

National Alzheimer's Coordinating Center Updates June 2024



A message from NACC leadership

Dear Colleagues,

It was wonderful connecting with so many of you at the ADRC Spring meeting last month. We were thrilled that over 1000 members from across the ADRC Program could join us in-person and virtually. Thank you to NIA, the ADRC executive committee, the ADRC steering committees, and partners like the Alzheimer's Association, that teamed up with us to make the meeting a success. The ADRC Program has a key role in tackling the most pressing challenges in Alzheimer's Disease and Related Dementia and these gatherings are critical for highlighting key developments in the field, fostering impactful collaboration across the consortium, and advancing AD/ADRD discovery and translation.

We are proud of the progress that we've made together in the past few years and are looking forward to finalizing UDSv4 and rolling out new components of the NACC Data Platform and Data Front Door in the coming months. We will be keeping you in the loop!

-- Walter Kukull, PhD and Sarah Biber, PhD



[View Slides and Recordings](#)

Alzheimer's & Dementia Special Issue

In celebration of the ADRC Program's 40th and NACC's 25th Anniversary, there will be a special issue of the *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*® highlighting the major impacts NACC and the ADRC Program have had on the field and the critical role that they will continue to play in tackling pressing questions in the field to advance AD/ADRD translation and discovery.

We welcome you to submit a research paper or review article for consideration for this special issue.

[**Submit to A&D Special Issue**](#)

NACC and Gates Ventures Digital Data Pilot Program

We had a great turnout at the inaugural Digital Data Pilot Program Pitch Competition on May 31, with over 250 attendees joining live to hear pitches from the top six applicants for the NACC and Gates Ventures AD/ADRD Digital Pilot Program! This event highlighted emerging digital technologies that are poised to transform AD/ADRD research and discovery across the ADRC Program and beyond.

Awardees will be announced in early July!

[**Learn about the Pilot Program**](#)

2024 New Investigator Award Winners

NACC is committed to supporting early career investigators across the ADRC Program. This year, we were thrilled to collaborate with the Alzheimer's Association to provide funding to 13 awardees through a new, combined NACC and Alzheimer's Association New Investigator Award Program. Each awardee will receive \$135,000 in direct costs to support their projects focused on tackling a range of pressing challenges in the field. We are also grateful to the Research Education Component (REC) for teaming up with us to provide mentorship to applicants for this program and are thrilled that 92 percent of mentees reported that this mentorship would also be valuable for future grant applications.



[Read about the 2024 Awardees](#)

UDSv4 Updates

Thank you to the Clinical Task Force (CTF) and the Electronic Data Capture (EDC) Workgroup

We are thrilled to be nearing the launch of UDSv4 and our new EDC system (powered by REDCap)! These new research instruments represent a major step forward for the ADRC Program and would not have been possible without NACC's close partnership with the CTF and the EDC Workgroup. The CTF, which included AD/ADRD leaders from across the country has volunteered their deep expertise to ensure that UDSv4 includes new content that is aligned with critical scientific advances in the field. The EDC Workgroup has teamed up with NACC to co-develop resources and infrastructure for more streamlined UDSv4 data collection. [Click here](#) to read about the latest UDSv4 updates from these hardworking groups.

UDSv4 Pilot

The transition from UDSv3 to UDSv4 has started. The UDSv4 Pilot, launched last month, is designed to help ADRCs gain familiarity with the new UDSv4 forms, test new data collection and submission options, assess administration time, and provide valuable feedback on forms and guidance documentation is underway. [Learn more about the pilot here.](#)

UDSv4 Resources

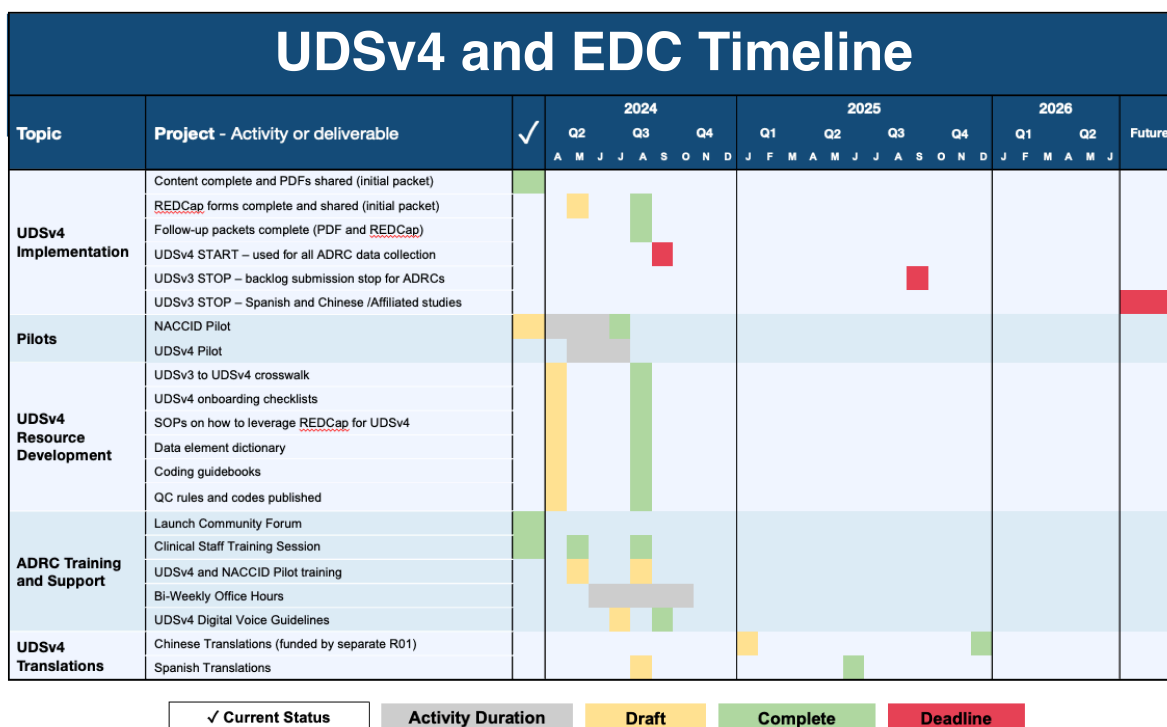
Resources available now:

- [Training webinars and presentations](#)
- Documentation on how to [Upload data to NACC programmatically via API or CLI](#)

Resources that will be available soon:

- NACC UDSv4 Onboarding Checklist for Electronic Data Capture (EDC), PDF uploads, and benchmarking/progress
- Website resources that provide details on Data Element Dictionaries, Data Crosswalks, XMLs, SOPs, Form Guidebooks, and other helpful guides.
- Live web training schedule and office hours
- Online Community Forum in Discourse to connect ADRCs to each other and to NACC for community conversation and sharing experiences and resources

UDSv4 Timeline*



*UDSv4 and EDC Timeline is subject to change

NACCID Pilot

To support the streamlined multimodal data integration via NACC's new Data Platform, NACC is introducing a new process for assigning NACCID's at the time of consent. NACC is running a pilot of the new NACCID process to gather feedback from constituents before rollout in Summer 2024.

[Learn about the NACCID Pilot](#)

Upcoming Events



Upcoming ADRC Meetings

- 2024 Fall ADRC Meeting, Sheraton Boston, Boston, MA
 - October 15-17, 2024 - [Add to your calendar](#)
- 2024 Spring ADRC Meeting, Palace Hotel, San Francisco, CA
 - May 5-6, 2025 - [Add to your calendar](#)

Webinars

Webinars are a great way to stay informed on the latest updates and information. Check out NACC's webinar library to see what you may have missed. Stay tuned for more information about upcoming webinars!

Recent webinars:

- [Digital Pathology Webinar: High-throughput digital quantification of Alzheimer disease pathology and associated infrastructure in large autopsy studies](#)
- [CLARiTI Webinar: NCRAD/Blood Biomarkers in CLARiTI & Neuropath Overview](#)
- [UDS 4.0 Digital Voice Training Workshop](#)

AAIC Workshop

NACC and the AD Knowledge Portal are hosting an in-person AD/ADRD Multimodal Data Workshop at the 2024 AAIC Meeting on July 26 and you are invited to join!

This dynamic and interactive workshop will provide a unique opportunity to connect with other researchers who are interested in leveraging multimodal data to tackle pressing questions in the field. Participants will have the chance to pitch research questions, receive input from NIA program officers, and help inform the design of future data infrastructure and access for the field. [Learn more about the workshop here.](#)

The NIH Aging and AD/ADRD Omics Data Resources: A Path to Interoperability

On July 11-12, 2024, NIA will host a hybrid workshop convening NIA-supported Aging and Alzheimer's disease and related dementias (AD/ADRD) omics data resources across and outside the NIH to explore opportunities and challenges for establishing a more equitable, effective omics data ecosystem to accelerate and improve NIA-supported research.

The workshop will tackle the challenges and opportunities to establish an interoperable data ecosystem for Aging, Alzheimer's disease (AD), and Alzheimer's disease related dementias (ADRD) research that is diverse, equitable, and inclusive. [Learn more about the workshop and register here.](#)



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