

INITIAL VISIT PACKET NACC UNIFORM DATA SET (UDS) **DOWN SYNDROME MODULE**

Form A1D: Participant Health History

ADC name: _____ Subject ID: _____ Form date: ____ / ____ / _____

Visit #: _____ Examiner's initials: _____

INSTRUCTIONS: This form is to be completed by intake interviewer based on ADC 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 Initial 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	____ _ (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	____ _ (888 = not applicable; 999 = unknown)
26. Menstrual history — age of onset of menopause	____ _ (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?	____ _ (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 (SKIP TO QUESTION 38) <input type="checkbox"/> 1 Yes (SPECIFY): (CONTINUE) _____ <input type="checkbox"/> 9 Unknown (SKIP TO QUESTION 38)

37a. Year of most recent congenital heart-defect repair	____ _ (9999 = unknown)
38. Major surgical procedures — adult cardiac surgery	<input type="checkbox"/> 0 No (SKIP TO QUESTION 39) <input type="checkbox"/> 1 Yes (SPECIFY): (CONTINUE) _____ <input type="checkbox"/> 9 Unknown (SKIP TO QUESTION 39)
38a. Year of most recent adult cardiac surgery	____ _ (9999 = unknown)
39. Major surgical procedures — spinal surgery	<input type="checkbox"/> 0 No (SKIP TO QUESTION 40) <input type="checkbox"/> 1 Yes (SPECIFY): (CONTINUE) _____ <input type="checkbox"/> 9 Unknown (SKIP TO QUESTION 40)
39a. Year of most recent spinal surgery	____ _ (9999 = unknown)
40. Major surgical procedures — lower-extremity orthopedic surgery	<input type="checkbox"/> 0 No (SKIP TO QUESTION 41) <input type="checkbox"/> 1 Yes (SPECIFY): (CONTINUE) _____ <input type="checkbox"/> 9 Unknown (SKIP TO QUESTION 41)
40a. Year of most recent lower-extremity orthopedic surgery	____ _ (9999 = unknown)
41. Major surgical procedures — upper-extremity orthopedic surgery	<input type="checkbox"/> 0 No (SKIP TO QUESTION 42) <input type="checkbox"/> 1 Yes (SPECIFY): (CONTINUE) _____ <input type="checkbox"/> 9 Unknown (SKIP TO QUESTION 42)
41a. Year of most recent upper-extremity orthopedic surgery	____ _ (9999 = unknown)
42. Major surgical procedures — thyroid surgery	<input type="checkbox"/> 0 No (SKIP TO QUESTION 43) <input type="checkbox"/> 1 Yes (SPECIFY): (CONTINUE) _____ <input type="checkbox"/> 9 Unknown (SKIP TO QUESTION 43)

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