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:

Launch Date: October 15, 2020

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UCSF IRB Protocol #: 19-28027
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CARE Key Partners

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- Natalie Ah Soon
- Boon Lead Tee
- Quyen Tiet
- Bexx Toomalatai
- Ranak B. Trivedi
- Jennifer Wang
- Michael Weiner
- Edie Yau

CARE Community Partners

- Alzheimer’s Association
- UCI MIND Institute for Memory Impairments and Neurological Disorders
- UC Davis Health
- UCSF
- MASALA
- National Asian Pacific Center on Aging
- ICAN
- Alzheimer’s California
- AARP
- OATS
- Vietnamese American Cancer Foundation
- Somang Society
- Optimal Aging Center
- Asian American Senior Citizens Service Centers
- Arch
- Ye-Ai Kui
- Asian Health Services
- Chinese Community Health Resource Center
- Asian American Resource and Information Network
- BrainHealth Registry

CARE Community Advisory Board
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: 35.1%
- Male: 63.2%
- Other (0.2%)
- Prefer not to answer (1.5%)

Language of survey completion

- English: 46.6%
- Vietnamese: 11.5%
- Korean: 25.6%
- Simplified Chinese: 9.3%
- Traditional Chinese: 5.7%
- Samoan: 1.3%
- Hindi added since February 2022
- Samoan added since March 2021

Regional distribution

- 88.1% reside in California
- 84.5% born outside the US

Cultural Groups

- Vietnamese: 37.4%
- Chinese: 33%
- Korean: 16.7%
- Asian Indian: 5.6%
- Filipino: 3.9%
- Japanese: 2.5%
- NHPs: 2.1%
- Other: 3%
- More than one: 78 (1%)
**Caregiving**

25.9% of participants are current caregivers

“[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.

“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.

**Commonly Reported Health Conditions**

- High blood pressure: 25.3%
- High cholesterol: 22.7%
- Diabetes (high blood sugar): 14.1%
- Sleep problems: 14.1%
- Osteoarthritis: 11.9%
- ADRD (Alzheimer’s disease and related dementias): 11.6%
- Overweight: 6.9%
- Mood related issues (anxiety or depression): 6.7%

**Prior experience in research participation**

- 80.2% did not have previous participation experience
- 13.0% Yes
- 6.8% No
- 6% Not sure

**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

Last updated: March 2022
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

24 (66.7%) 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, contraceptive decision-making, Type II diabetes, lung cancer, depression, and substance use

Cultural groups:
Almost half of the requesting studies were looking to recruit participants from a specific AAPI group.

Study design

<table>
<thead>
<tr>
<th>Study Design</th>
<th>Specific AAPI Subgroup (17)</th>
<th>All AAPI (19)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Observational</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td>Interventional</td>
<td></td>
<td>13</td>
</tr>
<tr>
<td>Interview/Focus group</td>
<td></td>
<td>5</td>
</tr>
<tr>
<td>Survey</td>
<td></td>
<td>9</td>
</tr>
</tbody>
</table>

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

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

- **26** referred studies
- **9** studies in English
- **6** studies in Mandarin
- **5** studies in Korean
- **5** studies in Vietnamese
- **2** studies in Cantonese
- **1** study in Tagalog
- **1** study in Japanese

Outreach Activities

Conducted 154 outreach activities as of February 2022.

- **63.6%** virtual presentation (e.g., Zoom)
- **16.9%** social media
- **7.1%** health fair
- **6.5%** other (e.g., newsletters)
- **5.2%** in-person conference or forum
- **1.6%** radio/TV

Language Used

- **English**: 127
- **Cantonese**: 14
- **Korean**: 12
- **Mandarin**: 19
- **Vietnamese**: 12

Some events were bilingual.

Target Audience

- **70.8%** community
- **16.2%** research
- **13.0%** both

Multilingual Outreach Materials

- Examples of Outreach
- Flyers
- Zoom Recordings
- Animated videos
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 enroll in [CARE](#)
- 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