NACC Pilots
NACCID Process & UDSv4

Jess Welsch, MBA – NACC Senior Project Manager

May 7, 2024 – NACC Session

Why are we doing pilots?

NACCID Pilot

- This is a new process, new workflow, new form
- Unique NACCID tying everything together

UDSv4 Pilot

- New forms and forms with major changes
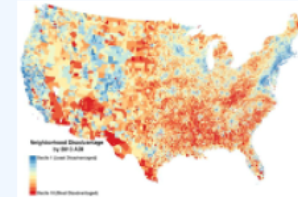- New diagnostic categories and new questions
- New submission options

ADRD-Disease Modifying Drugs

Form A4a: ADRD-Specific Treatments

Social Determinants of Health

A1a: Social Determinants of Health

New Concepts

- Subjective Cognitive Decline
- Mild Behavioral Impairment
- Addition of the new verbal learning test

More Inclusive

- More inclusive gender and sexual orientation questions
- Captures multi-racial identity

Pilot Rollout Timelines

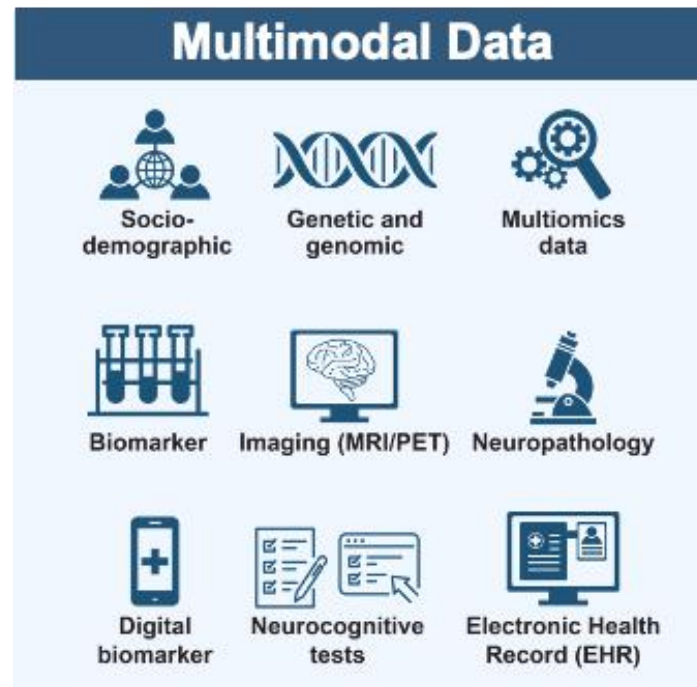| Category	Task	May	Jun	Jul	Aug	Sep
Pilot Nomination	ADRCs Nominate Primary Pilot Participants	▨				
Onboarding	Attend or watch kickoff meeting	▨				
	Pilot resources distributed	▨				
Pilot Period	UDSv4 Pilot sites obtain IRB approval	▨				
	ADRCs run pilot – Administer forms & provide feedback		▨	▨		
	Mid-pilot meeting		▨			
Go Live	New NACCID Process Required (estimated)			▨	▨	▨
	UDSv4 Forms used for data collection (estimated)					▨

NACCID Process Pilot

NACC Is Launching a New NACCID Process

NACCID Assignment & Transfer Process:

- Unique identifier assigned to each ADRC participant
- Used to link UDS data to the growing number of data types for the same participant that are housed within the NACC Data Platform

Multimodal Data

Socio-demographic · Genetic and genomic · Multiomics data · Biomarker · Imaging (MRI/PET) · Neuropathology · Digital biomarker · Neurocognitive tests · Electronic Health Record (EHR)

Example NACCID:
NACC000000

NACCID Assignment Steps

OLD Process (Current)	NEW Process (Summer 2024)
1. ADRC consents participant	1. ADRC consents participant
2. ADRC completes initial UDS visit	2. ADRC submits new NACCID Assignment Form
3. ADRC completes UDS packet submission to NACC	3. **NACC assigns NACCID** immediately
4. **NACC assigns NACCID** when initial visit packet submission is complete	4. ADRC completes initial UDS visit
	5. ADRC submits UDS packet to NACC

NACC

UNIVERSITY of WASHINGTON

New NACCID Process - How it works!
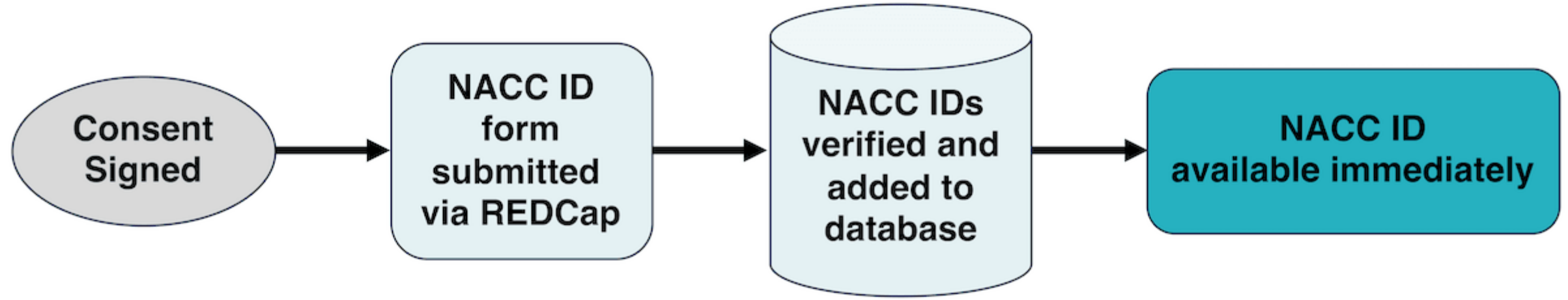
Benefits of New NACCID Process

- **Streamlines multimodal data collection, integration, and sharing**
  - Data types can be submitted to NACC Data Platform in any order
  - NACCID will accompany every data type that is submitted including UDS, SCAN, CLARiTI, and affiliated study data

- **Improves participant tracking**
  - Supports tracking subjects who change ADRCs
  - Allows for additional NACCID verification

- **NOTE: This new process will not affect how ADRCs assign their own site-specific IDs or NIA GUIDs.**

- **Planning to rollout alongside the UDSv4 transition**

UNIVERSITY *of* WASHINGTON

NACCID Pilot User Benefits

Pilot users will get to test and provide feedback on:

- ADRC Portal

- Updated Submission Site

- Updated Errors and alerts page

- New NACCID REDCap Form

NACC

UNIVERSITY *of* WASHINGTON

UDSv4 Pilot

Goals of UDSv4 Pilot

1. Gain familiarity with the new UDSv4 forms

2. Test new data collection and submission options (REDCap)

3. Assess administration time

4. Provide valuable feedback on forms and guidance documentation

UDSv4 Pilot Overview

- In-person administration of the UDSv4 Initial Visit Packet (IVP), focused on forms that are new or have been updated for UDSv4

  - The pilot is estimated to take 5-6 hours to complete

- Pilot data will be stored in a separate project and not integrated with "real" UDSv4 data

UDSv4 Pilot Site Steps

1. Obtain IRB approval

- NACC will provide a packet with UDSv4 IVP forms and Coding Guidebooks

UDSv4 Pilot Site Steps

1. **Obtain IRB approval**

2. **Administer UDSv4 forms to ≥5 participants:**

   - With different cognitive diagnoses (including ≥1 with normal cognition, ≥1 with MCI, and ≥1 with dementia)

   - Representing a diverse group, including underrepresented populations

   - Separately from, but within, 3 months of a UDSv3 visit

UDSv4 Pilot Site Steps

1. **Obtain IRB approval**

2. **Administer UDSv4 forms packet to 5+ participants**

3. **Submit data to NACC:**

   - Electronic Data Capture into NACC REDCap instance

   - Batch CSV file upload in ADRC Portal

   - Submit via Application Programming Interface (API)

UNIVERSITY *of* WASHINGTON

UDSv4 Pilot Site Steps

1. **Obtain IRB approval**

2. **Administer UDSv4 forms packet to 5+ participants:**

3. **Submit data to NACC:**

4. **Submit feedback to NACC**

   - Form flow issues

   - Administration time

   - Sufficiency of guidebooks for accurate and standardized administration

   - Functionality of submission processes

How to Get Involved
& Next Steps

How to get involved? Participate in the NACC Pilots!

Nominate someone from your ADRCs to participate in the NACCID and UDSv4 Pilots!

- Each ADRC will nominate a single point of contact for **each** pilot, they will forward information to other interested parties at their ADRC

- Nomination forms were emailed to ADRC Administrators, Directors and Data Core Leads on May 1, 2024

- **Sign up by May 10, 2024**

- Once you sign up, you will receive an invite to the kickoff meeting:
  - May 16: UDSv4 Pilot Kickoff
  - May 17: NACCID Pilot Kickoff

NACC

UNIVERSITY of WASHINGTON

What are the next steps?

- **May 10, 2024 -** Complete nomination form sent to you by NACC

- **May 16, 2024 -** Attend or watch UDSv4 Pilot Onboarding virtual meeting

- **May 17, 2024 -** Attend or watch NACCID Pilot Onboarding virtual meeting

- **For more details:** www.naccdata.org/pilots

Scan to sign up for the Pilots!

Connect with Jess Welsch

Jess Welsch, MBA – Senior Project Manager

jmwelsch@uw.edu

Thank you!