## Stanford Alzheimer's Disease Research Center

Participant Appreciation Day

November 4, 2023 Lisa Goldman Rosas, PhD MPH Assistant Professor

Department of Epidemiology and Population Health Co-lead Outreach Recruitment and Engagement Core







1

## Agenda

1:50-2:00 Introductions to the Outreach Engagement Recruitment Core & Community Advisory Board

2) 2:00-2:10 Introduction to breakout session

3 2:10-2:40 Breakout groups

2:40-2:55 Report back (3 min per table)

ว

#### **OREC Team**

#### Alzheimer's Disease Research Center





Rodriguez Espinosa, Ph Core Co-Lead JEDI Program Director





3

### **OREC Aims**



Enhance partnerships with the community, government, and key stakeholders to raise awareness and educate about Alzheimer's and related dementias.



Collaborate with our Community Advisory Board to design outreach strategies, enhance recruitment, and retain participants in Stanford ADRC research and affiliated projects.



Develop dementia course materials and workshops for community health workers and the public to boost referrals, retention, and sharing with sister ADRCs nationwide.



Collaborate with the Research Education component and other ADRC cores to assess outreach and recruitment needs of investigators and provide ongoing support.

4

#### Stanford ADRC Community Advisory Board

Name	Affiliation
Amy Yotopolous	Avenidas - President and CEO
Benjamin Yen	Caregiver
Denise Coley	Parkinson patient and advocate
Elissa Wellikson	Veteran
Kirk Leu	Caregiver
Leslie K DuBridge	Senior advocate, National Board Certified Health & Wellness Coach
Sandra Green	Alzheimer's Association – Norther California Chapter
Sandra Winters	Senior Coastsiders - Executive Director
Sara Langer	Stanford ADRC Patient
Scott Roney	Veteran
Stella De La Pena	Alzheimer's Association - Director of Diversity, Equity and Inclusion
Ting Pun	The Vi Senior Housing Community – Patient & Research Participant Advocate

5

# ADRC CAB Proposed Goals



Offer direction on Alzheimer's Disease services, education, and research priorities for the Stanford ADRC.



Steer community partnerships and outreach for the Stanford ADRC.



Advise on successful recruiting for underrepresent ed communities for ADRC research.



Advise on effective recruitment for diverse ADRC research participation.



Act as community ambassadors for dementia research outreach and recruitment.

6

#### Plan



- Group dynamics and structures
- Break into small groups and go to tables
- Small group discussion
- Report back
- Conclusion

7

#### Recruitment Successes

- The ADRC has recruited 63 people with Alzheimer's Disease and 251 healthy controls
- 72% of participants have been retained

#### Challenges

• Presently, Latinx involvement stands at 10%, with the aim to enhance it to 20%.



8

# Small group discussion questions



- Participant Research Motivation:
  - Why engage in research?
  - How can we enhance early ADRC engagement?



- Long-term Engagement Drivers:
  - What sustains participant involvement?
  - Meaningful benefits for better retention.



- · Addressing Barriers:
  - Challenges in underrepresented community involvement.
  - Overcoming engagement obstacles.

Facilitator Note: Target 20% Latinx participants (currently 10-12%).

#### · Caregivers:

- Barriers for caregivers from underrepresented groups
- Overcoming obstacles in supporting loved ones in research
- Focus on Latino/Hispanic/Latinx, Asian American, Pacific Islander, and Native Hawaiian communities
- Strategies to address caregiver challenges

# Thank you very much!





