Brain Trust Meeting

MARCH 13, 2023

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** *Joshua D. Grill, PhD (UC Irvine)*
10:30 – 10:40am	**CARE Referral Request Process and Updates** *Janice Tsoh, PhD (UC San Francisco)*
10:40 – 10:50am	**User Testimonial: Experiences with CARE for Study Recruitment** *Christina Miyawaki, PhD, MSW, MA (University of Houston)*
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

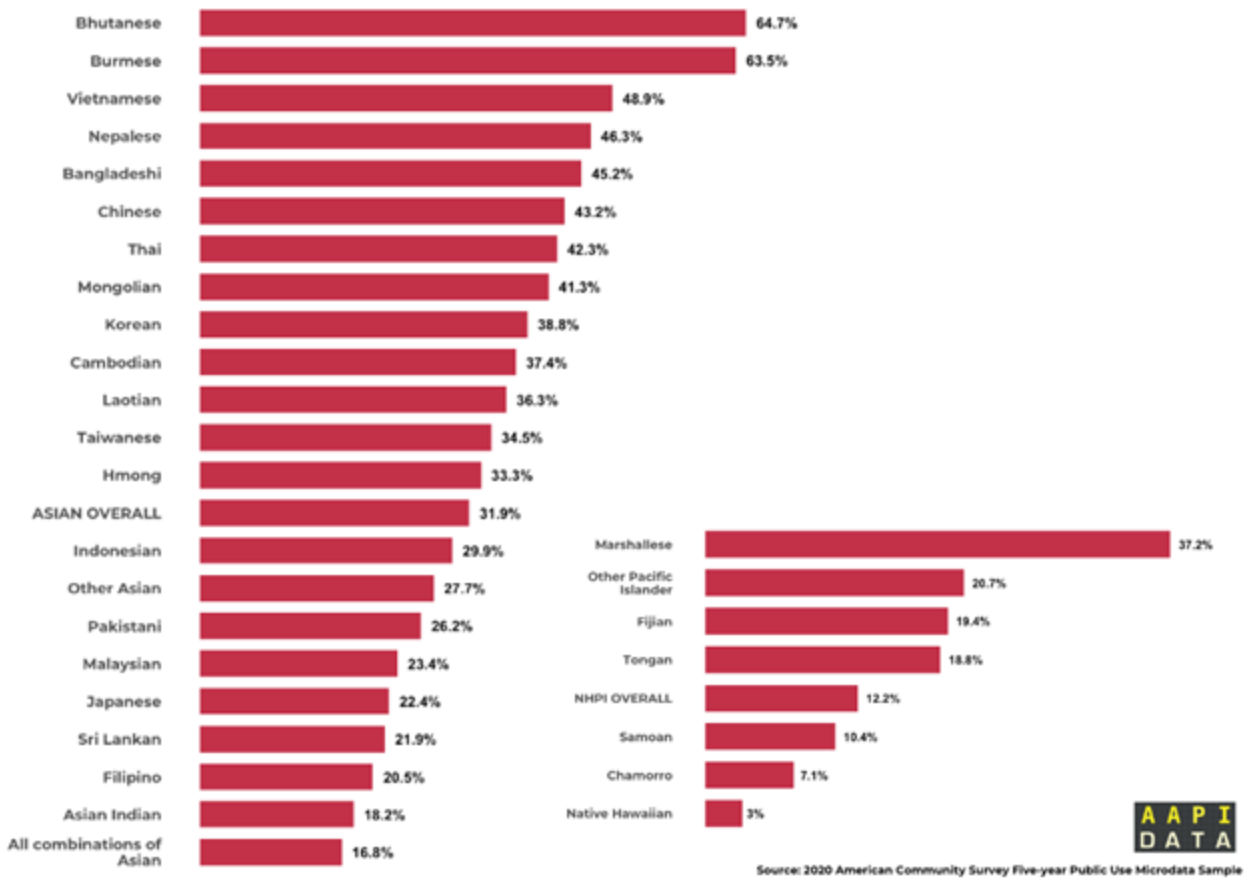
Asian Americans, Native Hawaiians & Pacific Islanders (AANHPI)

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

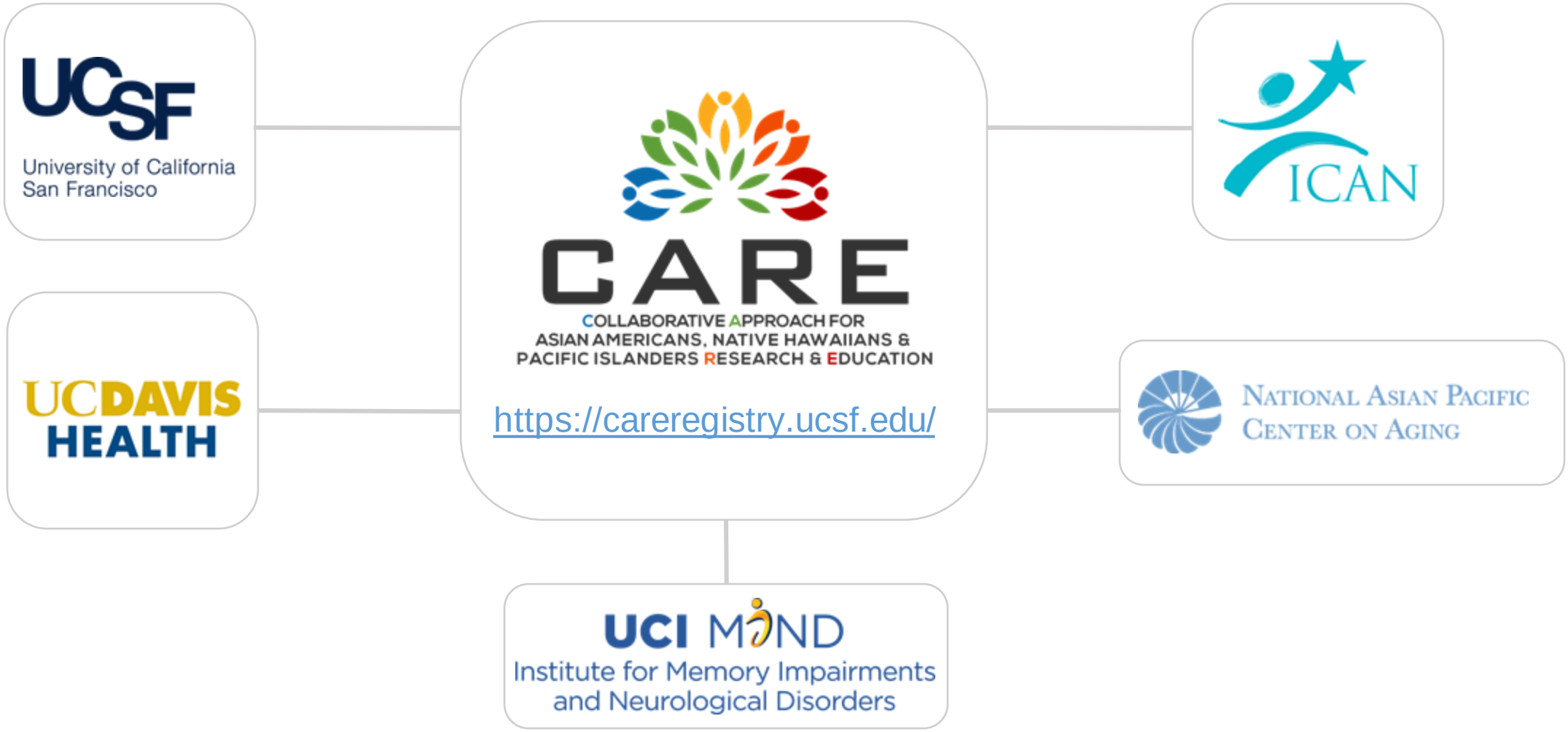
- Clinical research projects focusing on AANHPI participants funded by the National Institutes of Health (NIH) was less than 1% of its total budget between 1992 and 2018.[1]
- Of the 47,165 participants who were enrolled in ADRD studies at Alzheimer's Disease Research Centers, only 2.7% were AANHPI participants.[2]
- 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 March 7, 2023.

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

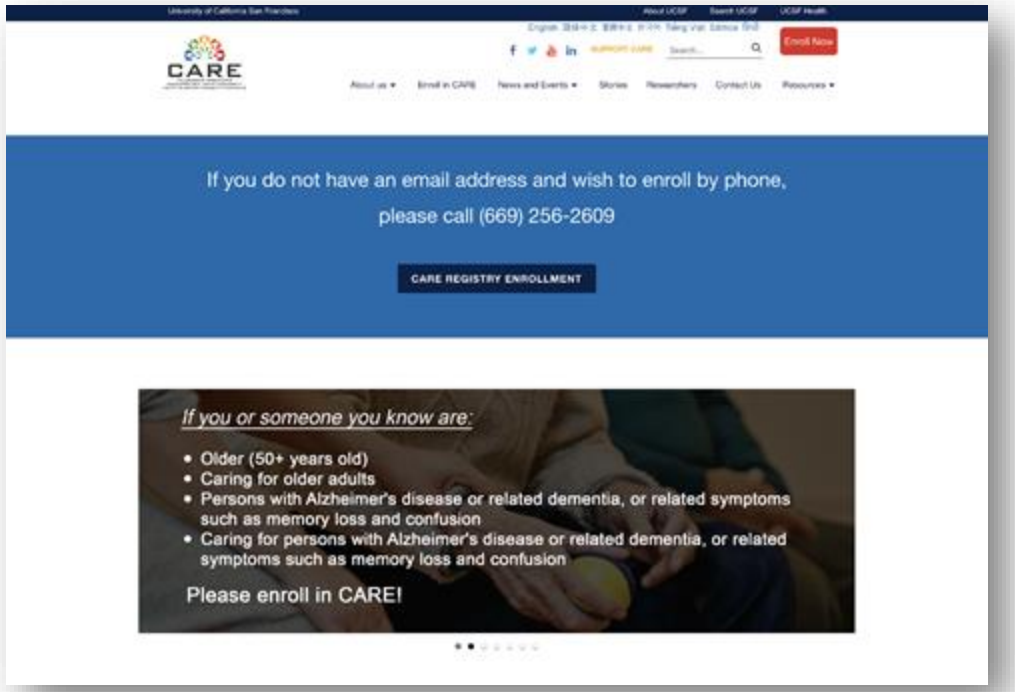
Participants complete an **online survey** (10-15 min) **by phone**, or in-person

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 Registry's Enrollment Survey Questions

Socio-demographic information

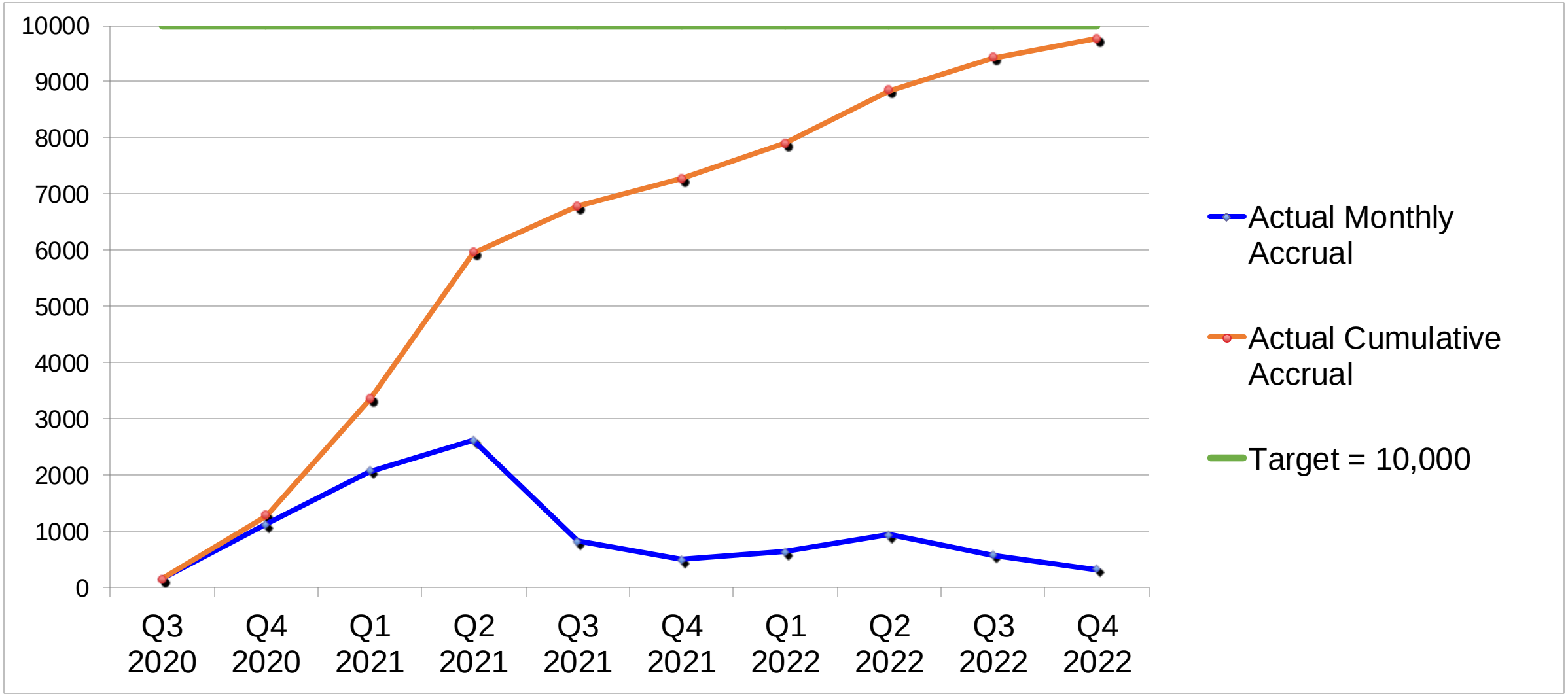
Health conditions (e.g., neurological disease and related symptoms such as Alzheimer's disease; heart disease; cancer; mood-related issues)

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

Caregiving experiences (if applicable)

CARE Registry Enrollment:

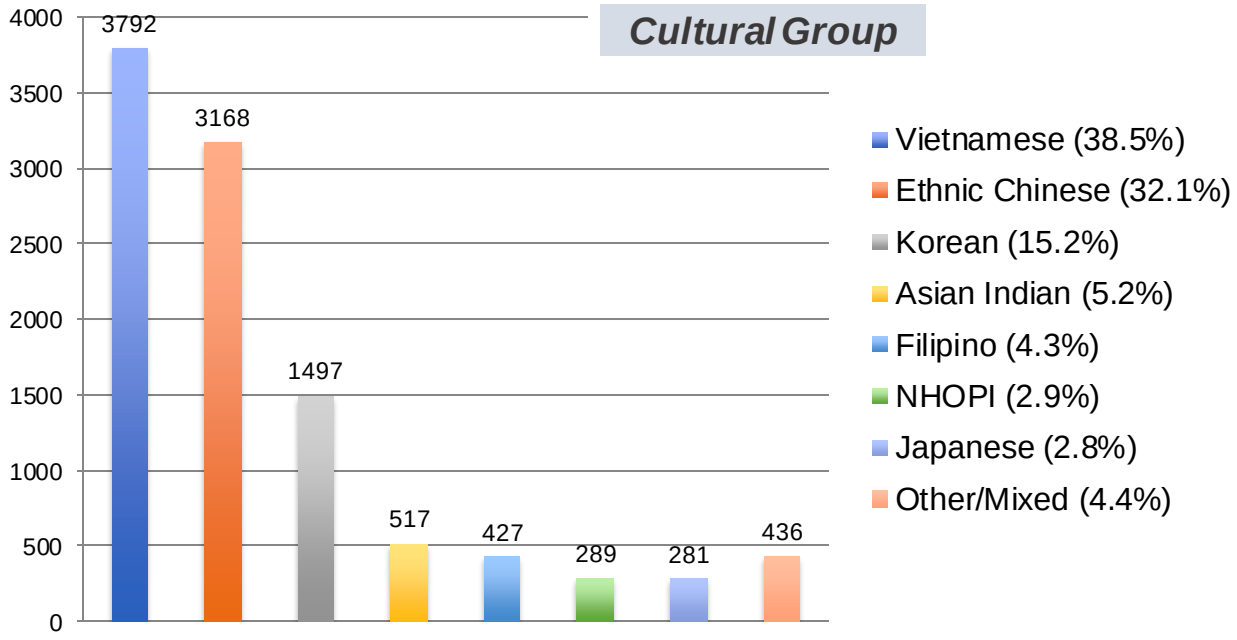
N=9,870 as of Mar 6, 2023 (99% of our 10,000 target goal)

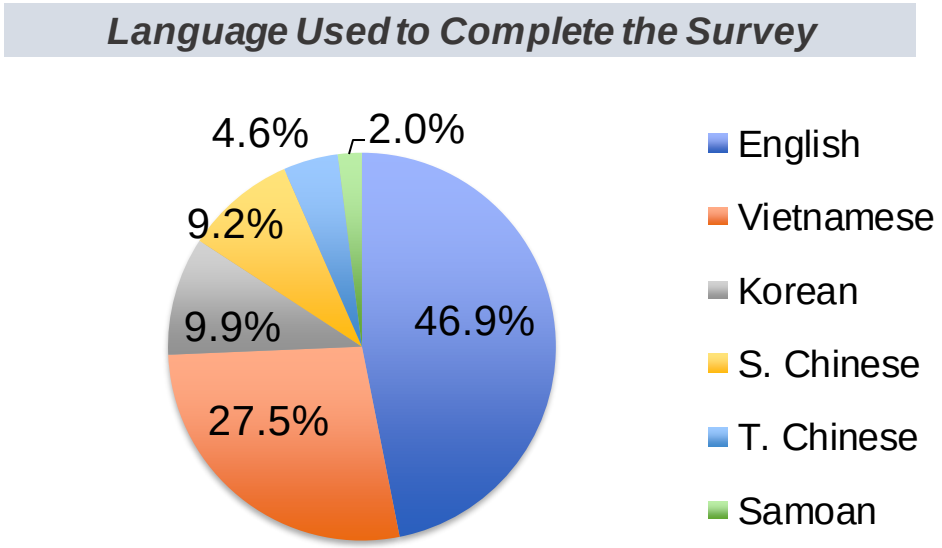


CARE Snapshot: N=9,870

- 83.8% Born outside of U.S.
- 85.4% Californian
- 10.8% Caregivers of older adults or person with special needs
- 81% no research participation experience

- Mean age = 54.2 (range 18-100)
  Age over 65 = 33.1%
- 62.6% Female
- 35.7% Male
- 53.3% Limited English proficiency
- 13.5% (N=1,330) with ADRD symptoms





How to Use CARE

Joshua D. Grill, PhD
CARE Co-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

- 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

Recruit AAPI to Your Study

- Recruit CARE registrants to your prospective study*
  - Answer specific questions about AANHPI
  - Recruit AANHPI CARE registrants to improve diversity in your sample
  - 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

- 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

Caveats and Conclusions

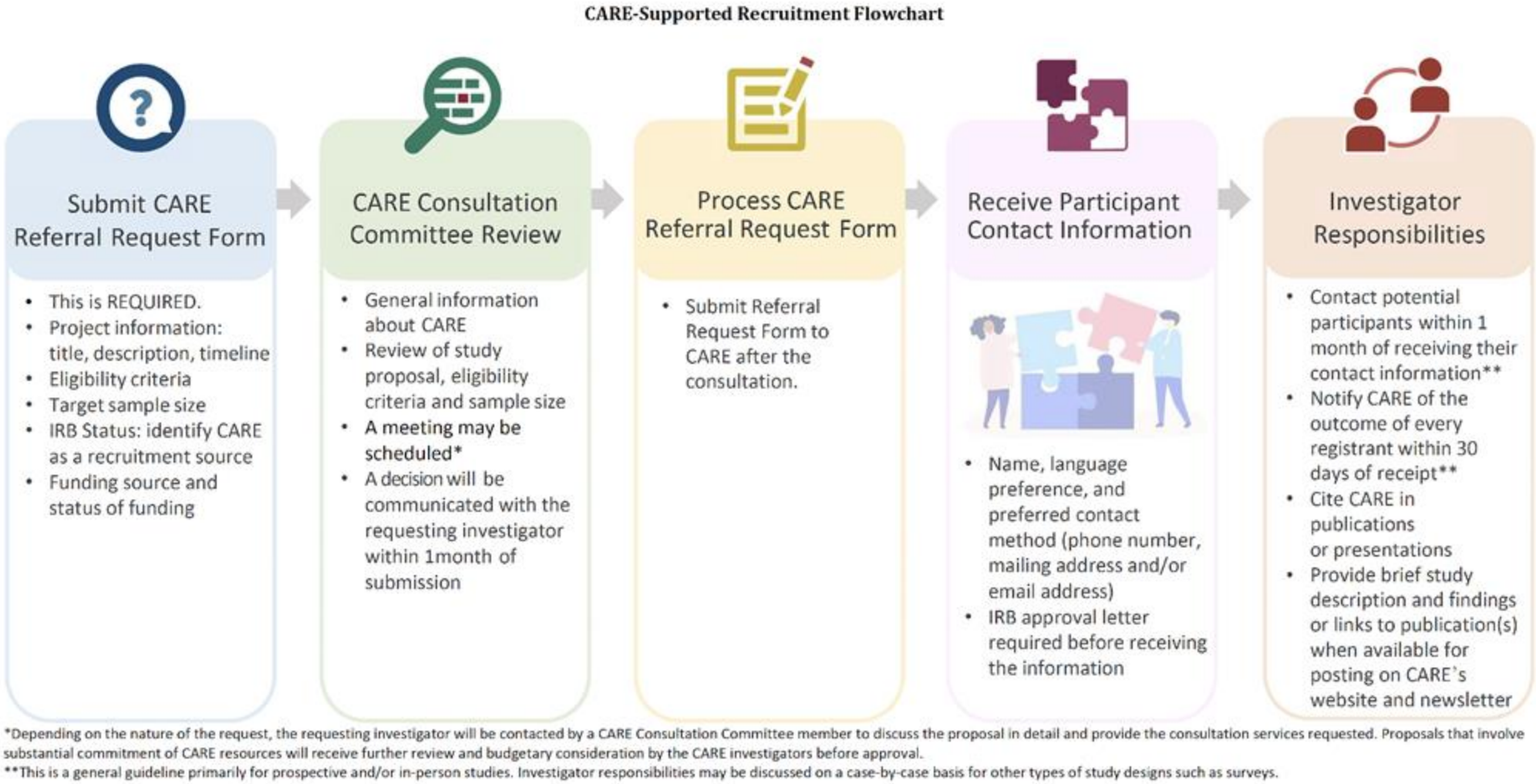
- CARE is not a community based epidemiologic cohort
- It cannot provide information (or opportunities to study) on disease prevalence or population characteristics
- It can assist in examining potential cultural and racial associations, hypothesis generation, and comparison studies
- It can improve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

CARE Referral Request Process and Updates

Janice Tsoh, PhD
CARE Co-Investigator

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

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 Step 1-3

Submit CARE Referral Request Form

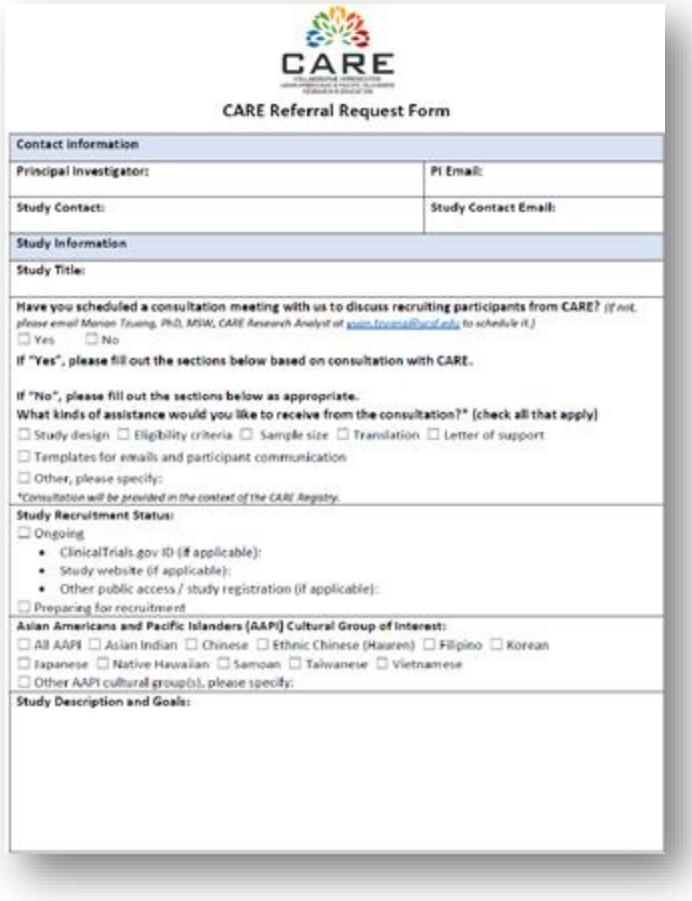
- This is REQUIRED.
- Project information: title, description, timeline
- Eligibility criteria
- Target sample size
- IRB Status: identify CARE as a recruitment source
- Funding source and status of funding

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

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 Manon Tsueng, PhD, MSW, CARE Research Analyst at [illegible] 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 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

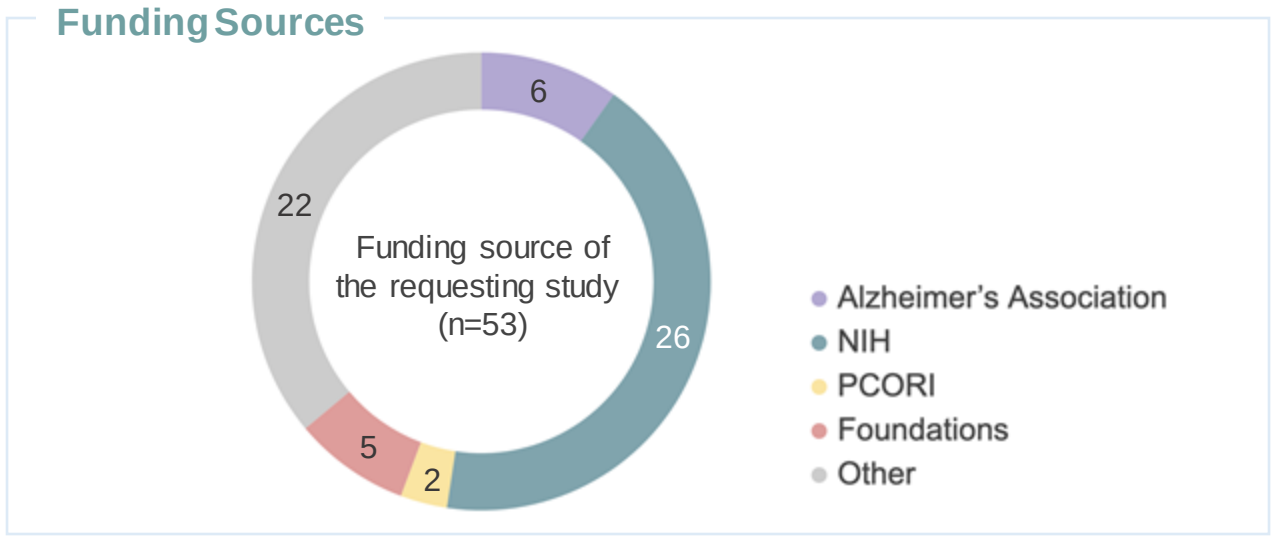
**This is a general guideline primarily for prospective and/or in-person studies. Investigator responsibilities may be discussed on a case-by-case basis for other types of study designs (e.g., surveys).

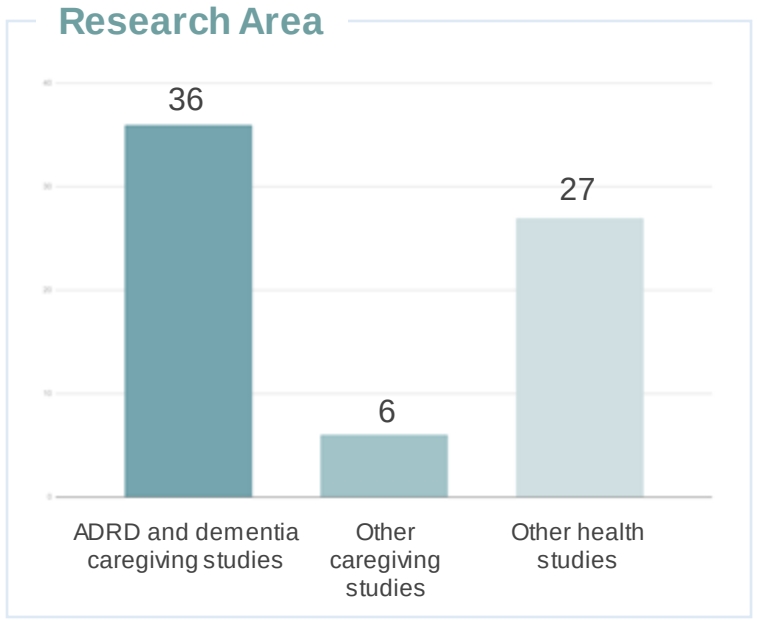
CARE-Supported Recruitment

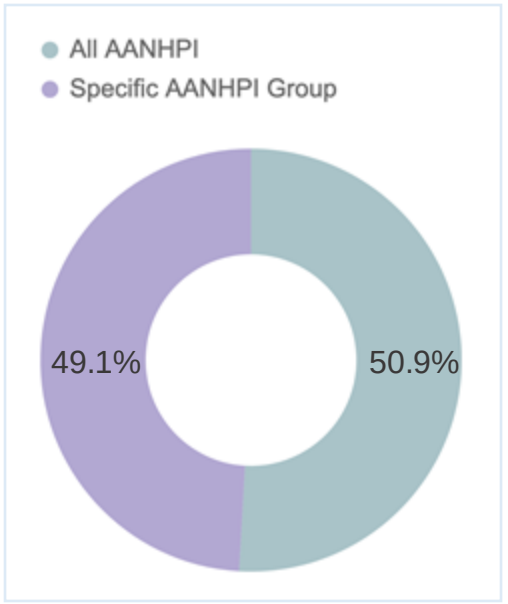
- Download CARE Recruitment Referral Form at: https://careregistry.ucsf.edu/researchers
- CARE team may request a consultation meeting to discuss the proposed recruitment referral in detail.
- Proposals that involve substantial commitment of CARE resources will receive further review and budgetary consideration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

CARE-Supported Recruitment Requests (N=69 as of March 7, 2022)

- Since January 2021, >8,200 CARE participants have been referred to 44 studies.
- 25 of the requesting studies have study materials or personnel support for participants in English and at least one other AANHPI language.







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

User Testimonial: Experiences with CARE for Study Recruitment

Christina Miyawaki, PhD, MSW, MA

University of Houston

Caregiver-Provided Life Review

What is a Life Review?

- A structured activity to remember one's past in chronological order
- Effective depression therapy for older adults
- Conducted by trained healthcare clinicians (therapist, counselor, social worker)

Life Review Therapy

- Life review sessions are held individually or in a group facilitated by a trained healthcare professional
- Life review sessions usually take 6 to 8 weeks
- Each life review session lasts 1-2 hours
- Costly!

What is a Caregiver-Provided Life Review?

- **Can "trained" caregivers provide life reviews to their loved ones at home?**

Caregiver-provided life review is "Innovative" in four ways!

1. Non-stigmatized delivery: Provided by caregivers!
2. Convenient delivery setting: Delivered at home!
3. Flexible delivery schedule: Based on caregivers and care recipients' schedule!
4. Economical delivery cost: Free!

Participant Recruitment

- **Care recipient's Eligibility**
  - ✓ 65 years and older
  - ✓ Experiencing low mood + a bit of forgetfulness
  - ✓ 5 min each pre- and post-intervention assessments
  - ✓ 6 weekly life review sessions (6 weeks)
- **Family member's Eligibility**
  - ✓ 1-hour online caregiver training
  - ✓ 5 min each pre- and post-intervention assessments + Interview
  - ✓ 5 weekly check-in calls
  - ✓ 6 weekly life review sessions (6 weeks)

Snapshot of Recruitment Activities

- **August 2020 – January 2021**
  140 Houston area facilities
  474 phone calls + 178 emails + 7 Zoom meetings → 2 dyads
- **Meals-on-Wheels flyers** 2000 flyers → 0 dyad
- **Senior Center & Community Center presentations**
  12 local centers → 1 dyad
- **Alzheimer's Association TrialMatch**
  243 inquiries → 10 dyads
- **Word-of-mouth, support groups, friends, internship sites, etc.**

Why CARE Registry?

- **No racial/ethnic diversity in the current sample**
  (only 1 Asian, 8 African American, no Hispanic dyad)
- **TrialMatch**:
  - ✓ Respondents tended to be with more advanced conditions
  - ✓ Hit and miss respondents
- **Ran out of places to outreach**

Recruitment Result of CARE Registry

- Period: May 2021-Jan 2023
- Total # of referrals contacted: 287
- Total # of inquiries received: 27
- Total # of registrants screened: 20 dyads (8 ineligible)
- Total of # of registrants enrolled: 12 dyads
- Total of # of registrants completed: 11 dyads
- Methods of initial contact: Email (92%), text message (4%), USPS mail (4%)

Experiences Using CARE Registry

- **Easy registration process**
  - ✓ One-time registration
  - ✓ Simple form to fill out
- **Quick turnaround time**
  - ✓ Receive your requested referrals within one week
  - ✓ When needed, can make an urgent request
- **Easy process with a timeline to follow**
  - ✓ List of registrants at once
  - ✓ Weekly email schedule

Experiences Using CARE Registry

- **Characteristics of CARE registrants**
  - ✓ AANHPI who are interested in research
  - ✓ Reliable and committed

- **Diverse AANHPI populations**
  - ✓ A variety of AANHPI ethnicities
  - ✓ English-speaking AANHPIs and AANHPIs who speak languages other than English

Lessons Learned & Challenge

- Include a response deadline in emails
- Respond to inquiries in a timely manner
- Communicate with potential participants often
- Be sensitive to cultural differences within AANHPI ethnic groups in responses
- Learn basic cultural mannerisms from native-speakers
- **Challenge**: How to encourage non-English-speaking AANHPI to participate in the study

THANK YOU VERY MUCH!

Christina Miyawaki

cemiyawaki@uh.edu or **(713) 743-0320**

Q&A + Raffles

Please complete our evaluation survey:

tiny.ucsf.edu/CAREbraintrustMar2023

Acknowledgments

Thank you to all the registry participants!

UC San Francisco

Van Ta Park (PI)
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Sarit Helman (DCE)
Niloufar Ameli (DCE)
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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)
Soo-Young Chin
Yoon Cho
Marion Grahek
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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