National Alzheimer's Coordinating Center

Updates December 2023

naccdata.org

NACC News, December 2023

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 ADRD 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)				Training happening at ADRCs						
	Data Manager Training (EDC WG, NACC, Data Core WG)										
	Analytics Team Training				TBD-varies by ADRC (90-240 days)						

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 80 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 - Join us for important updates!

Join us and the CLARiTI leadership team for the first CLARiTI informational webinar on Friday, December 15, 2023, at 12pm CT (10am PT, 1pm ET) via Zoom. This webinar will focus on many important topics such as preliminary protocol, payment for procedures, schedule, site responsibilities, readiness and much more! We will leave time at the end for a Q&A.

Join via Zoom

NOTE: Please use this link to post any advance questions or comments you would like covered in the webinar.

SCAN Updates

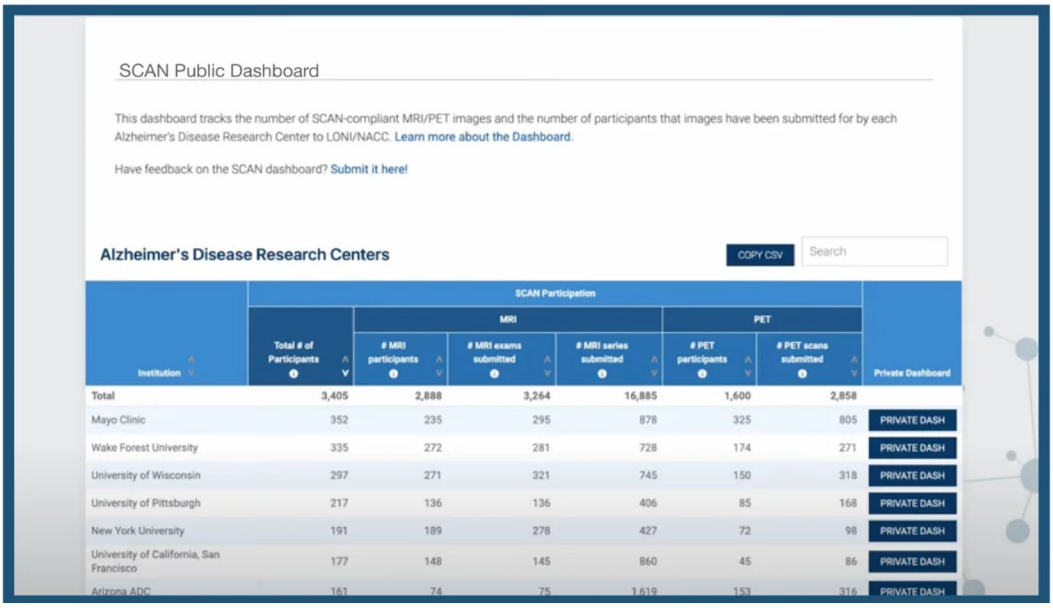
The SCAN Public Dashboard is now available to all on the NACC website! View up-to-date information on how much SCAN-compliant MRI/PET data is available from across the ADRC program. If you are new to the SCAN Dashboards, check out the SCAN Dashboard Quick Guide.

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.

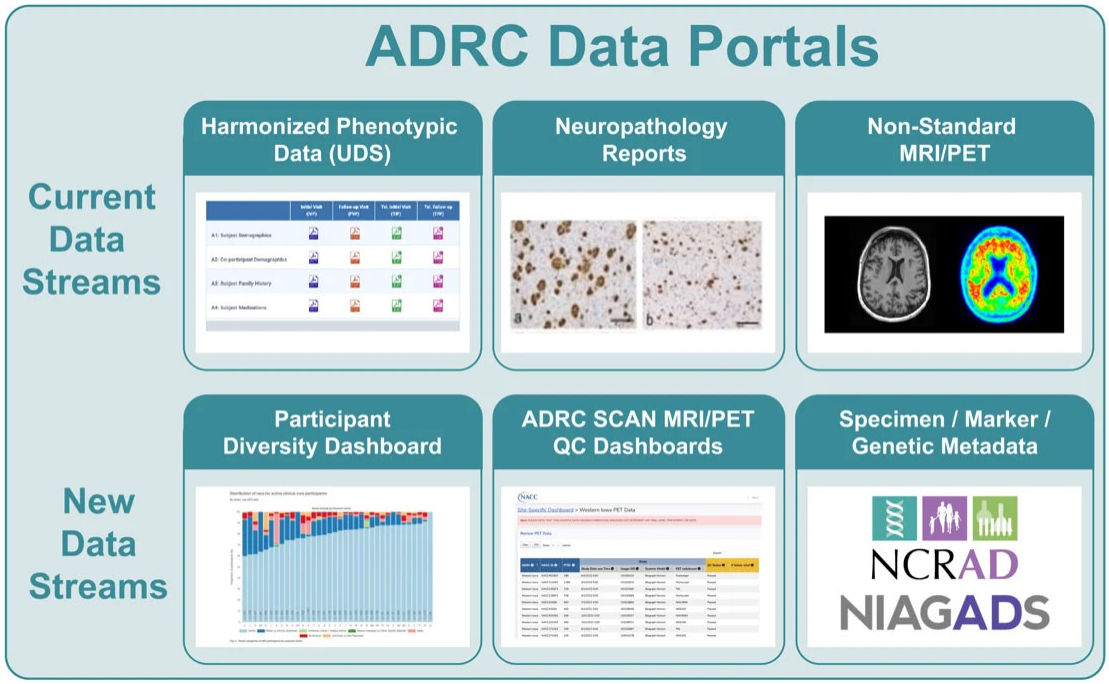


ADRC Portals: New Data available online

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.



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

January 19, 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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