

# ADRC Directors Meeting

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Co-Director, Alzheimer's Disease Research Centers Program

National Institute on Aging

May 2024

# Happy Anniversary!

**40**

**years  
of ADRCs**

**107**

ADRC Directors

**27**

States

**50,000+**

Participants with UDS data

**7,900+**

Neuropathology datasets (UDS)

**25**

**years  
of NACC**

**71,000+**

Participants with MDS data

**11,000+**

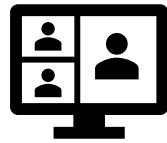
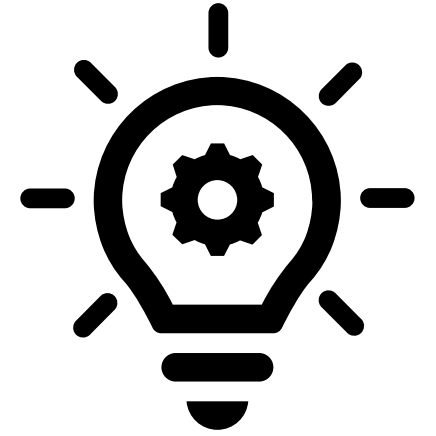
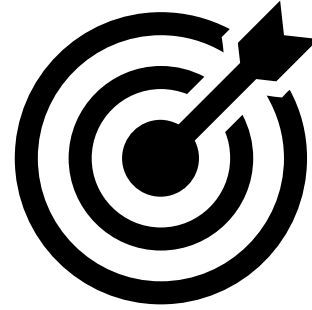
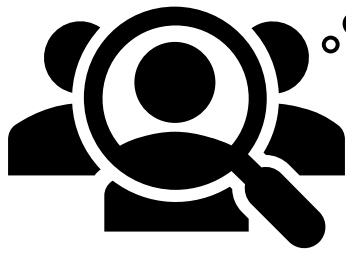
Neuropathology datasets (MDS)

**1,300+**

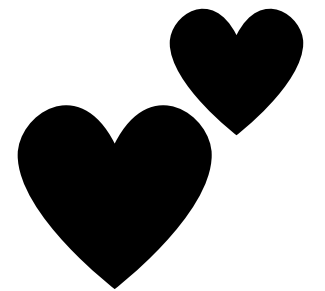
Published studies using NACC data

**188,000+**

Clinical Assessments (UDS)



Why are we here?



# Thank You

**All Steering  
Committees**

**Presenters**

**NACC**

**Clinical Task  
Force**

**Research  
Participants**

**Survey  
Respondents**

**NIH Staff**

**In-Person  
Attendees**

**Virtual  
Attendees**

**NGOs**

# 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
- Early Stage Investigators

## 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 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 Steering Committee

# ADRC Meeting Spotlight: Biomarker Core

- JAN. 2018:** Established Biomarker Cores
- APR. 2022:** Established Steering Committee
- JAN. 2023:** Fluid Biomarker Survey
- MAY 2023:** Survey Discussion & Call for Volunteers
- FEB. 2024:** Working Groups Kickoff
- APR. 2024:** Follow up Survey
- MAY 2024:** Survey & Working Groups Discussion

## **BIOMARKER BEST PRACTICES**

Co-Leads: Thomas Karikari and Timothy Van Meter

## **BIOMARKER DATA QUALITY AND VARIABLES**

Co-Leads: Fanny Elahi and Kristen Russ

## **VOLUNTEERS**

Jonathan Reader, Rachael Wilson, Kelley Faber, Lauren Chaby, Clairisa Stayton, Andy Liu, James Lah, Angus Nairn, Nicholas Kanaan, Tom Register, Neelesh Nadkarni, Edward Wilson, Jill Morris, Mingzhao Hu, James Galvin, Sudha Seshadri, Argentina Lario Lago, Nora Gray, Minerva Carrasquillo, Jagan Pillai, Gary Chan, Kaitlin Casaletto, Jennifer Gatchel, Matthew Perkins, Hesam Jahanian, Robert Rissman

Topic	Project - Activity or deliverable	✓	2024												2025												2026						Future
			Q2			Q3			Q4			Q1			Q2			Q3			Q4			Q1		Q2							
			A	M	J	J	A	S	O	N	D	J	F	M	A	M	J	J	A	S	O	N	D	J	F	M	A	M	J				
<b>UDSv4 Implementation</b>	Content complete and PDFs shared (initial packet)	✓																															
	REDCap forms complete and shared (initial packet)																																
	Follow-up packets complete (PDF and REDCap)																																
	UDSv4 START – used for all ADRC data collection																																
	UDSv3 STOP – backlog submission stop for ADRCs																																
	UDSv3 STOP – Spanish and Chinese /Affiliated studies																																
<b>Pilots</b>	NACCID Pilot																																
	UDSv4 Pilot																																
<b>UDSv4 Resource Development</b>	UDSv3 to UDSv4 crosswalk																																
	UDSv4 onboarding checklists																																
	SOPs on how to leverage REDCap for UDSv4																																
	Data element dictionary																																
	Coding guidebooks																																
	QC rules and codes published																																
<b>ADRC Training and Support</b>	Launch Community Forum	✓																															
	Clinical Staff Training Session																																
	UDSv4 and NACCID Pilot training																																
	Bi-Weekly Office Hours																																
	UDSv4 Digital Voice Guidelines																																
<b>UDSv4 Translations</b>	Chinese Translations (funded by separate R01)																																
	Spanish Translations																																

✓ Current Status

Activity Duration

Draft

Complete

Deadline

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			Q2	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4																
			A	M	J	J	A	S	O	N	D	J	F	M	A	M	J	J	A	S	O	N	D	J	F	M	A	M	J				
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**UPCOMING EVENTS:**

**NACC Session**  
 Tuesday, May 7<sup>th</sup> from 10:00 – 11:30 AM CT  
 Location: Zilker 1-2

**UDS 4.0 Virtual Training**  
 Tuesday, May 14<sup>th</sup> from 8:00 AM – 1:00 PM PT



# ADRC Meeting Spotlight: REC

## REC SESSION

Tuesday, May 7<sup>th</sup> 8:00 – 8:30 AM CT

Location: Zilker 1-2

## REC POSTER SESSION

Tuesday, May 7<sup>th</sup> 8:30 – 9:30 AM CT

Location: Zilker 3

## REC MOCK STUDY SECTION *(invite only)*

Wednesday, May 8<sup>th</sup> 8:00 – 11:30 AM CT

Location: Zilker 4

- **35 Early Stage Career Investigators**
- 2<sup>nd</sup> Mock Study Section for Spring 2024 Meeting in Austin, TX
- Steering Committee emails “REC Relay” Newsletter to REC Leaders
- REC Supporting Diversity Workgroup
- REC Scholars and Trainees Networking Social at AAIC

# CLARiTI Participants Do NOT Satisfy the P30 Imaging Requirement

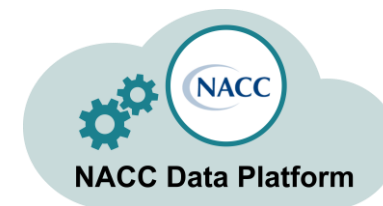
## SYNOPSIS

- GOAL:** Create individual etiologic profiles from imaging and plasma
- ATN imaging and plasma study superimposed on existing longitudinal UDS
  - **2,000 clinical core participants;** 60% impaired, 40% unimpaired
  - Diverse representation for generalizable science > 25% URG
  - Two time points [2-3 years apart]
  - **Embrace Heterogeneity:** syndromes and multi-pathologies



# CLARiTI

ADRC Consortium for Clarity in ADRD Research Through Imaging

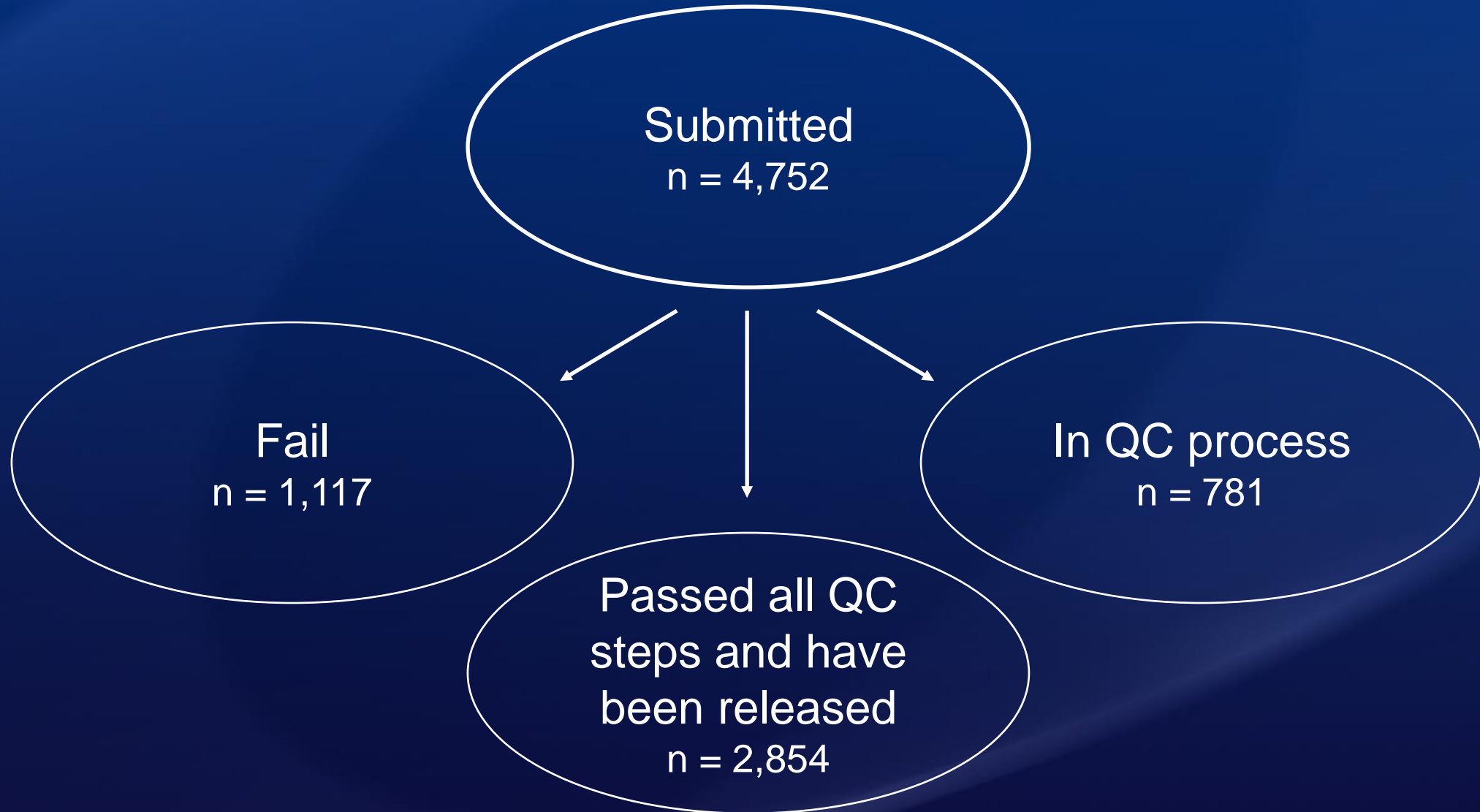


Alzheimer's Disease Research Centers

NOTE: Image submissions cannot overlap with the 24 image submissions that will now be required as part of the P30s.

# SCAN Update

Exam Level Summary: one exam = several series (i.e., 3D T1w, FLAIR, etc):  
mean 4.7 series per exam (range, 1-46 series/exam)



# SCAN: Requests to Sites

- Update certified scanner(s) to the ADNI 4 protocol – contact Bret Borowski ([SCANmri@mayo.edu](mailto:SCANmri@mayo.edu))
- Do not upload exams acquired prior to 01 January 2021
- Do not self deface series
  - This is done centrally by SCAN for all relevant series prior to release
  - Defacing free for all creates undesirable data heterogeneity
- Do not self anonymize DICOM
  - This is done by LONI at upload
  - May be impossible to protocol check or even display as an image
- Do not upload same exam(s) multiple times - adds unnecessary investigation and clean-up time/effort which diminishes throughput
- Do not upload exams with wrong patient ID

# AlzPED: Alzheimer's Disease Preclinical Efficacy Database

## Increasing the Predictive Value and Enabling Transparent and Reproducible Preclinical Efficacy Testing in AD Animal Models

- ❑ Develop a publicly available database of preclinical therapeutic studies that incorporates experimental details of positive and negative data for the AD scientific community

**AlzPED** ALZHEIMER'S DISEASE PRECLINICAL EFFICACY DATABASE  
Transparent. Reproducible. Translatable.

ABOUT AlzPED SEARCH AlzPED RESOURCES SUBMIT YOUR DATA

### Alzheimer's Disease Preclinical Efficacy Database

AlzPED is a publicly available, searchable, data resource that aims to increase the transparency, reproducibility and translatability of preclinical efficacy studies of candidate therapeutics for Alzheimer's disease.

Search by Model, Therapeutic Agent, Therapeutic Target or PI Name **ADVANCED SEARCH**

**NIA-AA Symposium: Enabling Precision Medicine for Alzheimer's Disease Through Open Science**  
Join NIA for the live session on July 31, 2020 at 8:30 AM CST  
**NIA-AA SYMPOSIUM**

<https://alzped.nia.nih.gov/>

- Hosts curated summaries of 1400 published studies (1996-2022) and provides easy access to information on study design methods, animal models, therapeutic agents, therapeutic targets, outcomes, patents and related clinical trials.
- Provides a platform for creating **citable reports/preprints** of unpublished studies, including studies with **negative** findings.
- Report on the rigor of each curated study by summarizing the elements of experimental design and identifying critical elements of experimental design missing from the study.



# Increase AANHPI representation in your study!

## DID YOU KNOW?

More than 10,000 **Asian American, Native Hawaiian and Pacific Islander (AANHPI)** adults enrolled in the CARE Registry who are willing to be contacted about potential research opportunities.

These participants have enrolled in various languages including **English, Chinese, Hindi, Korean, Samoan, or Vietnamese.**



## Seize the Opportunity!

If you're a researcher looking to enroll AANHPI adults in your studies or an organization striving to enhance AANHPI representation in research, CARE is here to assist you.



## Connect with CARE Today!

CARE aims to connect AANHPI adults to health research, with a focus on Alzheimer's disease and related dementias, aging, and caregiving-related research that affects health across the lifespan.

Visit our website: <https://careregistry.ucsf.edu/researchers>

Questions: [careapi@gmail.com](mailto:careapi@gmail.com)

*Referral  
Request  
Online Form*



# Attribute Credit to the ADRC

- Ensure that when ADRC resources are utilized, the **ADRC is accurately and adequately acknowledged.**
- Acknowledge related infrastructures, such as NACC, NCRAD, SCAN, when relevant.
- ADRC and associated infrastructure acknowledgement should be included in:
  - Publications
  - Posters
  - Presentations
- If possible, specifically mention the ADRC in addition to citing the full grant number (P30AGXXXX).

# RFA-AG-24-001

## SECOND RECEIPT DATE:

June 14, 2024

## LETTER OF INTENT:

Submit 30 days before  
application due date.  
Please include  
optional cores.

## THIRD RECEIPT DATE:

Sept. 26, 2025



<https://grants.nih.gov/grants/guide/rfa-files/RFA-AG-24-001.html>



# Data Management and Sharing

## WHAT WE EXPECT



- **Plan and budget** for the managing and sharing of data
- **Submit a DMS plan** for review when applying for funding
- DMS Plan should address the **six recommended elements** ([NOT-OD-21-014](#))
- **Comply** with the approved DMS plan

## DMS PLAN RESOURCES

- [NIA-Specific Sample DMS Plans](#)
- [NACC UDS DMS Guidance](#)
- <https://sharing.nih.gov/>

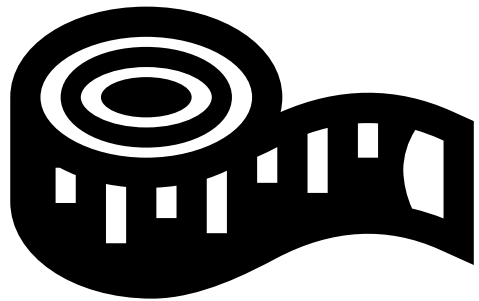
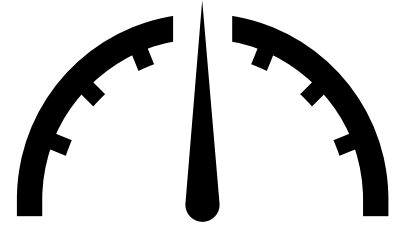
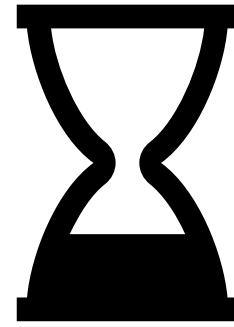
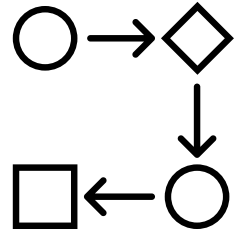
## REQUIREMENTS

- Final NIH Policy for Data Management and Sharing ([NOT-OD-21-013](#))
- [RFA-AG-24-001](#)

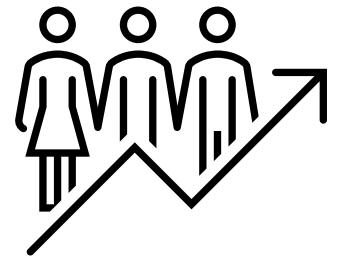
## WHAT YOU SHOULD EXPECT



- Request for DMS Plan revision from program staff
- Peer review will not see DMS Plan



# Measuring Progress



# Administrative Projects

## Administrative Table REDCap Automation

- Work is underway to streamline and improve reporting for the RPPR tables
- Collaboration between Administrative Steering Committee and NACC

## Administrative and ORE Core Collaboration

- Steering Committees are collaborating to better understand the recruitment and staffing activities for affiliated studies across the ADRC network

# Incentive for Fluid Biomarker Initiative Completed

Together, we have provided **21,031 blood samples** from **8,808 visits** and **6,756 participants** for the AD/ADRD research community

**APR. 2019**

**APR. 2022**

\$395,600 to distribute to Centers that initiated the submission of biospecimens to NCRAD

**JAN. 2023**

RFA-AG-24-001: \$925,000 additional direct costs funds attributed to P30 Centers following competition

**FEB. 2024**

P30 Award Terms and Conditions: Biological specimens collected by the Center must be made available to qualified researchers either locally or through NCRAD

**APR. 2024**

\$12,126 average reimbursement = <1% of the average 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.

# Brian Gray, Ph.D. | Health Science Policy Analyst



## Office of Legislation, Policy & International Activities (OLPIA)

- **Provides policy guidance** to and manages special projects for NIA's leadership
- **Serves as the NIA legislative liaison** for Congressional members and staff interested in Alzheimer's disease and other aging-related public health policy issues
- **Cultivates and manages NIA's relationships** with both national and international non-governmental organizations that have an interest in the NIA mission
- **Coordinates dementia-related policy activities** with the Advisory Council on Alzheimer's Research, Care, and Services (under the Department of Health and Human Services)
- **Collects and curates** the scientific output of the NIA

Thank you