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NACC UDS Milestones Form

Data Element Dictionary

(Version 1.1, December 2005)

Data Element Dictionary – UDS Milestones Form

Variable Number – Indicates order of appearance on the UDS Milestones Form.

Variable Name – For non-fixed-format files, variable name must match exactly.

Version – 1

Short Descriptor – Used on the web page to indicate variable.

Question – The question as it appears on the UDS Milestones 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.

Form: Header (Milestones)

Variable Number	0A
Variable Name	PACKET
Version	1
Short Descriptor	Packet code
UDS Question	
Length of Field	2
Column Positions	1 – 2
Data Type	Character
Allowable Codes	M = Milestones Packet
Variable Number	0B
Variable Name	FORMID
Version	1
Short Descriptor	Form ID
UDS Question	
Length of Field	3
Column Positions	4 – 6
Data Type	Character
Allowable Codes	M1
Variable Number	0C
Variable Name	FORMVER
Version	1
Short Descriptor	Form version number
UDS Question	
Length of Field	3
Column Positions	8 – 10
Data Type	Numeric
Allowable Codes	See bottom of current form, use integer portion of version number.
Comment	For example, version 1.1 is FORMVER = 1.

Form: Header (Milestones)

Variable Number	0D
Variable Name	ADCID
Version	1
Short Descriptor	Center ID
UDS Question	
Length of Field	2
Column Positions	12 – 13
Data Type	Numeric
Allowable Codes	<p>1 – 36, Use code below as your Center ID:</p> <ul style="list-style-type: none"> 1 = Baylor 2 = Boston U 3 = Case Western 4 = Columbia 5 = Duke 6 = Emory 7 = Massachusetts General Hospital 8 = Indiana U 9 = Johns Hopkins 10 = Mayo 11 = Mount Sinai 12 = New York U 13 = Northwestern 14 = Oregon Health Sciences 15 = Rush U 16 = U California, Davis 17 = U California, Los Angeles 18 = U California, San Diego 19 = U Kentucky 20 = U Michigan 21 = U Pennsylvania 22 = U Pittsburgh 23 = U Rochester 25 = U Texas Southwestern 26 = U Washington 27 = Washington U, Saint Louis 28 = U Alabama 30 = U Southern California 31 = U California, Irvine 32 = Stanford 33 = Arizona 34 = U Arkansas 35 = U California, San Francisco 36 = Florida
Comment	<p>Note: ADCID is converted to a randomly-generated Center ID in the non-ADC researcher data set (PUBADCID).</p>

Form: Header (Milestones)

<p>Variable Number</p> <p>Variable Name</p> <p>Version</p> <p>Short Descriptor</p> <p>UDS Question</p> <p>Length of Field</p> <p>Column Positions</p> <p>Data Type</p> <p>Allowable Codes</p> <p>Comment</p>	<p>0E</p> <p>PTID</p> <p>1</p> <p>ADC Subject ID</p> <p>ADC Subject ID</p> <p>10</p> <p>15 – 24</p> <p>Character</p> <p>Follow your Center’s Patient ID scheme; use same ID as in MDS, if enrolled in MDS.</p> <p>Number must be unique within data from your Center, and be used for each visit for subject.</p> <p>Note: PTID is not available to non-ADC researchers. It is replaced in the accessible UDS database by a randomly-generated NACC ID (PUBLICID).</p>
<p>Variable Number</p> <p>Variable Name</p> <p>Version</p> <p>Short Descriptor</p> <p>UDS Question</p> <p>Length of Field</p> <p>Column Positions</p> <p>Data Type</p> <p>Allowable Codes</p> <p>Comment</p>	<p>0F</p> <p>VISITMO</p> <p>1</p> <p>Date – month</p> <p>Date</p> <p>2</p> <p>26 – 27</p> <p>Numeric</p> <p>1 – 12</p> <p>The date on which the Milestones Form was completed, can not precede the data of the initial visit.</p>
<p>Variable Number</p> <p>Variable Name</p> <p>Version</p> <p>Short Descriptor</p> <p>UDS Question</p> <p>Length of Field</p> <p>Column Positions</p> <p>Data Type</p> <p>Allowable Codes</p> <p>Comment</p>	<p>0G</p> <p>VISITDAY</p> <p>1</p> <p>Date – day</p> <p>Date</p> <p>2</p> <p>29 – 30</p> <p>Numeric</p> <p>1 – 31</p> <p>The date on which the Milestones Form was completed, can not precede the data of the initial visit.</p> <p>Note: VISITDAY is not available to non-ADC researchers.</p>

Form: Header (Milestones)

Variable Number	0H
Variable Name	VISITYR
Version	1
Short Descriptor	Date – year
UDS Question	Date
Length of Field	4
Column Positions	32 – 35
Data Type	Numeric
Allowable Codes	2005 to present year
Comment	The date on which the Milestones Form was completed, can not precede the data of the initial visit.

Variable Number	0J
Variable Name	INITIALS
Version	1
Short Descriptor	Examiner's initials
UDS Question	Examiner's initials
Length of Field	3
Column Positions	41 – 43
Data Type	Character
Allowable Codes	Any text or numbers, but cannot use single quotes ('), double quotes ("), ampersands (&) or percentage signs (%). Note: INITIALS is not available to non-ADC researchers.

Form M1: Milestones

Variable Number	1
Variable Name	NPSYTEST
Version	1
Short Descriptor	Unable to do neuropsychological tests
UDS Question	Are you unable to collect neuropsychological test data on subject?
Length of Field	1
Column Positions	45
Data Type	Numeric
Allowable Codes	0 = No 1 = Yes

Variable Number	1A
Variable Name	NPCOGIMP
Version	1
Short Descriptor	Too cognitively impaired for neuropsychological tests
UDS Question	Too cognitively impaired for neuropsychological tests
Length of Field	1
Column Positions	47
Data Type	Numeric
Allowable Codes	0 = No 1 = Yes

Variable Number	1B
Variable Name	NPPHYILL
Version	1
Short Descriptor	Too physically ill for neuropsychological tests
UDS Question	Too physically ill to travel/participate for neuropsychological test
Length of Field	1
Column Positions	49
Data Type	Numeric
Allowable Codes	0 = No 1 = Yes

Form M1: Milestones

Variable Number	1C
Variable Name	NPHOMEN
Version	1
Short Descriptor	Homebound/nursing home, no neuropsychological tests
UDS Question	Homebound/entered nursing home for permanent care, unable to collect neuropsychological test data
Length of Field	1
Column Positions	51
Data Type	Numeric
Allowable Codes	0 = No 1 = Yes

Variable Number	1D
Variable Name	NPOTHREA
Version	1
Short Descriptor	Unable to collect neuropsychological test data, other reason
UDS Question	Unable to collect neuropsychological test data, other reason
Length of Field	1
Column Positions	53
Data Type	Numeric
Allowable Codes	0 = No 1 = Yes

Variable Number	1D1
Variable Name	NPOTHREX
Version	1
Short Descriptor	Unable to collect neuropsychological test data, other reason – specify
UDS Question	Unable to collect neuropsychological test data, other reason – specify
Length of Field	60
Column Positions	55 – 114
Data Type	Character
Allowable Codes	Any text or numbers but cannot use single quotes ('), double quotes ("), ampersands (&), or percentage signs (%).
Blanks	Blank if #1D, NPOTHREA = 0 (No) or blank.

Form M1: Milestones

Variable Number	2
Variable Name	PHYNDATA
Version	1
Short Descriptor	Unable to collect physical/neurological exam data
UDS Question	Are you unable to collect physical/neurological exam data on subject?
Length of Field	1
Column Positions	116
Data Type	Numeric
Allowable Codes	0 = No 1 = Yes

Variable Number	2A
Variable Name	PHYCOG
Version	1
Short Descriptor	Too cognitively impaired for physical/neurological exam
UDS Question	Too cognitively impaired for physical/neurological exam
Length of Field	1
Column Positions	118
Data Type	Numeric
Allowable Codes	0 = No 1 = Yes

Variable Number	2B
Variable Name	PHYILL
Version	1
Short Descriptor	Too physically ill for physical/neurological exam
UDS Question	Too physically ill to travel/participate for physical/neurological exam
Length of Field	1
Column Positions	120
Data Type	Numeric
Allowable Codes	0 = No 1 = Yes

Form M1: Milestones

Variable Number	2C
Variable Name	PHYHOME
Version	1
Short Descriptor	Homebound/nursing home, no physical/neurological exam
UDS Question	Homebound/entered nursing home for permanent care, unable to collect physical/neurological exam data
Length of Field	1
Column Positions	122
Data Type	Numeric
Allowable Codes	0 = No 1 = Yes

Variable Number	2D
Variable Name	PHYOTH
Version	1
Short Descriptor	Unable to collect physical/neurological exam data, other reason
UDS Question	Unable to collect physical/neurological exam data, other reason
Length of Field	1
Column Positions	124
Data Type	Numeric
Allowable Codes	0 = No 1 = Yes

Variable Number	2D1
Variable Name	PHYOTHX
Version	1
Short Descriptor	Unable to collect physical/neurological exam data, other reason – specify
UDS Question	Unable to collect physical/neurological exam data, other reason – specify
Length of Field	60
Column Positions	126 – 185
Data Type	Character
Allowable Codes	Any text or numbers but cannot use single quotes ('), double quotes ("), ampersands (&), or percentage signs (%).
Blanks	Blank if #2D, PHYOTH = 0 (No) or blank.

Form M1: Milestones

Variable Number	3
Variable Name	NURSEHOM
Version	1
Short Descriptor	Entered nursing home permanently
UDS Question	Has subject entered nursing home with expectation of permanent residence?
Length of Field	1
Column Positions	187
Data Type	Numeric
Allowable Codes	0 = No 1 = Yes

Variable Number	3A1
Variable Name	NURSEMO
Version	1
Short Descriptor	Date entered nursing home, month
UDS Question	Date entered nursing home, month
Length of Field	2
Column Positions	189 – 190
Data Type	Numeric
Allowable Codes	1 – 12
Blanks	Blank if #3, NURSEHOM = No.

Variable Number	3A2
Variable Name	NURSEDY
Version	1
Short Descriptor	Date entered nursing home, day
UDS Question	Date entered nursing home, day
Length of Field	2
Column Positions	192 – 193
Data Type	Numeric
Allowable Codes	1 – 31
Blanks	Blank if #3, NURSEHOM = No. Note: NURSEDY is not available to non-ADC researchers.

Form M1: Milestones

Variable Number	3A3
Variable Name	NURSEYR
Version	1
Short Descriptor	Date entered nursing home, year
UDS Question	Date entered nursing home, year
Length of Field	4
Column Positions	195 – 198
Data Type	Numeric
Allowable Codes	2005 to present year
Blanks	Blank if #3, NURSEHOM = No.
Comment	Date must be on or after 9/1/2005.

Variable Number	4
Variable Name	DISCONT
Version	1
Short Descriptor	Discontinued
UDS Question	Has the subject discontinued?
Length of Field	1
Column Positions	200
Data Type	Numeric
Allowable Codes	0 = No 1 = Yes

Variable Number	4A1
Variable Name	DISCMO
Version	1
Short Descriptor	Date discontinued, month
UDS Question	Date discontinued, month
Length of Field	2
Column Positions	202 – 203
Data Type	Numeric
Allowable Codes	1 – 12
Blanks	Blank if #4, DISCONT = No.
Comment	Date must be after initial visit date.

Form M1: Milestones

Variable Number	4A2
Variable Name	DISCDAY
Version	1
Short Descriptor	Date discontinued, day
UDS Question	Date discontinued, day
Length of Field	2
Column Positions	205 – 206
Data Type	Numeric
Allowable Codes	1 – 31
Blanks	Blank if #4, DISCONT = No.
Comment	Date must be after initial visit date. Note: DISCDAY is not available to non-ADC researchers.

Variable Number	4A3
Variable Name	DISCYR
Version	1
Short Descriptor	Date discontinued, year
UDS Question	Date discontinued, year
Length of Field	4
Column Positions	208 – 211
Data Type	Numeric
Allowable Codes	2005 to present year
Blanks	Blank if #4, DISCONT = No.
Comment	Date must be after initial visit date.

Variable Number	4B
Variable Name	DISCREAS
Version	1
Short Descriptor	Reason discontinued
UDS Question	Reason discontinued
Length of Field	1
Column Positions	213
Data Type	Numeric
Allowable Codes	1 = Refused to return 2 = Moved out of area 3 = Discontinued due to Center protocol 4 = Seeking care elsewhere 8 = Other

Form M1: Milestones

Variable Number	4B1
Variable Name	DISCREAX
Version	1
Short Descriptor	Reason discontinued, other – specify
UDS Question	Reason discontinued, other – specify
Length of Field	60
Column Positions	215 – 274
Data Type	Character
Allowable Codes	Any text or numbers but cannot use single quotes (‘), double quotes (“), ampersands (&), or percentage signs (%).
Blanks	Blank if #4B, DISCREAS not coded 8 (Other).

Variable Number	5
Variable Name	DECEASED
Version	1
Short Descriptor	Deceased
UDS Question	Deceased
Length of Field	1
Column Positions	276
Data Type	Numeric
Allowable Codes	0 = No 1 = Yes

Variable Number	5A1
Variable Name	DEATHMO
Version	1
Short Descriptor	Date of death, month
UDS Question	Date of death, month
Length of Field	2
Column Positions	278 – 279
Data Type	Numeric
Allowable Codes	1 – 12
Blanks	Blank if #5, DECEASED = No.
Comment	Date must be after initial visit date and any follow up visit dates.

Form M1: Milestones

Variable Number	5A2
Variable Name	DEATHDY
Version	1
Short Descriptor	Date of death, day
UDS Question	Date of death, day
Length of Field	2
Column Positions	281 – 282
Data Type	Numeric
Allowable Codes	1 – 31
Blanks	Blank if #5, DECEASED = No.
Comment	Date must be after initial visit date and any follow up visit dates. Note: DEATHDY is not available to non-ADC researchers.

Variable Number	5A3
Variable Name	DEATHYR
Version	1
Short Descriptor	Date of death, year
UDS Question	Date of death, year
Length of Field	4
Column Positions	284 – 287
Data Type	Numeric
Allowable Codes	2005 to present year
Blanks	Blank if #5, DECEASED = No.
Comment	Date must be after initial visit date and any follow up visit dates.

Variable Number	5B
Variable Name	AUTOPSY
Version	1
Short Descriptor	Autopsy
UDS Question	Was autopsy performed?
Length of Field	1
Column Positions	289
Data Type	Numeric
Allowable Codes	0 = No 1 = Yes
Blanks	Blank if #5, DECEASED = No.

Form M1: Milestones

Variable Number	6
Variable Name	UDSACTIV
Version	1
Short Descriptor	Subject's active status
UDS Question	What is subject's status following the milestone event(s) indicated above:
Length of Field	1
Column Positions	291
Data Type	Numeric
Allowable Codes	1 = Active: further in-person visits expected 2 = Active: telephone or other contact expected 3 = Active: followed for autopsy only 4 = Inactive: no further data expected
Comment	A milestones form should be submitted any time the subject's active status changes, even if there are no other milestone changes.