



UDSv4: Clinical Resources

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Thursday, October 17, 2024

2024 Fall ADRC Meeting

UDSv4 Forms

- UDSv4 forms are ready to preview
- Final forms pending small edits from pilot feedback

Preview UDSv4 Forms

As NACC and our partners are finalizing the content and supporting infrastructure for UDSv4, we are making forms and documentation available early to enable those collecting and using UDS data to start preparations for the new form data. NACC and the CTF are launching the UDSv4 Pilot in order to identify any improvements that are needed in the UDSv4 guidance documentation, and the final versions will be available once this pilot concludes to align with the UDSv4 Implementation Timeline.

Form	Form Name	CTF Status	PDF
A1	Participant Demographics	Approved	FORMA1-PREVIEW-APRIL2024.PDF
A1a	Social Determinants of Health	Approved	FORMA1A-PREVIEW-APRIL2024.PDF
A2	Co-Participant Demographics	Approved	FORMA2-PREVIEW-APRIL2024.PDF
A3	Participant Family History	Approved	FORMA3-PREVIEW-APRIL2024.PDF
A4	Participant Medications	Approved	FORMA4-PREVIEW-APRIL2024.PDF
A4a	AD-Specific Drug Treatment	Approved	FORMA4A-PREVIEW-APRIL2024.PDF
A5/D2	Participant Health History	Approved	FORMA5D2-PREVIEW-APRIL2024.PDF

All UDSv4 Resources
Accessible on the NACC Website

bit.ly/UDSv4Updates



General



Onboarding Checklist



Community Forums



Office Hours



FAQs



UDSv4 Website

Clinical



Forms & Coding Guidebooks



Training Webinars and Videos

Technical



REDCap Forms and Resources



dVoice Forms and Guidelines



UDSv4 GitHub Library



Data Collection Options



UDSv3 to UDSv4 Crosswalk



Data Submission Options



NACC Data Platform Sandbox



Training Webinars and Videos

UDSv4 Coding Guidebook

- Final Coding Guidebook coming soon (incorporating pilot feedback)
- **Primary resource** for questions on administering forms

What is your ethnicity and race? (Check all that apply)

3a. 1 American Indian or Alaska Native (AIAN)
(SPECIFY, for example, Navajo Nation, Blackfeet Tribe of the Blackfeet Indian Reservation of Montana, Native Village of Barrow Inupiat Traditional Government, Nome Eskimo Community, Aztec, Maya, etc.): _____

3b. 1 Asian

3b1. 1 Chinese

3b2. 1 Asian Indian

3b3. 1 Filipino

3b4. 1 Vietnamese

3b5. 1 Korean

3b6. 1 Japanese

3b7. 1 Other (SPECIFY, for example, Pakistani, Hmong, Afghan, etc.): _____

3c. 1 Black or African American

3c1. 1 African American

3c2. 1 Jamaican

3c3. 1 Haitian

3c4. 1 Nigerian

3c5. 1 Ethiopian

3c6. 1 Somali

3c7. 1 Other (SPECIFY): _____

3e. 1 Middle Eastern or North African

3e1. 1 Lebanese

3e2. 1 Iranian

3e3. 1 Egyptian

3e4. 1 Syrian

3e5. 1 Iraqi

3e6. 1 Israeli

3e7. 1 Other (SPECIFY, for example, Moroccan, Yemeni, Kurdish, etc.): _____

3f. 1 Native Hawaiian or Pacific Islander

3f1. 1 Native Hawaiian

3f2. 1 Samoan

3f3. 1 Chamorro

3f4. 1 Tongan

Ask the participant (or, if necessary for participants with dementia, the co-participant) what they consider the participant's race and ethnicity to be. The respondent should choose all that apply.

NOTE ON USING THESE NEW RACE/ETHNICITY OPTIONS FOR NIH RACIAL CATEGORIES

The Office of Management and Budget (OMB) introduced their new race/ethnicity question format in March 2024. Per [OMB](#), "If detailed race and ethnicity data are collected in an interviewer-administered setting, the minimum categories [e.g., Asian, Hispanic, or Latino] should be asked first, treating each category as a yes/no question, followed by the detailed categories associated with the selected minimum categories [e.g., Chinese, Mexican]."

Training Webinars and Videos

Neuropsychiatric symptoms and MBI (February 2024)



Operationalizing "Impaired, not MCI" (March 2024)



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Clinical training workshop (May 2024)

Forms A1 & A2	Presented by Clinical Task Force Member Dr. Greg Jicha of University of Kentucky ADRC.		
Form A1a	Presented by Clinical Task Force Members Dr. Lisa Barnes of Rush University ADRC and Dr. Megan Zuelsdorff of UW Madison ADRC.		
Form A4	Presented by Clinical Task Force Member Dr. Teresa Gomez-Isla of Massachusetts ADRC.		
Form A4a	Presented by Clinical Task Force Member Dr. Suzanne Schindler of Washington University ADRC.		
Form A5/D2	Presented by Clinical Task Force Member Dr. Aimee Pierce of OHSU ADRC.		
Form B3	Presented by Clinical Task Force Member Dr. Brad Boeve of Mayo Clinic ADRC.		
Form B8	Presented by Clinical Task Force Member Dr. Brad Boeve of Mayo Clinic ADRC.		
Form B9	Presented by Clinical Task Force Member Dr. Kostas Lyketsos of Johns Hopkins ADRC.		
Form C2/C2T	Presented by Clinical Task Force Members Dr. Lisa Barnes of Rush University ADRC and Dr. Andy Saykin of Indiana ADRC.		
Form D1a	Presented by Clinical Task Force Members Dr. Jeff Burns of Kansas University ADRC, Dr. Andy Saykin of Indiana ADRC, and Dr. Kostas Lyketsos of Johns Hopkins ADRC.		
Form D1b	Presented by Clinical Task Force Member Dr. Jeff Burns of Kansas University ADRC.		

Upcoming: DSM-5 webinar

Responding to your Pilot Feedback

A collaboration between NACC, CTF, and the EDC Workgroup

- **General**

- Website with centralized resources
- Additional implementation time

- **Clinical**

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

- **Technical**

- Changes to REDCap form logic and rules
- More accessible API documentation
- Hosting a sandbox environment where ADRC can practice data submission

Key UDSv4 Pilot Clinical Takeaways

Come to the CTF Session!

Thursday, May 17, 2024

2:15-3:45pm

- UDSv4 pilot survey results
- UDSv4 pilot panel
- UDSv4 Neuropsych Battery updates
- CTF Technology Workgroup update

Connect with me

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