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

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
- Samoan (Samoan)
- Tiếng Việt (Vietnamese)
- 简体中文 (Simplified Chinese)
- 繁體中文 (Traditional Chinese)
- 한국어 (Korean)
- हिंदी (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: 35.7%
- Male: 62.6%
- Other (0.2%)
- Prefer not to answer: 1.5%

**Language of survey completion**
- English: 50.9%
- Vietnamese: 9.9%
- Korean: 27.2%
- Simplified Chinese: 4.6%
- Traditional Chinese: 9.4%
- Samoan: 2.0%

Hindi added since February 2022
Samoan added since March 2021

**Regions**
- 85.4% reside in California
- 83.9% born outside the US

**AANHPI Cultural Groups**
- Vietnamese: 38.2%
- Chinese: 32.3%
- Korean: 15.3%
- Asian Indian: 5.2%
- Filipino: 4.4%
- Japanese: 2.8%
- NHPI: 3.1%
- Other: 3.1%
- More than one: 1.1%

50.9% have limited English proficiency
CARE Participant Characteristics

Commonly Reported Health Conditions

<table>
<thead>
<tr>
<th>Condition</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>High blood pressure</td>
<td>26.5%</td>
</tr>
<tr>
<td>High cholesterol</td>
<td>23.5%</td>
</tr>
<tr>
<td>Diabetes (high blood sugar)</td>
<td>14.4%</td>
</tr>
<tr>
<td>Sleep problems</td>
<td>14.1%</td>
</tr>
<tr>
<td>ADRD (Alzheimer's disease and related dementias)</td>
<td>13.2%</td>
</tr>
<tr>
<td>Osteoarthritis</td>
<td>11.9%</td>
</tr>
<tr>
<td>Overweight</td>
<td>6.8%</td>
</tr>
<tr>
<td>Mood related issues (anxiety or depression)</td>
<td>6.4%</td>
</tr>
<tr>
<td>Gastrointestinal diseases</td>
<td>6.1%</td>
</tr>
</tbody>
</table>

Prior research participation experience

- Yes: 81%
- No: 12.4%
- Not sure: 6.7%

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.

"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

44 (67.7%) 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:
- Over half of the requesting studies were looking to recruit participants from a specific AANHPI group.

Study design

- Observational: 12
- Interventional: 27
- Interview/Focus group: 11
- Survey: 15

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**

- **English**: 44
- **Mandarin**: 13
- **Vietnamese**: 8
- **Korean**: 7
- **Cantonese**: 7
- **Tagalog**: 4
- **Japanese**: 1
- **Hindi**: 1

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)**: 58.5%
- **Social media**: 14.4%
- **Health fair**: 11.2%
- **Other (e.g. newsletters)**: 5.3%
- **In-person conference or forum**: 4.3%
- **Radio/TV (0.6%)**: 1.1%

**Target Audience**

- Community: 71.8%
- Research: 14.9%
- Both: 13.3%

**Language Used**

- **English**: 151
- **Cantonese**: 16
- **Korean**: 15
- **Mandarin**: 24
- **Vietnamese**: 13

Some events were bilingual or multilingual.

**Multilingual Outreach Materials**

- Examples of Outreach
- Flyers
- Zoom Recordings
- Animated videos

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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**

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**CARE Links**

- Click [HERE](#) to learn more about the CARE Ambassadors Program
- Click [HERE](#) to sign up for the e-newsletter
- Click [HERE](#) to follow and support us:
- Click [HERE](#) to enroll in CARE

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Last updated: January 2023
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

<table>
<thead>
<tr>
<th>Araceli Antonio</th>
<th>Tatiana Makoni</th>
<th>Natalie Ah Soon</th>
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<tbody>
<tr>
<td>Joyce Cheng</td>
<td>Jennifer Masuda</td>
<td>Boon Lead Tee</td>
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<tr>
<td>David Choi</td>
<td>Becky Nguyen</td>
<td>Quyen Tiet</td>
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<td>Sadhna Diwan</td>
<td>Phuong Christine Nguyen</td>
<td>Bexx Toomalatai</td>
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<td>Sophie C. Horiuchi-Forrester</td>
<td>Stephanie Nguyen</td>
<td>Ranak B. Trivedi</td>
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<td>Joyce Javier</td>
<td>Paula Palmer</td>
<td>Jennifer Wang</td>
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<tr>
<td>Ryan Kawamoto</td>
<td>Lina Park</td>
<td>Michael Weiner</td>
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<tr>
<td>Ruobing Li</td>
<td>Hye-Won (Grace) Shin</td>
<td>Edie Yau</td>
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CARE Community and Academic Partners

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UCSF IRB Protocol #: 19-28027

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