Electronic Data Capture Workgroup: a NACC-ADRC collaborative effort

Sudeshna Das, PhD
MADRC, Boston MA

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Electronic Data Capture System for UDSv4

- Launched by NACC and Data Core Steering Committee in January 2022

- 90 people across 31 ADRCs that are collaborating across three subgroups

- Diverse representation from 32 ADRCs including 2 new ADRCs and 3 exploratory ADRCs
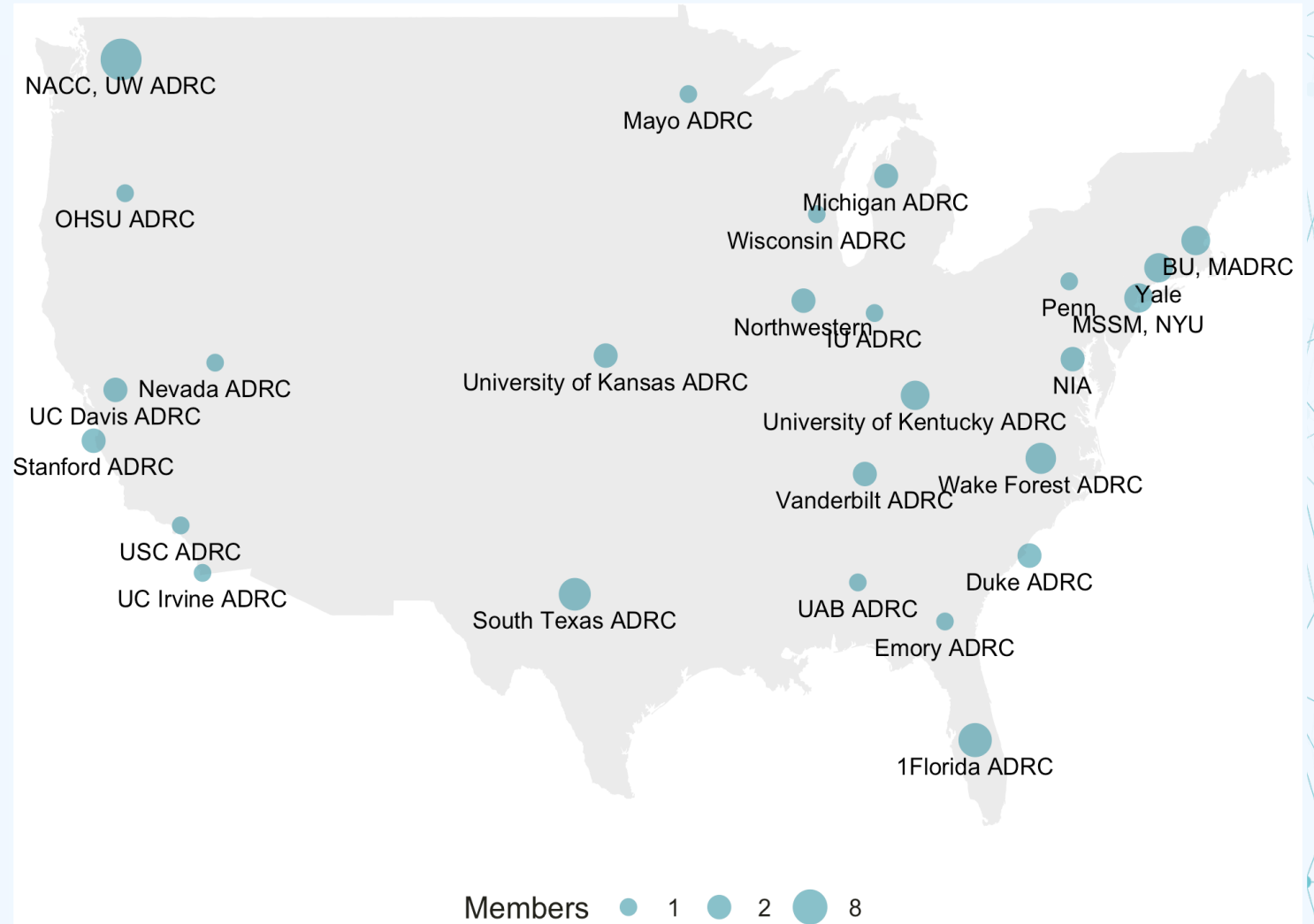
Goals of the Electronic Data Capture (EDC) Workgroup

- 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 Workgroup Progress - update

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 development process – form building to QA/QC
- Established the infrastructure for longitudinal data collection
- Target Completion of REDCap Forms Development by Q1

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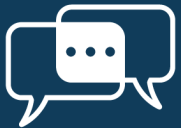
- Built a curated directory of valuable REDCap resources
- Developed NACC-specific REDCap SOPs to facilitate ADRCs submitting UDSv4 data to NACC
- Designing a webpage to make resources accessible to the ADRCs

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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

90 members across 31 ADRCs collaborating with NACC

Scan QR code and fill out the form to join!

naccdata.org/edc

Outline

- UDSv4 Pulse Check
  - Sarah Biber, PhD

- New NACC ID Process
  - Jess Welsch, MBA

- Creating a brand-new instrument – Form A1a
  - Chad Murchison

- Modifying of a REDCap Database – Form A1
  - Sarah Gothard

- Q&A

Connect with Dr. Das

Sudeshna Das, PHD, Harvard University

sdas5@mgh.harvard.edu