

# CARE Registry

## 2025 ANNUAL BRIEF REPORT



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

Established: October 15, 2020



4th Annual Brief Report

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CARE has

**15,105** participants

(as of Sept 22, 2025)

Because of your participation,

CARE supported **107** 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 awarded funding 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.

### RESEARCHER

#### REFERRAL REQUEST

Researchers submit an application to CARE

#### OBTAIN APPROVAL

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

*YOU DECIDE IF YOU WISH TO PARTICIPATE*

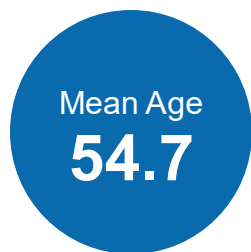
***There's NO cost to YOU  
or the RESEARCHERS***

\*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=15,105)

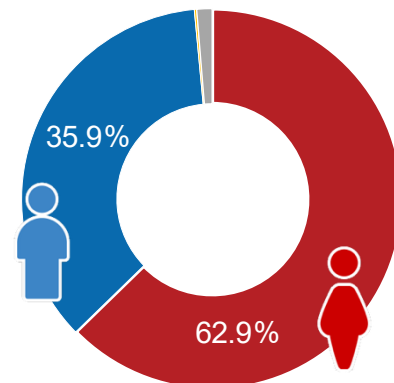
### Age



- Range: 18 - 103 years
- 62% were 50 years or older
- 37% were 65 years or older

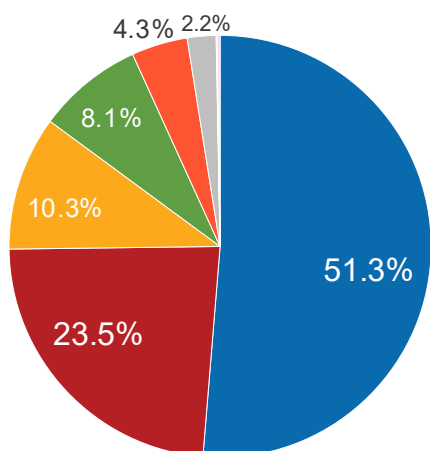
### Gender

- Female
- Male
- Other, such as but not limited to transgender and unsure (0.2%)
- Prefer not to answer (1.3%)

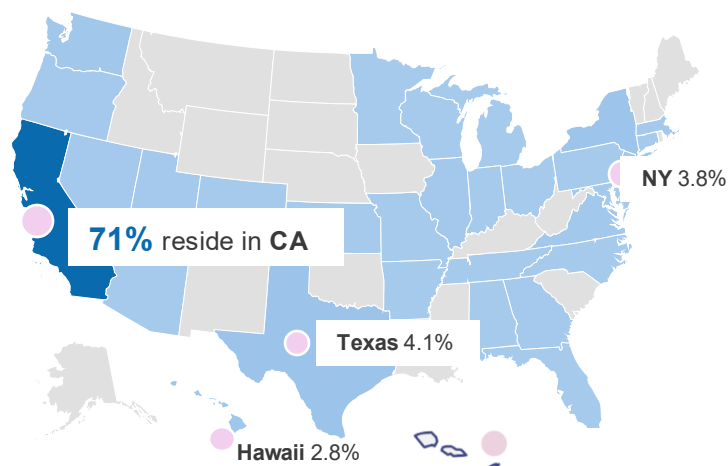


### Language of survey completion

- English
- Vietnamese
- Korean
- Simplified Chinese
- Traditional Chinese
- Samoan (Since March 2021)
- Japanese (0.05%)
- Tagalog (0.05%)



### Regions



**45.1%**

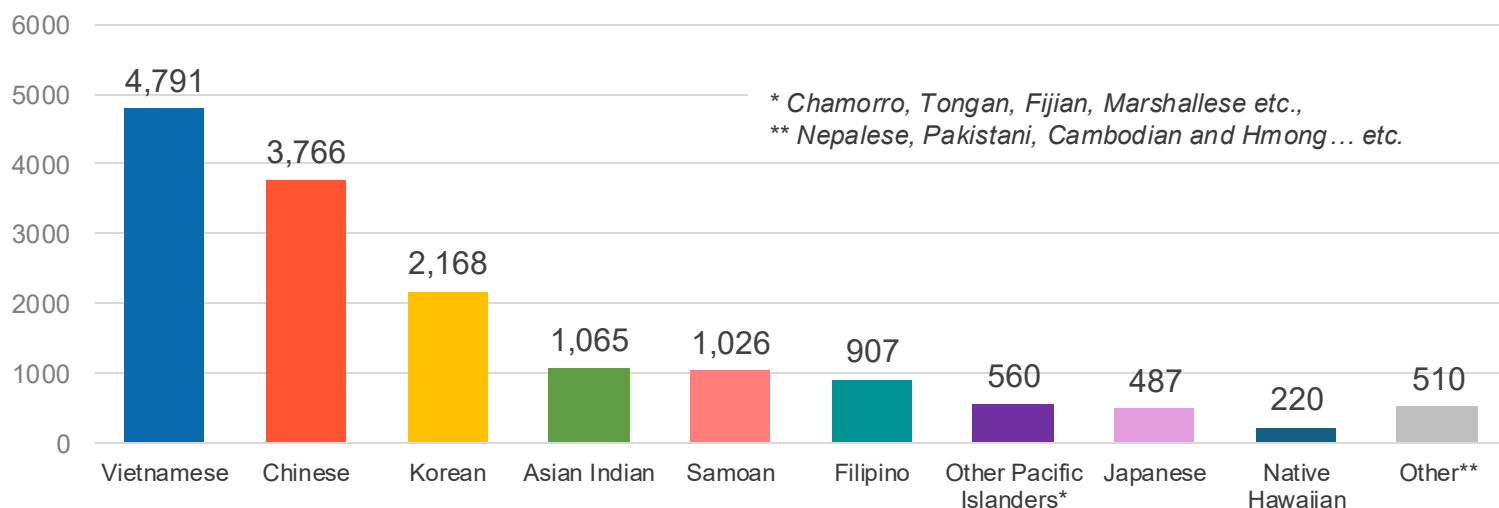
have **limited English** proficiency



**81.2%**

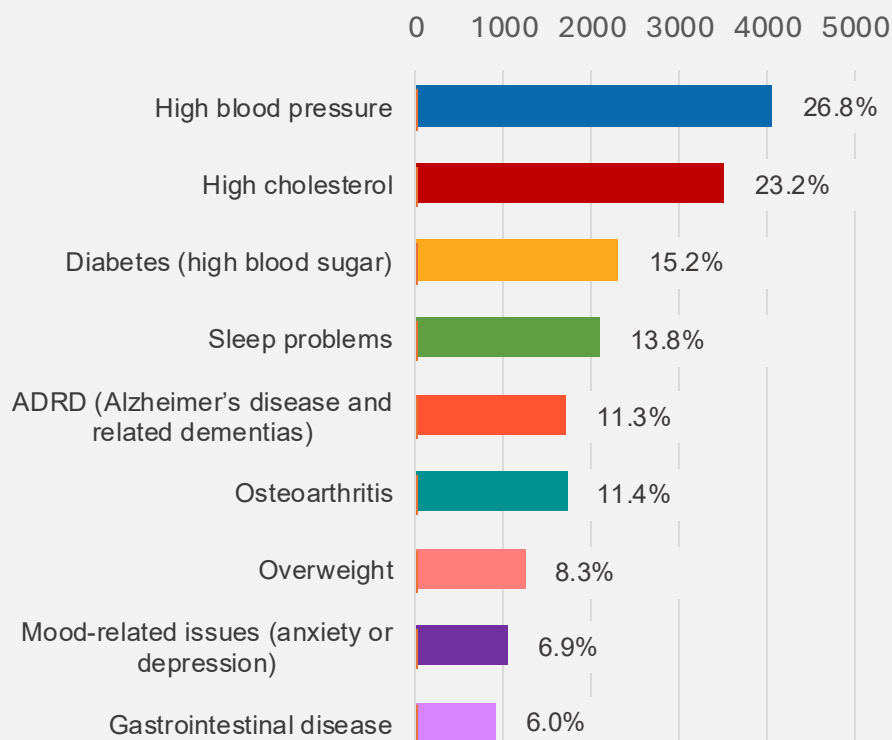
born **outside** the US

## AANHPI Cultural Groups *(Individuals may identify with more than 1 cultural group)*

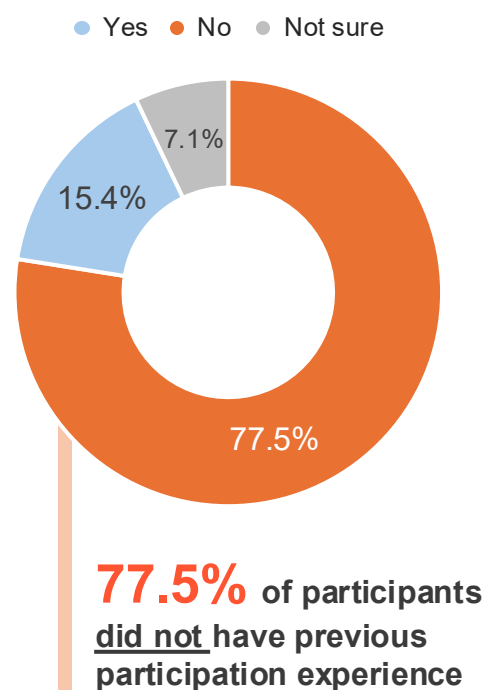


## CARE participant characteristics (N=15,105)

### Commonly Reported Health Conditions



### Prior research participation experience



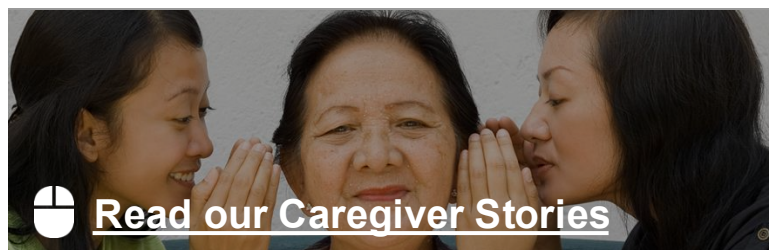
### Caregiving



of participants are current caregivers

Among caregivers (n=3,661):

- 58.8%** are caring for **minor children** ( $\leq 18$  years old)
- 43.5%** are caring for **older adults** (aged  $\geq 50$ )
- 6.8%** are caring for other **individuals with special needs**
- 8.6%** are caregivers to **more than one group**



[Read our Caregiver Stories](#)

*"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..."*

*"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."*



[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.

38 more studies are in the preparation stage (e.g., awaiting funding or IRB approval), and 22 did not receive support after consultation.



Nearly **17,400**

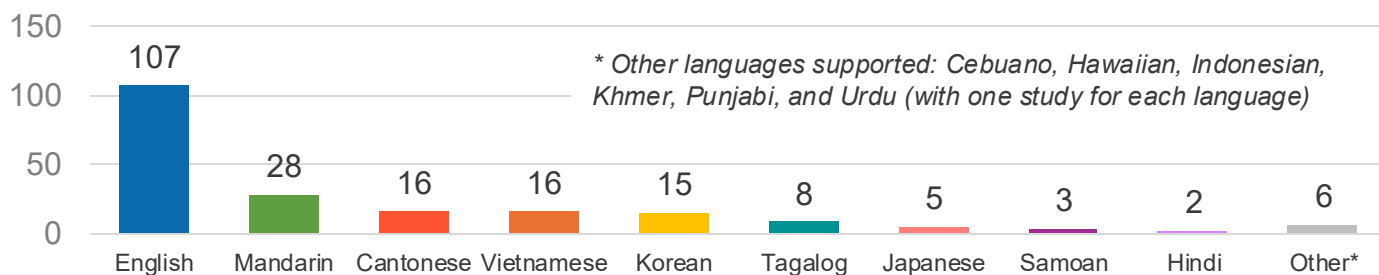
referrals were made to CARE-supported studies.

Referral outcome findings will be available soon.

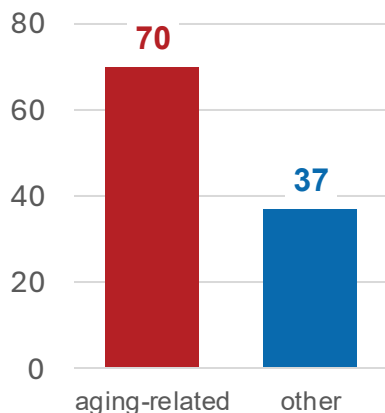


With your help, we are actively enhancing the representation of **AANHPI communities in health research**, and this is just the beginning. **Thanks for your support!**

### Languages Supported by Referred Studies



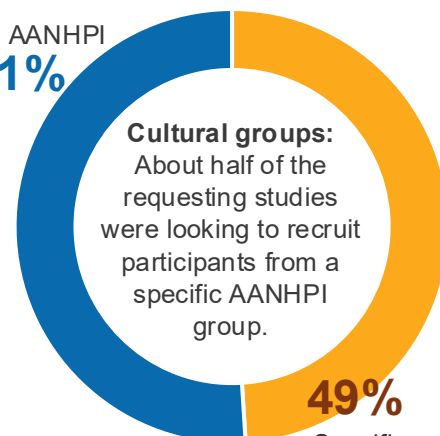
### Research Areas



**70 (65.4%)** of the requesting studies were aging-related, including AD/RD or caregiving studies.

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

All AANHPI  
**51%**



**Cultural groups:**  
About half of the requesting studies were looking to recruit participants from a specific AANHPI group.

Specific AANHPI Subgroup



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

## Researcher testimonials



Stacey L. Schepens Niemiec,  
PhD, OTR/L, DipACLM  
*Associate Professor,  
Univ. of Southern California*

CARE Registry has helped me connect with Asian, Native Hawaiian, and Pacific Islander communities in the greater Los Angeles area that I was not reaching before collaborating with CARE. Being able to do remote, targeted outreach and connect with people in their preferred language has made a huge difference in our recruitment success.



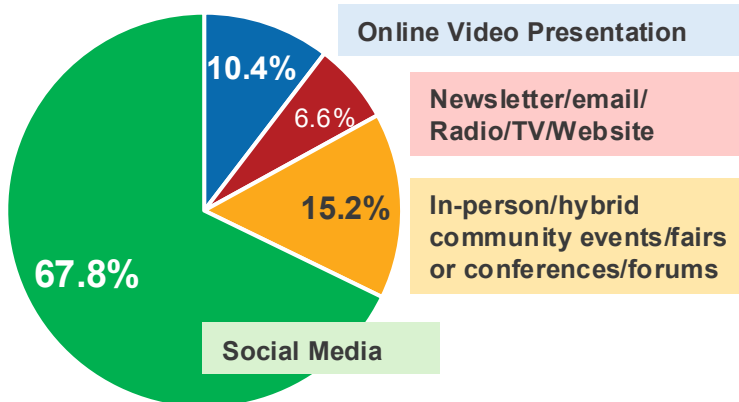
Kaipeng Wang, PhD  
*Associate Professor, Univ. of Denver*

With CARE's support, I was able to recruit older Vietnamese and Filipino participants to my study. It's an easy process and appreciate the support from CARE registry team.

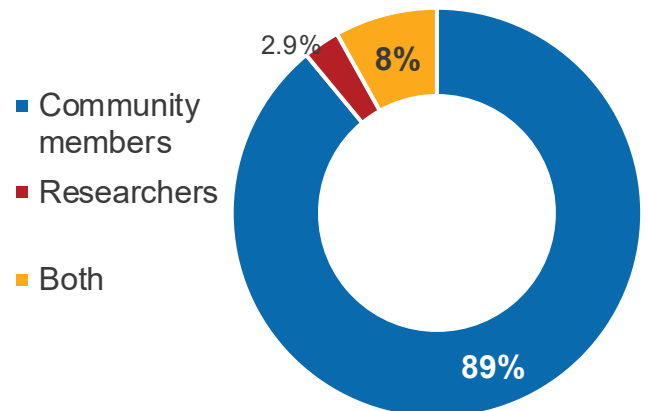
## How did CARE engage AANHPI communities?

Conducted **1,535+ outreach activities** as of September 2025

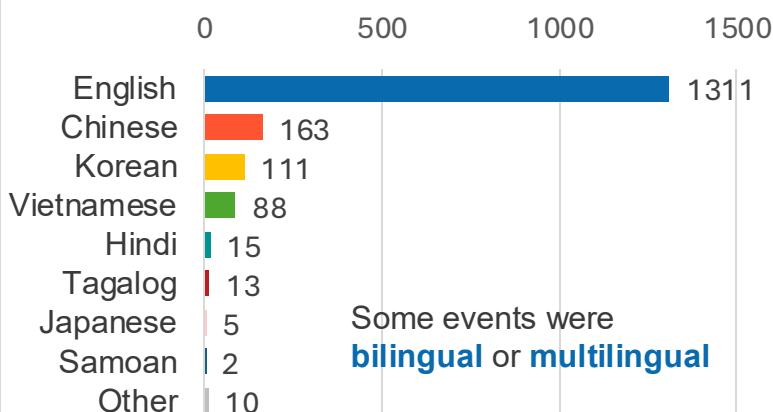
### Ways to Connect



### Target Audience



### Language Used



### Multilingual Outreach Materials





***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	Quyen Tiet	Taunu'u Ve'e
Eun Jeong Lee	Leezel Tanglao	Ranak B. Trivedi	Va'atausili Tofaeono

## CARE community and academic partners\*

\* Partners who have collaborated with CARE and contributed to recruitment and outreach efforts.

