



Electronic Data Capture Workgroup: a NACC-ADRC collaborative effort

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Goals of the Electronic Data Capture (EDC) Workgroup

- To develop a modern EDC solution to effectively serve the needs of the ADRC program
- To foster collaborative software development
- To build robust and scalable solutions
- To build a data community across NACC and ADRCs
- To promote and share best practices
- To make data driven decisions with user surveys

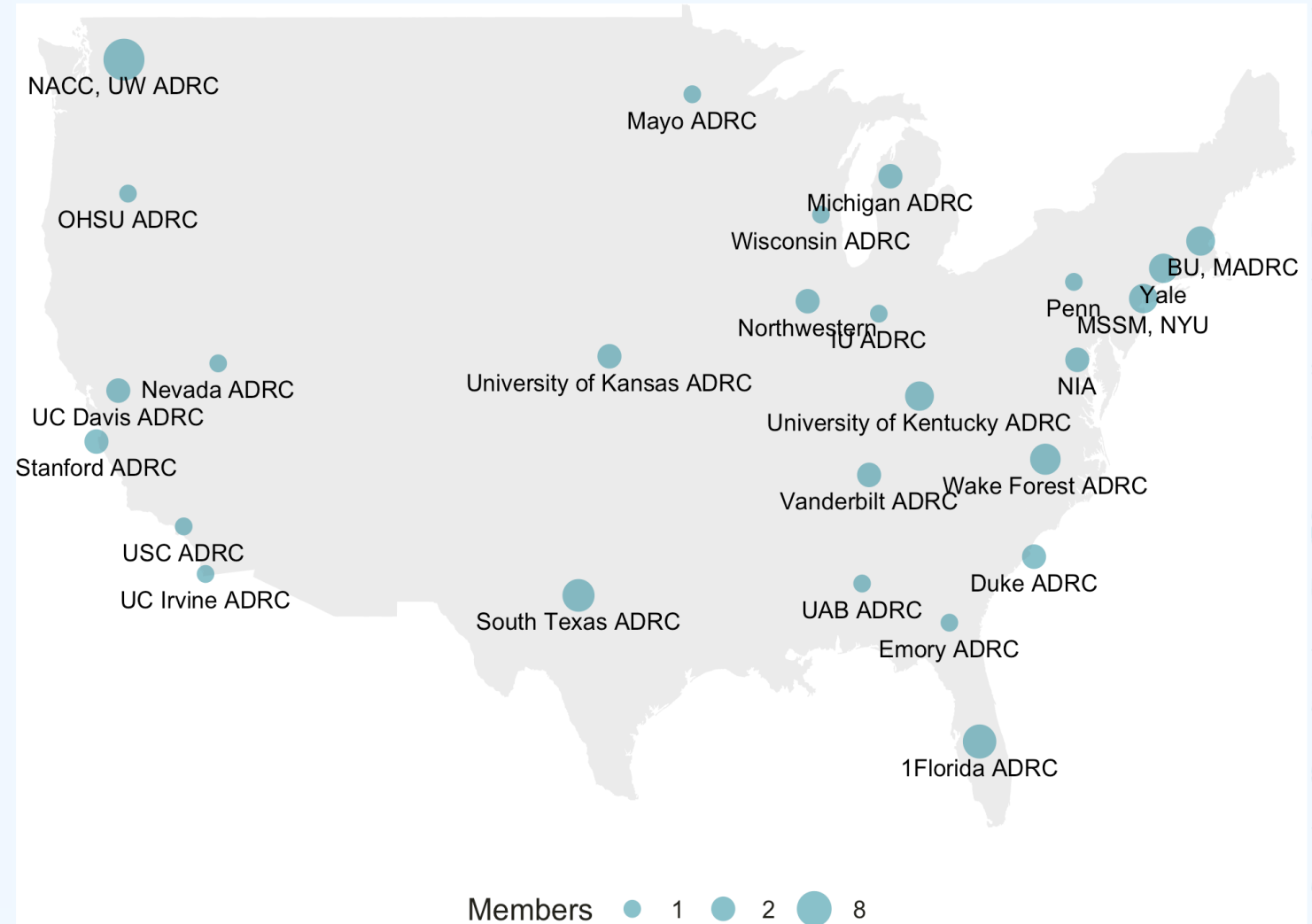
Modernization

Collaboration

Community

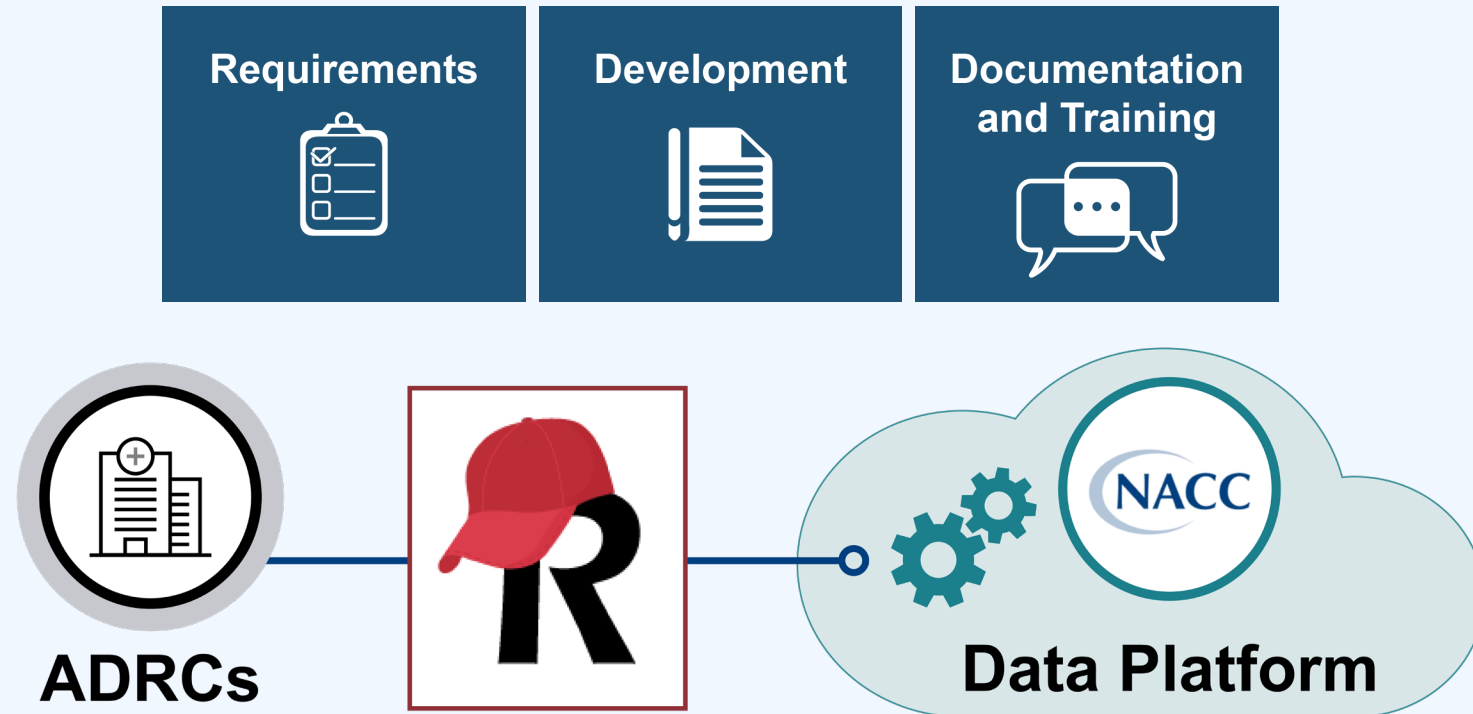
Electronic Data Capture System for UDSv4

- Launched by NACC and Data Core Steering Committee in January 2022
- 84 people across 32 ADRCs that are collaborating across three subgroups
- Diverse representation from 32 ADRCs including 2 new ADRCs and 3 exploratory ADRCs



Electronic Data Capture System for UDSv4

Electronic Data Capture Workgroup



We still have PDFs!

Deploy forms via iPads in waiting rooms or via any device from anywhere

Electronic Data Capture Workgroup Progress

Requirements



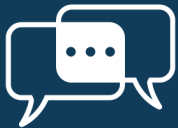
- **Determined the common UDS data flow used across 29 participating ADRCs: Survey to be sent to 37 all ADRCs**
- **Deployed data management plan in alignment with NIH's data sharing policy: Valuable for ADRCs seeking renewal**
- **Summarized data quality checks for UDSv4: To be shared with all ADRCs**

Development



- **Streamlined and standardized the REDCap submission process, quality checks, and variable names**
- **Established the infrastructure for longitudinal data collection**
- **40% of REDCap forms developed and review process is underway**

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**

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**

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 Melissa Lerch, PhD
- **Requirements Co-Leads:** Meredith Zozus, PhD, Chad Murchison, PhD, and Kari Stephens, PhD
- **Documentation and Training Co-Leads:** Sarah Gothard, BS, and Laura McLeod, BBA
- **Coordination:** Hannah Rosentreter



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naccdata.org/edc