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participants in a web-based registry: Baseline metrics from the Brain Health Registry

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Abstract

INTRODUCTION,—This culturally-tailored enrollment effort aims to determine the feasibility of enrolling 5,000 older Latino adults from California into the Brain Health Registries (BHR) over 2.25-years.

Acumen Pharmaceutical, ADNI, Alzheon, Inc., Biogen, Brain Health Registry, Cerecin, Dolby Family Ventures, Eli Lilly, Merck Sharp & Dohme Corp., National Institute on Aging (NIA), Nestle/Nestec, PCORI/PPRN, Roche, University of Southern California (USC), NervGen.

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METHODS,—This paper describes 1) the development and deployment of culturally-tailored BHR websites and digital ads, in collaboration with a Latino community science partnership board and a marketing company; 2) an interim feasibility analysis of the enrollment efforts and numbers, and participant characteristics (primary aim); as well as 3) an exploration of module completion and a preliminary efficacy evaluation of the culturally-tailored digital efforts compared to BHR's standard non-culturally-tailored efforts(secondary aim).

RESULTS,—In 12.5 months, 3,603 older Latino adults were enrolled (71% of the total CAL-BHR initiative enrollment goal). Completion of all BHR modules was low (6%).

DISCUSSION,—Targeted ad placement, culturally-tailored enrollment messaging, and culturally-tailored BHR websites increased enrollment of Latino participants in BHR, but did not translate to increased module completion.

Keywords

Brain Health Registry; Recruitment; Digital Marketing; Social Media; Facebook; Enrollment; Engagement; Alzheimer's; Dementia; Latino; Ethnicity; Diversity

1. Background

In the United States (U.S.), the number of Latino older adults diagnosed with Alzheimer's disease and related dementias (ADRD) is expected to grow by >800% (approximately 3.5 million affected individuals by 2060)¹. Compared to non-Latino White individuals, incidence and prevalence of ADRD is higher in some U.S. Latino ethnic groups^{2-4,5, 6}. The cause of ADRD disparities in older Latino individuals is likely related to differences in environmental and contextual influences, as well as social, psychological, behavioral and health factors⁷⁻¹⁴.

Our understanding of ADRD disparities is hindered by the failure of many research studies to recruit and retain Latino participants¹⁵⁻²¹. For example, compared to non-Latino White research participants, Latino participants were less likely to have genetic samples available²², less willing to participate in complex or invasive research²³, and less likely to complete brain donations²⁴. Participation of Latino adults in ADRD research is crucial for developing effective interventions⁹.

Many traditional enrollment strategies have not been successful in recruiting Latino individuals in ADRD research^{25, 26}. The science of recruitment and enrollment in ADRD, especially for typically under-included populations, is still in its infancy. So far, multifaceted efforts which included community outreach components have been most successful in recruiting Latino participants^{16, 27}. In the U.S., a variety of national and local ADRD-related research registries have been developed for efficient prescreening and referral to studies^{28, 29}. They differ in purpose, format, and target population³⁰⁻³⁶, but most underrepresent Latino adults^{32, 33, 35}. Evidence about effective registry enrollment strategies for Latino individuals is lacking^{16, 37}. With increasing technology adoption and internet use in the Latino community³⁸, online recruitment offers an avenue to reach potential research participants³⁹. Culturally-tailored online advertising and website improvements might increase enrollment of Latino participants in online registries. Approximately 72% of

U.S. Latino individuals use Facebook⁴⁰, which allows researchers to tailor advertisements using factors like age, location, and language. Facebook has previously been found to be successful in recruiting older adults for health research^{41 42}. However, with a limited amount of research investigating Latino and older adult online recruitment to ADRD-related research and registries, studies are needed to add knowledge.

The UC San Francisco Brain Health Registry (BHR)³⁵ is a public online ADRD-related registry with over 95,000 participants which assesses cognition, function, and health longitudinally. Compared to the U.S. Census data, the BHR underrepresents Latino individuals^{35, 43}. To increase enrollment of Latino individuals in BHR we undertook a community-engaged research approach, that included establishing and working closely with a community science partnership board (CSPB) and collaborating with marketing professionals experienced in promoting clinical research participation and marketing for Latino individuals to develop culturally-tailored digital enrollment campaign. The overall goal of this enrollment effort, the California Latino Brain Health Registry (CAL-BHR), was to determine the feasibility of enrolling 5,000 older adults (55+ years) that self-identify as Latino and are from California into BHR over a 2.25-year period. The purpose of this manuscript is 1) to describe the CAL-BHR initiative, including how we developed and implemented the culturally-tailored digital enrollment efforts and 2) to report results from an interim feasibility analysis of the CAL-BHR culturally-tailored digital enrollment efforts after one year. In terms of the interim results, the primary aim was to report on digital marketing efforts, BHR enrollment numbers, demographics characteristics of enrolled participants. In terms of the interim results, the primary aim was to report on digital marketing efforts, BHR enrollment numbers, and demographics characteristics of enrolled participants. The secondary aims were an exploration of BHR module completion and a preliminary evaluation of the efficacy of the culturally-tailored CAL-BHR digital enrollment efforts in enrolling and engaging Latino adults in the BHR compared to BHR's standard nonculturally-tailored enrollment efforts.

2. Methods

The goal of the CAL-BHR effort was to increase the enrollment of older Latino adults into the BHR. Funding for this initiative, including the culturally-tailored digital advertising, was obtained from the California Department of Public Health Alzheimer's Disease Program funding from the 2019 California Budget Act [RFA19-10616]. The current study is an interim feasibility analysis of CAL-BHR culturally-tailored digital enrollment efforts after one year.

2.1 The Brain Health Registry experience

The BHR is a public online registry to recruit, screen, and longitudinally monitor participants for aging and cognitive-related research, as well as to refer enrolled participants to other studies^{35, 44, 45}. Anyone over the age of 18 is eligible to participate. BHR includes online consent, self-administered neuropsychological tests (NPTs), self-report questionnaires, and study partner enrollment and questionnaires (see S1 for more details). The questionnaires collect demographic, health, cognitive, and lifestyle data. Participants are

asked to complete questionnaires and NPTs every six months. Participants do not receive feedback about their questionnaire replies or NPT results.

2.2 Enrollment efforts

2.2.1 Standard nonculturally-tailored enrollment efforts—For BHR’s standard nonculturally-tailored enrollment efforts, BHR participants are enrolled from different sources. This includes owned, paid, and earned media. Please see Table 1 and Weiner et al. 2018³⁵ for a detailed description of the standard BHR enrollment efforts. The overall messaging was nonculturally-tailored and focused on all adults over the age of 18. For these analyses, we refer to participants who enrolled in BHR through those efforts as coming from “standard nonculturally-tailored efforts”.

2.2.2 CAL-BHR culturally-tailored enrollment efforts—For the CAL-BHR enrollment efforts (see Table 1), BHR participants are enrolled from different sources, including paid and earned media. The focus of this enrollment effort was on older (55+ years) Latino adults living in California (the focus on California CA was a requirement of the grant), but anyone over the age of 18 was eligible to join the BHR. With the goal to create culturally-tailored BHR enrollment campaigns for older Latino adults (including websites, digital media ads, emails, and engagement on social media), we established a CSPB and also collaborated with marketing professionals experienced in promoting enrollment in clinical research for Latino adults.

2.2.2.1. CSPB Members and Role: Currently the CAL-BHR CSPB has a total of 20 members consisting of seven academics/professional researchers, two Latino marketing/recruitment experts, and 11 Latino community leaders/stakeholders and/or BHR participants. So far, CSPB has met bi-annually and has advised on multiple aspects (e.g., digital advertising themes and messaging, social media and participant communication strategies, Spanish translation).

2.2.2.2 CAL-BHR website improvements: In collaboration with the CSPB and the BHR team, the marketing company created two new culturally-tailored landing pages for the BHR website for two different Latino populations: (1) younger Latino individuals that are more likely to be U.S.-born, and (2) middle-aged Latino individuals that are more likely to be U.S. immigrants. Landing pages are websites, which individuals see in response to clicking on a digital advertisement, where the call to action to enroll is predominant and includes an enrollment form. The two landing pages used culturally-tailored images and themes designed to appeal to the audience in terms of ethnicity, age-group, and language. The landing page designed for middle-aged Latino also blended in some Spanish words/phrases with English messaging. See Supplement S2 and S3 for screenshots of the landing pages. In addition, BHR’s overall enrollment process was simplified to reduce the number of steps needed for sign-up, account, and consent. Aside from culturally-tailored landing pages, participants enrolled through the CAL-BHR effort underwent the same registration process and eligibility criterion (age 18+) and were presented with the same BHR experience in terms of design, questionnaires, and NPTs as participants recruited through other efforts.

Emails sent to individuals who did not complete enrollment were revised to include culturally-tailored messaging, similar to the language used in ads and the two landing pages.

2.2.2.3 CAL-BHR digital marketing campaign: A culturally-tailored digital advertising campaign was devised, which included Facebook, YouTube, Google, and Bing which are popular among Latino adults.⁴⁰ Enrollment messaging and imagery was developed based on a review of the literature, expertise of the marketing team with the Latino population, as well as input from the CSPB. The content was tailored to the Latino population to align with values and beliefs, which included imagery that depicted Latino people and other creative concepts that appealed to the Latino community (see S4 for an example of a Facebook ad and S5 for a more detailed description of the development enrollment messaging). Messaging was limited to English language and English language with some Spanish since BHR was not yet available in Spanish at the time. The digital ads considered age, geography (CA zip codes in metropolitan/suburban areas with large Latino populations), and user interest matching (e.g., Latino music). Digital advertising techniques including “look-alike” audiences (i.e., audiences with the closest match to the seed audience, for example, same music preference)²¹ and retargeting (i.e., individuals who clicked on the ad get served the retargeting ads)⁴⁶ were also employed. Each digital ad included a campaign-specific, unique hyperlink, which was created by adding Urchin Tracking Modules to the end of a landing page web address. Utilization of this tracking allowed researchers to identify the ad(s) that led each person to sign-up and/or enroll. Yet, when an individual does not click the link in a digital ad and instead types the BHR web address into a web browser, it is difficult to determine if/which digital ad led an individual to enroll. In these cases, we don’t attribute any advertising platform with the enrollment and instead say the source is other/unknown.

2.3 Evaluation Metrics

2.3.1 Advertisement metrics—Facebook, YouTube, Bing, and Google Analytics were used to obtain data on the performance of the advertisement campaign. Metrics included total cost of the marketing campaigns, reach (defined as the number of unique people who were shown digital ads), impressions (defined as the total number of times the ads were displayed to an individual), link clicks (link to a BHR landing page) and the click-through rate (defined as clicks/impressions), as well as measures of ad engagement (reactions, comments, shares, saves) for Facebook ads.

2.3.2 Enrollment metrics—All potential BHR participants must complete a sign-up form first, then create an account, and lastly review and agree to an online informed consent form. We recorded the number of sign-ups (someone who started the enrollment process by providing their email on the sign-up form), the number of enrollments (completing the online consent form), as well as the number of participants who declined to participate or withdrew after enrollment. We used enrollment as an important outcome metric for 2 reasons: 1) BHR in itself is cohort study and 2) refers to other studies. We further recorded entire cost of CAL-BHR, which includes costs for the marketing team and the advertisements on the digital platforms, as well as the cost per enrollment (defined as the total USD spend on digital advertising by the total number of enrolled participants) in \$USD.

2.3.3 Participant metrics—After enrollment, participants complete a questionnaire, which asks them to self-report sociodemographic information. This analysis focused on the following variables: age (continuous), gender (male, female, other, Prefer not to say), race (Asian, African American/ Black, Caucasian/White, Native American, Pacific Islander, other, decline to state), ethnicity (Latino, non-Latino, declined to state), endorsement of subjective memory concern (“Are you concerned that you have a memory problem?”), family history of AD/dementia, and education attainment (categorical), and birth region (USA, USA Territory, Outside USA, Don’t know, Prefer not to say). The categorical variable education attainment was converted into a continuous variable called years of education, ranging from 6–20 years. We also created a new race variable which in addition to the categories listed above also contains the category “multiracial” which included individuals who self-identified with more than one race. For the variables gender, ethnicity, and race, we added a category “unknown” if the information was missing. BHR only recently started collecting information about birth region from Latino participants (02/24/2021). A total of 995 participants completed the survey including birth region. We have therefore included an additional category “no data collected”.

2.3.4 BHR module completion metrics—Metrics of module completion were measured during participants’ baseline BHR visit and included whether they completed at least the core BHR module (the first questionnaire in the BHR experience which includes questions about demographic information, family history of AD, memory, mood, health, and medications) (yes, no), completed all baseline BHR modules (yes, no), completed at least one NPT (yes, no), tried an NPT but had technical difficulties (yes, no), and whether they have an enrolled study partner through the BHR Caregiver and Study Partner Portal⁴⁴. Participants were considered to have an enrolled study partner if their potential study partner completed online informed consent (yes/no) (see S5 for more information about study partner enrollment).

2.4 Statistical Analysis

Total frequencies of advertisement metrics were tabulated for Facebook, YouTube, Google, Bing, and across platforms. Summary statistics of participant characteristics were tabulated (for categorical variables: frequencies, percentages; for continuous variables: mean, standard deviation (SD), and range). We compared characteristics of participants who were recruited through culturally-tailored CAL-BHR efforts to characteristics of those recruited through BHR’s standard non culturally-tailored efforts using Mann-Whitney test for continuous variables and Chi-square test for categorical variables. For all participants self-identifying as Latino enrolled through the culturally-tailored efforts, the frequencies and percentages of the completion metrics are presented and statistically compared to BHR participants self-identifying as Latino not recruited through the standard non culturally-tailored efforts. All analyses were done in SAS 9.4 (SAS Institute, Cary NC).

3 Results

3.1 Advertising results

Table 2 provides an overview of the advertising metrics for four online platforms (Facebook, YouTube, Google, Bing). All four were piloted, but YouTube, Google and Bing were discontinued after 1–5 months as the cost per enrollment were deemed as too high and thus, we shifted our efforts to Facebook only which provided us with the most amount of enrollments for our budget. Between August 2020 (26th) and September 2021 (16th), there were a total of 321 Facebook ads which resulted in 8,006,240 impressions and reached 1,237,569 Facebook users. Across all Facebook advertisements, there were 20,538 reactions, 667 shares, 1,829 comments, and 2,136 saves. The total cost for Facebook ads were USD \$222,082.54. Across all four digital advertisement platforms, the links were clicked 134,387 times (1.25% click-through-rate).

3.2 Enrollment

A total of 15,575 individuals coming from CAL-BHR efforts completed BHR's sign-up form. Of those, six participants had previously enrolled in BHR through another effort, but tried to re-enroll after seeing a digital ad. Of the total 15,575 sign-ups, 7,582 (48.7%) did not proceed to the consent page, 640 (4.1%) declined invitation to enroll after signing up, and 7,353 (47.2%) fully enrolled by consenting to participate in BHR. Of all fully enrolled participants, 77% self-identified as Latino, and 53.6% of those who self-identified as Latino were age 55+. Figure 1 shows the cumulative and monthly enrollment of all CAL-BHR participants and CAL-BHR participants self-identifying as Latino over time. An average of 404.4 (SD=257.77) Latino participants enrolled in BHR per month. A total of 41 (0.6%) participants withdrew from the study after enrolling. Within one year, we were able to recruit 3,603 older adults who self-identify as Latino into the BHR, which is 71.1% of the total enrollment goal of 5,000 older adults who self-identify as Latino within a 2.25-year enrollment period. Overall, the CAL-BHR efforts increased the percent of Latino BHR participants from 6% to 12.2%, which is a 122.7% increase.

The total cost so far was \$421,188, which included \$119,332 for the marketing agency, \$50,000 for websites and other materials and creative, and \$251,856 for digital advertising. Across all platforms (Facebook, YouTube, Google, and Bing), the cost per enrollment was USD \$34.25. The cost per enrolled Latino participant was USD \$44.48 and the cost per enrolled Latino participant 55 years and older was USD \$69.90.

3.3 Participants characteristics

Characteristics of participants by enrollment source (culturally-tailored CAL-BHR efforts versus standard nonculturally-tailored efforts) are presented in Table 3. Compared to those enrolled through standard nonculturally-tailored BHR enrollment efforts, participants recruited through the culturally-tailored efforts reported fewer mean years of education (14.3 vs 15.9), self-identified more as female (79.8% vs 73.3%), **Latino (77.0% vs 5.9%)**, and less as White (44.3% vs 79.1%), reported more memory concerns (55.0% vs 48.5%) and less family history of AD (25.2% vs 28.8%) (all $p < .0001$). Figure 2 shows an enrollment heatmap of participant residence by county in California. The enrollment campaign was

targeted specifically at Latino individuals living in California, yet participants enrolled from across the U.S. with 69.8% coming from California.

3.4 Characteristics and BHR module completion of Latino Participants

Characteristics and BHR module completion of Latino participants by enrollment source (culturally-tailored CAL-BHR efforts versus standard nonculturally-tailored BHR enrollment efforts) are presented in Table 4. Among Latino participants recruited through the CAL-BHR culturally-tailored efforts (N=5,662), the mean age is 57 (SD=10.2), 3,603 (63.6%) were 55 years or older, and 1374 (13.5%) report being born outside the USA or US territory. Most participants identify as female (87.5%) and have an average of 14.3 years (SD=2.41) of education. Among Latino participants who joined through CAL-BHR efforts, at baseline, 99.8% completed at least the core module, 6.0% completed all questionnaires and NPTs, 30% completed at least one NPT, 11.2% tried to complete one NPT but had technical difficulties, and 1.9% have an enrolled study partner. Of all Latino participants enrolled through the CAL-BHR efforts, 93.7% agreed to be contacted about opportunities to enroll in other studies. Latino participants enrolled through the CAL-BHR culturally-tailored efforts were significantly older, reported fewer years of education, self-identified more as female, reported more memory concerns, reported more family history of AD, completed all modules less often, and completed at least one NPT less often compared to Latino participants who were enrolled through BHR's standard nonculturally-tailored efforts (all $p < .0001$).

4. Discussion

The major findings of this study were: (1) culturally-tailored enrollment websites and Facebook ads created through a community engaged research approach are a feasible and scalable strategy to increase the enrollment of Latino participants into an online ADRD-related research registry; (2) only 47% of those who completed the sign-up form went on to enroll in BHR; (3) this effort mainly recruited female Latino participants and Latino participants with a higher educational attainment (e.g., more than high school); and (4) completion of core BHR module was high (99.8%), but we failed to engage participants sufficiently for them to complete the entire BHR modules. Major challenges of this approach include the need for developing effective strategies to increase enrollment of male Latino participants and Latino participants with a lower education, and to increase the completion of BHR tasks of enrolled participants. Yet, despite challenges, these results show that our culturally-tailored digital enrollment approach has great potential as one strategy to increase enrollment of Latino individuals into online studies. Further investigation is necessary to determine whether this approach could be used to increase enrollment of other ethnocultural groups.

To our knowledge, the CAL-BHR study was the first to demonstrate the feasibility and success of using a digital culturally-tailored enrollment approach informed by a CSPB to increase enrollment of Latino participants in an online ADRD-related research registry. This is supported by enrolling 3,603 older Latino adults in one year, which is 71% of the total CAL-BHR initiative enrollment goal of 5,000 older Latino adults within a 2.25-

year initiative period. The feasibility was also supported by enrollment of 5,662 Latino participants of all ages in a little over a year, which resulted in 122.7% increase of Latino participants in the BHR. The representation of Latino participants in the BHR increased from 6% before the efforts to 12.2%, getting closer to being representative of the U.S. population (18.5% identify as Latino according to the U.S. Census⁴⁷) and to California (39% identify as Latino according to the U.S. Census⁴⁸). However, when looking at the monthly enrollment over time, we see signs of market saturation, which may mean that we might need more than the allotted time to reach our enrollment goal of 5,000 older Latino participants. The digital efforts of this study targeted Californians and we expect that if this effort is expanded to more states, the representation of Latino participants would increase as well. Our findings add to the emerging evidence of using digital marketing for increasing enrollment in digital studies^{42, 49–51} and provide further support for the importance of developing culturally-tailored enrollment efforts informed by the community to improve representation of online research registries^{24, 27, 37, 52–58}. Since the digital material can be tailored to other ethnocultural or socioeconomic populations and promoted via social media to adults living in other states, countries, and rural areas, this strategy has high potential for scalability and improving the reach of enrollment efforts. Researchers interested in developing and deploying culturally-tailored digital marketing campaigns should consider allocating resources for developing the digital marketing campaigns and placing digital advertisements in their proposed budget when applying for funding. This includes resources for paying the CSPB members for attending the CSPB meetings, hiring a marketing company with experience with the population of interest, and placing the advertisements on digital platforms.

Despite the overall success, our results show that more than 50% of participants who signed-up for BHR through this effort did not complete the enrollment process. The enrollment process may partially explain the attrition. All potential BHR participants must sign-up, then create an account, and lastly review and agree to an online informed consent form. We sent culturally-tailored reminder emails one and three days after the start of the enrollment process for those who did not complete the process. The efficacy of the culturally-tailored reminder emails will be investigated in future analysis. There is emerging evidence that videos developed with the Latino community, which feature ethnically-concordant community members and study investigators peers, can increase willingness and interest to participate in research⁵⁹. Therefore, enrollment effort videos which feature members of the CSPB, address concerns and/or barriers to participation, and clarify what it means to participate in BHR are under development and will be added to advertisements and websites.

CAL-BHR efforts resulted in a sample with a majority of female Latino participants and Latino participants with a higher educational attainment (e.g., more than high school). An underrepresentation of male participants exists in the overall BHR cohort³⁵ and has been found in other online AD/DRD-related registries^{60, 61}. According to the American Community Survey 2019, only 17.6% of Latino adults living in the U.S. have a bachelor's degree or higher⁶². This highlights our failure to recruit a representative sample of Latino individuals in terms of educational attainment. In relation to education attainment, Internet use and familiarity might be relevant barriers to enrollment. For example, a Pew Research Center

report highlighted that in Latino adults, internet use is among the lowest for those with a high school education or less (67%)⁶³. In addition, lack of Spanish language messaging and study materials might be a barrier among Latino participants with a lower education or years of living in the U.S. BHR has recently launched a Spanish language version of the BHR website, including translation of the informed consent form and all questionnaires and NPTs. A further contributing factor may be that marketing efforts so far have primarily targeted metropolitan areas. Future analyses will determine whether these efforts increase representation of Latinos with lower educational attainment. More future efforts are needed to tailor the enrollment strategies to increase representations of male participants and those with lower educational background to make study results more generalizable.

The success of the enrollment effort was limited by our failure to sufficiently engage Latino participants such that they completed all BHR modules. Even though the CAL-BHR culturally-tailored enrollment effort enhanced the enrollment of Latino participants, only a small percentage completed all BHR modules (all questionnaires and NPTs) or at least one NPT. This is also consistent with a previous analysis of BHR completion data which demonstrate BHR's failure to engage Latino participants in terms of completion of self-reported questionnaires and NPT modules⁶⁴. In addition, BHR completion rates are low among all BHR participants³⁵. The non-traditional open-ended structure of the BHR contributes to this problem and this is amplified for Latino participants. This failure leads to missing data, which in turn limits our ability to generalize findings. These results are also similar to in-clinic findings, which showed that studies were less successful in collecting genetic samples from Latino participants²² and brain donation compared to white non-Latino participants²⁴. In addition, only a very small percentage have an enrolled BHR study partner, which is especially relevant in ADRD research since trials typically need to enroll both a participant and their study partner⁶⁵. One positive aspect is that completion of the core BHR module was high, which includes important demographic, memory, and health data which can be used for referral to other studies and BHR data analysis. Our failure to engage enrolled Latino participants might be related to the fact that the effort's focus has been on increasing enrollment and not BHR module completion. In addition, the researchers and the design of the study might have hindered module completion. For example, potential explanations include the burden and time commitment of completing all modules in BHR, which have previously been identified as barriers to ADRD-related research participation among Latino individuals⁶⁶. There is also a long history of providing incentives to participants to improve task completion and retention in Internet-based⁶⁷⁻⁷⁰ studies, as well as in older adults and underrepresented populations⁷¹⁻⁷³. Providing financial incentives to older Latino participants may offset the participation cost/burden, make participants feel understood and respected, and decrease financial stress⁷⁴. Another contributing factor to low module completion may be that the call to action, theme, and messaging used in enrollment effort material may not adequately address the needs of the community. Efforts are underway to implement and evaluate the use of incentives to improve module completion of underrepresented ethnocultural groups in BHR and the BHR team is working with a company to improve the overall user experience of the registry. In addition, the entire CAL-BHR enrollment effort occurred during the COVID-19 pandemic. The increased use of technology during this time and the associated screen fatigue or digital

burnout may have contributed to lower BHR module completion.⁷⁵ Taken together, our study illustrates the differences between enrolling in a registry and completing of research registry modules and a crucial next step is to develop efforts which focus on enhancing BHR module completion. Despite the low module completion among the newly enrolled Latino participants, 93.7% agreed to be contacted about future studies opportunities increasing the number of Latino participants BHR can refer to other AD and aging research studies in the future. However, future studies will need to determine whether those participants will actually enroll in referral studies including in-clinic studies and trials.

4.1 Limitations

Due to the online nature of the marketing campaign and the online BHR design, this study suffers from multiple selection biases, for example, for those with internet access, ability to read and write in English (BHR was not available in Spanish until July 2021), as well as those familiar with scientific research and medical culture. As described above, our registry underrepresents males and individuals with an education attainment less than a high school degree. This impacts the interpretation of the findings and their generalizability. The Latino participants recruited and enrolled in BHR does not represent the characteristics of the overall U.S. Latino population. Enrollment efforts focused on individuals self-identifying as Latino in California, who are mostly of Mexican American/Chicanx heritage⁷⁶. It remains to be determined whether this effort would be successful in other U.S. Latino subpopulations (e.g., Caribbean, South American). Future analysis will use more fine-grained sociocultural information to inform within-group analyses and better contextualize the current findings (e.g., Latino heritage country/region, language/bilingualism, acculturation). No theoretical framework was used to develop the content of the advertisements. Currently, there is little evidence for theoretical frameworks to improve recruitment of under-included populations in AD/DRD research^{10, 16}. However, recently intersectional frameworks of research justice and participation have been proposed which could guide future efforts⁹. The current analyses also did not compare the effectiveness of the different ads used in terms of content and format (e.g., video, photo), as well as the marketing strategies. Future analysis should also include a systematic evaluation of effectiveness of the culturally-tailored efforts compared to the standard nonculturally-tailored efforts. In addition, future efforts need to specifically focus on the researchers and their study design and not exclusively on the low module completion of Latino BHR participants. Efforts will include a Spanish language BHR experience and could include surveying Latino BHR participants about what changes could be made to the study to facilitate BHR module completion. A further investigation could look at whether completion rates of participants vary by enrollment effort platform. It is also unclear whether the same culturally-tailored approach would be feasible for registries which collect blood samples, saliva samples, or imaging data.

4.2 Conclusion

This study provides an evidence-base for the feasibility of culturally-tailored efforts informed by the community for enrolling Latino individuals in a relatively short period of time into an online AD/DRD research registry that does not translate into an increase in BHR module completion among Latino participants. The CAL-BHR enrollment effort could be regarded as a tool that may facilitate enrollment into a registry, but not as a tool to

increase registry module completion. More work is needed to enroll a representative sample of Latino participants in terms of gender and education and to identify ways to increase module completion of enrolled participants. Future work will also evaluate effects of a newly released Spanish-language BHR website and digital ads, as well as long-term module completion of Latino BHR participants recruited through this effort.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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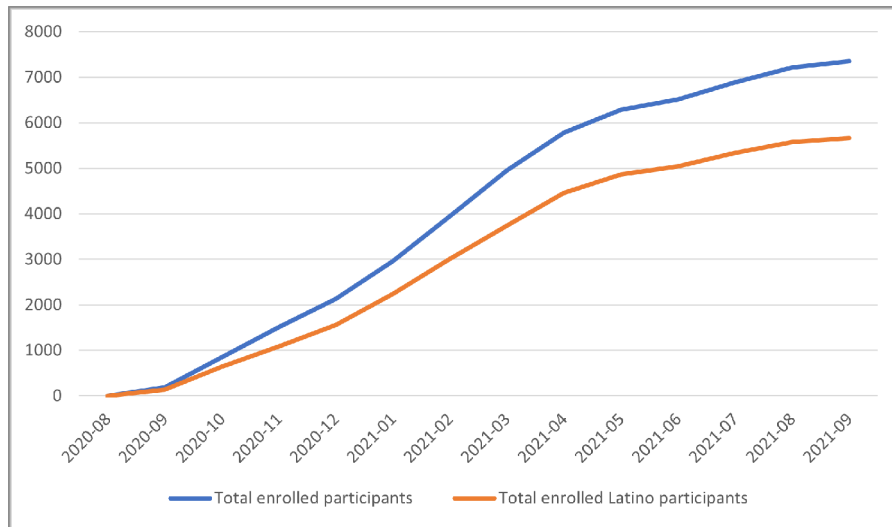


Figure 1.
Cumulative number of enrollments over time

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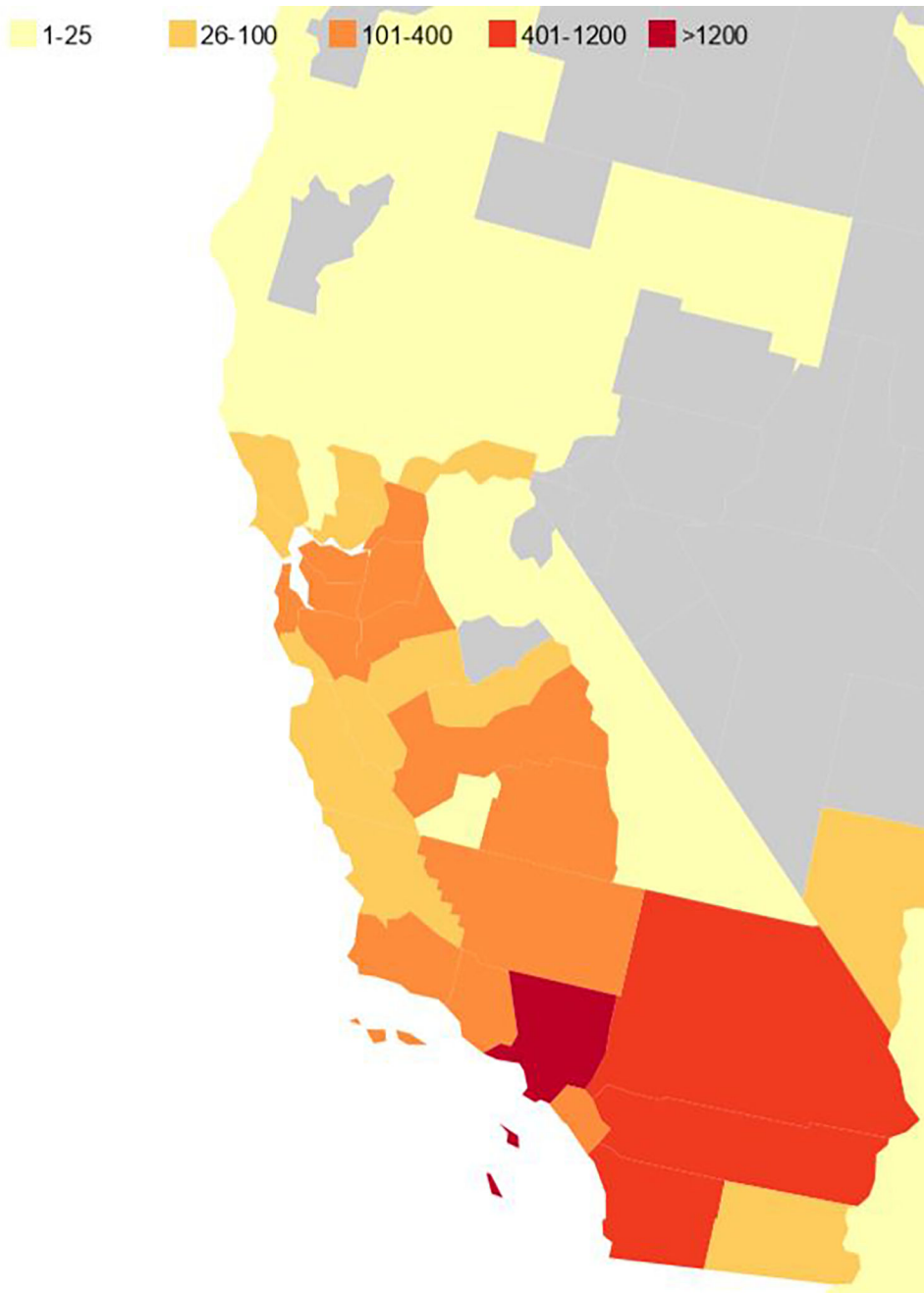


Figure 2.
Heatmap of enrolled CAL-BHR participants from CA counties

Table 1.

BHR enrollment effort methods

Effort	Enrollment effort period	Enrollment effort population focus*	Enrollment effort source	Enrollment effort funding and finances
Standard (nonculturally-tailored) BHR enrollment efforts	BHR inception in 2014 - Sept 16 th 2021	Any adults (18+ years old)	<p>Paid (e.g., digital media, direct mail, traditional)</p> <p>Owned (e.g., BHR website, emails, BHR online networks, BHR press releases)</p> <p>Earned (e.g., news publicity, influencers, word-of mouth)</p> <p>Refer to paper</p>	The BHR is funded by grants and donations. Both were used to pay for the development of BHR and any BHR enrollment effort-related contents and efforts.
Culturally-tailored enrollment efforts (CAL-BHR)	Aug 26th 2020 - Sept 16th 2021	Latinos age 55+ living in California	<p>Paid digital media:</p> <ul style="list-style-type: none"> - Facebook - YouTube - Google - Bing <p>Owned (e.g., culturally-tailored landing pages, simplified BHR enrollment process, revised/culturally-tailored BHR reminder emails)</p>	<p>Funded by <i>the</i> California Department of Public Health Alzheimer's Disease Program funding from the 2019 California Budget Act [RFA19-10616]. This grant supported a marketing company to develop the content (ads, landing pages) and payment to digital advertisement platforms.</p> <p><i>It also provided payment to CSPB members for participating in CSPB meetings.</i></p>

Note.

* This was the focus of the enrollment effort and not an eligibility criterion. The only BHR eligibility criterion is being 18+ years old. Limiting the focus to CA was a requirement of the grant.

Table 2.

Advertising results by digital advertisement platform

	Facebook	YouTube	Google	Bing	Other/ unknown	Total
Duration	Aug 26 th 2020 – Sept 16 th 2021	Feb 2021	Sept 2020 – Jan 2021	Nov 2020 – Mar 2021	Aug 26 th 2020 – Sept 16 th 2021	Aug 26 th 2020- Sept 16 th 2021
Cost, US\$	\$222,082.54	\$3,426.90	\$25,177.99	\$1,169.13	N/A	\$251,856.56
Impressions	8,006,240	301,837	2,402,082	17,119	N/A	10,727,278
Link clicks	90,338	2,879	39,872	1,298	N/A	134,387
Click-through rate, %	1.13%	0.95%	1.66%	7.58%	N/A	1.25%
Enrollment	6,181	6	341	33	792	7,353

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Table 3.

Characteristics of enrolled participants

	Enrollment from standard nonculturally-tailored efforts (N=76845)	Enrollment from CAL-BHR culturally-tailored efforts (N=7353)	<i>p</i>
Age in years, M(SD) Range	57 (14.1) 18–90	57.3 (10.7) 18–90	<.0001 ¹
Years education, M(SD) Range	15.9 (2.47) 6–20	14.3 (2.42) 6–20	<.0001 ¹
Gender, n(%)			<.0001 ²
Male	19532 (25.4%)	869 (11.8%)	
Female	56356 (73.3%)	5871 (79.8%)	
Other	12 (0.0%)	3 (0.0%)	
Prefer not to say	12 (0.0%)	6 (0.1%)	
Unknown	933 (1.2%)	604 (8.2%)	
Ethnicity, n(%)			<.0001 ²
Latino	4539 (5.9%)	5662 (77.0%)	
Non-Latino	66566 (86.5%)	658 (8.9%)	
Declined to state	2229 (2.9%)	148 (2.0%)	
Unknown	3511 (4.6%)	885 (12.0%)	
Race, n(%)			<.0001 ²
African American/Black	3283 (4.3%)	77 (1.0%)	
Asian	2305 (3.0%)	54 (0.7%)	
Native American	331 (0.4%)	392 (5.3%)	
Pacific Islander	120 (0.2%)	32 (0.4%)	
Two or more races	2703 (3.5%)	470 (6.4%)	
Other	2473 (3.2%)	1889 (25.7%)	
White	60883 (79.1%)	3261 (44.3%)	
Declined to state	1270 (1.7%)	293 (4.0%)	
Unknown	3510 (4.6%)	885 (12.0%)	
Self-report memory concern, n (%)	37249 (48.5%)	4045 (55.0%)	<.0001 ²
Report family history of AD, n (%)	22157 (28.8%)	1856 (25.2%)	<.0001 ²

Note.

¹=based on Mann-Whitney test,²=based on Chi-square test

Table 4.

Characteristics and study engagement of enrolled Latino participants

	Latino enrollment from standard nonculturally-tailored efforts (N=4539)	Latino enrollment from CAL-BHR efforts (N=5662)	<i>p</i>
Age in years, M(SD) Range	49.9 (14.9) 18–90	57 (10.2) 18–90	<.0001 ¹
Years education, M(SD) Range	15.3 (2.64) 6–20	14.3 (2.41) 6–20	<.0001 ¹
Gender, n(%)			<.0001 ²
Male	1200 (26.4%)	701 (12.4%)	
Female	3335 (73.5%)	4953 (87.5%)	
Other	1 (0.0%)	3 (0.1%)	
Prefer not to say	1 (0.0%)	5 (0.1%)	
Unknown	2 (0.0%)	0 (0.0%)	
Race, n(%)			<.0001 ²
African American/Black	106 (2.3%)	44 (0.8%)	
Asian	39 (0.8%)	24 (0.4%)	
Native American	126 (2.8%)	376 (6.6%)	
Pacific Islander	19 (0.4%)	24 (0.4%)	
Two or more races	389 (8.6%)	406 (7.2%)	
Other	1309 (28.8%)	1841 (32.5%)	
White	2274 (50.1%)	2728 (48.2%)	
Decline to state	277 (6.1%)	219 (3.9%)	
Birth region			.0024 ²
USA	596 (13.1%)	2653 (26.0%)	
USA Territory	61 (1.3%)	183 (1.8%)	
Outside USA	334 (7.4%)	1374 (13.5%)	
Don't know	2 (0.0%)	3 (0.0%)	
Prefer not to say	2 (0.0%)	18 (0.2%)	
No data collected*	3544 (78.1%)	5970 (58.5%)	
Self-report memory concern, n(%)	2461 (54.2%)	3480 (61.5%)	<.0001 ²
Report family history of AD, n(%)	1263 (27.8%)	1596 (28.2%)	<.0001 ²
Have an enrolled study partner	268 (5.9%)	110 (1.9%)	<.0001 ²
Completed at least one BHR module	4531 (99.8%)	5649 (99.8%)	.48 ²
Completed all BHR modules	797(17.6%)	337 (6.0%)	<.0001 ²
Completed at least one NPT	2170 (47.8%)	1697 (30.0%)	<.0001 ²
Had difficult completing NPT	496 (10.9%)	636 (11.2%)	.74 ²
Agreed to be contacted about study referrals	4194 (92.4%)	5306 (93.7%)	.26 ²

Note.

¹=based on Mann-Whitney test,

²=based on Chi-square test

* Birth region information was collected starting on 02/24/2021.

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