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# **Summary of Human Subjects Protection Issues Related to Large Sample Surveys**

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This report identifies best practices to ensure that large sample surveys such as the National Crime Victimization Survey (NCVS) are ethically sound and compliant with the Common Rule. There are three approaches used in this report to identify best practices:

- Identify regulations and statutes governing each question, and the position of the Office of Human Research Protections (OHRP) and of major Institutional Review Boards (IRBs) and investigators who oversee large sample survey research.
- Recognize that these are general guidelines. Federal regulations recognize that broad areas of investigator and IRB discretion are required to validly investigate sensitive topics. The IRB's mandatory reasoned discussion and decision-making must be based on a broad understanding of the issues, and the IRB must document its decision process in its minutes.
- Provide resources that would enable the Bureau of Justice Statistics (BJS) to increase its sophistication and to evolve as issues change with new regulatory requirements and interpretations and with changes in the country's social or political environment.

This report addresses the following nine issues:

- The risks and benefits of participating in sample surveys on sensitive topics.
- Procedures to protect respondent privacy and ensure the confidentiality of data.
- Procedures to minimize risks and promote benefits to respondents.
- Procedures to respond to requests for help or assistance.
- Procedures to respond to revelations of a situation that interviewers must, by statute, report to appropriate authorities.
- Dangers and safeguards for vulnerable populations, including children and teenagers, pregnant women, mentally disabled persons, and persons confined to an institution, particularly correctional facilities.
- Efforts to minimize refusals to participate in surveys concerned with sensitive topics.
- Survey procedures for informed consent; special procedures for obtaining consent for respondents under age 18.
- Effects of signed consent forms on response rates and other aspects of conducting a survey or other study.

## 1. Introduction

The NCVS, sponsored by the Bureau of Justice Statistics (BJS), is conducted and analyzed by the U.S. Census Bureau which then provides summary statistics and data files to BJS. This survey asks sensitive questions of the same set of respondents every 6 months over 3 years (seven times); respondents include all members of a given household who are at least age 12. Over 40,000 households or living groups are surveyed. This research is exempt from IRB review and from the Common Rule (45 CFR 46, subpart A). However because the NCVS involves complex ethical issues, BJS has requested this review of issues pertinent to the ethics and regulatory requirements of large-scale sample surveys that ask sensitive questions and study vulnerable populations.

The federal policy for the protection of human subjects, which formerly pertained only to Health and Human Services research (45 CFR 46, Subpart A), has now been incorporated into the regulatory structure of 17 federal agencies, eight of which have additional human subject protections.<sup>1</sup> Subpart A, which is now known as the Common Rule, as well as the rest of 45 CFR 46 (Subparts B, C, and D), may be found at <http://ohrp.osophs.dhhs.gov/> under Policy Guidance. Briefly, the Common Rule sets forth the role and operation of the IRB, the required elements of the research protocol and the informed consent, and general criteria for IRB review and approval. The Department of Justice regulation is found at 28 CFR Part 46.

### Limitations of the Common Rule with respect to survey research

The Common Rule poorly defines privacy and confidentiality in survey research. It promotes the prevalent misconception that self-report research is necessarily less risky than experimental or observational research. For example, it exempts anonymous surveys of adults from IRB review (45 CFR 46.101(b)(2)), on the premise that adults can freely protect their privacy by refusing to answer. In fact, self-report questions can induce respondents to reveal far more personal and sensitive aspects of their lives than can be studied ethically by observational or experimental methods (see section 2). Subjects should at least give informed consent based on an accurate understanding of the kinds of questions that will be asked.

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<sup>1</sup>These agencies and their relevant regulations are: Housing and Urban Development (24 CFR 60), Justice (28 CFR 46 with additional protections in 28 CFR 512 and 28 CFR Part 22), Transportation (49 CFR 11), Veterans Affairs (38 CFR 16 with additional protections in 38 CFR 17.85, M-3, Part 1, Chapters 9 and 15), Consumer Product Safety (16 CFR 1028), Environmental Protection (40 CFR 26), International Development (11 CFR 225), NASA (14 CFR 1230), NSF (46 CFR 690), Agriculture (7 CFR 16), Commerce (15 CFR 27), Defense (32 CFR 219, plus 12 additional regulatory protections), Education (with extensive additional protections to privacy and confidentiality as noted below), Energy (10 CFR 745), Health and Human Services (45 CFR 46 Subpart A), Social Security (P.I. 103-296), and CIA (Executive Order 12333); the last three agencies also employ Subparts B, C, and D of 45 CFR 46.

The Common Rule specifically requires that informed consent include a statement about how the researcher will maintain confidentiality. However it leaves to the IRB and the researcher the subtle matter of understanding what confidentiality is and how it relates to privacy. The Common Rule defines privacy obliquely by reference to private information, as follows:

*Private information includes information about behavior that occurs in a context in which an individual can reasonably expect that no observation or recording is taking place, and information which has been provided for specific purposes by an individual and which the individual can reasonably expect will not be made public (for example, a medical record). (45 CFR 46.102(f)(2))*

This oblique reference to privacy confuses it with confidentiality (an understanding or agreement about the disclosure or nondisclosure of identifiable information to others) and fails to convey the notions of personal privacy (discussed in section 3) that are important to ethical research. It also implies that everyone has the same concerns about others' access to themselves and to identifiable data about themselves, and that researchers and IRBs can accurately assess what others situated differently from themselves would consider as private.

Based on this confusing set of definitions, the Common Rule states that:

*(7) When appropriate, there are adequate provisions to protect the privacy of subjects and to maintain the confidentiality of data. (45 CFR 46.111(a)(7))*

Unfortunately, this requirement assumes a level of sophisticated knowledge concerning privacy and confidentiality that most IRBs and researchers do not possess.

Given these limitations of the Common Rule, the conscientious survey researcher might look beyond the Common Rule to Subparts B, C, or D of 45 CFR 46 for guidance. Subpart B pertains to biomedical research on fetuses, pregnant women, and human in vitro fertilization, and Subpart C pertains to persons under correctional supervision. Neither of these sections are relevant to the NCVS. However Subpart D pertains to minors and is sensitive to children's personal privacy interests. It requires the child's active assent (when assent would be meaningful) and parental permission, with either party having veto power. It recognizes that there are contexts in which parental permission is not a reasonable requirement to protect the subjects (such as neglected or abused children), and also recognizes a range of circumstances in which parental permission may be waived. The parental permission requirement respects the parents' right to control the conditions of their child's life and their ability to judge the degree of acceptable risk for their child to take. Subpart D requires IRB approval when the research involves minors and anonymous

surveys, interviews, and observation of public behavior in which the investigator participates in the activities being observed. It limits a child's exposure to risk, even if there is parental permission and the child's assent.

## **2. Risks and benefits of participation in sample surveys**

Risks to privacy and confidentiality have long been deemed the main risks in sample survey research. However the scope and magnitude of this risk has increased as more sensitive topics are studied, and as researchers begin to oversample vulnerable and marginalized populations. As Bersoff and Bersoff (2000) point out, surveys raise issues of privacy that are rarely found in other research. There is the potential for self-report research to glean clinically sensitive data and put it in the hands of non-clinicians. Even if the survey is anonymous, researchers should not ignore the potential for violation of confidentiality and for severe emotional upset to respondents.

### **Standard risk issues, researcher responses, and IRB requirements**

To prepare a research project for review by an IRB, researchers must provide appropriate discussion of risks and benefits in the protocol and in the informed consent documentation. The IRB is required to evaluate the adequacy of researchers' recognition of potential risk and benefit, their plans for reducing or preventing risk and enhancing benefit, and the appropriateness with which this information is presented in the informed consent.

The risks that can arise in survey research are the same basic risks that can arise in other research:

- Mere inconvenience when a survey is administered at an inconvenient time or place or simply takes too long to administer.
- Emotional or psychological risk when a survey causes upset, or worry, warranted or not, about breach of confidentiality.
- Social risk due to stigma or other negative social outcomes of breach of confidentiality.
- Physical risk if revelations about others get back to those persons, particularly when researchers study domestic violence, gang activity, or other phenomena concerning violence-prone individuals.
- Financial risk if revelations result in loss of employment or insurance coverage.
- Legal risk when illegal activities are disclosed.

Most researchers do not catalog every conceivable risk in their consent document or in their protocol, nor do IRBs expect them to do so. However IRBs are mindful of the risks that researchers may overlook, including those described above. Most of the risks have to do with breach of confidentiality or fear or worry about a possible breach. The IRB is likely to want to know specifically how confidentiality is handled, whether limits to confidentiality are

adequately disclosed, and whether promises of confidentiality can actually be guaranteed. IRBs are attuned to issues of “secondary subjects,” who are identifiable persons about whom the respondent is asked sensitive questions. These “secondary subjects” are considered subjects of survey research because they are identified and researchers obtain information about them. If feasible, investigators should obtain their informed consent as they too may be placed at risk. If it is deemed impractical or impossible to obtain their informed consent, the waiver of informed consent should meet the requirements specified in the Common Rule, and the IRB must document its discussion and decision in its minutes.

### **Long-term consequences**

A sensitive matter is usually a troubling one. It may be a matter the respondent fears to discuss lest others learn about their particular situation. Fears of social or economic reprisals can cause respondents to lie, refuse to answer, or answer honestly but worry for a long time afterward. IRBs should recognize the importance of accurately identifying the kinds of unwarranted fears respondents are likely to have, as well as the actual risks. They require investigators to take steps to reduce both kinds of fears, and to ensure that researchers can keep promises of confidentiality.

Some matters are so sensitive that the respondent may relive it when discussing it. For example events such as physical assault are so traumatic that the respondent would reexperience old pain by retelling the details yet again. IRBs customarily require that researchers who inquire about sensitive issues such as rape have referral information and even availability of several free therapy sessions for respondents who recount traumatic events and would welcome such assistance in restoring their emotional well being.

The benefits to respondents of participation in surveys (not to be confused with financial incentives, which are discussed in section 8) are usually limited to the benefits of an interesting exploration of some topic, an informative and satisfying exchange in the debriefing process, and some written information pertinent to the topics discussed. (See section 4 for other appropriate and feasible additional benefits.)

Depending on the particular survey, the IRB will question whether vulnerable populations, non-English speakers, children, and persons whose autonomy is somehow constrained are accorded due protection and respect. These issues are discussed in section 7.

### **Background issues**

As most skilled interviewers have learned, getting in the door to interview an individual is not as hard as getting out. A well-constructed survey and a skilled interviewer can create

powerful motivation to discuss personal matters. This is a source of both benefit and risk, especially with repeated-measure surveys (such as the NCVS) in which a relationship is built up over time. Properly constructed surveys begin with easy, non-threatening questions. Each new topic is initiated with a general, non-threatening question and followed by increasingly specific and sometimes more sensitive questions. This funneling from general to specific makes for easy recall of related information, good comprehension of related questions, and rapid responding. It also makes respondents comfortable with questions they otherwise would refuse to answer. Lonely or troubled respondents are especially likely to welcome the attention of a respectful and skilled interviewer who promises confidentiality.

Respondents may find the interview session interesting, and perhaps even a therapeutic opportunity to recall and reflect upon their experiences or to get some things “off their chest.” The ethical and well-prepared interviewer is a good listener and keeps private information confidential. In response to a request for help or to signs of problems, or simply as a routine part of debriefing, the interviewer may provide useful feedback, referrals, or reference materials.

It would seem apparent that the respondent can readily refuse to answer any question that is too personal. Answering a question seems tantamount to informed consent, hence it is often assumed that there is little risk involved. This assumption of respondent autonomy and ease of refusing to answer questions is somewhat illusory given what is known about the “foot in the door” technique (Freedman and Fraser, 1966). Once persons agree to a small and benign request, they can be gotten to agree to a larger and less benign request which they would ordinarily never agree to, or to which persons who did not receive the first benign request would not agree. Interviewers can lead respondents who would ordinarily refuse to answer highly personal or embarrassing questions about some aspect of their personal life to answer such questions by first asking them to answer a rather tame question on the same topic. The underlying principle is that people want to appear consistent and cooperative and hence will continue to answer questions even when they would otherwise judge it ill-advised to do so (Cialdini, 1993; Orne, 1962).

The power of the well-constructed survey to yield answers to sensitive questions is a good thing in the hands of an ethical, sensitive, well-trained interviewer, but it can be dangerous otherwise. There are several possibly serious risks. Details of some of these risks and associated risk prevention strategies are discussed in subsequent sections. Respondents may:

- reveal reportable criminal activities,
- reveal information damaging to their social or financial standing, employability, or reputation which the researcher fails to treat as confidential,
- reveal information that is treated with appropriate confidentiality but which nevertheless causes the respondent to worry about the confidentiality of the

disclosure or to feel embarrassed,

- reach out for help such as by revealing suicidal ideation to an insensitive interviewer whose inappropriate response confirms the respondent's sense of hopelessness,
- reach out for help but then feel betrayed or embarrassed that the interviewer took stronger action than was expected,
- recall and ruminate about unresolved issues that the interviewer fails to recognize or respond to appropriately,
- reveal information in a family, community, or organizational setting where their privacy or the privacy of others in that group is not accorded due respect, or reveal potentially damaging information about another identified person (the secondary subject),
- respond to emotionally charged topics that may cause them to focus long afterward on painful memories such as brutal crime victimization, or
- experiment with socially unacceptable behavior in response to an interviewer who uses the "everybody does it" approach to evoking answers about unacceptable behavior.

The appropriate safeguard is not to weaken the power of the survey to gather information, but to strengthen the protections offered. The IRB frequently identifies the possible risks, and helps the researcher become sensitive to possible signs of risk and to plan appropriate safeguards.

In addition to safeguards to confidentiality, investigators should consider how to conclude the interview. The respondent should have an opportunity to express reactions or ask questions. The conclusion should be a two-way conversation and should not be carried out in a perfunctory manner. It should adequately settle any questions or concerns the respondent may have, and return the respondent to a positive, satisfied state of mind.

Many interviewers are unprepared for risks even after they are sensitized to their possible occurrence. Researchers should develop referral and feedback information that might be generally useful to all respondents. They should also locate institutional or outside resources that can respond appropriately to respondents who reach out for help or indicate distress. There should be competent professionals who are available to researchers for consultation when issues arise which the researcher (interviewer) feels unprepared to handle. However the investigators must always respect the wishes of the respondent and keep promised conditions of confidentiality. Giving more help than is wanted is often harmful, not helpful. Moreover the interviewer should not attempt to help beyond providing referrals or other written resource information. These topics are discussed further in sections 3 through 7.

### **3. Procedures to protect privacy and maintain confidentiality**

The Common Rule and most guidelines for IRBs emphasize the importance of privacy and confidentiality but are neither specific nor detailed in their recommendations. There is a superb literature on approaches to respecting privacy and confidentiality with which survey researchers should be familiar.

#### **Standard issues and problems**

The Common Rule leaves much to the judgment of IRBs with respect to privacy and confidentiality, so that the same degree of caution need not be imposed on all research. 45 CFR 46.111 (a)(1) states that “Risks to subjects are minimized: (i) By using procedures which are consistent with sound research design, and which do not unnecessarily expose subject to risk,” and 45 CFR 46.111(a)(7) states that “When appropriate, there are adequate provisions to protect the privacy of subjects and to maintain the confidentiality of data.”

How do IRBs identify the relevant issues? Invasion of personal privacy is a subjective matter, and IRB members judge invasion of privacy on their own sense of propriety and on the particular circumstances of the study. This can be an inadequate basis for judgment.

Confidentiality is an objective but complex matter and involves many possible judgments depending on the research. Confidentiality pertains to data on identifiable persons. In recent times, IRBs have become increasingly concerned about what constitutes an identifiable respondent of survey research. When is a survey truly anonymous? Even when the names of respondents are never attached to their data, there is increasing concern about deductive identification of otherwise anonymous respondents on the basis of such elements of their data as birth date, occupation, zip code, race, and gender. The issue of an “identifiable subject” also arises if the researcher wants access to existing records to identify persons suitable for the proposed study; if the data being sought are sensitive, the IRB may judge that consent of subjects should be obtained for accessing those existing data. If existing school data are sought on youngsters, the Buckley Amendment (the General Education Provisions Act (20 USC 1232)) requires parental permission for release of identifiable information about children in public schools.

IRBs do not consider sample survey research anonymous (and hence exempt from IRB review) if identifiers that accompany the data are later stripped from the data. If a unique identifier was attached to it at some point in the process — for purposes of respondent selection and interviewing or for recontacting selected subjects by a supervisor checking on the work of the interviewer — it is not an anonymous survey. A survey that involves any identifiable data at any point in the research process is subject to IRB review.

If researchers are collecting sensitive survey data about identified individuals, the IRB will inquire whether there are provisions for protecting the confidentiality of the data. Such provisions typically include substituting codes for identifiers and storing the code key elsewhere, removing face sheets (typically containing such information as names, phone numbers, or addresses), destruction of identifying information such as computer sheets, keeping data in locked files, impressing on research assistants the importance of confidentiality, and limiting access to the data by various means. Data from large sample surveys are normally stored electronically for easy access and analysis. Whenever identifiers accompany these data or when deductive identification would be easy, there is major concern about the security of the computer system on which the data are stored, and researchers must satisfy these concerns.

A particularly difficult issue has to do with the training and supervision of interviewers and research assistants. Where possible, the research staff should not be persons who might know some of the respondents, though this is difficult to ensure. Researchers who are concerned about the cultural and linguistic matching of interviewers with subject populations should consider hiring and training local people. However, there is the risk that the interviewer will know the respondent.

The Common Rule defines and discusses privacy and confidentiality in ways more appropriate to biomedical research than to survey research. It fails to recognize both the aspects of personal privacy that the effective interviewer must respect and the individual subjectivity and diversity of people's sense of privacy. With respect to confidentiality, it gives no hint of the vast technical literature on methods of ensuring confidentiality in survey research.

### **Privacy**

The difficulty of defining invasion of one's own privacy is evocatively expressed by Melton (1992, p. 66):

*'I know it when I feel it.' A gut sense of personal violation may be the tie that binds such disparate events as being subjected to a body search, being the subject of gossip, having one's mail read, being asked one's income, or having one's house entered without permission. It should come as no surprise that such an intensely personal construct is difficult to define.*

It is difficult to define, understand, and respect the privacy of other persons situated differently from ourselves. Without a useful definition or theory of privacy to guide them, researchers and IRBs must depend on their own culture-bound notions of privacy. They

invoke their personal and idiosyncratic definitions, resulting in a capricious standard of protection.

The meaning of privacy in survey research inheres in the culture and personal circumstances of the particular subject, the context and nature of the research, and the social and political environment in which the research occurs. A useful definition of privacy that recognizes these manifold elements is borrowed from, and based on, the elegant theory of personal privacy developed by Laufer and Wolfe (1977):

*Privacy refers to persons and to their interest in controlling the access of others to themselves.*

This theory of personal privacy recognizes the manifold cultural, developmental, and situational elements by which individuals orchestrate their privacy. It recognizes that people have an interest in (a) controlling the time, place, and nature of the information they give to others, and (b) controlling the information or experiences that are proffered to them. Thus informed consent serves as a control mechanism, provided the prospective subjects of survey research are adequately informed of what it is they will be asked and what they may experience.

Laufer and Wolfe's theory would be highly useful to efforts to educate IRBs; to design ethical elements of recruitment, consent, location, circumstances, and content of surveys; and to train interviewers. Laufer and Wolfe's theory embodies four dimensions of privacy:

*The self-ego dimension* refers to the development of autonomy and personal dignity. Young children have an aversion to being alone. By middle childhood, children seek time alone to establish a sense of self and to nurture new ideas, creating a basis for self-esteem, personal strength, and dignity. By age 6 or 7, children have a need and right to privacy not found in infants and younger children. Teenagers are intensely private, as they seek to forge an identity separate from that of their parents. Teenagers would be embarrassed to be interviewed about personal matters in the presence of their parents or others, and in the presence of their parents would most likely refuse to be interviewed or lie in their answers. Adults continue to need time alone and develop many means of protecting that privacy.

*The environmental dimension* includes socio-physical, cultural, and life-cycle dimensions. Socio-physical elements are physical or technological elements that offer privacy; more affluent individuals tend to have more of such barriers to unwanted intrusion. Cultural elements include norms for achieving privacy; for example some cultures permit lying while others permit persons to have private rooms and telephones. Life-cycle elements vary with age, occupation, available technology, and changing socio-cultural patterns. The ways one

establishes privacy at one age, under one set of circumstances, may be unsatisfactory or unavailable at a later stage.

*The interpersonal dimension* refers to how interaction and information are managed. One's social setting and its physical characteristics provide options for managing social interaction; physical and social boundaries can be used to control people's access to one another.

*The control/choice dimension* grows out of the other dimensions. Young children have no control over their privacy except through hiding. They learn to use personal, cultural, and physical resources to control their privacy. Events that would threaten one's privacy early in the development of control/choice are later so easy to control that they are no longer considered a threat to privacy.

### ***Understanding and respecting the privacy of others***

How do the researcher and IRB learn about the privacy interests of persons situated differently from themselves? Networks of local researchers, educators and outreach workers such as social workers, farm agents, and public health nurses can share valuable information about the most appropriate ways to approach members of various cultures. Interviewers who are of the same culture and backgrounds are vital to some sensitive research in some kinds of communities. Focus groups and other forms of community consultation are useful ways to learn about a culture, how the individuals within that community perceive the research, and how the research that would be objectionable to them can be made acceptable. The community meetings held by Fisher and Wallace (2000) are a good example of learning the views and suspicions of members of inner-city African Americans about studies of adolescent risk behavior. The community consultation discussed in Melton et al. (1988) is a dramatic example of the explosive acquaintance process of AIDS activists with AZT researchers. While only the Fisher and Wallace account focuses on survey research, there is much that survey researchers could learn from both accounts about the importance of understanding the perspective of one's subjects in field-based applied research.

Community consultation can also ameliorate fears among potential respondents who feel a need to avoid strangers. For example, a large-scale survey of the housing needs of the elderly required that interviewers go to the homes of elderly people, who are fearful of scam artists, robbers, and burglars. The interview teams began by making well-advertised visits to senior centers in the neighborhoods where they would be conducting their survey. They explained their project, answered questions, and made certain that the local newspaper carried the story of their presentation and project, along with photographs of them. Their first contact with their prospective respondents was by letter, and it included a copy of the newspaper article with the pictures of the interviewers. The interviewers then phoned to

make an appointment for their visit. When they appeared at the door, they carried with them a copy of the newspaper article so that the respondents could see that they were indeed the designated interviewers.

### ***Confidentiality***

The following definition of confidentiality is adapted from that developed by Boruch and Cecil (1979):

*Confidentiality is an extension of the concept of privacy; it refers to (a) identifiable data (some information about a person that would permit others to identify the specific person, such as a non-anonymous survey, notes or a videotape of the person) and (b) agreements about how those data are to be handled in keeping with respondents' interest in controlling the access of others to information about themselves.*

The two critical elements of this definition — identifiable data and agreement about the handling of the data — indicate the critical role of informed consent, which states how the researcher will control access to the data and secures the respondent's agreement to participate under these conditions. This definition further underlines the importance of planning before gathering sensitive data. It is important that researchers make early plans regarding techniques to ensure confidentiality. They should incorporate these plans into the methodology and into any consent agreements with respondents or contractual agreements with subsequent users of the data, including funders who may wish to audit the data. Investigators should include all of these details in the IRB protocol.

This definition of confidentiality leads naturally to the literature on procedural, methodological, statistical, and legal approaches to ensuring the confidentiality of survey research data.

#### *Methods and procedures of ensuring confidentiality<sup>2</sup>*

Approaches to ensuring confidentiality of survey research fall into seven categories:

- Procedures that eliminate linkage of data to unique identifiers
- Intersystem linkage
- Statistical strategies

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<sup>2</sup>Portions of this section are drawn from an unpublished paper that was commissioned by the National Bioethics Advisory Commission: J. E. Sieber, *Privacy and Confidentiality: As Related to Human Research in Social and Behavioral Science*, 2000.

- Agreements: Data sharing, secondary analysis, or audit of data
- Legal protections
- Descriptive statistics and raw data releases
- Internet research

**Procedures that eliminate linkage of data to unique identifiers.** Anonymity offers the best insurance that disclosure of subjects' responses will not occur. Researchers have developed dozens of techniques that are responsive both to the need for anonymity and to other research needs. Different kinds of data — cross-sectional, longitudinal, and data from multiple sources — bring with them different research requirements and different ways of meeting those without using unique identifiers of subjects. The following brief summary is illustrative, not comprehensive. See Boruch and Cecil (1979) for a comprehensive review.

*Cross-sectional surveys*, in their simplest form, require just one data collection session. Anonymity in which even the researcher is at all times ignorant to the identity of subjects protects the respondent from legal prosecution, social embarrassment, and concern that the data may fall into the wrong hands. However it may be desirable to have some form of follow-up to test for sampling validity, response validity, or to do further research on some or all subjects. These refinements are impossible with complete anonymity, but can be achieved through temporarily identified responses with subsequent destruction of identifiers, or through use of brokers to provide anonymous data to the researcher after completing one or more of these refinements.

*Longitudinal surveys* track individual subjects over time. There are many ways in which aliases or arbitrary identifiers can be used as a basis for linking observations over time while preserving the confidentiality of individual responses. For example, subjects may choose an easily remembered alias and use it on repeated occasions. Some approaches are quite complex. For example, research by the American Council on Education (Austin and Boruch, 1970) on political activism among American college students used the following three-file linkage system:

1. Initial data collection:

- File A contains each subjects' data and arbitrary account number (X).
- File B pairs each subject's name with a second arbitrary account number (Y). File C matches the two sets of account numbers, X and Y.
- File C is shipped to a researcher in a foreign country.

## 2. Second data collection:

- Second set of identifiable longitudinal data are gathered.
- Names are replaced by their Y account number; this file is shipped to the foreign researcher.

## 3. Data analysis:

- Foreign researcher substitutes X account numbers with corresponding Y numbers.
- Each set of data files is returned to the data analysts.
- Data are organized in longitudinal sequences; the identity of each subject is unknown.
- The longitudinal data are analyzed.
- Foreign researcher destroys File C; the three files can never be merged to learn subject identities.

Thus the data were safe. Conceivably, foreign discovery procedures could be used to obtain some of the identifiable data before File C is destroyed. Therefore a Certificate of Confidentiality (see below) could be obtained to preclude that unlikely event.

**Intersystem linkage.** Intersystem linkage is sometimes necessary to link research records on subjects with other, independently stored records on the same individuals. In the case of highly sensitive data such as psychiatric or police records, a linkage strategy may be needed so that the researcher does not have access to any identified records.

One such method is as follows:

1. Researcher wishes to link data on 50 subjects with information from their police records.
2. Subject provides data and an alias (no name) to the researcher.
3. Subject provides to the archive (police) his name and alias.
4. Archive provides the requested police information with the aliases (not the names) attached
5. Researcher analyzes relationship between his research data and the police record data.

This brief summary is merely illustrative of some of the many specific procedures for preserving anonymity or confidentiality. The actual literature on this topic is immense. (See Boruch and Cecil (1979), and Campbell, Boruch, Schwartz, and Steinberg (1977). See also current U.S. Census Bureau papers on this topic.)

**Statistical strategies.** Researchers have developed various statistical strategies to eliminate any direct link between the respondent's identity and his true answer. All of these methods involve the injection of a specified amount of random error into the dataset so that researchers cannot ascertain an individual's true identity but can still perform a useful statistical analysis of the data.

The statistically elegant randomized response method is used in direct interview to protect privacy and to ensure confidentiality. The following is an oversimplified example: Suppose the researcher wished to ask whether respondents had struck their child in anger this week or cheated on their income tax this year — obvious invasions of respondents' privacy. Each respondent is instructed to roll a die in his cupped hands and observe which number came up without showing it to the researcher. If the predetermined number was rolled, the respondent is to respond "yes," irrespective of the true answer. By an algebraic removal of the expected number of false "yes" answers from the data, the researcher can determine the true proportion of "yes" responses. Neither the researcher nor anyone else besides the respondent knows who gave a true "yes" response.

The randomized response method has been in use since 1965, and researchers have developed many statistical variations of it. Although it has been tested in many settings, the jury is still out on its usefulness. It tends to produce somewhat more admissions of undesirable behavior than traditional face-to-face interviewing, but brings with it many disadvantages. It is difficult for subjects to understand and believe, and time-consuming to explain. The interviewer has an important role in establishing trust and understanding, and respondents of limited ability have difficulty understanding and trusting the procedure (Landsheer, van der Heijden, and van Gils, 1999). It injects random error necessitating larger samples. Without understanding the reasons why people might refuse to give candid answers, the routine use of a difficult method such as this seems inappropriate. For critical evaluations of the randomized response method, see Linden and Weiss (1994), Umesh and Peterson (1991), and van der Heijden, van Gils, Bouts, and Hox (2000).

Methodologists have designed statistical strategies for use with longitudinal and multiple source data; see Boruch and Cecil (1979).

**Agreements: Data sharing, secondary analysis, and audit of data.** Concern for the integrity of data and for extending the analyses of important datasets brings with it the need to do so without risk to privacy or confidentiality. The simplest solution is to render the data anonymous. However anonymity may render the data useless to the secondary user or auditor. To satisfy the needs of secondary users while also protecting the interests of respondents, the researcher can employ procedures that diminish (a) outright breach of confidentiality, (b) likelihood of deductive identification, (c) the sensitivity of the information to which the secondary users have access, or (d) the need for the secondary user to actually take possession of the data (see Boruch and Cecil, 1979). Researchers and IRBs need to

develop contractual agreements with funders who require audits and secondary analysts with whom they share data about how they will ensure confidentiality. They should also include information in the informed consent so that potential subjects understand what researchers will do with the data subsequent to the initial project.

**Legal protections of confidentiality.** Statutory protection of research data enables researchers to protect the confidentiality of research records on identifiable individuals from subpoena. Subpoena of social research data is rare. However if vulnerable data could not be protected from subpoena, there would be a chilling effect, especially on criminological and delinquency research. There is growing use of Certificates of Confidentiality. However researchers and IRBs are often unclear about the protections these provide and their limitations.

*Certificates of Confidentiality.* The Public Health Service Act (PHSA) was amended (1970) to authorize researchers to withhold information concerning the identity of participants in research on use and effect of drugs. The Secretary of the Department of Health and Human Services grants this authority by issuing Certificates of Confidentiality. A 1988 amendment broadened its scope to include mental health, biomedical, clinical, behavioral, and social research. Under this amendment, the Secretary of DHHS may

*authorize persons engaged in biomedical, behavioral, clinical, or other research (including research on mental health, including research on the use and effect of alcohol and other psychoactive drugs), to protect the privacy of individuals who are the subject of such research by withholding from all persons not connected with the conduct of such research the names or other identifying characteristics of such individuals. Persons so authorized to protect the privacy of such individuals may not be compelled in any federal, state, or local civil, criminal, administrative, legislative, or other proceedings to identify such individuals. (42 U.S.C. 242a(b)(1989))*

Various institutes within DHHS are authorized to issue certificates. Since 1993 DHHS can grant certificates for research that is not federally funded. DHHS regards a certificate's protection to supercede State law; this position has been challenged and upheld in the New York Court of Appeals (*People v. Newman*, 32 N.Y.2d 379, 298 N.E.2d 651, 345 N.Y.S.2d 502, 1973) (Boikess, 2000).

A certificate does not protect identifiable data of "secondary subjects," a point which researchers may fail to clarify in the informed consent. The certificate only protects researchers against compelled disclosure of subjects' names or other identifiers, coupled with their data. It does not protect subjects who voluntarily consent to disclose their research records, nor preclude a researcher from reporting the identity of subjects who disclose intentions to harm themselves or others. Moreover the language of PHSA is imprecise, which gives rise to uncertainty. It offers protection to "names and other

identifying characteristics,” but the data of a known subject may not necessarily be protected. Melton (1992, p. 81) provides an example of this possible loophole:

*[I]n one of my own studies, all of the children in a particular county who are involved in criminal child abuse prosecutions are invited to participate. Knowing that fact, a defense attorney might seek the data of a particular child (not the names of participants) as a fishing expedition for information intended to impeach the child's testimony. A literal interpretation of the statute would suggest that the subpoena might be enforceable if the data could be shown in some way to be relevant to the proceeding. Although it is also possible — perhaps even probable — that a court would interpret the statute more broadly in keeping with Congressional intent, the uncertainty prevents unequivocal offers of confidentiality to participants and, therefore, should be eliminated by a technical amendment.*

It is also unclear whether child abuse reporting laws are abrogated by a Certificate of Confidentiality. Is such reporting a “legal proceeding” that cannot be mandated under a certificate?

Researchers must request the certificate before each research undertaking. Subpoenas typically occur for reasons unrelated to the study itself and therefore are not reasonably foreseeable by either the subjects or the investigator. Hence the protections offered by a certificate may be unavailable when needed. Researchers sometimes send data to a foreign country, although this does not always guarantee protection.

*Placing data in a foreign country and laws governing foreign discovery.*<sup>3</sup> Many survey researchers believe that sending confidential data to a foreign country — such as to a colleague in Canada — protects the data from subpoena. However this is only a deterrent from subpoena, not a guarantee of protection. Federal Rules of Civil Procedure govern the procedures for discovery, including foreign discovery. Rule 26(b) states that parties may obtain discovery of anything that is relevant, not privileged, and admissible or “reasonably calculated to lead to the discovery of admissible evidence.” Rule 34 states:

*(a) Scope. Any party may serve on any other party a request (1) to produce and permit the party making the request, (2) to inspect and copy, any designated documents, or (3) to inspect and copy, test or sample any tangible things which constitute or contain matters within the scope of rule 26(b) and which are in the possession, custody, or control of the party upon whom the request is served....*

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<sup>3</sup>I am indebted to Dr. Joe Cecil and Jason Gilbert, Federal Judicial Center, for providing me with their detailed summary and analysis of these issues.

(c) *Persons Not Parties.* A person not a party to the action may be compelled to produce documents and things or to submit to an inspection.

The courts cannot compel a party to produce data if the party does not have “possession, custody, or control” of the documents, but it is unclear what constitutes “control.” If a researcher sends data out of the country for the express purpose of preventing subpoena, does this qualify as loss of control in the eyes of a court? Jason Gilbert (2000), a legal intern at the Federal Judicial Center, offers the following analysis of this question:

*While the courts seem to have settled on defining control as when a party has a legal right to obtain something, questions remain for the researcher seeking to give up control of research data to a foreign colleague in an attempt to protect it from being disclosed. Legal rights to possession can come from a variety of sources, particularly when one is considering intellectual property such as research data. If a researcher were to create a set of data, when exactly would he or she no longer have a legal right to that set of data? What if the researcher gave one part of the data to a colleague? What if the researcher only gave up a small “key” to the data that allowed the individuals who participated in the study to be identified? What if the researcher gave part, or even all, of the data to a colleague but still continued to collaborate with that colleague to perform analysis on the data even though it was not in the researcher’s possession? Would that researcher still have a legal right to get back what he or she had surrendered? While the concept of giving away the legal right of possession is relatively straightforward, the mechanics of how exactly a researcher can give away the legal right to possess his own data (particularly if one does not allow for a sale or some type of contract) remains unclear.*

Gilbert also reminds us of some other implications of “loss of control” of data. (1) Transfer of all data out of the country would mean loss of all electronic or hard copies in the researcher’s possession. (2) A researcher must never transfer data after receiving a subpoena. Even if it is done as a safeguard beforehand, the researcher may still be found to have acted not in good faith and be cited for contempt of court. (3) If the research is done under a contract requiring that the researcher maintain control of the data, relinquishing control to a foreign colleague would constitute a breach of that contract. (4) The researcher’s professional code of ethics or a future journal editor may require that the researcher maintain control of the data.

A researcher who loses control of data by sending it to a foreign colleague places that colleague at risk of receiving a subpoena for the data and of having to seek legal means of protecting confidentiality. However the rules and procedures of foreign discovery are complex, expensive, and time-consuming. If the colleague who controls the subpoenaed information is a foreign national residing outside of the United States, the party seeking the data must follow appropriate procedures for foreign production. The United States has ratified various treaties concerning obtaining of evidence from foreign countries, and each country has its own procedures. Discovery in a foreign country involves sending a formal

“letter of request” by the court where the action is pending to a court in the foreign country. This letter requests the foreign court to request documents of the person in possession of the desired information. There are various diplomatic and legal approaches to delivering such a request and accomplishing the discovery. These may make discovery of the information too unattractive to pursue.

**Descriptive statistics and raw data releases.** Statisticians in governmental agencies in the United States, Great Britain, and Sweden have developed practices of adjusting tabular presentations so that deductive identification is not possible. Deductive identification could occur if one knew some facts about an individual, perhaps in conjunction with their zip code. By searching the files for that zip code and locating the individual whose data matched those known facts one could deduce additional information from the other data associated with that individual. For example, if an 84-year-old Hispanic woman from the 01373 zip code area was known to have had quite a few husbands and to have become quite wealthy, it would confirm quite a few suspicions to learn that there was an 84-year-old Hispanic woman at that zip code whose annual interest income was in seven figures and who had had 20 husbands.

The most common way to prevent deductive disclosure is to broaden categories so that data from unique individuals or from groups of data containing some unique individuals such as top income earners or persons involved in high-profile criminal victimization are not apparent. Another is error inoculation so that no individual case could be assumed to be correct (as in the random-response method).

When the U.S. Census Bureau’s Disclosure Review Board reviews NCVS datasets in anticipation of their release to the InterUniversity Consortium for Political and Social Research (ICPSR), the Review Board’s primary role is to scrutinize data for extreme cases that might uniquely identify the individuals involved or even subject them to criminal investigation. Thus, instead of showing that a given 84-year-old Hispanic woman had been widowed 20 times and had an interest income of over \$1,000,000, it might show that the person had been widowed more than four times and had an annual interest income of over \$100,000.

**Internet research.** There is rapidly emerging literature on various kinds of Internet research, associated methods of solving problems of privacy and confidentiality, and uncertainties or vulnerabilities connected with these “solutions.” Researchers’ insouciant claims that Internet data are anonymous or that confidentiality will be protected are reminiscent of such promises regarding non-web research of several decades ago.

This area of research will grow rapidly since it enables researchers to reach far-flung subjects quickly, inexpensively, round-the-clock, and without a research staff. The problems and solutions to issues of privacy and confidentiality will change rapidly as new technologies

render old problems and old solutions obsolete. Some of the rapidly evolving issues include:

- How to ensure that researchers do not study children under rules that pertain to adults.
- How to ensure anonymity of responses given that web page software logs as header lines the IP address of the machine from which the respondent accessed the researcher's web page.
- How to store an on-line data file so that unauthorized persons cannot access it.

The advice offered by OHRP and generally heeded by IRBs is that the safest practice is to use the Internet for purposes of recruitment and screening. After locating a qualified respondent, a researcher can e-mail the survey and a respondent return it as an attachment.

Given the uncertainties, especially with regard to assurances of confidentiality, it is reasonable at this stage to recommend that assurances of confidentiality contain appropriate disclaimers.

### **Confidentiality assurances and their consequences**

The link between promises of confidentiality and willingness to participate in surveys is tenuous. Researchers' promises of confidentiality are not always effective in producing trust in research participants. Such promises cannot always be kept due to faulty data management practices and other possible compulsory disclosures. Moreover, the relationship between faith in confidentiality promises and participation in survey research is not what most suppose it to be.

Singer, Mathiowetz, and Couper (1993) investigated the relationship between concerns about confidentiality and mail returns to the 1990 census. Such concerns have only a very slight effect on survey participation, and this relationship holds even when demographic variables known to be related to concerns and survey participation are controlled. Similarly assurances of confidentiality have unexpected effects. Singer, VonThurn, and Miller (1995) conducted meta-analysis of 30 research reports on the relationship between various forms of confidentiality assurances (anonymity, use of the randomized response method, and verbal assurances). They found that the effect of confidentiality assurances on willingness to respond is small, positive, statistically significant, and robust in the presence of various control variables, but only when sensitive questions are asked. The effect is small and negative when the questions asked are not sensitive ones. Elaborate assurances of confidentiality defeat their purpose when the contents of the survey are not sensitive. Apparently such assurances of confidentiality heighten respondents' perceptions of the

sensitivity or threat of the survey or arouse their suspicions (Singer, Hippler, and Schwarz (1992)).

### **Emerging issues of privacy and confidentiality**

Electronic data collection and storage practices are changing rapidly. Interviewers and their subjects need not meet face-to-face and may even reside in different parts of the world. Emerging issues of confidentiality are more varied and dangerous than current policy makers can easily anticipate. Soon issues of confidentiality will be transformed in ways we cannot imagine today. There are already digital communication networks on a global scale, and hackers with a laptop computer and Internet technology could download any electronic data stored on any server anywhere in the world. There are also emerging technologies for protecting communication and personal identity, and there is a whole new cohort of technology-sophisticated privacy activists. Governments are developing and testing new laws that protect data, and globalization of culture and policy processes is occurring. The American Association for the Advancement of Science, the National Science Foundation, and various Internet research groups are now actively exploring these issues. Scientific societies concerned with the protection of social and behavioral research data — the American Statistical Association, American Psychological Association, and American Sociological Association — will continue discussing these issues at their annual meetings for years to come.

#### **4. Other procedures for minimizing risks and promoting benefits**

One cannot begin to minimize risks or promote benefits unless the risks and benefits are first identified. Although conducting a risk and benefit assessment is a fundamental concept in the planning of ethically responsible research, some of the possible risks and benefits are not immediately obvious. Possible risks and benefits are virtually unlimited.

##### **Identifying and minimizing risks**

In section 3, six kinds of risk were identified: inconvenience, physical risk, psychological or emotional risk, social risk, economic risk, and legal risk. They are but one dimension of the risk matrix that is presented here (figure 1). A second dimension is the location within the research process where the risk might occur. A third dimension is the specific vulnerability of the individual subject; for example, public figures are vulnerable, but in a different way than those engaged in illegal activities or those who are institutionalized.

The six kinds of risk could be elaborated or conceptualized in various ways. In section 3, we viewed them simply as subsets of risk related to invasion of privacy or breach of confidentiality. They are also issues of personal safety or well being. Some of these risks can come about through misunderstanding, outright deception or concealment in the way the survey is administered, and inequitable treatment by the researchers. Researchers can address these risks in the communication process of informed consent (with informed consent being regarded as an ongoing communication process, not simply a consent form). Issues of ownership of the data and the knowledge are also relevant. If shared, are the data shared responsibly? Is the new knowledge used in a way that benefits the respondents or harms them? What is the relationship of the project to the gatekeepers who facilitated the recruitment process, and to the opinion leaders who will create attitudes toward the project and the respondents?

Figure 1. Risk matrix, by part of the research process at which risk occurs and by type of respondent

Part of research process and type of respondent	Kind of risk					
	Inconve- nience	Physical	Psycho- logical	Social	Economic	Legal
The theory or idea						
Public figure						
Lack autonomy						
Lack resources						
Stigmatized						
Criminal						
Secondary subject						
Disabled						
The research process itself						
Public figure						
Lack autonomy						
Lack resources						
Stigmatized						
Criminal						
Secondary subject						
Disabled						
The setting in which the research occurs						
Public figure						
Lack autonomy						
Lack resources						
Stigmatized						
Criminal						
Secondary subject						
Disabled						
The use or dissemination of the findings						
Public figure						
Lack autonomy						
Lack resources						
Stigmatized						
Criminal						
Secondary subject						
Disabled						

Researchers may conceptualize the scientific or research activity as having four parts, each of which has risks (as well as benefits):

1. The *idea, theory, or hypotheses* that drives the design of the survey, sampling of populations of interest, and analysis and interpretation of the results. A new idea can affect individuals and change cultural values in fundamental ways. The idea may not be correct but it might be falsely confirmed by faulty analysis and interpretation. The idea may be correct, but be disseminated in a way that does harm. The researcher has four ways to reduce the risk of false confirmation or dissemination of damaging ideas: recognize that the null hypothesis could be true; design the research so that each possible theoretical orientation is tested fairly; remember the limitations of the models and measures employed and warn that application and generalization to other populations must be done with caution; and share the documented data with other scientists who want to verify the findings or test alternative hypotheses.
2. The *research itself* has several stages, each of which could involve risks: the recruitment, the induction, the consent and survey, the debriefing, data analysis, and data sharing.
3. The *institutional, community, or group setting* of the research. Research is rarely only a matter between researcher and respondent; there are usually third parties involved. Every setting has its members, structure, culture, and interests. Most settings have gatekeepers who impose rules on the research transaction. All of these elements may impose pressures and risks on both the respondents and the researcher. Because individuals vary in their degree of personal autonomy and institutions in their degree of control and coercive power, the kinds of harm that may result from research in those settings also range greatly.
4. *Uses of the research findings*. In their enthusiasm to use what is learned, investigators can overlook that many findings are based on measures of dubious reliability or account for so little of the variance that they should not be considered practically useful. Researchers can misuse findings that are useful for one purpose but harmful for other purposes.

Respondent vulnerabilities are covered in section 7. The following are some examples of the range of vulnerabilities researchers should consider when engaging in risk assessment. Respondents who are public figures are especially exposed to attention and criticism; for them privacy is a sought-after luxury. Those lacking in autonomy or resources to protect their privacy lack the usual means of preventing intrusions from others; these may include children and the mentally and emotionally disabled. Scapegoats and targets of prejudice, such as homosexuals, persons with HIV infection, and some racial minorities, are especially sensitive to researchers' interpretation of their lives and their data. Institutionalized persons lack the normal degree of autonomy and may also be stigmatized. Persons engaged in illegal activities have many fears concerning disclosure of information about themselves.

Persons damaged by the respondents' revelations, the "secondary subjects," are harmed often without any knowledge of the harmful disclosure.

The risk matrix serves to sensitize researchers and IRBs to the kinds of risks they may anticipate (figure 1). Once risks are identified the quest for safeguards or protections can begin. Researchers can minimize some of the risks identified by this matrix by use of approaches that respect privacy and ensure confidentiality. Researchers can minimize other risks through mindfulness of the possible harms that may result from the research findings.

**Identifying and maximizing possible benefits**

Survey research is typically considered to benefit respondents by giving them an opportunity to discuss a topic relevant to their life, and by providing valuable information to organizations and to society in general. However there are other benefits to the respondents and their community that are typically overlooked (figure 2).

Figure 2. Benefit matrix for survey respondents and their community

<b>Benefit</b>	<b>Respondents</b>	<b>Community</b>
Relationships	Gain rapport with respectful researcher	Create ties to the project
Knowledge	Conduct informative debriefing, having one's questions answered.	Understand victimization issues relevant to community improvement
Material resources	Provide informational handouts	Provide brochures, books, videotapes, and other communication media
Training	Develop relationship between some of the respondents and the community-based project	Teach crime deterrence
Earn esteem		Earn praise for program
Empowerment		Earn prestige from an effective program

Cultural anthropologists have pioneered in thinking about ways to benefit the respondent's community partly for practical reasons. Without making the research a win-win situation for themselves, respondents, and the host community, researchers would quickly lose support from the hosts. Anthropologists such as Pertti Pelto (described in Sieber, 1991) have hired selected community members as research assistants, then shared their data with the host community so that it can be used for public policy purposes. Thus they have left behind a cadre of new researchers who can remain in contact with the investigator or can continue to build on and analyze the dataset on behalf of their community.

With this model in mind, researchers should consider the potential value in employing and training members of some target communities to assist with some aspect of the NCVS interviews or dissemination of information. Conceivably, once researchers interview a cohort seven times and the project is ready to move on, researchers could distribute information on crime prevention to the particular respondents and to the community, and to assist the community (via the police department or other agencies) in helping its citizens make optimal use of that information.

Researchers should use both the risk and benefit matrices early in the research planning process to generate ideas. They can then translate the resultant assessment of possible risks and benefits into actual operations.

## **5. Procedures for responding to requests for help or assistance**

Effective interviewers are skilled at establishing trust and rapport. These qualities tend to instill in respondents a sense that the researcher is a responsive and capable professional. When the interview topic is a sensitive one that evokes concerns in a troubled respondent, it is not unusual for that person to reach out to the interviewer for help. The interviewer is often only that — a paid interviewer, not a helping professional. However because of the sensitivity of such situations — this may be the first time the individual has dared to reach out for help — it is important that the interviewer not rebuff or ignore the request, and respond in an appropriate and helpful manner without getting personally involved.

### **Standard procedures**

When researchers work with vulnerable populations or in situations where they may be asked to provide help or assistance, it is standard for IRBs to require that the researchers prepare a set of referrals. The required response varies with the type of research. In some cases researchers give respondents an information sheet (that may include referrals) to thank them for participating and as part of the debriefing. In other cases, researchers develop various referral sheets, depending on the kind of help that is requested. In research with vulnerable participants who are at high risk, the researchers establish a relationship with specific professionals and arrange for the referred respondents to have several sessions with the professional. In the case of high-risk respondents, IRBs may require appropriate training to help interviewers recognize and interpret responses indicative of need for help.

Research institutions that engage in research with high-risk populations usually require their interviewers to handle requests for help as follows: If the request comes at the beginning or during the interview, the interviewer is to ask if the interview can continue and promise to give help or assistance when the interview is concluded. At the end of the interview, the interviewer gives the respondent the appropriate referral information. If the respondent simply cannot wait for the end of the interview, the interviewer provides assistance, thanks the respondent for the information provided so far, and discards the interview responses. Researchers may write the costs of the professional's services into grant support for the project or into the research institute's budget.

### **Background considerations**

It is important to understand the degree of response that might be appropriate in a given project. When should interviewers actively intervene in the lives of persons who need help and when should they simply provide referral information? It is useful to consider a range of kinds of high-risk respondents.

Survey researchers who study social psychological aspects of HIV infection and injection drug use have faced the ultimate challenges of responding appropriately to requests for help. Hence investigators now apply, when appropriate, a range of practices that were developed in survey research on HIV infection and drug treatment to other high-risk settings.

Interviewers in the HIV and drug treatment fields receive HIV post-test counseling to acquaint them with the feelings, concerns, and behaviors of persons who have recently learned that they have HIV, who fear that they may have HIV, or who have significant others who have HIV. Contacts for counseling and treatment are set up prior to the interviews so that the referral process can work seamlessly. This includes a police contact.

In survey research in the HIV and drug treatment fields there is now a routine that is followed quite strictly. If an interviewer encounters someone who is distressed, or someone the interviewer is worried about, the interviewer has a telephone number and perhaps a cell phone he can use to call for help right away or give to the respondent to use right away.

When survey research is conducted on the streets, projects require that a team member accompany the interviewer to the interview, even if there is only one interview scheduled. The team approach is used for the safety of both the respondent and the interviewer. If the interview is held in the project's field office, another team member is always present when a respondent is in the office. For very immediate emergencies the interviewer helps the recruiter or receptionist until assistance arrives. Again, everyone has prearranged telephone numbers.

Ultimately, such field survey projects must rely upon the skill, humanity, and insight of their staff to sense incipient problems and to deal with them. This is one reason why researchers seek staff members who have related prior experience, including knowledge of this culture in their own lives and prior work with emergency situations. As one project director commented: "We seek staff among people who live on the edge. There is no substitute for experience."

Some of the same precautions are often used with survey research on prostitutes, drug dealers, and other members of street cultures. However most survey research is not conducted "on the edge." Interviewer training and preparedness remain important but the emergencies they may face are often more subtle, less immediate, and less frequent.

A "cry for help" may be implicit or explicit. Examples of implicit responses include statements indicating desperation, suicidal ideation, or a high score on a depression scale. Explicit responses might be a statement of extreme duress such as "My spouse has threatened to kill me," accompanied by a request for help or advice. It could be about someone else in danger, for example "My spouse threatened to kill his boss. What should I

do? Can you help me?" (There are also requests for help that would trigger mandated reporting to authorities; see section 6.) It may come from a respondent to an anonymous survey, from an identified survey respondent, or face-to-face in an interview. Interviewers have effective and responsible ways to answer such cries for help but must take appropriate precautions.

### ***Implicit request***

The ethical requirement of beneficence (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979) and the code of ethics of the American Psychological Association (1992) would seem to endorse the responsibility of researchers to intervene when serious distress is discovered or caused by the research procedure, but may conflict with the principles of respect for autonomy and privacy. If the researcher is to take any steps in response to apparent need, should the respondent be warned in the consent statement that such action would be taken? If this is done, what effect would such a warning have on willingness to participate or to be candid?

This set of questions was answered quite effectively in an experiment by Stanton, Burker, and Kershaw (1991) on the effects of researcher follow-up of distressed subjects. Since researchers studying depression often encounter respondents in serious preexisting distress, these investigators sought to study the ethical responsibilities of such researchers. A literature search revealed that researchers' responses to such subjects range from doing nothing to recontacting both the distressed subject and a significant other. Stanton et al. studied whether respondents adjust their reports of distress on three standardized measures of depression as a function of their expectation of experimenter follow up. The content of their informed consent was manipulated to reflect four levels of researcher intervention: (1) no intervention, (2) provision of a list of treatment resources to all subjects, (3) follow-up contact by the researcher with distressed subjects, and (4) follow-up contact by the researcher with the distressed subject and a significant other. Their results were quite dramatic and consistent across all three measures of depression. Respondents reported the highest average level of distress in condition 2, in which all subjects were to receive a list of treatment resources. The next highest average level of distress was reported in condition 1 (no intervention). Mean distress measures were markedly lower when subjects expected the researcher to recontact distressed subjects (condition 3), and much lower when they expected the researcher to recontact them and their significant other. Some of these effects were slightly stronger for men than for women, but the gender differences were minor.

The implications for survey researchers are quite clear:

- Respondents do not want to receive personal help unless they ask for it. However they appreciate receiving information that would enable them to better understand their situation or to seek help for themselves.

- The expectation that the researcher might intervene personally is so distasteful to most that respondents will falsify their answers to avoid this.
- The expectation that the researcher might contact family members or significant others is even more objectionable.

Obviously, the simple provision of information to all subjects both provides the desired kind of assistance and respects privacy and autonomy. Moreover it is easy to administer and the interviewer will not need any specialized training.

The anonymous survey that may reveal serious distress is a related issue. Researchers may administer anonymously surveys of topics such as mental health, stress and coping, high-risk behaviors, health concerns, and experience of abuse or violence due to the unwillingness of many respondents to reveal personal or embarrassing details about their lives. How does one intervene to help anonymous persons in serious difficulty? The Stanton et al. study emphasizes that personal or clinical intervention by the researcher is unwelcome if not requested. Researchers have used the following approaches. The interviewer may provide:

- a list of treatment resources, self-help guides, or useful factual information to all respondents,
- ample opportunity for debriefing in which the respondent can express any concerns or interests and receive a referral slip (with no name or other identifier) for a nearby clinic if the respondent so desires,
- an admission ticket to a nearby workshop or panel on the topic, or
- web addresses to constructive web discussion groups on the topic.

If respondents come from identifiable groups such as classrooms or workplaces the researcher may arrange for the organization to provide an appropriate educational program to the whole group.

### ***Explicit request***

The interviewer can respond less awkwardly to an explicit request for help because there is less chance of offending the individual by proffering assistance. The interviewer can offer assistance in proportion to the nature of the request. In extreme situations, the interviewer may step in, provide a therapeutic debriefing, and arrange for immediate referral. However interviewers must avoid getting drawn into the dual role of therapist/helper and interviewer. They must be prepared to explain to the respondent that they are not qualified to help but can provide the services of a competent caring person who can.

## **A specific recommendation: An experiment within the survey**

The U.S. Census Bureau faces an unusual dilemma regarding response to requests for assistance because its interviewers return to the same group seven times to study its members' experience of crime victimization. By offering referral information on any of the first six interviews, Census may alter the phenomenon that it seeks to study. Census interviewers currently respond to requests for help only after the last interview unless the individual is in truly dire circumstances. In those extreme cases the interviewer responds earlier in the sequence of interviews, but then drops that household from the survey, replacing it with a demographically similar household.

However the current Census practice raises several questions. How much difference does a referral actually make in the life of a respondent who asks for help? Is it helpful? Harmful? Does the person who asked for help actually use the referral? What if researchers provided a list of referrals to all respondents for all of the sorts of crime victimization surveyed? Does the making of a referral, requested or otherwise, impact the nature of the data subsequently gathered from that household? With what frequency are requests made for assistance?

There are several implicit concerns in this discussion: (a) concerns for statistical accuracy of estimates of amount of crime victimization, (b) concerns to learn whether providing a referral actually changes the course of events in a victim's life (other than impacting the kind of data Census seeks to gather), (c) concern to help someone who reaches out, (d) concern to provide possibly useful referral information to all respondents in return for their participation, (e) concern about the frequency and nature of requests for assistance, and (f) concern that Census avoids criticism for failure to help.

If interviewers do not already record the incidence and nature of requests for assistance, they should do so. What is the relative frequency of the various kinds of requests? What are the demographic characteristics of respondents who make each kind of request? How do requests change in relation to changes in crime rates? These baseline data would provide a useful backdrop for the following experiments:

*Experiment 1. Effects of referral sheets given to all respondents.* Researchers would draw a stratified random sample of respondents and divide them into experimental group members and matched controls. After the first interview, researchers would give all experimental group members a referral sheet recommending local sources of assistance for each of the kinds of crime victimization surveyed. Control group members would receive no referral sheet. At the end of the 3 years and seven interviews, interviewers would reinterview members of both groups to learn whether there were kinds of relevant assistance they had desired, whether they sought assistance, how they went about it, and with what result. Interviewers would note whether the experimental (referral) group

members mentioned the referral sheet, used it, were more likely to seek referral of any kind, and whether their data reflected a lowered rate of victimization than matched controls.

*Experiment 2. Effects of appropriate referrals provided in response to requests for help.*

When interviewers are asked for help they would use a randomizing procedure to decide whether to offer a referral — on odd dates give referral, on even dates do not. Interviewers would use this random assignment procedure in all but the most extreme cases where failure to make a referral would place the respondent in serious jeopardy. Interviewers would note who asked for help and other pertinent details, including whether the respondent was assigned to the experimental or control group, the kind of help requested, when in the sequence of interviews the request was made, and other relevant details. At the end of the seven interviews, interviewers would reinterview all members of the experimental and control groups to learn whether they had sought and obtained assistance, how they went about it, and with what results. Researchers would compare the experimental group's subsequent rate of reported victimization with that of the control group.

A conservative version of experiment 2 would employ the replacement sampling procedure Census currently uses. Census would provide referrals, drop those household from the survey, and replace it with a matched household. However Census would continue to interview the dropped households for the entire 3-year sequence so that Census could validly compare their data with that of the remaining households. The postexperiment reinterview would be the same as that described above.

By including small-scale experiments such as these into its survey procedure, Census can learn what happens when a referral is made, whether it is helpful, if it can be made more helpful, and whether referrals significantly impact subsequently reported victimization. If referral information is helpful to persons in avoiding or dealing with victimization, but impacts statistical results, researchers might provide referral information only at the end of the 3-year sequence or in response to those kinds of requests for which referrals were found to be helpful.

## **6. Procedures for responding to mandates to report**

There are various statutes that require researchers to report revelations of certain kinds of situations to appropriate authorities. These vary by State in terms of what must be reported and who must report. Because of the State-by-State variability of mandated reporting, national surveys that cross State boundaries must either modify their procedures for each State or adopt the most stringent reporting standard for the entire survey. The kinds of revelations that call for reporting to appropriate authorities may include child or elder abuse or neglect and intention to harm others or oneself.

It is assumed that the NCVS is exempt from mandates to report because the survey is conducted under Title 13, the U.S. Census Bureau confidentiality statute. Probably, NCVS interviewers would only report explicit verbal mention of abuse, which would occur rarely. In response to such mention, the interviewer could encourage the individual to self-report. The interviewers might have with them the 800 number of a nearby appropriate agency in that State. (See appendix A for State phone numbers to obtain local agency information and phone numbers.) This would satisfy both the moral duty to respond and the legal duty to abide by conditions of Title 13.

Researchers should anticipate (rather than respond to) possible revelations. In the interest of confidentiality, researchers should include a warning of the limits of confidentiality in the informed consent for surveys or interviews that might conceivably reveal evidence of reportable situations such as child abuse. While this might distort the random sampling scheme and jeopardize generalizability by eliminating those who decline to participate, it provides a higher level of confidence in those who choose to participate and eliminates the legal and ethical horrors of having to consider breaching confidentiality to comply with the law. If this procedure raises significant generalizability concerns, the researcher may consider conducting a parallel study of parents who have been convicted of child abuse.

### **Child maltreatment**

The Federal Child Abuse Prevention and Treatment Act of 1974 required that each State establish child protective services and develop its own mandated reporting laws. By 1978, State reporting laws were in place; Levine and Levine (1983) include the history of these laws. State laws mandate the kinds of situations that must be reported and the kinds of persons who must report — helping professionals only or anyone. There is considerable State-to-State variability of laws and unpredictability of court decisions. Because most large sample surveys cross State boundaries, IRBs and survey researchers must know the relevant State laws and trends in court decisions, and should have policies and procedures in place for interpreting those laws correctly. Specifically, researchers should consider State law in the formulation of the informed consent statement about the limits of confidentiality, in the education the IRB provides concerning kinds of evidence that require reporting, and in

the plans and consultation arrangements that the researcher and IRB develop for handling such cases. See Kalichman (1999, pp. 14-23) for the definitions of abuse and requirements to report that are excerpted from the reporting statutes of each State.

All States require reporting by certain helping professionals such as physicians, psychiatrists, clinical psychologists, counselors, teachers, nurses, and social workers. Some also require reporting by pharmacists and religious healers. In their efforts to locate makers of child pornographic films, Colorado and Illinois require reporting by commercial film developers.

Anyone who has reason to suspect child maltreatment must report in the following nine States: Florida, Indiana, Kentucky, Minnesota, Nebraska, New Hampshire, New Jersey, New Mexico, and North Carolina. Obviously, interviewers working in these States are operating under a different mandate than those working in the remaining States. However the likelihood of their discovering reportable cases is largely limited to situations in which they are explicitly told about the maltreatment, an event which would be exceedingly rare.

In evaluating a given protocol the IRB must consider whether there is a chance that the researcher will find reasonable evidence of a reportable situation. Reporting laws vary among States with respect to how one learns about the suspected abuse. In some States, a report is required even if the reporting individual learns of it through a third party. Most statutes require the reporting individual to testify in court proceedings, include a criminal penalty for failure to report, and permit civil action against a professional whose failure to report resulted in injury to the child. However all statutes provide immunity from a suit when a report made in good faith turns out to be unfounded (Levine, 1982).

If the IRB believes that a reportable revelation might occur, it will require that the informed consent statement include a warning about the limits of confidentiality. A statement adapted from one developed by David Ruja (Gil, 1982) is:

*What is discussed during our session will be kept confidential with two exceptions: I am compelled by law to inform an appropriate other person if I hear and believe that you are in danger of hurting yourself or someone else, or if there is reasonable suspicion that a child, elder or dependent adult has been abused.*

The same sort of warning must appear in the parental permission for research on a child. The problems of coping with mandatory reporting have resulted in creative approaches to recruitment and consent procedures. One researcher who wished to study the responses of non-abused children to anatomically correct dolls resorted to the following screening procedure. She told parents that children could not participate who: (a) were under treatment by a mental health worker, (b) did not speak English, (c) had been sexually

abused, or (d) had an infectious disease. Thus she could rule out children who had been abused without knowing who they were.

The major problem faced by IRBs and investigators is not the State-by-State variability of laws but the lack of clarity about their interpretation. It is not clear whether “reason to believe” refers to a clinical hunch or to firm evidence, nor do these laws define what constitutes abuse. This leaves researchers to consider cultural differences and to weigh these against the possibility that the legal bureaucracy may be more harmful to the victim than are their seemingly abusive relatives. The difficulties of defining abuse are many. Estimates of the amount of child abuse vary from 1% to 30% of all children depending on one’s definition (Weis, 1989). How is the act perceived by the child — to teach an important lesson (Corbin, 1987), to cure a disease (Gray and Cosgrove, 1985), or out of malice? Thus, added to the costs of breaching confidentiality is the possibility that reporting will harm both the “victim” and the “perpetrators.”

What is ethically responsible research behavior with respect to reporting? Should the researcher stop and warn the subject who starts to mention abuse that it is reportable information? Should the researcher actively seek and report evidence of abuse and neglect? BJS and U.S. Census Bureau researchers do not have to solve this dilemma. Census interviewers can respond to mention of abuse by encouraging the respondent to self-report and by providing an appropriate phone number.

For investigators who do not have statutory protection such as Title 13, this is an area in which IRBs and researchers need consultation. They should establish relationships with social workers, pediatric nurses and physicians, or clinical psychologists who are competent to judge evidence that may trigger reporting. Some IRBs may not recognize when there is risk of uncovering evidence of reportable activity. If risk is recognized, the ambiguity of State laws concerning reporting can lead to extreme IRB decisions such as rejecting the entire protocol or suggesting poor solutions. If the IRB does not have a knowledgeable clinician among its members, it should call upon such a person for advice as needed. Clinically trained practitioners know how to interpret verbal or behavioral communications and are able to determine the appropriate action. They probably are acquainted with the Child Protective Services agency in their area and with the strengths and weaknesses of its professional staff. They will know how to report suspected abuse in a way that maximizes the likelihood of a beneficial outcome.

IRBs that frequently review protocols for research that might happen upon evidence of abuse should arrange permanent institutional resources to advise and support researchers in this area. Without a trained clinician to advise on what constitutes “reasonable evidence,” a risk-averse researcher or IRB may overreport to protect themselves from possible prosecution. Their duty is to make a considered decision in consultation with others qualified to advise, not to jump to conclusions and report without consultation or sound

advice. IRBs should develop guidelines for reporting that are tailored to the specific State and local situation and to the resources available to them for consultation.

It is important that investigators at risk of discovering reportable abuse understand the significance of warning respondents of their duty to report. Federal regulations regarding confidentiality require that researchers warn subjects of mandatory reporting requirements, and researchers must be ready to respond appropriately to signs of abuse. Realistically, however, this requirement protects researchers and not victims. Moreover it does not apply to the U.S. Census Bureau.

The most authoritative, comprehensive and helpful source of information on mandated reporting of child abuse is Kalichman (1999), who provides comprehensive reporting requirements.

## **Elder abuse**

Elder abuse is a significant problem, and elderly respondents may self-report to NCVS interviewers. In 1996 a national incidence study found that over 500,000 elders experienced abuse that year, 75% of which was unreported. In 90% of cases, the perpetrator was a family member, two-thirds of whom were adult children or spouses. The generally accepted definitions of elder abuse include:

- Physical abuse which is the willful infliction of physical pain or injury, including slapping, bruising, sexually molesting, or restraining
- Sexual abuse which is non-consensual sexual contact of any kind.
- Financial exploitation which is using the resources of an older person without their consent for someone else's benefit.
- Neglect which is failure of caretaker to provide goods or services necessary to avoid physical harm, mental anguish, or mental illness.

The Administration on Aging (AoA), Department of Health and Human Services, is the only federal agency dedicated to policy development, planning, and delivery of supportive services to elders. There are also State elder abuse prevention programs. There is now federal legislation requiring that States develop legislation similar to that for child maltreatment. However this legislation is relatively new and the mandated programs are not fully developed.

AoA funds the National Center on Elder Abuse, which is located at 1225 I Street, N.W., Suite 725, Washington, D.C.; phone 202-898-2683; e-mail [NCEA@nasua.org](mailto:NCEA@nasua.org). Their web site,

<http://www.elderabusecenter.org>, includes a State-by-State listing of toll-free phone numbers for reporting elder abuse. Additionally, this web site contains comprehensive information on elder abuse.

After reporting, the agency screens calls for potential seriousness, keeping the information confidential. If the agency decides there is violation of State elder abuse laws, the agency assigns a case worker (in emergencies, usually within 24 hours). If the victim needs crisis intervention, services are available. If no abuse is substantiated, most agencies will work as necessary with other community agencies to obtain any needed social or health services for the elder. The elder has the right to refuse services offered.

As with child maltreatment, NCVS interviewers could respond to evidence of elder abuse appropriately by urging self-reporting and providing the appropriate State hotline numbers.

### **Intent to harm oneself or others**

The intent to harm oneself or others are issues that primarily impact mental health clinicians who probe into the motives and intentions of their clients. However it is conceivable that feelings of despair or anger evoked in an interview on crime victimization could give rise to statements about harming oneself or others.

Intent to harm oneself is discussed in section 5. An appropriate response is to urge the individual to seek help and to give them an appropriate referral (phone number).

Intent to harm another is an issue that rarely arises in either psychotherapy or social/behavioral research. However there are a few State laws governing the duty of psychotherapists to respond to such a threat by warning the intended victim. Consequently psychotherapists have had to include in their informed consent a warning of their duty to report such events. The disposition of courts to find that there is a duty to warn an intended victim has spread throughout the country. Despite the rarity of statements about intent to harm another, the cases in which actual harm has arisen resulted in some surprising court decisions and tremendous amounts of publicity. Under the protection of Title 13, the U.S. Census Bureau need not warn of a duty to report and may not report. However the U.S. Census Bureau may want to consider the kinds of referral information that it could provide to individuals who are planning to take justice into their own hands. This might include a range of alternatives that include counseling, mediation, and referral to appropriate law enforcement agencies.

The U.S. Census Bureau should stay current about the development and spread of legal mandates to warn intended victims. The case of *Tarasoff v. University of California Regents* is instructive. A University of California Berkeley graduate student, Prosenjit Poddar, revealed to a campus psychologist his pathological intent to kill Tatiana Tarasoff, who had spurned his affections. The psychiatrist notified the police, who found the man rational. Poddar understandably did not return to therapy, and stabbed Tarasoff to death. Through a series of appeals, the Tarasoff family persuaded the California Supreme Court (1976) that mental health professionals have a duty to intervene in such cases.

Depending on the case, intervention can include warning the intended victim, notifying authorities, or securing an involuntary commitment. Although some therapists and researchers consider this an unacceptable infringement on their duty to hold professional information confidential, the Tarasoff law mandates that professionals must intervene effectively when the client in therapy, including those in research on the therapeutic process, reveals an intent to harm another.

Other States have copied the Tarasoff law in various forms. Even in States that do not have "Tarasoff" law, it is reasonable to consider whether victims or their families might seek to apply the Tarasoff principle if a person indicates intent to harm and then commits a violent act. According to existing law, the Tarasoff principle applies only to therapists. However many IRBs require that researchers report to appropriate authorities any disclosure of intent to seriously harm another, irrespective of whether the researcher is a therapist.

Some researchers seek to protect themselves from lawsuits for breach of confidentiality by including in the informed consent a statement such as "Your data will be kept confidential within the limits of the law." This is inadvisable. Recent court cases have upheld respondents' rights to an informed consent that they can understand. IRBs are now increasingly careful about how they state their obligation to report.

On their IRB's web site, the University of Chicago provides the following example of a possible statement for inclusion in a consent document regarding a survey of persons with depressive symptoms:

*Some of the questions in the written forms and the interview ask about how you are feeling now. If your answers make us think that you might harm yourself or others, we are required to notify the proper authorities of this risk.*

The Census Bureau and BJS should prepare policy regarding a response to evidence of child or elder maltreatment, or threats of harm to oneself or others with appropriate referrals, and be sensitive to the requirements of investigators who do not operate under Title 13.

## **7. Vulnerable populations: Risks and special protections**

Vulnerable populations normally include children, teenagers, pregnant women, cognitively impaired persons, and institutionalized or imprisoned persons. For purposes of the NCVS and most other social surveys, the vulnerable populations requiring special precautions to minimize risks probably also include the elderly, minorities, economically or educationally disadvantaged persons, and other “institutionalized” groups such as students recruited as research subjects by their teachers and employees recruited as research subjects by their employer/supervisor.

### **IRB concerns**

In the case of prisoners and children, Subparts C and D of 45 CFR 46 permit IRBs to approve research that involves no more than minimal risk, or that may involve somewhat more risk but will benefit the participants. Subpart C is pertinent to survey research in that it provides extensive safeguards to confidentiality and against coercion so that prisoners are afforded autonomy in their role as research subject. Subpart D is pertinent to survey research in that it requires both parental approval and the child’s assent, except as noted in section 9.

In the case of each of these populations, IRBs are sensitive to whether it is appropriate to include the given population, consent is informed and autonomous, participation is free of coercion, and the language and presentation are appropriate to the needs of the particular population. Privacy and confidentiality have special significance for each population and researchers should safeguard them appropriately. Specific fears, not necessarily warranted, are germane to each group and investigators should learn and dispel them. Each group has its own culture and language characteristics, which researchers need to understand and respect.

### **Children and teenagers**

The privacy needs of children and teenagers change markedly as they grow from early childhood through the teen years. Thompson (1982) presents an excellent review of these changes, showing that popular ideas about vulnerability decreasing linearly with age are inaccurate. Older children and teenagers are more easily embarrassed, more concerned about personal and informational privacy, and more likely to feel upset if they reveal more than they intended. As they approach their teens children become sensitive and skeptical about situations in which an interviewer might conceal or withhold information and upset at the prospect of being deceived. In their efforts to forge their own sense of identity, youngsters approaching and in their teen years would not want to be interviewed on a

sensitive topic in front of their parents. They might even offer to disclose information only on the condition that the interviewer not reveal it to their parents. Because NCVS interviewers are exempt from mandatory reporting under Title 13, this is less of a dilemma for them than for other researchers. If appropriate, the NCVS interviewer might provide referral information to a troubled teen or urge that they confide in their parents, but need not take the matter farther.

Older children and teenagers are developing means of controlling their privacy. In middle childhood, children begin to want to have private places of their own, and are likely to post a sign on the door to their room saying "KEEP OUT." By the teen years, youngsters are intensely private, easily embarrassed, and interested in issues of informational privacy. Some will refuse to provide information if they feel intruded upon. Having a private place to be alone, or to communicate with friends in privacy becomes extremely important. For the teenager, promises of confidentiality are extremely important.

In contrast, young children, up to about age 7, are not easily embarrassed and have an insouciant charm and candor that comes from lack of self-awareness. Their means of protecting themselves from unwanted intrusion is their parent's protection of their privacy. Younger children's sense of privacy is enhanced when their parent is present during an interview. By the same token, the requirement of a parent's permission to have the child interviewed serves to protect the overly shy or emotionally unstable child from the researcher's intrusion.

The younger the child, the more important it is for investigators to pilot test consent (assent) information and surveys to determine whether children can understand the language. Young children, under age 6, usually do not understand statements dealing with hypothetical situations, and have difficulty with quantifiers and relational concepts. As children mature, they develop increased understanding of the hypothetical or conditional. The use of long sentences that would be understandable to an adult is problematic with younger respondents. Some guidelines for communicating with children in survey research follow:

- Use short sentences with easy words to improve comprehension.
- Avoid unnecessary clauses that complicate the question.
- Avoid use of the passive voice.
- Examine the child's understanding of words. The interviewer might ask "Tell me what a .....is?"
- Make sure the child understands the context of the question, perhaps by prefacing a question with a statement like: "Remember the time when (such and such) happened."

- Avoid asking a young child “why” they did something, which the child will likely perceive as critical and make the child feel defensive. It may work better to rephrase the question as a “what” question such as “What made you feel that way?”
- Rephrase questions to check for comprehension when the child seems to lack comprehension.

### **Pregnant women**

Since it is conceivable that pregnant women’s experience of crime victimization may differ from that of others, there is clear justification for their inclusion. The only regulatory issue pertaining to their inclusion is whether their participation in any way jeopardizes their health or that of their fetus. This is unlikely to happen in survey research.

### **Cognitively impaired persons**

Although there are no regulations pertaining to research on the cognitively disabled, there has been considerable discussion and concern (see at <http://ohrp.osophs.dhhs.gov/>, go to IRB Handbook) about interpretation of the regulations in their case. The primary concern is that persons with psychiatric, cognitive, or developmental disorders, or persons who are substance abusers may lack capacity to understand what interviewers are asking them to do or to make a reasoned decision about participation. Many in this population are institutionalized, which further compromises their ability to exercise free choice. Institutionalized persons may want to participate in research to appear “rational” and “cooperative” to those who make decisions about their release.

There is a growing consensus among ethicists that researchers should select cognitively disabled persons as subjects only when the research bears some relationship to their situation. In the case of the NCVS, the choice of those cognitively disabled persons who are competent to respond to the survey may be highly appropriate since they may be particularly vulnerable to certain forms of victimization. However from a researcher’s point of view the issue is whether they are competent to respond accurately to the survey. This underlines the more fundamental issue that the interviewers, the investigators, and the IRB need to work closely with persons who are knowledgeable about and experienced in working with cognitively impaired populations to decide whether and how to include them in the research.

Most that has been written on this topic pertains to biomedical and pharmaceutical research, and it is not easy to apply the same ideas to survey research such as the NCVS. OHRP’s primary concern is that incompetent subjects with court-appointed legal guardians provide consent in a responsible fashion. Persons deemed incompetent to decide about

participation probably would also be incompetent to participate in survey research. Conceivably, family members could provide a more accurate account of the crime victimization of cognitively impaired persons. However persons having minor cognitive impairment who are not institutionalized might be deemed competent to participate in the NCVS. They might be included, with advice and guidance from persons who are knowledgeable and experienced in administering similar instruments to cognitively impaired individuals.

## **Elderly persons**

The elderly are a heterogeneous group, not usually in need of special protections, except under circumstances of cognitive impairment and institutionalization. However investigators sometimes fail to include them in research because of difficulties in recruiting them. Older persons tend to avoid events that interrupt their daily routine, are inconvenient, or do not directly benefit them (Sachs and Cassell, 1990, p. 236). They are more likely than younger persons to drop out of studies so that investigators may need to recruit more elderly to account for this. Elderly persons who live alone tend to have warranted fears of scam artists and others who would harm them. The use of gatekeepers such as directors of senior centers may provide useful assistance in identifying the investigator as someone it is safe to associate with. Elderly persons who live with younger relatives have a different problem — keeping parts of their life private from younger members of their family. Researchers need to recognize this problem. The interviewer should ensure that the interview takes place in a private setting and that they can conduct a phone interview under conditions of privacy at the elder's end of the line.

Even those elders who are well educated and have kept abreast of news and changes in our culture may use a somewhat different vocabulary than younger cohorts and may be unfamiliar with some new concepts. The interviewer needs to be sensitive to these possibilities and be prepared to rephrase questions.

Elders may have hearing and vision problems that interfere with responding to a survey. Hence elders may require more time, large-print material, and patient explanation until the hard of hearing are able to accurately understand.

The very elderly, on average, are far less educated than younger cohorts. Those who have had little formal schooling are not test wise. Some of the formats of written surveys such as item ranking, Likert scales, and multiple choice items are foreign to them, hence difficult for them to use (Levine, 1982). Generally, education, health status, and inadequate communication about the research, rather than age, are responsible for lack of comprehension and recall (Sachs and Cassel, 1990, pp. 235-236). When interviewing poorly educated elderly, interviewers should use a more conversational approach to yield

more satisfactory responding. The wide-ranging demographic differences and corresponding response differences underline the importance of adequate stratified sampling, with oversampling of those segments of special scientific interest to the project.

## **Minorities**

The inclusion of racial and ethnic minorities in national surveys is vital to the generalizability of the results. However minority groups frequently have a negative perception of research, and it can be difficult to recruit minorities because they fear lack of confidentiality. Focus groups within minority communities can provide useful communication between investigators and community members. In that context, researchers can explain the aims and process of the research and the safeguards to confidentiality. Investigators can learn the perceptions and fears of community members, correct erroneous perceptions, and allay fears. A second reason to do pilot work within the relevant minority communities is to learn about possible linguistic problems. Often it is not simply a matter of obtaining an accurate translation from standard English to another standard language. The combination of dialects and variants can make standard translations inadequate for accurate communication. For example, immigrants from Mexico may speak a variant of Spanish according to their home region, and the Spanish of Mexico itself differs from the Spanish of Central America.

Members of racial or ethnic minorities in the United States are relatively more likely to have problems of transportation and child care to participate in studies, especially when repeated interviews are required. Interviewers should be sensitive to these problems and be prepared to offer solutions.

Interviewers also need to be sensitive to cultural norms of the respondents. Researchers should include members of the given cultural group on the research team to help ensure the survey's success. Investigators should consult with other researchers, clinicians, or outreach workers who have worked with the given cultural group in a given location. Federal Regulations recommend that IRBs reviewing research involving racial or cultural minorities have a representative of that group on the IRB or invite a consultant from that group to assist with review of the protocol.

## **Students, employees, and institutionalized persons**

Issues of coercion and confidentiality arise with respect to these groups of persons. Will their gatekeeper, including their employer, teacher, physician, or jailer, pressure them to participate? Will researchers keep their responses confidential and not disclose them to the gatekeeper or others? Do the respondents perceive that they will win favor within their institution by participating in the research? Is recruitment truly a voluntary process? As a

safeguard, are respondents given every opportunity to refuse to participate during the consent procedure, and to discontinue their participation at any point in the procedure? If they do not complete their participation in the research, is this fact kept confidential from their gatekeepers?

### **Economically or educationally disadvantaged persons**

Economic and educational disadvantage tend to go together, but create different problems.

The economically disadvantaged person is easily recruited when large financial incentives are offered, and their advocates would argue that large financial incentives may be appropriate. However IRBs are wary of the incentive that is so large that it is coercive. Moreover, if respondents perceive that the financial incentive is contingent on completion of the interview, there is the double threat of coercion and lack of candor. Noncontingent financial incentives are more beneficial in all respects, and they also are more effective in recruitment (Singer, Groves, and Corning, 1999).

Economically disadvantaged persons may require financial incentives that are higher than those for economically secure individuals. These incentives are likely to include costs of child care and transportation.

Middle-class interviewers may be ineffective at establishing rapport and communicating effectively with poor people. Some researchers employ and train as interviewers persons who are demographically similar to the respondents. For example, Kim (1997) used poor women to survey poor women in an evaluation of federally funded job training programs to determine whether job placement rates and earnings of program participants are higher than those of nonparticipants. Kim incorporated feminist approaches, including asking open-ended questions rather than multiple choice, that resulted in a somewhat more qualitative set of responses. The richness of detail provided perspectives that would otherwise have been overlooked. Kim reports that the approaches she used reduced interviewer bias, improved response rates, and facilitated trust in answering sensitive questions. The poor women trained as interviewers learned about scientific inquiry and earned money.

While educational disadvantage tends to be associated with economic disadvantage, that association is not always present. The respondent who seems not to understand questions or instructions and who cannot respond appropriately in test-like formats may simply be inexperienced with school-type activities. The respondent may be perfectly capable of describing the relevant experiences and attitudes, but not in the formats presented. More seriously, the respondent may be illiterate. Many apparently middle-class people are illiterate but have developed considerable skill at faking literacy. The interviewer needs to be sensitive to this possibility and be prepared to switch to an oral format that allows the respondent to answer in a more conversational and open-ended way.

## 8. Efforts to minimize refusals to participate in sensitive surveys

A major ethical value underlying survey research is that it yield valid and useful knowledge — a goal that is unattainable unless respondents participate candidly. However most of the human subject issues raised by IRBs and the Common Rule concern the protection of human subjects, not their willingness to participate and be candid. Consequently IRBs sometime reject approaches that seem to provide “too much” motivation to participate. For example, although it is well established that street people, particularly drug addicts, will not participate in research unless they are paid in cash, some IRBs do not want to approve this practice because such respondents will use the money to buy more drugs. IRBs do not want the monetary incentives to be more than the individual would ordinarily earn for that amount of work time. Thus airline pilots who are subjects could be paid far more to participate in a survey than a poor person, a notion to which many poor subjects and their advocates object.

There are two kinds of efforts: efforts to induce people to agree to participate in sensitive surveys, and efforts to induce them to give honest answers to sensitive questions.

### Efforts to induce participation

There are two factors that consistently and substantially increase participation: payment of monetary incentives and number of contacts. Regarding number of contacts, the standard practice is to recontact nonrespondents up to three times. By the third contact, investigators get response rates that are usually at least 30% higher than they would have gotten with only one contact. This procedure is viable even with mailed anonymous surveys. Researchers include a postcard containing the respondent’s name with the survey that the respondent is to drop in the mail at the same time the survey is mailed. Investigators send repeated mailings only to those who have not mailed their postcard. The postcard could also be used by the respondent to indicate which incentive they want in return for participation.

The effects of monetary incentives are more complicated and interesting. Church (1993) performed a meta-analysis of the experimental literature (38 studies) on the effects of incentives in mail surveys. He classified incentives into two categories: whether they were monetary or non-monetary, and whether they were offered with the initial mailing or made contingent on the return of the questionnaire. His conclusions were that:

- Prepaid incentives are more effective than promised incentives, such as incentives that are contingent on completion of the survey.
- Prepaid monetary incentives are more effective than gifts offered with the initial mailing.

- Response rates increase with increasing amounts of money
- The offer of contingent (promised) money and gifts does not significantly increase response rates.

Church's study leaves unanswered the question of whether the effects of incentives on response rates vary by mode of interviewing. Could Church's findings be replicated with face-to-face or phone interviews? Singer et al. (1999) performed a meta-analysis of 39 experiments and used the following independent variables: amount of incentive, type (gift or money), timing (before the interview or promised and given afterward), and burden (whether the interview was longer than an hour or if it included a diary, test, sensitive questions, or panel study). In addition to their main dependent variable, response rate, they also examined quality of data (nonresponse and number of words in response to open-ended questions), cost per interview, and relationship of response to incentives with demographic variables.

Singer et al. essentially replicated Church's mail survey findings with telephone and face-to-face survey findings. Moreover they showed that incentives are effective in increasing response rates in both low- and high-burden studies, and for fresh respondents, panel respondents, and those who have refused to respond previously. However they found that the effects of incentives are relatively modest. Some of the details are pertinent:

- Respondents preferred prepayment to promised payment even in face-to-face interviews.
- The effects of incentives are linear within the limits of the monetary incentives offered. The money offered varied from \$1 to \$100; 60% of incentives were less than \$10; mean value was \$11.39.
- Gifts were significantly less effective, even controlling for the cash value of the incentive.
- It was expected that high-burden surveys — surveys lasting more than 1 hour; surveys with ancillary tasks such as a test or diary, surveys with repeated or panel testing — would benefit more from high incentives than would low-burden surveys, but only an insignificant interaction was found.
- When low-burden phone or face-to-face interview studies were analyzed separately, they found that incentives had the same effects.
- When studies involving a diary, test, or other self-administered instrument were excluded, the effects of incentive remained significant.
- The higher the response rate to the no-incentive condition, the smaller the effect of an incentive.
- About one-third of the studies analyzed were unpublished, and Singer et al.

compared their findings with those of the published studies. They found no differences.

- Incentives tend to yield better quality responses.
- Paying an incentive tends to produce higher numbers of respondents in demographic categories such as low income or nonwhite respondents that might otherwise be underrepresented in sample surveys.

Singer et al. note that an important question that remains unanswered is whether the costs of surveys with incentives is cost effective in relation to the savings, including fewer calls and mailings to respondents.

This elegant analysis also left unanswered the question of whether respondents would regard it as inequitable to offer a monetary incentive to non-respondents. Subsequently, Singer, Groves, and Corning (1999) studied whether cooperative respondents would perceive the use of incentives to convert refusals as inequitable, and whether those who learn of the practice will be less willing to participate in future surveys. Singer et al. found that survey respondents are sensitive to issues of fairness in the distribution of incentives, but these issues are not especially salient and are not among the factors that motivate survey participation.

### **Efforts to evoke answers to sensitive questions**

A central concept for understanding how to evoke answers to sensitive questions is the “foot-in-the-door” technique (discussed in section 2). Respondents who are first asked innocuous, then mildly sensitive, and then very sensitive questions will cooperate and answer such a sequence of questions. However they would refuse to answer the most sensitive questions if such questions were asked in isolation or near the beginning.

A second major concept has to do with obtaining honest answers to sensitive questions. This problem includes self-report bias, in which respondents underreport disapproved, embarrassing, or illegal behavior, and overreport socially approved behaviors. Persons tend to present information about themselves in a way that they believe would enhance their worth to the interviewer. Sudman and Bradburn’s (1982, chapter 3) classic list of approaches to asking sensitive questions includes both of these concepts. They describe ways to manipulate the context or presentation of questions to lead from general/neutral to specific/sensitive, and ways to create a more permissive frame of reference. Current research has sought to refine these powerful techniques through experimentation.

A third major concept has to do with the respondent feeling respected and understood. Respondents may engage in self-report bias, lie, or refuse to answer sensitive questions if they feel badly about answering a sensitive question honestly. These problems are exacerbated when respondents feel that an “outsider” is poking insensitively into their business. Cultural sensitivity can sometimes help solve this problem. Interviewers can be matched with respondents, with respect to life experience, gender, ethnicity, dialect, or whatever other demographic factor may be relevant.

Researchers have tried various solutions to these problems, and there is a lot of literature about these issues as they pertain to survey research. Three kinds of literature are reviewed here:

- Research on data collection formats, such as computer-assisted self-administered surveys and sealed booklet surveys, which reduce self-consciousness because the respondent interacts privately with a computer, not with the interviewer.
- Research on better ways to ask sensitive questions.
- Research on interpersonal factors, including effects of presence of third parties at the interview, the data collection format, and development of better ways to ask questions.

### ***Data collection formats***

A promising way to obtain answers to sensitive questions is through self-administration of these questions. A large number of studies demonstrate that self-administration via computer increases levels of reporting compared to administration of the same questions by an interviewer. Respondents are apparently reluctant to admit to an interviewer that they have engaged in illegal or otherwise embarrassing activities.

Tourangeau and Smith (1996) reviewed many of these studies and observed that the effects of the computer are no more desirable than other kinds of self-administered survey. Moreover with a self-administered computer or written questionnaire, persons with poor reading skills will have difficulty comprehending the questions. Tourangeau and Smith propose that audio computer-assisted self-administered interviewing (ACASI) may solve this problem. ACASI may preserve the privacy of self-administration without requiring much respondent literacy. In one study, which controlled for the novelty and other aspects of computer use, they examined the willingness of respondents to admit (via computer) to extremely sensitive questions, including aspects of cocaine and marijuana use. They compared computer-assisted personal interviewing (CAPI) in which the interviewer was present, computer-assisted self-administered interviewing (CASI), and ACASI.

With CAPI, the questions appeared on the computer screen, the interviewer read them to the respondent, the respondent answered the interviewer, and the interviewer then entered the response.

With CASI, the respondent interacted directly with the computer after the interviewer gave instructions and helped the respondent get started. With each question, the respondent receives a reminder at the top of the screen on how to back up to the prior question, go on to the next, or refuse to answer a question.

With ACASI, the information displayed on the screen is simultaneously played via earphones. With both the CASI and ACASI conditions, the interviewers were instructed not to look at the screen while the respondent completed the question, but to listen for any beeps indicating the respondent was having problems with the computer.

Tourangeau and Smith found remarkably large differences in reporting of illegal drug use and multiple sexual partners, with the largest number of instances reported with ACASI and the smallest number of instances reported with CAPI. Others have also found that ACASI is superior to other methods. Moreover it can be used in a variety of settings, including homes. For example, Lesser and O'Reilly (1997) reviewed established strategies, self-administered questionnaires, and indirect questioning techniques to examine their effect on willingness to report stigmatizing behavior. They discuss ACASI extensively, describing its features and the results it has yielded. Similarly, Kissinger et al. (1999) report positive results using video-enhanced computer-assisted interviews and ACASI.

A "low tech" approach to achieving privacy is to administer the interview using a sealed booklet which the respondent fills out in the presence of the interviewer, providing anonymity to the respondent. Compared to the face-to-face interview, this method produces greater willingness and accuracy of answering in response to sensitive questions. However it does not solve the problem of respondents having poor reading skills (Makkai and McAllister, 1992).

### ***Development of better ways to ask sensitive questions***

A well-documented finding of experimental cognitive psychologists is that the way a question is framed will affect the way it is answered. Willis (1997) described a variety of developments designed to reduce response error using cognitive laboratory techniques in developing a survey. He described ways in which investigators can examine the thought processes of subjects in relation to the various ways questions are framed. The variables studied include the way respondents are introduced to the interview, if researchers test for comprehension, how researchers avoid embarrassing respondents, the effects of social

cues from the interviewer, use of demographic information in formulating questions and interpreting responses, and exploration of what makes questions sensitive and for what kinds of respondents.

Research on illegal or embarrassing behaviors has systematically examined the old “everybody does it” approach developed by Kinsey et al. (1953). “Counterbiasing” means framing the question so that the particular behavior is made to seem relatively frequent, normal, or unremarkable. Researchers have studied counterbiasing in various contexts and found that it is effective in producing more admissions of socially undesirable behavior. Raghubir and Menon (1996) and Tourangeau and Smith (1996) describe counterbiasing methods in a variety of settings.

### ***Interpersonal factors***

The research on the effects of interpersonal factors illustrates that the degree of sensitivity of the issue and contextual factors are critical to the results.

Johnson and Moore (1993) examined the effects of interviewer gender in a telephone survey of attitudes regarding sale and consumption of pornography. They found that interviewer gender effects were not significant.

Smith (1997) examined data from the 1994 General Social Survey (GSS) to determine whether presence of a third party such as a spouse or child effects responses to questions. For married respondents, the presence of a spouse did not effect answers to 15 questions about marriage and sexual matters. Among 13 questions about values, answers were scarcely effected by presence of a child, with one exception: Respondents appear less approving of premarital sex when a child age 6 or older is present. Self-reported items on health were somewhat affected by the presence of others. Overall the impact of third parties on survey responses was rare and small. Smith offers a host of good suggestions on ways to gain a better understanding of third-party effects. Given the similarity between his work with the GSS and the NCVS project, his comprehensive discussion of possible effects of third-party presence in such surveys would no doubt be of interest to BJS and Census.

Darrow et al. (1986) examined a series of studies of the responses of homosexual men to sensitive questions asked by physicians to learn the effects of place of interview and gender of interviewer. The difficulties of adjusting results to avoid confounding may have weakened the findings. However the conclusion was that the gender of interviewer and place of interview seemed to have little influence on the respondents. The authors speculate that the motivation to gain accurate answers and medical assistance may have overridden any deterrents to responding.

Kim (1997) found that having poor women interview poor women, using an open-ended interview format, evoked more detailed information and increased willingness to answer questions (see section 7).

The study by Barker and Cooper (1996) is another example of how little difference sensitive questions make in most survey research contexts. They included a sensitive question about sexual health in half of the 600 "lifestyle" questionnaires sent to individuals in Solihull, West Midlands. After 3 weeks, nonrespondents were sent a reminder and a second questionnaire. The response rates were virtually the same for the "sensitive" and "nonsensitive" groups for both the initial and the follow-up questionnaire. However their "sensitivity" induction may not have been strong enough to reveal possible effects.

## **9. Survey procedures for informed consent with special procedures for obtaining consent for respondents under age 18**

Informed consent is a primary ethical requirement of research with human participants. It expresses respect for the autonomy of persons by permitting them to make a reasoned decision of whether to participate. The process of informed consent is far more than a consent form or a one-time discussion. Informed consent should consist of friendly ongoing communication in which the individual is free to raise questions throughout the research process. In repeated-measure research such as the NCVS, the initial consent process may seem perfunctory to the respondent. As questions arise in the respondent's mind, the real informed-consent communication can take place. It is appropriate that the interviewer be prepared to engage in the ongoing communication required to continue to inform the respondent as appropriate.

### **Regulatory requirements**

The informed consent process is governed quite strictly by federal regulations (see 45 CFR 46.116(a)). Although it is intended as a respectful communication process, it is often treated as a bureaucratic formality by investigators seeking to conform to regulatory requirements.

Informed consent is legally required unless the following four conditions are met:

1. The research involves no more than minimal risk.
2. Waiver or alteration of the process will not adversely effect the rights and welfare of the subjects.
3. The research could not practicably be carried out without the waiver or alteration.
4. When appropriate, subjects are provided with additional pertinent information after they have participated in the study.

Documentation (45 CFR 46.117) involves written consent information that the subject signs, and the subject receives a copy of the consent information. Subjects tend to confuse the signed consent form with informed consent. This confusion does not make for good communication or a friendly process. It is possible to obtain informed consent that meets the criteria set forth in the federal regulations and to create a friendly, open, ongoing communication process. However the formal criteria do not foster ongoing communication.

As discussed in section 7, many individuals, particularly members of minority populations, do not want to sign documents but would participate in surveys otherwise. Fortunately, written documentation may be waived if (a) the documentation is the only link that identifies the subject with sensitive information, or (b) the research presents no more than minimal risk and involves procedures that do not require written consent when performed outside of a research setting (45 CFR 46.117). Most survey research meets one of these criteria.

The regulations governing informed consent were written for biomedical research. Issues that might be important to a respondent in a survey are not “risks and discomforts” or “alternative procedures or courses of treatment,” but rather what will the interviewer ask, how long the survey will take, and how will investigators keep identified data confidential. The adaptation of regulatory requirements for purposes of survey research has required ingenuity.

In a perfunctory effort to comply with the federal regulations, many consent forms are written in such a legalistic, vague, or specialized (scientific) language that they are incomprehensible to most respondents. It is important that researchers keep the communication process of informed consent understandable and engaging, and that they answer the questions that are important to the respondent. Interviewers should remember that informed consent is a two-way conversation, and a cognitive process that properly involves comprehension, trust, consideration, and autonomous decision-making on the part of the participant.

When survey research is conducted with minors, parental permission and documentation of that permission, as well as assent of the minor, are normally obtained. However IRBs may waive parental permission and documentation under the conditions in 45 CFR 46.117. While the legal requirements may be relaxed, ethical and practical considerations would still require the ongoing communication process of informal informed consent. It is especially important that the interviewer explain the research to the child in age-appropriate terms the child can readily understand.

### **Informed consent as practiced in survey research**

When survey researchers attempt to follow the formal requirements for informed consent a number of questions often arise:

- How can informed consent foster respect for privacy in survey research?
- How much information do subjects want to receive?
- How much and what kind of explanation are appropriate in obtaining children's assent?

- How can the researchers make a child understand complex details?
- When complex issues need to be explained, such as confidentiality and the limits to which it can be assured, how can the interviewer be sure the respondent understands?
- How can a researcher conduct and document consent in Internet surveys?

### ***Consent and privacy***

Informed consent is supposed to be a transaction, contract, or agreement between the investigator and the respondent. Moreover it is supposed to be ongoing, two-way communication in which the participant can renegotiate the agreement as needed. There are various reasons why the respondent may want to reopen the conditions of the research. For example, a survey that is conducted in a face-to-face interview or by phone may take longer or involve more unwanted experience than the respondent anticipated when initially consenting to participate.

Respect for privacy means:

- Giving persons freedom to pick and choose the time and circumstances under which facts about themselves are disclosed,
- Permitting them to share or withhold from others their attitudes, beliefs, behavior, and opinions, and
- Permitting them to reject information they do not want to receive.

All three of these conditions are pertinent to NCVS interviews. For example, setting up a phone interview about crime victimization entails some agreement about a convenient time and place and the respondent's willingness to participate. Once the interview begins, the respondent may feel constrained to answer questions that seem invasive, or that are being asked after someone else has entered the room and can overhear the conversation. The respondent may feel the questions to be upsetting. When this point is reached, the interview is damaged. A better procedure is to make sure the interview occurs under circumstances that are truly comfortable for the respondent, and for the interviewer to be sensitive enough to realize that the respondent would rather not answer or would like to resume the interview later. Such consideration on the part of the interviewer may seem costly in the short run, but in the long run it means that:

- the relationship of mutual trust and respect between respondent and interviewer is maintained and strengthened.

- the likelihood that the respondent will remain in the study for the full cycle is increased.
- the ease of scheduling future interviews is enhanced.
- the candor and mindfulness with which the respondent answers questions is increased.
- a smaller sample that produces high-quality data can be used in place of a larger sample that produces flawed data.

### ***How much information do respondents want?***

Since the inception of IRBs, social and behavioral scientists have pointed to the importance of providing reasonable amounts of information as opposed to overwhelming respondents with lengthy and complex consent statements. Singer and Frankel (1982) studied the effects of lengthy and detailed consent compared to simpler consents and found no significant differences in response rate or quality (see section 11). Singer (1993) reviewed the literature on informed consent in surveys, most of which focuses on the effects of promises of confidentiality. While promises of confidentiality are marginally important to respondents in sensitive research, they are counterproductive in nonsensitive research.

Investigators who conduct social and behavioral research observe that the formal content of the consent is largely ignored. Respondents focus on whether they like and trust the researcher. Some physicians have remarked that physicians who have good communication skills and a caring manner don't get sued. The formality of informed consent has little or nothing to do with the way patients feel about their treatment.

### ***Guidelines for obtaining children's assent***

In research on children, it is particularly important to regard informed consent as a friendly, understandable, engaging communication process. Section 7 includes guidelines for talking to children to obtain their assent. Researchers should present the information in a conversational manner that is responsive to the child's questions and comments.

IRB websites contain some good examples of assent statements designed for children. The Social and Behavioral Sciences IRB at the University of Chicago has an excellent example (<http://humansubjects.uchicago.edu/sbsirb/>).

Beyond oral communication, it may be useful to show children what they will be doing, and possibly show them a videotape of another child participating in the procedure.

### ***Ensuring comprehension of complex issues***

The rise of the use of computers in self-administered survey research has intriguing possibilities for providing informed consent information in a tutorial context. Although this procedure has been most seriously considered in the case of risky biomedical research, it has special potential for survey research involving computer-assisted self-administered surveys. In the case of surveys conducted on the Internet, the consent process can readily be administered on-line at the outset as an automated tutorial, so that respondents can not advance to the survey until they demonstrate comprehension of the consent statement.

## 10. Effects of signed consent on response rates and other aspects of conducting a survey or other study

In 46.117, “Documentation of Informed Consent,” the Common Rule sets forth the requirement that the interviewer read the consent form to the subject or a legally authorized representative or give the form to the subject to read, and that the subject or the representative sign the form. A number of alternative procedures are also set forth in the case of illiterate subjects or subjects who do not wish to sign a document for some reason.

Because there are various subcultures in the United States that are disinclined to sign documents, the general requirement of signed consent poses complications for research that depends on random sampling, such as sample surveys.

### Regulatory issues

The issue of signed consent does not arise in some survey research for two reasons:

- *Exemption of anonymous adult surveys from the regulations.* Research involving survey or interview procedures with adult subjects is exempt from the Federal Regulations unless the information obtained is recorded in such a manner that the subjects can be identified and the data could place the subjects at risk of criminal or civil liability or damage the subjects’ financial standing, employability, or reputation (45 CFR 46.101(b)(2)). However some IRBs review all surveys even if they meet the criteria for exemption.
- *Exemption from signed consent.* An IRB may waive signed consent, even when surveys are not anonymous, when the principal risks are connected with breach of confidentiality concerning the subject’s participation in the research — such as in the study of sensitive topics — and the consent document is the only record linking the subject with the research (45 CFR 46.117(c)). An IRB may waive signed consent or other elements of the consent procedure when it finds that the research involves no more than minimal risk to the subjects and involves no procedures for which written consent is normally required outside of the research context.

It is important to note that whenever an IRB exempts a survey from signed consent, including the consent of the primary or secondary subject, the IRB must record its analysis of the ways in which the protocol meets the above criteria in the documentation of its decision.

In the case of high-risk interviews in which the only link to the respondent might be the signed consent, researchers can use other procedures such as witnessed consent. For example, a researcher interviewed a 16-year-old concerning his gang membership and his decision to leave the gang. Because his parents did not know about his gang involvement, researchers waived parental permission. Because his decision to discuss the gang and to contemplate leaving it could be very dangerous to him, the interview was conducted out of town at a small restaurant during non-meal hours. A colleague of the interviewer sat in an adjacent booth; overheard, witnessed, and documented the oral consent; and served as lookout in case a likely gang member entered the restaurant.

## **Background considerations**

It is well-documented that there are many groups within the United States that are very wary of participating in research and signing any documents, especially consent forms connected with a government research project. These conclusions are drawn from many sources, most notably (a) the U.S. Census Bureau which must contend with problems of undercounting among those populations that are skeptical of being enumerated, and (b) cultural anthropologists who focus primarily on those American cultures that are politically, educationally, or economically marginal.

The problems experienced by the U.S. Census Bureau are particularly relevant to this discussion. Census has had a long tradition of maintaining the confidentiality of its data, but the number of people willing to be enumerated has declined. The proportion of non-white individuals who are unwilling to be enumerated is about triple that of white individuals. Turner (1982) describes the findings of several key studies of public attitudes toward being identified in surveys, including studies by the American Statistical Association, the National Academy of Sciences, and the U.S. Census Bureau. Since that report, the undercounting situation with respect to minority populations has worsened.

Cultural anthropologist Murray Wax, in his testimony before the National Bioethics Advisory Commission (2000), poignantly described the challenges facing cultural anthropologists who seek to study unassimilated Hispanic and Indian cultures. If their IRB insists on signed consent, their research is rendered impossible. The reasons for refusal to sign documents varies. Among many Native Americans, there is a long history of losing land by signing documents they do not understand. Among members of populations who are conducting underground commerce, there is fear of identification and prosecution. Among members of many non-Western cultures, there is the belief that a person's word is what counts, and that requiring marks on a piece of paper (the signature or X) is meaningless and insulting.

Both Singer (1978) and Trice (1987) found that a significant number of respondents refused to participate in a survey if required to sign the consent form, but would participate

otherwise. There has been no recent research on the effects of signed consent on response rates. However, if more current data were desired, specifically with respect to the NCVS, Census could readily research this. One approach would be to randomly assign a small proportion of each cultural subgroup studied to a condition in which they are asked to sign a consent form. The results of this condition could then be compared with the matched non-signing group with respect to refusals, and perhaps also with respect to the quality (detail) of responses and the distribution of crime victimization events reported.

The NCVS might be exempt from signed consent under the Common Rule. While some of the questions may be sensitive insofar as asking respondents to recall victimization, they do not involve more than minimal risk except for a very few cases where there may be risk of some emotional upset.

## 11. Researching ethical questions

This report was written to provide specific answers to pertinent ethical questions, and to provide an overview of the many highly complex ethical questions to which the answer is “It depends....” Typically, the tough ethical questions pit two competing kinds of good against one another, and usually each kind of good brings with it competing bad side-effects. For example, should the informed consent be so comprehensive that it answers every question any participant might have, or would this be so long and tedious a document that respondents would tune out and be less well informed? Would comprehensiveness destroy or deter comprehension?

The research organization and its IRB quickly learn that each ethical dilemma is a bit different because research contexts, resources, and scientific, social, and regulatory environments differ. Most ethical and regulatory questions are resolved through reasoned discussion by the researchers and IRB, who examine the pros and cons of alternative approaches in detail. The decision makers seek the solution that seems — to them — to best fit the situation. The IRB may weigh ethical and regulatory decision criteria above scientific and practical criteria, while the researchers may rank these decision criteria otherwise and may persuade the IRB to place more weight on certain scientific and practical considerations. In accord with regulatory requirements, the IRB summarizes in its minutes the discussion, its reasoning, and the grounding of that reasoning in the regulations and the Belmont principles (beneficence, respect, and justice), and finally its conclusion. At this point, the decision of the IRB is in compliance with the Common Rule, and the researchers must comply with the decision.

There are dangers to some of the assumptions that IRBs and researchers may bring to their reasoned discussions as the following examples illustrate. During the last 25 years many social and behavioral scientists have expressed certainty that requirements of informed consent would destroy their ability to conduct valid research, but most of these views have proven fallacious. Similarly, many IRBs have insisted on individual, and even signed, informed consent of subjects in cultures such as Native American tribes, where decisions are made at a tribal, not individual, level, and where signing documents is regarded as insulting or dangerous. For examples of cultures that do not regard autonomy of the individual or signed consent as acceptable, see Marshall (1992) and Wax (2000). IRBs are required to have at least one community member who might be better able to speak for at least one other culture than can the rest of the IRB, for example, a community member who is an experienced school teacher can speak for the culture of the local schools. Some researchers are quite familiar with the cultures they study. However there are many instances in which IRBs and researchers do not know enough about what is “out there” to make sound ethical decisions.

Although ethics is a normative discipline, the ethics of survey research raises many questions that are empirical and methodological. Ethics requires that researchers obtain children's informed assent to participate; but does not tell us what kinds of information children can understand or what kinds of decisions they are competent to make at a given age. Ethics requires that researchers respect confidentiality of information obtained from respondents, but does not tell us whether respondents believe promises of confidentiality or whether such promises make a difference in their willingness to participate candidly. As this literature search reveals, major survey research organizations — Survey Research Center of the Institute for Social Research, University of Michigan; National Opinion Research Center, University of Chicago; the U.S. Census Bureau — carry out continuous programs of research on ways to improve their research methods. Many of these programs are stimulated by changes in the ethical or regulatory environment of social research.

In their continuing quest to improve ethical and methodological aspects of the NCVS, BJS and Census will undoubtedly face many empirical questions, some of which were raised in this report. Is the NCVS designed to evoke the most accurate responses from young teenagers or would a somewhat different version work better? Does signed informed consent affect willingness to participate or to answer sensitive questions?

Survey researchers can use several approaches to answer empirical questions. Some useful approaches are: the experiment within a study or as a pilot test prior to a study, the focus group to explore reactions of respondents to aspects of the intended survey and to generate new hypotheses to be tested, the ethnographic study of one's research populations, and the study of meta-communication within the research process. A brief outline of these approaches follows.

### **The experiment within a study**

Researchers can add one or more experimental conditions to some aspect of the study, and examine the effects of the variations in relation to one or more dependent variables. Here are a few examples:

The experimental conditions may be integral to the survey, such as the effects of anonymity or various kinds of confidentiality. Investigators might try different wordings of sensitive questions and different ways to jog subjects' memories. Researchers might perform these experiments in pilot tests or build them into the main study.

Sometimes such experiments are not intended to yield generalizable knowledge about survey research, but rather to provide information about the particular research issue. An example of such an experiment follows. Sieber and Saks (1989) mailed a survey to all U.S.

and Canadian psychology departments that asked, essentially, whether departmental subject pool practices were in keeping with psychologists' code of research ethics and with the federal regulations of human research. Half of the respondents were asked to indicate the name of their university. Was the response rate or the admission of unethical or illegal practices equal for the two groups? Can either group be trusted to tell the truth? Clearly, anonymity had an impact, but not in the way expected. Response rate was unaffected, and there were only slightly more admissions of dubious practices by anonymous respondents. However all admissions by identified departments were accompanied by extensive rationales justifying their behavior. The profile of kinds of ethical improprieties was similar for the two groups. The survey had a 90% response rate. The results of the survey and the experiment within it indicated that departments were mindful of the ethical implications of their policies, sensitive or defensive about their breaches of ethical conduct, but basically honest in their responses to the survey. This is an example of an experimental result that probably could not be meaningfully generalized to other contexts but that provided additional information about both the ethical sensitivities of the respondents and the validity of their responses.

The experimental manipulation might precede the research itself, such as the mode in which researchers recruit subjects (for example letter, phone, or e-mail) the amount or kind of incentive researchers offer for participation, or the way researchers provide informed consent (for example individual verbal discussion, group discussion, pamphlet, videotape, or computer-assisted instruction). One prevalent idea that has not been reported yet in the literature is to present informed consent information via computer-assisted instruction when the research involves risks that are not easily understood. The subject would be tested, via the computer, on the information that the interviewer has presented, and not allowed to proceed until able to correctly answer questions about the informed consent process. The program then asks whether the respondent consents to participate. Researchers would electronically document the entire procedure for each subject. Dependent variables might include: willingness to participate, willingness and candor to respond to individual questions, satisfaction with the experience of participating, and how much the subject knows about the study right after participating.

The experimental manipulation might be in the technology of the survey itself. The survey may be administered in a face-to-face interview, web-based Internet survey, or computer-assisted self-interview. The experimental manipulation might be the systematic variation of respondent-researcher characteristics. For example, does it matter whether the interviewer is of the same gender, ethnicity, or age bracket as the respondent?

### **The focus group**

The focus group is a form of qualitative research that is best suited for generating, as opposed to testing, hypotheses, and for exploring people's reactions to questions that are

somewhat new to them and for which they do not have ready, thought-out answers. David Morgan (1988) suggests the following uses of focus groups:

- To orient oneself to a new field of study,
- To generate hypotheses based on informants' insights,
- To evaluate different research sites or study populations,
- To develop interview schedules and questionnaires, and
- To get participants' interpretations of results.

Researchers can ask a properly organized focus group of about 5 to 12 persons the kinds of questions that people could not or would not answer in a survey or questionnaire, but that would evoke extensive lively discussion in a focus group. There are no right answers to focus group questions. The participants are the experts; their role is to tell the researcher such things as how they feel about a certain issue, what they need or want, or what approach to some activity they would find preferable or believe would work.

For example, sociologist Benjamin Bowser (Bowser and Sieber, 1993) sought to find out what crack cocaine-using inner-city teenagers know about HIV infection and safe sex, and what kinds of sexual practices they engage in. He hung out in an inner-city neighborhood, got to know street kids, and invited them to focus groups over pizza. He told them what he needed to know to help kids help themselves, and asked their advice on how to go about surveying kids who frequent crack houses. Their advice led him to develop an innovative and successful survey research approach and to achieve major survey research findings on the risk behavior of this population.

Although the researcher has specific questions in mind for the group to answer, it is often unnecessary to ask more than the first question. As the group takes on a life of its own, it may raise and answer all of the researcher's unasked questions and provide powerful unexpected insights along the way. It is important that the researcher have goals in mind so that the group can be kept somewhat on the subject; but it is equally important that the researcher be flexible enough to permit unexpected but highly valuable new ideas to emerge. At the conclusion of the focus group, which often could go on much longer than the leader permits, the participants each have much clearer ideas about the topic, ideas which they are able and willing to articulate. It is a common practice to give individual respondents a questionnaire after the focus group so that they can give their individual responses to questions in a short answer or Likert Scale format.

Focus groups can be operated very inexpensively and simply. Commercial marketing firms may charge many thousands of dollars for one or more focus groups that involve one-way

mirrors, videotaping, and hours of transcribing. However most researchers find that an effective approach is to involve a discussion leader and two assistants who sit nearby and take notes on the main ideas that are raised. Near the end of the focus group the assistants may summarize their notes to the participants to ask if there are ideas they want to add or if the note-takers got it right. An outstanding source of information on conducting focus groups is Krueger (1994 or a later edition). A brief discussion of how to use and conduct a focus group is found in appendix B of this paper.

## **Ethnography**

Issues of respect for research participants, informed consent, risk/benefit assessment, privacy and confidentiality, and respondents' willingness to participate candidly and to answer sensitive questions take on a different character when surveying members of deviant or marginalized populations. Obviously each deviant population is different and requires a different ethnographic approach.

Some populations of interest to researchers conducting surveys on crime victimization are persons whose unconventional, transitory, or lower-status lifestyle make them highly likely candidates for crime victimization. These populations include groups of homeless people, unassimilated immigrants (legal and otherwise), prostitutes, households of drug dealers, and enclaves of young gay men who have migrated to cities where their lifestyle may be more acceptable. If researchers wish to interview members of such groups, they must know where, when, and how to do so; above all, they must know how to establish enough trust to create a viable relationship and obtain candid answers.

Researchers can use the knowledge of urban anthropologists and other professionals who have worked with the population they seek to study to prepare their survey. However this neither establishes the legitimacy of the researcher to ask for sensitive information nor gives the researcher the level of comfort needed to work in the environment of their respondents. It is well known that the personal characteristics of a participant observer affect his or her research practice (e.g., see Wax, 1979). Researchers may find it necessary to match backgrounds of interviewer and target population, including matching ethnicity, gender, or language. For example, a female doctoral student who had once been homeless conducted highly useful research and AIDS outreach with homeless women who used injection-drugs in San Francisco. She socialized with members of her target population for a few weeks, after which she rented a "flop house" and put on dinners for the people she wished to survey. She knew how to organize her interaction with them so that they could avoid police hassles. She respected them and conversed with them in a familiar way, and they knew and trusted her. Moreover, she was close enough to them and their lifestyles that she could evaluate their responses for candor, and interpret responses that would not be interpretable by persons unacquainted with this culture and setting.

## **Meta-communication in the research process**

It is well documented by those who perform empirical research on the process of survey research that there are considerable individual differences among trained interviewers in the results they achieve. An interesting example is found in the work of Singer and Frankel (1982) who studied informed consent procedures in telephone interviews. Two aspects of informed consent were varied: information about the content of the interview and information about its purpose. There was a brief and a more detailed and honest version of each. Singer and Frankel found that these factors made little difference in the quality of the data collected and the meaning of the experience for the respondents. By far the largest variation in response rate to the survey occurred among interviewers. The more experienced interviewers produced a higher response rate using the brief consent procedures that they were used to, while the less experienced interviewers produced a higher response rate using the more lengthy experimental procedure.

To date there is very little understanding of what factors enter into the success of well-trained interviewers. However it is obvious that there is considerable meta-communication that occurs between researcher and subject. Researchers know that tone of voice, body language, mirroring and congruence with the respondent, physical characteristics, room arrangement, and distance between persons make a difference in some situations (Sieber, 1996). The question is whether researchers need to be concerned with any of these differences to conduct survey research effectively and efficiently.

## 12. Keeping abreast of new developments and answering questions

A growing variety of informational resources on the ethics and regulation of human research attest to the need for researchers to keep abreast of new and old issues and to learn from others. The following resources are useful to researchers and IRBs.

### On-line resources

Relative to other areas of human research, researchers regard survey research as relatively risk free, and anonymous surveys that do not ask sensitive questions are exempt from IRB review. Consequently there are as yet no on-line tutorials concerned with ethics and regulations of survey research. In fact there are no tutorials dedicated to social and behavioral research; there are only tutorials for biomedical research. However there is indication that Office of Human Research Protections (OHRP), Department of Health and Human Services, which provides guidance on Common Rule questions, has plans to offer within the year an on-line tutorial concerned with social and behavioral research.

There are other ways in which survey researchers can find answers to their questions on-line. Members of any IRB that is instituted in connection with the NCVS should join the on-line discussion group entitled McWirb (<http://www.mcwirb.org>). Members may post questions, share information, and learn how other IRBs in the United States and Canada handle issues.

### Meetings

Two kinds of professional organizations regularly hold meetings that deal with ethical issues in research.

The primary organization is Public Responsibility in Medicine & Research (<http://www.primr.org>), which holds annual meetings in Boston in December and in San Diego in October. It holds other meetings at irregular intervals. It is located at 132 Boylston Street, Boston, MA 02116; phone 617-423-4112, FAX 617-423-1185.

The other professional organizations are scientific societies, such as the American Association for the Advancement of Science (<http://www.aaas.org>), American Sociological Association (<http://www.asanet.org>), and the American Psychological Association (<http://www.apa.org>). Their examination of ethical issues usually occurs at their annual scientific meetings, and is far less intense or focused than are the sessions at PRIM&R.

## Journals

There are two journals devoted largely to ethical issues in human research that carry articles of concern to survey researchers.

*Ethics & Behavior* is edited by Dr. Gerald Koocher, Department of Psychiatry, Children's Hospital, 300 Longwood Avenue, Boston, MA 02115 (<http://www.erlbaum.com/Journals>).

*IRB: Ethics and Human Research* is edited by Betty Criger, and published by the Hastings Institute. It is of particular interest to IRB members, research administrators, and investigators in the biomedical and behavioral/social sciences. It is published by the Hastings Center at Garrison, New York 10524, phone 845-424-4040, fax 845-424-4545, or see the journal index at <http://www.thehastingscenter.org/publications>.

Two other journals that may be of tangential interest to BJS are *Scientific & Engineering Ethics*, edited by Stephanie J. Bird and Raymond Spier, <http://www.opragen.co.uk>, and *Accountability in Research*, edited by Dr. Adil E. Shamoo, <http://www.gbhap.com/journals/149>. These journals rarely publish articles of interest to survey researchers.

## Informal local groups

NCVS researchers concerned with ethical issues may have more interests/issues in common with other government agencies that conduct survey research than with researchers engaged in other kinds of survey research. It may prove worthwhile to develop a consortium of government agency IRB chairs, administrators, researchers, and other interested members to discuss and exchange ideas and information.

## Office of Human Research Protections

The Office of Human Research Protections (OHRP), Department of Health and Human Services, can provide useful guidance. OHRP is at <http://ohrp.osophs.dhhs.gov/>. OHRP's phone number is 301-496-7005.

A useful document is the OHRP publication *Protecting Human Subjects: Institutional Review Board Guidebook*, which is available from OHRP and on-line at [http://ohrp.osophs.dhhs.gov/irb/irb\\_preface.htm](http://ohrp.osophs.dhhs.gov/irb/irb_preface.htm).

### 13. Briefly annotated bibliography of literature cited

American Psychological Association, *Ethical Principles of Psychologists and Code of Conduct* (Washington, D.C.: APA, 1992).

*While most of this code of ethics pertains to clinical practice and other non-research activities, Sections 6.06 to 6.26 concern research and are heavily relied upon not only by psychologists but by other organizations concerned with ethics and regulations of human research.*

A. W. Austin and R. F. Boruch, "A 'Link File System' for Assuring Confidentiality of Research Data in Longitudinal Studies," *American Educational Research Journal* 7, 615-624 (1970).

*This article describes highly sophisticated techniques for linking files without the possibility of discovery of individual identities.*

P. J. Barker and R. F. Cooper, "Do Sexual Health Questions Alter the Public's Response to Lifestyle Questionnaires?" *Journal of Epidemiology and Community Health* 50, 688 (1996).

*The finding that just one sensitive question did not affect response rate leaves one to wonder what is the threshold for making a survey too sensitive, and hence for affecting response rate.*

David M. Bersoff and Donald M. Bersoff, "Ethical Issues in the Collection of Self-Report Data," in A. A. Stone, J. S. Turkkan, C. A. Bachrach, J. B. Jobe, H. S. Kurtzman, and V. S. Cain, eds., *The Science of Self-Report: Implications for Research and Practice* (Mahwah, N.J.: Lawrence Erlbaum Associates, 2000), pp. 9-24.

*The risks connected with self-report surveys are discussed, pointing out that surveys can ask for far more personal information than is available by observation or experiment. An anonymous survey, requiring no IRB review or informed consent, may deeply invade privacy and cause much emotional upset by probing into painful experiences.*

O. Boikess, *Privacy Protection for Research Subjects: Certificates of Confidentiality*, personal communication, 2000.

*This communication sets forth details of a legal case, heard in the Supreme Court of New York, in which the power of the Certificate of Confidentiality was tested and upheld.*

R. F. Boruch and J. S. Cecil, *Assuring the Confidentiality of Social Research Data* (Philadelphia: University of Pennsylvania Press, 1979).

*This book, now out of print, might be regarded as the most important publication on*

*approaches to assuring the confidentiality of social research data. It catalogs and describes the many kinds of approaches to assuring confidentiality, such as procedural, statistical, and legal. Though a few parts of it would be rewritten in light of new information, it remains a seminal work.*

B. P. Bowser and J. E. Sieber, "AIDS Prevention Research: Old Problems and New Solutions," in C. M. Renzetti and R. M. Lee, eds., *Researching Sensitive Topics* (Newbury Park: Sage, 1993), pp. 160-176.

*The challenge of AIDS prevention calls for new combinations of research tools that enable social scientists to understand why a particular intervention succeeds or fails. This chapter describes a series of approaches, including the use of focus groups, to reconceptualize AIDS prevention research and to improve methods and theory in this area.*

D. T. Campbell, R. F. Boruch, R. D. Schwartz, and J. Steinberg, "Confidentiality-Preserving Modes of Access to Files and to Interfile Exchange for Useful Statistical Analysis," *Evaluation Quarterly* 1, 269-300 (1977).

*The authors present many techniques that enable useful data sharing and secondary analysis without jeopardizing confidentiality of data.*

A. H. Church, "Estimating the Effects of Incentives on Mail Survey Response Rates: A Meta Analysis," *Public Opinion Quarterly* 57, 62-79 (1993).

*This is a useful empirical study of the effects of financial incentives on willingness to participate in survey research.*

R. B. Cialdini, *Influence: The Psychology of Persuasion* (New York: Morrow, 1993).

*This important book helps us to better understand subtle forces of persuasion that are at work in survey research and other contexts.*

J. E. Corbin, "Child Abuse and Neglect: The Cultural Context," in R. E. Helfer and R. S. Kempe, eds., *The Battered Child* (Chicago: University of Chicago Press, 4<sup>th</sup> ed., 1987), pp. 239-255.

*The authors discuss a wide range of definitions of child abuse and neglect, and show that the incidence of abuse and neglect vary widely depending on definitions.*

W. W. Darrow, H. W. Jaffe, P. A. Thomas, H. W. Haverkos, M. F. Rogers, M. E. Guinan, D. M. Auerbach, T. J. Spria, and J. W. Curran, "Sex of Interviewer, Place of Interview, and Responses of Homosexual Men to Sensitive Questions," *Archives of Sexual Behavior* 15,

79-88 (1986).

*Their examination of a variety of physician-patient interviews revealed virtually no differences as a result of gender of interviewer and location of interview.*

C. B. Fisher and S. A. Wallace, "Through the Community Looking Glass: Reevaluating the Ethical and Policy Implications of Research on Adolescent Risk and Psychopathology," *Ethics & Behavior* 10, 99-118 (2000).

*This article, based on community focus groups, urges investigators to seek the perspectives of teenagers and parents in evaluating the personal and political costs and benefits of research on adolescent risk behaviors.*

J. L. Freedman and S. C. Fraser, "Compliance Without Pressure: The Foot-in-the-door Technique," *Journal of Personality and Social Psychology* 4, 195-202 (1966).

*This seminal study of the way in which persons could be gotten to accede to unreasonable requests has triggered a variety of studies that have informed survey researchers about ways to approach sensitive topics.*

E. Gil, *The California Child Abuse Reporting Law: Issues and Answers for Professionals* (Publication No. 132 [10/86]), 1982. Available from the State of California Department of Social Services, Office of Child Abuse Prevention, 744 P Street, M.S. 9-100. Sacramento, CA 95815.

*This document provides many useful tips to the professional who is subject to mandatory reporting of child abuse in California. Gil's recommended wording to warn respondents that confidentiality of survey or interview data is not absolute is of particular interest.*

J. Gilbert, *Protecting Confidential Research Information from Disclosure in Litigation*, personal communication, Federal Judicial Center Memo, July 7, 2000.

*In this memo, legal intern Gilbert sets forth the legal limits of protection to subpoenaed data; of particular interest is his discussion of the methods of legal discovery that can be used to obtain data that have been sent outside of the country.*

E. Gray and J. Cosgrove, "Ethnocentric Perceptions of Childrearing Practices in Protective Services," *Child Abuse and Neglect* 9, 389-396 (1985).

*Adding to the difficulty of defining child abuse is the prevalence of major differences among ethnic groups in punitiveness of childrearing practices.*

T. P. Johnson and R. W. Moore, "Gender Interactions Between Interviewer and Survey Respondents: Issues of Pornography and Community Standards," *Sex Roles* 28, 5-6 (1993).

*The authors did not find a gender effect in a study of responses to a phone survey on use of pornographic materials.*

S. C. Kalichman, *Mandated Reporting of Suspected Child Abuse: Ethics, Law and Policy* (Washington, D.C.: APA, 1999).

*Every State requires that human services professionals report suspected child abuse. Kalichman offers an innovative model for making the reporting decision.*

M. Kim, "Poor Women Survey Poor Women: Feminist Perspectives in Survey Research," *Feminist Economics* 3, 99-117 (1997).

*This article describes a highly qualitative and collaborative approach to telephone surveys of participants in job training programs. The use of poor women to interview poor women was highly effective in creating rapport, reducing interviewer bias, and facilitating the answering of sensitive questions.*

A. Kinsey, W. B. Pomeroy, C. E. Martin, and P. H. Gebhard, *Sexual Behavior in the Human Female* (Philadelphia: Saunders, 1953).

*Kinsey and his associates pioneered the development of survey techniques that enabled them to elicit candid answers to highly sensitive questions.*

P. Kissinger, J. Rice, T. Farley, S. Trim, K. Jewitt, V. Mangavio, and D. H. Martin, "Application of Computer-Assisted Interviews to Sexual Behavior Research," *American Journal of Epidemiology* 149, 950-954 (1999).

*The authors describe video-enhanced computer-assisted, self-administered interviews, which were shown to elicit more socially undesirable responses than face-to-face interviews.*

R. A. Krueger, *Focus Groups: A Practical Guide for Applied Research* (Newbury Park: Sage, 2<sup>nd</sup> ed., 1994).

*This handy guide and other works by Krueger have good advice for researchers who want to conduct focus groups.*

J. A. Landsheer, P. G. van der Heijden, and G. van Gils, "Trust and Understanding, Two Psychological Aspects of Randomized Response," *Quality and Quantity* 33, 1-12 (1999).

*This research established the importance of trust and understanding of the method in producing valid responses on socially undesirable topics.*

R. S. Laufer and M. Wolfe, "Privacy as a Concept and a Social Issue: A Multidimensional Developmental Theory," *Journal of Social Issues* 33, 44-87 (1977).

*Laufer and Wolfe's theory of personal privacy recognizes the manifold cultural, developmental, and situational elements by which individuals orchestrate their privacy.*

J. T. Lesser and J. M. O'Reilly, "Mode of Interview and Reporting of Sensitive Issues: Design and Implementation of Audio Computer-assisted Self-interviewing," *NIDA Research Monograph* 167, 366-382 (1997).

*The authors review various approaches to interviewing people about sensitive issues. They include the implementation and results of using audio-computer-assisted self-interviewing.*

E. K. Levine, "Old People Are Not All Alike: Social Class, Ethnicity/Race, and Sex Are Bases for Important Differences," in J. E. Sieber, ed., *The Ethics of Social Research: Surveys and Experiments* (New York: Springer Verlag, 1982), pp. 127-144.

*This account traces the history of avoiding research on the elderly, particularly elderly women, details the kinds of issues that are not raised in research publications, and shows how many incorrect assumptions about elderly persons have arisen out of poor sampling and assumptions of homogeneity of this population.*

M. Levine and A. Levine, *Helping Children: A Social History* (New York: Oxford University Press, 1983).

*A history of the development of child welfare reporting laws is presented.*

L. E. Linden and D. J. Weiss, "An Empirical Assessment of the Random Response Method of Sensitive Data Collection," *Journal of Social Behavior and Personality* 9, 823-836 (1994).

*The authors studied sensitive aspects of personal history in 285 undergraduates using written questionnaires. They found no difference between direct and randomized response methods of questioning.*

P. A. Marshall, "Research Ethics in Applied Anthropology," *IRB: A Review of Human Subjects Research* 14, November-December, pp. 1-5 (1992).

*Various problems arise when researchers apply culturally insensitive approaches to non-Western or non-mainstream cultures, and when researchers apply federal regulations designed for mainstream American culture elsewhere. This article describes the resulting dilemmas.*

T. Makkai and I. McAllister, "Measuring Social Indicators in Opinion Surveys: A Method to Improve Accuracy on Sensitive Questions," *Social Indicators Research* 27, 169-186 (1992).

*The authors compare sealed booklet technique with the face-to-face interview in terms of respondent's willingness to answer sensitive questions.*

G. B. Melton, "Respecting Boundaries: Minors, Privacy and Behavioral Research," in B. Stanley and J. Sieber, eds., *The Ethics of Research on Children and Adolescents* (Newbury Park: Sage, 1992), pp. 65-87.

*The problems of protecting privacy and assuring confidentiality of behavioral research on minors are discussed. The stages of development of minor's sense of privacy are illustrated. Melton discusses uses and limits of Certificates of Confidentiality.*

G. B. Melton, R. J. Levine, G. P. Koocher, R. Rosenthal, and W. Thompson, "Community Consultation in Socially Sensitive Research: Lessons from Clinical Trials on Treatments for AIDS," *American Psychologist* 43, 573-581 (1988).

*This classic article describes the process and benefits of consultation between members of vulnerable communities and researchers whose intentions are regarded with suspicion, anger, and plans for non-cooperation by those they seek to study.*

National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, *The Belmont Report* (Washington, D.C.: National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979).

*The Belmont Report sets forth the ethical principles upon which the Federal Regulations of Human Subjects are based.*

M. T. Orne, "On the Social Psychology of the Psychological Experiment: With Particular Reference to Demand Characteristics and Their Implications," *American Psychologist* 17, 776-783 (1962).

*This classical essay provided an important foundation for subsequent evaluation of the demand characteristics of various social science research activities.*

P. Raghubir and G. Menon, "Asking Sensitive Questions: The Effects of Type of Referent and Frequency Wording in Counter-biasing Methods," *Psychology & Marketing* 13, 633-652 (1996).

*The authors conducted two experiments that tested the effects of counter-biasing methods on respondent's willingness to admit to stigmatized behaviors.*

G. A. Sachs and C. K. Cassel, "Biomedical Research Involving Older Human Subjects," *Law, Medicine and Health Care* 18, 234-243 (1990).

*This excellent article outlines special issues arising in research on the elderly, and kinds of safeguards and best practices advisable with older populations.*

J. E. Sieber, ed., *Sharing Social Science Data: Advantages and Challenges* (Newbury Park: Sage, 1991).

*This edited volume discusses a range of data sharing arrangements and the attendant challenges of protecting identities and providing adequate documentation. It includes descriptions of a variety of innovative sharing relationships.*

J. E. Sieber, "Typically Unexamined Communication Processes in Research," in B. H. Stanley, J. E. Sieber, and G. B. Melton, eds. *Research Ethics: A Psychological Approach* (Lincoln: University of Nebraska Press, 1996).

*This article specifies a range of meta-communication processes that occur in research and that may be deserving of research in relation to ethical and methodological questions.*

J. E. Sieber and M. Saks, "A Census of Subject Pool Characteristics and Policies," *American Psychologist* 44, 1051-1063 (1989).

*This is an illustration of an experiment within a survey that examined the effects of anonymity on response rate and frequency of acknowledging unethical or illegal practices.*

E. Singer, "Informed Consent: Consequences for Response Rate and Response Quality in Social Surveys," *American Sociological Review* 43, 144-162 (1978).

*The author investigated the effects in face-to-face interviews of more versus less information about sensitive subject matter, of varied assurances of confidentiality, and of requiring or not requiring a signature to document consent. Varying information made no difference, but was noticed if it failed to mention pertinent elements of the study. Subjects were inaccurate in their perceptions of how much confidentiality they had been promised. However perception that one had been given absolute assurance of confidentiality was associated with higher estimates of sensitive behavior. Subjects assigned to a condition in which they were asked to sign a consent form significantly more often refused to do so but were willing to participate in the interview if they didn't have to sign the consent form.*

E. Singer, "Informed Consent in Surveys: A Review of the Empirical Literature," *Journal of Official Statistics*, 9, 361-375, (1993).

*This paper examines the effects of four elements of consent: the content of the interview and purpose of the research, assurances of confidentiality or anonymity; active versus passive*

*consent, and voluntariness of participation. Of particular interest was the finding that confidentiality promises have a small effect on willingness to participate in survey research. Highly detailed promises are counterproductive when the research questions are not sensitive; presumably such detail raises unwarranted concerns and suspicions.*

E. Singer and M. R. Frankel, "Informed Consent Procedures in Telephone Interviews," *American Sociological Review* 47, June, pp. 416-427 (1982).

*This paper reports an experiment with providing varying amounts of information on the content and purpose of the survey in the informed consent. Interestingly, the experimental variables had little impact on the willingness of respondents to be interviewed and the quality of the interview. However large variations in response rate occurred among interviewers, with experienced interviewers doing best with the short consent statement and the inexperienced ones doing best with the long statement.*

E. Singer, R. M. Groves, and A. D. Corning, "Differential Incentives: Beliefs about Practices, Perceptions of Equity, and Effects on Survey Participation," *Public Opinion Quarterly* 53, 251-260 (1999).

*This study found that use of incentives to convert refusals is perceived as inequitable but that this does not effect the response rate of cooperative subjects who know about this practice.*

E. Singer, H. Hippler, and N. Schwarz, "Confidentiality Assurances in Surveys: Reassurance or Threat?" *International Journal of Public Opinion Research* 4, 256-268 (1992).

*When non-threatening questions are accompanied by elaborate assurances of confidentiality, response rate is lowered.*

E. Singer, N. Mathiowetz, and M. P. Couper, "The Impact of Privacy and Confidentiality Concerns on Survey Participation: The Case of the 1990 U.S. Census," *Public Opinion Quarterly* 57, 465-482 (1993).

*The impact of privacy and confidentiality concerns are only slightly related to survey response.*

E. Singer, D. vonThurn, and E. Miller, "Confidentiality Assurances and Response: A Quantitative Review of the Experimental Literature," *Public Opinion Quarterly* 59, 66-77 (1995).

*Meta-analysis of 30 studies of the effect of confidentiality assurances (verbal assurances, anonymity, or use of randomized response method) showed that assurances of all three kinds are positively associated with response rate and response quality, but only when sensitive questions are asked.*

E. Singer, N. Gebler, J. Van Hoewyk, T. Raghunathan, and K. McGonagle, "The Effects of Incentives on Response Rates in Face-to-Face and Telephone Surveys," *Journal of Official Statistics* 15, 217-230, (1999).

*This experiment investigated the effects of various kinds of incentives on response rate in face-to-face and phone surveys.*

T. W. Smith, "The Impact of the Presence of Others on a Respondent's Answers to Questions," *International Journal of Public Opinion Research* 9, 33-47 (1997).

*This study examines the effects of the presence of spouses and children during interviews to determine whether different responses are evoked under these conditions.*

A. L. Stanton, E. J. Burker, and D. Kershaw, "Effects of Researcher Follow-up of Distressed Subjects: Tradeoff Between Validity and Ethical Responsibility?," *Ethics & Behavior* 1, 105-112 (1991).

*This excellent experiment provides strong evidence for the value of providing respondents with useful information and referrals, and for the importance of not seeking to intervene with help that was not requested.*

S. Sudman and N. M. Bradburn, *Asking Questions*. (San Francisco: Jossey-Bass, 1982).

*This is a highly practical and useful introductory treatise on formulating and asking questions of various types in survey research.*

R. Thompson, "Developmental Changes in Research Risk and Benefit: A Changing Calculus of Concerns," in B. Stanley and J. Sieber, eds., *Social Research on Children and Adolescents: Ethical Issues* (Newbury Park: Sage, 1982), pp. 31-64.

*In contrast to the usual view that minors become less vulnerable as they grow older, this chapter presents a description of kinds of vulnerabilities that arise through the developmental sequence from early childhood to adulthood, showing that there are forms of vulnerability that increase with age through adolescence.*

R. Tourangeau and T. W. Smith, "Asking Sensitive Questions: The Impact of Data Collection, Mode of Question Format, and Question Context," *Public Opinion Quarterly* 80, 275-304 (1996).

*This complex study examined the effects of three kinds of computer-assisted interviewing, open- versus closed-ended answer options, and contextual variables.*

A. D. Trice, "Informed Consent. VII. Biasing of Sensitive Self-report Data by Both Consent and Information," *Journal of Social Behavior and Personality* 2, 369-374 (1987).

*The author found that a significant number of subjects refused to participate if required to sign a consent form but were willing to participate otherwise.*

A. G. Turner, "What Subjects of Survey Research Believe about Confidentiality," in J. E. Sieber, ed., *The Ethics of Social Research: Surveys and Experiments* (New York: Springer Verlag, 1982).

*Turner summarizes a series of high-level studies of what American populations, especially minority populations, believe about survey research. Many see surveys as pointless since they believe the government already knows everything about them. They do not trust promises of confidentiality. When individuals find themselves in a position where they cannot refuse to participate, they may be very careful to say only those things that they believe will not come back to haunt them, and are careful to tell each survey taker the same story.*

U. N. Umesh and R. A. Peterson, "A Critical Evaluation of the Randomized Response Method: Applications, Validation, and Research Agenda," *Sociological Methods & Research* 20, 104-118 (1991).

*This article reviews recent applications of the randomized response method, identifies new issues being studied, and suggests future research.*

P. G. van der Heijden, G. van Gils, J. Bouts, and J. J. Hox, "A Comparison of Randomized Response, Computer-assisted Self Interview, and Face-to-Face Direct Questioning: Eliciting Sensitive Information in the Context of Welfare and Unemployment Benefit," *Sociological Methods & Research* 28, 505-537 (2000).

*This is one of the few validation studies conducted in which the respondents and interviewers did not know that the researchers knew about their welfare fraud. Respondents in the randomized response condition admitted more acts of fraud than either the face-to-face interviewed respondents or the computer-assisted self-interviewed respondents.*

M. L. Wax, "Gender and Age in Fieldwork and Fieldwork Education," *Social Problems* 26, 509-522 (1979).

*Characteristics of the ethnographer influence the talents he or she brings to the work, the interaction likely to occur in the field, and the way members of the community perceive the ethnographer.*

M. L. Wax, Testimony before the National Bioethics Advisory Commission on Problems raised by the Federal Regulations for Research in Cultural Anthropology, Washington, D.C., April 6, 2000.

J. G. Weis, "Family Violence Research Methodology and Design," in L. Ohlin and M. Tonry, eds., *Family Violence* (Chicago: University of Chicago Press, 1989), pp. 296-321.

*This provides a comprehensive perspective on the incidence of child abuse and the dependence of reported incidence on definitional and research criteria.*

G. B. Willis, "The Use of the Psychological Laboratory to Study Sensitive Survey Topics," *NIDA Research Monograph* 167, 416-438 (1997).

*The author describes various cognitive techniques for studying approaches to asking sensitive questions in ways that produce truthful answers, and offers recommendations for improving survey design.*

## Appendix A. State phone numbers for reporting child maltreatment

Childhelp USA is a non-profit organization dedicated to the prevention and treatment of child abuse. It assists States in establishing guidelines to make their own laws to protect abused and neglected children. It has no authority to intervene in individual child abuse and neglect cases.

Many States have a toll-free number to call to report suspected abuse. States with toll-free child abuse reporting numbers are listed. The reporting party and the child who is allegedly being abused must reside in the same State for the following reporting numbers to be valid. When the reporting party resides in a different State than the child, or for States not listed, call Childhelp's National Child Abuse Hotline at 1-800-422-4453 or visit Childhelp's website at <http://www.childhelpusa.org>. Childhelp is not involved in investigations by a government agency. Hotline counselors provide the State or county reporting number to callers or provide other referrals.

This document is current as of September 12, 2000.

	Iowa (800) 362-2178	New York (800) 342-3720
	Kansas (800) 922-5330	North Carolina (800) 662-7030
	Kentucky (800) 752-6200	Oklahoma (800) 522-3511
	Maine (800) 452-1999	Oregon (800) 854-3508
	Massachusetts (800) 792-5200	Pennsylvania (800) 932-0313
	Michigan (800) 942-4357	Rhode Island (800) 742-4453
	Mississippi (800) 222-8000	Texas (800) 252-5400
Arizona (800) 330-1822	Missouri (800) 392-3738	Utah (800) 678-9399
Arkansas (800) 482-5964	Montana (800) 332-6100	Virginia (800) 552-7096
Connecticut (800) 842-2288	Nebraska (800) 652-1999	Washington (800) 562-5624
Delaware (800) 292-9582	Nevada (800) 992-5757	West Virginia (800) 352-6513
Florida (800) 962-2873	New Hampshire (800) 894-5533	
Illinois (800) 252-2873	New Jersey (800) 792-8610	
Indiana (800) 562-2407	New Mexico (800) 432-2075	

## Appendix B. Using focus groups

A focus group is a homogeneous group of 4 to 12 people who are invited to present their views on a specific topic. Group members are put at ease (typically over a meal) in a gracious private setting. The moderator begins with a general question on the topic and leads members to discuss aspects about which information is desired. Often the moderator does not know just how the participants would frame or discuss the issue, and is open to unplanned turns in the discussion. A recorder or note-taker keeps track of the ideas discussed and recaps them at the end for further evaluation by the group.

Focus groups motivate participants to think deeply and develop new ideas. While a survey or interview generally only reveals which of various predetermined alternatives is true for individuals or gleans facts such as age, a focus group can reveal entirely new insights never contemplated before by the sponsor, the moderator, or the participants. A well-organized focus group can take on a life of its own with little apparent leadership from the moderator. However the moderator always has a store of questions or probes that can be used to get the discussion back on track if needed. Focus groups often go on longer than was planned, with participants asking "When can we come and discuss this again?" The discussion is usually highly involving and participants typically view the discussion as a valuable and rewarding experience.

Market researchers often pay focus group members because their own interest is obviously monetary, although the group may get excited about the new product or service, and find participation useful in its own right. In most other contexts, monetary incentives are inappropriate. Rather, researchers better express appreciation by giving participants a little gift or a packet of useful information. Some focus groups are designed to explore the possible value of new services, and the creation of the needed services is the most rewarding outcome of the focus group. The traditional use of focus groups in business is for market research. Homogeneous groups, representing segments of the target market, are given an opportunity to look over a proposed new product or service (perhaps alternative versions of it) to evaluate, discuss price point, use, and report what they like and dislike about it. They might also discuss possible product extensions and ways in which they would prefer to receive or use the product. The company uses the information to develop, advertise, promote, distribute, and merchandise the item.

Effective focus groups are carefully planned. It should include the following essential elements:

1. Know what questions you want answered and how to probe group members in case the relevant information is not readily forthcoming. Organize questions and probes starting with

the most general and introductory and concluding with a summary question. Reduce these to 5 to 7 very general questions.

2. Define target population. Who are the people whose opinion you want to know?
3. Select groups of about 6 to 12 people, keeping each group as homogeneous and compatible as possible. Do not mix genders, people of different status, or people who would be guarded around one another. Groups may include friends or strangers.
4. Select good gatekeepers — people who will help communicate to each group why their participation is a good idea, recruit individuals and groups, and find times and places to meet.
5. Effectively invite them. The invitation may be via more than one channel. The gatekeeper may do the initial recruitment, and follow up with a letter describing all of the pertinent information. Offer appropriate incentive to participate.
6. Create a comfortable and private setting for the focus group.
7. Conduct the focus group, serve appropriate food, and summarize.
8. Organize responses around main questions or emergent themes. If more than one focus group is conducted, identify main themes and tangential themes.
9. Prepare and disseminate report of findings.

It is important that focus group members perceive the moderator as neutral to the topic of the group. The idea is to get an entirely unbiased, uninhibited response to questions. If a focus group member thinks a particular product, service, or idea is "really lousy," they must feel free to say so. A focus group is of no value if its members feel constrained to say nice things when they may feel otherwise. For example, a representative of the company should not conduct a focus group evaluating a company's new product line and a representative of management should not conduct a focus group that asks employees' evaluation of a proposed new company policy.

### **Focus groups are the method of choice when:**

- \$ Exploring new ideas, such as proposed new product designs, services, or activities. Because people do not have experience or knowledge of these matters beforehand, they need to discuss the idea before they can say how they feel about it.
- \$ Exploring ideas germane to a specific group, such as ideas about how to improve a group activity that the group is engaged in, and about which group discussion and evaluation is likely to be more useful than individual evaluation.
- \$ Exploring how others conceptualize and talk about an idea, including an old idea but one that different groups conceptualize differently. Suppose, for example, a physical trainer wished to consider offering exercise programs to elders living in a retirement village. What would they like about such a program? What are their reservations? How would they want to be trained? Focus groups could show whether there is a market and how to reach it.
- \$ Seeking information from groups that will not respond to a survey. Literacy, time pressures, ability to speak English, suspicion of strangers, or cynicism about responding to surveys or phone interviews are factors that may necessitate use of focus groups. Because of the motivation built by gatekeepers and the enthusiasm that is sustained by the group setting — plus the possibility to tailoring the language, setting, and staffing to the demography of the focus group members — it is possible to get thoughtful, creative, and penetrating analysis from people who would not even bother to respond or would respond thoughtlessly to a survey.
- \$ A quick answer is needed. Sometimes researchers can assemble, conduct, and analyze results of one or more focus groups within a week or two, while a mailed survey is likely to take months.
- One needs to know what to ask and how to ask it on a survey. A focus group may be an essential prelude to developing and conducting a survey.

### **Surveys are useful when:**

- \$ Seeking cut and dried answers to simple questions. If one knows how to ask the questions in terms the respondents will understand, and researchers can locate and motivate a representative group of respondents, surveys are most efficient tools.
- \$ Seeking demographic differences in response. Cross-tabulation of attitudinal and behavioral responses with demographic variables shows who thinks (or does) what.
- One has a well defined target population and a directory enabling one to randomly sample from that population. Random sampling assumes that one has a list of all

members of the population from which to sample. If the target population is defined by a customer list or a membership directory, and if one's relationship with that population is such that they are motivated to respond to your survey, a reasonable approximation of a random sample might be achieved and valid responses may be obtained.

Interviews are useful when the topic has the characteristics of a focus group topic, but when:

- \$ The respondents are busy people who have neither the time nor inclination to fill out surveys or attend focus groups.
- \$ The topic is sensitive and difficult for people to discuss in a group setting or to respond to in a survey.
- \$ Logistics of meeting are impossible to surmount. When respondents are widely disbursed geographically or have incompatible schedules, it may be necessary to hold individual interviews rather than focus groups.
- While interviews have the advantage that persons' responses are individual and not contaminated by those of other (focus group) members, they have the disadvantage that they are not enriched by the creative process of group exchange and exploration.