

# The National Alzheimer's Coordinating Center (NACC) Database

## *An Alzheimer Disease Database*

Duane L. Beekly, BS,† Erin M. Ramos, MPH,† Gerald van Belle, PhD,†‡ Woodrow Deitrich, BS,†  
Amber D. Clark, BS,† Mary E. Jacka,† Walter A. Kukull, PhD,†  
and the NIA-Alzheimer's Disease Centers\*

**Abstract:** The National Alzheimer's Coordinating Center (NACC) is responsible for developing and maintaining a database of patient information collected from the 29 Alzheimer disease centers (ADCs) funded by the National Institute on Aging. Each of the centers collects center-determined data elements on patients enrolled into its center and transmits a minimum dataset to NACC. Data are managed differently at each center depending on that center's research needs. The centers' data systems vary from a single personal computer running spreadsheet software to a network of servers running an advanced data management system such as Oracle. The challenge for NACC is to expand and adjust previously collected data elements into an integrated database that could be used for administrative as well as research purposes. In addition, NACC sought to allow the centers to have the flexibility they needed for data submission. To accomplish this task, NACC designed a database that contained separate specific datasets each with individual data elements. NACC also designed a data management system to easily collect and manage these data. The NACC web site ([www.alz.washington.edu](http://www.alz.washington.edu)) was created to allow access to the data.

**Key Words:** database, dementia, NACC, SAS

(*Alzheimer Dis Assoc Disord* 2004;18:270–277)

The National Alzheimer's Coordinating Center (NACC) Database had its beginnings at the Rush-Presbyterian-St. Luke's Medical Center (Alzheimer's Disease Center Core) in 1997 with one dataset, the minimum dataset (MDS).<sup>1</sup> This dataset was transferred to NACC in August of 1999. The original MDS consisted of Center ID, Patient ID, and 59 other data elements. Once NACC received the MDS, NACC's task was to transform and expand this single dataset into a database

consisting of many datasets that could satisfy the National Institute on Aging (NIA) and the Alzheimer's Disease Center (ADC) needs for information. This process entailed designing and implementing a database, data collection process, and data access method. Experiences with other Alzheimer's Disease National Databases<sup>2–4</sup> were studied to gain insight into how to design the NACC database.

As a new initiative, to increase ADC collaboration, NACC solicited and funded collaborative research projects annually. Each of these projects develops its own research project database. NACC assists in the development of these databases and stores the final project's data within the NACC database.

### Purpose of the Database

The NACC Database has both an administrative and a research purpose. The administrative purpose is to account for the number and types of patients seen by the ADCs. Reports on each center and the overall combination of centers are generated each year for the NIA. These reports are used by the NIA to administer its Alzheimer disease (AD) programs as well as make reports to congress.

The research purposes include: 1) determining the number of different types of subjects at the centers so that future collaborative research projects may be designed using the NACC data along with newly collected data about these patients; 2) using the data contained in the database to determine new questions to ask and thus new types of data to be collected; and 3) analyzing the data contained in the database for AD research.

### Data Element Enhancement

Enlarging and modifying the data elements in the original MDS was a difficult process because of the variations in data element collection and storage practices at the ADCs. It was further complicated by the resulting requirement to recode all past center data into the new elements. Mapping data collected since 1984 into new MDS data elements proved to be a substantial and continuing challenge for the centers and for NACC. New and modified data elements had to be standardized so that centers would be able to collect the same elements. This was easiest if the data elements already collected at the centers could be mapped directly into the NACC data elements. It was also mandatory that the data elements

Received for publication August 26, 2003; accepted February 6, 2004.

\*Members of The NIA-Alzheimer Disease Centers are listed on page 277

From the †National Alzheimer's Coordinating Center, Department of Epidemiology, School of Public Health and Community Medicine, University of Washington, Seattle, Washington, and the ‡Department of Biostatistics, School of Public Health and Community Medicine, University of Washington, Seattle, Washington.

Supported by National Institute on Aging grant AG16976.

Reprints: Duane Beekly, BS, National Alzheimer's Coordinating Center, 4311 11<sup>th</sup> Avenue NE, Seattle, WA 98105 (e-mail: [beekly@u.washington.edu](mailto:beekly@u.washington.edu)).

Copyright © 2004 by Lippincott Williams & Wilkins

selected be useful for future research and administrative needs. At present, the original database has been expanded from one dataset containing 61 data elements to 9 datasets containing more than 900 data elements.

Many of the original MDS data elements have been refined to make them more useful for research and easier to collect, retrospectively and prospectively. To accomplish this task, committees of subject matter specialists were formed to determine the most relevant data elements for a content area. For example, the Neuropathology Core Leaders Steering Committee (elected by neuropathologists from the centers) developed new and more detailed neuropathology data elements. The committee determined which data elements to add and then submitted a data collection form with the data elements to NACC. Personnel at NACC reviewed the form for ease of data entry, made edits consistent with database structure and logic, and then returned the form to the neuropathology committee for further review. Once a final form was agreed upon, NACC designed and implemented the dataset and data collection methods.

## METHODS

### Software and Hardware

The NACC Database was developed using SAS (<http://www.sas.com>).<sup>5</sup> SAS products used include BASE SAS, SAS IntrNet, SAS AF, and SAS FSEDIT. NACC developed its own web data management software package for entering and managing data. The database is housed on a Sun Sparc Enterprise Server 250 using the Solaris 7 operating System.<sup>6</sup> The database can be accessed via the Internet using a web browser at [www.alz.washington.edu](http://www.alz.washington.edu).

### NACC Web Site

The NACC web site ([www.alz.washington.edu](http://www.alz.washington.edu)) is designed to serve the public, the ADC investigators, and the NIA. The website includes links to and information about NACC, AD, ADCs, NACC research, and access to the NACC database (Fig. 1). The web site is divided into two parts. The initial page is for the general public. The “members only” section requires a username and password. Member usernames and passwords are obtained from NACC, and a member must be authorized by one of the centers or the NIA. Once becoming a member, the user is granted access to data by security level (see below).

### Database Design

The overall NACC database currently consists of more than 900 data elements. These data elements are grouped into datasets that, in turn, are grouped into data areas (Fig. 2). Data areas are for conceptual purposes only. Data areas include datasets that contain data elements related to a particular subject area along with their associated metadata. The data areas were organized for ease of data collection, data access, and documentation. All datasets are relational to each other. The relational keys are center ID and/or patient ID. As seen in Figure 1, the data areas are Minimum Data, Neuropathology Data, Centers Data, Collaborative Data, and Other AD Data. These data areas can be accessed individually or in combination with other data areas. The NACC database, each data area, and each dataset also have associated metadata. Metadata<sup>7</sup> is data about the data. It is data that describes the database. The metadata includes a data element dictionary (Fig. 3) of each dataset. NACC also has technical documentation and user

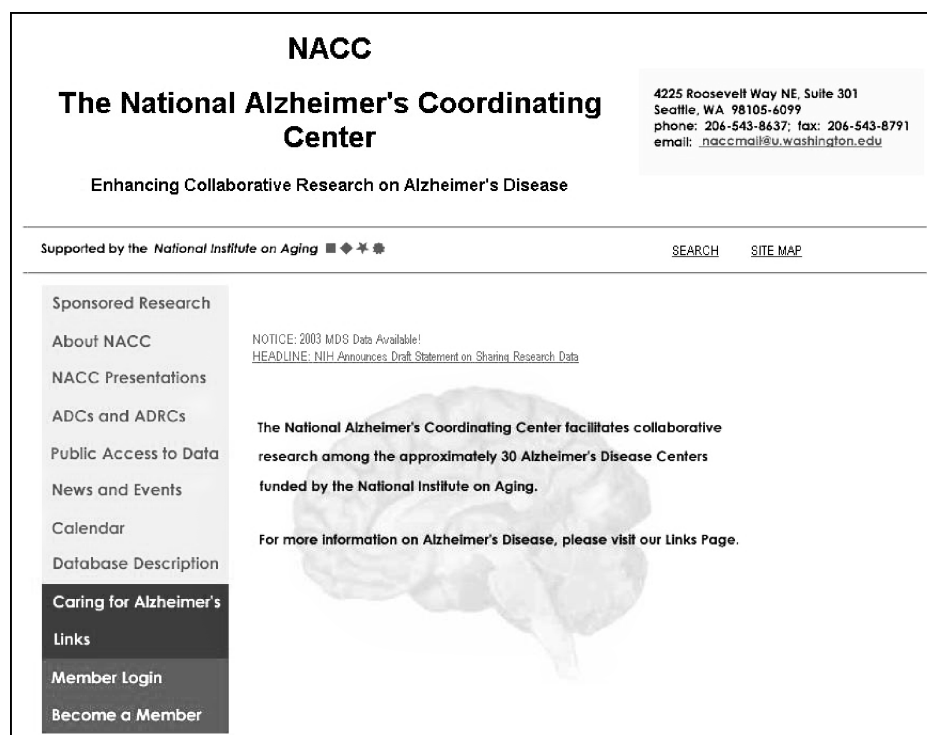
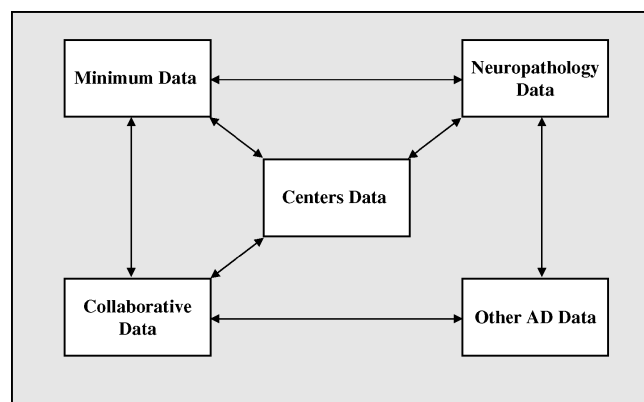


FIGURE 1. The National Alzheimer's Coordinating Center Public Home Page. This page can be found at <http://www.alz.washington.edu>.



**FIGURE 2.** A conceptualization of the data areas used to design the relational NACC database. These data areas include the Minimum Data, the Neuropathology Data, the Centers Data, the Collaborative Data, and the Other AD Data, and can be accessed individually or in combination with other data areas.

manuals that are kept in both hard copy and on the NACC web site. The data areas are detailed below.

### Minimum Data Area

The Minimum Data Area consists of the MDS and its associated metadata. The MDS consists of one record for each patient/subject ID received from a center. The relational keys are center code and patient ID. The subject ID is assigned by the center to represent one unique subject. Duplicate IDs within a center are not allowed, and each ID must correspond to a patient or control subject that meets the NACC MDS Eligibility Requirements. The current MDS has 68 data elements. This includes demographic data elements such as race, education, and gender; clinical data elements such as diagnosis, age of onset, stroke, and depression; and specimen availability such as DNA available, frozen tissue available, and MRI available.

Variable Name	<b>RACE</b>
Short Descriptor	<b>Race</b>
MDS Question	<b>Subject's Race</b>
Length of Field	<b>2</b>
SAS Variable Type	<b>Numeric</b>
SAS Variable Length	<b>8</b>
Column Positions	<b>46-47</b>
Allowable Codes	1-4, 50, 99
	1 = White
	2 = Black
	3 = AmericanIndian or AlaskanNative
	4 = Asian orPacific Islander
	50 = Other
Missing Code	99 = Missing / Unknown

**FIGURE 3.** An example of a data element description contained in the MDS data element dictionary. These descriptions are used by centers for preparing their data for submission to NACC. Investigators use these descriptions for interpreting data elements.

### Neuropathology Data Area

The Neuropathology Data Area contains three datasets and their associated metadata. These datasets all pertain to data elements gathered about subjects who received autopsies or neuropathologic examinations. The MDS is also in this area because it has data elements such as primary and secondary neuropathology diagnosis. Usually, these data are gathered from the neuropathology core at each center because neuropathology reports must be interpreted to accurately complete the NP data form for NACC.

### Neuropathology Data Set (NPDS)

The NPDS has one record for each autopsied ID in the MDS for which the center has autopsy data. The relational keys are center code and patient ID. The NPDS currently has more than 6500 IDs. There are 53 data elements in the NPDS, including specific information about the occurrence of various pathologic features including: neuropathologic diagnostic criteria, gross or microscopic pathology such as number of neuritic plaques, number of diffuse plaques, and Lewy bodies. The majority of these data were obtained from review of neuropathology examination reports completed as long ago as 1984. Although criteria, stains, and procedures have all changed over time, usually the original report data were entered because specimens were not restained or evaluated with newer techniques. Centers are however expected to faithfully complete all NPDS requested data on all autopsy cases occurring after January 1, 2002.

### Neuropathology Procedures Survey Form (NPPS)

The NPPS has one record for each center. This dataset contains 398 data elements describing a center's methods for acquisition, preparation, examination, and storage of specimens and tissue. Five types of data elements are used: 1) general data elements describing the center's inventory system and type of data collected; 2) specimen and tissue preparation data elements that include the type of specimens collected at autopsy and how they were prepared, such as hippocampus, entorhinal cortex, amygdala, and frontal cortex were collected and prepared by being fixed, frozen, or preserved; 3) histopathology data elements, which include the stains used for identifying various types of pathology; 4) neuropathology data elements that include the criteria used to evaluate different types of pathology; and 5) additional procedures data elements that include data elements for screening of HIV, hepatitis B, and hepatitis C.

### Neuropathology Inventory Software and Data

Neuropathology inventory software and its associated data were developed by NACC as a tool to allow centers to create their own customized inventories of neuropathology tissue. Each center can use the software through the NACC web site to create a customized database then enter and retrieve data from this database. Only authorized personnel from the specified center can access the data for that center. An example of an inventory system might be an inventory of freezers where frozen brain tissue was kept. The center could create data elements: patient ID, freezer number, shelf number, box number, type of tissue, and amount available. Data can be

entered through the NACC web site for each ID that has tissue in the freezer. Once entered reports for the sole authorized use of the individual, ADC can be generated and tissue locations retrieved (Fig. 4).

### Centers Data Area

The Centers Data Area consists of individual datasets that describe various aspects of an individual center or nuances of a center's data. The datasets are described below.

### Data Management Survey

This dataset consists of one record for each center. The data were collected from a survey that was designed by NACC and sent to each center. This survey requested information on the type of hardware, software, and data management used at each center. The responses obtained are used by NACC when contacting centers about data submission problems and are used by other centers and researchers also when exchanging datasets for research purposes.

Examples of questions included in the survey are:

- Describe the database software used to store data at your center.
- Describe how data are entered into the database at your center.
- Describe the hardware and associated operating systems used at your center.

Data Management Survey information can be accessed on the NACC web site in both summary and individual center's forms.

### Under Served Minority Audiences Survey

This dataset consists of one record for each center. There are 190 data elements. The data was collected from a survey sent to the centers. Examples of data elements include:

- What is the primary population or audience you are working with?
- What outreach activities do you have at your center?
- What products do you have at your center that support underserved minority audiences?

Each centers data can be viewed on the NACC web site.

### Center Descriptions

This dataset contains the overall narrative description of a center's data, including nuances of how the data were collected and issues with the quality of the data. Each center can submit information about the various datasets that it has submitted to NACC. For example, a center may explain how often longitudinal follow-ups are done or the protocol for enrolling new patients and/or controls.

### Neuropsychological Tests, Clinical Dementia Scales, and Other Instruments Survey

This dataset contains one record with 54 data elements for each center. These data elements deal with neuropsychological tests a center uses. The most common tests currently used are the Category Fluency Test, Boston Naming, MMSE (WORLD Backwards, Trail Making Test (Parts A or B), and CDR-Global Score. For each test, the center answers whether the test is currently used, used in the past, or rarely or never used. Data elements are also available for centers to describe their own or customized tests. The information from this dataset may be accessed as summarized reports or individual center's forms by using the NACC web site.

### MDS Center Data Element Description

This dataset describes the unique characteristics of MDS Data Elements collected at each center. For each data element in the MDS, there is a corresponding element in this dataset. These data elements allow a center to describe unique nuances

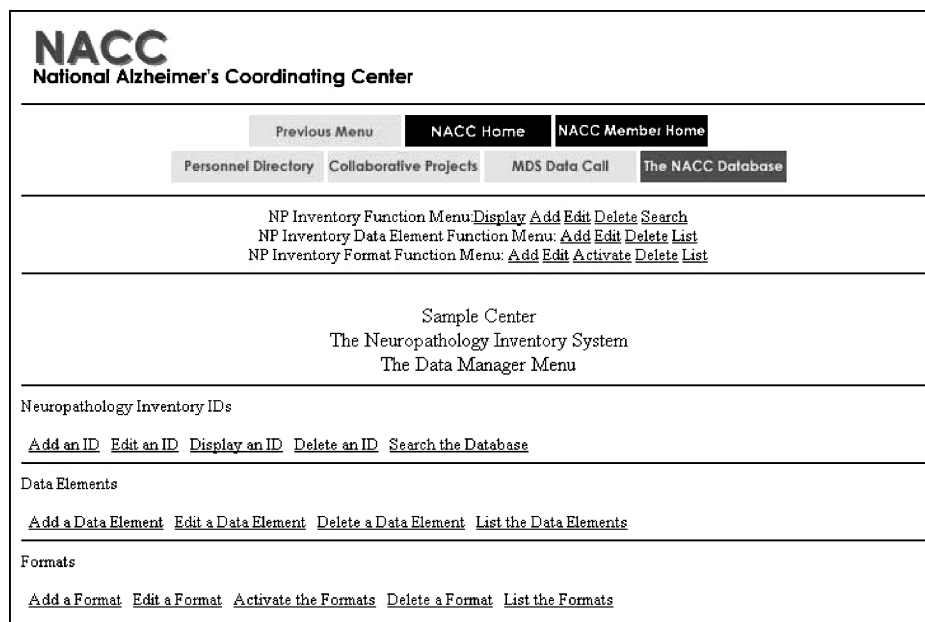


FIGURE 4. The Neuropathology Inventory Data Management Web Page. Each center can access their secured page through the NACC web site. This page is a gateway to the center customized inventory system.

about a particular data element. For example, for the MDS Data Element, multiple births, the comment listed may be “not collected at this center.” These descriptions may be accessed through the NACC web site.

### Neuropathology Center Data Element Description

This dataset describes the unique characteristics of Neuropathology Data elements collected at each center. For each data element in the Neuropathology Data Set, a data element is listed in this dataset. These data elements allow a center to describe unique nuances about a particular data element. For example, for the neuropathology data element, CERAD Criteria, the comment may be “not used at this center.”

### Other Data Sets

In the future, more centers' data will be collected and available on the web site so that each of the ADCs and their associated data can be described as completely as possible.

### Collaborative Data Area

For each collaborative project that NACC funds, there is a dataset or group of datasets. These datasets contain data elements related to the specific project. Patient ID and Center ID relate data to the other area's datasets. For each project, there is a metadata that includes documentation such as the data element dictionary. All projects at their conclusion must send their data to NACC for inclusion into the NACC database. Currently, NACC has funded 12 projects, 3 of these projects are actively managed by NACC, and all 12 will be archived at their conclusion. Collaborative projects actively managed with data currently in the NACC database are:

- Collaborative Study Group on Vascular Pathology: Neil Kowall Boston University
- Collaborative PET Imaging Study: Norman Foster, University of Michigan
- CSF Cortisol and APOE Genotype: Elaine Peskind, University of Washington

These data may be accessed with permission of NACC and the individual collaborative project's principal investigator.

### Other AD Data Area

The Other AD Data Area contains databases received by NACC from other AD studies that were not sponsored by NACC. NACC currently has data from CERAD and the ADC Consortium on APOE and Alzheimer's disease studies available to researchers. The CERAD Grant (Consortium to Establish a Registry for Alzheimer's Disease, A. Heyman, PI) was funded by the NIA in 1986. A battery of standardized assessments for the evaluation of patients with AD was developed. Patients and control subjects from 24 universities medical centers were evaluated at entry and longitudinally thereafter, to track the natural progression of AD. The ADC Consortium on APOE and Alzheimer's disease study (R. Mayeux, PI) collected data from 2188 patients who had been enrolled at 26 ADCs for diagnosis of dementia, subsequently died, and had postmortem examinations for APOE genotype and the presence or absence of AD pathology in the brain.

Investigators were ultimately able to examine records of 1108 women and 1080 men submitted by the ADCs.

Datasets from these studies can be transferred to researchers once permission has been obtained from the individual study PI and from NACC.

### Security

Access to the NACC website and thus database is divided into four security levels (levels 1–4). Level 1 users have the most access, while level 4 users have the least access. A security level is assigned to each registered user by agreement of NACC, the center the user is affiliated with, and the NIA. The security levels are as follows:

- Level 1, NACC restricted, only NACC and NIA personnel have this access.
- Level 2, ADC/ADRC restricted, center data managers have this access.
- Level 3, Authorized researchers, center researchers have this access.
- Level 4, Public.

## DATA COLLECTION

### Data Calls

Once a year, NACC holds a data call for the MDS and NPS datasets. Before the start of the data calls, NACC sends each center a packet of information that includes documentation for the data call and an error-checking program. Data are collected in a variety of ways to allow the centers more flexibility in submitting their data, including submission of files, web-based data entry, and submission of paper forms. Files may be submitted in a variety of formats, including ASCII fixed format, SAS, SPSS, or another format agreed upon by the center and NACC. Specialized web data entry and verification software have been developed by NACC to allow ease of entry and updating of subject data. One or more methods of data collection are available for an individual center. For example, a center may choose to update last year's submission using web data entry from the NACC web site and enter new IDs by sending paper forms to NACC. A center has the option of updating its current data in the specified NACC dataset or submitting a replacement of all its data in the specified NACC dataset.

### Data Call Process

During the data call, NACC monitors the progress of each center. As soon as data are received by NACC, a receipt is generated and returned to the center's data manager. The data elements are then checked for range, logical errors, and missing data. If errors or alerts are generated, the center's data manager is contacted and asked to correct the errors and verify that the alerts are correct. If missing data are not accounted for, the center is requested to fill out the missing data form. Once all errors and alerts have been corrected, a secondary error-checking program is executed by NACC. This program checks the IDs versus the IDs submitted last year for the presence of duplicates, dropped IDs, and/or new IDs. Also, the data submitted are checked versus other datasets for consistency. For example, date of death must be the same for an ID on the

MDS as on the NPS. A report is sent to the center of all errors found. The above process involves a great deal of communication between NACC and the centers. Each data submission generates many phone calls and e-mails. This not only improves the NACC database but also allows the individual centers to improve their databases. Once the data submitted are considered to be complete by both NACC and the Center's database manager, NACC generates a certification report. This report summarizes the center's data and the overall data so that the director and colleagues can compare the data at their center

to the data from other centers. The report requires the center's director's certification of completeness and accuracy. If the director believes the report does not reflect the center's data, then NACC, the director, and the center's data manager work to correct the data and submit the corrected data to NACC.

### Accessing Data

Data can be accessed through the NACC web site or by making direct requests to NACC for analysis files or customized reports. The NACC web site allows the creation

**NACC**  
National Alzheimer's Coordinating Center

[Previous Menu](#)   [NACC Home](#)   [NACC Member Home](#)  
[Personnel Directory](#)   [Collaborative Projects](#)   [MDS Data Call](#)   [The NACC Database](#)

---

Combined Neuropathology Search

---

Select From the Parameters Below then Click on Search

**MDS Data Elements:**

6. Gender:

7. Race:

23. Rel with Dementia:

36. DNA Done:

40b. PET Done:

17. Clinical Dementia:

22a. Stroke:

22b. Parkinsons:

22c. Depression:

19. Primary Clin DX:

31. Frozen Brain Sample:

---

**Neuropathology Data Elements:**

8A. NIA/Reagan Crit:

8B. CERAD Criteria:

8C. ADRDA/Khach Criteria:

8D. Other Criteria:

9. Braak & Braak Stage:

10. Neuritic Plaques:

11. Diffuse Plaques:

13. Lewy Bodies:

17A. Clinical Genetics:

18A. APOE:

18B. TAU Haplotype:

---

**Neuropathology Survey Data Elements:**

11. Stains used for identifying beta-amyloid pathology:

a. Silver stain:

b. Thioflavin-S:

c. Congo Red:

c. AB immunostain:

12. Stains used for identifying neurofibrillary pathology:

a. Silver stain:

b. Thioflavin-S:

c. Tau immunostain:

20. Additional special procedures performed on NP core tissue:

a. Immunoassay:

b. In situ hybrid:

c. Image analysis:

d. Stereology:

e. Electron Microscopy:

---

**FIGURE 5.** The combined Neuropathology Search Web Page. In this example, drop down menus are used to select the values for the data elements of interest.

of tables and individualized ID listings. The reports or listing may then be downloaded to the user's local computer in the form of Excel spreadsheets for local analysis. The NACC publications committee must first approve all publications using NACC data. The following is an example of how data could be accessed from the NACC web site.

- User requests all available autopsies with the following characteristics: 1) frozen brain sample available, 2) NIA/Reagan Institute neuropathology criteria of intermediate likelihood of dementia due to AD, and 3) tau immunostain ever used (Fig. 5).
- To obtain the results, three different datasets from the NACC database need to be accessed. These are the MDS, the Neuropathology Data Set, and the Neuropathology Procedures Survey Data Set.
- The accessing of these datasets is transparent to the user requesting information from the web site. The results of this request are shown in Table 1.
- There are 13 centers with autopsies meeting the above criteria with a total of 427 IDs. The requestor could then contact NACC or the individual centers if more information is needed on these IDs. (Note: a random algorithm generates NACC ID numbers so they cannot be associated with identifiable patient information except through individual center investigators.)

### Documentation/Data Backup

Documentation is imperative in the operation of all databases. NACC has developed both user and system documentation. This documentation is kept in hardcover versions and on the web site for ease of use. All data are backed up to tape every night. A tape is carried off-site to protect against disaster. Complete monthly backups are done and the tapes are kept perpetually.

**TABLE 1.** Number of IDs Meeting the NIA/Reagan Criteria of Intermediate Likelihood of Dementia due to AD, have a Frozen Brain Sample Available, and who were Autopsied at Centers that use of Tau Immunostain (N = 427)

Centers with autopsies meeting criteria	Total autopsies meeting criteria
A	18
B	282
C	7
D	4
E	20
F	2
G	4
H	26
I	31
J	27
K	3
L	2
M	1
Total	427

### RESULTS

The number of IDs collected each year has increased. The total number has increased by 55% since 1999. Currently, there are more than 66,000 IDs in the database. Table 2 stratifies these IDs by race and gender. The center's database has been successfully established to explain nuances in the data collected. Neuropathologic data have been collected on 83% of the IDs autopsied in the database. The quality and amount of neuropathology data collected have inspired the creation of an NIA ADC Clinical Task Force to similarly enhance the clinical content of the minimum dataset to create a more research oriented database.

The NACC web site has proven to be a good method to disseminate information and foster research across centers. Each year the use of the web site increases. NACC is installing larger servers to meet the demand of the web site and the expanded database. In the future, the data calls will be phased out in favor of using continuous data collection methods. This will allow for a more consistent database with data provided to researchers in a timelier manner.

### DISCUSSION

Creation of the NACC database has not only enhanced the reporting and research capabilities of the ADCs but it also has improved the database management at many of the centers. Centers have updated their data management systems to meet the demands of sending data to NACC. Increased standardization has also occurred as centers have complied with the requirements of the NACC database. This has created an environment where the centers are able to collect data elements specific for their individual research needs while collecting standardized data for collaborative research across centers. The database has also provided the NIA with rapidly available reports of subject status and enrollment at the individual centers and in the aggregate.

The keys to creating a database linking 32 diverse centers are: 1) keeping the database and the data collection methods flexible, 2) establishing good communication with the centers, and 3) implementing complete error checking and ID tracking. The database must allow for the addition and

**TABLE 2.** Race and Gender Stratification for the Total Number of Subjects Stored and Maintained in the NACC Database (N = 66,680)

Race	Gender		Total
	Male	Female	
White	22,615	32,371	54,986
Black	1948	5026	6974
American Indian/Alaskan Native	138	263	401
Asian or Pacific Islander	343	528	871
Other	943	1841	2784
Missing/unknown*	250	414	664
Total	26,237	40,443	66,680

\*A total of 664 subjects are missing data on race. These subjects are no longer being seen by the ADCs. Therefore, the data will not be collected.

change of data elements and datasets. Data collection from the centers with diverse capabilities must allow for many different ways to submit data. Each center must be communicated with in an individual manner to correct problem data and assure data quality. All data submitted to NACC are carefully checked for errors and checked for duplicate IDs. For example, IDs that are dropped from one year to the next are explained by the center so that data submitted to NACC are consistent. Data elements with inappropriate numbers of missing values are flagged and reported to the center and explanations are requested. Logical error checks must be done, not only within a current year's data call, but from year to year to ensure data integrity. It is important to do data cleaning year round.

As the NACC database matures, the data areas will continue to merge into a fully integrated database. In the future, NACC in conjunction with the NIA-appointed committees will continue to enlarge and enhance the data elements collected for the database.

## APPENDIX

The NIA-Alzheimer Disease Centers are as follows:

**Arizona ADC:** Eric M. Reiman, MD, Good Samaritan Regional Med Center, Phoenix, AZ; **Baylor College of Medicine:** Rachele Doody, MD, PhD, Houston, TX; **Boston University:** Neil Kowall, MD, Bedford VA Medical Center GRECC Program, Bedford, MA; **Case Western Reserve University:** Karl Herrup, PhD, Case Western Reserve University & University Hospitals of Cleveland, Cleveland, OH; **Columbia University:** Michael Shelanski, MD, PhD, Columbia University, New York, NY; **Duke University Medical Center:** Donald E. Schmechel, MD, Bryan ADRC, Durham, NC; **Emory University:** Allan I. Levey, MD, PhD, Emory University, Atlanta, GA; **Indiana University:** Bernardino Ghetti, MD, Indiana University School of Medicine, Indianapolis, IN; **Johns Hopkins University:** Donald Price, MD, Johns Hopkins University School of Medicine, Baltimore, MD; **Massachusetts General Hospital:** John H. Growdon, MD, Massachusetts General Hospital, Boston, MA; **Mayo Clinic:** Ronald C. Petersen, PhD, MD, Rochester, MN; **Mt. Sinai School of Medicine:** Mary Sano, PhD, Mt. Sinai School of Medicine, New York, NY; **New York University:** Steven H. Ferris, PhD, New York University Silberstein Aging & Dementia Research Center ADRC, New York, NY; **Northwestern University:** M.-Marsel Mesulam, MD, Northwestern University Medical School, Chicago, IL; **Oregon Health and Science University:** Jeffrey Kaye, MD, Oregon Health and Science University Aging & Alzheimer

Disease Center, Portland, OR; **Rush-Presbyterian-St. Luke's Medical Center:** David A. Bennett, MD, Rush Institute for Healthy Aging, Chicago, IL; **Stanford University:** Jerome Yesavage, MD, Stanford University, Palo Alto, CA; **University of Alabama at Birmingham:** Lindy E. Harrell, MD, PhD, University of Alabama at Birmingham Sparks Research Center, Birmingham, AL; **University of Arkansas:** Cornelia Beck, RN, PhD, University of Arkansas for Medical Science, Little Rock, AR; **University of California, Davis:** William Jagust, MD, University of California, Davis, Sacramento, CA; **University of California, Irvine:** Carl Cotman, PhD, University of California, Irvine, CA; **University of California, Los Angeles:** Jeffrey L. Cummings, MD, University of California, Los Angeles, Los Angeles, CA; **University of California, San Diego:** Leon J. Thal, MD, University of California, San Diego School of Medicine, La Jolla, CA; **University of Kentucky:** William Markesbery, MD, University of Kentucky, Lexington, KY; **University of Michigan:** Sid Gilman, MD, FRCP, University of Michigan, Ann Arbor, MI; **University of Pennsylvania:** John Q. Trojanowski, MD, PhD, University of Pennsylvania, Philadelphia, PA; **University of Pittsburgh:** Steven T. DeKosky, MD, University of Pittsburgh, Pittsburgh, PA; **University of Rochester:** Paul D. Coleman, PhD, University of Rochester Medical Center, Center for Aging & Development, Biology, Rochester, NY; **University of Southern California:** Caleb E. Finch, PhD, University of Southern California, Los Angeles, CA; **University of Texas Southwestern Medical Center:** Roger Rosenberg, MD, University of Texas SW Medical Center, Dallas, TX; **University of Washington:** Murray Raskind, MD, VA Puget Sound Health Care System Mental Health Services, Seattle, WA; **Washington University:** John C. Morris, MD, Washington University Medical Center, St. Louis, MO.

## REFERENCES

1. Cronin-Stubbs D, DeKosky ST, Morris JC, et al. Promoting interactions with basic scientists and clinicians: the NIA Alzheimer's Disease Data Coordinating Center. *Stat Med.* 2000;19:1453–1461.
2. Edland SD, Beekly D, Barnhart RL, et al. Design and implementation of a longitudinal multicenter database. *Neurology.* 1997;49(suppl 3):17–19.
3. Fillenbaum GG, Peterson B, Welsh-Bohmer KA, et al. Consortium to establish a registry for Alzheimer's disease: development, database structure, and selected findings. *Top Health Inf Manage.* 1997;18:47–58.
4. Pandav R, Mehta A, Belle SH, et al. Data management and quality assurance for an International project: the Indo-US Cross-National Dementia Epidemiology Study. *Int J Geriatr Psychiatry.* 2002;17:510–518.
5. SAS Institute. *Version 6.12.* Cary, NC: SAS Institute, 1997.
6. SUN Microsystems, Inc. *Solaris Operating Environment*, version 7. Santa Clara, CA: SUN Microsystems, 2000.
7. Colledge MJ. Statistical integration through metadata management. *Int Stat Rev.* 1999;67:79–98.