

NACC UNIFORM DATA SET (UDS) DOWN SYNDROME MODULE

Guidance for Down Syndrome Module Submission

ADRC name: _____ Participant ID: _____ Form date: ____/____/____

Visit #: _____ Examiner's initials: _____

INSTRUCTIONS: This form is intended **ONLY** as guidance for clinical personnel completing the Down Syndrome Module and will **not be collected in the data submission process**. NACC expects and intends that all Down Syndrome Module forms will be attempted on participants who have Down Syndrome, but we realize this may be impossible when the patient is terminally ill, or when there is no co-participant, or for other reasons.

UDS

Form	Description	
<input type="radio"/> Z1x	Form Checklist	Required
<input type="radio"/> A1	Subject Demographics	Required
<input type="radio"/> A2	Co-participant Demographics	Recommended
<input type="radio"/> A3	Subject Family History	Recommended
<input type="radio"/> A4	Subject Medications	Recommended
<input type="radio"/> A5	Subject Health History	Required
<input type="radio"/> B1	EVALUATION FORM Vital Signs and Anthropometrics	Recommended
<input type="radio"/> B1a	EVALUATION FORM Blood Pressure Addendum	Recommended
<input type="radio"/> B4	CDR® PLUS NACC FTLD	Not validated for use with people with Down Syndrome (Enter 99 for all fields for data submission)
<input type="radio"/> B5	BEHAVIORAL ASSESSMENT NPI-Q	Recommended
<input type="radio"/> B6	BEHAVIORAL ASSESSMENT GDS	Recommended
<input type="radio"/> B7	FUNCTIONAL ASSESSMENT NACC FAS	Recommended
<input type="radio"/> B8	EVALUATION FORM Neurological Examination Findings	Required
<input type="radio"/> B9	Clinician Judgment of Symptoms	Required
<input type="radio"/> C2	Neuropsychological Battery Scores	Form Replaced with DS Module Form C1D (Enter 97/997 on Q1–Q12 and "0" on Q13 for data submission)
<input type="radio"/> D1	Clinician Diagnosis	Required
<input type="radio"/> D2	Clinician-assessed Medical Conditions	Required

DOWN SYNDROME MODULE

Form	Description		Notes
<input type="radio"/> A1D	Participant Health History	Required	
<input type="radio"/> B1D	NTG – Early Detection Screen for Dementia	Required	
<input type="radio"/> B2D	DLD Summary Page	Required	
<input type="radio"/> C1D	Neuropsychological Battery Scores	Required	Replaces UDS Form C2
<input type="radio"/> D1D	Clinician Exam and Diagnosis	Required	