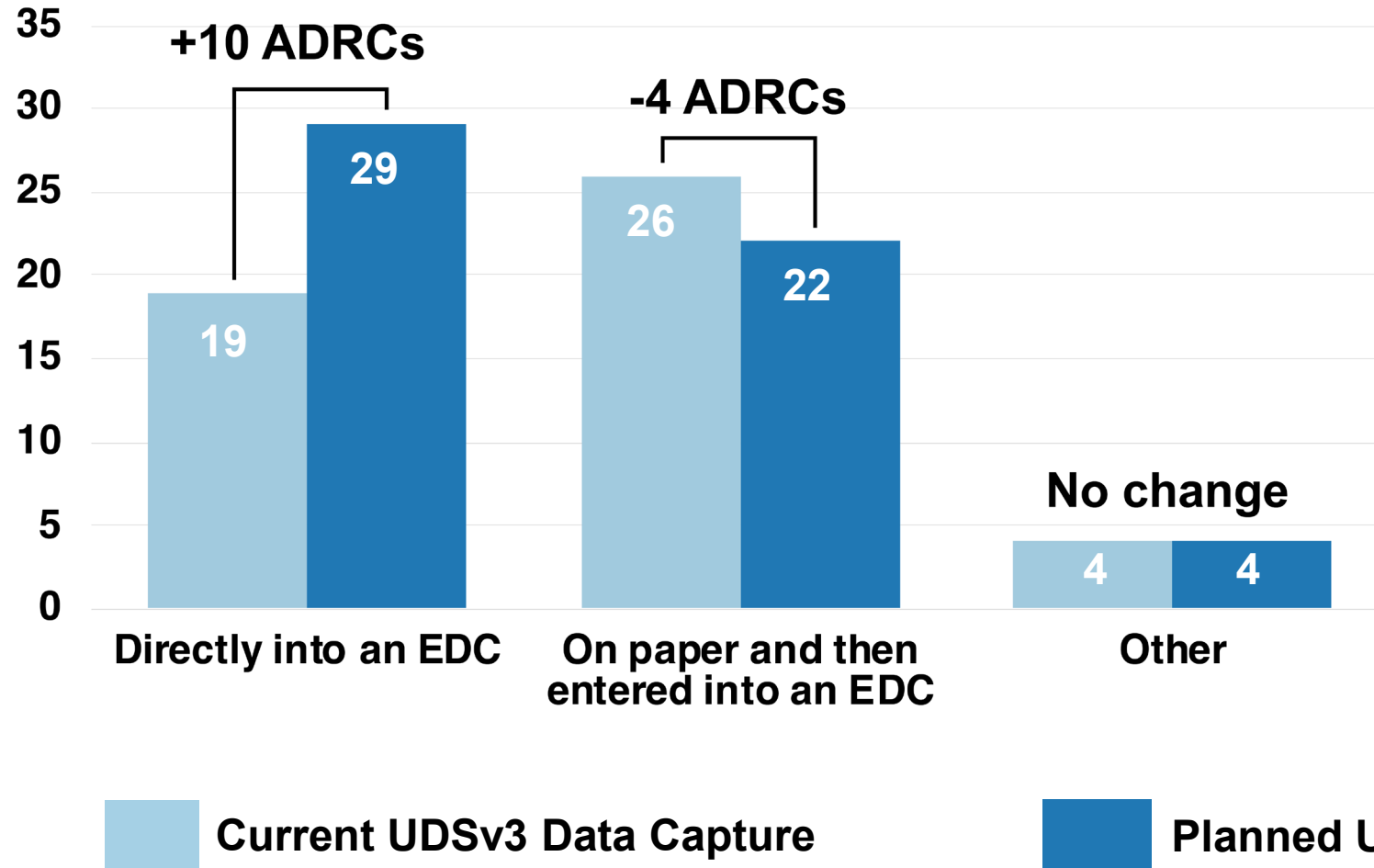


Benefits of Electronic Data Capture (EDC) for the UDS

Jeffrey M. Burns, MD, MS

NACC Session, October 20, Fall 2023 ADRC Meeting

Current vs. Planned Use of EDC by ADRCs



***Some ADRCs plan to use multiple methods**

COMPARISON: March 2022 to October 2023 Survey

KU Experience

- **New Center in 2011**
- **Transitioned to EDC in 2012 over 3 months**
 1. Clinicians manually entered from paper into REDCap
 2. Direct data entry into REDCap
- **Significant gains in efficiency** (*Graves et al., 2015 JMR*)
 - Reduced time from evaluation to Consensus (from 31 to 17 days)
 - Reduced NACC Time to Completion (from 211 to 95 days)

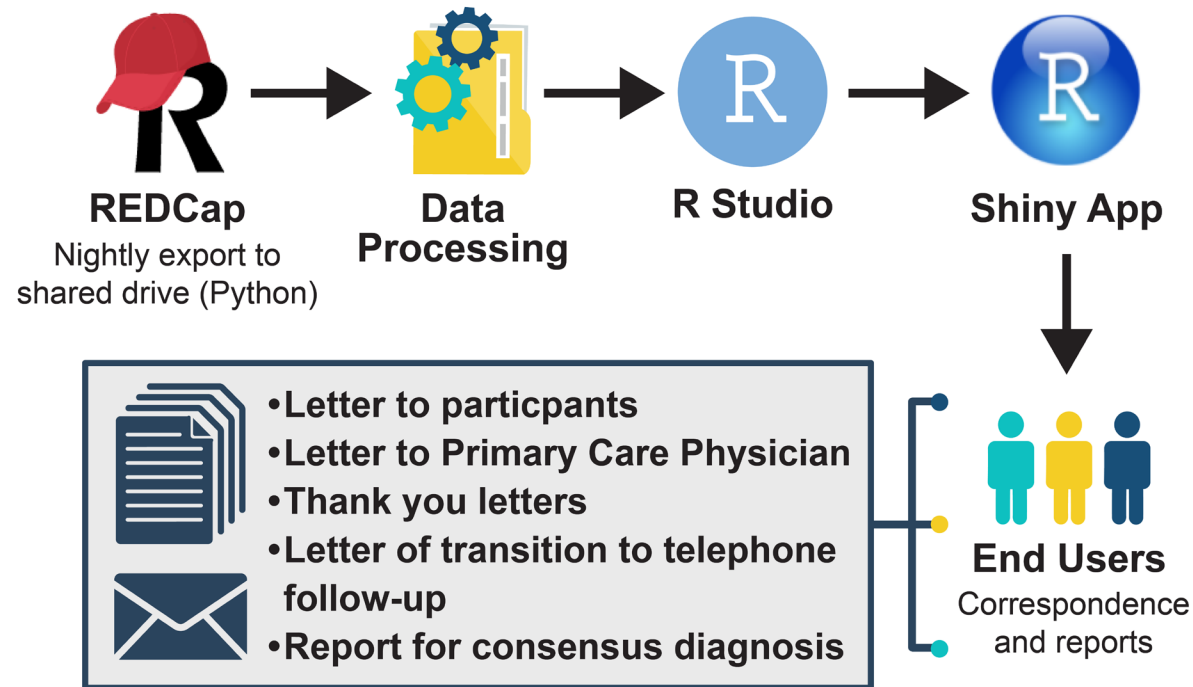
Benefits to Operations

- **Streamlining Processes**
 - Data immediately tracked, locked, available
 - Validate and mandate data entry
- **Reducing Burden and Cost**
 - Data entry staff
 - Reduce paper, printing, storage costs

Benefits to Operations


































- **Data Flow and Integration**

- Faster query resolution
- Ecosystem of automated reporting tools
 - Rapid Consensus preparation and 'Thank you' letters and reports



Benefits to the Team

- Improved teamwork and communication
- Status transparency
- Automation reduces time doing boring tasks
- Source doc tracking minimized without loss of accuracy
- Data history and audit inherent

 Data Collection Instrument	Annual Forms	1-NACC UNIFORM DATA SET (UDS)	Follow-up1	Follow-up2	Follow-up3	Follow-up4
KU Psychometric Battery						
Inclusion T1						
Checklist Z1						
F/U SP Demo A1 A2 A3 A5						
F/U Medications A4						
Fu Pass Questionnaires						
F/U Function B7 B5 CFI-SP						
F/U CFI B6						
F/U B1 KU Vitals Measurements						
KUPFT Activity						

Paper vs EDC

Paper-Based

- **Source document handling**
- **Manual data entry step**
 - Legibility
 - Communication process
 - Completeness
- **Source document storage**
 - Auditing data entry
 - Queries and resolutions

EDC

- **Direct data entry**
 - Skip logic
 - Data validation
- Coordinator checks for completeness
- Data manager error checks
- Data moves seamlessly to consensus
- Batch upload to NACC
- NACC queries

Thank you!





Connect with Dr. Burns

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