

# Brain Trust Meeting

September 9, 2024



**CARE**

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

# Agenda

12:00 – 12:15pm	<b>Introduction &amp; Overview of CARE Registry</b> Janice Tsoh, PhD (UC San Francisco)
12:15 – 12:30pm	<b>How to Use CARE</b> Joshua D. Grill, PhD (UC Irvine)
12:30 – 12:40pm	<b>Community Perspectives in Research: Partnership with CARE</b> Quyen Vuong, MSW, MBA (ICAN)
12:40 – 12:50pm	<b>User Testimonial: Experiences with CARE for Study Recruitment</b> Y. Alicia Hong, PhD (George Mason University)
12:50 – 1:00pm	<b>Q&amp;A + Raffles + Evaluation</b>



# Introduction & Overview of CARE Registry

**Janice Tsoh, PhD**

CARE Multiple Principal Investigator

Department of Psychiatry & Behavioral Sciences,  
UC San Francisco School of Medicine

# Asian Americans, Native Hawaiians & Pacific Islanders (AANHPI)

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

7.7% of the population

30 AA & 21 NHPI groups

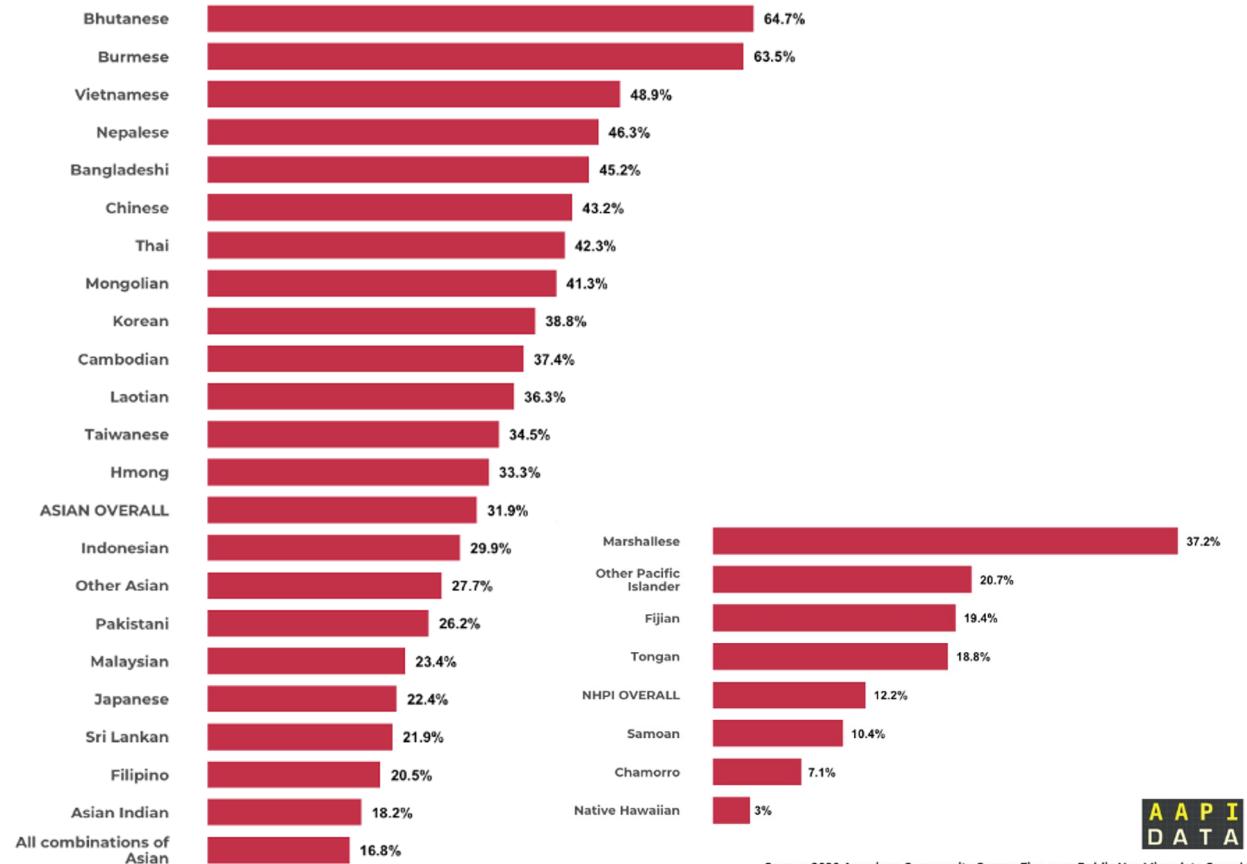
20 million AA & 1.6 million NHPI



- 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<sup>2</sup>



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



<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/blog/2022-national-demographics/>

# Background: Disparities in Research Participation for AANHPI Populations

- Clinical research projects focusing on AANHPI 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 51,836 participants who were enrolled in AD/DRD studies at Alzheimer's Disease Research Centers, only 2.8% were AANHPI participants.<sup>2</sup>
- 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



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

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

# Paving the Way for Meaningful Inclusion of AANHPI Participants in Research

- Funded by NIA R24AG063718 & R01AG083926
- Officially launched in October 2020
- 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 including Japanese, Tagalog, and Ilokano.

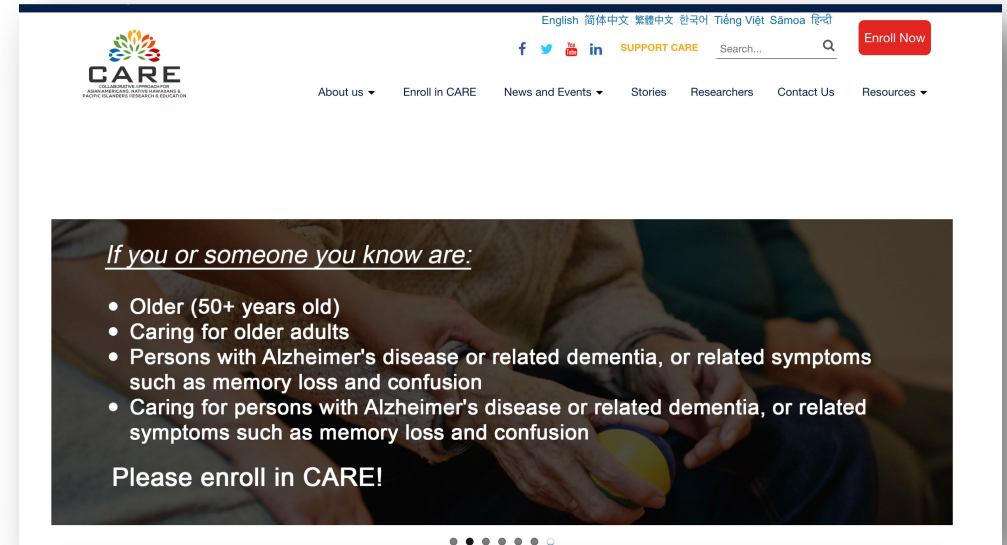


Participants have the option to **receive a \$10 gift card** after completing the enrollment survey



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

Website: [careregistry.ucsf.edu](http://careregistry.ucsf.edu)












CARE Registry Enrollment Survey includes:

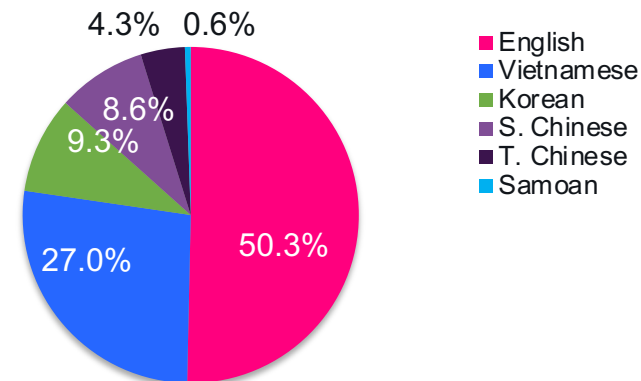
- Sociodemographic Information
- Health Conditions
- Health Behaviors
- Caregiving Experiences (if applicable)



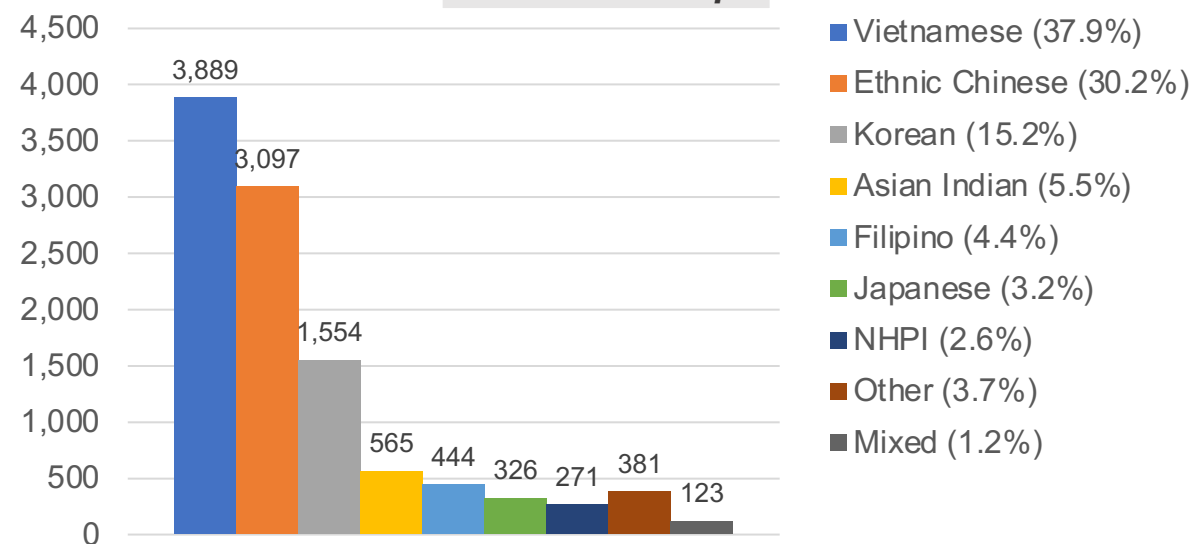
# CARE Participant Snapshot: N=10,257 (as of Sep 3, 2024)

	83.2%	Born outside of U.S.	
	84.6%	Californian	
	10.7%	Caregivers of older adults or person with special needs	
	80.3%	No research participation experience	
	54.4	Mean age (range 18-101)	
	35.2%	Age over 65	
	62.8%	Female	35.6% Male
	50.1%	Limited English proficiency	
	13.8%	(N=1,411) with ADRD symptoms	

Language Used to Complete the Survey



Cultural Group



# CARE-Supported Recruitment

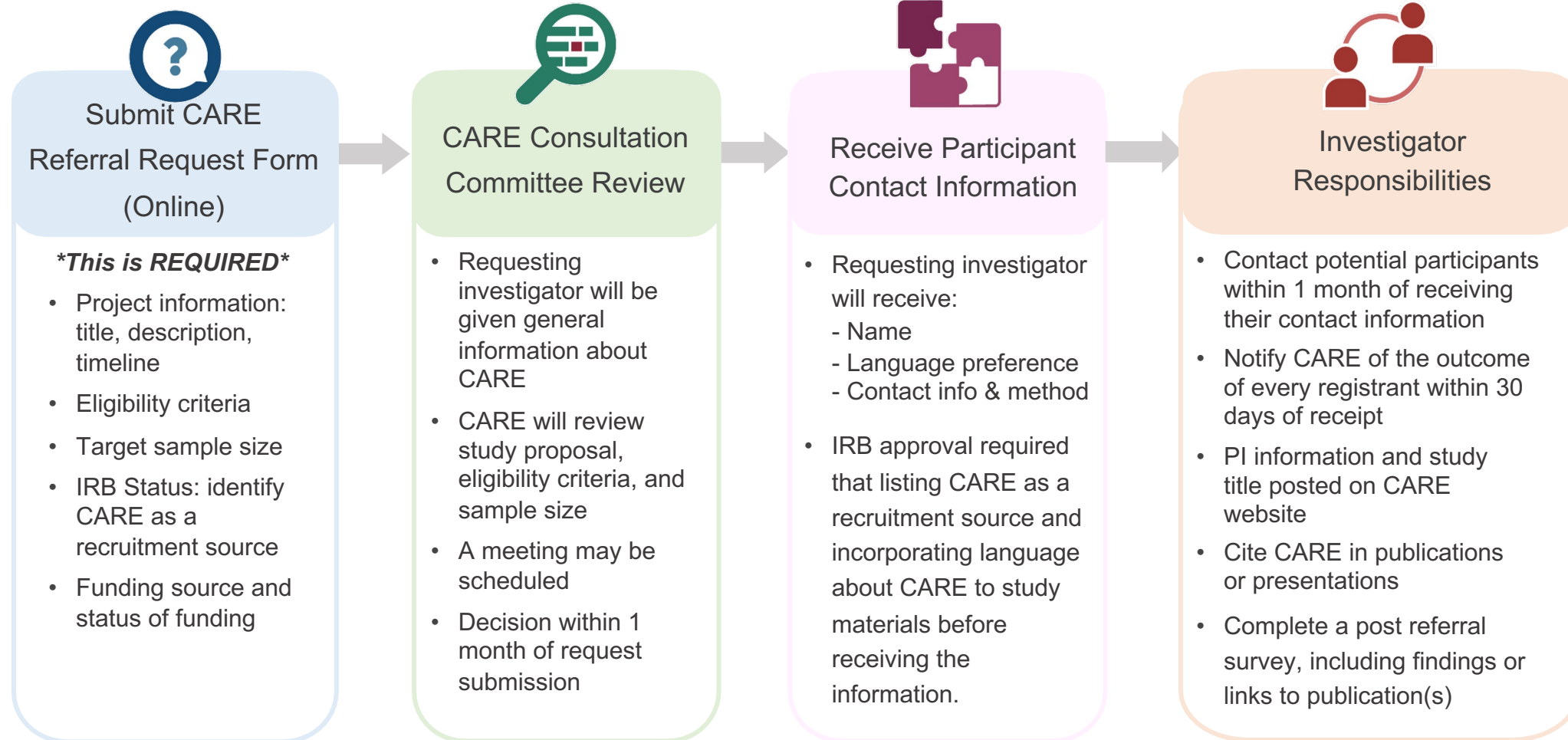
- Complete CARE Recruitment Referral Online Form: <https://tiny.ucsf.edu/CAREReferralRequest>
- CARE team may request a consultation meeting to discuss the proposed recruitment referral in detail.
- Proposals that involve substantial commitment of CARE resources will receive further review and budgetary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



<http://tiny.ucsf.edu/CAREReferralRequest>

# CARE Supported Recruitment Process

Referral  
Request  
Online Form

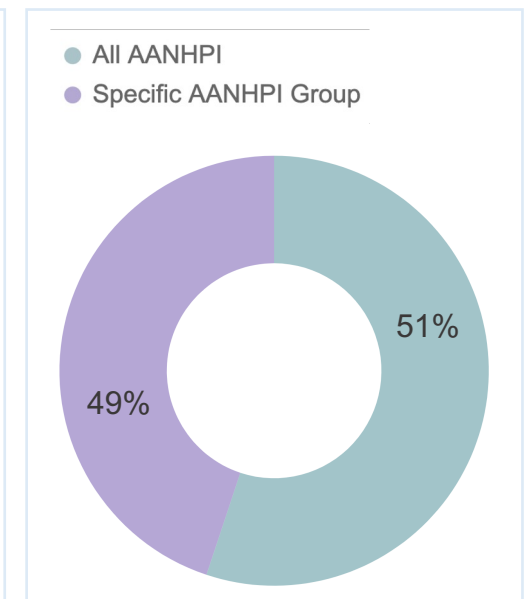
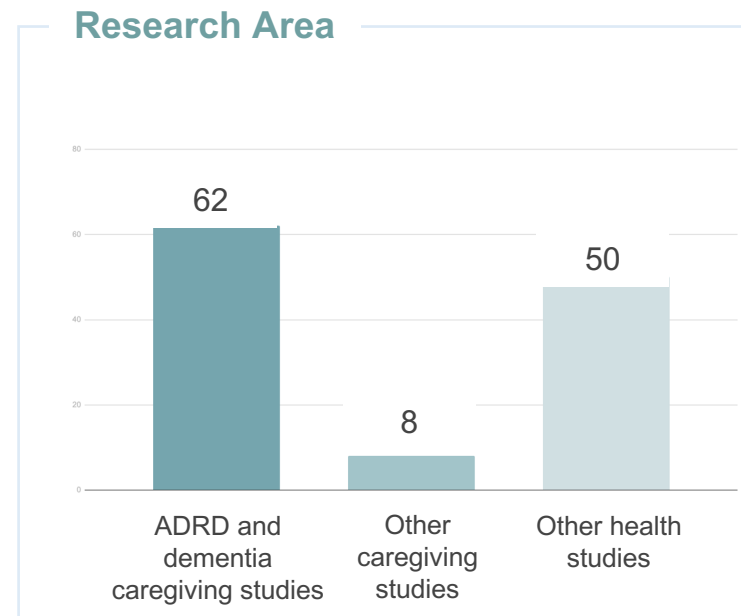
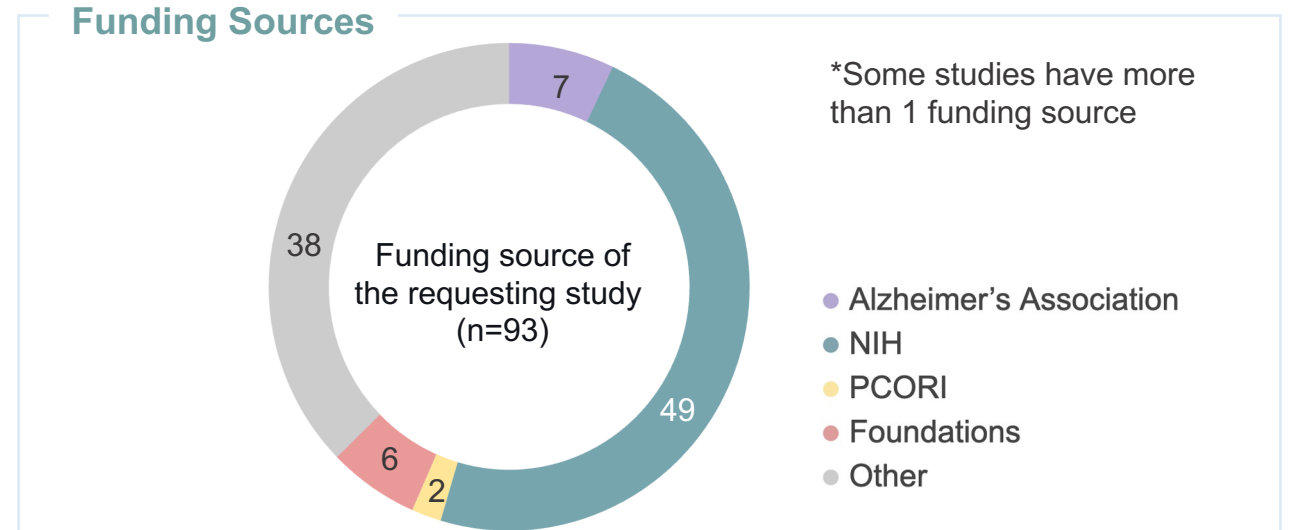


For more information on CARE referral requests for researchers: <https://careregistry.ucsf.edu/researchers>

# Supporting Recruitment to Many Studies & Grant Applications

(N=120 as of August 18, 2024)

- Since January 2021, 12,795 CARE participants have been referred to CARE-supported studies, and 6,609 CARE participants have been referred to at least one CARE-supported study.
- 45 of the requesting studies have study materials or personnel support for participants in English and at least one other AANHPI language.
- Letters of support provided to 20 investigators for grant application, 15 of which to the NIH (14 to NIA) and 1 to Alzheimer's Association



# 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

1. Recruit participants to increase diversity of a study population
2. Recruit participants as a novel comparison group
3. Ask novel research questions about AANHPI

# 1. Recruit AANHPI Participants to Increase Diversity in Your Study

## Faison et al.

Race/Ethnicity	Industry (n=10,800)	ADCS (n=737)
White	96.8%	90%
Black	1.9%	6%
Asian	0.9%	NR
Hispanic	0.4%	4%

Faison WE, et al. *Int Psychogeriatrics*. 2007;19:539-558.

## Franzen et al., Systematic review (n=101 trials)

Race/Ethnicity	% (IQR)
White	94.7% (81.0–96.7%)
Black	1.2% (0.4–1.7%)
Asian	4.4% (0.3–17.3%)
Hispanic	5.6% (4.2–11.4%)

Franzen, et al. *Alz & Dem*. 2021.



# CARE

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



Investigator

# Example: Study Recruitment

- Study design: Randomized interview study assessing the impact of biomarker testing and disclosure on AD prevention trial recruitment
- Use of CARE: Recruit participants meeting inclusion criteria (age, English-speaking, no major neurological or psychiatric disorders/diagnoses)
  - *Participants recruited from CARE included in study that also includes participants from other sources. Randomization overcomes issues around sample bias*
  - *Goal is to study more inclusive, representative sample*
  - *Secondary analyses might compare effect modification by race*



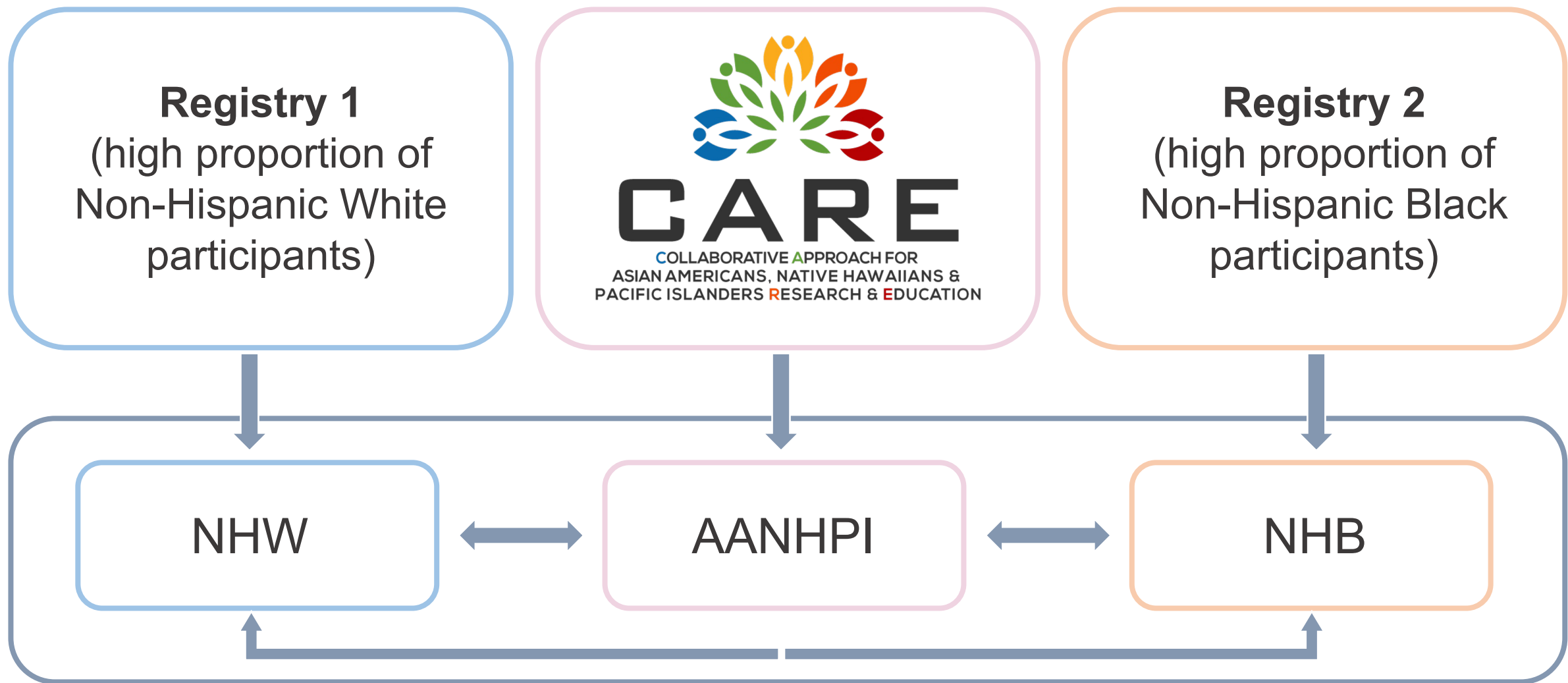
## 2. Recruit AANHPI Participants as a Novel Comparison Group

- Recruit CARE registrants to your prospective study\*
  - *Recruit specific CARE registrants of interest to compare to other groups (e.g., non-Hispanic Whites)*
  - *Compare different AANHPI groups*



\* Recruiting from CARE may produce important sample bias that is best addressed in study designs (post-recruitment)

# Example: Study Recruitment



### 3. Answer Novel Research Questions About AANHPI

- Disseminate a survey to the CARE registrants
  - *All CARE registrants*
  - *Specific CARE registrants (e.g., Chinese immigrants >65 years)*
  - *Compare within or across AANHPI groups*
- Utility:
  - *Needs assessments*
  - *Preliminary data*
  - *Complete studies*



# Example: Survey Study Design

- Hypothesis: Immigrants differ from second generation AANHPI in their attitudes toward Alzheimer's disease prevention research
- Participants: Older (age 55 and up) CARE participants
- Methods: Send an electronic (REDCap) survey to all eligible CARE registrants
- Primary Analysis: Compare AANHPI born in this country to those born in another country for differences in willingness to participate in AD prevention research

# Caveats and Conclusions

- CARE is not a community based epidemiologic cohort
- It cannot provide information (or opportunities to study) on disease prevalence or population characteristics
- Recruitment biases may differ among AANHPI subgroups in CARE
  
- CARE can assist in examining potential cultural and racial associations, hypothesis generation, and comparison studies
- CARE can improve recruitment of AANHPI and assist in diversifying research

***THANK YOU!!***



# Community Perspectives in Research: Partnership with CARE

**Quyen Vuong, MSW, MBA**

CARE Community Advisory Board Member, International  
Children Assistance Network (ICAN)

# International Children Assistance Network (ICAN)



**Quyen Vuong**  
*Executive Director*

# 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 AAPI 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/](http://careregistry.ucsf.edu/))
- Vietnamese Insights into Aging Program (VIP) (<https://health.ucdavis.edu/neurology/vip/index.html>)
- Asian Americans & Racism: Individual and Structural Experiences (ARISE) (<https://arise.ucsf.edu>)
- Dementia & caregiving related studies

# Recruiting underserved Asian American dementia caregivers into digital health interventions: **Case study of WE CARE**

Y. Alicia Hong, PhD  
Dept of Health Admin & Policy  
College of Public Health  
George Mason University

# Overview

- Background & Significance
- Case study: WECARE
- Recruitment process and numbers
- Experience and lessons learned

# Asian American dementia caregiver characteristics

- Underserved Asian Americans caregivers, especially those with limited English proficiency, experience high rates of stress, depression, and isolation
- High prevalence of caregiving within the community due to cultural norms
- Limited use of formal services and welfare due to language barriers and immigration status
- Marginalized from mainstream support groups of dementia caregivers

# Rationale for a WeChat-based intervention

- WeChat use: High penetration rate (>92%)
- Easy access and high sustainability (no need to learn a new app, no download)
- Can leverage existing functions of WeChat: Group-chat, digital wallet, multimedia content.

# WECARE (Wellness Enhancement for Caregivers)

- WECARE: 7-week program delivered via WeChat, targeting Chinese American dementia caregivers
- WECARE: multimedia articles 6 days/wk, 7wks, group chat, location-specific resources.
- Focus on improving caregiving skills, reducing stress, and enhancing psychosocial wellbeing.
  
- 2022: WECARE 1.0 pilot (pre-post)
- 2023-2024: WECARE 2.0 pilot (pre-post)
- 2024: WECARE 1.0 second follow-up (48-month)
- 2024-2025: WECARE 2.0 second follow-up (24-month)





# WECARE (Wellness Enhancement for Caregivers)

Figure 1: Sample screenshots of WECARE



1. Multimedia article with audio recording on how to deal with angry behaviors of dementia patients
2. Short video clip as a case study to explain the angry behaviors of dementia patients
3. Push notification & progress summary

# WECARE backend: User management system

The screenshot displays the 'user management system' interface for 'User details'. The left sidebar contains navigation options: 'main navigation', 'console', 'User Management', 'User Management', 'media information management', and 'Send management'. The main content area is divided into several sections:

- User Profile:** A blue header bar shows 'Intervention Group Account'. Below it, fields include: serial number (27), Nick name (masked), Phone number (Not yet filled), group (Intervent), Label, cd4 (0), cd4 update time (1900-01-01), Average number of steps last week (0), set a goal (0), Enrollment time, and Enrollment week.
- 4.3 Problem solving: Demented elderly beating and cursing:** A modal window showing reading statistics for three entries:
  - 1st reading:** 2022-03-31 09:58:55, User reading time: 245 seconds, User staying time: 176 seconds, Audio playing time: 176 seconds.
  - 2nd reading:** 2022-03-31 18:57:29, User reading time: 470 seconds, User staying time: 175 seconds, Audio playing time: 175 seconds.
  - 3rd reading:** 2022-04-01 10:39:16, User reading time: 45 seconds, User staying time: 0 seconds, Audio playing time: 0 seconds.
- Statistics last week:** A table showing: Number of articles received (7), Number of articles read (6), and Unread articles (1).
- User-set goals:** A table showing: number of workouts per week (0), minutes per workout (0), and daily steps (0).
- Historical push articles:** A list of articles with search and pagination controls. The list includes:
  - 12899: 3.3 Family Meeting for Communication with Family (Read)
  - 12929: The summary of the first online exchange meeting (has been read)
  - 12962: 3.4 Communication between children, grandchildren and the elderly (elderly)
  - 12992: 3.5 How to seek help (read)
  - 13022: 3.6 Solve problems with communication (communication)
  - 13052: 4.1 How to Solve Problems Effectively (Read)
  - 13082: 4.2 Problem Solving: Elderly Repeated Words or Actions (Read)
  - 13112: WECARE Second Online Conference (Unread)
  - 13145: 4.3 Problem Solving: Demented Elderly Beating and Cursing (elderly)



# Participant Eligibility



## Inclusion criteria:

- 1) 21 years or older,
- 2) self-identify as Chinese or Chinese American,
- 3) Own a smartphone and use WeChat, and
- 4) Currently care for a family member or loved one with ADRD and provide care for > 8 hours a week.

## Exclusion criteria:

- 1) signs of severe intellectual deficits or psychotic disorders, or
- 2) 2) the care-recipient is in hospice care or has < 6 months of life expectancy.

# WECARE: Recruitment numbers



	CCACC (DC/MD)	CARE (CA)	Silver Light (VA)	CaringKind (NY)	Other Wechat groups	Total (Baseline)	Follow-up (3-mon)	Follow- up (24-mon)
WECARE 1.0	11	13	--	--	--	24	23 (94%)	18 (75%)
WECARE 2.0	14	5	7	19	3	48	45 (93%)	Ongoing

# WECARE 1.0 & 2.0: Demographics of caregivers and care recipients

Characteristics		WECARE 1.0 Baseline (n=24)	WECARE 2.0 Baseline (n=48)
<b>Caregiver (CG)</b>			
	Age (years), mean (SD)	59.58 (11.99)	64.2 (12.4)
	Female sex (%)	17 (71%)	43 (90%)
	Married or living with a partner (%)	21 (88%)	39 (81%)
	Yrs of living in US, mean (SD)	23.4 (10.5)	28.5 (12.2)
	Limited English proficiency (%)	13 (54%)	18 (37%)
	Speaks Chinese home (%)	22 (92%)	45 (94%)
	Has difficulty paying for basics (%)	11 (46%)	12 (25%)
<b>Care Recipient (Person w. Dementia)</b>			
	Age (years), mean (SD)	81.38 (8.65)	83.6 (7.9)
	Female sex (%)	13 (54%)	27 (56%)
	CR and CG live together (%)	16 (67%)	35 (73%)
	Relationship to CG		
	Spouse (%)	7 (29%)	18 (38%)
	Child (%)	16 (67%)	24 (50%)
	Other relative or friend (%)	1 (4%)	6 (13%)
	ADL <sup>a</sup> score, mean (SD)	11.54 (9.47)	11.50 (8.25)
	IADL <sup>b</sup> score, mean (SD)	20.08 (5.64)	20.69 (4.49)

# RESULTS OF **WECARE 1.0** PILOT TEST



**Table 2: Caregivers' psychosocial wellbeing pre- and post-intervention comparison**

<b>Outcome</b>	<b>Baseline mean (SD)</b>	<b>Follow-up mean (SD)</b>	<b>Change mean (SD)</b>	<b>Effect size Cohen's d (95% CI)</b>
<b>Depression (0-10)</b>	5.74 (2.56)	3.35 (2.72)	<b>-2.39 (0.16)</b>	<b>-0.89***</b> (-1.37, -0.40)
<b>Life satisfaction (range 0~30)</b>	11.35 (6.66)	14.83 (7.11)	<b>3.48 (0.45)</b>	<b>-0.48*</b> (-0.90 to -0.04)
<b>Caregiving burden (range 0~48)</b>	25.78 (7.19)	21.91 (6.69)	<b>-3.87 (0.50)</b>	<b>0.55**</b> (0.10, 0.98)
<b>Social support (range 0~30)</b>	14.78 (5.15)	13.96 (6.39)	-0.83 (1.24)	--

# RESULTS OF **WECARE 2.0** PILOT TEST



Outcome	Baseline mean (SD)	Follow-up mean (SD)	Change mean (SD)	p-value
Depression (range 0-60)	18.27 (11.12)	16.6 (8.97)	-1.67 (-2.15)	0.2128
Life satisfaction (range 0~30)	12.62 (7.07)	14.87 (7.47)	2.25 (0.40)	<b>0.06401</b>
Caregiving burden (range 0~48)	20.07 (10.37)	18.53 (9.08)	-1.54 (-1.29)	0.1535
Caregiving mastery (range 0~28)	16.33 (4.13)	17.67 (4.05)	1.34 (-0.08)	<b>0.03002*</b>
Positive aspect of caregiving (range 0~36)	12.62 (7.58)	24.76 (8.09)	12.14 (0.51)	<b>0.00000001527*</b>
Problem behaviors (range 0~24)	12.82 (4.79)	12.18 (5.21)	-0.64 (0.42)	0.2748
Reactions to problem behaviors (range 0~96)	13.67 (13.96)	10.42 (12.24)	-3.25 (-1.72)	0.1577

# Participant characteristics differ

	Lower SES (Difficulty paying bills, Education)	Lower English proficiency	Poor caregiving skills	Poor outcomes at baseline
CCACC (MD/DC)		+		+
Silver Light (VA)	+	++	+	
CARE (CA)		+	+	
CaringKind (NY)	+	+		+



# CARE Registry Recruitment

Program	Potential Participants	1st attempt	2nd attempt	3rd attempt	Result
WECARE 1.0	Batch 1: n=50	2/18/2022 Email & message & call	2/21/2022 Email & call	3/2/2022 message	1- invalid number 2 – no longer a caregiver 3 – not a family caregiver 1 – do not read Chinese <b>5 – enrolled</b> 38 – unable to reach
	Batch 2: n=38	3/4/2022 Text	Recruitment paused; program started		1 – invalid number <b>4 – enrolled</b> 33 - unable to reach
WECARE 2.0	Batch 1: n=50	12/7/2023 Email	12/11/2023 Text	12/18/2023 Call	4 – invalid email 6 – invalid number 7 – not interested <b>3 - enrolled</b> 30 unable to reach
	Batch 2: n=13	1/25/2024 Email	1/26/2024 Text	1/29/2024 Call	1 – not eligible 1 – not interested <b>2 - enrolled</b> 9 - unable to reach

# Experience and lessons learned

- 1) Specified, correct, and easy-to-understand info on flyer.
- 2) A simple website with up-to-date info.
- 3) Be patient and courteous with older adults, willing to listen, and document their concern, collect data during recruitment.
- 4) Every recruitment channel has its blind spot.
- 5) Community-based organizations in the same region may be silos.
- 6) A registry like CARE is VERY important for clinical research recruitment from underserved populations: **Saves researchers' time in recruitment and allows innovative research to take place immediately.**



**Thank you!**

Dr. Alicia Hong  
[yhong22@gmu.edu](mailto:yhong22@gmu.edu)

# Acknowledgments

Thank you to all the registry participants!

## UC San Francisco

Van Ta Park (MPI)  
Janice Tsoh (MPI)  
Thomas Hoffmann

Bora Nam  
Marian Tzuang  
Nicole Phan  
Chandra Chak  
Annie Ching  
Bobin Kim  
Daren Huang  
Gabriel Fara-On  
Seoyeon Yum  
Anson Wong  
Nimita Gaggar  
Emily Dang  
Linh Nguyen  
CARE Interns & Ambassadors

## UC Davis

Oanh L. Meyer (Site PI)  
Ladson Hinton

## UC Irvine

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

## Stanford University

Dolores Gallagher-Thompson  
Cati Brown-Johnson

## ICAN

Quyên Vuong (Site PI)  
Lam Pham  
MaiHien Luu

## CSU East Bay

Arnab Mukherjea (Site PI)

## U of Hawaii

Christy Nishita (Site PI)



## Community Advisory Board

Natalie T. Ah Soon ▪ Araceli Antonio ▪ Poki'i Balaz ▪ Rejie Marie Baloyos ▪ Joyce Cheng ▪ David Choi  
Sadhna Diwan ▪ Sophie Horiuchi-Forrester ▪ Lindsey Ilagan ▪ Alka Kanaya ▪ Ryan Kawamoto ▪ Samira Khan ▪ Daphne Kwok  
Eun Jeong Lee ▪ Ruobing Li ▪ Kekoa Lopez-Paguyo ▪ Jennifer Masuda ▪ Christina Miyawaki ▪ Becky Nguyen  
Christine Nguyen ▪ Rey Paolo Roca ▪ Lina Park ▪ Tammie Pitkin ▪ Hye-Won Shin ▪ Leezel Tanglao  
Justina P. Tavanā ▪ Va'atausili Tofaeono ▪ 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/CAREbraintrustSep2024](https://tiny.ucsf.edu/CAREbraintrustSep2024)

