National Alzheimer's Coordinating Center

#### Dear Colleagues,

As the year comes to a close, we want to express our gratitude for your collaboration and dedication to our shared mission of advancing Alzheimer's Disease and Related Dementia (AD/ADRD) research. We are proud to highlight the incredible progress that NACC, together with our partners, has enabled this past year.

#### **2024 Highlights**

# 1. UDSv4: Setting a New Gold Standard for AD/ADRD Clinical Data Collection

We are thrilled to announce the official launch of UDSv4 on January 14, 2025, made possible by the extraordinary efforts, expertise, and collaboration of the <u>Clinical</u> <u>Task Force</u> and the <u>Electronic Data Capture and Submission (EDCS)</u>. <u>Workgroup</u> over the past three years. UDSv4 will replace UDSv3 as the gold standard for clinical phenotypic data collection in AD/ADRD across the ADRC Program and globally, driving critical new scientific advances. Key improvements include the incorporation of standardized data on social determinants of health, use of disease-modifying therapies, and mild behavioral impairment. Optional but important new UDSv4 components include guidelines for digital voice recording of the UDSv4 neuropsychological exam and a new form to capture biomarker data aligned with the new <u>2024 NIA-AA clinical criteria</u>.

UDSv4 also represents a significant technical leap for the ADRC Program, featuring **<u>REDCap forms</u>** and a <u>streamlined electronic data capture and submission</u> <u>system</u>, a core feature of the new NACC Data Platform.

2. Accelerating AD/ADRD Translation and Discovery by Providing Easy Access to a Growing Volume and Variety of Integrated ADRC Participant Data

- NACC data utilization by the global research community has seen remarkable and continued growth, with more than 150 data requests received each month—reflecting a 230% increase in the average monthly request volume over the past three years. This surge has already led to a 26% rise in publications utilizing NACC data with more than 1350 publications to date.
- <u>Standardized MRI/PET (SCAN) data</u> is now available to the global research community via the NACC Data Front Door! Researchers worldwide can access summary and analysis data from over 1,400 amyloid PET scans, 900 tau PET scans, and 2,400 MRI scans, all linked to UDS, defaced images, and other data modalities, by requesting the <u>NACC Quick</u> <u>Access File</u>. More than 700 SCAN data requests have been made since this

data was released in May 2024. Additionally, the <u>SCAN Public Dashboard</u> now provides up-to-date information on the volume of SCAN data available from across the ADRC Program. More exciting SCAN updates were shared at the <u>recent SCAN Webinar</u> hosted by NACC and CLARiTI.

 NACC has continued to expand its cloud-based <u>Data Platform</u>, enhancing its ability to support streamlined multimodal data collection, integration, harmonization, and sharing. Recent advancements include strengthening interoperability with partner repositories and initiatives and will offer researchers easy access to a growing variety of standardized, highquality data types for ADRC participants via the <u>NACC Data Front Door</u>. In 2024, NACC initiated or advanced pipelines to integrate new fluid biomarker, MRI/PET, genetic/genomic, multi-omic, digital biomarker, digital neuropathology, and real-world data. Additionally, the <u>new NACCID process</u>, launching on January 14, 2025, will improve multimodal data integration and sharing.

## 3. ADRC Portals: Empowering ADRCs to Manage their Participants and Data

The <u>ADRC Portals</u> provide self-service tools that enable ADRCs to efficiently manage their participants and submit, view, audit, and access their participants' multimodal data securely within the NACC Data Platform. Over the past year, NACC has introduced valuable new features to the ADRC Portals, each refined through feedback from across the ADRC Program (e.g. <u>UDSv4 Pilot</u>). These include:

- Launching a <u>new submission interface</u> that is <u>UDSv4 ready</u>.
- Additional SCAN data access: ADRCs can now track the real-time QC status of their SCAN data submissions and view all SCAN summary and analysis variables available for their ADRC participants
- ADRCs can now access GWAS data for their participants via the ADRC
  Portals thanks to a collaboration with NIAGADS
- ADRCs can request NACCIDs for their participants at the time of consent via the ADRC Portals using the <u>new NACCID process</u>, starting on January 14, 2025

4. Advancing Our Mission to Foster Meaningful Engagement and Collaboration Across the ADRC Program and Beyond to Propel Research Forward

- This past year, we proudly hosted our largest two biannual hybrid ADRC Meetings to date, each bringing together over 1,000 researchers, clinicians, and stakeholders from across the ADRC Program. These meetings served as crucial platforms for collaboration and knowledge exchange, with 88% of attendees reporting that they provided valuable insights into key scientific developments in the field. We extend our heartfelt thanks to the ADRC Executive Committee and the NIA for their collaboration and guidance in making these meetings a success, with a special acknowledgment to Dr. Sanjay Asthana for his leadership as committee chair this past year. Visit our website to revisit talks from the 2024 <u>Spring</u> and <u>Fall</u> meetings and please make sure to save the date for our upcoming <u>2025 Spring ADRC Meeting</u>, <u>May 5-6 in San Francisco</u>.
- We brought together 100 researchers for a sold-out <u>AD/ADRD</u>
  <u>Multimodal Workshop at AAIC>24</u>, organized in collaboration with the AD
  Knowledge Portal. This in-person event focused on leveraging multimodal
  data— including clinical phenotypic, EHR, genomics, biomarkers, and imaging
  —to tackle pressing challenges in AD/ADRD. Attendees collaborated to

identify and develop promising research questions, explore existing data repositories, and discuss the infrastructure needed to enhance multimodal data access and utilization. The workshop fostered valuable collaborations and provided key insights into advancing AD/ADRD research through improved data discovery and integration.

- NACC hosted a record <u>20 collaborative webinars</u> in 2024, a 60% increase over last year. The workshops covered a range of critical topics in AD/ADRD research and attracted hundreds of attendees from across the ADRC Program and beyond.
- NACC launched the <u>ADRC Program Community Forum</u>, a central hub for 24/7 knowledge sharing, networking, and collaboration across the entire ADRC Program. It facilitates efficient asynchronous communication on and provides FAQs for key initiatives, like UDSv4, and includes access to technical support from NACC.
- NACC continued to expand the <u>NACC Directory</u>, which serves as a centralized resource for connecting with ADRC researchers, clinicians, and institutions. The directory also empowers ADRC administrators to manage access permissions for their ADRC Portals within the NACC Data Platform.

#### 5. Strengthening Partnerships to Maximize Impact

NACC's success is built on the strength of our partnerships. This year, we expanded or initiated collaborations with key partners, including SCAN, CLARiTI, NIAGADS, NCRAD, the AD Knowledge Portal, the Alzheimer's Association, and Gates Ventures. These partnerships have been pivotal in expanding access to resources, enhancing data sharing, and driving innovative projects that propel AD/ADRD research forward on a global scale. Here are a few highlights:

#### Enhancing NACC's Operational and Informatics Infrastructure to Amplify and Accelerate <u>CLARITI</u>

We are thrilled to <u>partner with CLARiTI</u> to make cutting-edge imaging, bloodbased biomarkers, and digital neuropathology data from ADRC participants accessible to researchers worldwide through the NACC Data Front Door. The CLARiTI study aims to deepen our understanding of mixed-etiology dementia and accelerate the development of personalized treatments for individual patients. With the <u>first patient enrolled</u> last October, CLARiTI is off to a strong start. <u>NACC's operational and informatics infrastructure</u> has been—and will continue to be—crucial in ensuring the study's ongoing success.

#### Partnering with the Alzheimer's Association to Support the Next Generation of ADRC Researchers

We were excited to <u>partner with the Alzheimer's Association</u> this past year to expand our New Investigator Award program, offering increased support to early-career ADRC researchers. Thanks to their generous collaboration, we awarded 13 grants of \$135K (direct costs) in 2024 to fund promising projects to advance our understanding of AD/ADRD. The funded projects, representing 13 ADRCs, were selected from a record 154 proposals across 34 Centers marking a 357% increase in submissions. In collaboration with the Research Education Component (REC), we launched a mentorship program, with 77% of applicants participating. Of those, 92% reported that the mentorship would be valuable for future grant applications. Special thanks to Drs. Heather Snyder and Stefania Forner for their partnership, and we look forward to continuing this collaboration in the coming year.

• Launching a **Digital Pilot Program** with Gates Ventures to Advance

### AD/ADRD Research and Discovery

Another key accomplishment this year was launching our partnership with Gates Ventures to accelerate the development of digital tools to advance AD/ADRD research. The program <u>awarded nearly \$1.4 million</u> to two innovative pilot projects focused on enhancing data collection and generating new insights. Leveraging the ADRCs as a testbed, the program aims to develop impactful digital biomarkers. All digital data will be made accessible to the global research community via the NACC Data Front Door, alongside other ADRC participant data. This collaboration has the potential to advance biomarker discovery, deepen our understanding of AD/ADRD, and contribute to earlier diagnosis and improved quality of life for those affected.

As we look ahead to 2025, we are eager to celebrate the 40th Anniversary of the ADRC Program and the 25th Anniversary of NACC with a <u>special issue of</u> <u>Alzheimer's and Dementia.</u> (*Please note that the submission deadline has been extended to February 28, 2025.*)

Key priorities for the upcoming year include the official launch of UDSv4, expanding the NACC Data Platform to enhance interoperability and integrate more multimodal data, making CLARiT data available to the global research community via the NACC Data Front Door, and launching the Multimodal Query Tool to help researchers quickly identify data that aligns with their research questions. We also look forward to growing collaborations and ensuring that our tools and resources continue to meet the evolving needs of the ADRC Program and the broader AD/ADRD research community. A special thanks to the National Institute of Aging for its ongoing support which makes all of this progress possible.

### We are excited to continue our positive momentum and wish you all an excellent start to 2025!

With appreciation for your continued collaboration and support,

Bud Kukull, PhD Director, NACC

Sarah Biber, PhD Executive Director, NACC

and our entire team at NACC!



UNIVERSITY of WASHINGTON

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National Alzheimer's Coordinating Center, 4311 – 11th Avenue NE, Suite 300, University of Washington, Seattle, WA 98105, USA <u>Unsubscribe Manage preferences</u>