

## CONFIDENTIALITY AND CONSENT

Like all surveys, the National Longitudinal Surveys (NLS) rely on the cooperation of respondents to provide relevant, accurate, and timely information that researchers and policymakers can use to understand economic and social phenomena. At a minimum, securing cooperation requires survey administrators to explain clearly to potential respondents the uses of the survey and the importance of each respondent's information to the success of the survey. Ethical survey practice entails more than just convincing members of the survey sample to participate, however. Sample members need to be informed about how their confidentiality will be protected, how their information will be used, whether participation is voluntary or mandatory, the estimated amount of time it will take to complete the survey, and any risks of participating.<sup>1</sup> After survey administrators provide this and other relevant information to potential respondents, those potential respondents can provide what is called their "informed consent" to participate.

The NLS program has established a variety of procedures for ensuring respondent confidentiality and obtaining informed consent. These procedures comply with Federal law and the policies and guidelines of the U.S. Office of Management and Budget (OMB), the U.S. Bureau of Labor Statistics (BLS), and the U.S. Census Bureau. This chapter describes the process of protecting respondent confidentiality and gaining informed consent in the National Longitudinal Survey of Youth 1979 (NLSY79) and its associated Child and Young Adult surveys, the National Longitudinal Survey of Youth 1997 (NLSY97), and the now-discontinued NLS original cohorts of Mature Women, Young Women, Older Men, and Young Men.

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<sup>1</sup>Providing information about risks is particularly relevant for medical studies in which participants could suffer adverse reactions to drugs or treatments. Although the National Longitudinal Surveys have included health-related topics, information about these topics has been obtained only through questions asked of respondents, rather than through any medical exams or procedures. As such, NLS respondents bear no risk of participating.

<sup>2</sup> Surveys that are funded through Federal grants to universities and other organizations generally do not have to undergo this OMB

### OMB procedures

OMB is responsible for setting overall statistical policy among Federal agencies. For example, OMB has established standards on collecting information about race and ethnicity, industry, occupation, and geographic location. OMB also has established standards on the manner and timing of data releases for such principal economic indicators as the gross domestic product, the national unemployment rate, and the Consumer Price Index. In addition, OMB sets standards on whether and how much respondents to Federal surveys can be paid for their participation, an issue of particular concern in the NLS program.

Another of OMB's responsibilities is to review the procedures and questionnaires that Federal agencies use in collecting information from 10 or more respondents. Federal data collections reviewed by OMB include administrative data, such as the tax forms that the Internal Revenue Service requires individuals and corporations to complete. OMB also reviews all censuses and surveys that Federal agencies conduct, either directly or through contracts.<sup>2</sup>

OMB examines a variety of issues during these reviews, such as:

- The amount of time (and money, if any) that the agency collecting the information estimates respondents will spend to provide the requested information
- The agency's efforts to reduce the burden on respondents of providing the information
- The purpose and necessity of the data collection, including whether it duplicates the objectives of other Federal data collections
- The ways in which the agency obtains informed consent from potential respondents to participate in the data

review process unless the grantee in turn contracts with a Federal statistical agency such as the Census Bureau to collect the data. In place of OMB review, surveys funded through grants typically must undergo a competitive peer-review process established by the agency administering the grant, and that review process examines the procedures for maintaining respondent confidentiality and obtaining the informed consent of the participants. In addition, such surveys also typically are scrutinized by an institutional review board established at the grantee's institution.

collection

- The policies and procedures that the agency has established to ensure respondent confidentiality
- The statistical methods used to select representative samples, maximize response rates, and account for nonresponse
- The payment of money or the giving of gifts to respondents
- The questionnaire itself, including the quality of its design and whether it includes questions that respondents may regard as sensitive

These OMB reviews are very thorough. From the time an agency prepares an OMB information collection request until the time OMB approves the data collection, the process typically takes 7 months or more and includes multiple layers of review within the agency and at OMB. These reviews are helpful in improving survey quality and ensuring that agencies treat respondents properly, both in terms of providing them with information about the data collection and its uses and protecting respondent confidentiality.

The review process also provides the general public with two opportunities to submit written comments about the proposed data collection. The agency conducting the data collection publishes a notice in the *Federal Register* describing the data collection and inviting the public to request copies of the information collection request, questionnaires, and other materials that the agency eventually will submit to OMB. The public is invited to submit written comments to the agency sponsoring the data collection within 60 days from the time the *Federal Register* notice is published. In the history of the NLS program, the public very rarely has submitted comments to BLS, but when comments are received, they are summarized in the information collection request that ultimately is submitted to OMB.

After the request has been submitted to OMB, the agency sponsoring the data collection then publishes a second notice in the *Federal Register* and invites the public to submit comments directly to OMB within 30 days. Again, in the history of the NLS program, the public very rarely, if ever, has submitted comments to OMB.

Once OMB has received the information collection request, they have 60 days to review the package, ask follow-

up questions, suggest changes (or, occasionally, insist upon changes) to the survey questionnaire or procedures, and ultimately grant approval.

After OMB grants approval, the sponsoring agency can begin contacting potential respondents and collecting information from them. The process of contacting potential NLS respondents begins with sending them an advance letter several weeks before interviews are scheduled to begin. The advance letter serves several purposes. The obvious purpose is to inform respondents that an interviewer will be contacting them soon, but BLS and the organizations that conduct the surveys for BLS also use the letter to thank respondents for their previous participation and to encourage them to participate in the upcoming round. Another important objective of the advance letter is to remind respondents that their participation is voluntary and to tell them how much time the interview is expected to take. The letter also explains to respondents how the data will be used and how respondents' confidentiality will be protected by BLS and the organizations that conduct the surveys for BLS. An example of an advance letter is shown in figure 9.1.

### Institutional review boards

In addition to OMB review, each of the National Longitudinal Surveys is reviewed and approved by an institutional review board (IRB) at the institutions that manage and conduct the surveys under contract with BLS. Those institutions are The Ohio State University and the National Opinion Research Center (NORC) at the University of Chicago. BLS and OMB do not require these reviews; rather, the reviews are required under the policies of the universities. Obtaining approval from the IRBs involves completing a form signed by the Principal Investigator, providing a summary of the research project and submitting a description of the consent procedures and forms used in the survey. Additional documentation includes a copy of any materials used to recruit respondents, a detailed summary of the survey questionnaire, and any other information regarding the risks to humans of participating in the survey.<sup>3</sup>

The NLS project staff at The Ohio State University Center for Human Resource Research (CHRR) and at NORC obtain approval from their respective IRBs prior to the start of each round of data collection. Because each survey includes

<sup>3</sup> In the NLS program, OMB must review all data collections for the NLSW, NLSY97, NLSY79, and NLSY79 Child survey. For the NLSY79 Young Adult survey, OMB review is required only for respondents under age 21. Interviews with Young Adult respondents age 21 and older are not subject to OMB review because those interviews are not funded through the contract with BLS. Instead, those interviews are funded through a competitive grant from the National Institute of Child Health and Human Develop-

ment to The Ohio State University Center for Human Resource Research. Virtually the same procedures are used to conduct the NLSY79 Child and Young Adult interviews for respondents age 21 and older as are used for younger respondents, so OMB presumably would approve the data collection if asked to do so. Data collection for the NLSY79 Young Adults age 21 and older is subject to the approval of the institutional review boards at The Ohio State University and the University of Chicago.

Figure 9.1 NLSY79 round 21 advance letter



You are part of something truly **great**: the *National Longitudinal Survey of Youth 1979*.

Few people have the opportunity to make such a great and **lasting** contribution.

The study is a valuable tool for legislation and research. The study is also a moving picture of your life. And because you represent many others your contribution becomes a “living” record of the people of this nation... a record that may be available for generations to come.

Those of us who work on the study are **proud** to work with you. We are a **team** of researchers who carefully prepare the content of the study to make sure it continues to be so valuable to educators and government policymakers; professionals who prepare and complete materials for the study; and a staff of interviewers who work tirelessly to contact you.

We all appreciate your continued participation and dedication to this study, which is sponsored by the Bureau of Labor Statistics of the U.S. Department of Labor. As a small thank you, we have included a calendar magnet to help you keep track of important dates.

We remain extremely **grateful** to you for your continuing participation and look forward to speaking with you again in 2004. The average interview lasts 60 minutes. As always, the information you provide is protected by law.

One of our interviewers from NORC at the University of Chicago will be **contacting** you in the coming weeks to set up a convenient appointment for your interview. In the meantime, if you have any **questions** about the study, please feel free to call us toll free at 1-877-853-5908. The questions and answers shown on the back of this letter provide further information about this survey and your confidentiality.

We look forward to **talking** with you soon! And again,



only an interview and no invasive medical procedures, the IRBs typically focus on respondent compensation, consent procedures, and confidentiality protections for special populations, such as incarcerated or disabled respondents. Prisons, schools, and other institutions in which NLS sample members may reside often request the IRB approval statement and application as evidence that appropriate procedures are being followed and to judge whether to permit NLS interviewers to have access to individuals for whom the institutions are responsible.

### Federal laws

Three Federal laws govern policies and procedures for protecting respondent confidentiality and obtaining informed consent in the NLS program: the Privacy Act of 1974, the Confidential Information Protection and Statistical Efficiency Act (CIPSEA) of 2002, and Title 13 of the United States Code. The Privacy Act is discussed in the section on the NLSY79 and NLSY97 cohorts, as well as in the section on the NLS original cohorts. CIPSEA, which applies to all data collected by Federal agencies under a pledge of confidentiality for exclusively statistical purposes, also is discussed in both sections. Title 13 applies only to the NLS original cohorts and is described in that section of this chapter.

### NLSY79 and NLSY97 cohorts

The Privacy Act and CIPSEA protect the confidentiality of participants in the NLSY79, its associated Child and Young Adult surveys, and the NLSY97. CIPSEA protects the confidentiality of participants by ensuring that individuals who provide information to BLS under a pledge of confidentiality for statistical purposes will not have that information disclosed in identifiable form to anyone not authorized to have it. In addition, CIPSEA ensures that the information respondents provide will be used only for statistical purposes. While it always has been the BLS policy to protect respondent data from disclosure through the Privacy Act and by claiming exemptions to the Freedom of Information Act, CIPSEA is important because it specifically protects data collected from respondents for statistical purposes under a pledge of confidentiality. This law strengthens the ability of BLS to assure respondents that, when they supply information to BLS, their information will be protected. In addition, CIPSEA includes fines and penalties for any knowing and willful disclosure of specific information to unauthorized persons by any officer, employee, or agent of BLS. Since the enactment of the Trade Secrets Act and the Privacy Act, BLS officers, employees, and agents have been subject to criminal penalties for the mishandling of confidential data, and the fines and penalties under CIPSEA are consistent with those prior laws. CIPSEA now makes such fines and penalties uniform across all Federal agencies that collect data for exclusively statistical purposes under a pledge of confidentiality.

BLS policy requires that advance letters sent to potential respondents in these surveys include on the back of the letter the series of questions and answers about confidentiality and other survey topics shown in figure 9.2. In addition to these written questions and answers, survey interviewers are trained how to answer questions from respondents about how their privacy will be protected.

Interviewers explain to potential respondents that all the employees who work on the surveys at BLS, NORC, and CHRR are required to sign a document stating that they will not disclose the identities of survey respondents to anyone who does not work on the NLS program and is therefore not legally authorized to have such information. In fact, no one at BLS has access to information about respondents' identities, and only a few staff members at NORC and CHRR who need such information to carry out their job duties have access to information about respondents' identities.

Interviewers also explain that the answers respondents provide will be made available to researchers at BLS and other government agencies, universities, and private research organizations, but only after all personal identifiers—such as names, addresses, Social Security numbers, and places of work—have been removed. In addition, the publicly available data files exclude any information about the States, counties, metropolitan statistical areas, and other, more detailed geographic locations in which respondents live, making it much more difficult to infer the identities of respondents.

Respondents are told that some researchers are granted special access to data files that include geographic information, but only after those researchers undergo a thorough application process at BLS and sign a written agreement making them official agents of BLS and requiring them to protect the confidentiality of respondents. In no case are researchers provided with information on the personal identities of respondents.

Finally, the reference in the questions and answers to the National Archives and Records Administration and the General Services Administration may be confusing to some potential respondents, because those Federal agencies are not involved in the administration of the surveys. Interviewers explain to respondents that NLS data and materials will be made available to those agencies because they are responsible for storing the Nation's historical documents. The information provided to those agencies does not include respondents' personal identities, however.

The organizations involved in the NLS program continuously monitor their security procedures and improve them when necessary. Protecting the privacy of NLS respondents entails considerable responsibilities for BLS, the organizations that conduct the surveys for BLS, and the researchers who use the data. Indeed, researchers in particular may become frustrated that they cannot obtain access to all the

**Figure 9.2. Confidentiality and reporting burden information in the NLSY97 advance letter****WHY IS THIS STUDY IMPORTANT?**

Thanks to your help, policymakers and researchers will have a better understanding of the work experiences, family characteristics, health, financial status, and other important information about the lives of people in your generation. This is a voluntary study, and there are no penalties for not answering questions. However, missing responses make it more difficult to understand the issues that concern people in your community and across the country. Your answers represent the experiences of hundreds of other people your age. We hope we can count on your participation again this year.

**WHO AUTHORIZES THIS STUDY?**

The sponsor of the study is the U.S. Department of Labor, Bureau of Labor Statistics. The study is authorized under Title 29, Section 2, of the United States Code. The Center for Human Resource Research at The Ohio State University and the National Opinion Research Center at the University of Chicago conduct this study under a contract with the Department of Labor. The U.S. Office of Management and Budget (OMB) has approved the questionnaire and has assigned 1220-0157 as the study's control number. This control number expires on October 31, 2007. Without OMB approval and this number, we would not be able to conduct this study.

**WHO SEES MY ANSWERS?**

We want to reassure you that your confidentiality is protected by law. In accordance with the Confidential Information Protection and Statistical Efficiency Act of 2002, the Privacy Act, and other applicable Federal laws, the Bureau of Labor Statistics, its employees and agents, will, to the full extent permitted by law, use the information you provide for statistical purposes only, will hold your responses in confidence, and will not disclose them in identifiable form without your informed consent. All the employees who work on the survey at the Bureau of Labor Statistics and its contractors must sign a document agreeing to protect the confidentiality of your data. In fact, only a few people have access to information about your identity because they need that information to carry out their job duties.

Some of your answers will be made available to researchers at the Bureau of Labor Statistics and other government agencies, universities, and private research organizations through publicly available data files. These publicly available files contain no personal identifiers, such as names, addresses, Social Security numbers, and places of work, and exclude any information about the States, counties, metropolitan areas, and other, more detailed geographic locations in which survey participants live, making it much more difficult to figure out the identities of participants. Some researchers are granted special access to data files that include geographic information, but only after those researchers go through a thorough application process at the Bureau of Labor Statistics. Those authorized researchers must sign a written agreement making them official agents of the Bureau of Labor Statistics and requiring them to protect the confidentiality of survey participants. Those researchers are never provided with the personal identities of participants. The National Archives and Records Administration and the General Services Administration may receive copies of survey data and materials because those agencies are responsible for storing the Nation's historical documents.

**HOW MUCH TIME WILL THE INTERVIEW TAKE?**

Based on preliminary tests, we expect the average interview to take about 60 minutes. Your interview may be somewhat shorter or longer depending on your circumstances. If you have any comments regarding this study or recommendations for reducing its length, send them to the Bureau of Labor Statistics, National Longitudinal Surveys, 2 Massachusetts Avenue NE., Washington, DC 20212.

data that they want or that they must undergo a long review process at BLS to obtain some types of data. It is important to remember, however, that protecting respondent confidentiality must remain paramount. Any action that might jeopardize respondent confidentiality and erode the confidence of respondents could harm response rates in the NLS program and in other government or academic surveys. Thus, without the safeguards in place to protect respondent confidentiality, researchers would have far less data available to work with than they currently enjoy.

**Contractors' role in maintaining respondent confidentiality.** BLS, NORC, and CHRR are responsible for following the Federal requirements and maintaining their own security procedures. As mentioned earlier, all officers, employees, and agents of BLS are required to sign agreements stating that they will not disclose the identities of survey respondents to anyone who does not work on the NLS program and is therefore not legally authorized to have such information. Each contractor has in place procedures to ensure that the data are secure at each point in the survey process. (See the Data Handling section of this chapter for more information.)

Like all contractor staff, field interviewers are agents of BLS and are required to sign the BLS agent agreement before working on the NLSY79 or NLSY97. All interviewers also must undergo a background check when they are hired. Confidentiality is stressed during training and enforced at all times. Field interviewers receive specific instructions in their reference manuals to remind them of the appropriate procedures when locating or interacting with respondents or contacts.

At the end of each interview, interviewers ask respondents to provide information on family members, friends, or neighbors who can be contacted if the interviewers are unable to locate the sample member in a subsequent round of interviews. The interviewers then use those contacts to help in locating sample members who have moved. When contacting a sample member's relatives, friends, or neighbors about the sample member's whereabouts, interviewers never disclose the name of the survey they are conducting. They are instructed to maintain the confidentiality of any relative, friend, or neighbor who provides information about the sample member's whereabouts.

Answering machines can pose problems when interviewers are contacting sample members because it is difficult to confirm that the interviewer is calling a sample member's correct telephone number or that other household members will not hear the message. For those reasons, interviewers are instructed not to leave messages on answering machines.

When interviewers contact the appropriate household, they ask to speak with the sample member or the parent of a sample member under age 18. Interviewers introduce them-

selves and state the purpose of the call by saying that they are from the National Opinion Research Center at the University of Chicago and are calling concerning a national survey. The name of the survey is not disclosed to anyone but the sample member.

**Special situations.** The NLSY79 and NLSY97 are general population surveys and include a variety of sample members with special circumstances, such as incarcerated individuals, respondents in the military, other institutionalized persons, disabled persons, those with limited English proficiency, and so forth.

*Incarcerated respondents.* Incarcerated respondents constitute the largest group requiring special accommodations. The first challenge with incarcerated respondents is contacting them to schedule an interview. NLS interviewers must contact the prison administration to arrange for an interview, but the interviewers cannot legally reveal to the prison administration that the prisoner previously had participated in the survey without first obtaining the written, informed consent of the prisoner to reveal that information.

The process of obtaining prisoners' consent begins by sending them a letter. The letter reminds prisoners that they have participated previously in a NORC survey, but, in case the mail is monitored by prison staff, the letter does not name the survey or BLS so as not to reveal the prisoner's participation. The letter encourages the prisoner to participate in the upcoming round of the survey. It explains that NORC staff needs to set up an interview through the prison administration but that NORC cannot tell the prison administration about the prisoner's participation without the prisoner's informed consent. The letter then asks the prisoner to request a consent form by signing and dating an enclosed form letter and mailing it to NORC in a pre-addressed, postage-paid envelope. The letter reminds the prisoner that the mail at the institution may be monitored and explains that the consent form that NORC will send the prisoner will state the prisoner's name and the name of the survey. The letter emphasizes that, by returning the enclosed form letter, prison management or staff may learn that the prisoner is a participant in the survey.

If the prisoner chooses to send the form letter to NORC, NORC then sends the prisoner a cover letter and a consent form that names the specific survey. The prisoner is asked to sign the consent form and mail it to NORC in a pre-addressed, postage-paid envelope. Once NORC has received the signed consent form, NORC staff can contact the prison to request permission to interview the prisoner and learn about any restrictions that the prison administration may impose.

If the prison administration permits an interview and a date and time have been scheduled for the interview, NORC mails another letter to the prisoner. This letter serves two

purposes. First, it tells the prisoner when the interview will take place. Second, it informs the prisoner in writing that the interview very likely will be monitored by prison staff. That fact probably is obvious to any prisoner, but NLS staff feels that it is important to tell the prisoner in writing.

Once all of these steps are complete, the prisoner finally can be interviewed, but the NLS program takes additional steps to minimize the risk that prisoners might reveal illegal or illicit behavior in the presence of prison staff during the course of the interview. This concern generally is not an issue for the NLSY79, which has not asked questions on such sensitive topics in recent years, but it is an issue with the NLSY79 Child and Young Adult surveys and with the NLSY97.

As described later in this chapter, such sensitive questions are asked in the self-administered portions of the NLSY97. During these portions of the survey, the typical protocol for a respondent who is not incarcerated involves the interviewer turning the laptop computer around to enable the respondent to read the questions to him or herself and enter the answers directly into the laptop computer without the interviewer knowing the responses. (In fact, the interviewer does not even know which questions the respondent answered). In some relatively low-security correctional facilities, such as some county jails and halfway houses, this protocol still would be possible. In higher security facilities, the prison administrators would not permit the prisoner to touch the computer, so the questions either would have to be read to the respondent or skipped altogether.

NLS program staff have identified the questions that could be considered even moderately sensitive or risky for the prisoner to answer out loud. Given this examination, the NLS program has adopted the following protocol for administering sensitive questions to prisoners:

1. At the very beginning of the interview, the interviewer will indicate in the survey instrument whether a respondent is in a correctional facility of any kind and, if so, whether the facility permits the prisoner to touch the laptop and enter responses to the self-administered questions. For Federal prisons, the interviewer assumes that the prisoner is not permitted to touch the laptop.
2. If the facility permits the prisoner to enter responses to the self-administered questions directly into the laptop, then the full set of questions, including all of the sensitive questions, would be administered.
3. If the facility does not permit the prisoner to enter responses directly into the laptop, or if the interview is conducted over the telephone rather than in person, all survey questions will be asked orally by the interviewer, but the instrument is programmed to skip sensitive questions in which the prisoner might be asked about illegal or illicit behavior.

*Military respondents.* NLS respondents who are in the military tend to be very cooperative and willing to participate in the surveys, but it sometimes can be difficult to locate and contact them, particularly if they are stationed outside the United States. It sometimes is necessary to seek the help of military or civilian staff in the Department of Defense to locate and contact military respondents, but NLS program staff first must obtain the military member's written, informed consent to reveal to Department of Defense staff that he or she previously had participated in the survey and is willing to be contacted to participate in future rounds of the survey.

*Respondents with limited English proficiency.* Some respondents lack fluency in English and are more comfortable using another language. It is not possible to accommodate all of the different languages other than English that respondents might speak, but the NLSY79 and NLSY97 historically have made special arrangements for respondents and their parents who speak Spanish, the most commonly spoken language other than English among respondents. Staff members translate advance letters and other informational materials into Spanish to enable respondents and the parents of minor respondents to provide their informed consent based on information that is written in the language that they understand best. Survey questionnaires also have been translated into Spanish to ensure that the surveys are administered consistently, an alternative much preferable to having Spanish-speaking interviewers translate the English-language questionnaire during the interview. The first 6 rounds of the NLSY97 included a Spanish version of the questionnaire, but, because the number of respondents who speak only Spanish has continued to decline, it no longer is cost-effective to continue programming a computerized Spanish questionnaire. For that reason, Spanish questionnaires are not used starting with round 7 (2003-04) of the NLSY97. Advance letters and other informational materials still are available in Spanish, however. The main NLSY79 questionnaire continues to be translated into Spanish.

*Sensitive subjects.* The NLSY79 and NLSY97 have included questions on income and assets, religion, relationships with parents and other family members, sexual experiences, abortion, drug and alcohol use, criminal activities, homelessness, runaway episodes, and other topics that are potentially sensitive for respondents to discuss. Respondents are advised at the start of the interview that they can choose not to answer any questions that they prefer not to answer. During training, interviewers undergo exercises to teach them how to allay the concerns of respondents about answering sensitive questions and encourage them to respond. Interviewers are instructed not to coerce respondents into answering questions that they prefer not to answer, however.

All questions in the NLSY79 and most questions in the

NLSY97 are read to the respondent by an interviewer. The respondent then provides an answer, and the interviewer records that answer on a laptop computer. For especially sensitive questions, some respondents might be reluctant to answer truthfully—or at all—if they have to tell an interviewer their answers, even though interviewers can face criminal and civil penalties if they disclose the respondents' identities or answers to anyone not authorized to receive that information.

Obviously, it is important that respondents answer all questions truthfully, so the NLSY97 includes a self-administered portion of the questionnaire to reduce the potential reluctance to respond to sensitive questions. In this mode of data collection, the interviewer hands the laptop computer to the respondent and asks the respondent to read the questions and enter his or her responses with the keyboard. Sometimes, respondents have literacy problems or disabilities that prevent them from reading the questions on the computer screen. For this reason, the interviewer also provides the respondent with a set of headphones that plug into the computer and enable the respondent to listen to a computer-generated recording of someone reading the questions. While the respondent completes this computer-assisted self-interview, the interviewer does not see the respondent's answers and, in fact, does not even see what questions the respondent is answering. Even in the self-administered portion of the survey, however, respondents still have the option not to respond to individual questions.

*Guidelines for e-mailing sample members.* At the end of each interview, respondents are asked to provide information that will help interviewers contact them during subsequent rounds of the surveys. In addition to the information collected about relatives, friends, or neighbors, interviewers also obtain the e-mail addresses of sample members who have them. During round 5 of the NLSY97 (conducted during 2001-2002) and round 20 of the NLSY79 (conducted during 2002), the NLS contractors began using e-mail as a means to contact a small number of sample members who were hard to reach by other means. The following guidelines were enacted to ensure confidentiality:

1. The name of the survey is not contained in the subject line or text of the e-mail message. Some sample members may share the use of an e-mail address with other household members, so the survey name is omitted from the message to prevent other household members from learning the specific name of the survey.
2. E-mail is sent from one NORC address. Field interviewers are not permitted to use their individual e-mail accounts to contact sample members.

*Respondents knowing respondents.* One feature of the sample design in the NLSY79 and NLSY97 is that there often

are multiple respondents within the same original household, either siblings or, occasionally, spouses. It obviously is not possible in these cases to prevent family members from knowing that a relative is in the survey sample, but interviewers take steps to ensure that each respondent's answers remain private and are not revealed to other family members.

**Consent from NLSY97 respondents and parents.** Because of the young ages of this cohort in the initial survey years, additional measures were taken to obtain informed consent from minors and their parents. Consent procedures for rounds 1 through 5 of the NLSY97 included the following protocol:

1. For respondents age 17 and younger, parents were asked to complete a written Parental Permission to Interview Youth form prior to the youth's completion of the interview. Respondents themselves were asked to complete a written Youth Assent to Participate form prior to completing the interview. This protocol also applied to respondents whose interviews were completed by a proxy. (Proxy interviews are conducted in cases in which a disabled respondent could complete the interview only with the assistance of a parent, guardian, or other caretaker.) Respondents who were age 17 or younger and had attained independence or were considered "self-supportive" were not required to have a parent complete a permission form.
2. Whether or not a parent permission form was required, all youths, regardless of age, signed a consent form prior to completing the interview.

Through the completion of round 5 data collection in May 2002, a significant proportion of NLSY97 sample members required signed parental permission because they had not yet reached age 18 or established legal independence.

As of January 1, 2003, all NLSY97 sample members were at least age 18. Beginning in round 6, consent procedures changed to align with procedures of other large surveys of adults. Respondents age 18 and older now verbally consent prior to completing the interview. They read a consent statement similar to those used in previous rounds, but they no longer need to sign any documents.<sup>4</sup> For incarcerated respondents and respondents whose interviews are completed by proxy, the NLS program continues to require signed consent as an additional safeguard against possible coercion.

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<sup>4</sup> Data collection for round 6 began in November 2002, when approximately 250 respondents were still age 17. Interviews with these respondents were postponed until January 2003, when all had reached age 18.

**Consent from NLSY79 respondents and Young Adults age 18 and older.** Respondents are able to review the confidentiality and consent information presented in the advance letter. The respondent gives verbal consent to participate at the beginning of the interview.

**Children of the NLSY79, parental consent.** In the Children of the NLSY79, the biological children of female NLSY79 sample members are assessed, and the mothers are interviewed about their children. Children ages 4 to 14 are given a variety of assessments depending on their age; children younger than age 4 are not assessed. The mother's consent is required for these assessments to be administered. The field interviewer asks the mother to sign a consent form. The back of the parental permission form has the questions and answers shown in figure 2 of this chapter. In the rare cases in which the child is not assessed but the mother is interviewed by telephone about the child, the mother gives verbal consent over the telephone. The field interviewer signs the consent form and returns it to the central office of the NLS contractor for secure storage.

Children ages 10 to 14 are asked a series of questions through a self-administered questionnaire on a variety of potentially sensitive topics. After the mother verbally agrees that the child may answer these questions, the interviewer reads a consent statement to the child and obtains verbal consent. This consent statement is similar to the statement used with older respondents but has been cognitively tested and revised to ensure that it is appropriate for preteens.

**Young Adults under age 18, parental consent.** Parental permission is required for young adults ages 15 to 17 who undergo an interview modeled on the questionnaire used in the main NLSY79. For telephone interviews, the field interviewer asks to speak to the parent and requests permission from that parent to interview the young adult. When the parent grants permission, the interviewer signs the consent form and returns it to the central office of the NLS contractor for secure storage.

### **NLS original cohorts**

The NLS original cohorts were conducted for BLS by the Census Bureau. Title 13 of the U.S. Code authorizes the Census Bureau to conduct censuses and surveys and protects the confidentiality of respondents. Title 13 requires that information collected from respondents by the Census Bureau remain confidential. The information can be used only for statistical purposes at secure locations by Census Bureau employees who have been specifically authorized to have access to NLS data. Individuals not employed by the Census Bureau can have access to confidential NLS data only if they have obtained "Special Sworn Status" from the Census Bureau to use the data. Title 13 provides specific

penalties for violations of the confidentiality of companies, establishments, households, or individuals. Publication of NLS data must not include details that can identify individuals participating in the survey. Wrongful disclosure of confidential information could result in substantial monetary fines and jail time. The Census Bureau's internal Disclosure Review Board sets the confidentiality rules for all data releases.

The Privacy Act also applies to the NLS original cohorts. The law requires the Census Bureau to provide NLS sample members with information about the purpose of the survey, the legal authority for conducting the survey, and the ways in which the information about participants will be used. The Privacy Act also requires the Census Bureau to inform sample members that their participation is voluntary, rather than mandatory, and that there are no consequences to sample members who choose not to participate. This information enabled NLS original cohort sample members to provide their informed consent to participate. CIPSEA also applies to information collected by the Census Bureau for exclusively statistical purposes under a pledge of confidentiality.

The information provided to NLS Mature Women and Young Women sample members about their confidentiality and reporting burden was similar to the information provided to sample members in the NLSY79 and NLSY97. The information presented on the back of the advance letter for the 2003 NLS of Mature Women and Young Women is shown in figure 9.3.

If the sample member received the advance letter and agreed to participate, the Census Bureau regarded that agreement as informed consent and proceeded with the interview. If the sample member had not received the advance letter when the Census Bureau interviewer visited or called on the telephone to conduct an interview, the interviewer either handed the sample member a copy of the advance letter or read her a statement that contains the information required to obtain informed consent. If the sample member agreed to participate, the interviewer proceeded with the interview.

The great majority of NLS original cohort interviews were by self-response, meaning the sample member answers the questions. If the sample member is unable to respond because of a physical or mental condition, a proxy respondent can provide the information if the sample member is present. Because the proxy respondent usually is a family member living in the same household as the sample member, the Census Bureau assumes that the proxy has sufficient knowledge to respond on behalf of the sample member. The interviewer follows the same informed-consent protocol described earlier. That is, the interviewer makes sure that the proxy respondent has received a copy of the advance letter or has been read the statement that contains the information required to obtain informed consent.

Census Bureau interviewers are required to sign an affidavit affirming their responsibilities to protect the confidentiality of respondents. Interviewers receive training that stresses the importance of protecting respondent confidentiality. This training and the interviewer reference manuals explain the appropriate procedures to follow when locating or interacting with respondents or contacts. These proce-

dures are similar to those that interviewers from NORC must follow when conducting the NLSY79 and NLSY97, as described earlier in this chapter.

*Disclosure limitation.* Disclosure limitation is the process for protecting the confidentiality of data. An improper disclosure of data occurs when someone can use published

**Figure 9.3. Confidentiality and reporting burden information in 2003 NLS Mature Women and Young Women advance letter**

**SOME COMMONLY ASKED QUESTIONS**

**WHY IS THIS SURVEY IMPORTANT?**

Because of your help, the Department of Labor, as well as economists, sociologists, and other researchers, will get a clearer picture of how work-related decisions influence people's lives. If you are married, information about your husband will help provide a more complete picture. Policymakers can use the work information we obtain to shape economic policy. This is a voluntary survey, and there are no penalties for not answering questions. However, missing responses seriously hamper our ability to make statements and predictions about the country as a whole. Your answers represent hundreds of other women your age. We hope we can count on your participation again this year.

**WHO AUTHORIZES THIS SURVEY?**

The Census Bureau is conducting this survey for the Department of Labor. It is authorized under Title 29, Section 2, of the United States Code. The Office of Management and Budget (OMB) has approved the 2003 questionnaire and has assigned 1220-0110 as the study's control number. This control number expires on December 31, 2003. Without OMB approval and this number, we would not be able to conduct this survey.

**WHO SEES MY ANSWERS?**

We want to reassure you that your confidentiality is completely protected. We are conducting this survey under the authority of Title 13, United States Code, Section 8. Section 9 of this law requires us to keep all information about you and your household strictly confidential. We may use this information only for statistical purposes.

**HOW CAN I PREPARE FOR THE INTERVIEW?**

We will be asking questions about your family life, your participation in the labor force, health insurance and pension coverage, and special employment problems. If you are married, we will ask similar questions about your husband. It would be helpful if you would give some thought to these topics before the field representative visits.

**HOW MUCH TIME WILL THE INTERVIEW TAKE?**

Based on preliminary tests, we expect the average interview to take about 70 minutes. Since not everyone will complete all parts of the questionnaire, actual times do vary. Your interview may be somewhat shorter or longer depending on your circumstances. If you have any comments regarding this study or recommendations for reducing its length, send them to the Bureau of Labor Statistics, Office of Employment and Unemployment Statistics, National Longitudinal Surveys Division, Project 1220-0110, Washington, DC 20212.

statistical information to identify an individual who has provided information under a pledge of confidentiality. Using disclosure limitation procedures, the Census Bureau modifies or removes the characteristics that put confidential information at risk for disclosure. Although it may appear that a table shows information about a specific individual, the Census Bureau has taken steps to disguise the original data while making sure the results are still useful. Under these restrictions, survey contractors and researchers are prevented from receiving certain information on NLS original cohort respondents, particularly information on geographic location, employer names, school names, and some income data.

**Research Data Centers.** The Census Bureau's Center for Economic Studies has established a number of Research Data Centers throughout the United States. At Research Data Centers, researchers may have access to confidential data sets collected by the Census Bureau, with appropriate safeguards to protect respondent confidentiality.

A considerable amount of geographic information collected during NLS Mature Women and Young Women interviews is available for researchers to use at the Research Data Centers. The cohort-specific files contain the respondent identification number, survey year, and State code. Researchers may match these files to the data sets. The Research Data Centers have available the Federal Information Processing Standards (FIPS) State codes for each survey year. Having the State variables enables researchers to identify the census regions and divisions. Variables also are available at the Research Data Centers on county, metropolitan statistical area, ZIP Code, census tract and block, and latitude and longitude of residence for Mature Women and Young Women respondents. Selected environmental variables are available about the counties and metropolitan statistical areas where the women resided, and information also is available on the names of the colleges and universities that the women attended.

The Research Data Centers also have information on respondents' State and county of residence that was collected in the NLS Older Men and Young Men interviews. More information about the Research Data Centers is available online at [www.ces.census.gov](http://www.ces.census.gov).

### **Data handling in all NLS cohorts**

An important part of maintaining respondent confidentiality

is the careful handling and storage of data. Steps taken by BLS, the Census Bureau, CHRR, and NORC to ensure the confidentiality of all respondents to the NLS include maintaining secure networks, restricting access to geographic variables, and topcoding income and asset values.

**Network security.** The data that are stored and handled at each NLS organization's site are done so with maximum security in place. During data collection, transmission, and storage, password protection and encryption are used to secure the data. Standard protocols for network security are followed at each organization's site. Detailed information about these arrangements is not provided to the public to prevent anyone from circumventing these safeguards.

**Restricting access to geographic information.** Geographic information about NLSY79 or NLSY97 respondents is available only to researchers who are designated agents of BLS. These researchers must agree in writing to adhere to the BLS confidentiality policy, and their projects must further the mission of BLS and the NLS program to conduct sound, legitimate research in the social sciences. Applicants must provide a clear statement of their research methodology and objectives and explain how the geographic variables are necessary to meet those objectives. For more information about obtaining access to geographic variables in the NLSY79 and NLSY97, see the NLS Web site at [www.bls.gov/nls](http://www.bls.gov/nls).

Because of the confidentiality restrictions followed by the Census Bureau, geographic information for the NLS original cohorts is available only at Census Research Data Centers.

**Topcoding of income and asset variables.** Another step taken to ensure the confidentiality of NLS respondents who have unusually high income and asset values is to "topcode" those values in NLS data sets. Values that exceed a certain level are recoded so that they do not exceed the specified level. In each survey round, income and asset variables that include high values are identified for topcoding. For example, the wage and salary income variable usually is topcoded, but variables indicating the amount received from public assistance programs are not. Notes in the codebooks for topcoded income and asset variables provide more information about the exact calculations used to topcode each variable. Additional information about topcoding is provided in the user's guides for each NLS cohort.