Welcome
NACC is on a mission to modernize data collection, integration, and sharing to advance Alzheimer’s research.
Aligning with NIH's Data Science Strategy

**Clinical Task Force**
- Updated UDS Content

**EDC Workgroup**
- Streamlined Submission System

**Flywheel**
- Integrated Pipeline and Database

**NIAGADS/NCRAD/ADRCs**
- Expanded Search and Access Portal

**Modernization**

Digital advancements
- Social determinants
- Heterogeneity
- Gender

Clinical practices
UDSv4 – New Submission System

- Existing systems 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
How will we collect data from ADRCs?

Modern Electronic Data Submission Interface

- 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

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!

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

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<thead>
<tr>
<th>Requirements</th>
<th>Development</th>
<th>Documentation and Training</th>
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<td><img src="image1.png" alt="Checklist" /></td>
<td><img src="image2.png" alt="Document" /></td>
<td><img src="image3.png" alt="Speech Bubbles" /></td>
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</table>
## 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
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

Thank you EDC workgroup team members!
Electronic Data Capture Overview

About the Electronic Data Capture Workgroup

NACC is currently collaborating with the ADRCs to develop an electronic data capture systems for UDSv4 that will effectively serve the needs of the ADRC program.

The Electronic Data Capture (EDC) Workgroup was launched by NACC in collaboration with the Data Core Steering Committee in January 2022.

The EDC Workgroup is currently comprised of approximately 75 members from across approximately 28 ADRCs who are collaborating across three subgroups to co-develop REDCap forms, define requirements, and to develop training and education materials for UDSv4.

Interested in getting involved?

JOIN HERE
EDC Workgroup Social Members, please remember join your colleagues at this evening’s social!

**When:** Tonight from 7:30 – 9:00pm CT

**Where:** Swissôtel – Matterhorn Room, 42nd Floor
<table>
<thead>
<tr>
<th>Time</th>
<th>Event Description</th>
<th>Presenter</th>
<th>Institution</th>
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| 5:00pm - 5:10pm (CT) | **UPDATE FROM THE EDC WORKING GROUP** 10min | Welcome and Overview of EDC workgroup | Sarah Biber, PhD  
NACC               |
| 5:10pm - 5:25pm (CT) | **UPDATE FROM THE EDC WORKING GROUP** 15min | Development Update | Deborah Zemlock, BS  
Northwestern ADRC     |
| 5:25pm - 5:40pm (CT) | **UPDATE FROM THE EDC WORKING GROUP** 15min | Requirements Update | Chad Murchison, PhD  
UAB Exploratory ADRC  |
| 5:40pm - 5:55pm (CT) | **UPDATE FROM THE EDC WORKING GROUP** 15min | Documentation and Training Update | Sarah Gothard, BS  
Oregon Health and Science University, ADRC |
| 5:55pm - 6:00pm (CT) | **UPDATE FROM THE EDC WORKING GROUP** 5min | EDC Workgroup Q&A  | Laura McLeod, BBA  
NACC                  |
Connect with NACC

Sarah Biber, PhD

Biber@uw.edu
Thank You
UDSv4 EDC Update: Development Subgroup

Presented by: Deborah Zemlock – Northwestern University

October 19, 2022 | Data Core Workshop EDC Workgroup Session
Sub-Team Members

• Co-Leads:
  • Jonathan Reader (University of Michigan)
  • Ben Keller (NACC)

• 29 team members representing 17 ADRCs and NACC
Purpose of the USDv4 Development Subgroup

This sub-team will design, build and test EDC technologies. Specifically, contributing to development of UDSv4 projects in REDCap; providing technical review for NACC API designs and implementation; and contributing to development of related tools needed by sites. The scope of this work includes quality validation.
Accomplishments to Date

Developed and standardized the database architecture for longitudinal data collection – to streamline the submission process, extraction, and analysis.

Developed UDSv4 forms in REDCap utilizing REDCap features for better data entry and extraction.
USDv4 REDCap Project

- Fully functional REDCap UDSv4 Database.
- ADRCs will be able to download the REDCap project (XML) from the NACC website and begin entering data without any additional programming.
- For centers that are planning on using database software other than REDCap, the NACC UDSv4 REDCap data dictionary will be available on the NACC website in CSV format.
The Benefits of REDCap (Part 1)

• Highly customizable.
  • Centers can make changes to the NACC built project to customize it to individual center needs.

• Web-based, secure, and can be made compliant with standards like HIPAA and Part 11

• Data import functions
  • Data may be imported from external data sources to begin a study or to provide mid-study data uploads.
The Benefits of REDCap (Part 2)

• Export data to Microsoft Excel, SAS, STATA, R, or SPSS for analysis.

• REDCap API (Application Programming Interface)
  • Provides communication and data interaction with outside applications, allowing for the creation of scripted, reproducible reporting structures and data analysis.

• Data Quality
  • Advanced question features like auto-validation, branching logic and required fields to ensure accurate data entry.
UDSv4 REDCap Database Architecture

• Each participant has a unique record and Center ID.
• Each record has a dashboard reporting high level information about the longitudinal progress of the participant throughout the study and completion within each visit.
• The participant dashboard can be used to enter data, review data or modify past data.
### Participant Dashboard

#### ADC subject ID 0000002345

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## Participant Dashboard

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**NACC**

**UDSv4 REDCap Database Architecture**
Subject ID

The participant completed three visits from 2020 to 2022
The participant completed three visits from 2020 to 2022.

All NACC forms are available each visit.

Subject ID

Participant Dashboard

UDSv4 REDCap Database Architecture
Participant Dashboard

This example center administers the UDS and FTLD modules.
Participant Dashboard

This example center administers the UDS and FTLD modules.

The participant enrolled in the FTLD module at their second visit.

ADC subject ID 0000002345

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Repeating Instruments

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**Participant Dashboard**

The color of the circle represents completion.
- Grey = Not administered
- Green = Complete
- Red = Administered but data not fully entered

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</table>
Apart from visit data there is participant-level persistent data that does not change or data may need to be updated outside of regular visits.
## Participant Dashboard

Static participant information can include different study or center IDs, email address to send surveys, etc.

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1. M1, 10-11-2020
2. M2, 10-11-2021
Participant Dashboard

Static participant information can include different study or center IDs, email address to send surveys, etc.

The Milestone form can be filled out multiple times either at the time of the visit or outside a regular visit.
Participant Dashboard

Static participant information can include different study or center IDs, email address to send surveys, etc.

The Milestone form can be filled out multiple times either at the time of the visit or outside a regular visit.

Two milestone forms have been completed:

1. M1, 10-11-2020
2. M2, 10-11-2021
### Participant Dashboard

**ADC subject ID 0000002345**

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### Repeating Instruments

**Milestone Form**

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Add new: ![Image](image37.png)
UDSv4 REDCap Form Features

• Branching logic to hide questions within a form that are not applicable.
• Piping data from one visit to the next for information that will not change or information that is unlikely to change
• Calculated fields to automatically aggregate entered data when applicable or used for validation
• Enforce data types e.g. require integer values or date formats
• Limit data entry to pre-specified options rather than free text
Branching Logic

The race and ethnicity questions may trigger additional questions to show through branching logic.

Date field requires MM-DD-YYYY format.
### NACC Uniform Data Set (UDS)

**Form A1: Subject Demographics**

<table>
<thead>
<tr>
<th>Field</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Subject ID</td>
<td>00000023MS</td>
</tr>
<tr>
<td>NACC Uniform Data Set</td>
<td>(UDS)</td>
</tr>
<tr>
<td>Form A1: Subject</td>
<td>Demographics</td>
</tr>
</tbody>
</table>

#### Instructions

This form is to be completed by intake interviewer based on ADC scheduling records, subject interview, medical records, and proxy co-participant report (as needed). For additional clarification and examples, see UDS Coding dictionary for Initial Visit Packet, Form A1. Check only one box per question.

**Primary reason for coming to ADC:**

- [x] [ ]

**Presumed disease status at enrollment:**

- [ ] [ ]

**Subject's month of Birth:**

- [ ] [ ]

**Subject's year of Birth:**

- [ ] [ ]

**Subject's sex:**

- [ ] [ ]

**Does the subject report being of Hispanic/Latino ethnicity (i.e., having origins from a mainly Spanish-speaking Latin American country), regardless of race?**

- [ ] [ ]

**What does subject report as his or her race?**

- [ ] [ ]

---

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---

**Branching Logic**

---

**UDSv4 REDCap Form Features**

---

**UNIVERSITY of WASHINGTON**
Branching Logic

<table>
<thead>
<tr>
<th>ADC subject ID</th>
<th>NACC Uniform Data Set (UDS)</th>
</tr>
</thead>
</table>

**Form A1: Subject Demographics**

- **Form Date**: 10-19-2022
- **Examiner's initials**: DYZ

**INSTRUCTIONS**: This form is to be completed by intake interviewer based on ADC scheduling records, subject interview, medical records, and proxy co-participant report (as needed). For additional clarification and examples, see UDS Coding Guidebook for initial Visit Packet. Form A1. Check only one box per question.

**Primary reason for coming to ADC:**
- [ ] To participate in a research study
- [ ] To have a clinical evaluation
- [ ] Both (to participate in a research study and to have a clinical evaluation)
- [ ] Unknown

**Subject's month of Birth:**

**Subject's year of Birth:**

**Subject’s sex:**
- [ ] male
- [ ] female

Does the subject report being of Hispanic/Latino ethnicity (i.e., having origins from a mainly Spanish-speaking Latin American country), regardless of race?
- [ ] Yes
- [ ] No

**What does subject report as his or her race?**
- [ ] Other

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www.UDS.washington.edu

UDS Version 3.3, March 2015
### Branching Logic

**ADC subject ID:** 0030002345

**NACC Uniform Data Set (UDS)**

**Form A1: Subject Demographics**

<table>
<thead>
<tr>
<th>Form Date</th>
<th>10-19-2022</th>
<th>Today</th>
</tr>
</thead>
</table>

**Examiner’s initials:** DYZ

**INSTRUCTIONS:** This form is to be completed by intake interviewer based on ADC scheduling records, subject interview, medical records, and proxy co-participant report (if needed). For additional clarification and examples, see UDS Coding Guidebook for Initial Visit Packet, Form A1. Check only one box per question.

**Primary reason for coming to ADC:**

- [ ] To participate in a research study

**Presumed disease status at enrollment:**

- [ ] Case, patient, or proband
- [ ] Control (normal)
- [ ] No presumed disease status

**Subject’s year of Birth:**

**Subject’s sex:**

- [ ] Male
- [ ] Female

**Does the subject report being of Hispanic/Latina ethnicity (i.e., having origins from a mainly Spanish-speaking Latin American country), regardless of race?**

- [ ] Yes
- [ ] No

**What does subject report as his or her race?**

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Branching Logic
### Branching Logic

**Subject's month of Birth:**

<table>
<thead>
<tr>
<th>Month</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>1923</td>
</tr>
<tr>
<td>2</td>
<td>1924</td>
</tr>
<tr>
<td>3</td>
<td>1925</td>
</tr>
<tr>
<td>4</td>
<td>1926</td>
</tr>
<tr>
<td>5</td>
<td>1927</td>
</tr>
<tr>
<td>6</td>
<td>1928</td>
</tr>
<tr>
<td>7</td>
<td>1929</td>
</tr>
<tr>
<td>8</td>
<td>1930</td>
</tr>
<tr>
<td>9</td>
<td>1931</td>
</tr>
</tbody>
</table>

**Subject's year of Birth:**

<table>
<thead>
<tr>
<th>Year</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>1923</td>
<td></td>
</tr>
<tr>
<td>1924</td>
<td></td>
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<td>1925</td>
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<tr>
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<td>1929</td>
<td></td>
</tr>
<tr>
<td>1930</td>
<td></td>
</tr>
<tr>
<td>1931</td>
<td></td>
</tr>
</tbody>
</table>

**Subject’s sex:**

<table>
<thead>
<tr>
<th>Sex</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td></td>
</tr>
</tbody>
</table>

**Does the subject report being of Hispanic/Latino ethnicity (a U.S. American country), regardless of race?**

<table>
<thead>
<tr>
<th>Yes</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td></td>
</tr>
</tbody>
</table>

**What does subject report as his or her race?**

<table>
<thead>
<tr>
<th>Race</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td></td>
</tr>
<tr>
<td>Black</td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td></td>
</tr>
<tr>
<td>Native American</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
</tr>
</tbody>
</table>

---

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UDSv4 REDCap Form Features
Branching Logic
### NACC Uniform Data Set (UDS)

**Form A: Subject Demographics**

<table>
<thead>
<tr>
<th>Field</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADC subject ID</td>
<td>0030002345</td>
</tr>
<tr>
<td>NACC Uniform Data Set (UDS)</td>
<td></td>
</tr>
<tr>
<td>Form A: Subject Demographics</td>
<td></td>
</tr>
<tr>
<td><strong>Form Date</strong></td>
<td>10-19-2022</td>
</tr>
<tr>
<td><strong>Examiner's initials</strong></td>
<td>DVZ</td>
</tr>
</tbody>
</table>

**INSTRUCTIONS:** This form is to be completed by (name interviewer based on ADC scheduling records, subject interview, medical records, and proxy co-participant report (if needed). For additional clarification and examples, see UDS Coding Guidebook for Initial Visit Packet, Form A. Check only one box per question.

**Primary reason for coming to ADC:**
- To participate in a research study

**Presumed disease status at enrollment:**
- Control or normal

**Subject’s month of Birth:**
- 5

**Subject’s year of Birth:**
- 1930

**Subject’s sex:**
- Male

**Does the subject report being of Hispanic/Latino ethnicity (i.e., having origins from a mainly Spanish-speaking Latin American country, regardless of race)?**
- Yes

**If yes, what are the subject’s reported origins?**
- (If applicable)

**What does subject report as his or her race?**
- (If applicable)

---

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Branching Logic
A1 Form for current visit

<table>
<thead>
<tr>
<th>Data Collection Instrument</th>
<th>Visit Data</th>
<th>Visit Data</th>
<th>Visit Data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Static Participant Information</td>
<td>Static Data</td>
<td>#1</td>
<td>#1</td>
</tr>
<tr>
<td>UDS Visit Header</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>UDS Example Form 1, Telephone Only</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>UDS Example Form 2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>UDS Example Form 3, Initial Only</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>UDS Example Form 4, In-person Only</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>UDS Example Form 5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>UDS Example Form 6</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FTLD Module Visit Header</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FTLD Example Form 1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FTLD Example Form 2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FTLD Example Form 3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Milestone Form</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CLS Linguistic History Form</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Piped Data from one visit to another
Piped Data from one visit to another

The data is piped from the initial visit and is un-editable in the current follow up visit.
**Calculated Fields**

<table>
<thead>
<tr>
<th>Field</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADC subject ID</td>
<td>0000002345</td>
</tr>
</tbody>
</table>

**NACC Uniform Data Set (UDS)**

**Form C1F: Neuropsychological Battery Summary Scores**

**Form Date**
- 10-02-2022

**Examiner’s Initials**
- DYZ

**INSTRUCTIONS:** This form is to be completed by ADC or clinic staff. For test administration and scoring, see FTLD Module Coding Guidebook for Initial Visit Baseline, Form C1F. Time to completion of C1F and C2F tests should be reported at the end of Form C1F.

**KEY:** If the subject cannot complete any of the following exams, please give the reason by entering one of the following codes:
- 95 = Physical problem
- 96 = Cognitive/behavior problem
- 97 = Other problem
- 98 = Verbal refusal

**Semantic Associates Test**
- 3a. Total correct animal associations
  - 1
- 3b. Total correct tool associations
  - 4
- 3c. Sum of all correct associations (Semantic Associates Test total score)
  - 5

**Northwestern Anagram Test - Short Form**
- 4a. Correct subject who-questions
  - 1
- 4b. Correct object who-questions
  - 2
- 4c. Total score: sum of all correct questions
  - 3

**Calculated sum of correct animals and correct tools**

**Calculated sum of correct subject and object questions**
Thank you to our Team!

- Barnes, Christopher
- Brown, Steven
- Chase, Philip
- Dixon, Diane
- Emerson, Samantha
- Fischer, Eric
- Foster, Helen
- Gaussoin, Sarah
- Gothard, Sarah
- Hepler, John
- HewaNadungodage, Chandima
- Hoang, Dan
- Hunt, Suzanne
- Jones, Rodney
- Keller, Ben
- Manzanares, CeeCee
- McLeod, Laura
- Moreno, Melissa
- Murchison, Chad
- Rajeevan, Haseena
- Reader, Jon
- Sanns, Bill
- Shan
- Spalitta, Alice
- Vedvyas, Alok
- Vedvyas, Gaurav
- Williams, Marilyn
- Wilson, Ashley
- Zemlock, Deborah
We’d Love to Have you on the Team!

• If you’re interested in helping the EDC Workgroup go to:
  https://nacc.redcap.rit.uw.edu/surveys
  and enter the code – WH4JLAPWN

• You can also use QR Code
Thank you!

Your feedback is valuable!
Please be sure to complete your site’s survey
Questions
UDSv4 EDC Update: Requirements Workgroup

Chad Murchison, PhD – The University of Alabama at Birmingham

10/19/2022 – Data Core Workshop EDC Workgroup Session
Who We Are and What We Do
# Members of the Workgroup

## Co-Leads

<table>
<thead>
<tr>
<th>Co-Leads</th>
<th>Institution/Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kari Stephens</td>
<td>NACC</td>
</tr>
<tr>
<td>Meredith Zozus</td>
<td>South Texas STAC</td>
</tr>
</tbody>
</table>

## Contributors

<table>
<thead>
<tr>
<th>Contributors</th>
<th>Institution/Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jimmy Akrivos</td>
<td>Mt Sinai</td>
</tr>
<tr>
<td>Justin Barber</td>
<td>University of Kentucky</td>
</tr>
<tr>
<td>Chris Barnes</td>
<td>1Florida</td>
</tr>
<tr>
<td>Ari Bhaumik</td>
<td>University of Michigan</td>
</tr>
<tr>
<td>Kei Cheung</td>
<td>Yale</td>
</tr>
<tr>
<td>Sudeehna Das</td>
<td>Mass General</td>
</tr>
<tr>
<td>Boris Decourt</td>
<td>Nevada Cleveland Clinic</td>
</tr>
<tr>
<td>Sarah Farias</td>
<td>UC Davis</td>
</tr>
<tr>
<td>Sara Farmer</td>
<td>Mayo Clinic</td>
</tr>
<tr>
<td>Sarah Gaussoin</td>
<td>Wake Forest</td>
</tr>
<tr>
<td>Kathryn Gauthreaux</td>
<td>NACC</td>
</tr>
<tr>
<td>Clair Cassidy</td>
<td>NACC</td>
</tr>
<tr>
<td>Ben Keller</td>
<td>NACC</td>
</tr>
<tr>
<td>Tung Le</td>
<td>Washington University</td>
</tr>
<tr>
<td>Lingy Lu</td>
<td>Wake Forest</td>
</tr>
<tr>
<td>Sarah Gothard</td>
<td>OHSU</td>
</tr>
<tr>
<td>Kim Pechman</td>
<td>Vanderbilt</td>
</tr>
<tr>
<td>Leah Reuter</td>
<td>Wisconsin-Madison</td>
</tr>
<tr>
<td>Bill Sanns</td>
<td>South Texas STAC</td>
</tr>
<tr>
<td>Chad Murchison</td>
<td>U Alabama at Birmingham</td>
</tr>
<tr>
<td>Timothy Shannon</td>
<td>University of Kentucky</td>
</tr>
<tr>
<td>Niranjan Shashikumar</td>
<td>Vanderbilt</td>
</tr>
<tr>
<td>Robin Stillwell</td>
<td>University of Washington</td>
</tr>
<tr>
<td>Sudha Seshadri</td>
<td>South Texas STAC</td>
</tr>
<tr>
<td>Ashley Wilson</td>
<td>University of Kentucky</td>
</tr>
<tr>
<td>Carolyn Zhu</td>
<td>Mt Sinai</td>
</tr>
</tbody>
</table>
Purpose

Identify and recommend best practices for electronic / REDCap data capture to standardize methods of data collection, quality assurance, and data transformation from ADRC's to NACC
Goals of the Workgroup

1. Open up the “black box” of UDS and NACC data

2. Promote harmonization of NACC-ADRC data engagement
Our Primary Objectives

• Increase transparency of the NACC data process
• Formalize guiding principles of data management for ADRC’s
• Remain agnostic to method of data capture
• Identify minimum REDCap requirements for sufficient electronic capture needed for deployment at an ADRC
Accomplishments to Date

1. The UDS Data Flow Diagram

2. Stock Data Sharing Management Plan for NIH submission
Visualizing the Flow of UDS Data
UDS Data Flow Diagram

- Encompasses the full data capture lifecycle for UDS within a site
  - From participant enrollment to NACC upload
- Acknowledges non-EDC and non-REDCap data capture
- Explicitly details the QA/QC process during upload
- Currently piloting expansions e.g. onboarding EDC for an ADRC
Encompass the Entire Data Capture System Lifecycle

PRE-VISIT DATA COLLECTION
VISIT AND DATA COLLECTION (ANY TYPE IV/IV/TV)
SITE SPECIFIC PREP e.g. CONSENSUS Dx ON D1
DATA UPLOAD TO NACC SITE
Accommodate Data Capture Alternatives

**Pre-Visit Data Collection**
- Initial visit
- Patient specific data (e.g., NIA GUID, collateral identification)
- Subject enrollment / prescreen
- Follow-up or telephone / online visit
- Supplemental data not intended for NACC (e.g., additional batteries, clinical consensus)

**Visit and Data Collection**
- Non-computerized data collection / Web data entry
- QC check for data entry validation (e.g., double data entry)
- Initial visit
- Validation entry into field (e.g., REDCap field within form specific instrument)

**Site Specific Prep**
- Identify valid subjects AND events (e.g., prep the header)
- Use of paper forms only for direct entry to NACC data portal
- Export NACC specific data from system
- Validate field mapping to NACC data elements
- Restrict to NACC required data
- Validate data elements as NACC ready

**Data Upload to NACC Site**
- Direct entry to NACC data portal
- Upload to NACC data portal
- NACC error checking: data validation, cross-form and visit

**Legend**
- Known REDCap supported process
- Possible REDCap support, site specific
- Site dependent processes
- NACC specific support process
- Participant or staff engagement
- Data focused event or process

**Pipeline**
- Paper form only pipeline (upper track)
Encourage NACC-ADRC Standardization of QA/QC
Better Understand the NACC QA/QC Process

1. Export NACC specific data from system
2. Validate field mapping to NACC data elements
3. Restrict to NACC required data
4. Validate data elements as NACC ready
5. Alter formatting from system to NACC ready file (e.g. CSV)
6. Parse packet header information (outside data dictionary)
7. Cross-visit validation
8. Cross-form validation
9. NACC error checking: data validation, cross-form and visit
10. Upload to NACC data portal

- Known REDCap supported process
- Possible REDCap support, site specific
- Site dependent processes
- NACC specific support process
Flow Visualization Goals

• Easily digestible design for new and current ADRC’s regardless of data capture methods
• Increase transparency, understanding, and expectations of UDS data processing
• Promote best practices of quality assurance and control
• Collaborating with Documents Workgroup to develop an interactive figure
A NACC Data Sharing Plan for NIH Submissions
A Unified DMSP for ADRC Submissions to NIH

- Scoped to address the six elements required by NIH
- Specific to required NACC data while allowing for locally collected data
- Designed for use by ANY applying ADRC whether new or renewing
1 – Data Types

Data Types

Section 1: Data types
Describe all the data types and approximate amounts of each type to be collected during the study. Indicate which data will be preserved and shared and address security measures (if applicable). Include descriptions of metadata and if/where study protocols will be accessible.

- Addresses the five types of NACC data: UDS, neuroimaging, neuropathology, biological samples, genomic data
- Opportunities for expanded data types by NACC or Centers
- Adds language for relevant metadata
- Allows for Center-specific data collection and protocols along with projected recruitment numbers
2 – Related Tools, Software and/or Code

- Emphasizes REDCap as the preferred, although not required, electronic data capture system
- Describes well-known ADRC related tools like the NACCulator
- Can highlight local proprietary resources
- Describes the upload process to the NACC online portal
3 – Standards

Section 3: Data standards
Look up the data standards for each type of data output
Consult the NIH maintained list of common data elements
If there is no standard, note this information and build your own standard with a data dictionary

• Defines access and conventions for data standards **OF NACC DATA** as required for submission
• Room for common elements unique to Centers
• Materials provided by either NACC or local sites
• Includes training materials for instruments adapted by NACC e.g. modified CDR interview
4 – Preservation, Access, and Timelines

- Describes upload system to NACC
- Concurrent data processing and retention in local repositories
- Highlights persistence of IDs and mapping process
- Introduces the NACC data request process

Section 4: Data preservation, access, and timelines
Provide repository name(s) and indicate how data will be findable
Make sure to discuss access and distribution for all of the types of data generated in the study
Indicate what level of data will be shared (raw, aggregate, de-identified etc.) and when and how long it will be shared (not all data needs to be shared at the same level)
Avoid hyperlinks in the DMSP, save these for the RPPR submission
5 – Access, Distribution, and Reuse

• Further details data use agreements within NACC
• Considerations for protection of human subject data
• Site-specific data is subject to institutional regulations
• Describes the organization and GCDM practices of the upload and storage systems used by NACC

Section 5: Access, distribution or reuse considerations
Discuss limitations of the data sharing
Address security concerns here, including how access will be controlled
6 – Oversight of Data Management

- Reemphasizing regulatory control
  - NACC data is subject to NACC oversight
  - Center-specific data is regulated locally
- Information on portal usage for uploads and access
- Details data summarization process such as monthly NACC reports to the network

Section 6: Oversight
Oversight will usually be the responsibility of the PI
Oversight includes revising the DMSP and adhering to submission deadlines for sharing data. All members of the team should have training on the DMSP.
Where the Workgroup Is Going From Here
Next Steps

• Currently getting feedback from ADRC’s on flow/tiers for iterative improvements e.g. expanding Onboarding node

• Development of guidebook of recommended practices for sites to build their own data management plans

• NIH DSMP under review by Nina Silverberg and Cerise Elliot

• Help curate lists of data errors and warnings used by NACC to harmonize with QA/QC by local Centers
We’d Love to Have you on the Team!

• If you’re interested in helping the EDC Workgroup go to: https://nacc.redcap.rit.uw.edu/surveys
  and enter the code – WH4JLAPWN

• You can also use QR Code
Thank you!

Your feedback is valuable!
Please be sure to complete your site’s survey
Questions?
EDC Workgroup Social

EDC Workgroup Members, please remember join your colleagues at this evening’s social!

**When:** Tonight from 7:30 – 9:00pm CT

**Where:** Swissôtel – Matterhorn Room, 42nd Floor
UDSv4 EDC Update: Documentation & Training

Presented by: Laura McLeod, BBA

October 19, 2022 | Data Core Workshop EDC Workgroup Session
Sub-Team Members

• Co-Leads:
  • Sarah Gothard (Oregon Health & Sciences University)
  • Leah Reuter (University of Wisconsin-Madison)
  • Laura McLeod (NACC)

• 17 team members representing 12 ADRCs and NACC
Curate and consolidate electronic data capture materials and resources for ADRCs to leverage in collecting and uploading NACC data.
Accomplishments to Date

- Consolidation and enumeration of pre-existing REDCap resources.
- Development of NACC-specific REDCap SOPs that will facilitate UDSv4 data submission to NACC.
- Collaboration with NACC on designing and developing a webpage to make training resources readily available to the ADRC community.
End Vision

The consolidation of resources on the NACC website that is intuitive and highly accessible.

The website will include descriptions/definitions of NACC specific REDCap development, REDCap and NACC SOPs and materials from the other working groups.
As SOPs are developed, they will be distributed to members of the full working group for review and feedback.
Thank you to all our sub-group members!

- Alok Vedvyas (NYU)
- Ashley LaRoche (South Texas STAC)
- Beata-Gabriela Simpson (MGH)
- Clair Cassidy (NACC)
- Eric Fischer (Wake Forest)
- Helen Foster (South Texas STAC)
- Jimmy Akrivos (Mt. Sinai)
- Laura McLeod (NACC)
- Leah Reuter (University of Wisconsin-Madison)
- Lingyi Lu (Wake Forest)
- Niranjana Shashikumar (Vanderbilt)
- Robin Stillwell (University of Washington)
- Samantha Emerson (Florida)
- Sara Farmer (Mayo)
- Sarah Gothard (Oregon Health & Sciences University)
- Taryn Stoffs (Florida)
- Veronica Ramirez (Stanford University)
We’d Love to Have you on the Team!

• If you’re interested in helping the EDC Workgroup go to: https://nacc.redcap.rit.uw.edu/surveys

and enter the code – WH4JLAPWN

• You can also use QR Code
Thank you!

Your feedback is valuable!
Please be sure to complete your site’s survey
Questions?