



## CHAPTER ONE

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# THINKING ABOUT TOPICS FOR HEALTH SURVEYS

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### Chapter Highlights

1. Surveys systematically collect information on a topic by asking individuals questions to generate statistics on the group or groups that those individuals represent.
2. Health surveys ask questions about a variety of factors that influence, measure, or are affected by people's health.
3. Health survey researchers should review the major international, national, state, and local health surveys relevant to their interests before undertaking their own study.
4. Good survey design is basically a matter of good planning.
5. The total survey error and survey quality framework alerts researchers to ways to identify and mitigate both bias and variable errors in surveys.

This book provides guidance for designing and conducting health surveys. These surveys systematically collect information on a topic of interest (such as state health care reform legislation) by asking individuals questions (about whether they and their family members have insurance coverage) to generate statistics (percentage who are uninsured) for the group or groups those individuals represent (noninstitutionalized residents under sixty-five years of age).

This chapter addresses (1) the topics, techniques, and ethical issues that will characterize the design and conduct of health surveys in the future; (2) the defining features of surveys compared with other data collection methods; and (3) the reasons for studying health surveys. It also provides (4) a framework for classifying the topics addressed in health-related surveys, (5) illustrative examples of health surveys used in this book, and (6) an overview of the total survey design and survey quality approach to designing and conducting health surveys.

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## Future Health Surveys

Health surveys have been and will continue to be important sources of information for health care policymakers, public health professionals, private providers, insurers, and health care consumers concerned with the planning, implementation, and evaluation of health-related programs and policies. The design and conduct of health surveys in the future will be shaped by changes in the diversity, complexity, and sensitivity of the topics addressed in these studies; the innovative techniques and technologies that are being developed for carrying them out; and the new or intensified ethical dilemmas that are a result of these changes.

### Topics

The topics addressed in health surveys have been and will continue to be sensitive and complex. Such sociomedical morbidities as HIV/AIDS, child abuse, sexual dysfunction, drug and alcohol addiction, and family violence, among others, are now encompassed in definitions of public health and medical problems. The issue of access to medical care focuses on vulnerable and hard-to-locate populations differentially experiencing these sociomedical morbidities: gay/lesbian/bisexual/transgendered (GLBT) persons, drug abusers, the homeless, medically fragile children and the elderly, and undocumented migrant and refugee populations. Health care program designers are concerned with the number of people in these vulnerable groups; the particular health problems they experience; the barriers to care they confront; the ways in which their knowledge, attitudes, and behaviors exacerbate the risk of their contracting serious illnesses; and the resources they have to deal with these problems.

These trends in asking tough questions of hard-to-locate respondents in order to gain information for the design of cost-effective public and private health programs to address the needs of these respondents will continue.

## Techniques and Technologies

The topics to be addressed in health surveys present new and intensified challenges at each stage of the design and conduct of a study. Corresponding to these developments is the emergence of new technologies for assisting with these tasks.

Rapid growth in the number and diversity of journals and specialized publications dealing with health topics has made the job of identifying and evaluating the major research in any given area more challenging. Computerized text search programs have greatly facilitated access to published research, but knowledge of effective search techniques is required to carry out these searches efficiently. These databases encompass professional journals and related periodical literature, as well as increasingly expanded online access to books, government publications, and unpublished research in progress relevant to the topic of interest. For those health topics for which little information is available because of the newness of the topic or the corollary lag in the dissemination of research results, survey designers need to contact relevant public or private funding agencies and colleagues in the field who are known to have research in progress on the issue.

Training programs are needed to prepare both students and professionals for carrying out these searches and evaluating the credibility of sources that are identified. The credibility of Internet and unpublished research could be evaluated based on the authoritativeness and previous track record of the organization or individual to whom the work is credited (for example, National Center for Health Statistics reports are likely to be a more credible source than an unpublished manuscript posted by a university faculty member with little record of peer-reviewed publications or funding); the other research sources that the research draws on or references; as well as the standards for evaluating the possible sources of errors in research in general and surveys in particular discussed further later in this chapter and highlighted in each of the chapters that follow. (Also, see White, 1994, and Wortman, 1994, for a discussion of procedures and criteria for retrieving and evaluating scientific literature.)

In the interest of learning about health and health-related attitudes, knowledge, and behaviors, survey researchers are attempting to penetrate more deeply into the traditionally best-kept family and personal secrets. The application of principles of cognitive psychology to the design and evaluation of such questions has challenged many of the standardized approaches to asking questions. At a minimum, in the early stages of questionnaire development, survey designers should ask respondents what went through their minds when they were asked sensitive questions about themselves or other members of their family. Moreover, prominent survey methodologists have called for the development of theories of

surveys. These theories would focus on the decisions that could be made at each stage of designing and carrying out a survey to maximize quality and minimize costs (Biemer & Lyberg, 2003; Dillman, 2000, 2002; Groves, 1987, 1989; Groves, Dillman, Eltinge, & Little, 2002; Groves, Singer, & Corning, 2000; Sudman, Bradburn, & Schwarz, 1996).

The technology that has had the largest influence on the techniques used in the design and conduct of health surveys is computerized information processing. These methods can be used to facilitate research on different survey techniques or methodologies (such as using different approaches to sampling respondents, phrasing questions, and training interviewers). The rapid turnaround of information made possible by computerized methods should expedite choices among design alternatives of this kind. More attention needs to be given to evaluating the overall quality of the information obtained using emerging computerized approaches, the impact on the interviewers and respondents of using computers to display the questions and enter respondents' answers, and the costs at each stage of the study. Computerized survey technologies are wonderful innovations. As with any other new invention, however, the most effective and efficient means of producing and using it needs to be explored and tested rather than simply assumed (Jones, 1999).

The topics and technologies evolving for health surveys present both challenges and opportunities in designing the samples for these studies. Health surveys have increasingly focused on rare or hard-to-locate populations. Innovative approaches are required to identify the universe or target population of interest, develop cost-effective methods for drawing the sample, and then find individuals to whom the questionnaire or interview should be administered. Survey designers must be aware of the methods that have been developed to identify and oversample rare populations and be prepared to invest time and resources to come up with the best sample design for their study.

## Ethics

Asking people questions in surveys about aspects of their personal or professional lives always involves a consideration of the ethical issues posed by this process. Are the participants fully informed about the study, and do they voluntarily agree to participate? What benefits or harm may they experience if they participate? Will their right to remain anonymous and the confidentiality of the information they provide be maintained when the findings are reported? The evolution of the topics, techniques, and technologies just reviewed promises to heighten, rather than diminish, the importance of these ethical questions in the design and conduct of health surveys (Sudman, 1998).

The Privacy Rule enacted under the Health Insurance Portability and Accountability Act (HIPAA) of 1996 established minimum federal standards for protecting the privacy of individually identifiable health information. The Privacy Rule confers certain rights on individuals, including rights to access and amend their personal health information and to obtain a record of when and why this information has been shared with others for certain purposes. The Privacy Rule establishes conditions under which covered entities can provide researchers access to and use of personal health information when necessary to conduct research (National Institutes of Health, 2004; U.S. Department of Health and Human Services, Office for Civil Rights, 2005). The HIPAA legislation and related Privacy Rule requirements have imposed significant constraints on researchers in addressing issues of informed consent, the benefit versus harm to study participants, and rights of anonymity and confidentiality, as well as in obtaining Institutional Review Board (IRB) approval for the conduct of survey research. (An informative overview of the implications of these and related security and privacy issues for health surveys may be found in the series of papers presented in “Session 5: Security and Privacy,” National Center for Health Statistics, 2004b.)

***Informed Consent.*** The use of cold contact (unannounced) calls in random digit dialing telephone surveys permits very little advance information to be provided to the respondent about the nature of the study and the ways in which the information will be used. Survey designers are reluctant to spend much time giving respondents details on the survey for fear they will hang up. There is also little opportunity to elicit the formal written consent of respondents for what might be particularly sensitive topics. Respondents with what are perceived to be socially undesirable diseases and little means to pay for health care also may feel obligated to participate in a study if their providers ask them to do so, fearing that they will subsequently be refused treatment if they do not. From the providers’ or researchers’ perspectives, however, the increasingly complex and restrictive informed consent procedures may be viewed as seriously jeopardizing the ability to carry out reasonable scientific research protocols.

***Benefit Versus Harm.*** Rational and ethical survey design attempts to ensure that the benefits outweigh the costs of participating. Asking people sensitive questions about threatening or difficult topics may call forth memories or emotions that are hard for them to handle. Most survey designers do not explicitly consider such costs to the respondents.

Providing monetary incentives does increase people’s willingness to participate in surveys. However, more research is needed to examine the effect of such incentives on the quality of the information provided. Do respondents feel more

obligated, for example, to give answers they think the interviewer wants to hear? Offering large incentives may also be viewed as raising questions about whether this is unduly coercive for certain respondents, such as poor or uninsured patients.

***Rights of Anonymity and Confidentiality.*** Finally, an important issue in the design and conduct of surveys is guaranteeing the anonymity of survey respondents and the confidentiality of the information they provide. This issue is made more salient with the possibility of computerized linkages between sources, such as databases that link telephone numbers to household addresses or between survey data and medical records or billing information from providers. These issues have taken on even greater salience in the context of the HIPAA legislation, which sharply restricted the use of patient identifiers and introduced more stringent informed clearance for permitting access to medical record and related health plan data (National Institutes of Health, 2004; U.S. Department of Health and Human Services, Office for Civil Rights, 2005).

The United States has become an increasingly litigious society, as evidenced by the growing number of malpractice suits brought against health care providers. Survey designers can thus expect to confront more detailed and cumbersome review procedures for evaluating how the rights of study participants will be protected in carrying out the survey.

This environment compels that researchers, IRBs, and participating providers and funders devise means for constructive problem solving to protect the rights of study participants and ensure the feasibility of conducting sound research. *Reactive methodology* attempts to understand the dynamics that come into play and how best to resolve potential conflicts between those involved in the conduct and approval of the research (Sieber, 2004). “Reactive” refers to reactions to the proposed research by the potential study subjects, their community, the researchers, and other external forces such as HIPAA and related IRB procedures. It most essentially acknowledges that although regulations may dictate specific constraints on those who seek to conduct research, it is the relationships between and among the players that ultimately dictate whether the research can be conducted both responsibly and feasibly.

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## Defining Features of Surveys

Several key dimensions define the survey approach: (1) a research topic or problem of interest has been clearly delineated, (2) information on the issue is gathered by asking individuals questions, (3) the data collection process itself is systematic and well defined, (4) the purpose of the study is to generate group-level

summary statistics, and (5) the results are generalizable to the groups represented by the individuals included in the study (American Statistical Association, Section on Survey Research Methods, 1998a, 1998b).

A number of these features are not unique to surveys, but taken together they tend to distinguish this data-gathering method from such other approaches as using existing record data, conducting participant or nonparticipant observational studies, or carrying out case studies of one or a limited number of programs, institutions, or related units. Researchers should not necessarily assume that surveys are always the best approach to use in gathering data. That decision depends on what best enables investigators to address the research questions of interest to them. Furthermore, survey developers are increasingly making use of qualitative research methods such as focus groups, in-depth unstructured interviews, or ethnographies to guide the development and interpretation of more structured surveys (Sale, Lohfeld, & Brazil, 2002; Sudman et al., 1996). The similarities and differences among these methods and surveys are reviewed in the following discussion.

### Existing Record Sources

Health care investigators might decide that existing record data, such as the medical records available in hospitals or physicians' offices, claims data from private or public third-party insurers, or vital statistics records on births and causes of deaths, are the most useful and relevant sources for the types of information they need to gather for their study. Some of these sources may contain thousands of records that could be easily manipulated with high-powered personal computers. With these record sources, it will not be necessary to ask people questions directly to get the information. This is particularly true for factual data on concrete events that are fully and completely documented in existing sources. Data in such sources may, however, be inaccurate or incomplete, depending on the data quality standards governing gathering, entering, and verifying the information. If the investigator wishes to obtain more subjective, attitudinal data from individuals or to explore the probable accuracy or completeness of the information in the record sources, then designing a survey to ask people questions about the topic is required (Stewart & Kamins, 1993).

### Participant or Nonparticipant Observation

In a second important method of data collection that differs from the survey approach, the investigator directly observes rather than asks individuals questions about particular situations or events. These observations may be relatively unstructured ones in which the researchers become, in effect, direct participants in

the events. For example, this approach is used by medical anthropologists who live and work with members of a cultural subgroup (such as minority drug users or prostitutes) in order to establish the trust and rapport required to gain an understanding of certain health practices within that group (Jorgensen, 1989).

Structured observational methods require that the investigator have clearly delineated guidelines that indicate what to look for while observing the behaviors of interest. For example, researchers might want to record systematically patterns of interaction among family members during counseling sessions dealing with the addictive behavior of one of them. To do this, they could call on the procedures that social psychologists have developed for systematically inventorying and classifying such interactions. These approaches are also used in coding interviewers' and respondents' behaviors for the purpose of identifying problem questions during the instrument development phase of the study or to improve interviewer performance.

The principal way in which observational methods differ from surveys is that individuals are not asked questions directly to obtain needed information. In addition, the purpose of such research may be exploratory, that is, the investigator may want to get a better idea of what relationships or behaviors should be examined before going on to develop a comprehensive, formalized approach to gathering data on the topic. The investigator is usually not so interested in generating aggregate summary statistics that can be generalized to a larger target population when these methods are used. Instead, the focus is on the microcosm of activity being observed in the particular situation and what the investigator can learn from it.

## Case Studies

Case studies of particular institutions or agencies (such as hospitals, managed care organizations, or neighborhood clinics) ask key informants questions about the organization, observe aspects of what is going on in the agency, or examine extant administrative or other record sources. The main difference between case studies and surveys is that in case studies, the investigators tend to focus on *a few elements to illustrate the type of unit* they are interested in learning about, whereas in a survey, they gather information *on a number of elements intended to represent a universe of units of that type*. Case studies take on more of the features of survey-based approaches to the extent that individuals are asked questions about themselves or their institutions; that a systematic, well-defined approach is used in deciding what questions to ask; and that the institutions or informants are selected with consideration given to the groups they represent (Yin, 2003).

If the investigators determine that a survey is the preferred method to elicit the information they need, they then have to decide whether they will try to do



the study themselves, contract with a survey firm to carry it out, or make use of data that have already been gathered on the topic in other surveys.

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## Reasons for Studying Health Surveys

The reasons for studying health surveys are varied, but defining principles of survey design should guide the development, implementation, and assessment of all surveys.

### To Design Good Surveys with Small Budgets

Most designers of health surveys do not have large grants or substantial institutional resources to support the conduct of large-scale studies. Students generally have a shoestring budget to carry out required thesis research. Academic researchers often use students in their classes or draw on limited faculty research funds to carry out surveys locally in their institutions or communities. State and community agency budgets are generally tight, and the boards of hospitals and health care organizations may encourage staff interested in conducting surveys to make use of institutional resources such as telephone, mail, or computer services to keep survey costs down. And doing good surveys does not always require large budgets. Either a Cadillac or a Ford will get you where you want to go; the same basic principles of sound engineering design apply to both. Survey developers should be aware of the fundamental principles behind the good design of even small surveys. It may be a matter of what you can afford. However, it is important to remember that the costs of poor survey design are also high.

### To Learn About and from Well-Designed, Large-Scale Surveys with Large Budgets

Hundreds of millions of dollars have been spent in designing and executing large-scale national health surveys. The decennial census and Census Bureau-sponsored Current Population Surveys are useful sources of selected indicators of the health of the U.S. population. The National Center for Health Statistics routinely conducts surveys of the health of the U.S. population and the providers of health care. The Agency for Healthcare Research and Quality (formerly the Agency for Health Care Policy and Research) and the National Center for Health Statistics have conducted a number of large-scale special surveys on the health practices of the U.S. population and their levels and patterns of expenditures for medical care. In

addition, a variety of methodological studies have been conducted in conjunction with these and other large-scale health surveys to identify sources of errors in this type of study and the decisions that should be made to reduce or eliminate them (Cohen, 2003; Mokdad, Stroup, Giles, & Behavioral Risk Factor Surveillance Team, 2003). The results of such studies are routinely published in the proceedings of conferences held by the American Statistical Association and the U.S. Bureau of the Census, as well as other governmental agencies (see Resource D).

Individuals interested in health surveys should be aware of these large-scale studies because they are a rich source of data on the nation's health and health care system. They also provide a gold mine of questions for inclusion in related studies, the answers to which can then be compared with national data. Finally, they have a great deal to teach us about how to do good surveys since resources are provided in the budgets of these surveys to assess the quality of the research itself.

### **To Be Aware of What to Look for in Conducting Secondary Analyses of Existing Health Survey Data Sets**

Many researchers do not have the time or resources to carry out their own surveys. Extensive archives of national and local health survey data sets, such as the Inter-University Consortium for Political and Social Research at the University of Michigan, have been developed (see Resource D). Students, researchers, and program administrators and planners are being encouraged to make greater use of these secondary data sources, that is, data they were not involved in collecting (Kiecolt & Nathan, 1985; Moriarty et al., 1999; Shepard et al., 1999; Stewart & Kamins, 1993). These analyses can involve efforts to use existing data sets—state or national data collected for other purposes—to address a particular research question, such as the influence of the types of food children consume on obesity, or to make estimates for specific local areas or populations, such as the percentage of the population without insurance coverage. Small area estimation procedures have been developed to generate these latter estimates (Malec, 1995; Pfeffermann, 2002; Rao, 2003).

Users of secondary data sources should raise a number of questions, however, in considering the relevance of these data for their own research. How were people chosen for inclusion in the study? Were efforts made to evaluate the accuracy of the data obtained? How did researchers deal with people who refused to participate in the study or to answer certain questions? Are there particular features of how the sample was drawn that should be taken into account in analyzing the data? Awareness of these and other issues is essential to being an informed user of secondary health survey data sources.

## To Know How to Evaluate and Choose Firms to Conduct Health Surveys

Health survey research is big business. Nonprofit, university-based survey organizations as well as for-profit commercial firms compete to obtain contracts with government agencies, academic researchers, and provider institutions for conducting national, state, and local health surveys. Some university-based or -affiliated survey research organizations that have conducted health surveys on a variety of topics include NORC (National Opinion Research Center, University of Chicago), Survey Research Center (University of California, Berkeley), Survey Research Center (University of Michigan), Survey Research Laboratory (University of Illinois), and the Wisconsin Survey Research Laboratory (University of Wisconsin). Other nonprofit firms that have been engaged in conducting large-scale health surveys include the Research Triangle Institute (University of North Carolina) and the RAND Corporation (Santa Monica, California). A number of commercial, for-profit firms have also carried out a range of health surveys under contract with public and private sponsoring agencies, including Abt Associates (Cambridge, Massachusetts), Gallup (Princeton, New Jersey), Louis Harris and Associates (New York), Mathematica Policy Research (Princeton, New Jersey), and Westat (Rockville, Maryland). The Web sites of these and other survey research entities could be consulted for descriptions of ongoing or completed studies and, in some cases, copies of survey questionnaires, summaries of study findings, and methodological reports.

These organizations emphasize different methods of data collection—*in-person interviews, computer-assisted telephone interviews, or computer-assisted personal interviews*—and different basic sample designs, and they use different types of data editing and data cleaning procedures. Researchers and agency and organizational representatives considering contracting with such organizations need to know their experience in doing health surveys and evaluate their capabilities for carrying out the proposed study.

## To Become a Better-Informed Consumer of Health Survey Results

Opinion polls that summarize the American public's attitudes toward issues, such as whether children with HIV/AIDS should be admitted to public schools, often report that estimates vary plus or minus 3 percent for the sample as a whole or as much as plus or minus 7 percent for certain subgroups (African Americans, Hispanics) because only a small sample of the American public was interviewed to make these estimates. How does one use this information to decide whether a difference of 10 percent reported between African Americans and whites in support of the issue is "real" then? The administrator of a managed care organization is

interested in the results of a survey of plan members' satisfaction with services in which only 50 percent of the members returned the questionnaire. Should she be concerned about whether the survey accurately represents all enrollees' attitudes toward the plan? Students and faculty conduct literature reviews of studies relevant to concepts of interest prior to formulating their own research proposals. If a study reports that an indicator of patient functional ability had a reliability coefficient of .80 when administered at two different times in the course of a week to a group of elderly patients, does that mean it is a fairly good measure? These are examples of the types of questions that could occur to consumers of health survey findings. This book identifies the criteria that can be applied in seeking to answer these and other questions about the quality of health survey data.

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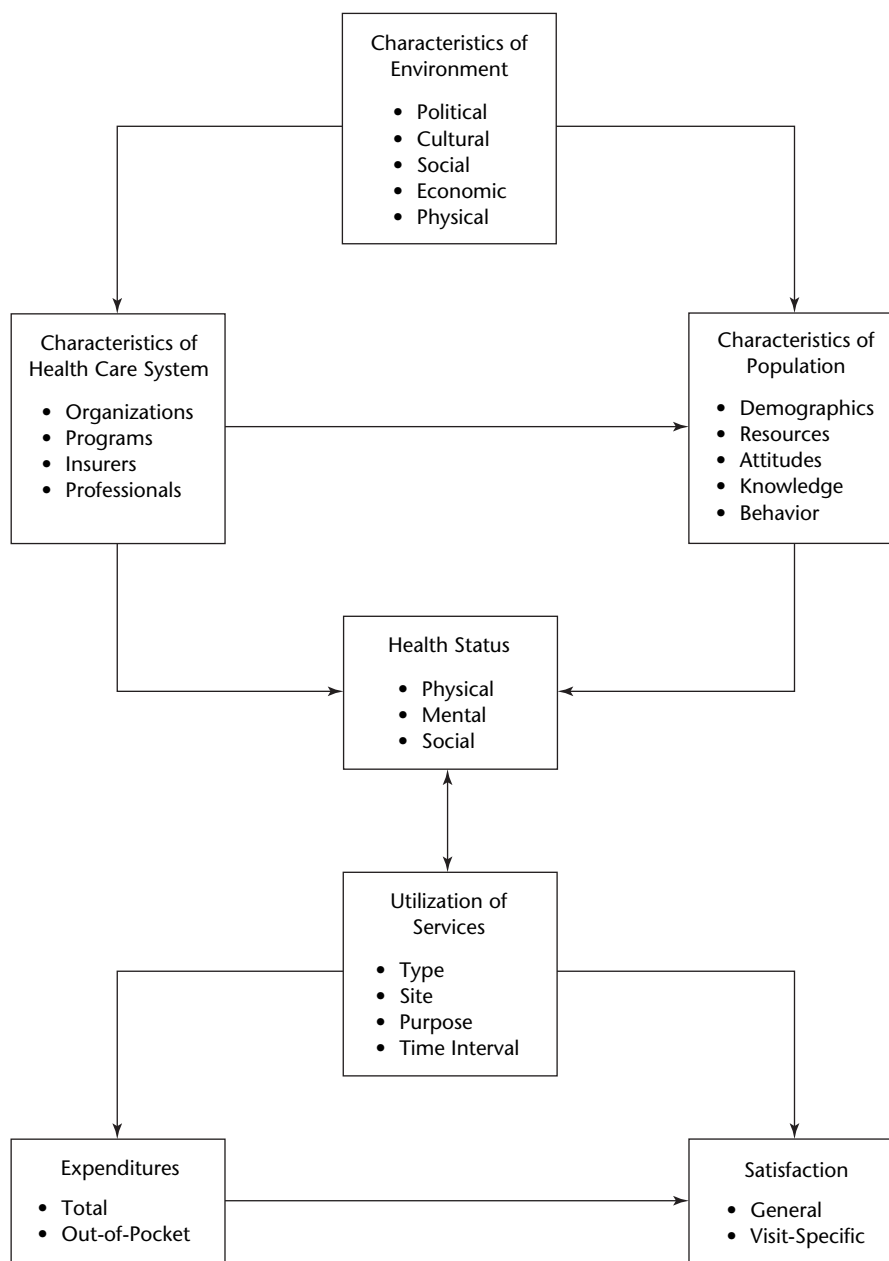
## Framework for Classifying Topics in Health Surveys

Health surveys can cover a variety of topics, such as the ecology (distribution) and etiology (causes) of disease, the response to illness or maintenance of health on the part of the patient or the public, and the personnel and organizations in the health care professions (see Resource E). Health status is the explicit or implicit focus of health surveys, as defined here—studies that ask questions about factors that directly or indirectly influence, measure, or are affected by people's health. It is important to point out that health surveys may address more than one topic. A study may focus on one area of interest (out-of-pocket expenditures for care) but also include a range of related issues (health status, use of services) to examine their relationships to the major study variable. As will be discussed later, a survey may be principally concerned with describing a particular situation or with analyzing relationships between variables to explain why the situation is the way it is. The blocks outlined in Figure 1.1 reflect aspects that influence, measure, or are influenced by a person's health, and the arrows between them indicate relationships commonly hypothesized to exist between those elements. Health surveys can be used to examine the broader political, cultural, social, economic, and physical environment of a community, as well as the characteristics of the people who live there and the health care system that has evolved to serve them.

### Characteristics of the Environment

Consideration of the predictors, indicators, and outcomes of health begins with the larger environment in which individuals live and work. Political, cultural, and social beliefs about health and medical care; the organization and status of the nation's or community's economy; and the nature of the physical environment itself

**FIGURE 1.1. FRAMEWORK FOR CLASSIFYING TOPICS IN HEALTH SURVEYS.**



define both the limits and possibilities for health and health care of the individuals residing in a particular community.

Anthropologists and social scientists, for example, conduct cross-national or cross-cultural comparative surveys of how different groups define or respond to illness or the types of medical providers they consider appropriate for different symptoms. National, state, and local polls measure public opinion on issues, such as pending state health care reform legislation, and on more specific questions, such as whether universal health insurance should be provided, indigent undocumented residents should be entitled to Medicaid benefits, or persons with infectious diseases should be quarantined. Environmental and occupational safety and health scientists gather data on the waste disposal practices of major corporations and the extent to which residents report symptoms associated with radiation or chemical waste hazards identified in their neighborhoods or places of work.

### Characteristics of the Health Care System

Surveys can be conducted of such health care organizations as hospitals, MCOs, community mental health centers, or hospices to learn about their basic structure or operations or their performance in terms of certain indicators—for example, the cost of delivering services. Many innovative health care programs have emerged in recent years, such as pain management clinics, programs for adult children of alcoholics, and employee work site programs, to deal with the special health care needs of selected groups. Surveys have been conducted of the client populations of these programs to determine whom they serve and what participants have gained from them. Managed care providers and health plans are developing and disseminating “report cards” on their performance, including the results of patient surveys of satisfaction and quality, to provide a more informed basis for consumers in choosing among competing options (Agency for Healthcare Research and Quality, n.d.-b; National Committee for Quality Assurance, n.d.).

Insurers are becoming an increasing focus of health care surveys because of concerns with the accelerating costs of medical care. Large-scale surveys of health care consumers often send questionnaires to insurers named by respondents to obtain detailed charge or cost data that individuals themselves may not be aware of when third parties pay their medical bills directly.

Health care professionals—physicians, dentists, nurses, allied health workers, and those in emerging health professions (such as complementary and alternative medicine specialties)—are a frequent focus of health care surveys. Surveys of health professionals have yielded information about the people who choose to go into the profession and why, the nature of the professional socialization experience and students’ responses to it, factors that enter into the choice of specialty or practice lo-

cation, the actual content and norms of care in professional practice, and the level of professional job or career satisfaction.

## Characteristics of the Population

Surveys of the population at risk in a community have been widely used in needs assessment and strategic planning or marketing studies for new health care facilities or programs. Demographics, such as the age, sex, ethnic, and racial composition of a community, indicate the potential need and demand for certain medical services, such as prenatal care, preventive immunizations, hypertension screening, or elderly day care. Income levels and the type and extent of insurance coverage in a community reflect the resources available to individuals for purchasing medical care when they need it.

Responses to questionnaires about an individual's health and health care attitudes and knowledge may signal which groups are at particular risk of contracting certain illnesses (such as HIV/AIDS or cervical cancer) because of beliefs that demonstrate their ignorance of the disease or its causes or their unwillingness to seek appropriate screening or treatment services for it. There is increasing evidence that people who engage in certain personal health practices or behaviors, such as excessive smoking or alcohol consumption, and not others, such as exercising or eating breakfast regularly, experience higher morbidity (disease) and mortality (death) rates. With the promulgation by the U.S. Department of Health and Human Services of national objectives for promoting health and preventing disease, there has been a corresponding increase in national and local surveys that collect information on individual lifestyles and preventive self-care behaviors (National Center for Health Statistics, 2004g).

**Health Status.** A tremendous amount of effort has gone into clarifying and defining what is meant by the term *health* and in trying to develop valid and reliable indicators of the concept. The World Health Organization (WHO) offered a comprehensive definition of health as a "state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity" (World Health Organization, 1948, p. 1). There is a growing interest in defining the goal of health policy to be improving the health of populations through broader medical and nonmedical public health and policy interventions. Measures of the health of populations reflect the health of individuals throughout the life course and take into account both premature mortality and measures of health-related quality of life (World Health Organization, 2002).

To determine health status, surveys can be based on individuals' own reports of their health or on clinical judgments or exams conducted by health professionals.

Furthermore, reports by individuals can reflect simply their subjective perceptions of how healthy they are (Is their health excellent, good, fair, or poor?) or describe the impact that being ill had on their ability to function in their daily lives (Did they have to take time off from work because of illness?). Differing conclusions about health can thus result depending on the dimension examined and the specific indicators chosen to measure it. A concern on the part of policymakers, consumers, insurers, and providers with measuring the outcomes of medical care has provided an added impetus to clarifying and refining both the predictors and indicators of health status (McDowell & Newell, 1996; Patrick & Erickson, 1993).

**Utilization of Services.** The environment in which individuals find themselves, the health care system available to serve them, their own characteristics and resources, and their state of health and well-being all influence whether they seek medical care and with what frequency. Surveys of health care utilization could ask questions to determine the type of service used (hospital, physician, dentist), the site or location at which the services are received (inpatient ward, emergency room, doctor's office, public health clinic), the purpose of the visit (preventive, illness related, or long-term custodial care), and the time interval of use (whether services were received, the volume of services received, or the continuity or pattern of visits during a given time period) (Aday & Awe, 1997). Presumably the use of health services also ultimately leads to improved health. This concept of health as both a predictor and an outcome of utilization is reflected in Figure 1.1 in the double-headed arrow between "health status" and "utilization of services." The growing focus on measuring the outcomes of medical care presents special challenges to survey researchers and others in developing or choosing the appropriate measures of health status and in designing studies that can accurately attribute observed outcomes to provider decision making. As when choosing health status measures in surveys, survey researchers should consider the particular dimensions they want to tap in their study and how precedents from other studies or methodological research on various ways of collecting health care utilization data inform those choices.

**Expenditures.** The cost of medical care has become a particular concern among consumers, policymakers, and health care providers. A number of large-scale national surveys and program demonstrations have examined patterns of expenditures for health care services for the U.S. population as a whole and for individuals in different types of health insurance plans (see Resource E).

Surveys are particularly useful for obtaining information on out-of-pocket expenditures for medical care and the private or public third-party payers, if any, that covered the bulk of the medical bills. As already mentioned, it is often nec-



essary to go to insurers or providers directly to obtain information on the total charges for services that individuals received. It may require even more effort and creativity on the part of the researcher to estimate the actual “costs” of the care, which may differ from the “charges” for it because of markups to cover other services or patients for whom no payment was received.

**Satisfaction.** The experience people have when they go for medical care and how much they have to pay for it out of pocket have been found to be important influences on their satisfaction with medical care in general or with a particular visit to a health provider. Because of an increased emphasis on patient-centered care, many hospitals and provider settings have assigned greater weight to developing and implementing surveys of patient satisfaction with the services received (Rao, Weinberger, & Kroenke, 2000; Wensing & Elwyn, 2002; Wensing & Grol, 2000). A number of questions and attitude scales for measuring patient satisfaction with medical care have been developed and used in health surveys. (Specific examples are discussed in Chapter Eleven.) Designers of health surveys incorporating patient satisfaction measures should learn about these and other ways of asking satisfaction questions, how well they have worked in other studies, their relevance for the particular survey being considered, and how to modify them to increase their relevance or applicability to the population to be studied.

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## Examples of Health Surveys

It is not possible in the context of this book to provide a comprehensive inventory of the health surveys that have been conducted in the United States and other countries. However, Resource D offers a summary of sources of information on health surveys, and Resource E provides selected examples of major surveys that have been conducted internationally, nationally, and at the state and local levels. For each survey, a profile of the topics addressed, the research design, the population or sample included, and the method of data collection used are provided. Health survey researchers should be aware of the analyses that these studies have yielded on the topics of interest to them as well as the questions or methods used in those studies that they might employ in designing their own surveys.

In addition to numerous other examples, three surveys in particular will be used to illustrate many of the aspects of survey and questionnaire design that are in the chapters that follow. The UNICEF Multiple Indicator Cluster Survey (MICS) was intended to measure and monitor World Summit for Children indicators of child survival and development in participating countries and to com-

pare the indicators within countries and across countries at mid-decade (1995) and end of decade (2000). A subsequent round of surveys (2005) was initiated to monitor World Fit for the Millennium Development Goals and related international health initiatives (UNICEF, n.d.). The California Health Interview Survey (CHIS) provides local-level estimates on a variety of public health topics, such as health status, health care access, and insurance coverage, for most counties in California as well as statewide estimates for California's overall population and its larger racial/ethnic groups, as well as for several smaller ethnic groups (UCLA Center for Health Policy Research, 2005). The CHIS was conducted in 2001, 2003, and 2005. The National Dental Malpractice Survey (NDMS) described dental malpractice insurance experience in a representative sample of U.S. dentists in 1991 and analyzed the practice characteristics that were predictive of dental malpractice insurance experience among U.S. dentists (Washington State University, Social and Economic Sciences Research Center, 1993). Sources for obtaining information on the questionnaires and the methodology for these studies are provided in Resources A, B, and C, respectively.

These three studies were chosen principally because they provide examples of the range of design alternatives that are available in doing health surveys. First, each involved different methods of data collection. The UNICEF MICS was conducted through personal interviews with family members in households selected for the study, the CHIS survey collected data through telephone interviews, and the dentist study sent a mail questionnaire to eligible providers. The UNICEF MICS is national and international in scope; the CHIS survey was a general population survey of people with telephones statewide, drawing sample from all counties; and the NDMS was based on a national list sample of dentists. The basic research designs for the studies were also different. (The different types of research designs that can be chosen in developing health surveys are discussed in Chapter Two.) The sample designs for the studies differed as well, with the UNICEF MICS relying on an area probability method of sampling, the CHIS primarily on random digit dialing, and the dentist survey on a list sample (these three designs are discussed in more detail in Chapter Six). The UNICEF MICS interview gathered information on the household in general, mothers, children under age five, and children ages five to fifteen, whereas the CHIS selected one adult respondent and, if present in the household, one child (under age twelve) and one adolescent (ages twelve to seventeen).

The survey questionnaires for the respective studies also reflect an array of health topics and different categories of questions relating to demographic characteristics, health behaviors, attitudes, knowledge, and need measured in a variety of ways. These three studies thus illustrate the range of choices that a researcher has in designing a survey.

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## Steps in Designing and Conducting a Survey

Good survey design is basically a matter of good planning. Exhibit 1.1 presents a picture of the survey research process experienced by investigators who fail to think about the steps involved in doing a study before they begin.

The principal steps in designing and conducting surveys and the chapters of this book in which they are discussed are displayed in Figure 1.2. A number of feedback loops appear in Figure 1.2 to reflect the fact that designing surveys is a dynamic, iterative, and interactive process. Many decisions have to be made in tandem; the advent of computerized systems that can be used to carry out many or all phases of the survey has made this even more true.

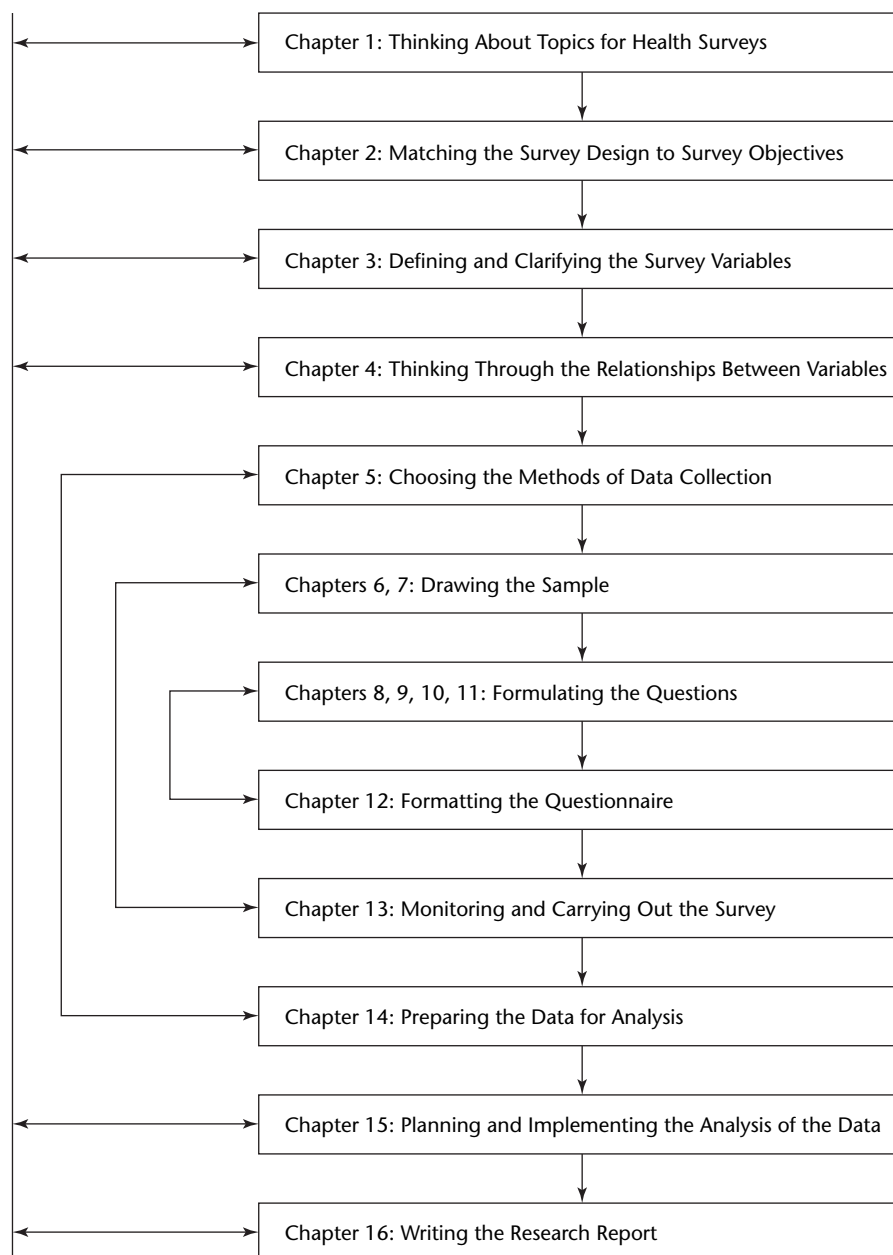
Previous experience and personal or professional interests can lead researchers to want more information about a particular issue. For academically oriented researchers, the problem could be stated in terms of study hypotheses about what they expect to find given their theoretical understanding of the topic. For business-oriented investigators, the problem could be stated in terms of precise questions that need to be answered to inform a firm's marketing, strategic planning, program development, or institutional evaluation decision-making activities.

The specification of the problem should be guided by what others have learned and written about it already. Reviewing the literature on related research, acquiring copies of questionnaires or descriptions of procedures used in studies on comparable topics, and consulting with experts knowledgeable in the field or associated with one's own institution can be extremely valuable in clarifying the focus of the survey.

The statement of the problem that emerges from this process should then serve as the reference point for all the steps that follow. This statement is the most visible marker on the landscape to guide the rest of the steps in the journey. These steps include defining the variables to be measured in the study, planning how the data will be used (or analyzed), choosing the methods for collecting the data, drawing the sample, formulating the questions and questionnaire to be used in the survey, collecting the data, preparing and analyzing them, and, finally, writing the research report.

A total survey design approach to planning surveys considers the impact of decisions at each of these steps on the overall quality and cost of the study (Biemer & Lyberg, 2003; Dillman, 2000; Groves, 1989). It also involves consideration of the fact that these steps are iterative and interdependent—that is, decisions made at one point in the survey design process should anticipate the steps that follow, and revisions to the original design will be required if unanticipated circumstances are encountered in the course of the study.



**FIGURE 1.2. STEPS IN DESIGNING AND CONDUCTING A SURVEY.**

The method chosen for preparing the data for analysis can affect how the investigator decides to collect the data (see Figure 1.2). For example, if the researcher wants to build in checks on the accuracy of the data at the time they are being collected or otherwise expedite subsequent coding and data-processing procedures, it would be well to use a computer-assisted data collection approach. The quality of the training of the field staff and the specification of the data collection procedures will affect how well the sample design for the study is executed. Decisions about the ultimate format of the questionnaire and the way in which it will be administered to respondents will influence the questions that can be asked and how. Furthermore, the final form of the research report and the analyses that are carried out with the data should be planned at the beginning—not at the end—of the study, and they should be based on careful formulation of the research questions and an analysis plan for the project.

---

## Framework for Minimizing Errors and Maximizing Quality in Surveys

A total survey error framework to guide decision making at each stage of the survey design process to help ensure accuracy and consistency of survey results will be used in presenting the steps for carrying out health surveys in the chapters that follow (see Table 1.1.) This framework is intended to provide a set of general principles, as well as specific guidelines, to facilitate survey developers' thinking critically about the implications of their decisions for the quality and usefulness of the data to which they and others have committed time and resources gathering.

A study carried out in the late 1970s by a special committee appointed by the Subsection on Survey Research Methods of the American Statistical Association, with support from the National Science Foundation, found—perhaps not surprisingly—that most surveys could be improved. Fifteen of twenty-six federal surveys and seven of ten nonfederal surveys studied had one or more major study design problems (Bailar & Lanphier, 1978).

In 1979 Andersen and his colleagues at the University of Chicago used a total survey error framework for identifying all the possible sources of bias and variable errors associated with both the sampling and nonsampling steps in designing health surveys. They then applied this framework to measure directly the magnitude of certain of these errors in a 1970 national survey of health care utilization and expenditures. The authors found that the type and magnitude of errors varied for different types of health and health care variables (Andersen, Kasper, Frankel, & Associates, 1979).

**TABLE 1.1. TYPES OF SURVEY ERRORS.**

---

*A. No Bias, Low Variable Error*

```

X
X
X
X
  X  X  X
  X  X  X
X  X  X  X  X
X  X  X  X  X
X  X  X  X  X
X  X  X  X  X
    
```

---

*B. High (-) Bias, Low Variable Error*

```

  X
  X
  X
  X
    X  X  X
    X  X  X
X  X  X  X  X
X  X  X  X  X
X  X  X  X  X
X  X  X  X  X
    
```

---

*C. No Bias, High Variable Error*

```

      X  X
      X  X  X  X
    X  X  X  X  X  X  X
  X  X  X  X  X  X  X  X
X  X  X  X  X  X  X  X  X
    
```

---

*D. High (-) Bias, High Variable Error*

```

      X  X
      X  X  X  X
    X  X  X  X  X  X
  X  X  X  X  X  X  X  X
X  X  X  X  X  X  X  X  X
    
```

---

– Bias
 $\bar{X}$ 
+ Bias

(True Value)

---

Presentations at a series of conferences on health survey research methods and procedures sponsored by the Agency for Healthcare Research and Quality (formerly the Agency for Health Care Policy and Research), National Center for Health Statistics, and other public and private sources have argued for the utility of a total survey design and related total survey error framework in enhancing the quality and reducing the costs of health surveys (National Center for Health Services Research, 1977, 1978, 1981, 1984, 1989; National Center for Health Statistics, 1996, 2001, 2004b). Robert Groves (1989), Don Dillman (2000), Paul Biemer, Lars Lyberg (Biemer, Groves, Lyberg, Mathiowetz, & Sudman, 1991; Biemer & Lyberg, 2003), and others (Lessler & Kalsbeek, 1992; Schwarz & Sudman, 1996; Sudman et al., 1996; Tanur, 1992; Weisberg, 2003) have made significant theoretical and empirical contributions to identifying and addressing the major types and costs of errors associated with the sampling and nonsampling aspects of designing both health and other surveys. The total survey error framework has led to the practical application of the related principles of Continuous Quality Improvement (CQI) and Total Quality Management (TQM) in designing systems to enhance the quality of survey data collection and processing (Biemer & Caspar, 1994; Biemer & Lyberg, 2003; Collins & Sykes, 1999; Lyberg et al., 1997; White & Hauan, 2002).

The field has evolved from focusing on constructing estimates of the total magnitude of error to designing and monitoring the study to ensure that standards of quality are maintained throughout the survey design and implementation process. Quantitative benchmarks of the quality of specific survey procedures become sentinel indicators of whether adjustments are needed to ensure a high-quality survey process and product. There is also a greater emphasis on the end users of survey data and results and whether the data and findings are applicable and interpretable on the part of the ultimate audience for the research.

The errors frequently made in designing and conducting surveys can be classified as either systematic ("bias") or random ("variable") errors (see Table 1.1). A bias involves a fixed departure of a statistic (such as a mean or proportion) across samples (or replications) in a particular (positive or negative) direction from the underlying actual (or true) population value for the estimate. Thus, the sample values are consistently higher or lower than the real value. Variable errors involve varying departures of the statistic (sometimes in a positive and sometimes in a negative direction) from the true population value. This means that the sample values vary or are spread out around the true value across samples (Andersen et al., 1979; Biemer & Lyberg, 2003; Groves, 1987, 1989). The combined or total error may be expressed as the mean square error (MSE), or the sum of the variable error (variance) and bias squared:



$$\text{MSE} = \text{VARIANCE} + \text{BIAS}^2$$

The further the estimate for the sample (such as a mean) is from the true population value—whether higher (+) or lower (−)—and the wider the spread (or variation) in the values obtained for a given sample, the greater the total survey error is. Though rarely measured fully and directly in a survey, the reference point provided by the concept of these two types of errors considered separately and in combination is useful for identifying and mitigating their occurrence or magnitude through thoughtful survey design. These two types of total survey error are portrayed graphically in Table 1.1, discussed in the following paragraphs, and elaborated in Chapter Sixteen (Table 16.2):

A. *No bias, low variable error.* When survey procedures yield estimates that basically cluster around the true value, as with example A in Table 1.1, they are said to be both unbiased and consistent. These are surveys in which the questions are valid and reliable. No substantial noncoverage or nonresponse problems were encountered in designing and executing the sample. That is, everyone who should have been eligible for the study had an opportunity to be included in the sample, a high proportion of those who were selected responded, and the size of the sample was large enough to minimize the standard (sampling) errors of the estimates derived from it.

B. *High bias, low variable error.* If procedures yield consistently inaccurate estimates (as with example B in the table), then the degree of bias is very high. One could, for example, design a question to ask about average weekly alcohol consumption that would yield fairly similar results if asked of the same respondents six months apart but that would still underestimate the rates of use for alcoholics. The refusal of heavy drinkers to participate in the survey could also create problems in this kind of study. The resulting nonresponse bias would contribute to the underestimation of alcohol use in the target population.

C. *No bias, high variable error.* Some measures or procedures may yield different results on different occasions or in different survey situations without any consistent pattern in one direction (higher or lower than the true value), as with example C in the table. These results could occur when questions with low reliability (stability) are used to measure the concept of interest (X) or when the sample size is too small to provide very precise estimates.

D. *High bias, high variable error.* If, in contrast, the researcher gets different answers each time the question is asked and these answers are consistently different (higher or lower, for example) from the right answer to the question, then the resulting estimate has a high degree of bias *and* variable error. Survey results are

just the opposite of those described in example A. They are neither consistent nor accurate (as in example D in the table).

The total survey error summarized here and depicted in Table 1.1 will guide the presentation of both specific and general principles to apply in the aspects of designing a survey addressed in the chapters that follow.

No survey is ever error free. However, this book is intended to increase awareness of standards to use in identifying the type and magnitude of the problems that can arise in designing and conducting surveys and the alternatives available to minimize them.

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## Supplementary Sources

For a history and general overview of academic, governmental, and market-oriented polling and survey research, see Bulmer, Bales, and Sklar (1991) and Hyman (1991). Consult Resources D and E for additional sources and examples of health surveys. For an overview of survey design in general, see Abramson and Abramson (1999), Alreck and Settle (2004), Fowler (2002), and *The Survey Kit* (Fink, 2003). The approach to total survey error is discussed more fully in Chapters Eight and Sixteen.