

National Alzheimer's Coordinating Center

Updates May 2023

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Explore the Latest Updates: ADRC Meeting Highlights, New Investigator Award Winners, Data Sharing Guidelines, UDSv4 Forms, EDC Workgroup Progress, and the NACC Data Platform.

Dear ADRC Colleague,

It was wonderful having so many folks join us in person and virtually for the 2023 Spring ADRC Meeting!

Thank you again to all the excellent presenters and to NIA, the NACC Executive Committee, and the ADRC Core leads for partnering with us to make this a successful event. These meetings are a great reminder of the amazing breadth and depth of AD/ADRD expertise across the ADRC Program.

We are excited to share that we had an exceptional turnout at the Spring ADRC Meeting, with 912 individuals joining us (in-person and virtually) from all 37 ADRCs and 45 AD/ADRD partner organizations.

The video presentations and slide decks from the Spring ADRC Meeting are [available for viewing on NACC's website.](#)



View all the highlights of the 2023 Spring ADRC Meeting by browsing and enjoying more photos on Flickr.

Spring ADRC Meeting Photos

Congratulations to the winners of the 2023 New Investigator Awards!

Dr. Shea Andrews, UNC/Duke, and Dr. Michael Devinney, UCSF!

These awards support new and early career investigators in advancing Alzheimer's Disease and Alzheimer's Disease Related Dementias (AD/ADRD) research.

NACC would like to thank the Scientific Review and NACC Steering Committee members for their considerable efforts and support of the New Investigator Award program.

For more information about the New Investigator Award winners and the New Investigator Award Program, [please see the full announcement on our website.](#)

Introducing NACC's Guidance for ADRC Data Sharing Plans for NACC Data!

We are excited to announce the release of NACC's new Guidance for Management and Sharing of NACC Data Plan, developed in collaboration with the National Institute on Aging (NIA) and the Electronic Data Capture (EDC) Workgroup.

NACC would like to give a special thanks to Chad Murchison, PhD, UAB ADRC and Sarah Gothard, BS, OHSU ADRC, for their valuable contributions to the Guidance for Management and Sharing of NACC Data Plan!



The NACC MSDP can be [downloaded as a PDF from the NACC website.](#) This guidance document will continue to evolve as our new NACC Data Platform progresses and new versions become available.

This NACC Guidance is intended to serve as a resource for ADRCs that are developing their own DMSP and covers that portion of their ADRC data that is shared through NACC.

Preview the UDSv4 Forms

ADRCs have expressed enthusiasm for the UDSv4 forms during the recent Spring ADRC Meeting. NACC is pleased to announce that the CTF-approved UDSv4 forms are now available for preview on the NACC website. As the CTF approves the remaining forms, they will be posted on this site.

[View the Latest UDSv4 Forms](#)

While the forms may undergo minor edits following the pilot phase, this preview allows ADRCs to stay ahead and familiarize themselves with the current format and content. NACC remains committed to keeping ADRCs informed about important changes during the UDS update process, ensuring seamless collaboration and effective implementation.

Stay tuned for announcements on the availability of the final forms!

Electronic Data Capture (EDC) Workgroup Updates

In the second quarter of 2023, significant EDC updates were implemented, establishing the NACC Data platform and achieving key milestones, including the successful transfer of existing NACC data (UDS/Neuropath forms) to the cloud and the deployment of an authorization system leveraging the NACC Directory.

Electronic Data Capture for UDSv4

NACC and the Electronic Data Capture (EDC) Workgroup are collaborating to streamline and reduce burden for UDSv4.

NACC is partnering with the EDC Workgroup to:

- Build REDCap forms for UDSv4
- Build transparent QC processes – will be available via Github
- Develop training and education materials

Download a PDF of the latest EDC Workgroup Updates:

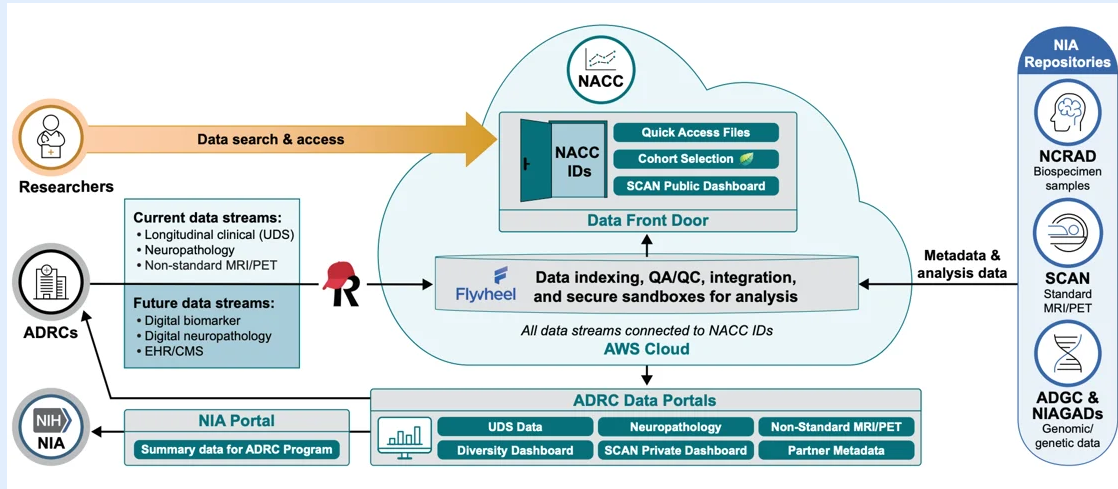
[EDC Workgroup Updates](#)

Visit the NACC website to discover more about the EDC Workgroup and how electronic data capture will streamline and reduce burden for ADRCs. It is not too late to sign up to get involved!

NACC Data Platform

Exciting progress is underway on the new NACC Data Platform (NACC DP), a secure and modern system that will transform ADRC data collection, integration, and sharing.

An overview of this platform can be found [here](#) and an update on the data platform was presented at the [2023 Spring ADRC Meeting](#)



We will be rolling out new components of the NACC Data Platform this coming year, including an ADRC Data Portal prototype this summer. Stay tuned for an invite to a webinar about this soon.

If you have questions about any of the NACC Updates or this email, please contact NACC at info@nacccdata.org.

Our Best,
The NACC Team



UNIVERSITY of WASHINGTON

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