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** Joshua D. Grill, PhD (UC Irvine)
10:30 – 10:40am	**Community Perspectives in Research: Partnership with CARE** Hye-Won Shin, PhD (Somang Society)
10:40 – 10:50am	**User Testimonial: Experiences with CARE for Study Recruitment** William Tsai, PhD (New York University)
10:50 – 11:00am	**Q&A + Raffles + Evaluation**

Introduction & Overview of CARE Registry

Van Ta Park, PhD, MPH
CARE Multiple 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]

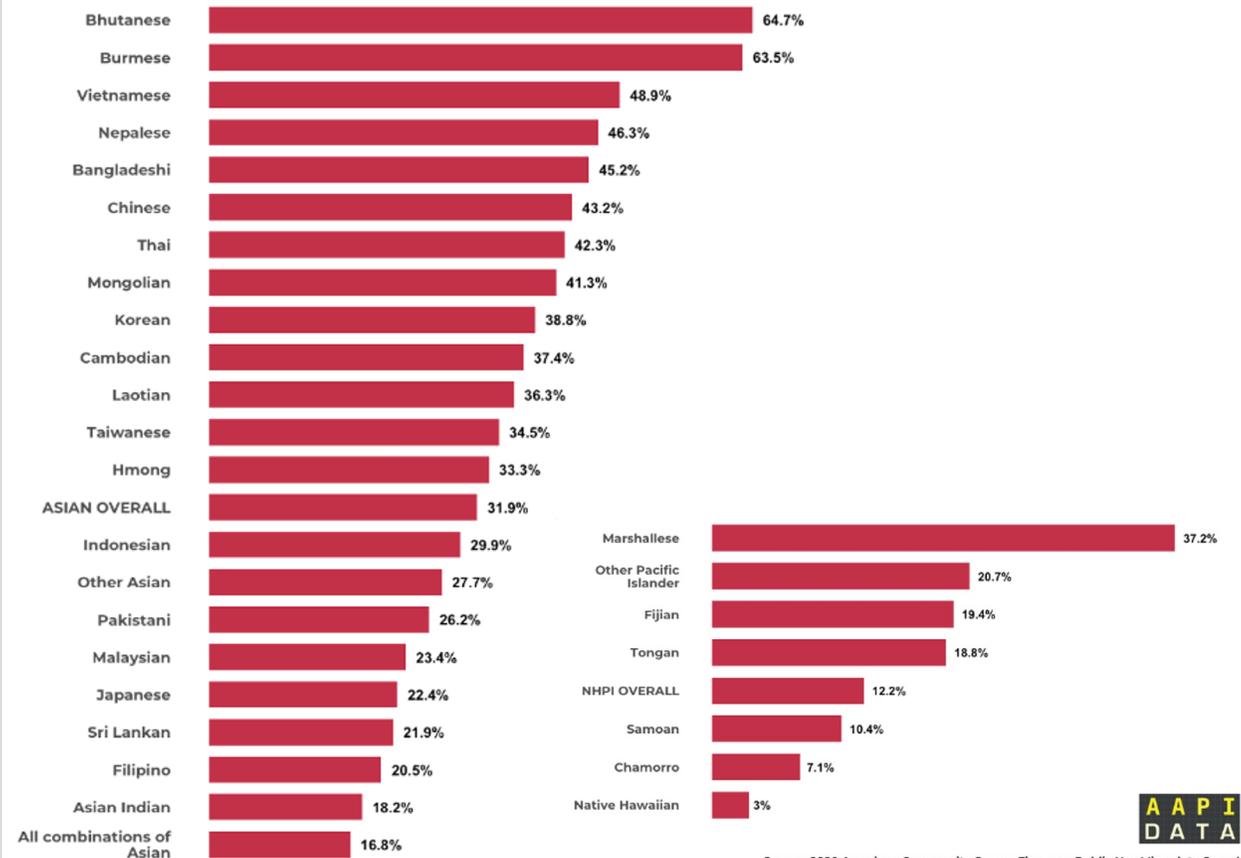- 7.7% of the population
- 30 AA & 21 NHPI groups
- 20 million AA & 1.6 million NHPI

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

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

National origin	%
Bhutanese	64.7%
Burmese	63.5%
Vietnamese	48.9%
Nepalese	46.3%
Bangladeshi	45.2%
Chinese	43.2%
Thai	42.3%
Mongolian	41.3%
Korean	38.8%
Cambodian	37.4%
Laotian	36.3%
Taiwanese	34.5%
Hmong	33.3%
ASIAN OVERALL	31.9%
Indonesian	29.9%
Other Asian	27.7%
Pakistani	26.2%
Malaysian	23.4%
Japanese	22.4%
Sri Lankan	21.9%
Filipino	20.5%
Asian Indian	18.2%
All combinations of Asian	16.8%

National origin	%
Marshallese	37.2%
Other Pacific Islander	20.7%
Fijian	19.4%
Tongan	18.8%
NHPI OVERALL	12.2%
Samoan	10.4%
Chamorro	7.1%
Native Hawaiian	3%

Source: 2020 American Community Survey Five-year Public Use Microdata Sample

AAPI DATA

Background: Disparities in Research Participation for AANHPI Populations

o Clinical research projects focusing on AANHPI participants funded by the National Institute of Health (NIH) was <u>less than 1%</u> of its total budget between 1992 and 2018.[1]

o Of the 50,259 participants who were enrolled in ADRD studies at Alzheimer's Disease Research Centers, only 2.9% were AANHPI.[2]

o Considerations when engaging AANHPI communities to participate in research:
- Cultural differences
- Linguistic limitations
- Need to increase awareness/outreach about what research is & the importance of research to targeted communities
- Need to increase awareness/education to "research" communities & funders

[1] Doan, Takata, Sakuma, & Irvin (2019). JAMA Network Open.

[2] National Alzheimer's Coordinating Center (NACC). Web-query System. 2024; https://naccdata.org/requesting-data/web-query. Accessed January 30, 2024.

Paving the Way for Meaningful Inclusion of AANHPI Participants in Research

o Funded by NIA R24AG063718 & R01AG083926

o Officially launched in October 2020

o CARE goals:

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 AANHPI populations.
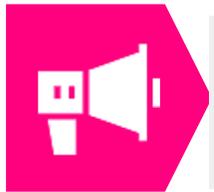
To give AANHPI individuals a voice and the opportunity to participate in research through enrollment in CARE.

To implement culturally appropriate and innovative recruitment strategies in collaboration with CARE's community partners to enroll AANHPI adults who are interested in participating in health research.

CARE Partners & Community Advisory Board

CARE Registry

Who can enroll?

- AANHPI adults
- 18+ years old
- Speak and/or read English, Chinese, Hindi, Korean, Vietnamese *or* Samoan
- Interested in participating in potential research

CARE Registry Enrollment Survey currently available in **6 languages**, in the process of expanding language options for CARE 2.0.
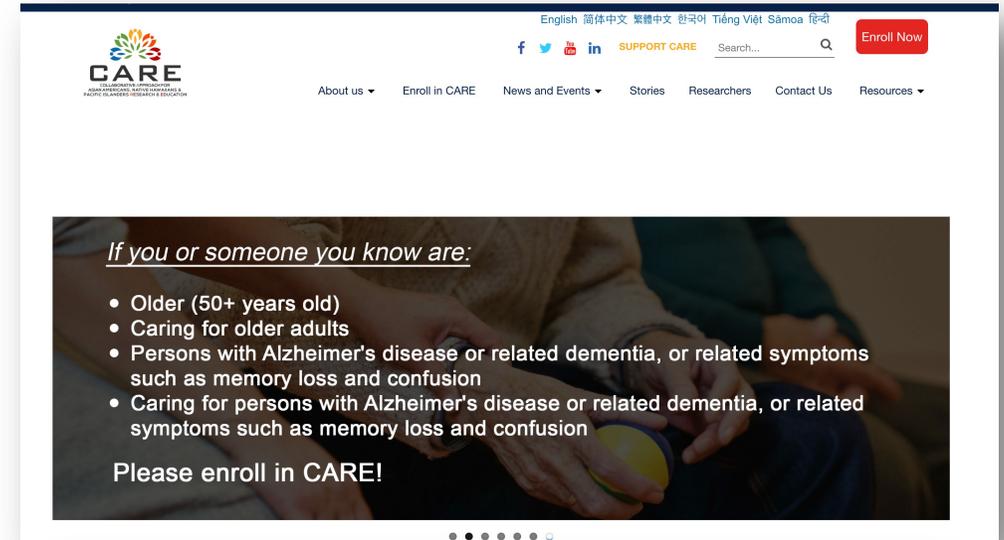
Participants have the option to **receive a $10 gift card** after completing the enrollment survey

Participants complete an **online survey** (10-15 min) **by phone**, or in-person
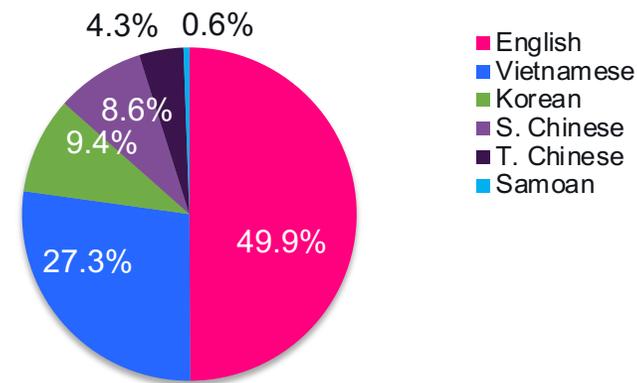
Website: careregistry.ucsf.edu

CARE Registry Enrollment Survey includes:
- Sociodemographic Information
- Health Conditions
- Health Behaviors
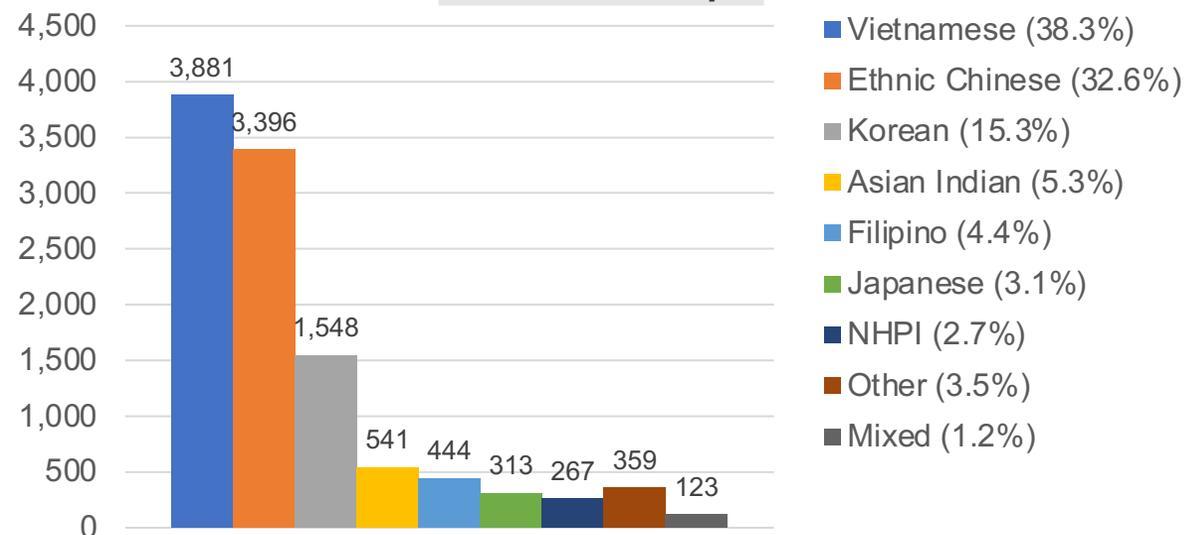- Caregiving Experiences (if applicable)

CARE Participant Snapshot: N=10,133 (as of Jan 1, 2024)

🌐	83.5%	Born outside of U.S.
	85.0%	Californian
🩺	10.9%	Caregivers of older adults or person with special needs
💡	80.7%	No research participation experience
🌐	51.8	Mean age (range 18-100)
🧓	31.9%	Age over 65
👫	62.6% Female	35.8% Male
💬	58%	Limited English proficiency
🧠	13.9%	(N=1,402) with ADRD symptoms

Language Used to Complete the Survey

Pie chart:
- English: 49.9%
- Vietnamese: 27.3%
- Korean: 9.4%
- S. Chinese: 8.6%
- T. Chinese: 4.3%
- Samoan: 0.6%

Cultural Group

Bar chart values:
- Vietnamese (38.3%): 3,881
- Ethnic Chinese (32.6%): 3,396
- Korean (15.3%): 1,548
- Asian Indian (5.3%): 541
- Filipino (4.4%): 444
- Japanese (3.1%): 313
- NHPI (2.7%): 267
- Other (3.5%): 359
- Mixed (1.2%): 123

CARE-Supported Recruitment Step 1-3

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 1 month of submission

Process CARE Referral Request Form

- Submit Referral Request Form to CARE after the consultation.

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:

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*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.
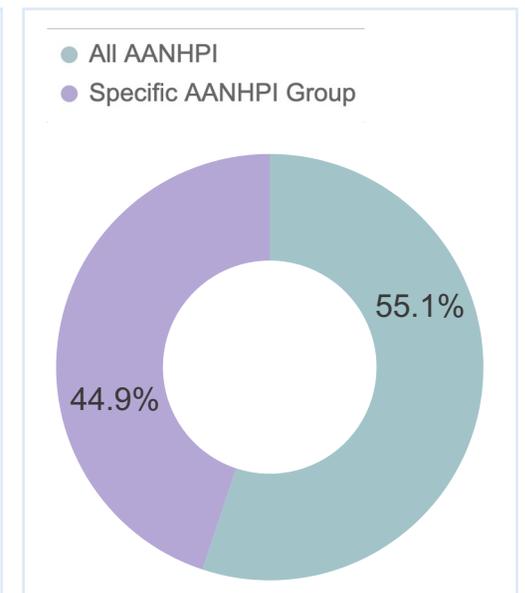
CARE-Supported Recruitment Step 4-5

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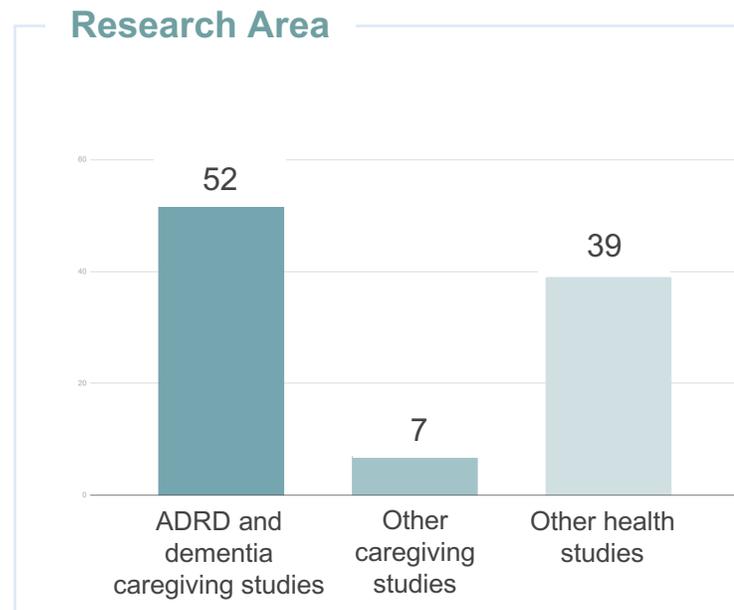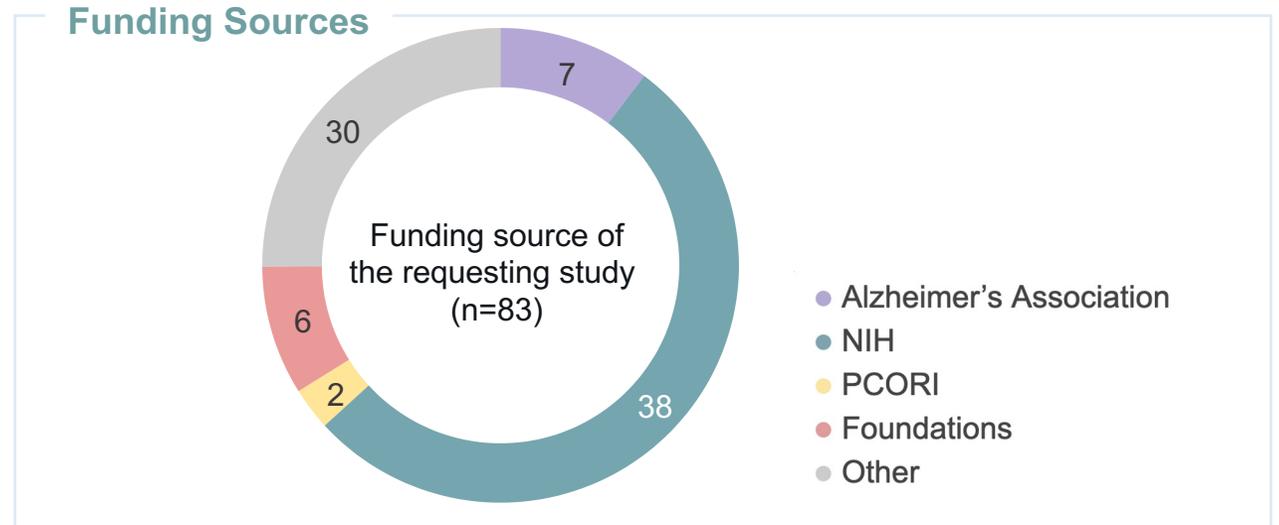
**This is a general guideline primarily for prospective and/or in-person studies. Investigator responsibilities may be discussed on a case-by-case basis for other types of study designs (e.g., surveys).

CARE-Supported Recruitment

o Download CARE Recruitment Referral Form at:
https://careregistry.ucsf.edu/researchers

o CARE team may request a consultation meeting to discuss the proposed recruitment referral in detail.

o 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=98 as of January 22, 2024)

- Since January 2021, >5,500 CARE participants have been referred to at least one CARE-supported studies.

- 32 of the requesting studies have study materials or personnel support for participants in English and at least one other AANHPI language.

Funding Sources

Funding source of the requesting study (n=83)

- 7 Alzheimer's Association
- 30 Other
- 6 Foundations
- 2 PCORI
- 38 NIH

- Alzheimer's Association
- NIH
- PCORI
- Foundations
- Other

Research Area

ADRD and dementia caregiving studies	Other caregiving studies	Other health studies
52	7	39

- All AANHPI
- Specific AANHPI Group

55.1%
44.9%

How to Use CARE

Joshua D. Grill, PhD
CARE Multiple Principal Investigator

Director, Institute for Memory Impairments and Neurological Disorders (UCI MIND)
Co-Director, Alzheimer's Disease Research Center
UC Irvine

Main Ways to Use CARE

- Ask novel research questions about AANHPI
  - *Surveys of CARE participants*
  - *Recruitment of whole samples from CARE*
- Recruit participants to increase diversity of a study population
- Recruit participants as a novel comparison group

Answer Novel Research Questions About AANHPI

o Disseminate a survey to the CARE registrants

    o *All CARE registrants*

    o *Specific CARE registrants
(e.g., Chinese immigrants >65 years)*

    o *Compare within or across AANHPI groups*

o Utility:

    o *Needs assessments*

    o *Preliminary data*

    o *Complete studies*

Investigator

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

Example Survey Study Design

o Hypothesis: Immigrants differ from second generation AANHPI in their attitudes toward Alzheimer's disease prevention research

o Participants: Older (age 55 and up) CARE participants

o Methods: Send an electronic (REDCap) survey to all eligible CARE registrants

o Primary Analysis: Compare AANHPI born in this country to those born in another country for differences in willingness to participate in AD prevention research

Example Study Recruitment

o Study design: Randomized interview study assessing the impact of biomarker testing and disclosure on AD prevention trial recruitment

o Use of CARE: Recruit participants meeting inclusion criteria (age, English-speaking, no major neurological or psychiatric disorders/diagnoses)

  o *Participants recruited from CARE included in study that also includes participants from other sources. Randomization overcomes issues around sample bias*

  o *Goal is to study more inclusive, representative sample*

  o *Secondary analyses might compare effect modification by race*

Recruit AANHPI Participants to Your Study

o Recruit CARE registrants to your prospective study*

- o *Answer specific questions about AANHPI*
- o *Recruit AANHPI CARE registrants to improve diversity in your sample*
- o *Recruit specific CARE registrants of interest to compare to other groups (e.g., non-Hispanic Whites)*
- o *Compare different AANHPI groups*

Investigator

Caveats and Conclusions

o CARE is not a community based epidemiologic cohort

o It cannot provide information (or opportunities to study) on disease prevalence or population characteristics

o It can assist in examining potential cultural and racial associations, hypothesis generation, and comparison studies

o It can improve recruitment of AANHPI and assist in diversifying research

Community Perspectives in Research: Partnership with CARE

Hye-Won Shin, PhD

CARE Community Advisory Board Member, Somang Society

UCI MIND

Somang Society Mission

Well-Aging

- o Somang Care Class (Korean)
- o Somang Dementia Education (Korean/English)
- o Caregiver Support Groups (Korean)

Somang Society Mission

Well-Dying

- Seminars, Forums, & Conferences
- Grief Support Group
- UCI Willed Body Donation
- Advanced Healthcare Directive
- Emergency Contact Cards

Somang Society Mission

Well-Being

- Somang Society is committed to saving lives in barren lands in Africa.
- Somang Water Well
- Somang school
- Family Sponsorship Services

Our Impact

- Annually serve **25,000+** Korean American seniors and their family members
- **350** seminars on end-of-life care, dementia and family caregiving
- **1.68K** subscribers to Somang Society YouTube channel
- **268** Videos on advance care planning, dementia and family caregiving/**150,000+** views
- 42 Newsletter Publications/**100,000+** copied delivered
- 2 Senior Resource Guide Publication/**15,000**+ copies delivered

- **15,947** completed advance healthcare directives
- **2,204** registered for the UCI Willed Body Program
- **576** Somang water wells and **10** schools in Chad,   Africa
- **4** active research projects, **2** active community projects, and **8** completed research and community projects (2018-2022)

Community Perspectives in Research: Partnership with CARE
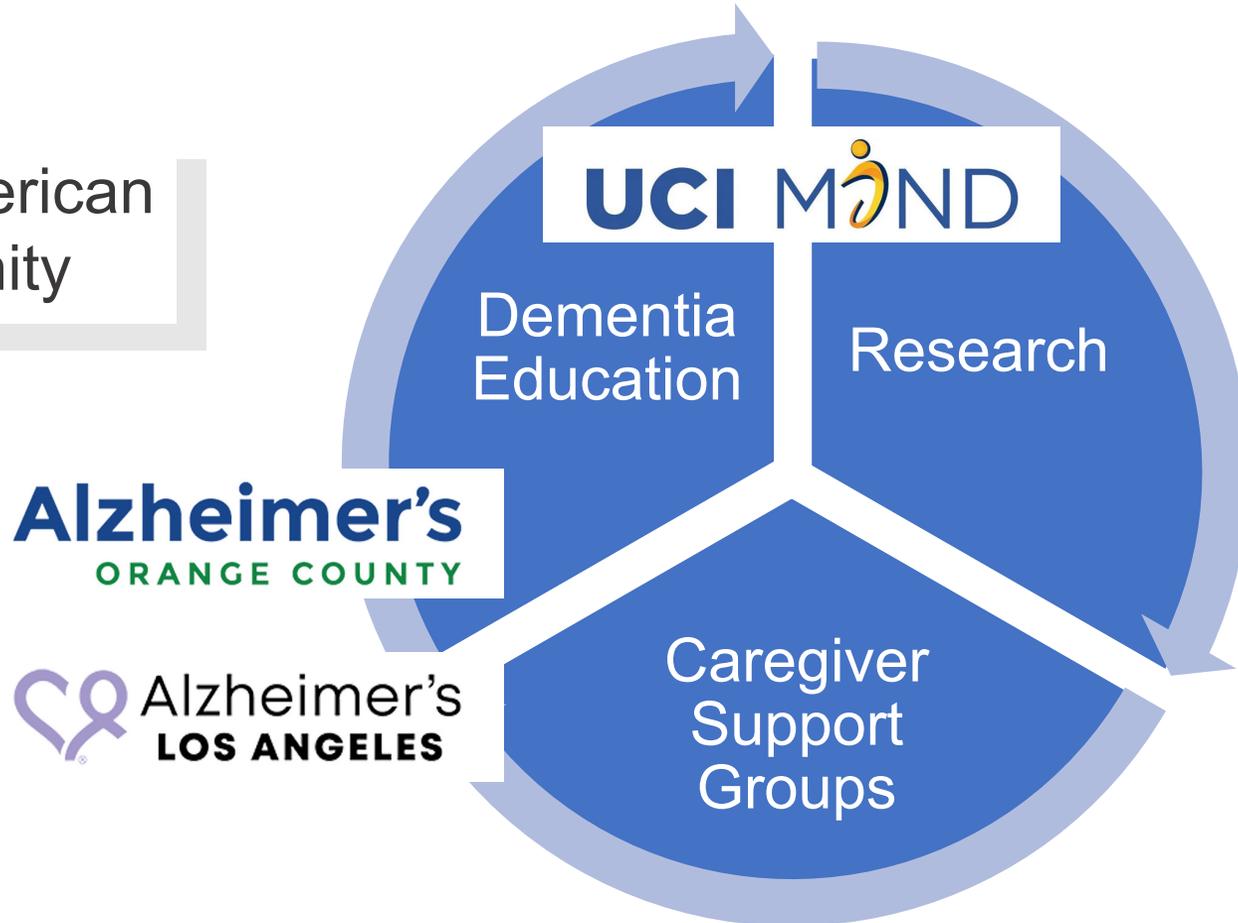
User Testimonial: Using the CARE Registry to recruit Chinese Cancer Caregivers and Survivors

William Tsai, PhD

New York University

Expressive Helping Intervention for Chinese Cancer Caregivers & Survivors

- Adapted from the Expressive Writing intervention paradigm (Pennebaker, 1997).

- Facilitates both emotional disclosure and peer-helping over writing (Rini et al., 2013).

- Intervention can be completed at home (online or printed materials).

- Cultural fit of writing interventions for this population.

  - Overcomes cultural stigma about help-seeking and greater ambivalence over emotional expression and self-stigma.

  - Written in their language of choice.

NYU

Two RCTs

<u>Caregivers of family member with cancer</u>

- >18
- Of Chinese descent
- Currently providing care to a family member diagnosed with cancer
- Live in the US

<u>Cancer survivors</u>

- 18 – 80 years old
- Of Chinese descent
- Completed cancer treatment within past five years
- Live in the US

Writing Excerpts

Chinese Caregiver

"Although I find nothing to smile about on this occasion, I have to attest that some positive things have happened to me so far. The bond you create with whom you are giving care is just great and something that gives you strength every day. You will see the essence of humanity and get to appreciate what life means. Peace and wellbeing are paramount to us and it is in caregiving that you get to see what it means. However, even though you are in that situation, one got to be cheerful and give its best."

Chinese Cancer survivor

"I'm especially grateful for my husband and daughter. They were there for everything, including taking me to the hospital, doctor visits, waiting outside the surgery room, to staying with me when I was hospitalized. Taking care of the house when I was unable to, cleaning me, feeding me, and never complaining. I am grateful that I can deeply feel the love of my family, the loyalty, and the care they gave to me. My partner is the one closest to me in this life and I treasure him."

Recruitment Strategies

- Online Ads (e.g., Facebook groups, Chinese forums)
- Newspaper ads (e.g., World Journal)
- Chinese-serving Community organizations (e.g., Chinese Planning Council in NYC)
- Physician collaborators
- Word-of-mouth
- CARE Registry

CARE Registry

Caregiver Trial

- 1st Batch (April 2022; 25 individuals; 10/25 reached)

  - 7* of 10 were not currently caregiving

  - 1 of 10 declined (too busy)

  - **2 enrolled and consented**

- 2nd Batch (May 2022; 14 individuals; 5/14 reached)

  - 3* of 5 were not currently caregiving

  - 2 of 5 were too busy

Cancer Survivor Trial

- 1st Batch (Sept 2022; 43 individuals; 24/43 reached)

  - 10/24* completed tx > 5 years ago

  - 6/24 declined (too busy, fatigue)

  - **8/24 enrolled and consented**

- 2nd batch (Dec 2022; 12 individuals; 6/12 reached)

  - 4/6* completed tx > 5 years ago

  - 1/6 declined

  - **1/6 enrolled and consented**

- 3rd batch (May 2023; 3 individuals ; 2/3 reached)

  - **2/3 enrolled and consented**

*reached but not eligible

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Experiences using the CARE registry

- Ease of use

  - Application instructions are clear, and the form is easy to use

  - IRB application and approval process was smooth

- Breadth and Depth

  - Rich demographic and ethnicity information availability

  - Caregiving variables (e.g., care recipient health issue, relationship with care recipient)

- High response rate

Lessons Learned

- Train the research team to expect first-time research participants

  - 81% do not have previous experience with research (2023 CARE Executive Summary)

- Language matching during the first encounter

- Persistence in reaching out and using all provided contact information

NYU

Thank you

- William Tsai, PhD

- Will.tsai@nyu.edu

Acknowledgments

Thank you to all the registry participants!

UC San Francisco

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Bobin Kim
Daren Huang
Gabriel Fara-On
Sushmita Majumdar
Seoyeon Yum
Jessie Deng

CARE Interns & Ambassadors

UC Davis

Oanh L. Meyer (Site PI)
Ladson Hinton

UC Irvine

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

Stanford University

Dolores Gallagher-Thompson
Cati Brown-Johnson

ICAN

Quyen Vuong (Site PI)

CSU East Bay

Arnab Mukherjea (Site PI)

U of Hawaii

Christy Nishita (Site PI)

Community Advisory Board

Araceli Antonio ▪ Rejie Marie Baloyos ▪ Joyce Cheng ▪ David Choi ▪ Sadhna Diwan ▪ Sophie C. Horiuchi-Forrester
Lindsey Ilagan ▪ Joyce Javier ▪ Ryan Kawamoto ▪ Ruobing Li ▪ Alka Kanaya ▪ Daphne Kwok ▪ Eun Jeong Lee
Jennifer Masuda ▪ Christina Miyawaki ▪ Becky Nguyen ▪ Phuong Christine Nguyen ▪ Stephanie Nguyen ▪ Lina Park
Tammie Pitkin ▪Hye-Won (Grace) Shin ▪ Natalie Ah Soon ▪ Angela Sun ▪ Leezel Tanglao ▪ Vaatausili (Va'a) Tofaeono
Boon Lead Tee ▪ Quyen Tiet ▪ Ranak B. Trivedi ▪ Paz Velasquez ▪ Michael Weiner ▪ Edie Yau

Q&A + Raffles

Fill out our evaluation survey for a chance to win a gift card!

tiny.ucsf.edu/CAREbraintrustFeb2024