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[Notices]  
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DEPARTMENT OF HEALTH AND HUMAN SERVICES

National Institutes of Health  
Privacy Act of 1974; New System of Records  
Agency: National Institutes of Health, HHS.  
Action: Notification of a New System of Records.

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**Summary:** In accordance with the requirements of the Privacy Act, the National Institutes of Health (NIH) is publishing a notice of a new system of records, 09-25-0200, "Clinical, Epidemiologic and Biometric Studies of the National Institutes of Health (NIH), HHS/NIH/OD." This system notice serves as an umbrella system for most NIH clinical, epidemiologic and biometric research studies. Thirty-eight existing NIH system notices were subsumed under this notice (listed in the system notice under System Manager(s)), to reduce the number and avoid future proliferation of like system notices. We are also proposing routine uses for this new system; with two exceptions, these routine uses were already contained in the preceding system notices. The first new routine use will allow disclosure to authorized organizations which provide health services to subject individuals or provide third-party reimbursement or fiscal intermediary functions. The purpose of the disclosure is to plan for or provide such services, bill or collect third-party reimbursements. The second new routine use will allow disclosure for the purpose of reporting child, elder, or spousal abuse or neglect, or any other type of abuse or neglect as required by State or Federal law.

**Dates:** NIH invites interested parties to submit comments on the proposed internal and routine uses on or before May 7, 1997. NIH has sent a report of a New System to the Congress and to the Office of Management and Budget (OMB) on November 6, 1996. This system of records will be effective 40 days from the date of publication unless NIH receives comments on the routine uses which would result in a contrary determination.

**Address:** Please submit comments to: NIH Privacy Act Officer, Building 31, Room 1B05, 31 Center Drive MSC 2075, Bethesda, MD 20892-2075, 301-496-2832. Comments received will be available for inspection at this same address from 9 a.m. to 3 p.m., Monday through Friday.

**For further information contact:** NIH Privacy Act Officer, Building 31, Room 1B05, 31 Center Drive MSC 2075, Bethesda, MD 20892-2075, 301-496-2832. The numbers listed above are not toll free.

**Supplementary information:** The National Institutes of Health (NIH) proposes to establish a new system of records: 09-25-0200, "Clinical, Epidemiologic and Biometric Studies of the National Institutes of Health (NIH), HHS/NIH/OD." This umbrella system of records will be used by NIH staff to document, track, monitor and evaluate NIH clinical, epidemiologic and biometric research activities. This inclusive system notice will achieve agency administrative efficiencies, avoiding confusion created by the current fragmented pool of Institute, Center and Division (ICD) system notices. Because of its unique organizational structure, NIH has, over the recent decades, experienced a proliferation of almost identical system notices that differ only by disease/disorder under study or ICD interest. This system notice subsumes thirty-eight existing system notices and will offer coverage for research not currently covered by an appropriate system notice. The consolidation of similar research systems of records into one generic-type notice will also serve the public interest. It will alleviate burden on the public associated with multiple attempts at notification, access and correction of record information when individuals are not sure which research system notice applied to their study participation.

The system will comprise records about individuals as relevant to a particular research study. Examples include, but are not limited to: Name, study identification number, address, relevant telephone numbers, Social Security Number (voluntary), driver's license number, date of birth, weight, height, sex, race; medical, psychological and dental information, laboratory and diagnostic testing results; registries; social, economic and demographic data; health services utilization; insurance and hospital cost data, employers, conditions of the work environment, exposure to hazardous substances/compounds; information pertaining to stored biologic specimens (including blood, urine, tissue and genetic materials), characteristics and activities of health care providers and educators and trainers (including curriculum vitae); and associated correspondence. The amount of information recorded on each individual will be only that which is necessary to accomplish the purpose of the system.

The records in this system will be maintained in a secure manner compatible with their content and use. NIH and contractor staff will be required to adhere to the provisions of the Privacy Act and the HHS Privacy Act Regulations. The System Manager will control access to the data. Only authorized users whose official duties require the use of such information will have regular access to the records in this system. Authorized users are HHS employees, and contractors responsible for implementing the research.

Records may be stored on index cards, file folders, computer tapes and disks (including optical disks), photography media, microfiche, microfilm, and audio and video tapes. Manual and computerized records will be maintained in accordance with the standards of Chapter 45-13 of the HHS General Administration Manual, "Safeguarding Records Contained in Systems of Records," supplementary Chapter PHS hf:45-13, the Department's Automated Information System Security Program Handbook, and the National Institute of Standards and Technology Federal Information Processing Standards (FIPS Pub. 41 and FIPS Pub. 31). Data on computer files is accessed by keyword known only to authorized users. Access to information is thus limited to those with a need to know. Rooms where records are stored are locked when not in use. During regular business hours rooms are unlocked but are controlled by on-site personnel. Researchers authorized to conduct research on biological specimens will typically access to the system through the use of encrypted identifiers sufficient to link individuals with records in such a manner that does not compromise confidentiality of the individual. All authorized users of personal information in connection with the performance of their jobs protect information from public view and from unauthorized personnel entering an unsupervised office. Depending upon the sensitivity of the information in the record, additional safeguard measures are employed.

The routine uses proposed for this system are compatible with the stated purposes of the system. The first routine use permits disclosure of a record for an authorized research purpose under specified conditions. The second routine use permitting disclosure to a congressional office is proposed to allow subject individuals to obtain assistance from their representatives in Congress, should they so desire. Such disclosure would be made only pursuant to a request of the individual.

The third routine use allows disclosure to the Department of Justice for use in litigation. The fourth routine use allows disclosure of records to contractor, grantee, experts, consultants or volunteers who have been engaged by the agency to assist in the performance of a service related to this system of records and who need to have access to the records in order to perform the activity. The fifth routine use allows disclosure to certain relevant third parties (e.g., relatives, prior employees, Motor Vehicle Administration, State vital statistics offices) when necessary to obtain information on morbidity and mortality experiences and to locate individuals for follow-up studies. The sixth routine use allows disclosure to tumor registries for maintenance of health statistics. The seventh routine use allows the PHS to inform the sexual and/or needle-sharing partner(s) of a subject individual who is infected with the human immunodeficiency virus (HIV) of their exposure to HIV, or to disclose such information to State or local public health departments under specified circumstances. The eighth routine use allows disclosure of certain diseases and conditions, including infectious diseases, to appropriate representatives of State or Federal Government as required by State or Federal law. The ninth routine use allows records to be disclosed to authorized organizations which provide health services to subject individuals or provide third-party reimbursement or fiscal intermediary functions, for the purpose of planning for or providing such services, billing or collecting third-party reimbursements. The tenth routine use allows disclosure to organizations deemed qualified by the Secretary, DHHS, to carry out quality assessment, medical audits or utilization reviews. The eleventh routine use allows information to be disclosed for the purpose of reporting child, elder or spousal abuse or neglect, or any other type of abuse or neglect as required by State or Federal law.

The following notice is written in the present, rather than future tense, in order to avoid the unnecessary expenditure of public funds to republish the notice after the system has become effective.

Dated: October 30, 1996.

Anthony L. Itteilag,

Deputy Director for Management, National Institutes of Health.

09-25-0200

**SYSTEM NAME:**

Clinical, Epidemiologic and Biometric Studies of the National Institutes of Health (NIH), HHS/NIH/OD.

**SECURITY CLASSIFICATION:** None.

**SYSTEM LOCATION:**

Records are located at NIH and Contractor research facilities which collect or provide research data for this system. Contractors may include, but are not limited to: Research centers, clinics, hospitals, universities, medical schools, research institutions/foundations, national associations, commercial organizations, collaborating State and Federal Government agencies, and coordinating centers. A current list of sites, including the address of any Federal Records Center where records from this system may be stored, is available by writing to the appropriate Coordinator listed under Notification Procedure.

**CATEGORIES OF INDIVIDUALS COVERED BY THE SYSTEM:**

Adults and/or children who are the subjects of clinical, epidemiologic, and biometric research studies of the NIH. Individuals with disease. Individuals who are representative of the general population or of special groups including, but not limited to: Normal controls, normal volunteers, family members and relatives; providers of services (e.g., health care and social work); health care professionals and educators, and demographic sub-groups as applicable, such as age, sex, ethnicity, race, occupation, geographic location; and groups exposed to real and/or hypothesized risks (e.g., exposure to biohazardous microbial agents).

**CATEGORIES OF RECORDS IN THE SYSTEM:**

The system contains data about individuals as relevant to a particular research study. Examples include, but are not limited to: Name, study identification number, address, relevant telephone numbers, Social Security Number (voluntary), driver's license number, date of birth, weight, height, sex, race; medical, psychological and dental information, laboratory and diagnostic testing results; registries; social, economic and demographic data; health services utilization; insurance and hospital cost data, employers, conditions of the work environment, exposure to hazardous substances/compounds; information pertaining to stored biologic specimens (including blood, urine, tissue and genetic materials), characteristics and activities of health care providers and educators and trainers (including curriculum vitae); and associated correspondence.

**AUTHORITY FOR MAINTENANCE OF THE SYSTEM:**

``Research and Investigation," ``Appointment and Authority of the Directors of the National Research Institutes," ``National Cancer Institute," ``National Eye Institute," ``National Heart, Lung and Blood Institute," ``National Institute on Aging," ``National Institute on Alcohol Abuse and Alcoholism," ``National Institute on Allergy and Infectious Diseases," ``National Institute of Arthritis and Musculoskeletal and Skin Diseases," ``National Institute of Child Health and Human Development," ``National Institute on Deafness and Other Communication Disorders," ``National Institute of Dental Research," ``National Institute of Diabetes, and Digestive and Kidney Diseases," ``National Institute of Drug Abuse," ``National Institute of Environmental Health Sciences," ``National Institute of Mental Health," ``National Institute of Neurological Disorders and Stroke," and the ``National Center for Human Genome Research," of the Public Health Service Act. (42 U.S.C. 241, 242, 248, 281, 282, 284, 285a, 285b, 285c, 285d, 285e, 285f, 285g, 285h, 285i, 285j, 285l, 285m, 285n, 285o, 285p, 285q, 287, 287b, 287c, 289a, 289c, and 44 U.S.C. 3101.)

**PURPOSE(S)**

To document, track, monitor and evaluate NIH clinical, epidemiologic and biometric research activities.

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

1. 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; e.g., disclosure of alcohol or drug abuse patient records will be made only in accordance with the restrictions of confidentiality statutes and regulations 42 U.S.C. 241, 42 U.S.C. 290dd-2, 42 CFR part 2, and where applicable, no disclosures will be made inconsistent with an authorization of confidentiality under 42 U.S.C. 241 and 42 CFR part 2a; (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; and (D) has secured a written statement attesting to the recipient's understanding of, and willingness to abide by, these provisions.

2. Disclosure may be made to a Member of Congress or to a Congressional staff member in response to an inquiry of the Congressional office made at the written request of the constituent about whom the record is maintained.

3. The Department of Health and Human Services (HHS) may disclose information from this system of records to the Department of Justice when: (a) The agency or any component thereof; or (b) any employee of the agency in his or her official capacity where the Department of Justice has agreed to represent the employee; or (c) the United States Government, is a party to litigation or has an interest in such litigation, and by careful review, the agency determines that the records are both relevant and necessary to the litigation and the use of such records by the Department of Justice is therefore deemed by the agency to be for a purpose that is compatible with the purpose for which the agency collected the records.

4. Disclosure may be made to agency contractors, grantees, experts, consultants, collaborating researchers, or volunteers who have been engaged by the agency to assist in the performance of a service related to this system of records and who need to have access to the records in order to perform the activity. Recipients shall be required to comply with the requirements of the Privacy Act of 1974, as amended, pursuant to 5 U.S.C. 552a(m).

5. Information from this system may be disclosed to Federal agencies, State agencies (including the Motor Vehicle Administration and State vital statistics offices, private agencies, and other third parties (such as current or prior employers, acquaintances, relatives), when necessary to obtain information on morbidity and mortality experiences and to locate individuals for follow-up studies. Social Security numbers, date of birth and other identifiers may be disclosed: (1) To the National Center for Health Statistics to ascertain vital status through the National Death Index; (2) to the Health Care Financing Agency to ascertain morbidities; and (3) to the Social Security Administration to ascertain disabilities and/or location of participants. Social Security numbers may also be given to other Federal agencies, and State and local agencies when necessary to locating individuals for participation in follow-up studies.

6. Medical information may be disclosed in identifiable form to tumor registries for maintenance of health statistics, e.g., for use in epidemiologic studies.

7. (a). PHS may inform the sexual and/or needle-sharing partner(s) of a subject individual who is infected with the human immunodeficiency virus (HIV) of their exposure to HIV, under the following circumstances: (1) The information has been obtained in the course of clinical activities at PHS facilities carried out by PHS personnel or contractors; (2) The PHS employee or contractor has made reasonable efforts to counsel and encourage the subject individual to provide the information to the individual's sexual or needle-sharing partner(s); (3) The PHS employee or contractor determines that the subject individual is unlikely to provide the information to the sexual or needle-sharing partner(s) or that the provision of such information cannot reasonably be verified; and (4) The notification of the partner(s) is made, whenever possible, by the subject individual's physician or by a professional counselor and shall follow standard counseling practices.

(b). PHS may disclose information to State or local public health departments, to assist in the notification of the subject individual's sexual and/or needle-sharing partner(s), or in the verification that the subject individual has notified such sexual or needle-sharing partner(s).

8. Certain diseases and conditions, including infectious diseases, may be reported to appropriate representatives of State or Federal Government as required by State or Federal law.

9. Disclosure may be made to authorized organizations which provide health services to subject individuals or provide third-party reimbursement or fiscal intermediary functions, for the purpose of planning for or providing such services, billing or collecting third-party reimbursements.

10. The Secretary may disclose information to organizations deemed qualified to carry out quality assessment, medical audits or utilization reviews.

11. Disclosure may be made for the purpose of reporting child, elder or spousal abuse or neglect or any other type of abuse or neglect as required by State or Federal law.

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

##### STORAGE:

Records may be stored on index cards, file folders, computer tapes and disks (including optical disks), photography media, microfiche, microfilm, and audio and video tapes. For certain studies, factual data with study code numbers are stored on computer tape or disk, while the key to personal identifiers is stored separately, without factual data, in paper/computer files.

##### RETRIEVABILITY:

During data collection stages and follow-up, retrieval is by personal identifier (e.g., name, Social Security Number, medical record or study identification number, etc.). During the data analysis stage, data are normally retrieved by the variables of interest (e.g., diagnosis, age, occupation).

##### SAFEGUARDS:

1. Authorized Users: Access to identifiers and to link files is strictly limited to the authorized personnel whose duties require such access. Procedures for determining authorized access to identified data are established as appropriate for each location. Personnel, including contractor personnel, who may be so authorized include those directly involved in data collection and in the design of research studies, e.g., interviewers and interviewer supervisors; project managers; and statisticians involved in designing sampling plans. Other one-time and special access by other employees is granted on a need-to-know basis as specifically authorized by the system manager. Researchers authorized to conduct research on biologic specimens will typically access the system through the use of encrypted identifiers sufficient to link individuals with records in such a manner that does not compromise confidentiality of the individual.

2. Physical Safeguards: Records are either stored in locked rooms during off-duty hours, locked file cabinets, and/or secured computer facilities. For certain studies, personal identifiers and link files are separated and stored in locked files. Computer data access is limited through the use of key words known only to authorized personnel.

3. Procedural Safeguards: Collection and maintenance of data is consistent with legislation and regulations in the protection of human subjects, informed consent, confidentiality, and confidentiality specific to drug and alcohol abuse patients where these apply. When anonymous data is provided to research scientists for analysis, study numbers which can be matched to personal identifiers will be eliminated, scrambled, or replaced by the agency or contractor with random numbers which cannot be matched. Contractors who maintain records in this system are instructed to make no further disclosure of the records. Privacy Act requirements are specifically included in contracts for survey and research activities related to this system. The OHS project directors, contract officers, and project officers oversee compliance with these requirements. Personnel having access are trained in Privacy Act requirements. Depending upon the sensitivity of the information in the record, additional safeguard measures may be employed.

4. Implementation Guidelines: DHHS Chapter 45-13 and supplementary Chapter PHS.hf: 45-13 of the HHS General Administration Manual and Part 6, "ADP System Security" of the HHS ADP Systems Security Manual.

##### 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. Collaborative Perinatal Project records are retained in accordance with item 3000-G-4, which does not allow records to be destroyed. William A. White Clinical Research Program medical records (Saint Elizabeths Hospital, NIMH) are retained for 5 years after last discharge or upon death of a patient and then transferred to the Washington National Records Center, where they are retained until 30 years after discharge or death. Refer to the NIH Manual Chapter for specific conditions on disposal or retention instructions.

#### SYSTEM MANAGER(S) AND ADDRESS:

See Appendix I for a listing of current system managers. This system is for use by all NIH Institutes, Centers, and Divisions. The following system notices have been subsumed under this umbrella system notice.

09-25-0001	Clinical Research: Patient Records, HHS/NIH/NHLBI
09-25-0010	Research Resources: Registry of Individuals Potentially Exposed to Microbial Agents, HHS/NIH/NCI
09-25-0015	Clinical Research: Collaborative Clinical Epilepsy Research, HHS/NIH/NINDS
09-25-0016	Clinical Research: Collaborative Perinatal Project, HHS/NIH/NINDS
09-25-0026	Clinical Research: Nervous System Studies, HHS/NIH/NINDS
09-25-0028	Clinical Research: Patient Medical Histories, HHS/NIH/NINDS and HHS/NIH/NIDCD
09-25-0031	Clinical Research: Serological and Virus Data in Studies Related to the Central Nervous System, HHS/NIH/NINDS
09-25-0037	Clinical Research: The Baltimore Longitudinal Study of Aging, HHS/NIH/NIA
09-25-0038	Clinical Research: Patient Data, HHS/NIH/NIDDK
09-25-0039	Clinical Research: Diabetes Mellitus Research Study of Southwestern American Indians, HHS/NIH/NIDDK
09-25-0040	Clinical Research: Southwestern American Indian Patient Data, HHS/NIH/NIDDK
09-25-0042	Clinical Research: National Institute of Dental Research Patient Records, HHS/NIH/NIDR
09-25-0044	Clinical Research: Sensory Testing Research Program, HHS/NIH/NIDR
09-25-0046	Clinical Research: Catalog of Clinical Specimens from Patients, Volunteers and Laboratory Personnel, HHS/NIH/NIAID
09-25-0053	Clinical Research: Vision Studies, HHS/NIH/NEI
09-25-0057	Clinical Research: Burkitt's Lymphoma Registry, HHS/NIH/NCI
09-25-0060	Clinical Research: Division of Cancer Treatment Clinical Investigations, HHS/NIH/NCI
09-25-0067	Clinical Research: National Cancer Incidence Surveys, HHS/NIH/NCI
09-25-0069	NIH Clinical Center Admissions of the National Cancer Institute, HHS/NIH/NCI
09-25-0074	Clinical Research: Division of Cancer Biology and Diagnosis Patient Trials, HHS/NIH/NCI
09-25-0077	Biological Carcinogenesis Branch Human Specimen Program, HHS/NIH/NCI
09-25-0126	Clinical Research: National Heart, Lung, and Blood Institute Epidemiological and Biometric Studies, HHS/NIH/NHLBI
09-25-0128	Clinical Research: Neural Prosthesis and Biomedical Engineering Studies, HHS/NIH/NINDS
09-25-0129	Clinical Research: Clinical Research Studies Dealing with Hearing, Speech, Language and Chemosensory Disorders, HHS/NIH/NIDCD
09-25-0130	Clinical Research: Studies in the Division of Cancer Cause and Prevention, HHS/NIH/NCI
09-25-0134	Clinical Research: Epidemiology Studies, National Institute of Environmental Health Sciences, HHS/NIH/NIEHS
09-25-0142	Clinical Research: Records of Subjects in Intramural Research, Epidemiology, Demography and Biometry Studies on Aging, HHS/NIH/NIA
09-25-0143	Biomedical Research: Records of Subjects in Clinical, Epidemiologic and Biometric Studies of the National Institute of Allergy and Infectious Diseases, HHS/NIH/NIAID
09-25-0145	Clinical Trials and Epidemiological Studies Dealing with Visual Disease and Disorders in the National Eye Institute, HHS/NIH/NEI
09-25-0148	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

09-25-0152 Biomedical Research: Records of Subjects in National Institute of Dental Research Contracted  
Epidemiological and Biometric Studies, HHS/NIH/NIDR

09-25-0153 Biomedical Research: Records of Subjects in Biomedical and Behavioral Studies of Child Health and  
Human Development, HHS/NIH/NICHHD

09-25-0154 Biomedical Research: Records of Subjects: 1) Cancer Studies of the Division of Cancer Prevention and  
Control, HHS/NIH/NCI; and 2) Women's Health Initiative (WHI) Studies, HHS/NIH/OD

09-25-0170 Diabetes Control and Complications Trial (DCCT) Data System, HHS/NIH/NIDDK

09-25-0172 Clinical Research: National Center for Human Genome Research, HHS/NIH/NCHGR

09-25-0201 Clinical Research: National Institute of Mental Health Patient Records, HHS/NIH/NIMH

09-25-0205 Alcohol, Drug Abuse, and Mental Health Epidemiologic and Biometric Research Data, HHS/NIH/NIAAA,  
HHS/NIH/NIDA and HHS/NIH/NIMH

09-25-0212 Clinical Research: Neuroscience Research Center Patient Medical Records, HHS/NIH/NIMH

#### NOTIFICATION PROCEDURE:

To determine if a record exists, write to the appropriate ICD Privacy Act Coordinator listed below. In cases where the requestor knows specifically which System Manager to contact, he or she may contact the System Manager directly (See Appendix I). Notification requests should include: Individual's name; current address; date of birth; date, place and nature of participation in specific research study; name of individual or organization administering the research study (if known); name or description of the research study (if known); address at the time of participation; and in specific cases, a notarized statement (some highly sensitive systems require two witnesses attesting to the individual's identity). A requestor must verify his or her identity by providing either a notarization of the request or by submitting a written certification that the requestor 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.

Individuals will be granted direct access to their medical records unless the System Manager determines that such access is likely to have an adverse effect (i.e., could cause harm) on the individual. In such cases when the System Manager has determined that the nature of the record information requires medical interpretation, the subject of the record shall be requested to 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. The representative may be a physician, other health professional, or other responsible individual. In this case, the medical/dental record will be sent to the designated representative. Individuals will be informed in writing if the record is sent to the representative. This same procedure will apply in cases where a parent or guardian requests notification of, or access to, a child's or incompetent person's medical record. The parent or guardian must also verify (provide adequate documentation) their relationship to the child or incompetent person as well as his or her own identity to prove their relationship. If the requester does not know which Institute, Center or Division Privacy Act Coordinator to contact for notification purposes, he or she may contact directly the NIH Privacy Act Officer at the following address: NIH Privacy Act Officer, Office of Management Assessment, Building 31, Room 1B05, 31 Center Drive MSC 2075, Bethesda, MD 20892-2075.  
NIH Privacy Act Coordinators

Office of the Director, (OD), NIH

Associate Director for Disease Prevention, OD, NIH  
Building 1, Room 260  
1 Center Drive  
Bethesda, MD 20892

National Cancer Institute (NCI)

Privacy Act Coordinator, NCI, NIH  
Building 31, Room 10A34  
31 Center Drive  
Bethesda, MD 20892

National Eye Institute (NEI)

Privacy Act Coordinator, NEI, NIH  
Building 31, Room 6A-19  
31 Center Drive  
Bethesda, MD 20892

National Heart, Lung and Blood Institute (NHLBI)

Privacy Act Coordinator, NHLBI, NIH  
Building 31, Room 5A08  
31 Center Drive  
Bethesda, MD 20892

National Institute on Aging (NIA)

Privacy Act Coordinator, NIA, NIH  
Building 31, Room 2C12  
31 Center Drive  
Bethesda, MD 20892

National Institute on Alcohol Abuse and Alcoholism (NIAAA)

Privacy Act Coordinator, NIAAA, NIH  
Wilco Building, Suite  
6000 Executive Blvd., MSC 7003  
Bethesda, MD 20892-7003

National Institute of Allergy and Infectious Diseases (NIAID)

Privacy Act Coordinator, NIAID, NIH  
Solar Building, Room 3C-23  
6003 Executive Blvd.  
Bethesda, MD 20892

National Institute of Arthritis and Musculoskeletal and Skin  
Diseases (NIAMS)

Privacy Act Coordinator, NIAMS, NIH  
Natcher Building, Room 5QS49  
45 Center Drive  
Bethesda, MD 20892

National Institute of Child Health and Human Development (NICHD)

Privacy Act Coordinator, NICHD, NIH  
6100 Executive Blvd., Room 5D01  
North Bethesda, MD 20892

National Institute on Deafness and Other Communication Disorders (NIDCD)

Privacy Act Coordinator, NIDCD, NIH  
Building 31, Room 3C02  
9000 Rockville Pike  
Bethesda, MD 20892

National Institute of Dental Research (NIDR)

Privacy Act Coordinator, NIDR, NIH  
Building 31, Room 2C-35  
31 Center Drive, MSC 2290  
Bethesda, MD 20892-2290

National Institute of Diabetes and Digestive and Kidney Disease (NIDDK)

Privacy Act Coordinator, NIDDK, NIH  
Building 31, Room 9A47  
31 Center Drive  
Bethesda, MD 20892

National Institute on Drug Abuse (NIDA)

Privacy Act Coordinator, NIDA, NIH  
Parklawn Building, Room 10A-42  
5600 Fishers Lane  
Rockville, Maryland 20857

National Institute of Environmental Health Sciences (NIEHS)

Chief, Epidemiology Branch, NIEHS, NIH  
P.O. Box 12233  
Research Triangle Park  
North Carolina 27709



National Institute of Mental Health (NIMH)

Privacy Act Coordinator, NIMH, NIH  
Parklawn Building, Room 7C-22  
5600 Fishers Lane  
Rockville, Maryland 20857

National Institute of Neurological Disorders and Stroke (NINDS)

Privacy Act Coordinator, NINDS, NIH  
Federal Building, Room 816  
7550 Wisconsin Avenue  
Bethesda, MD 20892

National Center for Human Genome Research (NCHGR)

Chief, Office of Human Genome Communications, NCHGR, NIH  
Building 38A, Room 617  
9000 Rockville Pike  
Bethesda, Maryland 20892

RECORD ACCESS PROCEDURE:

Same as notification procedures. Requesters should reasonably specify the record contents being sought. An individual may also request an accounting of disclosures of his/her record, if any.

CONTESTING RECORD PROCEDURE:

Contact the appropriate official at the address specified under Notification Procedure, and reasonably identify the record, specify the information being contested, and state corrective action sought, with supporting information to show how the record is inaccurate, incomplete, untimely, or irrelevant.

RECORD SOURCE CATEGORIES:

The system contains information obtained directly from the subject individual by interview (face-to-face or telephone), written questionnaire, or by other tests, recording devices or observations, consistent with legislation and regulation regarding informed consent and protection of human subjects. Information is also obtained from other sources, including but not limited to: Referring medical physicians, mental health/alcohol/drug abuse or other health care providers; hospitals; organizations providing biological specimens; relatives; guardians; schools; and clinical medical research records.

SYSTEMS EXEMPTED FROM CERTAIN PROVISIONS OF THE ACT:

None.

Appendix I: System Managers and Addresses

Office of the Director, NIH

Associate Director for Disease Prevention, OD, NIH  
Building 1, Room 260  
1 Center Drive  
Bethesda, MD 20892

National Cancer Institute

Computer Systems Analyst, DCBD, NCI, NIH  
Executive Plaza North, Room 344  
Bethesda, MD 20892

American Burkitt's Lymphoma Registry

Division of Cancer Etiology, NCI, NIH  
Executive Plaza North, Suite 434  
6130 Executive Blvd.  
Bethesda, MD 20892

Chief, Genetic Epidemiology Branch, EBP, DCE, NCI, NIH  
Executive Plaza North, Suite 439  
6130 Executive Blvd.  
Bethesda, MD 20892

Chief, Clinical Genetics Section  
Clinical Epidemiology Branch, DCE, NCI, NIH  
Executive Plaza North, Suite 400  
6130 Executive Blvd.  
Bethesda, MD 20892

Program Director, Research Resources  
Biological Carcinogenesis Branch, DCE, NCI, NIH  
Executive Plaza North, Room 540  
6130 Executive Blvd.  
Bethesda, MD 20892

Chief, Environmental Epidemiology Branch, DCE, NCI, NIH  
Executive Plaza North, Room 443  
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