



# CARE

COLLABORATIVE APPROACH FOR  
ASIAN AMERICANS & PACIFIC ISLANDERS  
RESEARCH & EDUCATION

HEALTH ACROSS THE LIFESPAN

## Brain Trust Meeting

October 1, 2021

# Agenda

9:00 – 9:10am	<b>Welcome and Background</b> <i>Oanh Meyer, PhD (UC Davis)</i>
9:10 – 9:20am	<b>Overview of CARE Registry</b> <i>Oanh Meyer, PhD (UC Davis)</i>
9:20 – 9:35am	<b>CARE-Supported Recruitment</b> <i>Marian Tzuang, PhD (UC San Francisco)</i>
9:35 – 9:45am	<b>Community Perspectives in Research: Partnership with CARE</b> <i>Hye-Won Shin, PhD (Somang Society / UC Irvine)</i>
9:45 – 9:55am	<b>Q&amp;A + Raffles</b>
9:55 – 10:00am	<b>Evaluation and Adjourn</b>

# Asian Americans and Pacific Islanders (AAPI)



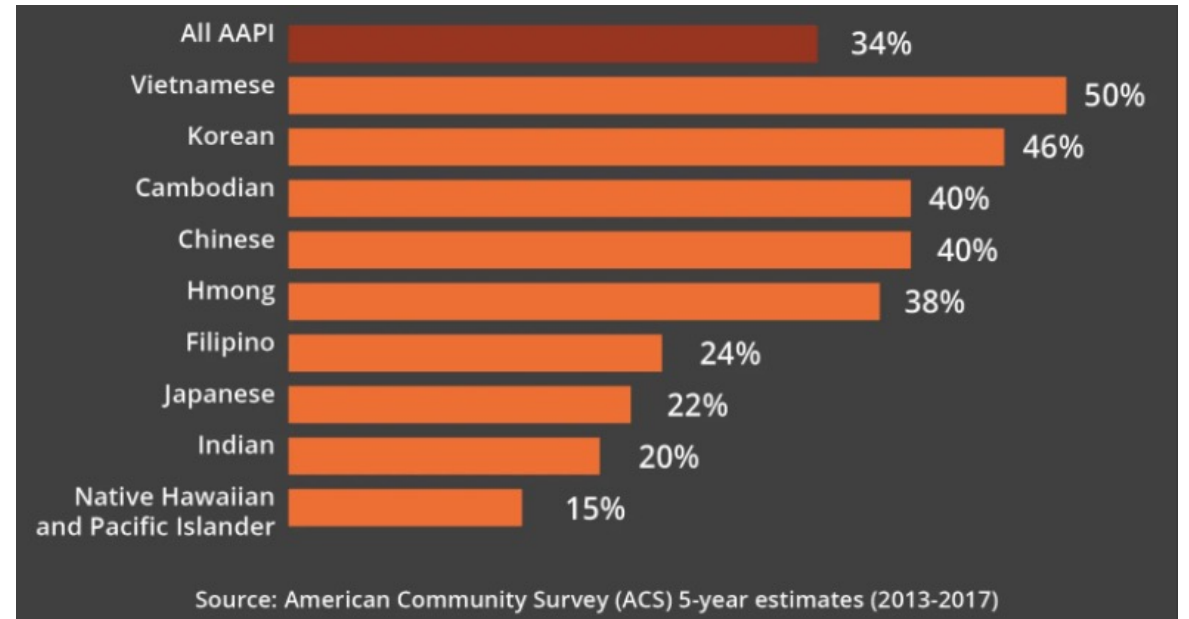
Asian Americans are the fastest growing racial group in the U.S.:<sup>1</sup>

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



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

## Percentage of AAPI with Limited English Proficiency <sup>2</sup>



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

<sup>2</sup> AAPI Data: <https://aapidata.com/infographic-limited-english-2-2/>

# Background: Disparities in Research Participation for AAPI

- Clinical research projects focusing on AAPI participants funded by the National Institute of Health (NIH) was less than 1% of its total budget between 1992 and 2018.<sup>1</sup>
- Of the 44,359 participants who were enrolled in ADRD studies at Alzheimer's Disease Research Centers, only 2.6% were AAPI.<sup>2</sup>
- Barriers to AAPI participation in research:
  - Cultural differences
  - Linguistic limitations
  - Lack of education in research practices



<sup>1</sup> Doan, Takata, Sakuma, & Irvin (2019). *JAMA Network Open*.

<sup>2</sup> National Alzheimer's Coordinating Center (NACC). Web-based Query System. 2018; <https://www.alz.washington.edu/WEB/naccquery.html>. Accessed September 28, 2021.

# Paving the Way for Meaningful Inclusion of AAPI in Research

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



# Overview of CARE Registry

**Oanh Meyer, PhD**  
CARE Co-Investigator

Department of Neurology,  
UC Davis School of Medicine

# CARE: Multi-Site Collaboration



University of California  
San Francisco



# CARE

COLLABORATIVE APPROACH FOR  
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<https://careregistry.ucsf.edu/>



NATIONAL ASIAN PACIFIC  
CENTER ON AGING



Institute for Memory Impairments  
and Neurological Disorders

# CARE Partners & Community Advisory Board





# CARE Registry

## Who can enroll?

- AAPI
- 18+ years old
- Speak and read English, Chinese, Korean, Vietnamese or Samoan
- Interested in participating in potential research



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

### NAPCA toll-free lines:

廣東話 / Cantonese (800) 582-4218      普通话 / Mandarin (800) 683-7427  
한국어 / Korean (800) 582-4259      Tiếng Việt / Vietnamese (800) 582-4336



CARE Enrollment Survey available in **6 languages**



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



The screenshot shows the CARE Registry website. At the top, there is a navigation bar with the CARE logo, the tagline "HEALTH ACROSS THE LIFE SPAN", and language options: English, 简体中文, 繁體中文, 한국어, Tiếng Việt, and Samoan. There is also a search bar and an "Enroll Now" button. Below the navigation bar, there is a blue banner with the text: "If you do not have an email address and wish to enroll by phone, please call (800)-336-2722". Below this banner is a dark blue button labeled "CARE REGISTRY ENROLLMENT". At the bottom of the screenshot, there is a section titled "If you or someone you know are:" followed by a list of bullet points: "Older (50+ years old)", "Caring for older adults", "Persons with Alzheimer's disease or related dementia, or related symptoms such as memory loss and confusion", and "Caring for persons with Alzheimer's disease or related dementia, or related symptoms such as memory loss and confusion". Below the list is the text "Please enroll in CARE!" and a row of six dots.

# CARE Enrollment Survey Questions

Socio-demographic information

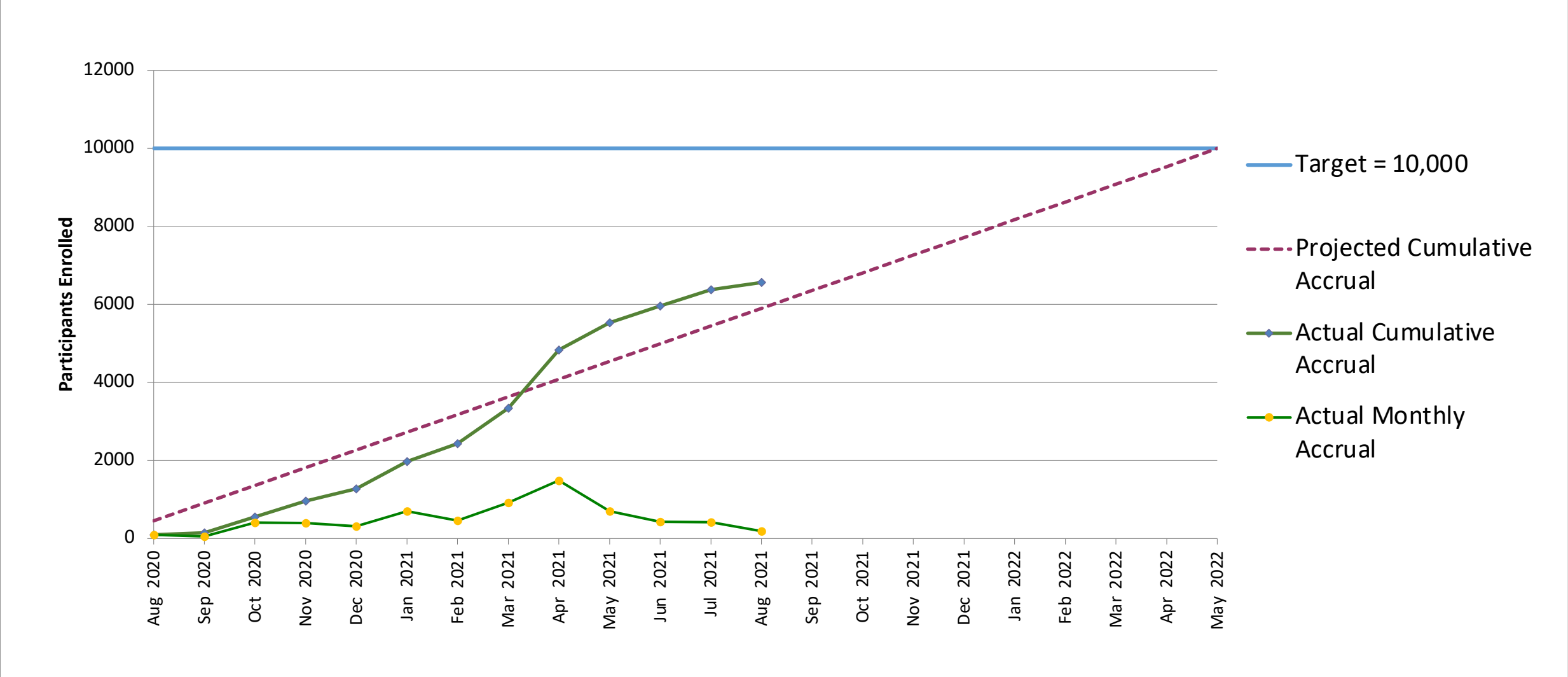
Health conditions (e.g., neurological disease and related symptoms such as Alzheimer's disease; heart disease; cancer; mood-related issues)

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

Caregiving experiences (if applicable)

# CARE Enrollment


N=6,693 as of Sep 19, 2021 (67% of our 10,000 target goal )




# CARE Snapshot: N=6,693

 **84.2%** Born outside of U.S.

 **87.8%** Californian

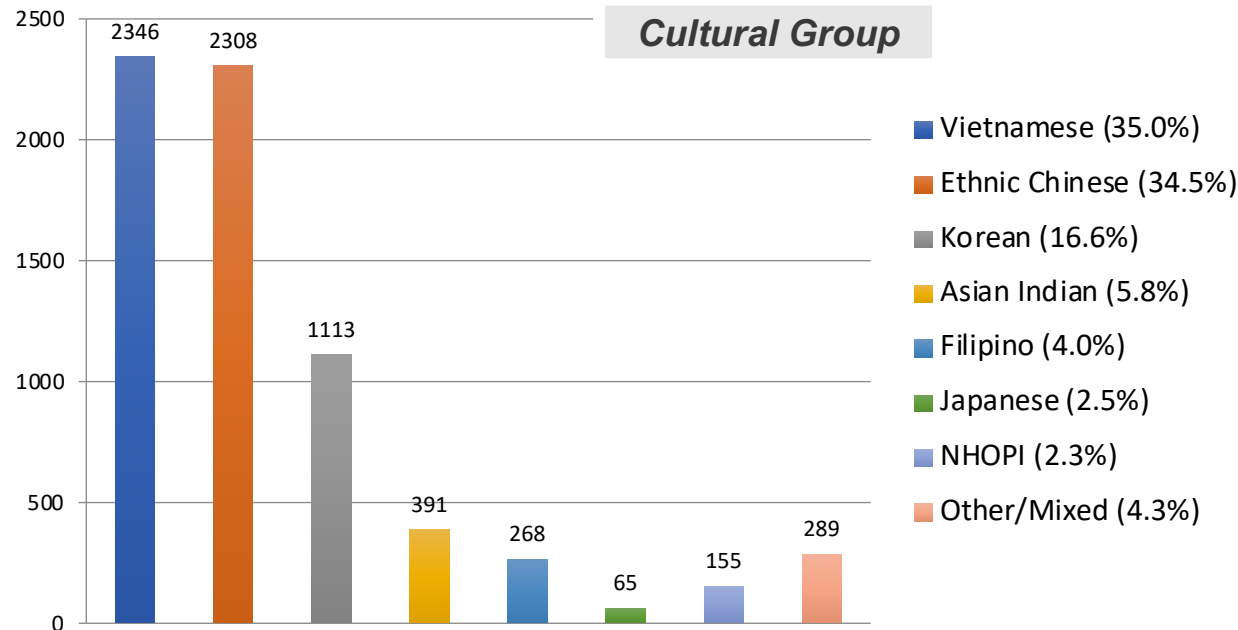
 **11.4%** Caregivers of older adults or person with special needs.

 Mean age = **52.6** (range 18-99)  
Age over 60 = **32.1%**

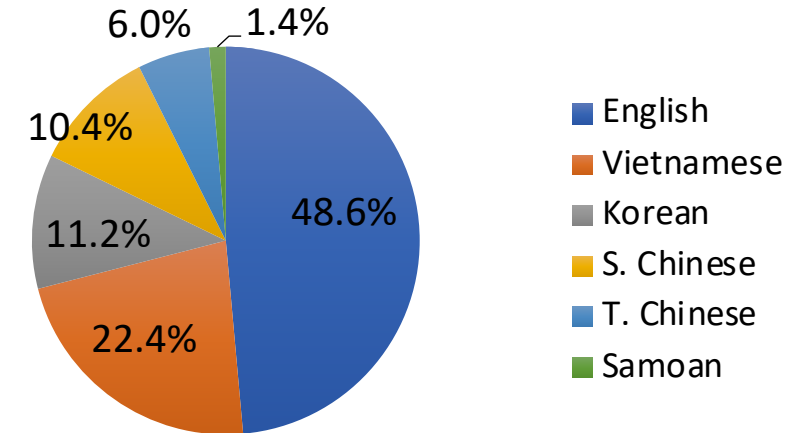
 **62.8%** Female  **35.4%** Male

 **56.9%** Limited English proficiency

 **8.6%** (N=578) with ADRD symptoms



**Language Used to Complete the Survey**



# Profile of CARE Participants (N(%) or mean $\pm$ SD)

	All (N=6,693)	Self-Reported ADRD (N=578)	ADRD Caregivers (N=255)
<b>Age</b>	52.6 $\pm$ 17.2	61.6 $\pm$ 15.7	53.3 $\pm$ 13.4
<b>Foreign-born</b>	5,636 (84.2)	552 (95.5)	194 (76.1%)
<b>Cultural groups</b>			
Vietnamese	2,346 (35.0)	458 (79.2)	70 (27.5)
Ethnic Chinese	2,308 (34.5)	96 (16.6)	123 (48.2)
Korean	1,113 (16.6)	12 (2.1)	25 (9.8)
Asian Indian	391 (5.8)	9 (1.6)	20 (7.8)
Filipino	268 (4.0)	4 (0.7)	11 (3.9)
Japanese	165 (2.5)	9 (1.6)	20 (7.8)
NHPI	155 (2.3)	5 (0.9)	8 (3.1)
Mixed	70 (1.0)	4 (0.7)	4 (1.6)
Other	219 (3.3)	3 (0.5)	1 (0.1)

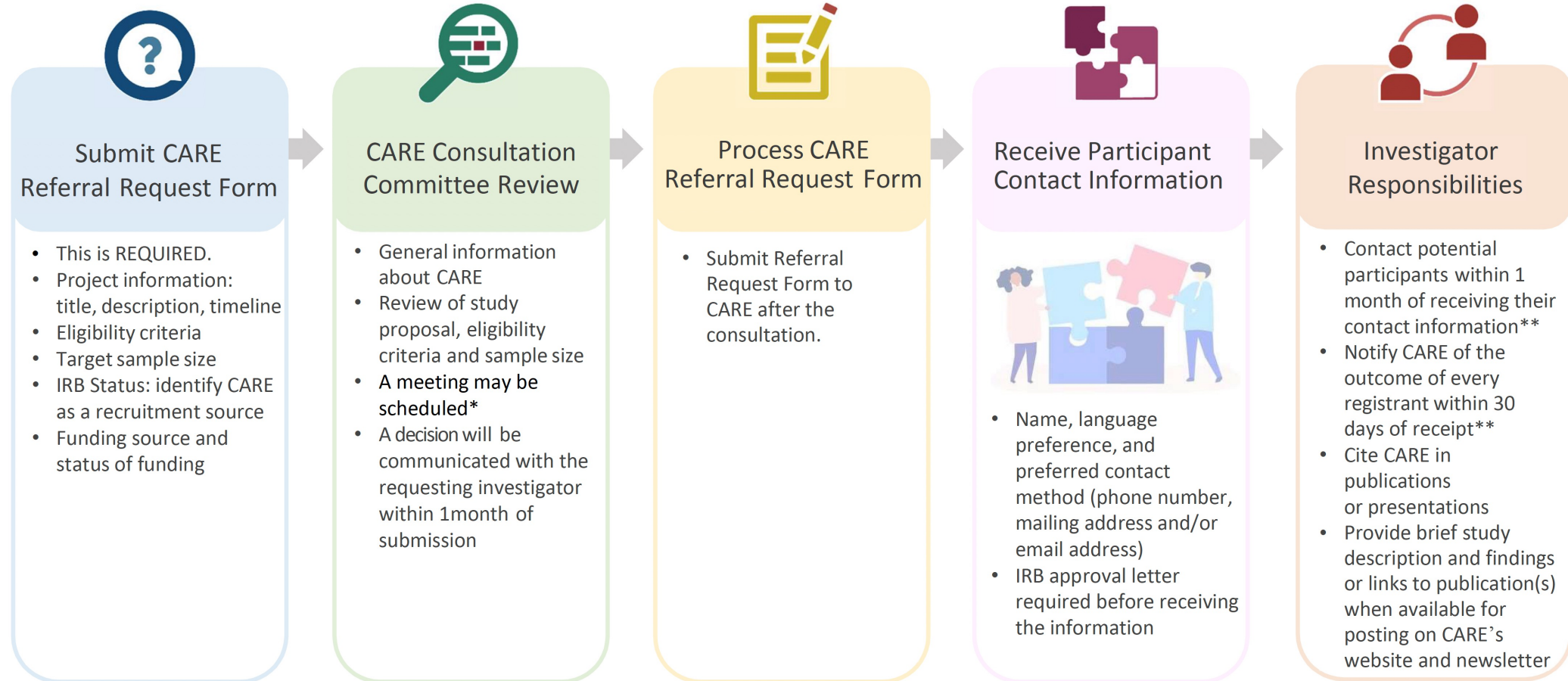
# **CARE-Supported Recruitment**

**Marian Tzuang, PhD**

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

# CARE-Supported Recruitment Flowchart

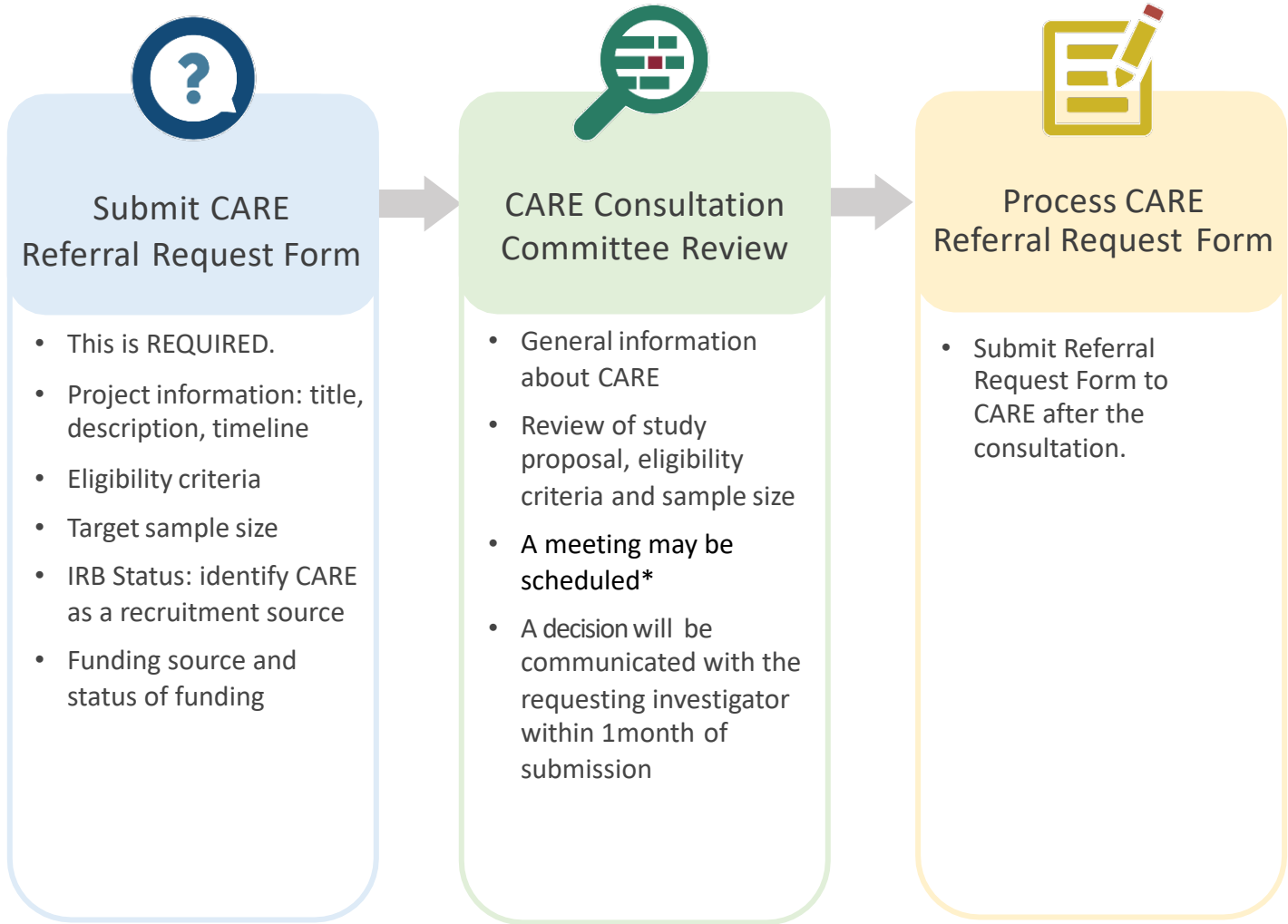
CARE-Supported Recruitment Flowchart




\*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 Steps 1-3





**CARE**  
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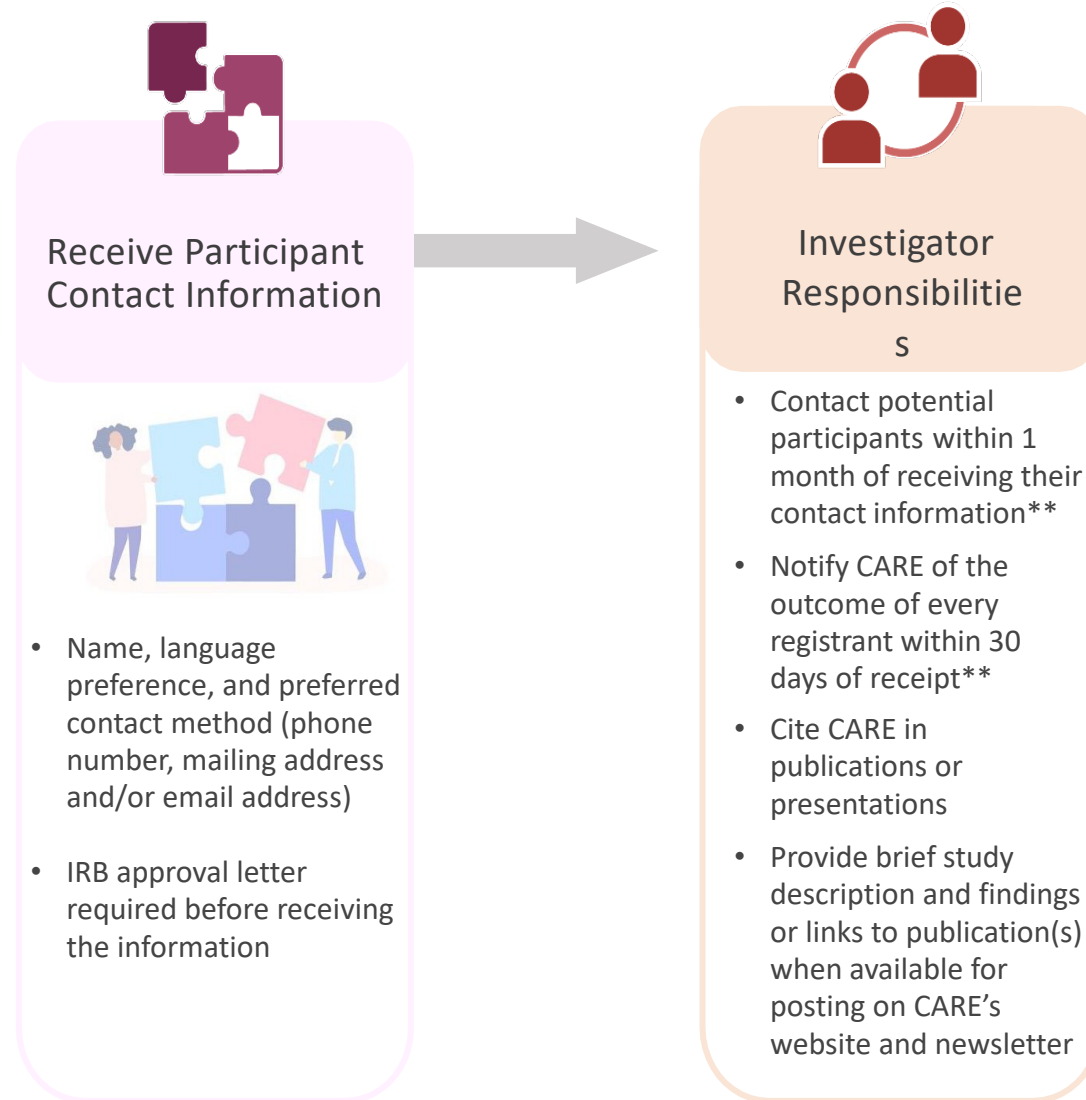
**CARE Referral Request Form**

<b>Contact information</b>	
<b>Principal Investigator:</b>	<b>PI Email:</b>
<b>Study Contact:</b>	<b>Study Contact Email:</b>
<b>Study Information</b>	
<b>Study Title:</b>	
<p><b>Have you scheduled a consultation meeting with us to discuss recruiting participants from CARE?</b> <i>(if not, please email Marian Tzuang, PhD, MSW, CARE Research Analyst at <a href="mailto:yuan.tzuang@ucsf.edu">yuan.tzuang@ucsf.edu</a> to schedule it.)</i></p> <p><input type="checkbox"/> Yes   <input type="checkbox"/> No</p> <p><b>If "Yes", please fill out the sections below based on consultation with CARE.</b></p> <p><b>If "No", please fill out the sections below as appropriate.</b></p> <p><b>What kinds of assistance would you like to receive from the consultation?*</b> <i>(check all that apply)</i></p> <p><input type="checkbox"/> Study design   <input type="checkbox"/> Eligibility criteria   <input type="checkbox"/> Sample size   <input type="checkbox"/> Translation   <input type="checkbox"/> Letter of support</p> <p><input type="checkbox"/> Templates for emails and participant communication</p> <p><input type="checkbox"/> Other, please specify:</p> <p><small>*Consultation will be provided in the context of the CARE Registry.</small></p>	
<b>Study Recruitment Status:</b>	
<input type="checkbox"/> Ongoing <ul style="list-style-type: none"> <li>ClinicalTrials.gov ID (if applicable):</li> <li>Study website (if applicable):</li> <li>Other public access / study registration (if applicable):</li> </ul> <input type="checkbox"/> Preparing for recruitment	
<b>Asian Americans and Pacific Islanders (AAPI) Cultural Group of Interest:</b>	
<input type="checkbox"/> All AAPI <input type="checkbox"/> Asian Indian <input type="checkbox"/> Chinese <input type="checkbox"/> Ethnic Chinese (Hauren) <input type="checkbox"/> Filipino <input type="checkbox"/> Korean <input type="checkbox"/> Japanese <input type="checkbox"/> Native Hawaiian <input type="checkbox"/> Samoan <input type="checkbox"/> Taiwanese <input type="checkbox"/> Vietnamese <input type="checkbox"/> Other AAPI cultural group(s), please specify:	
<b>Study Description and Goals:</b>	

\*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 Steps 4-5



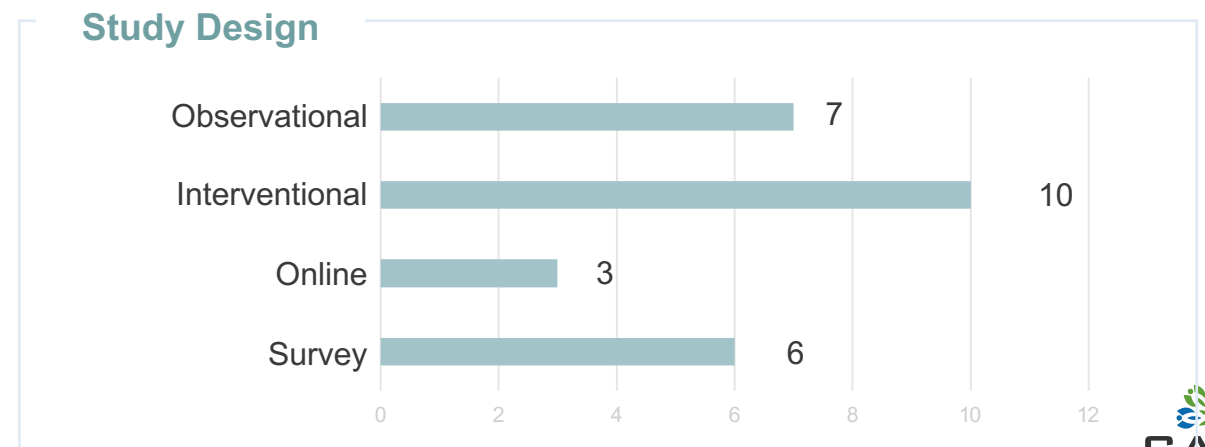
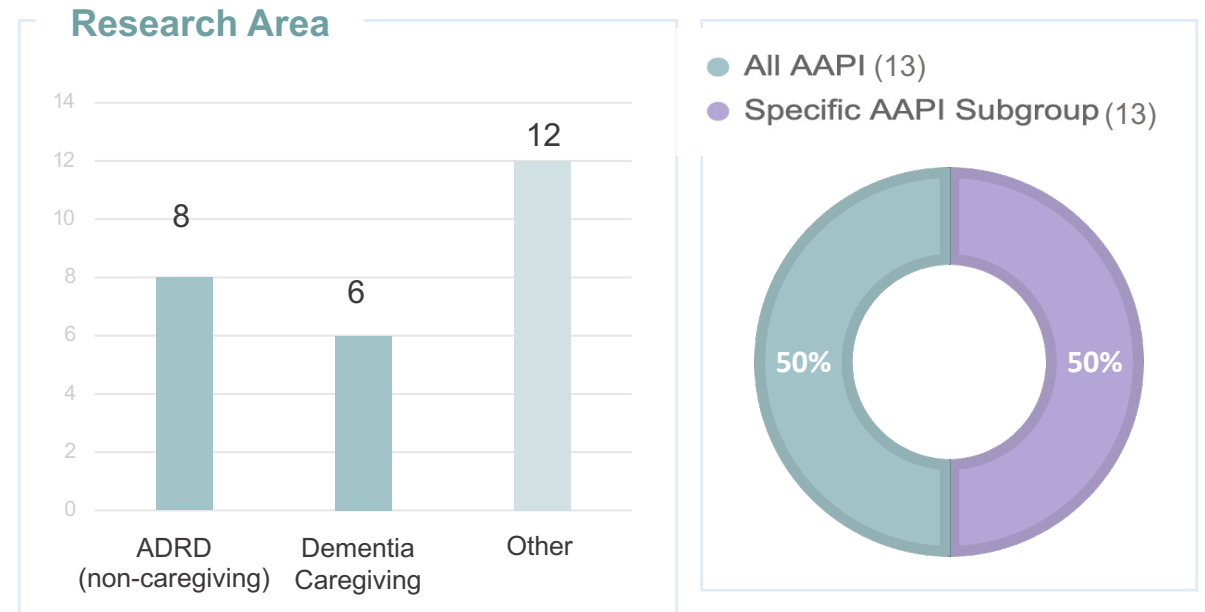
\*\*This is a general guideline primarily for prospective and/or in-person studies. Investigator responsibilities may be discussed on a case-by-case basis for other types of study designs (e.g., surveys).

# 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.
- The guidelines presented is 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 survey.

# CARE-Supported Recruitment Requests (N=26 as of September 28, 2021)

Institutions	# of request
UC San Francisco	12
Stanford University	3
University of Southern California	2
UC Irvine	1
UC Davis	2
UC Los Angeles	1
Texas State University	1
University of Houston	1
Montefiore Medical Center	1
University of Illinois at Urbana-Champaign	1
Korean Community Center of the East Bay	1



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

## Referral Request Received

Late January 2021

## CARE Committee Review

Early February 2021

- Ask PI to obtain IRB approval to include CARE as a recruitment source
- Clarify participant eligibility
- Initial query to identify potentially eligible participants:
  - 1) age  $\geq 50$ ; 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

**Hye-Won Shin, PhD**

CARE Community Advisory Board Member

UC Irvine Institute for Memory Impairments and Neurological Disorders (UCI MIND)



**SOMANG SOCIETY**  
Well-Being, Well-Aging, Well-Dying



# Somang Society Mission: **Well-Aging**

- Somang Care Class (Korean)
- Somang Dementia Education (Korean/English)
- 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 Preschool
- Family Sponsorship Services

**14,568**

SoMang WILL's

**1,276**

Emergency Contact Cards

**1,817**

Body Donations

**440**

SoMang Well

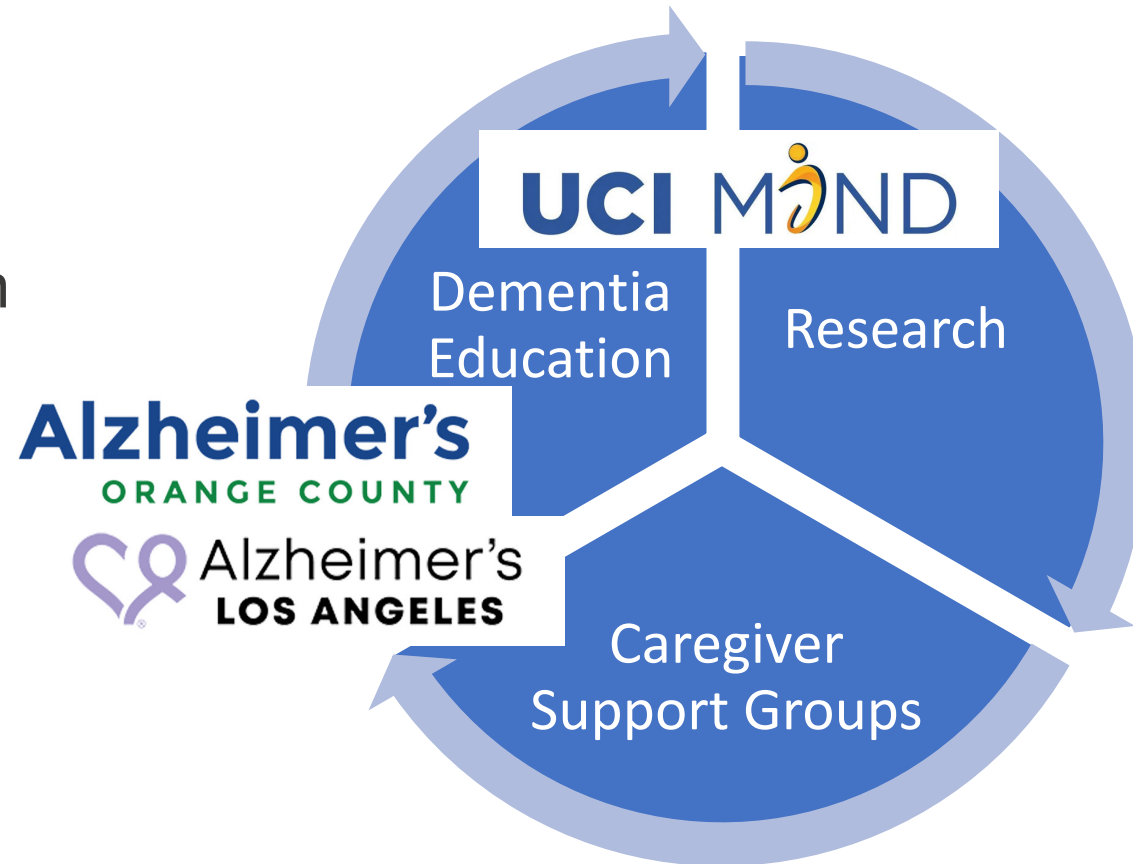
**5**

Preschool

# Community Perspectives in Research: Partnership with CARE



Korean American  
Community





# Q&A + Raffles

**Please complete our evaluation survey:**

**<https://tinyurl.com/CAREBrainTrustOct2021>**



# 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  
Shweta Srivastava  
Marian Tzuang  
Stuart Gansky (DCE)  
Sarit Helman (DCE)  
Niloufar Ameli (DCE)  
CARE Interns

*\* Special thanks to Bobin Kim, Bora Nam and Marian Tzuang for their support in developing this presentation.*

## UC Davis

Oanh L. Meyer (Site PI)  
Ladson Hinton (Co-I)  
Anna Bach  
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)  
Isabella Luong  
Anne Phan  
Cecilia Phan

## NAPCA

Joon Bang (Site PI)  
Heather Chun  
Dyanna Chung  
Lisa Thong

## Community Advisory Board

Araceli Antonio ▪ Joyce Cheng ▪ David Choi ▪ Sadhna Diwan ▪ Sophie C. Horiuchi-Forrester ▪ Joyce Javier ▪ Ryan Kawamoto  
▪ Ruobing Li ▪ Tatiana Makoni ▪ Gerard Manuel ▪ 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