

Outreach, Recruitment and Engagement Core

- Provide important liaison and engagement between the ADRC and people with dementia, their caregivers, and both the professional and local lay community so that information may be communicated bi-directionally, particularly in diverse populations. Augment participant and community engagement.
- Explain the role of the core in the Center and as a community resource on AD and related dementias.
- Provide an assessment of the outreach, engagement, recruitment, and retention needs that are unique to the Center as well as to the geographical area in the vicinity of the ADRC, including identifying underserved groups and conducting a needs assessment in collaboration with those communities

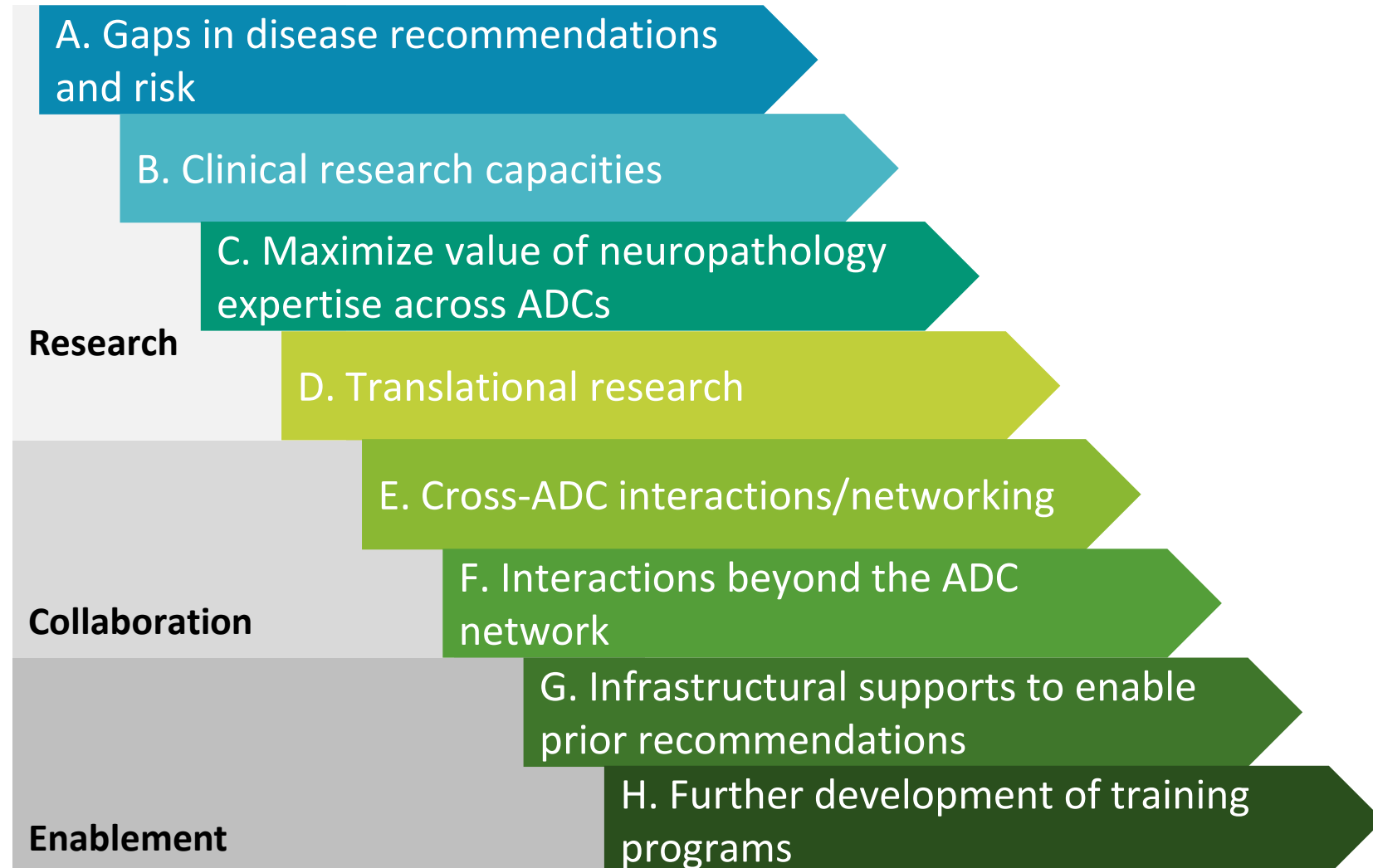
ORE Core Steering Committee

| Position | Term ends ^d | Name | Center |
|---|------------------------|------------------------------------|--------------------------|
| Outreach, Recruitment, and Education (ORE) Core Steering Committee | | | |
| Term remainder | Fall 2020 | Yakeel Quiroz, PhD | Massachusetts ADRC |
| Elected, Chair; Meeting: F20 | Fall 2020 | Allison Lindauer, PhD, APRN | OHSU |
| Elected | Fall 2021 | Dorene Rentz, PsyD | Massachusetts ADRC |
| Elected | Fall 2021 | Scott Roberts, PhD | University of Michigan |
| Elected | Fall 2022 | Crystal Glover, PhD | Rush University |
| Elected | Fall 2023 | Laura Baker, PhD | Wake Forest University |
| Elected | Fall 2023 | Corinne Pettigrew, PhD | Johns Hopkins University |

^d3-year term for members; Chair's term to be determined as needed

ADRC Steering Committees

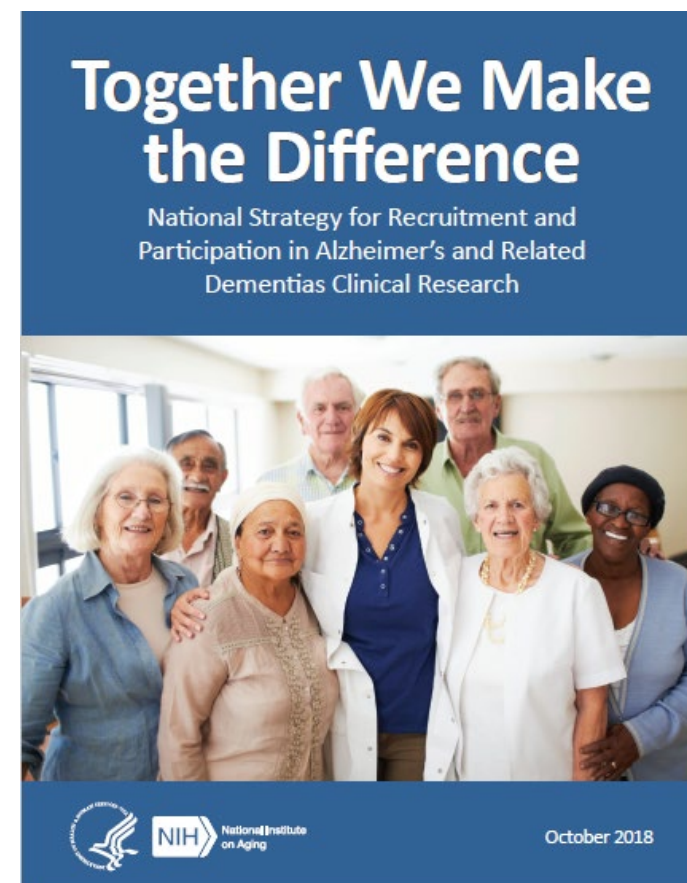
- NACC and NIA put together for each committee a list of
 - Duties
 - Including Chair and member responsibilities
 - “The Chair should work with NIA, NACC and the Committee to set and achieve **1-3 major goals** during their term.”
 - Terms of Office
 - Election Process
- Future planning will support better transitions for new members



National Strategy for Recruitment and Participation in Alzheimer's & Related Dementias Research

GOAL:

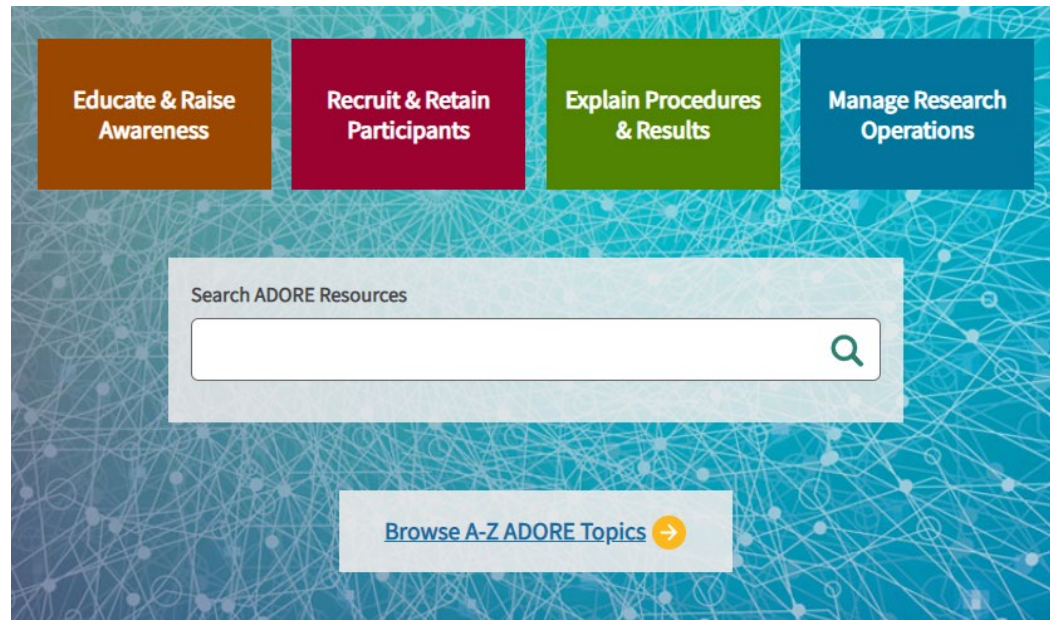
- Engage broad segments of the public in Alzheimer's and related dementias research
- Focus on underrepresented communities
- Assist studies in successfully and more quickly enrolling and retaining people in studies to better understand and eventually cure these disorders.





Alzheimer's and Dementia Outreach, Recruitment, and Engagement Resources

www.nia.nih.gov/research/ADORE



A searchable collection of materials for clinical trials recruitment and retention

- Find flyers, toolkits, recruitment plans, and more from Alzheimer's Disease Research Centers, NIH, and other agencies and organizations
- Submit your materials at www.nia.nih.gov/research/ADORE/contribute
- New section for disclosure protocols
- Questions or comments?
Email NIAADRR@mail.nih.gov

Events and Happenings

- October – Webinar: 10/23/20
- October – Today's meeting 10/1/20
- September – Webinar 9/3/20
 - <https://www.alz.washington.edu/NONMEMBER/adrc-webinars.html>
- September – Updates from NIA and ADEAR 8/25/20
 - New and updated publications
 - Resources in Alzheimer's & Dementia Outreach, Recruitment & Engagement repository
 - Project announcements
- April – Straight Facts about COVID19

African American Recruitment

Received: 31 March 2020

Revised: 24 June 2020

Accepted: 7 July 2020

DOI: 10.1002/alz.12160

PERSPECTIVE

Alzheimer's & Dementia[®]
THE JOURNAL OF THE ALZHEIMER'S ASSOCIATION

Perspective on the “African American participation in Alzheimer disease research: Effective strategies” workshop, 2018

ADC African American Interest Group

ADC_AfrAm@uw.edu

Latino ADC – Special Interest Group

Co-Leads: Yakeel T. Quiroz and Katya Rascovsky

Research Working Group:

- Accomplishments:
 - Website with information about ongoing research studies for Latinos
 - <http://mapp.mgh.harvard.edu/latino-adc/>
 - List of potential reviewers for papers/grants related to Latino issues
- Exploring opportunities for cross-Center research collaborations to improve the representation of diverse Latinos into our studies.
- Website will feature ongoing research with Latinos being conducted at the Centers, including our recent publications.

Assessment Working Group:

- Spanish translation and adaptation of UDS T-Cog, COVID and technology surveys. (formatted drafts in 1-2 weeks).
- Preliminary norms for Spanish UDS3 neuropsychological battery (ongoing)

Outreach, Caregiver and Central Repository Working Groups:

- Participated in listening / focus groups on recruitment and retention of Latino populations in ADRD Clinical research.
- Consulted on Spanish translation of NIA website and AD Fact Sheet.

Welcome information about new studies and new potential reviewers. Please email yquiroz@mgh.harvard.edu and katyaras@penmedicine.upenn.edu



Brain Donation Social Media Toolkit

Share these materials to educate individuals about why people donate their brains for research, the process of brain donation, and how to make a donation plan. Visit www.nia.nih.gov/braindonationtoolkit.

- Social Media Images & Posts
- Educational Flyer
- Brain Donation FAQ Infographic
- Newsletter Article

NIH National Institute on Aging
Be the **brain** behind the **breakthroughs**.
One donated brain makes a huge impact.
#braindonation

NIH National Institute on Aging
Talk with a loved one about leaving a **lasting legacy**.
One donated brain makes a huge impact.
#braindonation

NIH National Institute on Aging
Hable con su familia sobre su deseo de dejar un **legado que perdure**.
Donar un cerebro puede generar un impacto muy grande.
#donacióncerebro

Be the Brain Behind the Breakthroughs

Volunteering to donate your brain could help lead to better understanding, treatment, and prevention of brain diseases, such as Alzheimer's disease and related dementias.

- Why do people donate their brains to research at the end of life?**
 - Help researchers better understand the causes and potential treatments for brain diseases that affect millions of people.
 - Have a broad, positive impact on public health and future generations.
 - Help family members learn more about any diagnosis of brain diseases that may run in the family.
- How does brain donation work?**

To volunteer, register ahead of time through a brain donation program or research study. At the time of death, a designated loved one or health professional will call the brain donation center. A specialist will carefully remove the brain through the back of the head in a way that does not affect the person's appearance. The brain is then sent to a brain bank that coordinates with researchers working to understand brain diseases. The body is returned to the family for burial, cremation, or related ceremonies.
- What do I do next?**

Although topics around life and death matters can be difficult to address, the best time to think about brain donation is now. Learn more about brain donation and participating in research studies. Talk with your family and friends early in your decision-making process. If you choose to donate, consider registering for a brain donation program or research study soon.

Ready to learn more? Find the next steps for brain donation and more resources at www.nia.nih.gov/braindonation, or call the Alzheimer's Disease and Related Dementias Education and Referral (ADEAR) Center at 800-438-4380.

#braindonation

NIH National Institute on Aging

2021 Goals

**ORE Core
Recommendations**

**Collective
Engagement**

National Effort

NACC - Organizing Methods

- WEBINARS
- MEETING SUMMARIES
- SLACK
 - https://join.slack.com/t/adrc-program/shared_invite/zt-dx7nnjpx-5VqAeGfe~sOpAc1ITV7ghA
 - <https://adrc-program.slack.com/archives/C0117619FLN>
- LISTSERVs