive culturally sensitive, evidence-based messages to enroll diverse participants into registries that connect members to AD prevention trials and other AD-focused studies. The first step in this process was our recently reported study which conducted elicitation research to identify behavioral, normative, and control beliefs associated with joining a registry among our target audiences: Black, Hispanic, and male older adults.[23] The beliefs identified from the elicitation study were used to create an RAA quantitative survey for the target behavior of joining a registry and performing specific tasks required of online registries in the United States. The present study is focused on one component of the survey: intention to join a registry.

2.1 | Data collection

Data were collected from adults ages 50–80 (n = 1501) living in the United States, with oversamples of Black (n = 334) and Hispanic (n = 309) adults for group comparisons of our target audiences of interest, by the research firm SSRS (www.ssrs.com) from May 26, 2021, through June 15, 2021. The survey was completed online and was offered in English and Spanish. Respondents were recruited from their nationally representative probability-based web panels: the SSRS Probability Panel and the Ipsos Knowledge Panel. Members on the

SSRS Probability Panel Members are randomly recruited in one of two ways: (a) from a dual-frame random digit dial (RDD) sample, through the SSRS Omnibus survey platform; (b) through invitations mailed to respondents randomly sampled from an Address-Based Sample (ABS). The SSRS Omnibus survey is a nationally representative bilingual telephone survey designed to meet standards of quality associated with custom research studies. Respondents of the SSRS Omnibus represent the full US adult population (English- and Spanish-speaking). From this base, SSRS screens for internet access and then recruits those who have Internet access to be part of the SSRS Probability Panel. ABS respondents are randomly sampled from the US Postal Service's Computerized Delivery Sequence (CDS), a regularly updated listing of all known addresses in the US respondents from the Ipsos Knowledge Panel were recruited using ABS, based on a stratified sample from the CDS. Respondents are given incentives as part of recruitment, and for each study in which they participate. Those respondents from the SSRS Opinion Panel received an electronic gift card from SSRS that was commensurate with similar studies that the panelists receive; respondents from Ipsos were included in raffles and sweepstakes for cash prizes. In total, 3575 respondents from the SSRS Probability Panel and 269 from the Ipsos Panel were invited to participate, with response rates totaling 45% and 32%, respectively. Thirty-nine participants completed the survey in Spanish. All procedures were approved by the Institutional Review Board (IRB) at the University of Delaware.

Data were weighted in two stages. The first stage of the weighting was the application of a base weight to account for different selection probabilities and response rates across sample strata. In the second stage, sample demographics were post-stratified to match population parameters. The weighting ensures that the demographic profile of the sample matches the profile of the target population. The survey took approximately 27.7 min to complete. The survey system implemented several quality assurance procedures including personalized invitations to their panel members to complete the survey to ensure there were no repeated entries or "bots", a "speeder trap" to aid in identifying those who do not appear to be giving the survey the attention it requires to complete a quality survey. In addition, respondents with an interview length of less than 25% the average time it took all participants to complete, skipped or left blank more than 50% of the questions, or had the same response for all items in all grides (i.e., "straight lining") were removed.

2.2 | Measures

The intention measures were asked on a scale from 1 to 7, from extremely unlikely to extremely likely. Mean scores below the midpoint are considered low/unlikely. Participants were asked about their general intention to join a brain health registry (no specific task required), followed by intention to join a registry that specifies completing specific tasks (order of tasks/behaviors was randomized).

Intention to joining a brain health registry, no specific task required. Respondents were given the following definition for a "brain health registry": "A brain health registry is a list of people willing to be contacted to participate in studies designed to better understand, prevent, and treat AD or other related conditions. Each study you are contacted about through the registry is optional. You may decline to participate in a study for any reason. You can sign up for a registry online or in person and might learn about it through ads on social media, from your medical providers, or at presentations at community events" and were then asked, "How likely are you to sign up for a brain health registry in the next 30 days?"

Intention to join a brain health registry that specifies completing a behavioral task for enrollment. For this next set of intention measures, respondents were given the following information: "Brain health registries have varying requirements for membership. The following are some things that registries might ask you to do to become a member." Next, they were asked how likely would it be for them to sign up in the next 30 days for the kind of brain healthy registry that asked them to: give a DNA sample, take memory/thinking tests every 6 months, get a brain scan, give a blood sample, provide their name and contact information, fill out questionnaires about themselves and their health, and provide a family member's contact information.

Family history of AD. Respondents were asked if they have any biological parents, full siblings, or biological children who have been diagnosed with AD. Response options were yes, no, I don't know, or prefer not to say. Eight respondents had missing responses. All responses other than yes or no were recoded into missing for analyses.

Race and ethnicity and sex groups. Respondents indicated their race by selecting one of the following categories: White, Black or African American, American Indian or Alaskan Native, Asian, Native Hawaiian or Other Pacific Islander, or Other, and then whether or not they were of Hispanic ethnicity. Respondents were not able to select multiple race categories. For the analysis, racial and ethnic groups and sex were intersected to create six groups reflecting the primary focus of the STEP-UP project: White non-Hispanic males, White non-Hispanic females, Black males, Black females, Hispanic males, and Hispanic females.

2.3 | Statistical analyses

Means and standard deviations (SD) were calculated on all intention measures for the full sample (all races and ethnicities), by racial/ethnic/sex groups (for the target audiences of interest), and by family history of AD (full sample), using the weighted data. Differences between each racial and ethnic and sex group and between those with a family history and those without were tested using adjusted Wald tests (i.e., the **test** command in Stata 17.0). Correlations among all the intention variables were also estimated.

3 | RESULTS

Adults ages 50–80 (n = 1501) completed the online survey. Unweighted and weighted participant demographics are shown in Table 1. Approximately half the participants were women, had a mean age of 62.3 years, and just over half were White non-Hispanic.

TABLE 1 Sample characteristics ($n = 1501$).

Parameter	Unweighted %	Weighted %
Female	55.8	52.8
Age (years)	*M* 62.3 *SD* (7.6)	*M* 62.4 *SD* (7.7)
Race/ethnicity		
White non-Hispanic	54.1	71.4
Black	22.3	10.7
Hispanic	20.6	11.6
Other[a]	2.0	4.2
Region		
Northeast	16.9	18.2
Midwest	19.6	21.6
South	42.0	37.6
West	21.2	22.5
Education		
Some high school	3.5	4.1
High school graduate	28.7	31.7
Some college	29.8	33.6
College degree +	16.1	12.9
Post graduate schooling	21.9	17.7
Income		17.7
Less than $25,000	14.9	13.6
$25,000 to < $50,000	22.9	22.7
$50,000 to < $75,000	20.1	21.1
$75,000 to < $100,000	16.8	16.6
$100,000 and over	20.3	19.7
Blank	5.0	6.3
Marital status		
Single, never married	11.1	7.5
Single, living with partner	5.0	4.5
Married	55.4	64.0
Separated	2.7	1.9
Widowed	7.5	6.6
Divorced	18.9	15.0
Family history of AD		
Yes	14.3	13.1
No	80.2	82.0
I don't know	4.9	4.4
Prefer not to say	0.5	0.05

Abbreviation: SD, standard deviation.
[a]Other includes respondents who indicated the following for their race / ethnicity: American Indian or Alaskan Native, Asian, Native Hawaiian or other Pacific Islander, and those who responded "Other." Any participant who identified as Hispanic, regardless of race, was categorized as Hispanic.

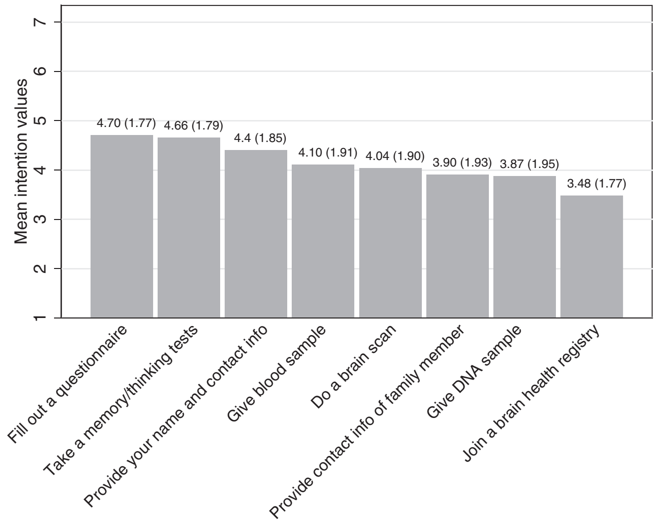

FIGURE 1 Means of intention measures to join a registry or join when enrolling required specific tasks for full sample, weighted.

Figure 1 displays the results of the intention measures from the full sample (weighted). The mean overall intention to join a registry in general (with no specific tasks required) within the next 30 days was 3.48 (SD 1.77), which was significantly lower than all other intention measures. When asked about their intention to join a registry that required completing or performing specific tasks, the highest intention was for completing surveys (M 4.70, SD 1.77). Intentions to enroll were lowest for registries that required providing a family member's contact information (M 3.90, SD 1.93) and those requiring a DNA sample (M 3.87, SD 1.93).

The correlations among all the variables are presented in Table 2. Requirements most like one another are highly correlated (e.g., giving a blood sample and DNA sample are correlated at 0.83; completing memory/thinking tests and filling out surveys are correlated at 0.87).

Table 3 shows the weighted means for each of the intention measures by racial, ethnic, and sex groups. In general, there were few differences between groups, and importantly there were no significant differences between racial, ethnic, or sex groups in overall intention to join a registry. The differences that did exist were primarily between White females and Black females, and in each of those instances, White females had higher intentions that Black females. Differences between other groups were limited: White non-Hispanic men had a significantly lower mean intention to join if the registry required completion of memory and thinking assessments compared to White non-Hispanic women; Hispanic men had a significantly lower mean intention to join if the registry required providing a family member's contact information compared to White non-Hispanic women; and last, Hispanic men, in addition to Black women, had a significantly lower mean intention to join a registry that required completing questionnaires about themselves and their health compared to White non-Hispanic women.

There were also few differences in mean intentions between those who reported having a family history of AD and those who did not (Table 4). Respondents with a family history of AD were more willing

TABLE 2 Pearson correlations among the intention measures (full sample weighted, n = 1488–1501).

Intention measures	1	2	3	4	5	6	7	8
To sign up for a brain health registry in the next 30 days	–							
Give a DNA sample	0.41	–						
Give a blood sample	0.43	0.83	–					
Take a memory/thinking test every 6 months	0.53	0.66	0.70	–				
Provide your name and contact information	0.50	0.71	0.78	0.80	–			
Get a brain scan	0.40	0.72	0.78	0.70	0.71	–		
Provide contact information of a family member	0.36	0.66	0.68	0.64	0.72	0.64	–	
Fill out a questionnaire about yourself and your health	0.53	0.69	0.74	0.87	0.84	0.71	0.67	–

TABLE 3 Means and standard deviations of intention measures for racial and ethnic and sex categories, weighted.

Intention measures	White male n = 395 Mean (SD)	White female n = 415 Mean (SD)	Black male n = 103 Mean (SD)	Black female n = 231 Mean (SD)	Hispanic male n = 104 Mean (SD)	Hispanic female n = 125 Mean (SD)
To sign up for a brain health registry in the next 30 days	3.50 (1.56)	3.60 (1.46)	3.28 (2.21)	3.39 (2.93)	3.44 (2.53)	3.37 (2.50)
To sign up for a brain health registry in the next 30 days that asks you to:						
Give a DNA sample	3.85 (1.74)	4.04 (1.63)[a]	3.68 (2.30)	3.58 (3.09)[b]	3.77 (2.56)	3.85 (2.67)
Give a blood sample	4.14 (1.67)	4.25 (1.58)[a]	3.82 (2.31)	3.75 (3.11)[b]	3.91 (2.60)	4.14 (2.68)
Take a memory/thinking test every 6 months	4.61 (1.58)[a]	4.90 (1.37)[b]	4.22 (2.22)[a,c]	4.47 (3.02)[a,c]	4.57 (2.47)	4.63 (2.65)
Provide your name and contact information	4.46 (1.61)[a]	4.57 (1.51)[a,b]	4.04 (2.30)[c]	4.05 (3.10)[c]	4.25 (2.45)	4.26 (2.73)
Get a brain scan	4.10 (1.67)[a]	4.09 (1.59)[a]	3.72 (2.34)	3.75 (3.03)[b]	3.84 (2.57)	4.13 (2.76)
Provide contact information of a family member	3.93 (1.76)	4.08 (1.61)[a]	3.70 (2.21)	3.60 (3.13)[b,c]	3.50 (2.66)[c]	3.73 (2.60)
Fill out a questionnaire about yourself and your health	4.72 (1.52)	4.94 (1.39)[a]	4.34 (2.22)	4.39 (3.08)[b]	4.57 (2.37)[b]	4.41 (2.69)[b]

Note: Different letter superscripts indicate significant differences between groups at the $p < 0.05$ level. Respondents in the other racial and ethnic group not shown here because of small sample sizes (Other males n = 43; Other female n = 497).
Abbreviation: SD, standard deviation.

to join a registry that required giving a blood sample or getting a brain scan (although this finding was marginally significant at the $p = 0.053$ level).

4 | DISCUSSION

To date, nearly all online AD-focused registries in the United States have failed to recruit participants from traditionally underrepresented racial and ethnic groups and have an imbalance of men and women.[11–15] The notable exception is CARE, a registry for Asian Americans and Pacific Islanders.[10] Behavioral theory can be used to identify beliefs associated with registry enrollment behavior and which beliefs are relevant to intention formation (i.e., joining a registry). In this study, we conducted a national, online survey of older adults in the United States, oversampling Black and Hispanic adults to allow for comparisons among racial, ethnic, and sex groups, and family history of AD, to assess intention to join a registry and join if it required performing specific tasks. Participants reported low intention to join a registry when asked about it in general. However, respondents reported higher intention to join a registry when it was tied to a specific behavioral registration requirement such as completing surveys and proving one's name and contact information. There were no significant differences among racial, ethnic, and sex groups or between those with and without a family history of AD in overall intention to join a registry. Differences emerged primarily between White women and Black women on intentions to join when the registry required performing specific tasks. Using the RAA as the theoretical framework, these data, along with our previous elicitation results,[23] can aid in the development of evidence-based outreach messages for enrollment of currently under-represented groups into registries and may be helpful when designing or implementing registries.

TABLE 4 Means and standard deviations of intention measures by history of family AD, full sample weighted.

Intention measures	No family members with AD history $n = 1198$ Mean (SD)	Family members with history of AD $n = 214$ Mean (SD)
To sign up for a brain health registry in the next 30 days	3.44 (1.71)	3.65 (2.15)
To sign up for a brain health registry in the next 30 days that asks you to:		
Give a DNA sample	3.82 (1.93)	4.07 (2.08)
Give a blood sample	4.05 (1.89)	4.41 (2.08)[a]
Take a memory/thinking test every 6 months	4.65 (1.77)	4.81 (1.90)
Provide your name and contact information	4.36 (1.82)	4.57 (1.98)
Get a brain scan	3.99 (1.87)	4.34 (2.09)[b]
Provide contact information of a family member	3.88 (1.90)	4.14 (2.15)
Fill out a questionnaire about yourself and your health	4.68 (1.76)	4.89 (1.81)

Abbreviations: AD, Alzheimer's disease; SD, standard deviation.
[a]Indicates a statistically significant difference between the two groups at least at the $p < 0.05$ level. "I don't know" ($n = 73$) or "Prefer not to say" ($n = 8$) responses for family history of AD were recoded into missing.
[b]$p = 0.053$.

Intention to join a registry was lower in all groups than intention to join when enrolling required performing specific tasks. This may reflect a general uncertainty about the term "registry" despite effort at the beginning and throughout the survey to explain a registry and its purpose. It may also reflect uncertainty or concern about next steps, hidden or surprise requirements that are not shared until after joining. Prior research has reported that adults often have difficulty defining a registry, instead preferring terms such as "list".[29] Based on these findings, evidence-based outreach messages developed using the RAA as the theoretical framework and registry collateral (e.g., website, emails, print materials) may need to include words or phrases describing what a registry is and/or what it does (e.g., research matchmaking service, online community of research volunteers) and the activities or tasks involved in registry enrollment and participation (e.g., complete memory and thinking tests regularly to be matched to a research study) rather than the broader behavior of "join a registry." If possible, researchers developing new registries may want to select terms or words other than "registry" for use in the program name.

Intention to join a registry did not differ among racial, ethnic, or sex groups, or by family history of AD. Differences were only evident on select intentions to join if the registry required completing completion of specific tasks or behaviors, with no clear pattern emerging regarding the level of risk or evasiveness of the required task or behavior, but White women had consistently higher intentions than Black women across the specific tasks. Factors driving the differences cannot be determined using the survey data and will be explored in focus group sessions. It is important to note that these data are consistent with prior findings from the Brain Health Registry, an online registry that requires completing questionnaires and memory and thinking assessments, that reported differences in participation by race, ethnicity, sex, and educational attainment. They reported (1) lower online registry participation among members reporting Hispanic ethnicity, non-White race, and lower educational attainment, and (2) higher completion of core questionnaires at baseline and longitudinally among women, though women had lower completion of memory and thinking assessments at baseline.[30] Data from the present study indicate that those with a family history of AD had higher intention to join a registry that required giving a blood sample and getting a brain scan (with marginal significance). Individuals with a family history of AD also had higher mean intention across the board for all behaviors/tasks compared to the full sample and each of the race/ethnicity and sex groups. This is consistent with current enrollment registry trends in that those with a family history of AD are more likely to enroll in registries.[11,13]

The results from the present study, particularly when used in conjunction with results from our elicitation study[23] and data being collected as part of our ongoing focus groups, can serve as the foundation for developing evidence-based outreach messages using the RAA as the theoretical framework for enrollment of Black and Hispanic adults and men into registries, complementing other efforts to develop messaging to increase enrollment into clinical research studies.[8,21,31] Previous research examining the effectiveness of culturally tailored website and recruitment messages reported success at increasing interest among Hispanic adults in signing up for an online ADRD-related research registry, although less than half who completed the initial sign-up form went on to fully enroll in the Brain Health Registry.[32] It is important to note that, in that study, the culturally tailored messages recruited more Hispanic women than men and were not effective at engaging participants to complete all the Brain Health Registry modules.[32] However, it may be the case that more universal messages instead of culturally tailored messages may also be effective depending on whether the beliefs that predict these similar intentions across groups overlap with one another.

There are some limitations to the present study. Respondents may be predisposed to having more positive attitudes about research, particularly online studies. That said, most participants said they did not have a family history of AD, whereas most enrollees in AD-focused registries report having a family history of the disease.[11–15] The low percentage may be due to wording of the question which asked about a diagnosis of AD specifically. Participants may be more familiar with the word dementia or their family member may not have received a diagnosis or been told their diagnosis.[33] As a result, this survey may not have been able to detect differences between those with and without a family history. This will be explored further in future surveys and focus groups. Second, we asked participants about their intention to join a "brain health" registry. Although the term "brain health" is being used increasingly in professional/academic settings, there is not a universally accepted definition, nor is the term used in all languages, cultures, or professional settings.[34] As a result, this may have negatively impacted respondents' intention of joining a brain health registry. Third, the survey was completed online, reflecting most registries in the United States. The results may not generalize to individuals without internet access. Last, although we asked about intention to join a registry and intention to join if it required completing or performing required tasks, it remains unknown whether the respondents would do so if presented with the opportunity in a real-world setting.

5 | CONCLUSION

Effective evidence-based message design requires formative research among the target audience, ideally guided by theoretical framework. The results from this national survey found that participants had low intention to join a registry. Respondents reported higher intention to join when it was linked with a requirement to complete or perform specific tasks. There were no significant differences among racial, ethnic, and sex groups or between those with a family history of AD and those without in overall intention to join a registry. Differences emerged primarily between White women and Black women on intentions to join when the registry required performing specific tasks. The results may be indicative of a general uncertainty about what a registry is and its purpose, hidden or surprise requirements after joining, and/or the concept of "brain health." The results suggest that the current lack of diversity in registries may be resolvable if evidence-based outreach messages are developed using the RAA as the theoretical framework that clearly describe the registry and the activities involved from the member's perspective rather than the broader (and perhaps vague) behavior of "join a registry." To accomplish this, future efforts will concentrate on conducting focus groups to gather insights into the data from this survey and prior elicitation interviews[23] and to develop the persuasive recruitment messages which will be tested against current, standard registry recruitment messages in real-world settings to determine the effectiveness of the theoretically-derived, evidence-based messages at increasing enrollment of individuals from historically underrepresented groups into registries.

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CONFLICT OF INTEREST STATEMENT

Jessica Langbaum received consulting fees from Alector, Biogen, Denovo Biopharma, and Provoc. She is a full-time employee of Banner Health. Banner Health receives or received funding from the NIH, Roche, and Eli Lilly for the conduct of Alzheimer's prevention trials for which she serves on the sponsor team. Rachel Nosheny receives funding to UCSF from National Institutes of Health, California Department of Public Health, and Genentech, Inc. Health Equity Innovations Fund. Jason Karlawish is a site investigator for clinical trials sponsored by Biogen and Lilly. Erin Maloney, Michael Hennessy, Kristin Harkins, and Amy Bleakley report no conflicts. Author disclosures are available in the supporting information.

CONSENT STATEMENT

The study was approved by the Institutional Review Board at the University of Delaware and participants provided informed consent.

REFERENCES

1. Alzheimer's Association. 2022 Alzheimer's disease facts and figures. *Alzheimers Dement*. 2022;18(4):700-789.
2. Mayeda ER, Glymour MM, Quesenberry CP, Whitmer RA. Inequalities in dementia incidence between six racial and ethnic groups over 14 years. *Alzheimers Dement*. 2016;12(3):216-224.
3. Kornblith E, Bahorik A, Boscardin WJ, Xia F, Barnes DE, Yaffe K. Association of race and ethnicity with incidence of dementia among older adults. *JAMA*. 2022;327(15):1488-1495.
4. Matthews KA, Xu W, Gaglioti AH, et al. Racial and ethnic estimates of Alzheimer's disease and related dementias in the United States (2015-2060) in adults aged >/= 65 years. *Alzheimers Dement*. 2019;15(1):17-24.
5. Lee M, Whitsel E, Avery C, et al. Variation in population attributable fraction of dementia associated with potentially modifiable risk factors by race and ethnicity in the US. *JAMA Netw Open*. 2022;5(7):e2219672.
6. Barnes LL, Bennett DA. Alzheimer's disease in African Americans: risk factors and challenges for the future. *Health Aff (Millwood)*. 2014;33(4):580-586.
7. Manly JJ, Glymour MM. What the aducanumab approval reveals about Alzheimer disease research. *JAMA Neurol*. 2021;78(11):1305-1306.
8. Massett HA, Mitchell AK, Alley L, et al. Facilitators, challenges, and messaging strategies for Hispanic/Latino populations participating in Alzheimer's disease and related dementias clinical research: a literature review. *J Alzheimers Dis*. 2021;82(1):107-127.
9. Raman R, Quiroz YT, Langford O, et al. Disparities by race and ethnicity among adults recruited for a preclinical Alzheimer disease trial. *JAMA Netw Open*. 2021;4(7):e2114364.
10. Ta Park VM, Meyer OL, Tsoh JY, et al. The Collaborative Approach for Asian Americans and Pacific Islanders Research and Education (CARE): a recruitment registry for Alzheimer's disease and related dementias, aging, and caregiver-related research. *Alzheimers Dement*. 2022;19:433-443.
11. Langbaum JB, High N, Nichols J, Kettenhoven C, Reiman EM, Tariot PN. The Alzheimer's prevention registry: a large internet-based participant recruitment registry to accelerate referrals to Alzheimer's-focused studies. *J Prev Alz Dis*. 2020;7(4):242-250.
12. Langbaum JB, Karlawish J, Roberts JS, et al. GeneMatch: a novel recruitment registry using at-home *APOE* genotyping to enhance referrals to Alzheimer's prevention studies. *Alzheimers Dement*. 2019;15(4):515-524.
13. Weiner MW, Nosheny R, Camacho M, et al. The brain health registry: an internet-based platform for recruitment, assessment, and longitudinal monitoring of participants for neuroscience studies. *Alzheimers Dement*. 2018;14(8):1063-1076.
14. Walter S, Clanton TB, Langford OG, et al. Recruitment into the Alzheimer Prevention Trials (APT) webstudy for a Trial-Ready Cohort for Preclinical and Prodromal Alzheimer's Disease (TRC-PAD). *J Prev Alzheimers Dis*. 2020;7(4):219-225.
15. Fockler J, Kwang W, Ashford MT, et al. Brain Health Registry GenePool study: a novel approach to online genetics research. *Alzheimers Dement (N Y)*. 2021;7(1):e12118.

16. Williams MM, Scharff DP, Mathews KJ, et al. Barriers and facilitators of African American participation in Alzheimer disease biomarker research. *Alzheimer Dis Assoc Disord*. 2010;24 Suppl :S24-S29.
17. Ketchum FB, Erickson CM, Chin NA, et al. What influences the willingness of blacks and African Americans to enroll in preclinical Alzheimer's disease biomarker research? a qualitative vignette analysis. *J Alzheimers Dis*. 2022;87(3):1167-1179.
18. Dilworth-Anderson P, Cohen MD. Beyond diversity to inclusion: recruitment and retention of diverse groups in Alzheimer research. *Alzheimer Dis Assoc Disord*. 2010;24 Suppl :S14-S18.
19. Lincoln KD, Chow T, Gaines BF, Fitzgerald T. Fundamental causes of barriers to participation in Alzheimer's clinical research among African Americans. *Ethn Health*. 2021;26(4):585-599.
20. Jefferson AL, Lambe S, Chaisson C, Palmisano J, Horvath KJ, Karlawish J. Clinical research participation among aging adults enrolled in an Alzheimer's disease center research registry. *J Alzheimers Dis*. 2011;23(3):443-452.
21. Marquez DX, Perez A, Johnson JK, et al. Increasing engagement of Hispanics/Latinos in clinical trials on Alzheimer's disease and related dementias. *Alzheimers Dement (N Y)*. 2022;8(1):e12331.
22. Glover CM, Creel-Bulos C, Patel LM, et al. Facilitators of research registry enrollment and potential variation by race and gender. *J Clin Transl Sci*. 2018;2(4):234-238.
23. Bleakley A, Maloney EK, Harkins K, Nelson MN, Akpek E, Langbaum JB. An elicitation study to understand Black, Hispanic, and male older adults' willingness to participate in Alzheimer's disease-focused research registries. *J Alzheimers Dis*. 2022;88:1499-1509.
24. Fishbein M, Ajzen I. *Predicting and Changing Behavior: A Reasoned Action Approach*. 1st ed. Taylor and Francis; 2010.
25. Fishbein M, Yzer M. Using theory to design effective health behavior interventions. *Communication Theory*. 2003;13(2):164-183.
26. Bleakley A, Piotrowski JT, Hennessy M, Jordan A. Predictors of parents' intention to limit children's television viewing. *J Public Health (Oxf)*. 2013;35(4):525-532.
27. Hennessy M, Bleakley A, Mallya G, Romer D. Beliefs associated with intention to ban smoking in households with smokers. *Nicotine Tob Res*. 2014;16(1):69-77.
28. Jordan A, Bleakley A, Harkins K, et al. Together make a visit; together make a plan": messaging to adult children with concerns about a parent's memory loss. *Health Commun*. 2020;35(4):512-523.
29. Harkins K, Maloney E, Bleakley A, Langbaum JB. What words and concepts do people enrolled in research registries use to describe them? *Alzheimers Dement*. 2021;17(S10):e056141.
30. Ashford MT, Eichenbaum J, Williams T, et al. Effects of sex, race, ethnicity, and education on online aging research participation. *Alzheimers Dement (N Y)*. 2020;6(1):e12028.
31. Parker LJ, Gaugler JE, Gitlin LN. Use of critical race theory to inform the recruitment of Black/African American Alzheimer's disease caregivers into community-based research. *Gerontologist*. 2022;62(5):742-750.
32. Ashford MT, Camacho MR, Jin C, et al. Digital culturally tailored marketing for enrolling Latino participants in a web-based registry: baseline metrics from the Brain Health Registry. *Alzheimers Dement*. 2022.
33. Alzheimer's Association As. 2015 Alzheimer's disease facts and figures. *Alzheimers Dement*. 2015;11(3):332-384.
34. Chen Y, Demnitz N, Yamamoto S, Yaffe K, Lawlor B, Leroi I. Defining brain health: a concept analysis. *Int J Geriatr Psychiatry*. 2021;37(1).

SUPPORTING INFORMATION

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

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