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NACC Neuropathology Data Submission Manual

(Version 8, July 2006)

NOTE: Version 8 is NOT the most current version of the NP form and is no longer used for data submission. For the most current version, please visit http://www.alz.washington.edu.

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General Instructions

A. The NP Data Submission System

The NP data submission system implemented by NACC is to be used for your data submission. This system is available through the NACC website at https://www.alz.washington.edu. Access to the system is under your particular Center's data management menu. Use the following steps to access it.

1. Point browser at https://www.alz.washington.edu.
2. Click on "Member Login".
3. Fill in the user name and password then click "OK" (If you do not have an account, contact NACC).
4. Click on "The NACC Database".
5. Click on "I accept the terms of this agreement".
6. Click on "The Neuropathology Data Set".
7. Click on the name of your Center.
8. Click on "Data Manager Menu".
9. Click on "Neuropathology Data Submission System".

The system is designed to allow an easy way to submit, error-check, verify and process your Center's data into the NACC database.

Data files may be uploaded from your local computer, or data entry can be done on the web. Most Centers will want to submit just new NP IDs and modifications to some previously submitted NP IDs, rather than submitting replacement datasets. However, replacement datasets are also acceptable.

Once a final submission has been created, primary and secondary error checks may be run from the website. Alerts and other discrepancies must be verified through the website programs. Once this has been accomplished, the data is processed into the NACC database and certification reports can be created. **NACC must be contacted once you have completed your data submission; click on the "Notify NACC" link on the website.**

This system allows the Center's Data Manager to control their data submission to NACC completely through the NACC website.

B. Data Submission Date and Transmission Options

There is no deadline for submitting NP data, and data may be submitted continuously. NACC will freeze the submitted data twice per year, typically on January 1st and July 1st, and prepare reports.

Be sure to notify NACC once you have finished submitting, error-checking and processing your data using the NP data submission system.

Data may be transmitted in one of two modes:

1. Upload a data file;
2. Web data entry. Use the NP web data entry to enter data directly through NACC's website, https://www.alz.washington.edu (see the section elsewhere in this manual entitled "NACC Neuropathology Web Data Management");

Data files should be submitted via NACC's website. The website is now using SSL encryption software, so it is not necessary to password protect or zip your file. The data will be protected automatically while it is being uploaded.

C. File Types (if submitting data by file)

NACC will accept three types of files for the Neuropathology Data Submission:

- Fixed-format ASCII files ("flat files")
- SAS files
- SPSS files

These file types are described in more detail below.

Fixed-format ASCII files ("flat files"):

Each variable has a designated column assignment. One blank space has been allotted to separate each item from the next item. If there is no data for a particular item, its position must be filled with the correct number of blanks for that item.

SAS Files:

Two kinds of SAS files may be accepted by NACC:

1. PC SAS Version 7.0 – 9.0 files: These files have an extension of **.sas7bdat**.
2. SAS transport files – These files can be created on any system that runs SAS. A SAS program must be written to create transport files. If you need help writing the transport program, contact NACC.

SAS files must have all neuropath variables, with each variable having the correct type and length. Extra variables and formatted variables are not allowed.

SPSS Files:

SPSS files must have all neuropathology variables, with each variable of the correct type and length. Extra variables and formatted variables are not allowed. SPSS files must be saved and submitted in the portable file format (with an extension of **.por**).

D. General Coding Instructions

1. Required Items: All data elements in the neuropathology data submission are required, except for NPID.

2. Leading Zeroes and Justification: While entries should be right-justified and leading zeroes avoided, the error-check program accepts leading zeroes as long as the item is right-justified.

3. Missing Codes: Missing codes should be used for missing values from all sources, including "not recorded," "not applicable," "patient refusals," and "unknown" for any reason.

   Data that are missing should be indicated by 9's. *Please fill the entire field with 9's.* For example, if the missing item has one column, enter one 9 in that item's field; if the missing item has two columns, enter two 9's; and so on.

   Missing data, signified by missing codes, may be used in most elements except as noted in the Data Element Dictionary. It is expected that some Centers will not have data for all the items. Please provide as complete a record as possible.

4. Skips and Blanks: Skip patterns occur when you are directed by an item's response to a subsequent item that does not immediately follow the item you are completing. For fixed-format files, the items that are skipped should remain blank and are the only items that should be blank. For SAS files, use a " . " instead of a blank for numeric fields. For character fields, use " ". NOTE: Skip patterns have been removed from NPGROSS and NPVASC.

5. Definition of Valid Date:

   If MONTH = 2, (February), then DAY cannot be greater than 28 except in years that are divisible by 4, in which DAY cannot be greater than 29. If MONTH = 4, 6, 9, or 11, then DAY cannot be greater than 30.

   A year of death (NPDODYR) that precedes 1970 will generate an error. A year of death between 1970 and 1983 will generate an alert, because the earliest funding date for any Center was 1984.

   Dates must occur in the following order (earliest to latest):

   Date of death
   Date neuropath form was completed

E. Error-Check Program

The error-check program is designed to check for and detect unallowable and unlikely values. See the "Error Checking" section for more details about types of errors generated.

NACC Neuropathology
Data Template

Summary of Changes:

The following **changes** are highlighted in **red** on the Neuropathology Data Template:

1. Items 20a1–20k3 have been added.

2. Items 21–24 were formerly collected on the MDS form, and item 25 has been added.

Files should be submitted via the NP data submission system on NACC's website, https://www.alz.washington.edu.

NACC Neuropathology Data Template

Variable length	Columns	Variable Name	Character or Numeric	Item #
2	1-2	ADCID	N	0
10	4-13	PTID	C	1
2	15-16	NPFORMMO	N	2a
2	18-19	NPFORMDY	N	2b
4	21-24	NPFORMYR	N	2c
10	26-35	NPID	C	3
1	37	NPSEX	N	4
3	39-41	NPDAGE	N	5
2	43-44	NPDODMO	N	6a
2	46-47	NPDODDY	N	6b
4	49-52	NPDODYR	N	6c
1	54	NPGROSS	N	7
1	56	NPNIT	N	8a
1	58	NPCERAD	N	8c
1	60	NPADRDA	N	8c
1	62	NPOCRIT	N	8d
1	64	NPBRAAK	N	9
1	66	NPNEUR	N	10
1	68	NPDIFF	N	11
1	70	NPVASC	N	12
1	72	NPLINF	N	12A
1	74	NPMICRO	N	12B
1	76	NPLAC	N	12C
1	78	NPHEM	N	12D
1	80	NPART	N	12E
1	82	NPNEC	N	12F
1	84	NPSCL	N	12G
1	86	NPAVAS	N	12H
1	88	NPARTER	N	12I
1	90	NPAMY	N	12J
1	92	NPOANG	N	12K
1	94	NPVOTH	N	12L
1	96	NPLEWY	N	13
1	98	NPPICK	N	14A

NACC Neuropathology Data Template (continued)

Variable length	Columns	Variable Name	Character or Numeric	Item #
1	100	NPCORT	N	14B
1	102	NPPROG	N	14C
1	104	NPFRONT	N	14D
1	106	NPTAU	N	14E
1	108	NPFTD	N	14F
1	110	NPFTDNO	N	14G
1	112	NPFTDSPC	N	14H
1	114	NPCJ	N	15A
1	116	NPPRION	N	15B
1	118	NPMAJOR	N	16A
30	120-149	NPMPATH1	C	16B1
30	151-180	NPMPATH2	C	16B2
30	182-211	NPMPATH3	C	16B3
1	213	NPGENE	N	17A
30	215-244	NPFHSPEC	C	17B
1	246	NPAPOE	N	18A
1	248	NPTAUHAP	N	18B
1	250	NPPRNP	N	18C
2	252-253	NPCHROM	N	19
1	255	NPPNORM	N	20A1
1	257	NPCNORM	N	20A2
1	259	NPPADP	N	20B1
1	261	NPCADP	N	20B2
1	263	NPPAD	N	20C1
1	265	NPCAD	N	20C2
1	267	NPPLEWY	N	20D1
1	269	NPCLEWY	N	20D2
1	271	NPPVASC	N	20E1
1	273	NPCVASC	N	20E2
1	275	NPPFTLD	N	20F1
1	277	NPCFTLD	N	20F2
1	279	NPPHIPP	N	20G1
1	281	NPCHIPP	N	20G2
1	283	NPPPRION	N	20H1
1	285	NPCPRION	N	20H2

NACC Neuropathology Data Template (continued)

Variable length	Columns	Variable Name	Character or Numeric	Item #
1	287	NPPOTH1	N	20I1
1	289	NPCOTH1	N	20I2
60	291-350	NPOTH1X	C	20I3
1	352	NPPOTH2	N	20J1
1	354	NPCOTH2	N	20J2
60	356-415	NPOTH2X	C	20J3
1	417	NPPOTH3	N	20K1
1	419	NPCOTH3	N	20K2
60	421-480	NPOTH3X	C	20K3
1	482	NPBRFRZN	N	21
1	484	NPBRFRM	N	22
1	486	NPBPARF	N	23
1	488	NPCSFANT	N	24
2	490-491	FORMVER	N	25

NACC Neuropathology
Data Element Dictionary

The format of the Data Element Dictionary is similar to that in the UDS manual. **Variable names** are indicated in **blue**. **Changes** are highlighted in **red**. Each box includes the following information:

Variable Number – Indicates order of appearance on the Neuropathology form.

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

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

NP Question – The question as it appears on the Neuropathology Data Form.

Length of Field – For fixed field formats, number of columns for this variable.

Column Positions – For fixed field formats, the column numbers for this variable.

SAS Variable Type – For non-fixed field formats, variable type as numerical or character.

SAS Variable Length – For non-fixed field formats, variable length.

Allowable Values – List of values with mapping instructions.

Skips and Blanks – Instructions for skip patterns.

Comments – Other instructions as needed.

NOTE: All data elements are required except NPID.

Variable Number	**0**
Variable Name	**ADCID**
Short Descriptor	Center
NP Question	Center ID
Length of Field	2
Column Positions	1–2
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Values	1–36, Use code below as your Center ID: 1 = Baylor 2 = Boston U 3 = Case Western 4 = Columbia 5 = Duke 6 = Emory 7 = Massachusetts General 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	**NOTE: ADCID will be converted to a randomly-generated Center ID in the Public Use Data Set.**

Variable Number	**1**
Variable Name	**PTID**
Short Descriptor	UDS/MDS ID
NP Question	UDS/MDS Patient ID
Length of Field	10
Column Positions	4–13
SAS Variable Type	Character
SAS Variable Length	10
Allowable Values	Follow your center's UDS/MDS Patient ID scheme
Comment	UDS/MDS Patient ID must be unique within data set from your center (no duplicates). UDS/MDS PTID for each subject must be the same at each data submission; UDS/MDS PTID cannot change once it has been assigned by your Center. PTID is the same for a given subject at both the UDS Data Freeze and the Neuropathology Data Submission. **NOTE: PTID is not available to researchers or the public. It is replaced in the accessible UDS/MDS database by a randomly-generated NACCID.**

Variable Number	**2a**
Variable Name	**NPFORMMO**
Short Descriptor	Date Form Completed
NP Question	Date Form Completed: Month
Length of Field	2
Column Positions	15–16
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Values	1–12
Comment	Must meet criteria for valid date. If submitting replacement datasets, this is the date the form was originally submitted to NACC, not the current submission date.

Variable Number	**2b**
Variable Name	**NPFORMDY**
Short Descriptor	Date Form Completed
NP Question	Date form completed: Day
Length of Field	2
Column Positions	18–19
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Values	1–31
Comment	Must meet criteria for valid date. If submitting replacement datasets, this is the date the form was originally submitted to NACC, not the current submission date.

Variable Number	**2c**
Variable Name	**NPFORMYR**
Short Descriptor	Date Form Completed
NP Question	Date form completed: Year
Length of Field	4
Column Positions	21–24
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Values	2001 – current year
Comment	Must meet criteria for valid date. If submitting replacement datasets, this is the date the form was originally submitted to NACC, not the current submission date.

Variable Number	**3**
Variable Name	**NPID**
Short Descriptor	Neuropath ID
NP Question	Neuropath ID
Length of Field	10
Column Positions	26–35
SAS Variable Type	Character
SAS Variable Length	10
Allowable Values	Follow your center's Neuropathology Patient ID scheme
Comment	Neuropath ID number must be unique within data set from your center (no duplicates). NPID for each subject must be the same each time data are submitted or received; NPID cannot change once it has been assigned by your Center. **NOTE: NPID will not be available in the Public Use Data Set.**

Variable Number	**4**
Variable Name	**NPSEX**
Short Descriptor	Gender
NP Question	Subject's sex
Length of Field	1
Column Positions	37
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Values	1 or 2 1 = Male 2 = Female
Comment	Missing (9s) not allowed. Must be same as UDS/MDS data element SEX.

Variable Number	**5**
Variable Name	**NPDAGE**
Short Descriptor	Age at Death
NP Question	Age at Death
Length of Field	3
Column Positions	39–41
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Values	0–130
Comment	NPDAGE must be rounded down (not up). Calculate the death age, then drop any decimal portion. For Example, if the death age is 81.9 then NPDAGE = 81. If death occurs on the birthday, the subject is considered to be one year older.

Variable Number	**6a**
Variable Name	**NPDODMO**
Short Descriptor	Date of Death
NP Question	Subject's date of death: Month
Length of Field	2
Column Positions	43–44
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Values	1–12
Missing Code	99
Comment	Must be same date as in UDS/MDS. Must meet criteria for valid date. Must be before the NP data form completed (2).

Variable Number	**6b**
Variable Name	**NPDODDY**
Short Descriptor	Date of Death
NP Question	Subject's date of death: Day
Length of Field	2
Column Positions	46–47
SAS Variable Type	Numeric
SAS Variable Length	8
Missing Code	99
Allowable Values	1–31
Comment	Must be same date as in UDS/MDS. Must meet criteria for valid date. Must be before the NP data form completed (2).

Variable Number	**6c**
Variable Name	**NPDODYR**
Short Descriptor	Date of Death
NP Question	Subject's date of death: Year
Length of Field	4
Column Positions	49–52
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Values	Cannot precede 1970; in most cases, should not precede 1984.
Comment	Must be same date as in UDS/MDS. Must meet criteria for valid date. Must be before the NP data form completed (2).

Variable Number	**7**
Variable Name	**NPGROSS**
Short Descriptor	Brain have G/M Path
NP Question	Does the brain have any gross or microscopic pathology (including any Alzheimer type pathology such as senile plaques and neurofibrillary tangles)?
Length of Field	1
Column Positions	54
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Values	1, 2 1 = Yes 2 = No
Comment	Code 9 (no neuropathology diagnosis available) not allowed. SKIP PATTERN REMOVED

Variable Number	**8A**
Variable Name	**NPNIT**
Short Descriptor	NIA/Reagan Ins Crit
NP Question	NIA/Reagan Institute neuropathological criteria used:
Length of Field	1
Column Positions	56
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Values	1–5 1 = High likelihood of dementia being due to Alzheimer's disease 2 = Intermediate likelihood of dementia being due to Alzheimer's disease 3 = Low likelihood of dementia being due to Alzheimer's disease 4 = Criteria not met 5 = Not Done
Missing Code	9 = Missing/unknown

Variable Number	**8B**
Variable Name	**NPCERAD**
Short Descriptor	CERAD Criteria
NP Question	CERAD neuropathological criteria used:
Length of Field	1
Column Positions	58
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Values	1–5 1 = Definite Alzheimer's disease 2 = Probable Alzheimer's disease 3 = Possible Alzheimer's disease 4 = Criteria not met 5 = Not done
Missing Code	9 = Missing/Unknown

Variable Number	**8C**
Variable Name	**NPADRDA**
Short Descriptor	ADRDA/Khach Criteria
NP Question	ADRDA/Khachaturian neuropathological criteria used:
Length of Field	1
Column Positions	60
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Values	1–3 1 = Alzheimer's disease 2 = Criteria not met 3 = Not done
Missing Code	9 = Missing/Unknown

Variable Number	**8D**
Variable Name	**NPOCRIT**
Short Descriptor	Other Criteria
NP Question	Other or unspecified neuropathological criteria used (e.g., Tierney, etc.):
Length of Field	1
Column Positions	62
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Values	1–3 1 = Alzheimer's disease, unspecified 2 = Criteria not met 3 = Not done
Missing Code	9 = Missing/Unknown

Variable Number	**9**
Variable Name	**NPBRAAK**
Short Descriptor	Braak & Braak Stage
NP Question	Braak & Braak Neurofibrillary Stage.
Length of Field	1
Column Positions	64
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Values	1–8
	1 = Stage I
	2 = Stage II
	3 = Stage III
	4 = Stage IV
	5 = Stage V
	6 = Stage VI
	7 = Neurofibrillary degeneration not present
	8 = Not assessed
Missing Code	9 = Missing/unknown

Variable Number	**10**
Variable Name	**NPNEUR**
Short Descriptor	Neuritic Plaques
NP Question	Neuritic plaques (plaques with argyrophilic dystrophic neurites with or without dense amyloid cores).
Length of Field	1
Column Positions	66
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Values	1–5
	1 = Frequent neuritic plaques
	2 = Moderate neuritic plaques
	3 = Sparse neuritic plaques
	4 = No neuritic plaques
	5 = Not assessed
Missing Code	9 = Missing/unknown

Variable Number	**11**
Variable Name	**NPDIFF**
Short Descriptor	Diffuse Plaques
NP Question	Diffuse plaques (plaques with non-compact amyloid and no apparent dystrophic neurites).
Length of Field	1
Column Positions	68
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Values	1–5 1 = Frequent diffuse plaques 2 = Moderate diffuse plaques 3 = Sparse diffuse plaques 4 = No diffuse plaques 5 = Not assessed
Missing Code	9 = Missing/unknown

Variable Number	**12**
Variable Name	**NPVASC**
Short Descriptor	Isch, Hemor, or Vasc
NP Question	Is ischemic, hemorrhagic or vascular pathology present?
Length of Field	1
Column Positions	70
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Values	1–3 1 = Yes 2 = No 3 = Not assessed
Missing Code	9 = Missing/Unknown
Comment	SKIP PATTERN REMOVED

Variable Number	**12A**
Variable Name	**NPLINF**
Short Descriptor	Large Art Infarcts
NP Question	Are one or more large artery cerebral infarcts present?
Length of Field	1
Column Positions	72
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Values	1–3 1 = Yes 2 = No 3 = Not assessed
Missing Code	9 = Missing/unknown

Variable Number	**12B**
Variable Name	**NPMICRO**
Short Descriptor	Mult Microinfarcts
NP Question	Are one or more cortical microinfarcts (including “granular atrophy”) present?
Length of Field	1
Column Positions	74
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Values	1–3 1 = Yes 2 = No 3 = Not assessed
Missing Code	9 = Missing/unknown

Variable Number	**12C**
Variable Name	**NPLAC**
Short Descriptor	One or More Lacunes
NP Question	Are one or more lacunes (small artery infarcts and/or hemorrhages) present?
Length of Field	1
Column Positions	76
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Values	1–3 1 = Yes 2 = No 3 = Not assessed
Missing Code	9 = Missing/unknown

Variable Number	**12D**
Variable Name	**NPHEM**
Short Descriptor	Hemorrhages
NP Question	Are single or multiple hemorrhages present?
Length of Field	1
Column Positions	78
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Values	1–3 1 = Yes 2 = No 3 = Not assessed
Missing Code	9 = Missing/unknown

Variable Number	**12E**
Variable Name	**NPART**
Short Descriptor	Arteriosclerotic
NP Question	Is subcortical arteriosclerotic leukoencephalopathy present?
Length of Field	1
Column Positions	80
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Values	1–3 1 = Yes 2 = No 3 = Not assessed
Missing Code	9 = Missing/unknown

Variable Number	**12F**
Variable Name	**NPNEC**
Short Descriptor	Laminar Necrosis
NP Question	Is cortical laminar necrosis present?
Length of Field	1
Column Positions	82
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Values	1–3 1 = Yes 2 = No 3 = Not assessed
Missing Code	9 = Missing/unknown

Variable Number	**12G**
Variable Name	**NPSCL**
Short Descriptor	Sclerosis
NP Question	Is medial temporal lobe sclerosis (including hippocampal sclerosis) present?
Length of Field	1
Column Positions	84
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Values	1–3 1 = Yes 2 = No 3 = Not assessed
Missing Code	9 = Missing/unknown

Variable Number	**12H**
Variable Name	**NPAVAS**
Short Descriptor	Ather Vascular
NP Question	Is atherosclerotic vascular pathology (of the circle of Willis) present?
Length of Field	1
Column Positions	86
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Values	1–5 1 = None 2 = Mild 3 = Moderate 4 = Severe 5 = Not assessed
Missing Code	9 = Missing/unknown

Variable Number	**12I**
Variable Name	**NPARTER**
Short Descriptor	Arteriosclerosis
NP Question	Is arteriosclerosis (small parenchymal arteriolar disease) present?
Length of Field	1
Column Positions	88
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Values	1–5 1 = None 2 = Mild 3 = Moderate 4 = Severe 5 = Not assessed
Missing Code	9 = Missing/unknown

Variable Number	**12J**
Variable Name	**NPAMY**
Short Descriptor	Amyloid Angiopathy
NP Question	Is amyloid angiopathy present?
Length of Field	1
Column Positions	90
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Values	1–5 1 = None 2 = Mild 3 = Moderate 4 = Severe 5 = Not assessed
Missing Code	9 = Missing/unknown

Variable Number	**12K**
Variable Name	**NPOANG**
Short Descriptor	Another Angiopathy
NP Question	Is another type of angiopathy (e.g., CADASIL or arteritis) present?
Length of Field	1
Column Positions	92
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Values	1–3 1 = Yes 2 = No 3 = Not assessed
Missing Code	9 = Missing/Unknown

Variable Number	**12L**
Variable Name	**NPVOTH**
Short Descriptor	Other Vascular
NP Question	Is there other pathology related to ischemic or vascular disease not previously specified present?
Length of Field	1
Column Positions	94
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Values	1–3 1 = Yes 2 = No 3 = Not assessed
Missing Code	9 = Missing/unknown

Variable Number	**13**
Variable Name	**NPLEWY**
Short Descriptor	Lewy Bodies
NP Question	Pathology is consistent with criteria of Consortium on Dementia with Lewy Bodies for:
Length of Field	1
Column Positions	96
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Values	1–6
	1 = Lewy body pathology, brainstem predominant type
	2 = Lewy body pathology, intermediate or transitional (limbic) type
	3 = Lewy body pathology, diffuse (neocortical) type
	4 = Lewy body pathology, unspecified or not further assessed
	5 = No Lewy bodies
	6 = Not assessed
Missing Code	9 = Missing/Unknown

Variable Number	**14A**
Variable Name	**NPPICK**
Short Descriptor	Picks Disease
NP Question	Pick's Disease:
Length of Field	1
Column Positions	98
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Values	1–3
	1 = Yes
	2 = No
	3 = Not assessed
Missing Code	9 = Missing/Unknown

Variable Number	**14B**
Variable Name	**NPCORT**
Short Descriptor	Corticobasal Deg
NP Question	Corticobasal degeneration:
Length of Field	1
Column Positions	100
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Values	1–3
	1 = Yes
	2 = No
	3 = Not assessed
Missing Code	9 = Missing/Unknown

Variable Number	**14C**
Variable Name	**NPPROG**
Short Descriptor	Prog Supra Palsy
NP Question	Progressive supranuclear palsy:
Length of Field	1
Column Positions	102
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Values	1–3 1 = Yes 2 = No 3 = Not assessed
Missing Code	9 = Missing/Unknown

Variable Number	**14D**
Variable Name	**NPFRONT**
Short Descriptor	Frontotemporal Dem
NP Question	Frontotemporal dementia and Parkinsonism with tau-positive or argyrophilic inclusions:
Length of Field	1
Column Positions	104
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Values	1–3 1 = Yes 2 = No 3 = Not assessed
Missing Code	9 = Missing/Unknown

Variable Number	**14E**
Variable Name	**NPTAU**
Short Descriptor	Tauopathy, Other
NP Question	Tauopathy, other (e.g., tangle-only dementia and argyrophilic grain dementia):
Length of Field	1
Column Positions	106
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Values	1–3 1 = Yes 2 = No 3 = Not assessed
Missing Code	9 = Missing/Unknown

Variable Number	**14F**
Variable Name	**NPFTD**
Short Descriptor	FTD with Ubiq
NP Question	FTD with ubiquitin-positive (tau-negative) inclusions:
Length of Field	1
Column Positions	108
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Values	1–4
	1 = FTD with motor neuron disease
	2 = FTD without motor neuron disease
	3 = None present
	4 = Not assessed
Missing Code	9 = Missing/Unknown

Variable Number	**14G**
Variable Name	**NPFTDNO**
Short Descriptor	FTD with No Hist
NP Question	Is there FTD with no distinctive histopathology (tau-negative, ubiquitin-negative, and no argyrophilic inclusions)?
Length of Field	1
Column Positions	110
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Values	1–3
	1 = Yes
	2 = No
	3 = Not assessed
Missing Code	9 = Missing/Unknown

Variable Number	**14H**
Variable Name	**NPFTDSPC**
Short Descriptor	FTD Not Specified
NP Question	Was FTD “not otherwise specified” present (e.g., “immunostaining for ubiquitin and tau not done”)?
Length of Field	1
Column Positions	112
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Values	1–3
	1 = Yes
	2 = No
	3 = Not assessed
Missing Code	9 = Missing/Unknown

Variable Number	**15A**
Variable Name	**NPCJ**
Short Descriptor	Creutz-Jak Disease
NP Question	Is Creutzfeldt-Jakob disease or variant CJD present?
Length of Field	1
Column Positions	114
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Values	1–3
	1 = Yes
	2 = No
	3 = Not assessed
Missing Code	9 = Missing/Unknown

Variable Number	**15B**
Variable Name	**NPPRION**
Short Descriptor	Other Prion
NP Question	Are other prion diseases present (e.g., Gerstmann-Straussler syndrome)?
Length of Field	1
Column Positions	116
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Values	1–3
	1 = Yes
	2 = No
	3 = Not assessed
Missing Code	9 = Missing/Unknown

Variable Number	**16A**
Variable Name	**NPMAJOR**
Short Descriptor	Other Maj Path
NP Question	Are other major pathological disorders present (not addressed by questions 8–15)?
Length of Field	1
Column Positions	118
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Values	1–3
	1 = Yes
	2 = No
	3 = Not assessed
Missing Code	9 = Missing/Unknown
Skips	If NPMAJOR = 2, 3 or 9, then go to #17A, NPGENE

Variable Number	**16B1**
Variable Name	**NPMPATH1**
Short Descriptor	Specify 1
NP Question	If 16A is yes, then specify below:
Length of Field	30
Column Positions	120–149
SAS Variable Type	Character
SAS Variable Length	30
Blanks	Blank if #16A NPMAJOR = 2, 3 or 9
Comment	For 16B1, 16B2, and 16B3 provide most prominent three disorders

Variable Number	**16B2**
Variable Name	**NPMPATH2**
Short Descriptor	Specify 2
NP Question	If 16A is yes, then specify below:
Length of Field	30
Column Positions	151–180
SAS Variable Type	Character
SAS Variable Length	30
Blanks	Blank if #16A NPMAJOR = 2, 3 or 9
Comment	For 16B1, 16B2, and 16B3 provide most prominent three disorders

Variable Number	**16B3**
Variable Name	**NPMPATH3**
Short Descriptor	Specify 3
NP Question	If 16A is yes, then specify below:
Length of Field	30
Column Positions	182–211
SAS Variable Type	Character
SAS Variable Length	30
Blanks	Blank if #16A NPMAJOR = 2, 3 or 9
Comment	For 16B1, 16B2, and 16B3 provide most prominent three disorders

Variable Number	**17A**
Variable Name	**NPGENE**
Short Descriptor	Family history
NP Question	Family history information relevant to neuropathologic diagnosis.
Length of Field	1
Column Positions	213
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Values	1–4 1 = Family history of similar neurodegenerative disorder 2 = Family history of other (dissimilar) neurodegenerative disorder 3 = No family history of similar or dissimilar neurodegenerative disorder 4 = Family history of both similar and dissimilar neurodegenerative disorder
Missing Code	9 = Family history unknown/not available/missing
Skips	If NPGENE = 1, 3 or 9, then go to #18A, NPAPOE. If NPGENE = 2 or 4, then continue.

Variable Number	**17B**
Variable Name	**NPFHSPEC**
Short Descriptor	Specify
NP Question	If 17A is 2 or 4, then specify:
Length of Field	30
Column Positions	215–244
SAS Variable Type	Character
SAS Variable Length	30
Blanks	Blank if #17A, NPGENE = 1, 3 or 9
Comment	Provide the one most prominent disorder.

Variable Number	**18A**
Variable Name	**NPAPOE**
Short Descriptor	APOE
NP Question	Apolipoprotein-E:
Length of Field	1
Column Positions	246
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Codes	1–6 1 = e3, e3 2 = e3, e4 3 = e3, e2 4 = e4, e4 5 = e4, e2 6 = e2, e2
Missing Code	9 = Missing/unknown/not assessed

Variable Number	**18B**
Variable Name	**NPTAUHAP**
Short Descriptor	Tau haplotype
NP Question	Tau haplotype:
Length of Field	1
Column Positions	248
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Codes	1–4
	1 = H1, H1
	2 = H1, H2
	3 = H2, H2
	4 = Other polymorphism (e.g., A0)
Missing Code	9 = Missing/unknown/not assessed

Variable Number	**18C**
Variable Name	**NPPRNP**
Short Descriptor	PRNP codon 129
NP Question	PRNP codon 129:
Length of Field	1
Column Positions	250
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Codes	1–3
	1 = M, M
	2 = M, V
	3 = V, V
Missing Code	9 = Missing/unknown/not assessed

Variable Number	**19**
Variable Name	**NPCHROM**
Short Descriptor	Gen or Chrom Abnorm
NP Question	Genetic or Chromosomal abnormalities.
Length of Field	2
Column Positions	252–253
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Codes	1–13, 50 1 = APP mutation 2 = PS1 mutation 3 = PS2 mutation 4 = Tau mutation 5 = α- Synuclein mutation 6 = Parkin mutation 7 = PRNP mutation 8 = Huntingtin mutation 9 = Notch 3 mutation (CADASIL) 10 = Other known genetic mutation (e.g., ABri, neuroserpin) 11 = Down Syndrome 12 = Other chromosomal abnormality 13 = No known genetic or chromosomal abnormality 50 = Not assessed 99 = Missing/unknown

Variable Number	**20A1**
Variable Name	**NPPNORM**
Short Descriptor	Normal Brain - Primary
NP Question	Is the primary pathologic diagnosis normal brain?
Length of Field	1
Column Positions	255
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Codes	1-2 1 = Yes 2 = No
Comment	**NOTE: Only one diagnosis in items 20A1 through 20K1 may be coded Yes for primary diagnosis.**

Variable Number	**20A2**
Variable Name	**NPCNORM**
Short Descriptor	Normal Brain - Contributing
NP Question	Is there a contributing pathologic diagnosis of normal brain?
Length of Field	1
Column Positions	257
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Codes	1-2 1 = Yes 2 = No
Comment	**NOTE: More than one diagnosis in items 20A2 through 20K2 may be coded Yes for contributing diagnosis.**

Variable Number	**20B1**
Variable Name	**NPPADP**
Short Descriptor	AD pathology present, but insufficient for AD diagnosis - Primary
NP Question	Is the primary pathologic diagnosis of AD pathology present, but insufficient for AD diagnosis?
Length of Field	1
Column Positions	259
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Codes	1-2 1 = Yes 2 = No
Comment	**NOTE: Only one diagnosis in items 20A1 through 20K1 may be coded Yes for primary diagnosis.**

Variable Number	**20B2**
Variable Name	**NPCADP**
Short Descriptor	AD pathology present, but insufficient for AD diagnosis - Contributing
NP Question	Is the contributing pathologic diagnosis of AD pathology present, but insufficient for AD diagnosis?
Length of Field	1
Column Positions	261
SAS Variable Type	Numeric
SAS Variable Length	1
Allowable Codes	1-2 1 = Yes 2 = No
Comment	**NOTE: More than one diagnosis in items 20A2 through 20K2 may be coded Yes for contributing diagnosis.**

Variable Number	**20C1**
Variable Name	**NPPAD**
Short Descriptor	Alzheimer's disease - Primary
NP Question	Is the primary pathologic diagnosis Alzheimer's disease?
Length of Field	1
Column Positions	263
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Codes	1-2 1 = Yes 2 = No
Comment	**NOTE: Only one diagnosis in items 20A1 through 20K1 may be coded Yes for primary diagnosis.**

Variable Number	**20C2**
Variable Name	**NPCAD**
Short Descriptor	Alzheimer's disease - Contributing
NP Question	Is there a contributing pathologic diagnosis of Alzheimer's disease?
Length of Field	1
Column Positions	265
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Codes	1-2 1 = Yes 2 = No
Comment	**NOTE: More than one diagnosis in items 20A2 through 20K2 may be coded Yes for contributing diagnosis.**

Variable Number	**20D1**
Variable Name	**NPPLEWY**
Short Descriptor	Lewy Body disease, with or without AD – Primary
NP Question	Is the primary pathologic diagnosis Lewy Body disease, with or without AD?
Length of Field	1
Column Positions	267
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Codes	1-2 1 = Yes 2 = No
Comment	**NOTE: Only one diagnosis in items 20A1 through 20K1 may be coded Yes for primary diagnosis.**

Variable Number	**20D2**
Variable Name	**NPCLEWY**
Short Descriptor	Lewy Body disease, with or without AD – Contributing
NP Question	Is there a contributing pathologic diagnosis of Lewy Body disease, with or without AD?
Length of Field	1
Column Positions	269
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Codes	1-2 1 = Yes 2 = No
Comment	**NOTE: More than one diagnosis in items 20A2 through 20K2 may be coded Yes for contributing diagnosis.**

Variable Number	**20E1**
Variable Name	**NPPVASC**
Short Descriptor	Vascular disease – Primary
NP Question	Is the primary pathologic diagnosis vascular disease?
Length of Field	1
Column Positions	271
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Codes	1-2 1 = Yes 2 = No
Comment	**NOTE: Only one diagnosis in items 20A1 through 20K1 may be coded Yes for primary diagnosis.**

Variable Number	**20E2**
Variable Name	**NPCVASC**
Short Descriptor	Vascular disease – Contributing
NP Question	Is there a contributing pathologic diagnosis of vascular disease?
Length of Field	1
Column Positions	273
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Codes	1-2 1 = Yes 2 = No
Comment	**NOTE: More than one diagnosis in items 20A2 through 20K2 may be coded Yes for contributing diagnosis.**

Variable Number	**20F1**
Variable Name	**NPPFTLD**
Short Descriptor	FTLD – Primary
NP Question	Is the primary pathologic diagnosis FTLD?
Length of Field	1
Column Positions	275
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Codes	1-2 1 = Yes 2 = No
Comment	**NOTE: Only one diagnosis in items 20A1 through 20K1 may be coded Yes for primary diagnosis.**

Variable Number	**20F2**
Variable Name	**NPCFTLD**
Short Descriptor	FTLD – Contributing
NP Question	Is there a contributing pathologic diagnosis of FTLD?
Length of Field	1
Column Positions	277
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Codes	1-2 1 = Yes 2 = No
Comment	**NOTE: More than one diagnosis in items 20A2 through 20K2 may be coded Yes for contributing diagnosis.**

Variable Number	**20G1**
Variable Name	**NPPHIPP**
Short Descriptor	Hippocampal sclerosis – Primary
NP Question	Is the primary pathologic diagnosis hippocampal sclerosis?
Length of Field	1
Column Positions	279
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Codes	1-2 1 = Yes 2 = No
Comment	**NOTE: Only one diagnosis in items 20A1 through 20K1 may be coded Yes for primary diagnosis.**

Variable Number	**20G2**
Variable Name	**NPCHIPP**
Short Descriptor	Hippocampal sclerosis – Contributing
NP Question	Is there a contributing pathologic diagnosis of hippocampal sclerosis?
Length of Field	1
Column Positions	281
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Codes	1-2 1 = Yes 2 = No
Comment	**NOTE: More than one diagnosis in items 20A2 through 20K2 may be coded Yes for contributing diagnosis.**

Variable Number	**20H1**
Variable Name	**NPPPRION**
Short Descriptor	Prion Associated Disease – Primary
NP Question	Is the primary pathologic diagnosis Prion Associated Disease?
Length of Field	1
Column Positions	283
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Codes	1-2 1 = Yes 2 = No
Comment	**NOTE: Only one diagnosis in items 20A1 through 20K1 may be coded Yes for primary diagnosis.**

Variable Number	**20H2**
Variable Name	**NPCPRION**
Short Descriptor	Prion Associated Disease – Contributing
NP Question	Is there a contributing pathologic diagnosis of Prion Associated Disease?
Length of Field	1
Column Positions	285
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Codes	1-2 1 = Yes 2 = No
Comment	**NOTE: More than one diagnosis in items 20A2 through 20K2 may be coded Yes for contributing diagnosis.**

Variable Number	**20I1**
Variable Name	**NPPOTH1**
Short Descriptor	Other 1 - Primary
NP Question	Is the primary pathologic diagnosis other?
Length of Field	1
Column Positions	287
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Codes	1-2 1 = Yes 2 = No
Comment	**NOTE: Only one diagnosis in items 20A1 through 20K1 may be coded Yes for primary diagnosis.**

Variable Number	**20I2**
Variable Name	**NPCOTH1**
Short Descriptor	Other 1 - Contributing
NP Question	Is the contributing pathologic diagnosis other?
Length of Field	1
Column Positions	289
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Codes	1-2 1 = Yes 2 = No
Comment	**NOTE: More than one diagnosis in items 20A2 through 20K2 may be coded Yes for contributing diagnosis.**

Variable Number	**20I3**
Variable Name	**NPOTH1X**
Short Descriptor	Other 1 - Specify
NP Question	What is the specification for other 1?
Length of Field	60
Column Positions	291–350
SAS Variable Type	Character
SAS Variable Length	60
Allowable Codes	Any valid characters except “, ‘, %, &

Variable Number	**20J1**
Variable Name	**NPPOTH2**
Short Descriptor	Other 2 - Primary
NP Question	Is the primary pathologic diagnosis other?
Length of Field	1
Column Positions	352
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Codes	1-2 1 = Yes 2 = No
Comment	**NOTE: Only one diagnosis in items 20A1 through 20K1 may be coded Yes for primary diagnosis.**

Variable Number	**20J2**
Variable Name	**NPCOTH2**
Short Descriptor	Other 2 - Contributing
NP Question	Is the contributing pathologic diagnosis other?
Length of Field	1
Column Positions	354
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Codes	1-2 1 = Yes 2 = No
Comment	**NOTE: More than one diagnosis in items 20A2 through 20K2 may be coded Yes for contributing diagnosis.**

Variable Number	**20J3**
Variable Name	**NPOTH2X**
Short Descriptor	Other 2 - Specify
NP Question	What is the specification for other 2?
Length of Field	60
Column Positions	356–415
SAS Variable Type	Character
SAS Variable Length	60
Allowable Codes	Any valid characters except “, ‘, %, &

Variable Number	**20K1**
Variable Name	**NPPOTH3**
Short Descriptor	Other 3 - Primary
NP Question	Is the primary pathologic diagnosis other?
Length of Field	1
Column Positions	417
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Codes	1-2 1 = Yes 2 = No
Comment	**NOTE: Only one diagnosis in items 20A1 through 20K1 may be coded Yes for primary diagnosis.**

Variable Number	**20K2**
Variable Name	**NPCOTH3**
Short Descriptor	Other 3 - Contributing
NP Question	Is the contributing pathologic diagnosis other?
Length of Field	1
Column Positions	419
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Codes	1-2 1 = Yes 2 = No
Comment	**NOTE: More than one diagnosis in items 20A2 through 20K2 may be coded Yes for contributing diagnosis.**

Variable Number	**20K3**
Variable Name	**NPOTH3X**
Short Descriptor	Other 3 - Specify
NP Question	What is the specification for other 3?
Length of Field	60
Column Positions	421–480
SAS Variable Type	Character
SAS Variable Length	60
Allowable Codes	Any valid characters except “, ‘, %, &

Variable Number	**21**
Variable Name	**NPBRFRZN**
Short Descriptor	Banked frozen brain tissue accessible
NP Question	Is banked frozen brain tissue accessible?
Length of Field	1
Column Positions	482
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Values	1–2 1 = Yes 2 = No

Variable Number	**22**
Variable Name	**NPBRFRM**
Short Descriptor	Formalin-fixed brain tissue accessible
NP Question	Is formalin-fixed brain tissue accessible?
Length of Field	1
Column Positions	484
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Values	1–2 1 = Yes 2 = No

Variable Number	**23**
Variable Name	**NPBRPARF**
Short Descriptor	Paraffin Brain Sample
NP Question	Are paraffin-embedded blocks of brain tissue accessible?
Length of Field	1
Column Positions	486
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Values	1–2 1 = Yes 2 = No

Variable Number	**24**
Variable Name	**NPCSFANT**
Short Descriptor	Postmortem cerebrospinal fluid (CSF) accessible
NP Question	Is banked postmortem cerebrospinal fluid (CSF) accessible?
Length of Field	1
Column Positions	488
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Values	1–2 1 = Yes 2 = No

Variable Number	**25**
Variable Name	**FORMVER**
Short Descriptor	Version of NP Form
NP Question	What is the version of the NP Form?
Length of Field	2
Column Positions	490-491
SAS Variable Type	Numeric
SAS Variable Length	8
Allowable Values	8 8 = Version 8

Primary Error Checking

NACC NP Error Messages

Several types of error messages may be generated by the NP primary error checking program**:** range errors, contingency errors, and errors related to type of file being checked (i.e., alignment or variable type).

Files with errors are not accepted for submission. Errors must be corrected before the NP submission system will allow you to proceed. Alerts are accepted if verified. Alerts are verified by going to Step 3 at the NP submission system's main menu (after any errors have been corrected).

Examples of types of Error Messages are as follows:

1. **Range** – Alpha item in numeric field (only for ASCII Files)

Line # in file:	1
UDS/MDS Patient ID #:	21
Variable Number:	4
Variable Name:	NPSEX
Type of Check:	Range
Action Required:	ERROR: Correct unallowable value.
Incorrect Value:	a
	Non-digits not allowed in this item.
(New Value):	

2. **Range** – Value not within defined limits

Line # in file:	1
UDS/MDS Patient ID #:	21
Variable Number:	4
Variable Name:	NPSEX
Type of Check:	Range
Action Required:	ERROR: Correct unallowable value.
Incorrect Value:	3
(New Value):	

3. **Contingency –** Data element should have been skipped

Line # in file:	1
UDS/MDS Patient ID #:	0000000001
Variable Number:	16a, 16b1
Variable Name:	NPMAJOR, NPMPATH1
Type of Check:	Contingency
Action Required:	ERROR: Correct by making values consistent.
Incorrect Value:	NPMPATH1=Smiths disorder The NPMPATH1 item should have been skipped (i.e. [BLANK]) because NPMAJOR=2.
(New Value):	

4. **Contingency** – Data element probably incorrect because of value of another data element

Line # in file:	1
UDS/MDS Patient ID #:	0000000001
Variable Number:	6a, 6b, 6c
Variable Name:	NPFORMMO, NPFORMDY, NPFORMYR NPDODMO, NPDODDY, NPDODYR
Type of Check:	Contingency
Action Required:	ERROR: Correct by making values consistent.
Incorrect Value:	Death date 11,22,2001 must precede or equal date form was completed 11, 9,2001.
(New Value):	

5. **Range Alert** – Data element incorrect because of unlikely year.

Line # in file:	1
UDS/MDS Patient ID #:	0000000001
Variable Number:	6c
Variable Name:	NPDODYR
Type of Check:	Range
Action Required:	ALERT: Check unlikely value. NPDODYR (death year) was Verified/Corrected (Circle one)
Incorrect Value:	1970
(New Value):	

6. **Range** – Duplicate ADCID and PTID with another record.
First record is checked for errors. Second is not checked any further for errors, beyond being a duplicate record.

Line # in file:	8
UDS/MDS Patient ID #:	0000000003
Variable Number:	
Variable Name:	ADCID, PTID
Type of Check:	Range
Action Required:	ERROR: Correct unallowable value.
Incorrect Value:	ADCID=4 PTID=0000000003 Same (ADCID, PTID)-value as Line #7. NB: No further checking of this UNALLOWABLE RECORD.
(New Value):	

7. **Alignment** – Spaces following data elements must be left blank (for ASCII files only). All error checking for this record is stopped if this happens.

Line # in file:	1
UDS/MDS Patient ID #:	0000000001
Variable Number:	3
Variable Name:	NPID
Type of Check:	Alignment
Action Required:	ERROR: Correct unallowable value.
Incorrect Value:	The space following this item was not left blank: Column 36 is filled in. NB: No further checking of this UNALLOWABLE RECORD.
(New Value):	

8. **Variable Length** – Variable must be of the correct length (SAS and SPSS files only).

NPGROSS	has the wrong length. Length = 4 Should be 8
SAS Input File Invalid! No further Error Checking.	

9. **Variable Existence** – Variable must exist on the input data set (SAS and SPSS files only).

NPID	is not on the Input File
SAS Input File Invalid! No further Error Checking.	

10. **Extra Variable**– Variable must be appropriate for the Input Data Set (SAS and SPSS files only).

LASTNAME is not a variable needed for the minimum dataset.
SAS Input File Invalid! No further Error Checking.

11. **Variable Type** – Variable must be of the correct type (SAS and SPSS files only).

NPDAGE has the wrong type. Type = Character. Should be Numeric
SAS Input File Invalid! No further Error Checking

Submitting Data

A. Preparing Your Data Submission

NP data submissions may be prepared locally and the files uploaded through the NACC website, or prepared using web data entry. Either a total replacement submission may be created or a submission which updates previously submitted data. All submissions are managed through the NP data submission system (see General Instructions). The Center Data Manager is able to manage a submission completely using the NACC website.

Once the local file(s) have been prepared or the web data entry completed, access the NACC website as detailed under General Instructions. Refer to step 1 of the submission menu. Select either 1A or 1B. For 1B, uploading data file(s) for your submission, note that **you should not encrypt or password-protect your files as this is automatically done by the website**.

When your file(s) have been uploaded or the web entry is complete, use option 1D, create your final submission. This allows creation of a final file of all IDs, including all IDs from past submissions, for error checking, verifying and processing into the NACC database. You may skip this step if you have uploaded one replacement data file and are using it as your submission.

B. Error-checking Your Submission

Once your final submission has been prepared then it must be error-checked. See option 2 on the NP data submission menu. First, execute the primary error checks. If there are errors a new file will have to be uploaded, or if using web data entry, appropriate changes will have to be made. Another final submission will have to be created. Once all errors have been fixed then any alerts will have to be verified. Use option 3 – verifying alerts and other discrepancies. The secondary error-checks can now be executed. Carefully examine the secondary error-check report for discrepancies that may be fixed. Again any fixes must be accomplished by uploading another file, or if using web data entry, modifying over the web. Another final file will have to be created, then the primary error-checks run, followed by the secondary.

C. Verifying Alerts and Other Discrepancies

Once the secondary error-checks have been successfully executed, all discrepancies must be verified. Choose options from the NP data submission menu. For each item on the list the discrepancy must be verified. Some verifications are for the whole submission and some must be done for each individual patient ID.

D. Processing Data into the NP Database

If all discrepancies have been verified your submission may be processed into the NACC database. Choose option 4 from the NP data submission menu.

E. Creating Certification Reports

The final step is to create your certification reports; choose options from the NP data submission menu. Once completed examine the reports carefully. If you are satisfied with the reports, click the "NOTIFY NACC" link in the NP data submission menu. NACC will then review your submission and issue the certification reports and certification form for your Director to sign.

NACC Neuropathology Web Data Management

A. Introduction

The NACC Neuropathology Web Data Management System was designed to allow ADCs/ADRCs to access their Center's NACC NP data through the NACC website. All autopsied IDs from the UDS, the final MDS Data Call, and the Neuropathology Data submissions are included in a Center's Neuropathology Data Set. Data entry may be done for new IDs, and modifications or updates may be done for previously submitted IDs.

New NP IDs may be added, but they must be included in the UDS and indicated as autopsied. **Newly-entered NP IDs which are not submitted in the UDS will be deleted from your Center's Neuropathology Data Set**.

IDs entered in the UDS as having been autopsied may **not** be deleted from the Neuropathology Web Data Management System.

1. Minimum System Requirements

Internet connection: A hard-wired connection is recommended; a modem can be used instead, but this may make data entry a slow, tedious process and cause possible data errors to occur.

Browser: Recommended minimum versions are Netscape Communicator 4.7 or Microsoft Internet Explorer 5.0.

Screen size: Recommended minimum is 17 inches (smaller sizes will work, but will be more difficult to use).

2. NACC Contacts

If a problem occurs with the system, please notify the NACC office via e-mail at naccmail@u.washington.edu or call us at 206-543-8637.

3. Future Submissions

NACC is always looking for ways to improve its software. Please feel free to contact us with comments/suggestions. We are interested in talking to you!

4. Advantages

There are many advantages to performing web-based data entry rather than submitting files or paper forms, including:

a. Immediate access to your data.

b. Frequent data submissions, at your convenience, instead of only once or twice a year.

c. The convenience of a web-based interface for access to this information by Center personnel.

5. Limitations

If you have a low-speed web connection or web traffic is high, entering data may be slow and possible errors could occur. Verifying data will minimize errors. Always check your data entry and submissions.

6. Security

The Neuropathology Web Data Management System is accessed through the NACC website. Only authorized neuropathology data managers may use the system, and these managers will have access to only the data from their own Center. To access the system, a manager must have an appropriate user name and password.

7. General Data Management

All UDS/MDS IDs which have been autopsied must have a corresponding Neuropathology Data Form. Each Center has a secured data file, and only that Center's data manager and other designated Center personnel have access to this data file. All UDS/MDS IDs which were autopsied have a form (record) in this data file. The UDS/MDS IDs for which data was submitted during the initial NP Data Submission will have a completed form (record) in this data file. UDS/MDS IDs for which neuropathology data was not submitted will have a form (record) in this data file, but all of the data elements will be blank.

It is very important that the UDS/MDS ID is correct. Please check all pertinent information before updating a UDS/MDS ID. The UDS/MDS ID *must* correspond to the UDS/MDS ID submitted by your Center's Data Manager.

Instructions for accessing the Neuropathology Web Data Management System are provided in section B.1, "Accessing the System". To enter data for an existing UDS/MDS ID, see section C.3, "Edit Function". To enter data for newly-autopsied IDs not currently in the UDS/MDS, first add the UDS/MDS ID (see section C.2, "Add Function"), and then enter the data using the "Edit" function.

In general, the steps for neuropathology data management are as follows:

Current UDS/MDS IDs:

a. Choose the "Edit" function.
b. Scroll down to find the desired UDS/MDS ID in the list displayed.
c. Choose the UDS/MDS ID.
d. Edit fields as appropriate.
e. Click on the "Update" button.
f. If errors are indicated, make corrections and then click on "Update" again.
g. The system will indicate "ID Updated" when the edit is accepted.
h. Choose the "Verify" function.
i. Choose the UDS/MDS ID.
j. Enter the data elements as appropriate.

k. Click on the “Verify” button.

l. If errors or verification issues are indicated, make corrections and then click on the “Verify” button again.

m. The system will indicate “ID Verified” if successful.

New UDS/MDS IDs:

a. Choose the “Add” function.

b. Type in the UDS/MDS ID as requested; if no errors are encountered, the system will indicate that the UDS/MDS ID has been added.

c. To enter data for the new UDS/MDS ID, follow the steps listed previously for current UDS/MDS IDs.

8. Disclaimer

As all websites are dynamic by nature, the sample screens provided in this manual may not be an exact representation of the most current page on the website itself. Though details may change, the sample screens still provide the user with a visual companion to the written instructions, as well as navigational orientation.

B. System Operation

1. Accessing the System

1) Go to the NACC website (https://www.alz.washington.edu) and click on “Data Submission”.

2) Enter your username and password, then click on “OK”.

3) Click on “NP Submission”.

4) Choose your Center’s name (see Figure 1); if you do not have authorized access for the Center selected, the system will deny access to that Center’s data.

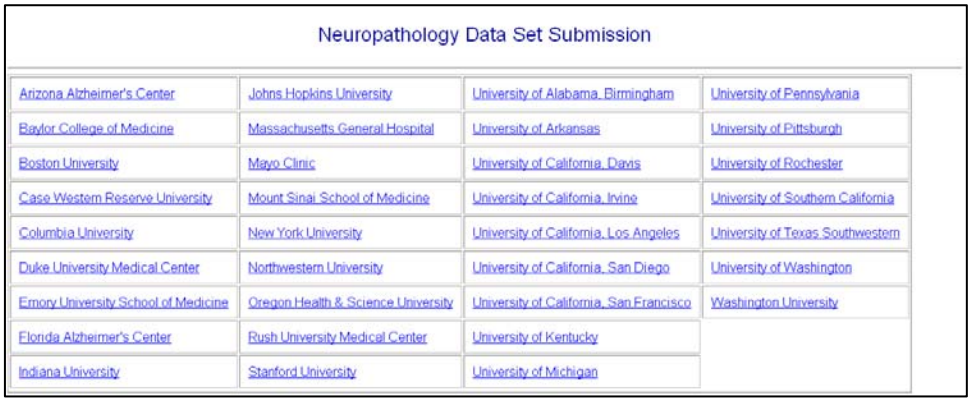


Figure 1.

5) This will display the Neuropathology Data Submission Menu for your Center (see example below). The menu items are described in detail in the following sections.

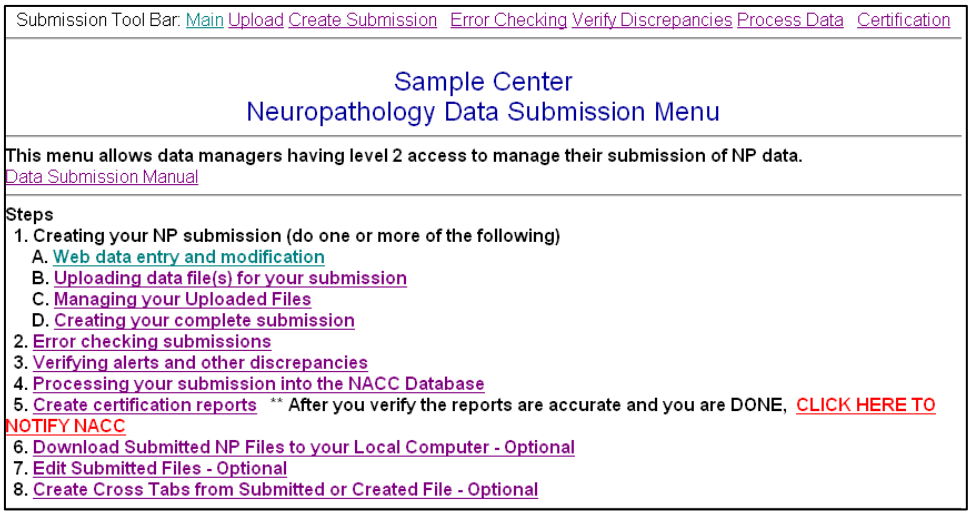


Figure 2.

2. Navigating the System

On each NACC web page is a group of buttons which allow the user to navigate easily through the NACC website (see below). Clicking on one of these buttons will display the corresponding web page:

Figure 3.

Previous Menu	Displays the previous menu in the Web Data Management System (unlike the browser's "Back" button, which will display the previously viewed page).
NACC Home	Displays the NACC home page.
NACC Member Home	Displays the home page for NACC members only.
Personnel Directory	Displays the *ADC Directory* page.
Collaborative Projects	Displays information regarding NACC projects.
MDS Data Call	Displays manuals for past MDS data calls.
The NACC Database	Displays the *NACC Database* page.

C. Web Data Entry and Modifications

Select "Web Data Entry and Modifications" from the Neuropathology Data Submission Menu, and the following menu will be displayed. This menu lets you choose functions that manipulate data for a specified ID.

Figure 4.

1. "Display" Function

This function allows the display of neuropathology data for a selected UDS/MDS ID. Selecting this function will open the *NACC Neuropathology Display Data (Select ID)* page (see figure below).

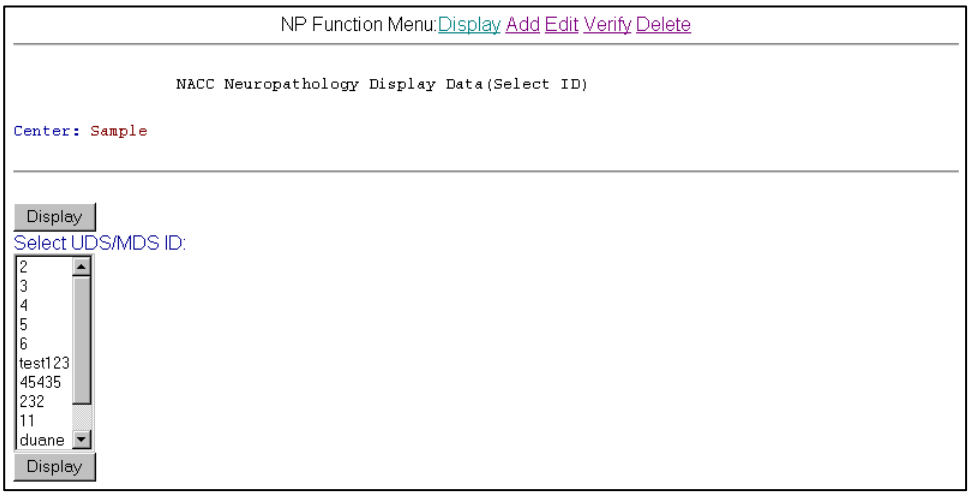


Figure 5.

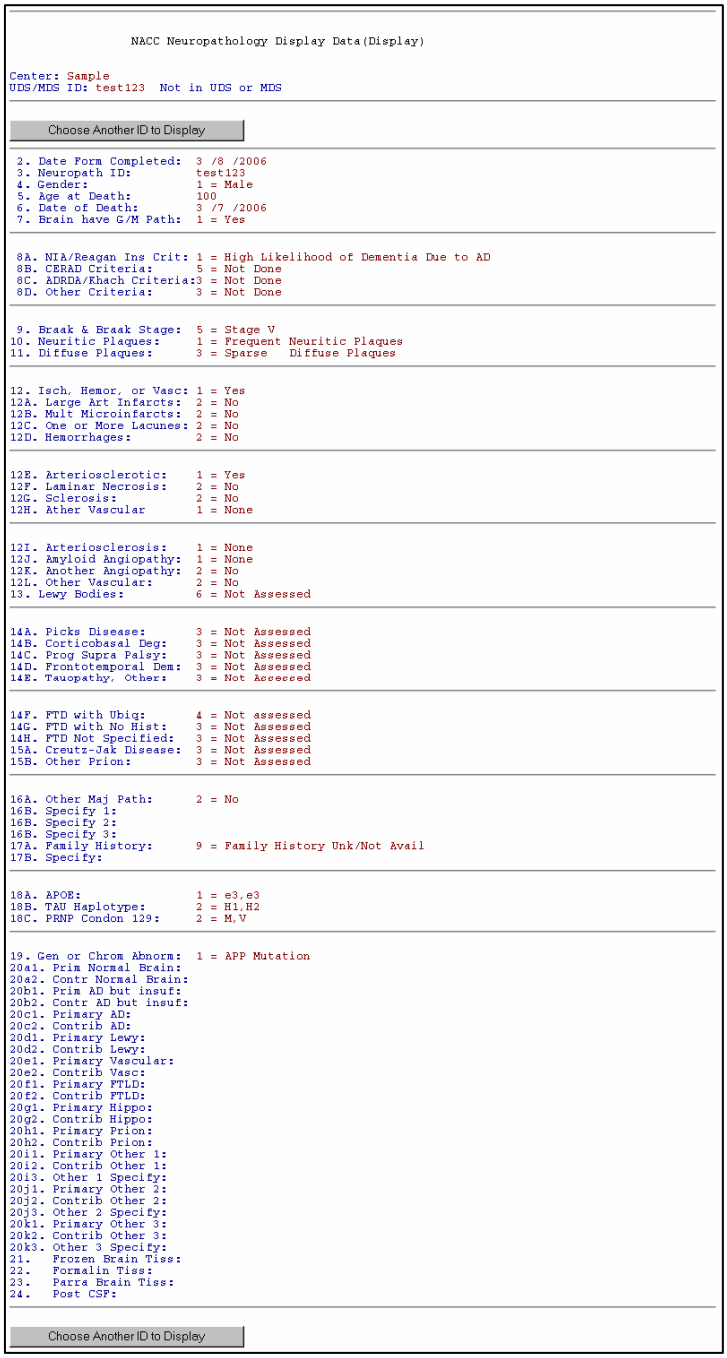
The UDS/MDS IDs displayed are those previously submitted to the MDS or UDS database by your Center. The IDs are usually in sequential order, but newly-added UDS

IDs may be displayed at the end of the list. IDs are shown exactly as entered into the UDS/MDS, except leading blanks are ignored.

To display data for a UDS/MDS ID:

- Scroll down to find the desired UDS/MDS ID.
- Choose the UDS/MDS ID.
- Click on the “Display” button.

This will display the *NACC Neuropathology Display Data (Display)* page, which shows the current data for the UDS/MDS ID selected (see example below).



NACC Neuropathology Display Data(Display)

Center: Sample
UDS/MDS ID: test123 Not in UDS or MDS

Choose Another ID to Display

2. Date Form Completed: 3 /8 /2006
3. Neuropath ID: test123
4. Gender: 1 = Male
5. Age at Death: 100
6. Date of Death: 3 /7 /2006
7. Brain have G/M Path: 1 = Yes

8A. NIA/Reagan Ins Crit: 1 = High Likelihood of Dementia Due to AD
8B. CERAD Criteria: 5 = Not Done
8C. ADRDA/Khach Criteria:3 = Not Done
8D. Other Criteria: 3 = Not Done

9. Braak & Braak Stage: 5 = Stage V
10. Neuritic Plaques: 1 = Frequent Neuritic Plaques
11. Diffuse Plaques: 3 = Sparse Diffuse Plaques

12. Isch, Hemor, or Vasc: 1 = Yes
12A. Large Art Infarcts: 2 = No
12B. Mult Microinfarcts: 2 = No
12C. One or More Lacunes: 2 = No
12D. Hemorrhages: 2 = No

12E. Arteriosclerotic: 1 = Yes
12F. Laminar Necrosis: 2 = No
12G. Sclerosis: 2 = No
12H. Ather Vascular 1 = None

12I. Arteriosclerosis: 1 = None
12J. Amyloid Angiopathy: 1 = None
12K. Another Angiopathy: 2 = No
12L. Other Vascular: 2 = No
13. Lewy Bodies: 6 = Not Assessed

14A. Picks Disease: 3 = Not Assessed
14B. Corticobasal Deg: 3 = Not Assessed
14C. Prog Supra Palsy: 3 = Not Assessed
14D. Frontotemporal Dem: 3 = Not Assessed
14E. Tauopathy, Other: 3 = Not Assessed

14F. FTD with Ubiq: 4 = Not assessed
14G. FTD with No Hist: 3 = Not Assessed
14H. FTD Not Specified: 3 = Not Assessed
15A. Creutz-Jak Disease: 3 = Not Assessed
15B. Other Prion: 3 = Not Assessed

16A. Other Maj Path: 2 = No
16B. Specify 1:
16B. Specify 2:
16B. Specify 3:
17A. Family History: 9 = Family History Unk/Not Avail
17B. Specify:

18A. APOE: 1 = e3,e3
18B. TAU Haplotype: 2 = H1,H2
18C. PRNP Condon 129: 2 = M,V

19. Gen or Chrom Abnorm: 1 = APP Mutation
20a1. Prim Normal Brain:
20a2. Contr Normal Brain:
20b1. Prim AD but insuf:
20b2. Contr AD but insuf:
20c1. Primary AD:
20c2. Contrib AD:
20d1. Primary Lewy:
20d2. Contrib Lewy:
20e1. Primary Vascular:
20e2. Contrib Vasc:
20f1. Primary FTLD:
20f2. Contrib FTLD:
20g1. Primary Hippo:
20g2. Contrib Hippo:
20h1. Primary Prion:
20h2. Contrib Prion:
20i1. Primary Other 1:
20i2. Contrib Other 1:
20i3. Other 1 Specify:
20j1. Primary Other 2:
20j2. Contrib Other 2:
20j3. Other 2 Specify:
20k1. Primary Other 3:
20k2. Contrib Other 3:
20k3. Other 3 Specify:
21. Frozen Brain Tiss:
22. Formalin Tiss:
23. Parra Brain Tiss:
24. Post CSF:

Choose Another ID to Display

Figure 6.

Click on the "Choose Another ID to Display" button to return to the *NACC Neuropathology Display Data (Select ID)* page. (The "Previous Menu" button will also open this page.)

2. "Add" Function

This function will allow the addition of new IDs to the Neuropathology Web Data Management System. New IDs entered must be included in the UDS/MDS database with the data element value of "Autopsy=Yes".

Click on the "Add" function to open the *NACC Neuropathology Add ID (Request ID)* page (Figure 7).

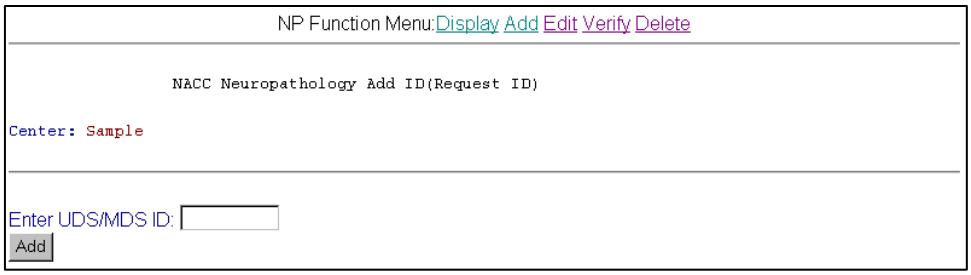


Figure 7.

To add a new UDS ID:

- Click on the box after "Enter UDS/MDS ID".
- Type the new ID.
- Click on the "Add" button.

A page will be displayed which lists the date of death, gender, and age at death for the subject, to allow verification that the correct UDS/MDS ID is being added (see example below).

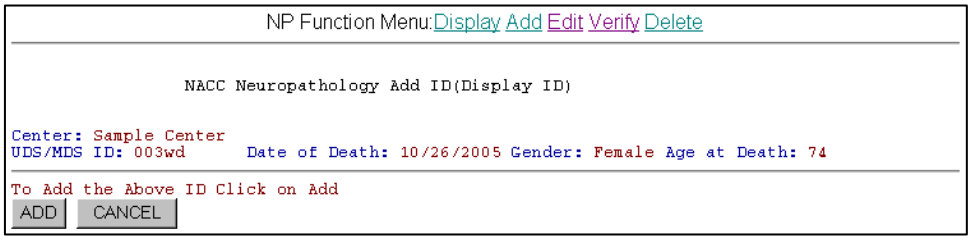


Figure 8.

Take care when adding new IDs to ensure that they are entered in the same format as IDs already in your UDS/MDS. For example, if all your current UDS/MDS IDs have leading zeros, then newly-added IDs should have leading zeros.

a. ID Added

If the UDS/MDS ID was successfully added, the *NACC Neuropathology Add ID (Request ID)* page will be displayed with the message "ID Added!" (see following example). You may continue to add additional IDs or click on the "Previous Menu" button to return to your Center's *Neuropathology Data Management* page.

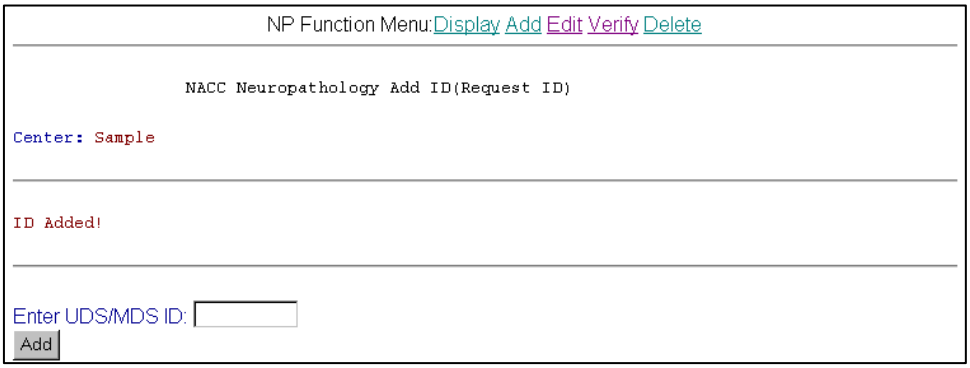


Figure 9.

b. Duplicate ID

If the ID already exists in the Neuropathology Data Set, a message will be displayed in the *NACC Neuropathology Add ID (ID Exists)* page (see below).

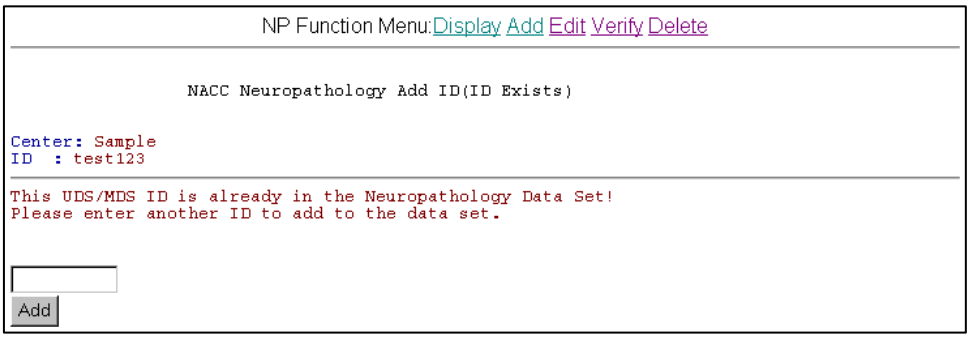


Figure 10.

Duplicate UDS/MDS IDs are not allowed. When the system searches for duplicates, leading zeros and blanks are ignored. Data for an existing UDS/MDS ID must be entered with the "Edit" function.

You may continue to add other UDS/MDS IDs or click on the "Previous Menu" button to return to your Center's *Neuropathology Data Management* page.

c. ID Not in UDS/MDS

If you type an ID that is not in the UDS/MDS, the *NACC Neuropathology Add ID (ID Not in UDS/MDS)* page will be displayed (see example below).

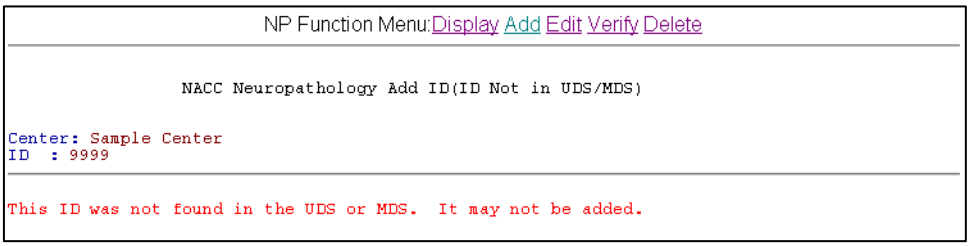


Figure 11.

Click on the "Previous Menu" button to return to your Center's *Neuropathology Data Management* page.

d. System Error

If the MDS ID could not be added, an error message will be displayed. This situation usually occurs when someone else at your Center is trying to submit the file at the same time. Try to enter the MDS ID again. If the problem persists, please contact NACC.

3. "Edit" Function

This function allows the entering or editing of neuropathology data for a UDS/MDS ID. Choose the "Edit" function to open the *NACC Neuropathology Edit (Select ID)* page (example below).

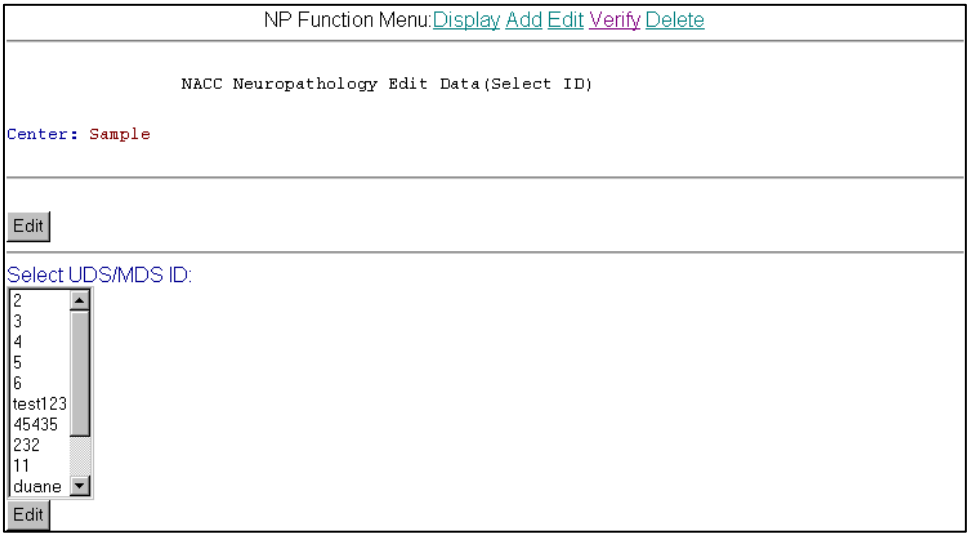


Figure 12.

The UDS/MDS IDs displayed are those submitted by your Center during the final MDS Data Call and any new UDS IDs added through the Neuropathology Web Data Management System. The UDS/MDS IDs are usually in sequential order, but newly-added UDS IDs may be displayed at the end of the list. IDs are shown exactly as entered into the UDS/MDS , except leading blanks are ignored. Leading zeros are not ignored.

To edit or enter data:

- Scroll down to find the desired UDS/MDS ID.
- Choose the UDS/MDS ID.
- Click on the “Edit” button.

The *NACC Neuropathology Edit Data (Edit ID)* page will be displayed (see example).

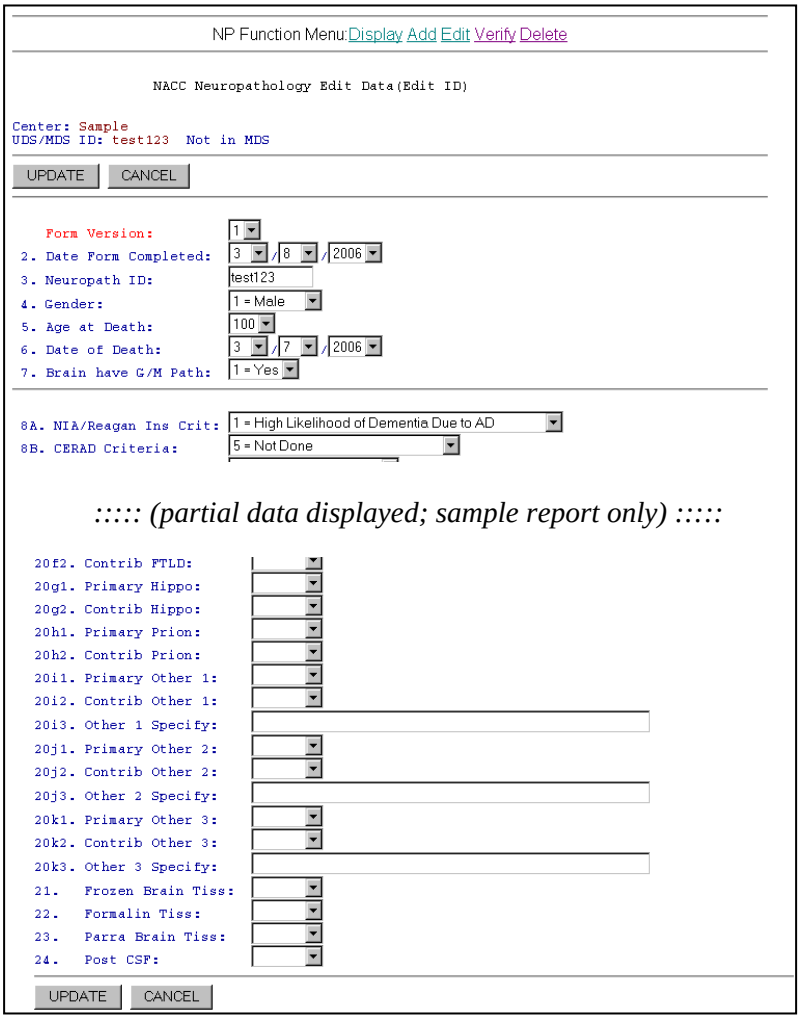


Figure 13.

Values initially displayed are the values currently in the database for this UDS/MDS ID. A blank value indicates a value has not yet been selected for this field or the data element is not applicable because of a value for a prior data element (skip pattern). Blank values are not acceptable for the final form submission to NACC unless they represent a ‘not applicable’ field.

The majority of the data elements have a pull-down list of values. Click on the arrow next to the element, use the scroll bar to display the values, and click on the appropriate value to select it. A few data elements are text boxes rather than pull-down lists. Type in the appropriate value for these elements.

Alternately, the tab key and the number keys may be used to enter data. Use the tab key to move to the desired data element and then type the number for the value of the data

element. (Note: this method will **not** locate the second digit of data elements with two-digit values).

Once all data elements have been entered for a UDS/MDS ID, click on the "Submit" button to execute the error check program. Data elements corresponding to UDS/MDS data elements are checked first (for example, date of death entered on this form must be the same as the date of death for this ID in the UDS/MDS). Each data element is then checked to determine that it is within the correct range. Logical checks are also performed on applicable data elements.

Click on the "Cancel" button to return to the *NACC Neuropathology Edit Data (Select ID)* page without updating the UDS/MDS ID.

a. ID Submitted

If the data elements entered for the UDS/MDS ID have no errors, the *NACC Neuropathology Edit Data (Select ID)* page will be displayed with the message "ID Updated!" (see following example).

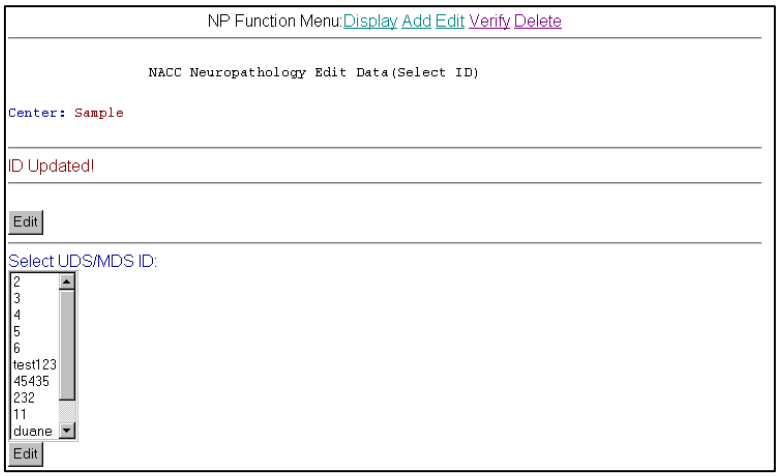


Figure 14.

You may continue to edit/enter additional UDS/MDS IDs or click on the "Previous Menu" button to return to your Center's *Neuropathology Data Management* page.

b. Data Entry Error

If data elements entered for the UDS/MDS ID have errors, the *NACC Neuropathology Edit Data (ID has Errors)* page will display a list describing all errors.

To correct the errors:

- Edit the appropriate data elements (review the instructions above).
- Click on the "Submit" button to run the error check program again; repeat this process until all errors are corrected and the UDS/MDS ID is submitted.

- If the error is a contingency error, where a Neuropathology variable just entered does not match UDS/MDS data submitted, then:
  - Establish which data is correct. If you are not the Data Manager who submitted the UDS/MDS data to NACC, then contact your Data Manager. If you need help determining who your Data Manager is, contact NACC.
  - If the Neuropathology data was wrong, enter the correct value.
  - If the MDS data was wrong, your Data Manager can go into the Web Data Management section for the MDS data and correct the variable. Once this is done, please contact NACC, and we will then run a program which allows the Neuropathology data management pages to recognize the newly-entered MDS data. We have plans to automate this process, but currently we must run the program manually.

Click on the "Cancel" button to return to the *NACC Neuropathology Edit Data (Select ID)* page without updating the UDS/MDS ID.

c. System Error

If the data elements entered for the UDS/MDS ID could not be submitted because of a system error, the *NACC Neuropathology Edit Data (Edit ID)* page will display an error message. This situation usually occurs when someone else at your Center is trying to submit the file at the same time. Try to submit the UDS/MDS ID again. If the problem persists, please contact NACC.

4. "Verify" Function

After the data elements for a UDS/MDS ID have been entered using the "Edit" function, the "Verify" function should be used to check, by double data entry, that the data was entered correctly. ***It is recommended that all data be verified by someone other than the person who entered the data*.** This function does not submit or change data. Its purpose is to allow a second entry of the data, in order to verify accuracy and minimize data entry errors. Selecting this function opens the *NACC Neuropathology Verify Data (Select ID)* page.

The UDS/MDS IDs displayed are those submitted by your Center during the final MDS Data Call and any new UDS IDs added through the Neuropathology Web Data Management System. The UDS/MDS IDs are usually in sequential order, but newly-added UDS IDs may be displayed at the end of the list. IDs are shown exactly as entered into the UDS/MDS , except leading blanks are ignored. Leading zeros are not ignored.

To verify data:

- Scroll down to find the desired UDS/MDS ID.
- Choose the UDS/MDS ID.
- Click on the "Verify" button.

A page will be displayed which lists the date of death, gender, and age at death for the subject ID entered, to allow verification that the correct UDS/MDS ID is being added (see following example).

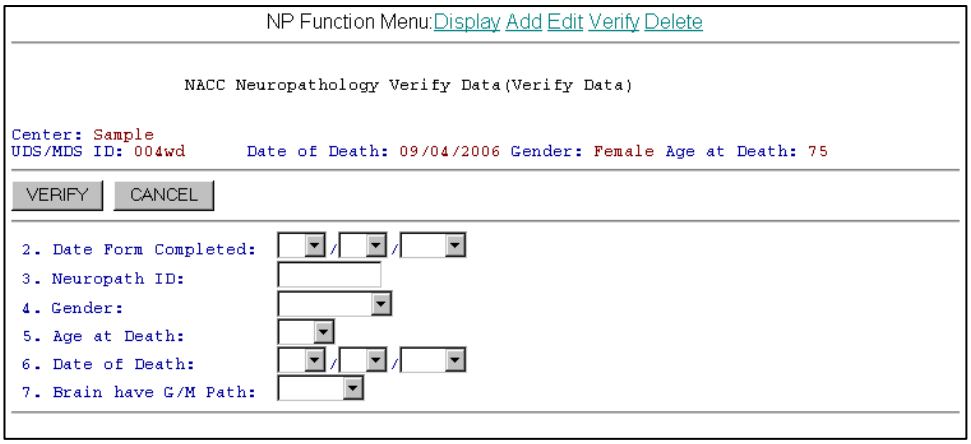


Figure 15.(partial data displayed for this sample report)

Click on the "Verify" button again and the *NACC Neuropathology Verify Data (Verify Data)* page will be displayed (sample follows).

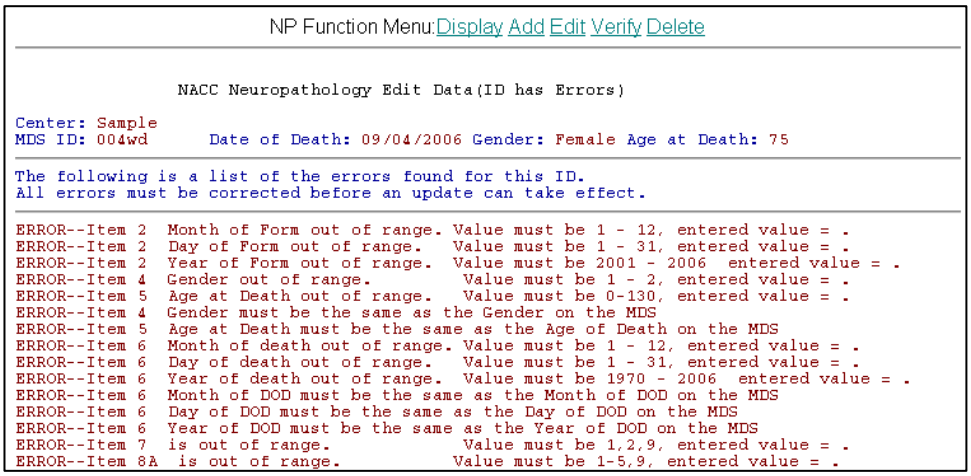


Figure 16.(partial data displayed for this sample report)

Initially, all values are blank on the "Verify" page, and values must be entered for each data element. The majority of the data elements have a pull-down list of values. Click on the arrow next to the element, use the scroll bar to display the value wanted, and click on the desired value to select it. A few data elements are text boxes rather than pull-down lists. Type in the desired value for these elements.

Alternately, the tab key and the number keys may be used to enter data. Use the tab key to move to the desired data element and then type the number for the value of the data element. (Note: typing the value number will **not** locate the second digit of data elements with two-digit values).

Once all data elements have been entered for a UDS/MDS ID, click on the "Verify" button to execute the error check program. Data elements corresponding to UDS/MDS data elements are checked first (for example, date of death entered on this form must be the same as the date of death for this ID in the UDS/MDS). Each data element is then checked to determine that it is within the correct range. Finally, the new data is checked against the data already entered in the Neuropathology Web Data Management System to determine if the values are the same.

Click the "Cancel" button to return to the *NACC Neuropathology Verify Data (Select ID)* page without verifying the UDS/MDS ID.

a. ID Verified

If data elements for the UDS/MDS ID have no errors and match the values already in the data set, the *NACC Neuropathology Verify Data (Select ID)* page will be displayed with the message "ID Verified!". When the UDS/MDS ID is successfully verified, you may continue to verify additional IDs, or click on the "Previous Menu" button to return to your Center's *Neuropathology Data Management* page.

b. Data Entry Error

If data elements entered for the UDS/MDS ID have errors or do not match the values already in the data set, the *NACC Neuropathology Verify Data (Verified Data has Errors)* page will display a list of all errors.

To correct the data, select one of the following options:

1) Errors on the verification page–

- Make corrections to the data elements as appropriate.
- Click on the "Verify" button to run the error check program again; repeat this process until the UDS/MDS ID data is verified.

2) Errors in the data set and not on the verification page–

- Click on "Edit" in the function menu.
- Locate and select the desired UDS/MDS ID.
- Change the data element values as appropriate and click on the "Submit" button.
- Use the browser's "Back" button to return to the verification page.
- Click on the "Verify" button to re-check the new values; repeat this process until all errors are corrected and the data is verified.

Click the "Cancel" button to return to the *NACC Neuropathology Verify Data (Select ID)* page without verifying the UDS/MDS ID.

c. System Error

If the data elements for the UDS/MDS ID could not be verified because of a system error, the *NACC Neuropathology Verify Data (Verify Data)* page will display an error message. This situation usually occurs when someone else at your Center is trying to submit the file at the same time. Try to verify the data again. If the problem persists, please contact NACC.

5. "Delete" Function

This function allows the deletion of UDS/MDS IDs which have been entered through the "Add" function of the Neuropathology Web Data Management System.

IDs identified in the UDS/MDS database as autopsied may not be deleted with this function. To delete these IDs from the MDS database, contact your Center's data manager prior to the next NACC Data Call.

To delete a UDS/MDS ID, click on "Delete" in the function menu to open the *Neuropathology Delete ID (Request ID)* page (see example below).

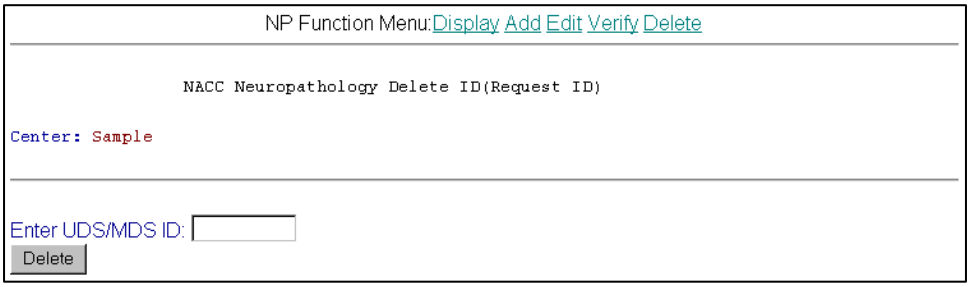


Figure 17.

Confirm that deletion is allowed:

- Click in the box after "Enter UDS/MDS ID".
- Type the UDS/MDS ID to be deleted, using the same format as IDs already entered for your Center (for example, if your current UDS/MDS IDs have leading zeros, then type this ID with a leading zero).
- Click on the "Delete" button.

a. ID Found

If the ID exists in the Neuropathology data set and can be deleted, the *NACC Neuropathology Delete ID (ID Found)* page will be displayed (sample below).

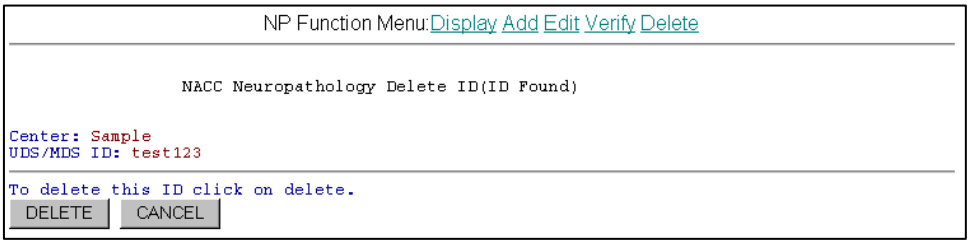


Figure 18.

Click on the "Delete" button again to remove the UDS/MDS ID, or click on the "Cancel" button to return to the *NACC Neuropathology Delete ID (Request ID)* page.

If the ID was successfully deleted, the *NACC Neuropathology Delete ID (Request ID)* page will be displayed with the message "ID Deleted!" (see example).

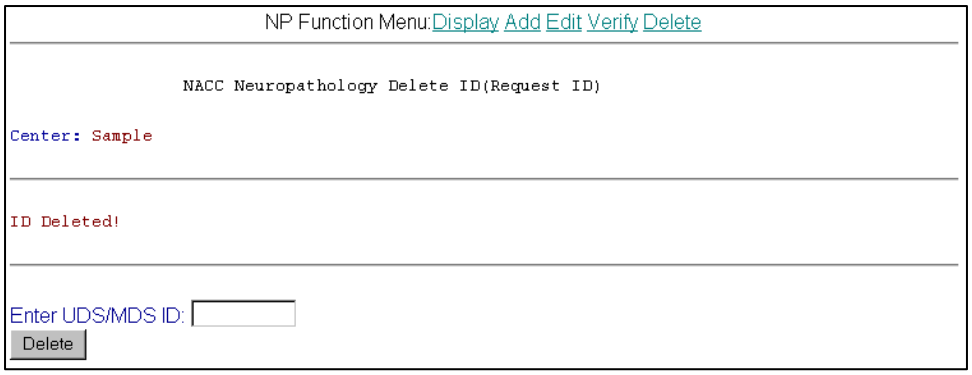


Figure 19.

You may continue to delete additional UDS/MDS IDs or click on the "Previous Menu" button in the web page header to return to your Center's Neuropathology Data Management page.

b. System Error

If the UDS/MDS ID could not be deleted, an error message will be displayed. This situation usually occurs when someone else at your Center is trying to submit the file at the same time. Try to delete the UDS/MDS ID again. If the problem persists, please contact NACC.

c. ID Cannot be Located

If the UDS/MDS ID could not be deleted because it is not in the Neuropathology Web Data Management System, the *NACC Neuropathology Delete ID (ID Not Found)* page will be displayed (see following figure). Check your UDS/MDS ID carefully using the "Display" function.

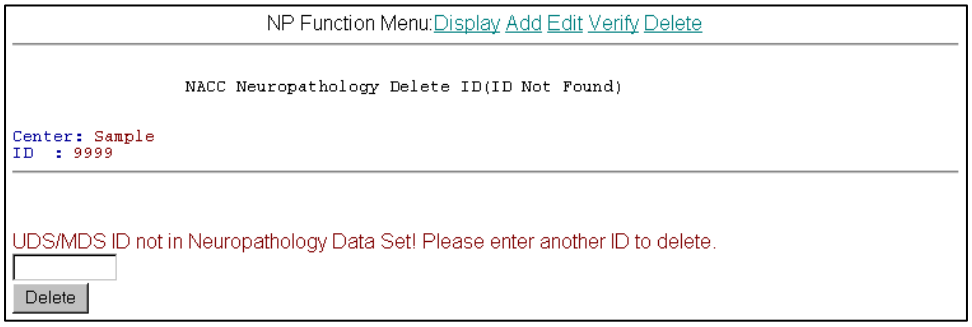


Figure 20.

You may continue to delete additional UDS/MDS IDs or click on the "Previous Menu" button to return to your Center's *Neuropathology Data Management* page.

d. ID Cannot be Deleted

If the ID could not be deleted because it is located in the UDS/MDS with an autopsy value of 'yes', the *NACC Neuropathology Delete ID (ID in MDS/UD)* page is displayed. Check the ID carefully using the "Display" function. **IDs that are in the UDS/MDS and have been autopsied cannot be deleted**. To delete or change these IDs, contact your Center's Data Manager.

You may continue to delete additional UDS/MDS IDs or click on the "Previous Menu" button to return to your Center's *Neuropathology Data Management* page.

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NACC Neuropathology Data Form

Center: _____ **Completed by:** _____

1. MDS/UDS Patient ID..... ☐☐☐☐☐☐☐☐☐☐

2. Date form completed..... ☐☐ ☐☐ ☐☐☐☐
month *day* *year*

3. Neuropath ID..... ☐☐☐☐☐☐☐☐☐☐

4. Gender..... ☐ *(M or F)*

5. Age at death..... ☐☐☐ *years*

6. Date of death ..... ☐☐ ☐☐ ☐☐☐☐
month *day* *year*

7. Does the brain have any gross or microscopic pathology (including any Alzheimer type pathology such as senile plaques and neurofibrillary tangles)?

(***mark one box)***

☐ 1 Yes

☐ 2 No

(Note: Items 8A through 16A must also be answered.)

Alzheimer's Disease. For all brains in which there is any degree of Alzheimer type pathology (ranging from a few senile plaques and neurofibrillary tangles to advanced Alzheimer's Disease), please indicate the nature of the pathology according to commonly used pathologic criteria.

8A. NIA/Reagan Institute neuropathological criteria used:

(*mark one box)*

☐ 1 High likelihood of dementia being due to Alzheimer's disease

☐ 2 Intermediate likelihood of dementia being due to Alzheimer's disease

☐ 3 Low likelihood of dementia being due to Alzheimer's disease

☐ 4 Criteria not met

☐ 5 Not done

☐ 9 Missing/unknown

8B. CERAD neuropathological criteria used:

(*mark one box)*

☐ 1 Definite Alzheimer's disease

☐ 2 Probable Alzheimer's disease

☐ 3 Possible Alzheimer's disease

☐ 4 Criteria not met

☐ 5 Not done

☐ 9 Missing/unknown

8C. ADRDA/Khachaturian neuropathological criteria used:

(*mark one box)*

☐ 1 Alzheimer's disease

☐ 2 Criteria not met

☐ 3 Not done

☐ 9 Missing/unknown

8D. Other or unspecified neuropathological criteria used (e.g., Tierney, etc.):

(*mark one box)*

☐ 1 Alzheimer's disease, unspecified

☐ 2 Criteria not met

☐ 3 Not done

☐ 9 Missing/unknown

Neurofibrillary Pathology. For all brains in which topographic staging of neurofibrillary degeneration was done, please indicate the stage with a number from 1–7. If Braak staging was not done, use number 8.

9. Braak & Braak Neurofibrillary Stage.

(*mark one box)*

☐ 1 Stage I

☐ 2 Stage II

☐ 3 Stage III

☐ 4 Stage IV

☐ 5 Stage V

☐ 6 Stage VI

☐ 7 Neurofibrillary degeneration not present

☐ 8 Not assessed

☐ 9 Missing/unknown

Plaque Score. For the most severely affected cortical region, please indicate the plaque score. Please use the Consortium to Establish a Registry of Alzheimer's Disease (CERAD) standards for sparse, moderate, and frequent.

10. Neuritic plaques (plaques with argyrophilic dystrophic neurites with or without dense amyloid cores).

(*mark one box)*

☐ 1 Frequent neuritic plaques

☐ 2 Moderate neuritic plaques

☐ 3 Sparse neuritic plaques

☐ 4 No neuritic plaques

☐ 5 Not assessed

☐ 9 Missing/unknown

11. Diffuse plaques (plaques with non-compact amyloid and no apparent dystrophic neurites).

(*mark one box)*

☐ 1 Frequent diffuse plaques

☐ 2 Moderate diffuse plaques

☐ 3 Sparse diffuse plaques

☐ 4 No diffuse plaques

☐ 5 Not assessed

☐ 9 Missing/unknown

12. Is ischemic, hemorrhagic or vascular pathology present?

(*mark one box)*

☐ 1 Yes

☐ 2 No

☐ 3 Not assessed

☐ 9 Missing/unknown

(Note: Items 12A through 12L must also be answered.)

12A. Are one or more large artery cerebral infarcts present?

(*mark one box)*

☐ 1 Yes

☐ 2 No

☐ 3 Not assessed

☐ 9 Missing/unknown

12B. Are one or more cortical microinfarcts (including "granular atrophy") present?

(*mark one box)*

☐ 1 Yes

☐ 2 No

☐ 3 Not assessed

☐ 9 Missing/unknown

CONTINUE with 12C on the next page.

12C. Are one or more lacunes (small artery infarcts and/or hemorrhages) present?

(*mark one box)*

☐ 1 Yes

☐ 2 No

☐ 3 Not assessed

☐ 9 Missing/unknown

12D. Are single or multiple hemorrhages present?

(*mark one box)*

☐ 1 Yes

☐ 2 No

☐ 3 Not assessed

☐ 9 Missing/unknown

12E. Is subcortical arteriosclerotic leukoencephalopathy present?

(*mark one box)*

☐ 1 Yes

☐ 2 No

☐ 3 Not assessed

☐ 9 Missing/unknown

12F. Is cortical laminar necrosis present?

(*mark one box)*

☐ 1 Yes

☐ 2 No

☐ 3 Not assessed

☐ 9 Missing/unknown

12G. Is medial temporal lobe sclerosis (including hippocampal sclerosis) present?

(*mark one box)*

☐ 1 Yes

☐ 2 No

☐ 3 Not assessed

☐ 9 Missing/unknown

CONTINUE with 12H on the next page.

12H. Is atherosclerotic vascular pathology (of the circle of Willis) present?

(*mark one box)*

☐ 1 None

☐ 2 Mild

☐ 3 Moderate

☐ 4 Severe

☐ 5 Not assessed

☐ 9 Missing/unknown

12I. Is arteriosclerosis (small parenchymal arteriolar disease) present?

(*mark one box)*

☐ 1 None

☐ 2 Mild

☐ 3 Moderate

☐ 4 Severe

☐ 5 Not assessed

☐ 9 Missing/unknown

12J. Is amyloid angiopathy present?

(*mark one box)*

☐ 1 None

☐ 2 Mild

☐ 3 Moderate

☐ 4 Severe

☐ 5 Not assessed

☐ 9 Missing/unknown

12K. Is another type of angiopathy (e.g., CADASIL or arteritis) present?

(*mark one box)*

☐ 1 Yes

☐ 2 No

☐ 3 Not assessed

☐ 9 Missing/unknown

CONTINUE with 12L on the next page.

12L. Is there other pathology related to ischemic or vascular disease not previously specified present?

(*mark one box)*

☐ 1 Yes

☐ 2 No

☐ 3 Not assessed

☐ 9 Missing/unknown

Lewy Body Pathology. For all brains in which Lewy bodies are detected, indicate the presence and distribution of Lewy-related pathology. This classification is independent of the clinical presentation, which may be variable and include Parkinsonism, dementia, psychosis, sleep disorders, etc.

13. Pathology is consistent with criteria of Consortium on Dementia with Lewy Bodies for:

(*select only one)*

☐ 1 Lewy body pathology, brainstem predominant type

☐ 2 Lewy body pathology, intermediate or transitional (limbic) type

☐ 3 Lewy body pathology, diffuse (neocortical) type

☐ 4 Lewy body pathology, unspecified or not further assessed

☐ 5 No Lewy bodies

☐ 6 Not assessed

☐ 9 Missing/unknown

Frontotemporal Degenerations (FTD). Use this for non-Alzheimer degenerative disorders that commonly have the brunt of cortical changes in frontal and temporal lobes, but may involve other cortical and subcortical regions and have variable clinical presentations, including frontal lobe dementia, progressive aphasia, progressive apraxia, etc.

14A. Pick's Disease:

(*mark one box)*

☐ 1 Yes

☐ 2 No

☐ 3 Not assessed

☐ 9 Missing/unknown

CONTINUE with 14B on the next page.

14B. Corticobasal degeneration:

(*mark one box)*

☐ 1 Yes

☐ 2 No

☐ 3 Not assessed

☐ 9 Missing/unknown

14C. Progressive supranuclear palsy:

(*mark one box)*

☐ 1 Yes

☐ 2 No

☐ 3 Not assessed

☐ 9 Missing/unknown

14D. Frontotemporal dementia and Parkinsonism with tau-positive or argyrophilic inclusions:

(*mark one box)*

☐ 1 Yes

☐ 2 No

☐ 3 Not assessed

☐ 9 Missing/unknown

14E. Tauopathy, other (e.g., tangle-only dementia and argyrophilic grain dementia):

(*mark one box)*

☐ 1 Yes

☐ 2 No

☐ 3 Not assessed

☐ 9 Missing/unknown

14F. FTD with ubiquitin-positive (tau-negative) inclusions:

(*mark one box)*

☐ 1 FTD with motor neuron disease

☐ 2 FTD without motor neuron disease

☐ 3 None present

☐ 4 Not assessed

☐ 9 Missing/unknown

CONTINUE with 14G on the next page.

14G. Is there FTD with no distinctive histopathology (tau-negative, ubiquitin-negative, and no argyrophilic inclusions)?

(*mark one box)*

☐ 1 Yes

☐ 2 No

☐ 3 Not assessed

☐ 9 Missing/unknown

14H. Was FTD "not otherwise specified" present (e.g., "immunostaining for ubiquitin and tau not done")?

(*mark one box)*

☐ 1 Yes

☐ 2 No

☐ 3 Not assessed

☐ 9 Missing/unknown

Prion-related Disorders:

15A. Is Creutzfeldt-Jakob disease or variant CJD present?

(*mark one box)*

☐ 1 Yes

☐ 2 No

☐ 3 Not assessed

☐ 9 Missing/unknown

15B. Are other prion diseases present (e.g., Gerstmann-Straussler syndrome)?

(*mark one box)*

☐ 1 Yes

☐ 2 No

☐ 3 Not assessed

☐ 9 Missing/unknown

Other Major Pathologic Disorders (e.g., infectious, immunologic, metabolic, neoplastic, toxic or degenerative).

16A. Are other major pathologic disorders present (not addressed by questions 8–15)?

(*mark one box)*

☐ 1 Yes

☐ 2 No

☐ 3 Not assessed

☐ 9 Missing/unknown

SKIP: If 2, 3 or 9, go to #17A.

16B. If 16A is yes, specify below (one disorder per line):

1 _____

2 _____

3 _____

17A. Family history information relevant to neuropathologic diagnosis. Choose one of the following categories that most accurately describes the **family** information available:

(*mark one box)*

☐ 1 Family history of similar neurodegenerative disorder

☐ 2 Family history of other (dissimilar) neurodegenerative disorder

☐ 3 No family history of similar or dissimilar neurodegenerative disorder

☐ 4 Family history of both similar and dissimilar neurodegenerative disorder

☐ 9 Family history unknown/not available/missing

SKIP: If 1, 3 or 9, go to #18A.

17B. If 17A is 2 or 4, specify disorder: _____

Genetic Variants or Polymorphisms. For each of the following three common genetic variants or polymorphisms, choose the patient's genotype, if known; select "not available or not assessed" if unknown:

18A. Apolipoprotein-E:

(*mark one box)*

☐ 1 e3, e3

☐ 2 e3, e4

☐ 3 e3, e2

☐ 4 e4, e4

☐ 5 e4, e2

☐ 6 e2, e2

☐ 9 Missing/unknown/not assessed

18B. Tau haplotype:

(*mark one box)*

☐ 1 H1, H1

☐ 2 H1, H2

☐ 3 H2, H2

☐ 4 Other polymorphism (e.g., A0)

☐ 9 Missing/unknown/not assessed

18C. PRNP codon 129:

(*mark one box)*

☐ 1 M, M

☐ 2 M, V

☐ 3 V, V

☐ 9 Missing/unknown/not assessed

19. Genetic or chromosomal abnormalities. Choose below the one known genetic or chromosomal abnormality that best describes the subject:

(*mark one box)*

☐ 1 APP mutation

☐ 2 PS1 mutation

☐ 3 PS2 mutation

☐ 4 Tau mutation

☐ 5 α-Synuclein mutation

☐ 6 Parkin mutation

☐ 7 PRNP mutation

☐ 8 Huntingtin mutation

☐ 9 Notch 3 mutation (CADASIL)

☐ 10 Other known genetic mutation (e.g., ABri, neuroserpin)

☐ 11 Down syndrome

☐ 12 Other chromosomal abnormality

☐ 13 No known genetic or chromosomal abnormality

☐ 50 Not assessed

☐ 99 Missing/unknown

20. What are the primary and contributing pathologic diagnoses or features which you judge to be responsible for the subject's cognitive status?

NOTE: *Mark only one diagnosis as "primary"; any number may be marked as "contributing".*

Primary	Contributing	
☐ A1	☐ A2	Normal brain (NC)
☐ B1	☐ B2	AD pathology present but insufficient for AD diagnosis
☐ C1	☐ C2	Alzheimer disease (AD)
☐ D1	☐ D2	Lewy body disease, with or without AD
☐ E1	☐ E2	Vascular disease
☐ F1	☐ F2	FTLD
☐ G1	☐ G2	Hippocampal sclerosis
☐ H1	☐ H2	Prion-associated disease
☐ I1	☐ I2	Other (specify): _____
☐ J1	☐ J2	Other (specify): _____
☐ K1	☐ K2	Other (specify): _____

Brain Tissue and Post Mortem CSF. Use this section to record information related to the storage and accessibility of brain tissue and post mortem CSF at your Center.

21. Is banked frozen brain tissue accessible?

(*mark one box)*

☐ 1 Yes

☐ 2 No

22. Is formalin-fixed brain tissue accessible?

(*mark one box)*

☐ 1 Yes

☐ 2 No

23. Are paraffin-embedded blocks of brain tissue accessible?

(*mark one box)*

☐ 1 Yes

☐ 2 No

24. Is banked postmortem cerebrospinal fluid (CSF) accessible?

(*mark one box)*

☐ 1 Yes

☐ 2 No

NACC Neuropathologic Diagnosis Coding Guidebook

The NACC Neuropathologic Diagnosis Coding Guidebook contains procedures to be followed when completing the NACC Neuropathology Data Form. This guidebook is authored by the members of the ADC Neuropathology Core Leaders' Steering Committee.

Typographical Conventions

Instructions will appear as a sans serif font against a shaded background... sample text.

General Instructions

1. Please answer *all* items for *all* subjects.

2. Explanation of allowable codes:
   - "Not done" and "Not assessed" – these responses are equivalent and some questions use one version or the other.
   - "Missing/unknown" – this response indicates the data is not available because it has been lost or is no longer retrievable.

DEMOGRAPHICS

1. MDS/UDS Patient ID ..... ☐☐☐☐☐☐☐☐☐☐

2. Date form completed ..... ☐☐ ☐☐ ☐☐☐☐
   month *day* *year*

3. Neuropath ID ..... ☐☐☐☐☐☐☐☐☐☐

4. Gender..... ☐ *(M or F)*

5. Age at death ..... ☐☐☐ *years*

6. Date of death..... ☐☐ ☐☐ ☐☐☐☐
   month *day* *year*

Please provide identification and demographic neuropathology information in questions 1– 6.

7. Does the brain have any gross or microscopic pathology (including any Alzheimer type pathology such as senile plaques and neurofibrillary tangles)?
(***mark one box)***

☐ 1 Yes

☐ 2 No

(Note: Items 8A through 16A must also be answered.)

Answer "no" only if the brain is completely devoid of any histopathologic changes. If there are only minimal Alzheimer type changes, please indicate this in the following questions.

ALZHEIMER TYPE PATHOLOGY

Alzheimer's Disease. For all brains in which there is any degree of Alzheimer type pathology (ranging from a few senile plaques and neurofibrillary tangles to advanced Alzheimer's Disease), please indicate the nature of the pathology according to commonly used pathologic criteria.

Follow the published guidelines for these entries. Answer "not done" for all criteria not used.

8A. NIA/Reagan Institute neuropathological criteria used:
(*mark one box)*

☐ 1 High likelihood of dementia being due to Alzheimer's disease

☐ 2 Intermediate likelihood of dementia being due to Alzheimer's disease

☐ 3 Low likelihood of dementia being due to Alzheimer's disease

☐ 4 Criteria not met

☐ 5 Not done

☐ 9 Missing/unknown

(Hyman BT, Trojanowski JQ. Editorial on Consensus recommendations for the postmortem diagnosis of Alzheimer's Disease from the National Institute on Aging and Reagan Institute Working Group on Diagnostic Criteria for the Neuropathological Assessment of Alzheimer's Disease. J Neuropathol Exp Neurol 1997;56:1095-1097.)

8B. CERAD neuropathological criteria used:
(*mark one box)*

☐ 1 Definite Alzheimer's disease

☐ 2 Probable Alzheimer's disease

☐ 3 Possible Alzheimer's disease

☐ 4 Criteria not met

☐ 5 Not done

☐ 9 Missing/unknown

(Mirra SM, Hart MN, Terry RD. Making the diagnosis of Alzheimer's disease. A primer for practicing pathologists. Arch Pathol Lab Med 1993;117:132-144.)

8C. ADRDA/Khachaturian neuropathological criteria used:
(*mark one box)*

☐ 1 Alzheimer's disease

☐ 2 Criteria not met

☐ 3 Not done

☐ 9 Missing/unknown

(Khachaturian S. Diagnosis of Alzheimer's disease. Arch Neurol 1985;42:1097-1105.)

8D. Other or unspecified neuropathological criteria used (e.g., Tierney, etc.):
(*mark one box)*

☐ 1 Alzheimer's disease, unspecified

☐ 2 Criteria not met

☐ 3 Not done

☐ 9 Missing/unknown

Neurofibrillary Pathology. For all brains in which topographic staging of neurofibrillary degeneration was done, please indicate the stage with a number from 1–7. If Braak staging was not done, use number 8.

Indicate the stage according to the scheme proposed by Braak and Braak. While the original methods employed Gallyas stains, other stains for neurofibrillary pathology (e.g., tau immunostains, other silver stains or thioflavin-S) may be used. The focus is on the distribution of neurofibrillary tangles. (Nagy Z, Yilmazer-Hanke DM, Braak H, et al. Assessment of the pathological stages of Alzheimer's disease in thin paraffin sections: a comparative study. Dementia & Geriatric Cognitive Disorders 1998;9:140-144; Braak H, Braak E. Neuropathological stageing of Alzheimer-related changes. Acta Neuropathol 1991;82:239-259.)

9. Braak & Braak Neurofibrillary Stage.

(*mark one box)*

- ☐ 1 Stage I
- ☐ 2 Stage II
- ☐ 3 Stage III
- ☐ 4 Stage IV
- ☐ 5 Stage V
- ☐ 6 Stage VI
- ☐ 7 Neurofibrillary degeneration not present
- ☐ 8 Not assessed
- ☐ 9 Missing/unknown

Stages I–II correspond to NFT limited to the transentorhinal/entorhinal region; Stages III–IV to limbic stages; and Stages V–VI to neocortical stages. Stage VI implies involvement of primary cortices. Answer “not assessed” if topographic staging has not been done.

Plaque Score. For the most severely affected cortical region, please indicate the plaque score. Please use the Consortium to Establish a Registry of Alzheimer’s Disease (CERAD) standards for sparse, moderate, and frequent.

10. Neuritic plaques (plaques with argyrophilic dystrophic neurites with or without dense amyloid cores).

(*mark one box)*

- ☐ 1 Frequent neuritic plaques
- ☐ 2 Moderate neuritic plaques
- ☐ 3 Sparse neuritic plaques
- ☐ 4 No neuritic plaques
- ☐ 5 Not assessed
- ☐ 9 Missing/unknown

Neuritic plaques are considered to be plaques with argyrophilic, thioflavin-S-positive or tau-positive dystrophic neurites with or without dense amyloid cores. Answer “not assessed” if neuritic plaques have not been specifically analyzed.

11. Diffuse plaques (plaques with non-compact amyloid and no apparent dystrophic neurites).

(*mark one box)*

- ☐ 1 Frequent diffuse plaques
- ☐ 2 Moderate diffuse plaques
- ☐ 3 Sparse diffuse plaques
- ☐ 4 No diffuse plaques
- ☐ 5 Not assessed
- ☐ 9 Missing/unknown

Diffuse plaques are considered to be plaques with non-compact amyloid and no apparent dystrophic neurites. Answer "not assessed" if diffuse plaques have not been specifically analyzed.

ISCHEMIC, HEMORRHAGIC AND VASCULAR PATHOLOGY

This section is meant to indicate the presence of vascular pathology, but not the absolute burden, volume, or severity of change. More detailed information about lesion distribution, burden, etc is presumed to be part of a research database. Questions about severity of vascular pathology are of necessity subjective, since current methods to easily and consistently assess severity of vascular disease have not been validated or widely implemented. Even if infarcts, focal sclerosis and hemorrhages are not present, and there is evidence of vascular pathology, be sure to answer questions 12I through 12K to record information about severity of atherosclerotic, arteriosclerotic, and amyloid vascular pathology.

12. Is ischemic, hemorrhagic or vascular pathology present?

(*mark one box)*

- ☐ 1 Yes
- ☐ 2 No
- ☐ 3 Not assessed
- ☐ 9 Missing/unknown

(Note: Items 12A through 12L must also be answered.)

Please include atherosclerosis, arteriosclerosis or amyloid angiopathy.

12A. Are one or more large artery cerebral infarcts present?

(*mark one box)*

- ☐ 1 Yes
- ☐ 2 No
- ☐ 3 Not assessed
- ☐ 9 Missing/unknown

This category refers to infarcts larger than 1 cm in diameter in the distribution of large and medium sized meningocerebral vessels rather than small parenchymal vessels. Infarcts meeting these criteria are included regardless of the histologic age and include acute lesions as well as chronic cystic lesions.

12B. Are one or more cortical microinfarcts (including "granular atrophy") present?
(*mark one box)*

☐ 1 Yes

☐ 2 No

☐ 3 Not assessed

☐ 9 Missing/unknown

This category refers to infarcts that are detected microscopically and may not be grossly visible, or may appear to the naked eye as cortical granularity. Microinfarcts in non-cortical areas should not be included in this category. Infarcts meeting these criteria are included regardless of the histologic age and include acute lesions as well as chronic cystic lesions.

12C. Are one or more lacunes (small artery infarcts and/or hemorrhages) present?
(*mark one box)*

☐ 1 Yes

☐ 2 No

☐ 3 Not assessed

☐ 9 Missing/unknown

This category refers to cystic/old infarcts or hemorrhages 1-cm or less in diameter that are usually grossly identified and in the distribution of small parenchymal vessels, most often in basal ganglia, thalamus, pons, cerebellum and cerebral white matter.

12D. Are single or multiple hemorrhages present?
(*mark one box)*

☐ 1 Yes

☐ 2 No

☐ 3 Not assessed

☐ 9 Missing/unknown

This category refers to cerebral hemorrhages, regardless of size in any region of the brain.

12E. Is subcortical arteriosclerotic leukoencephalopathy present?
(*mark one box)*

☐ 1 Yes

☐ 2 No

☐ 3 Not assessed

☐ 9 Missing/unknown

This category refers to multifocal or diffuse white matter pathology attributable to arteriosclerotic small vessel disease and will be associated with axonal and myelin loss in the centrum ovale, often associated with brain infarcts. White matter rarefaction confined to the immediate periventricular region (so-called periventricular "capping") should not be included. (Roman GC. Senile dementia of the Binswanger type, a vascular form of dementia in the elderly; JAMA 1987;258:1782-1788 and Caplan LR. Binswanger's disease – revisited. Neurology 1995;45:626-633.)

12F. Is cortical laminar necrosis present?

(*mark one box)*

☐ 1 Yes

☐ 2 No

☐ 3 Not assessed

☐ 9 Missing/unknown

This category refers to selective cortical necrosis of middle and lower cortical lamina most often associated with cerebral hypoperfusion and concentrated in border zones between major cerebral arteries.

12G. Is medial temporal lobe sclerosis (including hippocampal sclerosis) present?

(*mark one box)*

☐ 1 Yes

☐ 2 No

☐ 3 Not assessed

☐ 9 Missing/unknown

This category refers to selective neuronal loss and gliosis ("sclerosis") of medial temporal lobe structures. In the hippocampus, this is often limited to CA1 and the subiculum with variable involvement of endplate and CA2. The amygdala and entorhinal cortex may also be affected. In some cases there is a clear history of cerebral hypoperfusion. In others there may be a history of epilepsy. Similar pathology can also be seen in the setting of neurodegenerative disorders (e.g., FTD).

12H. Is atherosclerotic vascular pathology (of the circle of Willis) present?

(*mark one box)*

☐ 1 None

☐ 2 Mild

☐ 3 Moderate

☐ 4 Severe

☐ 5 Not assessed

☐ 9 Missing/unknown

Use this item to indicate the severity of atherosclerotic (intimal and medial fibrofatty atheromatous plaques) disease in the large (named) arteries at the base of the brain (i.e., the circle of Willis). The assessment is qualitative and subjective and should indicate an estimate of overall severity rather than an individual vessel.

12I. Is arteriosclerosis (small parenchymal arteriolar disease) present?
(*mark one box)*

☐ 1 None
☐ 2 Mild
☐ 3 Moderate
☐ 4 Severe
☐ 5 Not assessed
☐ 9 Missing/unknown

Use this item to indicate the severity of arteriosclerosis (arteriolosclerosis) (hyalinosis of the media and adventitia) of small parenchymal and/or leptomeningeal vessels. The assessment is qualitative and subjective and should indicate an estimate of overall severity rather than an individual vessel.

12J. Is amyloid angiopathy present?
(*mark one box)*

☐ 1 None
☐ 2 Mild
☐ 3 Moderate
☐ 4 Severe
☐ 5 Not assessed
☐ 9 Missing/unknown

Use this item to indicate the severity of cerebral amyloid angiopathy as demonstrated with special stains for amyloid (e.g., Congo red, thioflavin-S, or Aβ immunostaining). The assessment is qualitative and subjective, and should indicate an estimate of overall severity rather than an individual vessel.

12K. Is another type of angiopathy (e.g., CADASIL or arteritis) present?
(*mark one box)*

☐ 1 Yes
☐ 2 No
☐ 3 Not assessed
☐ 9 Missing/unknown

Use this item to indicate the presence of other forms of arteriopathy not mentioned in the above categories.

12L. Is there other pathology related to ischemic or vascular disease not previously specified present?
(*mark one box)*

☐ 1 Yes
☐ 2 No
☐ 3 Not assessed
☐ 9 Missing/unknown

This category refers to ischemic or vascular disease not specifically mentioned in the above categories.

Lewy Body Pathology. For all brains in which Lewy bodies are detected, indicate the presence and distribution of Lewy-related pathology. This classification is independent of the clinical presentation, which may be variable and include Parkinsonism, dementia, psychosis, sleep disorders, etc.

13. Pathology is consistent with criteria of Consortium on Dementia with Lewy Bodies for:
(*select only one)*

- ☐ 1 Lewy body pathology, brainstem predominant type
- ☐ 2 Lewy body pathology, intermediate or transitional (limbic) type
- ☐ 3 Lewy body pathology, diffuse (neocortical) type
- ☐ 4 Lewy body pathology, unspecified or not further assessed
- ☐ 5 No Lewy bodies
- ☐ 6 Not assessed
- ☐ 9 Missing/unknown

Characterization of Lewy body pathology should use guidelines set forth by "Consortium on Dementia with Lewy bodies." (McKeith IG, Galasko D, Kosaka K, et al. Consensus guidelines for the clinical and pathologic diagnosis of dementia with Lewy bodies (DLB): Report of the consortium on DLB international workshop. Neurology 1996;47:1113-1124).

The preferred method of assessment is with immunohistochemistry for synuclein. While ubiquitin has been used in the past, it is less specific than synuclein. If Lewy body pathology was assessed only with H&E stains (neither synuclein or ubiquitin), please specify "4 – Lewy body pathology, unspecified" as your answer.

While the published criteria recommend counts of Lewy bodies, this may not be necessary if one can indicate the topographic distribution of Lewy bodies in accordance with the scheme adopted. The criteria consider a cortical region to be positive if more than isolated neurons are affected (more than 5 Lewy bodies per region). The diffuse (neocortical) type implies involvement of neocortical areas beyond the limbic lobe. The transitional (limbic) type implies cortical involvement limited to limbic lobe. Cases with Lewy bodies limited to the amygdala were not specifically addressed in the Consortium criteria, but should be included in the transitional (limbic) type for the sake of this database.

Pathologic characterization of Lewy body pathology is to be performed independent of Alzheimer related pathology for the sake of this neuropathologic database. Alzheimer pathology on these cases will be recorded in the previous section, "Alzheimer Type Pathology" (questions 8A through 11).

Frontotemporal degenerations (FTD). Use this for non-Alzheimer degenerative disorders that commonly have the brunt of cortical changes in frontal and temporal lobes, but may involve other cortical and subcortical regions and have variable clinical presentations, including frontal lobe dementia, progressive aphasia, progressive apraxia, etc.

Use this category for non-Alzheimer degenerative disorders that commonly have the brunt of cortical changes in frontal and temporal lobes, but may involve other cortical and subcortical regions and have variable clinical presentations, including frontal lobe dementia, progressive aphasia, progressive apraxia, etc. (Trojanowski JQ, Dickson D: Update on the neuropathological diagnosis of frontotemporal dementias. J Neuropathol Exp Neurol 2001;60:1123-1126.)

14A. Pick's Disease:

(*mark one box)*

☐ 1 Yes

☐ 2 No

☐ 3 Not assessed

☐ 9 Missing/unknown

For sake of uniformity and consistency, Pick's disease in this database is considered to be the classic form of the disease, the form referred to as type A Pick's disease in the classification of Constantinidis (Constandinidis J, Richard J, Tissot R. Pick's disease. Histological and clinical correlations. Eur Neurol 1974;11:208.) Such cases have sharply circumscribed frontotemporal atrophy with argyrophilic Pick bodies and ballooned neurons ("Pick cells"). If there are no Pick bodies, then an alternative diagnosis should be used.

14B. Corticobasal degeneration:

(*mark one box)*

☐ 1 Yes

☐ 2 No

☐ 3 Not assessed

☐ 9 Missing/unknown

Corticobasal degeneration should refer to a condition in which there is circumscribed atrophy, often in a parasagittal distribution and microscopically characterized by extensive tau-positive or Gallyas-positive thread-like structures in gray and white matter of affected cortices, as well as the basal ganglia, thalamus and rostral brainstem. While ballooned neurons were emphasized in original description and are usually present, they are not essential to the diagnosis. Most cases will have tau-positive plaque-like structures, so-called astrocytic plaques.

14C. Progressive supranuclear palsy:
(*mark one box)*

☐ 1 Yes

☐ 2 No

☐ 3 Not assessed

☐ 9 Missing/unknown

Progressive supranuclear palsy should refer to a condition with tau pathology in the basal ganglia, thalamus, brainstem and cerebellum. Original descriptions emphasized globose neurofibrillary tangles, but tau-positive or Gallyas-positive glial inclusions, both astrocytic (tufted astrocytes) and oligodendroglial (coiled bodies) are a constant finding. Thread-like structures are also common, especially in the diencephalon and brainstem. Cortical involvement is variable, but often relatively restricted to the peri-Rolandic region.

14D. Frontotemporal dementia and Parkinsonism with tau-positive or argyrophilic inclusions:
(*mark one box)*

☐ 1 Yes

☐ 2 No

☐ 3 Not assessed

☐ 9 Missing/unknown

This classification will be used most often for cases of frontotemporal dementia and Parkinsonism linked to chromosome 17 (FTDP-17). Most cases have pathology that overlaps with CBD, PSP or Pick's disease and are associated with mutations in the Tau gene. Occasional cases with similar and extensive tau pathology in neurons and/or glia of the cortex and deep gray matter will have no family history or Tau mutations.

14E. Tauopathy, other (e.g., tangle-only dementia and argyrophilic grain dementia):
(*mark one box)*

☐ 1 Yes

☐ 2 No

☐ 3 Not assessed

☐ 9 Missing/unknown

Use this for non-Alzheimer degenerative disorders that have tau-positive or Gallyas-positive neuronal and/or glial lesions, but do not fit into any of the above groups. Argyrophilic grain disease should be used for cases with tau-positive or Gallyas-positive grains restricted to limbic and peri-limbic regions as originally described by Braak et al. (Braak H, Braak E. Cortical and subcortical argyrophilic grains characterize a disease associated with adult onset dementia. Neuropathol Appl Neurobiol 1989;15:13-26) Most cases also have a few ballooned neurons in the limbic lobe. Tangle-only or tangle-predominant dementia should have the brunt of neurofibrillary degeneration in the medial temporal lobe, often with many extracellular neurofibrillary tangles (Jellinger KA, Brancher C. Senile dementia with tangles (tangle predominant form of senile dementia.) Brain Pathol 1998;8:367-376). Presence of non-neuritic, diffuse amyloid plaques does not exclude this diagnosis.

14F. FTD with ubiquitin-positive (tau-negative) inclusions:

(*mark one box)*

☐ 1 FTD with motor neuron disease

☐ 2 FTD without motor neuron disease

☐ 3 None present

☐ 4 Not assessed

☐ 9Missing/unknown

Use this for non-Alzheimer degenerative disorders with focal atrophy of frontal, temporal or frontotemporal regions and relatively nonspecific histopathology with routine histopathologic methods, as well as with tau and synuclein immunostaining. Ubiquitin immunostaining will show perikaryal inclusions in affected cortices and often in the dentate fascia of the hippocampus. Many cases will show striatal or substantia nigra pathology and many have white matter changes, as well. Some cases will have clinical and/or pathologic evidence of motor neuron disease, but others will not. If immunohistochemical characterization has not been performed, list the case as FTD "not otherwise specified" (see question 14H).

14G. Is there FTD with no distinctive histopathology (tau-negative, ubiquitin-negative, and no argyrophilic inclusions)?

(*mark one box)*

☐ 1 Yes

☐ 2 No

☐ 3 Not assessed

☐ 9 Missing/unknown

Use this for non-Alzheimer degenerative disorders with focal atrophy of frontal, temporal or frontotemporal regions and relatively nonspecific histopathology with routine histopathologic methods, as well as with tau, synuclein and ubiquitin immunostaining. If immunohistochemical characterization has not been performed, list the case as FTD "not otherwise specified" (see question 14H).

14H. Was FTD "not otherwise specified" present (e.g., "immunostaining for ubiquitin and tau not done")?

(*mark one box)*

☐ 1 Yes

☐ 2 No

☐ 3 Not assessed

☐ 9 Missing/unknown

Use this for non-Alzheimer degenerative disorders with nonspecific histopathology that do not clearly fit the above categories or in which immunohistochemical or biochemical characterization is not available or has not been done.

Prion-related disorders:

15A. Is Creutzfeldt-Jakob disease or variant CJD present?
(*mark one box)*

☐ 1 Yes
☐ 2 No
☐ 3 Not assessed
☐ 9 Missing/unknown

Respond "yes" if the case has definite CJD. Such cases would have confirmation with either immunohistochemistry or western blot. If the case has spongiform change, but has not been confirmed with immunohistochemistry or western blot, it should be listed under "Other Major Pathologic Disorders" as "CJD, unconfirmed" (see question 16B).

15B. Are other prion diseases present (e.g., Gerstmann-Straussler syndrome)?
(*mark one box)*

☐ 1 Yes
☐ 2 No
☐ 3 Not assessed
☐ 9 Missing/unknown

Respond "yes" if the case has definite prion disease, other than CJD or variant CJD. Such cases would have confirmation with either immunohistochemistry or western blot. If the case has spongiform change, but has not been confirmed with immunohistochemistry or western blot, it should be listed under "Other Major Pathologic Disorders" as "CJD, unconfirmed" (see question 16B).

Other major pathologic disorders (e.g., infectious, immunologic, metabolic, neoplastic, toxic or degenerative).

16A. Are other major pathologic disorders present (not addressed by questions 8–15)?
(*mark one box)*

☐ 1 Yes
☐ 2 No
☐ 3 Not assessed
☐ 9 Missing/unknown

SKIP: If 2, 3 or 9, go to #17A.

16B. If 16A is yes, specify below (one disorder per line):

1 _____
2 _____
3 _____

Use this section to record infectious, immunologic, metabolic, neoplastic, toxic or degenerative disease processes. If there are more than three disorders present, enter the three most descriptive in the space provided and omit the other disorders.

GENETICS & FAMILY HISTORY

17A. Family history information relevant to neuropathologic diagnosis. Choose one of the following categories that most accurately describes the **family** information available:
(*mark one box)*

☐ 1 Family history of similar neurodegenerative disorder

☐ 2 Family history of other (dissimilar) neurodegenerative disorder

☐ 3 No family history of similar or dissimilar neurodegenerative disorder

☐ 4 Family history of both similar and dissimilar neurodegenerative disorder

☐ 9 Family history unknown/not available/missing

SKIP: If 1, 3 or 9, go to #18A.

17B. If 17A is 2 or 4, specify disorder: _____

Choose one of the following categories that most accurately describes the family information available. If there is more than one relevant disorder in the family history, enter the most descriptive in the space provided and omit the other(s).

Genetic variants or polymorphisms. For each of the following three common genetic variants or polymorphisms, choose the patient's genotype, if known; select "not available or not assessed" if unknown:

18A. Apolipoprotein-E:
(*mark one box)*

☐ 1 e3, e3

☐ 2 e3, e4

☐ 3 e3, e2

☐ 4 e4, e4

☐ 5 e4, e2

☐ 6 e2, e2

☐ 9 Missing/unknown/not assessed

One of the major genetic risk factors for Alzheimer's disease is apolipoprotein-E. Please note the genotype, if known.

18B. Tau haplotype:
(*mark one box)*

☐ 1 H1, H1

☐ 2 H1, H2

☐ 3 H2, H2

☐ 4 Other polymorphism (e.g., A0)

☐ 9 Missing/unknown/not assessed

For tauopathies such as PSP and CBD, there is increased frequency of the H1 haplotype in the tau gene. It may also be increased in Parkinson's disease. Other polymorphisms in the tau gene have also been described, such as the A0 dinucleotide repeat. If known, please include. (Baker M, Litvan I, Houlden H, et al. Association of an extended haplotype in the tau gene with progressive supranuclear palsy. Hum Molec Genetics 1999;8:711-715.)

18C. PRNP codon 129:

(*mark one box)*

☐ 1 M, M

☐ 2 M, V

☐ 3 V, V

☐ 9 Missing/unknown/not assessed

For prion cases the polymorphism (methionine or valine) at codon 129 influences the phenotype.

19. Genetic or chromosomal abnormalities. Choose below the <u>one</u> known genetic or chromosomal abnormality that best describes the subject:

(*mark one box)*

☐ 1 APP mutation

☐ 2 PS1 mutation

☐ 3 PS2 mutation

☐ 4 Tau mutation

☐ 5 α-Synuclein mutation

☐ 6 Parkin mutation

☐ 7 PRNP mutation

☐ 8 Huntingtin mutation

☐ 9 Notch 3 mutation (CADASIL)

☐ 10 Other known genetic mutation (e.g., ABri, neuroserpin)

☐ 11 Down syndrome

☐ 12 Other chromosomal abnormality

☐ 13 No known genetic or chromosomal abnormality

☐ 50 Not assessed

☐ 99 Missing/unknown

Genetic information on the case is recorded here. Please choose "13" when a reasonable clinical evaluation has provided no indication that one of the specific known genetic or chromosomal abnormalities listed should be used to characterize this case. Please choose "50" when neither sufficient clinical work-up nor genetic testing to reasonably observe whether one of the conditions listed might be present has been performed.

20. What are the primary and contributing pathologic diagnoses or features which you judge to be responsible for the subject's cognitive status?

NOTE: *Mark only one diagnosis as "primary"; any number may be marked as "contributing".*

Specify only one diagnosis as "primary"; any number may be marked as "contributing" (check the appropriate box(es) for each additional diagnosis).

Primary	Contributing	
☐ A1	☐ A2	Normal brain (NC)
		Normal control.
☐ B1	☐ B2	AD pathology present but insufficient for AD diagnosis
		This diagnosis is used for NIA/Reagan low likelihood, or cases which are not classifiable by NIA/Reagan criteria. This category has been added for normal controls with low level AD pathology, such as cognitively normal individuals with Braak stage III or IV and moderate or frequent plaques, subjects with MCI, other cognitive deficits and early dementia)
☐ C1	☐ C2	Alzheimer disease (AD)
		Refer to questions 8, 9, and 10 for plaque load, CERAD grade, Braak stage, NIA/Reagan category.
☐ D1	☐ D2	Lewy body disease, with or without AD
		Refer to question 13 for details and staging.
☐ E1	☐ E2	Vascular disease
		Refer to question 12 for details, use in this diagnosis section if it is relevant to the dementia.
☐ F1	☐ F2	FTLD
		Refer to question 14 for sub-type.
☐ G1	☐ G2	Hippocampal sclerosis
		Can be related to either vascular disease or FTLD.
☐ H1	☐ H2	Prion-associated disease
☐ I1	☐ I2	Other (specify): _____
☐ J1	☐ J2	Other (specify): _____
☐ K1	☐ K2	Other (specify): _____
		Any other neurologic or cognitive condition–Parkinson disease, ALS, MSA, SCA, etc.

Brain Tissue and Post Mortem CSF. Use this section to record information related to the storage and accessibility of brain tissue and post mortem CSF at your Center.

21. Is banked frozen brain tissue accessible?

(*mark one box)*

☐ 1 Yes

☐ 2 No

22. Is formalin-fixed brain tissue accessible?

(*mark one box)*

☐ 1 Yes

☐ 2 No

23. Are paraffin-embedded blocks of brain tissue accessible?

(*mark one box)*

☐ 1 Yes

☐ 2 No

24. Is banked postmortem cerebrospinal fluid (CSF) accessible?

(*mark one box)*

☐ 1 Yes

☐ 2 No

Check "yes" only if: (a) there is hard evidence that the specimen was taken; (b) there is some evidence that it was stored at your ADC; (c) there is a reasonable likelihood that the specimen, or any remaining portion, could be located at your ADC; and (d) the process of locating the specimen would be routine if ordinary effort were applied.

Check "no" if the indicated specimen is not stored in an easily accessible location at your Center.

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