

Understanding Factors Associated with the Effectiveness of a Recruitment Registry: Preliminary Findings of Referral Contact Outcomes from the CARE Registry

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Background

- Asian Americans, Native Hawaiians, and Pacific Islanders (AANHPIs) are the fastest-growing racial groups in the United States, comprising approximately 7% of the U.S. population.¹ However, AANHPI participation in Alzheimer's disease and related dementias (ADRD) or caregiving-related research is limited.^{2,4}
- The Collaborative Approach for Asian Americans, Native Hawaiians, and Pacific Islanders Research & Education (CARE) registry aims to address the gap in research participation among AANHPI.³
- Recruitment registries are tools to accelerate study recruitment, but more understanding of their effectiveness is needed.

Methods

- CARE registry launched in October 2020. There are 18,136 participants enrolled in CARE as of June 28, 2026.
- CARE began to accept referral requests in January 2021.
- Interested researchers submit an online CARE Referral Request Form, following the process for referral requests.³
- A referral was considered successful if the participant could be contacted by the researcher, regardless of whether they ultimately enrolled in the study.
- Participant characteristics include: (1) age group; (2) sex; (3) education level; (4) born in or outside the US; (5) prior research participation (Yes/No); and (6) self-reported ADRD symptoms (Yes/No).
- Multivariable logistic mixed-effects regression was used to investigate the associations between participant characteristics and successful contact.

Results

As of June 28, 2026:

200
studies submitted
referral requests

21,168
total referrals
made to studies

137
studies supported
including completed or
active referrals

10,766
unique CARE
participants referred to
at least one study

Researcher Testimonials

“The process is easy. The CARE participants we reached out were already interested in research and once they are enrolled in our study, they are very committed!”
Christina Miyawaki, PhD, MSW | University of Houston

“I am impressed with the attention paid to the different demographic and caregiving information that was collected. I was able to specifically request those who [...] met the specific criteria for my study [...] and the response rate was surprisingly high.”
William Tsai, PhD | New York University

Table 1. Requesting study characteristics (N=200)

CARE-supported studies	N (%)
Research topic	
ADRD and dementia caregiving	100 (50%)
Other caregiving	14 (7%)
Other health topics	86 (43%)
Target Population	
All AANHPI	82 (41%)
Specific AANHPI Group(s)	118 (59%)
Language Support	
Yes	87 (43.5%)
No	113 (56.5%)
Study Burden	
Low	36 (51.4%)
Moderate/High	34 (48.6%)

Referral Contact Outcomes

Figure 1. Referral contact outcomes flowchart
46.7% of studies used email-only contact method

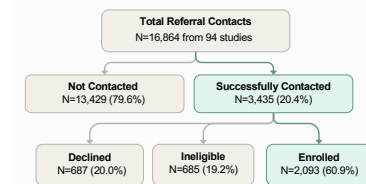
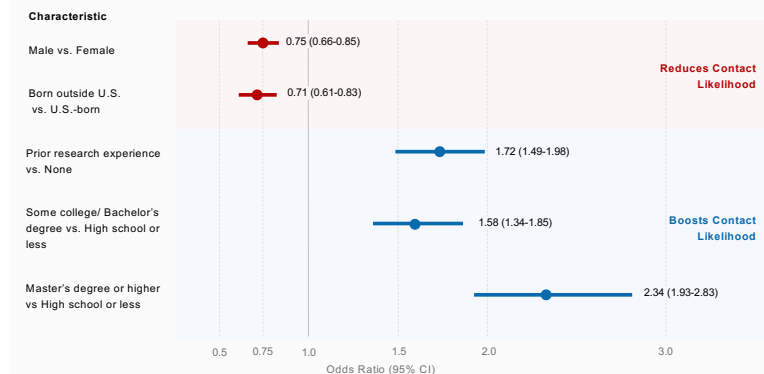


Figure 2. Referral contact outcome forest plot

Adjusted for study burden, contact attempts, and contact mode. All $p < 0.05$. $N=15,666$ referrals, 75 studies.



- Male participants and participants born outside the US had lower odds of successful study contact.
- Having prior research experience was associated with 72% higher odds of successful study contact.
- Having greater level of education were associated with greater odds of successful study contact.

Table 2. Referred participant characteristics (N=10,701)

Characteristics	N (%) or Mean (SD)
Age, mean (SD) [range]	57.2 (18) [18-103]
Sex	
Female	6,778 (63.3%)
Male	3,766 (35.2%)
Other/Prefer not to answer	157 (1.5%)
Education	
High school or less	3,696 (34.5%)
Some college/technical school	1,317 (12.3%)
Bachelor's degree	3,030 (28.3%)
Master's degree or higher	2,329 (21.8%)
Prefer not to answer	329 (3.1%)
Language used to complete survey	
English	5,786 (54.1%)
Vietnamese	2,415 (22.6%)
Chinese (Simplified)	980 (9.2%)
Korean	790 (7.4%)
Chinese (Traditional)	600 (5.6%)
Samoan	108 (1%)
Filipino/Tagalog	18 (0.2%)
Other characteristics	
Born outside U.S.	8,650 (80.8%)
Caregiver	2,787 (26.0%)
Self-reported ADRD symptoms	1,215 (11.4%)
Prior research participation	
Yes	1,721 (16.1%)
No	8,209 (76.7%)
Unsure	771 (7.2%)

Key Findings

- CARE has demonstrated success in connecting large numbers of AANHPI registrants to ADRD, caregiving, and other health studies.
- Notably, approximately 1 in 5 referred participants responded to study invitations, and almost 61% of these participants enrolled in studies.

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careregistry.ucsf.edu/care-supported-studies



Conclusion

- CARE has demonstrated success in referring large numbers of registry participants, over 3,435 of whom were successfully contacted by study teams.
- Future analyses will examine factors associated with study enrollment and seek to understand barriers for particular subgroups.
- Identifying meaningful predictors of referral outcomes will inform best practices for recruitment and retention strategies for CARE and researchers.

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