

CARE Registry 2024 ANNUAL BRIEF REPORT



<https://careregistry.ucsf.edu/>

Established: October 15, 2020



3rd Annual Brief Report



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

Because of your participation,
CARE supported **80** health research studies!



Background:



Asian Americans, Native Hawaiians, and Pacific Islanders (AANHPI) are the **fastest growing racial groups** in the US, comprising **8%** of the population.

However, **less than 1%** of total budget between 1992 - 2018 from the National Institutes of Health (NIH) were for AANHPI research.

[\(Doan, Takata, Sakuma, & Irvin \(2019\), JAMA Network Open\)](#)

≤ 1%

Mission: To improve research participation and reduce health disparities on Alzheimer's disease, aging, caregiving, and other health issues in AANHPI communities.

Languages: (Enrollment survey available in these languages)

English

简体中文 (Simplified Chinese)

繁體中文 (Traditional Chinese)

हिन्दी (Hindi)

Ilokano (coming soon)

日本語 (Japanese)

한국어 (Korean)

Sāmoa (Samoan)

Tagalog

Tiếng Việt (Vietnamese)

How does the CARE registry work?

This is how we increase representation of AANHPI adults in research and improve our community health!

PARTICIPANT (YOU)

ENROLL IN CARE

You complete a brief survey to enroll in CARE

SECURE DATABASE

Your information is saved in CARE's secure database*

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

RESEARCHER

REFERRAL REQUEST

Researchers submit an application to CARE

OBTAIN APPROVAL

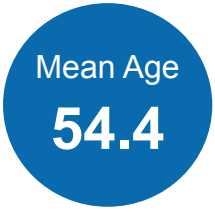
Researcher gets approval to use CARE data from their Institutional Review Board**

*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.

Who enrolled in CARE? (N=10,257)

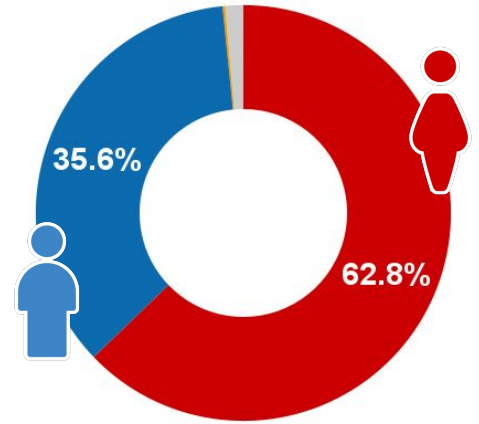
Age



- Range: 18 - 101 years
- 62% were 50 years or older
- 35% were 65 years or older

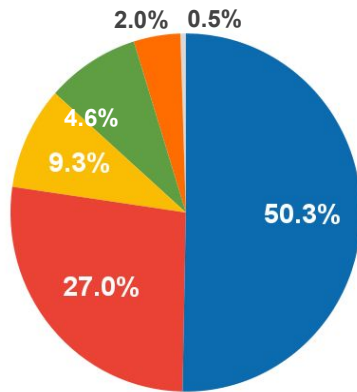
Gender

- Female
- Male
- Other, such as but not limited to transgender and unsure (0.2%)
- Prefer not to answer (1.5%)

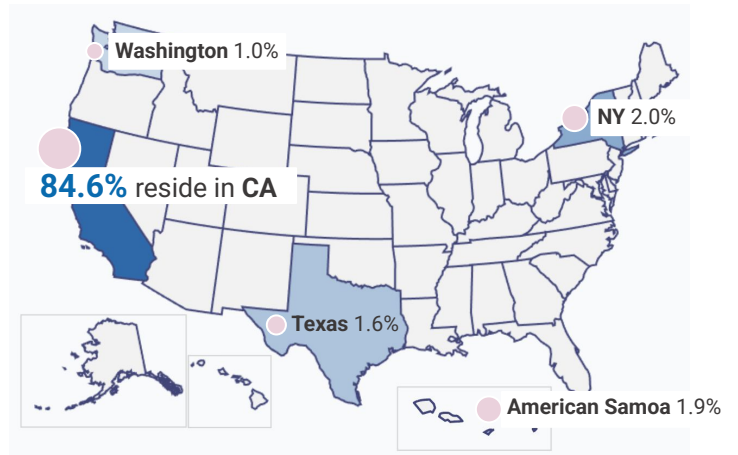


Language of survey completion

- English
- Vietnamese
- Korean
- Simplified Chinese
- Traditional Chinese
- Samoan (Samoan since March 2021)



Regions

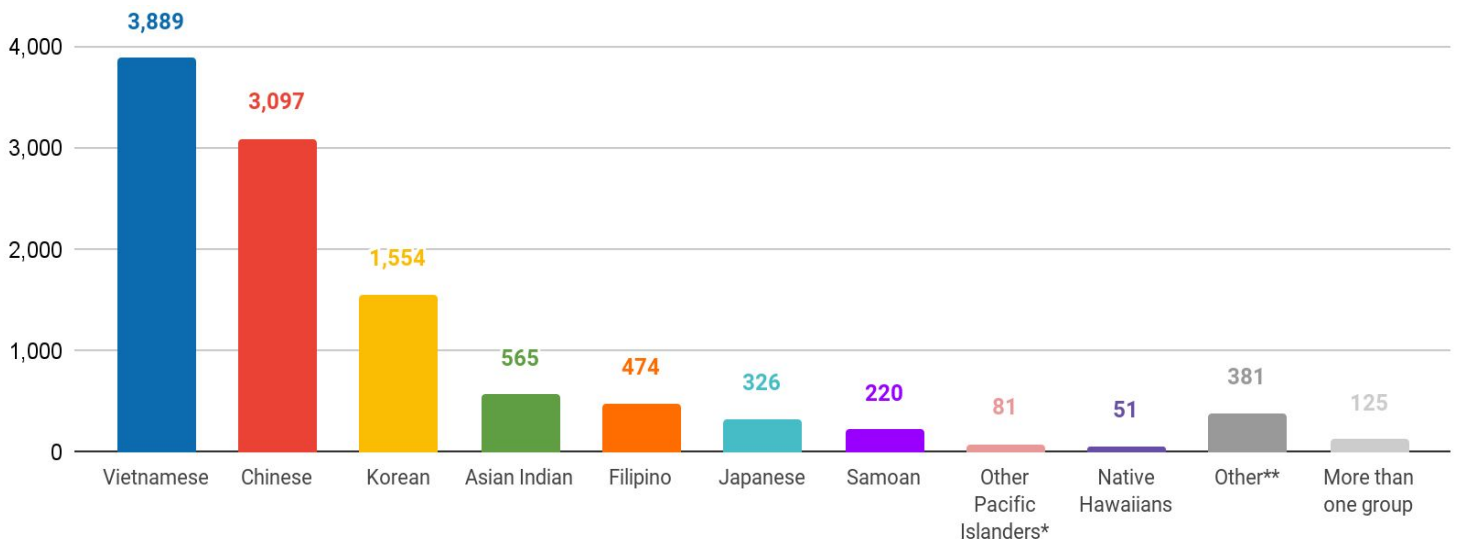


50.1% have **limited English** proficiency



83.2% born outside the US

AANHPI Cultural Groups

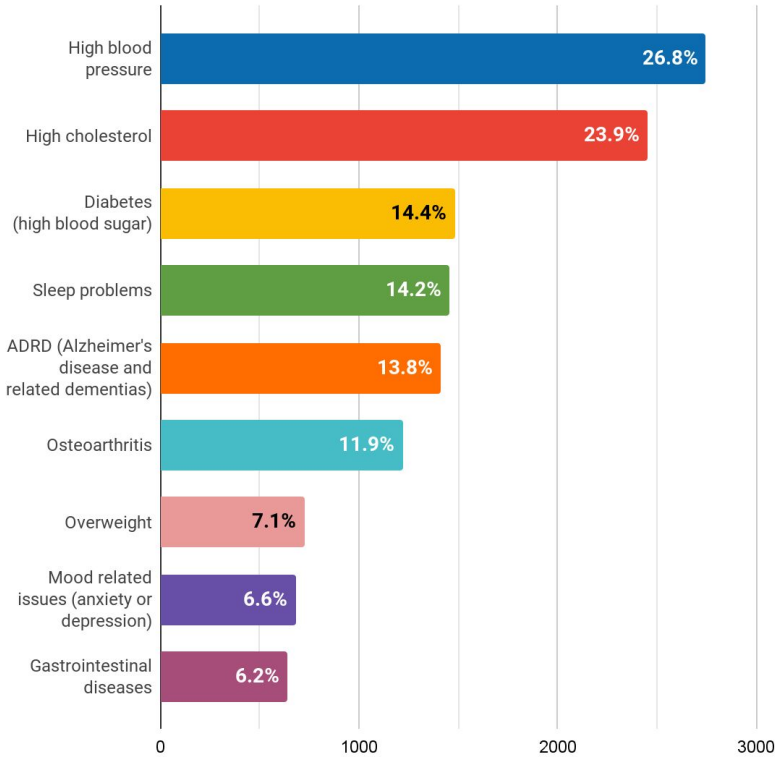


* Chamorro, Tongan, Fijian, Marshallese etc.,

** Nepalese, Pakistani, Cambodian and Hmong... etc.

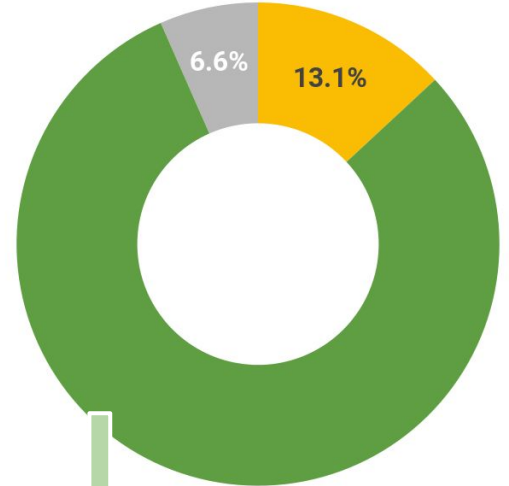
CARE participant characteristics (N=10,257)

Commonly Reported Health Conditions



Prior research participation experience

● Yes ● No ● Not sure



80.3% of participants **did not** have previous participation experience

Caregiving



1/4 of participants are current caregivers

Among caregivers (n=2,525):

63.0% are caring for **minor children** (≤ 18 years old)

38.1% are caring for **older adults** (aged ≥ 50)

6.3% are caring for other **individuals with special needs**

7.0% are caregivers to **more than one group**



"And I remembered thinking that it really did take a lot of love and compassion, and a lot of patience to become a caregiver especially [for] those with dementia..."

S.T.

"Research is very important to help people live out a dignified life. I'm angry because I feel they are being robbed of fully enjoying a wonderful fulfilled life that they both deserve."

J.Y.



[Watch our Caregiver Stories on Youtube](#)

CARE-supported research studies

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.



recruitment referral requests received since January 2021.



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.



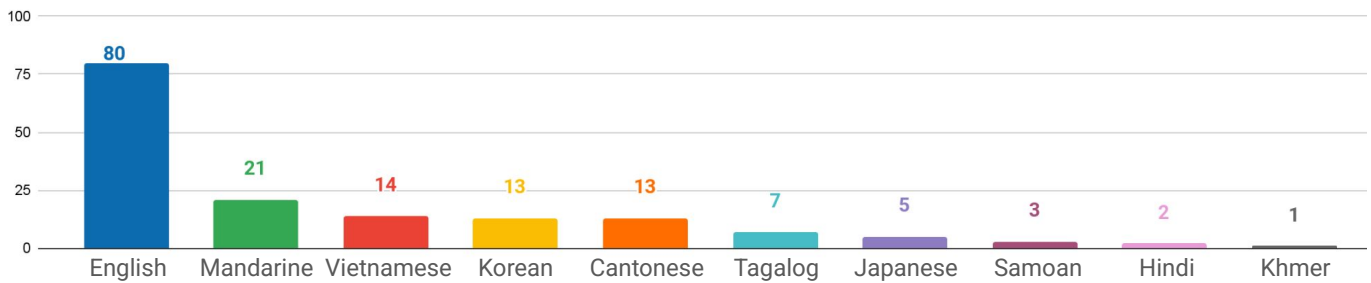
referrals were made to CARE-supported studies.

Referral outcome findings will be available soon.

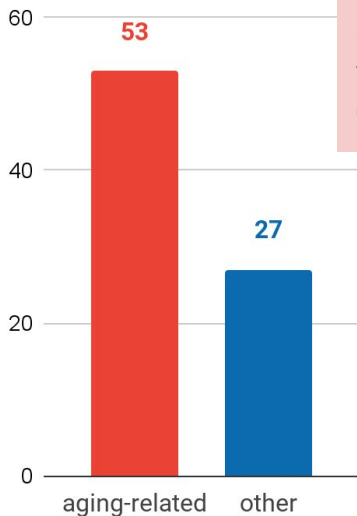


With your help, we are actively enhancing the representation of **AANHPI communities in health research**, and this is just the beginning. **Thanks for your support!**

Languages Supported by Referred Studies

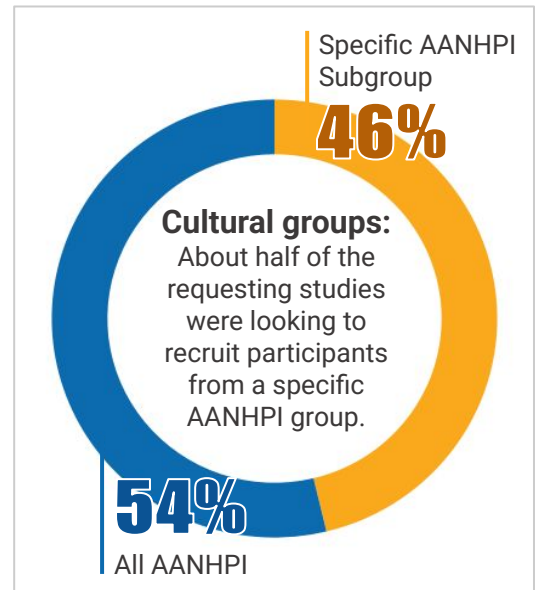


Research Areas



53 (66.3%) of the requesting studies were aging-related, including ADRD or caregiving studies.

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



[View](#) past **Brain Trust Meeting** recordings and learn about the referral request process.

Researcher testimonials



"It's [a] very, very easy registration process[...] The CARE registrants we reached out to were already interested in research and once they are enrolled in our study, they are very committed."

Dr. Christina Miyawaki | Associate Professor, Univ. of Houston

"I am extremely 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."

Dr. William Tsai | Assistant Professor, New York University



"Our study has a large sample of American Samoa adults that requires a community engagement process to build trust to begin recruitment. The CARE registry allowed us immediate access to eligible participants to recruit, while our team engaged the community to recruit more eligible participants."

Va'atausili Tofaeono | Executive Director, American Samoa Community Cancer Coalition (ASCCC)

"A registry like CARE is very important for clinical research recruitment from underserved populations. It saves researchers' time in recruitment and allows innovative research to take place immediately."

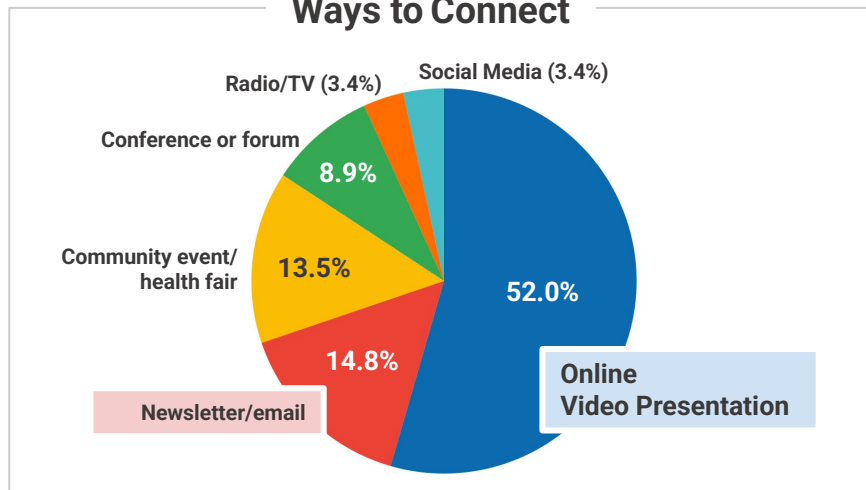
Dr. Alicia Hong | Professor, George Mason University



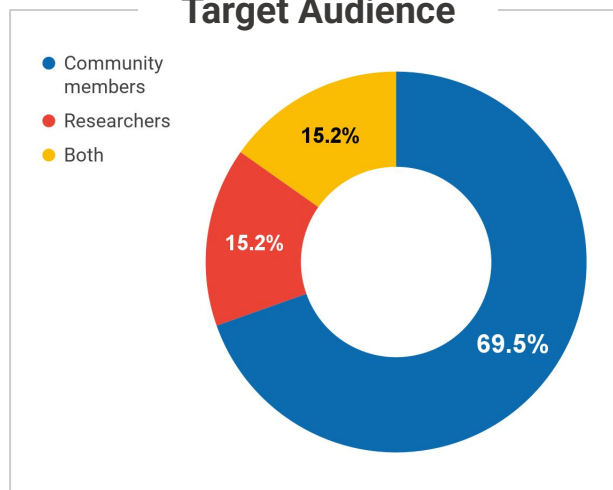
How did CARE engage AANHPI communities?

Conducted **246 outreach activities** as of September 2024

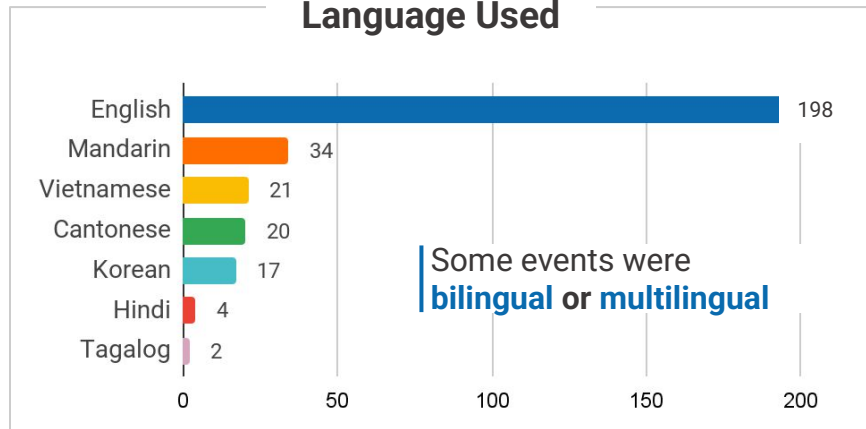
Ways to Connect



Target Audience



Language Used



Multilingual Outreach Materials

[Examples of Outreach](#)

[Flyers](#)

[Zoom Recordings](#)

[Animated videos](#)



We're just getting started to make a difference together!

CARE's vision and next steps



Sustain CARE's existing infrastructure, including our multicultural and multilingual team, and collaborate with academic and community partners



Provide continual outreach, education, and engagement to AANHPI communities to recruit another 10,000+ participants



Provide continual education & outreach to the research community



Strategically expand CARE with targeted efforts to other states beyond California



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



[Enroll](#) in CARE



Check our current [news](#)



Sign up for the quarterly [e-newsletter](#)



Learn more about the [CARE Ambassadors Program](#)

Follow and support us:



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 for their support.

CARE community advisory board

Alka M. Kanaya	Hye-Won (Grace) Shin	Lindsey Ilagan	Rejie Marie Balaoyos
Araceli Antonio	Joyce Cheng	Michael Weiner	Ryan Kawamoto
Becky Nguyen	Jennifer Masuda	Natalie Ah Soon	Sadhna Diwan
Christina Miyawaki	Joyce Javier	Paz Velasquez	Samira Khan
Daphne Kwok	Justina P. Tavanā	Phuong Christine Nguyen	Sophie C. Horiuchi-Forrester
David Choi	Kekoa Lopez-Paguyo	Poki'i Balaz	Tammie Pitkin
Edie Yau	Lina Park	Quyên Tiet	Taunu'u Ve'e
Eun Jeong Lee	Leezel Tanglao	Ranak B. Trivedi	Va'atausili Tofaeono

CARE community and academic partners

