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Neuropathology
Data Manual

Version 1.00, December 2001

NOTE: Version 1 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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NUMERICAL INDEX OF VARIABLES
Neuropathology Data Manual, version 1.00
(In order by variable name)

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ALPHABETICAL INDEX OF VARIABLES
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General Instructions

General Instructions

A. Verification of Receipt of *Neuropathology Data Manual*

Please verify that you have received this manual and the 3 ½" Data Call diskette by sending email to naccmail@alz.washington.edu or by calling (206) 543-8637.

The diskette contains:

1. Neuropathology error-check program – np2001.sas
2. PKZIP and PKZIP bat file – nacc.bat
3. ASCII file listing MDS IDs with autopsies for your Center.

   (*Note*: This is a PC diskette. You will need to copy the Neuropathology Error-check program (np2001.sas) onto your computer. Call NACC if you experience difficulty copying this program.)

A PDF version of this manual is also available on the NACC website.

B. Data Submission Date and Transmission Options

Data must be prepared and submitted to NACC by **Wednesday, February 28, 2002.**

Data may be transmitted in one of three modes:

1. Send a data file, as has been done for the MDS Data Call in the past (see "File Types" below);
2. Use the Neuropathology Web Data Management System to enter data directly through NACC's website, www.alz.washington.edu (see the section "Neuropathology Web Data Management" elsewhere in this manual);
3. Send the paper forms (Neuropathology Data Form) filled out for each MDS ID, and let NACC do the data entry; this might be appropriate at sites that have done few autopsies.

Data files may be submitted via 3 ½" diskette or by FTP. Instructions for transmission are included in the "File Transfers" section later in this manual. Prior to sending the data, it is expected that:

1. You have checked the data for unallowable and unlikely values using the error-check program (naccerr.sas);
2. Errors have been corrected;
3. Alerts (unlikely values) were verified and, if appropriate, corrected.

If using FTP to send data, you must encrypt the data with PKZIP prior to transmission.

C. File Types (if submitting data by file)

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

- 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.

SAS Files:
Five kinds of SAS files may be accepted by NACC:

1. PC SAS Version 6.12 files – These files have an extension of .sd2 and are created using PC SAS.
2. PC SAS Version 7.0 or 8.0 files.
3. Solaris Version 7, SAS Version 6.12 files – These files have an extension of .ssd01 and are created on a system running Solaris 7 (i.e., a Unix System).
4. Solaris Version 7, SAS Version 7.0 or 8.0 files – These files have an extension of .sas7bdat and are created on a system running Solaris 7 (i.e., a Unix System).
5. SAS transport files – These files can be created on any system which 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. Data to Include

The MDS IDs that are submitted in the Neuropathology Data Call, including IDs enrolled at your Center's clinical core and satellite core(s), can be categorized in one of three ways:

1. *Required*: All MDS IDs submitted to NACC in the 2001 MDS Data Call with an autopsy value of "yes." (We have provided a list of these IDs on the enclosed diskette. These IDs are also already in your Center's Neuropathology Data Set as accessed by the Neuropathology Web Data Management System.)
2. *Optional*: MDS IDs from the 2001 MDS Data Call with an autopsy value of "no" but which have been autopsied since the MDS Data Call. (These IDs must be submitted in the next MDS Data Call with an autopsy value of "yes.")
3. *Optional*: A newly-autopsied MDS ID that has never been submitted to NACC in an MDS Data Call, but which will be submitted in the next MDS Data Call.

E. General Coding Instructions

1. Required Items: All data elements in the neuropathology data call 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 " ".

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

F. 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.

We have tried to minimize the contingency checks with this program. We may be contacting individual centers at a later time to discuss specific data contingency problems not included in this program.

Data Template

Columns	Variable	Form
1-2	ADCID	0. Center ID (1-2) __ __
4-13	PTID	1. MDS Patient ID (4-13) __ __ __ __ __ __ __ __ __ __
		2. Date form completed:
15-16	NPFORMMO	2a. Month (15-16) __ __
18-19	NPFORMDY	2a. Day (18-19) __ __
21-24	NPFORMYR	2a. Year (21-24) __ __ __ __
26-35	NPID	3. Neuropath ID (26-35) __ __ __ __ __ __ __ __ __ __
37	NPSEX	4. Gender (37) __ 1 Male 2 Female
39-41	NPDAGE	5. Age at Death (39-41) __ __ __
		6. Date of death:
43-44	NPDODMO	6a. Month (43-44) __ __
46-47	NPDODDY	6b. Day (46-47) __ __
49-52	NPDODYR	6c. Year (49-52) __ __ __ __
54	NPGROSS	7. Does the brain have any gross or microscopic pathology (including any Alzheimer type pathology such as senile plaques and neurofibrillary tangles?) (54) 1 Yes 2 No 9 No neuropathology diagnosis available SKIP: If 2 or 9, go to #17A, “Clinical genetics and family history.”

Columns	Variable	Form
56	NPNIT	8A. NIA/Reagan Institute neuropathological criteria used: (56) 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
58	NPCERAD	8B. CERAD neuropathological criteria used: (58) 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
60	NPADRDA	8C. ADRDA/Khachaturian neuropathological criteria used: (60) 1 Alzheimer's disease 2 Criteria not met 3 Not done 9 Missing/unknown
62	NPOCRIT	8D. Other or unspecified neuropathological criteria used (e.g., Tierney, etc.): (62) 1 Alzheimer's disease, unspecified 2 Criteria not met 3 Not done 9 Missing/unknown

Columns	Variable	Form
64	NPBRAAK	9. Braak & Braak Neurofibrillary Stage: (64) 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
66	NPNEUR	10. Neuritic plaques (plaques with argyrophilic dystrophic neurites with or without dense amyloid cores): (66) 1 Frequent neuritic plaques 2 Moderate neuritic plaques 3 Sparse neuritic plaques 4 No neuritic plaques 5 Not assessed 9 Missing/unknown
68	NPDIFF	11. Diffuse plaques (plaques with non-compact amyloid and no apparent dystrophic neurites): (68) 1 Frequent neuritic plaques 2 Moderate neuritic plaques 3 Sparse neuritic plaques 4 No neuritic plaques 5 Not assessed 9 Missing/unknown
70	NPVASC	12. Is ischemic, hemorrhagic or vascular pathology present? (70) 1 Yes 2 No 3 Not assessed 9 Missing/unknown SKIP: If 2, 3 or 9, go to #13. If ischemic, hemorrhagic or vascular lesions are present, answer questions 12A through 12L.

Columns	Variable	Form
72	NPLINF	12A. Are one or more large artery cerebral infarcts present? (72) 1 Yes 2 No 3 Not assessed 9 Missing/unknown
74	NPMICRO	12B. Are one or more cortical, microinfarcts (including "granular atrophy") present? (74) 1 Yes 2 No 3 Not assessed 9 Missing/unknown
76	NPLAC	12C. Are one or more lacunes, (small artery infarcts and/or hemorrhages) present? (76) 1 Yes 2 No 3 Not assessed 9 Missing/unknown
78	NPHEM	12D. Are single or multiple hemorrhages present? (78) 1 Yes 2 No 3 Not assessed 9 Missing/unknown
80	NPART	12E. Is subcortical arteriosclerotic leukoencephalopathy present? (80) 1 Yes 2 No 3 Not assessed 9 Missing/unknown
82	NPNEC	12F. Is cortical laminar necrosis present? (82) 1 Yes 2 No 3 Not assessed 9 Missing/unknown
84	NPSCL	12G. Is medial temporal lobe sclerosis (including hippocampal sclerosis) present? (84) 1 Yes 2 No 3 Not assessed 9 Missing/unknown

Columns	Variable	Form
86	NPVOTH	12H. Is there other pathology related to ischemic or vascular disease not previously specified present? (86) 1 Yes 2 No 3 Not assessed 9 Missing/unknown
88	NPAVAS	12I. Is atherosclerotic vascular pathology (of the circle of Willis) present? (88) 1 None 2 Mild 3 Moderate 4 Severe 5 Not assessed 9 Missing/unknown
90	NPARTER	12J. Is arteriosclerosis (small parenchymal arteriolar disease) present? (90) 1 None 2 Mild 3 Moderate 4 Severe 5 Not assessed 9 Missing/unknown
92	NPAMY	12K. Is amyloid angiopathy present? (92) 1 None 2 Mild 3 Moderate 4 Severe 5 Not assessed 9 Missing/unknown
94	NPOANG	12L. Is there another type of angiopathy (e.g., CADASIL or arteritis) present? (94) 1 Yes 2 No 3 Not assessed 9 Missing/unknown

Columns	Variable	Form
96	NPLEWY	13. Pathology is consistent with criteria of Consortium on Dementia with Lewy Bodies for: (96) 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
98	NPPICK	14A. Pick's disease: (98) 1 Yes 2 No 3 Not assessed 9 Missing/unknown
100	NPCORT	14B. Corticobasal degeneration: (100) 1 Yes 2 No 3 Not assessed 9 Missing/unknown
102	NPPROG	14C. Progressive supranuclear palsy: (102) 1 Yes 2 No 3 Not assessed 9 Missing/unknown
104	NPFRONT	14D. Frontotemporal dementia and Parkinsonism with tau-positive or argyrophilic inclusions: (104) 1 Yes 2 No 3 Not assessed 9 Missing/unknown
106	NPTAU	14E. Tauopathy, other (e.g., tangle-only dementia and argyrophilic grain dementia): (106) 1 Yes 2 No 3 Not assessed 9 Missing/unknown

Columns	Variable	Form
108	NPFTD	14F. FTD with ubiquitin-positive (tau-negative) inclusions: (108) 1 FTD with motor neuron disease 2 FTD without motor neuron disease 3 None present 4 Not assessed 9 Missing/unknown
110	NPFTDNO	14G. Is there FTD with no distinctive histopathology (tau-negative, ubiquitin-negative, and no argyrophilic inclusions)? (110) 1 Yes 2 No 3 Not assessed 9 Missing/unknown
112	NPFTDSPC	14H. Was FTD “not otherwise specified” present (e.g., “immunostaining for ubiquitin and tau not done”)? (112) 1 Yes 2 No 3 Not assessed 9 Missing/unknown
114	NPCJ	15A. Is Creutzfeldt-Jakob disease or variant CJD present? (114) 1 Yes 2 No 3 Not assessed 9 Missing/unknown
116	NPPRION	15B. Are other prion diseases present (e.g., Gerstmann-Straussler syndrome)? (116) 1 Yes 2 No 3 Not assessed 9 Missing/unknown

Columns	Variable	Form
118	NPMAJOR	16A. Are other major pathological disorders present (not addressed by questions 8-15)? (118) 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):
120-149	NPMPATH1	1. _____
151-180	NPMPATH2	2. _____
182-211	NPMPATH3	3. _____
213	NPGENE	17A. **Clinical genetics and family history information relevant to neuropathologic diagnosis:** (213) 1 Family history of similar neurodegenerative disorder (but no known mutation or genetic locus) 2 Family history of other (dissimilar) neurodegenerative disorder 3 No family history of similar or dissimilar neurodegenerative disorder 9 Family history unknown/not available/missing SKIP: If 1, 3, or 9, go to #18A.
215-244	NPFHSPEC	17B. If 17A is 2, then specify: _____

Columns	Variable	Form
246	NPAPOE	18A. Apolipoprotein-E: (246) 1 e3, e3 2 e3, e4 3 e3, e2 4 e4, e4 5 e4, e2 6 e2, e2 9 Missing/unknown/not assessed
248	NPTAUHAP	18B. Tau haplotype: (248) 1 H1, H1 2 H1, H2 3 H2, H2 4 Other polymorphism (e.g., A0) 9 Missing/unknown/not assessed
250	NPPRNP	18C. PRNP codon 129: (250) 1 M, M 2 M, V 3 V, V 9 Missing/unknown/not assessed
252-253	NPCHROM	19. **Genetic or chromosomal abnormalities.** (252-253) 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

Data Element Dictionary

NACC Neuropathology
Data Element Dictionary

The data element dictionary is formatted the same as the one in the MDS manual, due to favorable feedback. Variable names are indicated in Blue. Each variable has its own Green box. 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.

Neuropathology (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 Codes and Missing Codes – List of codes 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 Codes	**1–34, 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 = U ARIZONA 34 = U ARKANSAS

Variable Number	**1**
Variable Name	**PTID**
Short Descriptor	**MDS ID**
NP Question	**MDS Patient ID**
Length of Field	**10**
Column Positions	**4–13**
SAS Variable Type	**Character**
SAS Variable Length	**10**
Allowable Codes	**Follow your center's MDS Patient ID scheme**
Comment	MDS Patient ID must be unique within data set from your center (no duplicates). MDS PTID for each subject must be the same at each data call; MDS PTID cannot change once it has been assigned by your Center. PTID is the same for a given subject at both the MDS Data Call and the Neuropathology Data Call.

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 Codes	**1–12**
Comment	Must meet criteria for valid 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 Codes	**1–31**
Comment	Must meet criteria for valid 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 Codes	**2001, 2002**
Comment	Must meet criteria for valid 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 Codes	**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 at each data call; NPID cannot change once it has been assigned by your Center.

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 Codes	**1 or 2** 1 = Male 2 = Female
Comment	***Missing (9s) not allowed.*** Must be same as 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 Codes	**0–130**

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 Codes	**1–12**
Missing Code	**99**
Comment	Must be same date as in 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 Codes	**1–31**
Comment	Must be same date as in 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 Codes	**Cannot precede 1970; in most cases, should not precede 1984.**
Comments	Must be same date as in 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 Codes	**1, 2** 1 = Yes 2 = No
Missing Code	9 = No neuropathology diagnosis available
Skips	If NPGROSS = 2 or 9, then go to #17A, "Clinical genetics and family history". If NPGROSS = 1 then continue.

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 Codes	**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
Blanks	Blank if #7, NPGROSS = 2 or 9

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 Codes	**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
Blanks	Blank if #7 NPGROSS = 2 or 9

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 Codes	**1–3** 1 = Alzheimer's disease 2 = Criteria not met 3 = Not done
Missing Code	9 = Missing/Unknown
Blanks	Blank if #7 NPGROSS = 2 or 9

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 Codes	**1–3** 1 = Alzheimer's disease, unspecified 2 = Criteria not met 3 = Not done
Missing Code	9 = Missing/Unknown
Blanks	Blank if #7 NPGROSS = 2 or 9

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 Codes	**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
Blanks	Blank if #7 NPGROSS = 2 or 9

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 Codes	**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
Blanks	Blank if #7 NPGROSS = 2 or 9

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 Codes	**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
Blanks	Blank if #7 NPGROSS = 2 or 9

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 Codes	**1–3** 1 = Yes 2 = No 3 = Not assessed
Missing Code	9 = Missing/Unknown
Blanks	Blank if #7 NPGROSS = 2 or 9
Skips	If NPVASC = 2, 3 or 9 go to #13, NPLEWY. If NPVASC = 1 then continue.

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 Codes	**1–3** 1 = Yes 2 = No 3 = Not assessed 9 = Missing/unknown
Missing Code	
Blanks	Blank if #7 NPGROSS = 2 or 9 Blank if #12 NPVASC = 2, 3 or 9

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 Codes	**1–3** 1 = Yes 2 = No 3 = Not assessed 9 = Missing/unknown
Missing Code	
Blanks	Blank if #7 NPGROSS = 2 or 9 Blank if #12 NPVASC = 2, 3 or 9

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 Codes	**1–3** 1 = Yes 2 = No 3 = Not assessed
Missing Code	9 = Missing/unknown
Blanks	Blank if #7 NPGROSS = 2 or 9 Blank if #12 NPVASC = 2, 3 or 9

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 Codes	**1–3** 1 = Yes 2 = No 3 = Not assessed
Missing Code	9 = Missing/unknown
Blanks	Blank if #7 NPGROSS = 2 or 9 Blank if #12 NPVASC = 2, 3 or 9

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 Codes	**1–3** 1 = Yes 2 = No 3 = Not assessed 9 = Missing/unknown
Missing Code	
Blanks	Blank if #7 NPGROSS = 2 or 9 Blank if #12 NPVASC = 2, 3 or 9

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 Codes	**1–3** 1 = Yes 2 = No 3 = Not assessed 9 = Missing/unknown
Missing Code	
Blanks	Blank if #7 NPGROSS = 2 or 9 Blank if #12 NPVASC = 2, 3 or 9

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 Codes	**1–3** 1 = Yes 2 = No 3 = Not assessed
Missing Code	9 = Missing/unknown
Blanks	Blank if #7 NPGROSS = 2 or 9 Blank if #12 NPVASC = 2, 3 or 9

Variable Number	**12H**
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	**86**
SAS Variable Type	**Numeric**
SAS Variable Length	**8**
Allowable Codes	**1–3** 1 = Yes 2 = No 3 = Not assessed
Missing Code	9 = Missing/unknown
Blanks	Blank if #7 NPGROSS = 2 or 9 Blank if #12 NPVASC = 2, 3 or 9

Variable Number	**12I**
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	**88**
SAS Variable Type	**Numeric**
SAS Variable Length	**8**
Allowable Codes	**1–5** 1 = None 2 = Mild 3 = Moderate 4 = Severe 5 = Not assessed
Missing Code	9 = Missing/unknown
Blanks	Blank if #7 NPGROSS = 2 or 9 Blank if #12 NPVASC = 2, 3 or 9

Variable Number	**12J**
Variable Name	**NPARTER**
Short Descriptor	**Arteriosclerosis**
NP Question	**Is arteriosclerosis (small parenchymal arteriolar disease) present?**
Length of Field	**1**
Column Positions	**90**
SAS Variable Type	**Numeric**
SAS Variable Length	**8**
Allowable Codes	**1–5** 1 = None 2 = Mild 3 = Moderate 4 = Severe 5 = Not assessed
Missing Code	9 = Missing/unknown
Blanks	Blank if #7 NPGROSS = 2 or 9 Blank if #12 NPVASC = 2, 3 or 9

Variable Number	**12K**
Variable Name	**NPAMY**
Short Descriptor	**Amyloid Angiopathy**
NP Question	**Is amyloid angiopathy present?**
Length of Field	**1**
Column Positions	**92**
SAS Variable Type	**Numeric**
SAS Variable Length	**8**
Allowable Codes	**1–5** 1 = None 2 = Mild 3 = Moderate 4 = Severe 5 = Not assessed
Missing Code	9 = Missing/unknown
Blanks	Blank if #7 NPGROSS = 2 or 9 Blank if #12 NPVASC = 2, 3 or 9

Variable Number	**12L**
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	**94**
SAS Variable Type	**Numeric**
SAS Variable Length	**8**
Allowable Codes	**1–3** 1 = Yes 2 = No 3 = Not assessed
Missing Code	9 = Missing/Unknown
Blanks	Blank if #7 NPGROSS = 2 or 9 Blank if #12 NPVASC = 2, 3 or 9

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 Codes	**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
Blanks	Blank if #7 NPGROSS = 2 or 9

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 Codes	**1–3** 1 = Yes 2 = No 3 = Not assessed
Missing Code	9 = Missing/Unknown
Blanks	Blank if #7 NPGROSS = 2 or 9

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 Codes	**1–3** 1 = Yes 2 = No 3 = Not assessed
Missing Code	9 = Missing/Unknown
Blanks	Blank if #7 NPGROSS = 2 or 9

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 Codes	**1–3** 1 = Yes 2 = No 3 = Not assessed
Missing Code	9 = Missing/Unknown
Blanks	Blank if #7 NPGROSS = 2 or 9

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 Codes	**1–3** 1 = Yes 2 = No 3 = Not assessed
Missing Code	9 = Missing/Unknown
Blanks	Blank if #7 NPGROSS = 2 or 9

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 Codes	**1–3** 1 = Yes 2 = No 3 = Not assessed
Missing Code	9 = Missing/Unknown
Blanks	Blank if #7 NPGROSS = 2 or 9

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 Codes	**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
Blanks	Blank if #7 NPGROSS = 2 or 9

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 Codes	**1–3** 1 = Yes 2 = No 3 = Not assessed
Missing Code	9 = Missing/Unknown
Blanks	Blank if #7 NPGROSS = 2 or 9

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 Codes	**1–3** 1 = Yes 2 = No 3 = Not assessed
Missing Code	9 = Missing/Unknown
Blanks	Blank if #7 NPGROSS = 2 or 9

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 Codes	**1–3** 1 = Yes 2 = No 3 = Not assessed
Missing Code	9 = Missing/Unknown
Blanks	Blank if #7 NPGROSS = 2 or 9

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 Codes	**1–3** 1 = Yes 2 = No 3 = Not assessed 9 = Missing/Unknown
Missing Code	
Blanks	Blank if #7 NPGROSS = 2 or 9

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 Codes	**1–3** 1 = Yes 2 = No 3 = Not assessed 9 = Missing/Unknown
Missing Code	
Blanks	Blank if #7 NPGROSS = 2 or 9
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 #7 NPGROSS = 2 or 9 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 #7 NPGROSS = 2 or 9 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 #7 NPGROSS = 2 or 9 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	**Clinical Genetics**
NP Question	**Clinical genetics and family history information relevant to neuropathologic diagnosis.**
Length of Field	**1**
Column Positions	**213**
SAS Variable Type	**Numeric**
SAS Variable Length	**8**
Allowable Codes	**1–3** 1 = Family history of similar neurodegenerative disorder (but no known mutation or genetic locus) 2 = Family history of other (dissimilar) neurodegenerative disorder 3 = No family history of similar or 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, then continue.

Variable Number	**17B**
Variable Name	**NPFHSPEC**
Short Descriptor	**Specify**
NP Question	**If 17A is 2, 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

Error-Checking

Operating the Neuropathology Error-Check Program

The Neuropathology error-check program is an SAS program named **np2001.sas**. This program should execute on any computer system which has SAS installed. It will accept fixed-format ASCII files, SAS files, and SPSS portable files as input. The steps below should allow you to successfully run the program. If problems occur, don't hesitate to call NACC at (206) 543-8637.

1. **Execute the program.**

   The program may be executed either from the command line or through the SAS Display Manager, depending upon your preferences and the parameters of your particular computer or operating software. We recommend that np2001.sas and your input data file reside in the same directory for ease of use.

   If you execute the program from the SAS Display Manager, use the command:

   include np2001.sas

   Then submit to execute.

2. **Screen 1 will look as follows:**

   ```
   Welcome to the NACC Neuropath Error Check Program

   Type of Input File? __

      1 = Fixed Format ASCII File
      2 = SAS Data File
      3 = SPSS Portable File
     99 = Exit Program
   ```

   Enter the number representing your data file type. Entering '99' exits the program without processing any data. Use the Enter or Return key once the number has been entered. A legal response (other than 99) will display Screen 2. Illegal responses will result in the display of an Error Message Screen as follows:

   ```
   Type must be 1, 2, 3 or 99 to quit

   Press Enter and try again
   ```

   Use Enter or Return to return to Screen 1.

3. Screen 2

The appearance of Screen 2 depends upon the type of input file entered on Screen 1.

3a. Fixed Format ASCII File: Input File Type = 1

```
NACC Neuropath Error Check Program Screen 2

Input ASCII File Name? _____

    99=Quit
```

Enter the name of your **Fixed Format ASCII** data file. Entering '99' exits the program without processing any data. Use the Enter or Return key once the name has been entered. If your input data file resides within the directory where SAS is being executed, its name can be entered directly. Input data files that reside in a different directory must include the whole path name (e.g., for PC SAS - C:\NACC\mdb.dat). If a legal file name is entered, Screen 3 will be displayed. If the file cannot be found, the following error screen will appear:

```
File Name Does not Exist

Press Enter and try again
```

Upon pressing Enter or Return, Screen 2 will return.

3b. SAS Data File: Input File Type = 2

```
NACC Neuropath Error Check Program Screen 2

Input SAS File Name? _____

    99=Quit

SAS Libname? _____
```

Enter the name of your SAS data file. The extension on the file name is assumed to be a valid SAS data file extension for the operating system you have so *DO NOT enter the file extension.* Entering '99' exits the program without processing any data. Use the Enter or Return key once the name has been entered.

Next enter the SAS libname. This is the directory where the SAS input data file is found. For some systems a '**.**'can be entered if the filename is in the directory where SAS is executing. If a legal file is entered, Screen 4 will be displayed. If the file cannot be found, the following error screen will appear:

```
File Name Does not Exist

Press Enter and try again
```

Use Enter or Return to return to Screen 2.

3c. SPSS Portable File: Input File Type = 3

```
NACC Neuropath Error Check Program Screen 2

Input SPSS Portable File Name? _____

    99=Quit
```

Enter the name of your SPSS portable input data file. *The extension '**.por**' is assumed, so DO NOT enter it as part of the name.* Entering '99' exits the program without processing any data. Use the Enter or Return key after you have entered the name. Files that reside within the directory where SAS is being executed can be entered directly (without including path name). Files that reside in different directories must include the whole path name (e.g. for PC SAS: C:\NACC\mdb). If a legal file is entered, Screen 3 will be displayed. If the file cannot be found, the following Error Screen will appear:

```
File Name Does not Exist

Press Enter and try again
```

Use Enter or Return to return to Screen 2.

4. Screen 3 will look as follows:

```
NACC Neuropath Error Check Program Screen 3
Enter the Parameters Below to start the program

Error Report File Name? _____

    99=Quit

    Line Size?      79
    Page Size?      59
```

Enter the name of the file you want to contain the Error Report listing. To protect your existing files, this must be a new name (not currently existing). Entering '99' exits the program without processing any data. If the Error Report file will reside in a different directory than the SAS program directory, then enter the pathname along with the filename. Use the Enter or Return key after the Error Report file name has been entered.

Next enter the line size and page size for your output. It is usually best to use the defaults. If all your inputs are valid and the filename doesn't currently exist, then Screen 4 will be displayed. If a filename that exists is entered, then the following Error Message Screen is displayed:

> Report File Name Exists
>
> Press Enter and try again

Use Enter or Return to return to Screen 3.

5. **Screen 4 will appear as follows:**

> Program Running
>
> When Complete Look at Report File – *<your Error Report file name>*

This screen just tells you the program is running. When the program is completed the screen will disappear. At that point, you will be able to check the Error Report file for errors; if you are using the SAS Display Manager it will be in a different window. Please fix the errors in your data file and execute the program again. Continue this process until all errors have been corrected and alerts verified. Then your data will be ready for submission to NACC.

NACC MDS Error Messages

Several types of error messages may be generated by the error checking program, **np2001.sas:** 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. NACC will be confirming that the data files that you submit are error-free prior to inclusion in the MDS. Alerts are accepted if verified. Please state that you have verified your alerts when you submit your data to NACC.

Examples of types of Error Messages are as follows:

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

Line # in file:	1
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
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
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
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
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
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
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).

RACE 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

File Transfers

File Transfers

Data submission deadline: **Wednesday, February 28, 2002**

Options for Transferring Files

After you have run your data through the error-check program, fixed all errors, and verified the alerts, you are ready to submit data. There are two options for transferring files to NACC — by floppy diskette or over the Internet.

A. Sending Files by Mail on a Diskette

1. Copy your file onto a PC diskette. You can send any of the three permitted file types (fixed format ASCII files, SAS files, SPSS files; see the "General Instructions" section of this manual).

2. If your data does not fit on one diskette, you may want to compress the file using PKZIP (see the section that follows, "PKZIP – Compressing and Securing Files Before Sending").

3. You do *not* need to send us the paper copy of the error-check output.

4. Mail the diskette to: NACC
   4225 Roosevelt Way NE, Suite 301
   Seattle, WA 98105-6099

5. Notify us by e-mail (naccmail@alz.washington.edu) or phone (206-543-8637) that you have sent the file, and that all error-check alerts have been verified. If you compressed the file using PKZIP, tell us the password you used.

B. Sending Files Over the Internet Using FTP

1. Get the logon information for your site's account on NACC's computer ("Coho").
   a. Send an e-mail to naccmail@alz.washington.edu or call (206) 543-8637.
   b. Request the username and password for your site's Coho account.

2. You can send any of the three permitted file types (fixed format ASCII files, SAS files, SPSS files; see the "General Instructions" section of this manual).

3. Compress and secure your file using PKZIP (see the section that follows, "PKZIP – Compressing and Securing Files Before Sending").

4. FTP the file to your account on Coho. See the appropriate section that follows if you need help using FTP. Files MUST be sent in binary mode.

5. Notify us by e-mail or phone that you have sent the file, and that all error-check alerts have been verified. Tell us the PKZIP password you used.

PKZIP – Compressing and Securing Files Before Sending

Files that are sent to NACC over the Internet using an FTP program must be protected, for security reasons. We recommend using PKZIP, a program that compresses (or "zips") files and protects them with a password.

If you plan to send your file to NACC by mail on a floppy diskette, you do not need to use PKZIP. However, you might *want* to use PKZIP – if your file is too large, compressing it with PKZIP might allow it to fit on one diskette.

We have placed a batch file, nacc.bat, which executes the program PKZIP, on the NP Data Call Diskette. This program works only on PCs using Windows 95/98/NT/2000. If you do not have a PC running these operating systems and wish to use PKZIP, please contact NACC.

NOTE: There are legal restrictions on our PKZIP license. You may use the PKZIP software only temporarily, for this data call. You may not install it permanently on your PC.

To use PKZIP, do the following for the file that is to be protected and compressed:

1. Insert the NP Data Call diskette into the floppy drive (drive A: is used in the steps below).

2. Go to the MS-DOS prompt (or "Command Prompt") from Windows 95/98/NT/2000.

3. Change to the directory (folder) where the file to be compressed is stored by entering the following command: cd <directory name>

   Depending on your PC, the directory name you provide may need to be the DOS pathname (e.g. c:\mydocu~1) or enclosed in quotes (e.g. "c:\My Documents").

4. Execute the program: a:\nacc <output file name> <input file name>

   The input file name is the file you want to compress, for example an ASCII (flat) file or a SAS file. The output file name is the name you want given to the compressed file that PKZIP creates. PKZIP puts the compressed output file in the same folder as the original, uncompressed input file; the program will append the extension ".zip" to its file name. The output file is the file you will send to NACC.

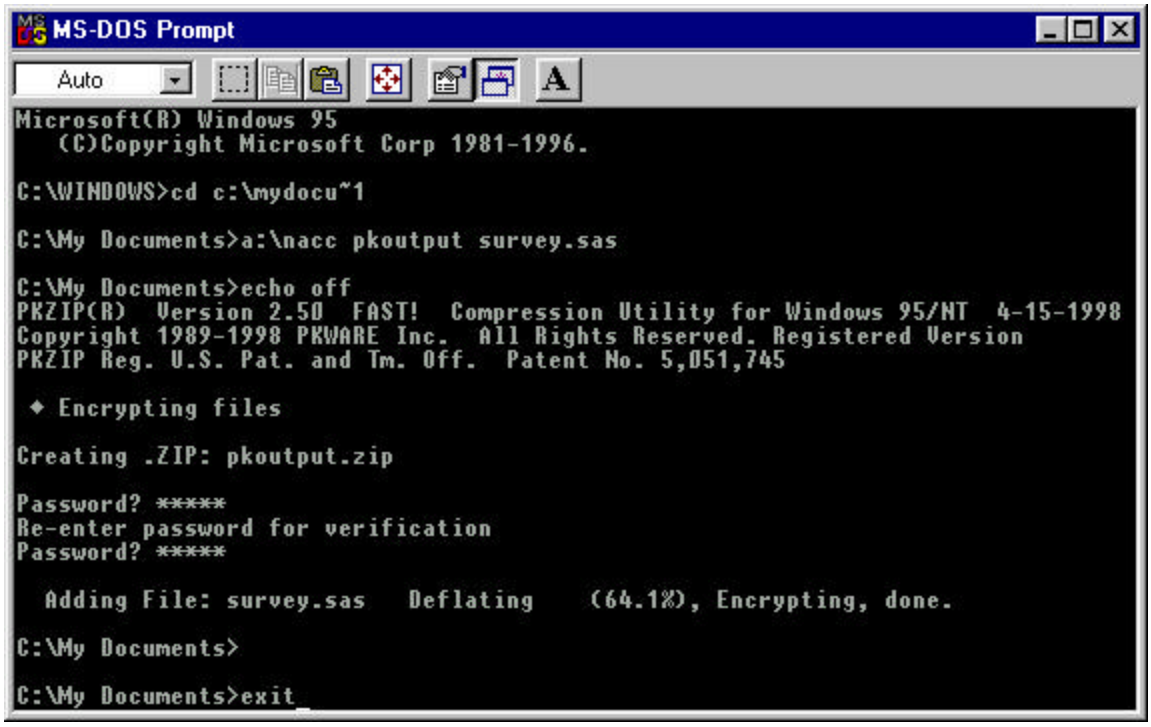
5. The program will ask for a password. Enter any password you want. Then re-enter it when asked. Write it down! Let NACC know this password, either by e-mail or phone, when you send the file.

6. Once the program is done, the compressed (zipped) file is ready to be sent to NACC. An example of a PKZIP session follows.

Example PKZIP Session (Using Windows 95)

In the following example, the user compresses a file named survey.sas which resides in the folder named My Documents. The resulting compressed, password-protected output file is created with the file name pkoutput.zip, also in My Documents.

Note that PKZIP requires you first to change to the directory (folder) where the file you want to compress is stored. You may need to use the DOS version of the directory's name with the cd (change directory) command. In this case, the file is stored in the directory "My Documents", which has a DOS name of mydocu~1. Therefore, the DOS pathname c:\mydocu~1 was used with the cd command, after which the DOS prompt changed to " C:\My Documents> ". (Or on your PC, when you use the cd command, you might need to enclose the entire pathname in quotes: "c:\My Documents".)



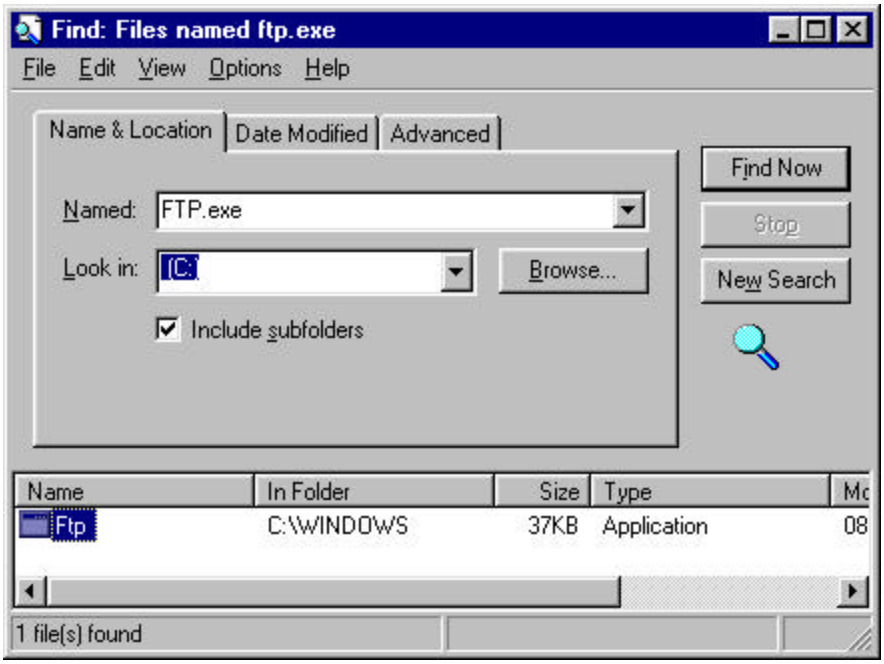
PC Users – How to FTP Your File to NACC

The following example pertains to Windows 95. There may be some differences for other versions of Windows.

1. If you have not already done so, use PKZIP to make a compressed, password-protected copy of the file you want to send by FTP (see "PKZIP – Compressing and Securing Files Before Sending").

2. If your computer is not hardwired to the Internet, establish your Internet connection.

3. Locate the command-line version of FTP on your PC. Go to the Start button, go to Find (or Search), then click "Files or Folders". A window for finding files will open. In the "Named:" box, type "ftp.exe" and click the Find Now button. You should see a result something like this:

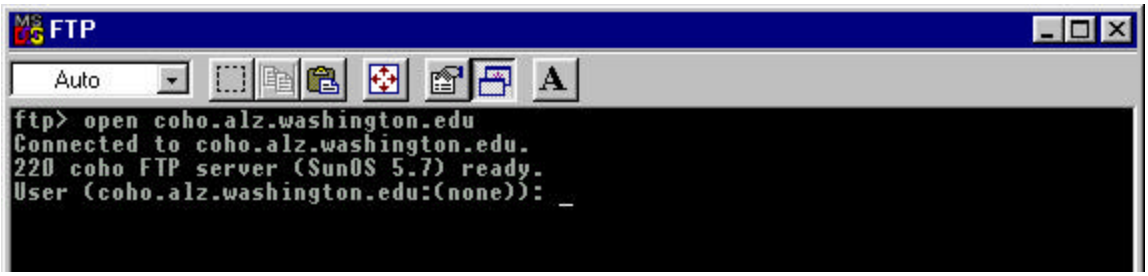


4. Under the Name column, an icon and the filename Ftp should appear. They should be highlighted in blue; if not, click the Ftp icon just once, to select it. Then click "File" on the toolbar at the top of the window, and click Open Containing Folder.

5. Move a copy of the compressed file you want to send NACC to the folder you opened in step 4. The file you want to send needs to be in the same folder as the ftp program.

6. Double-click the Ftp (or Ftp.exe) icon in the folder you opened in step 4. The FTP program will start in a new window, and you'll see the following prompt: ftp>

7. Next, request a connection across the Internet to NACC's computer, Coho. At the ftp> prompt, type "open coho.alz.washington.edu" and press Enter/Return. You should see something like this:



8. Enter your site's Coho username after the long prompt seen above, "User (coho.alz…:none)):", which will then be followed by a prompt for your Coho password. (You should have already obtained these from NACC according to previous instructions.)

9. If you make a mistake logging in to Coho and get an error message, you can use the command "user" to get another chance to log in. In this example, somebody logs in to the username ABC and enters the password "xyz" incorrectly, then gets another chance by using the command "user". Everything the person types is underlined.

    User (coho.alz.washington.edu: (none)): ABC
    331 Password required for ABC.
    Password: xhz
    530 Login incorrect.
    Login failed.
    ftp> user
    (username) ABC
    331 Password required for ABC.
    Password: xyz
    230 User ABC logged in.
    ftp>

10. After logging in to Coho, you can send files from your computer to your account on Coho. First issue the bin command, for binary mode, then use the send command:

    ftp> bin
    200 Type set to I.
    ftp> send <filename>

    Note that your file, "filename", should be in the same folder as your FTP program (see step 5 above).

11. When the FTP program has finished sending the file, it will say "Transfer complete".

12. Stop the FTP program by using the quit command: ftp> quit

13. Notify us by e-mail or phone that the transfer has been completed, and that all error-check alerts have been verified. Tell us the PKZIP password.

UNIX Users – How to FTP Your File to NACC

1. If you have not already done so, use PKZIP to make a compressed, password-protected copy of the file you want to send by FTP (see "PKZIP – Compressing and Securing Files Before Sending").

2. If your computer is not hardwired to the Internet, establish your Internet connection.

3. The following examples involve a UNIX computer named "Fred" and a user with the login name "abc" on Fred. The user will transfer a file from Fred to NACC's computer, "Coho". The user has an account on Coho with the username "idaho" and password "spud23". Everything the user types is underlined in the examples.

4. Activate the FTP program by typing "ftp" at the UNIX prompt, which should result in an ftp> prompt:

   fred% ftp
   ftp>

5. Next, request a connection across the Internet to NACC's computer, Coho. At the ftp> prompt, type "open coho.alz.washington.edu" and press Enter/Return. You should see something like this:

   ftp> open coho.alz.washington.edu
   Connected to coho.
   220 coho FTP server (SunOS 5.7) ready.
   Name (coho.alz.washington.edu:abc):

6. Enter your Coho username after the long prompt "Name (coho.alz…abc): " seen above, which will be followed by a prompt for your Coho password. (You should have already obtained these from NACC according to instructions on page 57.)

   Name (coho.alz.washington.edu:abc): idaho
   331 Password required for idaho.
   Password: spud23
   230 User idaho logged in.
   ftp>

7. If you make a mistake logging in to Coho and get an error message, you can use the command “user” to get another chance to log in. Here is an example of somebody logging in to Coho under the account “idaho” and entering the password “spud23” incorrectly, then getting another chance by using the command “user”.

    Name (coho.alz.washington.edu: abc): idaho
    331 Password required for idaho.
    Password: spud33
    530 Login incorrect.
    Login failed.
    ftp> user
    (username) idaho
    331 Password required for idaho.
    Password: spud23
    230 User idaho logged in.
    ftp>

8. After logging in to Coho, you can send your file, “filename”, from your computer to your account on Coho using the send command. First you must issue the bin command, for binary mode.

    ftp> bin
    200 Type set to I.
    ftp> send <filename>

9. When the FTP program has finished sending the file, it will say “Transfer complete”.

10. Stop the FTP program using the quit command: ftp> quit

11. Notify us by e-mail or phone that the transfer has been completed, and that all error-check alerts had been verified. Tell us the PKZIP password.

Mac Users – How to FTP Your File to NACC

Fetch and Anarchie are the two most popular versions of FTP for MacIntosh users. The following example uses Fetch:

1. There is no version of PKZIP for the Mac. Please e-mail or call NACC if you do not have access to a PC to use PKZIP to compress your file.

2. On a PC, use PKZIP to make a compressed, password-protected copy of the file you want to send by FTP (see "PKZIP – Compressing and Securing Files Before Sending").

3. If your Mac is not hardwired to the Internet, establish your Internet connection.

4. Start the Fetch program. It will open a "Fetch" box and an "Open Connection" box.

5. In the Open Connection box, enter the following underlined information (you should have already obtained your Coho username and password from NACC; as indicated previously):

   Host: coho.alz.washington.edu
   User ID: <your Coho username>
   Password: <your Coho password>

6. Then click OK. When the connection to Coho has been established, the files under your username on Coho will appear in the left side of the Fetch box.

7. In the Fetch box, click the Put File button.

8. A new box will open to the Fetch folder. Click the Desktop button, then select and open the disk and folder containing your file, "yourdatafile". Select and open your file.

9. A new box will open that says something like:

   Save file on coho.alz.washington.edu as:
   <yourdatafile>

10. Click OK and the file will be sent to Coho.

    NOTE: You will most likely be sending a binary file, rather than a plain text (ASCII) file. You'll need to change the format setting from "Format: Text" to "Format: Binary" in this step.

11. In the Fetch box, you will see how many bytes of data were transferred.

12. Click Close Connection in the Fetch box, and then quit the Fetch program.

13. Notify us by e-mail or phone that the transfer has been completed, and that all error-check alerts have been verified. Tell us the PKZIP password you used.

Web Data Management

NACC Neuropathology Web Data Management

A. Introduction

The NACC Neuropathology Web Data Management System was designed to allow ADCs/ADRCs to access the NACC Neuropathology Data Set through the NACC website. All autopsied IDs from the last Minimum Data Set (MDS) Data Call are included in your Center's Neuropathology Data Set.

New MDS IDs may be added, but they must be included in the next MDS Data Call and indicated as autopsied. **Newly-entered MDS IDs which are not submitted in the next MDS Data Call will be deleted from the Neuropathology Web Data Management System.**

IDs entered in the MDS 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 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@alz.washington.edu or call us at 206-543-8637.

3. Future Updates

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 updates, 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 updates.

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 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. Initially, all MDS IDs which were autopsied have a form (record) in this data file, and all data elements in the form are blank except for the MDS ID.

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

Instructions for accessing the Neuropathology Web Data Management System are provided in section B.1, *Accessing the System*. To enter data for an existing MDS ID, see section C.3, *"Edit" Function*. To enter data for newly-autopsied IDs not currently in the MDS, first add the 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 MDS IDs:

a. Choose the "Edit" function.
b. Scroll down to find the desired MDS ID in the list displayed.
c. Choose the 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 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 MDS IDs:

a. Choose the "Add" function.

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

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

B. System Operation

1. Accessing the System

The Neuropathology Web Data Management System is accessed through the NACC website (www.alz.washington.edu). Perform the following steps to access the data for your Center:

1) Choose “Member Login” and enter your username and password.

2) Choose “Data and Studies”.

3) Read and accept the Disclaimer and Confidentiality Agreement.

4) Choose “Neuropathology Data Management”.

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

Figure 1.

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 Figure 2). Clicking on one of these buttons will display the corresponding web page:

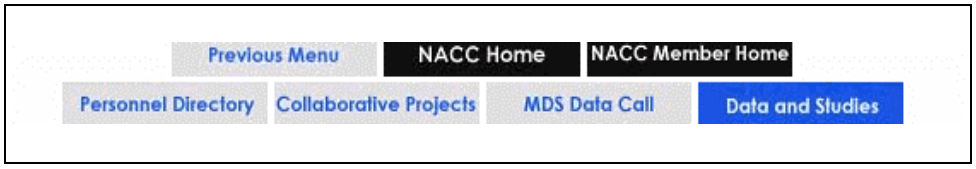


Figure 2.

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 information on the MDS Data Call.
Data and Studies	Displays the Data and Studies page.

C. Data Management Functions

Log-in to the Neuropathology Data Management system for your Center (see previous instructions in section B.1) and the *Neuropathology Data Management* page will be displayed (Figure 3). Click on a function name to display the corresponding web page.

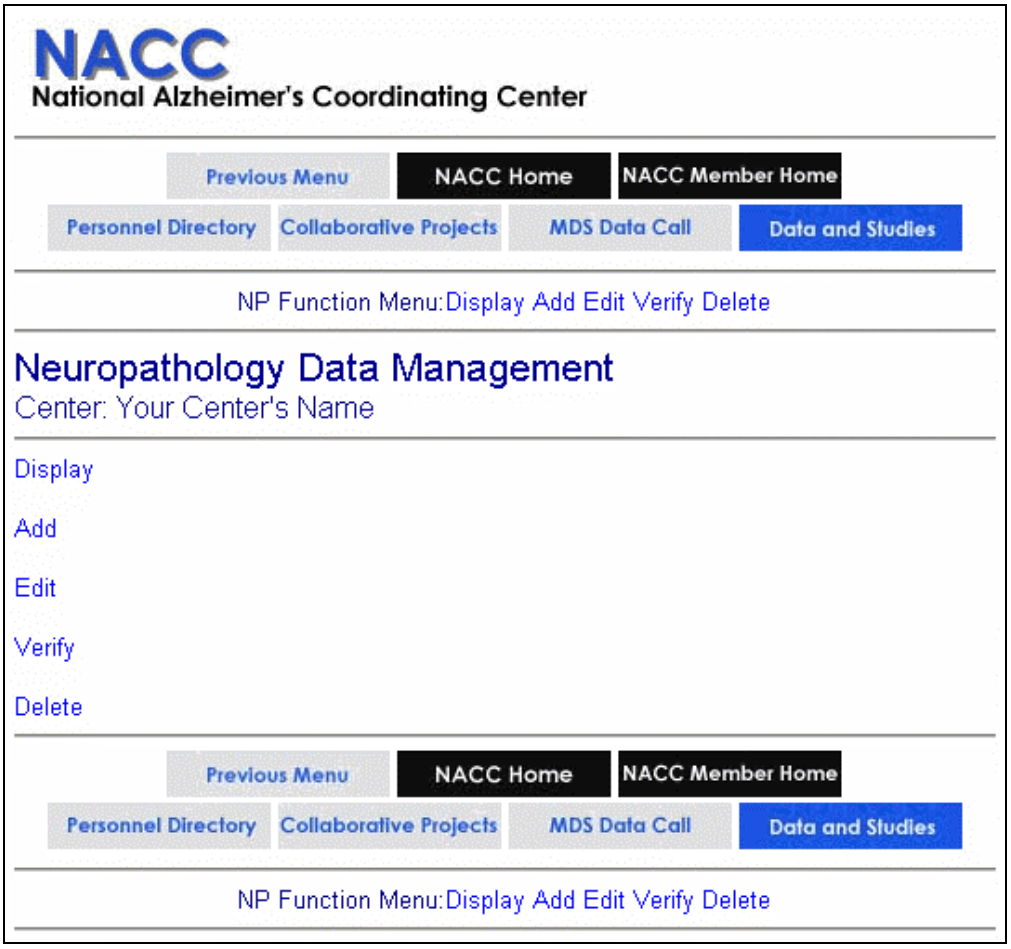


Figure 3.

1. "Display" Function

This function allows the display of neuropathology data for a selected MDS ID. Selecting this function will open the *NACC Neuropathology Display Data (Select ID)* page (Figure 4).

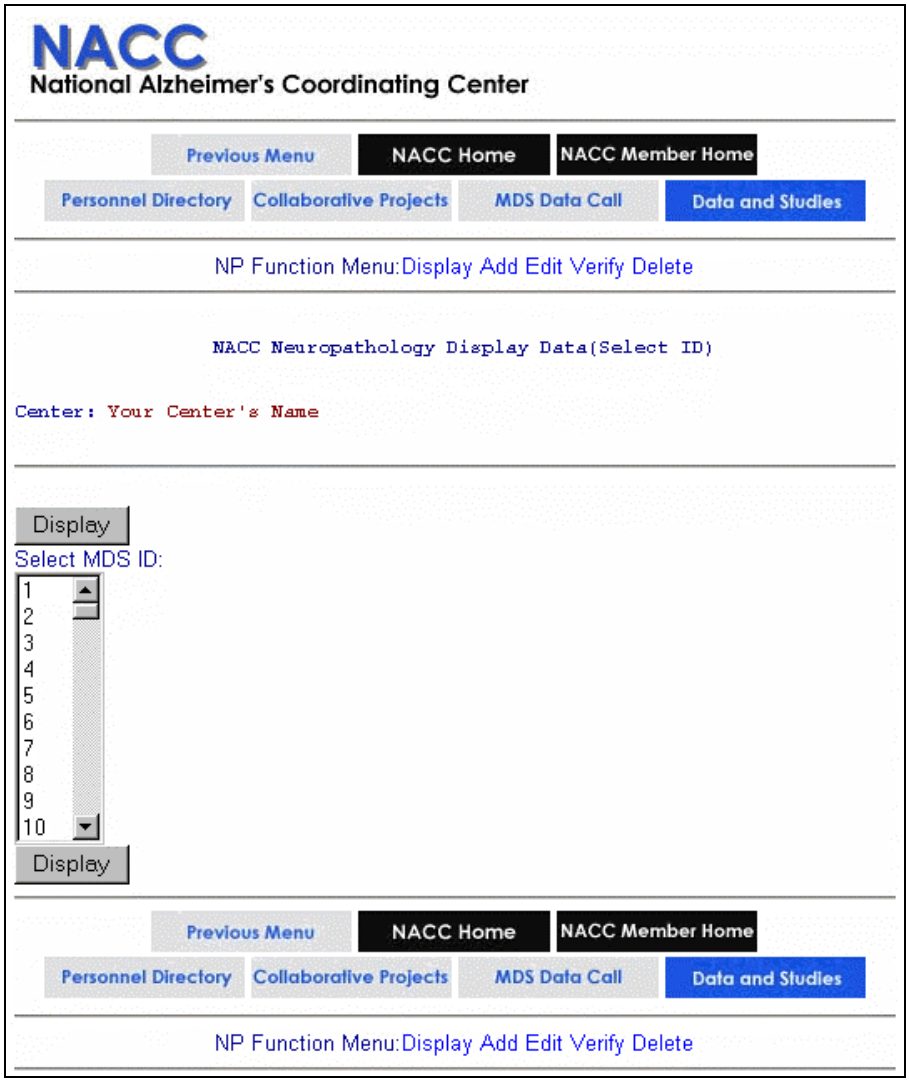


Figure 4.

The MDS IDs displayed are those submitted by your Center during the last MDS Data Call and any new MDS IDs added through the Neuropathology Web Data Management System since the last Data Call. The IDs are usually in sequential order, but newly-added MDS IDs may be displayed at the end of the list. IDs are shown exactly as entered into the MDS, except leading blanks are ignored.

To display data for an MDS ID:

- Scroll down to find the desired MDS ID.
- Choose the MDS ID.
- Click on the "Display" button.

The *NACC Neuropathology Display Data (Display)* page will show the current data for the MDS ID selected (Figure 5).

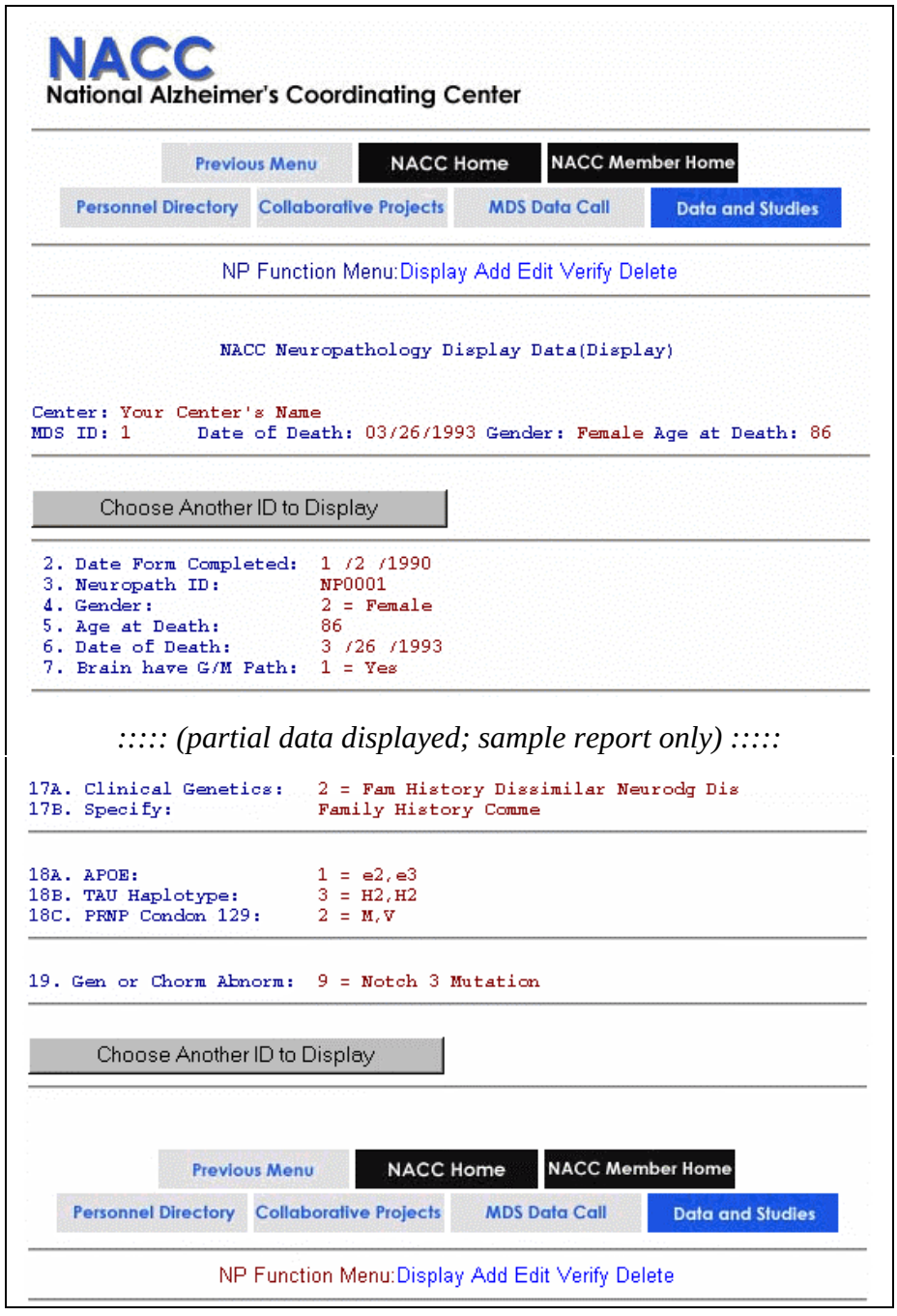


Figure 5.

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 MDS IDs to the Neuropathology Web Data Management System. New MDS IDs entered must be included in the next NACC Data Call, and have the data element "Autopsy=Yes". **If a newly-added MDS ID is not submitted in the next MDS Data Call, it will be deleted from the Neuropathology Web Data Management System.**

Click on the "Add" function to open the *NACC Neuropathology Add ID (Request ID)* page (Figure 6).

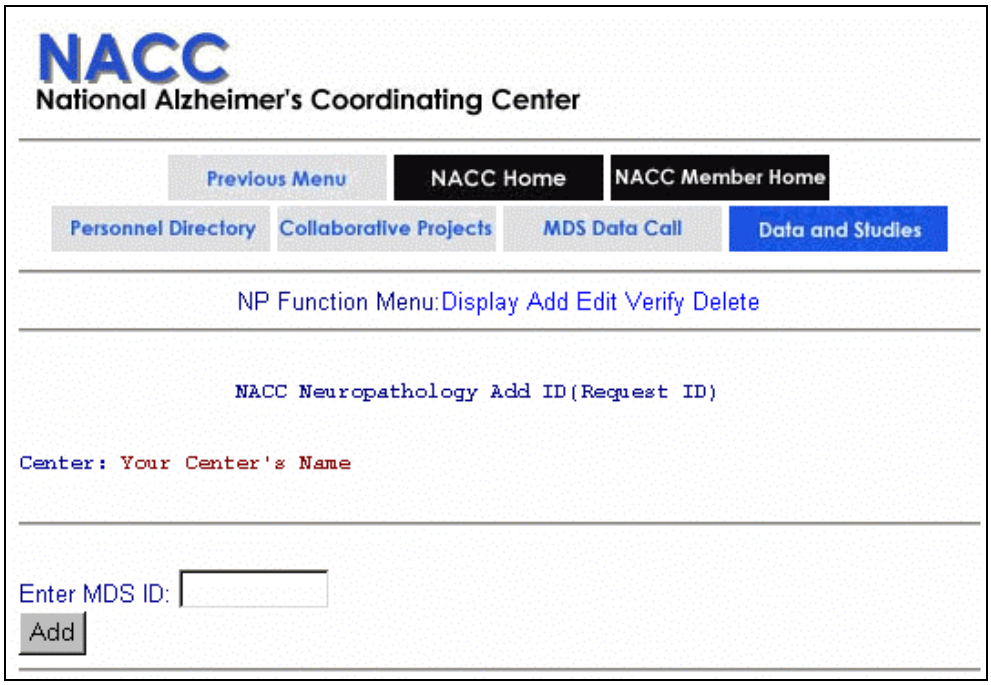


Figure 6.

To add a new MDS ID:

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

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

a. ID Added

If the MDS ID was successfully added, the *NACC Neuropathology Add ID (Request ID)* page will be displayed with the message "ID Added!" (Figure 7). You may continue to add additional MDS IDs or click on the "Previous Menu" button to return to your Center's *Neuropathology Data Management* page.

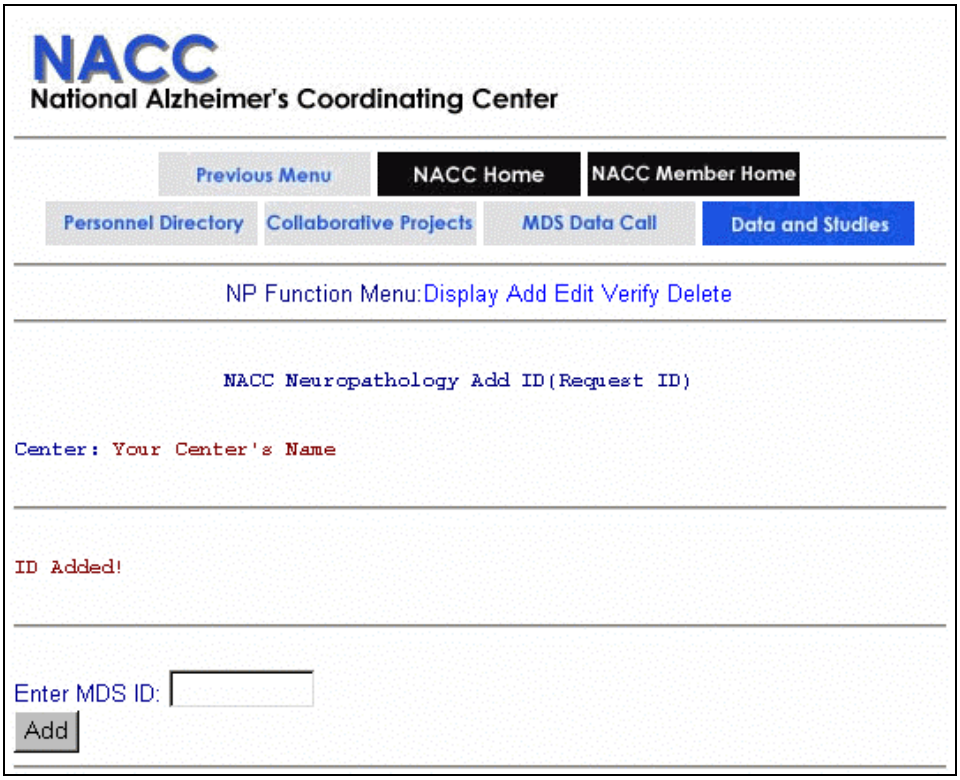


Figure 7.

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 (Figure 8). Duplicate MDS IDs are not allowed. When the system searches for duplicates, leading zeros and blanks are ignored.

Data for an existing MDS ID must be entered with the "Edit" function (see section C.3).

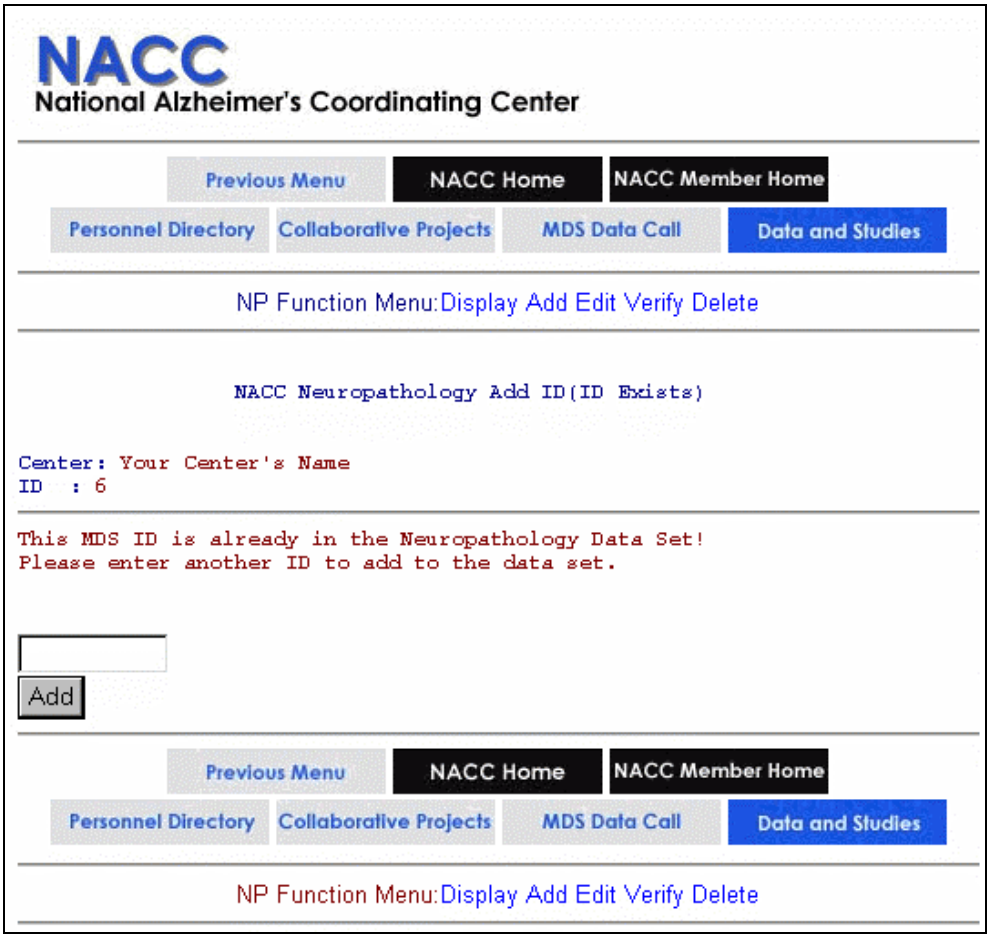


Figure 8.

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

c. ID Not in MDS

If you type an ID that is not in the MDS, the *NACC Neuropathology Add ID (ID Not in MDS)* page will be displayed (Figure 9).

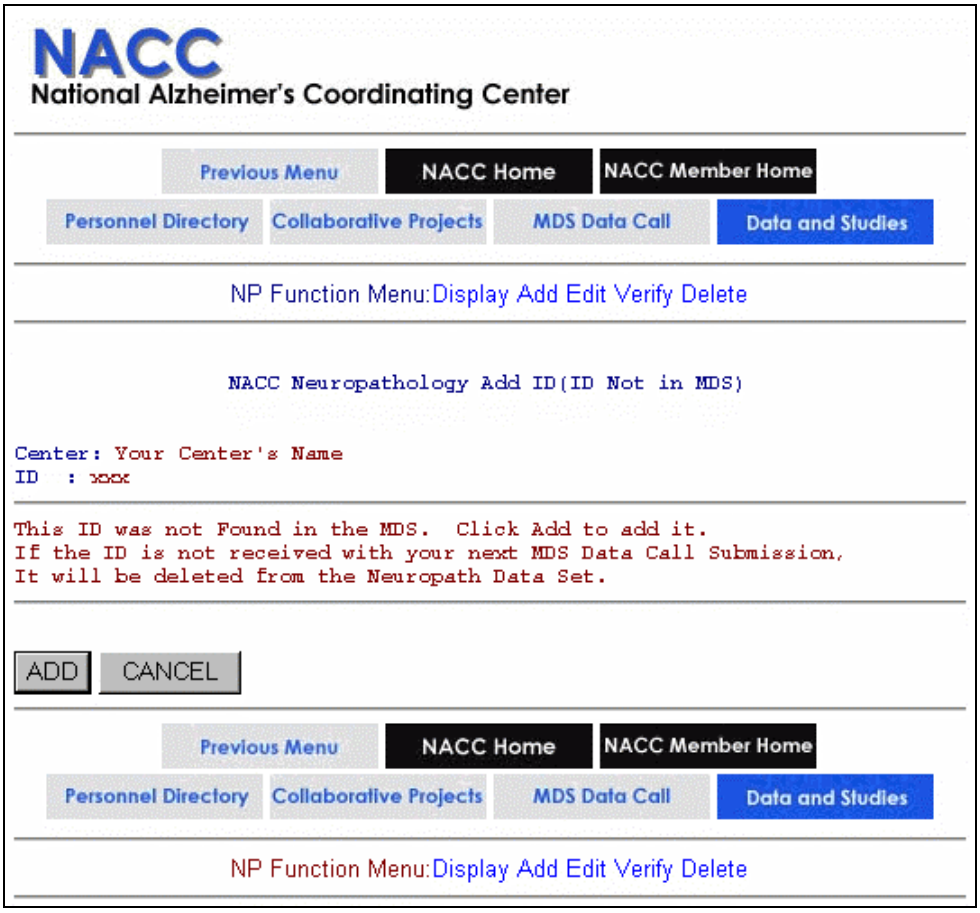


Figure 9.

Click the "Add" button and the MDS ID will be added to the Neuropathology Web Data Management System, even though it is not in the MDS. **If the MDS ID is not submitted during the next MDS Data Call, it will be deleted from the Neuropathology Web Data Management System.**

You may continue to add additional MDS IDs or click on the "Previous Menu" button to return to your Center's *Neuropathology Data Management* page. Click the "Cancel" button to return to the *NACC Neuropathology Add (Request ID)* page without adding the ID.

d. System Error

If the MDS ID could not be added, an error message will be displayed (Figure 10). This situation usually occurs when someone else at your Center is trying to update the file at the same time. Try to enter the MDS ID again. If the problem persists, please contact NACC.

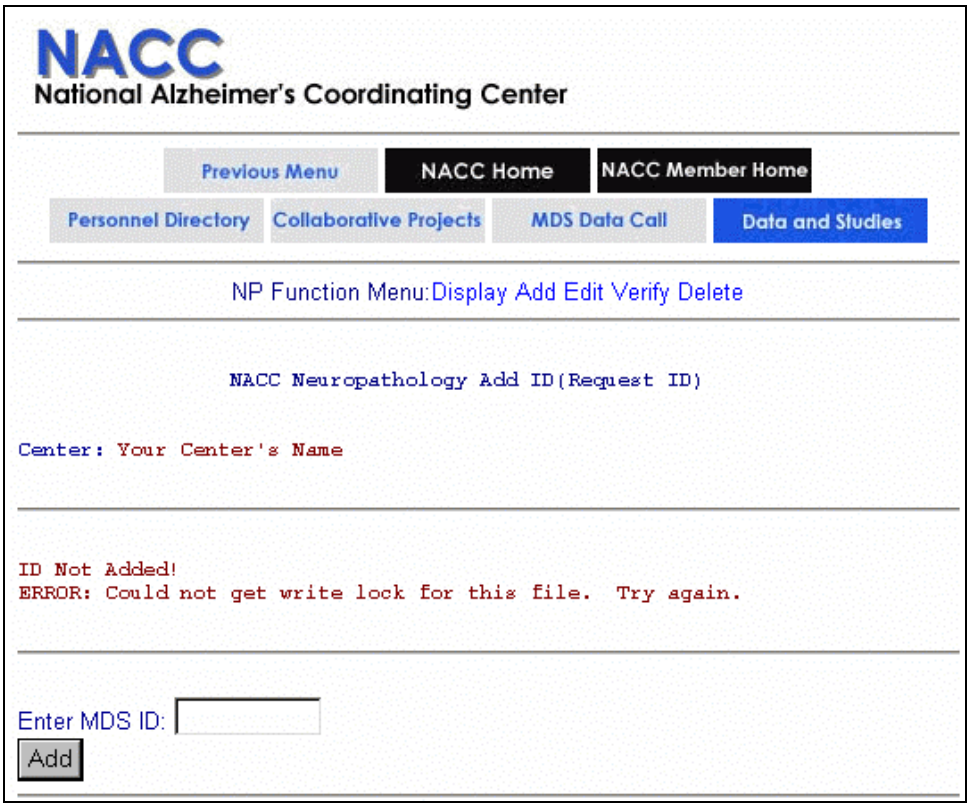


Figure 10.

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

3. "Edit" Function

This function allows the entering or editing of neuropathology data for an MDS ID. Choose the "Edit" function to open the *NACC Neuropathology Edit (Select ID)* page (Figure 11).

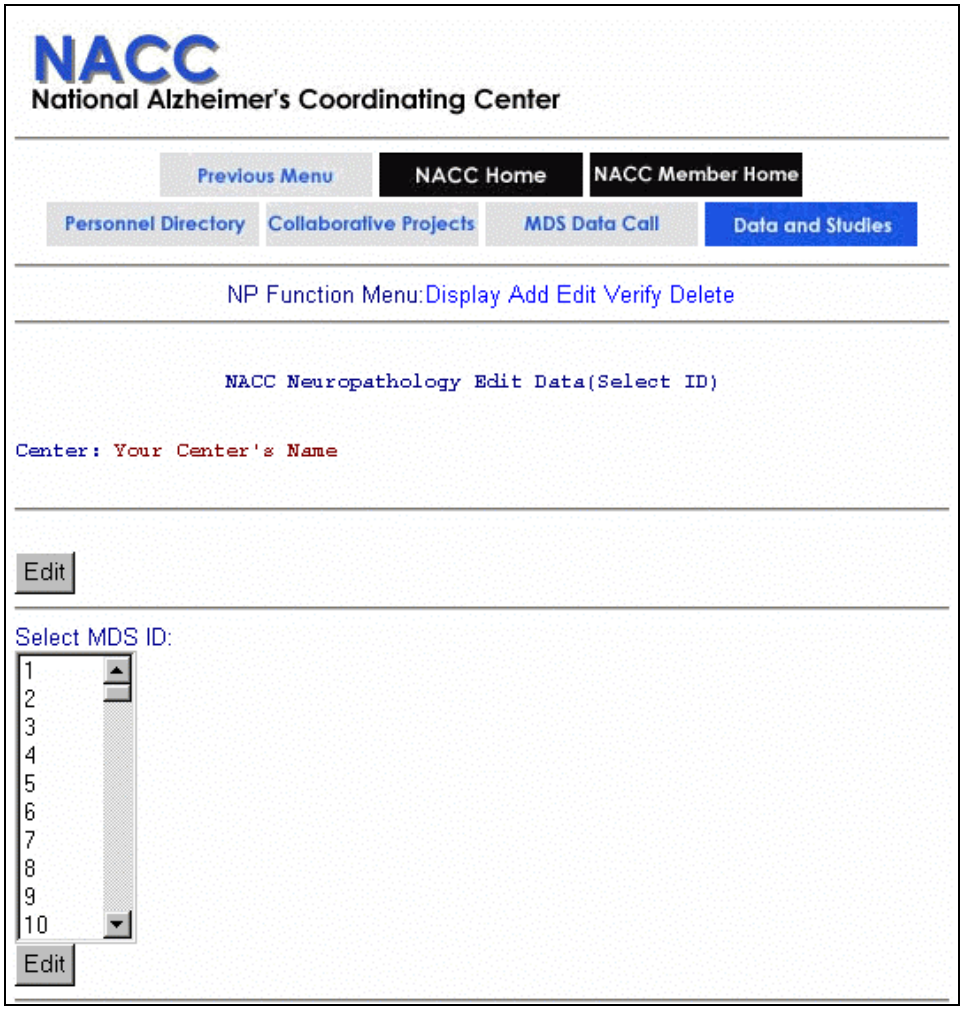


Figure 11.

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

To edit or enter data:

- Scroll down to find the desired MDS ID.
- Choose the MDS ID.
- Click on the "Edit" button.

The *NACC Neuropathology Edit Data (Edit ID)* page will be displayed (Figure 12).

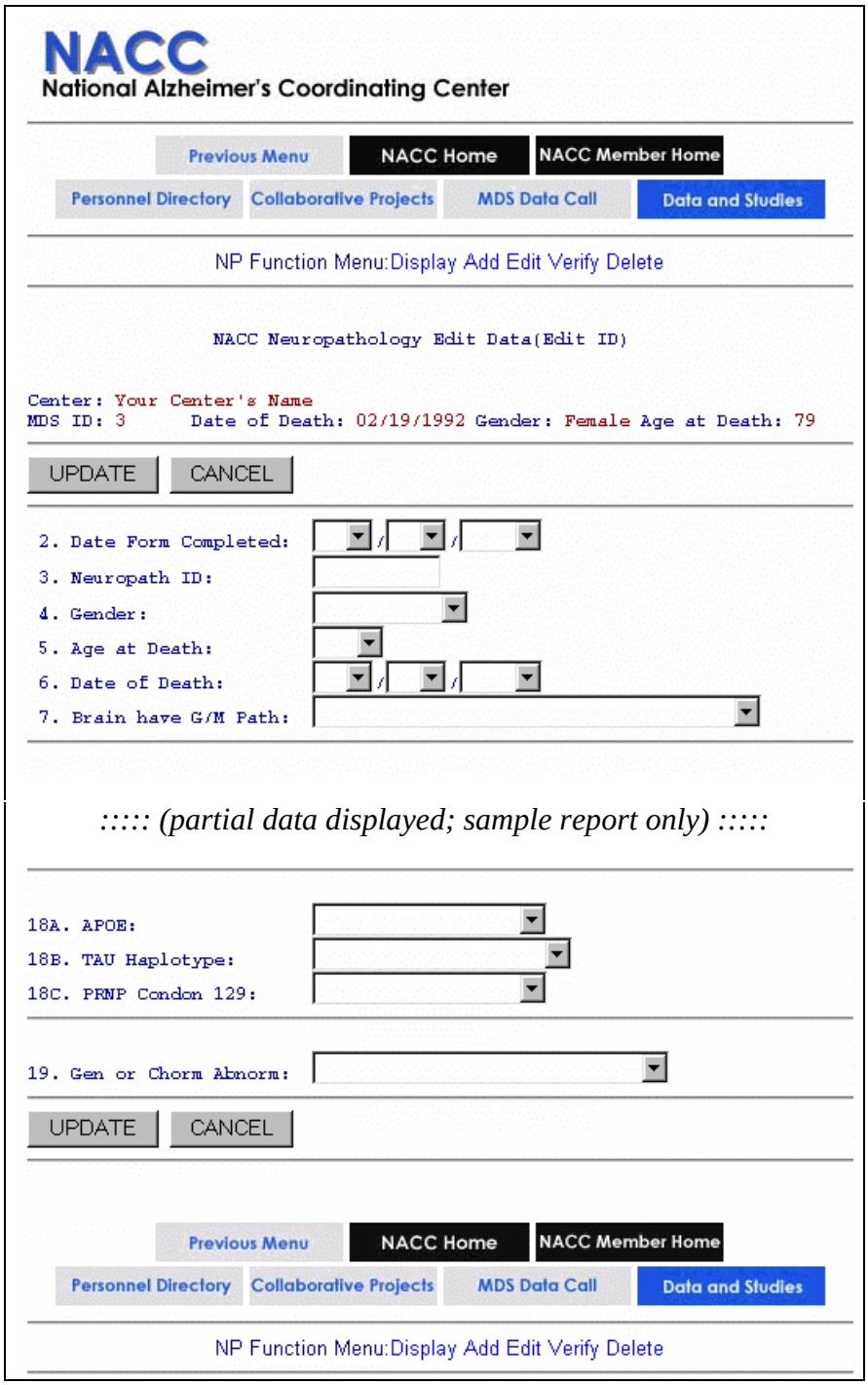


Figure 12.

Values initially displayed are the values currently in the database for this 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. 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 number of data elements with two-digit values).

Once all data elements have been entered for an MDS ID, click on the "Update" button to execute the error check program. Data elements corresponding to 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 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 MDS ID.

a. ID Updated

If the data elements entered for the MDS ID have no errors, the *NACC Neuropathology Edit Data (Select ID)* page will be displayed with the message "ID Updated!" (Figure 13).

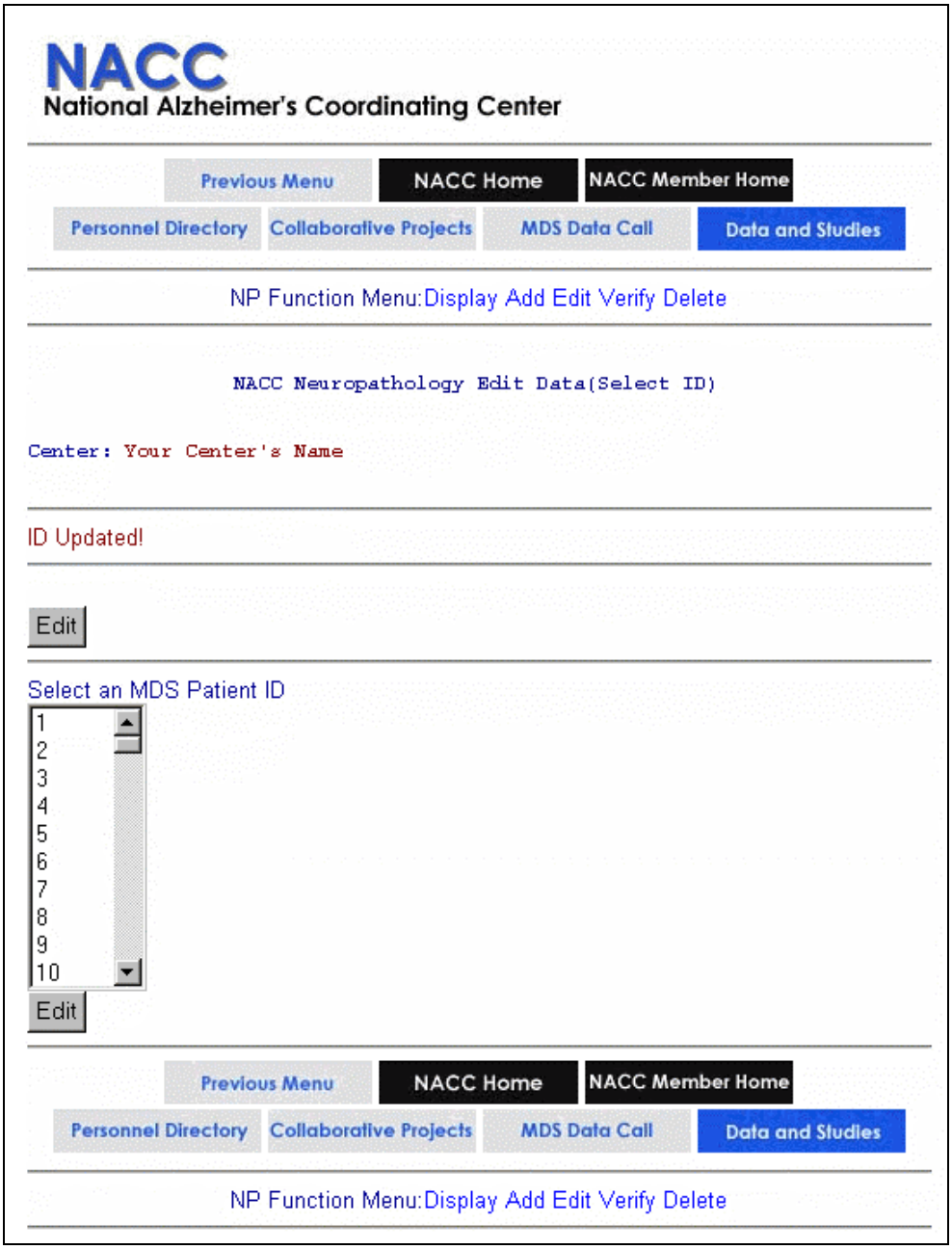


Figure 13.

You may continue to edit/enter additional 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 MDS ID have errors, the *NACC Neuropathology Edit Data (ID has Errors)* page will display a list describing all errors (Figure 14).

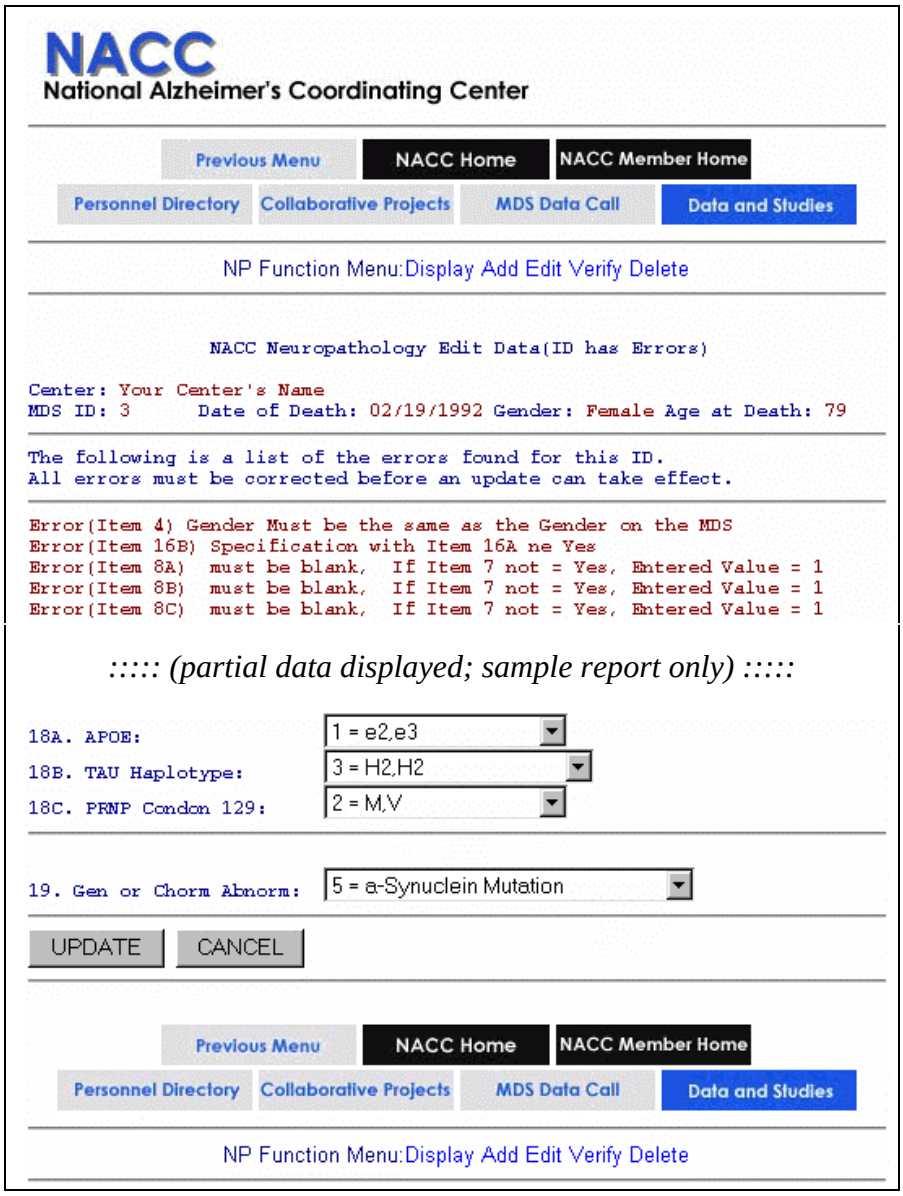


Figure 14.

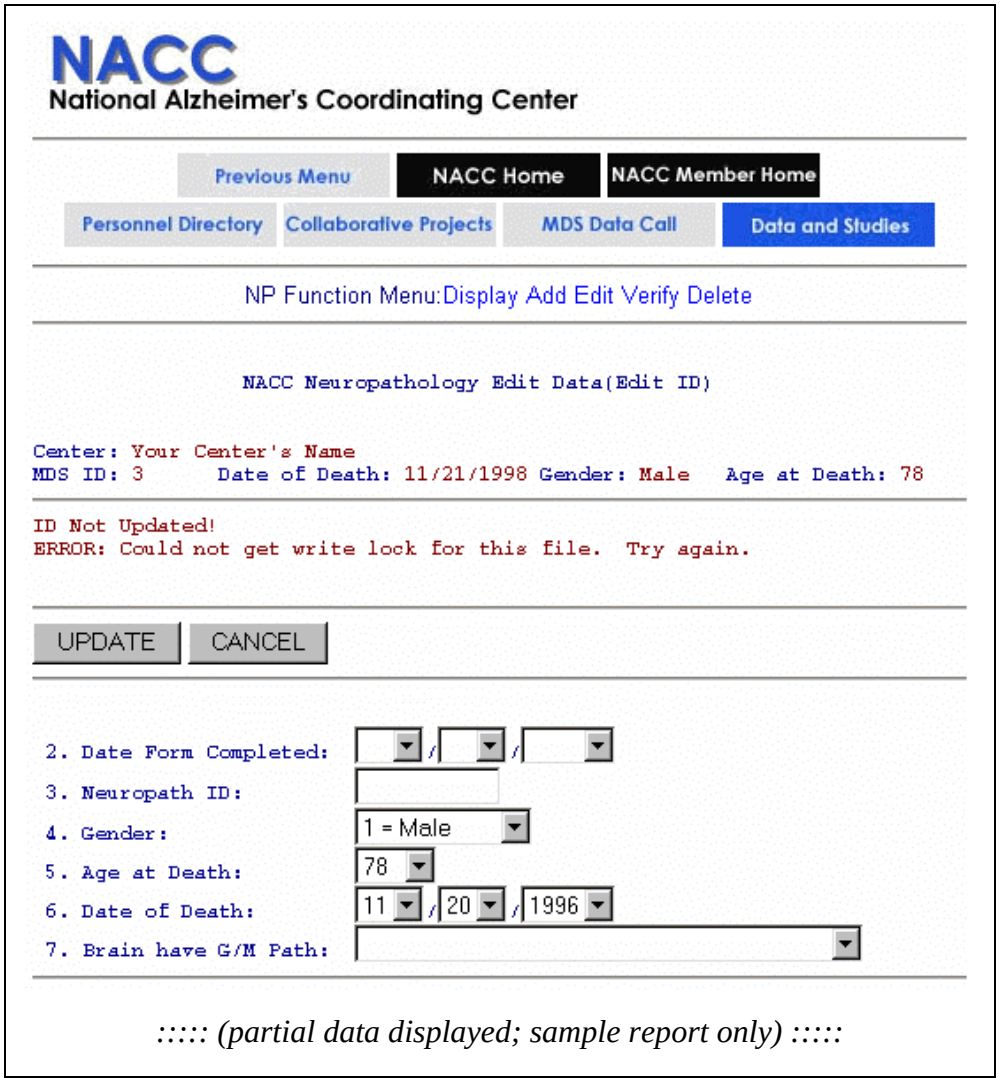
To correct the errors:

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

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

c. System Error

If the data elements entered for the MDS ID could not be updated because of a system error, the *NACC Neuropathology Edit Data (Edit ID)* page will display an error message (Figure 15). This situation usually occurs when someone else at your Center is trying to update the file at the same time. Try to update the MDS ID again. If the problem persists, please contact NACC.



::::: *(partial data displayed; sample report only)* :::::

Figure 15.

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

4. "Verify" Function

After the data elements for an MDS ID have been entered using the "Edit" function, the "Verify" function should be used to check 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 update 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 (Figure 16).

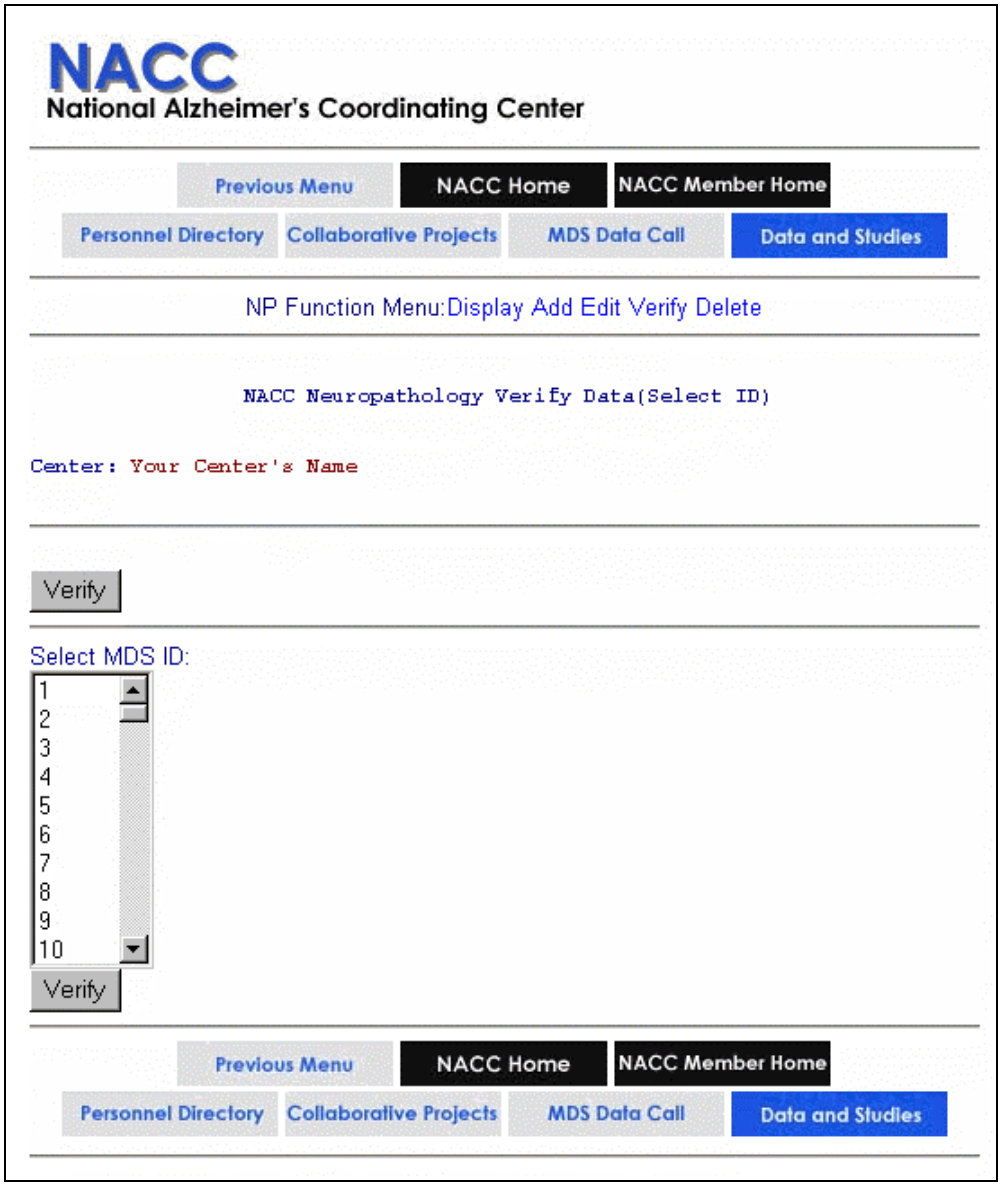


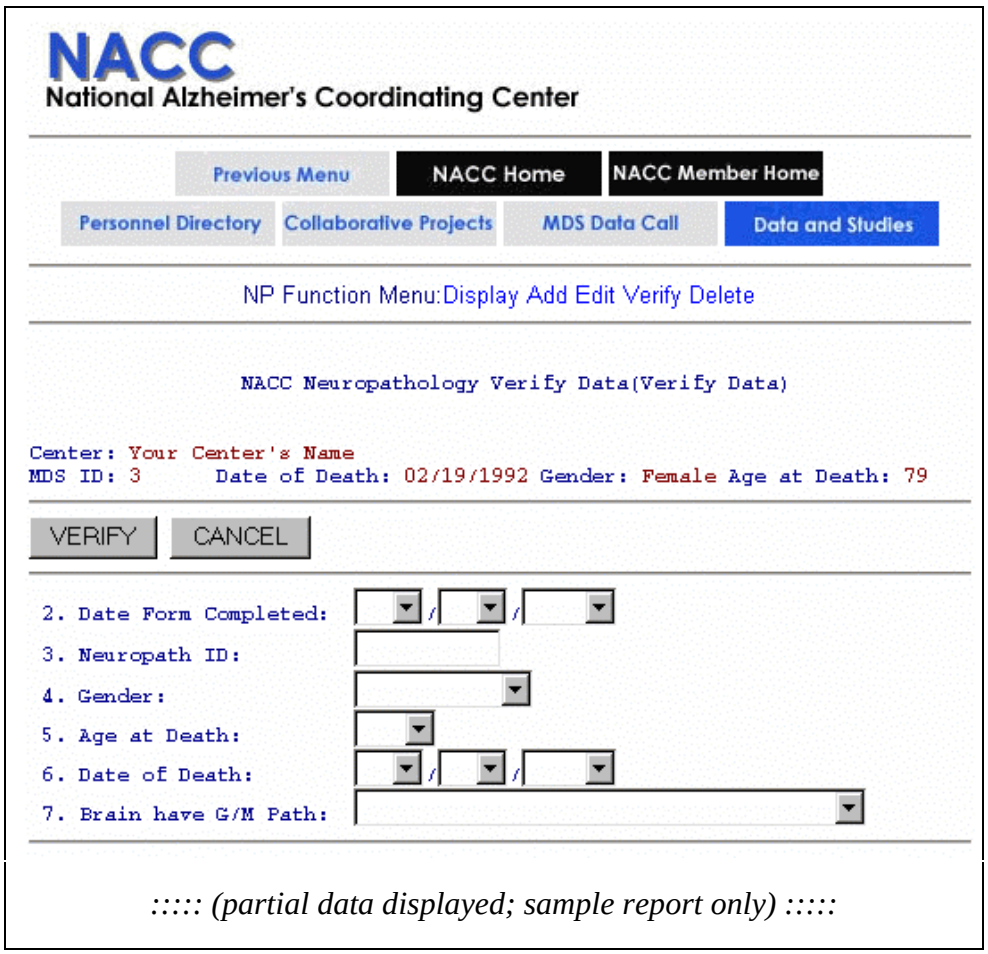
Figure 16.

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

To verify data:

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

The *NACC Neuropathology Verify Data (Verify Data)* page will be displayed (Figure 17).



::::: (partial data displayed; sample report only) :::::

Figure 17.

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 number of data elements with two-digit values).

Once all data elements have been entered for an MDS ID, click on the "Verify" button to execute the error check program. Data elements corresponding to 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 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 MDS ID.

a. ID Verified

If data elements for the 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!" (Figure 18). When the 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.

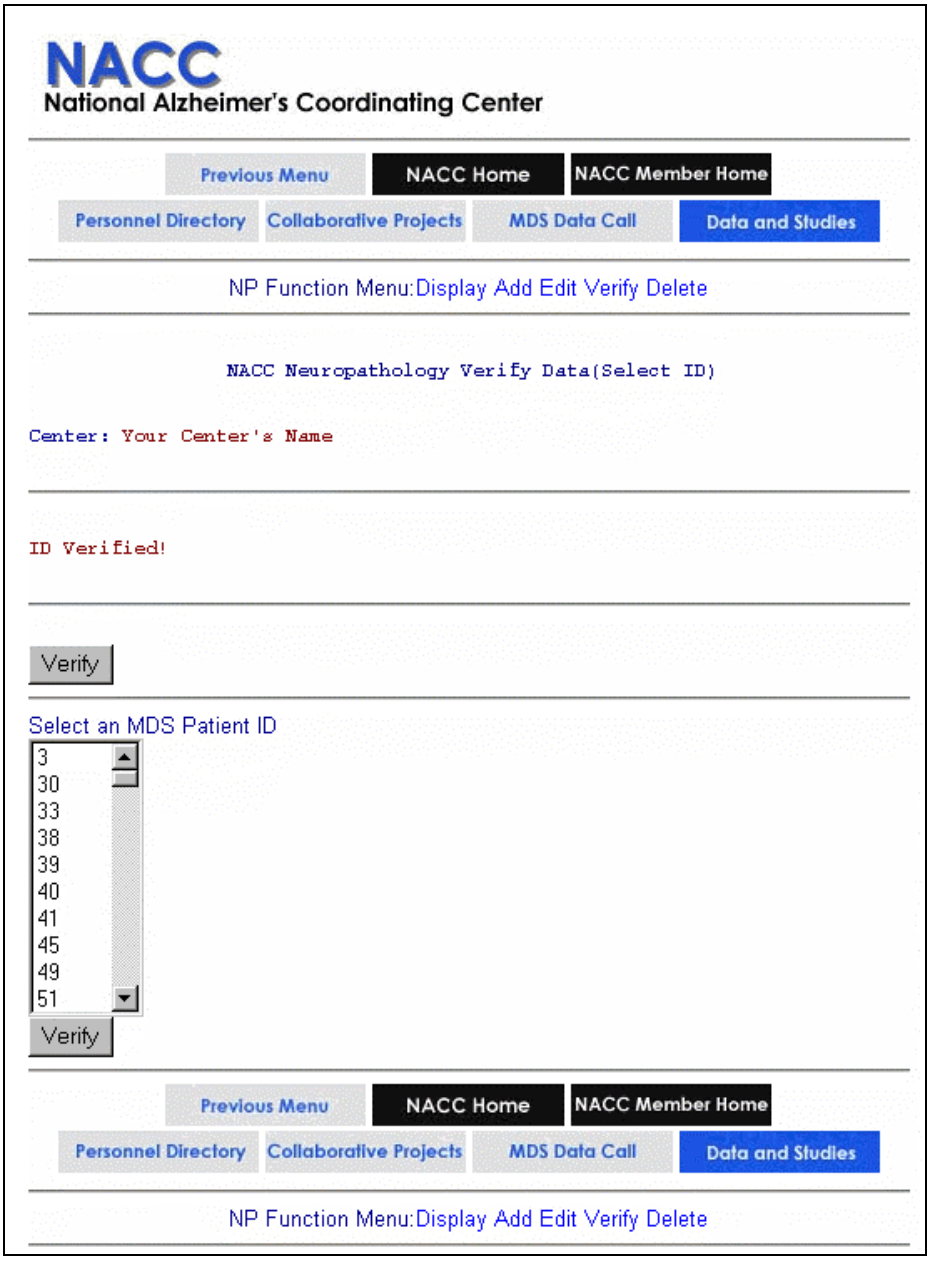


Figure 18.

b. Data Entry Error

If data elements entered for the 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 (Figure 19).

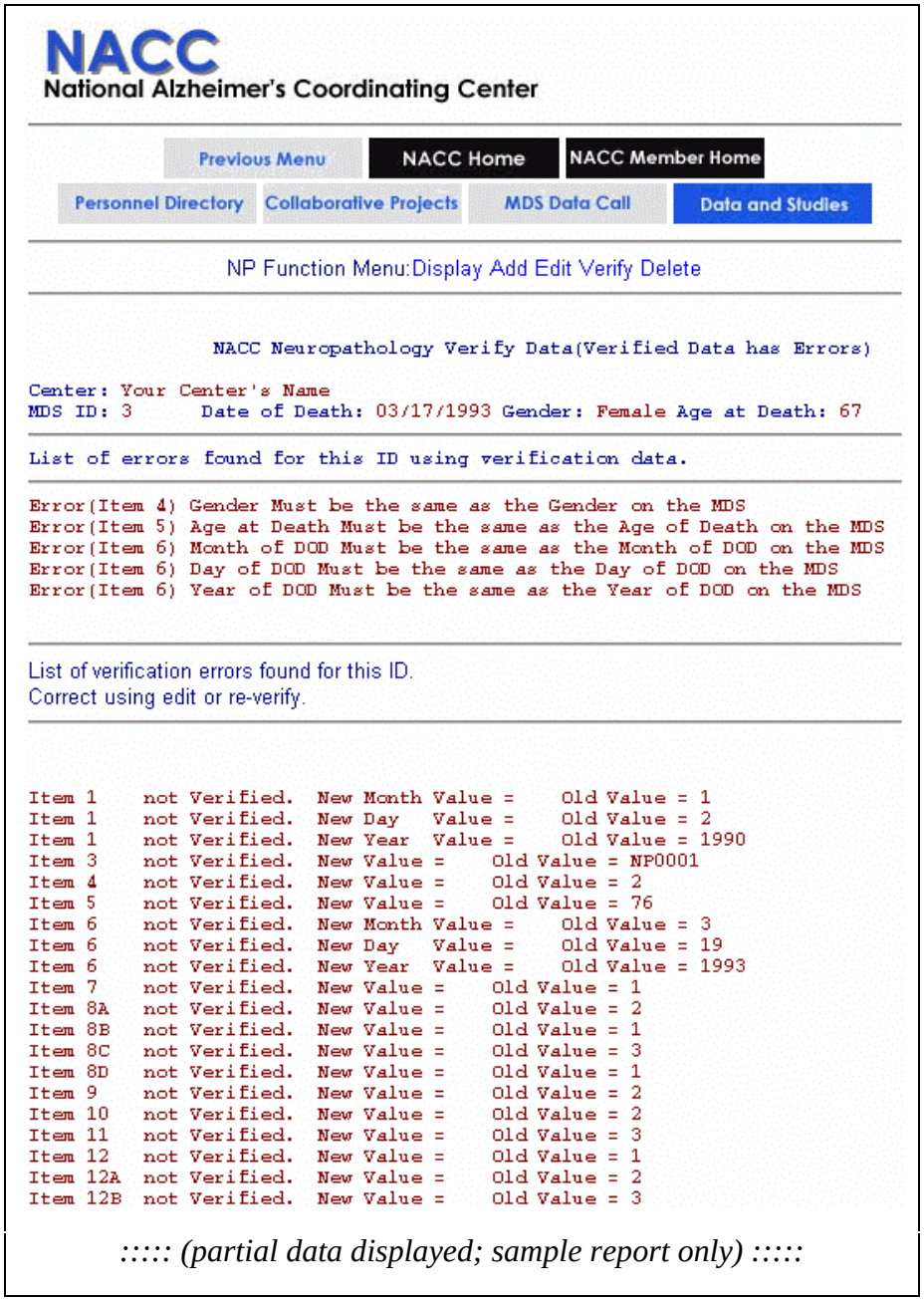


Figure 19.

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 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 MDS ID.
   - Change the data element values as appropriate and click on the "Update" 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 MDS ID.

c. System Error

If the data elements for the MDS ID could not be verified because of a system error, the *NACC Neuropathology Verify Data (Verify Data)* page will display an error message (Figure 20). This situation usually occurs when someone else at your Center is trying to update the file at the same time. Try to verify the data again. If the problem persists, please contact NACC.

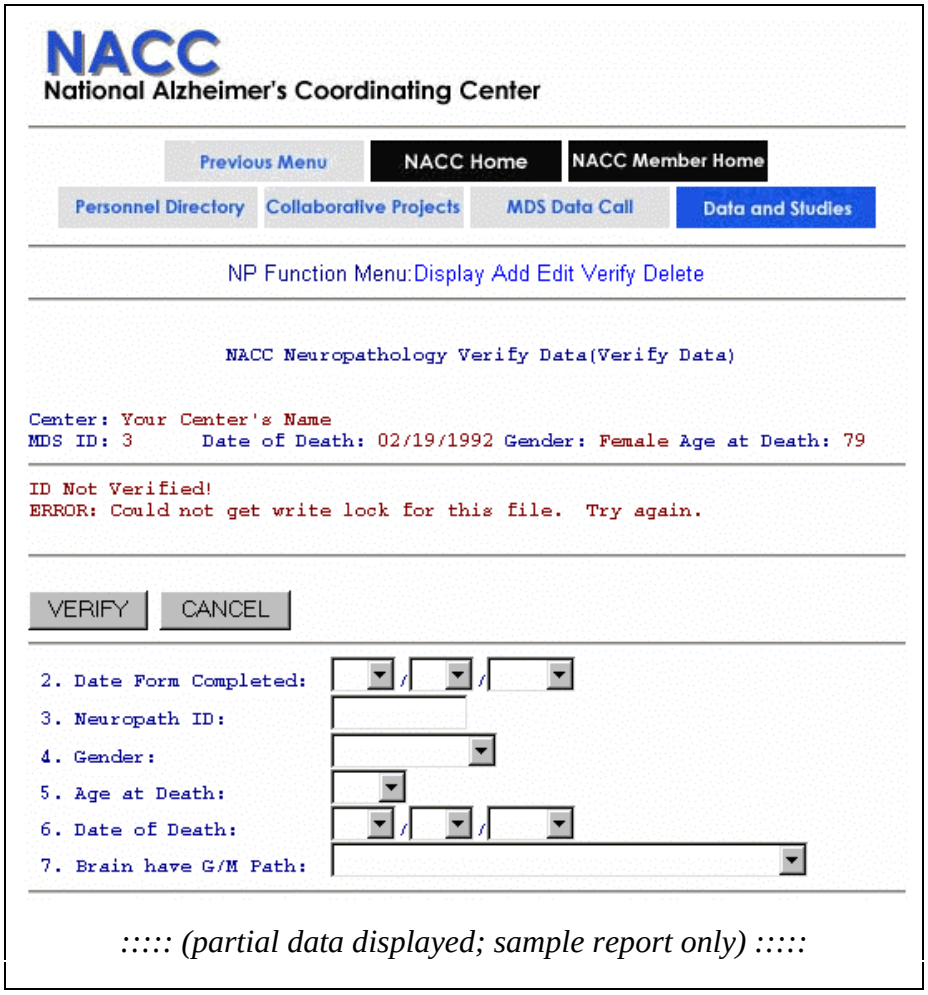


Figure 20.

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

5. "Delete" Function

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

IDs identified in the 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 an MDS ID, click on "Delete" in the function menu to open the *Neuropathology Delete ID (Request ID)* page (Figure 21).

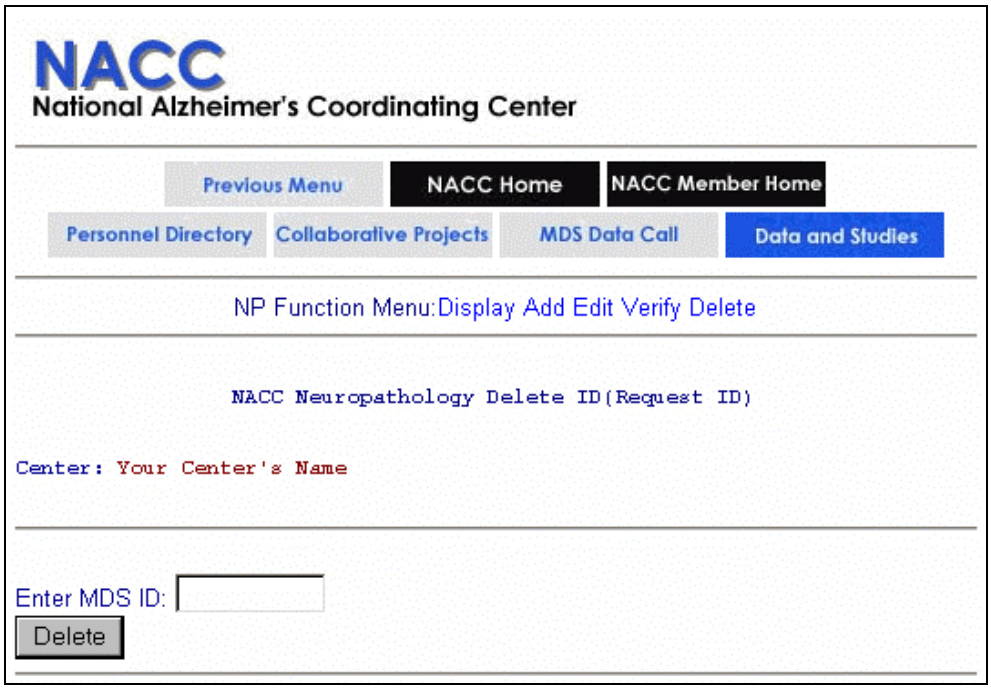


Figure 21.

Confirm that deletion is allowed:

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

a. ID Found

If the MDS ID exists in the neuropathology data set and can be deleted, the *NACC Neuropathology Delete ID (ID Found)* page will be displayed (Figure 22).

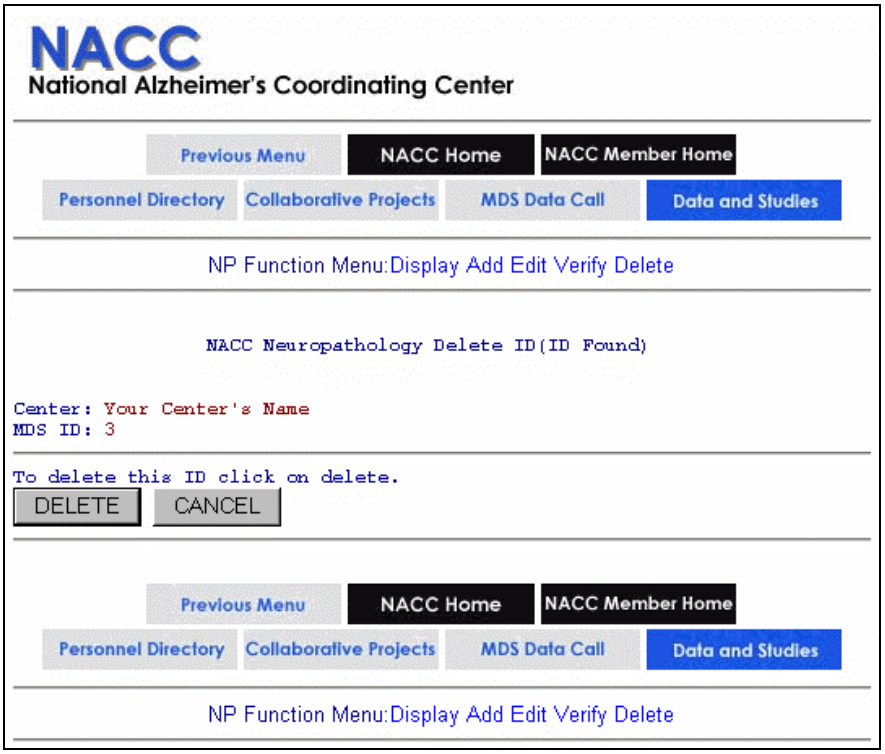


Figure 22.

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

If the MDS ID was successfully deleted, the *NACC Neuropathology Delete ID (Request ID)* page will be displayed with the message "ID Deleted!" (Figure 23). You may continue to delete additional MDS IDs or click on the "Previous Menu" button in the web page header to return to your Center's Neuropathology Data Management page.

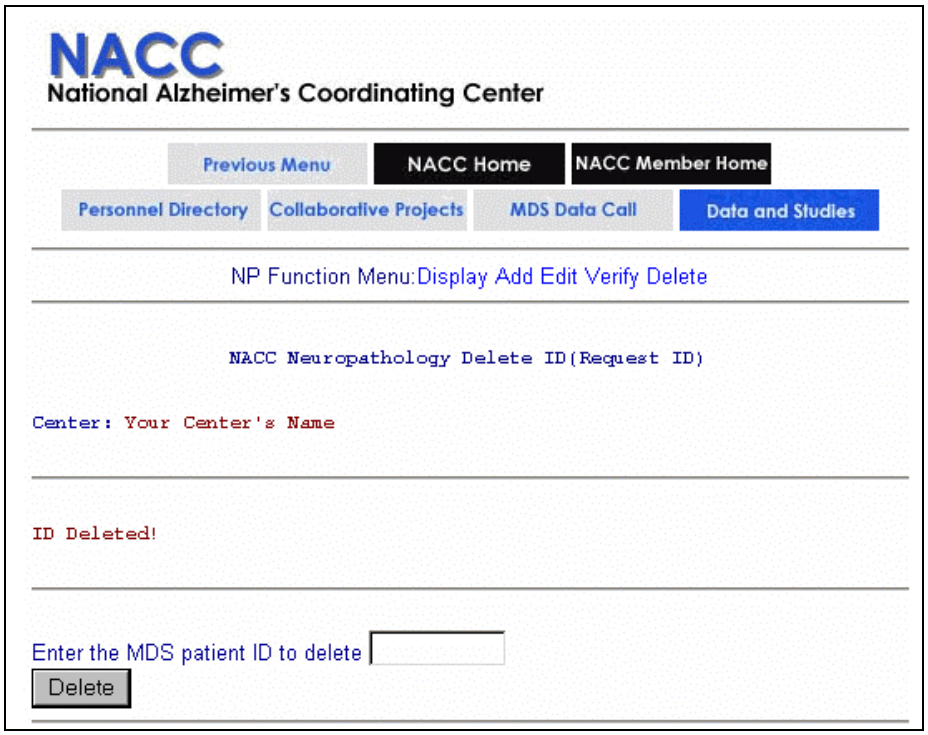


Figure 23.

b. System Error

If the MDS ID could not be deleted, an error message will be displayed (Figure 24). This situation usually occurs when someone else at your Center is trying to update the file at the same time. Try to delete the MDS ID again. If the problem persists, please contact NACC.

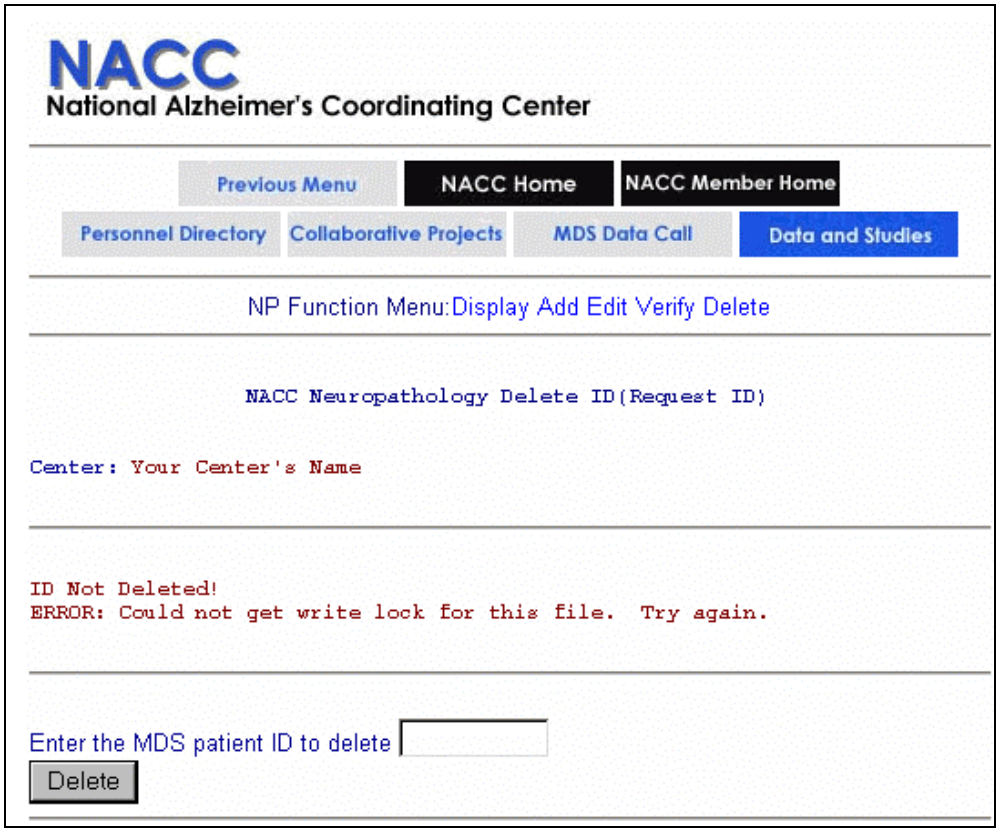


Figure 24.

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

c. ID Cannot be Located

If the 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 (Figure 25). Check your MDS ID carefully using the "Display" function.

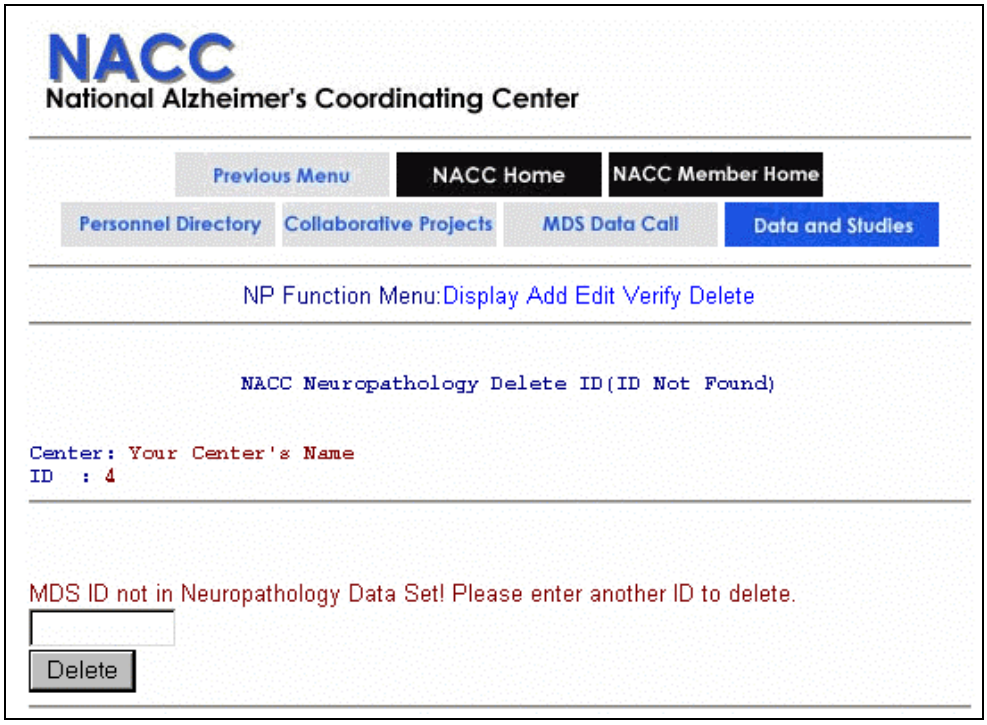


Figure 25.

You may continue to delete additional 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 MDS with an autopsy value of 'yes', the *NACC Neuropathology Delete ID (ID in MDS)* page is displayed (Figure 26). Check the ID carefully using the "Display" function.

IDs that are in the MDS and have been autopsied cannot be deleted. To delete or change these IDs, contact your Center's data manager prior to the next MDS Data Call.

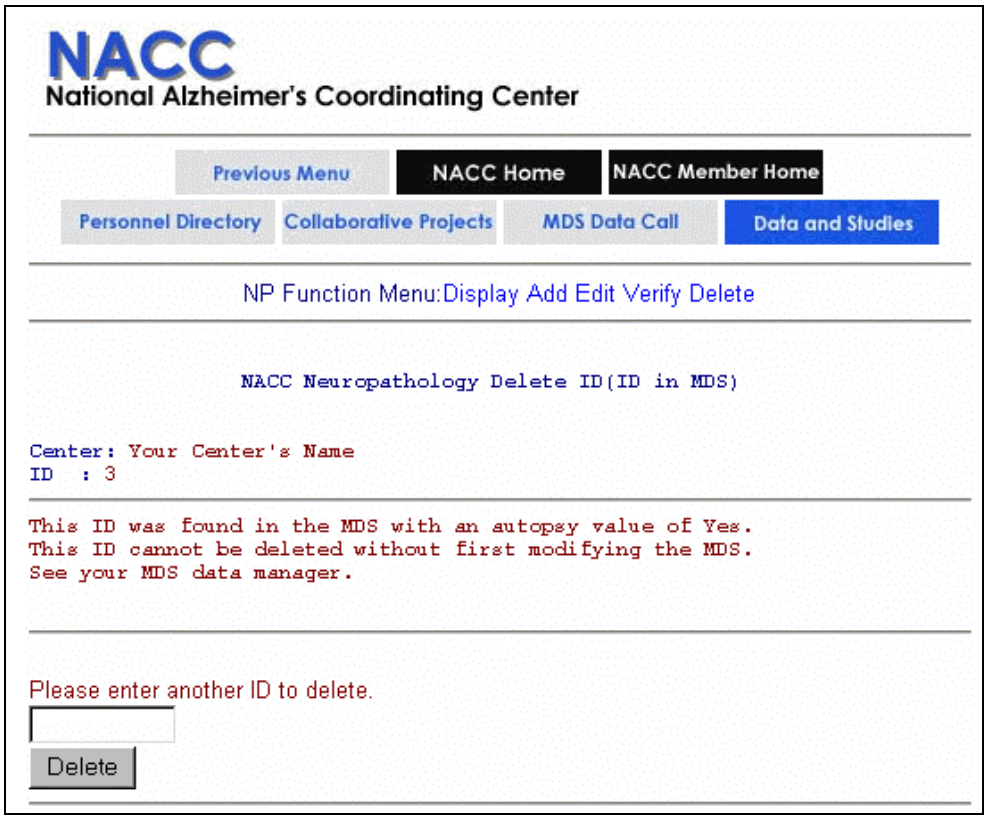


Figure 26.

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

Data Managers Directory

DIRECTORY
List of NACC Personnel

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U-Washington	Mary Jacka jacka@u.washington.edu 206-543-8641	Erin Pfeiffer pfeiffer@u.washington.edu 206-543-6724
Wash-U St.Louis	Betsy Grant betsy@wubios.wustl.edu 314-362-3612	Jack Baty jack@wubios.wustl.edu 314-362-3683

Neuropathology Data Form

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National Alzheimer's Coordinating Center
Department of Epidemiology, School of Public Health and Community Medicine, University of Washington

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Seattle, WA 98105-6099
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e-mail: naccmail@chinook.alz.washington.edu
website: www.alz.washington.edu

NEUROPATHOLOGY DATA FORM

ADRC: _____ **Completed by:** _____

1. MDS 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

☐ 9 No neuropathology diagnosis available

SKIP: If 2 or 9, go to #17A, "Clinical genetics and family history"

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

SKIP: If 2, 3 or 9, go to #13. If ischemic, hemorrhagic or vascular lesions are present, answer questions 12A through 12L.

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 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

12I. 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

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

(*mark one box*)

☐ 1 None

☐ 2 Mild

☐ 3 Moderate

☐ 4 Severe

☐ 5 Not assessed

☐ 9 Missing/unknown

12K. Is amyloid angiopathy present?

(*mark one box)*

☐ 1 None

☐ 2 Mild

☐ 3 Moderate

☐ 4 Severe

☐ 5 Not assessed

☐ 9 Missing/unknown

CONTINUE with 12L on the next page.

12L. Is another type of angiopathy (e.g., CADASIL or arteritis) 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, then specify below (one disorder per line):

1 _____

2 _____

3 _____

17A. Clinical genetics and family history information relevant to neuropathologic diagnosis. Choose one of the following categories that most accurately describes the genetic/family information available:

(mark one box)

☐ 1 Family history of similar neurodegenerative disorder (but no known mutation or genetic locus)

☐ 2 Family history of other (dissimilar) neurodegenerative disorder

☐ 3 No family history of similar or dissimilar neurodegenerative disorder

☐ 9 Family history unknown/not available/missing

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

17B. If 17A is 2, then specify: _____

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