Welcome!

Walter Kukull, PhD, NACC Director

May 14, 2022 – ADRC Spring Meeting
UDSv4 – The Full Picture

Sarah Biber, PhD, NACC Program Director

May 14, 2022 – ADRC Spring Meeting
UDS Data – Impact

- **45,000+** Participants with data at NACC
- **166,000+** Clinical assessments (1-17 visits per participant; median =3)
- **6,980+** Neuropathology datasets (From 58% of deceased participants)
- **900+** Published studies using NACC data
- **37** ADRCs are contributing data (Across 26 states)
UDSv4 – Content Update

• Expand UDS participation (Currently > 45,000 participants)
• Streamline and reduce participant burden
• Reflect advances in science, technology, clinical practice, and our understanding of social determinants
## UDSv4 – Collaboration with the CTF

<table>
<thead>
<tr>
<th>Collaboration with the Clinical Task Force (CTF)</th>
<th>Lead: Allen Levey, MD, PhD</th>
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<tbody>
<tr>
<td>Technology Workgroup</td>
<td>Lead: Rhoda Au, PhD</td>
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<tr>
<td>Clinical Measures and Diagnosis Workgroup</td>
<td>Co-leads: Cindy Carlsson, MD, MS and Greg Jicha, MD, PhD</td>
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<td>Behavioral Workgroup</td>
<td>Lead: Howie Rosen, MD</td>
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<td>Cognitive Workgroup</td>
<td>Co-leads: Andy Saykin, PsyD and Lisa Barnes, PhD</td>
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<tr>
<td>Social Determinants of Health Workgroup</td>
<td>Co-lead: Lisa Barnes, PhD and Megan Zuelsdorff, PhD</td>
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Collaborate on meeting agendas, setting strategic goals, and tracking deliverables
Update UDS
Content
UDS4 – The Full Picture

Updated UDS Content

Streamlined Submission System

Integrated Pipeline and Database

Expanded Search and Access Portal
UDSv4 – New Submission System

- Existing system is 20 years old and needs to be updated to be more cloud friendly and virtualized

- Goals:
  - Streamline UDS data collection for the ADRC program
  - NACC will continue to host a range of options

- Why are we starting with REDCap?
  - Canonical tool for forms data capture

20 centers already using REDCap with 9 more interested

Not interested: 8
All data will go through REDCap at NACC in the future via one of these options:

<table>
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<tr>
<th>Method Description</th>
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<tbody>
<tr>
<td>Direct data entry into NACC REDCap</td>
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<tr>
<td>Synchronize local ADRC REDCap instances through REDCap APIs</td>
</tr>
<tr>
<td>Bulk upload of .csv files into NACC REDCap</td>
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UDSv4 – Electronic Data Capture (EDC) Workgroup

• Electronic Data Capture Working Group:
  • Launched January 24th, 2022 in collaboration with the Data Core Steering Committee
  • 45 people across 17 ADRCs that are collaborating with us to:

Define Requirements

Develop Submission Forms

Create Training and Education
UDSv4 – Electronic Data Capture (EDC) Workgroup

• Thank you EDC Workgroup members!
  • Co-Leads: Sudeshna Das, PhD and Sarah Biber, PhD
  • Development Co-Leads: Jon Reader, MS and Ben Keller, PhD
  • Requirements Co-Leads: Meredith Zozus, PhD and Kari Stephens, PhD
  • Documentation and Training Co-Leads: Alice Spalitta, Leah Reuter, and Laura McLeod

Scan QR code and fill out the form to join!

Link Here
UDSv4 – Pipeline and Database

Stakeholders

Investigators

ADRCs

NIH

NIA

Coordinators

SCAN

NCRAD

ADGC & NIAGADs

Data Front Door

NACC IDs

Metadata

Data indexing, QA/QC, and integration

Reporting

Submission interfaces

Push/Pull Data
UDSv4 – Pipeline and Database

ADRCs → NACC IDs Connected → NACC

Current:
- Longitudinal clinical data
- Neuropathologic data
- Legacy MRI/PET

Future:
- Digital biomarker
- Digital neuropathology
- EHR/CMS
UDSv4 – Pipeline and Database

Metadata

NACC IDs Connected

ADRCs

SCAN

Standardized MRI/PET

NCRAD

Biospecimen samples

ADGC & NIAGADs

Genomic/genetic data

NACC

Current:
- Longitudinal clinical data
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Future:
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NACC IDs Connected
UDSv4 – Pipeline and Database

Metadata

NACC IDs Connected

Data Front Door

NACC IDs

One-stop-shop for ADRC data

Investigators

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ADGC & NIAGADs

NACC

Current:
- Longitudinal clinical data
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Future:
- Digital biomarker
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Standardized MRI/PET

Biospecimen samples

Genomic/ genetic data

NACC IDs Connected
UDSv4 – Search and Access Portal

Data Front Door

- Easy to use
- Self-service
- Cohort discovery enabled
- Real-time
- Integrated

One-stop-shop for ADRC data

Requirements Pilot Project

- Collaboration between NACC, NCRAD, and NIAGADS

Provide input!

- Visit our interactive DFD station to provide input on your needs – Solano Room, noon – 1:30pm

Join a thought leader focus group session

Provide input via a survey

Link Here

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Expanded Search and Access Portal

Clinical Task Force

EDC Workgroup

Future Collaborator

NCRAD/NIAGADS

Digital advancements

Heterogeneity

Gender

Social determinants

Clinical practices
So, when will all of this be available?

- **Timing constraints**
  - CTF content update
  - Architecture design and build

- **We're committed to keeping you in the loop!**
  - Regular progress updates to the ADRC community
    - Transparent tracking (shared CTF tracker and forms tracker)
    - Email, newsletters, website updates
  - Early forms access for testing with your systems

How do you want to receive updates?

Fill out the survey!
Learn all about the new UDSv4 forms!

- New content added for assessing:
  - Subjective cognitive decline
  - Mild behavioral impairment
- COVID-19 Forms
- Potential participant burden

Visit: https://go.naccdata.org/uds4-ctf-webinar-june-3
Thank you!
Thank you!
Thank you!

Bud Kukull
Connect with NACC

Sarah Biber – Program Director

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