



**Wisconsin Alzheimer's
Disease Research Center**

UNIVERSITY OF WISCONSIN
SCHOOL OF MEDICINE AND PUBLIC HEALTH

Clinical Task Force (CTF) Clinical Measures & Diagnosis Working Group Update

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UW-Madison School of Medicine and Public Health

Clinical Task Force (CTF) Organization and Working Groups



Administrative Oversight

Nina Silverberg – NIA
Cerise Elliott - NIA
Grayson Donley - NIA

Bud Kukull (Ex officio)
- NACC



Clinical Measures & Diagnosis Working Group

- Greg Jicha* (Co-lead, Neurology, Univ Kentucky)
- Cindy Carlsson* (Co-lead, Geriatrics, Univ Wisc)
- Liana Apostolova* (Neurology, Indiana Univ)
- Brad Boeve (Neurology, Mayo)
- Jeff Burns* (Neurology, Univ Kansas)
- Teresa Gomez-Isla (Neurology, Mass General)
- Howie Rosen* (Neurology, UCSF)
- Suzanne Schindler (Neurology, Wash Univ)

➤ Symptoms - Forms: B1, 4-9

➤ Risk factors - Forms: A1-5

- Demographics
- Family history
- Past medical history
- Medications
- Add social determinants of health

➤ Diagnosis - Forms: D1-2

Clinical Task Force

Allan Levey (Chair)

Cognitive Working Group

- Andy Saykin (Co-lead, Indiana Univ)
- Lisa Barnes (Co-lead, Rush)
- Rhoda Au (Boston Univ)
- Suzanne Craft (Wake Forest)
- Mary Sano* (Mt. Sinai)
- Sandy Weintraub (Northwestern)

➤ Existing Paper/Pencil tests - Forms: C

➤ Future Computerized tests - Forms: New C

➤ Future Wearables - Forms: New C

*Clinical Core Steering Committee member

Modified from schema created by Greg Jicha

Guidelines and Principles for Working Group in Long-term Planning for UDS4

1. Maintain and enhance value of longitudinal data
2. Improve standardization and quality control
3. Minimize participant and center burden
4. Facilitate important research efforts that otherwise can't be done readily by individual research studies
5. Facilitate expansion of disease and racial heterogeneity in the UDS
6. Improve capture of behavioral, cognitive, and motor symptoms to facilitate understanding of dementia trajectories
7. Move toward full electronic data capture and EMR data integration
8. Review all items, measures, and tests for reliability and administration efficiency
9. New instruments should be piloted and validated before center wide adoption, and cross-walk studies performed

CTF Clinical Measures & Diagnosis Working Group Update

- With onset of COVID-19 pandemic, emphasis shifted to development of short-term guidelines for ADRCs on remote data collection
- Most urgent need was telephone administered cognitive battery
- Current UDS3 Telephone Visit Packet (TVP) clinical and diagnostic measures reviewed to see if modifications needed during acute period
- Modified Delphi method used to assess TVP Form items

Current NACC UDS3 Telephone Visit Packet Checklist

UDS						
Form	Language:		Description	Submitted:		If not submitted, specify reason (see KEY):
	English	Spanish		Yes	No	
T1	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Inclusion Form			Required
A1	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Subject Demographics			Required
A2	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Co-participant Demographics			Required
A3	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Subject Family History	<input type="checkbox"/> 1	<input type="checkbox"/> 0	— —
A4	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Subject Medications	<input type="checkbox"/> 1	<input type="checkbox"/> 0	— —
B4	<input type="checkbox"/> 1	<input type="checkbox"/> 2	CDR® Plus NACC FTLD			Required
B5	<input type="checkbox"/> 1	<input type="checkbox"/> 2	BEHAVIORAL ASSESSMENT NPI-Q	<input type="checkbox"/> 1	<input type="checkbox"/> 0	— —
B7	<input type="checkbox"/> 1	<input type="checkbox"/> 2	FUNCTIONAL ASSESSMENT NACC FAS	<input type="checkbox"/> 1	<input type="checkbox"/> 0	— —
B9	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Clinician Judgment of Symptoms			Required
D1	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Clinician Diagnosis			Required
D2	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Clinician-assessed Medical Conditions			Required

KEY: If the specified form was not completed, please enter one of the following codes:

95=Physical problem

96=Cognitive or behavioral problem

97=Other problem

98=Verbal refusal

CTF Clinical Measures & Diagnosis Working Group Update

- Most UDS3 TVP Form Items will likely remain as they are for short-term period
- Issues still under discussion:
 - Should additional items be moved to “optional” status?
 - How to best capture COVID-19 disease burden and potential impact on general health, brain health, biomarkers, and cognition (questionnaire developed)
 - How to best capture physical exam findings over the phone/video
 - Use of telephone visit packets for initial visits (currently used only for follow up)
 - Completion and documentation of consensus conference diagnoses using remote data

