NACC UNIFORM DATA SET



DOWN SYNDROME MODULE Data Element Dictionary

For Initial Visit Packet

UDS Version 3.0, March 2015 DS Module Version 1.0, October 2020

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Form Header

Q #	Data element name	Ver	Description	Data type	Allowable codes	Comment
0a	PACKET_DS	1.0	Packet code	Char	IDS = Initial Visit Packet, DS Module	
0b	FORMVER_DS	1.0	Form version	Num	1	
0c	ADCID	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 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 65 = Cleveland ADRC 66 = U Alabama at Birmingham Note: In research data sets generated by NACC, the variable NACCADCID is replaced by a randomly generated NACCADC.

Center

Form Header (cont.)

Q #	Data element name	Ver	Description	Data type	Allowable codes	Comment
0d	PTID	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 sub- ject. NOTE: PTID is replaced by a randomly gener- ated NACCID in research data sets generated by NACC.
0e	VISITDATE	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 VISITDATE . If unsure, use the UDS Form A1 (Participant demographics) form date
Of	VISITNUM	1.0	Visit number	Num	Can be determined by the Center.	The Center can use its existing visit number scheme if desired. It is NOT required to start with 1.

Q	Data element name	Ver	Description	Data type	Allowable codes	Blanks, Skips, and Comments
For	m A1D: Par	ticip	ant Health History			
0a	FRMDATE_A1D	1.0	Form Date	Num	mm/dd/yyy Month: 1–12 Day: 1–31 Year: 2020 to the current year	Form date cannot precede January 1, 2020.
0b	INITIALS_A1D	1.0	Examiner's initials	Char	text	NOTE: INITIALS is never released in research data sets generated by NACC.
1a	DSDAYPRG	1.0	Participant's weekday activities: Day Program	Num	0 = No 1 = Yes 9 = Unknown	
1b	DSWRKSHP	1.0	Participant's weekday activities: Workshops	Num	0 = No 1 = Yes 9 = Unknown	
1c	DSHOME	1.0	Participant's weekday activities: Stays at home	Num	0 = No 1 = Yes 9 = Unknown	
1d	DSJOB	1.0	Participant's weekday activities: Community paid job	Num	0 = No 1 = Yes 9 = Unknown	
1e	DSOTHAC	1.0	Participant's weekday activities: Other	Num	0 = No 1 = Yes 9 = Unknown	
1e1	DSOTHACX	1.0	Other weekday activity: Specify	Char	text	Blank if Question 1e DSOTHAC ≠ 1 (Participant's weekday activities: Other)
2	DSMOMAGE	1.0	Age of participant's mother at participant's birth	Num	10 – 60 999 = unknown	
3	DSCHDASD	1.0	Congenital heart disease – atrial septal defect	Num	0 = Absent 1 = Present – resolved 2 = Present – repaired 3 = Present – unrepaired 9 = Unknown	
4	DSCHDVSD	1.0	Congenital heart disease – ventricular 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
5	DSCHDACD	1.0	Congenital heart disease – atrioventricular (AV) canal defect	Num	0 = Absent 1 = Present – resolved 2 = Present – repaired 3 = Present – unrepaired 9 = Unknown	
6	DSCHDTOF	1.0	Congenital heart disease – tetralogy of Fallot	Num	0 = Absent 1 = Present – resolved 2 = Present – repaired 3 = Present – unrepaired 9 = Unknown	
7	DSCHDOTH	1.0	Congenital heart disease – Other	Num	0 = Absent 1 = Present – resolved 2 = Present – repaired 3 = Present – unrepaired 9 = Unknown	
7a	DSCHDOTX	1.0	Other congenital heart disease: Specify	Char	text	Blank if Question 7 DSCHDOTH = 0 (Congenital heart disease – Other: Absent) Blank if Question 7 DSCHDOTH = 9 (Congenital heart disease – Other: Unknown)
8	DSHYPOTN	1.0	Cardiovascular disease – hypotension	Num	0 = Absent 1 = Recent/active 2 = Remote/inactive 9 = Unknown	
9	DSSYNC	1.0	Cardiovascular disease – syncope	Num	0 = Absent 1 = Recent/active 2 = Remote/inactive 9 = Unknown	
10	DSPNEUM	1.0	Pulmonary disease – pneumonia/ aspiration	Num	0 = Absent 1 = Recent/active 2 = Remote/inactive 9 = Unknown	
11	DSHEPAT	1.0	Hepatic conditions	Num	 1 = Hepatitis B carrier 2 = Hepatitis B infected 3 = Hepatitis B immune 4 = Had hepatitis B vaccine 9 = Unknown 	

Q	Data element name	Ver	Description	Data type	Allowable codes	Blanks, Skips, and Comments
12	DSROSAC	1.0	Dermatologic conditions – rosacea	Num	0 = Absent 1 = Recent/active 2 = Remote/inactive 9 = Unknown	
13	DSALOP	1.0	Dermatologic conditions – alopecia	Num	0 = Absent 1 = Recent/active 2 = Remote/inactive 9 = Unknown	
14	DSPSOR	1.0	Dermatologic conditions – psoriasis	Num	0 = Absent 1 = Recent/active 2 = Remote/inactive 9 = Unknown	
15	DSOSTEO	1.0	Musculoskeletal conditions – osteoporosis/osteopenia	Num	0 = Absent 1 = Recent/active 2 = Remote/inactive 9 = Unknown	
16	DSGOUT	1.0	Musculoskeletal conditions – gout	Num	0 = Absent 1 = Recent/active 2 = Remote/inactive 9 = Unknown	
17	DSATAXSU	1.0	Musculoskeletal conditions – atlanto-axial subluxation	Num	0 = Absent 1 = Present 9 = Unknown	
18	DSFRACT	1.0	Musculoskeletal conditions – fractures in the past five years	Num	0 = No 1 = Yes 9 = Unknown	
18a	DSFRACTX	1.0	Fractures in the past five years: Specify	Char	text	Blank if Question 18 DSFRACT ≠1 (Fractures in the past five years)
19	DSHYPOTH	1.0	Endocrine/metabolic conditions – hypothyroidism	Num	0 = Absent 1 = Recent/active 2 = Remote/inactive 9 = Unknown	
20	DSHASHIM	1.0	Endocrine/metabolic conditions – Hashimoto's thyroiditis	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
21	DSHYPER	1.0	Endocrine/metabolic conditions – hyperthyroidism	Num	0 = Absent 1 = Recent/active 2 = Remote/inactive 9 = Unknown	
22	DSTHYMED	1.0	Endocrine/metabolic conditions – currently on thyroid replacement medication	Num	0 = No 1 = Yes 9 = Unknown	
22a	DSTHYMEX	1.0	Thyroid replacement medication: Specify	Char	text	Blank if Question 22 DSTHYMED ≠1 (Currently on thyroid replacement medication)
23	DSVDDEF	1.0	Endocrine/metabolic conditions – vitamin D deficiency	Num	0 = Absent 1 = Recent/active 2 = Remote/inactive 9 = Unknown	
24	DSMENSTR	1.0	Menstrual history – has the participant ever menstruated?	Num	0 = No 1 = Yes, active 2 = Yes, menopausal 9 = Unknown/not applicable	
25	DSMNSAGE	1.0	Menstrual history – age of onset of menses	Num	8 – 20 888 = Not applicable 999 = Unknown	
26	DSMNPAGE	1.0	Menstrual history – age of onsent of menopause	Num	20 – 65 888 = not applicable 999 = unknown	
27	DSHRT	1.0	Hormone replacement therapy – has the participant received HRT?	Num	0 = No 1 = Yes 9 = Unknown	
28	DSAGEHRT	1.0	Hormone replacement therapy – at what age did HRT begin?	Num	0 – 110 888 = not applicable 999 = unknown	
29	DSYRSHRT	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	

Q	Data element name	Ver	Description	Data type	Allowable codes	Blanks, Skips, and Comments
30	DSCELIAC	1.0	Gastrointestinal conditions – celiac disease	Num	0 = Absent 1 = Recent/active 2 = Remote/inactive 9 = Unknown	
31	DSANIRON	1.0	Hematopoietic/lymphatic disease – anemia with iron deficiency	Num	0 = Absent 1 = Recent/active 2 = Remote/inactive 9 = Unknown	
32	DSANFOL	1.0	Hematopoietic/lymphatic disease – anemia with folate deficiency	Num	0 = Absent 1 = Recent/active 2 = Remote/inactive 9 = Unknown	
33	DSLUPUS	1.0	Autoimmune conditions – lupus	Num	0 = Absent 1 = Recent/active 2 = Remote/inactive 9 = Unknown	
34	DSNTRPN	1.0	Autoimmune conditions – chronic neutropenia	Num	0 = Absent 1 = Recent/active 2 = Remote/inactive 9 = Unknown	
35	DSTUMOR	1.0	Cancer – solid tumor	Num	0 = No 1 = Yes 9 = Unknown	
35a	DSTUMORX	1.0	Solid tumor: Specify primary site	Char	text	Blank if Question 35 DSTUMOR ≠1 (Cancer – solid tumor)
36	DSLEUKEM	1.0	Cancer – leukemia	Num	0 = No 1 = Yes, childhood transient myeloproliferative disorder 2 = Yes, childhood leukemia 3 = Yes, adult onset leukemia 9 = Unknown	
37	DSHRTRPR	1.0	Major surgical procedures – congenital heart-defect repair	Num	0 = No 1 = Yes 9 = Unknown	
37.1	DSHRTRPX	1.0	Congenital heart-defect repair: Specify	Char	text	Blank if Question 37 DSHRTRPR ≠ 1 (Congenital heart-defect repair)

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

Q	Data element name	Ver	Description	Data type	Allowable codes	Blanks, Skips, and Comments
42.1	DSTHYSRX	1.0	Thyroid surgery: Specify	Char	text	Blank if Question 42 DSTHYSRG ≠1 (Thyroid surgery)
42a	DSTHYSYR	1.0	Year of most recent thyroid surgery	Num	1900 to current year 9999 = Unknown	
43	DSONCSRG	1.0	Major surgical procedures – oncology surgery	Num	0 = No 1 = Yes 9 = Unknown	
43.1	DSONCSRX	1.0	Oncology surgery: Specify	Char	text	Blank if Question 43 DSONCSRG ≠ 1 (Oncology surgery)
43a	DSONCSYR	1.0	Year of most recent oncology surgery	Num	1900 to current year 9999 = Unknown	
44	DSOTHSRG	1.0	Major surgical procedures – other surgery	Num	0 = No 1 = Yes 9 = Unknown	
44.1	DSOTHSRX	1.0	Other surgery: Specify	Char	text	Blank if Question 44 DSOTHSRG ≠ 1 (Other surgery)
44a	DSOTHSYR	1.0	Year of most recent other surgery	Num	1900 to current year 9999 = Unknown	

Q	Data element name	Ver	Description	Data type	Allowable codes	Blanks, Skips, and Comments				
For	Form B1D: NTG – Early Detection Screen for Dementia									
0a	FRMDATE_B1D	1.0	Form Date	Num	mm/dd/yyy Month: 1–12 Day: 1–31 Year: 2020 to the current year	Form date cannot precede January 1, 2020.				
0b	INITIALS_B1D	1.0	Examiner's initials	Char	text	NOTE: INITIALS is never released in research data sets generated by NACC.				
Oc	DSLIV	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	DSLIVX	1.0	Other living arrangement: Specify	Char	text	Blank if Question 0 DSLIV \neq 9 (Lives in other)				
7	DSSEX	1.0	Sex	Num	0 = Female 1 = Male					
8	DSDISLEV	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	DSDX_AUT	1.0	Diagnosed condition: Autism	Num	0 = Blank 1 = Yes					
9b	DSDX_CP	1.0	Diagnosed condition: Cerebral palsy	Num	0 = Blank 1 = Yes					
9с	DSDX_DS	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	DSDX_FRX	1.0	Diagnosed condition: Fragile X syndrome	Num	0 = Blank 1 = Yes	
9e	DSDX_ID	1.0	Diagnosed condition: Intellectual disability	Num	0 = Blank 1 = Yes	
9f	DSDX_PW	1.0	Diagnosed condition: Prader–Willi syndrome	Num	0 = Blank 1 = Yes	
9g	DSDX_OTH	1.0	Diagnosed condition: other	Num	0 = Blank 1 = Yes	
9g1	DSDXOTHX	1.0	Other diagnosed condition: Specify	Char	text	Blank if Question 9g DSDX_OTH ≠ 1 (Diagnosed condition: other)
10	DSPHYS	1.0	General characterization of current physical health	Num	0 = Poor 1 = Fair 2 = Good 3 = Very good 4 = Excellent	
11	DSPHYSYR	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	DSMENTAL	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	DSCN_VIM	1.0	Condition present: Vision impairment	Num	0 = Blank 1 = Yes	
13b	DSCN_BLD	1.0	Condition present: Blind (very limited or no vision)	Num	0 = Blank 1 = Yes	
13c	DSCN_GLS	1.0	Condition present: Vision corrected by glasses	Num	0 = Blank 1 = Yes	
13d	DSCN_HIM	1.0	Condition present: Hearing impairment	Num	0 = Blank 1 = Yes	
13e	DSCN_DF	1.0	Condition present: Deaf (very limited or no hearing)	Num	0 = Blank 1 = Yes	

Center

Q	Data element name	Ver	Description	Data type	Allowable codes	Blanks, Skips, and Comments
13f	DSCN_HAD	1.0	Condition present: Hearing corrected by hearing aids	Num	0 = Blank 1 = Yes	
13g	DSCN_MIM	1.0	Condition present: Mobility impairment	Num	0 = Blank 1 = Yes	
13h	DSCN_UW	1.0	Condition present: Not mobile – uses wheelchair	Num	0 = Blank 1 = Yes	
13i	DSCN_MIW	1.0	Condition present: Not mobile – is moved about in wheelchair	Num	0 = Blank 1 = Yes	
14a	DSLE_CD	1.0	Significant life event: Death of someone close	Num	0 = Blank 1 = Yes	
14b	DSLE_CHL	1.0	Significant life event: Changes in living arrangement, work, or day program	Num	0 = Blank 1 = Yes	
14c	DSLE_CHS	1.0	Significant life event: Changes in staff close to the person	Num	0 = Blank 1 = Yes	
14d	DSLE_NRM	1.0	Significant life event: New roommate/housemates	Num	0 = Blank 1 = Yes	
14e	DSLE_ILL	1.0	Significant life event: Illness or impairment due to accident	Num	0 = Blank 1 = Yes	
14f	DSLE_SEM	1.0	Significant life event: Adverse reaction to medication or over- medication	Num	0 = Blank 1 = Yes	
14g	DSLE_SEI	1.0	Significant life event: Interpersonal conflicts	Num	0 = Blank 1 = Yes	
14h	DSLE_SEV	1.0	Significant life event: Victimization/ abuse	Num	0 = Blank 1 = Yes	
14i	DSLE_OTH	1.0	Significant life event: Other	Num	0 = Blank 1 = Yes	
14i1	DSLEOTHX	1.0	Significant recent life event: Specify	Char	Text	Blank if Question 14i DSLE_OTH ≠ 1 (Significant life event: other)
15	DSSEIZ	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	

Down Syndrome Module (V1.0, OCTOBER 2020) / UDS (V3.0, MARCH 2015)

Q	Data element name	Ver	Description	Data type	Allowable codes	Blanks, Skips, and Comments
16a	DSDXHS_NO	1.0	Diagnostic history: No diagnosis of MCI or dementia	Num	0 = Blank 1 = Yes	If Question 16a DSDXHS_NO = 1 (No diagnosis of MCI or dementia), then skip to Question 19
16b	DSDXHS_MCI	1.0	Diagnostic history: Yes, mild cognitive impairment (MCI)	Num	0 = Blank 1 = Yes	
16c	DSDXHS_DEM	1.0	Diagnostic history: Yes, dementia	Num	0 = Blank 1 = Yes	
16a1	DSMCIMO	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 DSDXHS_MCI ≠ 1 (MCI)
16a2	DSMCIYR	1.0	MCI diagnosis year	Num	1950 to current year 9999 = Unknown	Blank if Question 16b DSDXHS_MCI ≠ 1 (MCI)
16b1	DSDEMMO	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 DSDXHS_DEM ≠ 1 (Dementia)
16b2	DSDEMYR	1.0	Dementia diagnosis year	Num	1950 to current year 9999 = Unknown	Blank if Question 16c DSDXHS_DEM ≠ 1 (Dementia)

Q	Data element name	Ver	Description	Data type	Allowable codes	Blanks, Skips, and Comments
16b3	DSDXTYPE	1.0	Type of dementia	Char	text	Blank if Question 16c DSDXHS_DEM ≠ 1 (Dementia)
16d	DSDXBY	1.0	MCI/dementia diagnosed by	Num	1 = Geriatrician 2 = Neurologist 3 = Physician 4 = Psychiatrist 5 = Psychologist 6 = Other	Blank if Question 16a DSDXHS_NO = 1 (No diagnosis of MCI or dementia)
16d1	DSDXBYX	1.0	MCI/dementia diagnosed by other: Specify	Char	text	Blank if Question 16d DSDXBY ≠ 6 (Diagnosed by: other)
17a	DSONSTMO	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 DSDXHS_NO = 1 (No diagnosis of MCI or dementia)
17b	DSONSTYR	1.0	Note approximate YEAR of onset of MCI/dementia	Num	1950 to current year 9999 = Unknown	Blank if Question 16a DSDXHS_NO = 1 (No diagnosis of MCI or dementia)
18	DSDEMCOM	1.0	Comments/explanations about dementia suspicions	Char	text	Blank if Question 16a DSDXHS_NO = 1 (No diagnosis of MCI or dementia)
19a	DSADL1	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	DSADL2	1.0	Activites 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	DSADL3	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	DSADL4	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	DSADL5	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	DSADL6	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	DSADL7	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	DSLANG1	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	DSLANG2	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	DSLANG3	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	DSLANG4	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	DSLANG5	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	DSLANG6	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	DSSLEEP1	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	DSSLEEP2	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	DSSLEEP3	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	DSSLEEP4	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	DSSLEEP5	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	DSSLEEP6	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	DSSLEEP7	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	DSSLEEP8	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	DSAMB1	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	DSAMB2	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	DSAMB3	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	DSAMB4	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	DSMEM1	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	DSMEM2	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	DSMEM3	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	DSMEM4	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	DSMEM5	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	DSMEM6	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	DSMEM7	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	DSMEM8	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	DSMEM9	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	DSBEH1	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	DSBEH2	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	DSBEH3	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	DSBEH4	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	DSBEH5	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	DSBEH6	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	DSBEH7	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	DSBEH8	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	DSBEH9	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	DSBEH10	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	DSBEH11	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	
24	DSBEH12	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	DSBEH13	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	DSBEH14	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	
240	DSBEH15	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	DSBEH16	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	DSBEH17	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	DSSELF1	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	DSSELF2	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	DSSELF3	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	DSSELF4	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	DSSELF5	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	DSSELF6	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	DSOTHER1	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	DSOTHER2	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	DSOTHER3	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	DSOTHER4	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	DSOTHER5	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	DSOTHER6	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	DSARTHR	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	DSOSTEOP	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	DSHRTCON	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	DSCHOL	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	DSHGHBP	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	DSLOWBP	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	DSSTROKE	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	DSDIAB	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	DSTHYR	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	DSASTHMA	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	DSBRONCH	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	
271	DSSLPDIS	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	DSALCSUB	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	DSANXIET	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 	
270	DSADD	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	
27р	DSBIPOLR	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	DSAD	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	DSDEP	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	DSEATDIS	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	DSOCD	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	DSSCHIZ	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	DSMHOTH	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	DSMHOTHX	1.0	Other mental health: Specify	Char	text	Blank if Question 27v DSMHOTH = 0 (Mental health: Other condition not present)
27w	DSBACK	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	DSCONST	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	
27у	DSFOOT	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	DSGASTRO	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	DSHEAD	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	DSHIP	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	DSNECK	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	DSDIZZ	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	DSIMPHR	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	DSIMPVS	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	DSCANCER	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	DSCANCX	1.0	Cancer type: Specify	Char	text	Blank if Question 27gg DSCANCER = 0 (Cancer is not present)
27hh	DSCHRFAT	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	DSEPILEP	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	DSREFLUX	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	DSINCONT	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
27	DSAPNEA	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	DSTICS	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	DSDENTAL	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	DSCHRNRX	1.0	Reason for current medication: Treatment of chronic conditions	Num	0 = No 1 = Yes	
28b	DSMHRX	1.0	Reason for current medication: Treatment of mental health disorders or behavior problems	Num	0 = No 1 = Yes	
28c	DSPAINRX	1.0	Reason for current medication: Treatment of pain	Num	0 = No 1 = Yes	
29	DSCOMM	1.0	Comments related to other notable changes or concerns	Char	text	
30a	DSRE_REF	1.0	Recommendations: Refer to treating physician for assessment	Num	0 = Blank 1 = Yes	
30b	DSRE_INT	1.0	Recommendations: Review internally by clinical personnel	Num	0 = Blank 1 = Yes	
30c	DSRE_ANN	1.0	Recommendations: Include in annual review/annual wellness visit	Num	0 = Blank 1 = Yes	
30d	DSRE_REP	1.0	Recommendations: Repeat in months	Num	0 = Blank 1 = Yes	
30d1	DSREPMO	1.0	Recommendations: Specify number of months to repeat	Num	Numeric free-text	Blank if Question 30d DSRE_REP \neq 1 (No recommendation to repeat in <u>months</u>)

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

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Q	Data element name	Ver	Description	Data type	Allowable codes	Blanks, Skips, and Comments
3f	DSDLDOR9	1.0	Spatial & temporal orientation, page 9	Num	0 – 2	
3	DSDLDOR	1.0	Spatial & temporal orientation total	Num	0 – 14	
4a	DSDLDSP2	1.0	Speech, page 2	Num	0 – 2	
4b	DSDLDSP4	1.0	Speech, page 4	Num	0 – 2	
4c	DSDLDSP5	1.0	Speech, page 5	Num	0 – 2	
4d	DSDLDSP6	1.0	Speech, page 6	Num	0 – 2	
4	DSDLDSP	1.0	Speech total	Num	0 - 8	
5a	DSDLDPR3	1.0	Practical skills, page 3	Num	0 – 2	
5b	DSDLDPR4	1.0	Practical skills, page 4	Num	0 - 4	
5c	DSDLDPR5	1.0	Practical skills, page 5	Num	0 – 2	
5d	DSDLDPR8	1.0	Practical skills, page 8	Num	0 - 4	
5e	DSDLDP10	1.0	Practical skills, page 10	Num	0 – 4	
5	DSDLDPRC	1.0	Practical skills total	Num	0 – 16	
ба	DSDLDMD7	1.0	Mood, page 7	Num	0 – 2	
6b	DSDLDMD8	1.0	Mood, page 8	Num	0 - 6	
бс	DSDLDMD9	1.0	Mood, page 9	Num	0 – 2	
6d	DSDLDM10	1.0	Mood, page 10	Num	0 – 2	
6	DSDLDMD	1.0	Mood total	Num	0 – 12	
7a	DSDLDAI3	1.0	Activity & interest, page 3	Num	0 – 2	
7b	DSDLDAI4	1.0	Activity & interest, page 4	Num	0 – 2	
7c	DSDLDAI5	1.0	Activity & interest, page 5	Num	0 - 4	
7d	DSDLDAI6	1.0	Activity & interest, page 6	Num	0 – 2	
7e	DSDLDAI7	1.0	Activity & interest, page 7	Num	0 – 2	
7	DSDLDAI	1.0	Activity & interest total	Num	0 – 12	

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DATA ELEMENT DICTIONARY

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

DATA ELEMENT DICTIONARY

Down Syndrome Module (V1.0, OCTOBER 2020) / UDS (V3.0, MARCH 2015)

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

DSAPINT DSAPTRAN	1.0 1.0	Apraxia – Intransitive	Num	0-2	
DSAPTRAN	1.0			0 – 2 8 = Not assessed	Blank if Question 1 DSMSEADM ≠ 1 (DSMSE administered)
		Apraxia – transitive	Num	0.0 – 2.0 8.8 = Not assessed	Blank if Question 1 DSMSEADM ≠ 1 (DSMSE administered)
DSAPTOT	1.0	Apraxia – Total Score	Num	0.0 – 4.0 8.8 = Not assessed	Blank if Question 1 DSMSEADM ≠ 1 (DSMSE administered)
DSLGNAM	1.0	Language – Naming	Num	0 – 11 88 = Not assessed	Blank if Question 1 DSMSEADM ≠ 1 (DSMSE administered)
DSLGREP	1.0	Language – Repetitions	Num	0 – 30 88 = Not assessed	Blank if Question 1 DSMSEADM ≠ 1 (DSMSE administered)
DSLGCOMP	1.0	Language – Comprehension	Num	0.0 – 12.0 88.8 = Not assessed	Blank if Question 1 DSMSEADM ≠ 1 (DSMSE administered)
DSLGTOT	1.0	Language – Total Score	Num	0.0 – 53.0 88.8 = Not assessed	Blank if Question 1 DSMSEADM ≠ 1 (DSMSE administered)
DSVISUO	1.0	Visuospatial	Num	0.0 – 8.0 8.8 = Not assessed	Blank if Question 1 DSMSEADM ≠ 1 (DSMSE administered)
DSVISTT	1.0	Visuospatial – Total Score	Num	0.0 – 8.0 8.8 = Not assessed	Blank if Question 1 DSMSEADM ≠ 1 (DSMSE administered)
DSKNOWL	1.0	Knowledge of the examiner	Num	0 – 3 8 = Not assessed	Blank if Question 1 DSMSEADM ≠ 1 (DSMSE administered)
DSKNWTT	1.0	Knowledge of the examiner – Total Score	Num	0 – 3 8 = Not assessed	Blank if Question 1 DSMSEADM ≠ 1 (DSMSE administered)
DSMSETT	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 DSMSEADM ≠ 1 (DSMSE administered)
DSCRADM	1.0	Was any part of the Cued Recall Task administered?	Num	0 = No 1 = Yes	
DSCRREAS	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 DSCRADM ≠ 0 (Cued Recall Task not administered) If Question 2a DSCRADM = 0 (No), then skip to Question 3a
	DSLGREP DSLGCOMP DSLGTOT DSVISUO DSVISTT DSKNOWL DSKNWTT DSMSETT DSCRADM DSCRREAS	DSLGREP 1.0 DSLGCOMP 1.0 DSLGTOT 1.0 DSVISUO 1.0 DSVISTT 1.0 DSKNWTT 1.0 DSMSETT 1.0 DSMSETT 1.0 DSCRADM 1.0	DSLGREP1.0Language – RepetitionsDSLGCOMP1.0Language – ComprehensionDSLGTOT1.0Language – Total ScoreDSVISUO1.0VisuospatialDSVISTT1.0Visuospatial – Total ScoreDSKNOWL1.0Knowledge of the examinerDSKNWTT1.0Knowledge of the examiner – Total ScoreDSKNWTT1.0Knowledge of the examiner – Total ScoreDSKNWTT1.0Cued Recall ScoreDSCRADM1.0Cued Recall Task not administered?DSCRREAS1.0Cued Recall Task not administered: Specify reason	DSLGREP1.0Language - RepetitionsNumDSLGCOMP1.0Language - ComprehensionNumDSLGTOT1.0Language - Total ScoreNumDSVISUO1.0VisuospatialNumDSVISTT1.0Visuospatial - Total ScoreNumDSKNOWL1.0Knowledge of the examinerNumDSKNWTT1.0Knowledge of the examiner - TotalNumDSKNWTT1.0Knowledge of the examiner - TotalNumDSKNWTT1.0Cued Recall ScoreNumDSCRADM1.0Qued Recall Task not administered: Specify reasonNum	DSLGREP1.0Language – RepetitionsNum0 – 30 88 = Not assessedDSLGCOMP1.0Language – ComprehensionNum0.0 – 12.0 88.8 = Not assessedDSLGTOT1.0Language – Total ScoreNum0.0 – 53.0 88.8 = Not assessedDSVISUO1.0VisuospatialNum0.0 – 8.0 8.8 = Not assessedDSVISUO1.0Visuospatial – Total ScoreNum0.0 – 8.0 8.8 = Not assessedDSVISUO1.0Visuospatial – Total ScoreNum0.0 – 8.0 8.8 = Not assessedDSVISUT1.0Knowledge of the examinerNum0.0 – 3 8 = Not assessedDSKNWVT1.0Knowledge of the examiner – TotalNum0.– 3 8 = Not assessedDSKNWTT1.0Knowledge of the examiner – TotalNum0.– 13.0 8 = Not assessedDSKNWTT1.0CoreNum0.– 13 8 = Not assessedDSCRADM1.0Was any part of the Cued Recall Task administered?Num0 = No 1 = YesDSCRRAS1.0Cued Recall Task not administered: Specify reasonNum95 = Physical problem 96 = Cognitive/behavioral problem 97 = Other problem<

Down Syndrome Module (V1.0, OCTOBER 2020) / UDS (V3.0, MARCH 2015)

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

Q	Data element name	Ver	Description	Data type	Allowable codes	Blanks, Skips, and Comments
2d6	DSCRT2IF	1.0	Test trial – Trial 2, intrusions to free recall	Num	0 – 999	Blank if Question 2a DSCRADM ≠ 1 (Cued Recall Task administered)
2d7	DSCRT2CR	1.0	Test trial – Trial 2, cued recall	Num	0 – 12	Blank if Question 2a DSCRADM ≠ 1 (Cued Recall Task administered)
2d8	DSCRT2IC	1.0	Test trial – Trial 2, intrusions to cued recall	Num	0 – 999	Blank if Question 2a DSCRADM ≠ 1 (Cued Recall Task administered)
2d9	DSCRT3FR	1.0	Test trial – Trial 3, free recall	Num	0 – 12	Blank if Question 2a DSCRADM ≠ 1 (Cued Recall Task administered)
2d10	DSCRT3IF	1.0	Test trial – Trial 3, intrusions to free recall	Num	0 – 999	Blank if Question 2a DSCRADM ≠ 1 (Cued Recall Task administered)
2d11	DSCRT3CR	1.0	Test trial – Trial 3, cued recall	Num	0 – 12	Blank if Question 2a DSCRADM ≠ 1 (Cued Recall Task administered)
2d12	DSCRT3IC	1.0	Test trial – Trial 3, intrusions to cued recall	Num	0 – 999	Blank if Question 2a DSCRADM ≠ 1 (Cued Recall Task administered)
2d13	DSCRTTFR	1.0	Free recall – Total	Num	0 – 36	Blank if Question 2a DSCRADM ≠ 1 (Cued Recall Task administered)
2d14	DSCRTTIF	1.0	Intrusions to free recall – Total	Num	0 – 999	Blank if Question 2a DSCRADM ≠ 1 (Cued Recall Task administered)
2d15	DSCRTTCR	1.0	Cued recall – Total	Num	0 – 36	Blank if Question 2a DSCRADM ≠ 1 (Cued Recall Task administered)
2d16	DSCRTTIC	1.0	Intrusions to cued recall – Total	Num	0 – 999	Blank if Question 2a DSCRADM ≠ 1 (Cued Recall Task administered)
За	DSMSEBEH	1.0	Participant behavior during: DSMSE	Num	 1 = Cooperative and engaged 2 = Cooperative but distracted 3 = Uncooperative 9 = Not administered 	
3b	DSCRBEH	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				
For	orm D1D: Clinician Exam and Diagnosis									
0a	FRMDATE_D1D	1.0	Form Date	Num	mm/dd/yyy Month: 1–12 Day: 1–31 Year: 2020 to the current year	Form date cannot precede January 1, 2020.				
0b	INITIALS_D1D	1.0	Examiner's initials	Char	text	NOTE: INITIALS is never released in research data sets generated by NACC.				
1	DSHEADCM	1.0	Head circumference (cm)	Num	45 – 70 888 = Not assessed					
2	DSGRASP	1.0	Pathological reflexes – grasp	Num	1 = Absent 2 = Present 9 = Unknown/not assessed					
3	DSSNOUT	1.0	Pathological reflexes – snout	Num	1 = Absent 2 = Present 9 = Unknown/not assessed					
4	DSROOT	1.0	Pathological reflexes – rooting	Num	1 = Absent 2 = Present 9 = Unknown/not assessed					
5	DSCHROM	1.0	What is the participant's chromosome diagnosis?	Num	1 = Trisomy 21 2 = Translocation DS 3 = Mosaic DS 9 = Unknown/not assessed					
6	DSCOGST	1.0	What is the participant's cognitive status	Num	1 = Cognitively stable 2 = MCI-DS 3 = Dementia 9 = Unable to determine					

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