

New NACC ID Process

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EDC Workgroup Update – Data Core Workshop – October 18, 2023 2023 Fall ADRC Meeting





New NACC ID Process – Key Points

- Crucial step in becoming more multimodal
- NACC ID assigned at the time of consent
- Benefits:
 - Supports multimodal data collection, integration, and sharing
 - Data types can be submitted to NACC in any order
 - Supports tracking subjects who change ADRCs
 - Uses minimal information already collected by Centers
- Planning to rollout alongside the UDSv4 transition





New Form – NACC Participant Enrollment/Transfer Form

- Minimum Initial Data Collection
 - ADC ID
 - Examiner Initials
 - PT ID
 - NIA GUID? (yes/no)
 - Existing NACC id? (yes/no)
- Supports Updates and Transfers
 - Update (yes/no)
 - Enrolled at a previous center? (yes/no)

NACC

NACC Participant Enrollment/Transfer Form

Submit this form to activate or update the enrollment of a participant at NACC.

- Activation: If this is a new participant at your center and you would like to enroll them in the NACC database and/or
 procure a NACCID for this participant, select 'Activation'.
- Update: If this is an existing participant at your center and you would like to make a change to their record in the NACC database or indicate the transfer of a participant between centers, select 'Update'.

 Activation 			
O Update			
	reset		
3 characters remaining			
	O Update		

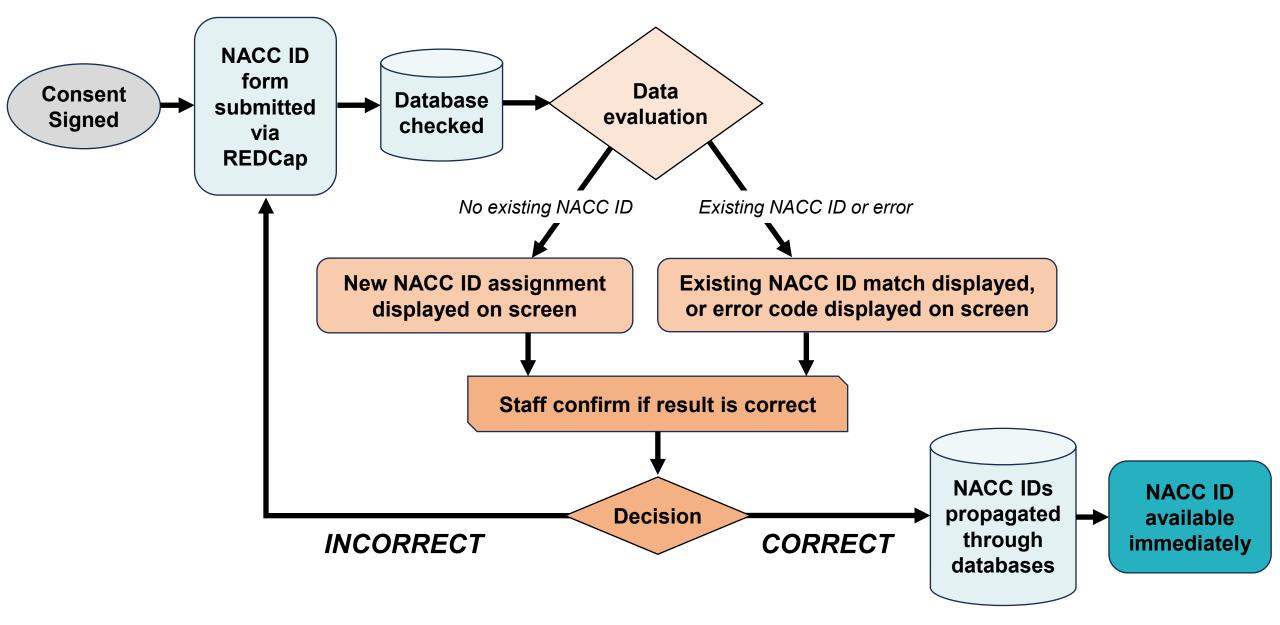




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NACC ID Estimated Rollout Timeline

• Change announced at ADRC Meeting: October 20th, 2023!

Category			Q4 2023			Q1 2024			Q2 2024	FUTURE	
	Task - Anticipated activity or completion	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	Jun	FUTURE
NACC ID Assignment Process	NACC ID change announced	10/20									
	NACC ID trial										
	ADRCs start using new process										
	New NACC ID process required										



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- NACC ID pilot trial testing period: Feb Apr 2024
- ADRCs start using new NACC ID process: Feb 2024

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- ADRCs start using new NACC ID process: Feb 2024
- New NACC ID process required: May 2024 *Estimate

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Considerations for Clinical Staff

- 1. Change in workflow
- 2. Done right after consent
- 3. May entail minimal demographic data is collected
- 4. Requires validating a participant has (or has not) been a participant at another ADRC





Considerations for Data Managers

- 1. Change in workflow
- 2. Must be uploaded quickly and in advance of ALL other data modalities (SCAN, NCRAD, etc.)
- 3. NACC ID is returned immediately with accompanying email
- 4. Is independent on visit completion metrics, won't impact performance
- 5. Adds another ID to track for persistence





Considerations for Participants

- 1. Extra time in intake/consent process
- 2. Added time is really the only burden at intake
- 3. May ask some questions twice e.g. sex, race [Again, contingent on things that are being collected]
- 4. Needs to be considered upon transfer to a new Center





Next Steps

- 1. Watch for communications from NACC with timing updates
- 2. Participate in the NACC ID trial to provide feedback
- 3. Onboarding documentation, training and troubleshooting documentation will be available





Connect with Jess Welsch

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