

**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): <hr/> <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> <hr/> <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 (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	____ _ (7777 = provided at previous visit; 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	____ _ (7777 = provided at previous visit; 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	____ _ (7777 = provided at previous visit; 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	____ _ (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)