

National Alzheimer's Coordinating Center

Updates January 2024



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NACC News, January 2024

UDSv4 Update

The National Alzheimer's Coordinating Center (NACC) is excited for the transition from UDSv3 to UDSv4. Here are a few important updates, which were shared at the Fall ADRC Meeting.

UDSv4: The Countdown is On

NACC, the Clinical Task Force, and the Electronic Data Capture Workgroup are working hard to facilitate the transition to UDSv4 in collaboration with the ADRC program! UDSv4 will advance ADRC research and discovery by aligning the UDS with important scientific and clinical advances in the field. Key updates include incorporating 1) social determinants of health, 2) more inclusive demographic questions, 3) new concepts such as subjective cognitive decline, mild behavioral impairment, and a verbal learning test to assess new cognitive domains, and 4) data on use of disease modifying drugs.

The ADRCs will continue to have opportunities to review and provide feedback throughout the UDSv4 roll out.

The current anticipated UDSv4 timeline is shown below and available [on our website](#). We welcome your feedback [HERE](#).

Category	Task - Anticipated activity or completion	Q4 2023			Q1 2024			Q2 2024			FUTURE
		Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	Jun	
UDSv4	Content complete and PDF versions shared				Draft		Final				
	REDCap forms complete and shared					Draft		Final			
	UDSv4 trial						Trials				
	UDSv4 START – UDSv4 used for all data collection UDSv3 STOP – UDSv3 backlog submission stop date										TBD
NACC Infrastructure	ADRC Portal testing	V1				V2					
	ADRC Portal live		Testing and Feedback								
	New Submission Interface live										
	Sandbox staging system available							Sandbox			
NACC ID Assignment Process	NACC ID change announced	10/20									
	NACC ID trial					Trial					
	ADRCs start using new process										
	New NACC ID process required										
Resources/ Tools	UDSv3 to UDSv4 crosswalk					Draft		Final			
	UDSv4 checklists				Draft			Final			
	Data element dictionary and coding guidebooks					Draft		Final			
	QC rules and codes							Final			
ADRCs	Fall ADRC Meeting – review draft timeline	10/20									
	Clinical Staff Training (CTF/NACC resources)										
	Data Manager Training (EDC WG, NACC, Data Core WG)										
	Analytics Team Training										

The draft UDSv4 forms are available and can be accessed [on the UDSv4 updates site](#).

2023 Fall ADRC Meeting NACC Session

Check out the NACC Session recording to learn more about the transition to UDSv4, new ways to access your data, and how we’re becoming more multimodal.



Get involved with the Electronic Data Capture Workgroup

The [Electronic Data Capture Workgroup](#), in collaboration with the Data Core Steering Committee. The group has brought together more than 90 members across 32 ADRCs to collaboratively develop REDCap forms, define requirements, share best practices, and develop training and education materials to support the transition to UDSv4.

It is not too late to get involved! We encourage you to join the conversation and contribute to co-developing impactful electronic data capture solutions for the ADRC Program.

Join the EDC Workgroup

CLARiTI Webinar

CLARiTI hosted the first in a series of informational webinars on December 15, 2023!

This informational webinar focused on many important topics such as study protocol, payment for procedures, disclosure, site readiness, and held an open Q&A session at the end of the webinar.

[Watch the Webinar Recording](#)

Access the webinar slides, view the recording, and learn more about the CLARiTI project on the [CLARiTI website](#).

SCAN Updates

The **SCAN Public Dashboard** is now available to all on the NACC website! View up-to-date information on how much SCAN-compliant MRI/PET data is available from across the ADRC program. If you are new to the SCAN Dashboards, check out the [SCAN Dashboard Quick Guide](#).

[View the SCAN Public Dashboard](#)

ADRC-Specific SCAN QC Dashboards:

ADRC members with access permissions can now track the QC status of their SCAN submissions. Simply follow the ADRC-specific links in the SCAN Public Dashboard to view your center's data. PLEASE NOTE: To view your center's data, you will need data privilege access, please review the [SCAN Dashboard Quick Guide](#) for details.

SCAN summary and analysis data will soon be available to researchers anywhere:

All SCAN variables, including summary, QC, and analysis variables, will be added to the NACC Quick Access File Data Request System this winter. [Learn more about NACC's easy to use Data Request Process](#).

DO NOT SUBMIT YOUR NON-STANDARD DATA TO SCAN:

Please note that the SCAN initiative does not accept non-SCAN compliant MRI and PET images. Existing MRI and PET images collected before January 1, 2021, and prospective images that don't meet SCAN protocol are still accepted by NACC. [Review the SCAN protocol](#) and [learn more about submitting non-standard MRI/PET data](#).

SCAN Public Dashboard

This dashboard tracks the number of SCAN-compliant MRI/PET images and the number of participants that images have been submitted for by each Alzheimer's Disease Research Center to LONI/NACC. [Learn more about the Dashboard.](#)

Have feedback on the SCAN dashboard? [Submit it here!](#)

Alzheimer's Disease Research Centers COPY CSV

Institution	SCAN Participation						Private Dashboard
	Total # of Participants	MRI			PET		
	# MRI participants	# MRI exams submitted	# MRI series submitted	# PET participants	# PET scans submitted		
Total	3,405	2,888	3,264	16,885	1,600	2,858	
Mayo Clinic	352	235	295	878	325	805	PRIVATE DASH
Wake Forest University	335	272	281	728	174	271	PRIVATE DASH
University of Wisconsin	297	271	321	745	150	318	PRIVATE DASH
University of Pittsburgh	217	136	136	406	85	168	PRIVATE DASH
New York University	191	189	278	427	72	98	PRIVATE DASH
University of California, San Francisco	177	148	145	860	45	86	PRIVATE DASH
Arizona ADRC	161	74	75	1,610	153	316	PRIVATE DASH

ADRC Portals: New Data available online

ADRCs can now access their ADRC-specific SCAN QC dashboards online. This resource enables ADRCs to track in real-time what imaging data they have submitted to SCAN, where it is in the pipeline, and what errors they need to address.

You can also view, audit, and download all your ADRC's SCAN-compliant MRI and PET metadata via the ADRC Portal. Sign in via your [site-specific SCAN QC Dashboard link in the SCAN Public Dashboard](#).

You can [learn more about additional features](#) that will be added to the ADRC Portals in the coming year.

ADRC Data Portals

Current Data Streams

Harmonized Phenotypic Data (UDS)

Neuropathology Reports

Non-Standard MRI/PET

New Data Streams

Participant Diversity Dashboard

ADRC SCAN MRI/PET QC Dashboards

Specimen / Marker / Genetic Metadata

New NACC ID Assignment Process

To support expanded and more flexible multimodal data collection and integration, NACC is changing the way that NACC IDs are assigned. The biggest changes are that:

- NACC IDs will be assigned at the time the participant is consented and submitted to NACC using a simple form
- NACC ID forms can be entered directly, or uploaded through a CSV or API
- This new system will enable data modalities for participants to be submitted to NACC in any order, integrated, and connected to NACCIDs

[Learn more about the new NACC ID assignment process.](#)

Over the coming months NACC will send updates about the development of the new process. We will also open the process for trial and feedback between February and April 2024.

NACC/Gates Ventures Digital Biomarker Pilot Program

NACC is partnering with Gates Ventures to fund up to three proposals, at \$250k-\$1M (in direct costs) each, focused on advancing Alzheimer's disease and related dementias research and discovery through digital innovation!

[Learn more and apply](#)

February 21, 2024: Deadline for applications

- Proposed projects should leverage technology to capture richer and more objective data and advance the development and validation of digital biomarkers. Example tools include wearable devices, sensors, apps, software, large language modals, AI, and more.
- The awards are open to anyone. All applicants must have at least two Alzheimer's Disease Research Center (ADRC) partners.

2023 Fall ADRC Meeting

It was wonderful seeing so many of you at the 2023 Fall ADRC Meeting. There were more than 950 ADRC members that participated in-person or virtually. All meeting content is [now available online for viewing.](#)

Best regards,

The NACC Team



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National Alzheimer's Coordinating Center, 4311 – 11th Avenue NE, Suite 300, University of Washington, Seattle, WA 98105, USA, (206) 543-8637

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