NACC Session

Thursday, October 20 – 2022 Fall ADRC Meeting
Welcome

Walter Kukull, PhD

October 20 – ADRC Fall 2022
## Welcome to the NACC Session!

<table>
<thead>
<tr>
<th>Topic</th>
<th>Speaker Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>Delivering on NACC’s mission and modernization</td>
<td>Sarah Biber, PhD</td>
</tr>
<tr>
<td><strong>NACC’s New Data Pipeline and Repository Solution: Benefits for the ADRC Program</strong></td>
<td>Ben Keller, PhD</td>
</tr>
<tr>
<td>Building a novel platform to expand longitudinal COVID-19 data collection, integrate new data streams, and open the door to impactful new COVID-19 and ADRD discoveries</td>
<td>Sean Mooney, PhD, Melissa Lerch, PhD, Kari Stephens, PhD</td>
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<tr>
<td>Amplifying the SCAN Initiative</td>
<td>Sarah Biber, PhD</td>
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<tr>
<td>Progressing Towards a Digital UDS</td>
<td>Sean Mooney, PhD</td>
</tr>
<tr>
<td>The New NACC Directory</td>
<td>Laura McLeod</td>
</tr>
</tbody>
</table>
Delivering on NACC's Mission through Modernization

Sarah Biber, PhD

October 20 – ADRC Fall 2022
Overview of NACC's Expanded Mission and Role

NACC serves as the data, collaboration, and communication hub for NIA's ADRC Program

<table>
<thead>
<tr>
<th>Data</th>
<th>Communication &amp; Collaboration</th>
</tr>
</thead>
<tbody>
<tr>
<td>Findable</td>
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<tr>
<td>Accessible</td>
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<td>Interoperable</td>
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<td>Reusable</td>
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</table>
NACC Communication and Collaboration Hub

- Program Support
- Surveys
- NACC Directory
- Reports
- Newsletter
- Dynamic Website
NACC Communication and Collaboration Hub

ADRC Partners

Dynamic Website
Podcasts
Reports
Program Support
Newsletters
Directories
Surveys
UDSv4 Transition: Content Update

Updated UDS Content

CTF Status of the UDSv4 Forms Content (IVP)

<table>
<thead>
<tr>
<th>Approved by CTF</th>
<th>Under Review by CTF</th>
<th>Pending Content</th>
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</thead>
<tbody>
<tr>
<td>• Form B1</td>
<td>• Form A1a: SDOH</td>
<td>• Form A1: SCD</td>
</tr>
<tr>
<td>• Form B3: UPDRS</td>
<td>• Form A2: SCD</td>
<td>• Form A4</td>
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<tr>
<td>• Form B4 *</td>
<td>• Form A3</td>
<td>• Form C2</td>
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<tr>
<td>• Form B5 *</td>
<td>• Form A4a: AD-Specific Drugs</td>
<td>• Form Z1X</td>
</tr>
<tr>
<td>• Form B6 *</td>
<td>• Form A5/D2</td>
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<tr>
<td>• Form B7 *</td>
<td>• Form B9: MBI, SCD</td>
<td></td>
</tr>
<tr>
<td>• Form B8</td>
<td>• Form D1a: MBI</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Form D1b</td>
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</tbody>
</table>

* No changes from UDSv3

Virtual and in-person versions of each form are being developed

Learn more at the CTF Session!
Aligning with NIH's Data Science Strategy

How will we collect data from the ADRCs?
How will we integrate the new data streams?
How will we share the data with researchers?
How will we collect data from the ADRCs?
How Will We Collect Data From ADRCs?

Modern Electronic Data Submission Interface

ADRCs

Direct data entry into NACC REDCap

Synchronize local ADRC REDCap instances through REDCap APIs

Bulk upload of .csv files into NACC REDCap

We still have PDFs!
How Will We Collect Data From ADRCs?

Modern Electronic Data Submission Interface

We still have PDFs!

Forms can be used by researchers and clinicians anywhere in the world on any device
Electronic Data Capture Workgroup:

- Launched January 24th, 2022 in collaboration with the Data Core Steering Committee
- 75 people across 29 ADRCs that are collaborating across three subgroups
- 1,500+ people hours and counting
# Electronic Data Capture Workgroup Progress

## Development
- Streamlined and standardized the REDCap submission process, quality checks, and variable names
- Established the infrastructure for longitudinal data collection

## Requirements
- Determined the common UDS data flow used across 29 participating ADRCs: Survey to be sent to 37 all ADRCs
- Developed data management plan in alignment with NIH's data sharing policy: Valuable for ADRCs seeking renewal
- Summarized data quality checks for UDSv4: To be shared with all ADRCs

## Documentation and Training
- Built a curated directory of valuable REDCap resources
- Developed NACC-specific REDCap SOPs to facilitate ADRCs submitting UDSv4 data to NACC
- Designing a webpage to make resources accessible to the ADRCs
Electronic Data Capture Workgroup

Thank you EDC workgroup team 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:** Sarah Gothard, BS, Leah Reuter, BA, and Laura McLeod, BBA
• **Coordination:** Clair Cassidy

Scan QR code and fill out the form to join!

naccdata.org/edc
How will we integrate new data streams?
NACC is on a Mission to Modernize Data Collection, Integration, and Sharing to Advance Alzheimer’s Research
How Will We Integrate the Data?

Flywheel Will Integrate and Organize All ADRC Data Within our AWS Cloud and Provide Secure Sandboxes for Collaborative Data Analysis

Learn more from Ben Keller, PhD in the next talk!

NACC’s New Data Repository and Pipeline Solution: Benefits for the ADRC Program
Modern Integration of Data from ADRCs and Partners

- Investigators
- Data search & cohort selection
- Current data streams:
  - Longitudinal clinical data
  - Neuropathologic data
  - Legacy MRI/PET
- Future data streams:
  - Digital biomarker
  - Digital neuropathology
  - EHR/CMS
- ADRCs
- NIA

- NACC
- NACC IDs
- Data Front Door
- Data indexing, QA/QC, and integration
- AWS Cloud
- Reporting and real-time dashboards
- Metadata & analysis data
- NCRAD Biospecimen samples
- SCAN Standard MRI/PET
- ADGC & NIAGADs Genomic/genetic data

UNIVERSITY of WASHINGTON
UDS Data Impact

- **46,000+** Participants with data at NACC
  (16,000+ active participants)
- **172,000+** Clinical assessments
  (1-17 visits per participant; median =3)
- **7,230+** Neuropathology datasets
  (From 58% of deceased participants)
- **1,100+** Published studies using NACC data
- **37** ADRCs are contributing data
  (Across 26 states, +2 provisional ADRCs)

*State with NIA-Designated Center(s)*
*State with Exploratory Center*
Legacy MRI and PET Data

Data Cleaning and Labeling Station

QA/QC

MRI: DeCarli Lab
PET: Mormino Lab

MRI/PET images, metadata & analysis data

NACC IDs

Data Front Door
918 Amyloid PET Scans from Unique NACC participants Analyzed

Contributing sites:
- Cleveland ADRC
- Northwestern University ADRC
- Stanford University ARDC
- University of California Davis ADRC
- University of Florida ADRC
- University of Kansas ADRC
- University of Wisconsin ADRC

Will release curated images to LONI/NACC, extracted variables (SUVRs, CLs) to NACC

Primary Etiology

<table>
<thead>
<tr>
<th></th>
<th>AD</th>
<th>Lewy Bodies/PD</th>
<th>FTLD</th>
<th>Vascular</th>
<th>Neurologic/Genetic</th>
<th>Psychiatric</th>
<th>Toxic/Metabolic</th>
<th>NA, Not Impaired</th>
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<tbody>
<tr>
<td>Dementia</td>
<td>60</td>
<td>10</td>
<td>4</td>
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<td>1</td>
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<tr>
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<td>8</td>
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<td>8</td>
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<tr>
<td>Unimpaired</td>
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<td>25</td>
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<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>645</td>
</tr>
</tbody>
</table>

Email Beth Mormino, PhD to contribute data: bmormino@stanford.edu
Modern Integration of Data from ADRCs and Partners

Data search & cohort selection

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

Future data streams:
- Digital biomarker
- Digital neuropathology
- EHR/CMS

NACC

Data Front Door

NACC IDs

AWS Cloud

Data indexing, QA/QC, and integration

Metadata & analysis data

NCRAD
Biospecimen samples

SCAN
Standard MRI/PET

ADGC & NIAGADs
Genomic/genetic data

Reporting and real-time dashboards

Investigators

ADRCs

NIA
NACC is establishing a platform to collect and link clinical (EHR) and claims (CMS) data with genetic data (NIAGADS/ADSP) and phenotypic data (NACC) for consented ADRC participants.
Building a novel platform to expand longitudinal COVID-19 data collection, integrate new data streams, and open the door to impactful new COVID-19 and ADRD discoveries.

Kari Stephens, PhD, Sean Mooney, PhD and Melissa Lerch, PhD (NACC)
Administrative Supplement: Digital Data and Phenotyping

Collaborators: Rhoda Au, PhD and Allan Levey, MD, PhD
Progressing Towards a Digital UDS
Sean Mooney, PhD

Learn more in the NACC Session later today!
Digital Neuropathology Data
Modern Integration of Data from ADRCs and Partners

Data search & cohort selection

Data Front Door

NACC

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

Future data streams:
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Data indexing, QA/QC, and integration

Flywheel

Reporting and real-time dashboards

NCRAD
- Biospecimen samples

SCAN
- Standard MRI/PET

ADGC & NIAGADs
- Genomic/genetic data

Investigators

ADRCs

NIA

Metadata & analysis data
Metadata and Analysis Data from Partners

- **SCAN**
  - Standard MRI/PET

- **NCRAD**
  - Biospecimen samples

- **ADGC & NIAGADs**
  - Genomic/genetic data

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**Flywheel**

**NACC IDs**

**Data Front Door**

**NACC**
**SCAN Scope**

- Standardization of image acquisition protocols
- Infrastructure for curation and analysis
- Funding (via NIA) for image acquisition through short-term ADRC administrative supplements
- [https://scan.naccdata.org](https://scan.naccdata.org)

**ADRCs**
Data generation and submission

- Raw image files
- Curated files

**NACC**
Data collection, integration, and sharing

- Data returned to sites
- Summary & analysis data
  - MRI measurements (e.g. volume)
  - PET measurements (e.g. SUVR for amyloid and tau)

**LONI**
Image Storage

- Raw image files
- Curated files

**Investigators**

- NACC IDs

**SCAN**
QC and data analysis

- Investigators
- Site reporting
## SCAN Dashboard

### Alzheimer's Disease Research Centers

<table>
<thead>
<tr>
<th>Institution</th>
<th>SCAN Readiness</th>
<th>Current SCAN readiness status</th>
<th>MRI</th>
<th>PET</th>
<th>Review SCAN Submissions</th>
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<tbody>
<tr>
<td></td>
<td>Update</td>
<td>Completed Checklist</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>TOTAL</td>
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<td>1724</td>
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<tr>
<td></td>
<td>Update</td>
<td></td>
<td>1148</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

- **AN EXAMPLE ADC**
  - Update
  - Completed Checklist
  - 65 participants
  - 53 MRI participants
  - 53 MRI exams submitted
  - 433 MRI series submitted
  - 12 PET participants
  - 17 PET scans submitted

- **Arizona ADC**
  - Update
  - N/A
  - 113 participants
  - 28 MRI participants
  - 28 MRI exams submitted
  - 640 MRI series submitted
  - 106 PET participants
  - 212 PET scans submitted

- **Boston University**
  - Update
  - N/A
  - 42 participants
  - 42 MRI participants
  - 42 MRI exams submitted
  - 629 MRI series submitted
  - 0 PET participants
  - 0 PET scans submitted

- **Cleveland Clinic, Lerner COM - CWRU**
  - Update
  - Completed Checklist
  - 120 participants
  - 105 MRI participants
  - 105 MRI exams submitted
  - 212 MRI series submitted
  - 106 PET participants
  - 106 PET scans submitted

- **Cleveland Clinic, Las Vegas**
  - Update
  - N/A
  - 37 participants
  - 37 MRI participants
  - 37 MRI exams submitted
  - 411 MRI series submitted
  - 0 PET participants
  - 0 PET scans submitted

- **Columbia University**
  - Update
  - N/A
  - 62 participants
  - 62 MRI participants
  - 65 MRI exams submitted
  - 764 MRI series submitted
  - 0 PET participants
  - 0 PET scans submitted

- **Emory University**
  - Update
  - Completed Checklist
  - 17 participants
  - 17 MRI participants
  - 17 MRI exams submitted
  - 34 MRI series submitted
  - 0 PET participants
  - 0 PET scans submitted

- **Indiana University**
  - Update
  - N/A
  - 1 participant
  - 1 MRI participant
  - 1 MRI exams submitted
  - 5 MRI series submitted
  - 0 PET participants
  - 0 PET scans submitted

- **Johns Hopkins University**
  - Update
  - N/A
  - 22 participants
  - 22 MRI participants
  - 22 MRI exams submitted
  - 65 MRI series submitted
  - 0 PET participants
  - 0 PET scans submitted
Modern Integration of Data from ADRCs and Partners

 Investigators

 ADRCs

 NIA

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

 Future data streams:
 - Digital biomarker
 - Digital neuropathology
 - EHR/CMS

 Data search & cohort selection

 NACC

 NACC IDs

 Data Front Door

 AWS Cloud

 Data indexing, QA/QC, and integration

 Flywheel

 Reporting and real-time dashboards

 Metadata & analysis data

 NCRAD
 Biospecimen samples

 SCAN
 Standard MRI/PET

 ADGC & NIAGADs
 Genomic/genetic data
Progress on Integrating SCAN Data

Learn more in the NACC Session later today!

Amplifying SCAN
Sarah Biber, PhD
Returning blood-based biomarker assay values to the ADRCs

- Earlier this month: NACC distributed these values to the ADRCs for their participants (via REDCap)
NCRAD: Biospecimen Metadata and Analysis Data – Future Integration

ADRCs

Self-service access

Blood

Metadata & analysis data:
All biospecimen and blood-based biomarker assay data (longitudinal)

NCRAD
Biospecimen storage and inventory

Data Front Door

Flywheel

NACC IDs

Data search & cohort selection

Investigators
NIAGADS: Genetic and Genomic Metadata and Analysis Data

Blood

ADRCs
Self-service access

Metadata:
Genomic and genetic

NIAGADS
Genetic and genomic data storage and inventory

Data search & cohort selection

Data Front Door

NACC IDs

Investigators

Flywheel

NACC
How will we share the data with researchers?
We will make all ADRC data findable and accessible to researchers across the world through a one-stop-shop data search and access interface – the Data Front Door.

- Cohort-discovery enabled
- Easy to use
- Self-service
- Real-time
- Integrated
- MVP: Connecting Flywheel to Leaf
Data Front Door – How to get involved!

Requirements Pilot Project

• Collaboration between NACC, NCRAD, NIAGADS, and hopefully you!

Provide input!

• Focus group sessions will be held in January 2023
• We will be soliciting nominations from ADRC Directors
• You can all sign up to participate

bit.ly/DFDFocusGroup
Aligning with NIH's Data Science Strategy

Clinical Task Force
- Updated UDS Content
  - Digital advancements
  - Social determinants
  - Heterogeneity
  - Gender
  - Clinical practices

EDC Workgroup
- Streamlined Submission System

Flywheel
- Integrated Pipeline and Database

NIAGADS/NCRAD/ADRCs
- Expanded Search and Access Portal
  - NACC IDs
  - Data Front Door
How will we facilitate more inclusive ADRD research to advance our understanding of ADRD and health disparities?
New UDSv4 Tools to Support DEI and Disparities Research

Forms focused on the social determinants of health:

• Mandatory (Form A1)
  • Area Deprivation Index (Amy Kind)
  • SDOH – 11 Questions - income, access to healthcare, discrimination exposure

• Optional
  • SDOH – transportation access, financial security, social connections, access to healthcare

Expanding UDSv4 Access:

- Providing validated and harmonized multilingual cognitive assessments: **Spanish and Chinese**
- Tele-cognitive assessments
Developing and Distributing Best Practices for Responsible Management and Sharing of AI/AN Participant Data

Data Sovereignty Initiative:
- A collaboration led by the Indigenous ADRD Advisory Board

**Understand**
Understand Tribal sovereignty and laws, regulations, policies, and preferences

**Engage**
Engage early with Tribes when developing a data management and sharing plan, before research begins, and continue throughout research

**Establish**
Establish mutually beneficial partnerships

**Agree**
Agree who will manage data (e.g., Tribe, researcher, trusted 3rd party)

**Consider**
Consider additional protections, as necessary

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JORDAN P. LEWIS, PHD
Associate Director, Professor
Wisconsin ADRC

L.W. YOWELUNH MCLESTER-DAVIS
PhD Candidate
Wisconsin ADRC

CAREY GLEASON, PHD. MS
Associate Professor,
Wisconsin ADRC
# Supporting DEI-Related Initiatives Across the ADRC Program

## DEI-Focused ADRC Meeting

<table>
<thead>
<tr>
<th>Speaker/Interviewee Highlights</th>
<th>Talk Title</th>
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</thead>
<tbody>
<tr>
<td>Lisa Barnes, PhD&lt;br&gt;Rush University Alzheimer’s Disease Center</td>
<td>Social Determinants of Health and Health Equality</td>
</tr>
<tr>
<td>Margaret Pericak-Vance, PhD&lt;br&gt;John P. Hussman Institute for Human Genomics</td>
<td>Genetics of AD in Minoritized Populations</td>
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<tr>
<td>Michelle Mielke, PhD&lt;br&gt;Wake Forest University ADRC</td>
<td>Impact of Race and Ethnicity on AD Biomarkers</td>
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<tr>
<td>Monica Rivera Mindt, PhD&lt;br&gt;Fordham University</td>
<td>Race and Ethnic Differences in Clinical AD phenotype</td>
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<tr>
<td>Gina Green-Harris, MBA&lt;br&gt;Wisconsin ADRC</td>
<td>Building Strong, Bi-directional, and Sustainable Community Partnerships to Support Recruitment for AD trials</td>
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<tr>
<td>Amy Kind, MD, PhD&lt;br&gt;Wisconsin ADRC</td>
<td>The New Paradigm of Federal Equity Policy: Role of the ADI</td>
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<tr>
<td>Crystal Glover, PhD&lt;br&gt;Rush ADRC</td>
<td>The Diversification of Brain Tissue: Why and Ways Forward</td>
</tr>
<tr>
<td>Maria Carrillo, PhD&lt;br&gt;Alzheimer’s Association</td>
<td>A Personal Perspective: The Importance of Equal Access to Care and Intervention in AD</td>
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New Investigator Awards: Call for Applications!

Two awards will be given ($135k each):

Two tracks to choose from:

1. **Traditional award**: Open to proposals focused on any ADRD–related research topic

2. **New! DEI–focused award**: Open to proposals with a strong DEI or health disparities research focus within ADRD

Application deadline: January 17th, 2023

Find out more and apply: bit.ly/NI-awards
Facilitating More Inclusive ADRD Research to Advance Our Understanding of ADRD and Health Disparities

Expanding UDS Participant Diversity and Access

Building Tools for DEI and Disparities Research

Promoting Best Practices

Supporting DEI-Related Research

New Investigator Awards
Funding Opportunity
Impact on Scientific Discovery

Opens the door to asking and answering new questions in ADRD

- Access to integrated longitudinal standardized data streams for research and analysis

- Data available for developing, testing, and scaling algorithms

- Facilitating earlier disease detection and the development of more impactful therapeutics

- Understanding the impact of SDOH on ADRD

- More opportunities to build bridges with other NIH big data initiatives
<table>
<thead>
<tr>
<th>Category</th>
<th>Task</th>
<th>Q4 2022</th>
<th>Q1 2023</th>
<th>Q2 2023</th>
<th>Q3 2023</th>
<th>FUTURE</th>
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<tbody>
<tr>
<td>Flywheel</td>
<td>Existing NACC data (forms and legacy images) transferred to Flywheel</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Authorization system deployed leveraging NACC Directory</td>
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<tr>
<td></td>
<td>Sites will be able to see their own data</td>
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<td></td>
<td>COVID v2 data submission system active</td>
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<tr>
<td>UDSv4 Implementation</td>
<td>UDSv4 content finalized (Initial VP, Follow-up VP, Remote: TIP, TFP)</td>
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<tr>
<td></td>
<td>UDSv4 pilot at select centers</td>
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<tr>
<td></td>
<td>UDSv4 forms developed in REDCap</td>
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<tr>
<td>UDSv4 Training</td>
<td>UDSv4 coding guidebooks and videos</td>
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<tr>
<td></td>
<td>UDSv4 training: clinicians and data managers</td>
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<tr>
<td>UDSv4 Initiation</td>
<td>Centers start using and submitting UDSv4 (REDCap and PDF)</td>
<td></td>
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<td></td>
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<tr>
<td></td>
<td>Centers start using new participant registration process</td>
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<td></td>
</tr>
<tr>
<td></td>
<td>Stop date for UDSv3 submission</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Additional Data Integrations</td>
<td>SCAN metadata and analysis data integrated</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>NCRAD/NIAGADS metadata and analysis data pilots</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>EHR/CMS pilot data</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Digital Biomarker &amp; Digital Neuropathology</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DFD Prototype</td>
<td>Flywheel connected to Leaf (data queries and access)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Keeping You in the Loop!

UDSv4 Webpage

UDSv4 Webinars and Presentations
June 3, 2022 CTF/NACC UDSv4 Webinar
The June 3rd Webinar covered some of the new UDS content, provided an overview of the modern systems coming online at NACC, and how REDCap can facilitate capturing the UDS at ADRCs.

UDSv4 Update
June 3, 2022 Webinar - Hosted by NACC & the ADRC Clinical Task Force (CTF)

Agenda
- Overview of UDSv4
  - Allan Levey, MD of Emory University, Goizueta ADRC
- Neuropsychiatric Symptoms (NPS) & MRI
  - Kostas Sylvestros, MD of John’s Hopkins ADRC
- AD Specific Treatment Form
  - Suzanne Schindler, MD, PhD of Washington University, Knight ADRC
- Subjective Cognitive Decline
  - Andrew Saykin, PhD of Indiana ADRC
- Social Determinants of Health
  - Lisa Barnes, PhD of Rush ADRC and Megan Zuelderot, PhD of Wisconsin ADRC
- COVID-19 Forms
  - Carlos Cruchaga, PhD of Washington University, Knight ADRC
- UDSv4 - Next Steps
  - Sarah Ibanez, PhD and Laura McLeod of NACC

bit.ly/UDSv4Updates

UDSv4 Email Updates

Dear ADRC Colleague,

NACC and the CTF are making great progress towards completing the content for UDSv4.

We wanted to update you on some key areas of progress and highlight some new resources that we have built to keep you in the loop.

NACC and the CTF will be sharing updates on UDSv4 and the modern UDSv4-related infrastructure that we are developing at the Fall ADRC Meeting.

We hope you can join us there!

Register for 2022 Fall ADRC Meeting

bit.ly/nacc-stay-connected
### How Can You Get Involved?

<table>
<thead>
<tr>
<th><strong>• Join the Electronic Data Capture Workgroup</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>naccdata.org/edc</td>
</tr>
<tr>
<td><strong>• Sign up to participate in a DFD Focus Group</strong></td>
</tr>
<tr>
<td>bit.ly/DFDFocusGroup</td>
</tr>
<tr>
<td><strong>• Apply for the NI Award</strong></td>
</tr>
<tr>
<td>bit.ly/NI-awards</td>
</tr>
<tr>
<td><strong>• Learn more about NACC Data</strong></td>
</tr>
<tr>
<td>naccdata.org</td>
</tr>
<tr>
<td><strong>• Give feedback on Flywheel as you start to interact with it by emailing us</strong></td>
</tr>
<tr>
<td><a href="mailto:nacchelp@uw.edu">nacchelp@uw.edu</a></td>
</tr>
</tbody>
</table>
Connect with NACC

Sarah Biber, PhD, Program Director

Biber@uw.edu
Thank you!
Data Repository and Pipeline

Ben Keller, Ph.D.

20 October 2022 – Fall ADRC 2022
NACC is migrating to Flywheel as the data repository

This will make data submission, harmonization, dissemination scalable and more user friendly for ADRCs and ADRD researchers.
The Architecture We Are Building

Flywheel will integrate and organize all ADRC data

Data Front Door

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

Future data streams:
- Digital biomarker
- Digital neuropathology
- EHR/CMS

AWS Cloud

Data indexing, QA/QC, and integration

Reporting and real-time dashboards

Investigators

ADRCs

NIA

NACC

Flywheel

NCRAD
- Biospecimen samples

SCAN
- Standard MRI/PET

ADGC & NIAGADs
- Genomic/ genetic data
Why Flywheel?

Flywheel allows the integration of current and future data streams

- Flywheel used at ADRC institutions for imaging
- NACC 6-week pilot demonstrated our ability to use Flywheel for forms data
- File-based – going beyond forms and images
- Opens potential for sandboxed analysis
New Capabilities

• More consistent ways to submit data
• Easier to see, track and use your submitted data
• Scalable to new data types for ADRC collaborative proposals
• Streamlined access management
Future ADRC Data Pipeline

- **ADRCs**
  - Forms
  - Legacy images
  - Future data types

- **NACC**

- **Flywheel**
  - Ingest
    - Data Transfer
    - QC Validation
    - Transforms
  - Accepted
    - Data Transfer
    - Audits
    - Reports
  - Release
    - Freeze
    - Build & Export Views

- **Data Front Door**

- **Published data**

- **NACC IDs**
The Future of NACC Data Submission

- Actively building REDCap-based submission of forms
- Expect REDCap to REDCap, and submission portal
- Other data types (legacy images, digital data, clinical data/EHR) through Flywheel
- Form QC resources will be available to centers
The Future of NACC Access Management

- NACC will support single sign on with institutional credentials via InCommon (using CILogin or ORCID)
- Accounts and authorizations will be managed by integrating the REDCap-based NACC directory with Flywheel
## Roadmap

<table>
<thead>
<tr>
<th>Quarter</th>
<th>Objective</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q4 2022</td>
<td>Design and configure</td>
</tr>
<tr>
<td>Q1 2023</td>
<td>Build infrastructure</td>
</tr>
<tr>
<td>Q2 2022</td>
<td>Move-in</td>
</tr>
<tr>
<td>Q3 2023</td>
<td>Move-out*</td>
</tr>
<tr>
<td>Q4 2023</td>
<td>Enhance and extend</td>
</tr>
</tbody>
</table>

*Some tasks tied to end of UDSv3 submission*
NACC will be reaching out for input as new systems are implemented
Connect with NACC

Ben Keller – Tech Lead

bjkeller@uw.edu
Opportunity

Build a platform to facilitate uncovering the relationship between COVID-19 and ADRD

16% Increase in Alzheimer’s and Dementia Deaths During the COVID-19 Pandemic in the USA
NACC COVID-19 Supplement

• **Aim 1:** Support study design, recruitment and enrollment at three pilot sites and collect baseline data.

• **Aim 2:** Demonstrate integration of EHR and CMS data with phenotypic and previously collected genetic data.

• **Aim 3:** Facilitate computational analysis of genetic information with participant phenotypic and genetic data.
NACC COVID-19 Supplement

NACC is establishing a platform to collect and link clinical (EHR) and claims (CMS) data with genetic data (NIAGADS/ADSP) and phenotypic data (NACC) for consented ADRC participants.
Building a Roadmap for Expansion to All 37 ADRCs

Standard operating procedures are under development to facilitate governance and data linkage processes.

Why? Unique Value of NACC Data

- Includes cognitively normal, MCI, and dementia participants
- Rich longitudinal neurocognitive data from populations at high risk for the development of Long Covid - collected prior to infection
- 16,000+ active participants - one of the largest and most comprehensive longitudinal datasets in the world for an age group at high risk for COVID-19 infection
- Integrated with a multitude of valuable data streams for ADRC participants - including standardized MRI/PET imaging
- NACC has the infrastructure to track participants longitudinally
Why Expand to All ADRCs?

Builds on NIH/NIA’s investments:

• Build on NIA’s investments in NACC, NIAGADS, and the ADRC Program

• Promotes MedRIC platform (NIA funded partner)
  • Secure computer enclave for combining and analyzing the data collected through this new consortium model for the ADRC community

• If the pilot is expanded to the full ADRC Program, it will also complement other NIH-funded COVID studies such as RECOVER and N3C and create promising opportunities for collaboration.

• RECOVER
• ADSP (Collaborating with NIAGADS to improve integration of phenotypic and genetic data)
• Align with VA projects (Working with VA data)
• N3C
COVID Form Update
COVID Data Collection from the ADRC Program

COVID Technology Assessment
• Focus: Determining the best follow-up with participants during the pandemic:
• Released: June 2020
• Collected 2070 responses from 12 ADRCs

Original COVID Impact Survey Forms
• Focus: COVID testing, infections, and impact of pandemic from participant and co-participant
• Released: June 2020
• About 5000 COVID Impact Surveys v1 forms from 22 ADRCs
Recent Publication

• Manuscript from OHSU accepted
• Participants want to connect with ADRCs using a variety of methods irrespective of cognitive state
• Participants with dementia/MCI were less likely to use the internet

COVID Impact Survey

- COVID-positive participants have increased self-reported changes in memory compared to COVID-negative
- Data from 4500 participants in June data freeze
As the pandemic evolved, the COVID forms were adapted to capture:
- Vaccinations
- Outpatient treatments
- Hospitalizations

Forms provide a tool for capturing long COVID data

New! COVID Impact F2/F3 v2 forms released July 2022
- Currently being translated into Spanish

Data Submission system being developed in REDCap
Dynamic Response to the Pandemic

Required lots of effort from lots of folks – thank you!

- James Noble and Carlos Cruchaga designed the v2 Form
- ADRCs provided feedback through surveys
- CTF worked to approve the form for use
- Katya Rascovsky working on Spanish translation with CADLAS (US Consortium of Aging, Dementia and Latino Studies)
New COVID Impact v2 Forms are Ready

Two formats available on NACC website:

- Traditional Form (.pdf) with DED
- REDCap XML and DED (.csv) are available

REDCap forms offer advantages:

- Use in waiting rooms on iPads
- Send by email anytime
- Currently being developed into a dynamic auto-populated form for multiple use

Supplement Progress Update
Supplement Progress

Infrastructure for linking NACC phenotypic, clinical EHR, claims (CMS Medicare), and NIAGADS (genetic) data on a well-studied population with informed consent.

Creating Governance

- IRB modifications for COVID-19 and EHR data collection have been approved at all sites

- IRB modifications for CMS data collection in progress

- Consortia model has been developed and MedRIC agreements are being negotiated by NACC, MedRIC, and the sites
  - Will enable establishment of a secure enclave to access CMS data
Discussions are underway with NIAGADS for linking NACC phenotypic, clinical EHR, claims (CMS Medicare), and NIAGADS (genetic) data on a well-studied population with informed consent.
Supplement Progress

Infrastructure for linking NACC phenotypic, clinical EHR, claims (CMS Medicare), and NIAGADS (genetic) data on a well-studied population with informed consent.

Developing a Clinical (EHR) Workflow

- EHR specification and extraction processes are under development
- OMOP data model and alignment with other national data sharing efforts
Supplement Progress

Infrastructure for linking NACC phenotypic, clinical EHR, claims (CMS Medicare), and NIAGADS (genetic) data on a well-studied population with informed consent.

Developing a Clinical (CMS) Workflow

- Workflow being developed in anticipation of the MedRIC enclaves being implemented
  - MedRIC provides access to CMS claims data using a cloud-centric computing platform that NACC will manage on behalf of the ADRC Program

Medicare & Medicaid Resource Information Center (MedRIC)
Supplement Progress

Infrastructure for linking NACC phenotypic, clinical EHR, claims (CMS Medicare), and NIAGADS (genetic) data on a well-studied population with informed consent.

Pilot Study Development

NACC and three ADRCs to develop observational study to test data linkages

• Targeting group launch in September 2022

<table>
<thead>
<tr>
<th>Table 1. Projected Cohort Data</th>
<th>Controls</th>
<th>MCI</th>
<th>Dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td>Estimated total # of UDS participants from the three pilot sites (from July 2022 to July 31, 2024)</td>
<td>1,109</td>
<td>214</td>
<td>224</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Data Types and Projected # of Participants (From the Above Total UDS Participants)</th>
<th>Controls</th>
<th>MCI</th>
<th>Dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td>EHR</td>
<td>637</td>
<td>137</td>
<td>184</td>
</tr>
<tr>
<td>(57%)</td>
<td>(64%)</td>
<td></td>
<td>(82%)</td>
</tr>
<tr>
<td>Modified COVID-19 Form V2</td>
<td>1,066</td>
<td>202</td>
<td>215</td>
</tr>
<tr>
<td>(96%)</td>
<td>(94%)</td>
<td></td>
<td>(96%)</td>
</tr>
<tr>
<td>Genomic data from NIAGADS</td>
<td>1,090</td>
<td>208</td>
<td>216</td>
</tr>
<tr>
<td>(98%)</td>
<td>(97%)</td>
<td></td>
<td>(96%)</td>
</tr>
<tr>
<td>EHR + Modified COVID-19 Form V2 + Genomic data from NIAGADS</td>
<td>619</td>
<td>132</td>
<td>176</td>
</tr>
<tr>
<td>(56%)</td>
<td>(62%)</td>
<td></td>
<td>(79%)</td>
</tr>
</tbody>
</table>
• Identify genetic and other biomarkers associated with the risk of dementia and cognitive complaints after COVID-19 infection

• Quantify polygenic risk of poor outcomes in ADRD with and without history of COVID-19

• Investigate long term effects of COVID-19 on cognitive impairment

• Characterize the relationship between healthcare access and outcomes in COVID-19 and ADRD
Thank you!
SCAN Data collection, integration, and sharing

ADRCs
Data generation and submission

NACC
Data Front Door

Raw image files

Summary & analysis data
- MRI measurements (e.g. volume)
- PET measurements (e.g. SUVR for amyloid and tau)

Investigators

LONI
Image Storage

SCAN
QC and data analysis

Raw image files

Curated files

Scan Scope
- Standardization of image acquisition protocols
- Infrastructure for curation and analysis
- Funding (via NIA) for image acquisition through short-term ADRC administrative supplements
- https://scan.naccdata.org
# SCAN - How is it going?

## SCAN Submission Summary

<table>
<thead>
<tr>
<th>Participant #</th>
<th>SCAN Types</th>
</tr>
</thead>
<tbody>
<tr>
<td>1,402</td>
<td>MRI scan submitted</td>
</tr>
<tr>
<td>790</td>
<td>PET scan submitted</td>
</tr>
<tr>
<td>401</td>
<td>Both MRI and PET scan submitted</td>
</tr>
<tr>
<td></td>
<td>- 51% of PET participants have at least 1 MRI scan</td>
</tr>
</tbody>
</table>

51% of PET participants have at least 1 MRI scan.
PET - How is it going?

1,098 PET Scans Received from 15 ADRCs

<table>
<thead>
<tr>
<th>Scans Uploaded</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>PIB</td>
<td>236</td>
</tr>
<tr>
<td>Florbetapir</td>
<td>146</td>
</tr>
<tr>
<td>Florbetaben</td>
<td>185</td>
</tr>
<tr>
<td>NAV4694</td>
<td>97</td>
</tr>
<tr>
<td><strong>Total Amyloid</strong></td>
<td><strong>664 (69% ADNI protocol)</strong></td>
</tr>
<tr>
<td>Flortaucipir</td>
<td>134</td>
</tr>
<tr>
<td>MK6240</td>
<td>177</td>
</tr>
<tr>
<td>PI2620</td>
<td>84</td>
</tr>
<tr>
<td><strong>Total tau</strong></td>
<td><strong>395</strong></td>
</tr>
</tbody>
</table>

FDG (Fluorodeoxyglucose) 105
MRI - How is it going?

1,289 Exams Submitted from 27 ADRC

<table>
<thead>
<tr>
<th>Series Type</th>
<th># Received</th>
</tr>
</thead>
<tbody>
<tr>
<td>T1</td>
<td>1,378</td>
</tr>
<tr>
<td>FLAIR</td>
<td>1,220</td>
</tr>
<tr>
<td>T2</td>
<td>448</td>
</tr>
<tr>
<td>dTI</td>
<td>406</td>
</tr>
<tr>
<td>ASL</td>
<td>274</td>
</tr>
<tr>
<td>GRE or MEGRE</td>
<td>336</td>
</tr>
<tr>
<td><strong>Total Series Received</strong></td>
<td><strong>5,772</strong></td>
</tr>
</tbody>
</table>
Amplifying the SCAN initiative

Developed and deployed a SCAN Checklist

Purpose:
- Roadmap for getting SCAN ready
- Standard tool for assessing SCAN readiness
  - REDCap-based
  - Can be updated by sites in real-time

Impact:
- 100% of queried sites found the checklist helpful or thought it would have been helpful in getting SCAN ready

Next steps:
- Will survey all sites on SCAN readiness in early November 2022
Amplifying the SCAN initiative

20 Site Interviews Conducted (May - June 2022)

- **Goal:**
  - Discuss SCAN progress and identify roadblocks
  - Identify how to best support and amplify site participation in the SCAN initiative

- **How sites were selected for interviews:**
  - SCAN Co-I
  - Represented in the imaging steering committee
  - Received an admin supplement for SCAN participation

- **Interviewees:**
  - ADRC directors, imaging core leaders, admins

- **Outcomes:**
  - Identified common site challenges and barriers to participation
  - Informed the development of several tools and solutions to amplify the SCAN initiative
How is it going? PET

1,204 scans submitted as of October 2022

Data from graph in folder: here
How is it going? PET

1,204 scans submitted as of October 2022

Data from graph in folder: here
How is it going? MRI

Data from graph in folder: here

5,972 scans submitted as of October 2022

Cumulative number of MR scans submitted to SCAN

Time (by month since the initiation of SCAN)
How is it going? MRI

Data from graph in folder: [here](#)
SCAN Solutions Being Built in Collaboration with SCAN/LONI

• **Real-time SCAN Dashboards**
  - SCAN - Public Dashboard
  - SCAN - Site-Specific Dashboards with downloadable data submission records and QA/QC feedback

• **Streamlined and Harmonized SCAN Resources**

• **New Scalable NACC ID Assignment Process**

• **New SCAN Web Portal**

• **Optimizing MRI/PET search through the Data Front Door**
  - Metadata and analysis data
  - Cohort selection tools
SCAN: Public Dashboard

Real-time Public Dashboard – [view here](#)

- Tracks each ADRC's SCAN readiness and participation
- Self-service tool for sites to update their readiness and track their SCAN submissions
- Provides researchers with up-to-date information on the number of standard images that are available for analysis
SCAN: Public Dashboard

Real-time Public Dashboard

• Tracks each ADRC’s SCAN readiness and participation
• Self-service tool for sites to update their readiness and track their SCAN submissions
• Provides researchers with up-to-date information on the number of standard images that are available for analysis
SCAN: Site-Specific Dashboards

Features:

- Sites can track the QC status of their MRI submissions
- Record of all SCAN MRI data submitted to date – downloadable as a csv file

MRI Example
SCAN: Site-Specific Dashboards

Features:

• Sites can track the QC status of their PET submissions
• Record of all SCAN PET data submitted to date – downloadable as a csv file

PET Example

Site-Specific Dashboard > Western Iowa PET Data

Alert: PLEASE NOTE THAT THIS EXAMPLE DATA HAS BEEN FABRICATED AND DOES NOT REPRESENT ANY REAL ADRC, PARTICIPANT, OR DATA.

Review PET Data

<table>
<thead>
<tr>
<th>ADRC</th>
<th>NACC ID</th>
<th>PTID</th>
<th>Study Date and Time</th>
<th>Image UID</th>
<th>Scanner Model</th>
<th>PET radiotracer</th>
<th>QC Status</th>
<th>If failed, why?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Western Iowa</td>
<td>NACC462907</td>
<td>188</td>
<td>6/1/2022 00:00</td>
<td>101016420</td>
<td>Biograph Horizon</td>
<td>Florbetapir</td>
<td>Passed</td>
<td></td>
</tr>
<tr>
<td>Western Iowa</td>
<td>NACC114052</td>
<td>1189</td>
<td>4/1/2022 00:00</td>
<td>101015975</td>
<td>Biograph Horizon</td>
<td>Florbetapir</td>
<td>Passed</td>
<td></td>
</tr>
<tr>
<td>Western Iowa</td>
<td>NACC228673</td>
<td>728</td>
<td>6/3/2022 00:00</td>
<td>101015995</td>
<td>Biograph Horizon</td>
<td>PI稳定</td>
<td>Passed</td>
<td></td>
</tr>
<tr>
<td>Western Iowa</td>
<td>NACC228673</td>
<td>728</td>
<td>6/1/2022 00:00</td>
<td>101015996</td>
<td>Biograph Horizon</td>
<td>Florbetapir</td>
<td>Passed</td>
<td></td>
</tr>
<tr>
<td>Western Iowa</td>
<td>NACC42459</td>
<td>450</td>
<td>7/1/2021 00:00</td>
<td>100933850</td>
<td>Biograph Horizon</td>
<td>NAV4694</td>
<td>Passed</td>
<td></td>
</tr>
</tbody>
</table>
NACC is on a mission to modernize data collection, integration, and sharing to advance Alzheimer’s research
SCAN Dashboard Demo Station

Check out the demo!

Located in the Foyer at the Swissotel, Chicago

Thursday, Oct 20th
5:30-6:00pm CT
After the Data Core Session

Friday, Oct 21st
9:00-9:30am CT
During the Networking Break
How to Access the Data

Launch SCAN Public Dashboard
ADRCs and researchers can view summary data for full SCAN initiative and each ADRC

Q4 2022

Launch SCAN Site-Specific Dashboards: ADRCs will be able to access their own SCAN data at NACC
• ADRCs can access and download their own SCAN data at NACC (connected to NACC IDs)
• QC feedback, summary, and analysis data
• Raw image access: LONI data request

Q1 2023

SCAN data accessible to all investigators
• MVP: Summary and analysis data available via NACC data request (connected to NACC IDs)
• Raw image access: LONI data request

Q2 2023

Future: SCAN data searchable and accessible to all investigators through the Data Front Door
• Available to all investigators
• Includes analysis data
• Cohort selection tools available - multiple integrated data streams
• Raw image access: Automatic data requests submitted to LONI

Data Front Door
Stay Tuned for the SCAN Survey

- Coming this November!
- Update your SCAN readiness using the SCAN MRI and PET Checklist (REDCap-based)
- Roadmap for getting SCAN ready
- In the future, ADRCs will be able to access their SCAN readiness anytime
Thank You

SCAN MRI team
- Clifford Jack MD (PI)
- Chadwick Ward
- Bret Borowski
- Christopher Schwarz
- Denise Reyes
- Leonard Matoush
- Robert Reid
- Anne Effron
- Gregory Preboske MS
- Jeffrey Gunter PhD
- Matthew Senjem MS

SCAN PET team
- William Jagust MD (PI)
- Bob Koepppe PhD
- Susan Landau PhD
- JiaQie Lee
- Pablo Aguilar
- Tessa Harrison

Other SCAN Contributors
- Charles DeCarli, MD
- Suzanne Baker

LONI
- Arthur Toga PhD
- Karen Crawford MLIS

NACC Team
- Bud Kukull, PhD
- Sarah Biber PhD
- Ben Keller PhD
- Dean Shibata MD
- Jeevan Anandasakaran
- Brittany Hale
- Hannah Rosentreter

Bill Jagust and Clifford Jack will be available for questions during the Q+A at the end of the NACC session
2:45pm – 3:00pm CT
Connect with NACC

Sarah Biber, PhD

Biber@uw.edu
Moving Toward Routine Digital Data Collection

Sean Mooney, PhD
Thursday, October 20 – ADRC Fall 2022
Moving from Paper to Digital

There are substantial efforts to digitize existing paper-based or other administered assessments as phenotyping or diagnostic tools.
Moving from Paper to Digital

**Advantages:**
- Structured data elements
- Preservation of computable data
- No scanning – less likely to be lost in EMR or research EDC system
- Less waste
Digital Data and Phenotyping

Clinically Administered
- MOCA, Balance and Gait

Remotely Administered
- Remote Cognitive Assessments

Out of Clinic Collection
- Heart Rate, Mobility, Steps, Accidental Falls, Sleep, Consumer Testing, Home Monitoring
Axes of Digital Data

There are many questions around data that can be collected. These could include:

- Active vs Passive out of clinic data collection
- A test that is established UDS vs novel
- A test that is Validated vs Innovative
- In clinic vs active assessments outside of clinical in person visit

Collaboration with Rhoda Au and Allan Levey
Overview

Digital data collection covers a lot of concepts and is very heterogenous.

Many are collecting data and there are few, if any, standards or standardization.
Bringing Some Harmonization

At NACC, we feel that we should help standardize, harmonize, ensure efficacy, and collect established instruments.

... And ...

Facilitate discovery using new technologies that have research value that are very likely to be unharmonized.
Significant Opportunity to Digitally Collect Established Tools

Established assessments can be implemented for in clinic and remote administration digitally and include:

- MOCA
- Image recall tests
- Digital clock drawing test
- Category naming tests
- Candy theft picture description
- TabCAT
- DANA
- VisMET
Digital Tools Enable AI-Based Decision Support

Human interpretation takes time, is variable, and could potentially be replaced by supervised machine learning algorithms.
Out of clinic administered tests or digital health tools are far less standardized but are important for research.

There are needs:
• Access to participants and good phenotypes
• Sandboxes for data collection and analysis
• Unbiased assessments for data
GOAL: Establish a common platform and develop processes for ADRCs to collect and share digital biomarker data

Aim 1: Demonstrate intake of existing pipeline with Boston University
- Send existing data for five tasks that are in Linus to NACC, connected to NACC IDs

Aim 2: Analyze the integrated clinical and digital data in the NACC cloud

Aim 3: Establish the collection of prospective digital data from 2 ADRCs who will pilot the same digital tasks
# Digital Data and Phenotyping

<table>
<thead>
<tr>
<th>UDS Tests</th>
<th>Non-UDS Tests</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Digital clock drawing test</strong></td>
<td><strong>Candy theft picture description</strong></td>
</tr>
<tr>
<td>• Administered via Linus tablets</td>
<td>• Capturing digital voice recordings</td>
</tr>
<tr>
<td><strong>Category naming tests</strong></td>
<td><strong>TabCAT</strong></td>
</tr>
<tr>
<td>• Digital recall/memory test</td>
<td>• Cognitive, memory, language, and motor skills and visuospatial tests</td>
</tr>
<tr>
<td></td>
<td><strong>VisMET</strong></td>
</tr>
<tr>
<td></td>
<td>• Visuospatial memory assessment with eye tracking</td>
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</tbody>
</table>
Open Science on Digital Data

Data Science ‘Community Challenges’ are a popular way to do science

They pose questions that data scientists can answer and the answers are only known by the organizers

These challenges have facilitated unbiased improvement in machine learning in many fields

My group (Mooney) has been leading, participating, and advising these challenges for decades
Open Science on Digital Data

Collection of digital data opens the possibility of doing new approaches to facilitate open science

DREAM Challenges and Kaggle, have platforms for building and evaluating machine learning

We are strategizing a potential challenge around data on the most technical forefront of potential markers of disease or treatment response such as Digital Recordings of clinics
Connect with NACC

Stay Tuned!
Digital Footprint Survey for feedback from ADRC digital capability
We are also developing a digital roadmap and will, with Rhoda Au's team, be looking to collaborate with ADRCs!

Sean Mooney, PhD and Sarah Biber, PhD
sdmooney@uw.edu | biber@uw.edu
Thank you!
The New NACC Directory

Laura McLeod

October 21, 2022 at 2:40 pm | NACC Session
Overview

Purpose:
- To provide resource with contact information about ADRCs, NACC, and NACC Strategic AD/ADRD partners

Previously:
- Called the ADRC Personnel Directory
- Limited to only ADRC information and was a static document
The new NACC directory is:

- Comprehensive, spanning across ADRD organizations
- Online
- Interactive
- Dynamic
Content Timeline

1. ADRC Leadership and Committee information
2. Individuals update their information
   - Confirmed/approved information is published
3. Monthly reporting/freeze process
4. Portal/FlyWheel access management
5. Listserv management
Advantages

✓ Information is always up to date
✓ Ability for members to update information themselves
✓ Search interface to find content you need
✓ Allows members to find and connect with others
✓ Easier for researchers across the world to identify potential collaborators from across the ADRC program
Key Components

Content Management:
• Members update their own information
• Administrators update Center information
• NACC updates Committee information

Authentication system

Published content:
• Private (with email addresses)
• Public (without email addresses)
Search the Directory now!

Go to bit.ly/NACCDirectory or scan this QR code!
This directory provides information about ADRC, NACC and NACC Strategic AD/ADRD partners.

General ADRC Information
(address, website, grant #s, etc)
ADRC Contact Information

ADRC Leadership Information
ADRC Administrators
ADRC Core Leaders
ADRC Directors

Committee/WorkGroup information
ADRC Committees
Electronic Data Capture Workgroup
NACC Committees
Share your feedback!

Information table

Thursday, Oct. 20th
• 3:10 – 3:30 p.m. (During Networking Break)
• 5:30 – 6:00 p.m. (During Administrators Gathering)

Friday, Oct. 21st
• 9:00 – 9:30 a.m. (During Networking Break)
• 1:00 – 1:45 p.m. (Second half of Lunch Break)
<table>
<thead>
<tr>
<th></th>
<th>Timeline</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>ADRC Leadership and Committee information <em>(public version)</em></td>
</tr>
</tbody>
</table>
| 2 | Individuals update their information  
- Confirmed/approved information is published |
| 3 | Monthly reporting/freeze process |
| 4 | Portal/FlyWheel access management |
| 5 | Listserv management |

Ongoing: Automated Reminders to members/Center Administrators to review/update information on a bi-annual basis
Thank you to Center Administrators + NACC!

- Andrea Schmitt (Arizona ADRC)
- Beverly Young (Boston University ADRC)
- Anna Sturtevant & Darcy Loviscek (Cleveland ADRC)
- Allison Heaps (Columbia University ADRC)
- Sara Patillo (Duke/UNC ADRC)
- Cecelia Manzanares (Emory University, Goizueta ADRC)
- Christy Steinway-Rodkin (1Florida ADRC)
- Sarah Van Heiden (Indiana University ADRC)
- Jamie Lester (Johns Hopkins ADRC)
- Catherine Ribeiro (Massachusetts ADRC)
- Josie Williams (Mayo Clinic ADRC)
- Allison Ardlolino (Mount Sinai School of Medicine ADRC)
- Freley Hosannah & Kirsten Calvin (Nevada Exploratory ADRC)
- Jill Prestopnik (New Mexico Exploratory ADRC)

- Eskedar Alem (Northwestern ADRC)
- Karyn Marsh (NYU ADRC)
- Heather Schiffke (Oregon Health and Science University, ADRC)
- Kathy Jedrziewski (Penn ADRC/Penn Memory Center)
- Annie Barz (Rush University Alzheimer’s Disease Center)
- Eric Shipp (South Texas ADRC)
- Nusha Askari (Stanford ADRC)
- Carol Chambless (UAB Exploratory ADRC)
- Delia Roberts (UC Davis ADRC)
- Andrea Wasserman (UC Irvine, ADRC)
- Emily Little (UCSD Shiley-Marcos ADRC)
- Rosalie Gearhart & Harli Grant (UCSF ADRC)
- Anne Arthur (University of Kansas ADRC)
- Beverly Baesler (University of Kentucky ADRC)

- Arijit Bhaumik & Nancy Laracey (University of Michigan ADRC)
- Leslie Dunn & Kathie Savage (University of Pittsburgh ADRC)
- Annika Noreen (University of Washington ADRC)
- Helena Chui (USC ADRC)
- Jenna Boué (Vanderbilt Exploratory ADRC)
- Sharon Letchworth & Hari Vittal Rao (Wake Forest University, ADRC)
- Krista Moulder (Washington University Knight ADRC)
- Hanna Blazel (Wisconsin ADRC)
- Charlene Bloch (Yale University ADRC)

**NACC**
Amy Young, Hannah Rosentreter
Brendan Smith, Janene Hubbard
Ben Keller, Clair Cassidy