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NACC Uniform Data Set (UDS)

DATA ELEMENT DICTIONARY

for Milestones Form

(Version 2.0, February 2008)

Data Element Dictionary – NACC UDS Milestones Form (M1)

GLOSSARY OF TERMS

Variable Number: Indicates order of appearance on the UDS Milestones form.

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

Version: 2

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	2
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	2
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	2
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 2.0 is FORMVER = 2.

Form Header (Milestones)

Variable Number	0D
Variable Name	ADCID
Version	2
Short Descriptor	Center ID
UDS Question	
Length of Field	2
Column Positions	12 – 13
Data Type	Numeric
Allowable Codes	<p>2 – 38, Use code below as your Center ID:</p> <ul style="list-style-type: none"> 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 School of Medicine 12 = New York University 13 = Northwestern University 14 = Oregon Health & Science University 15 = Rush University 16 = U 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 <p>Note: ADCID is converted to a randomly generated NACCADC in research data sets generated by NACC.</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>2</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 replaced by a randomly generated NACCID in research data sets generated by NACC.</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>2</p> <p>Form date – month</p> <p>Form date – month</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; cannot 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>2</p> <p>Form date – day</p> <p>Form date – day</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; cannot precede the data of the initial visit.</p>

Form Header (Milestones)

Variable Number	0H
Variable Name	VISITYR
Version	2
Short Descriptor	Form date – year
UDS Question	Form date – year
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; cannot precede the data of the initial visit.
Variable Number	0J
Variable Name	INITIALS
Version	2
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 never released in research data sets generated by NACC.

Form M1: Milestones

Variable Number	1
Variable Name	DECEASED
Version	2
Short Descriptor	Deceased
UDS Question	Subject has died
Length of Field	1
Column Positions	45
Data Type	Numeric
Allowable Codes	0 = No (Box is not checked) 1 = Yes (Box is checked)
Variable Number	1MO
Variable Name	DEATHMO
Version	2
Short Descriptor	Date of death, month
UDS Question	Date of death, month
Length of Field	2
Column Positions	47 – 48
Data Type	Numeric
Allowable Codes	1 – 12
Missing Codes	99 = month unknown
Blanks	Blank if #1, DECEASED = 0 (No).
Comment	Date must be after the last visit date.
Variable Number	1DY
Variable Name	DEATHDY
Version	2
Short Descriptor	Date of death, day
UDS Question	Date of death, day
Length of Field	2
Column Positions	50 – 51
Data Type	Numeric
Allowable Codes	1 – 31
Missing Codes	99 – day unknown
Blanks	Blank if #1, DECEASED = 0 (No).
Comment	Date must be after the last visit date. Note: DEATHDY is not available to non-ADC researchers.

Form M1: Milestones

Variable Number	1YR
Variable Name	DEATHYR
Version	2
Short Descriptor	Date of death, year
UDS Question	Date of death, year
Length of Field	4
Column Positions	53 – 56
Data Type	Numeric
Allowable Codes	2005 to present year
Blanks	Blank if #1, DECEASED = 0 (No).
Comment	Date must be after the last visit date.
Variable Number	1A
Variable Name	AUTOPSY
Version	2
Short Descriptor	Autopsy
UDS Question	ADC autopsy done (data pending or submitted)
Length of Field	1
Column Positions	58
Data Type	Numeric
Allowable Codes	0 = No (Box is not checked) 1 = Yes (Box is checked)
Blanks	Blank if #1, DECEASED = 0 (No).
Variable Number	2
Variable Name	DISCONT
Version	2
Short Descriptor	Discontinued
UDS Question	Subject has discontinued ADC participation
Length of Field	1
Column Positions	60
Data Type	Numeric
Allowable Codes	0 = No (Box is not checked) 1 = Yes (Box is checked)

Form M1: Milestones

Variable Number Variable Name Version Short Descriptor UDS Question Length of Field Column Positions Data Type Allowable Codes Missing Codes Blanks Comment	2MO DISCMO 2 Date discontinued, month Date discontinued, month 2 62 – 63 Numeric 1 – 12 99 = month unknown Blank if #2, DISCONT = 0 (No). Date must be after the last visit date.
2DY Variable Name Version Short Descriptor UDS Question Length of Field Column Positions Data Type Allowable Codes Missing Codes Blanks Comment	2DY DISCDAY 2 Date discontinued, day Date discontinued, day 2 65 – 66 Numeric 1 – 31 99 = day unknown Blank if #2, DISCONT = 0 (No). Date must be after the last visit date. Note: DISCDAY is not available to non-ADC researchers.
Variable Number Variable Name Version Short Descriptor UDS Question Length of Field Column Positions Data Type Allowable Codes Blanks Comment	2YR DISCYR 2 Date discontinued, year Date discontinued, year 4 68 – 71 Numeric 2005 to present year Blank if #2, DISCONT = 0 (No). Date must be after the last visit date.

Form M1: Milestones

Variable Number Variable Name Version Short Descriptor UDS Question Length of Field Column Positions Data Type Allowable Codes Blanks	2A DISCREAS 2 Reason discontinued Primary reason discontinued 1 73 Numeric 1 = Refused further participation in ADC 2 = Moved out of area 3 = Discontinued by ADC decision/protocol 4 = Seeking care elsewhere 8 = Other Blank if #2, DISCONT=0 (NO).
Variable Number Variable Name Version Short Descriptor UDS Question Length of Field Column Positions Data Type Allowable Codes Blanks	2AX DISCREAX 2 Reason discontinued, other – specify Reason discontinued, other – specify 60 75 – 134 Character Any text or numbers but cannot use single quotes (‘), double quotes (“), ampersands (&), or percentage signs (%). Blank if #2, DISCONT=0 (NO) or Blank if #2A, DISCREAS ≠ 8 (Other).
Variable Number Variable Name Version Short Descriptor UDS Question Length of Field Column Positions Data Type Allowable Codes	3 REJOINED 2 Rejoined ADC participation after discontinuing Subject has rejoined ADC participation after discontinuing. 1 136 Numeric 0 = No (Box is not checked) 1 = Yes (Box is checked)

Form M1: Milestones

Variable Number Variable Name Version Short Descriptor UDS Question Length of Field Column Positions Data Type Allowable Codes	4 NURSEHOM 2 Entered nursing home permanently Subject has entered nursing home with expectation of permanent residence 1 138 Numeric 0 = No (Box is not checked) 1 = Yes (Box is checked)
Variable Number Variable Name Version Short Descriptor UDS Question Length of Field Column Positions Data Type Allowable Codes Missing Codes Blanks	4MO NURSEMO 2 Date entered nursing home, month Date entered nursing home, month 2 140 – 141 Numeric 1 – 12 99 = month unknown Blank if #4, NURSEHOM = 0 (No).
Variable Number Variable Name Version Short Descriptor UDS Question Length of Field Column Positions Data Type Allowable Codes Missing Codes Blanks	4DY NURSEDY 2 Date entered nursing home, day Date entered nursing home, day 2 143 – 144 Numeric 1 – 31 99 = day unknown Blank if #4, NURSEHOM = 0 (No). Note: NURSEDY is not available to non-ADC researchers.

Form M1: Milestones

Variable Number	4YR
Variable Name	NURSEYR
Version	2
Short Descriptor	Date entered nursing home, year
UDS Question	Date entered nursing home, year
Length of Field	4
Column Positions	146 – 149
Data Type	Numeric
Allowable Codes	2005 to present year
Blanks	Blank if #4, NURSEHOM = 0 (No).
Comment	Date must be on or after 9/1/2005.
Variable Number	5
Variable Name	PROTOCOL
Version	2
Short Descriptor	NACC data collection protocol change
UDS Question	Subject's NACC data collection protocol has changed as indicated:
Length of Field	1
Column Positions	151
Data Type	Numeric
Allowable Codes	1 = To UDS telephone follow-up 2 = To minimal ADC contact (e.g., followed only to obtain autopsy) 3 = To UDS in-person visit
Variable Number	6
Variable Name	NPSYTEST
Version	2
Short Descriptor	Unable to collect neuropsychological test data
UDS Question	Unable to collect neuropsychological test data
Length of Field	1
Column Positions	153
Data Type	Numeric
Allowable Codes	0 = No (Box is not checked) 1 = Yes (Box is checked)
Blanks	Blank if #5 PROTOCOL=3 (Changed to In-person Visit)

Form M1: Milestones

Variable Number	6A
Variable Name	NPCOGIMP
Version	2
Short Descriptor	Too cognitively impaired
UDS Question	Unable to collect neuropsychological test data due to: Too cognitively impaired
Length of Field	1
Column Positions	155
Data Type	Numeric
Allowable Codes	0 = No (Box is not checked) 1 = Yes (Box is checked)
Blanks	Blank if #5 PROTOCOL = 3 (changed to in-person visit)
Variable Number	6B
Variable Name	NPPHYILL
Version	2
Short Descriptor	Too physically impaired
UDS Question	Unable to collect neuropsychological test data due to: Too physically impaired
Length of Field	1
Column Positions	157
Data Type	Numeric
Allowable Codes	0 = No (Box is not checked) 1 = Yes (Box is checked)
Blanks	Blank if #5 PROTOCOL = 3 (changed to in-person visit)
Variable Number	6C
Variable Name	NPHOMEN
Version	2
Short Descriptor	Homebound/nursing home/cannot travel
UDS Question	Unable to collect neuropsychological test data due to: Homebound/nursing home/cannot travel
Length of Field	1
Column Positions	159
Data Type	Numeric
Allowable Codes	0 = No (Box is not checked) 1 = Yes (Box is checked)
Blanks	Blank if #5 PROTOCOL = 3 (changed to in-person visit)

Form M1: Milestones

Variable Number	6D
Variable Name	NPREFUS
Version	2
Short Descriptor	Refused testing
UDS Question	Unable to collect neuropsychological test data due to: Refused testing
Length of Field	1
Column Positions	161
Data Type	Numeric
Allowable Codes	0 = No (Box is not checked) 1 = Yes (Box is checked)
Blanks	Blank if #5 PROTOCOL = 3 (changed to in-person visit)
Variable Number	6E
Variable Name	NPOTHREA
Version	2
Short Descriptor	Other– specify
UDS Question	Unable to collect neuropsychological test data due to: Other– specify
Length of Field	1
Column Positions	163
Data Type	Numeric
Allowable Codes	0 = No (Box is not checked) 1 = Yes (Box is checked)
Blanks	Blank if #5 PROTOCOL = 3 (changed to in-person visit)
Variable Number	6EX
Variable Name	NPOTHREX
Version	2
Short Descriptor	Other– specify
UDS Question	Unable to collect neuropsychological test data due to: Other– specify
Length of Field	60
Column Positions	165 – 224
Data Type	Character
Allowable Codes	Any text or numbers but cannot use single quotes (‘), double quotes (“), ampersands (&), or percentage signs (%).
Blanks	Blank if #5 PROTOCOL = 3 (changed to in-person visit) or #6E, NPOTHREA ≠ 1 (Yes).

Form M1: Milestones

Variable Number	7
Variable Name	PHYNDATA
Version	2
Short Descriptor	Unable to collect physical/neurological data
UDS Question	Unable to collect physical/neurological data
Length of Field	1
Column Positions	226
Data Type	Numeric
Allowable Codes	0 = No (Box is not checked) 1 = Yes (Box is checked)
Blank	Blank if #5 PROTOCOL = 3 (Change to In-person Visit)
Variable Number	7A
Variable Name	PHYCOG
Version	2
Short Descriptor	Too cognitively impaired
UDS Question	Unable to collect neuropsychological data due to: Too cognitively impaired
Length of Field	1
Column Positions	228
Data Type	Numeric
Allowable Codes	0 = No (Box is not checked) 1 = Yes (Box is checked)
Blanks	Blank if #5 PROTOCOL = 3 (changed to in-person visit)
Variable Number	7B
Variable Name	PHYILL
Version	2
Short Descriptor	Too physically impaired
UDS Question	Unable to collect neuropsychological data due to: Too physically impaired
Length of Field	1
Column Positions	230
Data Type	Numeric
Allowable Codes	0 = No (Box is not checked) 1 = Yes (Box is checked)
Blanks	Blank if #5 PROTOCOL = 3 (changed to in-person visit)

Form M1: Milestones

Variable Number Variable Name Version Short Descriptor UDS Question Length of Field Column Positions Data Type Allowable Codes Blanks	7C PHYHOME 2 Homebound/nursing home/cannot travel Unable to collect neuropsychological data due to: Homebound/ nursing home/cannot travel 1 232 Numeric 0 = No (Box is not checked) 1 = Yes (Box is checked) Blank if #5 PROTOCOL = 3 (changed to in-person visit)
Variable Number Variable Name Version Short Descriptor UDS Question Length of Field Column Positions Data Type Allowable Codes Blanks	7D PHYREFUS 2 Refused examination Unable to collect physical/neurological data due to: Refused examination 1 234 Numeric 0 = No (Box is not checked) 1 = Yes (Box is checked) Blank if #5 PROTOCOL = 3 (changed to in-person visit)
Variable Number Variable Name Version Short Descriptor UDS Question Length of Field Column Positions Data Type Allowable Codes Blanks	7E PHYOTH 2 Other Unable to collect physical/neurological data due to: Other 1 236 Numeric 0 = No (Box is not checked) 1 = Yes (Box is checked) Blank if #5 PROTOCOL = 3 (changed to in-person visit)

Form M1: Milestones

Variable Number	7EX
Variable Name	PHYOTHX
Version	2
Short Descriptor	Other– specify
UDS Question	Unable to collect physical/neurological data due to: Other– specify
Length of Field	60
Column Positions	238 – 297
Data Type	Character
Allowable Codes	Any text or numbers but cannot use single quotes (‘), double quotes (“), ampersands (&), or percentage signs (%).
Blanks	Blank if #5 PROTOCOL = 3 (changed to in-person visit) or #7E PHYOTH ≠ 1 (Yes).