Brain Trust Meeting

September 19, 2022

CARE

COLLABORATIVE APPROACH FOR
ASIAN AMERICANS, NATIVE HAWAIIANS &
PACIFIC ISLANDERS RESEARCH & EDUCATION

HEALTH ACROSS THE LIFESPAN

Agenda

10:00 – 10:15am	**Introduction & Overview of CARE Registry** *Van Ta Park, PhD, MPH (UC San Francisco)*
10:15 – 10:30am	**How to use CARE** *Janice Tsoh, PhD (UC San Francisco)*
10:30 – 10:40am	**Community Perspectives in Research: Partnership with CARE** *Quyen Vuong, MSW, MBA (International Children Assistance Network)*
10:40 – 10:50am	**Potential Research Opportunities** *Oanh Meyer, PhD, MAS (UC Davis)*
10:50 – 11:00am	**Q&A + Raffles + Evaluation**

Introduction & Overview of CARE Registry

Van Ta Park, PhD, MPH
CARE Principal Investigator

Department of Community Health Systems,
UC San Francisco School of Nursing

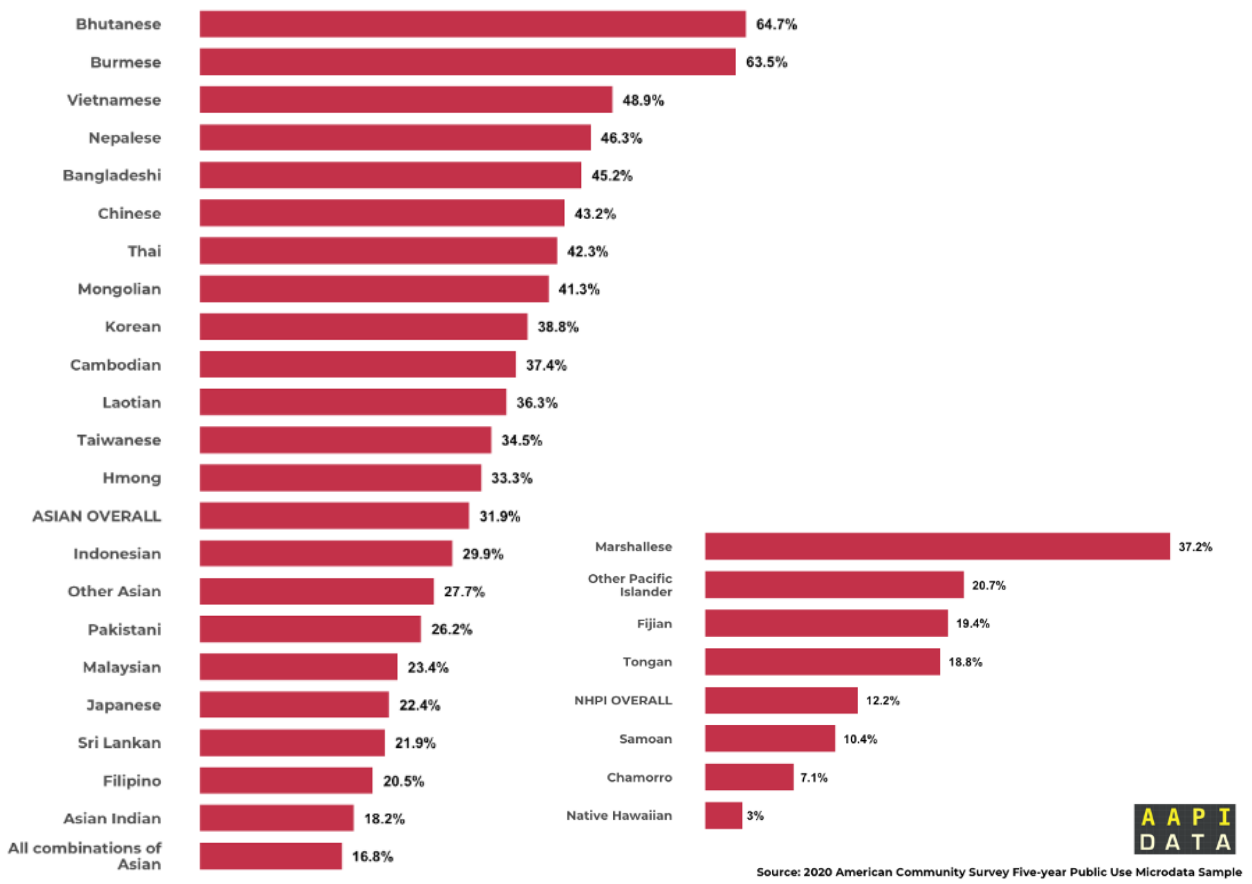
Asian Americans, Native Hawaiians & Pacific Islanders (AANHPI)

Asian Americans are the fastest growing racial group in the U.S.:[1]

- 7.7% of the population
- 30 AA & 21 NHPI groups
- 20 million AA & 1.6 million NHPI

- Heterogeneous group
- Languages & dialects (>100)
- Cultural groups (>50)
- Immigration patterns
- Religions
- Diet
- SES

Percentage of population with Limited English Proficiency by Asian and NHPI national origin[2]



[1] Census Bureau: https://www.census.gov/library/stories/2021/08/improved-race-ethnicity-measures-reveal-united-states-population-much-more-multiracial.html

[2] AAPI Data: https://aapidata.com/blog/2022-national-demographics/

Disparities in Research Participation for AANHPI Populations

- Clinical research projects focusing on AANHPI participants funded by the National Institutes of Health (NIH) was less than 1% of its total budget between 1992 and 2018.[1]
- Of the 45,923 participants who were enrolled in ADRD studies at Alzheimer's Disease Research Centers, only 2.7% were AANHPI participants.[2]
- Challenges to participation in research:
  - Cultural differences
  - Linguistic limitations
  - Lack of education in research practices

[1] Doan, Takata, Sakuma, & Irvin (2019). *JAMA Network Open*.
[2] National Alzheimer's Coordinating Center (NACC). Web-based Query System. 2018; https://www.alz.washington.edu/WEB/naccquery.html. Accessed August 30, 2022.

Paving the Way for Meaningful Inclusion of AANHPI Participants in Research

- To address the gap and reduce disparities in research participation in ADRD, aging, caregiving, and other health issues across the lifespan among AANHPI populations.
- CARE implements culturally appropriate and innovative recruitment strategies with our community partners to enroll 10,000 AANHPI adults.
- We aim to give AANHPI communities a voice and the opportunity to participate in such future research through enrollment in the CARE registry!

CARE's Multi-Site Collaboration

CARE Partners & Community Advisory Board

CARE Registry

Who can enroll?

- Self-identify as AANHPI background
- 18+ years old
- Speak and/or read English, Chinese, Hindi, Korean, Vietnamese *or* Samoan
- Interest in participating in potential research

Participants complete an **online survey** (10-15 min) **by phone**, or in-person

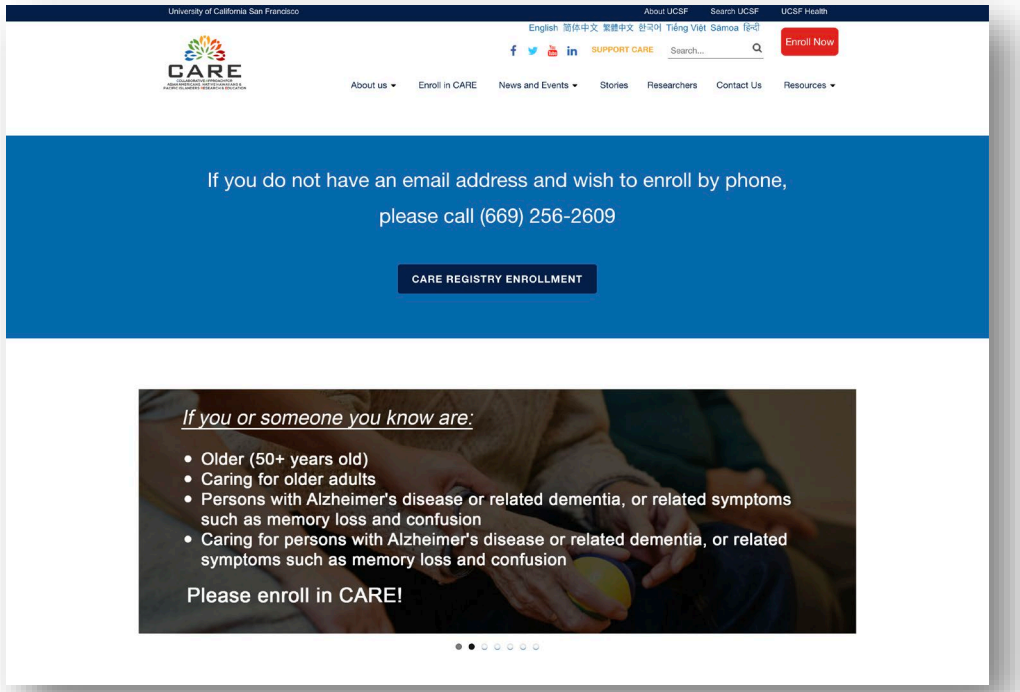
CARE phone lines:

廣東話 / Cantonese (415) 735-6809	普通话 / Mandarin (415) 735-6809
한국어 / Korean (415) 742-1357	Tiếng Việt / Vietnamese (415) 580-0845

CARE Enrollment Survey available in **6 languages**

Participants have the option to **receive a $10 gift card** after completing the enrollment survey

CARE



CARE Registry's Enrollment Survey Questions

Socio-demographic information

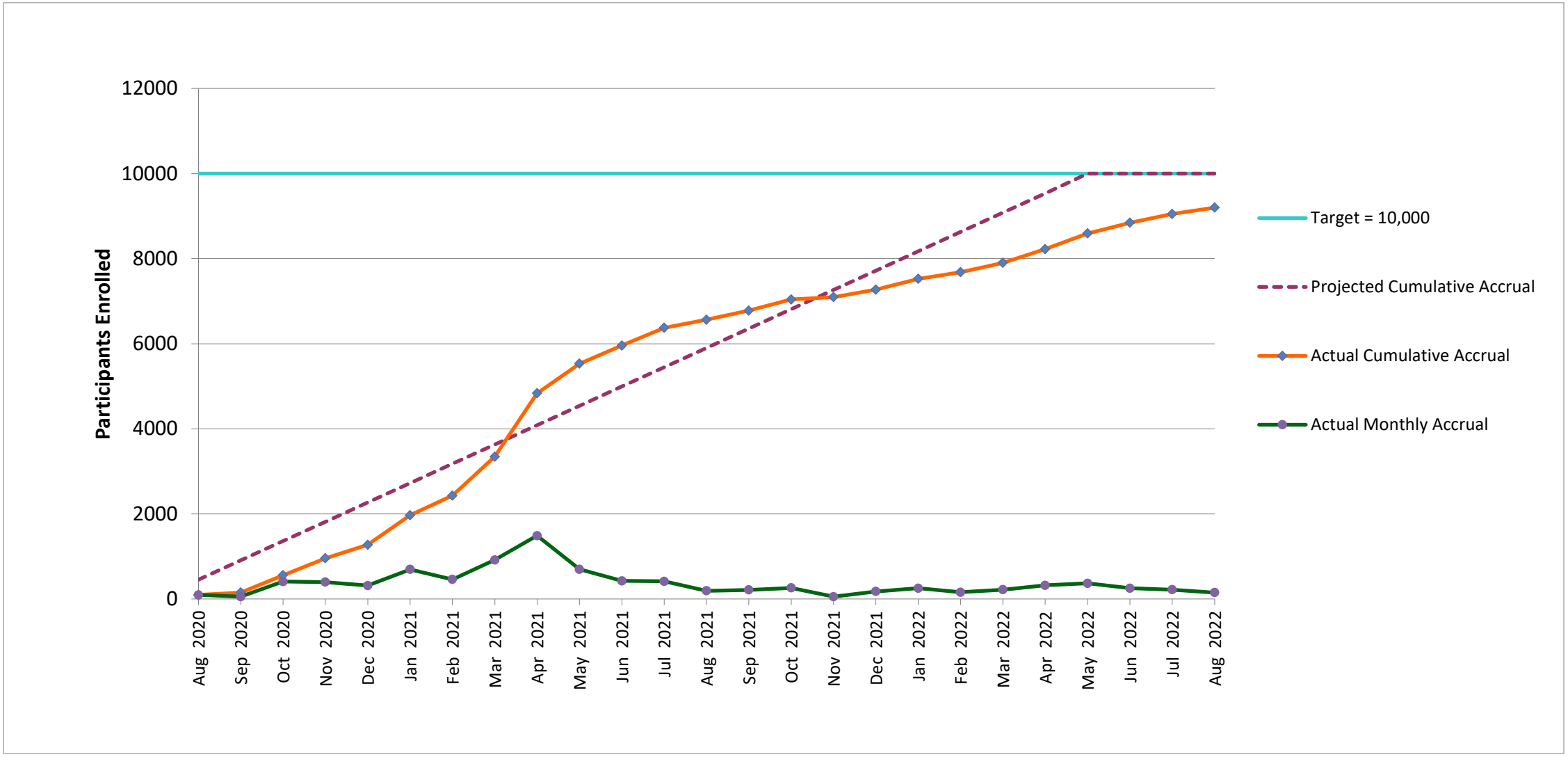
Health conditions (e.g., neurological disease and related symptoms such as Alzheimer's disease; heart disease; cancer; mood-related issues)

Health behaviors (e.g., smoking; physical activity; diet)

Caregiving experiences (if applicable)

CARE Registry Enrollment:

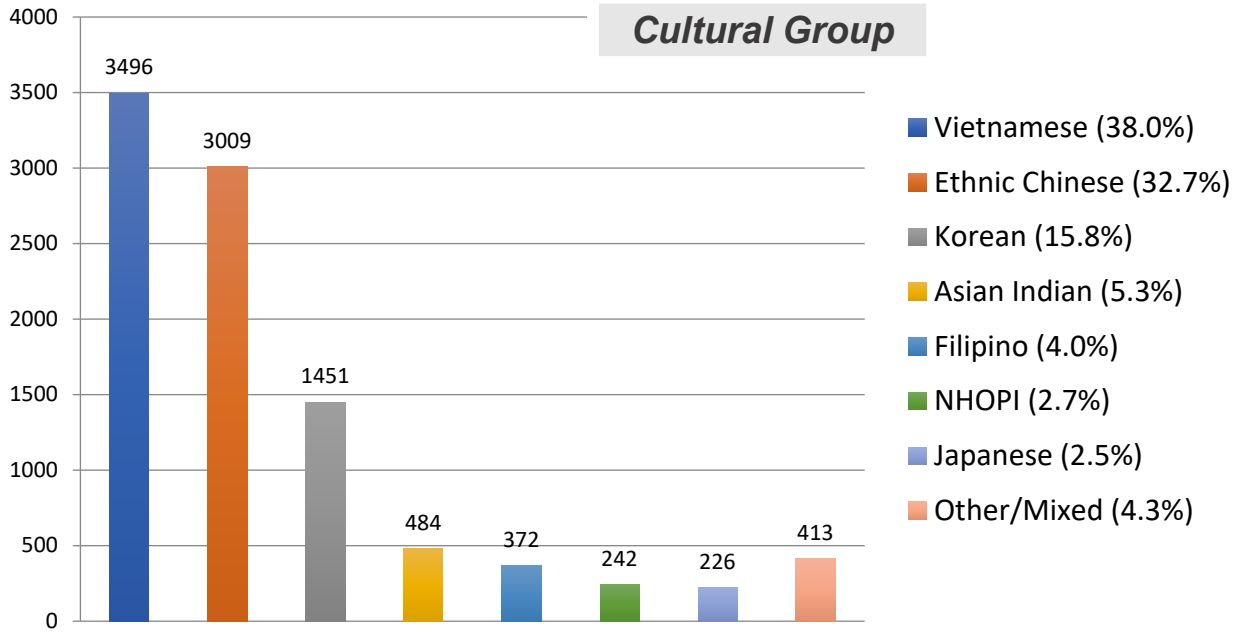
N=9,277 as of Sep 11, 2022 (93% of our 10,000 target goal)

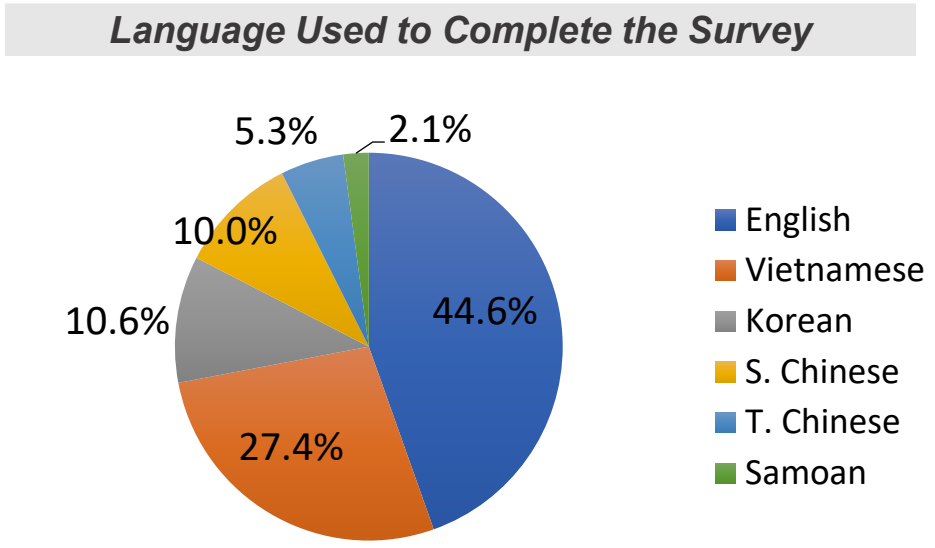


CARE Snapshot: N=9,277

- 84.3% Born outside of U.S.
- 86.7% Californian
- 10.7% Caregivers of older adults or person with special needs
- 81% no research participation experience

- Mean age = 54.1 (range 18-100)
  Age over 65 = 31.9%
- 62.6% Female 35.7% Male
- 55.9% Limited English proficiency
- 13.1% (N=1,218) with ADRD symptoms





How to Use CARE

Janice Tsoh, PhD
CARE Co-Investigator

Department of Psychiatry and Behavioral Sciences,
UC San Francisco Weill Institute for Neurosciences

CARE-Supported Recruitment Flowchart

CARE-Supported Recruitment Flowchart

Submit CARE Referral Request Form

- This is REQUIRED.
- Project information: title, description, timeline
- Eligibility criteria
- Target sample size
- IRB Status: identify CARE as a recruitment source
- Funding source and status of funding

CARE Consultation Committee Review

- General information about CARE
- Review of study proposal, eligibility criteria and sample size
- A meeting may be scheduled*
- A decision will be communicated with the requesting investigator within 1month of submission

Process CARE Referral Request Form

- Submit Referral Request Form to CARE after the consultation.

Receive Participant Contact Information

- Name, language preference, and preferred contact method (phone number, mailing address and/or email address)
- IRB approval letter required before receiving the information

Investigator Responsibilities

- Contact potential participants within 1 month of receiving their contact information**
- Notify CARE of the outcome of every registrant within 30 days of receipt**
- Cite CARE in publications or presentations
- Provide brief study description and findings or links to publication(s) when available for posting on CARE's website and newsletter

*Depending on the nature of the request, the requesting investigator will be contacted by a CARE Consultation Committee member to discuss the proposal in detail and provide the consultation services requested. Proposals that involve substantial commitment of CARE resources will receive further review and budgetary consideration by the CARE investigators before approval.

**This is a general guideline primarily for prospective and/or in-person studies. Investigator responsibilities may be discussed on a case-by-case basis for other types of study designs such as surveys.

CARE-Supported Recruitment Step 1-3

Submit CARE Referral Request Form

- This is REQUIRED.
- Project information: title, description, timeline
- Eligibility criteria
- Target sample size
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CARE Consultation Committee Review

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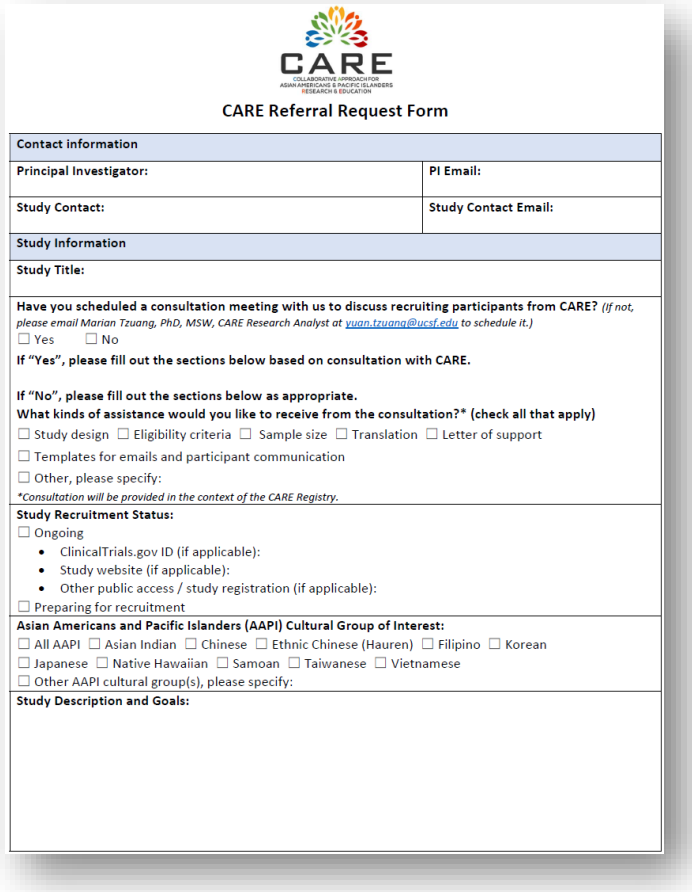


CARE

CARE Referral Request Form

Contact information	
Principal Investigator:	**PI Email:**
Study Contact:	**Study Contact Email:**

Study Information

Study Title:

Have you scheduled a consultation meeting with us to discuss recruiting participants from CARE? *(If not, please email Marian Tzuang, PhD, MSW, CARE Research Analyst at yuan.tzuang@ucsf.edu to schedule it.)*

☐ Yes ☐ No

If "Yes", please fill out the sections below based on consultation with CARE.

If "No", please fill out the sections below as appropriate.

What kinds of assistance would you like to receive from the consultation?* (check all that apply)

☐ Study design ☐ Eligibility criteria ☐ Sample size ☐ Translation ☐ Letter of support

☐ Templates for emails and participant communication

☐ Other, please specify:

**Consultation will be provided in the context of the CARE Registry.*

Study Recruitment Status:

☐ Ongoing

- ClinicalTrials.gov ID (if applicable):
- Study website (if applicable):
- Other public access / study registration (if applicable):

☐ Preparing for recruitment

Asian Americans and Pacific Islanders (AAPI) Cultural Group of Interest:

☐ All AAPI ☐ Asian Indian ☐ Chinese ☐ Ethnic Chinese (Hauren) ☐ Filipino ☐ Korean

☐ Japanese ☐ Native Hawaiian ☐ Samoan ☐ Taiwanese ☐ Vietnamese

☐ Other AAPI cultural group(s), please specify:

Study Description and Goals:

*Depending on the nature of the request, the requesting investigator will be contacted by a CARE Consultation Committee member to discuss the proposal in detail and provide the consultation services requested. Proposals that involve substantial commitment of CARE resources will receive further review and budgetary consideration by the CARE investigators before approval.

CARE-Supported Recruitment Step 4-5

Receive Participant Contact Information

- Name, language preference, and preferred contact method (phone number, mailing address and/or email address)
- IRB approval letter required before receiving the information

Investigator Responsibilities

- Contact potential participants within 1 month of receiving theircontact information**
- Notify CARE of the outcome of every registrant within 30 days of receipt**
- Cite CARE inpublications or presentations
- Provide brief study description and findings or links to publication(s) when available for posting on CARE's website and newsletter

**This is a general guideline primarily for prospective and/or in-person studies. Investigator responsibilities may be discussed on a case-by-case basis for other types of study designs (e.g., surveys).

CARE-Supported Recruitment

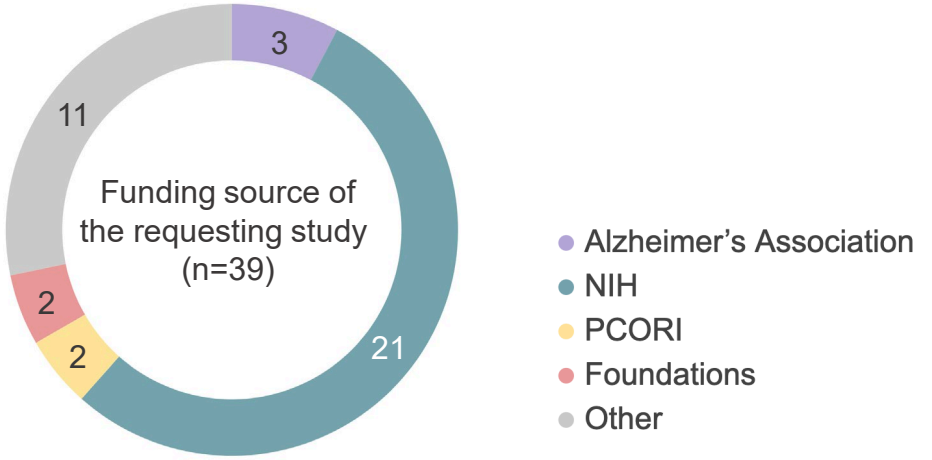
- Download CARE Recruitment Referral Form at: https://careregistry.ucsf.edu/researchers
- CARE team may request a consultation meeting to discuss the proposed recruitment referral in detail.
- Proposals that involve substantial commitment of CARE resources will receive further review and budgetary consideration by the CARE investigators before approval.

CARE-Supported Recruitment Requests (N=50 as of Sep 7, 2022)

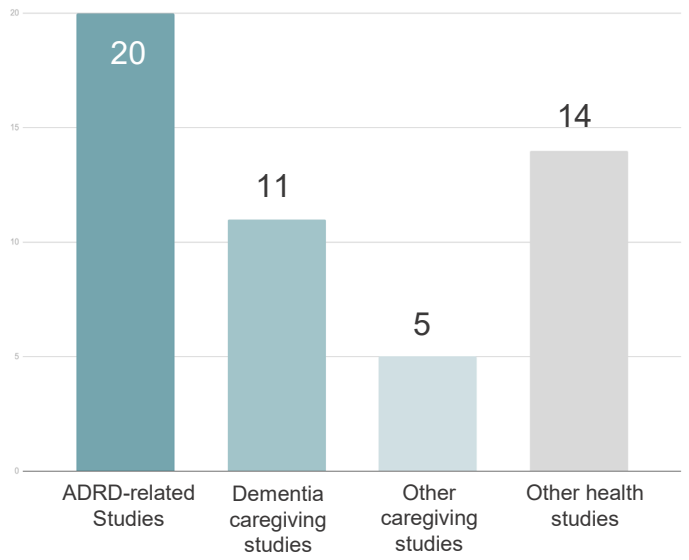
As of September 7, 2022, 5,530 CARE participants have been referred to 27 studies.

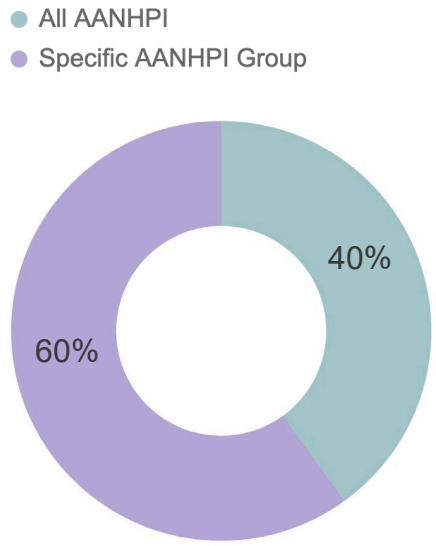
24 of the requesting studies (48%) have study materials or personnel support for participants in English and at least one other AANHPI language.

Funding Sources



Research Area





Example: SHARE Project (PI: Dr. JiWon Choi)

Referral Request Received — Late January 2021

CARE Committee Review — Early February 2021

- Asked PI to obtain IRB approval to include CARE as a recruitment source
- Clarified participant eligibility
- Initial query to identify potentially eligible participants:
  1) age ≥50; 2) male; 3) self-identified as Korean American; 4) caring for someone with dementia

Share CARE Participant Contact Information — Mid-February 2021

- Received IRB approval letter (including protocol that list CARE as recruitment source) from PI
- Name, language preference, and preferred contact method were shared with the study team
- Provided templates for invitation letter, email and phone script to explain why CARE participants are contacted
- Provided tracking log to study team to document contact outcomes (to be returned within 30 days of receiving participant contact information)

Notify CARE of Contact Outcomes — Mid-March 2021

Community Perspectives in Research – Partnership with CARE

Quyen Vuong, MBA, MSW, ASW
CARE Co-Investigator
Executive Director

International Children Assistance Network (ICAN)

International Children Assistance Network (ICAN)

ICAN's Mission

To ENGAGE, INFORM, and INSPIRE Vietnamese-Americans to raise the next generation of Caring leaders through Humanitarian Programs, Culturally Responsive Social Programs, and Community Based Research

We strive to help children and youth realize their potential by building strong families and community support networks to provide them with the skills, confidence, and opportunities to succeed in life.

Through our programs, we empower children and youth to become caring, responsible, and productive members of their families and communities. By spreading the spirit of "youth empowering youth," they will pioneer the way to a brighter future.

Engaged, Informed, Inspired -

To Raise the Next Generation of Caring Leaders

Quyen Vuong – Executive Director

“What inspires ICAN to partner with the CARE team is the opportunity to give Vietnamese Americans a voice in research.

We believe that if we can help produce relevant information about Vietnamese Americans in research, then the Vietnamese American community can get relevant research about ourselves that would benefit our community as well as the broader AANHPI community.

The key to CARE is the important relationship between the academic partners (UCSF, UCD, UCI) and the community engagement partners like ICAN.”

Community-based Research

Outreach through different angles and address different needs

Engage and educate community on variety of issues

Increase representation of Vietnamese Americans in research

Build lasting impact and trust with the community

Ongoing studies

- CARE (careregistry.ucsf.edu/)
- COMPASS I & II (compass.ucsf.edu/)
- Vietnamese Insights into Aging Program (VIP) (health.ucdavis.edu/neurology/vip/)
- Dementia & caregiving related studies

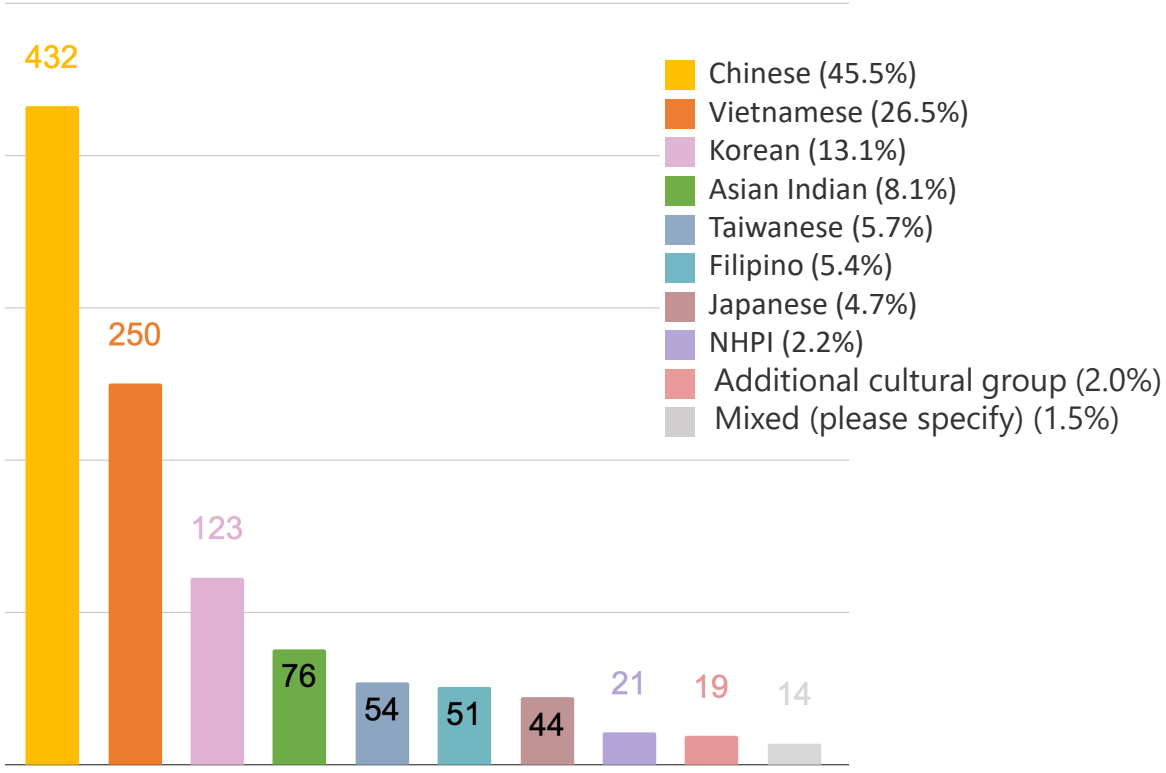
Potential Research Opportunities with CARE

Oanh Meyer, PhD, MAS
CARE Co-Investigator

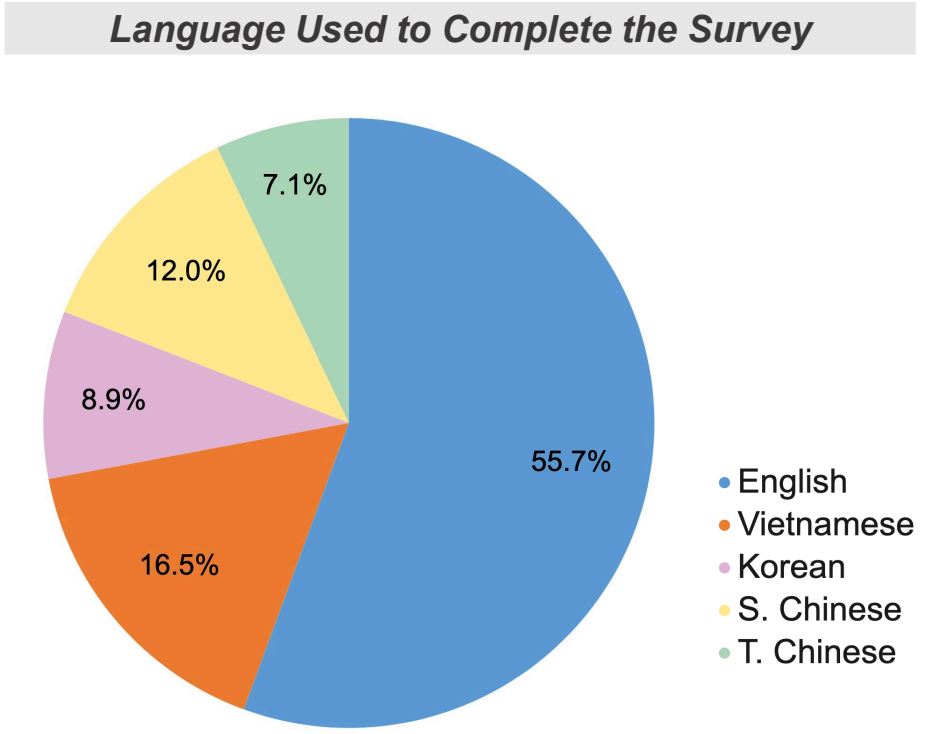
University of California Davis

Snapshot of Caregivers (N=950)

- Mean age: 50.9 years (Range 18-88)
- Female: 74.3%; Male 24.5%
- Cultural groups:



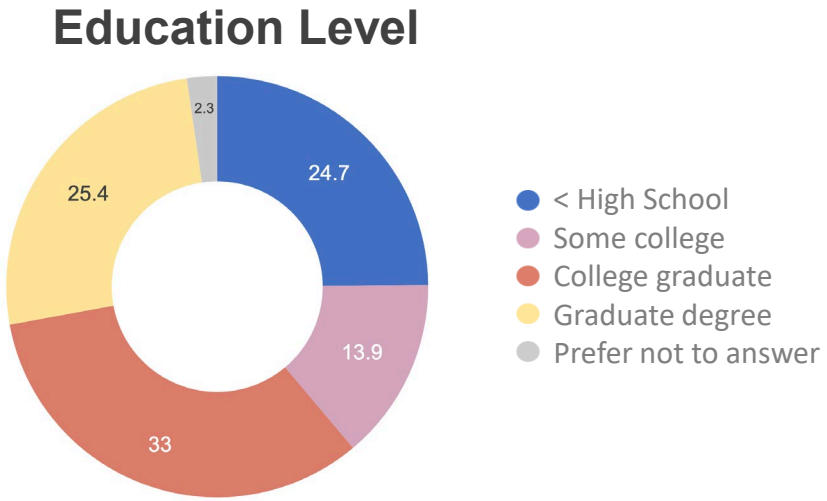
- Foreign born: 79%
- Limited English Proficiency: 43.6%

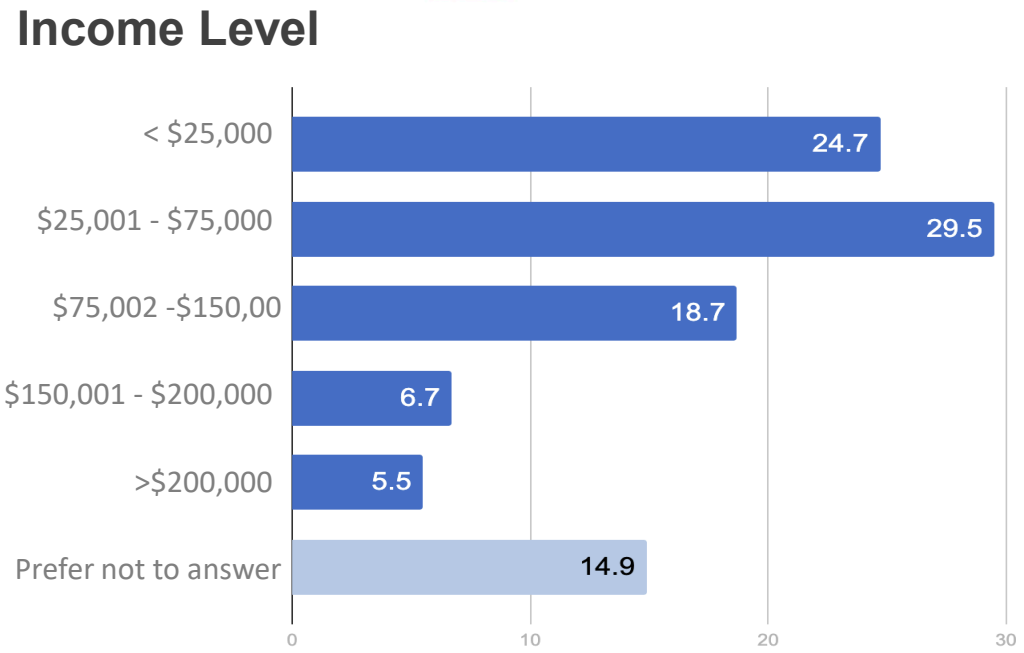


Snapshot of Caregivers (cont.)

- 39% of caregivers were caring for someone with ADRD

- Care recipient health issues:
  - High blood pressure: 40.9%
  - High cholesterol: 26.0%
  - Heart disease: 12.4%
  - Diabetes: 23.5%
  - Sleep problems: 18.5%
  - Hard of hearing or hearing loss: 14.9%
  - Osteoarthritis: 14.8%
  - Mood related issues: 13.9%
  - Chronic Pain: 12.2%
  - Cancer: 7.8%





Caregiver-related data in CARE Registry

- Care recipient:
  - Minor children
  - Older adults (≥50 years)
  - Individuals with special needs (<50 years)
- Relationship
- Living together
- Age of care recipient
- Health issues of care recipient
- Hours of caregiving
- Activities provided for care recipient

Profile of CARE Participants (N(%) or mean ± SD)

	All (N=9,198)	Self-Reported ADRD (N=1,186)	ADRD Caregivers (N=371)
Age	53.0 ± 17.2	64.6 ± 14.5	53.3 ± 13.2
Foreign-born	7,763 (84.4)	1,153 (96.7)	241 (77.5%)
Cultural groups			
Vietnamese	3,496 (38.0)	1,020 (86.0)	110 (29.6)
Ethnic Chinese	3,009 (32.7)	118 (9.9)	164 (44.2)
Korean	1,451 (15.8)	23 (1.9)	42 (11.3)
Asian Indian	484 (5.3)	14 (1.2)	25 (6.7)
Filipino	372 (4.0)	8 (0.7)	16 (4.3)
Japanese	226 (2.5)	12 (1.0)	26 (7.0)
NHPI	242 (2.7)	7 (0.6)	7 (1.9)
Mixed	96 (1.0)	7 (0.6)	7 (1.9)
Other	317 (3.4)	5 (0.4)	7 (1.9)

Q&A + Raffles

Please complete our evaluation survey:

tinyurl.com/CAREbraintrustSep2022

Acknowledgments

Thank you to all the registry participants!

UC San Francisco

Van Ta Park (PI)
Alka M. Kanaya (Co-I)
Janice Tsoh (Co-I)
Myka Lay
Bora Nam
Nicole Phan
Shweta Srivastava
Marian Tzuang
Stuart Gansky (DCE)
Sarit Helman (DCE)
Niloufar Ameli (DCE)
CARE Interns & Ambassadors

UC Davis

Oanh L. Meyer (Site PI)
Ladson Hinton (Co-I)
Duyen Thi Ky Tran

UC Irvine

Joshua D. Grill (Site PI)
Ruobing Li
Hye-Won (Grace) Shin

Stanford University

Dolores Gallagher-Thompson (Co-I)

ICAN

Quyen Vuong (Site PI)
Cecilia Phan

NAPCA

David Kim (Site PI)
Mary Ann Bui
Christian Flores

Community Advisory Board

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

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