

Frequently Asked Questions

2014 National Survey of the Diagnosis and Treatment of Attention-Deficit/Hyperactivity Disorder and Tourette Syndrome

The 2014 National Survey of the Diagnosis and Treatment of Attention-Deficit/Hyperactivity Disorder and Tourette Syndrome (NS-DATA) assessed the diagnostic experiences and the service and treatment utilization of families raising children aged 4-17 with attention-deficit/hyperactivity disorder (ADHD) and with Tourette syndrome (TS). The questions and answers below summarize key information about the NS-DATA survey, which is a follow-up survey to the 2011-2012 National Survey of Children's Health (NSCH). A detailed report on the design and operation of the NS-DATA survey is forthcoming and will be released online as soon as possible.

The design of the 2011-2012 NSCH is similar to the 2003 NSCH and the 2007 NSCH. Detailed descriptions of the design and operation of these surveys, as well as descriptions of the publicly available files and data editing procedures, are published online (<http://www.cdc.gov/nchs/slaits/nsch.htm>). Similar detail for the 2011-2012 NSCH is not yet available. However, a "Frequently Asked Questions" document for the 2011-2012 NSCH has been posted online (<http://tinyurl.com/nschfaq>) that highlights changes made to the design and administration of the survey. Users of the NS-DATA survey data are encouraged to review these documents.

This document highlights general information unique to the NS-DATA survey design. Please read it before analyzing the NS-DATA data.

BACKGROUND

Who sponsored the National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome?

- The Centers for Disease Control and Prevention (CDC), the National Center on Birth Defects and Developmental Disabilities, and the National Center for Health Statistics.

Who conducted the National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome?

- CDC's National Center for Health Statistics (NCHS), State and Local Area Integrated Telephone Survey (SLAITS) program.

SAMPLE DESIGN

What was the 2014 NS-DATA sample design?

- A follow-up survey to the 2011-2012 NSCH, which was a cross-sectional random-digit-dial telephone survey (including landlines and cell phones) of US households with at least one child aged 0 to 17 years at the time of the NSCH interview.
- A sample of children identified as having (or having had) Attention-Deficit/Hyperactivity Disorder (or Attention Deficit Disorder) and/or Tourette Syndrome. Their parents and guardians were re-contacted by telephone for the NS-DATA interview 2-3 years after the original NSCH interview.
- Because the NS-DATA survey follows the NSCH, it shares the complex survey design of the NSCH, with clustering of children within households and stratification by state and sample type (landline or cell phone).

How was eligibility determined?

- Telephone numbers for the randomly selected NS-DATA-eligible NSCH households were called and screened to ensure that the children still met all three eligibility criteria:
 - The NS-DATA-eligible child was still under 18 years of age at the time of the NS-DATA interview.
 - The NS-DATA-eligible child continued to live in the contacted household.
 - The respondent confirmed or reported that a doctor or other health care provider had ever said that the child had ADHD or TS.
- If the child no longer met all of the above eligibility criteria, the call was terminated.
- If the telephone number no longer reached the household containing the NS-DATA-eligible child, additional efforts were made to try to locate a respondent living in the household with the NS-DATA-eligible child by 1) calling any available telephone numbers for the respondent or alternate contact that were provided during the NSCH, and 2) performing extensive searches using various Internet sites. If the information did not lead to a household containing the selected NS-DATA-eligible child, the case was deemed not locatable.

QUESTIONNAIRE

What is the content of the NS-DATA survey?

- The NS-DATA survey consists of two telephone interview modules. One was administered to respondents with children ever diagnosed with ADHD and the other was administered to respondents with children ever diagnosed with TS. If a child had ever been diagnosed with both conditions, respondents were administered both modules. Both instruments are available online at http://www.cdc.gov/nchs/slaits/ns_data.htm.
- The telephone interview asked respondents about the emergence of symptoms, the context of the original diagnoses, the providers who made the diagnoses, the child's current diagnostic status, the types of clinical treatments/interventions and educational services, and other parental concerns.
- Only the ADHD interview module data are publicly available. The TS interview module data can be made available through the NCHS Research Data Center: <http://www.cdc.gov/rdc>. For more information please contact slaits@cdc.gov.

What is the source of the National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome survey questions?

- Most of the NS-DATA survey questions were developed especially for the survey to meet various data needs. However, the questionnaire does include several question sets drawn from other sources, including the 2011 Survey of Pathways to Diagnosis and Services, the 2011-2012 National Survey of Children's Health, and the 2009-2010 National Survey of Children with Special Health Care Needs. Additional sources are as follows:
 - Questions in section D of the ADHD module come directly from the Vanderbilt Attention Deficit/Hyperactivity Parent Rating Scale, a scale designed to measure ADHD symptomatology, as well as the child's academic performance (Wolraich *et al.*, 2003).
 - Question ADHD_D2C_1 came from the Developmental Coordination Disorder Questionnaire (Wilson *et al.*, 2009).
 - Questions in section G of the ADHD module come directly from the American Community Survey (Brault, 2009).

DATA COLLECTION

When were the data collected?

- NS-DATA telephone interviewing began on January 22, 2014 and ended on June 25, 2014.

Who was the respondent?

- The parent or guardian with knowledge of the health and health care of the child. Of these respondents, 71% were the mother (biological, step, foster, or adoptive), 18% were the father (biological, step, foster, or adoptive), and 11% were some other relative or guardian.

What was the average interview length?

- The average telephone interview length for eligible respondents for the ADHD module was 37 minutes and 34 seconds, and the median time was 36 minutes and 17 seconds. The average telephone interview length for eligible respondents for the TS module was 22 minutes and 32 seconds, and the median time was 23 minutes and 39 seconds.

How many interviews were completed?

- 3,018 telephone interviews were completed.
- A total of 73 respondents completed both the TS and the ADHD module for their child.
- The following table gives the number of completed interviews by the developmental conditions children have ever been told to have, as reported by their parents or guardians:

Condition	Count
ADHD only	2,903
TS only	42
Both ADHD and TS	73
Total	3,018

- Some new children with ADHD were identified among households who were contacted regarding their child's TS and likewise some new children with TS were identified among households who were contacted about their child's ADHD. New ADHD cases (n=10) are not included in the ADHD module data file, but new TS cases are available in the TS module data file (n=37).

How much time elapsed between completion of the 2011-2012 NSCH and the NS-DATA survey?

- Re-contact for the NS-DATA survey took place an average of 29 months after the initial NSCH interview.

What was the interview completion rate?

- Response rates are only available for respondents of children ever diagnosed with ADHD in the NSCH. Children who were sampled for TS in the NSCH were excluded from this calculation given the small sample size and weighting scheme.
- The response rate is the number of completed interviews as a proportion of the number of eligible units in the sample. For NS-DATA, this rate is the product of the recontact rate (58.4%) and the interview completion rate among recontacted households (80.8%), or 47.2%.
- However, the NSCH response rate was 23%. Thus, accounting for nonresponse to the NSCH, the overall NS-DATA response rate is the product of the NS-DATA response rate and the NSCH response rate, or 11%. See the NSCH “Frequently Asked Questions” document for more detail about the NSCH response rate.
- It should be noted that the NSCH response rate of 23% does not mean that three-quarters of eligible households refused to participate in the NSCH. The NSCH response rate is low in part because of phone numbers that ring with no answer and for whom eligibility cannot be determined. The NSCH cooperation rate among eligible households, or interview completion rate, was 51.4%.

Were parents and guardians offered monetary incentives to participate?

- To improve the likelihood that parents and guardians of eligible children would participate in the survey, a detailed incentive plan was implemented. All parents and guardians were offered an incentive. The value of the incentive to complete the initial telephone interview was \$20, with \$40 being offered to those who completed both the ADHD and TS module among eligible respondents. [A subset of respondents were offered an additional \$5 based on multiple factors including previous locating efforts, child’s condition and previous contact attempts].

What non-English languages were used to complete the interviews?

- The NS-DATA ADHD module was administered in English and Spanish only, while the NS-DATA TS module was only administered in English.

DATA FILES

How many interviews were included on the final data files?

- The publicly released microdata file includes data from all completed NS-DATA ADHD module telephone interviews (n = 2,966) among those initially sampled for ADHD. Children with TS at NSCH who were later discovered to have been diagnosed with ADHD since the NSCH interview and whose caregivers completed the ADHD module (n=10) are not included in the final data file.

If respondents were permitted to provide multiple answers for the same question, how is this reflected in the data file?

- When respondents were permitted to provide multiple answers for the same question, a dummy variable was created for each possible answer. The values for these new dummy variables are “1” (yes, this answer was given) and “0” (no, this answer was not given). When respondents could not or did not provide an answer to the question, a value of “6” (don’t know) or “7” (refused) is reported for each of the dummy variables.

What variables were suppressed to protect confidentiality of NS-DATA participants?

- NCHS takes extraordinary measures to assure that the identity of survey subjects cannot be disclosed. The risk of inadvertent disclosure of confidential information regarding individual respondents is higher with a publicly released data set having detailed geography variables, a detailed and extensive set of survey observations, and a sizeable proportion of the total population of interest. Coarsening a data set by suppressing survey variables, collapsing multiple variables into one, and/or collapsing response categories for other variables are common techniques to reduce the risk of inadvertent disclosure. These techniques have been applied to the publicly available NS-DATA microdata file to reduce the risk of inadvertent disclosure for children with severe functional limitations, heavy use of clinical services, or unusual patterns in their diagnostic history and service utilization:
 - Age at time of survey (AGE_NSDATA) was collapsed into two or three year age brackets (AGE_NSDATAR).
 - Whether a child had received a changed diagnosis (captured in question ADHD_A4_1CA) to either schizophrenia/schizoaffective disorder (ADHD_A4_1CA_X11) or personality disorder (ADHD_A4_1CA_X12) has been suppressed from the dataset. Individuals who were diagnosed with these conditions were placed in the “other” category of the series (ADHD_A4_1CA_X14).
 - Current and lifetime diagnoses of intermittent explosive disorder (ADHD_B1_1_12 & ADHD_B1_2_12), eating disorder (ADHD_B1_1_14 & ADHD_B1_2_14), and substance use disorder (ADHD_B1_1_15 & ADHD_B2_1_15) were suppressed in the dataset and instead collapsed into a new variable of “other disorders” (ADHD_B1_1_16 & ADHD_B1_2_16).
 - The specific medications children were taking (ADHD_C1_4_NEW) were suppressed and converted into ten derived medication class variables (ADHD_MEDS_CLASS_1 – ADHD_MEDS_CLASS_10).
 - Specific grades repeated by the child (ADHD_E4_X01-ADHD_E4_X13) were suppressed and converted into derived variables ADHD_E4R and MULT_REPEATS.
 - Specific grades when the child was expelled from school (ADHD_E6_X01-ADHD_E6_X15) were suppressed and converted into derived variables ADHD_E6R and MULT_EXPELS.
 - The specific dollar value of family income (ADHD_H3_Q01-ADHD_H3_Q06) and year of income (INC_YR) were suppressed and converted into derived variable POVLEVEL1_4.
 - Health insurance questions (ADHD_H2_Q01-ADHD_H2_Q04) were suppressed and converted into derived variables TYPEINS and CONTINS.
 - The respondent’s relationship to the child (ADHD_H1_Q03) was suppressed and converted into a collapsed derived variable (ADHD_RELATION).
 - The specific individuals living in the household (ADHD_H1_Q04_X01-ADHD_H1_Q04_X26), whether the child was adopted (ADHD_H1_Q03_ADOPT), whether the child has appeared in court (ADHD_E7), and the language of the interview (LANG) was suppressed.
 - The number of individuals living in the household (ADHD_H1_Q01), the number of medications currently taken by the child (ADHD_C1_7) and the number of health care provider visits for medication management (ADHD_C1_8) were top-coded.
- Most sociodemographic data for NS-DATA eligible children were collected as part of the NSCH. Please refer to documentation for the NSCH for information about suppression, coarsening, and other edits to the sociodemographic data.

The exact responses for all questions requiring verbatim response were also suppressed. However, where possible, the responses were coded back into the available response options for the original questions as appropriate. In certain cases, new response options or variables were created, which include the following:

- Question ADHD_A1_1 has added response option 18 (in variable ADHD_A1_1_NEW).
- Question ADHD_A1_3 has added three response variables ADHD_A1_3_NEW_X17, ADHD_A1_3_NEW_X18, ADHD_A1_3_NEW_X19.
- Additional responses to question ADHD_A2_1E lead to the creation of response variable ADHD_A2_1F.
- Additional responses to question ADHD_A4_1D lead to the creation of response variables ADHD_A4_1E and ADHD_A4_1F.
- Additional response to question ADHD_C1_5L lead to the creation of response variables ADHD_C1_5M, ADHD_C1_5N, ADHD_C1_5O, ADHD_C1_5P, ADHD_C1_5Q, ADHD_C1_5R, ADHD_C1_5S, and ADHD_C1_5T.
- Question ADHD_C1_9 has added response option 10 (in variable ADHD_C1_9_NEW).
- Responses to question ADHD_C3_8 lead to the creation of response variables ADHD_C3_8_X01, ADHD_C3_8_X02, ADHD_C3_8_X03, ADHD_C3_8_X04, ADHD_C3_8_X05, and ADHD_C3_8_X06.
- Responses to questions ADHD_C3_8A - ADHD_C3_8C lead to the creation of response variables ADHD_C3_8_X01A, ADHD_C3_8_X02A, ADHD_C3_8_X03A, ADHD_C3_8_X04A, ADHD_C3_8_X05A, and ADHD_C3_8_X06A.

- Analysts interested in working with data that were suppressed may apply to access unmodified data files through the NCHS Research Data Center (RDC). For more information about how to apply for access, analysts may visit the website at <http://www.cdc.gov/rdc>.

Can I link the NS-DATA data file to the 2011-2012 NSCH data file?

- Data on the publicly released NS-DATA ADHD module microdata file can be linked to data for the same child from the publicly released NSCH microdata files. To merge the NS-DATA data with the NSCH household data, sort both files by the household identification number (IDNUMR). Once the files are properly sorted, merge them by IDNUMR.

SAMPLING WEIGHTS

How were the data weighted for the ADHD module?

- The NS-DATA sample was selected from children identified in the 2011-2012 NSCH as being eligible for the NS-DATA survey. Therefore, the final child weights from the NSCH weighting process were the base sampling weights for the NS-DATA survey.
- Adjustments to the base sampling weights included the following steps and calculations:
 - Adjustment for non-contact of released eligible telephone numbers
 - Adjustment for incomplete condition-eligibility screener at the start of the NS-DATA telephone interview
 - Adjustment for condition-ineligible cases
 - Adjustment for incomplete age and residency screeners, for age ineligibility, and for residency ineligibility
 - Adjustment for age ineligible cases who were 15 years old at NSCH
 - Adjustment for nonresponse to the NS-DATA telephone questionnaire
 - Raking adjustment of nonresponse-adjusted telephone interview weights

What is the final sampling weight variable?

- ADHD_WT: This NS-DATA telephone interview weight should be used when the units of analysis are children with completed NS-DATA telephone interviews.

ESTIMATION AND HYPOTHESIS TESTING

From what population was the sample drawn?

- The population was all noninstitutionalized children in the US who were aged 2-15 years and living in English- or Spanish-speaking households in 2011-2012.
- When survey weights are used, the resulting estimates are intended to be representative of the noninstitutionalized population of US children ever diagnosed with ADHD, as estimated from the 2011-2012 NSCH.
- These weighted estimates generalize to a population of children. The weighted estimates do not generalize to the population of parents, mothers, or pediatric health care providers.
- Due to the limited sample size and because the weights are not representative at the state level, the NS-DATA survey should not be used for state-level estimates.

Should I use a special computer program to analyze these data?

- Yes. For proper variance estimation, your computer program must be able to account for the complex sample design structure. Examples include SUDAAN, Stata, SPSS Complex Samples module, WesVar, the SAS SURVEY procedures, and the base program R with the separate SURVEY package.

What variables should be used to estimate variance?

- Stratum identifiers: STATE (NSCH strata for variance estimation) and SAMPLE (NSCH telephone sample type)
- Primary sampling unit (PSU) variable: IDNUMR (household identifier)
- The SAMPLE variable, which reflects the telephone sample type (landline or cell phone), must be included when specifying the sample design. Because of the weighting procedures for the NSCH, the data files should not be used to compare children from cell-phone-only households to children from landline households.
- Some analysts may be using statistical programs that only permit the specification of a single stratum variable. These users should define a new variable with 102 levels by crossing SAMPLE (2 levels) with STATE (51 levels). This new variable can then be used as the stratum variable. For example, Stata users can specify only one variable in the strata() option of svyset. This new variable (named here as STRATACROSS) can be created using the following statement:

```
EGEN STRATACROSS = GROUP (STATE SAMPLE)
```

- SUDAAN users can identify both STATE and SAMPLE in the NEST statement. However, SUDAAN users should note that the first variable listed after the word NEST is assumed to be the stratum variable, and the second variable listed is assumed to be the PSU. To properly identify the PSU variable, the PSULEV option must be invoked in the NEST statement as shown here:

```
NEST STATE SAMPLE IDNUMR / PSULEV = 3;
```

Can the data be subsetted before analysis?

- The procedure of keeping only selected records and list-wise deleting other records is called subsetting the data. Most software packages that analyze complex survey data will incorrectly compute standard errors for subsetted data, because subsetting the data can delete important design information needed for variance estimation. Analysts should not subset the data. Analysts interested in examining specific population subgroups (such as children who currently have ASD) should use the appropriate options in their software package (e.g., SUBPOPN in SUDAAN).

WORKING WITH MISSING DATA

How are missing data identified on the data files?

- The SAS data files for the NS-DATA survey include special missing value codes for analysts who may wish to differentiate between different types of missing values.
 - “.L” (Legitimate skip)—Variable is missing due to valid questionnaire paths based on a previous answer to a root question.
 - “.M” (Missing)—May indicate that the variable is missing due to interviewer or system errors. In addition, all missing values for derived variables (i.e., variables whose response was not directly provided by the respondent) receive a “.M” code regardless of the reason for the missing data.
 - “.P” (Partially completed interview)—Variable is missing because the respondent ended the interview after reaching question ADHD_D1_1, but before completing the full interview.
- Data missing because the respondent did not know the answer or refused to provide the answer have been treated differently. A numeric code was used to identify these responses. Typically, unknown answers are coded as “6,” or “96.” Refused responses are coded as “7,” or “97.” However, the codes may be different for specific variables; therefore, analysts are encouraged to consult the data documentation and frequency lists to identify the correct codes for each variable. Failure to do so may result in inappropriate calculations, especially for variables measured using ordinal, interval, or ratio scales.

Have missing data for demographic variables been imputed?

- Although no data was imputed for NS-DATA, users are encouraged to retrieve the multiply imputed microdata file available for the 2011-2012 NSCH. The imputation file includes imputed data for household income relative to the poverty threshold. The file also contains a flag variable identifying which cases have imputed data. Those without missing data are shown with the original valid values, while those originally with missing data have had those missing data replaced with imputed data. The file contains a set of five imputations for each NSCH data record.
- Analysts can merge this imputed file to the publicly-released NS-DATA interview file. Statistical software products such as SAS and SUDAAN can be used to accomplish analysis while accounting for the uncertainty in the imputation process. To merge the imputed file to the NS-DATA interview file, first sort both files by the unique identifier (IDNUMR), and then merge both files by the same identifier variable.
- For more information about the use of the multiply-imputed data, see the reports and “Frequently Asked Questions” at: http://www.cdc.gov/nchs/slait/imp_data.htm.

GUIDELINES FOR DATA USE

The Confidential Information Protection and Statistical Efficiency Act (Section 512b) and the Public Health Service Act (Section 308d) provide that these data collected by NCHS may be used only for the purpose of health statistical reporting and analysis. Any effort to determine the identity of any reported case is prohibited by these laws. NCHS takes extraordinary measures to assure that the identity of survey subjects cannot be disclosed. All direct identifiers, as well as any characteristics that might lead to identification, have been omitted from the data set. Any intentional identification or disclosure of a person or establishment violates the assurances of confidentiality given to the providers of the information. Therefore, users must:

- Use the data in this data set for statistical reporting and analysis only;
- Make no use of the identity of any person discovered, inadvertently or otherwise, and advise the Director, NCHS, of any such discovery (301-458-4500);
- Not link this data set with individually identifiable data from any other NCHS or non-NCHS data sets.

Use of the data set signifies users’ agreement to comply with the above-stated statutory-based requirements.

FURTHER INFORMATION

Whom do I contact if I still have questions about the NS-DATA survey after I read this document?

- We recognize that this summary of frequently asked questions may not provide all of the information that analysts need regarding the design and operation of the survey. If you have further questions, please send an email to slaits@cdc.gov.

How should this document be cited?

- The suggested citation is:

Centers for Disease Control and Prevention, National Center for Health Statistics, State and Local Area Integrated Telephone Survey. 2014 National Survey of the Diagnosis and Attention-Deficit/Hyperactivity Disorder and Tourette Syndrome: Frequently Asked Questions. May 2015. Available from URL: http://www.cdc.gov/nchs/slait/ns_data.htm.

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