

## **NHANES DATA RELEASE and ACCESS POLICY**

This policy addresses when, to whom, and in what form the Division of Health Examination Statistics (DHANES) disseminates National Health and Nutrition Examination Survey (NHANES) data and also outlines dissemination procedures. This DHANES policy is consistent with the CDC and NCHS policies, including the guiding principles of making high quality data available

- as widely as practicable
- as soon as possible after data collection
- in as much detail as possible

while maintaining survey participant confidentiality.

Various mechanisms of data release and access will be used to meet the requirements of these principles including public data release as well as limited data access arrangements.

### **DHANES Policy on Public Release Data:**

- A. Beginning with NHANES 1999-2000, public use data releases will be made on a biannual basis. Due to the voluminous nature of NHANES and the large amount of post data-collection processing, release of all data from two years of data collection will not occur at one point in time. It is anticipated that release will occur twice a year until all releasable data are available for public use. More frequent releases may occur if needed. See Appendix.
- B. Public use data releases from prior NHANES (through NHANES III) will consist predominantly of additional datasets derived from surplus sera projects or special use agreements and will be released on an ad hoc basis. Data release will occur after data cleaning, editing, documentation and DRB review, estimated to be within three months of receipt of the data, subject to manpower limitations.
- C. ‘Need to Know Release’: Urgent policy or legislative-related requests on estimates developed from targeted analyses of data not yet publicly released
  - a. Recipients: CDC, HHS, OMB, OIG, GAO, or the Office of the Surgeon General
  - b. How: Analyses will be conducted by staff in DHANES and approved for release by the Director, DHANES or his/her designee
  - c. Process: Submission of a data analysis request in writing to the Director, DHANES

### **DHANES Policy on Obtaining Access to Data that will not be Publicly Released:**

Several mechanisms will be used for access to non-public data. Each mechanism has specific access criteria and associated procedures.

1. NHANES Data Support Agreements:

- a. Recipients: Identified experts under signed agreement to assist in data collection or processing.
  - b. When: During survey planning, data collection or editing.
  - c. Process: These agreements are initiated by the NHANES program.
2. NHANES QA/QC Collaborator datasets:
    - a. Recipients: Current NHANES Collaborators, as outlined in inter-agency agreements (IAAs) instituted during component planning or funding process.
    - b. When: approximately three months prior to public release.
    - c. Process: Inter-agency QA/QC dataset agreement (*see appendix*) noting restrictions on QA/QC dataset sharing, analysis and publication prior to public release.
  3. NHANES Special Use Data Agreements: Under special circumstances NCHS enters into an agreement to provide a limited non-public special dataset that cannot be released publicly. The user must agree to all conditions of data use for this data.
    - a. Recipients:
      - i. NHANES current Collaborators – e.g. odd year datasets
      - ii. CDC employees on-site at NCHS – e.g. non-DHANES employees
      - iii. Any researcher – physical samples from an NHANES survey such as surplus sera projects, DNA, imaging studies, or data that has been approved for release by the DRB under a special use agreement
    - b. When: (ongoing) Timing of access may be limited by manpower resources to prepare a dataset; agreements to access the data cannot exceed a two year period.
    - d. Process: Requestors must submit a request for a Special Use Data Agreement to the Director, DHANES. These agreements shall be reviewed for approval by the Director, DHANES or his/her designate, and the NCHS Confidentiality Officer.
  4. NCHS RDC applications: Requests to match NHANES data to external data sources; to analyze lower level geography or indirect identifiers; for access to non-public release data which are the basis of published analyses (e.g. published analyses based on one year of data).
    - a. Recipients: Any researcher
    - b. When: (ongoing) RDC proposals are reviewed and approved by the Director, DHANES or his/her designee; timing of access may be limited by manpower resources to prepare a dataset
    - c. Process: Submission of a research proposal to the RDC

**DHANES Policy on Release of New Data Items Derived from NHANES Physical Samples:**

Whenever new data items are developed using physical samples from an NHANES survey such as surplus sera projects, DNA, imaging studies, these new data items will be

made publicly accessible under either public use; special use agreement, or RDC access, depending on the nature of the derived data item and disclosure risk. If requested data are not currently collected or available in NHANES, a proposal to obtain (and fund) the new data items can be made to the Director, DHANES. The proposal will be reviewed by the Director, DHANES or his/her designee. Any data developed under this mechanism will be made accessible under either public use; special use agreement, or RDC access to appropriate recipients as noted above.

APPENDIX.

1. NHANES Public Use Data Release schedule:

[Http://www.cdc.gov/nchs/data/nhanes.htm](http://www.cdc.gov/nchs/data/nhanes.htm)

2. DHANES Collaborator Agreement for Access to QA/QC Datasets:

THE DEPARTMENT OF HEALTH AND HUMAN SERVICES  
The Public Health Service  
The Centers for Disease Control and Prevention (CDC)  
The National Center for Health Statistics (NCHS)  
And  
*Agency Name*

**AGREEMENT BETWEEN NCHS AND *Agency Initials*  
REGARDING PROVISION OF ACCESS TO *Year* NHANES DATA FILE.**

Pursuant to its authority to support statistical and epidemiological activities to improve the effectiveness, efficiency, and quality of health services in the United States, (42 U.S.C. 242k(a)), the National Center for Health Statistics (NCHS) agrees to provide to **Agency Name**, (**AGENCY INITIALS**), a data file from the National Health and Nutrition Examination Survey (NHANES) containing **Year** NHANES data. This will enable the **AGENCY INITIALS** to review for quality purposes the **Year** NHANES data before general release. Prior to being granted access to the data, an individual with organizational oversight over the persons (staff and contractors) accessing the data will sign this agreement.

**AGENCY INITIALS** agrees that no abstracts or manuscripts will be submitted or public presentations occur using the data in this data set prior to the general release. The general release is planned to occur on the NCHS Internet in **Date**.

The individual signing this agreement assures that appropriate administrative, technical, procedural, and physical safeguards shall be established by **AGENCY INITIALS** to prevent unauthorized access to or publication or presentation of the data. If these responsibilities are transferred within **AGENCY INITIALS**, NCHS will be notified promptly and before such official transfer is made.

At the time of general release **AGENCY INITIALS** will return to NCHS this data file (including any copies or backup files) or document that the file has been destroyed.

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**Project Officer, AGENCY INITIALS**  
**E-mail address**

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**Name**  
Director, DHANES, NCHS

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