



Department of Epidemiology, School of Public Health and Community Medicine, University of Washington

4311 11th Avenue NE #300
Seattle, WA 98105
phone: (206) 543-8637; fax: (206) 616-5927
e-mail: naccmail@u.washington.edu
website: <https://www.alz.washington.edu>

NACC Minimum Data Set (MDS) Data Submission Manual

(Version 8, 2006)

Eligibility Criteria for NACC Minimum Data Set Subjects

1. Subjects who were evaluated and enrolled in the Center’s Clinical Core or Satellite after NIA Alzheimer Center funding began.
2. Subjects who were evaluated and enrolled in another study *before* NIA Alzheimer Center became funded, then maintained by the Center after funding began, should be included in the NACC Minimum Data Set **if**:
 - 2.1 They have had a “Center-quality” diagnostic evaluation before *or* after Center activation; *and*
 - 2.2 They were alive and not discontinued when the Center became active; *and*
 - 2.3 *New data collection* (e.g., follow-up visits, exams) has taken place since Center activation and that data collection was supported by the NIA Alzheimer Center grant.
3. For the subjects described in #2 above, the following conventions apply concerning NACC Minimum Data:
 - 3.1 The date of first evaluation must be the date the subject was evaluated and enrolled in the Center (it is NOT the date the subject was first evaluated *before* Center activation);
 - 3.2 The first Mini-Mental must be one obtained at Center enrollment (NOT one obtained *before* Center activation);
 - 3.3 If Mini-Mental is not done by your Center, or not done when the subject is enrolled into the Center, it should be coded missing;
 - 3.4 All other MDS data elements pertaining to the clinical evaluation must be reaffirmed after NIA Alzheimer Center funding began.
4. Subjects who were evaluated and enrolled in another study *after* the NIA Alzheimer’s Center became funded should be included in the NACC Minimum Data Set if they had a “Center-quality” diagnostic evaluation AND are currently being followed using ADC funding.
5. Subjects who do not meet criteria 1 through 4 above may be eligible for inclusion in either the NACC MDS or the NACC Centers database as Center-affiliated subjects. *Submission of Center-affiliated subject data is **not** required; however, if submitted as part of the MDS, the data must be flagged as such.*
 - 5.1 Center-affiliated subjects are those subjects primarily enrolled in, or supported by, another study (not the ADC). All must have had a “Center-quality” diagnostic evaluation.
 - 5.2 The ADC Director will choose among the following three options for submission of Center-affiliated subject data:
 - Option 1.* Submit **no** Center-affiliated subject data to NACC.

Option 2. Submit all of the MDS data elements for each of the Center-affiliated subjects (each subject must be flagged as Center-affiliated). If this option is chosen, the following conditions must be met:

- a. The ADC must have supplied/funded a substantial part of subject identification, clinical evaluation, follow-up, new data collection or neuropathology.
- b. The ADC Director *must complete and certify all NACC MDS data* and provide information for any other NACC data requests (e.g., neuropathology data) for these subjects.
 - 1) All subjects must have a unique MDS ID number consistent with the format of “regular” MDS subjects; no duplicate ID numbers are allowed.
 - 2) MDS data must be submitted consistent and coincident with NACC data calls; data must be complete and flagged as Center-affiliated.
 - 3) The ADC Director will insure that appropriate consent and IRB approval has been obtained from the affiliated study PI, and will act as the intermediary between potential collaborators and study PIs for these subjects.

Option 3. Submit the “NACC Center-Affiliated Study Form” for inclusion in the NACC Centers database. One form will be completed for *each* ‘Center-affiliated’ study; *no individual subject data will be submitted*. The ADC Director may choose this data submission option provided:

- a. No subjects already included in the MDS will be counted here.
- b. The Center-affiliated study is a direct or indirect consequence of the ADC existence (e.g., due to clinical or research consultation, good will or other factors), *as judged by the ADC Director*.
- c. The ADC Director will provide NACC a study form for each Center-affiliated study (*no individual subject data*) for inclusion in the NACC Centers database. (The format and content of the study description will be developed by NACC; e.g., the description may include study PI, study title, period of funding, number of subjects, list of publications.)

NACC Center-Affiliated Study* Form

*(See *Eligibility Criteria* for detailed description; this form is optional.)

Date submitted: _____

Submitting Alzheimer's Disease Center: _____

Title of Study:	
Principal Investigator:	
Funding Agency/Number:	Project dates:
Abstract (e.g., aims/objectives, design, setting):	
Please list recent or representative study publications on a separate sheet (<i>optional</i>).	

Number of Subjects:

Ethnic Category	Sex/Gender			Total
	Females	Males	Unknown/ not reported	
Hispanic or Latino				
Not Hispanic or Latino				
Unknown (ethnicity not reported)				
Total of all subjects by ethnicity				

Racial Category

American Indian/Alaska Native				
Asian				
Native Hawaiian/Other Pacific Islander				
Black or African-American				
White				
More than one race				
Unknown or not reported				
Total of all subjects by race				

General Instructions

A. The MDS Data Submission System

This system is available through the NACC website at <https://www.alz.washington.edu>. Access to the system is under your particular Center's data management menu. Use the following steps to access it.

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

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

Data files may be uploaded from your local computer or data entry can be done on the web. Replacement data set(s) may be used or dataset(s) that modify and/or add on to last year's submission. If you do not submit a replacement data set your data will need to be combined with last year's MDS data. Once a total submission has been created, primary and secondary error checks may be run from the website. Alerts and other discrepancies must be verified through the website programs. Once this has been accomplished, the data is processed into the NACC database and certification reports are created. **NACC must be contacted once you have completed your data submission by clicking on the "Notify NACC" link on the website.**

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

B. Data Submission Date and Transmission Options

Data must be prepared and submitted to NACC by **Friday, April 14, 2006**.

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

Data may be transmitted in one of two modes.

1. Upload a data file (See above);
2. Web data entry. Use the MDS web data entry to enter data directly through NACC's website, <https://www.alz.washington.edu> (see the section entitled "MDS Web Data Entry").

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

C. File Types

NACC will accept three types of files for input into the MDS database:

- 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. A blank space has been allotted to separate each item from the next item. **There are no column changes this year.** Each record, or line of data, contains 209 columns. The filename must have an extension of ".txt", for example uwmds04.txt.

SAS Files:

Two kinds of SAS files may be accepted by NACC:

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

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

SPSS Files:

SPSS files must have all MDS 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

Each Center is expected to prepare a data file that represents all patients who have been evaluated by the Center since the beginning of funding by the National Institute on Aging (NIA). **This includes patients who were enrolled and/or evaluated at a satellite clinic.** Please study the Eligibility Criteria section carefully to make sure you are including all required subjects. Optionally, you can also submit subjects from Center-affiliated studies. Again, please check the Eligibility Criteria carefully and discuss any questions you have with your Center's Director, Core Leaders, and NACC.

E. General Coding Instructions

1. Required Items:

- Form Identifier (MDB001)
- Center ID (ADCID)
- Patient ID (PTID)
- Abstraction Date (ABSMO, ABSDAY, ABSYEAR)
- Birth Year (BIRTHYR)
- Gender (SEX)
- Clinical Dementia (CLINDEM)
- Vital Status (VITALST)
- Autopsy (AUTOPSY)
- Biopsy (BIOPSY)
- Frozen Brain Sample (BRNFRZN)
- Formalin Brain Sample (BRNFRMLN)
- Paraffin Brain Sample (BRNPARFN)
- CSF Postmortem (CSFPOSTM)
- CSF Antemortem (CSFANTEM)
- DNA(DNA)
- Serum (SERUM)
- APOE (APOE)
- Neuropsych Tests (NPSYCH)
- CT Scan (CT)
- PET (PET)
- SPECT (SPECT)
- MRI (MRI)
- Active/Inactive Status of ID (ACTIVE)
- Form Version (VERSION)

Required items must be completed without unallowable values. If any of the information in these items is blank, or if an unallowable value is discovered by the error-check program, no further checking of that record will be done and the record will be considered unusable.

- ### 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 (MMSEFRST, MMSELAST, RLDEM, NUMRLDEM and MULTBRTH also have codes (8 or 88) for “Not collected at this Center for this type of ID”).

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 all the elements except for the required items listed above. NOTE: The error-checking program will generate a “Missing Data Alert for Documentation,” which is a table of all missing data in your MDS data set.

Please provide as complete a record as possible. For those items that ask if data are accessible or available (e.g., items 31 through 40), the answer should be “2 = No” if data are not accessible to researchers in a reasonable amount of time (i.e., within a few hours).

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.

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.

Subject’s birth date must fall between 1875 and 1991. Date of death cannot be more than 130 years beyond birth date.

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

- Birth date
- Center Funding Start Date
- Date of First Evaluation; Date of First MMSE
- Date of most Recent Evaluation; Date of Last MMSE
- Date of Last Contact
- Date of Death
- Date of Record Abstraction

6. Identical information in several variables: If the subject has only had one MMSE, MMSEFRST will be the same as MMSELAST.

Dates may often be the same as other dates. For example, Date of Last Contact will equal Date of Death when the subject has died. Date of Most Recent Evaluation will equal Date of First Evaluation when the subject has only had one evaluation. Date of Last MMSE may be the same as the Dates of First and Last Evaluation if the subject only completed one MMSE at the first and only evaluation. Date of Last Contact may be the same as

Dates of First Evaluation and Last Evaluation if there has been no contact with the subject since enrollment.

F. Error-Check Program

The error-check program is designed to check for unallowable and unlikely values. See the “Error Checking” section for details about types of errors generated. NOTE: We may be contacting individual Centers at a later time to discuss specific data contingency problems not evaluated by the error-check program.

No Changes in 2006 to the MDS Error-Checking Program

To assist you in coding ACTIVE correctly, you may find the following “Table for Error-checking of ACTIVE” to be a helpful supplement to the coding instructions in the Data Element Dictionary.

Table for Error-checking of ACTIVE (Data Item #44)

ACTIVE (Item #44)	Legal value for VITALST (#25) 1 = alive 2 = dead	Legal value for AUTOPSY (#27) 1 = yes 2 = no	NP Form (submitted during Neuropath data calls)	Other data Items checked
1	1	blank	--	If REVALYR (#15c) prior to 2001, alert generated
2	1	blank	--	If CONTYR (#43c) prior to 2001, alert generated
3	1	blank	--	--
4	2	1	NP Form will be submitted	If DEATHYR (#26c) prior to 2002, alert generated
5	2	1	NP Form was or will be submitted	--
6	2	1	NP Form will not be submitted	If DEATHYR (#26c) after 2001, error generated
7	2	2	--	--
8	1	blank	--	--

Example of "Aggregate Alert on Follow-up In-person Visits"

```
*****
* Aggregate ALERT on Follow-up In-person Visits *
*       for IDs coded ACTIVE = 1               *
*****

The following IDs were coded ACTIVE = 1,
but had the most recent evaluation prior to 2001.
Please verify that the data being submitted
for these IDs are the most current data available:

PTID (#3)          REVALYR (#15c)
00000000006       1999
00000000213       2000
00000000279       1997
00000000305       2000
```

Example of "Aggregate Alert on Not-in-person Visits"

```
*****
* Aggregate ALERT on Not-in-person Visits      *
*       for IDs coded ACTIVE = 2               *
*****

The following IDs were coded ACTIVE = 2,
but had the most recent contact prior to 2001.
Please verify that the data being submitted
for these IDs are the most current data available:

PTID (#3)  CONTYR (#43c)
A0004      2000
A0006      2000
A0013      1998
A0027      2000
```

Example of “MDS Missing Data Alert for Documentation”

```

*****
* MDS Missing Data Alert for Documentation *
*
* Please document on the MDS Missing Data Form *
* all missing data listed below and submit the *
* form to NACC. *
*
* (The MDS Missing Data Form can be found in *
* the MDS Manual or on NACC's web site.) *
*****

Center ADCID = XX
Total IDs Reported = 10
-----
Data          #          %          #          % Not          # Not
Element       Eligible   Missing   Missing   Assessed      Assessed
-----
Primary Language(9)**  10          10          1          0          0
Age Dementia(18)**    7           29          2          0          0
CSF Antemortem(35)*  10          70          7          0          0
Rel with Dem(23)**   10         100         10         0          0
Mult Birth(24)**     10         100         10         0          0
-----
Notes:
* Must be coded as "No" if not accessible at your center.
  Missing value codes are NOT allowed for this item in the 2003 MDS.
** Critical data element for researchers.
   Avoid using missing value code if possible. "Missing" may be
   logically or clinically inconsistent with other data on case.
   Missing value codes must be documented in the MDS Missing Data Form.

```

NACC MDS Error Messages

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

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:    6
Variable Name:      SEX
Type of Check:      Range
Action Required:    ERROR: Correct unallowable value.
Incorrect Value:    f
                   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:    6
Variable Name:      SEX
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 #:   0000001098
Variable Number:    17, 18
Variable Name:      CLINDEM, AGEDEM
Type of Check:      Contingency
Action Required:    ERROR: Correct by making values consistent.
Incorrect Value:    AGEDEM=86
                   The AGEDEM item should have been skipped (i.e. [BLANK])
                   because CLINDEM=2.
(New Value):
```

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

```
Line # in file:      1
MDS Patient ID #:   0000001098
Variable Number:    26a, 26b, 26c
Variable Name:      REVALMO, REVALDAY, REVALYR
                   DEATHMO, DEATHDAY, DEATHYR
Type of Check:      Contingency
Action Required:    ERROR: Correct by making values consistent.
Incorrect Value:    Patient Date of Most Recent Evaluation
                   06,19,1999 must precede Date of Death
                   05,21,1999.
(New Value):
```

5. Contingency – Data element incorrect because of value of another data element

```
Line # in file:      23
MDS Patient ID #:   A00092
Variable Number:    25, 44
Variable Name:      VITALST, ACTIVE
Type of Check:      Contingency
Action Required:    ERROR: Correct by making values consistent.
Incorrect Value:    ACTIVE=1
                   The value of ACTIVE is inconsistent with
                   VITALST=2.
(New Value):
```

6. Contingency – Data element incorrect because of value of another data element

```
Line # in file:      57
MDS Patient ID #:   A00312
Variable Number:    26c, 44
Variable Name:      DEATHYR, ACTIVE
Type of Check:      Contingency
Action Required:    ERROR: Correct by making values consistent.
Incorrect Value:    ACTIVE=6   DEATHYR=2002
                   The value of ACTIVE is incorrect, NP data
                   must be submitted for all autopsies after
                   2001.
(New Value):
```

7. Contingency Alert – Data element incorrect because of value of another data element.

```
Line # in file:      1
MDS Patient ID #:   2313
Variable Number:    15c
Variable Name:      REVALYR
Type of Check:      Range
Action Required:    ALERT:  Check unlikely value.
                   REVALYR and FEVALYR are both missing.
                   VERIFIED/CORRECTED (Circle one)
Incorrect Value:    9999
(New Value):
```

8. Range – Duplicate ADCID and PTID with another record.

First record is checked for errors. Second is not checked for errors.

```
Line # in file:      8
MDS Patient ID #:   0000001098
Variable Number:    2, 3
Variable Name:      ADCID, PTID
Type of Check:      Range
Action Required:    ERROR: Correct unallowable value.
Incorrect Value:    ADCID=4  PTID=0000001098
                   Same (ADCID, PTID)-value as Line #1.
                   NB: No further checking of this UNALLOWABLE
                   RECORD.
(New Value):
```

9. 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 #:   0000001098
Variable Number:    44
Variable Name:      VERSION
Type of Check:      Alignment
Action Required:    ERROR: Correct unallowable value.
Incorrect Value:    The space following this item was not left
                   blank:
                   Column 206 is filled in.
                   NB: No further checking of this UNALLOWABLE RECORD.
(New Value):
```

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

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

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

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

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

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

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

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


Submitting Data

Data submission deadline: **Friday, April 14, 2006**

A. Preparing your Data Submission

MDS data submissions may be prepared locally and the files uploaded through the NACC website or prepared using web data entry. Either a total replacement submission may be created or a submission which updates last year's data.

All submissions are managed through the MDS data submission system (see General Instructions). The Center Data Manger is able to manage his/her submission completely using the NACC website.

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

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

B. Error-checking your Submission

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

C. Verifying Alerts and Other Discrepancies

Once the secondary error-checks have been successfully executed, all discrepancies must be verified. Choose option 3 from the MDS data submission menu. For each item on the list the discrepancy must be verified. Some verifications are for the whole submission and some must be done for each individual patient ID.

D. Processing Data into the MDS

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

E. Creating Certification Reports

The final step is to create your certification reports, choose option 5 from the MDS data submission menu. Once completed examine the reports carefully. **If correct contact NACC by clicking on the “Notify NACC” link on the website.** NACC will then review your submission and issue the certification reports for your Director to sign.

NACC MDS Web Data Management

A. Introduction

The NACC MDS Web Data Management System was designed to allow Centers to access their Minimum Data Set (MDS) through the NACC website. All autopsied IDs from the last MDS Data Call and those entered via the MDS Web Data Management System since the last data call are included in your Center's Minimum Data Set.

IDs that have been entered via the previous version of the MDS Web Data Management System have not been error-checked and need to be scrutinized and edited before they are submitted for the MDS Data Call.

1. Minimum System Requirements

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

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

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

2. NACC Contacts

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

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

7. General Data Management

When the MDS Web Data Management System is used for submitting data for a data call, the following data must be updated/entered:

- a. New IDs.
- b. New evaluations.
- c. Change in vital status.
- d. New autopsy information.
- e. Changes to data on existing IDs.
- f. NACC changes to data element descriptions.

When a Center has enrolled a new ID, this ID must be added to the NACC MDS using the Add IDs Menu. Duplicate ID numbers cannot be used. Once the ID is added, the rest of its data may be entered through the Edit IDs Menu.

Changes to data on existing IDs are also entered through the Edit IDs Menu. IDs that have been entered via the previous version of the MDS Web Data Management System are error-checked using the Edit IDs Menu as well. Click "Update" to run the error-checking program on individual IDs.

The general order of performing data management is as follows:

- a. Add new IDs.
- b. Edit new IDs data.
- c. Update all ID data changes (including new NACC data definitions, change in vital status, new evaluation data, new autopsy information, etc).
- d. Error-check all data.
- e. Submit data to NACC.

Data may be added during the year or all at once before the NACC Data Call deadline.

8. Disclaimer

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

B. System Operation

1. Accessing the System

The MDS 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:

- a. Choose “Member Login” and enter your username and password.
- b. Choose “The NACC Database”.
- c. Read and accept the Disclaimer and Confidentiality Agreement.
- d. Choose “The Minimum Data Set”.
- e. Choose your Center’s name (Figure 1); if you do not have authorized access for the Center selected, the system will deny access.
- f. Choose “Data Manager Menu”.
- g. Chose “MDS Data Submission System”.
- h. Choose “Web Data Entry and Modification”. Your account must be specially authorized to access this area.

Previous Menu NACC Home NACC Member Home

Personnel Directory Collaborative Projects MDS Data Call **The NACC Database**

Minimum Data Set Access

Access is granted to the NACC Minimum Data Set by user name and password. You will have access to your own center's data and possibly combined data from other centers depending on the security level assigned to your account. Please select the name of your center. Access will only be granted by selecting your assigned center. Selecting any other center will deny access.

If more access is needed, please contact NACC.

National Institute of Health			
Arizona Alzheimers Center	Johns Hopkins University	Stanford University	University of Michigan
Baylor College of Medicine	Massachusetts General Hospital	University of Alabama, Birmingham	University of Pennsylvania
Boston University	Mayo Clinic	University of Arkansas	University of Pittsburgh
Case Western Reserve University	Mount Sinai School of Medicine	University of California, Davis	University of Rochester
Columbia University	New York University	University of California, Irvine	University of Southern California
Duke University Medical Center	Northwestern University	University of California, Los Angeles	University of Texas Southwestern
Emory University School of Medicine	Oregon Health & Science University	University of California, San Diego	University of Washington
Indiana University	Rush-Presbyterian-St. Luke's Medical Center	University of Kentucky	Washington University

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 below). Clicking on one of these buttons will display the corresponding web page.

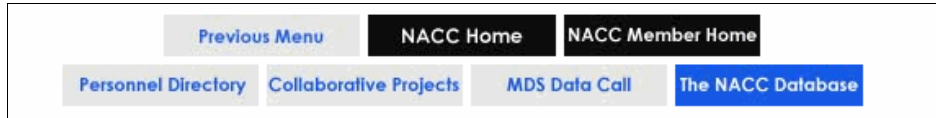


Figure 2.

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.
The NACC Database	Displays the menu for accessing NACC data.

C. Data Management Functions

Log-in to the MDS Web Data Management system for your Center (see previous instructions in section B.1) and the *MDS Data Management* page will be displayed, as shown below. Click on a function name (Display, Add, Edit, Delete) to display the corresponding web page.

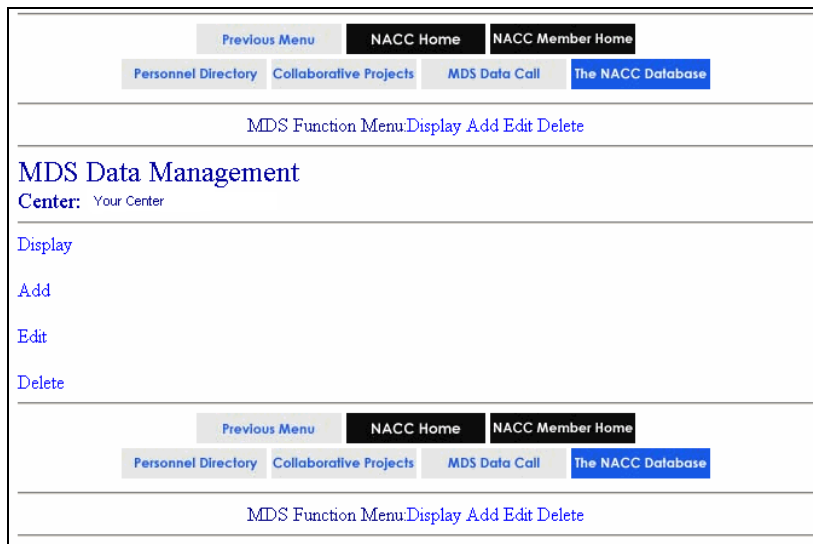


Figure 3.

1. “Display” Function

This function allows the display of MDS data for a selected PTID. Selecting this function will open the *NACC MDS Display Data (Select ID)* page shown below.

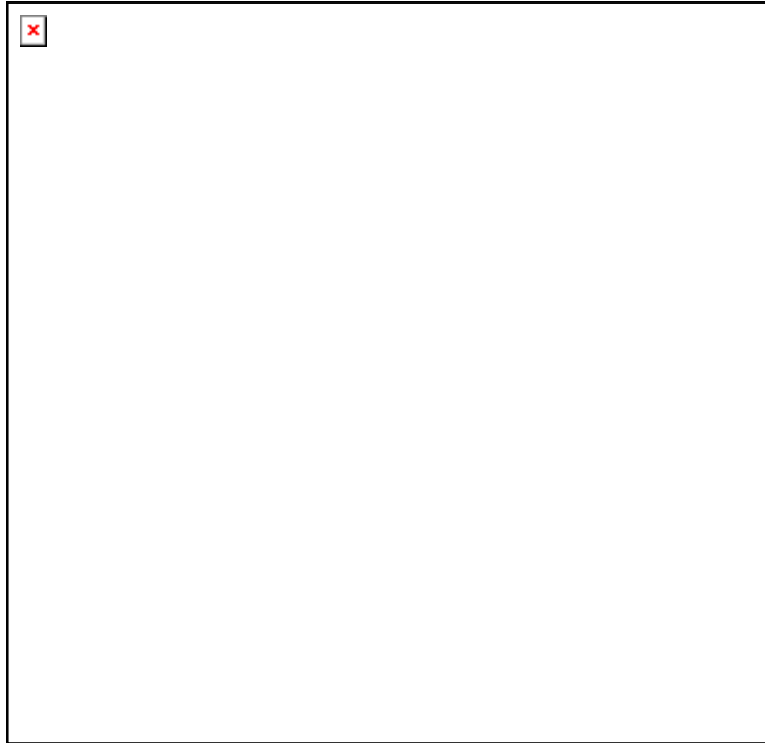


Figure 4.

The PTIDs displayed are those submitted by your Center during the last MDS Data Call and any new PTIDs added through the MDS Web Data Management System since the last Data Call. The IDs are usually in sequential order, but newly-added PTIDs 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 PTID:

- Scroll down to find the desired PTID.
- Choose the PTID.
- Click on the “Display” button.

The *NACC MDS Display Data (Display)* page will show the current data for the PTID selected, as in the example below.

Previous Menu NACC Home NACC Member Home

Personnel Directory Collaborative Projects MDS Data Call The NACC Database

MDS Function Menu: Display Add Edit Delete

NACC MDS Display Data (Display)

Center: Your Center
MDS ID: 100004

Choose Another ID to Display

4. Date Form Completed: 5 / 1 / 2002
5. Date of Birth: 9 / 8 / 1915
6. Sex: 1 = Male
7. Race: 1 = White
8. Spanish/Hispanic/Latino: 2 = No
9. Primary Language: 1 = English

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

41. Source: 1 = Clinical Core
42. Date of Last MMSE: 6 / 5 / 1996
43. Date of Last Contact: 5 / 11 / 1999
44. Active: .

Choose Another ID to Display

Previous Menu NACC Home NACC Member Home

Personnel Directory Collaborative Projects MDS Data Call The NACC Database

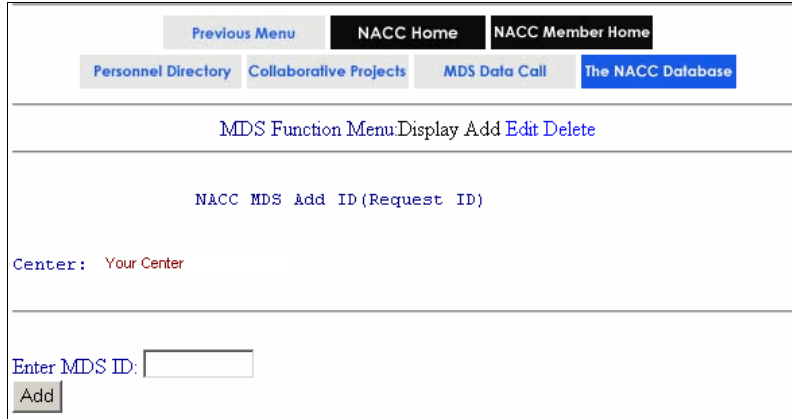
MDS Function Menu: Display Add Edit Delete

Figure 5.

Click on the “Choose Another ID to Display” button to return to the *NACC MDS 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 PTIDs to the MDS Web Data Management System. Click on the “Add” function to open the *NACC MDS Add ID (Request ID)* page, as shown below.



Previous Menu NACC Home NACC Member Home

Personnel Directory Collaborative Projects MDS Data Call The NACC Database

MDS Function Menu: Display Add Edit Delete

NACC MDS Add ID (Request ID)

Center: Your Center

Enter MDS ID:

Add

Figure 6.

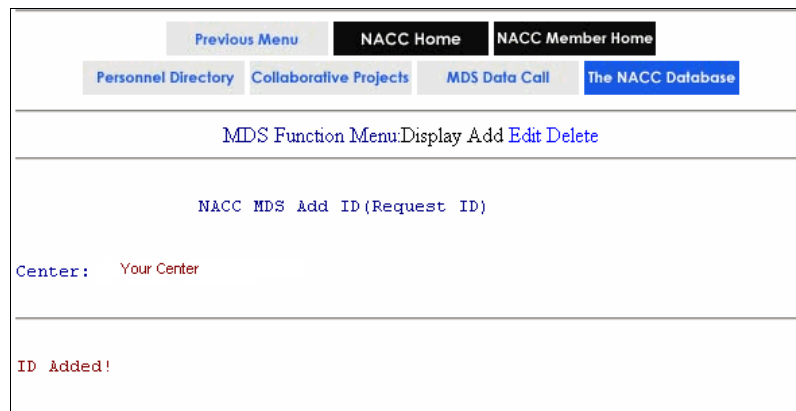
To add a new PTID:

- Click on the box after “Enter MDS ID”.
- Type the new PTID.
- Click on the “Add” button.

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

a. ID Added

If the PTID was successfully added, the *NACC MDS Add ID (Request ID)* page will be displayed with the message “ID Added!” (see below).



Previous Menu NACC Home NACC Member Home

Personnel Directory Collaborative Projects MDS Data Call The NACC Database

MDS Function Menu: Display Add Edit Delete

NACC MDS Add ID (Request ID)

Center: Your Center

ID Added!

Figure 7.

You may continue to add additional PTIDs or click on the “Previous Menu” button to return to your Center’s *MDS Data Management* page.

b. Duplicate ID

If the ID already exists in the MDS Data Set, a message will be displayed in the *NACC MDS Add ID (ID Exists)* page, as shown below. Duplicate PTIDs are not allowed.

When the system searches for duplicates, leading zeros and blanks are ignored.

Data for an existing PTID must be entered with the “Edit” function (see section C.3 later in this manual).

Previous Menu NACC Home NACC Member Home

Personnel Directory Collaborative Projects MDS Data Call The NACC Database

MDS Function Menu: Display Add Edit Delete

NACC MDS Add ID (ID Exists)

Center: Your Center
ID : testID05

This MDS ID is already in the MDS Data Set!
Please enter another ID to add to the data set.

Add

Previous Menu NACC Home NACC Member Home

Personnel Directory Collaborative Projects MDS Data Call The NACC Database

MDS Function Menu: Display Add Edit Delete

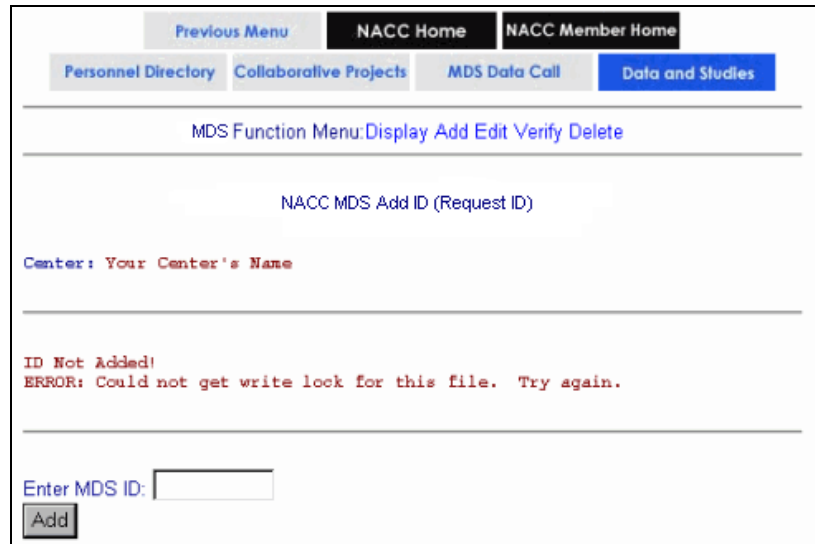
Figure 8.

You may continue to add additional PTIDs or click on the “Previous Menu” button to return to your Center’s *MDS Data Management* page.

c. System Error

If the PTID could not be added, an error message will be displayed (see example below). This situation usually occurs when someone else at your Center is trying to update the file at the same time. Try to enter the PTID again.

If the problem persists, please contact NACC.



The screenshot shows a web interface with a navigation bar at the top containing buttons for "Previous Menu", "NACC Home", and "NACC Member Home". Below this is a secondary navigation bar with "Personnel Directory", "Collaborative Projects", "MDS Data Call", and "Data and Studies". The main content area displays "MDS Function Menu: Display Add Edit Verify Delete" and "NACC MDS Add ID (Request ID)". A red error message reads: "ID Not Added! ERROR: Could not get write lock for this file. Try again." Below the error is a text input field labeled "Enter MDS ID:" and an "Add" button.

Figure 9.

You may continue to add additional PTIDs or click on the “Previous Menu” button to return to your Center’s *MDS Data Management* page.

2. “Edit” Function

This function allows the entering or editing of MDS data for an PTID. Choose the “Edit” function to open the *NACC MDS Edit (Select ID)* page (see example below).

Previous Menu NACC Home NACC Member Home

Personnel Directory Collaborative Projects MDS Data Call The NACC Database

MDS Function Menu: Display Add Edit Delete

NACC MDS Edit Data(Select ID)

Center: Your Center

Edit

Select MDS ID:

100001
100002
100003
100004
100005
100006
100007
100008
100009
100010

Edit

Previous Menu NACC Home NACC Member Home

Personnel Directory Collaborative Projects MDS Data Call The NACC Database

MDS Function Menu: Display Add Edit Delete

Figure 10.

The PTIDs displayed are those submitted by your Center during the last MDS Data Call and any new PTIDs added through the MDS Web Data Management System since the last Data Call. The PTIDs are usually in sequential order, but newly-added PTIDs 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 PTID.
- Choose the PTID.
- Click on the “Edit” button.

The *NACC MDS Edit Data (Edit ID)* page will be displayed, as shown in the following example.

Previous Menu	NACC Home	NACC Member Home	
Personnel Directory	Collaborative Projects	MDS Data Call	
The NACC Database			
MDS Function Menu: Display Add Edit Delete			
NACC MDS Edit Data (Edit ID)			
Center: Your Center			
MDS ID: xxxx			
<input type="button" value="UPDATE"/> <input type="button" value="CANCEL"/>			
4. Date Form Completed:	5	1	2002
5. Date of Birth:	9	8	1915
6. Sex:	1 = Male		
7. Race:	1 = White		
8. Spanish/Hispanic/Latino:	2 = No		
9. Primary Language:	1 = English		
10. Education:	20		
11. Marital Status:	1 = Married		
12. Residence:	1 = Private Residence		
::::: (partial data displayed; sample report only) :::::			
40b. PET Scan:	2 = No		
40c. SPECT:	2 = No		
40d. MRI:	2 = No		
41. Source:	1 = Clinical Core		
42. Date of Last MMSE:	6	5	1996
43. Date of Last Contact:	5	11	1999
44. Active:			
<input type="button" value="UPDATE"/> <input type="button" value="CANCEL"/>			
Previous Menu	NACC Home	NACC Member Home	
Personnel Directory	Collaborative Projects	MDS Data Call	
The NACC Database			
MDS Function Menu: Display Add Edit Delete			

Figure 11.

Values initially displayed are the values currently in the database for this PTID. 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 PTID, click on the “Update” button to execute the error check program. The error checking program checks to determine that each variable is within the correct range, and that the skip patterns are followed correctly. Logical checks are also performed on applicable data elements.

Please note that the error checking performed by the website software is of a preliminary nature and that further error checking will be performed after the data has been submitted to NACC, by you through the MDS Data Submission System.

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

a. ID Updated

If the data elements entered for the PTID have no errors, the *NACC MDS Edit Data (Select ID)* page will be displayed with the message “ID Updated!” (see below).

The screenshot displays a web application interface for NACC MDS data management. At the top, there are navigation buttons: "Previous Menu", "NACC Home", and "NACC Member Home". Below these are four tabs: "Personnel Directory", "Collaborative Projects", "MDS Data Call", and "The NACC Database". The main content area features a header "MDS Function Menu: Display Add Edit Delete" and a sub-header "NACC MDS Edit Data (Select ID)". A message "Center: Your Center" is displayed. A prominent red message "ID Updated!" is shown. Below this is an "Edit" button and a "Select MDS ID:" label. A list box contains MDS IDs from 100001 to 100010. Another "Edit" button is located below the list. The bottom of the page mirrors the top navigation and function menu.

Figure 12.

You may continue to edit/enter additional PTIDs or click on the “Previous Menu” button to return to your Center’s *MDS Data Management* page.

b. Data Entry Error

If data elements entered for the PTID have errors, the *NACC MDS Edit Data (ID has Errors)* page will display a list describing all errors, as shown in the example below.

Previous Menu NACC Home NACC Member Home

Personnel Directory Collaborative Projects MDS Data Call The NACC Database

MDS Function Menu: Display Add Edit Delete

NACC MDS Edit Data (ID has Errors)

Center: Your Center
MDS ID: xxx

The following is a list of the errors found for this ID.
All errors must be corrected before an update can take effect.

Error (Item 26) Month of Form out of Range. Value Must be 1 - 12. Entered
Error (Item 26) Day of Form out of Range. Value Must be 1 - 31. Entered
Error (Item 26) Year cannot be blank.
Error (Item 27) is not valid. Value must be 1,2. Entered Value = .
Error (Item 44) is not valid. Value must be 1-8. Entered Value = .

UPDATE CANCEL

4. Date Form Completed: 5 / 1 / 2002

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

41. Source: 1 = Clinical Core
42. Date of Last MMSE: 6 / 5 / 1996
43. Date of Last Contact: 5 / 11 / 1999
44. Active:

UPDATE CANCEL

Previous Menu NACC Home NACC Member Home

Personnel Directory Collaborative Projects MDS Data Call The NACC Database

MDS Function Menu: Display Add Edit Delete

Figure 13.

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 PTID is updated.

c. System Error

If the data elements entered for the PTID could not be updated because of a system error, the *NACC MDS Edit Data (Edit ID)* page will display an error message, as shown in the example below. This situation usually occurs when someone else at your Center is trying to update the file at the same time. Try to update the PTID again.

If the problem persists, please contact NACC.

The screenshot shows a web interface for editing MDS data. At the top, there are navigation tabs: 'Previous Menu', 'NACC Home', and 'NACC Member Home'. Below these are four buttons: 'Personnel Directory', 'Collaborative Projects', 'MDS Data Call', and 'Data and Studies'. The main content area is titled 'MDS Function Menu: Display Add Edit Delete' and 'NACC MDS Edit Data (Edit ID)'. It displays the following information:

- Center: Your Center
- MDS ID: xxx
- ID Not Updated!**
- ERROR: Could not get write lock for this file. Try again.**

Below the error message are two buttons: 'UPDATE' and 'CANCEL'. Further down, there are several data entry fields:

- 2. Date Form Completed: [dropdown] / [dropdown] / [dropdown]
- 3. Neuropath ID: [text input]
- 4. Gender: [dropdown] (1 = Male)

Below these fields is a separator line with the text: *::::: (partial data displayed; sample report only) :::::*

Below the separator line are more data entry fields:

- 43. Date of Last Contact: [dropdown] / [dropdown] / [dropdown] (6 / 27 / 2001)
- 44. Active: [text input]

At the bottom of the form area are two buttons: 'UPDATE' and 'CANCEL'. At the very bottom, there are navigation tabs: 'Previous Menu', 'NACC Home', and 'NACC Member Home'. Below these are four buttons: 'Personnel Directory', 'Collaborative Projects', 'MDS Data Call', and 'The NACC Database'. The footer text is 'MDS Function Menu: Display Add Edit Delete'.

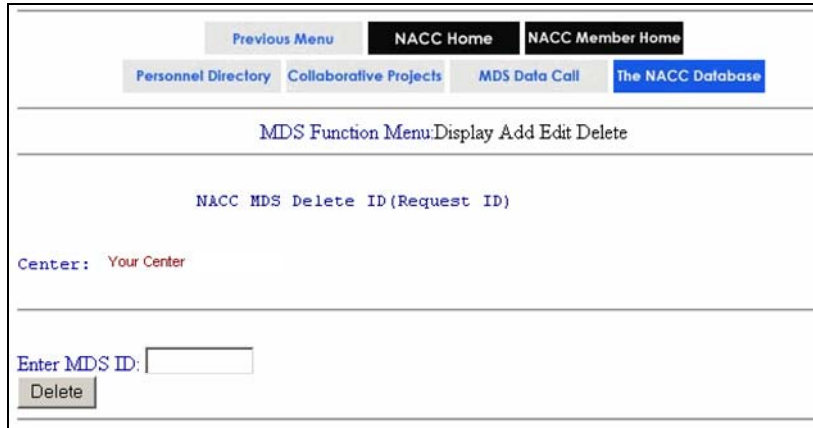
Figure 14.

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

5. “Delete” Function

This function allows the deletion of PTIDs, which have been entered through the “Add” function of the MDS Web Data Management System.

To delete an PTID, click on “Delete” in the function menu to open the *MDS Delete ID (Request ID)* page, as shown below.



Previous Menu NACC Home NACC Member Home

Personnel Directory Collaborative Projects MDS Data Call The NACC Database

MDS Function Menu: Display Add Edit Delete

NACC MDS Delete ID (Request ID)

Center: Your Center

Enter MDS ID:

Delete

Figure 15.

To delete a PTID:

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

a. ID Found

If the PTID exists in the MDS data set and can be deleted, the *NACC MDS Delete ID (ID Found)* page will be displayed (see example below).

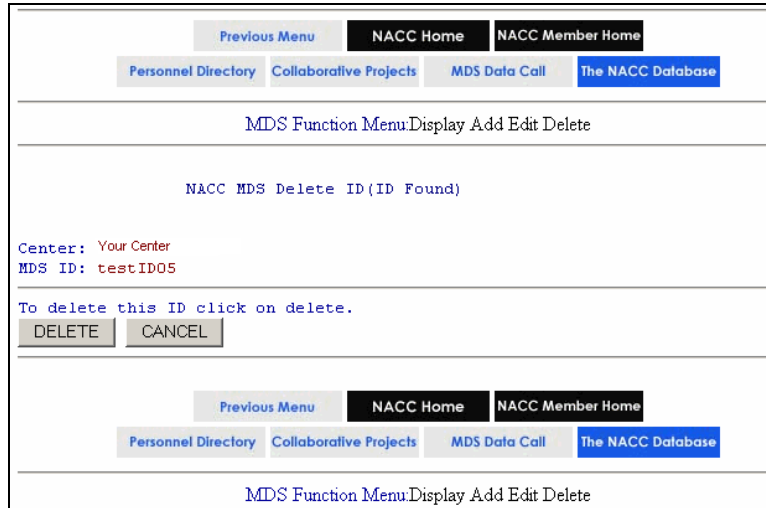


Figure 16.

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

If the PTID was successfully deleted, the *NACC MDS Delete ID (Request ID)* page will be displayed with the message “ID Deleted!”, as shown in the example below. You may continue to delete additional PTIDs or click on the “Previous Menu” button in the web page header to return to your Center’s MDS Data Management page.

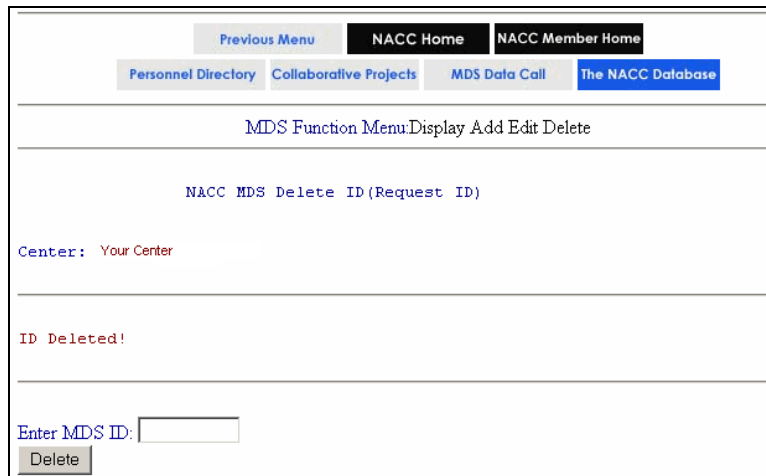
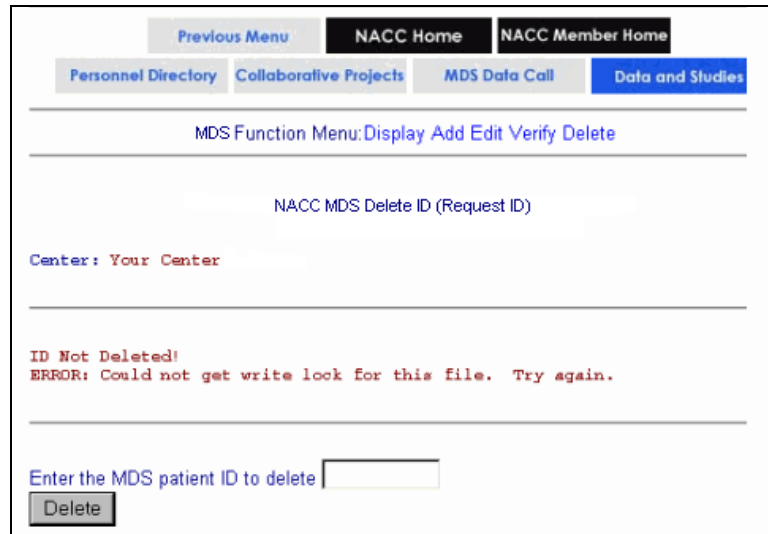


Figure 17.

b. System Error

If the PTID could not be deleted, an error message will be displayed (see example below). This situation usually occurs when someone else at your Center is trying to update the file at the same time. Try to delete the PTID again.

If the problem persists, please contact NACC.



The screenshot shows a web interface with a navigation bar at the top containing buttons for 'Previous Menu', 'NACC Home', and 'NACC Member Home'. Below this is a secondary menu with 'Personnel Directory', 'Collaborative Projects', 'MDS Data Call', and 'Data and Studies'. The main content area displays 'MDS Function Menu: Display Add Edit Verify Delete' and 'NACC MDS Delete ID (Request ID)'. A red error message reads: 'ID Not Deleted! ERROR: Could not get write lock for this file. Try again.' Below the error is a text input field labeled 'Enter the MDS patient ID to delete' and a 'Delete' button.

Figure 18.

You may continue to delete additional PTIDs or click on the “Previous Menu” button to return to your Center’s *MDS Data Management* page.

c. ID Cannot be Located

If the PTID could not be deleted because it is not in the MDS Web Data Management System, the *NACC MDS Delete ID (ID Not Found)* page will be displayed, as shown in the example below. Check your PTID carefully using the “Display” function.

Previous Menu NACC Home NACC Member Home

Personnel Directory Collaborative Projects MDS Data Call The NACC Database

MDS Function Menu: Display Add Edit Delete

NACC MDS Delete ID (ID Not Found)

Center: Your Center
ID: testID04

ID not in MDS Data Set! Please enter another ID to delete.

Figure 19.

You may continue to delete additional PTIDs or click on the “Previous Menu” button to return to your Center’s *MDS Data Management* page.