

# National Alzheimer's Coordinating Center Updates October 2024



## A message from NACC leadership

Dear Colleagues,

It was wonderful connecting with so many of you at the 2024 Fall ADRC meeting the other week. The meeting brought together over 1,100 participants, physically and virtually, marking our largest ADRC meeting yet. 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 plan an impactful and engaging meeting.

We are excited to launch UDSv4 across the ADRC Program in the coming months and know that this initiative will provide critical new data to advance the field. Our team, together with our CTF and EDC Workgroup partners, are committed to providing valuable tools, resources, and support to help ensure a successful transition at your site.

The ADRC Program has a pivotal role to play in empowering the research community to tackle the most pressing challenges in AD/ADRD and these gatherings are essential 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 look forward to the next steps!

Warm regards,

-- Walter Kukull, PhD and Sarah Biber, PhD

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# 2024 Fall ADRC Meeting



We want to offer a HUGE thank you to all speakers and attendees at the 2024 Fall ADRC Meeting on October 15-17! Session recordings are available on [Hubilo for all registered attendees](#). Slide decks and recordings will be publicly available on our website in November.

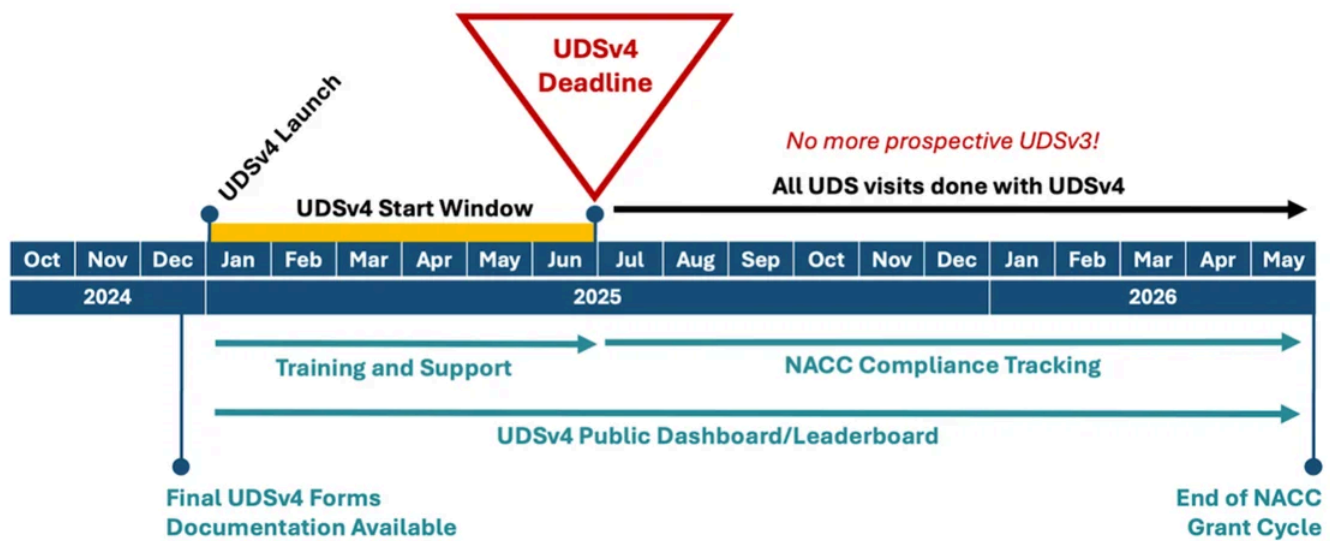
We hope to see everyone in San Francisco, CA or virtually for the 2024 Spring ADRC Meeting on May 5-6, 2025!

Your input is important to help us learn more about what is working well and where we can improve these meetings. Please complete [this 5-minute survey on the 2024 Fall ADRC Meeting](#) by Monday, 10/28.

[➡ Explore past meeting recordings.](#)

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## UDSv4 Transition



The UDSv4 transition is fast approaching! Once NACC launches all finalized UDSv4 materials, the **UDSv4 Start Window** will begin. ADRCs can access the UDSv4 training materials to help onboard their site on the [UDSv4 Updates webpage](#). ADRCs can begin collecting and submitting UDSv4 data starting in January 2025 and will have until the end of June 2025 to complete the transition to UDSv4 for all prospective data collection at their center. Sites can transition gradually during this window or on a single date.

The **UDSv4 Deadline** is the date by which all ADRCs must switch over to UDSv4 collection (unless an extension has been approved by the CTF and NACC). After this date, all prospective data collection must be done with UDSv4. NACC will track ADRC compliance to ensure all UDS visits are done with UDSv4 after this date. Please see next section for information on how NACC is preparing to support ongoing collection of UDSv3 for Spanish and Chinese-speaking participants.

➡ [Visit the UDSv4 Updates page to see the detailed timeline and access tools and resources.](#)

## Next Steps for Spanish and Chinese Translations of UDSv4

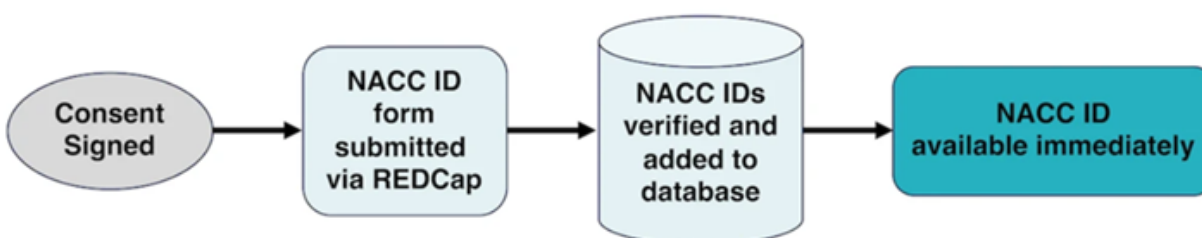
NACC is committed to supporting uninterrupted collection of UDS for Spanish and Chinese speaking populations across the ADRC Program through the UDSv4 transition. We are collaborating with ADRC partners through two funded projects, to provide Spanish and Chinese (Cantonese and Mandarin) translations of the UDSv4 Forms. The translation teams are working to ensure these translations are validated

and thoroughly tested and maintain accuracy and cultural relevance. The Spanish translations are expected to be available to ADRCs by July 2025 and the Mandarin/Cantonese translations are expected to be available by January 2026.

NACC will be meeting with individual ADRCs with large Spanish and/or Chinese-speaking populations to evaluate their needs and how we can best support them through the UDSv4 transition. We will be holding a webinar with our translation partners to address any questions from ADRCs. NACC will continue to support prospective UDSv3 collection beyond June 2025 and until the UDSv4 translations are available. Please contact Jess Welsch, Senior Project Manager ([jmwelsch@uw.edu](mailto:jmwelsch@uw.edu)), for more details.

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## New NACCID Process



Starting January 1, 2025, the ADRC Program will begin using a new process to assign NACCIDs at the time of consent. **With the new NACCID process, ADRCs will submit a simple form to NACC to assign NACCIDs to participants at the time of consent.**

**Join us on November 13, 2024, for an informational webinar on [How to Start Using the New NACCID Process](#).**

NACCIDs are the unique identifiers assigned by NACC for ADRC participants. The new process will allow for additional NACCID verification, improve flexibility by enabling participant data types to be submitted to the NACC Data Platform in any order, and streamline multimodal data integration. This new process will not affect how ADRCs assign their own site-specific IDs or NIA GUIDs.

[➔ Read more about the new NACCID Process.](#)

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# SCAN Data Now Available at NACC

Standardized Centralized Alzheimer's & Related Dementias Neuroimaging (SCAN) data is now available the NACC Quick Access File request system! The data currently available includes over 1,400 amyloid PET scans, 900 tau PET scans, and 2,400 MRI scans and numerical summaries such as Standardized Uptake Value Ratios (SUVRs), brain volumes, and white matter hyperintensities (WMHs). Additionally, there are more than 2,300 PET and 11,000 MRI (including 3,700 T1/FLAIR) scans still in the pipeline being processed by the SCAN team.



The goal of SCAN is to enable standardized PET and MRI data collection from across the ADRC Program so that it can be combined and shared with researchers around the world via the NACC Data Platform. NACC is excited to make this goal a reality by providing free access to this groundbreaking data to researchers everywhere.

[\*\*➔ Learn more and request SCAN data now.\*\*](#)

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## Call for Papers - A&D Special Issue

Submit your original work to the Alzheimer's & Dementia Special Issue celebrating the 40th anniversary of the ADRC Program and the 25th anniversary of NACC. Submissions are open to all. The goal of this Special Issue is to highlight the impact NACC and the ADRC Program have had on advancing AD/ADRD translation and discovery and their ongoing and critical role in tackling the most pressing challenges in the field, including:

- Advancing early detection



- Disentangling disease heterogeneity
- Validating blood biomarkers
- Identifying and stratifying risk factors and protective mechanisms
- Developing precision medicine solutions
- Ensuring diversity and the generalizability of findings

The deadline for open call submissions is December 31, 2024.

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## 2025 New Investigator Award Program

Submit a Letter of Intent (LOI) form by **November 8, 2024, 5pm ET**, to confirm your eligibility and access the application portal for the 2025 New Investigator Award Program (NIAP). The form takes about 10 minutes to complete. Applicants who fill out an LOI are not required to submit a full application.

NACC and the Alzheimer's Association are excited to once again offer 10 awards of \$135k per award in direct costs to early career investigators affiliated with an ADRC. This program offers a fantastic opportunity for postdoctoral fellows, residents, and junior faculty who have not yet received an R01 grant to support their AD/ADRD research.

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## CLARiTI Initiative Announces First Scan



The Wisconsin ADRC is the first site to conduct scans as part of the Clarity in Alzheimer's Disease and Related Dementias Research Through Imaging (CLARiTI) initiative. This five-year study will gather advanced imaging and blood-based biomarker data that will be freely available to researchers everywhere via the NACC Data Platform.

Barbara Smith Ballen (*pictured above with Dr. Sterling Johnson*), one of CLARiTI's first study participants says, "I am committed to doing whatever I can to help end this devastating disease and hopefully others will follow my lead. I truly believe that this research team has what it takes to make a breakthrough; they just need to stay persistent."

[!\[\]\(99f58673407353e96a019fbca558fd72\_img.jpg\) Read the full article to learn more.](#)

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## **Coming Soon - ADRC Program Community Forum**

The ADRC Program Community Forum was created in response to feedback from the ADRCs regarding the need for a one-stop shop for asking questions, getting answers, and collaborating with colleagues across the ADRC Program. The Forum is a private, invite-only moderated forum for all ADRC members. Points of contact for the UDSv4 and NACCID pilots and ADRC Administrators have been invited and

are encouraged to participate in the Forum. All other ADRC members will receive an invitation in November. We look forward to collaborating with you on the Forum!

[➔ Explore ADRC Community Forum resources and FAQs.](#)



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National Alzheimer's Coordinating Center, 4311 – 11th Avenue NE, Suite 300, University of Washington, Seattle, WA 98105, USA

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