

# Informed Consent in U.S. Government Surveys

Robert H. Mugge<sup>1</sup>

**Abstract:** Informed consent is discussed as it is applied in U.S. Government social surveys and other information requests. From a survey of government surveys a representative group of 16 data programs is reviewed for the adequacy and propriety of their notifications to respondents. Special attention is given to requests for Social Security Num-

bers. The notifications are generally found to meet legal and moral requirements. Various implications of the notifications and major issues are discussed.

**Key words:** Privacy; confidentiality; social surveys.

## 1. Introduction

“Informed consent” is a *sine qua non* of social surveys. In order to request information from individuals or organizations regarding themselves, their characteristics and activities, the requester must first inform the respondent about the request – what information is required and why and any relevant facts, and any possible ways the responses might affect the respondent – and then must obtain the respondent’s approval, implied or explicit, to cooperate. Informed consent was defined by the Department of Health, Education, and Welfare (DHEW) (now the Department of Health and Human Services) as “the agreement obtained from a subject, or from his authorized representative, to the subject’s participation in an activity.” The informa-

tion on which this consent is based, according to DHEW, must include the following components: “(1) a fair explanation of procedures, (2) a description of risks and discomforts, (3) a description of benefits, (4) disclosure of alternative procedures, (5) an offer to answer inquiries about procedures, and (6) an instruction that the subject is free to withdraw consent and discontinue participation at any time” (Public Health Service 1971, p. 7). While this definition was written with medical research experimentation in mind, it has parallel applications to inquiries in social surveys, if appropriately modified to adjust to the situation prevailing in these surveys.

It is generally accepted in the United States that individuals have both a moral and a legal right to privacy (Faden and Beauchamp 1986, pp. 23–49). When answering questions in social surveys about themselves, they give up a degree of their privacy rights. The social scientist may be justified in asking individuals to com-

<sup>1</sup> The author is retired. Formerly Assistant to the Director, National Center for Health Statistics, U.S. Department of Health and Human Services. Correspondence should be directed to: 222 Hillsboro Drive, Silver Spring, Maryland 20902, U.S.A.

promise their privacy in behalf of a larger good, but the social scientist should have to demonstrate this justification and prove it to the subject's satisfaction before the subject should be asked to divulge information. Through the information provided in the notification statement, the social scientist is obligated to advise respondents as to all the important consequences of their providing the information.

Informed consent is thus an essential feature of social surveys, even when there is no clearly apparent way that a subject can be harmed through his/her participation in a particular survey. Even in the most innocuous survey a subject may suffer inconvenience, time loss, embarrassment, or psychological distress in giving an interview, and one may also suffer harm through the disclosure, the misuse, or even the planned use of the data to be provided. Furthermore, our society considers every individual to be autonomous, that is, having a right of privacy and the freedom to choose whether to divulge personal information, except where society has limited that right for what it considers to be the greater good of the community. The researcher must respect the respondent's rights of autonomy. It is therefore the obligation of researchers to provide survey subjects with full and fair information about the survey before soliciting the subject's information for the survey.

Statisticians have developed and announced principles on the conduct of social surveys. The International Statistical Institute in its Declaration on Professional Ethics has made the following statement with regard to obtaining informed consent: "Statistical inquiries involving the active participation of human subjects should be based as far as practicable on their freely given informed consent. Even if participation is required by law, it should still be as informed as possible. In voluntary

inquiries, subjects should not be under the impression that they are required to participate; they should be aware of their entitlement to refuse at any stage for whatever reason and to withdraw data just supplied. Information that would be likely to affect a subject's willingness to participate should not be deliberately withheld" (International Statistical Institute 1986, p. 235).

The importance of respondent notification is demonstrated in a brochure entitled *Surveys and Privacy*, prepared by the Committee on Privacy and Confidentiality (1990, pp. 22–24) of the American Statistical Association. In advising individuals whether or not to cooperate with requests for participation in surveys, the brochure states that they should ask the following questions before agreeing: "Who is this survey for?" "What will be done with the information you give?" "What does your participation involve?" and "Is the survey taker trying to sell you something or get you to give money?" Thus, the Committee suggests that these questions should be clearly answered in the notification to respondents.

In regard to most federal government collections of information about individual persons, Congress, in the Privacy Act of 1974, stipulated the content of the informed consent notification as follows:

e. Agency requirements:

"Each agency that maintains a system of records shall . . .

3. Inform each individual whom it asks to supply information, on the form which it uses to collect the information, or on a separate form that can be retained by the individual;
  - A. The authority (whether granted by statute, or by Executive order of the President) which authorizes the solicitation of the information and whether disclosure of such informa-

- tion is mandatory or voluntary;
- B. The principal purpose or purposes for which the information is intended to be used;
  - C. The routine uses which may be made of the information, as published pursuant to paragraph (4) (D) of this subsection; and
  - D. The effects on him, if any, of not providing all or any part of the requested information" (Privacy Act 1974, sec. 552a).

This paper investigates the provision of informed consent by U.S. government agencies and comments on the content and form of these provisions and major related issues. It seeks to determine how well the agencies are meeting the legal and moral requirements for informed consent. Data provided are based on information furnished by federal agencies in 1989 and 1990 in response to a request from the Panel on Confidentiality and Data Access, on the conduct of many of their surveys. The notifications, constituting their informed consent, are outlined for a set of sixteen surveys, selected arbitrarily for their importance, relevance, and variety. Implications of the various aspects of these notifications are discussed, together with major related issues.

## 2. Agency Practices in Providing Notification

In order to see how the relevant principles and requirements are actually applied by federal agencies in their data collections I have reviewed the notifications provided in 15 data programs of various federal agencies as they have been reported to the Panel on Confidentiality and Data Access, together with the notification given respecting the individual income tax reporting forms. I looked for the answers to the following questions with regard to each collection activity. The first five are the Privacy

Act requirements; the remaining three, though not required under the Privacy Act, are also of interest to social scientists:

1. Legal authority for collecting the information.
2. Whether providing the information is mandatory or voluntary.
3. The principal purpose(s) for which the information is to be used.
4. Routine uses of the information. ("Routine uses" are defined by the Privacy Act as transfers of information outside the agency for uses compatible with the purpose for which the data were obtained.)
5. Effects on the individual of not providing any or all of the requested information.
6. Does the notification contain a confidentiality pledge? (While the Privacy Act does not explicitly require it, most statistical agencies believe it is most important for the subject to be advised of the nature of the protection from disclosure which the data will receive.)
7. The form(s) which the notification takes. This form may affect the communicating of the informed consent.
8. Any other observations.

### 2.1. *Comments on the Review of Agency Practices*

1. I cannot be absolutely sure of the accuracy of the following summary observations on the notifications provided to respondents in these particular data programs. In particular, when certain features are reported as omitted it really means that I could not find them. Perhaps they are to be found on other pieces of paper that failed to be included in the set received by the Panel.

It should also be noted that some of these data programs are ongoing, some of the materials may change from one year to the next, and we may not in each case have the latest version. So certain items previously omitted may actually appear in the newest notification from the agency.

2. There is now another common feature of agency notifications on data collections, the paperwork reduction statement, which includes the estimated time it will take respondents to provide the information, and where one can write to give the agency comments on the paperwork burden involved. This notice is included in all data requests printed since July 1, 1988, under regulations published by the Office of Management and Budget (Federal Register 1988, pp. 16618–16632).
3. In only two instances are routine uses found to be reported. This does not necessarily indicate that agencies are failing to report routine uses (which permit disclosure to another agency), in some cases it may be because there are simply no routine uses provided for with respect to the given data program.
4. In several instances there is no mention of any penalties that might result from failure to respond. It always has been a moot question as to whether the Privacy Act actually requires such a mention when reporting is voluntary and there are actually no penalties for not responding. The Act states that the agency shall supply information on “the effects on him, *if any*, of not providing all or any part of the requested information” [emphasis added]. This can be taken to mean that the agency does not have to say anything if there are no such effects. However, some agencies

have come to require an explicit statement to respondents that there are no penalties, if such is the case, even when response is clearly voluntary.

5. Are these 16 cases representative? The first 12 cases are of surveys of individual persons and are assumed to be subject to the Privacy Act requirements, since they involve the maintenance of systems of records; they definitely represent the range of data programs on which the Subcommittee received reports. For some agencies, such as the Bureau of the Census, the Bureau of Labour Statistics, the National Center for Health Statistics, and the National Center for Educational Statistics, we also have reports on additional surveys, but it did not seem necessary to present them, since the notification practices with respect to them were generally the same as for the agency’s other programs that are reported on.

Four other data programs are discussed. One is the Form 1040 Individual Income Tax Return, which provides an interesting comparison. The other three are surveys of establishments or legal persons to which the Privacy Act does not apply; they are also included here for purposes of comparison, to see whether the Privacy Act requirements are also met when they do not apply, as standards which perhaps should apply in any data requests, and also to see whether any different standards prevail in such cases.

*Example 1. Prices Paid for Petroleum Products.* Apparently for 1990. Agency: National Agricultural Statistics Service, U.S. Department of Agriculture. Subjects: farmers.

1. General authority of 7 U.S.C. 2204.
2. Voluntary.

3. General and specific purposes of the information are given.
4. No routine uses are stated.
5. There is no statement on any effects of not reporting.
6. "Individual reports are kept confidential."
7. The notification is given in a letter and side blurbs on the one-page form.

*Example 2. Current Population Survey, 1990.* Agency: Bureau of the Census, U.S. Department of Commerce. Subjects: sample of U.S. households.

1. Authorized by 13 U.S.C. 182, 29 U.S.C. 1-9, and other laws for particular questions.
2. Voluntary.
3. Purpose: to develop various national estimates.
4. No routine uses given.
5. "Although there are no penalties for failure to answer any question . . ."
6. "By law, Census Bureau employees hold all information you give in strict confidence."
7. The notification is included in (a) a letter to the respondent, (b) question and answer information on the back of the letter, and (c) a brochure that is provided, and (d) the telephone number of the Regional Director, from whose office more information may be obtained, is given.

*Example 3. Survey of Income and Program Participation, 1988.* Agency: Bureau of the Census, U.S. Department of Commerce. Subjects: sample of U.S. households.

1. Authorized by 13 U.S.C. 182.
2. Voluntary.
3. General purpose given. Statistical purposes only.
4. No routine uses.
5. "There are no penalties for failure to answer any questions . . ."

6. ". . . law requires that we hold all the information given to the interviewer in strictest confidence."
7. The notification is given in (a) a letter to the household, (b) questions and answers on the back of the letter, and (c) a brochure.
8. Respondent is told an interviewer will return every four months to update the information.

*Example 4. 1990 Survey of Department of Defense (DOD) Overseas Civilian Personnel and Dependents.* Agency: Defense Manpower Data Center, U.S. Department of Defense. Subjects: All DOD overseas civilian personnel and their dependents.

1. Authority: 10 U.S.C. 136.
2. Voluntary.
3. Principal purposes given. To count the employees and dependents.
4. Routine use: to the Bureau of the Census for residency information on the personnel and dependents. (However, we are informed that no confidential information is received by the Census Bureau (Correspondence from Gerald W. Gates, July 1, 1991)).
5. "Failure to respond will not result in penalty to the respondent."
6. There is no mention of confidentiality on the sheet.
7. All we have is the notification given on the cover sheet of the report form.

*Example 5. National Education Longitudinal Study of 1988.* Agency: National Center for Education Statistics, U.S. Department of Education. Subjects: students, parents of students, teachers, and school principals.

1. Authorized by Section 406 of the General Education Provisions Act (20 USC 1221e-1).
2. Voluntary. "You may skip any questions you do not wish to answer."

3. Purpose: "to gather information about what happens to students as they move through high school and make decisions about postsecondary education and work."
4. No routine uses reported.
5. No effects stated for not providing data.
6. "Your responses will be merged with those of others, and the answers you give will never be identified as yours."
7. Notification is printed on the cover page of the respective questionnaires for students, parents, teachers, and principals.
8. The word "longitudinal" in the title suggests that there will be follow-up investigations in the future, but no mention is made of this to participants.

*Example 6. National Postsecondary Student Aid Study: 1990 Field Test.* Agency: National Center for Education Statistics, U.S. Department of Education. Subjects: students and parents.

1. Authorized by 20 U.S.C. 1221e.1.
2. The word "voluntary" is not used, but a paragraph containing confidentiality information includes the words, "... you are not required to respond, ..."
3. Study is "to determine how you and your family are financing your education . . . The results will be used to help determine future Federal policy regarding student financial aid."
4. No routine uses are reported.
5. No effects are stated for not providing data.
6. Information obtained "will be kept strictly confidential and cannot be disclosed or released to your school or any other group or individual."
7. The notification is provided in an advance letter to the participants.

*Example 7. Schools and Staffing Survey: 1990 Field Test.* Agency: National Center for Education Statistics, U.S. Department of Education. Subjects: public school districts, public and private school administrators, and public and private school teachers.

1. Authorized by 20 U.S.C. 1221e.
2. Voluntary.
3. Combines the purposes of several former surveys in seeking to measure conditions of school system staffing.
4. No routine uses reported.
5. No penalties are stated for failing to respond.
6. "The data will be treated as confidential and will be reported only in statistical summaries that preclude the identification of any individual. . . ."
7. Notification is given in a letter on the back of the cover sheet of each questionnaire.

*Example 8. Residential Energy Consumption Survey, 1987.* Agency: Energy Information Administration, U.S. Department of Energy. Subject: sample of households.

1. Authorized by PL 93-275, Sec. 52.
2. Voluntary.
3. Purpose to study trends in residential energy use.
4. No routine uses stated.
5. "There is no penalty for not answering."
6. "The information you provide and your identity will be held confidential . . . ."
7. Notification is included in (a) the covering letter to the resident and (b) a Privacy Act Notice on the back of the letter. A number to call for additional information (not an 800 number) is also given.

*Example 9. National Maternal and Infant Health Survey.* Agency: National Center

for Health Statistics, U.S. Department of Health and Human Services. Subjects: sample of mothers who had a live birth, a still-birth, or an infant death in 1988.

1. Authorized by 42 U.S.C. 242k.
2. "Your help is voluntary . . . ."
3. Purpose is to enable statistical research that will help reduce still-births, etc.
4. No routine uses given.
5. ". . . there is no penalty for not answering some or all of the questions."
6. "The answers . . . are kept strictly confidential."
7. Notification is contained in (a) the covering letter to the mother, as well as in letters to the doctors and hospitals to which the mother authorizes the agency to send inquiries, and in (b) a brochure on the study. (c) A telephone number is also given for obtaining additional information.
8. There is also a statement that "it may be necessary to recontact" the respondent.

*Example 10. National Health Interview Survey, 1989.* Agency: National Center for Health Statistics, U.S. Department of Health and Human Services. Subjects: sample of U.S. households.

1. Authorized by 42 U.S.C. 242k.
2. Voluntary.
3. Purposes of collecting national health statistics explained. Only for statistical purposes.
4. No routine uses reported.
5. ". . . no penalties for failure to answer any question . . . ."
6. The Bureau of the Census and also NCHS and its contractors will hold the reported information confidential.
7. Notification is included (a) in the letter

to respondents, (b) in additional information on the back of the letter, and (c) in a brochure. (d) A number to call for more information is given.

8. It is noted that "We may contact some of the persons in the survey at a later date . . . ."

*Example 11. Housing Survey, 1991.* Agency: Bureau of Labor Statistics, U.S. Department of Labor. Subject: About 60,000 houses and apartments in 85 selected areas.

1. Authorized by 29 U.S.C. 2.
2. Voluntary cooperation.
3. Used in improving Consumer Price Index; statistical purposes only.
4. No routine uses stated.
5. No effects stated for not providing data.
6. "All information we obtain will be held in strictest confidence."
7. Notification appears on a covering letter and the cover page of the schedule.

*Example 12. 1989 National Survey of Natural and Social Scientists and Engineers.* Agency: National Science Foundation. Subject: Scientific and technical personnel.

1. Authorized by 42 U.S.C. 1862.
2. Voluntary.
3. Purposes given – statistically analyze how changes in science and technology affect those in these fields.
4. No routine uses given; data held by Census Bureau.
5. "No penalties for failing to answer questions."
6. "By law, Census Bureau employees hold all information you give in strict confidence."
7. Notification is provided by letter and blurbs on the schedule cover sheet.

The remaining four examples are not social surveys; they include the data request on the income tax return and three economic surveys to which the Privacy Act does not apply. They are introduced for purposes of comparison, to see how federal agencies treat notifications in these other types of data requests.

*Example 13. U.S. Individual Income Tax Return (Form 1040), 1990.* Agency: Internal Revenue Service, U.S. Department of the Treasury. Subjects: All reporting taxpayers.

1. Authorization: Internal Revenue Code sections 6001, 6011, and 6012(a).
2. Mandatory.
3. "So we know who you are and can process your return and papers."
4. Routine uses: "We may give the information to the Department of Justice and to other Federal agencies, as provided by law. We may also give it to cities, states, the District of Columbia, and U.S. commonwealths or possessions to carry out their tax laws. And we may give it to foreign governments because of tax treaties they have with the United States."
5. "If you do not file a return, do not provide the information we ask for, or provide fraudulent information, the law says you may be charged penalties and, in certain cases, you may be subject to criminal prosecution."
6. No confidentiality pledge is given.
7. Notification is given in the section entitled "Privacy Act and Paperwork Reduction Act Notice," on page 4 of the instruction booklet.

*Example 14. Benchmark Survey of U.S. Direct Investment Abroad – 1989.* Agency: Bureau of Economic Analysis, U.S. Department of Commerce. Subjects: Each U.S.

person (defined as any individual, branch, partnership, associated group, association, estate, trust, corporation, or other organization . . . and any government) with an interest of 10% or more in a foreign business enterprise.

1. Authorized by 22 U.S.C. 3101–3108.
2. Mandatory.
3. General uses of the information given. Analytical and statistical purposes only.
4. No routine uses given.
5. Penalties for not reporting on the form: Up to \$10,000 in fines and up to 1 year in jail.
6. "... the information reported . . . will be held confidential."
7. The notification is given in (a) the Introduction Letter of the Instruction Booklet, (b) a section on confidentiality in the booklet, (c) the cover page of the report form, and (d) the instructions which are part of the form.

*Example 15. Coal Production Report, 1987.* Agency: Energy Information Administration, U.S. Department of Energy. Subject: All coal mining companies.

1. Authorized by PL 93-275.
2. Mandatory.
3. Purpose is to provide Congress with basic statistics on various aspects of coal production, in accordance with PL 93-275.
4. No routine uses as such, but provisions for transferring data to other agencies are discussed.
5. "Late filing, failure to file, or failure otherwise to make information available to EIA in accordance with these instructions, may result in criminal fines, civil penalties and other sanctions as provided by Section 13(i) of the FEA Act (PL 93-275)."



6. "The following data elements will not be treated as confidential data elements by EIA: (a) Total production quantity and (b) Coal beds mined. Also the name and address of the responding company, the mine or plant type, and location will be released upon request . . . . All other information will be kept confidential to the extent that it satisfies the criteria set forth in the FOIA exemption for trade secrets and confidential commercial information . . . ." Requests for the additional information will be reviewed and a determination on release made in accordance with the laws and regulations.
7. Notification is given on the cover sheet and in the instructions for completing the form.

*Example 16. Annual Occupational Injuries and Illnesses Survey Covering Calendar Year 1989.* Agency: Bureau of Labor Statistics for the Occupational Safety and Health Administration, U.S. Department of Labor, jointly with cooperating State agencies. Subject: Stratified sample of establishments.

1. Authorized by 29 U.S.C. 2.
2. Mandatory.
3. Purpose: to collect, compile, and analyze statistics on occupational injuries and illnesses.
4. No routine uses are stated; data are to be held by BLS, OSHA, and the State agencies cooperating.
5. "Failure to report can result in the issuance of citations and assessment of penalties."
6. "The information collected on this form will be used for statistical purposes only . . . ."
7. Notification is contained on the letter and the reporting form.

### 3. Requirements when Requesting the Social Security Number

Because of concerns about violations of privacy resulting from the use of the Social Security Number (SSN), the following Section 7 was included in the Privacy Act of 1974:

- a1. It shall be unlawful for any Federal, State, or local government agency to deny to any individual any right, benefit, or privilege provided by law because of such individual's refusal to disclose his social security account number.
2. The provisions of paragraph (1) of this subsection shall not apply with respect to:
  - A. any disclosure which is required by Federal statute, or
  - B. the disclosure of a social security number to any Federal, State, or local agency maintaining a system of records in existence and operating before January 1, 1975, if such disclosure was required under statute or regulation adopted prior to such date to verify the identity of an individual.
- b. Any Federal, State, or local government agency which requests an individual to disclose his social security account number shall inform that individual whether that disclosure is mandatory or voluntary, by what statutory or other authority such number is solicited, and what uses will be made of it."

It is part b of Section 7 which applies to the voluntary social and economic surveys conducted by agencies of the federal government. The SSN is sometimes desired for these surveys, in order to enable the match-

ing for statistical purposes of survey findings with information in other files, such as income tax files, files of the Social Security Administration, or Medicare files. I investigated three of the major surveys cited above to determine how these requirements are being met.

*Example 1. Current Population Survey.* The questionnaire asks (Question 26a), "What is the Social Security or Railroad Retirement number of each person in this household who is 15 years of age or older?" There are no special notification statements directly related to this request, but it is covered by the general statements in the advance letter to respondents and the questions and answers on its back, where it is stated that the survey is voluntary, the authorizing legislation is cited, and uses to be made of the data are given. The question and answers include the statement, "Occasionally, we may combine data from the CPS with data from other Government agencies to provide a comprehensive set of summary information about employment, income, and participation in various Government programs." The more sophisticated respondents may understand that this is likely to be a way that the SSN could be used.

*Example 2. Survey of Income and Program Participation (SIPP).* The SIPP for 1988 included Question 33a: "What is . . . 's Social Security or Railroad Retirement number?" There is no special notification in this part of the survey, but the following question and answer are included on the back of the advance letter to respondents from the Director of the Bureau of the Census:

"WHY DOES THE CENSUS BUREAU WANT TO KNOW MY SOCIAL SECURITY NUMBER? We would like to

know your social security number so we can obtain information that you have provided to other government agencies. This will help us avoid asking questions for which information is already available and will help ensure the accuracy and completeness of the survey results. The administrative records information we obtain from these agencies will be protected from unauthorized use just as the survey responses are protected. Providing your social security number is voluntary. All data in this survey are collected under Section 182 of Title 13, United States Code, which gives us the authority to conduct surveys to produce demographic and economic data."

*Example 3. National Health Interview Survey.* Section L. Demographic Background Page of the NHIS questionnaire for 1989 reads as follows in item 11:

Read to respondent(s): We also need – Social Security Number. This information is voluntary and collected under the authority of the Public Health Service Act. There will be no effect on – benefits and no information will be given to any other government or nongovernment agency.

Read if necessary: The Public Health Service Act is title 42, United States Code, Section 242k.

#### 11. What is – Social Security Number?

At the top of the same questionnaire page is the following instruction to the interviewer:

Read to respondent(s): In order to determine how health practices and conditions are related to how long people live, we would like to refer to statistical records maintained by the National Center for Health Statistics.

#### **4. Inferences from the Review of Notification Practices**

##### *4.1. Adequacy of notifications*

Judging from the given examples, together with other examples which have come to my attention, it appears that agencies are following quite scrupulously the Privacy Act mandate for items to be included in the notification to respondents of social and economic surveys.

Question may be raised, however, whether the notification provided by the Internal Revenue Service with respect to the Individual Income Tax Return adequately explains what will or may be done with the identified information when it is released to other agencies, cities, states, foreign governments, etc. The statement to individuals is that the information will be given "as provided by law;" most people will not know what the law provides, so this statement seems inadequate.

##### *4.2. How Supportable is the Pledge of Confidentiality?*

In all of these surveys the agency promises confidentiality in one form or another. And yet in many cases, in the absence of other special protective legislation, the agency could be required to divulge the confidential information "pursuant to the order of a court of competent jurisdiction," (5 U.S.C. Sec. 552a(b) (11)) or "to either House of Congress, or, to the extent of matter within its jurisdiction, any committee or subcommittee thereof, any joint committee of Congress or subcommittee of any such joint committee," (Sec. 552a(b) (9)). These possibilities are extremely remote, and to point them out in the notification statement could seriously jeopardize the efficacy of any survey. Perhaps assurances of confidentiality in these circumstances should simply

promise that confidentiality of information will be protected "to the fullest extent possible under the law." However, even this might rouse suspicions on the part of the respondent. The situation presents a serious dilemma to agencies.

##### *4.3. Routine uses and record linkages*

As noted, there were only two instances in which "routine uses," i.e., as defined by the Privacy Act, transfers of information to other agencies for uses compatible with the purpose for which the data were obtained, were reported. If the data were to be matched for statistical analysis to data from another agency, or even with data in other files of the same agency, this is apparently often considered a bona fide statistical use not requiring specific mention if the data are not to be transferred to another agency in identified form. Statistics Canada takes a different view, placing considerable stress on notifying respondents of any linking of the data with other data files, even if the data are not to be transferred to another agency in identifiable form (Statistics Canada 1986, Policy no. 41).

##### *4.4. Establishment surveys*

Also, judging from the given examples, together with other information I have, agencies apply the same standards of inclusion for notifications when the respondents are to be establishments or other organizations. The National Center for Health Statistics, as an added example, in its published policy requires the same items to be included in surveys of establishments as in surveys of individual persons (National Center for Health Statistics 1984).

##### *4.5. Form of the notification*

The form of the notification varies. All or parts of it may appear on (a) a letter to

the respondent, (b) a separate "Privacy Act Notice," (c) a question and answer sheet, perhaps on the back of the letter, (d) a separate brochure describing various facets of the survey, (e) separate instructions for completing the survey questionnaire, or (f) on the face sheet or elsewhere on the questionnaire itself. Any of approaches (a) through (e) should satisfy the provision in the act that the information be provided "on a separate form that can be retained by the individual;" (f) satisfies the alternative that the information be "on the form which (the agency) uses to collect the information."

#### *4.6. The multi-tiered approach*

In most cases the notification requirements are covered in a letter to the respondent, and then this statement is amplified by additional information in the other locations. Frequently, also, the respondent is provided with a telephone number which he/she may call in order to obtain additional information, either on confidentiality questions or on other aspects of the survey. Thus the notification is provided in a "multi-tiered approach." The respondent who is satisfied with the general statements in the letter (which also meet the agency's minimum requirements for notification) need not read on; if more explanation is wanted this may be obtained through the additional information provided. If this should still not be considered sufficient, presumably full explanations can be obtained by calling the telephone number.

#### *4.7. Telephone surveys*

Since the Privacy Act was originally passed in 1974, telephone surveys have come into increased use by governmental agencies, as they have found in many instances such surveys can be used to develop social information quickly, reliably, and less expensively

than through personal interviews or mailed-in questionnaires. Congress appears not to have taken telephone surveys into account when it required that Privacy Act notifications be on the questionnaire form (which the respondent presumably would see) or on a paper to be retained by the individual, as this is not feasible in certain types of telephone surveys, such as those based on random digit dialing. The National Center for Health Statistics, one of the pioneers in the use of telephone surveys, raised this question with the Department's Office of the General Counsel, and a solution was worked out consistent with the spirit of the law (National Center for Health Statistics 1984, pp. 7-8). This has the telephone interviewer reciting the specified notification to the respondent prior to asking for the desired survey information. After reading the full notification to the respondent the interviewer signs a statement that this has been done. In computer assisted telephone interviewing, in which no paper is used, the interviewer is instructed to make appropriate entries into the computer to indicate that the notification was read.

#### *4.8. Soliciting the Social Security Number*

In quite different ways the three agencies in our examples covered the Privacy Act requirements for notification with respect to a request for providing the respondent's SSN. The Act specifically requires that the respondents being asked for their SSNs be notified (a) whether the request is mandatory or voluntary, (b) the statutory authority for making the request, and (c) the uses to be made of the number. Since these three requirements also apply to the entire survey, it has always been a moot point as to whether the law actually requires such information to be repeated with respect to the request itself for the SSN.

It would be very useful to know, when the SSN is not provided by the respondent, whether this was because the SSN is not known or the respondent is refusing to give it. The SIPP questionnaire provides space for indicating "1. Don't know," "2. Refusal," or "3. None," when the SSN is not given. The NHIS questionnaire provides a box for "DK" but none for "refusal" when the SSN is not given. The CPS provides for neither response.

#### 4.9. Notification as a personal commitment

Survey agency heads authorize the notifications which commit their agencies to protecting the privacy of data subjects and the confidentiality of their information provided for the survey. Do these individuals carry a *personal* responsibility to see that these promises are implemented? In particular, what should persons in charge of a survey do when a higher authority demands information that has been guaranteed to be confidential?

In the writer's experience there was an incident in which the secretary of a department of the U.S. Government demanded that certain respondents' information be turned over; the secretary wanted the information in order to take administrative action against the respondents whose information suggested that they had disobeyed particular regulations. The director of the statistical agency which had promised confidentiality to the respondents replied that "over my dead body" would the information be supplied to the secretary. The secretary eventually dropped the matter, and nothing came of it.

In another instance an outside organization requested information obtained about a group of institutions in a survey. When the Freedom of Information Act request was denied the organization threatened to

sue for the information. The institutions had been assured of confidential treatment for their data, and the threatened publication of the data could have caused serious harm to the institutions. Staff of the agency involved then destroyed the files which related the data to identified institutions; fortunately, this file was no longer needed for statistical analysis purposes. The outside organization did not pursue the case, which reportedly was because it suspected what agency staff had done.

The secretary could have discharged or otherwise penalized the statistical director for insubordination. The agency staff which destroyed records could also have been punished, by either the court or the government department. Do those persons who are in charge of social surveys have a moral obligation to put themselves and their careers in jeopardy in order to protect survey subjects' information from unexpected disclosure? There are many in the profession who feel strongly that they do indeed have such a moral obligation, that they are personally responsible to keep the promises made to respondents, and that if they did otherwise they do not deserve to belong to the social science profession. The social scientist is in a position similar to that of a news reporter who submits to imprisonment rather than reveal sources.

What if it turns out that the law is on the side of the person or group who requested the information, since the promise given to the respondent was illegal, i.e., that the survey had *overpromised* in terms of what the law provided? Of course, it is unprofessional for a survey director to make any illegal promises, but once made they are the survey director's responsibility. However, the issue may not be so clear-cut. In the first case cited it turns out that the secretary had a legal right to demand the information, since under the prevailing law

the data were to be kept confidential "subject to the regulations of the secretary." However, the secretary had never used the authority to abrogate survey assurances, and the survey agency believed the secretary never would, as it would seem unconscionable to do so. It was well known that if this group of respondents had ever thought their identified data could reach the secretary, who could use the information against them, they would not have responded to the survey. (Some years after that incident the law was changed, and the departmental secretary no longer has the authority to abrogate survey assurances respecting identified respondents.)

In the second incident cited the agency believed it had clear authority to promise confidentiality to the respondent institutions. However, considering the vagaries of the law a judge may have ruled against them. If the files remained in existence they could have been seized, destroying their confidentiality.

It seems clear to the writer that when survey operators present confidentiality assurances to a respondent the survey operators are making a personal as well as an agency commitment to respondents. The operators are obligated to do all that is in their power to protect the data's confidentiality. The researchers should personally make sure that the respondents do not suffer for their trust; if anyone must suffer it should be those responsible for conducting the survey.

## 5. Major Issues

There are two principal issues faced by agencies with respect to providing notifications to those from whom they need survey information: (1) *What* set of information is proper, fair, and adequate to provide to individuals and establishments when seeking their informed consent to provide eli-

cited survey information? and (2) Consistent with providing proper, fair, and adequate notifications, how can agencies present such notifications in ways that will most effectively induce respondents to cooperate?

### 5.1. What information should be provided?

Jabine (1986, pp. 1–5) has written a thorough discussion of this subject. Addressing the question, "What information should be given to participants in voluntary surveys conducted by the Federal government?" he provided the following suggested guidelines, with explanations: On "Method of Notification" there are three guidelines: "(1) Written statements should be the primary means of notification. (2) Whenever possible, written notification statements should be provided in advance of the survey interview or at the time of the survey. (3) Provisions should be established to respond fully to additional questions that survey participants may have." On "Content of Notification Statements" there are also three guidelines: "(1) Make no false statements. (2) Do not make promises of confidentiality for which you do not have clear legal authority. (3) Advise survey participants of any planned or potential non-statistical uses of information about them." And finally there are two guidelines on "Other Issues": "(1) No uses should be made of survey information that are incompatible with the notification statement to survey participants. (2) In surveys where linkages based on social security numbers (SSNs) are to be undertaken: (a) No linkages should be undertaken in cases for which SSNs are refused, and (b) Linkages should not be used to obtain refused data items, even if SSNs have been provided."

Federal agencies which plan only statistical uses for a particular data set generally present a notification statement to the effect that the data requested will be used "only for statistical research and reporting purposes." Is this a sufficient statement to cover the many different kinds of uses the statement may entail, given that none of these uses should affect the respondent personally and directly? In the past the statement has sometimes been taken to include the possible need for callbacks to obtain additional or clarifying information, and the possibilities of linking the current survey findings with other data sets. However, statistical agencies have increasingly accepted the principle that the notification should include explicit statements on anticipated callbacks, as well as on any linkages to be made with other data sets. It seems proper that notifications should include these items.

It is generally admitted that when most microdata files are released there exists the possibility, however remote, that some subjects may be made identifiable in the files through highly sophisticated analysis. If there is such a possibility, even though the probability of this happening is one in millions, is it necessary to advise respondents of it, when this virtually nonexistent risk may persuade a number of respondents not to cooperate? Moral and legal requirements would appear to answer yes. Yet agencies sometimes tend to state or imply that there is absolutely no way that a subject in such files could be identified. These absolutist statements need to be modified in accord with the truth. Agencies must work to develop a way of noting, without unduly alarming the respondent, that there may be the remote possibility of disclosure. And the very possibility of even a rare disclosure through microdata tapes would suggest that agencies should be care-

ful, when possible, not to include items in such files that have any serious likelihood of causing severe harm to the respondent if it is unintentionally disclosed.

## 5.2. *How best to present notifications?*

The forms used in presenting notifications, the wording, the length, the juxtaposition of items, and other similar factors may have psychological effects on respondents that would lead them either to cooperate or not cooperate with the survey agency. Since cooperation is crucial to the success of any survey, it will pay the agency to do its utmost to assure that when respondents do refuse it is for sound reasons and not for extraneous factors. Singer, Hippler, and Schwarz (1990) have reported on research on this subject and have contributed important experiments of their own. Their opening statement is, "The most important requirement for representative sample surveys is a willingness on the part of the public to be interviewed." How can that willingness reasonably be maximized?

Briefly stated, the findings reported from earlier research indicate that response rates are depressed if a signature of approval is requested, and they are increased if respondents are given an "absolute" assurance of confidentiality. In certain circumstances the existence of a confidentiality assurance may lead to greater nonresponse than no statement at all. The original experiments conducted by Singer, Hippler, and Schwarz indicated (1) willingness to participate in a "nonthreatening survey" declines as confidentiality assurances are made more elaborate;" and (2) "elaborate assurances of confidentiality arouse expectations that the interview will be sensitive, and such assurances are not enough to overcome the resulting reluctance to participate . . . ." Additional experimentation of this nature

should help agencies to sharpen their confidentiality assurances so they elicit maximum cooperation along with improved understanding of the confidentiality protection afforded. There should also be more cognitive research to assure that notifications are written in such a way that respondents understand them correctly.

## 6. Concluding Statement

Agencies, then, in designing their notifications to respondents, should have two principal concerns:

1. The agency must provide clear, accurate, and complete notifications, fully meeting the agency's legal *and* moral obligations to give the respondents a good understanding of the implications of their cooperating in the request.
2. A great deal rides on the success of the surveys and other data programs. They usually involve a heavy investment in money and personnel, and important decisions will be made by society, based on the findings. Therefore, while meeting the principles of (1) above, the agency must present the notification in such a way that it is most likely to elicit a favorable response and cooperation from the respondent. Art must combine with science in designing forms and utilizing words that will best serve this mission.

## 7. References

Committee on Privacy and Confidentiality (1990). *Surveys and Privacy*. Amstat News, December 1990.

- Faden, R.R. and Beauchamp, T.L. (1986). *A History and Theory of Informed Consent*. New York: Oxford University Press.
- Federal Register (1988). Control of Paperwork Burden on the Public. Regulatory Changes Reflecting Amendments to the Paperwork Reduction Act; Final Rule. 5CFR Part 132. Vol. 53, no. 90. Tuesday, May 10, 1988.
- International Statistical Institute (1986). Declaration on Professional Ethics. Adopted August 1985. *International Statistical Review*. (See also Jowell, R. (1986). The Codification of Statistical Ethics. *Journal of Official Statistics*, 2, 217-253.)
- Jabine, T.B. (1986). Selected Guidelines for Notification to Survey Participants. *Proceedings of the Section on Survey Research Methods*, American Statistical Association, 1-5.
- National Center for Health Statistics (1984). *NCHS Staff Manual on Confidentiality*. DHHS Publication no. (PHS) 84-1244. Hyattsville, MD: U.S. Department of Health and Human Services, Public Health Service.
- The Privacy Act of 1974, 5 U.S.C.
- Public Health Service (1971). *The Institutional Guide to DHEW Policy on Protection of Human Subjects*. DHEW Publication no. (NIH) 72-102.
- Singer, E., Hippler, H-J., and Schwarz, N. (1990). The Effect of Confidentiality Assurances on Survey Response. Paper presented at the International Conference on Measurement Errors in Surveys. Tucson, AZ, November 1990.
- Statistics Canada (1986). *Policy Manual*. Ottawa, Canada: Statistics Canada.

Received September 1992  
Revised January 1993