



NACC UNIFORM DATA SET

**DOWN SYNDROME MODULE**

# **Data Element Dictionary**

**For Follow-up Visit Packet**

**UDS Version 3.0, March 2015**

**DS Module Version 1.0, August 2022**

Copyright© 2020 University of Washington. Created and published by the Down syndrome work group of the ADRC Program and the National Alzheimer's Coordinating Center (Walter A. Kukull, PhD, Director). All rights reserved.

This publication was funded by the National Institutes of Health through the National Institute on Aging (Co-operative Agreement U01 AG016976).

## Form Header

Q #	Data element name	Ver	Description	Data type	Allowable codes	Comment
0a	<b>PACKET_DS</b>	1.0	Packet code	Char	FDS = Follow-up Visit Packet, DS Module	
0b	<b>FORMVER_DS</b>	1.0	Form version	Num	1	
0c	<b>ADCID</b>	1.0	Center ID	Num	2 – 68; use appropriate code below: 2 = Boston University 4 = Columbia University 6 = Emory University 7 = Massachusetts ADRC 8 = Indiana University 9 = Johns Hopkins University 10 = Mayo Clinic 11 = Mount Sinai 12 = New York University 13 = Northwestern University 14 = Oregon Health & Science University 15 = Rush University 16 = University of California, Davis 18 = University of California, San Diego 19 = University of Kentucky 21 = University of Pennsylvania 22 = University of Pittsburgh 26 = University of Washington 27 = Washington University in St. Louis	30 = University of Southern California 31 = University of California, Irvine 32 = Stanford University 33 = Arizona ADC 34 = University of Arkansas 35 = University of California, San Francisco 37 = University of Wisconsin 38 = University of Kansas 39 = Stanford University #2 40 = Yale University 41 = 1Florida ADRC 42 = Wake Forest University 43 = University of Michigan ADC 46 = Cleveland Clinic, Las Vegas 47 = Vanderbilt University 48 = University of New Mexico 49 = Duke/UNC ADRC 65 = Cleveland ADRC 67 = South Texas ADRC 68 = U Alabama at Birmingham  Note: In research data sets generated by NACC, the variable NACCADCID is replaced by a randomly generated NACCADC.

Q #	Data element name	Ver	Description	Data type	Allowable codes	Comment
Od	<b>PTID</b>	1.0	ADRC participant ID	Char	Follow your Center's Patient ID scheme; use same ID as in MDS, if subject is enrolled in MDS.	Number must be unique within data from your Center and be used across all visits for the subject. <b>NOTE: PTID is replaced by a randomly generated NACCID in research data sets generated by NACC.</b>
0e	<b>VISITDATE</b>	1.0	Form date	Num	Month: 1–12 Day: 1–31 Year: 2020 to the current year	Visit date cannot precede January 1, 2020. Use the date that the UDS visit was started ( <i>i.e., first form date</i> ) for <b>VISITDATE</b> . If unsure, use the UDS Form A1 (Participant demographics) form date
Of	<b>VISITNUM</b>	1.0	Visit number	Num	Can be determined by the Center.	The Center can use its existing visit number scheme if desired. It is <b>NOT</b> required to start with 1.

Q	Data element name	Ver	Description	Data type	Allowable codes	Blanks, Skips, and Comments
<b>Form A1D: Participant Health History</b>						
0a	<b>FRMDATE_A1D</b>	1.0	Form Date	Num	mm/dd/yyyy Month: 1–12 Day: 1–31 Year: 2020 to the current year	Form date cannot precede January 1, 2020.
0b	<b>INITIALS_A1D</b>	1.0	Examiner's initials	Char	text	NOTE: <b>INITIALS</b> is never released in research data sets generated by NACC.
1a	<b>DSDAYPRG</b>	1.0	Participant's weekday activities: Day Program	Num	0 = No 1 = Yes 9 = Unknown	
1b	<b>DSWRKSH</b>	1.0	Participant's weekday activities: Workshops	Num	0 = No 1 = Yes 9 = Unknown	
1c	<b>DSHOME</b>	1.0	Participant's weekday activities: Stays at home	Num	0 = No 1 = Yes 9 = Unknown	
1d	<b>DSJOB</b>	1.0	Participant's weekday activities: Community paid job	Num	0 = No 1 = Yes 9 = Unknown	
1e	<b>DSOTHAC</b>	1.0	Participant's weekday activities: Other	Num	0 = No 1 = Yes 9 = Unknown	
1e1	<b>DSOTHACX</b>	1.0	Other weekday activity: Specify	Char	text	Blank if Question 1e <b>DSOTHAC</b> ≠ 1 (Participant's weekday activities: Other)
2	<b>DSMOMAGE</b>	1.0	Age of participant's mother at participant's birth	Num	10 – 60 777 = provided at previous visit 999 = unknown	
3	<b>DSCHDASD</b>	1.0	Congenital heart disease – atrial septal defect	Num	0 = Absent 1 = Present – resolved 2 = Present – repaired 3 = Present – unrepaired 9 = Unknown	

Q	Data element name	Ver	Description	Data type	Allowable codes	Blanks, Skips, and Comments
4	<b>DSCHDVSD</b>	1.0	Congenital heart disease – ventricular septal defect	Num	0 = Absent 1 = Present – resolved 2 = Present – repaired 3 = Present – unrepaired 9 = Unknown	
5	<b>DSCHDACD</b>	1.0	Congenital heart disease – atrioventricular (AV) canal defect	Num	0 = Absent 1 = Present – resolved 2 = Present – repaired 3 = Present – unrepaired 9 = Unknown	
6	<b>DSCHDToF</b>	1.0	Congenital heart disease – tetralogy of Fallot	Num	0 = Absent 1 = Present – resolved 2 = Present – repaired 3 = Present – unrepaired 9 = Unknown	
7	<b>DSCHDOTH</b>	1.0	Congenital heart disease – Other	Num	0 = Absent 1 = Present – resolved 2 = Present – repaired 3 = Present – unrepaired 9 = Unknown	
7a	<b>DSCHDOTX</b>	1.0	Other congenital heart disease: Specify	Char	text	Blank if Question 7 <b>DSCHDOTH</b> = 0 (Congenital heart disease – Other: Absent) Blank if Question 7 <b>DSCHDOTH</b> = 9 (Congenital heart disease – Other: Unknown)
8	<b>DSHYPOTN</b>	1.0	Cardiovascular disease – hypotension	Num	0 = Absent 1 = Recent/active 2 = Remote/inactive 9 = Unknown	
9	<b>DSSYNC</b>	1.0	Cardiovascular disease – syncope	Num	0 = Absent 1 = Recent/active 2 = Remote/inactive 9 = Unknown	
10	<b>DSPNEUM</b>	1.0	Pulmonary disease – pneumonia/ aspiration	Num	0 = Absent 1 = Recent/active 2 = Remote/inactive 9 = Unknown	

Q	Data element name	Ver	Description	Data type	Allowable codes	Blanks, Skips, and Comments
11	<b>DSHEPAT</b>	1.0	Hepatic conditions	Num	1 = Hepatitis B carrier 2 = Hepatitis B infected 3 = Hepatitis B immune 4 = Had hepatitis B vaccine 9 = Unknown	
12	<b>DSROSAC</b>	1.0	Dermatologic conditions – rosacea	Num	0 = Absent 1 = Recent/active 2 = Remote/inactive 9 = Unknown	
13	<b>DSALOP</b>	1.0	Dermatologic conditions – alopecia	Num	0 = Absent 1 = Recent/active 2 = Remote/inactive 9 = Unknown	
14	<b>DSPSOR</b>	1.0	Dermatologic conditions – psoriasis	Num	0 = Absent 1 = Recent/active 2 = Remote/inactive 9 = Unknown	
15	<b>DSOSTEO</b>	1.0	Musculoskeletal conditions – osteoporosis/osteopenia	Num	0 = Absent 1 = Recent/active 2 = Remote/inactive 9 = Unknown	
16	<b>DSGOUT</b>	1.0	Musculoskeletal conditions – gout	Num	0 = Absent 1 = Recent/active 2 = Remote/inactive 9 = Unknown	
17	<b>DSATAXSU</b>	1.0	Musculoskeletal conditions – atlanto-axial subluxation	Num	0 = Absent 1 = Present 9 = Unknown	
18	<b>DSFRACT</b>	1.0	Musculoskeletal conditions – fractures in the past five years	Num	0 = No 1 = Yes 9 = Unknown	
18a	<b>DSFRACTX</b>	1.0	Fractures in the past five years: Specify	Char	text	Blank if Question 18 <b>DSFRACT</b> ≠ 1 (Fractures in the past five years)
19	<b>DSHYPOTH</b>	1.0	Endocrine/metabolic conditions – hypothyroidism	Num	0 = Absent 1 = Recent/active 2 = Remote/inactive 9 = Unknown	

Q	Data element name	Ver	Description	Data type	Allowable codes	Blanks, Skips, and Comments
20	<b>DSHASHIM</b>	1.0	Endocrine/metabolic conditions – Hashimoto's thyroiditis	Num	0 = Absent 1 = Recent/active 2 = Remote/inactive 9 = Unknown	
21	<b>DSHYPER</b>	1.0	Endocrine/metabolic conditions – hyperthyroidism	Num	0 = Absent 1 = Recent/active 2 = Remote/inactive 9 = Unknown	
22	<b>DSTHYMED</b>	1.0	Endocrine/metabolic conditions – currently on thyroid replacement medication	Num	0 = No 1 = Yes 9 = Unknown	
22a	<b>DSTHYMEX</b>	1.0	Thyroid replacement medication: Specify	Char	text	Blank if Question 22 <b>DSTHYMED</b> ≠ 1 (Currently on thyroid replacement medication)
23	<b>DSVDDEF</b>	1.0	Endocrine/metabolic conditions – vitamin D deficiency	Num	0 = Absent 1 = Recent/active 2 = Remote/inactive 9 = Unknown	
24	<b>DSMENSTR</b>	1.0	Menstrual history – has the participant ever menstruated?	Num	0 = No 1 = Yes, active 2 = Yes, menopausal 9 = Unknown/not applicable	
25	<b>DSMNSAGE</b>	1.0	Menstrual history – age of onset of menses	Num	8 – 20 777 = provided at previous visit 888 = Not applicable 999 = Unknown	
26	<b>DSMNPAGE</b>	1.0	Menstrual history – age of onset of menopause	Num	20 – 65 777 = provided at previous visit 888 = not applicable 999 = unknown	
27	<b>DSHRT</b>	1.0	Hormone replacement therapy – has the participant received HRT?	Num	0 = No 1 = Yes 9 = Unknown	
28	<b>DSAGEHRT</b>	1.0	Hormone replacement therapy – at what age did HRT begin?	Num	0 – 110 777 = provided at previous visit 888 = not applicable 999 = unknown	

Q	Data element name	Ver	Description	Data type	Allowable codes	Blanks, Skips, and Comments
29	<b>DSYRSHRT</b>	1.0	Hormone replacement therapy – how many years has the participant been on HRT?	Num	1 = 1–3 years 2 = 4–6 years 3 = >6 years 9 = Unknown/not applicable	
30	<b>DSCELIAC</b>	1.0	Gastrointestinal conditions – celiac disease	Num	0 = Absent 1 = Recent/active 2 = Remote/inactive 9 = Unknown	
31	<b>DSANIRON</b>	1.0	Hematopoietic/lymphatic disease – anemia with iron deficiency	Num	0 = Absent 1 = Recent/active 2 = Remote/inactive 9 = Unknown	
32	<b>DSANFOL</b>	1.0	Hematopoietic/lymphatic disease – anemia with folate deficiency	Num	0 = Absent 1 = Recent/active 2 = Remote/inactive 9 = Unknown	
33	<b>DSLUPUS</b>	1.0	Autoimmune conditions – lupus	Num	0 = Absent 1 = Recent/active 2 = Remote/inactive 9 = Unknown	
34	<b>DSNTRPN</b>	1.0	Autoimmune conditions – chronic neutropenia	Num	0 = Absent 1 = Recent/active 2 = Remote/inactive 9 = Unknown	
35	<b>DSTUMOR</b>	1.0	Cancer – solid tumor	Num	0 = No 1 = Yes 9 = Unknown	
35a	<b>DSTUMORX</b>	1.0	Solid tumor: Specify primary site	Char	text	Blank if Question 35 <b>DSTUMOR</b> ≠1 (Cancer – solid tumor)
36	<b>DSLEUKEM</b>	1.0	Cancer – leukemia	Num	0 = No 1 = Yes, childhood transient myeloproliferative disorder 2 = Yes, childhood leukemia 3 = Yes, adult onset leukemia 9 = Unknown	



Q	Data element name	Ver	Description	Data type	Allowable codes	Blanks, Skips, and Comments
37	<b>DSHRTRPR</b>	1.0	Major surgical procedures – congenital heart-defect repair	Num	0 = No 1 = Yes 9 = Unknown	
37.1	<b>DSHRTRPX</b>	1.0	Congenital heart-defect repair: Specify	Char	text	Blank if Question 37 <b>DSHRTRPR</b> ≠ 1 (Congenital heart-defect repair)
37a	<b>DSHRTRYR</b>	1.0	Year of most recent congenital heart-defect repair	Num	1900 to current year 777 = provided at previous visit 9999 = Unknown	
38	<b>DSCRDSRG</b>	1.0	Major surgical procedures – adult cardiac surgery	Num	0 = No 1 = Yes 9 = Unknown	
38.1	<b>DSCRDSRX</b>	1.0	Adult cardiac surgery: Specify	Char	text	Blank if Question 38 <b>DSCRDSRG</b> ≠ 1 (Adult cardiac surgery)
38a	<b>DSCRDSYR</b>	1.0	Year of most recent adult cardiac surgery	Num	1900 to current year 777 = provided at previous visit 9999 = Unknown	
39	<b>DSSPIN</b>	1.0	Major surgical procedures – spinal surgery	Num	0 = No 1 = Yes 9 = Unknown	
39.1	<b>DSSPINX</b>	1.0	Spinal surgery: Specify	Char	text	Blank if Question 39 <b>DSSPIN</b> ≠ 1 (Spinal surgery)
39a	<b>DSSPINYR</b>	1.0	Year of most recent spinal surgery	Num	1900 to current year 777 = provided at previous visit 9999 = Unknown	
40	<b>DSLWORTH</b>	1.0	Major surgical procedures – lower-extremity orthopedic surgery	Num	0 = No 1 = Yes 9 = Unknown	
40.1	<b>DSLWORTX</b>	1.0	Lower-extremity orthopedic surgery: Specify	Char	text	Blank if Question 40 <b>DSLWORTH</b> ≠ 1 (Lower-extremity orthopedic surgery)
40a	<b>DSLWORYR</b>	1.0	Year of most recent lower-extremity orthopedic surgery	Num	1900 to current year 777 = provided at previous visit 9999 = Unknown	
41	<b>DSUPORTH</b>	1.0	Major surgical procedure – upper-extremity orthopedic surgery	Num	0 = No 1 = Yes 9 = Unknown	

Q	Data element name	Ver	Description	Data type	Allowable codes	Blanks, Skips, and Comments
41.1	<b>DSUPORTX</b>	1.0	Upper-extremity orthopedic surgery: Specify	Char	text	Blank if Question 41 <b>DSUPORTH</b> ≠ 1 (Upper-extremity orthopedic surgery)
41a	<b>DSUPORYR</b>	1.0	Year of most recent upper-extremity orthopedic surgery	Num	1900 to current year 777 = provided at previous visit 9999 = Unknown	
42	<b>DSTHYSRG</b>	1.0	Major surgical procedures – thyroid surgery	Num	0 = No 1 = Yes 9 = Unknown	
42.1	<b>DSTHYSRX</b>	1.0	Thyroid surgery: Specify	Char	text	Blank if Question 42 <b>DSTHYSRG</b> ≠ 1 (Thyroid surgery)
42a	<b>DSTHYSYR</b>	1.0	Year of most recent thyroid surgery	Num	1900 to current year 777 = provided at previous visit 9999 = Unknown	
43	<b>DSONCSRG</b>	1.0	Major surgical procedures – oncology surgery	Num	0 = No 1 = Yes 9 = Unknown	
43.1	<b>DSONCSRX</b>	1.0	Oncology surgery: Specify	Char	text	Blank if Question 43 <b>DSONCSRG</b> ≠ 1 (Oncology surgery)
43a	<b>DSONCSYR</b>	1.0	Year of most recent oncology surgery	Num	1900 to current year 777 = provided at previous visit 9999 = Unknown	
44	<b>DSOTHSRG</b>	1.0	Major surgical procedures – other surgery	Num	0 = No 1 = Yes 9 = Unknown	
44.1	<b>DSOTHSRX</b>	1.0	Other surgery: Specify	Char	text	Blank if Question 44 <b>DSOTHSRG</b> ≠ 1 (Other surgery)
44a	<b>DSOTHSYR</b>	1.0	Year of most recent other surgery	Num	1900 to current year 777 = provided at previous visit 9999 = Unknown	

Q	Data element name	Ver	Description	Data type	Allowable codes	Blanks, Skips, and Comments
<b>Form B1D: NTG – Early Detection Screen for Dementia</b>						
0a	<b>FRMDATE_B1D</b>	1.0	Form Date	Num	mm/dd/yyyy Month: 1–12 Day: 1–31 Year: 2020 to the current year	Form date cannot precede January 1, 2020.
0b	<b>INITIALS_B1D</b>	1.0	Examiner's initials	Char	text	NOTE: <b>INITIALS</b> is never released in research data sets generated by NACC.
0c	<b>DSLIV</b>	1.0	Current living arrangement of person	Num	1 = Lives alone 2 = Lives with spouse or friends 3 = Lives with parents or other family members 4 = Lives with paid caregiver 5 = Lives in community group home, apartment, supervised housing, etc. 6 = Lives in senior housing 7 = Lives in congregate residential setting 8 = Lives in long term care facility 9 = Lives in other	
0c1	<b>DSLIVX</b>	1.0	Other living arrangement: Specify	Char	text	Blank if Question 0 <b>DSLIV</b> ≠ 9 (Lives in other)
7	<b>DSSEX</b>	1.0	Sex	Num	0 = Female 1 = Male	
8	<b>DSDISLEV</b>	1.0	Best Description of intellectual disability	Num	1 = No discernible intellectual disability 2 = Borderline (IQ 70 - 75) 3 = Mild ID (IQ 55 - 69) 4 = Moderate ID (IQ 40 - 54) 5 = Severe ID (IQ 25 - 39) 6 = Profound ID (IQ 24 and below) 9 = Unknown	
9a	<b>DSDX_AUT</b>	1.0	Diagnosed condition: Autism	Num	0 = Blank 1 = Yes	
9b	<b>DSDX_CP</b>	1.0	Diagnosed condition: Cerebral palsy	Num	0 = Blank 1 = Yes	
9c	<b>DSDX_DS</b>	1.0	Diagnosed condition: Down syndrome	Num	0 = Blank 1 = Yes	

Q	Data element name	Ver	Description	Data type	Allowable codes	Blanks, Skips, and Comments
9d	<b>DSDX_FRX</b>	1.0	Diagnosed condition: Fragile X syndrome	Num	0 = Blank 1 = Yes	
9e	<b>DSDX_ID</b>	1.0	Diagnosed condition: Intellectual disability	Num	0 = Blank 1 = Yes	
9f	<b>DSDX_PW</b>	1.0	Diagnosed condition: Prader–Willi syndrome	Num	0 = Blank 1 = Yes	
9g	<b>DSDX_OTH</b>	1.0	Diagnosed condition: other	Num	0 = Blank 1 = Yes	
9g1	<b>DSDXOTHX</b>	1.0	Other diagnosed condition: Specify	Char	text	Blank if Question 9g <b>DSDX_OTH</b> ≠ 1 (Diagnosed condition: other)
10	<b>DSPHYS</b>	1.0	General characterization of current physical health	Num	0 = Poor 1 = Fair 2 = Good 3 = Very good 4 = Excellent	
11	<b>DSPHYSYR</b>	1.0	Compared to one year ago current physical health is	Num	0 = Much worse 1 = Somewhat worse 2 = About the same 3 = Somewhat better 4 = Much better	
12	<b>DSMENTAL</b>	1.0	Compared to one year ago current mental health is	Num	0 = Much worse 1 = Somewhat worse 2 = About the same 3 = Somewhat better 4 = Much better	
13a	<b>DSCN_VIM</b>	1.0	Condition present: Vision impairment	Num	0 = Blank 1 = Yes	
13b	<b>DSCN_BLD</b>	1.0	Condition present: Blind (very limited or no vision)	Num	0 = Blank 1 = Yes	
13c	<b>DSCN_GLS</b>	1.0	Condition present: Vision corrected by glasses	Num	0 = Blank 1 = Yes	
13d	<b>DSCN_HIM</b>	1.0	Condition present: Hearing impairment	Num	0 = Blank 1 = Yes	
13e	<b>DSCN_DF</b>	1.0	Condition present: Deaf (very limited or no hearing)	Num	0 = Blank 1 = Yes	

Q	Data element name	Ver	Description	Data type	Allowable codes	Blanks, Skips, and Comments
13f	<b>DSCN_HAD</b>	1.0	Condition present: Hearing corrected by hearing aids	Num	0 = Blank 1 = Yes	
13g	<b>DSCN_MIM</b>	1.0	Condition present: Mobility impairment	Num	0 = Blank 1 = Yes	
13h	<b>DSCN_UW</b>	1.0	Condition present: Not mobile – uses wheelchair	Num	0 = Blank 1 = Yes	
13i	<b>DSCN_MIW</b>	1.0	Condition present: Not mobile – is moved about in wheelchair	Num	0 = Blank 1 = Yes	
14a	<b>DSLE_CD</b>	1.0	Significant life event: Death of someone close	Num	0 = Blank 1 = Yes	
14b	<b>DSLE_CHL</b>	1.0	Significant life event: Changes in living arrangement, work, or day program	Num	0 = Blank 1 = Yes	
14c	<b>DSLE_CHS</b>	1.0	Significant life event: Changes in staff close to the person	Num	0 = Blank 1 = Yes	
14d	<b>DSLE_NRM</b>	1.0	Significant life event: New roommate/housemates	Num	0 = Blank 1 = Yes	
14e	<b>DSLE_ILL</b>	1.0	Significant life event: Illness or impairment due to accident	Num	0 = Blank 1 = Yes	
14f	<b>DSLE_SEM</b>	1.0	Significant life event: Adverse reaction to medication or over-medication	Num	0 = Blank 1 = Yes	
14g	<b>DSLE_SEI</b>	1.0	Significant life event: Interpersonal conflicts	Num	0 = Blank 1 = Yes	
14h	<b>DSLE_SEV</b>	1.0	Significant life event: Victimization/abuse	Num	0 = Blank 1 = Yes	
14i	<b>DSLE_OTH</b>	1.0	Significant life event: Other	Num	0 = Blank 1 = Yes	
14i1	<b>DSLEOTHX</b>	1.0	Significant recent life event: Specify	Char	Text	Blank if Question 14i <b>DSLE_OTH</b> ≠ 1 (Significant life event: other)
15	<b>DSSEIZ</b>	1.0	Seizures	Num	0 = No history of seizures 1 = Seizures in childhood, not occurring in adulthood 2 = Long term occurrence of seizures 3 = Recent onset seizures	

Q	Data element name	Ver	Description	Data type	Allowable codes	Blanks, Skips, and Comments
16a	<b>DSDXHS_NO</b>	1.0	Diagnostic history: No diagnosis of MCI or dementia	Num	0 = Blank 1 = Yes	If Question 16a <b>DSDXHS_NO</b> = 1 (No diagnosis of MCI or dementia), then skip to Question 19
16b	<b>DSDXHS_MCI</b>	1.0	Diagnostic history: Yes, mild cognitive impairment (MCI)	Num	0 = Blank 1 = Yes	
16c	<b>DSDXHS_DEM</b>	1.0	Diagnostic history: Yes, dementia	Num	0 = Blank 1 = Yes	
16a1	<b>DSMCIMO</b>	1.0	MCI diagnosis month	Num	1 = January 2 = February 3 = March 4 = April 5 = May 6 = June 7 = July 8 = August 9 = September 10 = October 11 = November 12 = December 99 = Diagnosis month is unknown	Blank if Question 16b <b>DSDXHS_MCI</b> ≠ 1 (MCI)
16a2	<b>DSMCIYR</b>	1.0	MCI diagnosis year	Num	1950 to current year 9999 = Unknown	Blank if Question 16b <b>DSDXHS_MCI</b> ≠ 1 (MCI)
16b1	<b>DSDEMMO</b>	1.0	Dementia diagnosis month	Num	1 = January 2 = February 3 = March 4 = April 5 = May 6 = June 7 = July 8 = August 9 = September 10 = October 11 = November 12 = December 99 = Diagnosis month is unknown	Blank if Question 16c <b>DSDXHS_DEM</b> ≠ 1 (Dementia)
16b2	<b>DSDEMYR</b>	1.0	Dementia diagnosis year	Num	1950 to current year 9999 = Unknown	Blank if Question 16c <b>DSDXHS_DEM</b> ≠ 1 (Dementia)

Q	Data element name	Ver	Description	Data type	Allowable codes	Blanks, Skips, and Comments
16b3	<b>DSDXTYPE</b>	1.0	Type of dementia	Char	text	Blank if Question 16c <b>DSDXHS_DEM</b> ≠ 1 (Dementia)
16d	<b>DSDXBY</b>	1.0	MCI/dementia diagnosed by	Num	1 = Geriatrician 2 = Neurologist 3 = Physician 4 = Psychiatrist 5 = Psychologist 6 = Other	Blank if Question 16a <b>DSDXHS_NO</b> = 1 (No diagnosis of MCI or dementia)
16d1	<b>DSDXBYX</b>	1.0	MCI/dementia diagnosed by other: Specify	Char	text	Blank if Question 16d <b>DSDXBY</b> ≠ 6 (Diagnosed by: other)
17a	<b>DSNSTMO</b>	1.0	Note approximate MONTH of onset of MCI/dementia	Num	1 = January 2 = February 3 = March 4 = April 5 = May 6 = June 7 = July 8 = August 9 = September 10 = October 11 = November 12 = December 99 = Diagnosis month is unknown	Blank if Question 16a <b>DSDXHS_NO</b> = 1 (No diagnosis of MCI or dementia)
17b	<b>DSNSTYR</b>	1.0	Note approximate YEAR of onset of MCI/dementia	Num	1950 to current year 9999 = Unknown	Blank if Question 16a <b>DSDXHS_NO</b> = 1 (No diagnosis of MCI or dementia)
18	<b>DSDECOM</b>	1.0	Comments/explanations about dementia suspicions	Char	text	Blank if Question 16a <b>DSDXHS_NO</b> = 1 (No diagnosis of MCI or dementia)
19a	<b>DSADL1</b>	1.0	Activities of daily living: Needs help washing and/or bathing	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	
19b	<b>DSADL2</b>	1.0	Activities of daily living: Needs help with dressing	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	

Q	Data element name	Ver	Description	Data type	Allowable codes	Blanks, Skips, and Comments
19c	<b>DSADL3</b>	1.0	Activities of daily living: Dresses inappropriately (e.g., back to front, incomplete, inadequately for weather)	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	
19d	<b>DSADL4</b>	1.0	Activities of daily living: Undresses inappropriately (e.g., in public)	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	
19e	<b>DSADL5</b>	1.0	Activities of daily living: Needs help eating (cutting food, mouthful amounts, choking)	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	
19f	<b>DSADL6</b>	1.0	Activities of daily living: Needs help using the bathroom (finding, toileting)	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	
19g	<b>DSADL7</b>	1.0	Activities of daily living: Incontinent (including occasional accidents)	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	
20a	<b>DSLNG1</b>	1.0	Language & Communication: Does not initiate conversation	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	
20b	<b>DSLNG2</b>	1.0	Language & Communication: Does not find words	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	
20c	<b>DSLNG3</b>	1.0	Language & Communication: Does not follow simple instructions	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	
20d	<b>DSLNG4</b>	1.0	Language & Communication: Appears to get lost in middle of conversation	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	



Q	Data element name	Ver	Description	Data type	Allowable codes	Blanks, Skips, and Comments
20e	<b>DSLNG5</b>	1.0	Language & Communication: Does not read	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	
20f	<b>DSLNG6</b>	1.0	Language & Communication: Does not write (including printing own name)	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	
21a	<b>DSSLEEP1</b>	1.0	Sleep/wake change patterns: Excessive sleep (sleeping more)	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	
21b	<b>DSSLEEP2</b>	1.0	Sleep/wake change patterns: Inadequate sleep (sleeping less)	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	
21c	<b>DSSLEEP3</b>	1.0	Sleep/wake change patterns: Wakes frequently at night	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	
21d	<b>DSSLEEP4</b>	1.0	Sleep/wake change patterns: Confused at night	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	
21e	<b>DSSLEEP5</b>	1.0	Sleep/wake change patterns: Sleeps during the day more than usual	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	
21f	<b>DSSLEEP6</b>	1.0	Sleep/wake change patterns: Wanders at night	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	
21g	<b>DSSLEEP7</b>	1.0	Sleep/wake change patterns: Wakes earlier than usual	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	

Q	Data element name	Ver	Description	Data type	Allowable codes	Blanks, Skips, and Comments
21h	<b>DSSLEEP8</b>	1.0	Sleep/wake change patterns: Sleeps later than usual	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	
22a	<b>DSAMB1</b>	1.0	Ambulation: Not confident walking over small cracks, lines on the ground, patterned flooring, or uneven surfaces	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	
22b	<b>DSAMB2</b>	1.0	Ambulation: Unsteady walk, loses balance	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	
22c	<b>DSAMB3</b>	1.0	Ambulation: Falls	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	
22d	<b>DSAMB4</b>	1.0	Ambulation: Requires aids to walk	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	
23a	<b>DSMEM1</b>	1.0	Memory: Does not recognize familiar persons (staff/relatives/friends)	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	
23b	<b>DSMEM2</b>	1.0	Memory: Does not remember names of familiar people	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	
23c	<b>DSMEM3</b>	1.0	Memory: Does not remember recent events (in past week or less)	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	
23d	<b>DSMEM4</b>	1.0	Memory: Does not find way in familiar surroundings	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	

Q	Data element name	Ver	Description	Data type	Allowable codes	Blanks, Skips, and Comments
23e	<b>DSMEM5</b>	1.0	Memory: Loses track of time (time of day, day of the week, seasons)	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	
23f	<b>DSMEM6</b>	1.0	Memory: Loses or misplaces objects	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	
23g	<b>DSMEM7</b>	1.0	Memory: Puts familiar things in wrong places	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	
23h	<b>DSMEM8</b>	1.0	Memory: Problems with printing or signing own name	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	
23i	<b>DSMEM9</b>	1.0	Memory: Problems with learning new tasks or names of new people	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	
24a	<b>DSBEH1</b>	1.0	Behavior and Affect: Wanders	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	
24b	<b>DSBEH2</b>	1.0	Behavior and Affect: Withdraws from social activities	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	
24c	<b>DSBEH3</b>	1.0	Behavior and Affect: Withdraws from people	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	
24d	<b>DSBEH4</b>	1.0	Behavior and Affect: Loss of interest in hobbies and activities	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	

Q	Data element name	Ver	Description	Data type	Allowable codes	Blanks, Skips, and Comments
24e	<b>DSBEH5</b>	1.0	Behavior and Affect: Seems to go into own world	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	
24f	<b>DSBEH6</b>	1.0	Behavior and Affect: Obsessive or repetitive behavior	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	
24g	<b>DSBEH7</b>	1.0	Behavior and Affect: Hids or hoards objects	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	
24h	<b>DSBEH8</b>	1.0	Behavior and Affect: Does not know what to do with familiar objects	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	
24i	<b>DSBEH9</b>	1.0	Behavior and Affect: Increased impulsivity (touching others, arguing, taking things)	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	
24j	<b>DSBEH10</b>	1.0	Behavior and Affect: Appears uncertain, lacks confidence	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	
24k	<b>DSBEH11</b>	1.0	Behavior and Affect: Appears anxious, agitated, or nervous	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	
24l	<b>DSBEH12</b>	1.0	Behavior and Affect: Appears depressed	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	
24m	<b>DSBEH13</b>	1.0	Behavior and Affect: Shows verbal aggression	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	

Q	Data element name	Ver	Description	Data type	Allowable codes	Blanks, Skips, and Comments
24n	<b>DSBEH14</b>	1.0	Behavior and Affect: Shows physical aggression	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	
24o	<b>DSBEH15</b>	1.0	Behavior and Affect: Temper tantrums, uncontrollable crying, shouting	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	
24p	<b>DSBEH16</b>	1.0	Behavior and Affect: Shows lethargy or listlessness	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	
24q	<b>DSBEH17</b>	1.0	Behavior and Affect: Talks to self	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	
25a	<b>DSSELF1</b>	1.0	Self-reported problems: Changes in ability to do things	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	
25b	<b>DSSELF2</b>	1.0	Self-reported problems: Hearing things	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	
25c	<b>DSSELF3</b>	1.0	Self-reported problems: Seeing things	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	
25d	<b>DSSELF4</b>	1.0	Self-reported problems: Changes in "thinking"	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	
25e	<b>DSSELF5</b>	1.0	Self-reported problems: Changes in interests	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	

Q	Data element name	Ver	Description	Data type	Allowable codes	Blanks, Skips, and Comments
25f	<b>DSSELF6</b>	1.0	Self-reported problems: Changes in memory	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse 3 = Always been the case	
26a	<b>DSOTHER1</b>	1.0	Changes observed by others: In gait (e.g., stumbling, falling, unsteadiness)	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse	
26b	<b>DSOTHER2</b>	1.0	Changes observed by others: In personality (e.g., subdued when was outgoing)	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse	
26c	<b>DSOTHER3</b>	1.0	Changes observed by others: In friendliness (e.g. now socially unresponsive)	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse	
26d	<b>DSOTHER4</b>	1.0	Changes observed by others: In attentiveness (e.g., missing cues, distracted)	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse	
26e	<b>DSOTHER5</b>	1.0	Changes observed by others: In weight (e.g., weight loss or weight gain)	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse	
26f	<b>DSOTHER6</b>	1.0	Changes observed by others: In abnormal voluntary movements (head, neck, limbs, trunk)	Num	0 = Does not apply 1 = New symptom in past year 2 = Always but worse	
27a	<b>DSARTHR</b>	1.0	Bone, Joint, and Muscle: Arthritis	Num	0 = Condition not present 1 = Recent condition (past year) 2 = Condition diagnosed in last 5 years 3 = Lifelong condition	
27b	<b>DSOSTEOP</b>	1.0	Bone, Joint, and Muscle: Osteoporosis	Num	0 = Condition not present 1 = Recent condition (past year) 2 = Condition diagnosed in last 5 years 3 = Lifelong condition	
27c	<b>DSHRTCON</b>	1.0	Heart and Circulation: Heart condition	Num	0 = Condition not present 1 = Recent condition (past year) 2 = Condition diagnosed in last 5 years 3 = Lifelong condition	

Q	Data element name	Ver	Description	Data type	Allowable codes	Blanks, Skips, and Comments
27d	<b>DSCHOL</b>	1.0	Heart and Circulation: High cholesterol	Num	0 = Condition not present 1 = Recent condition (past year) 2 = Condition diagnosed in last 5 years 3 = Lifelong condition	
27e	<b>DSHGHBP</b>	1.0	Heart and Circulation: High blood pressure	Num	0 = Condition not present 1 = Recent condition (past year) 2 = Condition diagnosed in last 5 years 3 = Lifelong condition	
27f	<b>DSLOWBP</b>	1.0	Heart and Circulation: Low blood pressure	Num	0 = Condition not present 1 = Recent condition (past year) 2 = Condition diagnosed in last 5 years 3 = Lifelong condition	
27g	<b>DSSTROKE</b>	1.0	Heart and Circulation: Stroke	Num	0 = Condition not present 1 = Recent condition (past year) 2 = Condition diagnosed in last 5 years 3 = Lifelong condition	
27h	<b>DSDIAB</b>	1.0	Hormonal: Diabetes (type 1 or 2)	Num	0 = Condition not present 1 = Recent condition (past year) 2 = Condition diagnosed in last 5 years 3 = Lifelong condition	
27i	<b>DSTHYR</b>	1.0	Hormonal: Thyroid disorder	Num	0 = Condition not present 1 = Recent condition (past year) 2 = Condition diagnosed in last 5 years 3 = Lifelong condition	
27j	<b>DSASTHMA</b>	1.0	Lungs/breathing: Asthma	Num	0 = Condition not present 1 = Recent condition (past year) 2 = Condition diagnosed in last 5 years 3 = Lifelong condition	
27k	<b>DSBRONCH</b>	1.0	Lungs/breathing: Chronic bronchitis, emphysema	Num	0 = Condition not present 1 = Recent condition (past year) 2 = Condition diagnosed in last 5 years 3 = Lifelong condition	
27l	<b>DSSLPDIS</b>	1.0	Lungs/breathing: Sleep disorder	Num	0 = Condition not present 1 = Recent condition (past year) 2 = Condition diagnosed in last 5 years 3 = Lifelong condition	

Q	Data element name	Ver	Description	Data type	Allowable codes	Blanks, Skips, and Comments
27m	<b>DSALCSUB</b>	1.0	Mental health: Alcohol or substance abuse	Num	0 = Condition not present 1 = Recent condition (past year) 2 = Condition diagnosed in last 5 years 3 = Lifelong condition	
27n	<b>DSANXIET</b>	1.0	Mental health: Anxiety disorder	Num	0 = Condition not present 1 = Recent condition (past year) 2 = Condition diagnosed in last 5 years 3 = Lifelong condition	
27o	<b>DSADD</b>	1.0	Mental health: Attention deficit disorder	Num	0 = Condition not present 1 = Recent condition (past year) 2 = Condition diagnosed in last 5 years 3 = Lifelong condition	
27p	<b>DSBIPOLR</b>	1.0	Mental health: Bipolar disorder	Num	0 = Condition not present 1 = Recent condition (past year) 2 = Condition diagnosed in last 5 years 3 = Lifelong condition	
27q	<b>DSAD</b>	1.0	Mental health: Dementia/ Alzheimer's disease	Num	0 = Condition not present 1 = Recent condition (past year) 2 = Condition diagnosed in last 5 years 3 = Lifelong condition	
27r	<b>DSDEP</b>	1.0	Mental health: Depression	Num	0 = Condition not present 1 = Recent condition (past year) 2 = Condition diagnosed in last 5 years 3 = Lifelong condition	
27s	<b>DSEATDIS</b>	1.0	Mental health: Eating disorder (anorexia, bulimia)	Num	0 = Condition not present 1 = Recent condition (past year) 2 = Condition diagnosed in last 5 years 3 = Lifelong condition	
27t	<b>DSOCD</b>	1.0	Mental health: Obsessive- compulsive disorder	Num	0 = Condition not present 1 = Recent condition (past year) 2 = Condition diagnosed in last 5 years 3 = Lifelong condition	
27u	<b>DSSCHIZ</b>	1.0	Mental health: Schizophrenia	Num	0 = Condition not present 1 = Recent condition (past year) 2 = Condition diagnosed in last 5 years 3 = Lifelong condition	



Q	Data element name	Ver	Description	Data type	Allowable codes	Blanks, Skips, and Comments
27v	<b>DSMHOTH</b>	1.0	Mental health: Other	Num	0 = Condition not present 1 = Recent condition (past year) 2 = Condition diagnosed in last 5 years 3 = Lifelong condition	
27v1	<b>DSMHOTHX</b>	1.0	Other mental health: Specify	Char	text	Blank if Question 27v <b>DSMHOTH</b> = 0 (Mental health: Other condition not present)
27w	<b>DSBACK</b>	1.0	Pain/discomfort: Back pain	Num	0 = Condition not present 1 = Recent condition (past year) 2 = Condition diagnosed in last 5 years 3 = Lifelong condition	
27x	<b>DSCONST</b>	1.0	Pain/discomfort: Constipation	Num	0 = Condition not present 1 = Recent condition (past year) 2 = Condition diagnosed in last 5 years 3 = Lifelong condition	
27y	<b>DSFOOT</b>	1.0	Pain/discomfort: Foot pain	Num	0 = Condition not present 1 = Recent condition (past year) 2 = Condition diagnosed in last 5 years 3 = Lifelong condition	
27z	<b>DSGASTRO</b>	1.0	Pain/discomfort: Gastrointestinal pain or discomfort	Num	0 = Condition not present 1 = Recent condition (past year) 2 = Condition diagnosed in last 5 years 3 = Lifelong condition	
27aa	<b>DSHEAD</b>	1.0	Pain/discomfort: Headaches	Num	0 = Condition not present 1 = Recent condition (past year) 2 = Condition diagnosed in last 5 years 3 = Lifelong condition	
27bb	<b>DSHIP</b>	1.0	Pain/discomfort: Hip/knee pain	Num	0 = Condition not present 1 = Recent condition (past year) 2 = Condition diagnosed in last 5 years 3 = Lifelong condition	
27cc	<b>DSNECK</b>	1.0	Pain/discomfort: Neck/shoulder pain	Num	0 = Condition not present 1 = Recent condition (past year) 2 = Condition diagnosed in last 5 years 3 = Lifelong condition	

Q	Data element name	Ver	Description	Data type	Allowable codes	Blanks, Skips, and Comments
27dd	<b>DSDIZZ</b>	1.0	Sensory: Dizziness/vertigo	Num	0 = Condition not present 1 = Recent condition (past year) 2 = Condition diagnosed in last 5 years 3 = Lifelong condition	
27ee	<b>DSIMPHR</b>	1.0	Sensory: Impaired hearing	Num	0 = Condition not present 1 = Recent condition (past year) 2 = Condition diagnosed in last 5 years 3 = Lifelong condition	
27ff	<b>DSIMPVS</b>	1.0	Sensory: Impaired vision	Num	0 = Condition not present 1 = Recent condition (past year) 2 = Condition diagnosed in last 5 years 3 = Lifelong condition	
27gg	<b>DSCANCER</b>	1.0	Other chronic conditions: Cancer	Num	0 = Condition not present 1 = Recent condition (past year) 2 = Condition diagnosed in last 5 years 3 = Lifelong condition	
27gg1	<b>DSCANCX</b>	1.0	Cancer type: Specify	Char	text	Blank if Question 27gg <b>DSCANCER</b> = 0 (Cancer is not present)
27hh	<b>DSCHRFAT</b>	1.0	Other chronic conditions: Chronic fatigue	Num	0 = Condition not present 1 = Recent condition (past year) 2 = Condition diagnosed in last 5 years 3 = Lifelong condition	
27ii	<b>DSEPILEP</b>	1.0	Other chronic conditions: Epilepsy/ seizure disorder	Num	0 = Condition not present 1 = Recent condition (past year) 2 = Condition diagnosed in last 5 years 3 = Lifelong condition	
27jj	<b>DSREFLUX</b>	1.0	Other chronic conditions: Heartburn/acid reflux	Num	0 = Condition not present 1 = Recent condition (past year) 2 = Condition diagnosed in last 5 years 3 = Lifelong condition	
27kk	<b>DSINCONT</b>	1.0	Other chronic conditions: Urinary incontinence	Num	0 = Condition not present 1 = Recent condition (past year) 2 = Condition diagnosed in last 5 years 3 = Lifelong condition	

Q	Data element name	Ver	Description	Data type	Allowable codes	Blanks, Skips, and Comments
27II	<b>DSAPNEA</b>	1.0	Other chronic conditions: Sleep apnea	Num	0 = Condition not present 1 = Recent condition (past year) 2 = Condition diagnosed in last 5 years 3 = Lifelong condition	
27mm	<b>DSTICS</b>	1.0	Other chronic conditions: Tics/movement disorder/spasticity	Num	0 = Condition not present 1 = Recent condition (past year) 2 = Condition diagnosed in last 5 years 3 = Lifelong condition	
27nn	<b>DSDENTAL</b>	1.0	Other chronic conditions: Dental pain	Num	0 = Condition not present 1 = Recent condition (past year) 2 = Condition diagnosed in last 5 years 3 = Lifelong condition	
28a	<b>DSCHNRX</b>	1.0	Reason for current medication: Treatment of chronic conditions	Num	0 = No 1 = Yes	
28b	<b>DSMHRX</b>	1.0	Reason for current medication: Treatment of mental health disorders or behavior problems	Num	0 = No 1 = Yes	
28c	<b>DSPAINRX</b>	1.0	Reason for current medication: Treatment of pain	Num	0 = No 1 = Yes	
29	<b>DSCOMM</b>	1.0	Comments related to other notable changes or concerns	Char	text	
30a	<b>DSRE_REF</b>	1.0	Recommendations: Refer to treating physician for assessment	Num	0 = Blank 1 = Yes	
30b	<b>DSRE_INT</b>	1.0	Recommendations: Review internally by clinical personnel	Num	0 = Blank 1 = Yes	
30c	<b>DSRE_ANN</b>	1.0	Recommendations: Include in annual review/annual wellness visit	Num	0 = Blank 1 = Yes	
30d	<b>DSRE_REP</b>	1.0	Recommendations: Repeat in .... months	Num	0 = Blank 1 = Yes	
30d1	<b>DSREPMO</b>	1.0	Recommendations: Specify number of months to repeat	Num	Numeric free-text	Blank if Question 30d <b>DSRE_REP</b> ≠ 1 (No recommendation to repeat in __ months)

Q	Data element name	Ver	Description	Data type	Allowable codes	Blanks, Skips, and Comments
<b>Form B2D: DLD Summary Page</b>						
0a	<b>FRMDATE_B2D</b>	1.0	Form Date	Num	mm/dd/yyyy Month: 1–12 Day: 1–31 Year: 2020 to the current year	Form date cannot precede January 1, 2020.
0b	<b>INITIALS_B2D</b>	1.0	Examiner's initials	Char	text	NOTE: <b>INITIALS</b> is never released in research data sets generated by NACC.
1a	<b>DSDLDST2</b>	1.0	Short-term memory, page 2	Num	0 – 4	
1b	<b>DSDLDST4</b>	1.0	Short-term memory, page 4	Num	0 – 2	
1c	<b>DSDLDST5</b>	1.0	Short-term memory, page 5	Num	0 – 4	
1d	<b>DSDLDST6</b>	1.0	Short-term memory, page 6	Num	0 – 2	
1e	<b>DSDLDST7</b>	1.0	Short-term memory, page 7	Num	0 – 2	
1	<b>DSDLDSTM</b>	1.0	Short-term memory total	Num	0 – 14	
2a	<b>DSDLDLT2</b>	1.0	Long-term memory, page 2	Num	0 – 2	
2b	<b>DSDLDLT3</b>	1.0	Long-term memory, page 3	Num	0 – 2	
2c	<b>DSDLDLT6</b>	1.0	Long-term memory, page 6	Num	0 – 2	
2d	<b>DSDLDLT8</b>	1.0	Long-term memory, page 8	Num	0 – 2	
2e	<b>DSDLDLT9</b>	1.0	Long-term memory, page 9	Num	0 – 8	
2	<b>DSDLDLTM</b>	1.0	Long-term memory total	Num	0 – 16	
3a	<b>DSDLDOR2</b>	1.0	Spatial & temporal orientation, page 2	Num	0 – 2	
3b	<b>DSDLDOR3</b>	1.0	Spatial & temporal orientation, page 3	Num	0 – 4	
3c	<b>DSDLDOR4</b>	1.0	Spatial & temporal orientation, page 4	Num	0 – 2	
3d	<b>DSDLDOR6</b>	1.0	Spatial & temporal orientation, page 6	Num	0 – 2	
3e	<b>DSDLDOR8</b>	1.0	Spatial & temporal orientation, page 8	Num	0 – 2	

Q	Data element name	Ver	Description	Data type	Allowable codes	Blanks, Skips, and Comments
3f	<b>DSDLDOR9</b>	1.0	Spatial & temporal orientation, page 9	Num	0 – 2	
3	<b>DSDLDOR</b>	1.0	Spatial & temporal orientation total	Num	0 – 14	
4a	<b>DSDLDSP2</b>	1.0	Speech, page 2	Num	0 – 2	
4b	<b>DSDLDSP4</b>	1.0	Speech, page 4	Num	0 – 2	
4c	<b>DSDLDSP5</b>	1.0	Speech, page 5	Num	0 – 2	
4d	<b>DSDLDSP6</b>	1.0	Speech, page 6	Num	0 – 2	
4	<b>DSDLDSP</b>	1.0	Speech total	Num	0 – 8	
5a	<b>DSDL DPR3</b>	1.0	Practical skills, page 3	Num	0 – 2	
5b	<b>DSDL DPR4</b>	1.0	Practical skills, page 4	Num	0 – 4	
5c	<b>DSDL DPR5</b>	1.0	Practical skills, page 5	Num	0 – 2	
5d	<b>DSDL DPR8</b>	1.0	Practical skills, page 8	Num	0 – 4	
5e	<b>DSDL DP10</b>	1.0	Practical skills, page 10	Num	0 – 4	
5	<b>DSDL DPRC</b>	1.0	Practical skills total	Num	0 – 16	
6a	<b>DSDL DMD7</b>	1.0	Mood, page 7	Num	0 – 2	
6b	<b>DSDL DMD8</b>	1.0	Mood, page 8	Num	0 – 6	
6c	<b>DSDL DMD9</b>	1.0	Mood, page 9	Num	0 – 2	
6d	<b>DSDL DM10</b>	1.0	Mood, page 10	Num	0 – 2	
6	<b>DSDL DMD</b>	1.0	Mood total	Num	0 – 12	
7a	<b>DSDL DAI3</b>	1.0	Activity & interest, page 3	Num	0 – 2	
7b	<b>DSDL DAI4</b>	1.0	Activity & interest, page 4	Num	0 – 2	
7c	<b>DSDL DAI5</b>	1.0	Activity & interest, page 5	Num	0 – 4	
7d	<b>DSDL DAI6</b>	1.0	Activity & interest, page 6	Num	0 – 2	
7e	<b>DSDL DAI7</b>	1.0	Activity & interest, page 7	Num	0 – 2	
7	<b>DSDL DAI</b>	1.0	Activity & interest total	Num	0 – 12	

Q	Data element name	Ver	Description	Data type	Allowable codes	Blanks, Skips, and Comments
8a	<b>DSDLDBD3</b>	1.0	Behavioral disturbance, page 3	Num	0 – 2	
8b	<b>DSDLDBD4</b>	1.0	Behavioral disturbance, page 4	Num	0 – 2	
8c	<b>DSDLDBD6</b>	1.0	Behavioral disturbance, page 6	Num	0 – 2	
8d	<b>DSDLDBD7</b>	1.0	Behavioral disturbance, page 7	Num	0 – 4	
8e	<b>DSDLDBD8</b>	1.0	Behavioral disturbance, page 8	Num	0 – 2	
8	<b>DSDLDBD</b>	1.0	Behavioral disturbance total	Num	0 – 12	
9	<b>DSDLSCS</b>	1.0	Sum of Cognitive Scores (Category 1 – 3)	Num	0 – 44	
10	<b>DSDLDSOS</b>	1.0	Sum of Social Scores (Category 4 – 8)	Num	0 – 60	

Q	Data element name	Ver	Description	Data type	Allowable codes	Blanks, Skips, and Comments
<b>Form C1D: Neuropsychological Battery Scores</b>						
0a	<b>FRMDATE_C1D</b>	1.0	Form Date	Num	mm/dd/yyyy Month: 1–12 Day: 1–31 Year: 2020 to the current year	Form date cannot precede January 1, 2020.
0b	<b>INITIALS_C1D</b>	1.0	Examiner's initials	Char	text	NOTE: <b>INITIALS</b> is never released in research data sets generated by NACC.
1	<b>DSMSEADM</b>	1.0	Was any part of the DSMSE administered?	Num	0 = No 1 = Yes	
1a	<b>DSMSEREA</b>	1.0	Was not administered: Specify reason	Num	95 = Physical problem 96 = Cognitive/behavior problem 97 = Other problem 98 = verbal refusal	Blank if Question 1 <b>DSMSEADM</b> ≠ 0 (DSMSE not administered) If Question 1 <b>DSMSEADM</b> = 0 (No), then skip to Question 2a
1a1	<b>DSPRSINF</b>	1.0	Personal information	Num	0 – 7 8 = Not assessed	Blank if Question 1 <b>DSMSEADM</b> ≠ 1 (DSMSE administered)
1b1	<b>DSSEASDY</b>	1.0	Season/Day	Num	0 – 4 8 = Not assessed	Blank if Question 1 <b>DSMSEADM</b> ≠ 1 (DSMSE administered)
1b2	<b>DSORTOT</b>	1.0	1b2 Total Score	Num	0 – 11 88 = Not assessed	Blank if Question 1 <b>DSMSEADM</b> ≠ 1 (DSMSE administered)
1c1	<b>DSSMIMM</b>	1.0	Shoebox memory – Immediate	Num	0 – 9 88 = Not assessed	Blank if Question 1 <b>DSMSEADM</b> ≠ 1 (DSMSE administered)
1c2	<b>DSSMDEL</b>	1.0	Shoebox memory – Delay	Num	0 – 9 88 = Not assessed	Blank if Question 1 <b>DSMSEADM</b> ≠ 1 (DSMSE administered)
1c3	<b>DSSMTOT</b>	1.0	Shoebox memory – Total Score	Num	0 – 18 88 = Not assessed	Blank if Question 1 <b>DSMSEADM</b> ≠ 1 (DSMSE administered)
1d1	<b>DSMEMIMM</b>	1.0	Memory – Immediate	Num	0 – 3 8 = Not assessed	Blank if Question 1 <b>DSMSEADM</b> ≠ 1 (DSMSE administered)
1d2	<b>DSMEMDEL</b>	1.0	Memory – Delay	Num	0 – 3 8 = Not assessed	Blank if Question 1 <b>DSMSEADM</b> ≠ 1 (DSMSE administered)
1d3	<b>DSMMTOT</b>	1.0	Memory – Total Score	Num	0 – 6 8 = Not assessed	Blank if Question 1 <b>DSMSEADM</b> ≠ 1 (DSMSE administered)

Q	Data element name	Ver	Description	Data type	Allowable codes	Blanks, Skips, and Comments
1e1	<b>DSAPINT</b>	1.0	Apraxia – Intransitive	Num	0 – 2 8 = Not assessed	Blank if Question 1 <b>DSMSEADM</b> ≠ 1 (DSMSE administered)
1e2	<b>DSAPTRAN</b>	1.0	Apraxia – transitive	Num	0.0 – 2.0 8.8 = Not assessed	Blank if Question 1 <b>DSMSEADM</b> ≠ 1 (DSMSE administered)
1e3	<b>DSAPTOT</b>	1.0	Apraxia – Total Score	Num	0.0 – 4.0 8.8 = Not assessed	Blank if Question 1 <b>DSMSEADM</b> ≠ 1 (DSMSE administered)
1f1	<b>DSLGNAM</b>	1.0	Language – Naming	Num	0 – 11 88 = Not assessed	Blank if Question 1 <b>DSMSEADM</b> ≠ 1 (DSMSE administered)
1f2	<b>DSLGREP</b>	1.0	Language – Repetitions	Num	0 – 30 88 = Not assessed	Blank if Question 1 <b>DSMSEADM</b> ≠ 1 (DSMSE administered)
1f3	<b>DSLGCOMP</b>	1.0	Language – Comprehension	Num	0.0 – 12.0 88.8 = Not assessed	Blank if Question 1 <b>DSMSEADM</b> ≠ 1 (DSMSE administered)
1f4	<b>DSLGTOT</b>	1.0	Language – Total Score	Num	0.0 – 53.0 88.8 = Not assessed	Blank if Question 1 <b>DSMSEADM</b> ≠ 1 (DSMSE administered)
1g1	<b>DSVISUO</b>	1.0	Visuospatial	Num	0.0 – 8.0 8.8 = Not assessed	Blank if Question 1 <b>DSMSEADM</b> ≠ 1 (DSMSE administered)
1g2	<b>DSVISTT</b>	1.0	Visuospatial – Total Score	Num	0.0 – 8.0 8.8 = Not assessed	Blank if Question 1 <b>DSMSEADM</b> ≠ 1 (DSMSE administered)
1h1	<b>DSKNOWL</b>	1.0	Knowledge of the examiner	Num	0 – 3 8 = Not assessed	Blank if Question 1 <b>DSMSEADM</b> ≠ 1 (DSMSE administered)
1h2	<b>DSKNWTT</b>	1.0	Knowledge of the examiner – Total Score	Num	0 – 3 8 = Not assessed	Blank if Question 1 <b>DSMSEADM</b> ≠ 1 (DSMSE administered)
1i1	<b>DSMSETT</b>	1.0	DSMSE Total Score	Num	0.0 – 103.0 995.0 = Physical problem 996.0 = Cognitive/behavior problem 997.0 = Other problem 998.0 = Verbal refusal	Blank if Question 1 <b>DSMSEADM</b> ≠ 1 (DSMSE administered)
2a	<b>DSCRADM</b>	1.0	Was any part of the Cued Recall Task administered?	Num	0 = No 1 = Yes	
2a1	<b>DSCRREAS</b>	1.0	Cued Recall Task not administered: Specify reason	Num	95 = Physical problem 96 = Cognitive/behavioral problem 97 = Other problem 98 = Verbal refusal	Blank if Question 2a <b>DSCRADM</b> ≠ 0 (Cued Recall Task not administered) If Question 2a <b>DSCRADM</b> = 0 (No), then skip to Question 3a



Q	Data element name	Ver	Description	Data type	Allowable codes	Blanks, Skips, and Comments
2b	<b>DSCRVERS</b>	1.0	Which cue card set was used?	Num	1 = Version 1 (Set A) 2 = Version 2 (Set B)	Blank if Question 2a <b>DSCRADM</b> ≠ 1 (Cued Recall Task administered)
2c1	<b>DSCRT1C1</b>	1.0	Training trial – Trial 1, Card 1	Num	0 – 4	Blank if Question 2a <b>DSCRADM</b> ≠ 1 (Cued Recall Task administered)
2c2	<b>DSCRT1C2</b>	1.0	Training trial – Trial 1, Card 2	Num	0 – 4	Blank if Question 2a <b>DSCRADM</b> ≠ 1 (Cued Recall Task administered)
2c3	<b>DSCRT1C3</b>	1.0	Training trial – Trial 1, Card 3	Num	0 – 4	Blank if Question 2a <b>DSCRADM</b> ≠ 1 (Cued Recall Task administered)
2c4	<b>DSCRT2C1</b>	1.0	Training trial – Trial 2, Card 1	Num	0 – 4	Blank if Question 2a <b>DSCRADM</b> ≠ 1 (Cued Recall Task administered)
2c5	<b>DSCRT2C2</b>	1.0	Training trial – Trial 2, Card 2	Num	0 – 4	Blank if Question 2a <b>DSCRADM</b> ≠ 1 (Cued Recall Task administered)
2c6	<b>DSCRT2C3</b>	1.0	Training trial – Trial 2, Card 3	Num	0 – 4	Blank if Question 2a <b>DSCRADM</b> ≠ 1 (Cued Recall Task administered)
2c7	<b>DSCRT3C1</b>	1.0	Training trial – Trial 3, Card 1	Num	0 – 4	Blank if Question 2a <b>DSCRADM</b> ≠ 1 (Cued Recall Task administered)
2c8	<b>DSCRT3C2</b>	1.0	Training trial – Trial 3, Card 2	Num	0 – 4	Blank if Question 2a <b>DSCRADM</b> ≠ 1 (Cued Recall Task administered)
2c9	<b>DSCRT3C3</b>	1.0	Training trial – Trial 3, Card 3	Num	0 – 4	Blank if Question 2a <b>DSCRADM</b> ≠ 1 (Cued Recall Task administered)
2d1	<b>DSCRT1FR</b>	1.0	Test trial – Trial 1, free recall	Num	0 – 12	Blank if Question 2a <b>DSCRADM</b> ≠ 1 (Cued Recall Task administered)
2d2	<b>DSCRT1IF</b>	1.0	Test trial – Trial 1, intrusions to free recall	Num	0 – 999	Blank if Question 2a <b>DSCRADM</b> ≠ 1 (Cued Recall Task administered)
2d3	<b>DSCRT1CR</b>	1.0	Test trial – Trial 1, cued recall	Num	0 – 12	Blank if Question 2a <b>DSCRADM</b> ≠ 1 (Cued Recall Task administered)
2d4	<b>DSCRT1IC</b>	1.0	Test trial – Trial 1, intrusions to cued recall	Num	0 – 999	Blank if Question 2a <b>DSCRADM</b> ≠ 1 (Cued Recall Task administered)
2d5	<b>DSCRT2FR</b>	1.0	Test trial – Trial 2, free recall	Num	0 – 12	Blank if Question 2a <b>DSCRADM</b> ≠ 1 (Cued Recall Task administered)

Q	Data element name	Ver	Description	Data type	Allowable codes	Blanks, Skips, and Comments
2d6	<b>DSCRT2IF</b>	1.0	Test trial – Trial 2, intrusions to free recall	Num	0 – 999	Blank if Question 2a <b>DSCRADM</b> ≠ 1 (Cued Recall Task administered)
2d7	<b>DSCRT2CR</b>	1.0	Test trial – Trial 2, cued recall	Num	0 – 12	Blank if Question 2a <b>DSCRADM</b> ≠ 1 (Cued Recall Task administered)
2d8	<b>DSCRT2IC</b>	1.0	Test trial – Trial 2, intrusions to cued recall	Num	0 – 999	Blank if Question 2a <b>DSCRADM</b> ≠ 1 (Cued Recall Task administered)
2d9	<b>DSCRT3FR</b>	1.0	Test trial – Trial 3, free recall	Num	0 – 12	Blank if Question 2a <b>DSCRADM</b> ≠ 1 (Cued Recall Task administered)
2d10	<b>DSCRT3IF</b>	1.0	Test trial – Trial 3, intrusions to free recall	Num	0 – 999	Blank if Question 2a <b>DSCRADM</b> ≠ 1 (Cued Recall Task administered)
2d11	<b>DSCRT3CR</b>	1.0	Test trial – Trial 3, cued recall	Num	0 – 12	Blank if Question 2a <b>DSCRADM</b> ≠ 1 (Cued Recall Task administered)
2d12	<b>DSCRT3IC</b>	1.0	Test trial – Trial 3, intrusions to cued recall	Num	0 – 999	Blank if Question 2a <b>DSCRADM</b> ≠ 1 (Cued Recall Task administered)
2d13	<b>DSCRTTFR</b>	1.0	Free recall – Total	Num	0 – 36	Blank if Question 2a <b>DSCRADM</b> ≠ 1 (Cued Recall Task administered)
2d14	<b>DSCRTTIF</b>	1.0	Intrusions to free recall – Total	Num	0 – 999	Blank if Question 2a <b>DSCRADM</b> ≠ 1 (Cued Recall Task administered)
2d15	<b>DSCRTTCR</b>	1.0	Cued recall – Total	Num	0 – 36	Blank if Question 2a <b>DSCRADM</b> ≠ 1 (Cued Recall Task administered)
2d16	<b>DSCRTTIC</b>	1.0	Intrusions to cued recall – Total	Num	0 – 999	Blank if Question 2a <b>DSCRADM</b> ≠ 1 (Cued Recall Task administered)
3a	<b>DSMSEBEH</b>	1.0	Participant behavior during: DSMSE	Num	1 = Cooperative and engaged 2 = Cooperative but distracted 3 = Uncooperative 9 = Not administered	
3b	<b>DSCRBEH</b>	1.0	Participant behavior during: Cued Recall Task	Num	1 = Cooperative and engaged 2 = Cooperative but distracted 3 = Uncooperative 9 = Not administered	

Q	Data element name	Ver	Description	Data type	Allowable codes	Blanks, Skips, and Comments
<b>Form D1D: Clinician Exam and Diagnosis</b>						
0a	<b>FRMDATE_D1D</b>	1.0	Form Date	Num	mm/dd/yyyy Month: 1–12 Day: 1–31 Year: 2020 to the current year	Form date cannot precede January 1, 2020.
0b	<b>INITIALS_D1D</b>	1.0	Examiner's initials	Char	text	NOTE: <b>INITIALS</b> is never released in research data sets generated by NACC.
1	<b>DSHEADCM</b>	1.0	Head circumference (cm)	Num	45 – 70 777 = provided at previous visit 888 = Not assessed	
2	<b>DSGRASP</b>	1.0	Pathological reflexes – grasp	Num	1 = Absent 2 = Present 9 = Unknown/not assessed	
3	<b>DSSNOUT</b>	1.0	Pathological reflexes – snout	Num	1 = Absent 2 = Present 9 = Unknown/not assessed	
4	<b>DSROOT</b>	1.0	Pathological reflexes – rooting	Num	1 = Absent 2 = Present 9 = Unknown/not assessed	
5	<b>DSCHROM</b>	1.0	What is the participant's chromosome diagnosis?	Num	1 = Trisomy 21 2 = Translocation DS 3 = Mosaic DS 9 = Unknown/not assessed	
6	<b>DSCOGST</b>	1.0	What is the participant's cognitive status	Num	1 = Cognitively stable 2 = MCI-DS 3 = Dementia 9 = Unable to determine	