

# Data Use Agreement for 2014 NS-DATA Tourette Syndrome Pre-RDC Data File

DEPARTMENT OF HEALTH AND HUMAN SERVICES  
Centers for Disease Control and Prevention  
National Center for Health Statistics

**Instructions:**

*The Primary Investigator/Requestor must read and complete pages 1-4.*

*Each additional user of this file must read and complete **page 4** (Confidentiality Agreement).*

**Return completed form to:**

Director, Division of Health Interview Statistics, National Center for Health Statistics, 3311 Toledo Road,  
Hyattsville, MD 20782

This is a data use agreement between CDC/NCHS and the Primary Investigator (PI)/Requestor named below, regarding use of the **2014 National Survey of Diagnosis and Treatment of ADHD and Tourette Syndrome (NS-DATA), Tourette Syndrome (TS) Pre-RDC Data File**.

The National Center for Health Statistics (NCHS) agrees to provide to

\_\_\_\_\_ at \_\_\_\_\_  
(name of PI/requestor) (organization)

the **2014 NS-DATA TS Pre-RDC file**, a file intended solely for preliminary and/or feasibility analysis in preparation for submitting a Research Data Center (RDC) proposal to access data from the TS module in the RDC.

\_\_\_\_\_ **agrees that:**  
(PI/requestor)

**1. The 2014 NS-DATA TS Pre-RDC file will be used only for purposes of statistical research: specifically, to inform subsequent research using the unperturbed TS data in the NCHS Research Data Center (RDC).** *(PI/Requestor will attach a brief written description of the analyses that are to be conducted using this file.)* No attempt will be made to learn or disclose the identity of any individual in the survey sample, and survey information will not be used in any way to affect directly any individual survey participant including any administrative or judicial purposes. To this end, the PI/requestor is responsible for obtaining and keeping on file a signed copy of this agreement and the attached "Data User's Confidentiality Agreement" from each person approved to access the TS Pre-RDC file. Strict penalties apply to any willful disclosure of confidential information about NCHS survey participants or to non-statistical uses of these data.

**2. The PI/requestor and all persons using the file understand the limitations of and potential uses of the 2014 NS-DATA TS Pre-RDC file, including:**

- a. that the file includes both weighted and unweighted cases. The 78 completed interviews with parents or guardians of children who had been identified as having TS during the administration of the 2011-2012 National Survey of Children's Health (NSCH) were weighted to attempt to represent the population of children who had TS as of 2011-2012. However, the sample size was too small to adequately adjust the weights to account for differential nonresponse in several demographic categories, and the representativeness of the sample weights is thus suspect. There were 37 additional TS cases discovered during the administration of the NS-DATA interview, all

of whom were children who had been identified as having ADHD, but not TS, in the NSCH interview, and were discovered to have been diagnosed with TS during the NS-DATA interview; since they were not part of the population of children with TS in 2011-2012, and because there was no source of population control totals for the population of children with TS in 2014, these additional cases are not included in the sample weights.

- b. Analysts should therefore plan to use the 2014 NS-DATA TS Pre-RDC file to investigate differences using the 78 weighted cases versus using the full file unweighted, to decide which to use in subsequent analyses in the RDC.
- c. The 2014 NS-DATA TS Pre-RDC file is not appropriate for population estimation purposes. Because of the disclosure risk associated with the very rare and observable TS condition, the TS pre-RDC file is not linkable to the public NSCH data. To prevent such linkage, some data elements have been perturbed slightly and data elements common to both NSCH public data and the TS data from NS-DATA have been dropped from the TS Pre-RDC file to prevent matching. The list of such suppressed data elements includes the sample design variables necessary to appropriately generate population variance estimates. Thus, variance estimates will be incorrect without the sample design information. Population estimates should only be generated using the unperturbed data with the sample design variables in the RDC.
- d. Analysts wishing to examine frequency distributions of variables to gauge the feasibility of analysis are advised to use the TS pre-RDC file to examine the variables in that file. For variables excluded from the file due to matching data elements in the NSCH public data, analysts are encouraged to examine the distributions of the NSCH variables among the population of children ages 2-15 with Tourette Syndrome.
- e. Questions concerning the 2014 NS-DATA TS Pre-RDC file should be directed to the SLAITS team at NCHS ([slaits@cdc.gov](mailto:slaits@cdc.gov)) for a response.

3. The only persons to be allowed access to the 2014 NS-DATA TS Pre-RDC file on this project will be those who have signed a copy of this User Agreement. The PI/requestor is personally responsible for the physical security of data file. The PI/requestor will employ measures to prevent unauthorized computer access to the file, and will describe those measures specifically in the written request for the file.

4. The 2014 NS-DATA TS Pre-RDC file is provided to the PI/requestor, not to his or her institution. Co-investigators, including colleagues, graduate and undergraduate students and research assistants, working with or under the direction of the primary investigator shall provide a signed Data User's Confidentiality Agreement (page 4 of this document) before having access to the data file.

5. Users are reminded that Title 18, Section 1001 of the United States Code states that "Deliberately making a false statement in any matter within the jurisdiction of any Department or Agency of the Federal Government violates 18 USC 1001 and is punishable by a fine of up to \$10,000 or up to 5 years in prison." In addition, the Confidential Information and Protection of Statistical Information Act (CIPSEA) of 2002 stipulates that any "knowing and willful disclosure of confidential information" constitutes a Class E Felony, carrying a penalty up to \$250,000 or up to 5 years in prison.

6. The 2014 NS-DATA TS Pre-RDC file will not be copied for use beyond this project. All requests from others for this file will be referred to NCHS. Such requests or orders should be referred to the SLAITS team at NCHS ([slaits@cdc.gov](mailto:slaits@cdc.gov)) for a response.

7. Manuscripts, presentations and other products for public dissemination shall not be prepared from analyses using the 2014 NS-DATA TS Pre-RDC file. The file shall only be used to inform planned analyses of the unperturbed data in the RDC. All output resulting from analyses in the RDC will be reviewed by Matthew Bramlett, SLAITS Program representative to the RDC, for disclosure risk prior to release from the RDC. Any products intended for public dissemination that use analyses of the unperturbed TS data in the RDC must also be sent to Dr. Bramlett for review before being submitted for publication (for the purpose of assessing disclosure risk only).

8. The 2014 NS-DATA TS Pre-RDC file will remain the responsibility of the requestor. When the requestor finishes using the file, or if the requestor changes her or his place of employment, she or he will retain the files, return the files to NCHS, or destroy them. The requestor will submit a written statement to SLAITS ([slaits@cdc.gov](mailto:slaits@cdc.gov)) confirming a change in storage status of the files and will provide a certificate of destruction of the data at the termination of the Agreement. No copy of the variable or data files will be left behind.

9. This Agreement limits the requestor's use of the 2014 NS-DATA TS Pre-RDC file to 1 year from the date these data are sent from NCHS. It may be extended for one year, upon written request 30 days prior to the termination of the Agreement. Otherwise, these data must be destroyed or returned to NCHS by the termination date. The requestor will provide a certificate of destruction of the data at the termination of the Agreement.

**Signatures:**

Primary Investigator/Requestor (date)

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Program Representative, SLAITS (date)

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***Primary Investigators:***

***Please continue to page 4 to read and sign the Confidentiality Agreement.***

***Recall that EACH additional data user on this project must sign a separate copy of the Confidentiality Agreement on page 4, listing you as the Primary Investigator.***

## Data User's Confidentiality Agreement

SLAITS data are collected under a pledge of confidentiality and promise to use the data for statistical purposes only. SLAITS data are protected under CIPSEA, Title V of the E-Government Act of 2002 (Public Law 107-347) and the Public Health Service Act, which specify that data collected by the National Center for Health Statistics may not be used for any purpose other than that for which it was supplied. The information on the microdata public use files was supplied to NCHS for statistical research and reporting purposes. It is necessary, therefore, that the individual using such files sign the following assurance:

**Being aware that I am subject to all of the requirements of Public Law 107-347 (CIPSEA) and the Public Health Service Act (42 U.S.C. 242m(d)), I agree that:**

1. The data will be used only for purposes of statistical research. No attempt will be made to learn the identity of individuals in the survey; and data will not be used in any way to affect directly any survey participant.
2. Only persons who have signed and returned this confidentiality agreement will have access to the 2014 NS-DATA Tourette Syndrome Pre-RDC data file.
3. Should I receive a request for the 2014 NS-DATA TS Pre-RDC data file from anyone who has not signed this agreement, that request shall be referred to NCHS.
4. The data are being provided to me, not to my institution. I am personally responsible for observance of all conditions of use and for the establishment of and maintenance of security arrangement to prevent unauthorized use of these files. These responsibilities will not be transferred to another person without first obtaining written permission from NCHS.
5. Users are reminded that Title 18, Section 1001 of the United States Code states that "Deliberately making a false statement in any matter within the jurisdiction of any Department or Agency of the Federal Government violates 18 USC 1001 and is punishable by a fine of up to \$10,000 or up to 5 years in prison." In addition, the Confidential Information and Protection of Statistical Information Act (CIPSEA) of 2002 stipulates that any "knowing and willful disclosure of confidential information" constitutes a Class E Felony, carrying a penalty up to \$250,000 or up to 5 years in prison.

Date: \_\_\_\_\_

Name (print): \_\_\_\_\_ Signature: \_\_\_\_\_

Title: \_\_\_\_\_ Email: \_\_\_\_\_

Organization: \_\_\_\_\_

Name of Primary Investigator (if other than you): \_\_\_\_\_