## **NHANES Data Release and Access Policy**

This policy addresses when, to whom, and in what form the Division of Health Examination Surveys (DHANES) disseminates National Health and Nutrition Examination Survey (NHANES) data and 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; and
- While maintaining survey participant confidentiality.

Various mechanisms of data release and access are 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:

- Since NHANES 1999-2000, public use data releases have been and continue to 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 an initial data release will occur approximately nine months after the completion of each two-year data collection cycle, and intermittent releases will follow as remaining data are processed, until all releasable data are available for public use.
- 2. Public use data releases from prior NHANES (through NHANES III) will consist predominantly of additional datasets derived from stored sera projects or special use agreements and will be released on an ad hoc basis. Data release occurs after data cleaning, editing, documentation and Disclosure Review Board (DRB) review, estimated to be within three months of receipt of the data, subject to work force limitations.

## DHANES policy on obtaining access to data that have not been publicly released:

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

- 1. For quality assurance/quality control (QA/QC) purposes:
  - a. Recipients: current NHANES Collaborators, as outlined in inter-agency agreements (IAAs) instituted during component planning or funding process, or identified experts to assist in data collection or data processing;
  - b. Process: DHANES will work with NCHS Confidentiality Office to initiate a Data Sharing Agreement (DSA) or a Designated Agency Agreement (DAA) noting restrictions on QA/QC dataset sharing, analysis and publication prior to public release. The NCHS Confidentiality Office will assess the level of potential disclosure risk and stipulate the type of agreement to be used (i.e., DSA or DAA). The Director of DHANES or his/her designate, and the NCHS Confidentiality Officer or his/her designate, review agreements for approval.
- 2. For research purposes:
  - a. Recipients: Any researcher;
  - b. Process: Submission of a research proposal to the NCHS Research Data Center (RDC).

## DHANES policy on release of new data items derived from NHANES physical samples:

Whenever new data items are developed using physical samples from a NHANES survey such as stored sera, DNA, or imaging studies, these new data items are made publicly accessible under either public use, 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 submitted via email to NHANES Biospecimen Program. The NHANES Project Officer and a technical panel evaluate all proposals for scientific merit. The NCHS Human Subject Contact and Ethics Review Board (ERB) then review the proposal for any potential human subjects concerns and the NCHS Confidentiality Officer for disclosure risk. Any data developed under this mechanism are made accessible under either public use, or RDC access to appropriate recipients as noted above. Please refer to the NHANES Biospecimen Program website for more detailed information: <a href="https://www.cdc.gov/nchs/nhanes/biospecimens/biospecimens.htm">https://www.cdc.gov/nchs/nhanes/biospecimens/biospecimens.htm</a>.