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

Launch Date: October 15, 2020

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)
- हिन्दी (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

Mean Age 53.4
- Range: 18 - 100 years
- 60% were 50 years and older
- 33% were 65 years and older

Gender

- Female: 62.6%
- Male: 35.7%
- Other (0.2%)
- Prefer not to answer (1.5%)

Language of survey completion

- 50.9% have limited English proficiency
- 9.9% English
- 27.2% Vietnamese
- 4.6% Korean
- 9.4% Simplified Chinese
- 2.0% Traditional Chinese
- 4.6% Samoan

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%

Hindi added since February 2022
Samoan added since March 2021

Last updated: January 2023
CARE Participant Characteristics

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

24.5% 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.

"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.

"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.

"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

<table>
<thead>
<tr>
<th>Study Design</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Observational</td>
<td>12</td>
</tr>
<tr>
<td>Interventional</td>
<td>27</td>
</tr>
<tr>
<td>Interview/Focus group</td>
<td>11</td>
</tr>
<tr>
<td>Survey</td>
<td>15</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.

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**

<table>
<thead>
<tr>
<th>Language</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>English</td>
<td>44</td>
</tr>
<tr>
<td>Mandarin</td>
<td>13</td>
</tr>
<tr>
<td>Vietnamese</td>
<td>8</td>
</tr>
<tr>
<td>Korean</td>
<td>7</td>
</tr>
<tr>
<td>Cantonese</td>
<td>7</td>
</tr>
<tr>
<td>Tagalog</td>
<td>4</td>
</tr>
<tr>
<td>Japanese</td>
<td>1</td>
</tr>
<tr>
<td>Hindi</td>
<td>1</td>
</tr>
</tbody>
</table>

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%)

**Target Audience**

<table>
<thead>
<tr>
<th>Type</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community</td>
<td>71.8%</td>
</tr>
<tr>
<td>Research</td>
<td>14.9%</td>
</tr>
<tr>
<td>Both</td>
<td>13.3%</td>
</tr>
</tbody>
</table>

**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

Last updated: January 2023
CARE’s Vision and Next Steps

We need your help!

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

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
- Click to follow and support us:
  - YouTube
  - Instagram
  - Twitter
  - Facebook
- Click **HERE** to enroll in CARE
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

Araceli Antonio       Tatiana Makoni       Natalie Ah Soon
Joyce Cheng          Jennifer Masuda      Boon Lead Tee
David Choi           Becky Nguyen         Quyen Tiet
Sadhna Diwan         Phuong Christine Nguyen  Bexx Toomalatai
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Joyce Javier          Paula Palmer         Jennifer Wang
Ryan Kawamoto         Lina Park           Michael Weiner
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CARE Community and Academic Partners

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