



EDC System to Streamline and Reduce Burden

Meredith Zozus, PhD CCDM

NACC Session, October 20, Fall 2023 ADRC Meeting

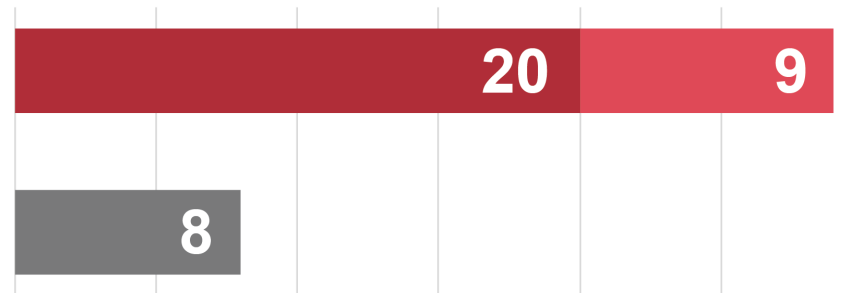
Why RedCAP?

- Existing systems was 20 years old and needed 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?**
 - It is already adopted and available at many ADRCs for forms data capture



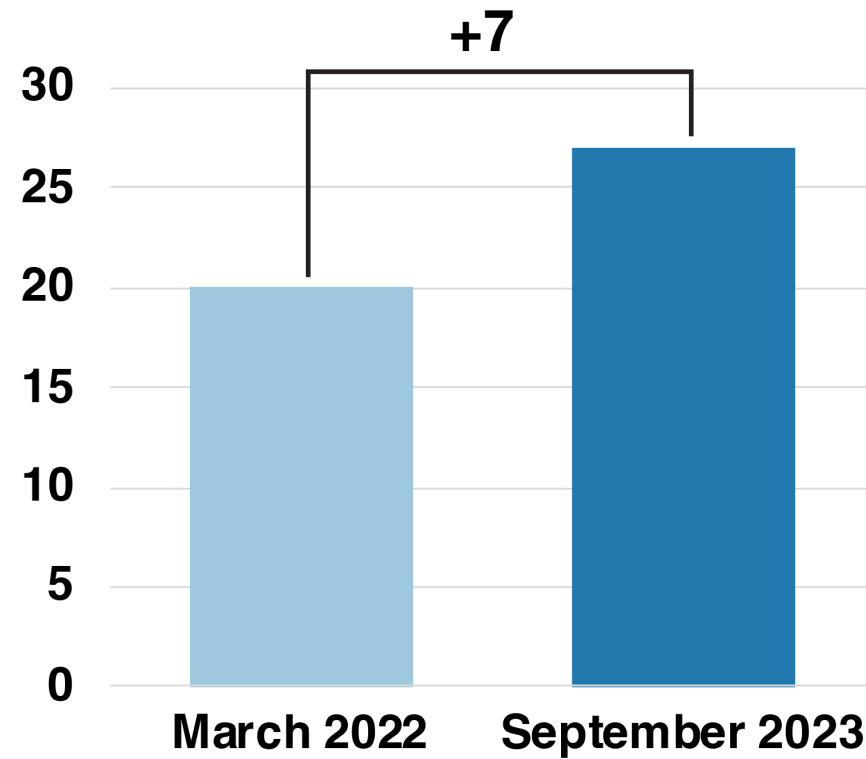
20 centers already using REDCap
with 9 more interested

Not interested



Increased REDCap Adoption

7 more ADRCs are using REDCap since March 2022



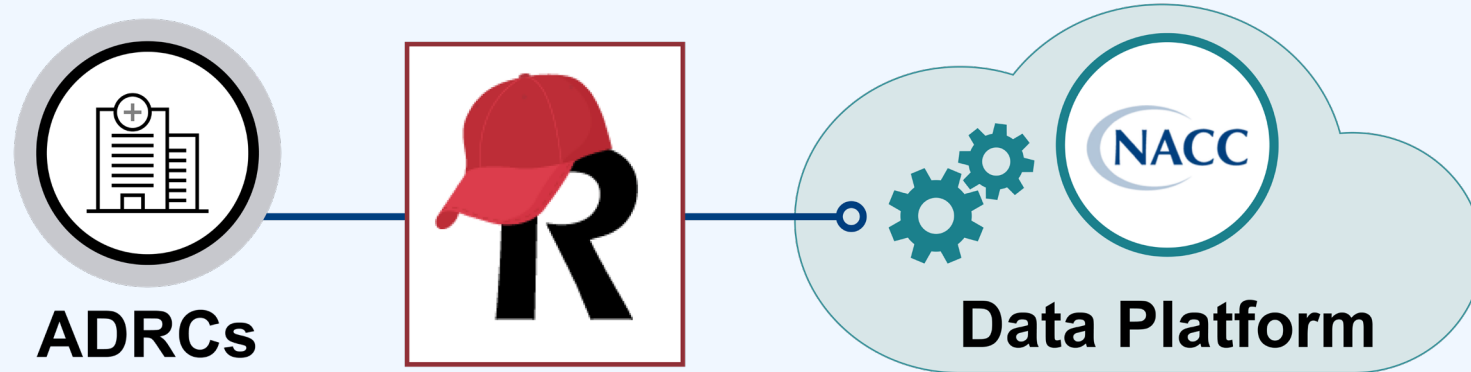
Electronic Data Capture (EDC) Workgroup Updates

- **Launched January 24th, 2022 in collaboration with the Data Core Steering Committee**
- **90 people across 31 ADRCs that are collaborating across three subgroups**



UDS 4 forms will be built and offered to ADRCs by this group along with documentation and training.

Electronic Data Capture System for UDSv4



ADRCs can deploy forms via iPads in waiting rooms or via any device from anywhere

We still have PDFs!

- NACC will continue to accept PDF forms
- It will be possible to do batch CSV upload into REDCap

A decorative background featuring a network diagram with light blue lines connecting various nodes. Some nodes are highlighted with larger, darker blue circles, while others are smaller and lighter. The network is spread across the top and bottom of the slide.

Electronic Data Capture System Demo: Skip Logic and Direct Data Entry

Demo: Skip Logic and Direct Data Entry



SARAH GOTHARD, MA
OHSU ADRC

A screenshot of a web browser displaying a REDCap data entry form. The browser address bar shows the URL: nacc.redcap.ni.uw.edu/redcap_v13.7.6/DataEntry/index.php?pid=216&page=d1a_clinical_syndrome&id=1&event_id=482&instance=1. The page has a left sidebar with navigation options like 'Survey Distribution Tools', 'Record Status Dashboard', and 'Add / Edit Records'. Below these is a list of 'Data Collection Instruments' including 'Form Header', 'A1: Participant Demographics', 'A2: Coparticipant Demographics', 'A3: Participant Family History', 'A4: Subject Medications', 'A4a: ADRC Specific Treatments', 'A5/D2: Participant Health History', 'B1: Vital Signs and Anthropometrics', 'B3: UPDRS - Parkinson's', 'B4 Cdr Dementia Staging Instrument', 'B5 Neuropsychiatric Inventory Questionnaire (NPI-Q)', 'B6: Geriatric Depression Scale', 'B7 Functional Assessment Scale Fas', 'B8: Neurological Examination Findings', 'B9: Clinician Judgment of Symptoms', 'C2: Neuropsychological Battery Scores', 'D1a: Clinical Syndrome', 'D1b: Biomarker-based Diagnostics', and 'Z1X: Form Checklist'. The 'D1a: Clinical Syndrome' instrument is selected. The main content area shows the form structure: 'Section 1: Cognitive and behavioral status: Normal cognition / MCI / dementia and dementia syndrome' and 'Section 2: Etiological diseases: Primary or contributing non-neurodegenerative or non-CVD conditions'. Below the sections are questions: 'Diagnosis method - responses in this form are based on diagnosis by:' with radio buttons for 'A single clinician', 'A formal consensus panel', and 'Other (e.g., two or more clinicians or other informal group)'; 'Was neuropsychological data used to inform the clinical diagnosis?' with 'Yes' and 'No' radio buttons; and 'SECTION 1: Cognitive and behavioral status' with the question 'Does the participant have normal cognition (global CDR=0 and/or neuropsychological testing within normal range) and normal behavior (i.e., the participant does not exhibit behavior sufficient to diagnose MCI or dementia due to FTLD or LBD)?'. Below this question, it shows 'Sum of Boxes: 2.5' and 'Current CDR Global score: 1.0 = Mild impairment'. At the bottom of the form, there is a section titled 'ALL-CAUSE DEMENTIA' with a partially visible question: 'The participant has cognitive or behavioral/neuropsychiatric symptoms that meet all of the following criteria:'. The form has 'Save & Exit Form', 'Save & Go To Next Form', and 'Cancel' buttons in the top right. At the bottom of the browser window, there are navigation icons (play, pause, stop) and a volume icon.

Learn More at the NACC Data Platform Booth!

Streamlining and Reducing Burden with Electronic Data Capture

Save Time

- **Auto-filled drug options (RXNorm)**
- **Auto-populated health history data for follow-up visits**
- **Skip-logic**
- **Access to automated NACC tools connected to data**
- **On-demand centralized robust training**

Enhance Sharing

- **Improved solution co-development and sharing amongst ADRCs**
- **Conserved resources through centralization**
- **Automatic EHR (Epic) to REDCap extractions for ADRCs that capture EHR data for UDS visits**

Improve Data Quality

- **Real-time form error checks**
- **Reduced multiple choice errors**
- **Transparent and replicable QC processes**
- **Improved standardization and error checks via centralization**
- **Enhanced utilization for analysis and other scholarly activities**

Thank You EDC Workgroup Members!

- **Co-Leads:** Sudeshna Das, PhD and Sarah Biber, PhD
- **Development Co-Leads:** Jon Reader, MS and Kathryn Gauthreaux, PhD
- **Requirements Co-Leads:** Meredith Zozus, PhD, Chad Murchison, PhD, and Kari Stephens, PhD
- **Documentation and Training Co-Leads:** Sarah Gothard, BS, Laura McLeod, BBA, and Brittany Fair, MS
- **Project Management:** Jess Welsch, MBA and Hannah Rosenstreter

Scan QR code and fill out the form to join!



naccdata.org/edc

Thank you!





Connect with Dr. Zozus

Meredith Zozus, PhD CCDM

zozus@uthscsa.edu