Participant Appreciation Day
Stanford Alzheimer’s Disease Research Center

November 4, 2023
Lisa Goldman Rosas, PhD MPH
Assistant Professor
Department of Epidemiology and Population Health
Co-lead Outreach Recruitment and Engagement Core

Agenda

1 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
4 2:40-2:55 Report back (3 min per table)
OREC Team
Alzheimer’s Disease Research Center

Lisa Goldman Rosas, PhD MPH
Core Leader

Patricia Rodriguez Espinosa, PhD MPH
Core Co-Lead
JEDI Program Director

Wei-Ting Chen, PhD
Community Engagement Specialist

Diana Carbajal
Clinical Research Associate

OREC Aims

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

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

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

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

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<th>Name</th>
<th>Affiliation</th>
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<tbody>
<tr>
<td>Amy Yotopolous</td>
<td>Avenidas - President and CEO</td>
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<td>Benjamin Yen</td>
<td>Caregiver</td>
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<td>Denise Coley</td>
<td>Parkinson patient and advocate</td>
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<td>Elissa Wellikson</td>
<td>Veteran</td>
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<td>Kirk Leu</td>
<td>Caregiver</td>
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<td>Leslie K DuBridge</td>
<td>Senior advocate, National Board Certified Health &amp; Wellness Coach</td>
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<td>Sandra Green</td>
<td>Alzheimer’s Association – Northern California Chapter</td>
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<td>Sandra Winters</td>
<td>Senior Coastsiders - Executive Director</td>
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<td>Sara Langer</td>
<td>Stanford ADRC Patient</td>
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<td>Scott Roney</td>
<td>Veteran</td>
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<td>Stella De La Pena</td>
<td>Alzheimer’s Association - Director of Diversity, Equity and Inclusion</td>
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<td>The Vi Senior Housing Community – Patient &amp; Research Participant Advocate</td>
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ADRC CAB Proposed Goals

1. Offer direction on Alzheimer's Disease services, education, and research priorities for the Stanford ADRC.
2. Steer community partnerships and outreach for the Stanford ADRC.
3. Advise on successful recruiting for underrepresented communities for ADRC research.
4. Advise on effective recruitment for diverse ADRC research participation.
5. Act as community ambassadors for dementia research outreach and recruitment.
Plan

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

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%.
Small group discussion questions

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

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

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

- **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

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

Thank you very much!

ADRC for healthy brain aging

Stanford Medicine