#### SAFEGUARDS:

Measures to prevent unauthorized disclosures are implemented as appropriate for each location and for the particular records maintained in each project. Each site implements personnel, physical and procedural safeguards such as the following:

- Authorized users: Access will be limited to principal investigators, collaborating researchers and necessary support staff.
- 2. Physical safeguards: Hard copy data will be maintained in locked file cabinets. Information stored in computer systems will be accessible only through proper sequencing of signal commands and access codes specifically assigned to the Project Officer or contractor.
- 3. Procedural safeguards: Access to the information will be controlled directly by the Project Officer or his or her representative at remote locations, and by the system manager at NIA locations. Contractors and collaborating researchers will be notified that they are subject to the provisions of the Privacy Act, and will be required to make formal agreements to comply with these provisions.

The particular safeguards implemented in each project are developed in accordance with Chapter 45–13 and supplementing Chapter PHS hf: 45–13 of the HHS General Administration Manual and Part 6, ADP Systems Security, of the HHS Information Resources Management Manual, and the National Institute of Standards and Technology Federal Information Processing Standards (FIPS Pub. 41 and FIPS Pub. 31).

## RETENTION AND DISPOSAL:

Records are retained and disposed of under the authority of the NIH Records Control Schedule contained in NIH Manual Chapter 1743, Appendix 1— "Keeping and Destroying Records" (HHS Records Management Manual, Appendix B–361), item 3000–G–3, which allows records to be kept as long as they are useful in scientific research. Refer to the NIH Manual Chapter for specific disposition instructions.

# SYSTEM MANAGER AND ADDRESS:

Associate Director, Epidemiology, Demography and Biometry Program, National Institute on Aging, Gateway Building, Suite 3C309, 7201 Wisconsin Avenue, Bethesda, MD 20892

# NOTIFICATION PROCEDURE:

To determine if a record exists, write to the System Manager at the above

address and provide the following information in writing:

- 1. Full name at time of participation in the study.
  - 2. Date of birth.
  - 3. Home address at the time of study.
- 4. The facility where the examination was given or where information was collected.
- 5. Approximate date or dates of participation.
  - 6. Name of study, if known.
- 7. Current name, address and telephone number.

The requester must also verify his or her identity by providing either a notarization of the request or a written certification that the requester is who he or she claims to be and understands that the knowing and willful request for acquisition of a record pertaining to an individual under false pretenses is a criminal offense under the Act, subject to a five thousand dollar fine.

An individual who requests notification of or access to a medical or dental record shall, at the time the request is made, designate in writing a responsible representative who will be willing to review the record and inform the subject individual of its contents at the representative's discretion.

### RECORD ACCESS PROCEDURE:

Contact the system manager at the above address and provide the same information as outlined under the notification procedures. Requesters should also reasonably specify the record contents being sought. Individuals may also request listings of accountable disclosures that have been made of their records, if any.

# CONTESTING RECORD PROCEDURE:

Contact the System Manager at the above address. The contestor must reasonably identify the record, specify in writing the information being contested, and state the corrective action sought and the reasons for the correction. The right to contest records is limited to information which is incomplete, irrelevant, incorrect or untimely (obsolete).

# RECORD SOURCE CATEGORIES:

Information will be obtained directly from individual participants and from medical and clinical research observations, or indirectly from existing source documents such as disease registries.

# SYSTEMS EXEMPTED FROM CERTAIN PROVISIONS OF THE ACT:

None.

#### 09-25-0148

#### SYSTEM NAME:

Contracted and Contract-Related Research: Records of Subjects in Clinical, Epidemiological and Biomedical Studies of the National Institute of Neurological Disorders and Stroke and the National Institute on Deafness and Other Communication Disorders, HHS/NIH/NINDS and HHS/ NIH/NIDCD.

## SECURITY CLASSIFICATION:

None.

#### SYSTEM LOCATION:

At National Institutes of Health facilities in Bethesda, Maryland, and at hospitals, medical schools, universities, research institutions, commercial organizations, state agencies, and collaborating Federal agencies. Inactive records may be retired to Federal Records Centers. A list of locations is available upon request from the respective System Managers of the subsystems included in this notice.

# CATAGORIES OF INDIVIDUALS COVERED BY THE SYSTEM:

Patients with neurological diseases, communicative disorders, stroke, hearing loss, chemosensory deficits, and related diseases; normal, healthy volunteers who serve as controls for comparison with patients, relatives of patients; and other individuals whose characteristics or conditions are suited for possible connections with the occurrence of the diseases and disorders under investigations. Subject individuals include both adults and children.

### CATEGORIES OF RECORDS IN THE SYSTEM:

This system consists of a variety of clinical, biomedical, and epidemiological information resulting from or contained in direct observations, medical records and other histories, vital statistics reports, records on biological specimens (e.g., blood, urine, etc.), personal interviews, questionnaires, progress reports, correspondence, or research findings.

## **AUTHORITY FOR MAINTENANCE OF THE SYSTEM:**

Sections 241, Research and Investigation, and 289a, Establishment of Institutes, of the Public Health Service Act (42 U.S.C. 301, 431).

## PURPOSE(S):

This system will be used to support (1) contracted and contract-related epidemiological, clinical and biometric investigations into the causes, nature, outcome, therapy, prevention and cost of neurological and communicative