



HEALTH ACROSS THE LIFE SPAN

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

**Brief Report from the CARE Registry
October 2020 ~ March 2022
A Focus on Asian American & Pacific Islander
(AAPI) Communities and Aging**

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 and Pacific Islander (AAPI) 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](#))

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 among AAPIs.



To give AAPIs 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 AAPIs.

Languages Available:

English
Samoan (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

Launch Date: October 15, 2020

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UCSF IRB Protocol #: 19-28027

Acknowledgements

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CARE Key Partners



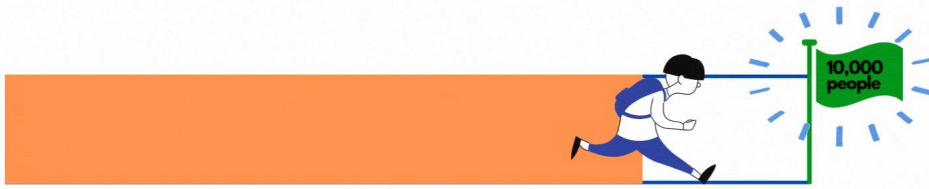
CARE Community Advisory Board

- | | |
|------------------------------|----------------------|
| Araceli Antonio | Stephanie Nguyen |
| Joyce Cheng | Paula Palmer |
| David Choi | Lina Park |
| Sadhna Diwan | Hye-Won (Grace) Shin |
| Sophie C. Horiuchi-Forrester | Natalie Ah Soon |
| Joyce Javier | Boon Lead Tee |
| Ryan Kawamoto | Quyen Tiet |
| Ruobing Li | Bexx Toomalatai |
| Tatiana Makoni | Ranak B. Trivedi |
| Gerard Manuel | Jennifer Wang |
| Jennifer Masuda | Michael Weiner |
| Becky Nguyen | Edie Yau |
| Phuong Christine Nguyen | |

CARE Community Partners



CARE Participants Demographics



Enrollment Number:
7,810 participants
(as of March 13, 2022)

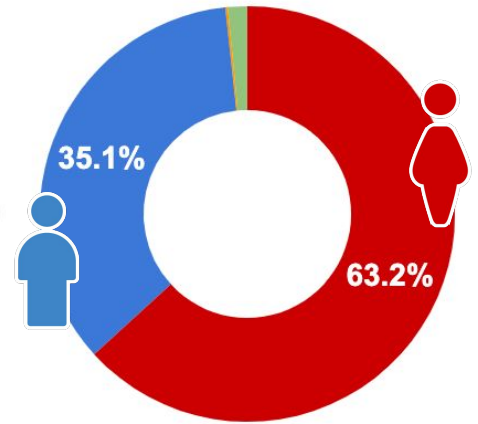
Age

Mean Age
53.5

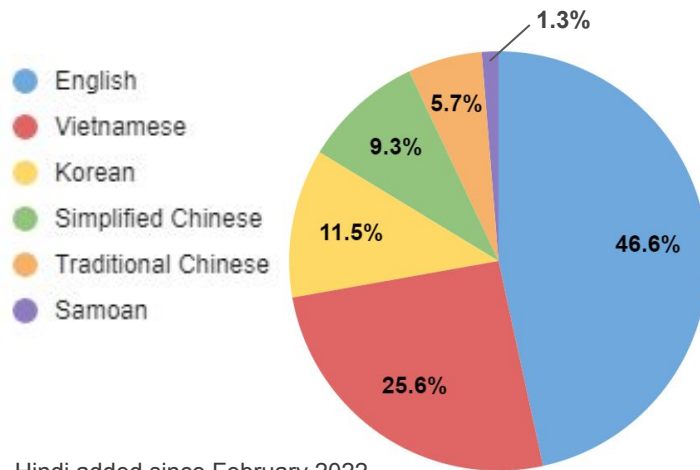
- Range: 18 - 99 years
- 51% were 50 years and older
- 32% were 65 years and older

Gender

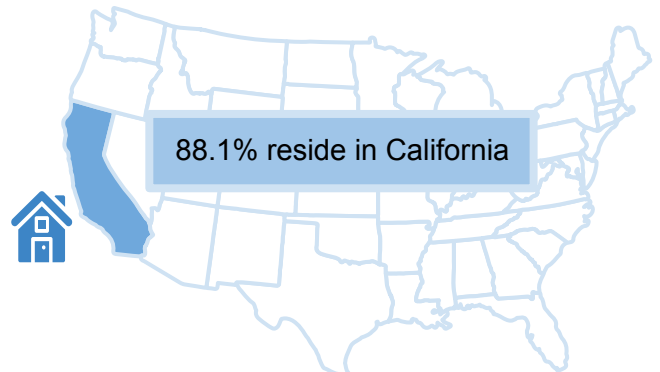
- Female
- Male
- Other (0.2%)
- Prefer not to answer (1.5%)



Language of survey completion



Regions

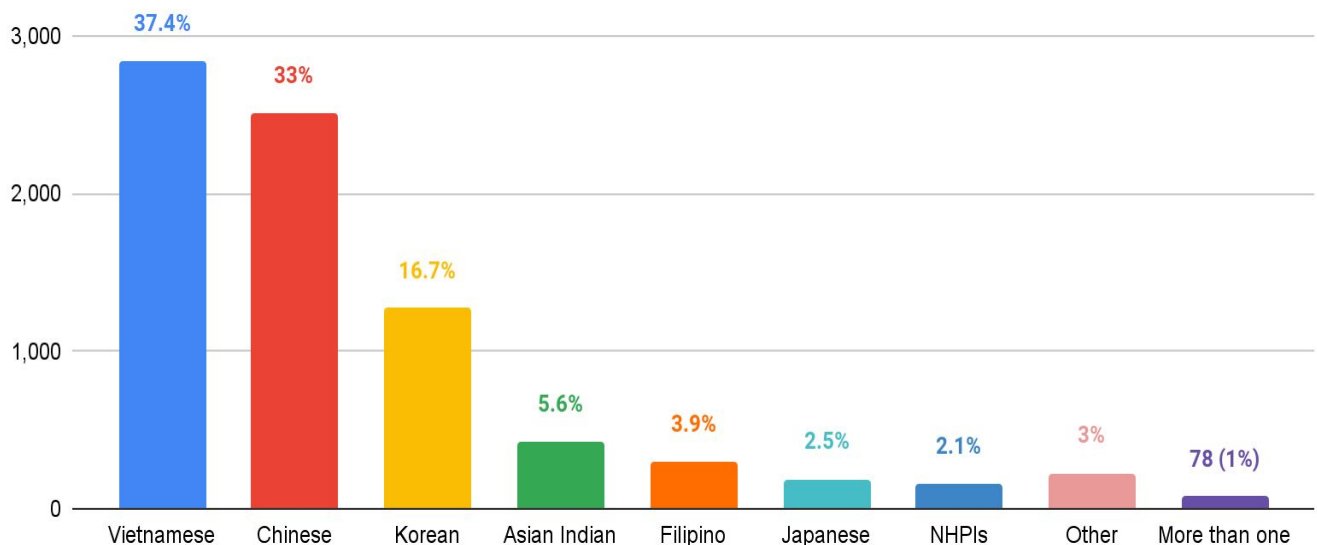


Hindi added since February 2022
Samoan added since March 2021

59.5% have limited English proficiency

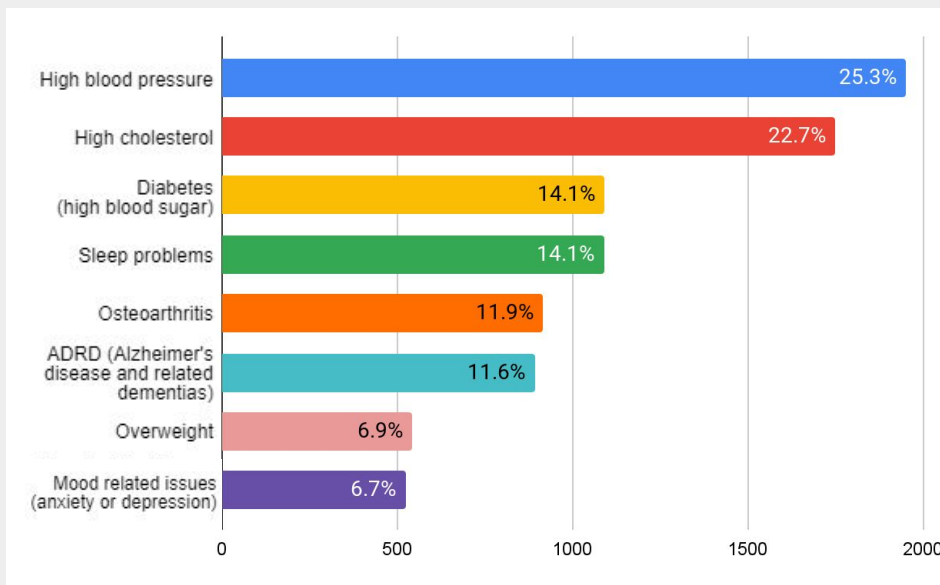
84.5% born outside the US

Cultural Groups

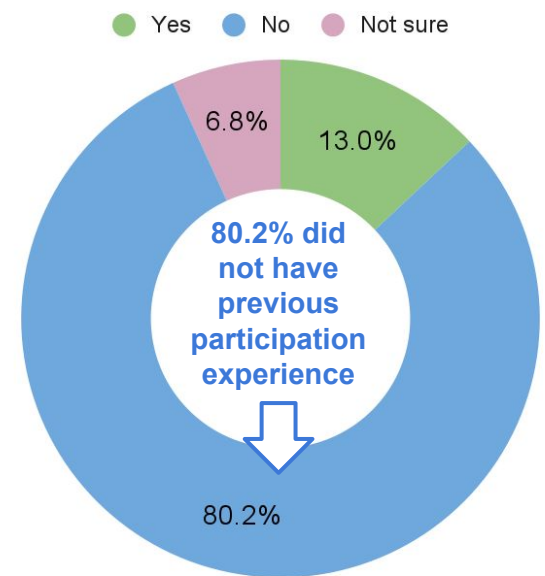


CARE Participant Demographic

Commonly Reported Health Conditions



Prior experience in research participation

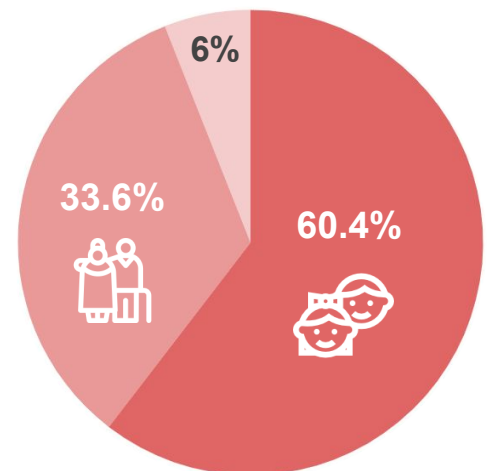


Caregiving

25.9% of participants are current caregivers

Among caregivers:

- I am caring for minor children (≤ 18 years old)
- I am caring for older adults (aged ≥ 50)
- I am caring for other individuals with special needs



"[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](#)

"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.

"Many people don't recognize dementia, and not recognizing it can lead to death. Most caregivers are unprepared to manage dementia in their own family." - Q.V.

CARE Referral Requests from Research Investigators

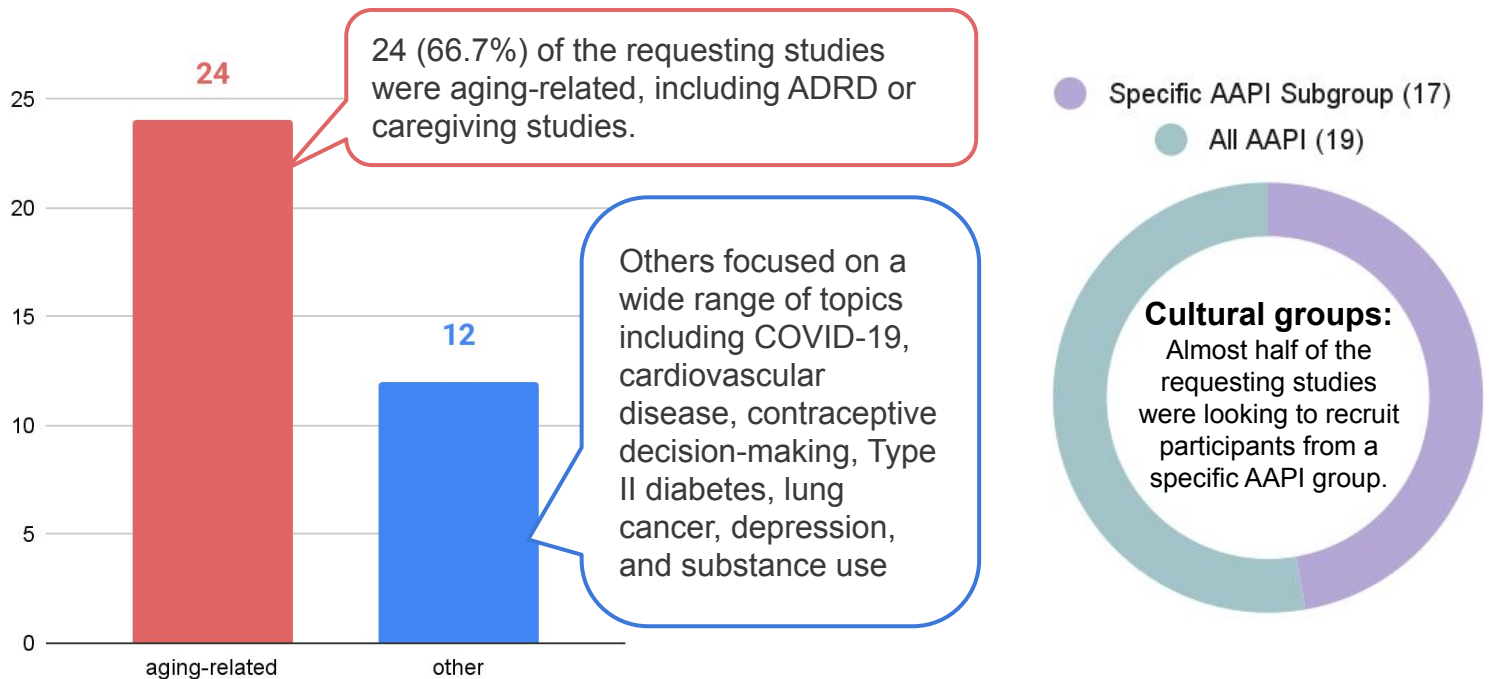
CARE Registry can support recruitment for researchers who want to include the AAPIs in their studies.

 Received 36 recruitment referral requests from January 2021 through March 2022

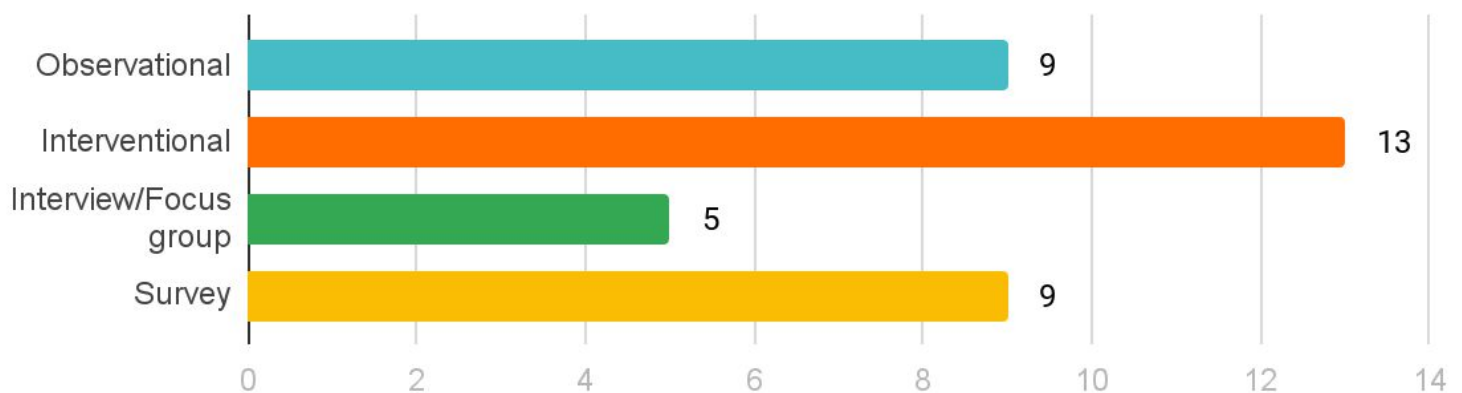
Click [HERE](#) to view past Brain Trust Meeting recordings and learn about the referral request process



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.

CARE Referral Requests from Research Investigators

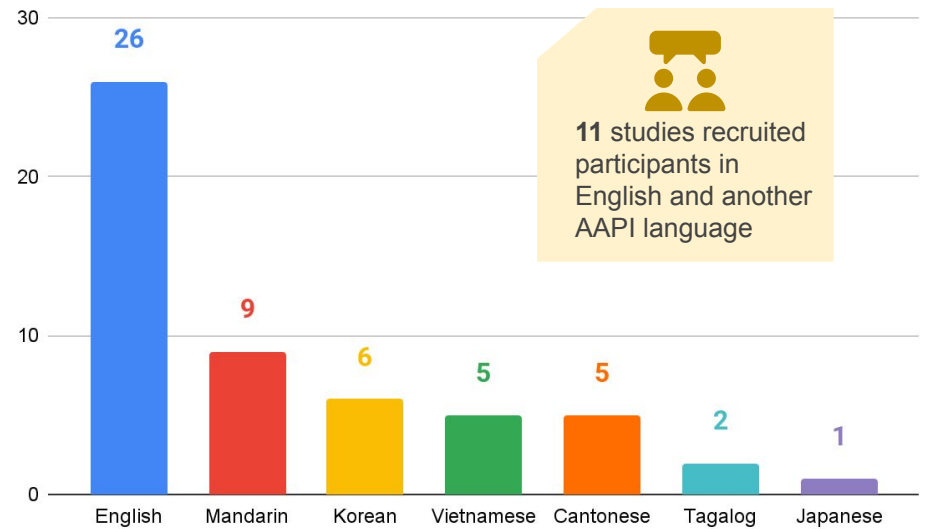
As of February 2022, **2,289** CARE participants were referred to 26 studies.

26 Referred studies

10 Studies in preparation stage

The remaining 10 studies are in the preparation stage (e.g., awaiting IRB approval) to receive the CARE registry referral data.

Languages Supported by Referred Studies

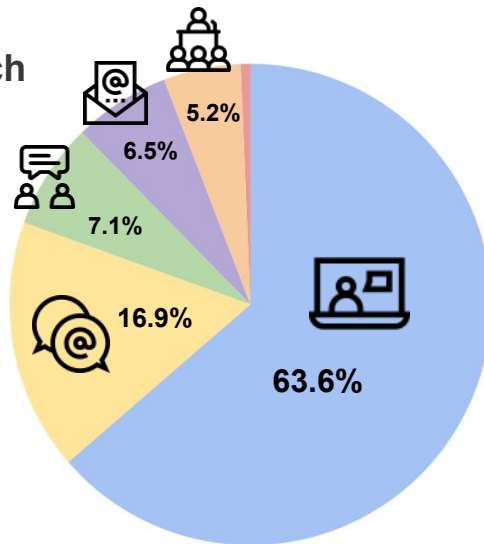


Outreach Activities

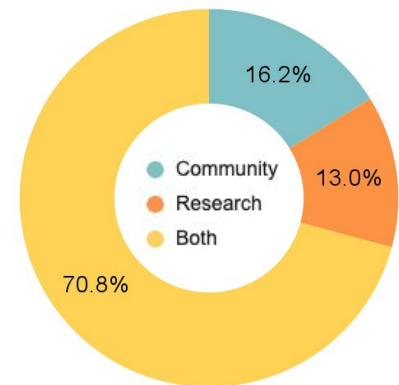
Conducted **154 outreach activities** as of February 2022

Modes of Outreach

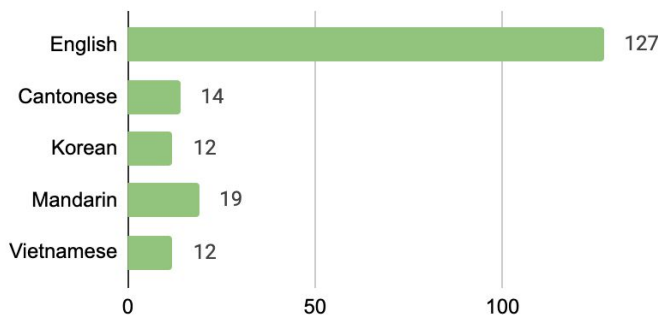
- Virtual presentation (e.g. Zoom)
- Social media
- Health fair
- Other (e.g. newsletters)
- In-person conference or forum
- Radio/TV (0.6%)



Target Audience

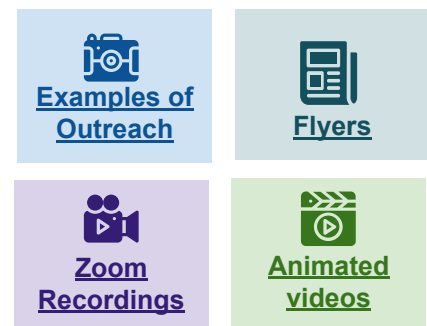


Language Used



Some events were **bilingual**

Multilingual Outreach Materials



CARE's Vision and Next Steps

We need your help!



To continue to help address AAPIs' 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 AAPI 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 AAPI communities such as Filipino, Japanese, Native Hawaiians, Pacific Islanders, & South Asians



Expand on CARE's reach with AAPIs 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

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Click [HERE](#) to enroll in CARE

