

Guidance on Granting Access to Nonpublic Use NCHS Data

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Background: NCHS data release policy, consistent with that of CDC and the NCHS authorizing legislation, other relevant legislation and applicable OMB directives and policies, is to make high quality data available as widely as practicable, as soon after data collection as possible, and in as much detail as feasible, while maintaining survey participant confidentiality. Nonpublic data are sometimes needed by researchers or collaborators for data support purposes and quality control, or statistical research on files that will not be made public. Although NCHS will not provide preferential early access to microdata files or tabulations prior to public release, limited files or tabulations that might not be approved for public release due to risk of disclosing confidential information may be made available through the [NCHS Research Data Centers](#), or through limited special use agreements where justified and consistent with NCHS confidentiality and data release policies.

Access to nonpublic NCHS data may be granted for the purposes and using the mechanisms described below. Irrespective of the purpose, data items that increase risk of identification will be transformed to reduce disclosure risk to the extent possible. Access to nonpublic NCHS data may occur only after the required agreement (generally a [Designated Agent Agreement \(DAA\)](#)) for population survey or examination data, and a [Data Use Agreement for Vital Statistics data](#) has been signed and system security requirements have been met. Access will be limited to only the information needed to complete the identified task. Record identifiers enabling linkage to public use files will not be provided. Access to personally identifiable data will rarely be granted and only be granted if required for linkage to administrative data. Linkage activities are generally restricted to the [NCHS Research Data Center](#).

In cases where limited nonpublic data are made available for research purposes to one user, NCHS will consider requests by other users for the same data and grant access if confidentiality and data security provisions are met and the use falls within the purpose for which the data were collected. NCHS programs must make notification on the NCHS internet site that limited nonpublic data files are available under restricted use conditions.

Survey and Examination data:

1. Data support provided under contract and/or by identified experts to assist in data collection or processing: Agreements will be initiated by NCHS during the survey planning, data collection or editing stages. No abstracts, presentations, nor publications may be developed from this work unless specifically identified in a contract or other mechanism as well as in the [Designated Agent Agreement](#) executed as part of the access agreement.

2. Quality Control/Quality Assurance Collaborator activities designed to evaluate or improve the quality of data items: Collaborators, identified in Interagency Agreements (IAA) or contracts during the data collection planning or funding process may enter into a [Designated Agent Agreement \(DAA\)](#) to obtain short-term access to subsets of variables for quality control/quality assurance purposes prior to public release of data. Entire microdata files (i.e. all variables for all records) will not be made available. **Use of a [NCHS RDC](#) is the strongly preferred method of access.** Where use of a NCHS RDC is not feasible due to the type of programming procedures utilized or output required, access to files outside NCHS computing environments may be permitted if documentation of security equivalent to that of NCHS is provided and such capacity is documented in the DAA. Analysis must be confined to evaluating quality on a subset of variables identified in the DAA. No abstracts, presentations, or manuscripts using this data set may be created or released prior to the release of the public use file of which they are a part. If access occurs outside the RDC environment, the original data, backup files and derivative files must be destroyed or returned according to the schedule specified in the DAA.

3. Special Use activities such as analysis of limited nonpublic special datasets that will not be released publicly or development of new data items derived from physical samples from a NCHS survey: Collaborators and researchers may enter into a [Designated Agent Agreement \(DAA\)](#) to obtain access to subsets of variables for purposes of statistical analysis, including development of new data items. Entire microdata files will not be made available. **Use of a [NCHS RDC](#) is the strongly preferred method of access.** Justification for not using the NCHS RDC must be submitted to the NCHS Confidentiality Officer who will review it, and after consultation with the data program, decide whether an exception to NCHS RDC use is warranted. Where use of a NCHS RDC is not feasible, access to files outside NCHS computing environments may be permitted if documentation of system security equivalent to that of NCHS (see attached) is provided and such capacity is documented in the DAA. Matching to external data sources through use of direct identifiers, analysis of subnational geography (generally at the state or lower geography level), or use of genetic information or administratively linked files may occur only within a NCHS RDC. Abstracts, presentations, or manuscripts using limited nonpublic special datasets must be reviewed for confidentiality by the NCHS designee identified in the DAA prior to release for publication. If access occurs outside the RDC environment, the original data, backup files and derivative files must be destroyed or returned according to the schedule specified in the DAA.

Whenever new data items are developed using physical samples from an NHANES survey such as surplus sera projects, DNA, or imaging studies, these new data items will be made publicly accessible through the appropriate mechanism: public use, special use

agreement, or RDC access. Original materials must be returned to NCHS or destroyed as specified in the DAA.

Vital Statistics Data:

1. State laws, regulations on re-release of vital statistics data, and NCHS contracts with the States to obtain access to vital data underlie the policy regarding re-release of restricted data on births and deaths. The NCHS agreements with the states on the re-release of restricted data require a review of all such data requests by the [National Association for Public Health Statistics and Information Systems \(NAPHSIS\)](#), which represents state vital registrars. The review by NAPHSIS is conducted prior to the NCHS review and includes both federal and non-federal requests for restricted data files. The review process involves the researcher submitting a completed [project review form](#), available from NAPHSIS, to the NAPHSIS review team. Some states have laws, regulations or policies that prohibit release of certain data items. In the course of the review the NAPHSIS review team will determine whether the request violates any of the state limitations. The researcher will be notified by NAPHSIS of their decision on the data request. NCHS will also be apprised of the NAPHSIS review decision, at which time NCHS will conduct its usual review. If the proposal is approved, the NCHS Division of Vital Statistics point-of-contact will send the researcher (and his/her contractors if federal) a [Data Use Agreement](#). All data users associated with the research must agree to the conditions of usage, which include using the files only for the purpose stated in the proposed scope of work, returning the files at the time specified in the data user agreement, and not sharing the data with anyone not listed in the data use agreement. If a project proposal is denied, alternative access may be available through the [NCHS Research Data Center](#), which has specific procedures to follow for controlled access to microdata files.
2. Researchers may request microdata files (birth, death, fetal death, and linked birth/infant death) containing geographic detail for all States and counties. Non-federal researchers may access exact dates of vital events only through the [NCHS Research Data Center](#).
3. Researchers in federal agencies, as well as their on-site or off-site contractors, may request exact dates of vital events as well as geographic details for birth, death, fetal death, and linked birth/infant death microdata files.
4. Researchers may request the matched multiple birth file with all States and counties or exact dates included. Access to these files is limited to the [NCHS Research Data Center](#).
5. Researchers may request compressed files (death only) containing geographic detail for all States and counties. Compressed files replace identical records with a single record

and the count of the number of times that record occurs in the file. Compressed mortality files list the year and county of death, race (white, black, other), cause of death, sex, and broad age group categories.

Guest Researchers:

The Guest Researcher program is a non-FTE program managed through the CDC/ATSDR and Office of the Chief Operating Officer/Human Capital and Resources Management Office/Executive and Scientific Resources Office (OCOO/HCRMO/ESRO). The purpose of this program is to allow qualified research investigators (scientists, engineers, and faculty) to use CDC facilities in order to take part in CDC research investigations or to carry out their own research. Individuals approved as guest researchers are not CDC/ATSDR employees and are not paid directly by the CDC for their research. See the [Guest Researcher Program webpage](#) for information on this program and the requirements for a guest researcher.

1. The [NCHS RDC](#) is the preferred work station for NCHS guest researchers because it affords the most protection for NCHS data. A researcher working solely in the NCHS RDC will not access the wider CDC computer systems and therefore will not need to request a computer account. The researcher must complete the paperwork required by the RDC (confidentiality training, designated agent agreement, affidavit of non-disclosure, etc.) and CDC forms for entrance into the NCHS buildings. The Director of the NCHS RDC should be consulted for requirements for guest researchers wishing to use the RDC. Access to NCHS non-public data may only occur after all approvals have been obtained.
2. Although the [NCHS RDC](#) is the preferred work station for guest researchers, a NCHS division or office Director may request a guest researcher be assigned work space near NCHS staff for purposes of collaboration. The guest researcher working outside the RDC will access data using CDC systems and therefore must complete forms requesting a CDC computer account. The guest researcher must also complete CDC paperwork required for entering the NCHS buildings. *In addition to completing forms permitting access to the CDC computer system and physical facilities, a NCHS guest researcher must* (1) take the on-line NCHS Confidentiality training and provide a printed certificate of completion; (2) complete a [Designated Agent Agreement](#)¹, and (3) be granted

¹ The NCHS policy and procedure (including the Designated Agent form and affidavit of non-disclosure) are found at <http://inside.nchs.cdc.gov/omo/Policy/Guest%20Researcher/Guest-Researcher-ORISE-Procedures.pdf>. Under part IV Procedures, Guest Researcher, step 2, click on the bullet “NCHS Designated Agent Form”; go to page 9 Parts A, B, and C to access the NCHS forms to be completed by on-site agents who are not working in the RDC.

permission by the Division/Program to access the CIPSEA server and its files. Access to NCHS non-public data may only occur after all approvals have been obtained.

For questions concerning the guidance, contact the NCHS Confidentiality Officer, nchsconfidentiality@cdc.gov.

Additional Resources:

NCHS Data Release Policy: http://www.cdc.gov/nchs/about/policy/data_release.htm

NHANES Data Release Policy: http://www.cdc.gov/nchs/data/nhanes/nhanes_release_policy.pdf

NCHS Legislative Authorities: <http://www.cdc.gov/nchs/data/misc/legislation2014.pdf>

NCHS Guidelines for Ensuring the Quality of Information Disseminated to the Public: <http://www.cdc.gov/nchs/about/policy/quality.htm>

Designated Agent Authority Policy at the National Center for Health Statistics: http://inside.nchs.cdc.gov/opbl/data/NCHS_Designated_Agent_Policy_and_Forms.pdf

NCHS Confidentiality Training: http://www.cdc.gov/nchs/about/policy/confidentiality_training/index.html