

State and Local Area Integrated Telephone Survey
OMB # 0920-0406

Supporting Statement B

Three-year generic clearance granted 04/25/11
Expires 04/30/14

GenIC request to add additional topics:

National Survey of the Diagnosis and Treatment of ADHD and Tourette Syndrome
(NS-DATA)

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**The State and Local Area Integrated Telephone Survey (SLAITS)
OMB clearance number 0920-0406
Expiration 04/30/14**

**GenIC: National Survey of the Diagnosis and Treatment of ADHD
and Tourette Syndrome (NS-DATA)**

B: Collection of Information Employing Statistical Methods

1. Respondent Universe and Sampling Methods

For the National Survey of the Diagnosis and Treatment of Attention-Deficit/Hyperactivity Disorder and Tourette Syndrome the sample frame consists of approximately 6,300 English- and Spanish-speaking households which were already screened as part of the 2011 – 2012 National Survey of Children’s Health (NSCH) and were identified as having a resident child who has been diagnosed with Attention Deficit/Hyperactivity Disorder (ADHD) or Tourette Syndrome (TS) or both conditions between the ages of 2-17. These households will be re-contacted to participate in the follow-up NS-DATA. The respondent will be a parent or guardian who is knowledgeable about the child’s health, most often the original NSCH respondent. No children will be interviewed during the course of data collection.

The NS-DATA sampling frame from the 2011-2012 NSCH is nationally representative of all non-institutionalized children ages 2-15 years in the United States in 2011-2012 because the NSCH itself is nationally representative of all non-institutionalized children ages 0-17 years in the United States in 2011-2012. Children who have aged to age 18 or older since the original interview will be classified as out-of-scope to avoid asking an adult to provide information on another adult who has not provided informed consent.

The NSCH sampling frame included both landline and cell phone numbers and the sampling weights were adjusted to account for nonresponse to the NSCH and to match to demographic control totals from external (Census) population counts. We expect approximately 3,700 completed NS-DATA telephone interviews. Approximately a 55-60% interview completion rate, calculated as the number of completed interviews divided by the number of eligible children sampled for re-contact. While based on previous SLAITS experience, it is entirely possible that our estimated interview completion rate is a conservative estimate. Nonresponse bias to the NS-DATA can be minimized or even eliminated given that we already have NSCH data for the eventual NS-DATA respondents and non-respondents alike. (See additional detail in Section 3 (non-response bias) below).

Beginning with the implementation of the 2009-2010 National Survey of Children with Special Health Care Needs, SLAITS modules have employed a dual-frame landline and cell phone sample. Approximately one third of NSCH interviews in 2011 – 2012 were cell phone interviews. Thus, approximately one third of NS-DATA interviews are expected to be completed by cell phone and the rest by landline telephone.

Because the sample of eligible households for NS-DATA consists of households that completed the 2011-2012 NSCH, the pool of eligible households is pre-screened for the presence of children ever diagnosed with ADHD or TS and ready for calling. Parents will be asked to confirm these conditions in a series of screener questions prior to administering the full NS-DATA questionnaire. If they deny that the child has had either TS or ADHD, the interview is terminated. Children whose initial diagnosis occurred after NSCH participation are not identified. As the NSCH was nationally representative, the NS-DATA will also nationally representative, that is, after weighting adjustments to account for re-interview nonresponse.

We anticipate the following distribution of children for the NS-DATA

	Number of Interviews	Average Length of Interview
ADHD only	3600	30 minutes
TS only	50	30 minutes
ADHD and TS	50	50 minutes

2. Procedures for the Collection of Information

At the end of the NSCH interview, respondents were told that they may be contacted for future surveys. In order to locate the original respondent at a future date, the interviewer asked for additional contact information. This information will be used to contact and interview eligible respondents for the NS-DATA.

Computer-assisted telephone interviews (CATI) will be conducted using the procedures described in the original SLAITS information collection request. The advance letter and introductory telephone script are found in Attachments B & E. All telephone interviews (Attachment A) will be conducted from the data collection contractor's telephone center in Chicago, Illinois. Interviews will be regularly monitored for quality by the contractor. The study interviews will only be conducted in English and Spanish (NSCH interviews were similarly conducted only in English and Spanish).

All NS-DATA eligible cases from the NSCH will be released for calling, and those with a known mailing address (approximately 90%, because most NSCH respondents received incentives) will be mailed an advance letter (Attachment B). Respondents will be offered \$20 at first contact (to be mailed after completion of the interview) and an additional \$5 after they have refused participation twice. The interview for children with either ADHD or TS will be approximately 30 minutes in length. For children with both conditions, the interview will last 50 minutes. Respondents of children with ADHD and TS who complete the 50 minute interview will receive \$40.

Interviewers will be recruited from among the contractor's experienced staff. A 6 hour survey-specific training will be conducted including methods for refusal aversion and conversion. Interviewers will be taught to navigate the questionnaire and to respond to the questions and

concerns that might arise during the course of the interview. Interviewers are monitored intensively at the beginning of each survey and then intermittently throughout the field period.

The first few completed interviews will be carefully scrutinized to ensure that the survey operations are working as intended. Problems identified with programming or other concerns will be corrected prior to resuming interviewing.

We anticipate completing all telephone interviews by the end of April 2014. Once all necessary steps are taken to ensure that the identity of survey subjects is protected, a publicly available data file should follow.

Advance Letter

Addresses are available for approximately 90% of eligible households. Most NSCH respondents provided their addresses so that they could receive their incentive payment for participating in NSCH. For the NS-DATA follow-back, a survey-specific advance letter will be used (Attachment B).

The NS-DATA letter invites recipients to participate in a study on the health and well-being of children and provides survey information in a concise format. The letter also

- advises recipients of their eligibility for the survey based on responses to a previous survey, and indicates they will be called in the next few weeks;
- briefly explains the purpose of the survey and the intended uses of the data;
- cites and explains the authorizing legislation;
- tells potential respondents that they may refuse to participate completely or refuse individual items, that their responses will be held in strictest confidence, the survey is voluntary, and that their responses will be used for statistical purposes only;
- includes a list of ‘frequently asked questions’ or FAQs on the back of the letter; and
- invites hearing impaired respondents to contact the contractor with a TTY machine at a toll free number to be interviewed.

Estimate Precision

It is important to note that the survey is subject to the usual variability associated with sample surveys. Small differences between survey estimates may be due to random survey error and not to true differences among subgroups of children. We anticipate the final sample will include approximately 3,600 children who have been diagnosed with ADHD, 50 children who have been diagnosed with TS, and 50 children who have been diagnosed with both TS and ADHD. The precision of the survey estimates is based on the sample size and the measure of interest. Research questions restricted to specific subsamples of the NS-DATA will dictate the corresponding level of precision. Estimates at the national level are based on larger sample sizes than those at the state level. While the NSCH 2011-2012 is representative at both the national and state levels, the NS-DATA will be representative at the national level only.

Power Calculation

A power calculation was not conducted to determine the target NS-DATA sample size, because the 2011-2012 NSCH was planned and implemented before the NS-DATA follow-back was conceived. All households with eligible children identified in the NSCH as having ever been diagnosed with ADHD and/or TS, will be invited to participate in the NS-DATA. Based on past experience with similar follow-back surveys of adopted children from the 2007 NSCH and the 2005-2006 National Survey of Children with Special Health Care Needs, we do expect to be able to examine and detect differences in NS-DATA outcomes for children in various subgroups.

3. Methods to maximize response rates and deal with non-response

Response rates provide one measure of the potential for nonresponse bias but are not the sole indicator of survey and data quality. Although telephone survey response rates have declined, the telephone as a mode of data collection is still one of the most useful and economical means to obtain population-based data. Successful conduct of a SLAITS telephone module depends on a combination of techniques to maximize response rates and understand the impact of nonresponse on data quality. Standard proven survey procedures have been refined through deliberate testing and experience over time. Among those techniques routinely implemented in SLAITS modules are the:

- use of a carefully constructed advance letter for those households where a name and address are available (Attachment B),
- effective interviewer recruitment and training,
- thorough review of confidentiality, privacy, and security requirements,
- maintenance of a toll-free number and website to facilitate participation,
- flexible interview schedules to maximize convenience to the respondent,
- judicious use of incentives,
- quality control and interviewer monitoring,
- refusal aversion/conversion training with experienced interviewers, and
- A carefully constructed refusal conversion letter (Attachment B).

Answering machine messages are left on every third call where no contact with the household is made so long as no more than one message is left in any given week. An exception to this rule is made if the respondent missed a scheduled appointment. In cases of missed appointments an answering machine message is always left to let the respondent know an attempt was made to keep the appointment, regardless of the frequency of previous answering machine messages.

These measures do not assure high response rates. For each SLAITS module, analysis is conducted to evaluate the extent to which non-sampling error impacts data quality. Comparison to other surveys and related data, expected demographic characteristics, interview breakoffs, and other qualitative and quantitative measures will be constantly reviewed and assessed. Should changes to the survey design be warranted due to low response rates, OMB will be consulted.

Generally, nonresponse bias can be thought of as the degree to which non-respondents differ from respondents in key survey variables. This quantity is generally unknown, but in the case of NS-DATA, a follow-back survey to a previous module, we will have demographic and other

information collected in the NSCH for all NS-DATA-eligible households, those that respond and those that do not. This enables a very powerful nonresponse bias analysis, and also allows us to adjust the sampling weights very precisely to ensure that the final sample of completed interviews represents the same population of children as that represented by the full pool of eligible cases identified in the NSCH. Please see Appendix 9 of the National Survey of Adoptive Parents (NSAP) methodology report¹ (available online) for a detailed example of how this nonresponse bias analysis and weighting correction works. (NSAP was a follow-back to the 2007 NSCH.) After this process was completed for NSAP, we had very strong evidence that nonresponse bias in the NSAP was no greater than nonresponse bias in the 2007 NSCH. Comparisons of demographic and socioeconomic outcomes and of variables from the NSCH that were topically similar to the NSAP data elements, using the unadjusted and adjusted weights, demonstrated that nonresponse bias accruing from NSAP nonresponse on variables that were used to adjust the weights was reduced to zero after adjustment. For other variables that were not used in the weighting adjustment, nonresponse bias accruing from NSAP nonresponse was greatly reduced (to near-zero) and any remaining bias was small and inconsistent in direction after adjustment. We expect similar results for the NS-DATA. Because the pool of eligible NS-DATA cases is nationally representative of all non-institutionalized children ages 2-15 years ever diagnosed with ADHD or TS in the United States in 2011-2012, after the adjustment to the weights to account for NS-DATA nonresponse, the final sample of NS-DATA respondents will also represent this population accurately.

Note that the nonresponse bias analysis described above using data from the NSCH for all NS-DATA-eligible respondents and non-respondents does not address bias resulting from nonresponse to the underlying NSCH – the pool of eligible NS-DATA sample cases consists only of households that completed the NSCH. Based on our experience with NSAP (as shown in Appendix IX of the cited report and described above) and our expected adjustments to the final sampling weights to account for NS-DATA nonresponse, we are confident that nonresponse bias in the NS-DATA should be no greater than nonresponse bias in the NSCH. The NSCH 2011-2012 nonresponse bias analysis has now been completed, but has not yet been published or posted to the web (it will be included as an appendix in the NSCH 2011-2012 Design and Operation report, which should be published in 2014). Our experience with previous SLAITS surveys has consistently shown that estimated biases resulting from nonresponse tend to be small and inconsistent in direction, and this has generally held true for the 2011-2012 NSCH as well. Nonresponse bias was assessed using multiple methods, and the typical findings were that either biases were small and insignificant or the direction of bias found depended on the method used (that is, where bias was found, different methods of assessing bias suggested either a positive or negative bias, and this was not consistent across different variables). Overall, there was evidence that the responding sample was more likely than the non-respondents to live in rural areas and areas with lower household density, lower home values, higher rates of home ownership and a higher percentage of non-Hispanic white persons, but after weighting adjustments, only minor differences by home ownership, home values and race remained.

¹ Bramlett MD, Foster EB, Frasier AM, *et al* (2010). Design and operation of the National Survey of Adoptive Parents, 2007. National Center for Health Statistics. *Vital and Health Statistics* 1(50). Available online at: http://www.cdc.gov/nchs/data/series/sr_01/sr01_050.pdf

The final overall weighted response rate for the follow-up survey is dependent on NS-DATA response and the underlying response rates for the 2011 – 2012 NSCH. After NS-DATA data collection is completed, we will calculate and report this overall weighted response rate in the methodology report. The calculation will be consistent with the Standard Definitions provided by the American Association for Public Opinion Research (AAPOR), and the methodology report will include the specific calculations and summaries of the disposition of the sample cases. We expect to achieve a 55-60% interview completion rate, calculated as the number of completed interviews divided by the number of eligible children sampled for re-contact.

4. File release, disclosure review

When a NS-DATA public use file (PUF) is produced, it will be subject to a thorough confidentiality review, and released only upon approval of the NCHS Disclosure Review Board (DRB). The goal of NCHS is to maximize data release through this PUF, to which data perturbation procedures will be applied if needed to ensure (as best we can) that cases are protected from disclosure.

Any release of data, whether PUF or the results of statistical analyses, will be consistent with confidentiality provisions under which the data were collected. In the case of data collected or obtained by NCHS, Section 308(d) of the Public Health Service Act (42 U.S.C. 242m(d)) and the NCHS Staff Manual on Confidentiality do not permit the release of data that are either identified or identifiable to persons outside of NCHS (and its contractors with a need to know). To preserve privacy and confidentiality, details that might identify or facilitate identification of persons and/or organizations participating in surveys and data systems are suppressed in published data products. A restricted-access data file, which would permit analysis of confidential but not identified data, may also be made available through the NCHS Research Data Center (RDC). Given the rarity of children diagnosed with TS and the subsequent increased risk for disclosure, all data that are derived from questions that are exclusively asked about children with TS will likely be contained within the RDC. The publicly available dataset will likely only contain data from questions asked about children with ADHD. There will not likely be a variable included in the dataset that indicates whether a child had been diagnosed with TS.

In-house files are maintained on a SLAITS-only server that can be accessed only by six SLAITS staff members.

5. Individuals Consulted on Statistical Aspects and Individuals Collecting and/or Analyzing Data

The following persons were consulted on the statistical aspects of design, data collection, and analysis:

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List of Attachments

- A. 2014 NS-DATA Questionnaire**
- B. 2014 NS-DATA Advance letter, refusal conversion letter, thank you letter**
- C. SLAITS/NCBDDD Efforts to Improve Data on Children with Developmental Conditions selected analytic and methodological published references**
- D. Selected persons involved in the NS-DATA planning process**
- E. 2014 NS-DATA Introductory Scripts and Answering Machine/Voice Mail Messages**
- F. NS-DATA 30-day federal register notice**