UDSv4: Technical Resources

Sudeshna Das, PhD – Massachusetts ADRC Thursday, October 17, 2024 2024 Fall ADRC Meeting





Built a Modern Electronic Data Capture & Submission System

Electronic Data Capture & Submission (EDCS) Workgroup

Documentation Launched in January 2022 **Requirements Development** and Training 111 people across 33 ADRCs UCI MOND LJ_ Sanders-Brown Wake Forest University SCIENCES NIH School of Medicine Center on Aging CENTER FOR MEMOR National Institute BU Alzheimer's Disease Research Center Cleveland on Aging M Northwestern Medicine **Alzheimer's Disease Research Center** Feinberg School of Medicine University of Pittsburgh | Alzheimer's Disease Research Center Vanderbilt Memory & Alzheimer's Center COLUMBIA UNIVERSITY COLUMBIA NIAGADS The National Institute on Aging Senetics of Algheimer's Disease beta Storage filte DEPARTMENT OF NEUROLOGY UCSF Weill Institute for | Memory and UT Health Neurosciences Aging Center UC San Diego NYULangone Health NACC San Antonio **IOHNS HOPKINS** SIN Sleven Biggs Institute for Alibuinter SCHOOL OF MEDICINE SCHOOL of MEDICINE & Neurodegenerative Diseases SHILEY-MARCOS ALZHEIMER'S Rush DISFASE RESEARCH CENTER NCRAD USC Alzheimer's Disease Alzheimer's UCDAVIS MAYO CLINIC ARIZONA Disease The University of Kansas Medical Cente Research Center ALZHEIMER'S **ALZHEIMER'S DISEASE** Center KnightADRC WASHINGTO CENTER ፍወ A·D·R·C Icahn School for healthy brain aging of Medicine at Goizueta Alzheimer's Mount EMORY OHSU SC Sinai Disease Research Center Michigan Perelman DISEASE Wisconsin Alzheimer's ADRC SCHOOL OF MEDICINE 1Florida MASSACHUSETTS Disease Research Center NDIANA ALZHEIMER'S DISEASE RESEARCH CENTER

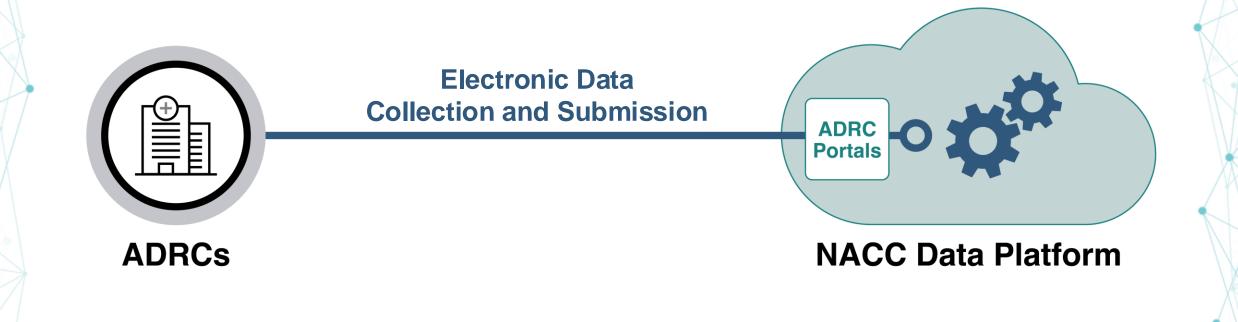
NACC

Go to <u>naccdata.org/edc</u> to learn more!



Built a Modern Electronic Data Capture & Submission (EDCS) System

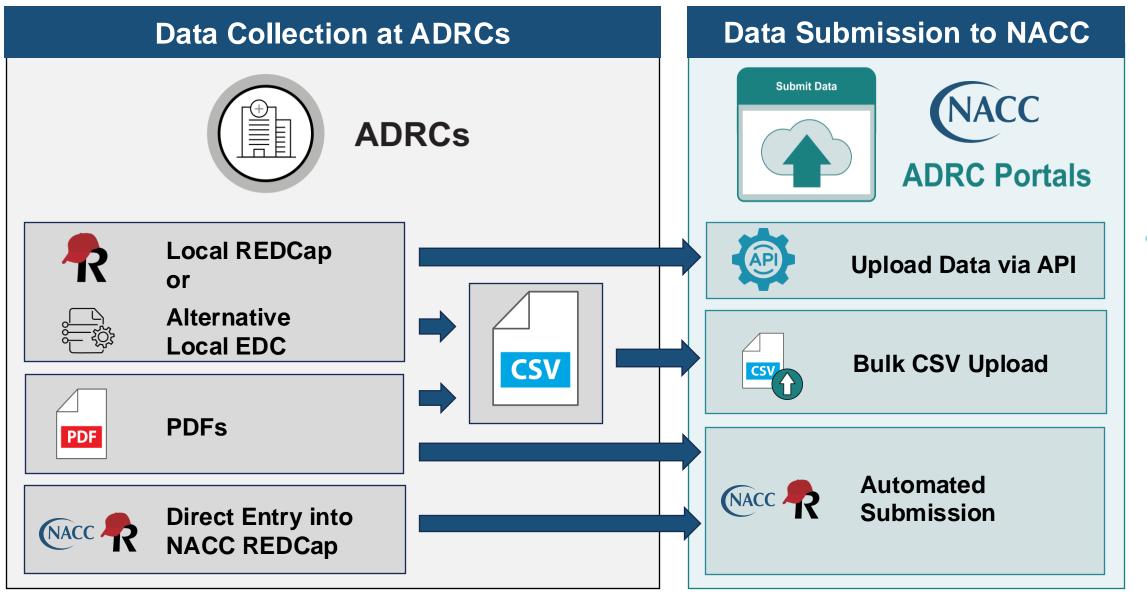
Saves time, enhances sharing, and improves data quality







Modern Electronic Data Collection and Submission System



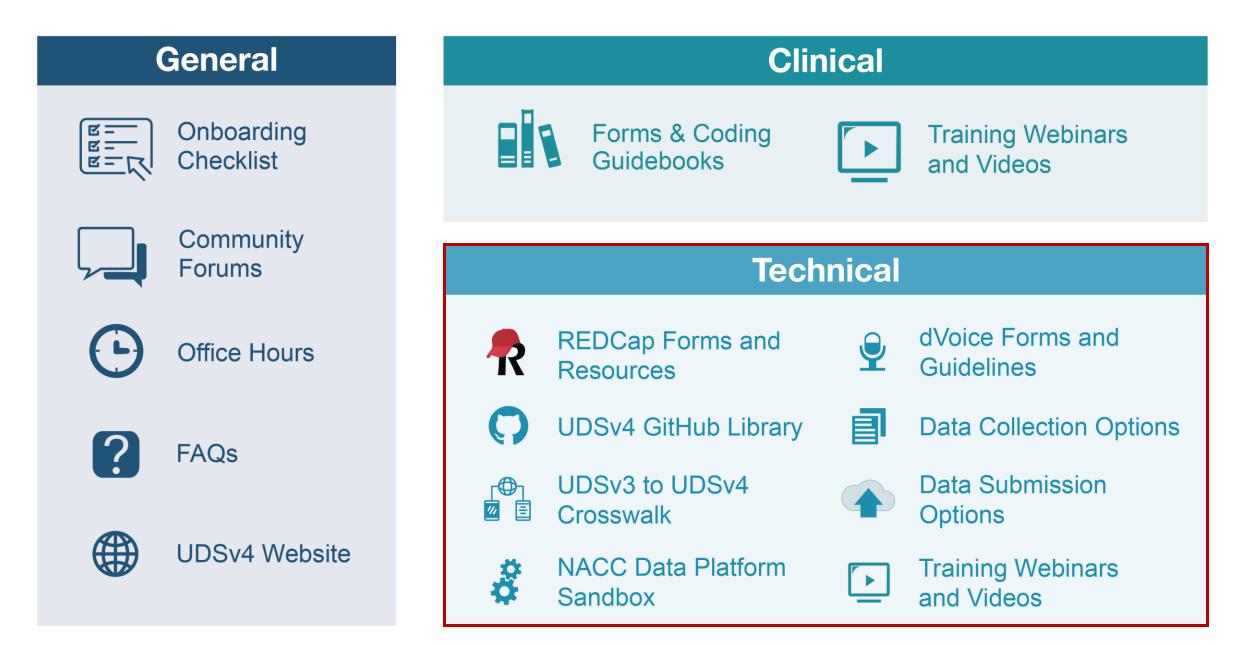






UDSv4 Support and Resources





RedCap Forms & Resources

GitHub Library: Copies of REDCap forms, error checks, coding guidebooks

o https://github.com/naccdata/uniform-data-set



Technical Documentation & REDCap SOPs

- \odot Downloads of PDFs, JSON files, XML, and more
- \circ Data dictionaries
- Data quality rules
- Calculated fields, custom reporting, data access groups, customization of user roles

o https://docs.naccdata.org



bit.ly/UDSv4Updates







EDC Workgroup Website

Features

- Designed for intuitive navigation
- Guidance at every step of the data lifecycle

bit.ly/EDCDocs

Electronic Data Capture V	Norkgr	up		
Electronic Data Capture	\sim	Electronic Data Capture		
Intro				
Data Capture Overview	\sim	Basics		
REDCap High Level Overview	\sim	2 minutes to learn the most important Docusaurus concepts.		
Benefits of REDCap				
Brief Overview of REDCap				
Detailed Overview of REDCap		Intro	😂 Data Capture Overview	
Project Level Specifics	\sim	Welcome to the EDC Docs! This is the place to find all the informatio	3 items	
E-consent / PDF Auto Arch	hiver			
My Projects Homepage				
Operations Project		📦 Data Capture Development	💊 Visit and Data Collection	
Data Capture High Level	>	1 items	1 items	
Data Capture Development	>			
Visit and Data Collection	>			
Data Upload to NACC	>		Data Quality Processing 3 items	
Data Quality Processing	>	Data Upload to NACC		
NACC Portal	\sim	4 items		
Landing Page				
			Next Intro »	





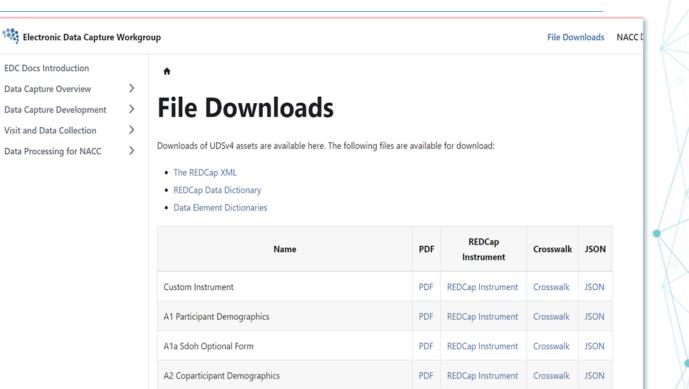
REDCap Files

EDC Workgroups UDSv4 REDCap Project and forms

- XML File
 - Creates entire project
 - Data export reports
- REDCap Data Dictionary
 - Implements form level infrastructure (branching logic, variables)

• Zip Files

- Individual form level files
- Update existing projects



PDF

REDCap Instrument

bit.ly/EDCDownloads github.com/naccdata

A3: Participant Family History



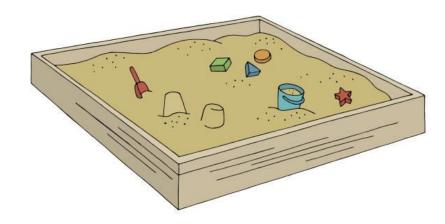
JSON

Crosswalk

NACC Data Platform Sandbox

UDSv4 Pilot

 23 ADRCs participated in the UDSv4 Pilot (16 ADRCs administered to clinical core participants)



NACC Data Platform Sandbox

 \circ Coming soon!

 Practice environment for ADRCs to test out REDCap, CSV, and API data submissions



bit.ly/UDSv4Updates







Responding to your Pilot Feedback

A collaboration between NACC, CTF, and the EDC Workgroup

General

- $_{\odot}$ Website with centralized resources
- $_{\odot}$ Additional implementation time

Clinical

- $_{\odot}$ Updating some forms and clinical guidance documentation
- $_{\odot}$ Additional clinical trainings and webinars
- $_{\odot}$ Boiler plate language for IRBs
- $_{\odot}$ Clinical support via the ADRC Community Forum
- $_{\odot}$ Recommend forms that can be sent to participants in advance

Technical

- $_{\odot}$ Changes to REDCap form logic and rules
- More accessible API documentation
- $_{\odot}$ Hosting a sandbox environment where ADRC can practice data submission



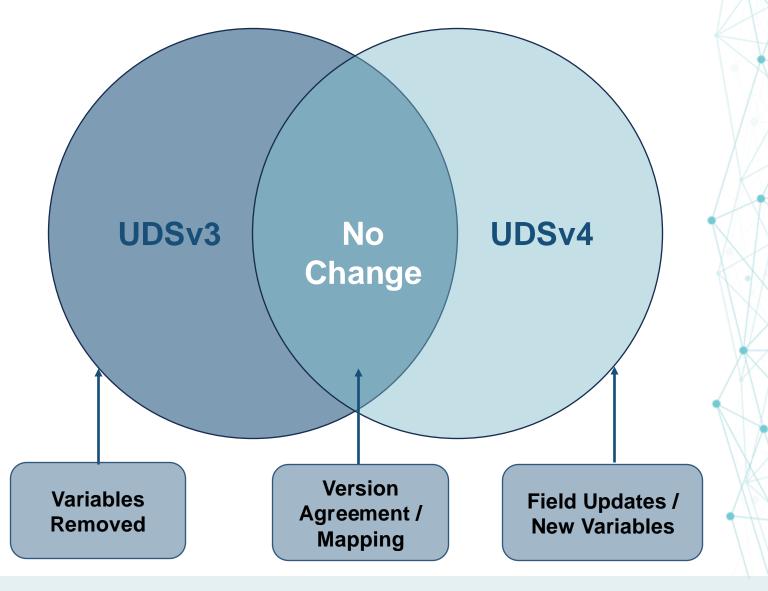
Data Element Crosswalks

Chad Murchison, PhD & Sarah Gothard, BS

SITY of WASHINGTON

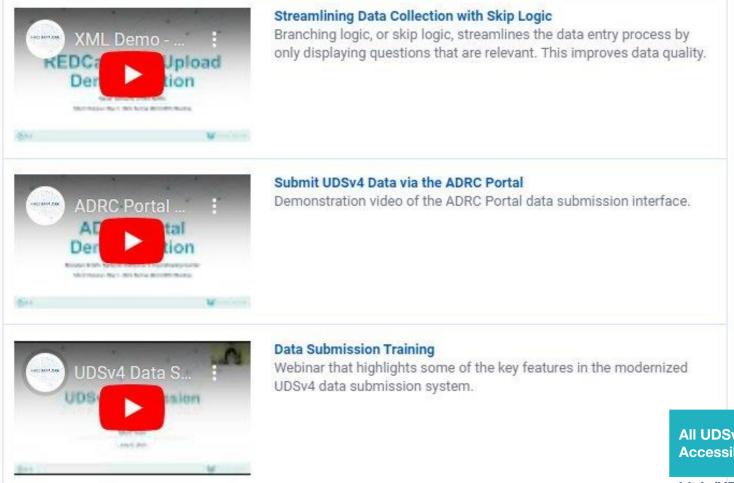
Multiple Functions

- 1) Novel resource new to UDS 4 transition
- 2) Maps out all changes between UDSv3->UDSv4
- 3) Tool for harmonizing downstream efforts across UDS 4 and previous UDS data set





UDSv4 Training Videos



All UDSv4 Resources Accessible on the NACC Website

bit.ly/UDSv4Updates











Q & A

Connect with me

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