



NACC UNIFORM DATA SET

Data Element Dictionary For the Milestones Form

Version 3.0, March 2015

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Revisions made to this DED since UDS3 implementation (March 15, 2015)

Date yyyy-mm-dd	Description	Form(s) affected	Question(s) affected	Data element(s) affected
2015-09-30	Corrected variable name from DISCR to DISCYR	Milestones	6a3	DISCYR
2015-09-30	Added three new ADCs and their allowable codes to Form Header section	Milestones	Form header	ADCID

GLOSSARY OF TERMS

Variable number	Indicates order of appearance on the UDS form
Variable name	For non-fixed-format files, variable name must match exactly
Version	3
UDS question	The question as it appears on the UDS form
Length of field	For fixed-field formats, number of columns for this variable
Column positions	For fixed-field formats, column numbers for this variable
Data type	For non-fixed-field formats, variable type as numerical or character
Allowable codes	List of codes with mapping instructions
Blanks and skips	Instructions for skip patterns
Comments	Other instructions as needed

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Data Element Dictionary for the Milestones Form

Form Header

Q	Data element name	UDS Ver	Description	Length of field	Column positions	Data type	Allowable codes	Comment
OA	PACKET	3	Packet code	2	1 – 2	Char	M = Milestones	
OB	FORMID	3	Form ID	3	4 – 6	Char	M1	
OC	FORMVER	3	Form version number	3	8 – 10	Num	See bottom of current form; use integer portion of version number.	Example: version 3.0 is FORMVER = 3.

Q	Data element name	UDS Ver	Description	Length of field	Column positions	Data type	Allowable codes	Comment
OD	ADCID	3	Center ID	2	12 – 13	Num	2 – 38; use appropriate code below: 2 = Boston University 3 = Case Western University 4 = Columbia University 5 = Duke 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 17 = University of California, Los Angeles 18 = University of California, San Diego 19 = University of Kentucky 20 = University of Michigan 21 = University of Pennsylvania 22 = University of Pittsburgh 25 = University of Texas Southwestern 26 = University of Washington 27 = Washington University in Saint Louis 28 = University of Alabama 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 36 = Florida ADC 37 = University of Wisconsin 38 = University of Kansas 39 = Stanford University 40 = Yale University 41 = University of Florida	Note: ADCID is replaced by a randomly generated NACCADC in research data sets generated by NACC.

Q	Data element name	UDS Ver	Description	Length of field	Column positions	Data type	Allowable codes	Comment
OE	PTID	3	ADC subject ID	10	15 – 24	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. NOTE: PTID is replaced by a randomly generated NACCID in research data sets generated by NACC.
OF	VISITMO	3	Form date — month	2	26 – 27	Num	1 – 12	Date on which the Milestones Form was completed; cannot precede the date of the initial visit.
OG	VISITDAY	3	Form date — day	2	29 – 30	Num	1 – 31	
OH	VISITYR	3	Form date — year	4	32 – 35	Num	2005 to the present year	
OJ	INITIALS	3	Examiner's initials	3	41 – 43	Char	Any text or numbers with the exception of single quotes ('), double quotes ("), ampersands (&), and percentage signs (%).	NOTE: INITIALS is never released in research data sets generated by NACC.

Form M1: Milestones

Q #	Data element name	UDS Ver	UDS question	Length of field	Column positions	Data type	Allowable codes	Blanks and skips
1a	CHANGEMO	3	Date of status change, month	2	45–46	Num	1–12 99=Unknown	Blank if Question 4a DECEASED = 1 (Yes) Blank if Question 4b DISCONT = 1 (Yes)
1b	CHANGEDY	3	Date of status change, day	2	48–49	Num	1–31 99=Unknown	Blank if Question 4a DECEASED = 1 (Yes) Blank if Question 4b DISCONT = 1 (Yes)
1c	CHANGEYR	3	Date of status change, year	4	51–54	Num	2015 to current year	Blank if Question 4a DECEASED = 1 (Yes) Blank if Question 4b DISCONT = 1 (Yes)
2a	PROTOCOL	3	UDS data collection status changed; subject's new status is:	1	56–56	Num	1 = Annual UDS follow-up by telephone 2 = Minimal contact 3 = Annual in-person UDS follow-up	Blank if Question 4a DECEASED = 1 (Yes) Blank if Question 4b DISCONT = 1 (Yes) SKIPS: If Question 2a PROTOCOL = 1 (Annual UDS follow-up by telephone), continue to Question 2a1. If Question 2a PROTOCOL = 2 (Minimal contact), continue to Question 2a1.
2a1	ACONSENT	3	Autopsy consent on file?	1	58–58	Num	0 = No 1 = Yes	Blank if Question 2a PROTOCOL = 3 (Annual in-person follow-up) Blank if Question 4a DECEASED = 1 (Yes) Blank if Question 4b DISCONT = 1 (Yes)
2b1	RECOGIM	3	Subject is too cognitively impaired	1	60–60	Num	0 = No (box is not checked) 1 = Yes (box is checked)	Blank if Question 4a DECEASED = 1 (Yes) Blank if Question 4b DISCONT = 1 (Yes)
2b2	REPHYILL	3	Subject is too ill or physically impaired	1	62–62	Num	0 = No (box is not checked) 1 = Yes (box is checked)	Blank if Question 4a DECEASED = 1 (Yes) Blank if Question 4b DISCONT = 1 (Yes)
2b3	REREFUSE	3	Subject refuses neuropsychological testing or clinical exam	1	64–64	Num	0 = No (box is not checked) 1 = Yes (box is checked)	Blank if Question 4a DECEASED = 1 (Yes) Blank if Question 4b DISCONT = 1 (Yes)
2b4	RENAVAIL	3	Subject or co-participant unreachable, not available, or moved away	1	66–66	Num	0 = No (box is not checked) 1 = Yes (box is checked)	Blank if Question 4a DECEASED = 1 (Yes) Blank if Question 4b DISCONT = 1 (Yes)

Q #	Data element name	UDS Ver	UDS question	Length of field	Column positions	Data type	Allowable codes	Blanks and skips
2b5	RENURSE	3	Subject has permanently entered nursing home	1	68–68	Num	0 = No (box is not checked) 1 = Yes (box is checked)	Blank if Question 4a DECEASED = 1 (Yes) Blank if Question 4b DISCONT = 1 (Yes)
2b5a	NURSEMO	3	Date permanently moved to nursing home, month	2	70–71	Num	1–12 99 = Unknown	Blank if Question 2b5 RENURSE ≠ 1 (Yes) Blank if Question 4a DECEASED = 1 (Yes) Blank if Question 4b DISCONT = 1 (Yes)
2b5b	NURSEDY	3	Date permanently moved to nursing home, day	2	73–74	Num	1–31 99 = Unknown	Blank if Question 2b5 RENURSE ≠ 1 (Yes, entered nursing home) Blank if Question 4a DECEASED = 1 (Yes) Blank if Question 4b DISCONT = 1 (Yes)
2b5c	NURSEYR	3	Date permanently moved to nursing home, year	4	76–79	Num	2015 to current year	Blank if Question 2b5 RENURSE ≠ 1 (Yes, entered nursing home) Blank if Question 4a DECEASED = 1 (Yes) Blank if Question 4b DISCONT = 1 (Yes)
2b6	REJOIN	3	Subject is rejoining ADC	1	81–81	Num	0 = No (box is not checked) 1 = Yes (box is checked)	Blank if Question 4a DECEASED = 1 (Yes) Blank if Question 4b DISCONT = 1 (Yes)
3	FTLDDISC	3	Subject will no longer receive FTLD Module follow-up, but annual in-person UDS visits will continue	1	83–83	Num	0 = No (box is not checked) 1 = Yes (box is checked)	Blank if Question 4a DECEASED = 1 (Yes) Blank if Question 4b DISCONT = 1 (Yes)
3a	FTLDREAS	3	FTLD discontinued reason	1	85–85	Num	1 = ADC decision 2 = Subject/informant refused 3 = Informant not available 4 = Other, specify below	Blank if Question 3 FTLDDISC ≠ 1 (Discontinue FTLD) Blank if Question 4a DECEASED = 1 (Yes) Blank if Question 4b DISCONT = 1 (Yes)
3a1	FTLDREAX	3	Other, specify	60	87–146	Char	Any text or numbers with the exception of single quotes ('), double quotes ("), ampersands (&), and percentage signs (%).	Blank if Question 3a FTLDREAS ≠ 4 (Other) Blank if Question 4a DECEASED = 1 (Yes) Blank if Question 4b DISCONT = 1 (Yes)

Q #	Data element name	UDS Ver	UDS question	Length of field	Column positions	Data type	Allowable codes	Blanks and skips
4a	DECEASED	3	Subject has died	1	148–148	Num	0 = No (box is not checked) 1 = Yes (box is checked)	Blank if Question 2a PROTOCOL =1 (Follow-up by telephone) Blank if Question 2a PROTOCOL =2 (Minimal contact) Blank if Question 2a PROTOCOL =3 (Annual in-person follow-up) Blank if Question 3 FTLDDISC =1 (Discontinue FTLD) Blank if Question 4b DISCONT =1 (Yes) SKIPS: If subject died, skip to Question 5a.
4b	DISCONT	3	Subject has been dropped from ADC	1	150–150	Num	0 = No (box is not checked) 1 = Yes (box is checked)	Blank if Question 2a PROTOCOL = 1 (Follow-up by telephone) Blank if Question 2a PROTOCOL = 2 (Minimal contact) Blank if Question 2a PROTOCOL = 3 (Annual in person follow-up) Blank if Question 3 FTLDDISC = 1 (Discontinue FTLD) Blank if Question 4a DECEASED = 1 (Yes) SKIPS: If subject dropped from ADC, skip to Question 6a.
5a1	DEATHMO	3	Date of death, month	2	152–153	Num	1–12 99 = Unknown	Blank if Question 2a PROTOCOL = 1 (Follow-up by telephone) Blank if Question 2a PROTOCOL = 2 (Minimal contact) Blank if Question 2a PROTOCOL = 3 (Annual in person follow-up) Blank if Question 3 FTLDDISC = 1 (Discontinue FTLD) Blank if Question 4a DECEASED ≠ 1 (Yes)
5a2	DEATHDY	3	Date of death, day	2	155–156	Num	1–31 99 = Unknown	Blank if Question 2a PROTOCOL = 1 (Follow-up by telephone) Blank if Question 2a PROTOCOL = 2 (Minimal contact) Blank if Question 2a PROTOCOL = 3 (Annual in person follow-up) Blank if Question 3 FTLDDISC = 1 (Discontinue FTLD) Blank if Question 4a DECEASED ≠ 1 (Yes)
5a3	DEATHYR	3	Date of death, year	4	158–161	Num	2015 to current year	Blank if Question 2a PROTOCOL = 1 (Follow-up by telephone) Blank if Question 2a PROTOCOL = 2 (Minimal contact) Blank if Question 2a PROTOCOL = 3 (Annual in person follow-up) Blank if Question 3 FTLDDISC = 1 (Discontinue FTLD) Blank if Question 4a DECEASED ≠ 1 (Yes)
5b	AUTOPSY	3	ADC autopsy	1	163–163	Num	0 = No ADC autopsy expected 1 = An ADC autopsy has been done; data submitted or pending	Blank if Question 2a PROTOCOL = 1 (Follow-up by telephone) Blank if Question 2a PROTOCOL = 2 (Minimal contact) Blank if Question 2a PROTOCOL = 3 (Annual in person follow-up) Blank if Question 3 FTLDDISC = 1 (Discontinue FTLD) Blank if Question 4a DECEASED ≠ 1 (Yes)

Q #	Data element name	UDS Ver	UDS question	Length of field	Column positions	Data type	Allowable codes	Blanks and skips
6a1	DISCMO	3	Date dropped from ADC, month	2	165–166	Num	1–12 99=Unknown	Blank if Question 2a PROTOCOL = 1 (Follow-up by telephone) Blank if Question 2a PROTOCOL = 2 (Minimal contact) Blank if Question 2a PROTOCOL = 3 (Annual in person follow-up) Blank if Question 3 FTLDDISC = 1 (Discontinue FTLD) Blank if Question 4b DISCONT ≠ 1 (Yes)
6a2	DISCDAY	3	Date dropped from ADC, day	2	168–169	Num	1–31 99=Unknown	Blank if Question 2a PROTOCOL = 1 (Follow-up by telephone) Blank if Question 2a PROTOCOL = 2 (Minimal contact) Blank if Question 2a PROTOCOL = 3 (Annual in person follow-up) Blank if Question 3 FTLDDISC = 1 (Discontinue FTLD) Blank if Question 4b DISCONT ≠ 1 (Yes)
6a3	DISCYR	3	Date dropped from ADC, year	4	171–174	Num	2015 to current year	Blank if Question 2a PROTOCOL = 1 (Follow-up by telephone) Blank if Question 2a PROTOCOL = 2 (Minimal contact) Blank if Question 2a PROTOCOL = 3 (Annual in person follow-up) Blank if Question 3 FTLDDISC = 1 (Discontinue FTLD) Blank if Question 4b DISCONT ≠ 1 (Yes)
6b	DROPREAS	3	Primary reason subject discontinued ADC participation	1	176–176	Num	1 = ADC decision or protocol 2 = Subject or co-participant asked to be dropped	Blank if Question 2a PROTOCOL = 1 (Follow-up by telephone) Blank if Question 2a PROTOCOL = 2 (Minimal contact) Blank if Question 2a PROTOCOL = 3 (Annual in person follow-up) Blank if Question 3 FTLDDISC = 1 (Discontinue FTLD) Blank if Question 4b DISCONT ≠ 1 (Yes)