CARE Registry 2024 Executive Summary



https://careregistry.ucsf.edu/

Established: October 15, 2020

CARE has
10,257 participants
(as of August 31, 2024)

Because of your participation,

CARE supported 80 health research studies!



Mission

To improve research participation and address Alzheimer's disease, aging, caregiving, and other related health issues in Asian American, Native Hawaiian, and Pacific Islander communities.



CARE is Expanding!

We're thrilled to announce exciting updates:

- Broader Outreach: Connecting with more AANHPI communities.
- **New Languages:** Adding <u>Japanese</u>, <u>Ilokano</u>, <u>& Tagalog</u> to serve more AANHPI populations.
- Stronger Engagement: Deepening ties with our CARE participants.

With your help, we are actively increasing participation from **AANHPI communities in health research**, and this is just the beginning. **Thanks for your support!**

Who enrolled in CARE?

Mean age **54.4 years** (Range: 18 - 101 years)

δą

62.8% Female **35.6**% Male

0.1% Other/unsure **1.5%** Didn't answer



83.2% Foreign born



50.1% have limited English proficiency

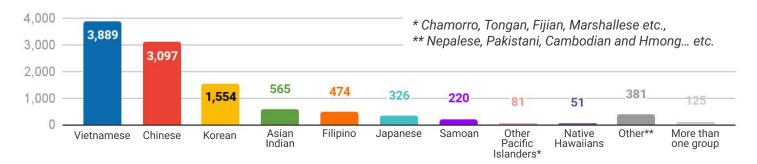


80.3%No prior research experience



1/4 are caregivers

44 AANHPI Cultural Groups enrolled



Funder: Research reported in this publication was supported by the National Institute on Aging of the National Institutes of Health (R24AG063718 & R01AG083926). The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health. **UCSF IRB Protocol #:** 23-39121

How does the CARE registry work?

PARTICIPANT (YOU)

ENROLL IN CARE

You complete a brief
Survey to enroll in CARE
Your information is saved in CARE's secure database*

RESEARCHER

REFERRAL REQUEST

Researchers submit an application to CARE

OBTAIN APPROVAL

SECURE DATABASE

Researcher gets approval to use CARE data from their Institutional Review Board**

WE MATCH YOU!

We connect researchers with participants who might be eligible for studies. You may be contacted by email, phone, text, or postal mail.

YOU DECIDE IF YOU WISH
TO PARTICIPATE

THERE'S NO COST TO YOU

*CARE's database is HIPAA compliant, meaning it follows security measures to store protected health information.
**An Institutional Review Board (IRB) is made up of qualified individuals who carefully review research involving human participants. They ensure that these studies are ethical, follow all laws, and protect participants' rights and safety.

How has CARE made an impact in AANHPI populations' representation in research?

Because of your participation in CARE,

we are able to support researchers in recruiting AANHPI participants for their studies.



124

recruitment referral requests received since January 2021.



80

studies received referrals from CARE.

27 more studies are in the preparation stage (e.g., awaiting IRB approval), and 17 did not receive support after consultation.

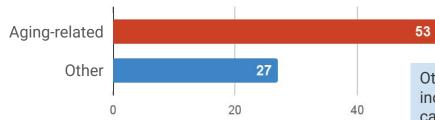


Nearly **12800**

referrals were made to CARE-supported studies.

Referral outcome findings will be available soon.

Research Areas of CARE Supported Studies



53 (66.3%) of the requesting studies were aging-related, including Alzheimer's Disease and Related Dementias (ADRD) or caregiving studies.

Others focused on a wide range of topics including COVID-19, cardiovascular disease, cancer and mental health.

CARE Links





Check our current news



Sign up for the quarterly e-newsletter



Learn more about the CARE Ambassadors Program

CARE Brief Report

Please refer to our <u>brief report</u> for more detailed information.