



NACC UNIFORM DATA SET

**DOWN SYNDROME MODULE**

# Follow-up Visit Packet

**UDS Version 3.0, March 2015**

**DS Module Version 3.0, August 2022**

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**FOLLOW-UP VISIT PACKET** NACC UNIFORM DATA SET (UDS) DOWN SYNDROME MODULE

# Form A1D: Participant Health History

ADRC name: \_\_\_\_\_ Participant ID: \_\_\_\_\_ Form date: \_\_\_\_/\_\_\_\_/\_\_\_\_  
 Visit #: \_\_\_\_\_ Examiner's initials: \_\_\_\_\_

*INSTRUCTIONS: This form is to be completed by intake interviewer based on ADRC scheduling records, subject interview, medical records, and proxy co-participant report (as needed). For additional clarification and examples, see **Down Syndrome Module Coding Guidebook for Follow-up Visit Packet, Form A1D**. Check only one box per question.*

1. What are the participant's weekday activities?	
1a. Day program	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <input type="checkbox"/> 9 Unknown
1b. Workshops	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <input type="checkbox"/> 9 Unknown
1c. Stays at home	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <input type="checkbox"/> 9 Unknown
1d. Community paid job	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <input type="checkbox"/> 9 Unknown
1e. Other (SPECIFY): _____	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <input type="checkbox"/> 9 Unknown
2. Age of participant's mother at participant's birth	____ _ (777 = provided at previous visit; 999 = unknown)
3. Congenital heart disease — atrial septal defect	<input type="checkbox"/> 0 Absent <input type="checkbox"/> 1 Present — resolved <input type="checkbox"/> 2 Present — repaired <input type="checkbox"/> 3 Present — unrepaired <input type="checkbox"/> 9 Unknown
4. Congenital heart disease — ventricular septal defect	<input type="checkbox"/> 0 Absent <input type="checkbox"/> 1 Present — resolved <input type="checkbox"/> 2 Present — repaired <input type="checkbox"/> 3 Present — unrepaired <input type="checkbox"/> 9 Unknown

5. Congenital heart disease — atrioventricular (AV) canal defect	<input type="checkbox"/> 0 Absent <input type="checkbox"/> 1 Present — resolved <input type="checkbox"/> 2 Present — repaired <input type="checkbox"/> 3 Present — unrepaired <input type="checkbox"/> 9 Unknown
6. Congenital heart disease — tetralogy of Fallot	<input type="checkbox"/> 0 Absent <input type="checkbox"/> 1 Present — resolved <input type="checkbox"/> 2 Present — repaired <input type="checkbox"/> 3 Present — unrepaired <input type="checkbox"/> 9 Unknown
7. Congenital heart disease — other (SPECIFY): _____	<input type="checkbox"/> 0 Absent <input type="checkbox"/> 1 Present — resolved <input type="checkbox"/> 2 Present — repaired <input type="checkbox"/> 3 Present — unrepaired <input type="checkbox"/> 9 Unknown
8. Cardiovascular disease — hypotension	<input type="checkbox"/> 0 Absent <input type="checkbox"/> 1 Recent/active <input type="checkbox"/> 2 Remote/inactive <input type="checkbox"/> 9 Unknown
9. Cardiovascular disease — syncope	<input type="checkbox"/> 0 Absent <input type="checkbox"/> 1 Recent/active <input type="checkbox"/> 2 Remote/inactive <input type="checkbox"/> 9 Unknown
10. Pulmonary disease — pneumonia/aspiration	<input type="checkbox"/> 0 Absent <input type="checkbox"/> 1 Recent/active <input type="checkbox"/> 2 Remote/inactive <input type="checkbox"/> 9 Unknown
11. Hepatic conditions	<input type="checkbox"/> 1 Hepatitis B carrier <input type="checkbox"/> 2 Hepatitis B infected <input type="checkbox"/> 3 Hepatitis B immune <input type="checkbox"/> 4 Had hepatitis B vaccine <input type="checkbox"/> 9 Unknown

12. Dermatologic conditions — rosacea	<input type="checkbox"/> 0 Absent <input type="checkbox"/> 1 Recent/active <input type="checkbox"/> 2 Remote/inactive <input type="checkbox"/> 9 Unknown
13. Dermatologic conditions — alopecia	<input type="checkbox"/> 0 Absent <input type="checkbox"/> 1 Recent/active <input type="checkbox"/> 2 Remote/inactive <input type="checkbox"/> 9 Unknown
14. Dermatologic conditions — psoriasis	<input type="checkbox"/> 0 Absent <input type="checkbox"/> 1 Recent/active <input type="checkbox"/> 2 Remote/inactive <input type="checkbox"/> 9 Unknown
15. Musculoskeletal conditions — osteoporosis/ osteopenia	<input type="checkbox"/> 0 Absent <input type="checkbox"/> 1 Recent/active <input type="checkbox"/> 2 Remote/inactive <input type="checkbox"/> 9 Unknown
16. Musculoskeletal conditions — gout	<input type="checkbox"/> 0 Absent <input type="checkbox"/> 1 Recent/active <input type="checkbox"/> 2 Remote/inactive <input type="checkbox"/> 9 Unknown
17. Musculoskeletal conditions — atlanto-axial subluxation	<input type="checkbox"/> 0 Absent <input type="checkbox"/> 1 Present <input type="checkbox"/> 9 Unknown
18. Musculoskeletal conditions — fractures in the past five years	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes (SPECIFY): _____ <input type="checkbox"/> 9 Unknown
19. Endocrine/metabolic conditions — hypothyroidism	<input type="checkbox"/> 0 Absent <input type="checkbox"/> 1 Recent/active <input type="checkbox"/> 2 Remote/inactive <input type="checkbox"/> 9 Unknown

20. Endocrine/metabolic conditions — Hashimoto's thyroiditis	<input type="checkbox"/> 0 Absent <input type="checkbox"/> 1 Recent/active <input type="checkbox"/> 2 Remote/inactive <input type="checkbox"/> 9 Unknown
21. Endocrine/metabolic conditions — hyperthyroidism	<input type="checkbox"/> 0 Absent <input type="checkbox"/> 1 Recent/active <input type="checkbox"/> 2 Remote/inactive <input type="checkbox"/> 9 Unknown
22. Endocrine/metabolic conditions — currently on thyroid replacement medication	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes (SPECIFY): _____ <input type="checkbox"/> 9 Unknown
23. Endocrine/metabolic conditions — vitamin D deficiency	<input type="checkbox"/> 0 Absent <input type="checkbox"/> 1 Recent/active <input type="checkbox"/> 2 Remote/inactive <input type="checkbox"/> 9 Unknown
24. Menstrual history — has the participant ever menstruated?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes, active <input type="checkbox"/> 2 Yes, menopausal <input type="checkbox"/> 9 Unknown/not applicable
25. Menstrual history — age of onset of menses	____ _ (777 = provided at previous visit; 888 = not applicable; 999 = unknown)
26. Menstrual history — age of onset of menopause	____ _ (777 = provided at previous visit; 888 = not applicable; 999 = unknown)
27. Hormone replacement therapy — has the participant received HRT?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <input type="checkbox"/> 9 Unknown
28. Hormone replacement therapy — at what age did HRT begin?	____ _ (777 = provided at previous visit; 888 = not applicable; 999 = unknown)
29. Hormone replacement therapy — how many years has the participant been on HRT?	<input type="checkbox"/> 1 1 – 3 years <input type="checkbox"/> 2 4 – 6 years <input type="checkbox"/> 3 >6 years <input type="checkbox"/> 9 Unknown/not applicable

30. Gastrointestinal conditions — celiac disease	<input type="checkbox"/> 0 Absent <input type="checkbox"/> 1 Recent/active <input type="checkbox"/> 2 Remote/inactive <input type="checkbox"/> 9 Unknown
31. Hematopoietic/lymphatic disease — anemia with iron deficiency	<input type="checkbox"/> 0 Absent <input type="checkbox"/> 1 Recent/active <input type="checkbox"/> 2 Remote/inactive <input type="checkbox"/> 9 Unknown
32. Hematopoietic/lymphatic disease — anemia with folate deficiency	<input type="checkbox"/> 0 Absent <input type="checkbox"/> 1 Recent/active <input type="checkbox"/> 2 Remote/inactive <input type="checkbox"/> 9 Unknown
33. Autoimmune conditions — lupus	<input type="checkbox"/> 0 Absent <input type="checkbox"/> 1 Recent/active <input type="checkbox"/> 2 Remote/inactive <input type="checkbox"/> 9 Unknown
34. Autoimmune conditions — chronic neutropenia	<input type="checkbox"/> 0 Absent <input type="checkbox"/> 1 Recent/active <input type="checkbox"/> 2 Remote/inactive <input type="checkbox"/> 9 Unknown
35. Cancer — solid tumor	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes (SPECIFY PRIMARY SITE): _____ <input type="checkbox"/> 9 Unknown
36. Cancer — leukemia	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes, childhood transient myeloproliferative disorder <input type="checkbox"/> 2 Yes, childhood leukemia <input type="checkbox"/> 3 Yes, adult onset leukemia <input type="checkbox"/> 9 Unknown
37. Major surgical procedures — congenital heart-defect repair	<input type="checkbox"/> 0 No ( <b>SKIP TO QUESTION 38</b> ) <input type="checkbox"/> 1 Yes (SPECIFY): ( <b>CONTINUE</b> ) _____ <input type="checkbox"/> 9 Unknown ( <b>SKIP TO QUESTION 38</b> )

37a. Year of most recent congenital heart-defect repair	____ _ (7777 = provided at previous visit; 9999 = unknown)
38. Major surgical procedures — adult cardiac surgery	<input type="checkbox"/> 0 No ( <b>SKIP TO QUESTION 39</b> ) <input type="checkbox"/> 1 Yes (SPECIFY): ( <b>CONTINUE</b> ) _____ <input type="checkbox"/> 9 Unknown ( <b>SKIP TO QUESTION 39</b> )
38a. Year of most recent adult cardiac surgery	____ _ (7777 = provided at previous visit; 9999 = unknown)
39. Major surgical procedures — spinal surgery	<input type="checkbox"/> 0 No ( <b>SKIP TO QUESTION 40</b> ) <input type="checkbox"/> 1 Yes (SPECIFY): ( <b>CONTINUE</b> ) _____ <input type="checkbox"/> 9 Unknown ( <b>SKIP TO QUESTION 40</b> )
39a. Year of most recent spinal surgery	____ _ (7777 = provided at previous visit; 9999 = unknown)
40. Major surgical procedures — lower-extremity orthopedic surgery	<input type="checkbox"/> 0 No ( <b>SKIP TO QUESTION 41</b> ) <input type="checkbox"/> 1 Yes (SPECIFY): ( <b>CONTINUE</b> ) _____ <input type="checkbox"/> 9 Unknown ( <b>SKIP TO QUESTION 41</b> )
40a. Year of most recent lower-extremity orthopedic surgery	____ _ (7777 = provided at previous visit; 9999 = unknown)
41. Major surgical procedures — upper-extremity orthopedic surgery	<input type="checkbox"/> 0 No ( <b>SKIP TO QUESTION 42</b> ) <input type="checkbox"/> 1 Yes (SPECIFY): ( <b>CONTINUE</b> ) _____ <input type="checkbox"/> 9 Unknown ( <b>SKIP TO QUESTION 42</b> )
41a. Year of most recent upper-extremity orthopedic surgery	____ _ (7777 = provided at previous visit; 9999 = unknown)

42. Major surgical procedures — thyroid surgery	<input type="checkbox"/> 0 No ( <b>SKIP TO QUESTION 43</b> ) <input type="checkbox"/> 1 Yes (SPECIFY): ( <b>CONTINUE</b> ) _____ <input type="checkbox"/> 9 Unknown ( <b>SKIP TO QUESTION 43</b> )
42a. Year of most recent thyroid surgery	____ ____ ____ ____ (7777 = provided at previous visit; 9999 = unknown)
43. Major surgical procedures — oncology surgery	<input type="checkbox"/> 0 No ( <b>SKIP TO QUESTION 44</b> ) <input type="checkbox"/> 1 Yes (SPECIFY): ( <b>CONTINUE</b> ) _____ <input type="checkbox"/> 9 Unknown ( <b>SKIP TO QUESTION 44</b> )
43a. Year of most recent oncology surgery	____ ____ ____ ____ (7777 = provided at previous visit; 9999 = unknown)
44. Major surgical procedures — other surgery	<input type="checkbox"/> 0 No ( <b>END FORM HERE</b> ) <input type="checkbox"/> 1 Yes (SPECIFY): ( <b>CONTINUE</b> ) _____ <input type="checkbox"/> 9 Unknown ( <b>END FORM HERE</b> )
44a. Year of most recent other surgery	____ ____ ____ ____ (7777 = provided at previous visit; 9999 = unknown)



**FOLLOW-UP VISIT PACKET** NACC UNIFORM DATA SET (UDS) DOWN SYNDROME MODULE

**Form B1D: NTG — Early Detection Screen for Dementia**

ADRC name: \_\_\_\_\_ Participant ID: \_\_\_\_\_ Form date: \_\_\_/\_\_\_/\_\_\_\_\_  
 Visit #: \_\_\_\_\_ Examiner's initials: \_\_\_\_\_



# NTG-EDSD

(7) Sex:

	Female
	Male

**Instructions:**  
 For each question block, check the item that best applies to the individual or situation.

(8) Best description of intellectual disability

	No discernible intellectual disability
	Borderline (IQ 70-75)
	Mild ID (IQ 55-69)
	Moderate ID (IQ 40-54)
	Severe ID (IQ 25-39)
	Profound ID (IQ 24 and below)
	Unknown

(9) Diagnosed condition (check all that apply)

	Autism
	Cerebral palsy
	Down syndrome
	Fragile X syndrome
	Intellectual disability
	Prader-Willi syndrome
	Other:

**Current living arrangement of person:**

- Lives alone
- Lives with spouse or friends
- Lives with parents or other family members
- Lives with paid caregiver
- Lives in community group home, apartment, supervised housing, etc.
- Lives in senior housing
- Lives in congregate residential setting
- Lives in long term care facility
- Lives in other: \_\_\_\_\_

**(10) General characteristics of current physical health:**

	Excellent
	Very good
	Good
	Fair
	Poor

**(11) Compared to one year ago, current physical health is:**

	Much better
	Somewhat better
	About the same
	Somewhat worse
	Much worse

**(12) Compared to one year ago, current mental health is:**

	Much better
	Somewhat better
	About the same
	Somewhat worse
	Much worse

**(13) Conditions present (check all that apply)**

	Vision impairment
	Blind (very limited or no vision)
	Vision corrected by glasses
	Hearing impairment
	Deaf (very limited or no hearing)
	Hearing corrected by hearing aids
	Mobility impairment
	Not mobile — uses wheelchair
	Not mobile — is moved about in wheelchair

**(14) Significant recent [in past year] life event (check all that apply)**

	Death of someone close
	Changes in living arrangement, work, or day program
	Changes in staff close to the person
	New roommate/housemates
	Illness or impairment due to accident
	Adverse reaction to medication or over-medication
	Interpersonal conflicts
	Victimization / abuse
	Other:

**(15) Seizures**

	Recent onset seizures
	Long term occurrence of seizures
	Seizures in childhood, not occurring in adulthood
	No history of seizures

**If MCI or dementia is documented, complete 16, 17, & 18**

**(16) Diagnostic History**

Mild cognitive impairment [MCI] or dementia previously diagnosed (Dx)?

No

Yes, MCI

Date of Dx:

Yes, dementia

Date of Dx:

Type of dementia:

Diagnosed by:

Geriatrician

Neurologist

Physician

Psychiatrist

Psychologist

Other:

**(17) Reported date of onset of MCI/dementia**

[When suspicion of dementia first arose]

Note approximate year and month:

**(18) Comments / explanations about dementia suspicions:**

[Check column option as appropriate]

	Always been the case	Always but worse	New symptom in past year	Does not apply
<b>(19) Activities of Daily Living</b>				
Needs help with washing and/or bathing				
Needs help with dressing				
Dresses inappropriately (e.g., back to front, incomplete, inadequately for weather)				
Undresses inappropriately (e.g., in public)				
Needs help eating (cutting food, mouthful amounts, choking)				
Needs help using the bathroom (finding, toileting)				
Incontinent (including occasional accidents)				
<b>(20) Language &amp; Communication</b>				
Does not initiate conversation				
Does not find words				
Does not follow simple instructions				
Appears to get lost in middle of conversation				
Does not read				
Does not write (including printing own name)				
<b>(21) Sleep-Wake Change Patterns</b>				
Excessive sleep (sleeping more)				
Inadequate sleep (sleeping less)				
Wakes frequently at night				
Confused at night				
Sleeps during the day more than usual				
Wanders at night				
Wakes earlier than usual				
Sleeps later than usual				
<b>(22) Ambulation</b>				
Not confident walking over small cracks, lines on the ground, patterned flooring, or uneven surfaces				
Unsteady walk, loses balance				
Falls				
Requires aids to walk				

	Always been the case	Always but worse	New symptom in past year	Does not apply
<b>(23) Memory</b>				
Does not recognize familiar persons (staff/relatives/friends)				
Does not remember names of familiar people				
Does not remember recent events (in past week or less)				
Does not find way in familiar surroundings				
Loses track of time (time of day, day of the week, seasons)				
Loses or misplaces objects				
Puts familiar things in wrong places				
Problems with printing or signing own name				
Problems with learning new tasks or names of new people				
<b>(24) Behavior and affect</b>				
Wanders				
Withdraws from social activities				
Withdraws from people				
Loss of interest in hobbies and activities				
Seems to go into own world				
Obsessive or repetitive behavior				
Hides or hoards objects				
Does not know what to do with familiar objects				
Increased impulsivity (touching others, arguing, taking things)				
Appears uncertain, lacks confidence				
Appears anxious, agitated, or nervous				
Appears depressed				
Shows verbal aggression				
Shows physical aggression				
Temper tantrums, uncontrollable crying, shouting				
Shows lethargy or listlessness				
Talks to self				
<b>(25) Adult's Self-reported Problems</b>				
Changes in ability to do things				
Hearing things				
Seeing things				
Changes in 'thinking'				
Changes in interests				
Changes in memory				
<b>(26) Notable Significant Changes Observed by Others</b>				
In gait (e.g., stumbling, falling, unsteadiness)				
In personality (e.g., subdued when was outgoing)				
In friendliness (e.g., now socially unresponsive)				
In attentiveness (e.g., misses cues, distracted)				
In weight (e.g., weight loss or weight gain)				
In abnormal voluntary movements (head, neck, limbs, trunk)				

[Check column option as appropriate]

	<sup>(27)</sup> Chronic Health Conditions*	Recent condition (past year)	Condition diagnosed in last 5 years	Lifelong condition	Condition not present
	<b>Bone, Joint, and Muscle</b>				
1	Arthritis				
2	Osteoporosis				
	<b>Heart and Circulation</b>				
3	Heart condition				
4	High cholesterol				
5	High blood pressure				
6	Low blood pressure				
7	Stroke				
	<b>Hormonal</b>				
8	Diabetes (type 1 or 2)				
9	Thyroid disorder				
	<b>Lungs/breathing</b>				
10	Asthma				
11	Chronic bronchitis, emphysema				
12	Sleep disorder				
	<b>Mental Health</b>				
13	Alcohol or substance abuse				
14	Anxiety disorder				
15	Attention deficit disorder				
16	Bipolar disorder				
17	Dementia/Alzheimer's disease				
18	Depression				
19	Eating disorder (anorexia, bulimia)				
20	Obsessive-compulsive disorder				
21	Schizophrenia				
22	Other:				
	<b>Pain / Discomfort</b>				
23	Back pain				
24	Constipation				
25	Foot pain				
26	Gastrointestinal pain or discomfort				
27	Headaches				
28	Hip/knee pain				
29	Neck/shoulder pain				
	<b>Sensory</b>				
30	Dizziness / vertigo				
31	Impaired hearing				
32	Impaired vision				
	<b>Other</b>				
33	Cancer — type:				
34	Chronic fatigue				
35	Epilepsy / seizure disorder				
36	Heartburn / acid reflux				
37	Urinary incontinence				
38	Sleep apnea				
39	Tics/movement disorder/spasticity				
40	Dental pain				

\*Items drawn from the Longitudinal Health and Intellectual Disability Survey (University of Illinois at Chicago)

**(28) Current Medications**

**Yes    No    Indicate type**

- Treatment of chronic conditions
- Treatment of mental health disorders or behavior problems
- Treatment of pain

For reviews, attach list of current medications, dosage, and when prescribed

- List is attached for reviews

**(29) Comments related to other notable changes or concerns:**

**(30) Next Steps / Recommendations**

- Refer to treating physician for assessment
- Review internally by clinical personnel
- Include in annual review / annual wellness visit
- Repeat in \_\_\_\_\_ months

Acknowledgment: Derived from the DSQIID (\*Dementia Screening Questionnaire for Individuals with Intellectual Disabilities; Deb, S., 2007) as adapted into the Southeast PA Dementia Screening Tool (DST) – with the assistance of Carl V. Tyler, Jr., MD – and the LHIDS (Longitudinal Health and Intellectual Disability Survey; Rimmer & Hsieh, 2010) and as further adapted by the National Task Group on Intellectual Disabilities and Dementia Practices as the NTG Early Detection Screen for Dementia for use in the USA.

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National Task Group on Intellectual Disabilities and Dementia Practices

[www.aadmd.org/ntg/screening](http://www.aadmd.org/ntg/screening)

**FOLLOW-UP VISIT PACKET** NACC UNIFORM DATA SET (UDS) DOWN SYNDROME MODULE

# Form B2D: DLD Summary Page

ADRC name: \_\_\_\_\_ Participant ID: \_\_\_\_\_ Form date: \_\_\_/\_\_\_/\_\_\_\_\_  
 Visit #: \_\_\_\_\_ Examiner's initials: \_\_\_\_\_

**INSTRUCTIONS:** For DLD purchasing information, see **Down Syndrome Module Coding Guidebook for Follow-up Visit Packet, Form B2D.**

## Summary: Dementia Questionnaire for People With Learning Disabilities

Category →	1	2	3	4	5	6	7	8
Totals ↓	Short-term memory	Long-term memory	Spatial & temporal orientation	Speech	Practical skills	Mood	Activity & interest	Behavioral disturbance
Page 2					X	X	X	X
Page 3	X			X		X		
Page 4		X				X		
Page 5		X	X			X		X
Page 6					X	X		
Page 7		X	X	X	X			
Page 8	X			X			X	
Page 9	X			X	X		X	X
Page 10	X	X	X	X			X	X
<b>Category total</b>								

SCS = Sum of cognitive scores (1 – 3):

SOS = Sum of social scores (4 – 8):

**FOLLOW-UP VISIT PACKET** NACC UNIFORM DATA SET (UDS) DOWN SYNDROME MODULE

# Form C1D: Neuropsychological Battery Scores

ADRC name: \_\_\_\_\_ Participant ID: \_\_\_\_\_ Form date: \_\_\_\_/\_\_\_\_/\_\_\_\_  
 Visit #: \_\_\_\_\_ Examiner's initials: \_\_\_\_\_

**INSTRUCTIONS:** This form should be completed by ADRC or clinic staff. For test administration and scoring, see **Down Syndrome Module Coding Guidebook for Follow-Up Visit Packet, Form C1D.**

**KEY:** If the subject cannot complete any of the following exams, please give the reason by entering one of the following codes: **95=Physical problem; 96=Cognitive/behavior problem; 97=Other problem; 98=Verbal refusal**

## 1. Down Syndrome Mental Status Examination (DSMSE)

1. Was any part of the DSMSE administered?

- 0  No (If No, enter reason code, 95–98: \_\_\_\_ and **SKIP TO QUESTION 2**)  
 1  Yes (If Yes, **CONTINUE**)

		TOTALS (Score 1)	TOTALS (Score 2)
Personal information IA+IIIA+IIIB	1a1. ____ (0–7; 8=Not assessed)	1b2. ____ (0–11; 88=Not assessed)	1b3. ____ (0–11; 88=Not assessed)
Season/day IIIC+IIID	1b1. ____ (0–4; 8=Not assessed)	(1a1 + 1b1)	(1a1 + 1b1)
<b>Shoobox Memory</b>			
Object IIA	Immediate 1c1. ____ (0–9; 88=Not assessed)	Delay VA 1c2. ____ (0–9; 88=Not assessed)	1c3. ____ (0–18; 88=Not assessed) 1c4. ____ (0–18; 88=Not assessed)
		(1c1 + 1c2)	(1c1 + 1c2)
<b>Memory</b>			
Place VIIA	Immediate 1d1. ____ (0–3; 8=Not assessed)	Delay XA 1d2. ____ (0–3; 8=Not assessed)	1d3. ____ (0–6; 8=Not assessed) 1d4. ____ (0–6; 8=Not assessed)
		(1d1 + 1d2)	(1d1 + 1d2)
<b>Apraxia</b>			
Intransitive XIA	1e1. ____ (0–2; 8=Not assessed)	1e3. ____ (0.0–4.0; 8.8=Not assessed)	1e4. ____ (0.0–4.0; 8.0=Not assessed)
Transitive XIB	1e2. ____ (0.0–2.0; 8.8=Not assessed)	(1e1 + 1e2)	(1e1 + 1e2)
<b>Language</b>			
Naming VIA+VIIIA	1f1. ____ (0–11; 88=Not assessed)	Language Score 1 1f5. ____ . ____ (0.0–31; 88.8=Not assessed) (1f1 + 1f2 + 1f4)	Language Score 2 1f6. ____ . ____ (0.0–53; 88.8=Not assessed) (1f1 + 1f3 + 1f4)
Repetitions IVA (Method 1)	1f2. ____ (0–8; 88=Not assessed)		
Repetitions IVA (Method 2)	1f3. ____ (0–30; 88=Not assessed)		
Comprehension VIB	1f4. ____ . ____ (0.0–12; 88.8=Not assessed)		
<b>Visuospatial</b>			
IXA+IXB	1g1. ____ (0.0–8.8; 88.8=Not assessed)	1g2. ____ (0.0–8.8; 88.8=Not assessed)	1g3. ____ (0.0–8.8; 88.8=Not assessed)



**1. Down Syndrome Mental Status Examination (DSMSE)**

Knowledge of the Examiner			
IIIE+IIIF	1h1. ____ (0 – 3; 8=Not assessed)	1h2. ____ (0 – 3; 8= Not assessed)	1h3. ____ (0 – 3; 8= Not assessed)
<b>DSMSE TOTAL SCORE:</b>		<b>TOTAL SCORE 1:</b>	<b>TOTAL SCORE 2:</b>
		1i1. _____ (0.0 – 81; 995 – 998)	1i2. _____ (0.0 – 103; 995 – 998)

**2. Cued Recall Task (whole integer range)**

2a. Was any part of the Cued Recall Task administered?

- 0  No (If No, enter reason code, 95 – 98: \_\_\_\_ and **SKIP TO QUESTION 3**)  
 1  Yes (If Yes, **CONTINUE**)

2b. Indicate which cue card set was used: 1  Version 1 (Set A)  
 2  Version 2 (Set B)

2c. Training trial

	TRIAL 1	TRIAL 2	TRIAL 3
<b>Card 1</b>	2c1. ____ (0 – 4)	2c4. ____ (0 – 4)	2c7. ____ (0 – 4)
<b>Card 2</b>	2c2. ____ (0 – 4)	2c5. ____ (0 – 4)	2c8. ____ (0 – 4)
<b>Card 3</b>	2c3. ____ (0 – 4)	2c6. ____ (0 – 4)	2c9. ____ (0 – 4)

2d. Test trials

	FREE RECALL	INTRUSIONS TO FR	CUED RECALL	INTRUSIONS TO CR
<b>Trial 1</b>	2d1. ____ (0 – 12)	2d2. ____ ____ (no limit)	2d3. ____ (0 – 12)	2d4. ____ ____ (no limit)
<b>Trial 2</b>	2d5. ____ (0 – 12)	2d6. ____ ____ (no limit)	2d7. ____ (0 – 12)	2d8. ____ ____ (no limit)
<b>Trial 3</b>	2d9. ____ (0 – 12)	2d10. ____ ____ (no limit)	2d11. ____ (0 – 12)	2d12. ____ ____ (no limit)
<b>TOTAL SCORE</b>	2d13. ____ ____ (0 – 36)	2d14. ____ ____ (no limit)	2d15. ____ ____ (0 – 36)	2d16. ____ ____ (no limit)

**3. Appraisal of participant engagement**

Select the best description of the participant’s behavior during each test:

	COOPERATIVE AND ENGAGED	COOPERATIVE BUT DISTRACTED	UNCOOPERATIVE	NOT ADMINISTERED
3a. DSMSE	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	9 <input type="checkbox"/>
3b. Cued Recall Task	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	9 <input type="checkbox"/>

**FOLLOW-UP VISIT PACKET** NACC UNIFORM DATA SET (UDS) DOWN SYNDROME MODULE

## Form D1D: Clinician Exam and Diagnosis

ADRC name: \_\_\_\_\_ Participant ID: \_\_\_\_\_ Form date: \_\_\_\_/\_\_\_\_/\_\_\_\_

Visit #: \_\_\_\_ Examiner's initials: \_\_\_\_

**INSTRUCTIONS:** This form is to be completed by the clinician. For additional clarification and examples, see **Down Syndrome Coding Guidebook for Follow-up Visit Packet, Form D1D**. Check only one box per question.

1. Head circumference	_____ cm (777 = provided at previous visit, 888 = Not assessed)
2. Pathological reflexes — grasp	<input type="checkbox"/> 1 Absent <input type="checkbox"/> 2 Present <input type="checkbox"/> 9 Unknown/not assessed
3. Pathological reflexes — snout	<input type="checkbox"/> 1 Absent <input type="checkbox"/> 2 Present <input type="checkbox"/> 9 Unknown/not assessed
4. Pathological reflexes — rooting	<input type="checkbox"/> 1 Absent <input type="checkbox"/> 2 Present <input type="checkbox"/> 9 Unknown/not assessed
5. What is the participant's chromosome diagnosis?	<input type="checkbox"/> 1 Trisomy 21 <input type="checkbox"/> 2 Translocation DS <input type="checkbox"/> 3 Mosaic DS <input type="checkbox"/> 7 Provided at previous visit <input type="checkbox"/> 9 Unknown/not assessed
6. What is the participant's cognitive status?	<input type="checkbox"/> 1 Cognitively stable <input type="checkbox"/> 2 MCI-DS <input type="checkbox"/> 3 Dementia <input type="checkbox"/> 9 Unable to determine