disorders, hearing loss, chemosensory deficits, and stroke; (2) review and evaluation of the progress of these research projects, and identification and planning for improvements or for additional research.

ROUTINE USES OF RECORDS MAINTAINED IN THE SYSTEM, INCLUDING CATEGORIES OF USERS AND THE PURPOSES OF SUCH USES:

- 1. Disclosure may be made to HHS contractors, grantees and collaborating researchers and their staff in order to accomplish the research purpose for which the records are collected. The recipients are required to protect such records from improper disclosure.
- 2. Disclosure may be made to organizations deemed qualified by the Secretary to carry out quality assessments, medical audits or utilization review.
- 3. A record may be disclosed for a research purpose, when the Department: (A) Has determined that the use or disclosure does not violate legal or policy limitations under which the record was provided, collected, or obtained; (B) has determined that the research purpose (1) cannot be reasonably accomplished unless the record is provided in individually identifiable form, and (2) warrants the risk to the privacy of the individual that additional exposure of the record might bring; (C) has required the recipient to (1) establish reasonable administrative, technical, and physical safeguards to prevent unauthorized use or disclosure of the record, (2) remove or destroy the information that identifies the individual at the earliest time at which removal or destruction can be accomplished consistent with the purpose of the research project, unless the recipient has presented adequate justification of a research or health nature for retaining such information, and (3) make no further use or disclosure of the record except (a) in emergency circumstances affecting the health or safety of any individual, (b) for use in another research project, under these same conditions, and with written authorization of the Department, (c) for disclosure to a properly identified person for the purpose of an audit related to the research project, if information that would enable research subjects to be identified is removed or destroyed at the earliest opportunity consistent with the purpose of the audit, or (d) when required by law; (D) has secured a written statement attesting to the recipient's understanding of, and willingness to abide by these provisions.
- The Department contemplates that it may contract with a private firm for the purpose of collating, analyzing,

- aggregating or otherwise refining records in this system. Relevant records will be disclosed to such a contractor. The contractor will be required to maintain Privacy Act safeguards with respect to such records.
- 5. In the event of litigation where the defendant is (a) the Department, any component of the Department, or any employee of the Department in his or her official capacity; (b) the United States where the Department determines that the claim, if successful, is likely to directly affect the operations of the Department or any of its components; or (c) any Department employee in his or her individual capacity where the Justice Department has agreed to represent such employee, for example, in defending against a claim based upon an individual's mental or physical condition and alleged to have arisen because of activities of the Public Health Service in connection with such individual, the Department may disclose such records as it deems desirable or necessary to the Department of Justice to enable that Department to present an effective defense, provided that such disclosure is compatible with the purpose for which the records were collected.
- 6. Disclosure may be made to a congressional office from the record of an individual in response to an inquiry from the congressional office made at the request of that individual.

POLICIES AND PRACTICES FOR STORING, RETRIEVING, ACCESSING, RETAINING, AND DISPOSING OF RECORDS IN THE SYSTEM:

STORAGE:

Data may be stored in file folders, computer-accessible forms (e.g. tapes or discs), punched cards, bound notebooks, microfilm, charts, graphs and X-rays.

RETRIEVABILITY:

Information is retrieved by name and/or patient identification number.

SAFEGUARDS:

- 1 Authorized users: Access to or disclosure of information is limited to collaborating researchers, contractors and employees, and other authorized biomedical researchers who are involved in the conduct, support or review and evaluation of the research activities supported by this system.
- 2. Physical safeguards: Data are kept in secured areas (e.g. rooms which are locked when not in regular use, buildings with controlled access). Data stored in computer-accessible form is accessed through the use of key words known only to principal investigators or

authorized personnel; all other information is stored in locked files.

3. Procedural safeguards: Contractors and collaborating or other researchers are required to comply with the provisions of the Privacy Act and with HHS Privacy Act regulations.

These and other appropriate safeguards are implemented in each project in accordance with Chapter 45–13, "Safeguarding Records Contained in Systems of Records," of the HHS General Administration Manual, supplementary Chapter PHS.hf: 45–13, 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(S) AND ADDRESS:

NINDS and NIDCD research activities are divided, functionally and administratively. In effect, there are six subsystems within this single umbrella system. NINDS has five programs and NIDCD one. System Managers have been designated for each subsystem as follows:

Director, Division of Human Communication, NIDCD, NIH, Executive Plaza South, Room 400B, 620 Executive Boulevard, Rockville, MD 20852

and

Director, Division of Fundamental Neurosciences, NINDS, NIH, Federal Building, Room 916, 7550 Wisconsin Avenue, Bethesda, MD 20892

and

Deputy Director, Division of Convulsive, Developmental and Neuromuscular, Disorders, NINDS, NIH, Federal Building, Room 816, 7550 Wisconsin Avenue, Bethesda, MD 20892

and

Director, Division of Demyelinating Atrophic, and Dementing Disorders, NINDS, NIH, Federal Building, Room 810, 7550 Wisconsin Avenue, Bethesda, MD 20892

and