



2023 CARE Registry Brief Report

Enrollment Number: **9,759** participants
(as of January 1, 2023)


Launch Date: October 15, 2020



Purpose:

-  To address the gap and reduce disparities in research participation in Alzheimer's disease and related dementias (ADRD), aging, caregiving, and other health issues across the lifespan in Asian American and Native Hawaiian/Pacific Islander (AANHPI) communities.
-  To give members of AANHPI communities a voice and the opportunity to participate in research through enrollment in CARE.
-  To implement culturally appropriate and innovative recruitment strategies in collaboration with CARE's community partners to enroll 10,000 AANHPI participants.

Background:

-  Asian Americans are the **fastest growing racial group** in the US, comprising 7.7% of the population. Clinical research projects focusing on Asian American, Native Hawaiian, and Pacific Islander (AANHPI) participants funded by the National Institutes of Health was **less than 1%** of its total budget between 1992 and 2018 ([Doan, Takata, Sakuma, & Irvin \(2019\), JAMA Network Open](#))

Enrollment survey available in these languages:

English
Samoa (Samoan)
Tiếng Việt (Vietnamese)
简体中文 (Simplified Chinese)
繁體中文 (Traditional Chinese)
한국어 (Korean)
हिन्दी (Hindi)

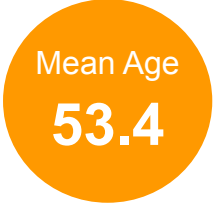
Hindi since February 2022 | Samoan since March 2021

What you can find in this report:

- [Who enrolled in CARE?](#)
- [Has CARE increased participation of AANHPI individuals in research studies?](#)
- [How did CARE engage AANHPI communities?](#)
- [What are CARE's vision and next steps?](#)

Who enrolled in CARE?

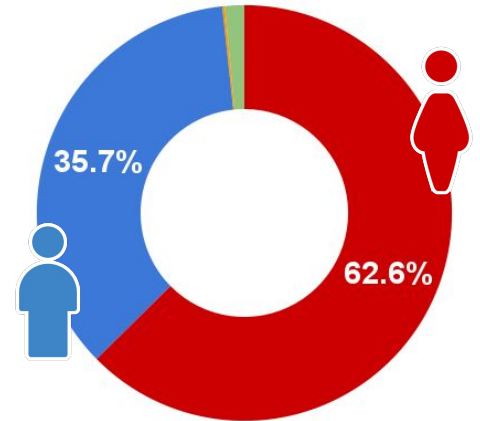
Age



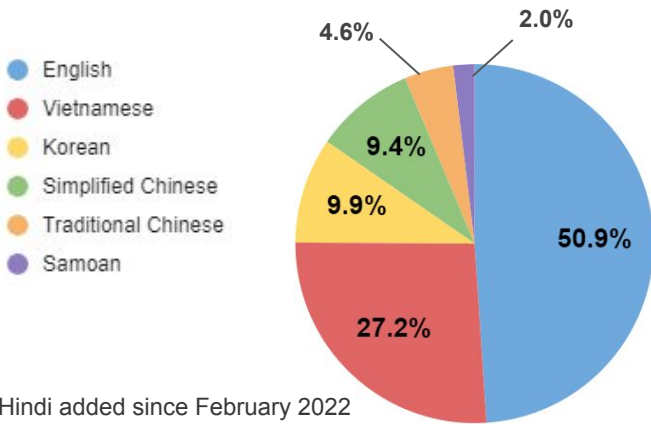
- Range: 18 - 100 years
- 60% were 50 years and older
- 33% were 65 years and older

Gender

- Female
- Male
- Other (0.2%)
- Prefer not to answer (1.5%)

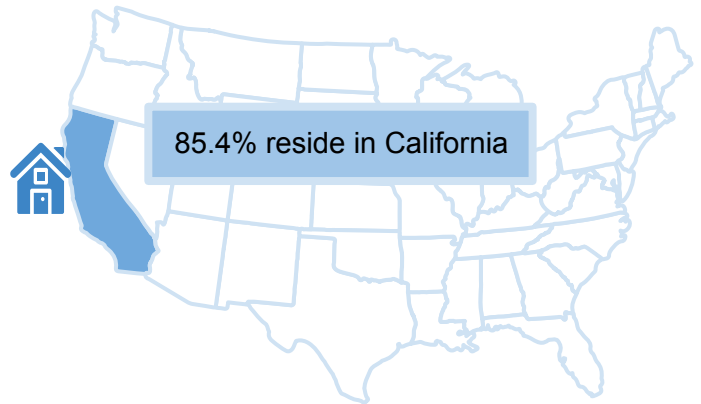


Language of survey completion



Hindi added since February 2022
Samoan added since March 2021

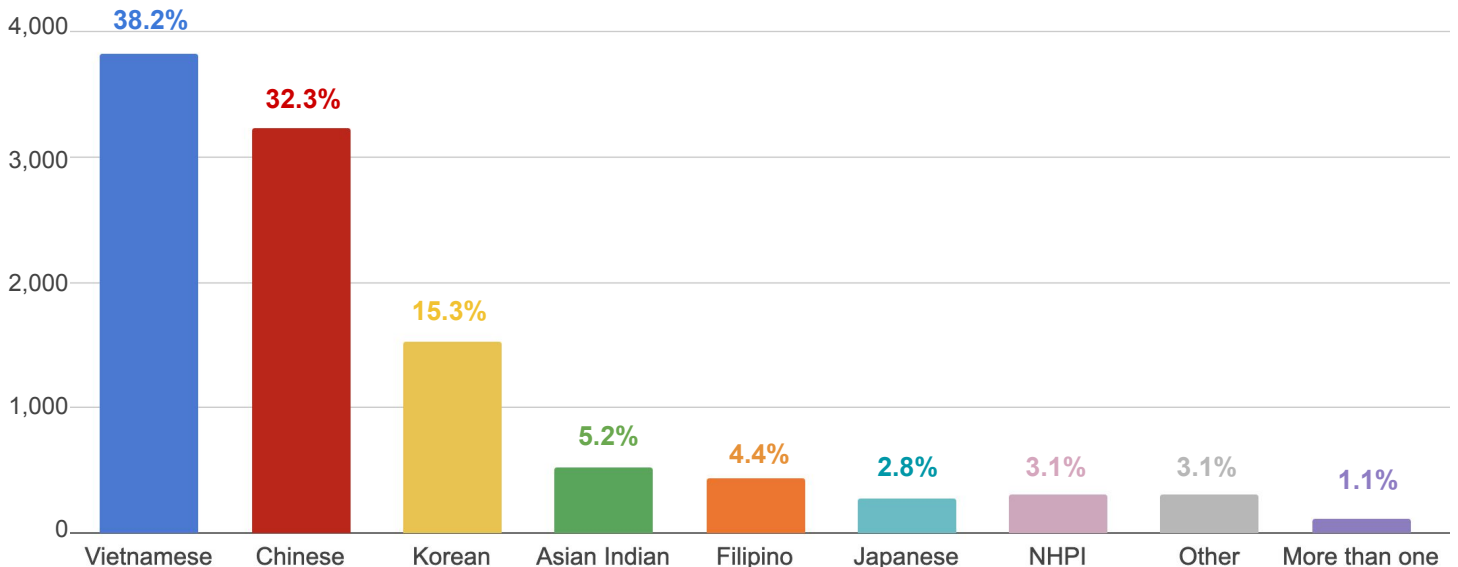
Regions



83.9% born outside the US

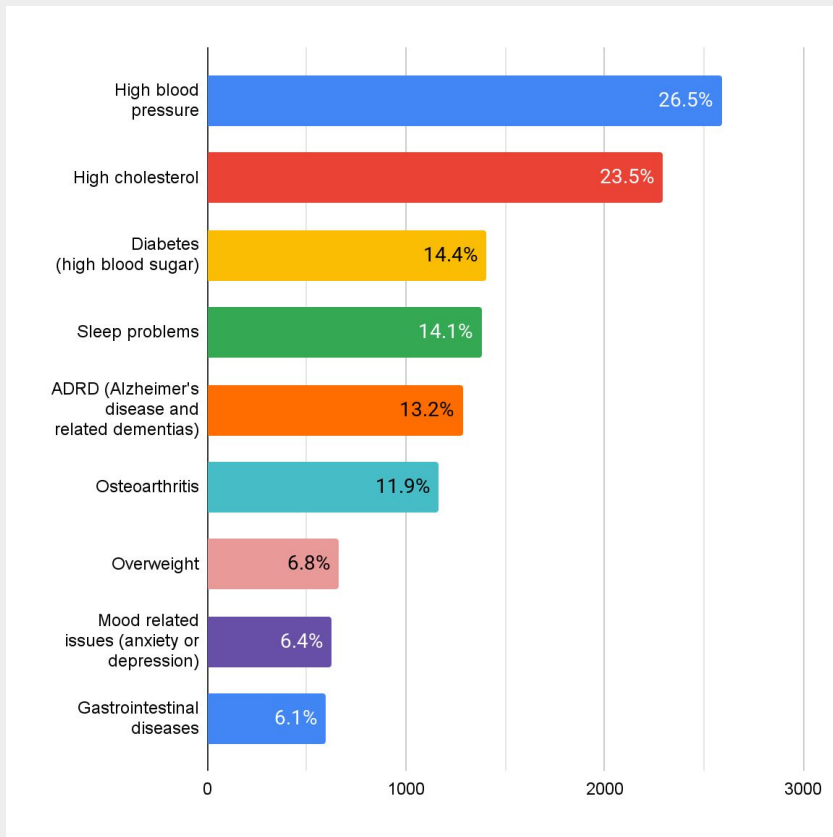
50.9% have limited English proficiency

AANHPI Cultural Groups

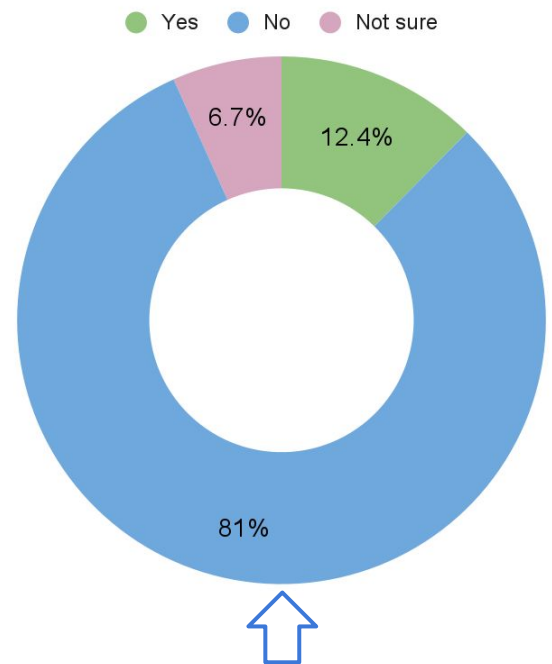


CARE Participant Characteristics

Commonly Reported Health Conditions



Prior research participation experience



81% of participants did not have previous participation experience

Caregiving



24.5% of participants are current caregivers

Among caregivers (n=2390):

- **63.5%** are caring for **minor children** (≤ 18 years old)
- **37.4%** are caring for **older adults** (aged ≥ 50)
- **6.5%** are caring for other **individuals with special needs**
- **5.1%** are caregivers to **more than one group**

"[Dementia] does not announce its arrival but develops gradually in life. I think everyone in our society should be aware of this disease."
- A.G.



[Read our Caregiver Stories](#)



[Watch our Caregiver Stories on Youtube](#)


"Research can be useful for future generations... Hopefully, treatments will be more effective and will be able to delay dementia better than the treatment my mother received many years ago."
-M.N.

CARE-Supported Research Studies

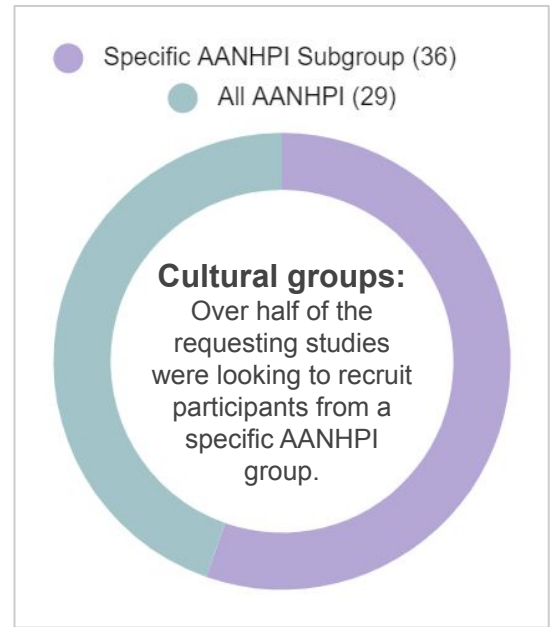
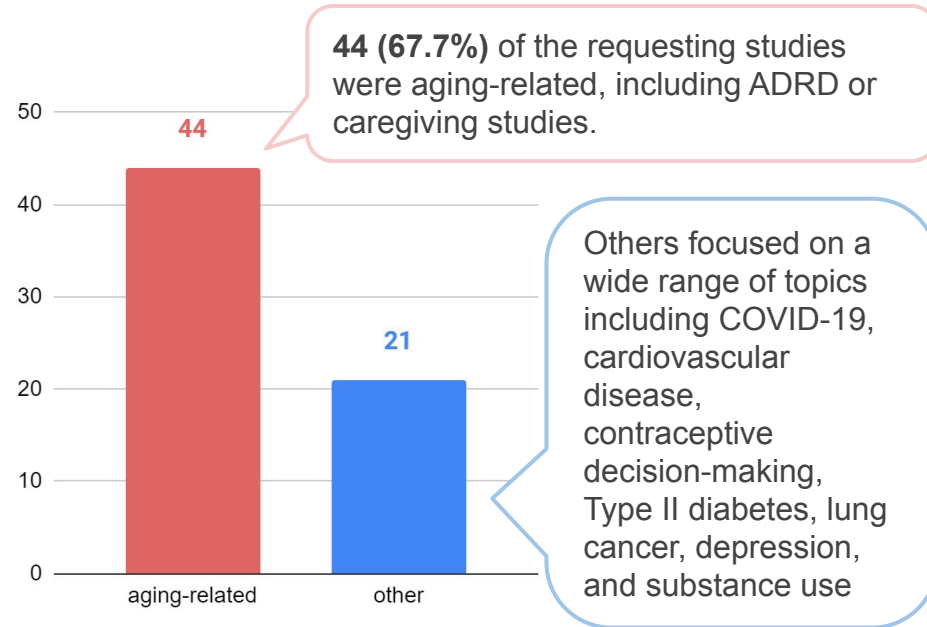
Have CARE increased participation of AANHPI individuals in research studies?

CARE Registry can support recruitment for researchers who want to include AANHPI participants in their studies.

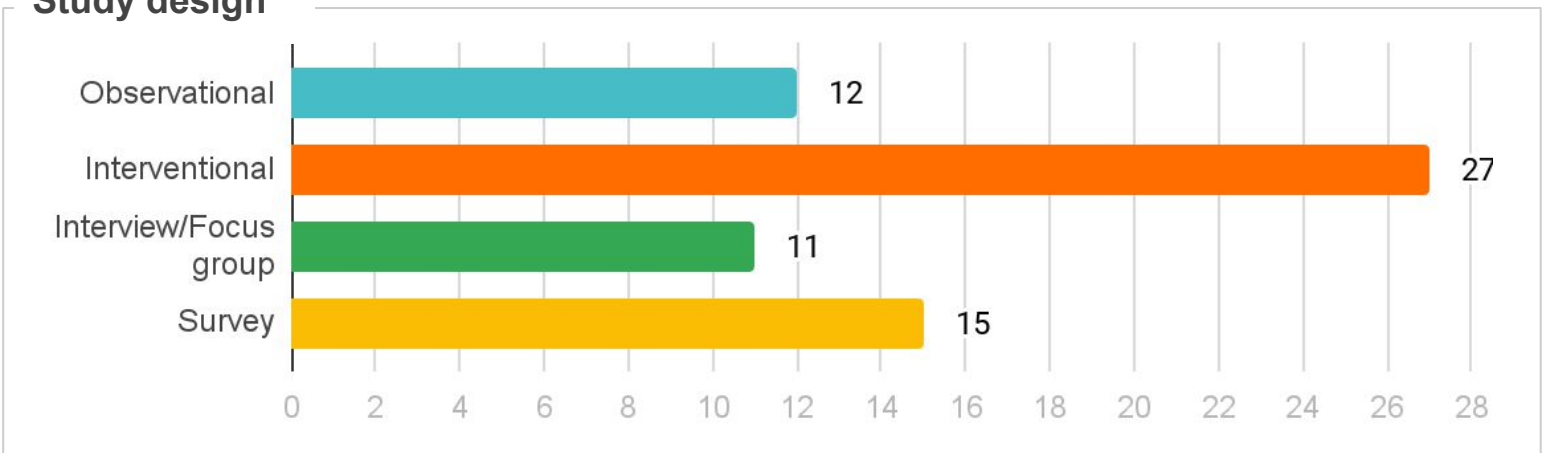
Since January 2021:  Received **65** recruitment referral requests

 **>7,100** CARE participants were referred to **44** studies


Research Areas




Study design




Note: Studies are “observational” when participants are observed or certain outcomes are measured, and no attempt is made to affect the outcome (e.g., no treatment is given). “Interventional” studies refer to a type of clinical study in which participants are assigned to groups that receive one or more intervention/treatment (or no intervention) so researchers can evaluate the effects of the interventions on biomedical or health-related outcomes.

 Click [HERE](#) to view past Brain Trust Meeting recordings and learn about the referral request process.

CARE-Supported Research Studies

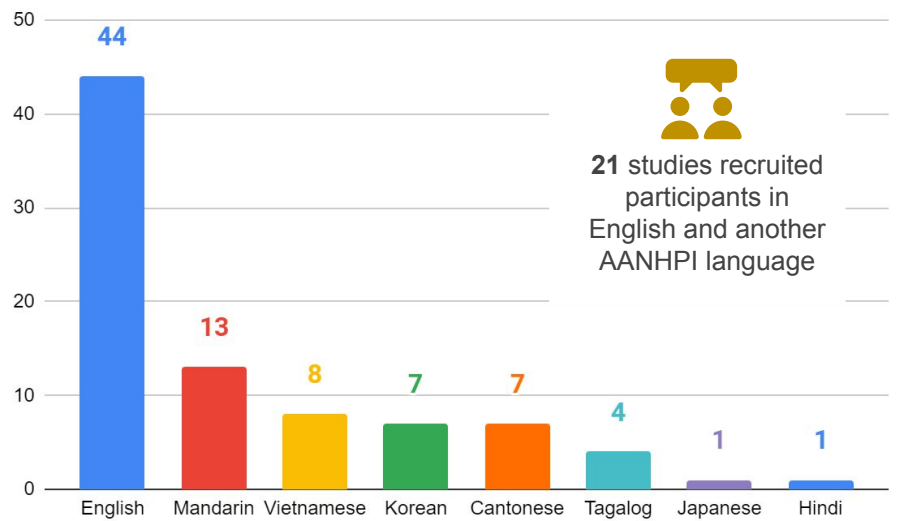
 **44** Studies received referrals of participants from CARE


 **19** additional studies in preparation stage to receive referrals

Studies in the preparation stage include those awaiting IRB approval to receive CARE referral data or awaiting funding support.

Click [HERE](#) for more information about the referral request process.

Languages Supported by Referred Studies



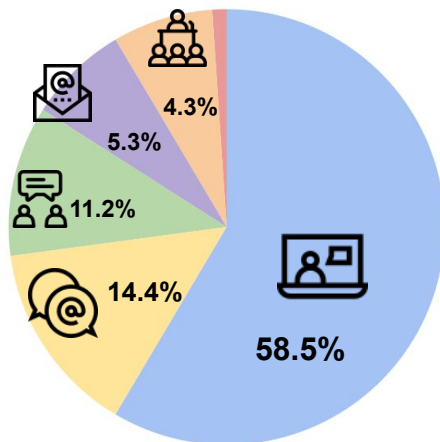
 **21** studies recruited participants in English and another AANHPI language

How did CARE engage AANHPI communities?

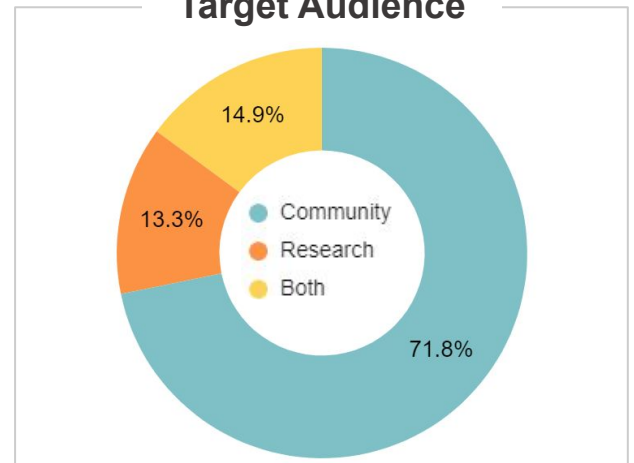
 Conducted **188 outreach activities** as of January 2023

Modes of Outreach

- Virtual presentation (e.g. Zoom)
- Social media
- Health fair
- Other (e.g. newsletters)
- In-person conference or forum
- Radio/TV (0.6%)



Target Audience

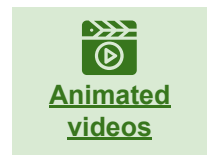


Language Used



Some events were **bilingual or multilingual**

Multilingual Outreach Materials



CARE's Vision and Next Steps

We need your help!



To continue to help address the AANHPI populations' underrepresentation in research, CARE is seeking support to:



Sustain CARE's existing infrastructure including bilingual/bicultural staff & work with academic community partnerships



Provide continual outreach, education, engagement to AANHPI communities (& recruit more participants)



Provide continual education & outreach to the research community



Strategically expand CARE with targeted efforts to other states



Improve CARE's reach with some AANHPI communities such as Filipino, Japanese, Native Hawaiians, Pacific Islanders, & South Asians



Expand on CARE's reach with AANHPI with limited English proficiency and limited access to digital technology

CARE Links



Click [HERE](#) to sign up for the e-newsletter

Click [HERE](#) to learn more about the CARE Ambassadors Program



Click [HERE](#) for current news and events

Click to follow and support us:



Click [HERE](#) to enroll in CARE



Acknowledgements

We extend our deepest appreciation to our registry participants, staff, investigators, community and academic partners, community advisory board members, and the National Institute of Aging (R24AG063718) for their support.

CARE Community Advisory Board

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CARE Community and Academic Partners



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