

ADRC Directors Meeting

Cerise Elliott, Ph.D.

Co-Director, Alzheimer's Disease Research Centers Program

National Institute on Aging

October 19, 2023

Thank you to Jeff Kaye and John Morris for their contributions.



Jeff Kaye
OHSU ADRC



John Morris
Knight ADRC

Welcome New ADRC Directors



Miranda Lim, MD, PhD
OHSU ADRC



Lisa Silbert, MD, MCR
OHSU ADRC



David Holtzman, MD
Knight ADRC

Fall ADRC Meeting Kudos

- Thank you to:
 - All the Steering Committees
 - Presenters
 - NACC
 - CTF
 - Research participants
 - Survey Respondents
 - NIH Staff
 - In-person and virtual attendees
 - NGOs

The logo for the 2023 Fall ADRC Meeting is centered in a white square with a light blue border. The text "2023 FALL" is in a smaller font, with "2023" in blue and "FALL" in orange. Below it, "ADRC" is written in large, bold, blue letters, and "MEETING" is in large, bold, orange letters.

2023 FALL
ADRC
MEETING

October 18th - 20th, 2023
Hybrid Event
The Westin San Diego Gaslamp Quarter, San Diego

OutreachPro NIA's Free Online Recruitment Materials Generator

OutreachPro helps researchers and research teams create customized outreach materials, designed for and tested with specific audiences.

OutreachPro and its materials were systematically created through literature reviews, listening sessions with stakeholders, focus groups, surveys, and user feedback testing.

Nakakaranas ng unang bahagi ng pagkawala ng memorya o demensya?

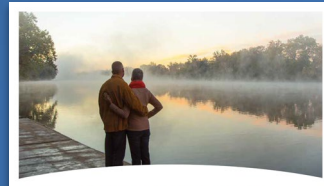


Sumali sa isang pag-aaralan ng utak upang matutunay ang tungkol sa mga op...



Hope for generations to come.

Join a brain health study to learn more about treatment options.

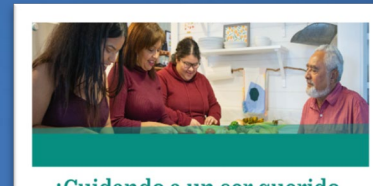


Experiencing early stage memory loss or dementia?

Join the latest dementia study to see your options

What is this study about?
Lorem ipsum dolor sit amet, consectetur adipiscing elit. Sed consequat elit lacus, vitae augue ornare a. Phasellus lorem tellus, varius id nulla nec, viverra rutrum neque. Aliquam nibh purus, aliquet et consequat et blandit et sapien.
• Morbi facilisis nunc, aliquet viverra pretium.

Why should I participate?
Lorem ipsum dolor sit amet, consectetur adipiscing elit. Sed consequat elit lacus, vitae augue ornare a. Phasellus lorem tellus, varius id nulla nec, viverra rutrum neque. Aliquam nibh purus, aliquet et consequat et blandit et sapien. Morbi facilisis nunc, aliquet viverra pretium, lectus magna, mollis et faucibus et, consectetur quis diam. Suspendisse tempor libero ut posuere. Class nec, velit auctor odio liberoam liborits.



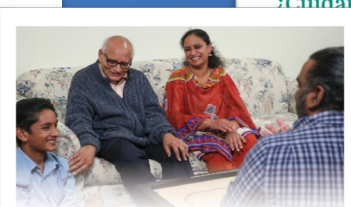
¿Cuidando a un ser querido con demencia?

¿focalizado en el bienestar de los cuidadores.

¿Por qué se debería participar?
Lorem ipsum dolor sit amet, consectetur adipiscing elit. Sed consequat elit lacus, vitae augue ornare a. Phasellus lorem tellus, varius id nulla nec, viverra rutrum neque.

¿Qué incluyen?
Lorem ipsum dolor sit amet, consectetur adipiscing elit. Sed consequat elit lacus, vitae augue ornare a. Phasellus lorem tellus, varius id nulla nec, viverra rutrum neque.

Para conocer más, contacte:
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jsmith@nichd.nih.gov
nichd.nih.gov



शोधक: स्मृति हानि के बारे में जितना अधिक हमें पता चलेगा, वह उतना ही बेहतर करेगी।

किस बात को भी याद रखने में मदद करने के बारे में अधिक जानें।

अपने विचारों को साझा करने का अवसर
अनुसंधान में भाग लेने में मदद करने के बारे में अधिक जानें।



NIH

Place logo here

outreachpro.nia.nih.gov

OutreachPro's current library has:
5 Languages:
20 materials - Tagalog
42 materials - Spanish
13 materials - Hindi
20 materials - Chinese (Mandarin)
135 materials - English

Formats:
Handouts, Brochures, Posters, Social media assets, Videos, and Radio Scripts



ADRC Meeting Spotlight: Clinical Task Force

UDS4.0 Updates and Next Steps

Thursday, 2:15 – 3:45 PM PT

Location: California B & C

- Thank you for the outstanding engagement of the centers, continued participation in the process, and future feedback as the UDS4.0 updates are put in place to move the field forward and address critical scientific issues.
- Key areas of revisions for UDS4.0 include addressing **social determinants of health, mild behavioral impairment, the UPDRS, new disease modifying treatments, biomarkers, diagnosis forms**, and more.
- Q4 2023: updating the guidelines and reviewing instructions to ensure that the UDS4.0 will be administered consistently across the network.
- NACC is working closely with the CTF and concurrently integrating the new UDS forms into the data platform, and leveraging its new tools and processes facilitated by the RedCap working group.

ADRC Meeting Spotlight: REC

REC Poster Session & Ice Cream Social

Thursday, 4:00 – 5:30 PM PT

Location: California A

NACC & REC's New Investigator Award Mentorship Breakfast

Friday, 7:00 – 8:00 AM PT

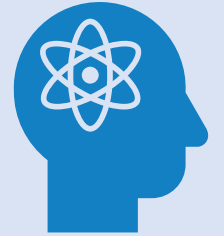
Location: Plaza Room

- Steering Committee emails “REC Relay” Newsletter to REC Leaders
- NACC New Investigators Awardees Mentorship Program
- Established REC Supporting Diversity Workgroup
- Developing a REC Toolkit
- November 14th: 2023 Spring Rising Star Presentations (online)
- 2nd Mock Study Section for Spring 2024 Meeting in Austin, TX
- REC Scholars and Trainees Networking Social at AAIC

Summary of REC Scholars and Trainees

ADRC REC :

- Current support for 634 Scholars and Trainees
- Past support 343 Scholars and Trainees



Of Past ADRC REC Scholars and Trainees:

- 52% are currently affiliated with an ADRC
- 62% are working or collaborating within the ADRC field



Data compiled using FY23 RPPRs Table G1 from 29 ADRCs

ADRC Steering Committees

- Steering Committees sets goals to accomplish for the year and plan their session for the ADRC Meeting
- Interested in taking a more active role in the direction of the ADRC Program?
 - Consider participating in ADRC Steering Committees
 - Look for nomination email from NACC
- List of current Steering Committee members available on the NACC Directory

Fall ADRC Meeting

ADRC Executive Committee

Neuropathology Core Steering Committee

Outreach, Recruitment, and Education Core Steering Committee

Data Management and Statistical Core Steering Committee

Research Education Core Steering Committee



Spring ADRC Meeting

ADRC Executive Committee

Clinical Core Steering Committee

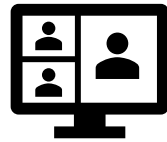
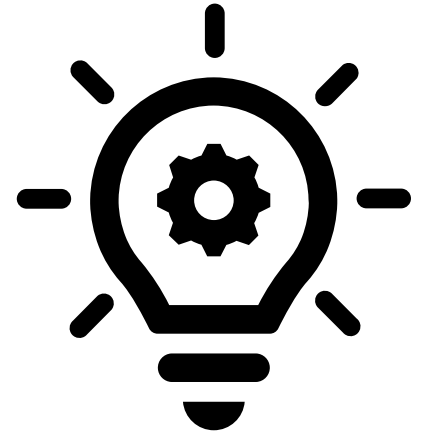
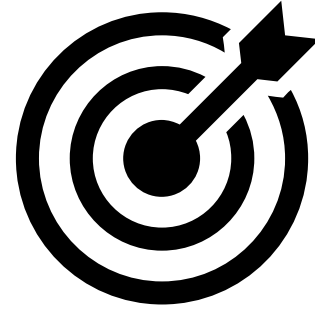
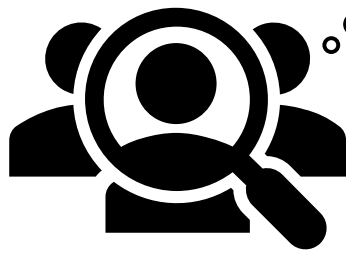
Biomarker Core Steering Committee

Administrators Steering Committee

Imaging Core Steering Committee

Research Education Core Steering Committee





Why are we here?



ADRC Consortium for Clarity in ADRD Research Through Imaging (CLARiTI) U01AG082350-01A1

- Intentional diversity and inclusion recruitment
- Examining clinical heterogeneity and multi-etiology causes in AD/ADRD
- Better diagnoses can improve research and clinical outcomes
- Increase local imaging capacity and outputs leveraged with SCAN infrastructure
- CLARiTI participants are not the requested 24 participants in RFA-AG-24-001

SCAN

NACC Session 8am Friday, October 20

- Dashboards available immediately following meeting
- **November 2023** Data to Quick Access File
- **May 2024** Spring Meeting Imaging Core Steering Committee

Remaining Procedural Updates

- Obtaining images (MRI and PET) with standard acquisitions
<https://dev.scan.naccddata.org/>
- Development of new methods for data flow between SCAN labs, LONI, and NACC including new data dictionaries, reconciliation methods, reports
- Implementation of “de-facing”

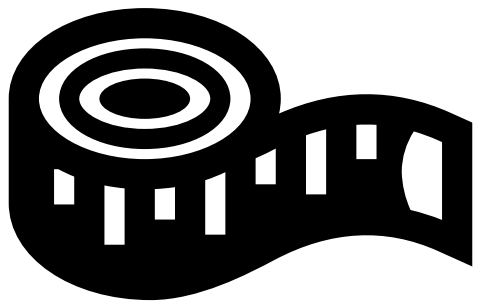
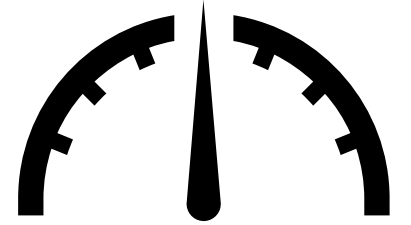
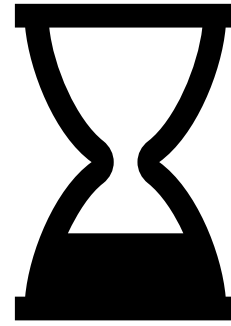
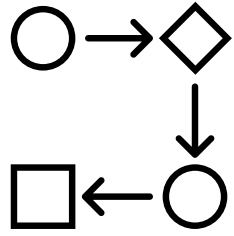
Progress Reports

1. RPPR Guidelines

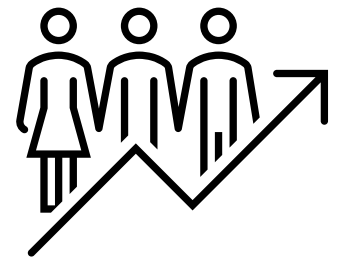
- Do not provide more information than is requested in the Administrative Table templates
2. Turn in on time
 - 1st of the month preceding the month in which the current budget period ends
 3. Include **new** developmental projects as a RPPR component
 4. Include developmental projects progress reports as a RPPR component
 5. Update Inclusion Enrollment Report (age included)
 6. Don't have a large unobligated balance

Unobligated Balances

- NIA Leadership is considering the balances of the parent grants for administrative supplements and will require a spend down plan and an explanation for your balance with your requests.
- NIH Prior approval for carryover is required of P30/P20 ADRCs and this requirement is included in your Notice of Award.
 - The NIH Grants Policy Statement (Section 8.1.2.4) outlines the information the AOR should submit in requesting approval for carryover of unobligated balances
 - ✓ A detailed budget by direct cost category with the F&A cost information (base and rate) for the proposed use of the carryover funds.
 - ✓ A scientific justification for the use of funds.
 - ✓ The reason for the unobligated balance.
- The NIH Grants Policy Statement (Section 8.4.1.5.4) states using the principle of “first in-first out,” unobligated funds carried over are expected to be used before newly awarded funds.
 - If the funds available exceed the NIH share of the approved budget for the current budget period, the GMO may select one of the following options: In response to a written request from the recipient, revise the current NoA to authorize the recipient to spend the excess funds for additional approved purposes. **Offset the current award or a subsequent award by an amount representing some or all of the excess.**



Measuring Progress



Summary of Underrepresented Group-Related Activities

1,528

**URG-Targeted
Events**



173

**URG-Related
Publications**



542

**URG-Targeted
Materials**



850

**URG Groups
Contacted**



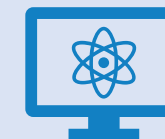
477

**URG Groups
Collaborating**



272

**URG-Related
Grants**



Data compiled using FY23 RPPRs Table E2 from 30 ADRCs

DMS Plan Requirements Beyond NACC Guidelines

Element 1: Data Type

- Should include size and types of data

Element 2: Related Tools, Software and/or Code

- Should be a standalone document, without reference to application or future publications

Element 3: Standards

- Details of standards are to be written

Element 4: Data Preservation, Access, and Associated Timelines

- Details of repository for metadata are to be written

Element 5: Access, Distribution, or Reuse Considerations

- Details about privacy and confidentiality should be specific and written

Element 6: Oversight of Data Management and Sharing

- Details regarding overseer of plan and frequency of oversight meetings

EAC Membership

- We appreciate your willingness to serve the ADRC community and we look forward to your assistance in providing targeted nominations that will enhance the growth of the institutions' centers.
- We recently evaluated Centers External Advisory Committees to provide additional individuals the opportunity to serve.
- We would like to rebalance this participation to no more than 3 institutions.

NACC Subaward Usage for Data Core

- [RFA-AG-21-014](#) instructs NACC to provide sufficient resources to support data and sample collection at ADRCs as well as assuring secure transmission of de-identified data from ADRCs to NACC
- The annual NACC \$25K Subaward is to be used for by the Data Management and Statistical Cores to facilitate collaborations between and among Centers and with NACC and the broader research community.
 - **1.43 calendar months is the average support for data personnel**
- There is a lack of timely invoice submissions to NACC for this subaward to be used by the end of the fiscal year. **We are instructing NACC to prepare timelines and communications in fiscal year 23 (6/1/23 – 5/31/24).**
 - If the deadlines for invoicing are missed by ADRCs in FY23, there will be no carryover of funds for the subawards to the Center.
- Large available balances are concerning regarding effective use of the Subaward. The following activities may be partially supported by the subaward:
 - Electronic Data Capture Workgroup
 - SCAN Data Coordination
 - NACC Data submissions

Thank you